

**AIDS ORPHANS AND VULNERABLE CHILDREN IN  
AFRICA: IDENTIFYING THE BEST PRACTICES  
FOR CARE, TREATMENT AND PREVENTION**

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**HEARING  
BEFORE THE  
COMMITTEE ON  
INTERNATIONAL RELATIONS  
HOUSE OF REPRESENTATIVES  
ONE HUNDRED SEVENTH CONGRESS**

**SECOND SESSION**

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## C O N T E N T S

---

	Page
<b>WITNESSES</b>	
Dr. E. Anne Peterson, Assistant Administrator for Global Health, U.S. Agency for International Development .....	32
Father Angelo D'Agostino S.J., M.D., Founder and Medical Director, The Nyumbani Orphanage of Kenya .....	40
Nathaniel Dunigan, Founder and Director, AIDchild .....	42
Ken Casey, Senior Vice President, World Vision International and Special Representative to the President for HIV/AIDS .....	46
Laelia Gilborn, Program Director, Horizons Global Research on HIV/AIDS Project, Population Council .....	58
<b>LETTERS, STATEMENTS, ETC., SUBMITTED FOR THE HEARING</b>	
The Honorable Henry J. Hyde, a Representative in Congress from the State of Illinois, and Chairman, Committee on International Relations: Prepared statement .....	3
Information submitted for the hearing record by the Honorable Barbara Lee, a Representative in Congress from the State of California .....	7
Information submitted for the hearing record by the Honorable Robert Menendez, a Representative in Congress from the State of New Jersey .....	19
The Honorable Diane E. Watson, a Representative in Congress from the State of California: Prepared statement .....	31
Dr. E. Anne Peterson: Prepared statement .....	35
Father Angelo D'Agostino S.J.: Prepared statement .....	41
Nathaniel Dunigan: Prepared statement .....	44
Ken Casey: Prepared statement .....	48
Laelia Gilborn: Prepared statement .....	61
Article written by Senator Jesse Helms submitted for the hearing record by the Honorable Henry J. Hyde .....	63
Information submitted for the record by the Honorable Diane E. Watson: Prepared statement of Bonnie Marshall, President & CEO, Global Initiative on AIDS in Africa .....	69
<b>APPENDIX</b>	
The Honorable J.C. Watts, Jr., a Representative in Congress from the State of Oklahoma: Prepared statement .....	73
Information submitted for the hearing record by the Honorable Joseph R. Pitts, a Representative in Congress from the State of Pennsylvania .....	74



## **AIDS ORPHANS AND VULNERABLE CHILDREN IN AFRICA: IDENTIFYING THE BEST PRAC- TICES FOR CARE, TREATMENT AND PRE- VENTION**

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**WEDNESDAY, APRIL 17, 2002**

**HOUSE OF REPRESENTATIVES,  
COMMITTEE ON INTERNATIONAL RELATIONS,  
*Washington, DC.***

The Committee met, pursuant to call, at 10:15 a.m. in Room 2172, Rayburn House Office Building, Hon. Henry Hyde presiding.

Chairman HYDE. We will come to order. The AIDS pandemic continues to claim lives in sub-Saharan Africa, the epicenter of the scourge. Seventy percent of the AIDS cases exists there. Each day more than 5000 Africans are dying from the disease. Children are suffering profoundly. Approximately 6000 African children are getting infected each year with the HIV virus.

They were infected through their mothers, either when they were born or when they were breast-fed. They have become orphans or otherwise vulnerable because their parents, either have fallen ill or died. These children rarely live past the age of 6 because they die from an AIDS-related illness or hunger.

Some of these children are the head of their household at age 8, and others as young as 3 years old are left roaming the streets for survival. They suffer from psychological distress, economic hardship, forced withdrawal from school, malnutrition and the increased exposure to abuse. If they grow up at all, they grow up poor and uneducated and they face every kind of abuse imaginable.

I'm horrified to learn about the rape of infant children by adult males in South Africa who believe a myth that such a transgression is a form of prevention from getting AIDS. According to Reuter's News Service more than 21,000 cases of infant rape were reported to the South African police in the Year 2000. One decade from now there will be 40 million children orphaned worldwide and without adequate care or education.

Two decades from now any surviving orphans will mature into poverty-stricken adults who are able to transmit the virus to the following generation. In sub-Saharan African where the extended family is the only Social Security AIDS has quickly claimed the wage-earning population. Abandoned children and the elderly who need care have been left to their own devices. Their grandparents often struggle to meet the burden placed upon them.

Without worldwide committed intervention, this international problem will wash up on the shore of every nation. The magnitude

of damage increases exponentially. The world's blood supply will diminish. The number of deaths could rival any form of genocide witnessed by human kind to date. The street kids, the broken families, severed communities and fallen economies could swell into a tidal wave of instability across Africa and beyond.

We've already come to the gruesome realization that this scenario creates an enabling atmosphere for religious extremism and terrorist activity. Our enemies abroad will have a ready supply of terrorists recruits to act upon the vengeful wishes of their leaders.

Worldwide the death toll has climbed up to 22 million. That amounts to 8000 deaths per day. Ten years from now the number is forecasted at 80 million deaths across the globe. Currently, the pandemic is spreading to our next door neighbors in the Caribbean region, to Latin America, Russia and to Asia. This creates a clear and present danger to our national security.

For example, infections are rising rapidly in Haiti and the Caribbean where 5 percent of the population has AIDS or is HIV positive. As President Bush has stated, this is America's third border. Unchecked, the pandemic will hit our nation with a rising tide of new infections. Thanks to the support of many Members in Congress, the AIDS pandemic has received its proper focus as a humanitarian, national security and developmental crisis.

With the support of the Ranking Member Tom Lantos, we urged the successful passage in the House of H.R. 2069, the Global Access to HIV/AIDS Prevention Awareness, Education and Treatment Act of 2001 on December 11, 2001. This legislation addresses both bilateral and multilateral portions of our response to the AIDS threat. While the appropriations outlook remains unclear, we urge serious consideration of the \$750 billion allotment for multilateral assistance, which has received bipartisan support in the House.

It is our wish that the same bipartisan spirit will inspire the Senate to pass this or a similar bill before the close of the season, of the session rather, so that the President can sign it into law. Many accolades go to a dear friend and colleague from North Carolina, Senator Jessie Helms, for his commitment to the AIDS cause. With such help, we will ensure that the funds Congress has allocated for AIDS reach the voiceless victims, the children and the elderly.

I commend the many organizations that have assisted in HIV/AIDS programs. I especially commend the faith-based organizations for their exemplary efforts at educating and caring for child victims of AIDS. Church groups and humanitarian organizations have also responded creatively and effectively to help Africa and other continents cope with the consequences of AIDS.

Now after Mr. Lantos makes his statement, I would like to indulge the Committee with a presentation of 7-minute video by Christophe Putzel. He took the opportunity to shoot a documentary on the impact of the AIDS pandemic on Kenya's children. He documents the lives of orphans who inherited the HIV virus from their parents. The poverty-stricken communities where the virus thrives and the children are left behind to fend for themselves in the harsh conditions around the city.

As I have said, this tape is only 7 minutes, but it is worth watching. And after Mr. Lantos is finished, we will play the 7 minutes

and then we will hear from our first witness. I also would ask unanimous consent to introduce into the record at the conclusion of Mr. Lantos' statement a copy of the statement made March 24, 2002 by Senator Jesse Helms on this subject. It is one of the most powerful statements I've ever read about the responsibility of human kind to look after this scourge.

So without objection, so ordered. It is my pleasure to introduce Mr. Tom Lantos.

[The prepared statement of Chairman Hyde follows:]

PREPARED STATEMENT OF THE HONORABLE HENRY J. HYDE, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ILLINOIS, AND CHAIRMAN, COMMITTEE ON INTERNATIONAL RELATIONS

The AIDS pandemic continues to claim lives in sub-Saharan Africa, the epicenter of the scourge. Seventy percent of AIDS cases exist there. Each day, more than 5000 Africans are dying from the disease. Children are suffering profoundly. Approximately 600,000 African children are getting infected each year with the HIV virus. They were infected through their mothers either when they were born, or when they were breast-fed. They have become orphans or otherwise vulnerable because their parents either have fallen ill or died. These children rarely live past the age of six because they die from an AIDS related illness or hunger. Some of these children are the head of their house hold at age eight and others as young as 3 years old, are left roaming the streets for survival. They suffer from psychological distress, economic hardship, forced withdrawal from school, malnutrition, and increased exposure to abuse. If they grow up at all, they grow up poor and uneducated, and they face every kind of abuse imaginable. I am horrified to learn about the rape of infant children by adult males in South Africa, who believe a myth that such a transgression is a form of prevention from getting AIDS. According to Reuters News Service, more than 21,000 cases of infant rape were reported to the South African police in the year 2000.

One decade from now, there will be 40 million children orphaned worldwide and without adequate care or education. Two decades from now, any surviving orphans will mature into poverty-stricken adults who are able to transmit the virus to the following generation. In Sub-Saharan Africa where the extended family is the only social security, AIDS has quickly claimed the wage-earning population. Abandoned children and the elderly who need care have been left to their own devices. Their grandparents often struggle to meet the burden placed upon them. Without worldwide, committed intervention, this international problem will wash upon the shore of every nation. The magnitude of damage increases exponentially. The world's blood supply will diminish. The number of deaths could rival any form of genocide witnessed by humankind to date. The street kids, the broken families, severed communities, and fallen economies could swell into a tidal wave of instability across Africa and beyond. We have already come to the gruesome realization that this scenario creates an enabling atmosphere for religious extremism and terrorist activity. Our enemies abroad will have a ready supply of terrorist recruits to act upon the vengeful wishes of their leaders. Worldwide, the death toll has climbed to 22 million. That amounts to 8,000 deaths per day. Ten years from now, the number is forecasted at 80 million deaths across the globe. Currently, the pandemic is spreading to our next door neighbors in the Caribbean region, to Latin America, Russia, and to Asia. This creates a clear and present danger to our national security concerns.

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Mr. LANTOS. Thank you very much, Mr. Chairman. Let me first pay public tribute to your leadership on this whole important issue. You have been steadfast and you have been creative and you have been moved by your principles and values and I deeply appreciate it. Let me also join you in recognizing the very powerful and moving statement of our colleague, Senator Jessie Helms, and I'm delighted that he has joined in this effort because his help and the help of Senator Joe Biden, on the Democratic side of the Senate Foreign Relations Committee will be invaluable to our work.

And I am delighted to acknowledge the enormous help I received from my associate, Pearl Alice Marsh, who has done so much in this field. Deeply grateful to you, Pearl Alice.

Mr. Chairman, thank you very much for convening what is clearly one of the most important hearings on the issue of HIV/AIDS in the current session of Congress. As Save the Children has so aptly put it, HIV/AIDS rivals poverty and war as a threat to the lives of millions of children in Africa. AIDS is killing parents and threatening the very life of African communities and disrupting African society. Life expectancy in Africa has plummeted, and in the most heavily effected countries, may drop to the alarming figure of just 30 years.

The pandemic is leaving in its wake millions of young boys and girls who must be cared for by families, often old relatives already too poor to sustain themselves. While vulnerable children include the victims of conflict, child slaves, children living with dying parents and children living in abject poverty, HIV/AIDS accounts for the vast majority of these vulnerable little children.

According to UNAIDS, there are 13 million children worldwide who have been orphaned because of AIDS, and 12 million of these children are in sub-Saharan Africa. These children have lost either their mother or both parents to AIDS. Our Agency for International Development estimates that by the Year 2010 the number of orphans and vulnerable children will exceed 40 million. According to UNICEF, before the AIDS epidemic hit Africa, approximately 2 percent of the children were orphaned. Now that figure has risen to over 15 percent in some countries, and it is growing daily.

Orphan children are poorer, less educated and much less healthy than other African children. The burden care for this impoverished youth is falling to families in the communities who themselves are extremely poor. Traditional coping mechanisms are being overwhelmed by this crisis.

There is no doubt, Mr. Chairman, that caring for children in community settings is consistent with African social and cultural norms that have been cultivated over centuries. While there is no single best-practice that fits all countries, all children and all needs, it is safe to say that the African way still favors extended

family or other families within the kinship network as the primary caregivers for orphans and vulnerable children.

Mr. Chairman, today we will hear from witness who will discuss a range of care options for African orphans. In addition to extended family-centered care some will propose orphanages, children's villages and other institutional arrangements. No doubt, where there is no family or community to care for a child, institutional arrangements must be made available to guarantee the well-being of that child. But institutional care in Africa is the care of last resort. I believe the current policy of building the capacities of families and communities is the most effective response to the needs of these children.

All the studies on this subject have shown that institutional care is very expensive. A study by the World Bank found that institutional care at one facility in Tanzania costs a thousand dollars per child per year. A figure six times more expensive than the average cost of family care in that country. Other studies have found that institutional care is as much as 20 times as expensive as care provided within the family structures. Think of what these extra resources could do to increase the ability of many families to care for their own.

To deal with the problem of orphans and vulnerable children, we must deal with the wider context in which they live. That means investing in communities, in schools and in clinics, in self-help and incoming-generating projects, in the kind of development that offers food security. It is imperative, Mr. Chairman, that we help families provide the social and economic protection for their children and create thriving communities where children can flourish and grow.

Mr. Chairman, we all look forward to hearing from our witnesses and learning from them some of the ways in which we in the Congress can help shape a global AIDS strategy that truly will leave no child behind. The future of Africa will be determined by how we care for these vulnerable children and we must do our best. Thank you, Mr. Chairman.

Chairman HYDE. Thank you, Mr. Lantos. Before we proceed to the film, Mr. Gilman requests the opportunity to make a statement.

Mr. GILMAN. Thank you, Mr. Chairman. I want to thank Chairman Hyde for arranging today's important hearing. The scourge of AIDS and its effect on children, particularly in Africa as well as elsewhere around the world is a matter that deserves our Committee's close attention and an ongoing commitment. As President Bush has said, we must leave no child behind—and that applies to AIDS as well.

More than 58 million people worldwide have been affected with HIV/AIDS, making it more than just a humanitarian issue. And over 28 million of those are in Africa, and an estimated 2.8 million died of AIDS just last year. HIV/AIDS has been a national security and developmental crisis. It's been reported that 95 percent of the world's HIV infected people live in developing nations. Children are the most vulnerable victims of HIV/AIDS and over 6.5 million children have been orphaned because of this disease.

Last winter, the House adopted H.R. 2069, legislation authorizing \$1.3 billion in assistance to prevent, treat, and monitor HIV/AIDS in sub-Saharan Africa and other developing nations. And I strongly supported that measure as well as co-sponsoring it. I'm pleased, therefore, that today we'll have the opportunity to hear from our witnesses about this important crisis and efforts at identifying the best practices for care, for treatment and for prevention.

It was Secretary Powell who said it well when he stated that the United States has an obligation to do more. If we believe in democracy and freedom, then we must work to stop this catastrophe from destroying whole economies and families and societies and cultures and nations.

We look forward today to the testimony of Dr. Peterson. Father D'Agostino came out of the sick bed to be with us today. Our Director Dunigan, Vice President Casey, and Mrs. Gilborn. Thank you, Mr. Chairman.

Chairman HYDE. Thank you, Mr. Gilman. Ms. Lee of California.

Ms. LEE. Thank you, Mr. Chairman. I want to thank you and our Ranking Member for holding today's hearings on AIDS orphans and vulnerable children. And also, for your leadership in ensuring that our response continues to be bipartisan.

I would also like to thank our distinguished panelists who have joined us today to share their expertise in responding to the AIDS pandemic and its impact on orphans and vulnerable children. The global AIDS, Tuberculosis and Malaria pandemics really represent the greatest humanitarian crisis of our time. More than 2000 children worldwide are infected with HIV every day, and 90 percent are in resource-poor nations.

Each day 15,000 people die from AIDS, TB, and Malaria. These are manageable and treatable disease. According to a report by UNICEF, young people that have lost one or both parents are among the most vulnerable members of society. In sub-Saharan Africa, this is especially true because few support systems exist outside the family and basic social services are not provided broadly.

I recently returned from Africa. I participated in a bipartisan delegation lead by Department of Health and Human Services Secretary Tommy Thompson. This was a very powerful and very successful visit. We visited facilities in several countries where care was being provided, but there were still orphans, orphanages and hospices on one facility at one site. In Mozambique, I looked around and realized that the people in our delegation actually were the oldest people around because the average life expectancy now is between 36 to 37 years old.

These were very powerful and moving reminders, but also, Mr. Chairman, they were mind-boggling. What immediately came to mind was that the majority of the people that are dying are in what really should be the most productive times of their lives. Yet, at a time when families are developing and sowing deep roots in the community, AIDS, TB, and Malaria are destroying the social fabric of these communities.

The number of children who are forced to raise each other is growing because their families, their parents are dying at alarming rates. In many instances, orphan children are sent to live with extended family members who are forced to stretch scarce resources

to care for them and are dealing with AIDS in their immediate families as well.

In Botswana, due to AIDS alone, the population growth is negative. And this means, of course, there are more people dying from AIDS than there are babies being born. The AIDS, TB and Malaria pandemic present and represent a great challenge. This crisis is complex and requires a multi-faceted and comprehensive response. It is urgent that we mobilize strong United States and international action to prevent infants from becoming infected with HIV, and that we care for those who are infected and affected by the horrific disease.

If we are to have a positive impact on this issue, our response must include mother-to-child treatment programs and community-based strategies to provide health care, education, nutrition and psycho-social support. I am convinced that if we focus only on building orphanages, we will only help a small number of children. We do need a village-based, multi-faceted strategy. The use of Nevarapin to reduce the transmission of HIV from mother to child must not end there. Nevarapin and other AIDS medicines must also be used to maintain the health of mothers so that they can care and participate in their children's lives. This will help reduce the impact of AIDS on these families.

Now I understand the lack of resources and infrastructure in many of these communities, but I have heard from health experts who work in countries on orphans and vulnerable children programs, and according to them, as our Ranking Member so eloquently said earlier, extended families and village-centered strategy should be a priority and orphanages should be an intervention of last resort.

As children experience the death of one or both parents, they must have the necessary tools and support to deal with the stress, anxiety and depression that accompany these horrific circumstances.

At this time, I'd like to request the Chairman's permission to include for the record a report recently released by the Elizabeth Glazer Pediatric AIDS Foundation, which provides background information and recommendations for United States government policy on the prevention of mother-to-child transmission of HIV and AIDS.

Currently, USAID is spending \$20 million—that is about 5 percent of their global AIDS budget. At a minimum, I believe that number should be increased to 20 percent.

Chairman HYDE. Without objection, the gentlelady's motion to include, for the record, the report of April 2002 from the Elizabeth Glazer Pediatric AIDS Foundation is agreed to.

[The information referred to follows:]

UNITED STATES GOVERNMENT POLICY ON PREVENTION OF MOTHER-TO-CHILD  
TRANSMISSION (MTCT) OF HIV IN RESOURCE POOR NATIONS:

BACKGROUND AND RECOMMENDATIONS FROM THE ELIZABETH GLASER PEDIATRIC AIDS  
FOUNDATION—APRIL 2002

For more information on the topic of this policy paper, please contact:

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#### **ABOUT THE FOUNDATION**

*The Elizabeth Glaser Pediatric AIDS Foundation is the leading worldwide nonprofit organization dedicated to identifying, funding, and conducting pediatric HIV/AIDS research as well as promoting global education, awareness and compassion about HIV/AIDS in children. In addition, the Foundation is committed to working on other serious and life threatening diseases facing children through the newly created Glaser Pediatric Research Network. The Network brings together five of the nation's pre-eminent academic medical centers in an unprecedented collaboration that will accelerate better treatments for seriously ill children, help train the next generation of pediatric clinical investigators, and serve as a united voice to advocate policies that improve children's health worldwide. Since 1988, the Foundation has raised more than \$130 million to ensure that children are at the forefront of every scientific breakthrough. Please visit our Web site for more details at [www.pedaids.org](http://www.pedaids.org).*

#### **EXECUTIVE SUMMARY**

*Simple, Low-Cost Intervention Can Save Lives:* More than 2,000 children are infected with HIV worldwide every day, and 90 percent are in resource poor nations. It is urgent that we mobilize strong U.S. and international action to prevent infants from becoming infected with HIV. By bringing simple, effective interventions to mothers and newborns in resource poor countries, we can dramatically reduce the rate of MTCT. A joint Uganda/U.S. study showed that one such drug, nevirapine, reduces transmission of HIV from a mother to her newborn by approximately 50 percent. Other interventions are also available. If we were able to reach every HIV-positive pregnant mother with counseling, testing, and a drug intervention, we could prevent 400,000 infections per year.

*Treatment and Care of Family Members—The Next Step:* In addition, efforts to prevent mother-to-child transmission are also important because they provide the basis for a wider response that includes care of mothers, fathers, and other family members. A program to accomplish this, called "MTCT-Plus," was recently spearheaded by the Rockefeller Foundation.

*Current U.S. Government Policy on Preventing MTCT of HIV:* Current law recognizes the importance of prevention of MTCT in responding to global HIV/AIDS. The Global AIDS and Tuberculosis Relief Act of 2000 directs the United States Agency for International Development (USAID) to make MTCT prevention activities "a major objective" of its work to combat HIV/AIDS in resource poor nations. The law specifically requires that 8.3 percent of all funds appropriated for global AIDS efforts by USAID be made available for MTCT prevention activities. Appropriators are insisting that USAID meet this target by the end of fiscal year 2003.

In addition, the Bush Administration committed the United States to a series of goals at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS). These goals include reducing the proportion of infants infected with HIV by 20 per cent by 2005, and by 50 per cent by 2010.

*Current Activities of U.S. Agencies Aimed at Preventing MTCT Abroad:* USAID is currently collaborating on MTCT prevention efforts at more than 10 sites in 6 nations, and CDC is providing partial support in at least 6 different nations.

*Status of Private and In-Country Efforts to Prevent MTCT of HIV:* Several non-profit entities, including the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), UNICEF, Medecins San Frontieres (Doctors Without Borders), and the Catholic Medical Mission Board (CMMB), have initiated projects to prevent mother-to-child transmission of HIV in resource poor nations. Some resource poor countries have initiated in-country programs to prevent MTCT of HIV. These programs vary in size and quality.

#### **Policy Recommendations for the U.S. Government in Preventing MTCT:**

##### *Recommendations for Authorization Legislation:*

- Rapid expansion of programs to prevent MTCT should be a priority activity for USAID and CDC;
- U.S. spending on MTCT prevention should be aimed at meeting the UNGASS targets of a 20 percent reduction in MTCT infections by 2005 and a 50 percent reduction by 2010. The current 8.3 percent spending target for USAID MTCT activities should be the current goal for both USAID and CDC, and spending should be boosted above these amounts as needed to meet UNGASS targets;

- USAID, CDC, and NIH should sponsor operational research aimed at improving the success of MTCT prevention programs;
- The MTCT efforts of USAID and CDC should be closely coordinated;
- The two agencies should continue to stress partnerships with NGOs and efforts to scale up to nationwide programming in some nations;
- With non-MTCT resources, the agencies should expand services at established MTCT sites to include care and treatment for families;
- Congress should receive detailed yearly reports on progress in meeting UNGASS MTCT prevention targets; and
- USAID and CDC should continue to increase MTCT prevention programs in Africa but should also expand to regions where the AIDS pandemic is also threatening, including Latin America, Eastern Europe and Russia, and Southeast Asia (including India and China).

*Recommendations for Appropriations Legislation:*

- For fiscal year 2003, a minimum of \$1.3 billion should be provided for U.S. bilateral HIV/AIDS programs, coupled with at least \$1.2 billion for the Global Fund to Fight AIDS, Tuberculosis, and Malaria;
- Appropriators should insist on rapid expansion of MTCT prevention activities and improvement in the quality of these programs;
- There should not be any waiver of specific spending targets included in authorizing legislation;
- The Helms-Frist proposal for \$500 million in emergency spending on MTCT prevention should be approved with some modifications; and
- Appropriators should also insist on key policies (described in detail above) that will advance MTCT efforts in resource poor countries.

*Other Recommendations:*

- The United States should use its influence to ensure that the Global Fund to Fight AIDS, Malaria and Tuberculosis places an appropriate emphasis on approval of grants for prevention of MTCT and for related treatment and care of other family members;
- Diplomatic, trade, and development discussions with resource poor nations should make clear that the United States views a strong response to HIV/AIDS as an essential element in protecting economic, social, and security interests of those nations and the entire world.

WHY PREVENTION OF MOTHER-TO-CHILD TRANSMISSION IS SO IMPORTANT:

*Simple, Low-Cost Intervention to Save Lives:* More than 2,000 children are infected with HIV worldwide every day, and 90 percent are in resource poor nations. HIV transmission from mother to child can occur during pregnancy, during labor and delivery, and through breast milk. Reducing mother-to-child transmission (MTCT) of HIV is vital, particularly in areas of the world most affected, such as sub-Saharan Africa. In some nations, more than a third of pregnant women are infected with HIV, and 25–35% of their children will be born infected. Other regions, including Latin America, Eastern Europe and Russia, and Southeast Asia have rapidly increasing rates of infection.

By bringing simple, effective interventions to mothers and newborns in countries, we can dramatically reduce the rate of MTCT. A joint Uganda/U.S. study showed that one such drug, nevirapine, reduces transmission of HIV from a mother to her newborn during birth by approximately 50 percent. Although breast-feeding continues to infect infants afterward, this Ugandan study found that nevirapine still reduced transmission by 41% for babies that are breastfed through 18 months of age. Nevirapine is administered in a single dose to the mother at the onset of labor and in a single dose to the baby during the first three days of life. The entire course costs less than \$4, and the drug is now available free or at a reduced cost in many instances.

There are also several other drug regimens that can be used to prevent mother-to-child transmission of HIV, including zidovudine (AZT) or zidovudine and lamivudine (AZT and 3TC). The Elizabeth Glaser Pediatric AIDS Foundation believes strongly that decisions on which regimen should be used are most appropriately made by local authorities. However, it is urgent that one of these interventions be made available to HIV-positive pregnant women.

Despite the efforts of several non-profits, including the Elizabeth Glaser Pediatric AIDS Foundation, and a limited initial U.S. government investment in preventing

MTCT, there are inadequate resources to meet the enormous need. As a result, over 800,000 children continue to become infected with HIV each year. It is imperative that we mobilize strong U.S. and international action to prevent infants from becoming infected with HIV. If we were able to reach every HIV-infected pregnant mother with counseling, testing, and if needed, a drug intervention, we could prevent as many as 400,000 infections per year.

*Treatment and Care of Family Members—The Next Step*

In addition, efforts to prevent mother-to-child transmission are also important because they provide the basis for a wider response that includes care of mothers, fathers, and other family members.

In order to put in place a program to prevent mother-to-child transmission, it is necessary to mobilize communities, train health care workers, initiate voluntary counseling, establish laboratory testing of mothers, and create an infrastructure for the delivery of a simple drug intervention. Women who are not infected receive information to help them protect themselves from acquiring infection. Once these steps have been taken, it is possible to begin to provide counseling and testing to additional adults and children. A population of HIV-positive women and children may be identified to receive care, including treatment of opportunistic infections and/or antiretroviral therapy.

While it is vitally important to prevent HIV transmission to children, the infants whose lives are spared through these interventions face a difficult existence if one or both of their parents become ill or die due to HIV infection. According to UNAIDS, more than 13.2 million children have been orphaned by the AIDS epidemic since it began, and that number is forecast to more than double by 2010. Many of these orphans will be susceptible to malnutrition, illness, abandonment, loss of education, abuse or recruitment into gangs or militias. The entire world has an interest in preventing this from happening by keeping parents alive and families together. The simplest and most logical way to do this is to widen the array of services offered at MTCT prevention sites to include family members.

Luckily, a major initiative to accomplish this goal is already underway. "MTCT-Plus," a program recently spearheaded by the Rockefeller Foundation and funded by a group of major foundations, will commit up to \$100 million to expand MTCT sites to include care and treatment services for family members, including treatment of opportunistic infections associated with HIV/AIDS and antiretroviral therapy. The program is being coordinated through the Mailman School of Public Health at Columbia University.

While a comprehensive response to the global HIV/AIDS epidemic may seem at times too massive and difficult to organize and fund, MTCT Plus offers a realistic initial strategy for expanding care and treatment services so that entire families are spared the worst ravages of the disease. These efforts will have an immediate and long-lasting positive impact on the entire world's economic, social, and security interests.

CURRENT U.S. GOVERNMENT POLICY ON PREVENTING MTCT OF HIV:

There is a consensus among many congressional and executive branch leaders that prevention of MTCT of HIV is an essential element of the global effort to combat HIV/AIDS that deserves special emphasis.

*Current Authorizing Law:* The Global AIDS and Tuberculosis Relief Act of 2000 is the law that provides authorization for the government's current efforts to combat HIV/AIDS around the world. This legislation contains several references to efforts to prevent MTCT.

Among the findings of this law is the fact that "the discovery of a relatively simple and cheap means of interrupting the transmission of HIV from an infected mother to the unborn child . . . has created a great opportunity for an unprecedented partnership between the United States Government and the governments of Asian, African and Latin American countries to combat mother-to-child transmission (also known as 'vertical transmission') of HIV." The law further finds that "a mother-to-child antiretroviral drug strategy can be a force for social change, providing the opportunity and impetus needed to tackle often long-standing problems of inadequate services and the profound stigma associated with HIV-infection and the AIDS disease. Strengthening the health infrastructure to improve mother-and-child health, antenatal, delivery and postnatal services, and couples counseling generates enormous spillover effects toward combating the AIDS epidemic in nations."

In addition, the law specifically amends the Foreign Assistance Act to emphasize the importance of preventing MTCT. The amended Act (22 U.S. C. 2151b(c)(4) now reads as follows:

(A) Congress recognizes the growing international dilemma of children with the human immunodeficiency virus (HIV) and the merits of intervention programs aimed at this problem. Congress further recognizes that mother-to-child transmission prevention strategies can serve as a major force for change in regions, and it is, therefore, a major objective of the foreign assistance program to control the acquired immune deficiency syndrome (AIDS) epidemic.

(B) The agency primarily responsible for administering this part shall-

- (i) coordinate with UNAIDS, UNICEF, WHO, local governments, and other organizations to develop and implement effective strategies to prevent vertical transmission of HIV; and
- (ii) coordinate with those organizations to increase in scale intervention programs and introduce voluntary counseling and testing, antiretroviral drugs, replacement feeding, and other strategies.

Further, the law provides that authorized assistance will include funding for voluntary counseling and testing, and medications to prevent the transmission of HIV from mother to child. Importantly, the law specifically requires that 8.3 percent of all funds appropriated for global AIDS efforts by the United States Agency for International Development (USAID) be made available to carry out the strategy for preventing MTCT.

*Current Appropriations Language:* House and Senate appropriators have concurred with the authorizing committees about the importance of preventing mother-to-child transmission. In the conference report to accompany the Foreign Operations Appropriations Act for fiscal year 2002, appropriators "urge that expanded resources be made available to mother-to-child transmission (MTCT) programs." However, appropriators also expressed their opinion that USAID would be unlikely to meet the specific target of devoting 8.3 percent of overall HIV/AIDS funding to MTCT prevention programs this year. Therefore, the appropriators indicated that they expect the agency to meet this goal by the end of fiscal year 2003.

*Commitment to United Nations Goals:* The United States participated in the United Nations Special Session on HIV/AIDS in June 2001. A delegation appointed by President Bush attended the session and committed the United States to a series of goals that were endorsed by participating nations. These goals include the following specific goal for prevention of MTCT:

"By 2005, reduce the proportion of infants infected with HIV by 20 per cent, and by 50 per cent by 2010, by ensuring that 80 per cent of pregnant women accessing antenatal care have information, counselling and other HIV-prevention services available to them, increasing the availability of and providing access for HIV-infected women and babies to effective treatment to reduce mother-to-child transmission of HIV, as well as through effective interventions for HIV-infected women, including voluntary and confidential counselling and testing, access to treatment, especially anti-retroviral therapy and, where appropriate, breast-milk substitutes and the provision of a continuum of care;"

#### CURRENT ACTIVITIES OF U.S. AGENCIES AIMED AT PREVENTING MTCT ABROAD

Several agencies of the United States government are working in nations to reduce mother-to-child transmission of HIV.

*United States Agency for International Development (USAID):* As noted above, USAID has been directed by Congress to expend at least 8.3 percent of overall global HIV/AIDS funds on programs to prevent mother-to-child transmission.

USAID has initiated a number of collaborative programs aimed at meeting this directive. As of March 2002, USAID is providing direct support to 10 MTCT prevention sites, including 3 in Kenya, 2 in Zambia, 4 in Rwanda, and one in Ukraine. USAID is also providing indirect support to other sites in Uganda and South Africa. USAID has also invested in operations research aimed at improving the delivery of MTCT prevention services.

USAID works in a decentralized manner and cannot dictate directly to its missions their participation in specific programs, including MTCT prevention programs. However, USAID can work cooperatively with its missions to emphasize the importance of MTCT prevention programs and to make clear that additional funds are available for this purpose.

*Centers for Disease Control (CDC):* According to material compiled by the Centers for Disease Control in August 2001, the CDC has assisted with mother-to-child transmission prevention programs in at least 6 different nations, including Botswana, Cote D'Ivoire, Kenya, Uganda, South Africa, and Thailand. EGPAF is a partner in Uganda, Kenya and South Africa.

According to separate information received from CDC, preventing mother-to-child transmission is a priority in most countries where CDC's global AIDS program is active. As of March 2002, specific information about CDC's involvement in MTCT prevention activities in other nations was being compiled by the agency.

In general, CDC seeks to collaborate with other government agencies, multilateral institutions and NGO partners to provide funding and technical assistance to address host countries' needs. CDC has prepared a technical strategy for MTCT that emphasizes development of a monitoring database and computer system for national programs; training manuals and training capacity; videos and counseling media packages; community mobilization strategies and activities; and development of evaluation and operational research projects.

CDC works through programs that are initiated in-country. CDC can successfully influence the extent of emphasis on prevention of MTCT in-country by emphasizing scale-up as part of its support.

*Department of Defense:* The U.S. Army maintains research labs in several parts of the world that conduct research on several HIV/AIDS related issues, including vaccines and mother-to-child transmission. While this agency does not implement programs aimed at preventing mother-to-child transmission, it is providing laboratory support for an EGPAF program in Kericho district in Kenya, and it will soon do the same for 12 other sites in Kenya. In addition, the Army has provided important technical assistance.

#### STATUS OF PRIVATE AND IN-COUNTRY EFFORTS TO PREVENT MTCT OF HIV

*Private Non-Profit Efforts:* Several private, non-profit entities, including the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), Medecins San Frontieres (Doctors Without Borders), and the Catholic Medical Mission Board (CMMB), have initiated projects to prevent mother-to-child transmission of HIV in nations.

- *Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)*'s "Call to Action" Program: EGPAF's Call to Action program provides funds to in-country applicants for community mobilization and training of health care workers, HIV counseling and testing, antiretroviral prevention regimens, and infant feeding education. EGPAF-funded projects have already trained more than 450 health care workers and tested approximately 40,000 women. The project's site total has grown to over 100 locations in the following 13 countries: Angola, Cameroon, Congo, Kenya, Malawi, Russia, Rwanda, South Africa, Tanzania, Thailand, Uganda, Zambia, and Zimbabwe. These sites have projected the capacity to bring prevention of mother-to-child transmission programs to more than 250,000 women in prenatal care in the next two years. Experience gained from these diverse sites, which are rural, urban, large and small, will be helpful in determining policy for nations that have yet to initiate MTCT prevention programs.

EGPAF is planning to scale up its programs to help achieve nationwide coverage in several nations, beginning in Uganda. A grant to the Ministry of Health and a cost benefit analysis to help accomplish the Uganda scale-up has already been approved by the Foundation.

Many EGPAF sites are expected to become early participants in the MTCT-Plus initiative and are currently planning to expand their services to provide care and support, including antiretroviral therapy for mothers, families, and children affected by HIV/AIDS.

The goal of EGPAF's international program is to demonstrate the success of MTCT programs in rural and urban areas throughout the parts of the world where the epidemic is most threatening, including Africa, Eastern Europe and Russia, the Caribbean, Latin America, and Southeast Asia. It is hoped that this success will spur governments, private donors, and international organizations to rapidly expand and improve the quality of this important service so that more HIV-positive mothers and families are offered life-saving interventions.

- *Medecins Sans Frontieres (Doctors Without Borders)*: Doctors Without Borders, an international organization providing health care to those who have no access, has a number of sites where MTCT prevention services are offered, including a site near Capetown, South Africa, and a site in the Ukraine. EGPAF has requested additional information from Doctors Without Borders, which maintains a U.S. office in New York City.
- *Catholic Medical Mission Board (CMMB)*: CMMB, a Catholic charity providing humanitarian assistance in nations, has one existing MTCT prevention project near Durban, South Africa and is likely to initiate two others in South

Africa in the near future. In the Durban program, women attending a clinic are offered counseling, treatment of some opportunistic infections (OIs), education on nutrition and breastfeeding options, and advice on caring for themselves and their babies.

*UNICEF's MTCT Prevention Efforts:* UNICEF has initiated a series of projects aimed at preventing mother-to-child transmission of HIV. In an August 2001 document on its efforts to prevent MTCT, UNICEF reports that it is providing funding at 79 sites in 16 countries, two of which are national programs.

In Africa, UNICEF reports sites in Uganda, Kenya, Tanzania, Malawi, Zimbabwe, Botswana, Zambia, Burundi, Rwanda, and Cote d'Ivoire. In Southeast Asia, UNICEF reports programs in India, Myanmar, and Cambodia. In Eastern Europe, UNICEF has assisted the governments in initiating nationwide programs in Belarus and Ukraine. And in Central America, UNICEF has sites in Honduras.

Through July 2001, over 300,000 women have been reached, 220,000 have been counseled, 138,000 have been tested, and out of the 11,400 HIV positive mothers identified, over 4,500 have received antiretroviral therapy to reduce MTCT.

A recent document from UNICEF stresses that in reaching the goals agreed to at UNGASS for prevention of MTCT (reducing the number of infected children by 20 percent by 2005; and by 50 percent by 2010), "the challenge will be to scale up with much improved levels of counseling, acceptance of HIV testing, and compliance with intervention. Cooperation between implementing partners and development of a common operational strategy are needed."

UNICEF is also one of the key players expected to apply for support from the MTCT-Plus initiative described above.

*In-Country Programs:* Finally, many countries have initiated domestic programs to prevent MTCT of HIV.

The leadership of some nations in reducing MTCT is particularly noteworthy. Thailand's Ministry of Health initiated a nationwide effort to reduce MTCT several years ago, working with partners including the Elizabeth Glaser Pediatric AIDS Foundation and the Centers for Disease Control. As noted above, Uganda is currently planning to scale up its programs on a nationwide basis in partnership with the Elizabeth Glaser Pediatric AIDS Foundation, UNICEF, and others.

In these instances, governments have the will to act but do not have all of the resources needed to achieve results. However, in other instances, leadership is tragically absent. For example, the South African government has failed over an extended period of time to provide women in that nation with universal access to necessary preventive interventions, despite a scientific consensus that this will save thousands of lives. The government has dragged its feet, even after activists successfully obtained a court ruling ordering the government to provide universal preventive treatment to pregnant women who request it.

#### CURRENT CONGRESSIONAL LEGISLATION ON MTCT:

Reflecting the importance placed on MTCT by policymakers, several global AIDS authorizing bills contain provisions emphasizing the importance of MTCT prevention activities. These include:

*H.R. 2069, Global Access to HIV/AIDS Prevention, Awareness, Education, and Treatment Act of 2001 (Hyde/Lantos/Lee):*

H.R. 2069 is the broad authorizing bill passed by the House of Representatives in 2001. This bill increases authorized funding levels for both bilateral and multilateral funding for HIV. There is language that says that the US should provide assistance in Africa and other affected countries thru prevention, treatment and care and that assistance should be particularly focused on women and youth. Prevention of MTCT is specifically mentioned as part of this assistance.

*H.R. 684, Legislation to Authorize Assistance for Mother-to-Child Transmission Prevention Efforts (Millender-McDonald):*

This bill authorizes the CDC to establish pilot programs in sub-Saharan Africa and India to prevent MTCT through effective partnerships with non-government organizations and university-based research facilities. The legislation authorizes \$5 million per year from 2002-2004 to carry out these programs, which will provide voluntary counseling and testing, nevirapine and education around replacement feeding. These pilot programs will establish best practices locally before expanding services more widely.

*S. 1120, the Global AIDS Research and Relief Act of 2001 (Boxer/Smith):*

This bill focuses on the needs of children affected by HIV, with a strong emphasis on prevention of mother-to-child transmission and orphan care. It calls on USAID to coordinate with other U.S. agencies, UN agencies, national and

local governments to implement MTCT prevention strategies. It also calls on USAID to develop a comprehensive and coordinated effort to fight HIV/AIDS which would include voluntary counseling and testing, the provision of drugs for MTCT prevention, and additional support for health care infrastructure. The bill authorizes \$600 million FY 2002 and 2003 to fight global HIV/AIDS, with a strong priority placed on prevention of MTCT and orphan support.

*S. 1032, the International Infectious Diseases Control Act of 2001 (Frist/Kerry/Helms):*

This bill is designed to authorize U.S. contributions to the Global Fund to Fight AIDS, Tuberculosis and Malaria. It also sets standards for U.S. participation in the Fund. The bill emphasizes the importance of prevention activities and lists prevention of MTCT as one important prevention activity.

*S. 1230, Global Leadership in the Expanded Response (GLIDER) Act (Frist/Clinton):*

This bill authorizes and coordinates the activities of different federal agencies that fight global HIV/AIDS. The bill specifically authorizes CDC to conduct MTCT prevention programs, but makes no mention of a State Department or USAID role in MTCT prevention.

*S. 1936, the Global Coordination of HIV/AIDS Response Act/Global CARE Act (Durbin):*

This bill, which focuses on authorizing and coordinating the activities of each federal agency, authorizing contributions to the Global Fund to Fight AIDS, Tuberculosis, and Malaria, and authorizing a global physician corps, does not contain any specific MTCT provisions.

*Helms/Frist Amendment to Supplemental Appropriations Act for Fiscal Year 2002:*

While not introduced in bill form, Senator Helms and Frist have proposed an amendment to the Supplemental Appropriations Act for Fiscal Year 2002 that calls for \$500 million in additional spending for prevention of mother-to-child transmission of HIV. This proposal would be contingent on a one-to-one match with private sector contributions for this purpose.

#### POLICY RECOMMENDATIONS FOR THE U.S. GOVERNMENT IN PREVENTING MTCT

Efforts to prevent mother-to-child transmission of HIV are a bright spot in the AIDS epidemic. We have a successful, simple and relatively low-cost technique of preventing a substantial number of infections in children that can be applied in the world. If we were able to reach all infected mothers with the needed intervention, we could prevent as many as 400,000 infections per year. Thus, we should take a series of important steps aimed at scaling up the world's efforts:

- *Authorize Expanded U.S. Efforts:* At the end of 2001, the House of Representatives passed global AIDS authorizing legislation aimed at expanding U.S. bilateral and multilateral efforts to stem the tide of the pandemic. It is now expected that the Senate will consider similar legislation in the near future. It is important that the U.S. government send a signal through this legislation that it is firmly committed to a comprehensive and amply funded response to global HIV/AIDS. Such legislation should strongly emphasize the importance of rapid expansion and improvement in the quality of MTCT prevention programs. Specifically, authorizing legislation should accomplish the following important recommendations:
  - *Rapid Expansion of MTCT Should be a Priority Activity for USAID, CDC:* It is important that the United States emphasize rapid expansion of USAID's and CDC's MTCT prevention efforts. The UNGASS targets agreed to by the Bush Administration call for a 20 percent reduction in MTCT infections by 2005 and a 50 percent reduction by 2010. USAID has already adopted UNGASS targets as benchmarks for its own programs, and CDC should do the same.
  - *Spending Should Aim to Meet UNGASS Targets:* The Global AIDS and Tuberculosis Relief Act calls on USAID to spend at least 8.3 percent of its total AIDS funding on MTCT prevention, and appropriators are insisting that USAID meet this target by the end of 2003. While EGPAF is working successfully in partnership with both USAID and CDC and has great admiration for their expertise and commitment, we are concerned that expansion of their MTCT activities is not occurring as rapidly as possible. While we have been reluctant to advocate for a specific numerical goal, we now believe that the global AIDS authorizing legisla-

tion should insist on the 8.3 percent target as a current target for spending on the MTCT prevention activities of both USAID and CDC. Further, spending should be boosted above these amounts as needed to meet UNGASS targets.

If Congress chooses to implement this recommendation, it should be careful not to include in the calculation funds over which USAID and CDC have no control, such as funds that have been earmarked for other purposes, or funds specifically devoted to the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Ultimately, in assessing the performance of U.S. agencies, it is important to note that UNGASS targets are worldwide goals and will require the effective participation of many players if the goals are to be successfully reached.

- *Immediate Research Needed to Improve Effectiveness of Programs:* While it is crucial, funding is not the only obstacle to the success of MTCT prevention programs. The current quality of MTCT programs is not sufficient to meet the UNGASS targets. USAID, CDC, and NIH should initiate additional operational research aimed at increasing the number of women who agree to counseling and testing, and the number of HIV positive women who receive a drug intervention, along with their infants, to prevent HIV infection. Careful consideration should be given to new policies, such as offering nevirapine to mothers who refuse testing or wish to opt out of testing, or offering nevirapine to all mothers in high prevalence areas, if these policies are found to achieve significant reductions in the number of infections. In addition, the agencies should move ahead forcefully with study of other MTCT-related issues, such as the best strategies for preventing infection through breastfeeding, that will further decrease the number of infants infected.
- *MTCT Efforts of Both Agencies Should Be Coordinated:* It is important that *both* USAID and CDC be authorized to move ahead rapidly on MTCT prevention activities, since both have shown commitment and expertise in this area. The two agencies already coordinate some of their activities, and they should be strongly encouraged to expand this coordination in order to ensure that there is not overlap or duplication of services. They should also be urged to coordinate with the Global Fund to Fight AIDS, Tuberculosis, and Malaria. All of this coordination should be accomplished through a common strategy aimed at achieving the UNGASS targets.
- *Partnerships and Nationwide Programs Should be Emphasized:* Rapid expansion should include close cooperation with the governments of nations, non-governmental organizations, and international organizations. In many instances, it will be most advantageous for USAID and CDC to become partners in joint ventures that include these participants, as they now do. Along these lines, USAID and CDC should join in cooperative efforts to expand MTCT programs nationwide in some select nations that have shown excellent progress to date.
- *Agencies Should Support Additional Care and Treatment:* As USAID and CDC expand MTCT prevention efforts, they should also initiate efforts—with other HIV/AIDS resources not specifically devoted to MTCT prevention—to provide services at established MTCT sites to include care and treatment for family members, including treatment of opportunistic infections (OIs), psychosocial support, antiretroviral therapy, family planning, and STD diagnosis and treatment. During fiscal year 2002 and then in subsequent years, established MTCT sites should be examined to determine if such an expansion of services could be successfully achieved. Ultimately, consideration should be given to expanding MTCT sites to include access to key non-medical services, such as economic assistance, nutrition education, food assistance, legal assistance, and succession planning for children.
- *Congress Should Request Yearly Reporting:* Congress should ask for yearly reporting on progress in expanding MTCT efforts by both agencies, including information on the number of sites supported, the specific activities supported, the number of women tested and counseled, the number of women receiving preventive drug therapies, the percentage of global HIV/AIDS funds expended for MTCT activities, and the progress of U.S. activities in helping achieve UNGASS targets. USAID and CDC

should also report yearly on their efforts to expand care and treatment services for families at established MTCT prevention sites.

- *USAID and CDC Should Expand Geographically:* While programs in Sub-Saharan Africa are of crucial importance at this point in time, it is also very important that USAID and CDC be encouraged to develop programs in parts of the world where the AIDS pandemic is expanding rapidly. This includes Latin America, Eastern Europe and Russia, and Southeast Asia (including India and China).
- *Rapidly Expand Appropriations:* Appropriators must recognize the urgency of the worldwide HIV/AIDS pandemic by rapidly increasing the United States contribution to bilateral and multilateral programs. For fiscal year 2003, a minimum of \$1.3 billion should be provided for U.S. bilateral HIV/AIDS programs, coupled with at least \$1.2 billion in contributions to the Global Fund to Fight AIDS, Tuberculosis, and Malaria. Appropriators should also insist on rapid expansion of MTCT prevention activities:
  - *No Waiver of Numerical Targets:* While it is understandable that USAID and CDC have had some difficulties in expanding MTCT activities, it is now urgent that the agencies move ahead as swiftly as possible. Therefore, appropriators should not waive numerical targets contained in authorizing legislation and should require accounting, as described above, of progress to date.
  - *Insist on Strong MTCT Efforts by Agencies:* The Appropriations Subcommittees should also insist on key policies (described in detail above) that will advance MTCT efforts in countries as quickly as possible. This should include strong efforts to improve the quality of MTCT prevention programs by increasing the number of HIV-positive women who receive drug interventions to prevent infection of their infants.
  - *Pass Helms-Frist Proposal for Supplemental Funding in Fiscal Year 2002:* EGPAF strongly supports the Helms-Frist proposal to appropriate \$500 million in emergency funds to prevent mother-to-child transmission of HIV in the developing world. This proposal can have a tremendous impact in a short time frame in reducing AIDS deaths. Moreover, it can also be an effective first step toward providing expanded care and treatment of entire families. Along with new funds for USAID, appropriators should include funds for MTCT prevention efforts by CDC. Appropriators should consider whether a strict one-to-one match with private sector contributions would be too onerous a burden. They should also insist that funds already be expended in the private sector, as well as in-kind contributions, be counted toward whatever match is ultimately adopted.
- *Ensure that Global Fund Acts to Support MTCT and Care and Treatment of Infected Family Members:* As one of the major contributors to the Global Fund to Fight AIDS, Tuberculosis and Malaria, the United States should use its influence to ensure that the Fund places an appropriate emphasis on approval of grants for prevention of MTCT and for treatment and care of infected family members.
- *Work with Resource Poor Nations on Strong MTCT Prevention Plans:* Diplomatic, trade, and development discussions with resource poor nations should stress the importance of these nations providing strong leadership in responding to HIV/AIDS in general and to prevention of MTCT specifically. Resource poor nations should be well aware that the United States views a strong response to HIV/AIDS as an essential element in protecting economic, social, and security interests in those nations and throughout the world.

#### SPECIFIC BILL AND REPORT LANGUAGE RECOMMENDATIONS:

##### *Suggested Bill Language:*

- *USAID:*

Bill language should make clear that:

- MTCT prevention is a priority goal of U.S. global AIDS policy;
- USAID is authorized to conduct MTCT and related treatment and care of family members in furtherance of that goal;
- USAID's MTCT activities should be coordinated with CDC; and

- The spending target for MTCT prevention activities contained in the Global AIDS and Tuberculosis Relief Act of 2000 is a current goal, and spending should rise above this level as needed to meet UNGASS targets.
- *CDC:*
  - Bill language should make clear that:
    - MTCT prevention is a priority goal of U.S. global AIDS policy;
    - CDC is authorized to conduct MTCT and related treatment and care of family members in furtherance of that goal;
    - CDC's MTCT activities should be coordinated with USAID; and
    - The spending target for MTCT prevention activities by USAID contained in the Global AIDS and Tuberculosis Relief Act of 2000 should be applied to CDC as a current goal; and spending should rise above this level as needed to meet UNGASS targets.

*Suggested Report Language:*

The managers continue to believe that a strong emphasis on preventing mother-to-child transmission (MTCT) is one of the most important steps that can be taken to stem the tide of the HIV/AIDS pandemic. The managers applaud the Bush Administration's agreement to reduce global infections of infants in accordance with the targets agreed to at the United Nations General Assembly Special Session on HIV/AIDS. Among other things, these targets call for a 20 percent reduction in the rate of infection of infants by 2005, and a 50 percent reduction by 2010.

Both USAID and CDC have skills and experience in preventing MTCT abroad, and they are both specifically authorized to proceed with rapid scale-up of MTCT programs in resource poor nations, with an emphasis on meeting the UNGASS targets.

Funding is not the only obstacle to preventing mother-to-child transmission. USAID, CDC, and NIH should support operational research aimed at improving the success of these programs by increasing the number of pregnant women who participate and the number of women and infants who receive a drug intervention to prevent HIV infection of the infant. To prevent duplication and overlap, USAID and CDC shall carefully coordinate their MTCT prevention efforts.

In addition, the two agencies shall report to the House and Senate Committees by February 2003, and on an annual basis in subsequent years on their efforts to achieve the UNGASS goals. These reports shall include information on the number of MTCT sites supported in the developing world, the specific activities funded, the number of women tested and counseled, the number of women receiving preventive drug therapies to protect their infants, and the overall progress of U.S. activities in helping achieve UNGASS targets. USAID and CDC should also report yearly on their efforts to implement MTCT-Plus by expanding care and treatment services for families at established MTCT prevention sites.

Rapid expansion of prevention of MTCT activities by USAID and CDC shall include close cooperation with the governments of resource poor nations, non-governmental organizations, and international entities such as UNICEF, WHO, UNAIDS, and the Global Fund to Fight AIDS, Tuberculosis, and Malaria. In addition, USAID and CDC shall specifically work to support nationwide scale up of MTCT prevention programs in a select number of nations that are prepared to take this step. The agencies are encouraged to expand the availability of care and treatment services for family members at MTCT prevention sites that are well established and ready to achieve this next goal.

While it is particularly important to initiate programs to prevent MTCT in Africa, where more than one third of pregnant mothers are HIV-positive in some nations, the managers strongly urge that USAID and CDC strive to initiate MTCT prevention programs in other regions of the world that are threatened with a similar tragedy if strong action is not taken immediately. These regions include Latin America, Eastern Europe and Russia, and Southeast Asia (including India and China).

Chairman HYDE. Would the gentlelady wind up.

Ms. LEE. Thank you, Mr. Chairman. Yes. I just want to mention the figure that we're looking at is a recommendation of \$80 million for fiscal year 2003 and increases thereafter to really begin to deal with this. And thank you very much, Mr. Chairman for the time and thank you very much for your leadership on this issue.

Chairman HYDE. Thank you. Mr. Royce?

Mr. ROYCE. Yes, Mr. Chairman. I'm going to be very brief on this. Based on the estimates that we've seen, within the next decade, there will be 40 million orphans in Africa as a result of AIDS. Often, it's the girls that suffer the most because they're forced onto the street. They're forced into that harsh environment.

The Africa Subcommittee has held a hearing on the AIDS crisis in Africa, and frankly, for the Full Committee here, HIV/AIDS has been a priority and the Chairman, Mr. Hyde, deserves credit for that. But we should do more and I think that, as a Nation, we will be doing considerably more to address this plague. But we also need African leaders to do more. The effort on the continent has been spotty while some governments tackling HIV/AIDS head on.

I've been in Ugandan villages and seen what a meaningful HIV/AIDS prevention campaign is. We've seen that in Botswana. I mean, there is progress being made in countries where it's being tackled head on; but other governments, tragically, are doing, in some cases, more harm than good. We've seen this in South Africa where Nevarapin is, you know, to treat the mother-to-child AIDS transmission is being denied. And certainly in Zimbabwe where, frankly, the very existence of AIDS has been denied.

If we're going to make a difference, we need credible African partners, and that should be our challenge to African leaders as we challenge our colleagues here to do more in the United States. I look forward to this hearing. And Mr. Chairman, again, I commend you for holding this hearing today.

Chairman HYDE. Thank you, Mr. Royce. Mr. Payne?

Mr. PAYNE. Thank you very much, Mr. Chairman. I will be very brief, too, because of the time constraints. But I just want to personally commend you for calling this hearing of the Full Committee. As we look at this pandemic, I think that we should remember that the potential for it to spread throughout the continent and the whole question of orphans is just horrific.

I'd like to, as I mentioned, commend you and many of your colleagues who have shown an interest, not only on this side like Mr. Royce and Mr. Kolbe and the gentleman from Iowa, Mr. Leach, who have shown tremendous leadership. Also, on the other side of the Capitol, the leadership that Chairman Biden is showing and the new revelation of people who, in the past, have not. And Mr. Gilman, of course, has been a true leader. For folks in the past who have not looked at this positively, for example, I understand that Senator Helms has now taken a look at the pandemic and has indicated that there needs to be a different approach. I believe that the bipartisanship regarding this whole humanitarian crisis is to be commended. We know Ms. Lee and Mr. McDermott and folks on this side of the aisle have also been involved. I'd also like to compliment—I see the Ambassador from Senegal here. Senegal has been a country where the AIDS pandemic has not gotten a foothold and I commend his government for having proactive programs all along.

I'd also like to commend the government of Uganda that has actually had a leveling off of the increase of the AIDS rate. Also although the AIDS pandemic is a tremendous problem in Botswana, President Festes has made this the number one issue. And a year

ago, on his Christmas card, he sent out just an AIDS symbol to all the people to remind them that this is such a terrible pandemic.

Mr. Chairman, as I conclude, I'd like to submit, for the record, Mr. Menendez has two full statements and two documents that he would like to have included in the record with your approval.

Chairman HYDE. Without objection, so ordered.

[The information referred to follows:]

Ouagadougou, 11 December 2001  
Joint UNAIDS/WHO Press Release

#### UN EFFORTS BROADEN AVAILABILITY OF ANTIRETROVIRALS

"ACCELERATING ACCESS" INITIATIVE MOVING FORWARD;  
72 COUNTRIES WORLDWIDE EXPRESS INTEREST

**Ouagadougou, Burkina Faso, 11 December 2001**—Efforts of the United Nations to broaden access to antiretroviral drugs (ARVs) are gaining momentum, with tangible results beginning to be seen in one in five African countries, according to officials of both the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

The number of patients who have access to antiretrovirals in countries that have negotiated agreements with pharmaceutical companies has increased over 18 months, although the total numbers are still only a small fraction of those in need of the medicines. Moreover, 72 countries worldwide have already indicated their interest in the "Accelerating Access" process and 14 have signed agreements, including 10 in Africa. Prices of some antiretroviral drugs have been cut on average by 85% in sub-Saharan Africa in countries where agreements have been negotiated through "Accelerating Access."

"This is just the beginning. But the results so far show that significant progress can be made in accelerating access to ARVs in the countries that need it the most," said Dr Tomris Türmen, Executive Director in charge of HIV/AIDS at WHO. "The biggest challenge remains bringing broad based care and support, including antiretrovirals, to as many people as possible living with HIV/AIDS."

"Accelerating Access" represents a redoubling of efforts to assist countries in implementing comprehensive packages of care for people living with HIV/AIDS. It includes advocacy and policy guidance on HIV care at the global level and also involves "fast track" support for those developing countries who have formally indicated that they wish to significantly expand access to HIV care, support and treatment, and who want assistance from the UN system. The initiative emerged out of a partnership between the United Nations (the UNAIDS Secretariat, UNICEF, UNFPA, WHO and the World Bank) and five pharmaceutical companies (Boehringer-Ingelheim, Bristol-Myers Squibb, F. Hoffmann - La Roche, GlaxoSmithKline, and Merck & Co., Inc.) which has since been broadened to include other members of the industry.

A number of encouraging approaches are now being developed. Regional pricing, for example, allows the process to move more quickly and may favour lower drug prices through regional procurement. In addition, the creation of regional networks allows countries improved access to technical support that underpins their programmes.

"Challenges remain, however, and the greatest lies in reaching not thousands, but millions of people. With 95% of the world's 40 million HIV-infected people living in developing countries, better and faster access to care is essential. The challenge now is to improve access to care, including treatments for opportunistic infections and antiretroviral therapy, in the hardest-hit regions of the world," said Dr Türmen.

*For more information, please contact Anne Winter, UNAIDS, Ouagadougou (+226) 20 22 09 (mobile), Leyla Alyanak, UNAIDS, Geneva (+41 22) 791 4451 or Andrew Shih, UNAIDS, New York (+ 1 212) 584 5024. You may also visit the UNAIDS website on the Internet for more information about the programme (<http://www.unaids.org>).*

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## GLOBAL CRISIS - GLOBAL ACTION



## HIV/AIDS care and support

*Important initiatives are underway to bring life-prolonging drugs and treatment to people living with HIV/AIDS. But access to drugs is only one of the many things that people with HIV infection need if they are to live healthy, productive lives.*

### Comprehensive care: meeting a wide range of needs

- While access to medicines is extremely important, the needs of people with HIV/AIDS extend far beyond drugs and health care. HIV/AIDS care strategies therefore need to be comprehensive.
- Comprehensive care and support rest on several pillars, and need to include voluntary HIV counselling and testing so that people can know their HIV status and deal effectively with it. Comprehensive care must include psychological support to help people cope with the implications of having a life-threatening disease. It requires social support to help HIV-positive people, their families and their communities cope with the economic and social consequences of sickness and death due to AIDS.
- The role of communities and community organizations—especially those involving people living with HIV/AIDS—is especially important. Their work promotes social solidarity with HIV-affected individuals and their families, provides them with emotional support, and helps protect them against discrimination and violations of their rights. Often their activism helps prompt governments to devote more resources to the AIDS response and spurs companies to lower drug prices.
- Comprehensive care and support depends upon improved health systems to boost access to comprehensive care and support services, including to the life-saving drugs people living with the virus need. In Africa, where two-thirds of the world's HIV-positive people live, health care

systems were already weak and underfinanced before the advent of AIDS. They are now buckling under the added strain of millions of new patients. In many places, facilities for diagnosis are inadequate and drug supplies are erratic, even for HIV-related conditions that are easy to diagnose and inexpensive to treat. Access will remain uneven and compromised until countries are able to afford AIDS-related drugs and diagnostic equipment and equip their health systems with the necessary infrastructure and adequately trained staff.

• Many developing countries, however, struggle to allocate sufficient portions of their national budgets to the health sector. In Africa, governments are spending considerably more on servicing foreign debts than they spend on health and education. Increased debt relief and international development assistance can help countries invest more in poverty alleviation and AIDS prevention and care.

• In places unable to mobilize sufficient resources (health staff, infrastructure and funding), people living with HIV/AIDS must have access to basic pain relief and treatment for "simpler" opportunistic infections such as pneumonia and tuberculosis.

### Care and treatment boosts prevention

- Care and support for people living with HIV can help to protect the health of the public at large by making prevention more effective. The vast majority of people living with HIV do not know their HIV status. Greater use of voluntary counselling and HIV testing is an important key to encouraging changes in risky behaviour and, in

Global crisis - Global action

HIV/AIDS

**GLOBAL CRISIS - GLOBAL ACTION**

turn, to more effective prevention. The availability of HIV care and treatment, a source of hope, can be a powerful incentive for people to come forward and find out their HIV status

- People who know they are infected and have access to care can break through the denial about HIV that so often hinders prevention efforts. Care providers who look after HIV-positive people demonstrate to others that there is no need to fear being infected through everyday contact and thus help dispel misguided beliefs about HIV transmission.
- Providing diagnosis and treatment for tuberculosis and sexually transmitted infections, common among people with HIV, also helps decrease the spread of infections among people who are HIV-negative.
- For these reasons, AIDS-related care is increasingly recognized as a good investment that directly benefits people with HIV/AIDS, while also boosting AIDS prevention.

**Accelerating access**

- Launched in May 2000, the Accelerating Access Initiative represents a redoubling of efforts by the UNAIDS Secretariat and Cosponsors to assist countries in implementing comprehensive packages of care for people living with HIV/AIDS. The initiative proceeds along two tracks. The first involves dialogue with the pharmaceutical industry to make quality drugs more affordable in developing countries. The second entails technical collaboration with countries as they set about boosting their capacity to deliver care, treatment and support (including the introduction of antiretroviral therapy).
- The support is tailored to each country's situation. Upon request, support is provided for the preparation of national action plans on care that form part of wider HIV/AIDS strategies in countries. Information from other countries on the prices of drugs (including generics) and diagnostics is made available to the responsible national authorities that are engaged in negotiations with companies supplying drugs and equipment.
- So far, 36 countries in Africa, Europe, Asia, the Caribbean and Latin America have decided to take advantage of the initiative. Ten of these countries (all in Africa) have reached agreements with manufacturers on significantly reduced drug prices.

**Drug prices**

- The prices of a number of important drugs for people living with HIV/AIDS, including a number of antiretrovirals, have decreased dramatically in recent months. Price reductions have been achieved through a combination of efforts. They have included advocacy (to draw attention to the enormous impact of the epidemic and the treatment gap in developing countries), pressure from activists and civil society, and competition from generic drug manufacturers. Also important have been differential (discounted) prices from pharmaceutical companies for use exclusively in developing countries, as well as ventures like the Accelerating Access Initiative. Some companies have also offered donations of drugs, for example an antiretroviral to prevent mother-to-child transmission and an antifungal to treat certain opportunistic infections.
- Price has been an obstacle to expanding access to treatment. But other important conditions for expanding access to drugs include mobilizing sustainable financing for bringing medicines and equipment to developing countries, and strengthening health facilities and personnel so that the drugs can be prescribed and used safely. Proper prescription and monitoring of compliance with drug regimes is essential for the benefit of patients and for avoiding the serious potential of drug resistance.
- Even with greatly reduced drug prices, however, drugs of importance to people living with HIV remain out of reach of the vast majority of people who need them. For example, current prices being offered in developing countries to treat one patient for a year are still much higher than the annual per capita GDP of many of the hardest hit countries.
- In addition to advocating the pricing of HIV medicines in line with the purchasing power of countries, other avenues are being pursued. They include reducing or eliminating import duties and taxes; encouraging patent-holder companies to grant voluntary licenses that allow other manufacturers to produce their products at lower cost; the use of safeguards in international trade agreements that can help governments expand access to medicines and protect public health; and promoting South-South and North-South cooperation. New funding mechanisms are also being devised to channel more private and public sector resources toward care and support programmes.

**COUNTRIES THAT HAVE EXPRESSED INTEREST  
IN ACCELERATING ACCESS**  
*Updated 22 November 2001*

Countries	Completed/advanced planning	Agreement on prices/ national plans <sup>1</sup>
<b>AFRICA (41)</b>		
Algeria		
Angola		
Benin		
Botswana		
Burkina Faso	yes	yes
Burundi	yes	yes
Cameroun	yes	yes
Cap Vert		
CAR		
Chad		
Congo (DRC)		
Côte d'Ivoire	yes	yes
Ethiopia	yes	
Gabon	yes	yes
Gambia		
Ghana		
Guinea		
Guinea-Bissau		
Kenya		
Lesotho		
Liberia		
Malawi	yes	
Mali	yes	yes
Mauritius		
Morocco	yes	yes
Mozambique		
Namibia		
Niger		
Nigeria		
Rwanda	yes	yes
Sierra Leone		
Senegal	yes	yes
Seychelles		
South Africa		
Swaziland	yes	
Togo	yes	
Tunisia		
Uganda	yes	yes
Tanzania		
Zambia		
Zimbabwe		

<sup>1</sup> Countries which, with involvement from UNAIDS, have reached agreement on reduced drug prices in the context of national plans. Individual companies have reached agreement with additional countries.

LATIN AMERICA/CARIBBEAN (24)		
Antigua & Barbuda		
Bahamas		
Barbados	yes	
Belize		
Chile	yes	yes
Costa Rica		
Domenica		
Grenada		
Guatemala		
Guyana		
Haiti		
Honduras	yes	yes
Jamaica		
Mexico		
Montserrat		
Nicaragua		
Panama		
San Salvador		
St Kitts & Nevis		
St Lucia		
St Vincent/Grenadin		
Suriname		
Trinidad and Tobago	yes	yes
Venezuela	yes	
EUROPE (4)		
Belarus		
Moldavia		
Romania	yes	yes
Ukraine	yes	
SOUTHEAST ASIA (3)		
Malaysia		
Thailand		
Vietnam	yes	

<sup>1</sup> Countries which, with involvement from UNAIDS, have reached agreement on reduced drug prices in the context of national plans. Individual companies have reached agreement with additional countries.

**SPECIAL COMMUNICATION**

## Do Patents for Antiretroviral Drugs Constrain Access to AIDS Treatment in Africa?

Amir Attaran, DPhil, LLB

Lee Gillespie-White, LLB

**I**N RECENT MONTHS, THERE HAS BEEN a great deal of controversy about access to antiretroviral medicines to treat human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) in poor countries, where tens of millions have HIV infection and face certain death without antiretroviral treatment. A dramatic, often heated element of this debate has focused on the role of intellectual property law—specifically, patents—which activists blame for creating monopolies that keep drugs inaccessible or unaffordable, and which pharmaceutical companies extol as necessary incentive for expensive research and development. This has led to highly organized campaigns, critiques of the international patent law system, White House executive orders, and calls to limit the scope of pharmaceutical patents in poor countries.<sup>1,2</sup>

In this article, we examine the current relationship between patents and antiretroviral drug access. We test the hypothesis that patents are a leading barrier to widespread AIDS treatment in Africa by presenting for the first time, to our knowledge, comprehensive data on whether patents for antiretroviral drugs exist on that continent. We discuss the findings of our case study in light of the current controversy regarding AIDS medicines and the legal options for enhancing access to antiretroviral treatment for the world's poor.

### METHODS

Between October 2000 and March 2001, we issued written inquiries to the

public attention and debate recently have focused on access to treatment of acquired immunodeficiency syndrome (AIDS) in poor, severely affected countries, such as those in Africa. Whether patents on antiretroviral drugs in Africa are impeding access to lifesaving treatment for the 25 million Africans with human immunodeficiency virus infection is unknown. We studied the patent statuses of 15 antiretroviral drugs in 53 African countries. Using a survey method, we found that these antiretroviral drugs are patented in few African countries (median, 3; mode, 0) and that in countries where antiretroviral drug patents exist, generally only a small subset of antiretroviral drugs are patented (median and mode, 4). The observed scarcity of patents cannot be simply explained by a lack of patent laws because most African countries have offered patent protection for pharmaceuticals for many years. Furthermore, in this particular case, geographic patent coverage does not appear to correlate with antiretroviral treatment access in Africa, suggesting that patents and patent law are not a major barrier to treatment access in and of themselves. We conclude that a variety of de facto barriers are more responsible for impeding access to antiretroviral treatment, including but not limited to the poverty of African countries, the high cost of antiretroviral treatment, national regulatory requirements for medicines, tariffs and sales taxes, and, above all, a lack of sufficient international financial aid to fund antiretroviral treatment. We consider these findings in light of policies for enhancing antiretroviral treatment access in poor countries.<sup>1,3</sup>

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intellectual property divisions of major pharmaceutical companies that produce or market antiretroviral drugs, seeking disclosure and affirmation of each patent or similar legal right in Africa of which those companies had knowledge. Our inquiries captured the patent status of the antiretroviral drugs invented or marketed by the companies in question, unless a single active ingredient is marketed in multiple formulations, in which case we sought data for the first marketed (primary) formulation. All companies we contacted agreed to furnish data in response to our inquiry. We summarized

the data in tabular form and then returned the data to each of the respondent companies for 1 or more rounds of clarification, verification, or correction as needed.

Our inquiries captured several different types of legal rights: product patents (covering the pharmacologically

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active chemical or formulation), process patents (covering a manufacturing process for the same), use patents (covering the use of a drug for a medical indication), and "exclusive marketing rights" (an interim legal status in international patent law that pertains only to the least-developed countries under the World Trade Organization Agreement on Trade-Related Aspects of Intellectual Property Rights [TRIPS]). For the purposes of this study, it is generally unnecessary to distinguish among these because they all confer a degree of market exclusivity (ie, an exclusive right to manufacture, import, or sell) in similar ways.

Because our method is survey based, we cannot exclude the possibility that even after verification some inaccuracies exist because of human error in reporting data to us. However, in this large crosswise scrutiny of 15 antiretroviral drugs and 53 countries (comprising 795 data points), a small number of such inaccuracies would not materially affect our broad conclusions. Although this is satisfactory for an academic study, given the serious legal consequences of patent infringement, we strongly recommend that anyone placing reliance on these findings seek independent legal advice.

## RESULTS

A total of 15 antiretroviral drugs patented by 8 pharmaceutical companies were screened for patent status in 53 African countries. TABLE 1 and the FIGURE summarize the data and record every patent in force at the time we were notified. We do not present data on expired or withdrawn patents, which are of no legal force, or pending patent applications, since it cannot be presumed that these will be granted or rejected. Where a patent is shown, some form of market exclusivity exists, although this exclusivity may not preclude all uses of the pharmacologically active ingredient (eg, in the case of a formulation patent).

The data in the Table and Figure can be interpreted as disclosing 1 general rule and 2 specific exceptions. The rule is that

among antiretroviral drugs, most are patented in few African countries (median, 3; mode, 0 countries) and that among the subset of countries where 1 or more patents exist, the number of patented antiretroviral drugs is typically few (median and mode, 4 drugs). The exceptions are South Africa, where a comparatively large number of antiretroviral drugs are patented (13/15), and Agyron, Boehringer Ingelheim, and GlaxoWellcome (now GlaxoSmithKline) products, which are patented in a large number of countries (up to 37 of 53 countries). Overall, of a theoretically possible 795 instances of patenting that we might have identified (assuming generously that all countries offer pharmaceutical patents, which is not true), only 172 (21.6%) actually exist. While patents do limit the use of some highly active antiretroviral therapy regimens on a "no patent" basis (especially those using zidovudine, lamivudine, or both), the US Department of Health and Human Services (DHHS) clinical guidelines list several "strongly recommended" regimens for which there are encouraging clinical trials and which are unpatented in up to 52 of 53 African countries. In addition, other regimens are available on a "1 patent" basis, where that patented drug may be available at discounted prices. Examples of regimens recommended by the DHHS and their patent statuses are provided in TABLE 2.

## COMMENT

This study demonstrates that patent protection for antiretroviral drugs in Africa is not extensive. This is surprising since earlier studies have shown that patent applications were filed in many African countries.<sup>13</sup> We now infer that most of these applications were probably abandoned because it is common practice to name a large number of countries on an international patent application, given the option of establishing a patent later on, and later abandon many or most of them when the patent fees are due.<sup>14</sup> Therefore, it is not surprising that the number of applications is large while the number of patents in force is few.

These results rely on patent self-reporting and may contradict isolated press reports.<sup>15</sup> However, we believe there are 2 independent reasons that patent holders and licensees are the most reliable source for these data when queried systematically.

First, the relationship between a patent and a product is not always self-evident to anyone other than the patent holder or a licensee. A patent may not refer explicitly to the name of a product or the formula of the pharmaceutically active chemical (eg, a process patent for a synthetic intermediate). As such, even a highly skilled observer searching the records of a national patent office (an extremely difficult or impossible undertaking in much of Africa) could easily overlook patents pertaining to a product of interest. This problem is avoided when the patent holder or licensee self-reports the data, and to the limited extent that our data were verifiable against those obtained directly from 1 national patent office (Kenya), the results match perfectly.<sup>16</sup>

Second, companies that self-report the lack of a patent probably would do so truthfully because there is no incentive to conceal the existence of a patent. Concealment would invite unwanted competition from generic drug suppliers. While theoretically companies may benefit from exaggerating the extent of their patent protection, there is no plausible commercial benefit in denying the existence of valid patents they own.

As most of the antiretroviral drugs we studied are infrequently patented in Africa, is this situation likely to persist in coming years? Most national patent systems follow the Paris Convention, which stipulates a 1-year grace period during which all patent applications ordinarily are filed.<sup>17</sup> This period elapsed long ago for the antiretroviral drugs we studied, meaning that the opportunity to file further patent applications and obtain future patents generally has expired. It is conceivable that "after-thought" applications could be still filed to patent incidental features of these drugs (eg, a drug's crystalline form or its

## PATENTS AND ACCESS TO AIDS TREATMENT IN AFRICA

Table 1. Patent Coverage in Africa for Antiretroviral Drugs, by Country\*

	NRTIs						NNRTIs			Protease Inhibitors				Total		
	Lamivudine-Zidovudine (Combivir) [GSK]	Lamivudine (Epivir) [GSK]	Zalcitabine (Hivid) [Roche]	Zidovudine (Retrovir) [GSK]	Didanosine (Videx) [BMS]	Stavudine (Zerit) [BMS]	Aztreavir (Gilead) [GSK]	Darunavir (Replavir) [Pharmacia]	Efavirenz (Sustiva) [Merck]	Nevirapine (Viramune) [BII]	Amphotericin (Agenerase) [GSK]	Indinavir (Crixivan) [Merck]	Saquinavir (Fortovase) [Roche]	Ritonavir (Norvir) [Abbott]	Nelfinavir (Viracept) [Agouron]	
Algeria															0	
Angola															0	
Benin	X	X							X					X	4	
Botswana	X	X	X		X				X	X					6	
Burkina Faso	X	X							X				X		4	
Burundi	X		X												2	
Cameroun	X	X								X			X		4	
Cape Verde															0	
Central African Republic	X	X							X				X		4	
Chad	X	X							X				X		4	
Comoros	X	X	X												3	
Congo (Republic)	X	X					X		X				X		5	
Congo (Democratic Republic)	X										X				2	
Côte d'Ivoire	X	X							X						3	
Djibouti															0	
Egypt	X	X													2	
Equatorial Guinea															0	
Eritrea															0	
Ethiopia															0	
Gabon	X	X							X				X		4	
Gambia	X	X	X		X				X	X			X		7	
Ghana	X	X	X		X					X			X		6	
Guinea										X			X		2	
Guinea-Bissau													X		1	
Kenya	X	X	X		X				X	X			X		7	
Lesotho	X	X			X				X	X			X		6	
Liberia															0	
Loya															0	
Madagascar	X	X													2	
Malawi	X	X	X						X	X			X		6	
Mali	X	X								X			X		4	
Mauritania	X	X								X			X		4	
Mauritius															0	
Morocco	X	X													2	
Mozambique															0	
Namibia															0	
Niger	X	X											X		3	
Nigeria	X	X	X												4	
Rwanda	X		X												2	
Sao Tome and Principe															0	
Senegal	X	X								X			X		4	
Seychelles	X	X	X		X										4	
Sierra Leone	X		X		X										3	
Somalia															1	
South Africa	X	X	X	X	X	X	X	X	X	X	X	X	X		13	
Sudan	X	X	X		X				X	X			X		7	
Swaziland	X	X			X				X	X			X		6	
Tanzania	X	X	X		X				X						5	
Togo	X	X													3	
Tunisia	X	X													2	
Uganda	X	X	X		X				X	X			X		7	
Zambia	X	X	X		X				X	X					6	
Zimbabwe	X	X	X		X				X	X	X	X	X		6	
Total	37	33	0	17	1	1	15	1	1	25	12	2	3	0	24	172

\*NRTI indicates nucleoside reverse transcriptase inhibitor; NNRTI, non-NRTI; GSK, Glaxo SmithKline; BMS, Bristol-Myers Squibb; and BII, Boehringer Ingelheim.

## PATENTS AND ACCESS TO AIDS TREATMENT IN AFRICA

metabolite), but such claims may be regarded skeptically by courts outside the United States.<sup>18-20</sup> We think it is unlikely that the observed omissions to patent in Africa could now be reversed, meaning that current antiretroviral drugs will remain largely unpatented in Africa (future antiretroviral drugs, of course, may be another matter).

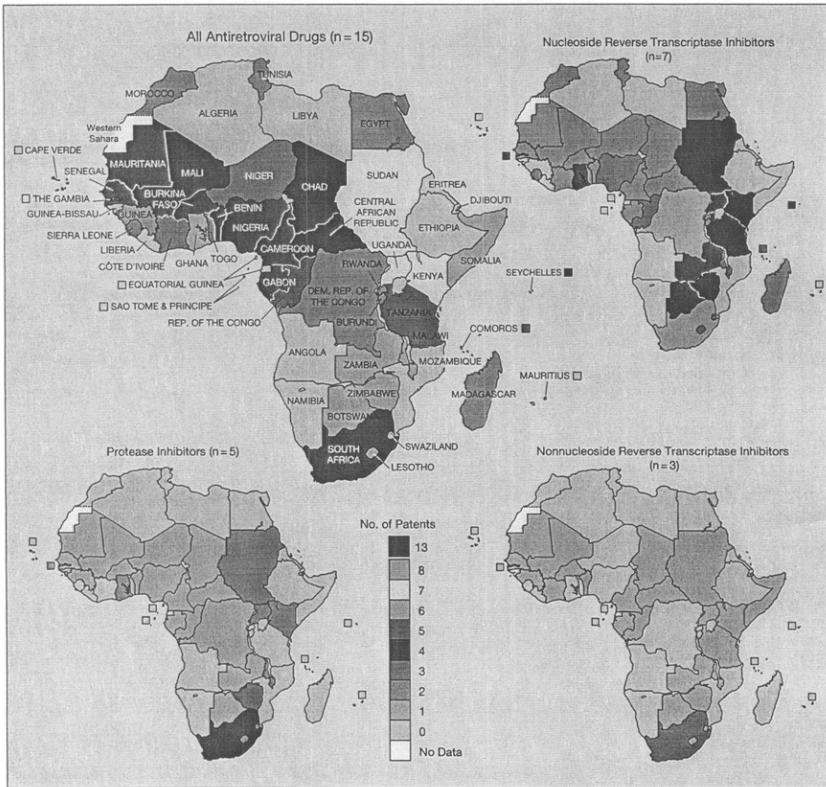
It is an interesting question why there are not more antiretroviral drug pat-

ents in Africa. Certainly, it is not simply because the option to patent has been lacking. Although the laws of some African countries do not permit pharmaceutical patents, or did not when applications to patent these antiretroviral drugs were filed, most have allowed pharmaceutical patents for years.<sup>21</sup> The 15 member countries of Francophone West Africa in OAPI (the Organisation Africaine de la Propriété

Intellectuelle) have offered a system of pharmaceutical product and process patents since the Bangui Agreement of 1977.<sup>22</sup> Similarly, pharmaceutical patent protection has been available in most of the 15 Anglophone countries of ARIPO (the African Regional Industrial Property Organization) since at least 1984.<sup>23</sup>

Despite these and other opportunities to patent antiretroviral drugs in Af-

**Figure.** Patent Coverage by Country



## PATENTS AND ACCESS TO AIDS TREATMENT IN AFRICA

**Table 2.** Patent Status of Antiretroviral Drugs Used in Selected Highly Active Antiretroviral Therapy Regimens (N = 53)\*

Regimen	DHHS Assessment <sup>b</sup>	No. (%) of Countries With		Multiyear Clinical Trial?
		0 Patents	0 or 1 Patents	
Stavudine-didanosine-indinavir	Strongly recommended	51 (96.2)	52 (96.1)	Yes <sup>c</sup>
Stavudine-didanosine-ritonavir-indinavir	Strongly recommended	51 (96.2)	52 (96.1)	Yes <sup>c</sup>
Stavudine-lamivudine-indinavir	Strongly recommended	19 (35.8)	52 (96.1)	Yes <sup>c</sup>
Zidovudine-lamivudine-nefarnavir	Strongly recommended	15 (28.3)	25 (47.2)	Yes <sup>c</sup>
Stavudine-didanosine-efavrenz	Strongly recommended	52 (96.1)	52 (96.1)	No <sup>d</sup>
Lamivudine-stavudine-nevirapine	Recommended as alternative	18 (34.0)	30 (56.6)	No <sup>e</sup>
Didanosine-stavudine-nevirapine	Recommended as alternative	28 (52.8)	52 (96.1)	Yes <sup>f</sup>

\*DHHS indicates US Department of Health and Human Services.

rica, patents were not often sought, suggesting 2 important conclusions.

First, and perhaps surprisingly, it is doubtful that patents are to blame for the lack of access to antiretroviral drug treatment in most African countries. Conventional wisdom has spuriously assumed that drugs patented in Europe or North America must also be patented in Africa, or that a lack of generic competition and high retail prices (sometimes in excess of those charged in developed countries) are *prima facie* evidence of patents, which they are not.<sup>23,24</sup> Determining actual patent coverage is therefore instructive, and in doing so, we observe that there is no apparent correlation between access to antiretroviral treatment, which is uniformly poor across Africa, and patent status, which varies extensively by country and drug. We were unable to identify any evidence, systematic or anecdotal, that antiretroviral treatment is more accessible in countries with few or no antiretroviral patents (eg, Mozambique, Namibia). Similarly, we were unable to identify any evidence that the antiretroviral drugs of, for example, Abbott, patented in 0 countries, are consumed in any greater numbers than those of GlaxoSmithKline, patented in up to 37 countries. These observations are necessarily qualitative given that accurate data on African antiretroviral drug consumption do not exist, but are based on the consensus that very few of the 25 million HIV-positive Africans now receive treatment (perhaps 25 000, or just 1 in 1000, receive 1 antiretroviral drug).<sup>25</sup> This scarcity of treatment cannot rationally be ascribed to antiretroviral patents that are few—or

nonexistent—in most African countries. Other factors, and especially the ubiquitous poverty of African countries, must be more to blame.

Second, also perhaps surprisingly, it is doubtful that pharmaceutical research and development will always require the incentive of patentability in poor countries, since the option to patent antiretroviral drugs in Africa has frequently gone unexercised. The economics and profitability of antiretroviral drug research (unlike that of, say, malaria) are driven by consumption of drugs by AIDS patients in the lucrative North American and European markets. In comparison, the entire African pharmaceutical market, at 1.1% of the global whole, is commercially negligible, as is the market share of antiretroviral drugs sold to the poorest third of the world (0.5%) (Jean O. Lanjouw, PhD, written communication, August 7, 2001).<sup>26</sup> Patenting in poor countries therefore yields very small financial returns, and, given the cost of patenting and the difficulty of enforcing one's patents before sometimes weak judicial systems, most companies appear to have decided that extensive patenting in Africa is not worthwhile.

Thus, the data suggest that patents in Africa have generally not been a factor in either pharmaceutical economics and antiretroviral drug treatment access (South Africa, with its larger affluent market, is an exception). This counters some of the sweeping policy arguments made for or against patents, and, within the limited scope of this study, it is no more correct to allege that "intellectual property protection [has] huge [adverse] influences on . . . access to medicines" than

it is to claim that ongoing pharmaceutical research and development finds it "necessary to protect intellectual property rights on a global scale."<sup>27,28</sup> Although we agree that either or both of these statements may be correct in other contexts, neither is borne out as true in this case study.

Our data or conclusions should not be misinterpreted. It would be wrong to cite this study as proof that patents never affect access to medicines—that conclusion would require research well beyond antiretrovirals in Africa in 2001. Also, in reporting data on antiretroviral patent status, it must be remembered our data reflect only the existence of patents, and never their validity, which is testable only through a legal challenge. We presume that all patents reported to us are valid, as is the rule until being judicially invalidated.

What are the nonpatent barriers impeding antiretroviral treatment in Africa? Certainly, access to treatment can be impeded many ways: by insufficient finances to purchase relatively costly antiretroviral drugs; by a lack of political will among countries; by poor medical care and infrastructure; by inefficient drug regulatory procedures that exclude competing products from the marketplace; by high tariffs and sales taxes; and so on. Such barriers have been identified by others.<sup>29-31</sup> A comprehensive treatment access plan for Africa must overcome these nonpatent barriers and make use of expeditious strategies that combine affordability, compliance with patent laws, and sufficient finance. We consider these in turn.

At this writing, both brand name and generic sources of antiretroviral drugs are available at reduced price, typically about 90% less than in the United States. Prices range from \$350 a year for the cheapest possible 3-drug combination of stavudine, lamivudine, and nevirapine (Cipla) to perhaps \$1000 for a regimen containing a more expensive protease inhibitor, which might cost \$600 itself (eg, indinavir).<sup>32</sup>

Patent status a central consideration when sourcing drugs. Where a drug is not patented in a given country, one may freely manufacture, import, and buy the brand-name drug or its generic equivalent (provided that both are registered for use by the local drug regulatory authorities, which is not always the case since some authorities decline to register generic products [Richard O. Laging, MD, written communication, August 7, 2001]). Therefore, competition can lead to a concurrent market for brand-name and generic antiretroviral drugs, such as exists for other medicines. Purchasing for the public or charitable sector in poor countries could be assisted by a single global brokering facility that would receive orders and put them to a competitive tender among a number of high-quality suppliers. A central, tender-based system like this has been very successful in increasing access to tuberculosis drugs for poor countries at prices near the marginal cost of production, or as much as 97% below prices in United States or Japan.<sup>33,34</sup> However, the risk of driving prices down while simultaneously increasing the funds available to purchase antiretroviral drugs for Africa (as the much-anticipated international trust fund for infectious disease might soon do<sup>35</sup>) is that it creates market conditions in which it could become lucrative to patent antiretroviral drugs more widely in the future. The TRIPS agreement will make this possible in all developing countries belonging to the World Trade Organization by no later than 2006.

On the other hand, in African countries where antiretroviral drug patents do exist, the international community should ensure a supply of affordable

drugs. An equitable balance is that countries ought to respect patent laws, but that patent holders reciprocally supply medicines to the global poor without profit, but also without loss. Various solutions to achieve this exist. Merck, Bristol-Myers Squibb, and Abbott have discounted antiretroviral drugs to prices not above their stated costs of production and distribution, and GlaxoSmithKline has taken similar steps for malaria medicines as well. These examples should be followed by other pharmaceutical companies. Alternatively, various legal proposals have been made to limit the patentability of certain medicines in poor countries without markedly affecting revenues.<sup>36,37</sup> Brand-name pharmaceutical companies might also consider adhering to a code of practice, in which they agree to voluntarily license patents for important medicines (antiretroviral drugs and others) to high-quality generic manufacturers willing to supply at low prices (the licenses would be geographically restricted to poor countries, and generic firms would pay a modest royalty for the privilege<sup>38</sup>). Arrangements like these would signify ethical business leadership and would affect revenues negligibly, given the diminutive pharmaceutical market in poor countries. Without them, poor countries have only the last resort of compulsory licensing (a governmental authorization that allows competitors to use a patent without the patent holder's consent), which both TRIPS and the Paris Convention legitimately allow them to do.<sup>39,40</sup>

Given these options to procure medicines at reduced prices, finance and distribution remain as impediments to treatment access. The impossibility of poor countries paying for antiretroviral treatment themselves cannot be overemphasized; countries such as Ghana, Nigeria, and Tanzania have annual national health budgets of \$8 or less per capita.<sup>41</sup> In contrast, estimates endorsed by 140 faculty members of Harvard University for a treatment plan of diagnosis, care, and antiretroviral drugs are about \$1200 per patient-year (including infrastructure development and training would cost somewhat more).<sup>42</sup> This vast fi-

nance gap means that even if health budgets were radically expanded and all waste or corruption banished, Africa's impoverished economies could never afford more than a few percent of the cost of treatment—and this is true even if antiretroviral drug prices continued to decline significantly, which is unlikely. Therefore, for antiretroviral treatment to take place, which it must, international aid finance is essential.

Based on these data, the extreme dearth of international aid finance, rather than patents, is most to blame for the lack of antiretroviral treatment in Africa. It is remarkable that the world's richest nations of North America, Western Europe, and Asia-Pacific together set aside only \$74 million specifically for African AIDS in 1998—about \$3 per HIV-infected African, or what it costs to build 3 miles (5 km) of rural freeway.<sup>43</sup> Such sums do not come close to financing the physicians, clinics, and infrastructure needed to administer antiretroviral therapy, much less to screen patients for HIV infection, and this has the lamentable result that even in cases in which pharmaceutical companies discount or freely donate antiretroviral drugs, poor African countries still cannot afford to use them. Lack of finance thwarts not only "expensive" AIDS treatment but even the highly cost-effective use of antiretroviral drugs in preventing pediatric HIV infection at birth (1 such drug, nevirapine, is donated by Boehringer Ingelheim but is rarely used in Africa).<sup>44</sup> The failure of wealthy governments to provide sufficient aid to fund these highly necessary interventions violates not only basic medical ethics but possibly international human rights laws as well.<sup>45</sup>

In summary, patents generally do not appear to be a substantial barrier to antiretroviral treatment access in Africa today. Activists, industry, physicians, and media who have so successfully raised public awareness of AIDS treatment issues are in a position to challenge the more important barriers. We agree that there are other patent issues of public health importance beyond the scope of this study (eg, access to new medicines after 2005, when TRIPS comes into force

## PATENTS AND ACCESS TO AIDS TREATMENT IN AFRICA

for all World Trade Organization members), but concern for the lives of those now dying of AIDS in Africa makes it necessary to unbundle those issues and proceed toward furnishing antiretroviral treatment concertedly and with speed. Acquired immunodeficiency syndrome is now the most numerically lethal pandemic since the Black Death 650 years

ago—a pandemic so rare that it presents a literally unprecedented test to Western democracy, which is not 650 years old. History will not judge kindly an avoidable delay.

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Chairman HYDE. Ms. Watson?

Ms. WATSON. Thank you so much, Mr. Chairman. I also want to commend you for holding this most important and timely hearing. I would like to submit my statement for the record and have you take that action. But I just would like to let you know that in the audience is a young woman, Bonnie Marshall, who sits to my right and who has created a program to reunite orphans with family members who have migrated to other countries. And if time would so allow, and you're interested, I would like to have her make some comments on her program.

But in the meantime I just want to mention this. We need to look at the partnership. It's already been mentioned here, with not only the government, but the private sector, too. We saw a fine example of that partnership when I was with Congresswoman Barbara Lee's staff in South Africa with Daimler-Chrysler. So at some point, I will ask a question or make a comment. So I'd like to submit my statement, Mr. Chairman, to the record.

Chairman HYDE. Without objection, so ordered.

[The prepared statement of Ms. Watson follows:]

**PREPARED STATEMENT OF THE HONORABLE DIANE E. WATSON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA**

Mr. Chairman, I want to commend you for holding this important and timely hearing on AIDS and its devastating effects on children in Africa. Sub-Saharan Africa continues to be the most severely affected region in the world, currently representing approximately 70% of the global AIDS pandemic. The impact of the disease on children has been devastating. According to UNAIDS, more than 13 million children have been orphaned due to AIDS, 12 million of whom are in Sub-Saharan Africa. By 2010, the number could exceed 40 million. In effect, what we are witnessing is an AIDS holocaust on the African continent.

The social and economic consequences of the growing number of AIDS orphans in Africa are dire. Increasingly, adolescents are heading households and resorting to prostitution and other criminal activities in order to support themselves and their families. The African extended family and kinship network is now on overload and may break down due to massive family dislocation and growing urbanization throughout Africa. The current health and social service infrastructure in most African nations is woefully inadequate to deal with the onslaught of AIDS orphans.

We also must not overlook the foreign policy implications of a growing AIDS orphan population in Africa. Significant numbers of children are being raised in an environment without a mother or father, which is the most basic of human support structures. The psychological and emotional consequences of this growing phenomenon may not be known until the next generation. But we all know that the outcome will not be good unless we aggressively address the problem in the present. If we decide not to address the problem effectively, we could, in effect, be condoning massive human dislocation and political unrest throughout Africa and perhaps the world.

This past August, I visited South Africa to examine the AIDS pandemic. While in Durban, I visited King Edward Hospital, a public hospital, and was told that the infection rate among children had soared to 35% of those seen by doctors at the hospital. At least one half of all adults were testing HIV positive. The situation had become so severe that nurses told me that they were limiting their examinations and treatments to children. I was also told that South Africa was experiencing a sharp rise in its orphan population, a completely new phenomenon in its urban areas. Many of these children now roam the streets with no supervision and fend for themselves. This is an unacceptable situation.

The situation is complex and there are no easy answers. In many instances, addressing the AIDS orphan phenomenon will require greater attention and cooperation of African governments, the international community, and the private sector. It will require removing the stigma of AIDS from society, better prevention and public education programs, and a stronger public health infrastructure. It will also require the introduction of anti-retroviral medications, which are now still unavailable to most Africans.

Again, Mr. Chairman, thank you for holding this hearing. I look forward to the testimony and the discussion that follows.

Chairman HYDE. We will now see the 7-minute video taken by Christophe Putzel on the effect of the AIDS pandemic on Kenya's children.

[Video presentation.]

Chairman HYDE. I would like to welcome our first witness, Dr. E. M. Peterson. Prior to her appointment as Assistant Administrator for Global Health in November at the United States Agency for International Development, Dr. Peterson served as Commissioner of Health for the State of Virginia. She has an extensive background in both U.S. and international public health and has served as consultant to the Centers for Disease Control and Prevention and the World Health Organization.

Dr. Peterson has spent almost 6 years in sub-Saharan Africa doing community development, public health training and AIDS prevention. She received her M.D. from the Mayo Medical School in Rochester, Minnesota and has authored numerous scientific publications. Dr. Peterson provides health leadership to USAID's Euro Proposal Health, which is formulating solutions to the many challenges handed out.

I kindly ask that you summarize your statement within 5 minutes, give or take, and your full statement will be placed in the hearing record. Welcome and please proceed.

**STATEMENT OF DR. E. ANNE PETERSON, ASSISTANT ADMINISTRATOR FOR GLOBAL HEALTH, U.S. AGENCY FOR INTERNATIONAL DEVELOPMENT**

Dr. PETERSON. Thank you very much, Chairman Hyde and Members of the Committee. It is an honor to speak before this Committee today. I thank you for inviting me. I will try and make my remarks shorter than I had intended.

The issue of children affected by AIDS is a priority for USAID. It's also an issue that I care about, both personally and professionally. A good deal of my time in sub-Saharan Africa was specifically working with youth and with AIDS issues. I went and joined Congresswoman Lee on the trip with Secretary Thompson to Africa just recently and I came back from Haiti last night, looking at the HIV/AIDS and orphan issues in Haiti.

The problem is enormous and you have spoken to the statistics and the scope of the problem. I would like, today, to tell you some of what the U.S. government is doing in response. USAID has been in the forefront of bringing attention to the orphan and children affected by AIDS issue. In 1997 we published *Children on the Brink*, which first brought some of the statistics to light.

In 2000 we updated the numbers. Those are the ones that you have heard recently, and with our partners, UN AIDS and UNICEF, we are updating those statistics, which will be available this summer. These preliminary estimates show that the numbers are growing and that this is a long-term crisis.

Even if the new infections with HIV leveled off today, the proportion of children orphaned would remain high with all of the social and health consequences at least through 2030. AIDS is changing family and community structures. Children are caring for sick par-

ents. They're running households. They're caring for younger siblings. They're living on the streets. And I spent a lot of time in Harare Zimbabwe working with children on the streets.

This has psychological, social and health consequences to these children. Stigma associated with HIV/AIDS in many places leads to neglect and abuse. They are far more vulnerable than many other children. Two days ago I visited a program in Jeremie, Haiti that had made amazing strides in beginning to overcome the stigma of HIV/AIDS and for the children orphaned by AIDS.

When I worked with the street kids in Zimbabwe, one of the things that they said to me was that their greatest health concern was exposure to STD and AIDS because of the economic necessity of supporting themselves. USAID has made support to children affected by AIDS a key component of our AIDS programs. We're working with host countries, citizen groups, other donors. We have more than 60 projects in 22 countries working with children affected by AIDS. Most of these are in sub-Saharan Africa.

Last year, approximately \$20 million was used for support of programs affected by AIDS as Congresswoman Lee said and we expect to increase that to \$40 million this fiscal year and expand the existing coverage.

I would also like to submit for the record USAID's publication *Project Profiles—Children Affected by AIDS*, which provides details of these projects. It will be updated again in July and we will be doing this regularly so that we can track the course of the epidemic.

Our experience with children affected by AIDS show that there are five major strategies. Number one, and I really concur with all of the testimony earlier, is that we need to support families and communities in their response to the AIDS epidemic. Families and communities have been the major source of response. But the scale is so huge that it's putting a strain on the coping mechanisms of the extended family. Therefore, what we're trying to do is improve the ability of families and communities to cope as they reach out to children affected and orphaned by AIDS.

For example, in Uganda, USAID made a commitment to provide \$30 million in food aid over the next 5 years. I saw a program in Haiti, again, providing food to families who have HIV/AIDS, people living with HIV/AIDS as well as families that have taken in AIDS orphans. This helps, not only relieve economic burden, but it also helps extend the life of those who are living with HIV/AIDS.

Supporting community programs is also a great necessity. One NGO in Zimbabwe tracked the progression of the AIDS orphan issue. First, the orphan is going to aunts and uncles. Then as the younger adults died, more grandparent-headed households, then growing numbers of sibling-headed households and children living on the streets. Many communities are struggling with this increased burden. Some don't know what to do. Supporting the community-led initiatives to care for the children and adolescents affected by AIDS is a priority for USAID.

Following successful African models, we're supporting the communities in two ways—providing direct assistance and by supporting NGOs that, in turn, support community efforts. The communities themselves are best able to determine which children and

households are the most vulnerable. They also are able to identify and integrate children who slipped through the safety net.

In Malawi District AIDS committees have aided almost 13,000 orphans and vulnerable children. Faith-based institutions are often the catalyst for action within communities, and this is why we've provided support for the First Conference of Religious Leaders to discuss children affected by AIDS which will take place in Nairobi this June.

More and more we're having to go to a third strategy, and that is helping young people themselves to meet their own needs. The children are faced often with a premature need to support themselves, to work as their parents have. Many are forced out of school just when they are needing their own education. Girls are often the first and most vulnerable to these pressures. Enabling children to stay in school, providing food, providing school fees allows them to stay in their homes and continue their education so that the cycle of vulnerability doesn't expand the HIV/AIDS epidemic.

Siblings that have been orphaned by HIV/AIDS have already had many losses as well in their families, and as much as they can be kept together as opposed to being spread out among many families, you increase the support of one another and the community keeping children together in their homes is one way to do this.

The fourth strategy is to strengthen community action. Concerted efforts have been done. Uganda's example is a prime example, but more needs to be done to strengthen the national government response. Laws and policies can make a huge difference. Last week, USAID, along with UNICEF, UNAIDS, Save the Children and Family Health International sponsored the first ever West and Central Africa meeting on children affected by AIDS. Representatives from 21 countries attended, including a delegation of four first ladies from these countries. They drafted plans of action and country teams committed themselves to taking these plans back to their countries. This is the kind of scaling up that national attention can bring.

They're also supporting environments that need to be encouraged. Stigma and discrimination is a major factor that limits many AIDS endeavors. It's directed at people living with HIV/AIDS. It is also often directed at the orphans left behind. When all sectors, faith-based organizations, civic associations, government and NGOs work together, they can raise awareness and decreasing stigma as I just saw demonstrated in Haiti.

Many of you have already spoken eloquently about the role of orphanages and residential facilities and USAID concurs that we need to focus our efforts on community support. One estimate in Zimbabwe predicted that to care for only 10 percent of the expected number of orphans would require construction of 100 orphanages a month for a year.

International child welfare organizations has shown that children benefit greatly from care, personal attention and social connections of family and community. This is the norm in most African countries. Orphanages, however, can provide temporary care. They can be a place to reach out from into the communities, but preferably, that they would be used as a last resort for long-term care.

Earlier this month, Secretary Thompson and I did visit two orphanages. One in Mozambique and one in South Africa that were playing this kind of critical role. We've also been pleased to support community-base care of children affected by AIDS and their families with the Lea Tota Program, which is a sister program to the Nyumbani Orphanage in Kenya, which you will be hearing more about. Reducing the vast numbers of, and providing care and support to, children made vulnerable by AIDS will require action from communities at all levels—global, national and local.

We're proud of what we've been able to do, but we know we can't do it all and we look forward to working with U.N. agencies, with multilateral partners and with the many NGOs and community groups across the world. We thank Congress for supporting this work and for convening this testimony. Thank you.

[The prepared statement of Dr. Peterson follows:]

**PREPARED STATEMENT OF DR. E. ANNE PETERSON, ASSISTANT ADMINISTRATOR FOR  
GLOBAL HEALTH, U.S. AGENCY FOR INTERNATIONAL DEVELOPMENT**

Chairman Hyde, members of the Committee, thank you for inviting me to testify today. The issue of children affected by AIDS is a priority for USAID. It is also an issue that I am very close to personally, as I spent six years in Africa, and part of my time there was dedicated to working with children affected by HIV/AIDS and other vulnerable children.

**SCOPE OF THE PROBLEM**

The problem of children infected and affected by AIDS is enormous, increasing rapidly and unfortunately, one that will haunt us for decades to come. In 2000, USAID released a study that concluded that over 34 million children had lost one or both parents to AIDS or other causes. This number is expected to increase to 44 million children by 2010.

Already in five countries in sub-Saharan Africa, more than 20 percent of children younger than age 15 are orphans. In another seven countries, more than 15 percent of children fall into this category.

As devastating as these numbers are, they do not tell the whole story. In addition to children who have become orphans, there are millions more children who are affected by AIDS. These are children who live with parents who are sick or dying of AIDS. The urgent needs of these children begins before the death of their parents, and it is important that we include these children when we try to understand the consequences for children affected by AIDS. In addition there are nearly 3 million children infected with the virus. Last year, over 800,000 children contracted HIV/AIDS, primarily through mother-to-child transmission of HIV, and the overwhelming majority of these cases are in sub-Saharan Africa. Most of the 580,000 children under the age of 15 who died of HIV/AIDS in 2001 were African.

The U.S. Agency for International Development has been at the forefront of drawing attention to the issue of children affected by AIDS. In 1997, we published *Children on the Brink*, which first alerted people to the staggering impact of AIDS on children. In 2000, our new and updated version of this report provided the devastating statistics mentioned above. We will update those numbers this summer. The preliminary estimates are that the orphan crisis will become graver as the pandemic spreads and infections increase.

In many African countries, even if new HIV infections leveled off today, infection rates would still remain high for at least 10 years. Deaths would not level off until at least 2020. Therefore the proportion of children orphaned will be unusually high through at least 2030.

**CONSEQUENCES**

As you know, the AIDS pandemic is reversing several decades of development gains in Africa, in particular with regard to child morbidity and mortality. Increasingly hard hit are the health and education services. It also potentially has far-reaching consequences on social structure, economic development and human productivity.

AIDS is changing family and community structures. Children are forced to care for sick parents. When their parents die, children are sometimes forced to run the

households themselves, and care for their younger siblings. Or, they may be sent to live with a member of their extended family. These relatives may already be caring for their own children, and may also be caring for the children of other family members who have died.

Individual children are impacted in many ways. They face the loss of their parents, and the psychological distress that goes along with such a loss. They may live in poverty, be forced to drop out of school and live with malnutrition. In addition, they face isolation, because in too many places, there is still a great stigma attached to HIV/AIDS. This stigma may also cause them to be neglected or abused. They also face a risk of contracting HIV themselves as their vulnerability increases, only adding to the cycle of HIV infection.

#### USAID'S RESPONSE

USAID has made support to children affected by AIDS a key component of our HIV/AIDS program. We are working with host country governments, citizen groups, and other donors, to meet the goal of ensuring that countries with a high prevalence of HIV-infection can provide community support services to at least 25 percent of children affected by AIDS (including children in households with sick or dying parents and orphaned children) by 2007.

As part of our effort to improve our use of scarce resources in this critical area, we are developing and testing new indicators to measure coverage of assistance programs for children affected by AIDS. This is more difficult than it may seem for several reasons. In many of the countries we work in, the concept of being an "orphan" is not part of the culture, as extended families take in children who have lost their parents. Because of the stigma attached to HIV/AIDS, it is important that children not be identified as "AIDS orphans." In addition, the issues impacting children affected by AIDS begin before a child is orphaned. All of these factors make it difficult to quantify exact coverage of these programs.

Currently, we have more than 60 projects in 22 countries working with children affected by AIDS, the vast majority of these in sub-Saharan Africa. Last year, approximately \$20 million was used for children affected by AIDS to expand existing activities and initiate new ones. We expect to increase this to \$40 million this fiscal year, and will continue to expand the coverage of existing activities, and support the initiation of new efforts to reach increasing numbers of children affected by AIDS.

I'd like to submit for the record USAID's publication, "Project Profiles: Children Affected by AIDS," which provides details on each of these projects. This summary was first published in October 2001. We will update it in July, and regularly thereafter, as a way to monitor our progress toward reaching our goal.

Experience to date in USAID has shown that five complementary strategies are required to best protect and care for children affected by HIV/AIDS:

- Strengthen the capacity of families to cope
- Mobilize and strengthen community-based responses
- Strengthen the capacity of children and young people to meet their own needs
- Ensure that government to protect the most vulnerable children and provide essential services
- Create an enabling environment for affected children and families

Let me explain and give some examples of each of these program areas.

#### FAMILIES

The fundamental principle underlying our programs for children affected by AIDS is that children are best helped by keeping them within a family environment. Twenty years into the pandemic, families and communities have provided, and continue to provide, the first line of response, and traditional African value systems support this approach.

However, the scale of the pandemic is causing enormous strain on the traditional coping mechanisms of the extended family and their communities. As these structures are weakened under the increasing pressure caused by illness, death, and subsequent emotional and economic deterioration, children lack food, shelter, medical care, school expenses, protection from neglect and abuse, economic support, and emotional care. Increasingly, children slip through weakened safety nets to live on the streets or in child-headed households.

Therefore, USAID's programs provide families with support to cope with the strains caused by AIDS. These programs give attention to both immediate survival needs and the longer-term issues of how to improve the ability of households and families to sustain themselves.

Our programs include a combination of material and psychosocial support. We help treat parents for infections, like tuberculosis, so they can live longer and with dignity. And we provide them with assistance to improve their economic situation, and to increase food security.

In Uganda, USAID has made a commitment to provide \$30 million in food aid in the next five years. By providing food to people living with HIV/AIDS and their families, it will improve nutritional status and will help remove one of the burdens a family faces as health deteriorates—providing an adequate food supply. In addition food is being used to provide assistance to faith groups and other civil society groups providing home based care and support, including support for orphans and other vulnerable children. In Rwanda, several programs work together toward the goal of providing food to 22,000 AIDS-affected children.

Reducing daily labor demands within vulnerable households provides support to family members whose time is consumed by caregiving activities. Such efforts have included cooperative community childcare, extending piped water to villages, planting crops that are less labor intensive, and production of fuel-efficient stoves by local artisans to reduce the time required to collect firewood.

In Kenya, the K-Rep project receives support to provide vulnerable households with business training, access to low-interest credit, and group savings schemes.

#### COMMUNITIES

For children whose families cannot adequately provide for their basic needs, the community is the next safety net. Community groups can help vulnerable children directly or assist AIDS-affected families to provide for children's needs.

Supporting community-led initiatives to care for children and adolescents affected by HIV/AIDS is a priority for USAID. We support communities in two ways: giving them direct assistance, and by supporting non-governmental organizations that in turn support a greater number of community efforts.

Community mobilization often starts with non-governmental organizations, often with the active support of government ministries. Many work with local churches. Some have organized district-level structures that, in turn, stimulate and support village efforts. Communities that have organized themselves to protect and care for vulnerable children are able to determine which children and households are most vulnerable and to channel outside resources to those most in need. They are also able to identify and reintegrate those children who have slipped through the primary safety net back into families and communities.

In Malawi, district AIDS committees have learned mobilization skills and have set up AIDS committees, which in turn, have organized and supported 208 village committees to raise funds and channel resources to affected children and adults. These committees have aided almost 13,000 orphans and vulnerable children.

If communities are key to helping children affected by AIDS, faith-based institutions are often the catalyst for action within communities. That's why we have provided support for the first conference of religious leaders to discuss children affected by AIDS, to be held this June, in Nairobi.

Through USAID's Core Initiative, which provides grants to faith and community-based organizations, we have given the Rob Smetherham Bereavement Service for Children a small grant to educate and train community members to meet the emotional needs of children affected by AIDS deaths and the grieving they experience as a result of the death of a parent.

#### YOUNG PEOPLE—MEETING THEIR OWN NEEDS

HIV/AIDS catches children in a double bind. Faced with a premature need to support themselves, other economic pressures, and the need to replace lost labor of their parents, many are forced out of school at the very time they most need to prepare for their own futures with an education. Girls are often forced to drop out first, which not only undermines their own health and well being, but also that of the next generation. Enabling children to stay in school and providing them with opportunities to learn vocational skills improves their ability to provide for their own needs—now and as they grow into adulthood. Measures can be taken to protect those children who must work, often as the result of the illness and death of a parent. These include: promoting safe ways for children to earn income; working with employers to improve children's working conditions, shelter, education, and training, and sensitizing police to the plight of children who work on the street and enforcing laws that protect them.

Upon the death of the parents, helping siblings to remain together is another way of strengthening orphans' ability to cope. Many poor extended families disperse orphaned siblings among different households to share the cost of their care. Interven-

tions that enable families to keep siblings together help these children recover from their loss, support each other, and remain in their own community.

In some rural areas, remaining in their parents' house is a way for children to retain possession of the land, to support themselves, and to have a sense of continuity. To do so, they need help and support from their extended family and community, who can monitor their situation and help with cultivation, home repairs, and basic needs. Legislation and informal community interventions can help protect the property rights of orphans and widows. Child-headed households often receive on-going support from extended family, neighbors, teachers, welfare officials, faith-based groups, non-governmental organizations, and other community initiatives. At USAID, we increasingly include support to child-headed households, as they are often the most vulnerable.

#### GOVERNMENTS

Concerted efforts are needed by governments to strengthen action to protect vulnerable children and provide essential services. National governments have generally recognized their responsibility to ensure that children are protected and cared for if they are on their own or live with adults unable or unwilling to adequately care for them. Laws and policies are fundamental to developing the necessary legal framework to protect increasing numbers of vulnerable children.

Just last week, USAID, along with UNICEF, UNAIDS, Save the Children/UK, and Family Health International, sponsored the first-ever West African meeting on children affected by AIDS. Representatives from 21 countries attended, including a delegation of four first ladies from West and Central Africa. This resulted in the development of individual country draft national action plans for children affected by AIDS. Participants committed to take the draft action plans back to their individual countries and to start a process of consulting with other stakeholders.

#### ENVIRONMENT

A fundamental area for action is increasing awareness among policy makers, community leaders, organizations, and the public about the impacts of HIV/AIDS on children and families. This involves generating a broadly shared sense of responsibility to support and protect those affected and a vision of how to do it.

Religious bodies, civic associations and other non-governmental organizations can assist in raising awareness. In many countries, faith-based networks are extensive and can be influential in urging a compassionate response to people with AIDS and their families. Religious groups can also play a critical role by identifying the most vulnerable among those affected and helping to mobilize community responses.

#### THE ROLE OF INSTITUTIONS

Many have suggested that building more orphanages or other group residential facilities is an effective way to care for the increasing numbers of orphans in AIDS-affected countries.

However, the experience of international child welfare organizations has shown that children benefit greatly from the care, personal attention and social connections that families and communities can provide. Particularly in the developing world, where the extended family and community are the primary social safety nets, the absence of such connections greatly increases long-term vulnerability. Children raised in institutions often have difficulty re-entering society once they reach adulthood; many are ill equipped to fend for themselves in the outside world.

The costs for providing care to children in institutions is also exceptionally high compared to community care. Cost comparisons conducted in Uganda show the ratio of operating costs for an orphanage to be 14 times higher than those for community care. A 1992 study by the World Bank found that institutional care at one facility in Tanzania cost \$1000 per year per child, a figure six times more expensive than the average cost of foster care in that country.

In developing nations, the extended family and community are the traditional and the best mechanisms for caring for orphaned children. Where circumstances prevent immediate care within a family, care in an orphanage is best used as a temporary measure until more appropriate placement or fostering within a family can be arranged.

Therefore, orphanages do provide critical services. Earlier this month, HHS Secretary Thompson and I visited two orphanages in Mozambique and South Africa, which were serving in this critical role. And we are pleased to support the community-based care of children infected by AIDS and their families through the Lea Toto program, which is a sister organization to Nyumbani Orphanage in Kenya, which you will be hearing more about on the next panel from Father D'Agostino.

## WORKING TOGETHER MATTERS

Reducing the vast numbers of, and providing care and support to, children made vulnerable due to AIDS will require action from communities at all levels: global, regional, national and local.

We are proud of all the work we are doing for children affected by AIDS. But we do not do it alone. We work closely with other bilateral donors, United Nations agencies—in particular UNICEF, national governments, non-governmental organizations, faith-based organizations and others. Together, we are working to identify and scale up model programs and to share these successes.

We thank Congress for your support on our work on children affected by AIDS, and thank you for holding this important hearing today.

Chairman HYDE. I think we'll go to our next panel and then we will withhold the questions until the second panel has finished testifying. Doctor, if you have to leave, we understand.

Dr. PETERSON. I'll be here.

Chairman HYDE. Will you be able to stay?

Dr. PETERSON. I'll stay.

Chairman HYDE. Alright. Thank you. Now we will have our next panel. I want to extend a warm welcome to these witnesses, Father Angelo D'Agostino is the Founder and Medical Director of the Nyumbani Orphanage in Kenya. He holds an M.D. from Tufts University. Father D'Agostino has served as chief of inpatient psychiatric services and associate clinical professor of psychiatry at George Washington University Hospital. In 1992 he founded the Nyumbani Orphanage, which has been a valuable refuge for children abandoned by their families because of their HIV/AIDS status. Welcome, Father.

Mr. Nathaniel Dunigan? Is Mr. Dunigan here? Mr. Nathaniel Dunigan is the Founder and Director of the AIDchild, a hospice and care center for parentless in Masaka, Uganda. He previously served as Director of Special Projects of Leadership in Rimrock, Arizona and was Deputy Director of the Executive Office of the Governor of Arizona. Mr. Dunigan works as an HIV/AIDS prevention educator, and through AIDchild, has provided a voice and resource for the immense needs of sick and orphaned children in Masaka, Uganda. Welcome, Mr. Dunigan.

Mr. Ken Casey is Senior Vice President of World Vision and Special Representative to the President for the HIV/AIDS Hope Initiative. He is chiefly responsible for leading World Vision's global response to the AIDS/HIV crisis. Previously, he served as Vice President for Business Affairs at Viola University at La Mirinda, California for 17 years. Mr. Casey joined World Vision in 1993 where his expertise has helped World Vision make exemplary use of private funds to keep sibling orphans together and in family living situations. Welcome Mr. Casey.

Our final witness is Ms. Laelia Gilborn. She is Program Director for Population Council/Horizons Programs for HIV/AIDS where she oversees numerous country studies as part of the Horizons project, a 10-year program of operations research to test and refine HIV/AIDS interventions and care in developing countries. Ms. Gilborn previously served at Population Council's Thailand office, where she contributed to and edited the winning proposal in response to USAID's \$40 million research funding agreement for research on HIV/AIDS. She also worked as an HIV/AIDS media project consult-

ant at UNICEF's East Asia and the Pacific regional office. Welcome to Ms. Gilborn and all of our witness.

I ask if you can possibly summarize your statement in about 5 minutes or less. Your full statement will be made a part of the record and that will leave time for some questions. So Father D'Agostino, if you would proceed.

**STATEMENT OF FATHER ANGELO D'AGOSTINO S.J., M.D.,  
FOUNDER AND MEDICAL DIRECTOR, THE NYUMBANI OR-  
PHANAGE OF KENYA**

Mr. D'AGOSTINO. Thank you, Mr. Chairman. I promise to keep it limited and have presented the full statement for the record.

Mr. Chairman, 10 years ago I founded a home for HIV positive orphans in Kenya. Today, we have 76 happy, healthy, well-adjusted and developed children. All go to school and are on anti-retroviral medication. To extend our services to a larger number, we started a community-based program, which at present cares for almost 400 HIV positive orphans, 200 of which are funded by the USAID.

This program includes a mobile clinic, comprised of a registered nurse, community nurse, social worker, community worker and a driver of a four-wheel drive vehicle, which is necessary to negotiate the slum-area roads. When we compare the costs of the orphanage and the community program, we find that the annual budget for the 76 orphans is about \$150,000 while the community program, caring for 200 from the AIDS grant is \$125,000.

Granted the community program has quantity, but it certainly lacks quality because not any of the community children receive the anti-retroviral drugs or go to school. The death rate of our orphans has dropped drastically in the past 2 years. So that instead of two and three deaths a month, we're happy to report only two deaths in the past 2 years.

Unless the greed of the international drug cartel is curbed, Mr. Chairman, in 10 years 25 million presently HIV people in Africa will die. It is my conviction then that despite the somewhat greater costs, the orphanage in Africa today is superior because the alleged community is rapidly disappearing, and in Kenya at the rate of 900 deaths a day. It can no longer absorb those orphans that need help.

What I recommend then is a third option. We must begin now by building planned villages comprised of orphans and another very needy, but rarely thought of, group—the elderly. More concretely, I have planned a Village of Hope, which will house, educate and care for some 600 orphans and 400 elderly. With a plot of 500 acres, the village will be self-sustaining because the elderly can supervise the agriculture, dairy, poultry and other projects while the young can provide the energy and enthusiasm.

The elderly will also be able to educate the young about the history and the culture which is passed on orally in that society, and which won't be passed on because so many of the parents are dead.

In conclusion, Mr. Chairman, I'm happy to report that Mr. Franklin Graham of the Samaritan's Purse has already pledged to provide \$1 million to construct the village that I mentioned, but we need more funds for the infrastructure. This village will serve as an example to the rest of Africa to begin preparing for the future cataclysm of at least 25 million, maybe 40 million orphans, who

will be roaming the continent without direction, shelter, sustenance and prone to crime in order survive.

Thank you, Mr. Chairman, for the invitation to share my experience and reflection, and I pray that they will serve to avoid a catastrophe greater than any in human history. Thank you.

[The prepared statement of Father D'Agostino follows:]

**PREPARED STATEMENT OF FATHER ANGELO D'AGOSTINO S.J., M.D., FOUNDER AND MEDICAL DIRECTOR, THE NYUMBANI ORPHANAGE OF KENYA**

Mr. Chairman, thank you for the opportunity to share with you my on-site observations in Kenya for the past 10 years. In 1992, I started a home for HIV+ children. The numbers grew rapidly. Today we have 76 HIV+ orphans living in our orphanage called Nyumbani, which in Swahili means "home." But since our effort was so limited in the face of the overwhelming problem, in 1998 we instituted a community-based care program named "Lea Toto," which means "to raise a child" in Swahili.

For 2 full years, even with the endorsement and help of the Director of the Children's Department in the Ministry of Home Affairs, I tried unsuccessfully to develop a foster care program. Why didn't it work? Well, first of all, the concept of fostering is alien to the Kenyan culture, or should I say cultures? There are 47 different tribes with their own distinct customs and language, and therein rests a problem because many of our children have been abandoned, and we know nothing of their tribal roots. In our 2 years of trying—and we have a good quality social service—we could not succeed because the potential foster parents would not agree unless we could give them all the details of tribe, village or city, family, etc., from which the child came.

Finally, one of our resourceful social workers hit upon a rather obvious stratagem: find a street child who is HIV+ and determine from them if they know of any extended family member. Then we would approach that person, who might be an aunt, a grandparent or even an older sibling. Our goal then was to convince this relative to take in the child, and we would supply instructions, medications for anti-opportunistic infection, food, clothing, etc. The child would be given a full physical examination by our pediatrician and treated appropriately. The relative would then be taken to our orphanage for a day of training and gain knowledge about the care of the HIV+ child. After our initial funder withdrew, we were able to obtain a 2 year grant from USAID to expand the program in one slum area and now we care for almost 400 HIV+ children.

But this does not come cheap. We had, first of all, to obtain a four-wheel drive vehicle to negotiate the non-roads in the slums where all the children came from. The team of care givers consists of a registered nurse, a community nurse, a social worker, and community worker. This team would not only identify a child in need, but they would also visit the child in 2 or 3 week intervals if he/she could not come to our central clinic. You will appreciate the fact that when a child is placed with relatives, there are usually 4, 5, or more children in that family, and so we are obliged to provide them with food or appropriate medicine even though they are not HIV+.

Is the community-based program more economical? Well our orphanage budget is about \$150,000 annually for 75 children, while the community program costs \$125,000 per annum for 200. But you realize that our orphanage children all go to school, all receive anti-retro viral medication as needed, and many other social psychological aids which result in a healthy, physical and mental development. In fact, a recent review of our statistics shows that our long-term survival rates compares very favorably with U.S. figures prior to anti-retro viral medication. Any and all visitors are surprised to find the children so happy, healthy, sociable, and well-adjusted.

So, I have seen both programs at work and am convinced that the orphanage, though a bit more expensive, is by far superior in many ways. Some critics do not agree and believe that the community should absorb the children. Mr. Chairman, that alleged community, in Kenya at least, is rapidly dissolving. With 900 deaths a day, that community is overstretched in its ability to survive, and soon will be reduced to a level of existence we cannot imagine. Mr. Chairman, after struggling with this problem every day for the past 10 years and seeing the tragic ongoing growth of HIV infection still, I have come up with what I believe is the solution for the future—if not immediately.

What lead me to my proposal is an appreciation of the following facts: there are some 25 to 50 million HIV+ people in Sub-Saharan Africa. Because of the inhumane greed of the international drug cartel, most of those people will die within 10 years.

May I point out that Hitler killed only 7 million because of a deviant philosophy? Despite what you read in the papers, the anti retro viral medications are not available to 90% of Africans because of the price. The drug companies are perpetrating a crime against humanity this very moment, and it goes completely unrestricted. Again, while Hitler killed 7 million, the drug cartels are responsible for the deaths of at least 25 million who are HIV+ and who could otherwise live if they had access to the drugs. Brazil has defied international laws and is manufacturing those drugs and distributing them free to any HIV+ person. They present a shining example to the world of what can and must be done if we are to succeed in stemming the tide of this plague.

As I mentioned, 25 to 50 million people will be dead in 10 years—and that certainly is an appalling tragedy—but even more cataclysmic is the fact that at each one, on average, will leave one orphan. So, not counting the children who die, etc., there inevitably will be some 20 million orphans roaming the continent without dwelling, sustenance or education, forging for survival. The potential for disorder is great.

That being said, I have conceived of establishing a "Village of Hope," which would house some 600 orphans and about 400 of another very needy, yet totally overlooked group: the elderly. The elderly have no social security whatsoever, they depend on their wage-earning children to support them, as is the tradition. But with those supporting children dying, the elderly are not only left destitute, but they inherit anywhere up to 5 to 10 orphan grandchildren.

Putting these groups in close proximity would not only make-up for the cultural gap due to the death of the parents, but the elderly could share their wisdom and experience while the young people who would supply the energy and enthusiasm. The village will be sustainable, as the plan calls for a 500-acre site which could be cultivated and/or sustain poultry and dairy animals.

The cost for the construction of such a village is extremely economical: 1 million dollars since a reputable architectural group in Nairobi is offering a 3 bedroom dwelling with bath and living space for \$5,000. Happily, Franklin Graham of the Samaritan's Purse has agreed to construct the dwellings, but another million is needed to provide infrastructure such as water, power, roadways, sanitation, etc.

In closing then, Mr. Chairman, let me say that to support a community-based project is flogging a dead horse, as I see it, and we must start now to present a viable option to the rest of the continent by establishing villages of hope.

Thank you for your invitation and the opportunity to share my experience with the Committee.

Chairman HYDE. Thank you very much, Father. Mr. Dunigan.

#### **STATEMENT OF NATHANIEL DUNIGAN, FOUNDER AND DIRECTOR, AIDCHILD**

Mr. DUNIGAN. Good morning. Thank you for this opportunity. I'm very grateful for it. And in the interest of time I am also presenting a summary of the longer statement, which I have presented for the record.

I'm grateful to you for your leadership, and we work closely with the USAID in Uganda and it's a pleasure to do so. I thank Dr. Peterson for her presentation this morning.

As I begin, may I invite you to imagine that you're standing with me in a banana field in Africa. It is October 1998. My first visit to the continent and I have come with hope. That is the precious product of HIV prevention education. I've been deposited here with a talented interpreter and left to find my way through the drapes of leafy trees and across the carpets of fallen foliage.

Soon enough I find my destination, a tiny mud hut, the space the crowded beyond capacity. I suddenly realize that everyone here is familiar with death. They know that their families are dying, and in so many cases they sense that they, themselves, are dying. I'm here to provide prevention education.

I step to the front and begin my hopeful presentation. Once finished, I answer questions. Finally, the space clears. Through the

rear opening of the hut sits a woman who looks to be quite aged, and with her there a young boy. He is covered with sores, wounds. His body is weak. I reach down and I pick him up. I feel that he is burning with fever. And I look into his eyes. There I see something I have seen many times since, the early maturity of a suffering soul.

This is a dear person like your children, your grandchildren, like you, like me. The older speaks. She says this is my grandson. His name is Simon. His father, my son, died when Simon was 2 months old with AIDS. His mother died 3 months ago with AIDS. It seems apparent to me that he also has AIDS. She pauses. She swallows and then she says today you talked to us about AIDS and you talked about hope. So I was just wondering what can you do for my grandson?

That day in the middle of that banana field my life changed because my thinking underwent a revolution. You see, I knew that there are more orphans in Uganda than in any other country in the world, 2.1 to 2.3 million, according to most observers. But the revolution of my thinking took place only once I was able to individualize those daunting and disturbing statistics.

As I held Simon in my arms, and as I looked into his eyes, I came face to face with the reality that our fight with HIV/AIDS is not about numbers and dollars, but about real people with names and faces. Further investigation, and now 19 months of on-the-job experience in Uganda have shown me that when more than 10 percent of a population is orphaned, there is a need which transcends culture, society, government, church, and home.

When the world loses massive numbers of people, there are survivors left to neglect and abandonment and disease. Yes, in Uganda the HIV infection rate has drastically reduced. You realize, of course, that this means that many of those who are infected have died and that not as many new infections have occurred. I've just told you that more than 2 million children are orphaned in Uganda, just one country. A country we rightly tout as currently edging toward victory in our desperate war.

Many of these children are already HIV positive. Many of them, thankfully, are not. I have a desperate worry, though, a plaguing concern about what happens as this group of children ages. Some of these little hearts and personalities are often left alone, regularly ignored, rarely cared for. What happens when their yearnings for intimacy and acceptance develop into a sexual activity in adulthood not reared with benefits of kisses on the forehead nor an elder's wisdom.

My great worry, though, is for the children who are already infected with HIV, an HIV that has rapidly destroyed their immune systems and has given them AIDS. They are suffering and most often, suffering unnecessarily. There is much that can be done for them. Like at AIDchild, the hospice and palliative care center I founded and currently direct in Masaka, Uganda. When nutrition, proper hygiene and loving care replace abuse, neglect and desperately over-taxed, extended families.

This unnecessary suffering is transformed into a preciously simple condition of comfort, strength and hope. Surely, this is a basic human right, worthy of provision for children who have no one.

I walk around my home in Uganda everyday saying three words. It's so easy. The everyday activities required to help these children are more ordinary than heroic.

Please allow me to close with a story of one my children, Ivan. He was 9 years old when came to live with me. Before Ivan was referred to AIDchild, he was surviving in the ransacked police barracks of my town. More than one policeman has told me that Ivan would awake early every morning to pray. In a loud voice he would say, 'Oh, God, please send someone to help me. I am hurting. I am sad. I am alone.' Once with us, Ivan became perfect joy. He became stronger. His blind eye is retreated. His Malaria, TB, Shingles, aches and pains were carefully tended. He was quicker to rejoice than to weep.

Months had gone by when he started to sleep a lot in his own bed, a clean comfortable space, free of mosquitos and daunting heat. One day he awoke from his slumber and looked at my staff members. He said, "I have seen that you love me so much," and then he did something that I find quite extraordinary and special. He said, "Thank you." He returned his head to his pillow and listened to the soft music we play as a part of our hospice care. Again, he spoke, "That music is so nice," he said and then went back to sleep. My little Ivan died early the next morning, but most of my children are still living with me—strong, happy and hopeful with AIDS, even months later. And some have died. Others will also die, but perhaps, Ivan's is the greatest hope. May we all one day be able to say "I have seen that I am loved. I am grateful. I'm comfortable and I am going to go to sleep now."

Robert Lewis Stevenson once wrote,

"So long as we are loved by others, we are indispensable and no one is useless when they have friend."

From the front lines, I report to you that this must become the reality for millions of children around the world. Extended family networks are exhausted, even destroyed. Foster homes are often perfect and wonderful, but will always be too few. If we are to offer this basic right to as many children as we possible can, we simply cannot afford to rule out any one type of care for this terrific number of dear hearts, sweet faces and precious individuals.

Working together we must make a difference. We can make a difference. And more over, I absolutely maintain it is so easy. Thank you.

[The prepared statement of Mr. Dunigan follows:]

#### PREPARED STATEMENT OF NATHANIEL DUNIGAN, FOUNDER AND DIRECTOR, AIDCHILD

May I invite you to imagine that you are standing with me in a banana field in Africa? It is October of 1998, my first visit to the continent, and I have come with hope; the precious product of HIV prevention education.

I have been deposited here with a talented interpreter, and left to find my way through the drapes of leafy trees and across the carpets of fallen foliage. Soon enough, I find my destination: a tiny mud hut. It is obvious, even from a distance, that the space is crowded beyond capacity. It is explained to me that these individuals have eagerly gathered because it has been promised that I will be providing information about HIV/AIDS. I suddenly realize that everyone here is familiar with death. They know that their families are dying. Their mothers. Their fathers. Their grandchildren.

And in so many cases, they sense that they themselves are dying.

I step to the front and begin my hopeful presentation. Once finished, I answer questions. Finally, the space clears. I am left with my interpreter and with a local leader. We wait for the Land Cruiser to come to collect me. I fall in love with the magic of Africa.

Through the rear opening of the hut steps a woman who looks to be quite aged. With her, a very young boy. With each step that they take towards me, I become increasingly aware of the severity of this sweet child's condition. He is covered with sores. Wounds. His body is weak. I reach down and pick him up. I feel that he is burning with fever.

And I look into his eyes. There, I see something I have seen many times since: the early maturity of a suffering soul. This is dear person. Like your children. Your grandchildren.

Like you.

Like me.

Only, he has seen so much. So much that is terrible. So little that is good.

The elder speaks. She says, "This is my grandson. His name is Simon. His father, my son, died when Simon was two months old. With AIDS. His mother died three months ago. With AIDS. It seems apparent to me that he also has AIDS."

She pauses. She swallows. Then, "Today, you talked to us about AIDS, and you talked about hope. So I was just wondering, what can you do for my grandson."

That day, in the middle of that banana field, my life changed as my thinking underwent a revolution. You see, in preparation for that trip, I had learned that there were 1.7 million orphans in Uganda. According to the *World health Organization, USAID* statistics, and Ugandan government studies, this is more than in any other country of the world. Presently, that number is alarmingly larger: 2.1 to 2.3 million children are orphaned in Uganda today.

The revolution in my thinking, though, took place only once I was able to individualize the daunting and disturbing statistics. As I held Simon in my arms, and as I looked into his eyes, I came face to face with the reality that our fight with HIV/AIDS is not about numbers and dollars, but about real people—with names and faces. With sorrow and pain.

I also realized that much of this suffering, even for those already infected, is unnecessary. And I knew that I could not walk away from Simon, or that reality.

Further investigation, and now nineteen months of on-the-job experience in Uganda, have shown me that when more than ten percent of a population is orphaned, there is a need which transcends culture, society, government, church, and home. When the world loses massive numbers of people, there are survivors left to neglect and abandonment.

And disease.

Yes, in Uganda, the HIV infection rate has drastically reduced. You realize, of course, that this means that all those who were infected have died. And that not as many new infections have occurred.

Yet.

I have just told you that more than two million children are orphaned in Uganda. Just one country. A country we rightly tout as currently edging towards victory in our desperate war. Many of these children are already HIV positive. Many of them, thankfully, are not. I have a desperate worry; a plaguing concern about what happens as this group of children ages. Some of these little hearts and personalities are often left alone. Regularly ignored. Rarely cared for. What happens as their yearnings for intimacy and acceptance develop into a sexual activity and adulthood not reared with the benefits of kisses-on-the-forehead nor an elder's wisdom?

My greater worry, though, is for the children who are already infected with HIV, an HIV that has rapidly destroyed their immune systems, and has given them AIDS. They are suffering—and are most often suffering unnecessarily. There is much that can be done for them. Like at AIDchild, the hospice and palliative care center I founded and currently direct in Masaka. When nutrition, proper hygiene and loving care replace abuse, neglect and desperately overtaxed extended families, this unnecessary suffering is transformed into a preciously basic condition of comfort, strength and hope. Surely this is a basic human right worthy of provision.

I walk around my home in Uganda everyday saying three words: "It's so easy. It's so easy." While the tasks of fundraising and project building in a new environment may be more challenging than I would like, the actual-every-day-activities required to help these children are more ordinary than heroic.

To exemplify, please allow me to close with the story of one of my children, Ivan. He was nine or ten years old. Little is known about his past. Before Ivan was referred to AIDchild, he was surviving in the police barracks of my town. More than one policeman has told me that Ivan would awake early every morning to pray. In

a loud voice he would say, "Oh God, please send someone to help me. I am hurting and sad, and I need someone. Please help me."

Once with us, Ivan became perfect joy. He became stronger. His blind eyes were treated. Some sight returned. His cough subsided. His malaria, TB, shingles, aches and pains were carefully tended. His dementia was understood and catered for. He was quicker to rejoice than to weep. He was always grateful in prayer for his rescue. Months had gone by when he started to sleep a lot. In his own bed. A clean, comfortable space, free of mosquitoes and daunting heat. One day, he awoke from his slumber and looked at my staff members who were there with him. He said, "I have seen that you people love me so much." And then, he did something I find quite extraordinary and special. He said, "Thank you." He returned his head to his pillow, and listened to the soft music we play as a part of our hospice care. Again he spoke, "That music is so nice," he said. And then went back to sleep.

My little Ivan died early the next morning.

I have many, many other children. All came to me with a diagnosis of about thirty days to live. A diagnosis based on their living conditions and available resources. But most are still living with me—strong, happy and hopeful. With AIDS. Even months later.

And some have died. Others will also die. Their condition is eventually fatal.

But perhaps Ivan's is the greatest hope. May we all one day be able to say, "I have seen that I am loved. I am grateful. I'm comfortable. And I'm going to go to sleep now."

Robert Louis Stevenson once wrote, "*So long as we are loved by others, we are indispensable, and no (one) is useless (when they) have a friend.*"

From the frontlines, I report to you that this must become a reality for millions of children around the world. And it can be done. I know firsthand. Extended family networks are exhausted, even destroyed. Foster homes are often perfect and wonderful—but will always be too few. If we are to offer this basic right to as many children as we possibly can, we simply cannot afford to rule out any one type of care for this terrific number of dear hearts, sweet faces, and precious individuals.

Working together, we must make a difference.

We can make a difference.

And, moreover, I absolutely maintain: it's so easy.

Thank you.

Chairman HYDE. Thank you, Mr. Dunigan. Mr. Casey.

#### **STATEMENT OF KEN CASEY, SENIOR VICE PRESIDENT, WORLD VISION INTERNATIONAL AND SPECIAL REPRESENTATIVE TO THE PRESIDENT FOR HIV/AIDS**

Mr. CASEY. Thank you, Mr. Chairman and distinguished Members of the Committee. I want to thank you for the opportunity to speak with you this morning. I wanted just to applaud your leadership on this critically important issue, and to also say I was quite encouraged by the passion.

Chairman HYDE. I'm not sure your mic is working well. Would you try Dr. Peterson's.

Mr. CASEY. Okay.

Chairman HYDE. That's better, please.

Mr. CASEY. The light was on, but the sound wasn't coming.

Let me just say I was encouraged by the opening statements of the Members of the Committee, and thank you for the passion reflected in those.

I speak to you this morning representing an organization, World Vision, that has spent the last 50 years addressing the needs of vulnerable children and their families around our world. We're working in 25 countries in Africa and a total of 90 countries around the globe. But more importantly, I hope I can speak on behalf of the tens of millions of children whose quality of life has been severely diminished by the HIV/AIDS pandemic.

World Vision first began addressing the issue of AIDS, orphans and vulnerable children in partnership with the World Bank and the Government of Uganda back in 1990. At that time, we were working at the ground zero of the AIDS epidemic in the Rakai and Masaka districts in Southern Uganda. Over the succeeding 12 years, we have sought to build on the lessons learned from those initial programs to develop sound and effective programs for orphans and vulnerable children. I would like to share from that experience.

First, let me introduce you to Mrs. Mzamba who lives in Northern Zambia, and is desperately trying to care for a family of 14. Mrs. Mzamba had seven children. Five of those children have died of AIDS, leaving her with six grandchildren to care for. These grandchildren are included in the estimated 13 million children orphaned by AIDS, 12 million of which are in sub-Saharan Africa.

Mrs. Mzamba's other daughter is also HIV positive and is in the final stages of tuberculosis. She's unable to care for her four children, and so they, too, are left to Mrs. Mzamba's care. However, since their mother is still alive, these children are not included in the 12 million children in Africa who are orphaned, even though they are highly vulnerable as a result of AIDS. Mrs. Mzamba has one more daughter who, at this point, is still healthy and has a son of her own. He is also not part of the 12 million children, but like many children living in families fostering AIDS orphans, he, too, is highly vulnerable because family resources that would have been available for him are having to be divided amongst so many.

I use Mrs. Mzamba's family to illustrate that when you include children living with HIV positive parents; particularly, chronically ill ones, and children living in families fostering AIDS orphans, the total number of orphans and vulnerable desperately needing help is probably several times greater than the highly publicized 13 million orphans.

Our experience has taught us that leveraging and supporting existing community resources provides the most developmentally sound and cost effective care for these children. We feel that the best practices for caring for orphans is within the extended family structure, and feel that keeping families together as much as possible is critically important. Not only is this in keeping with traditional desire of Africans for caring for their children within their families, but it also provides the best opportunity to compliment programming designed to ensure essentials like good education, nutrition and health care with the psycho-social and socialization so vitally needed to ensure holistic development of the child.

The greatest need we're all facing right now is the challenge of scaling up programs commensurate with the magnitude of the need, and generally speaking, community-based programs provide the most cost effective means of doing that.

I would like to draw just some specific attention to the role that faith-communities can play in our efforts to support these children. Let me give you five quick reasons why I believe they should be considered as key program partners for providing meaningful support for the children.

The first is reach. They are present in virtually every community. The second is call. Most religious traditions include a central

theme of loving and caring for one's neighbor. It's the people in faith communities are not driven simply by sympathy or guilt to care for the needs of their neighbors or extended family, but rather they have the added motivation of being called to do this as a central tenet of their faith. The third is they're also sustainable. The faith community is embedded in the community. It was there before the NGOs and the government agencies arrived, and it will be there long after we all leave.

The fourth reason is the moral authority they have. At the root of the AIDS pandemic are people's choices about sexual behavior. Personal choices on sexual behavior are primarily guided by personal beliefs and values. They are not primarily cognitive decisions. The faith community alone has the moral authority to speak to these issues.

And the final piece is hope. These children need hope. They need a sense that there's something positive about their future. In addition to nourishment for their bodies, they need nourishment for their souls. The local faith community has a unique capacity to address this need.

Given these five unique characteristics of the faith community, we should look to how we can strengthen and enhance their capacity to play a significant role in the lives of these children.

Finally, just a word about resources, the magnitude of suffering of these children demands our immediate and wholehearted attention. The character of our country has been built on a spirit of generosity and compassion. However, never in the 225 years of our country's existence have we been confronted with suffering of this magnitude of those beyond our borders, and particularly, children.

While you and your colleagues on this Committee and in the Senate have shown leadership in addressing the AIDS crisis, much more is needed. World Vision would join with a number of our colleagues in urging you to commit a billion dollars to the global AIDS funds this year, and also to provide \$2.5 billion per year of funding beginning with the FY '03 budget. We would also suggest that in the area of 20 percent of this funding should be for the care of orphans and vulnerable children.

So Mr. Chairman, I just respectfully ask you, on behalf of these children, that you and this Committee do all you can to provide these needed resources and help these millions of children experience a hope-filled future. Thank you.

[The prepared statement of Mr. Casey follows:]

PREPARED STATEMENT OF KEN CASEY, SENIOR VICE PRESIDENT, WORLD VISION INTERNATIONAL AND SPECIAL REPRESENTATIVE TO THE PRESIDENT FOR HIV/AIDS

I. INTRODUCTION

Thank you Chairman Hyde for the opportunity to offer testimony on best practices in caring for AIDS orphans and vulnerable children in Africa. My name is Ken Casey, Sr. Vice President and Special Representative to the President for HIV/AIDS initiatives for World Vision International, the largest privately-funded international relief and development organization in the U.S. World Vision has relief and long-term development operations in 25 sub-Saharan African countries, and is operational in a total of 95 countries worldwide.

II. OVERVIEW OF AIDS, ORPHANS AND VULNERABLE CHILDREN

Mr. Chairman, as you know, AIDS is a disease that knows no borders. Particularly in Africa, AIDS is not just an epidemic it is an inter-generational pandemic.

In the first decade of the 21st century, AIDS will claim more lives than all of the wars of the 20th century. Although sub-Saharan Africa represents 10% of the world's population, it accounts for two-thirds of all AIDS-related deaths. Some 28 million people in Africa, including 6.5 million children, are living with HIV/AIDS. And with every death there is usually one orphan, but often several. Current estimates show that today there are 13 million orphans as a direct result of the AIDS pandemic, and 12 million of those orphaned are African. Epidemiologists warn that this is barely the tip of the iceberg: only 10% of AIDS-related illnesses and deaths have been seen. Millions of Africans are infected but have not yet started to fall ill, and according to UNAIDS, 90% of Africans living with HIV don't even know they are HIV positive.

Experts say that AIDS is far worse than the fabled Black Plague of the medieval period. Unlike the plague and most other diseases, AIDS usually strikes people in their prime. Most people who acquire HIV in Africa become infected before they are 25 years old, and are usually dead before their 35th birthday. This age factor makes AIDS uniquely threatening to families, communities, and economies. In the most heavily AIDS-affected countries in Africa, average life expectancy has fallen from sixty years to below forty: an unprecedented and horrifying drop in just a few years. The worst is yet to come.

As millions of adults lose their lives to HIV/AIDS, millions more children are orphaned, and millions of others are rendered highly vulnerable. Who are the orphaned and highly vulnerable children? At World Vision, we define *orphans* as children who have lost a mother, a father, or both parents to any cause. This is not an attempt to overlook the fact that the majority of orphans are as a result of AIDS; rather, 'AIDS orphans' will not be singled out because parents rarely know of their HIV status. We also define orphans in this way because this helps to prevent stigmatization of children with parents who are HIV+, as well as preventing discrimination against orphans whose parents are not HIV+. *Vulnerable children* include those whose parents are chronically ill (and thus likely HIV+). These children are often even more vulnerable than orphans, because they are coping with the psychosocial burden of caring for dying parents, while simultaneously bearing the family economic burdens stemming from the loss of parental income and increased health care expenses. Other vulnerable children include those who are living in households that have taken in orphans. When a household absorbs orphans, existing household resources must be spread more thinly among all children in the household. It is more difficult to quantify vulnerable children, however, it is estimated that the number of vulnerable children is at least 2–3 times the number of children who are orphaned.

### III. THE IMPORTANCE OF FAITH BASED ORGANIZATIONS IN COMBATING HIV/AIDS AND CARING FOR ORPHANS AND VULNERABLE CHILDREN

#### *The Role of Faith-Based Organizations in Combating HIV*

The vast majority of HIV prevention resources allocated to date has gone to condom promotion, and to the treatment of sexually transmitted infections (STIs). While very important, the pivotal role of faith-based organizations (FBOs) is often overlooked, thus decreasing the overall effectiveness and sustainability of existing approaches. In Uganda and Jamaica, two countries that have experienced a stabilization and a decline in their HIV rate, there is growing documentation that the work of faith-based organizations in HIV prevention through behavior change has made a significant impact in stabilizing and preventing new cases of HIV.

I believe there are 5 primary reasons why faith-based organizations are critical to stemming the tide of HIV:

1. *Reach.* Faith-based organizations have a very broad presence. FBOs operate between 40–50% of all the health care and educational facilities on the continent. The World Bank estimates, they have capacity to reach 95% of the poor, when facilitated to do so.
2. *Call.* As a part of practicing their faith, most people in religious communities are called to serve and care for their neighbors or other people in need. This mandate of faith is an important and sustaining motivation factor in the prevention and care for those living with HIV/AIDS.
3. *Sustainability.* Long after government programs have finished or NGOs have left the area, faith institutions remain and are a permanent part of the foundation of local communities and societies at large.
4. *Moral Voice.* Because HIV is primarily contracted through sex, addressing sexual behaviors is one of the most important parts of prevention. Faith institutions speak to the deepest human values and beliefs, and are thus best

positioned to speak with authority to the intimate practices of individuals and communities.

5. *Hope.* Faith-based organizations address issues of the spirit, which is at the core of nurturing and restoring hope for those living with HIV/AIDS, and those who have been orphaned by it. In our own experience in the field, those who have hope are the best advocates for prevention.

Because of the severity of the HIV/AIDS pandemic in Africa, no approach or institution is mutually exclusive, but rather all resources must be mobilized. This means that faith-based organizations (FBOs), community-based organizations (CBOs), national and local governments all have vital roles to play, and thus need to be strengthened to address the pandemic and its impacts on children.

*World Vision's Work to Strengthen Faith-Based Organizations and Communities Caring for Orphans and Vulnerable Children (OVC)*

Because of the enormous and rapidly increasing number of orphans and vulnerable children (OVC), World Vision believes that providing effective care means looking beyond our existing community operations to partner with faith and community-based organizations in order to reach as many affected children as possible. We have seen that effective care for orphans and vulnerable children involves addressing 7 core needs:

1. *Education*
  - Ensuring that all barriers to primary school attendance are overcome (e.g. fees, uniforms, supplies, stigma and discrimination, etc.)
  - Arranging apprenticeships/vocational education for older OVC
2. *Emergency nutritional support* (when necessary)
3. *Referrals and transport to health outreach workers, clinics, and other health facilities* (when necessary)
4. *Protection against abuse and neglect*—through negotiation, advocacy, and referrals
5. *Spiritual and psychosocial counseling and support*
6. *Succession planning* (Preparing for the loss of a parent)
  - a. Memory books and memory boxes
  - b. Identification of standby guardian
  - c. Protection of inheritance rights
7. *HIV prevention and awareness* (Peer education, values education, reproductive health education, etc.)

In addition to addressing this core set of needs, World Vision in partnership with FBOs and community groups, provide other forms of assistance to orphans and vulnerable children based on local needs, strengths, and priorities. In response to requests by these groups, and based on available resources, World Vision collaborates with other partners to provide training, financing, materials, and/or other forms of assistance to the groups for a variety of relevant activities, including the following:

- *Training for OVC on how to support themselves and their family* (household management skills, negotiation skills, basic agricultural or vocational skills where appropriate, etc.)
- *Agricultural training and inputs*
- *Community-managed day care for young children* (under six years)
- *Youth clubs focused on HIV prevention*
- *Provision of treated bednets, oral re-hydration therapy, micronutrient supplements, and related training*
- *Care for chronically ill adults in the household:*
  - a. Palliative care—simple assistance to reduce suffering, including basic medicines and/or traditional remedies that are safe, effective, and available
  - b. Nutrition—provision of training and supplements (when available)
  - c. Hygiene training—to protect from HIV transmission
  - d. Spiritual and psychosocial support
- *Spiritual and psychosocial counseling and support for guardians of orphans and vulnerable children.*
- *Micro-enterprise development support*—primarily through linkages to micro-finance institutions and other institutions specializing in economic strengthening.

- *Other activities that benefit OVC*, particularly innovative efforts developed by church/community groups and other partners that World Vision can learn from and share widely.

#### *Sustainability*

The key to lasting improvement in the lives of orphans and other vulnerable children is sustained care for all OVC by their families and communities. Sustainability is best achieved through strengthening the capacity of OVC-focused community initiatives. World Vision's current capacity building component entails training, advising, and other forms of technical assistance to strengthen two types of capacities essential for church/community groups caring for orphans and vulnerable children:

1. *General organizational development capacities*, including proposal writing, planning, budgeting, bookkeeping, monitoring, reporting, linking with information and funding opportunities at district and national levels, local fund-raising, etc. Strengthening these capacities will enable church/community groups to improve the quality of their OVC care, as well as to access external resources to expand and sustain their efforts.
2. *Improve CBO/FBO capacities specific to caring for orphans and vulnerable children*, providing technical support as needed to ensure the seven core benefits noted above.

In partnering with faith and community-based organizations, World Vision works with groups to define criteria for assessing vulnerability within the community. Local groups then take responsibility for identifying orphans and vulnerable children in the community, using the established criteria. Once OVC are identified, the members from the FBO/CBO make regular visits to the homes of orphans and vulnerable children. These group members are trained and supported by World Vision and other partners to enable them to provide quality care for orphans and vulnerable children.

Our experience shows that partnering with local faith and community initiatives is a sustainable, effective approach to assisting orphans and other vulnerable children in AIDS-affected areas, at large scale and low cost.

#### IV. RESOURCES

The magnitude of suffering experienced by these children demands our immediate attention. Never before has the world been confronted with suffering of this magnitude; and suffering especially experienced by children.

The \$7–\$10 billion per year estimate made by the Global Fund is a reasonable estimate of how much is needed annually to confront and turn the tide of this epidemic. The US share of this should be in the area of 25%–30%. Time and money are indicators of care and commitment. Mr. Chairman, I applaud your leadership and that of this Committee in investing the time to expose and explore the issues of care for HIV/AIDS orphans and vulnerable children in Africa. Allocation of additional resources is the ultimate indicator of our care for African orphans and vulnerable children. World Vision joins the many voices in calling the U.S. to make its full FY2002 contribution of \$1 billion to the Global Fund, and to commit a total of \$2.5 billion for FY2003. While the US government has made initial overtures to addressing the AIDS crisis, much more is needed. Mr. Chairman, I respectfully ask you and your colleagues to match your commitment of time with an increased commitment of resources in fighting HIV/AIDS and caring for orphans and vulnerable children.

#### V. A MODEL OF LEARNING: UGANDA

World Vision has been implementing a major program of assistance for the orphans of HIV/AIDS and war in Uganda since 1990. At the start of the program, HIV/AIDS had emerged as a national crisis, with some of the highest prevalence rates in the world. Distribution of the epidemic was unclear due to the lack of data, but based on the numbers of orphans left behind, the districts of Rakai and Masaka in southern Uganda were considered to constitute the epicenter of the epidemic. Both of these districts, along with Gulu district in the north, had also experienced prolonged period of warfare during the campaign to rid the country of dictator Idi Amin. Both HIV/AIDS and conflict had created many orphans and the number was still on the increase. A rough estimate made by UNICEF at the time indicated that there were anywhere between 500,000 to 700,000 orphans in the country. This number has now increased to more than 1.7 million orphans in Uganda alone.

Implementation of this program has occurred in two distinctive phases. Phase I covering the period 1990 to 1995 entailed implementation of a multi-sectoral pro-

gram covering the districts of Masaka, Rakai and Gulu. Support for this program came from the Government of Uganda (through a World Bank IDA credit) and World Vision. When IDA funding ended, a major restructuring was carried out beginning 1998. This resulted in the reconstitution of the program into 6 Area Development Programs (ADPs) that received support from World Vision's Child Sponsorship Fund.

The program started in 1990 with a target of reaching between 30,000 and 40,000 needy children (18 years and under) that had lost at least one parent due to war and HIV/AIDS. However, this criterion was changed soon into the program following in-depth dialogue with communities. Qualifying children became those that a community identified as being very vulnerable following guidelines developed jointly by the community and World Vision. Typically, this criteria took in children that had lost both parents due to any cause and were in the care of (1) elderly guardians (70 years old +) with no dependable income, (2) household headed by other children, (3) households where the care givers were chronically ill (most likely AIDS), and (4) households where the care givers were healthy but where the number of orphans taken in was so large that family food security became a serious problem.

#### *Best Practice: Families Caring for Orphans and Vulnerable Children*

In most African societies, institutional arrangements are the exception rather than the norm. In Uganda for instance, only 2,500 children out of a total of more than 1.7 million orphans receive care from the 70 orphanages in country. Capacity is not the issue. The accepted traditional coping mechanism is to integrate orphaned children within extended families. There is a general feeling that children who are raised in orphanages and other institutions will lose out on family life, socialization into their culture, and their identity and sense of belonging to a distinctive community. Further, strong feelings emerged that children of the community should not be put into a situation where they would be raised as second-class citizens. This view was well conveyed by the question of one-woman leader at a focus group discussion: "Do we want to let our children go to institutions so that they will be the ones to be selected for all the jobs people do not want to do?"

#### *Challenges to Informal Fostering*

Although fostering within the extended family has always been the preferred method, this system exhibited certain shortcomings at the initiation of the program. Most families were overwhelmed. The scale of AIDS was such that many families were experiencing multiple deaths of relatives, so there were many orphans to support. Extended families were taking in children from outside their own families. The burden was considerable coming as at a time when families were still struggling to recover from the general deprivation brought about by years of civil war.

In many focus group discussions, schooling was stated to be the most critical need for orphans. Extended families would try to send an orphan to school. However, the orphan would be the first child to drop out when family funds diminished. Some people were taking advantage of the orphans; they would speak out at an extended family meeting pledging to take in a particular child, whereas the underlying motive to those people was exploitation of the child's labor. It was also reported that some people were taking in children in order to gain access to their inherited property.

The lessons from informal fostering are closely linked to the well being of the children involved. The health and nutrition of the orphans became a major issue depending on the age and health status of the orphan. Children of age 0-3 years may be HIV positive or AIDS symptomatic in which case, they will be sickly. Care will be expensive and tiresome. Ages 0-5, are the formative years during which nutrition, stimulation, health, parental love and socialization are crucial. These were not being provided for some orphans, and there were fears expressed by teachers and mothers that the orphans' personality could be affected.

Foster parents also expressed other crucial needs as well, including difficulty in producing enough food for the household (especially in cases where these were elderly), and difficulty in ensuring children were adequately clothed. The plight of foster parents was aggravated by the effects of war, and the related asset destruction, which had left many of them poor and in need of support to get started. The total effect of this situation was in turn causing orphan siblings to be distributed among several households, at times creating a situation where siblings would never get to see each other. This made the recovery of children from the trauma of losing loved ones especially difficult.

#### *Strategies and interventions*

A number of steps were taken to identify effective approaches for addressing the above challenges. Because it was understood progress would be made only when the people themselves took ownership of the solutions, the first step was to get them

to fully understand the dynamics of the problem they were facing. Facilitating communities to give their views in focus group discussions as well as discussing with them the results of the baseline survey attained this. In this manner, communities were able to express their views on a variety of options, helping to guide the program as to which interventions would generate community interest and participation. Some of the outputs of this process were:

- *Identification of beneficiary families.* A process was agreed to as how to go about identifying the most vulnerable households within the community. The names were to be vetted by community committees in an open process. For the most vulnerable to emerge, the process would be repeated several times, since people often did not get to learn about meetings being held the first time. Local administrators or their representative would attend each funeral within their jurisdiction to witness the recording of names and educational characteristics of the surviving children right at burial. This process helped to create a community-managed database upon which selection of beneficiaries was partly based. Qualifying families were those that had taken in orphans and which, in the eyes of the community) needed additional support to be able to cope.
- *Target age group:* Community dialogue helped raise the upper end of target age group from 15 years to 18. There was a common feeling that the 15-year age cut off would find many children just beginning their high school education. Furthermore, most people were of the view that children of 15 still needed a great deal of guidance and supervision to be able to fend on their own.
- *Partnership.* Most of all, community sensitization and dialogue helped to clarify at the outset that this was a community program to which WV had come to assist, as opposed to visualizing the initiative as a World Vision program that was seeking community support. This led to the development of community structures that would guide and work alongside World Vision in its efforts. Agreement was also secured as to which activities World Vision should assist in and which activities would best be left to the community. Through this dialogue it quickly emerged that the best way to support orphans was to devise a multi-sector package of interventions that combined direct support to the children themselves while at the same time assisting families and communities to recover. A summary description of the interventions is presented in the Addendum.

#### *Project Delivery*

The delivery of project services was achieved through partnership between community members and a team of full time employees based at parish, sub-county and district levels. Parish development workers (PDWs) were selected in conjunction with communities. Their role was to ensure that all planned project activities were implemented at the grassroots level. Each sub-project had a total of 60 PDWs. These were coordinated by sub-county based development workers, and by a team of technical staff at district level. These were qualified in health, social work/ counseling, agriculture, rural extension and finance.

Project staff collaborated with existing structures for effective and sustainable implementation. These structures included operational ministry staff, RCs and chiefs, and other NGOs with complementary programs. Collaboration would ensure that projects complemented one another and that duplication of effort was avoided.

Communities played a significant role in planning and implementation, and in the monitoring and evaluation of program goals and activities. Communities were encouraged to commit their own resources so that they became real partners in the program. Program committees were set up and operated at parish, sub-county and at district level.

The parish committee was made up of elected representatives from each of the villages within the parish. The sub-county committee was made up of elected representatives from each parish committee. Members of the sub-county committee then elected a representative to the project management committee. Other members of this committee included respective civil servants in the area, who would attend as ex-officio. Each committee elected its own chairperson as well as secretary. The main functions of the committees were to motivate communities, provide feedback to project staff about community views about the program and to indicate whether changes were needed. The project committee at the district level, in particular, played the critical function of providing both community and then local government input to the program.

*Role of Other Organizations*

World Vision actively collaborated with a number of international and national NGOs in order to increase effectiveness on the ground. Working under the principle that no single agency could alone address all issues related to HIV/AIDS, agencies in the field developed multiple forms of collaboration, including referral of cases that some agencies could not handle to those that could.

World Vision worked with a number of other NGOs to form the umbrella organization called Uganda Community-Based Orphan Care Association—a forum for sharing information, coordinating action, and undertaking joint advocacy. This forum met with government, donors, and other key stakeholders on a regular basis to exchange information. It provided vital input into the formulation of policies regarding the conditions under which orphanages should be established. It made responses into the draft legislation on inheritance and the rights of widows and orphans. It has remained a vocal entity on issues of child protection, and was instrumental in calling for the establishment of a special wing of the police to address issues of child abuse. During the 1995 political campaign, this group framed education of orphans into a major campaign issue. Further input was made into other networks active in the Uganda Debt Network and in the preparation of the country's Poverty Reduction Strategy Paper (PRSP). The outcome of this process was to strengthen the commitment of the country to the launch of the Universal Primary Education (UPE) program in 1997, which eliminated primary school fees for all children in Uganda.

V. CONCLUSIONS

The HIV/AIDS pandemic in Africa has left in its wake at least 13 million orphans and 2–3 times the number of vulnerable children. The massive and growing number of orphans and other vulnerable children in HIV/AIDS-affected areas constitute a humanitarian and development crisis of unprecedented proportions. If the international community does not respond immediately and at large scale to this crisis, the potential threats to national, regional, and global security and stability will be severe. A generation of marginalized young people who grow up without guidance and support are highly susceptible to recruitment by terrorist networks, warlords and guerilla groups, criminal gangs, and other forces who can tear societies apart.

In the face of this crisis, faith and community-based organizations have been effective partners in promoting HIV prevention and providing sustainable care both for adults living with HIV/AIDS and orphans and vulnerable children. Churches and other faith-based organizations are especially well-positioned to provide quality care for orphans and vulnerable children, as well as those living with HIV/AIDS, because they:

- 1) have a wide reach and presence in most communities;
- 2) have a spiritual call to serve and care for neighbors, especially those who are needy;
- 3) have a moral and authoritative voice on the personal issues related to HIV transmission;
- 4) provide a sense of hope and empowerment to those living with and affected by HIV/AIDS.,
- 5) they have a lasting presence in communities, which is essential to sustainable and effective care for orphans, vulnerable children, and those living with HIV/AIDS.

World Vision has been a leader in innovative care for orphans and vulnerable children since the early stages of the HIV/AIDS crisis. In some of the world's most heavily AIDS-affected areas, World Vision is working in partnership with communities and faith-based organizations to address the seven core needs of orphans and vulnerable children:

- 1) education support;
- 2) emergency nutritional support (where needed);
- 3) referrals and transportation to health outreach and social workers (where needed);
- 4) protection from abuse and neglect;
- 5) spiritual and psychosocial counseling and support;
- 6) succession planning to prepare for parental death; and
- 7) HIV prevention and awareness.

The OVC crisis will continue to widen and worsen for at least another decade. The severity and duration of the crisis demands strategic and decisive action. Efforts by World Vision and other international humanitarian organizations to assist orphans and vulnerable children can only be sustainable when they are undertaken in partnership with local faith and community organizations. Likewise, when there is local and international partnership with governments of goodwill, like the U.S. who will commit to providing political and financial support, best practices will always result.

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#### ADDENDUM

##### THE WORLD VISION AND THE GOVERNMENT OF UGANDA PROGRAM OF ASSISTANCE TO ORPHANS OF AIDS AND WAR.

###### *Program Objectives*

*1. Increase productive capacities of families:* The objective was to increase the productive capacity of the foster families through training, provision of agricultural inputs, and credit. The target number of families to be supported was 6,000–7,500. The rationale was that through this mechanism the needs of children including orphans would be addressed in a sustainable way and within a caring family environment.

The years of turmoil had brought extension work in the area to a halt. Extension officers were unable to reach the farmers because of lack of transportation. At the same time poverty was afflicting many farmers such that many of them could hardly afford the cost of simple and yet vital inputs (hoes, spray pumps, seed, and tillage services). Overall, agricultural production in the program area had dropped as a result, leading to the prevalence of high malnutrition levels among children. In fact, during 1991–1993, the district of Rakai experienced famine.

World Vision collaborated with the Ministry of Agriculture at the district level to actively enhance foster family agricultural skills. This was accomplished by promoting and encouraging farmers to form groups of 20 to 40 individual farmers each. Group formation was in line with the MOA farmer skill enhancement strategy. Farmers in-groups were then trained in modern methods of farming, poultry keeping, passion fruit production, and vegetable growing. The training emphasized food production (crops and animals), increased income, improved nutrition, and environmental protection.

Qualifying farmers were those that showed interest in the specific agricultural activity and agreed to form a group for more effective training. Farmers that qualified to receive the inputs were those that had taken in orphans, or who agreed to become model farmers so that their farm plots could be used for on-farm demonstration and training. Other farmers could obtain the training, if they were interested. But in order to get inputs, they had to pay some of the cost.

Farmers who completed the training were then given critical inputs. The program supplied the initial stock of passion fruit grafts, maize, beans, and vegetable seed. Other inputs included 177 spray pumps, 20,944 hoes and other tools, pesticides and fertilizer. Handouts of farm inputs is not sustainable, but this was done at the beginning of the program, in part as a relief measure to help farmers recover from the effects of war and famine.

A second component in the attempt to increase productive capacity was the introduction of credit to enable families to acquire critical inputs for both their agricultural and other activities. Some of this was group credit and involved groups of farmers applying for loans after they had taken the training and submitted a business plan. In some cases, the credit was in kind, where groups of farmers received a grinding mill, oil extractor or rice huller to operate as an income generating activity. Some groups opted for daily farming and used the project to receive exotic heifers as credit. A particularly significant aspect of the in-kind credit was a tractor hire service which foster families would use to increase acreage.

*2. Enable orphaned children to stay in school:* The objective was to assist 30,000–40,000 with tuition, clothing and scholastic materials needed for primary education. Orphan children constituted close to one third of total enrollment in a number of schools, and their inability to pay tuition and contributions into the school building fund was keeping many orphans out of school and had become a threat to the survival of the educational system itself.

Fulfillment of the educational support objective was attained in three main ways. (1) The program undertook to pay school fees for up to 25,000 qualifying children to attend primary school. The education was to be carried out in the existing primary schools within the project area, most of which had on average as many as 100

orphans out of an enrollment of 324. (2) The program made contributions to the cost of scholastic materials, which included; exercise books, pencils, geometry sets, and in some cases some clothing and a blanket. (3) The program supported community efforts to renovate and construct 24 primary schools. This assistance took the form of contributing cement, roofing materials, doors and windows as well as providing transportation to move materials contributed by communities to the building site. In addition the program undertook to cover the wages of artisans contracted to undertake the construction. The standard school construction, which World Vision supported, was a 7-classroom block together with a headmaster's office and a staff room, all built in permanent materials. In addition, up to four teachers' houses were constructed as well as installing a water tank and building two latrine blocks.

The selection of the students to be supported depended on four criteria:

- Being orphaned.
- Coming from an extremely needy family, where both heads were 70 years+ and with no meaningful income source.
- Being a member of a child headed household.
- Coming from a large family that had taken in orphans and with no meaningful source of income.
- Except where children were already part of an existing WV program, registration into the education system was given to those that had registered with the program by their 12th birthday.
- In the case of support in secondary school, the youth had to have passed the Primary School Leaving Examination, scoring at least grade C and above. (There were thousands of youths who had dropped out of school due to lack of tuition. The test criteria were applied in part as a prudent measure to select those to fill the limited slots that the program could fund).

The criteria applied in selecting the schools to rehabilitate or build were as follows:

- Recommendation by the district authorities in light of their district development plan.
- Schools in very remote parts of the program areas and where there were very few options.
- Schools that had a very large number of qualifying children (at least 80 and above).
- Schools where, after mobilization, parents and the community at large demonstrated verifiable determination and willingness to contribute something (usually building sand, stones, bricks, labor to protect the assembled materials) for the rehabilitation of their school.

*3. Enable older orphans to attain self-reliance skills:* The objective was to establish and equip 18 simple rural vocational training centers at which some 4,500 youths would be provided with self-reliance skills. In the needs assessment exercise, several community and local government officials had expressed this issue as an urgent need. The existing centers at Kyotera and Kalisizo were much too limited in capacity to handle the large numbers of youths falling out of school. Informed officials contacted indicated that the area had great demand for skilled people in brick-making, brick-laying, tailoring, roofing homes, fishing, shoe repair, carpentry, and baking.

The program devised a threefold approach to address this critical need. These included: (i) Encouraging existing technical schools to expand capacity and then take in youths sponsored by the program; (ii) Attaching vocational training to existing primary schools to which master craftsmen and women from the community would come and provide the training; (iii) Contracting with existing artisans in the community to take on a few students at a time as apprentices and then over a period of time teach them the skills of the trade. Remuneration for their effort would come in the form of free sets of tools (at the time tools were very difficult to get in Uganda and it was anticipated the program could get sets of tools through WV's Gifts-In-Kind program. Vocational training centers were expected to realize some profit from the sale of items made. Such proceeds could go towards the cost of equipping each graduating youth with essential tools kit with which to get started.

Selection of the youths to be trained depended on several criteria. In the case where training was attained through attaching a particular youth to a practicing artisan, the criteria used included:

- Interest of the youth in the skill being offered.

- Recommendation by the local counseling and development worker.
- Distance from the youth's home (in many instances youths were looking after other siblings and hence needed to reside close to home).
- Marketability of the particular skill that a youth was requesting for.
- Character of the trainer (whether he/ she was reliable, non-exploitative and had a genuine concern for the trainee).

In the case where training was to be attained in a formal vocational training institute, the criteria for selection included;

- Interest of the youth in the skill being offered.
- Proof that the youth had passed the minimum academic requirements for entry into a technical school.
- Ability of the youth or guardian to contribute 20–40% of the training costs. (Some youths did so through providing labor at the institutions).
- Distance from the training institutions.
- Marketability of the skill to be pursued.

*4. Ensure counseling services to orphans and their foster families:* The objective was to train a team of 100–120 community based parish development and counseling workers to provide counseling services to orphans and their foster families. The aftermath of AIDS had created a sense of fear and helplessness among orphans. Many were angry at the sense of being left behind. Even in the case of adults, knowledge was often scarce. Some suspected they would contract the disease by simply paying courtesy calls to homes of victims.

Psychological support services were very thin in Uganda and up to the time of the AIDS epidemic, had never figured among the critical services provided through the Ministry of Health. The MOH had tried to initiate the ACP (AIDS Control Program) with part of its activities confined to patient care. NGOs had also tried some programs, the well known ones being those of TASO (The AIDS Support Organization). But, in both cases, attention was mostly to those dying from the disease, and not those being left behind. In discussions with government and school officials, concern was expressed about the need to design programs that would enable orphans and their foster families to get over the loss of their departed ones and participate effectively in community life and development.

World Vision set out to address this need by encouraging communities to establish a community-based system of counseling along similar lines as a community-based health care system. The backbone of this was to be a team of 100–120 Parish Development and Counseling Workers (PDCW's) who would be selected from within their respective parishes, trained and then posted to serve within their communities; approximately 10 for each sub-county over a three year period. These would be co-ordinated by project specialists in Social Work based in each of the sub-projects. The candidates would be carefully selected relying on consultations from local communities, schoolteachers and religious leaders. The aim was to ensure that those selected for training were people whom the public respected and often turned to for advice.

An essential part of developing the counseling training program was a needs assessment carried out in the area. Through this exercise, it was found children needed re-assurance, guidance on how to make decisions (especially regarding continuation in school), responsible living, when to alert others that help was needed, and then basic health and hygiene. The needs assessment became the basis for drawing up the training program. Parents and guardians needed someone to talk to, exchange views on how best to cope, how to care for the terminally sick, how best to integrate new arrivals into the family. The training covered; basic listening skills, emotional support, stress management, alleviating fear, conflict resolution, as well as how to access overall survival needs of households when making home visits. Much of the counseling was group counseling provided to children alone, using the medium of the school; but some was family focused conducted within the home. Some involved awareness raising on the part of community leaders (women groups, youths groups, elders) so that they strengthen the 'protective cover' vital for the survival of vulnerable ones within a community. Some of the counseling was conducted in confidential settings, especially when it came to preparation or interpretation of wills, seeking advice as to when to go for blood testing, or seeking advice. In general individuals that community picked on as ideal for this type of work were those already respected in the community such as teachers, clergy, and elders.

*5. Support and augment Ministry of Health (MOH) programs in the area:* The general objective was to strengthen and extend the primary health care initiatives of

the MOH through renovation of health facilities, and training of community-based health workers (CBHWs) and traditional birth attendants (TBAs) at the periphery. Primary Health Care was adopted by the Government of Uganda (GOU) several years before to minimize the burden of institutions and to improve the access of the population to basic health services such as immunization, endemic disease control and maternal health services.

The program set out to accomplish this goal by undertaking to renovate 14 priority dispensaries in the area and training 480–600 Community-Based Health Workers and TBA's, and equipping them with health kits and bicycles. The program also undertook to facilitate the formation of parish and village health committees, which in turn took responsibility for selecting candidates to be trained as CBHW and TBA's. The primary function of the CBHW was to mobilize community support for the health activities in their community, thereby enabling communities to experience an improvement in health by the end of the project.

The choice of health units to repair or build was based on the following:

- Recommendation of the district authorities in light of the district development plan.
- Health units in remote areas where the population had no other option.
- Health units that were serving too large a population for the existing physical plant.
- Health units where after community mobilization, local leadership and the beneficiary communities demonstrated determination and willingness to contribute what was within their means (sand, stones, bricks, protection of assembled materials) for the rehabilitation of their facility.

Chairman HYDE. Thank you, Mr. Casey. And as the saying goes, last but very much not least, Ms. Gilborn.

**STATEMENT OF LAELIA GILBORN, PROGRAM DIRECTOR, HORIZONS GLOBAL RESEARCH ON HIV/AIDS PROJECT, POPULATION COUNCIL**

Ms. GILBORN. Thank you, Chairman Hyde and Members of the Committee for this opportunity to testify at this important hearing on orphans and vulnerable children.

I'm a researcher with the USAID-funded Horizons Program at the Population Council, and have been conducting research in Uganda on programs for AIDS-affected children for several years. I'm going to discuss today what is being done on the ground for orphans and vulnerable children, whom I will be referring to as OVC.

A wide body of literature tells us that children affected by AIDS are vulnerable in almost aspects of their lives. AIDS-affected children have lower school enrollment rates, nutritional status in comparison to their peers. They have less access to health care. They suffer from poverty and emotional distress and they're also vulnerable to exploitation.

What does the research tell us about the best response to OVC in the developing world? The most important thing that can be done, and this is often overlooked, is to prolong the lives of their parents. In addition, several approaches have been effective in making a difference. One is to support families, communities and local organizations in their ongoing care for OVC. Another is to strengthen professional and government capacity to respond to this crisis. And another is to provide interim or permanent shelter for children in especially difficult circumstances.

Families and communities will always provide the vast majority of day-to-day care for vulnerable children. Most orphans are taken in by aunts, uncles and grandparents: A response built on a long-standing tradition of extended family networks and informal fos-

tering. As we sit here today, 5 million grandparents in Africa are raising their orphaned grandchildren. All of these children have lost their parents to AIDS. There is nothing that outsiders can do to approach the scale, the effectiveness, the sustainability and the cultural relevance of the local response. But as the epidemic escalates, families and communities are straining in their efforts to care for orphans. Local efforts can be strengthened through capacity building and support for NGOs, faith-based organizations and other community organizations, and through a range of development efforts that ensure access to food, health care, school and legal assistance.

Community activities that can be supported by outsiders include visiting programs, mobilizing resources for school fees, engaging local leaders and advocacy and offering economic opportunities for families fostering orphans. It is also essential to include, as part of the solution, the Ministries, the political officials and the professional who have the skills and the responsibility to care for the OVCs in their own countries now and in the future.

There hardly exists a sector that is not deeply affected by AIDS, and at the same time, does not bear some of the burden for prevention and care. When the Ministry of Education in Uganda introduced universal primary education (UPE), the enrollment gap between orphans and non-orphans disappeared. But there are other things that remain to be addressed in the education sector, such as the high rate of mortality among teachers and the need to train teachers in giving emotional support to AIDS-affected students.

Countries like Malawi have begun to develop national policies on orphans and vulnerable children. And as stated earlier, USAID and other groups just supported this kind of political commitment in a workshop in which delegates in West and Central Africa engaged in technical exchange and drafted country action plans.

But what are the nuts and bolts of successful community interventions? As I mentioned earlier, we can prolong relationships between children and their caregivers by addressing the critical health needs of both parents and guardians. For example, programs that prevent transmission of HIV during pregnancy and delivery can stay with that mother and child dyad, offering ongoing care and support for both. And orphan-support programs can provide health services for guardians, many of whom are elderly and some of whom are HIV positive.

Half of people living with AIDS in Africa succumb to tuberculosis. By providing prophylaxis and treatment, millions of children would have a few more years with their parents and their guardians. Second, children and their families can be reached before their parents die. The research leaves no doubt that the setbacks incurred by AIDS orphaned children start while their parents are still alive, struggling to feed their families and relying heavily on these children to take on adult responsibilities.

The National Association of Women Living with AIDS in Uganda (NACWOLA) and also PLAN International, have pioneered an approach now known as succession planning, in which parents are supported to appoint guardians, prepare wills and make memory books, akin to our family albums so that children will always know where they came from and where they can go to for help.

For example, typically, a child's father might fall sick first, reducing the family income. Then perhaps her mother becomes ill. Soon this child may be pulled from school as you've heard. She may be caring for younger sibling, may be nursing her own parents who, as you know, succumb slowly to AIDS. One after another her parents die and maybe she's lost someone else, a teacher or a sister. And finally, she moves into the house of her grandmother with whom she may or may not be comfortable, possibly losing touch with her siblings. She may even become the head of her own household. Is this the time to intervene? No. Children must be reached earlier to avert the many impacts of AIDS.

Basic emotional support is also essential. It goes without saying that seeing your parents fall ill and pass away is very traumatizing. Community volunteers, teachers, HIV positive parents and guardians can be trained in adult-child communication. Our research in Uganda demonstrated, for example, that the vast majority of older children want their parents to be honest with them about their HIV infection. Memory books have provided a wonderful medium for fostering communication in families. Another program in Tanzania trains orphaned adolescents to support their peers and to serve as mentors to younger orphans. This is an excellent example of how children can be part of the solution.

Expanding access to education is also extremely important. Eliminating school-related costs helps bring these children back to school. Not only does school provide obvious educational and social benefits, but it is enormously important in integrating OVC with other children and giving them a chance to play and escape from troubles at home.

In addition, more must be done to protect the property rights of women and children. I work in two rural districts in Uganda where one in four widows loses her inheritance, including the land on which she grows her food, when her husband dies. This is devastating for a household that has just lost its primary breadwinner. Right now, lawyers and community volunteers are training parents to write wills. Local officials are becoming involved in property disputes. This program has already helped orphans to hold onto their family property and land; and in some cases, even to support themselves with small gardens.

Before I conclude, I would like to add a word of caution about programs that go out of their way to target and identify AIDS-affected children exclusively. It is surprisingly difficult to determine which children are affected by AIDS when so few people know or reveal their HIV status. Community programs can spend valuable resources on elaborate systems of identifying AIDS-affected children only to further label them and to leave behind other vulnerable children. With programs that elevate the well-being of all vulnerable children, these pitfalls can be avoided and the entire community is helped.

These outstanding program approaches fill us all with hope for the future of OVC. But in the year 2000 the Uganda AIDS Commission surveyed sources of outside assistance for orphans and vulnerable children and found that only 5 percent of OVC received support programs. Our work is cut out for us, but we have a valuable foundation of lessons learned on which to build. Thank you.

[The prepared statement of Ms. Gilborn follows:]

PREPARED STATEMENT OF LAELIA GILBORN, PROGRAM DIRECTOR, HORIZONS GLOBAL RESEARCH ON HIV/AIDS PROJECT, POPULATION COUNCIL

*Chairman Hyde and members of the Committee,* thank you for the opportunity to testify on orphans and vulnerable children (OVC) in Africa. The Population Council is an international, nonprofit, nongovernmental organization that seeks to improve the well-being and reproductive health of current and future generations around the world and to help achieve a humane, equitable, and sustainable balance between people and resources. The Council conducts biomedical, social science, and public health research and helps build research capacities in developing countries. Horizons is a USAID-funded cooperative agreement mandated to conduct interventions research in order to refine HIV/AIDS programming in developing countries. Ms. Peterson of USAID spoke on the magnitude of the problem. I am going discuss what is being done on the ground for orphans and vulnerable children, whom I will be referring to as OVC.

A wide body of literature tells us that children affected by AIDS are vulnerable in almost all aspects of their lives. AIDS-affected children often have lower school enrollment rates and nutritional status in comparison to their peers. They have less access to basic health care. They suffer from poverty and emotional distress and are vulnerable to various forms of exploitation.

What does research tell us about the best response to orphans and vulnerable children in the developing world? The most important thing that can be done—and this is often overlooked—is to prolong the lives of their parents. In addition, we have found several complementary approaches that have been effective in making a difference for children. One is to support families, communities and local organizations in their ongoing care for OVC. The second is to strengthen professional and governmental capacity to respond to this crisis. The third is to provide interim or permanent shelter for children in especially difficult circumstances.

*Families and communities* will always provide the vast majority of day-to-day care for vulnerable children. Most OVC are taken in by aunts, uncles, and grandparents—a response built on a strong and long-standing tradition of extended family networks and informal fostering. As we sit here today, five million grandmothers and grandfathers in Africa are raising orphaned grandchildren who have lost their parents to AIDS. Nothing that outsiders can do could approach the scale, effectiveness, sustainability, and cultural relevance of the local response. Yet, as the epidemic escalates, families and communities are increasingly strained in their efforts to care for orphans.

Local efforts can be strengthened through capacity-building and support for NGOs, faith-based and other community organizations, and through a wide range of development efforts that ensure access to food, safe water, health care, school, psychosocial support and legal assistance. Community activities that can be supported by outsiders include: visiting programs, mobilizing resources for school fees, engaging local leaders in advocating for OVC, and offering economic opportunities for families fostering orphans.

It is also important to include as part of the solution *the ministries, the political officials, and the professionals—teachers, psychologists, social workers, lawyers*—who have the skills and the responsibility to protect OVC in their own countries—now and in the future. There hardly exists a sector that is not deeply affected by HIV/AIDS and at the same time does not bear some of the burden for prevention and care for the infected and affected.

When the Ministry of Education in Uganda introduced universal primary education, the enrollment gap between orphans and non-orphans disappeared. But *there are other things that remain to be addressed in the education sector, such as the high rate of mortality among teachers and the need to train teachers to better respond to the emotional and other needs of orphans and vulnerable children.* Countries like Malawi have begun to develop national policies on Orphans and Vulnerable Children. Just last week, USAID and other groups supported this kind of political commitment by sponsoring the West and Central Africa Regional Workshop on Orphans and Vulnerable Children. This enabled delegates from throughout the region to engage in technical exchange and to draft country action plans.

So what are the nuts and bolts of successful community interventions for AIDS-affected children? What specifically has research shown should be done for OVC? First, as I mentioned earlier, we can *prolong relationships between children and their caregivers by addressing the critical health needs of both parents and guardians.* For example, programs that prevent mother-to-child transmission of HIV during pregnancy and delivery, can then stay with that mother-child dyad, offering on-

going care and support for both. And orphan support programs can provide health services for guardians, many of whom are elderly and some of whom are HIV positive. Half of the people living with AIDS in Africa succumb to tuberculosis. By providing TB prophylaxis and treatment, millions of children would have a few more years with their caregivers.

Second, *children and their families can be reached before their parents die*. The research leaves no doubt: the setbacks incurred by AIDS-orphaned children in terms of health, nutrition, emotional well-being, and access to education all start while the parents are still alive, ill, struggling to feed their families and relying heavily on their children to take on adult responsibilities. Nearly all HIV-positive parents express serious concerns about their children. They worry about their children's education, access to love, food, and shelter, and their vulnerability to exploitation. The National Association of Women Living with AIDS (NACWOLA) and PLAN International in Uganda pioneered an approach now known as succession planning or future-planning in which parents were offered the opportunity to earn income, arrange guardians, prepare wills protecting their children, and make Memory Books—akin to our family albums—so that their children would always know where they came from and who they could go to for help.

Let's take an example. Typically a child's father might fall sick first, reducing the family income. Then perhaps her mother becomes ill. Soon this girl may be pulled out of school for lack of fees or because her help is needed at home. She may be caring for younger siblings, cooking for the family, looking to earn some money on the side, and nursing her own parents who—as you know—succumb slowly and painfully to AIDS. One after the other her parents die. Most likely she has lost someone else too: a sister, an uncle, a teacher. And finally she moves into the house of her grandmother, with whom she may or may not be comfortable, possibly losing touch with siblings shunted off to different households. She may even become the head of a household. Is this the time to intervene? No, children must be reached earlier to avert and mitigate the many impacts of AIDS.

Basic emotional support is essential. It goes without saying that seeing your parents fall ill and pass away is very traumatizing. Community volunteers, teachers, HIV-positive parents and guardians can be trained in adult-child communication. Our research in Uganda demonstrated, for example, that the vast majority of older children want their parents to be honest with them about their HIV-infection. They want to do what they can to help, they want to know the truth, and they don't want to learn about their parents' infection through gossip. Memory books provide a wonderful medium for fostering communication in families. Another program in Tanzania trains orphaned adolescents to support their peers and serve as mentors to younger orphans. This is an excellent example of how children can be part of the solution.

Expanding access to education is also extremely important. Again, many OVC drop out of school. Eliminating school fees and other school-related costs helps bring these children back to school. Not only does school provide obvious educational and social benefits, but it is enormously important in integrating OVC with other children and giving them a chance to play and take a break from troubles at home.

More can be done to protect the property rights of women and children. I work in two rural districts in Uganda where one in four widows loses her inheritance—including the land on which she grows food and the roof over her head—when her husband dies. This is devastating for a household that has just lost its primary breadwinner. Lawyers, paralegals, and even community volunteers are training parents to write wills. Local officials have been involved in disputes over property. This program has already helped orphans hold on to their family property and land, and in some cases to support themselves with small gardens.

Before I conclude, I would like to add a word of caution about programs that go out of their way to target and identify AIDS-affected children exclusively. It is surprisingly difficult to determine which children are affected by AIDS when so few people know or reveal their HIV status. Community programs can spend valuable resources on elaborate systems of identifying AIDS-affected children, only to further label them and to leave behind other vulnerable children. With programs that elevate the well being of all vulnerable children, these pitfalls can be avoided, and the entire community is helped.

Today I have shared with you some outstanding program approaches that fill all of us with hope for the future of these children. But in the year 2000, the Uganda AIDS Commission surveyed sources of outside assistance for orphans and vulnerable children and found that only 5% of OVC receive support from programs. Our work is cut out for us, but we have a valuable foundation of lessons learned on which to build.

*The Population Council is an international, nonprofit, nongovernmental organization that seeks to improve the well-being and reproductive health of current and future generations around the world and to help achieve a humane, equitable, and sustainable balance between people and resources. The statement above is based on a variety of sources, including research conducted by the Population Council. However, the opinions and conclusions expressed are those of the author and should not be interpreted as representing those of the Population Council, the collaborating organizations of the Horizons Program, or any of the agencies or others sponsoring its research.*

Chairman HYDE. Thank you very much. We will now go into the question period, but we'll have to quit about 3 minutes or so to noon because we have—the President of Columbia is having lunch upstairs and we should be there, some of us, anyway.

I want to say a couple of things. First of all, I want to say how the word "refreshing" is very inadequate, but it's in the right direction, to hear from you people who are working and living in Africa combatting this horrible scourge. Someone once wrote when Napoleon died that it was because God finally got bored with him. I wonder if God isn't bored with us and all the killing going on in the name of religion throughout the world.

But if you look around the globe, you'll find places in Africa where you people are doing just the opposite. You're doing God's work and it's marvelous just to hear you and see you and to know that you are out there.

Secondly, I put in the record a statement by Senator Helms, which really was an op-ed piece March 24th in the *Washington Post*. It's so good that I just want to read a part of it, and then we'll go to the questions.

[The information referred to follows:]

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 BODY:

This year more than half a million babies in the developing world will contract from their mothers the virus that causes AIDS, despite the fact that drugs and therapies exist that could virtually eliminate mother-to-child transmission of the killer disease.

It is my intent to offer an amendment with Sen. Bill Frist (R-Tenn.) to the emergency supplemental appropriations bill to add \$500 million—contingent on dollar-for-dollar contributions from the private sector—to the U.S. Agency for International Development's programs to fight the HIV-AIDS pandemic. The goal of this new money will be to make treatment available for every HIV-positive pregnant woman. As President Bush would say, we will leave no child behind. There is no reason why we cannot eliminate, or nearly eliminate, mother-to-child transmission of HIV-AIDS—just as polio was virtually eliminated 40 years ago. Drugs and therapies are already provided to many in Africa and other afflicted areas. Only more resources are needed to expand this most humanitarian of projects.

The stakes could not be higher. Already in many African nations, an entire generation has been lost to AIDS. Mother-to-child transmission of HIV could eliminate another. Although reliable numbers are hard to come by, experts believe that more than 2 million pregnant women in sub-Saharan Africa have HIV. Of these, nearly one-third will pass the virus on to their babies through labor, childbirth or breast feeding, making mother-to-child transmission of AIDS the No. 1 killer of children under 10 in the world.

There will be obstacles to achieving universal availability of drugs and therapies. Many African nations lack the infrastructure and trained personnel to deliver health care on this scale. Some governments may not be cooperative. My amend-

ment will provide the administration with the flexibility to deliver the necessary assistance while addressing these obstacles. For instance, if the new Global Fund to Fight AIDS, Tuberculosis and Malaria is deemed the most efficient way to deliver assistance, then the president can transfer money there.

The United Nations has already set an ambitious goal of reducing the portion of infants infected with HIV by 20 percent by 2005 and by 50 percent by 2010. We can accelerate these efforts, saving hundreds of thousands of lives, with a larger investment of public and private funds now. Private contributions, either financial or in kind—such as the donations of the drug nevirapine by the German pharmaceutical company Boehringer Ingelheim—are an essential part of a successful anti-AIDS strategy.

In addition, national commitment is absolutely essential. The government of Uganda can serve as an example. Through the leadership of Uganda's first lady, Janet Museveni, that country has cut in half its HIV infection rate.

In February I said publicly that I was ashamed that I had not done more concerning the world's AIDS pandemic. I told this to a conference organized by Samaritan's Purse, the finest humanitarian organization I know of. Indeed, it is their example of hope and caring for the world's most unfortunate that has inspired action by so many. Samaritan's Purse is led by Franklin Graham, son of Billy Graham—both of whom I count as dearest friends—but the organization was founded by the late Bob Pierce. Dr. Pierce's mission was to "Let my heart be broken with the things that break the heart of God." I know of no more heartbreaking tragedy in the world today than the loss of so many young people to a virus that could be stopped if we simply provided more resources.

Some may say that, despite the urgent humanitarian nature of the AIDS pandemic, this initiative is not consistent with some of my earlier positions. Indeed, I have always been an advocate of a very limited government, particularly as it concerns overseas commitments. Thomas Jefferson once wrote eloquently of a belief to which I still subscribe today: that "our wisdom will grow with our power, and teach us, that the less we use our power the greater it will be."

The United States has become, economically and militarily, the world's greatest power. I hope that we have also become the world's wisest power, and that our wisdom will show us how to use that power in the most judicious manner possible, as we have a responsibility to those on this earth to exercise great restraint.

But not all laws are of this earth. We also have a higher calling, and in the end our conscience is answerable to God. Perhaps, in my 81st year, I am too mindful of soon meeting Him, but I know that, like the Samaritan traveling from Jerusalem to Jericho, we cannot turn away when we see our fellow man in need.

*The writer is a Republican senator from North Carolina.*

LOAD-DATE: March 24, 2002

Chairman HYDE. This is part of what Senator Helms wrote:

"In February I said publicly that I was ashamed that I had not done more concerning the world's AIDS pandemic. I told this to a conference organized by Samaritan's Purse, the finest humanitarian organization I know. Indeed, it is their example of hope and caring for the world's most unfortunate that has inspired action by so many.

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power and teach us that the less we use our power the greater it will be.

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"But all laws are not of this earth. We also have a higher calling, and in the end our conscience is answerable to God. Perhaps in my 81st year, I'm too mindful of soon meeting him, but I know that like the Samaritan traveling from Jerusalem to Jericho, we cannot turn away when we see our fellow man in need."

That's a very ringing statement and echoes your life's work. For questions, I'm going to ask Ms. Davis in case she might have one. We've neglected her and I feel very sorry about that. Ms. Davis from Virginia.

Ms. DAVIS. Thank you, Mr. Chairman, and I never feel neglected by you.

Chairman HYDE. Good.

Ms. DAVIS. Dr. Peterson, the video that we saw of the young boys on the street, is that more the norm or is that the exception?

Dr. PETERSON. Communities have done a marvelous job bringing orphans into homes and extended family and even the sibling-headed households that are supported by communities and allow the children to stay with their other siblings and get support, get food. We do some micro-enterprise, but what you saw is not uncommon. I worked with street kids in Harare. I am sure that the numbers are correct and the description and the lifestyle that you saw for Nairobi. So what we have is many, many children that are living on the streets as well as those that have been absorbed into families.

And one of the messages that I brought, as we talked about the AIDS epidemic in the Caribbean is that we need now, in the Caribbean, to do what we didn't do in Africa, and that's get ready for the thousands and maybe millions of children who will need care.

Ms. DAVIS. Mr. Casey, you stated that the best way to handle the children is to bring them into their extended families. How do you explain the children that are on the street? Do they not have extended families or do the extended families not want to take them?

Mr. CASEY. Well, there is really a variety of answers to that. I think in many cases children on the street are there because of poverty. Their families aren't able to care for them, or for example, circumstances in the families like deaths of parents or parents leaving, that they're just left on their own.

As Dr. Peterson mentioned, the issue of street children and the growing number of street children is a critical issue.

Ms. DAVIS. Which then brings the problem of drug addiction, glue addiction, what have you?

Mr. CASEY. That's right.

Ms. DAVIS. Mr. Chairman, I have a million more questions, but for the sake of time, I'll pass on to someone else.

Mr. GILMAN.[Presiding.] I'm sorry. I was engaged in conversation.

Ms. DAVIS. That's okay. I just said I would yield my time to someone else.

Mr. GILMAN Thank you, since our Chairman has asked that we conclude by noon, I'm going to ask Members to please have one question and be as brief as possible. I'll now go to Mr. Payne.

Mr. PAYNE. Thank you very much. I, too, would like to commend each of the witnesses because you all bring the very humanitarian touch to this tremendous pandemic. I have many, many questions, too. But maybe I might just ask very briefly if you had something you feel should be done, what would be the best thing that we could do right now? I just wondered what each of you would propose that we do immediately. I'll just start with you Father D'Agostino?

Mr. D'AGOSTINO. First of all, if you could influence the drug companies to make available the life-prolonging drugs to Africa. It would be the first step toward bringing about a great amount of relief. But in view of the fact that that's not happening, and probably won't happen, there will be many orphans left roaming Africa, I think the only thing to do is to make some sort of livable arrangement for those orphans. And we have to start now because in 5 years there will be 40 million or more.

Mr. PAYNE. Thank you, yes. Thank you very much.

Mr. DUNIGAN. I think we're very much on the right track. We're bringing attention to the issue. Lots of money is being committed to the issue. People who know what they're talking about, and who understand the issues, are being very active. I wish that we could come up with one solution today. I know that's not what you're asking, but I think that by continuing to commit dollars and committing them to places that really help these children—I wish that we could ideally say this is going to fix it. I find that, so often, as I share my story with people in this country and in other places, I find that they want to make it go away in some way. To some that means writing a check, to others that means blaming it on a certain activity or another.

I don't think we can afford to do that. I think that we have to keep pressing on, committing dollars and finding places that are really making a difference and really working and really have effective results.

Dr. PETERSON. Thank you. And I would echo that I think that we are using the right strategies and heading in the right direction. There have been assessments of need, and one of the things that I have said often in many venues is that the need for resources for HIV/AIDS, similar to almost any health problem, exceeds the available resources and many will probably speak to that. But I would say equally important, and Uganda is a great example, where leadership and political will bring a voice to the issue as you've done today is critically important.

Secretary Thompson will be meeting with all of the Ministers of Health in the Caribbean this weekend, on Saturday, again, to try and get the national governments, also, to become a stronger voice for their own countries, for their own policies, and as much as you can facilitate that, it can make a critical difference.

Mr. CASEY. I would add that over the last several years, I think, we've made a lot of progress in identifying what could be done. The biggest limitation at this point are the resources to scale up what can be done. As you well know, in the first round of submissions of proposals to the global fund a few weeks ago—and awards which will be announced next week—they'll only be able to be aware of a fraction of the requests that were submitted from countries around the world purely for lack of resource.

So in terms of a specific action, I would reiterate what I mentioned earlier in terms of funding. I feel we need the billion dollar funding to the global fund, and then increasing total U.S. government funding for international AIDS in the FY '03 budget and beyond.

Ms. GILBORN. Thank you. The Population Council tries to do research that will enable policy-makers like yourselves to make these sorts of decisions. So I won't reflect on the policy, but I will just say that in my experience this is an issue that really needs to be addressed from many different angles at once. There is not going to be one solution. We can't focus on care and forget about prevention. We can't focus on children and forget about their parents and their guardians. So I would just offer that we need to think about all the different sectors. We need to think about collaboration across countries. And we really need to keep in mind what can be done to scale. Many small, exciting programs have been done, but scale is essential.

Mr. GILMAN The gentleman's time has expired. Mr. Cooksey, please be brief.

Mr. COOKSEY. Yes. First I want to tell you it's great to see Father D'Agostino again. I was fortunate enough to visit his facility in Kenya. I worked in Kenya off and on from '86 to '92, and what he is doing in his facility should be a role model for all of Africa, all of America, all of the world. He does a great job and it's good to see you here.

I would certainly agree with Ms. Gilborn's comments. I'm a physician, an eye surgeon, and I feel that we need a multi-faceted approach to solve this problem with AIDS. I still think it's very important to put a lot of money into R&D and develop the ultimate vaccine. Inhibitors have been wonderful. It's expensive. It costs countries a lot to develop them, but I would like to see them made available to everyone. To achieve this level of sophistication in drugs, we still have to have R&D. I wish that there was some way that the leaders of these countries that have so much mineral wealth would take their resources and put it into R&D instead of their Swiss bank accounts.

We visited a—we were in one country. I won't mention the country. The current President is a wonderful man and he's doing all the right things. But his predecessor died under some interesting circumstances. When they audited his home, he had \$75 million in cash there. If some of that money had been put into AIDS research or AIDS treatment or AIDS families or AIDS clinics, a lot of people would have benefitted. So we need to encourage the leadership in these countries that has—sub-Saharan Africa has half the infectious disease in the world. So I think it would be very worthwhile to get these countries to put some of their resources—the resources are

there, but they're not getting to the people. They end up in the hands of the dictators.

Mr. GILMAN The gentleman's time has expired. Ms. Lee.

Ms. LEE. Thank you, Mr. Chairman, I just want to associate myself with the remarks of our Chair and commend all of you for really being on the front line of this pandemic each and every day and making very personal sacrifices as you attempt to, and very successfully in many instances, prolong and save lives.

I'd like to ask Dr. Peterson a question about USAID's strategy. Is part of your strategy to help keep parents alive by providing access to treatment and care? And then, secondly, on the \$20 million, I'd just like to know if you have any numbers for us? How many families and children that served? Of course, I'm concerned some of this funding has been taken from vital maternal health and tuberculosis programs and if you can just kind of mention a couple of points about that. Thank you very much, Mr. Chairman.

Dr. PETERSON. USAID has a policy of going from prevention all the way through support to include treatment and care. Very important, when we talk about treatment and care, is that we recognize that most people with AIDS die of TB. They die of other infections, many of which can be prevented, many of which can be easily treated. So the treatment of opportunistic infections can add years to the life of a person with AIDS before we even get to talking about ARVs. We're very active in the nutritional support as well as the education of people living with HIV/AIDS as well as to encourage longer life spans. That is possible, even in an African setting.

I don't have the numbers for how many people are reached by the \$20 million with the money that is focused on the orphans. I can try and get that for you. We are planning on doubling that, and that doesn't include the food aid that would be coming to them through other routes. That would be in addition. I will also say that some of it is going to be very hard to measure. We work with families where the parents are still alive in doing micro-enterprise so that the parents who can't go out to work, can still work in the home—keep income. That helps the children and they won't necessarily get counted in the numbers.

So we're trying to reach out in as many different ways as we can as early as we can to support the kids.

Mr. GILMAN The gentlelady's time has expired. I'm sorry, we're trying to keep within the time limits set by the Chairman, and Ambassador Watson?

Ms. WATSON. Thank you so much, Mr. Chairman. And I'd like to add my commendations to the Chair and our presenters here for their very, very fine and substantial statements of progress in terms of the care of people suffering with HIV and AIDS. I want to ask permission, Mr. Chairman, to add the statement of Bonnie Marshall, and hope that we can invite her to testify at another time.

Mr. GILMAN Without objection.

Ms. WATSON. Yes. And she has, just to finish, a unique program that unites youngsters, as I mentioned before, with extended families here in this country and other places, too.

Mr. GILMAN Ms. Watson, let me suggest that if she has a written statement she'd like to add, we could incorporate that into the record.

Ms. WATSON. Yes, she does. Thank you very much, Mr. Chairman.

[The information referred to follows:]

PREPARED STATEMENT OF BONNIE MARSHALL, PRESIDENT & CEO, GLOBAL INITIATIVE ON AIDS IN AFRICA

AIDS & CHILDREN: PREVENTION AND CARE IN AFRICA

Chairman Hyde, Congressman Members of the Committee, Members of Congress, Dignitaries and other esteemed guest. Thank you for this opportunity to speak.

First I would like to *define* the most vulnerable orphans and children on the continent of Africa today. They are the "Street Children". Advocacy for "Street Children" is rare. How many times have we heard "Street Children" mentioned here today? Yet, these are indeed the most vulnerable children in Africa.

There are an estimated 8 million "Street Children" in Africa and we have been told, the number is expected to increase to as many as *40 million* by the year 2010. *Many of these children will end up in the streets.* Clearly an entire generation of children are in danger of succumbing to physical and emotional abuse, societal exclusion, slavery, forced prostitution, malnutrition, mental illness, depression, opportunistic diseases, illiteracy, poverty, theft of inheritance, stigmatization and an increased risk of contracting HIV and AIDS unless they receive immediate, critical, support.

Allow me to tell you a little about these children. A few of them maintain loose family ties, surviving by begging, selling trinkets or shining shoes. Most live in groups with other children and many are below the age of 12. Many resort to prostitution and petty theft to survive while others become addicted to drugs ranging from heroin to glue. Glue sniffing can cause kidney failure, irreversible brain damage and death.

Rape, prison, prostitution, slavery, violence and death are the most common fates awaiting street children. Many are born into societies brutalized by civil wars and many are left disfigured and often with severe handicaps. Raised in violence, they may go on to repeat it. Ex-soldiers, for whom violence has become normal, join police forces and are then ordered to rid the streets of these children who are often considered delinquents'. Police brutality is well documented in many African countries. Street kids are easy targets; they become scapegoats for spiraling crime rates provoked by social disintegration and are often considered expendable.

Millions of these children are drawn into the sex trade each year, either to support themselves or to aid their impoverished siblings or families. Sex tourism has become a multi-billion dollar global market. In Mauritania and Sudan, OVC's can be purchased for about \$15 to work as slaves.

While hundreds of street children are murdered or tortured, their assailants go unpunished. Corrupt officials within the police, military and private security forces—coupled with judicial systems, which fail to punish the abusers—mean they can literally get away with murder. If the children are not killed, they are left with physical and psychological scars, which stay with them for life, yet these very children are Africa's future.

The United Nations Convention on the Rights of the Child (CRC), signed by all but two countries, states (Article 39) "that all children who have been neglected, abused or exploited should be assisted in their recovery and re-integration into society and that this should take place in an environment which fosters health, self-respect and dignity." Yet thousands continue to die every year. Yet, the biggest killer of these unwanted orphans and vulnerable children is our own indifference.

While we talk about reintegrating children back into their families we must acknowledge that most of these families can barely feed, cloth and house themselves let alone the children that have been left for them to care for. Therefore as much as we would like to keep the children in their homes, with family and in their communities as opposed to orphanages and institutional care, the reality is that the capacity of the family units are exhausted leaving *institutional care or the streets* as the only option in many cases. However, we have the experience, resources and best practices to drastically improve institutional care system.

An estimated 2.3 million people died in 2001 in Africa from AIDS and 6.5 million children with AIDS are now orphaned. We continue to hear about the prevention of mother to child transmission before birth, yet we hear nothing about mother to

child transmission after birth. In preventing some estimated 600,000 MTC transmissions annually we must not stop with just preventing the transmission only for the child to contract AIDS during breast feeding, for the child to end up in the streets after the parents have died, or for the child to contract HIV after being sexually abused or forced into slavery or prostitution. Is this the lifestyle that we fought so hard to bring them into? Therefore, I ask the committee to allocate funds to care for the children born to HIV positive mothers.

Further, I ask that the committee allocate funds to establish treatment and prevention centers for HIV positive street children. Additionally it is necessary to provide allocations for ARVs for positive street kids while assisting with the development of a viable distribution infrastructure to insure that the demands for the drugs are met without delay. Although American pharmaceuticals have agreed to lower their prices and have implemented fast track programs of distribution the challenges remain great. Treatment centers are requiring more staff to specifically handle the HIV patients, yet there is no "profit" from the discounted drugs. Therefore, how are these cost to be absorbed?

African pharmacists need basic training on the pharmacology of ARV's. Many adults and OVCs are unwilling to listen to instructions on how to use their medication which is most likely due to stigma. In Kenya alone treatment centers are receiving prescriptions from surrounding countries like Somali, Rwanda, DRC, Tanzania and others. Since patients prefer to stockpile the drugs it is leading to stock ruptures. Many treatment centers cannot cope with the demand for ARVs nor were they able to increase the amount of staff required to dispense the drugs. BMS and others have seen demands for discounted ARVs in Africa go from 200 patients to 2000 in less than 6 months. Needless to say they are struggling to keep up while trying to develop a reliable, stable distribution/supply network. Now that the pharmaceuticals are making the drugs available to the people of Africa, we must work with them to insure that OVC's have immediate access. In doing so, we must likewise insure that the distribution, training and access are in place to insure immediate and quality care for these children.

In closing, it is imperative that we all understand that the war against HIV/AIDS and all of our best practices cannot be successful if we do not engage, empower, collaborate with and respect the people on the ground . . . the African people who are truly on the front-line doing the work with little or no support. We must bridge the gap between the top and the caregivers on the ground strengthening *their* capacity to care for, feed, cloth, educate and provide housing for the children. As it stands now the majority of the funds that have been allocated to fight AIDS in Africa actually remain here in the US or in US Agencies and governmental projects in Africa and rarely get to the people on the ground. While it is a fact that many of Africa's people are poor, sick, and dying there are many others that are clearly qualified to sit at the table. We must all work together with mutual respect. There is no time for delay; even as I speak millions of children are suffering on the continent of Africa and around the world.

Thank You.

**Mr. GILMAN** We're joined by one of Senior Members of our Committee who's spent a lot of time working the AIDS issue, the gentleman from Iowa, Mr. Leach.

**Mr. LEACH.** Mr. Chairman, I recognize the time constraints, and thank you for holding this testimony and bringing together such a distinguished group of witnesses.

**Mr. GILMAN** Thank you very much, Mr. Leach.

**Mr. PAYNE.** Mr. Chairman?

**Mr. GILMAN** Mr. Payne?

**Mr. PAYNE.** Just before you adjourn, I just want to add my commendation to Mr. Casey. I do, too, believe that the aid should be no less than \$1 billion. We're spending in excess of a billion dollars every day on homeland security and defense. Our budget is about \$380 billion, 365 days a year. So you can figure that out. So I think it should be that and the \$2.5 billion.

And finally, I would like to comment, as I did earlier, that the reading of Senator Helm's editorial really has said a lot. I think we're winning this war on AIDS when we can have converts like that. So I know we're on the right track. Thank you.

Mr. GILMAN In conclusion, let me thank our panelists. All of you have extreme expertise in what we're trying to do throughout the world, and we can't thank you enough for what you're doing. We'll keep the record open if you'd like to forward any further comments to us to include in the record, and we wish you well. God's speed. Thank you and the hearing stands adjourned.

[Whereupon, at 12:05 p.m., the Committee was adjourned.]



## A P P E N D I X

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### MATERIAL SUBMITTED FOR THE HEARING RECORD

#### PREPARED STATEMENT OF THE HONORABLE J.C. WATTS, JR. A REPRESENTATIVE IN CONGRESS FROM THE STATE OF OKLAHOMA

Mr. Chairman: Thank you for your extraordinary leadership, interest and support in addressing HIV/AIDS. I would also like to thank Dr. Ann Peterson and the other distinguished witnesses for their forward leaning approach and commitment. The horrific problem of HIV/AIDS in Africa, and the related problem of legions of AIDS orphans and vulnerable children, cries out for effective solutions. We in the world's richest country have a special role to play in helping those who are not only less fortunate, but in fact who are dying of this disease.

Having traveled twice to Sub-Saharan Africa last year and seen first hand the devastation and suffering caused by HIV/AIDS, I know that there are no easy or quick answers to controlling and ultimately stopping the disease. While most public health experts agree that ultimately a vaccine will be needed to tackle the pandemic, despite the best efforts of public and private sector research we all know that we are years away from an effective vaccine.

What we do know from the experience of donor programs, including private sector programs in countries such as Botswana is that sustainable solutions to tackling HIV/AIDS in the Africa will come from comprehensive, targeted approaches that draw on the complementary expertise of all stakeholders. With the strong leadership of key players on the world health stage—the US and other developed country Governments, UN agencies and multilateral banks, foundations; the health care industry; and governments committed to be serious about the fight for better health—we can catalyze new efforts to improve the lives of millions.

As part of my TradeAid coalition, I've been working with the Safe Blood for Africa Foundation, a non-profit corporation whose goal is to safeguard the blood supply in sub-Saharan Africa from infectious diseases, including HIV, Malaria, Hepatitis B and Hepatitis C. These diseases are currently being transmitted through Africa's blood supply at unprecedented rates. Sadly, blood transfusions meant to save human lives may account for approximately 15% of HIV transmissions in sub-Saharan Africa. Safe Blood for Africa seeks to implement a country-by-country plan to manage, track, and test the estimated 6 million blood transfusions performed in Africa each year. With a properly implemented program, approximately 1 to 1.5 million lives per year could be saved.

Additionally, I know of several other programs; the African Health Council and the International Executive Service Corps that have incredible programs that address HIV/AIDS in sub-Saharan Africa. These companies provide healthcare improvement services to create reliable, self-sustaining healthcare centers and establish technical capacity building initiatives that we hope will lead to better healthcare delivery systems. I also found this to be true in my meetings with certain sub-Saharan African Presidents. Without question, they are concerned about the building infrastructure and capacity that will lift them out of poverty and address HIV/AIDS over the long-term, not just short-term welfare initiatives. They want our help in not only building, but sustaining a healthy future.

Mr. Chairman, in some parts of sub-Saharan Africa, an estimated 38.8% of pregnant women age 15 to 49 years old are HIV-positive, approximately one baby is infected with HIV every hour and the average life expectancy for a person with AIDS is 39 years. Again, we must do more to help protect the children and the best way I know to do that is to address the long-term challenges of capacity building and sustainment. Mr. Chairman, here in the United States we speak of "Leaving no Child Behind" and in passing that legislation we helped lay claim to America's future. Orphans and children in Africa infected with HIV/AIDS through no fault of

their own must be given the same opportunity for life and a bright future. Of the 36 million people infected with the HIV virus world-wide, an estimated 25 million (or about 70 percent) are Africans and the number of AIDS orphans is expected to reach 15 million by 2003. Africa has already lost some 12 million people from AIDS—more than the number of deaths from all the African wars—and 11,000 new cases are diagnosed every day.

In closing, Mr. Chairman, the war on HIV/AIDS requires not only Congressional support but public-private ventures as well. I would like to applaud the efforts of The African Comprehensive HIV/AIDS Partnership which is a joint effort of the Republic of Botswana, the Bill and Melinda Gates Foundation and Merck and Company Incorporated and the Merck Company Foundation to support the goals of Botswana by significantly advancing HIV/AIDS prevention, healthcare access, patient management and treatment of HIV in Botswana. Each foundation has dedicated \$50 million over five years and Merck is donating antiretroviral medicines such as Crixivan and Stocrin for the duration of the program. These type of partnerships must continue. Thank you and your committee for your time and sincere interest in winning the war on HIV/AIDS. You have my support.

INFORMATION SUBMITTED FOR THE HEARING RECORD BY THE HONORABLE JOSEPH R. PITTS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF PENNSYLVANIA

**Global Humanitarian Programs of America's Leading Research-Based Pharmaceutical Companies**

\$1.9 BILLION IN HEALTH AND INFRASTRUCTURE DONATIONS TO DEVELOPING WORLD FROM 1998–2001\*

- **Abbott Laboratories**, with Abbott Laboratories Fund, created *Step Forward . . . for the world's children*, a program that offers aid to orphans with AIDS and vulnerable children around the world.
- **American Home Products/Wyeth** donates products, including anti-infectives, antifungals, analgesics and vaccines against Hib bacteria, a leading cause of infant death, to developing countries.
- **Aventis** supports programs for children in Brazil, health care in Burkina Faso, and dispensaries in Vietnam; the company donated its sleeping sickness drug patent rights to the WHO.
- **Bayer**, with the German Pharma Health Fund, supports development and use of a portable, tropics-compatible mini-lab in developing countries to detect counterfeit and substandard drugs. Bayer donates drug products to missionary projects and supports production of health education materials.
- **Boehringer Ingelheim's** donations to the Elizabeth Glaser Pediatric AIDS Foundation support programs to reduce mother-to-infant HIV transmission in sub-Saharan Africa and Thailand. The company participates in the *Accelerating Access Initiative* (see page two).
- **Bristol Myers Squibb**, through its *Secure the Future* program, supports orphan and home-based care in Africa for women and children with HIV/AIDS, medical research and educational exchange programs. The company works with Baylor Children's Hospital and Project Hope to combat pediatric AIDS in Mexico, sponsors public health master's degree programs and pledged aid for medical infrastructure in China. (*Accelerating Access Initiative* participant)
- **Eli Lilly** donates medical relief annually to more than 50 countries, and partners with the Ghana Diabetes Care, International Diabetes Foundation, WHO, Partners in Health: Multi-Drug Resistant Tuberculosis and Doctors Without Borders.
- **GlaxoSmithKline** created the Malarone Donation Programme and works with national ministries of health to limit malarone's drug resistance. The company supports HIV/AIDS patient programs in the developing world, donates medicines to Project HOPE and established Action TB to find new therapies. GSK also spearheads the program to eliminate lymphatic filariasis and donates albendazole (in conjunction with Merck's Mectizan donation) free-of-charge until the disease is eliminated. (*Accelerating Access Initiative* participant)
- **Hoffman-La Roche** founded the Sight and Life program to combat vitamin A deficiency, which increases children's susceptibility to infections. The company donates vitamin A, grants and education materials and sponsors blindness prevention programs in Africa, Asia and Latin America.

- **Johnson & Johnson** supports treatment for burn patients in a Soweto hospital and contributed to the facility's construction costs, equipment, and maintenance. J&J supports the Vietnam Ministry of Health's infection control project and programs in Thailand that help orphaned HIV-infected children.
- **Merck** donates mectizan tablets to fight river blindness in Africa, Latin America and the Middle East, donates a hepatitis B vaccine, established the *Enhancing Care Initiative* with the Merck Company Foundation, and has donated funding and medicine to the *Botswana Comprehensive HIV/AIDS Partnership* to improve HIV/AIDS education and care. (*Accelerating Access Initiative* participant)
- **Novartis**, a member of the Global Alliance to Eliminate Leprosy, is donating treatment for all leprosy patients in the world until 2005. The company donates medications to disaster victims around the world. Recently, Novartis offered to sell its anti-malarial medicine, Coartem, at cost in Africa. Its Foundation also supports country-level efforts to dispel the stigma surrounding leprosy and improve patient access to leprosy services.
- **Pfizer** and the Edna McConnell Clark Foundation launched the International Trachoma Initiative to eliminate trachoma, the leading cause of preventable blindness. The program operates in Morocco, Tanzania and Vietnam and soon will be in Ghana and Mali. Pfizer supports clinical malaria and cholera studies in developing countries.
- **Pharmacia** provides medicines and financial assistance to developing countries for disaster relief and other projects. The company's partners include Project Hope, MAP International, International Aid and Interchurch Medical Assistance.
- **Roche** supports SHARE, a multinational program that teaches doctors, health workers and others about HIV. Roche supports clinical HIV studies in Thailand, and Roche African Research Foundation supports tuberculosis, malaria and viral hepatitis research. (*Accelerating Access Initiative* participant)
- **Schering-Plough** donates medical products in Central and South America, India, Egypt, Philippines, Romania, Russia and other countries. It supports a prison conditions program in South Africa, hepatitis institutions in India, rectal cancer screening in the Philippines and medical scholarships.
- **SmithKline Beecham** supports malaria vaccine pediatric trials in Africa and donates its meningitis vaccine to the WHO and other medicines in the Dominican Republic. The company supports UNICEF's Personal Hygiene and Sanitation Education (PHASE) program.

#### RECENT AIDS MEDICINES INITIATIVES

April, 2000	<b>Pfizer</b> offers to give away Diflucan, an anti-fungal medicine, to people in South Africa with AIDS. In December, Pfizer and the SA government agree to make Diflucan available at no charge to HIV/AIDS patients suffering from cryptococcal meningitis or oesophageal candidiasis.
May, 2000	<b>Bristol-Myers Squibb, GlaxoSmithKline, Merck, Boehringer-Ingelheim and Roche</b> establish the <i>Accelerating Access Initiative</i> to sell HIV/AIDS medicines at a discounted price to developing nations. By May 2001, ten African nations-including Rwanda, Uganda, Senegal, Cote d'Ivoire, Cameroon, Mali and Burundi-are receiving discounted drugs under the program.
July, 2000	<b>Boehringer Ingelheim</b> offers to supply Viramune for free to developing nations for five years to prevent mother-to-child transmission of HIV.
February, 2001	<b>GlaxoSmithKline</b> extends its offer of a 90% discount on HIV/AIDS medicines to include NGOs in developing countries and employers in Africa who offer care to workers through workplace clinics.
March, 2001	<b>Merck</b> offers to sell Crixivan and Stocrin, two antiretroviral medicines for the treatment of HIV infection, for, respectively, \$600 and \$500 per patient per year, announcing it "will make no profit on these medicines in the developing world." <b>Bristol-Myers Squibb</b> announces that the patent for Zerit [d4T] "will be made available at no cost to treat AIDS in South Africa." It offers full transparency in pricing for drugs in Africa, pledges to

raise funding for its *Secure the Future* program and offers to sell ddI and Zerit "below cost."

March, 2001      **Abbott** offers its two antiretrovirals medications, Ritonavir and Kaletra, and its HIV test, Determine, in Africa at no profit to Abbott.

June, 2001      **Pfizer** announces the Diflucan Partnership, which offers Diflucan at no charge to HIV/AIDS patients in 50 least-developed countries. This program is an expansion of Pfizer's South African Diflucan Partnership Program and was developed in cooperation with the UN and WHO.

**Pfizer** establishes the Academic Alliance for AIDS Care and Prevention in Africa, a union of African and Western infectious disease experts that will build the first large-scale HIV/AIDS clinic in Africa for training medical personnel on treatment options. The Pfizer Foundation will fund the clinic, and the Alliance will operate it in partnership with Makerere University.

**GlaxoSmithKline** offers discounted HIV/AIDS and anti-malarial drugs to 63 developing nations, including all of sub-Saharan Africa. The preferential pricing policy is expanded to include additional AIDS-fighting drugs and the malaria medications malarone and halfan. The company extends its offer to least-developed countries identified by the U.N.

06/16/01

\*SOURCE: Partnership for Quality Medicine Donation

# AIDS:

## A flicker of hope in Africa

David Fine, Judith Hazlewood, David Hughes, and Adele Sulcas

As HIV/AIDS rages in Africa, few can afford treatment. A UN-sponsored initiative is changing this bleak scenario.

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**I**n developed countries, antiretroviral (ARV) treatments have turned AIDS from a death sentence into something more like a chronic disease, extending the active lives of many of those living with HIV/AIDS by ten years or more. But these revolutionary treatments have reached only a few thousand of the more than 2.5 million Africans infected with HIV or suffering from full-blown AIDS.

The popular view—embraced by many aid agencies and nongovernmental organizations, as well as some African politicians—blames this problem on the high cost of ARVs. There have even been calls for African governments to override the pharmaceutical companies' patents and encourage the local manufacture of ARV drugs—an action that some people believe has been sanctioned by the World Trade Organization in countries facing national emergencies. Pharmaceutical companies, which price these treatments at \$1,000 to \$1,500 a month in the United States, defend their intellectual



property by arguing that a return on their R&D investment is essential to finance the continuing development of AIDS treatments and that African countries lack the infrastructure to administer ARVs effectively, no matter what the price. On the latter point, the risks are indeed great: improperly administered ARVs could hasten the mutation of the AIDS virus into treatment-resistant forms.

### Responding to the challenge

Out of this seemingly intractable situation arose the Accelerating Access initiative, a recent collaboration between the Joint United Nations Program on HIV/AIDS (UNAIDS) and four of its cosponsors, plus five pharmaceutical companies and a number of African governments.<sup>1</sup> The leaders of this initiative want to move beyond polarized debate to a more practical and collaborative drive against the disease. To this end, they have won commitments from everyone involved.

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Five pharmaceutical companies have individually agreed to reduce **the prices they charge** for their AIDS drugs by up to 100 percent

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publicized price reductions from some 25 percent to a full 100 percent, depending on the product, the company, and the country. The others are also reported to be offering significant reductions.

Meanwhile, the governments of the participating countries have agreed to develop sustainable national strategies to counter the spread of HIV and to expand treatment for the infected. Given the difficulties of educating people about the disease and of overcoming cultural taboos that discourage infected persons from acknowledging their illness, this national commitment is vital. More important still, the Accelerating Access initiative has given rise to a concerted effort against two AIDS treatment problems that are much thornier and more complicated than the price of drugs: Africa's limited medical infrastructure and the difficulty of distributing drugs securely.

McKinsey has worked (on a *pro bono* basis) with the Accelerating Access initiative in Uganda to help ameliorate these two problems in that country. As in most of Africa, progress there is difficult because of the sheer scale of

<sup>1</sup>The World Bank, the World Health Organization (WHO), the United Nations Children's Fund (UNICEF), and the United Nations Population Fund (UNFPA) are the cosponsors. The pharmaceutical companies are Boehringer Ingelheim, Bristol-Myers Squibb, GlaxoSmithKline, Hoffmann-La Roche, and Merck; the countries are Botswana, Burkina Faso, Burundi, Cameroon, the Central African Republic, Chile, Ethiopia, Gabon, Ivory Coast, Kenya, Nigeria, Senegal, Swaziland, Uganda, Ukraine, and Zimbabwe.

the problem and the resources required to solve it. Even optimistically, only a minority of Ugandans with HIV/AIDS can be helped. But Uganda's experience so far suggests that a practical, sustainable effort to expand access to drug treatment can be mounted even in a very poor country if there is a clear national commitment to that effort. Also, a genuine and enduring public-private partnership is essential to making it work.

### **Uganda: Hope amid devastation**

Certainly, Uganda is poor: its per capita gross domestic product is only around \$25 a month. And with some 1.4 million HIV/AIDS cases (Exhibit 1), representing 10 percent of the population aged 15 to 49, the country has one of the highest rates of infection in the world. AIDS has had a devastating human and economic impact. The life expectancy of economically productive Ugandans dropped from 48 years in 1990 to 38 in 1997. The country is losing its teachers, doctors, and other professionals to the disease, and tremendous resources are pouring into terminal care. Even so, by the end of 2000, only about 1,500 Ugandans were able to access ARV treatment. Unless treatment becomes available to many more people, the disease will cripple the country's development for years to come.

Grounds for hope lie in the Ugandan government's sustained commitment to prevention. AIDS education in schools, the mass distribution of condoms, and advertising have reduced the rate of HIV infection in working-age adults from 18.5 percent in 1995 to the current 10 percent. More than 60 percent of the adult population now knows that condoms prevent transmission, and more than 15 percent of married women use barrier contraception—an unusually high percentage in Africa. Uganda is one of only a handful of countries outside the West where the spread of the epidemic has stalled (Exhibit 2, on the next page).

Of course, Uganda must make some difficult trade-offs in allocating scarce resources: it has to make progress in treating AIDS without jeopardizing its successful prevention efforts. These trade-offs will be even tougher in

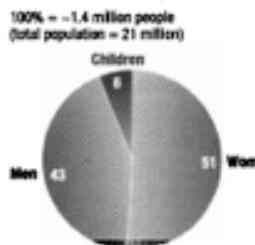
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#### **EXHIBIT 1**

#### **Uganda's challenge**

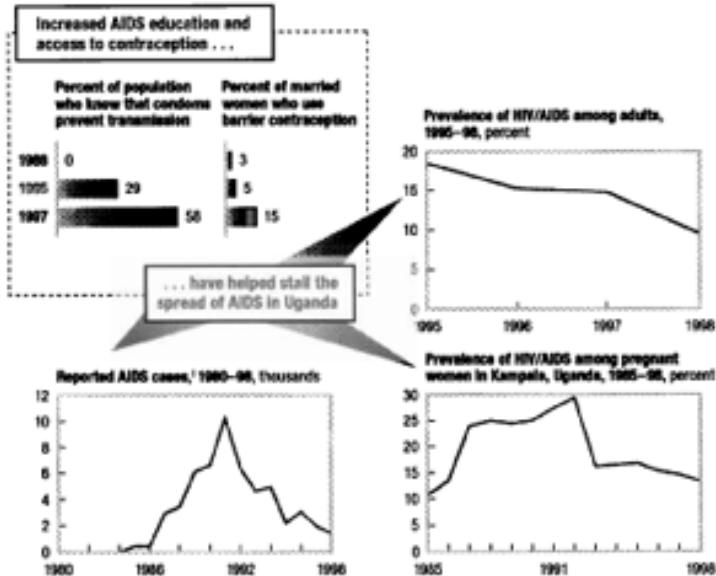
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**Prevalence of HIV/AIDS in Uganda, 2000, percent**



Source: UNAIDS Country Report, 2000

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**EXHIBIT 2****Uganda's commitment**

<sup>1</sup>Results are not nationwide, as data were reported from sentinel sites.

Source: World Health Organization; Uganda AIDS Commission; US Agency for International Development (USAID) survey, October 1998; UNAIDS, Africa.com

countries that have made less progress on prevention. But the political will and practical application that Uganda has brought to the challenge of prevention will serve the country well in its drive to expand treatment.

**Building the infrastructure**

The five pharmaceutical companies are reported to have offered significant discounts on ARV drugs in Uganda. But without a substantial improvement in the country's health care infrastructure and a reliable distribution system, little progress will be made in getting the drugs to more people.

ARV drugs must be administered through so-called highly active antiretroviral therapy (HAART) combining two to five ARVs, which are taken as often as five times a day. HAART is tailored, under medical supervision, to a patient's needs and viral-resistance profile. The therapy is monitored with frequent blood tests, and sometimes there are side effects, which also have to be treated.

The health infrastructure in most African countries, including Uganda, can provide these services to only a few people with HIV/AIDS. In the past, many donated drugs failed to reach their intended recipients. Often, drugs have been used inappropriately, thus helping to make the disease more resistant to treatment—as has happened, for example, with tuberculosis. Sporadic supply, a lack of medical oversight, or inappropriate use of ARVs not only harms the health of patients but may also encourage drug-resistant strains of HIV, posing a substantial public-health risk.

In addition, the absence of a secure distribution system for these valuable drugs encourages theft, substitution, and parallel trade. Besides posing risks to public health, these activities threaten the commercial markets of the pharmaceutical companies in the developed world, thereby jeopardizing their support for the scheme.

Before large numbers of low-cost ARVs could be used and monitored effectively in Uganda, many locals would need to be trained to administer and track the therapy, to counsel patients, and to perform diagnostic tests. Moreover, equipment would have to be purchased to monitor the therapy. We found that Uganda's existing medical infrastructure had the capacity to treat 5,000 to 10,000 people with AIDS—many more than were receiving care, but still less than 1 percent of the total number of sufferers. To treat 50,000 patients, additional referral centers would be needed, as well as extra capacity for counseling, testing, and monitoring, at a cost of some \$5 million. Reaching more than 50,000 patients would require even more dramatic improvements, including expanded access to clean water and basic medical services. That goal therefore appears to be unrealistic in the near future.

Distribution has become less of a problem in Uganda, thanks to an existing United Nations effort: the Drug Access Initiative. Since 1998, Medical Access (Uganda) Limited, a private not-for-profit company financed by four pharmaceutical companies,<sup>2</sup> has worked with another not-for-profit company called Joint Medical Store to handle inventory and distribution for the initiative's small ARV program in Uganda. Medical Access has been responsible for procuring and managing inventory, as well as for ensuring the secure and reliable distribution of products to specially equipped pharmacies in five approved centers. The system, which is reliable, secure, and

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Sporadic supply, a lack of medical oversight, and inappropriate use of ARVs may all help to promote **drug-resistant strains** of HIV

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<sup>2</sup>Abbott Laboratories, Bristol-Myers Squibb, Hoffmann-La Roche, and GlaxoSmithKline.

reasonably cost-efficient, adds 15 percent to the end-user cost of bringing medicines from factory to patient.

But Medical Access lacks the capacity to meet a 50-fold increase in the number of people undergoing HAART, and the company's reach is limited to the area surrounding Uganda's capital, Kampala. To cope with the large-scale distribution of ARVs, Medical Access would require additional capacity and security systems and might also have to supplement its operations with entirely new approaches to distribution.

### Using cost to release pent-up demand

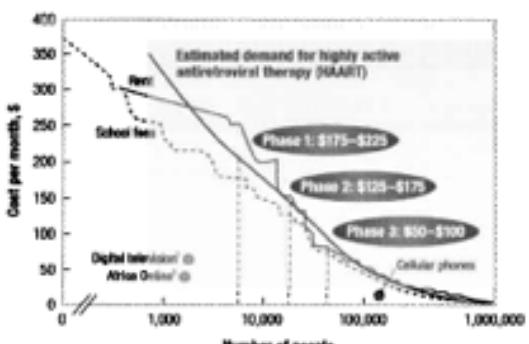
Our recommendation to the Accelerating Access initiative and the Ugandan government was to use the out-of-pocket cost of treatment to the patient—the cost of ARV treatments, of the blood tests required to monitor them, and of medical care, less contributions by companies, foundations, and governments—to manage pent-up demand for AIDS treatments while the country's medical infrastructure and distribution capacity were improved. The team working in Uganda projected demand at different cost levels by using an analysis of purchasing power and of demand for other goods and services (such as rent and school fees) that Ugandans pay for out of pocket (Exhibit 3). The team then suggested that out-of-pocket costs to the patient

should decline in phases to regulate demand and to match it to the supply of infrastructure.

#### EXHIBIT 3

##### Cost and reach of treatment

Accessibility of antiretroviral treatments at different cost levels



During phase one, 5,000 to 10,000 people with AIDS would receive ARVs almost immediately; the existing infrastructure can support such an expansion. This would require the reduction of the out-of-pocket cost to the patient—currently \$500 to \$800 under the UNAIDS-supported program—to roughly \$200 a month. Also during

phase one, swift action could prepare the system to serve 10,000 to 20,000 patients in phase two. To bring demand up to this level, the out-of-pocket cost to the patient would have to fall to about \$150 a month. Referral centers capable of diagnosing HIV would need to be established in three out-lying regions to serve a broader range of patients, and health care workers and counselors would need to be trained at the new sites. In phase two, the existing Medical Access system would have to be modified to expand distribution. To encourage patients to adhere to HAART's demanding drug regimens, a public-education campaign targeting the relevant areas would be required as well.

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The pharmaceutical companies alone **can't cut the price** of HIV drugs sufficiently to make them affordable for 50,000 Ugandans

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Phase three would expand the system to reach roughly 50,000 patients—some 65 percent of them in rural areas—by reducing the monthly out-of-pocket cost to the patient to \$50 to \$100. Achieving this expansion would require a change in the program's scope and complexity. Uganda would have to provide about seven more centers where health workers could initiate treatment and monitor the clinical response to it. The country would also have to expand laboratory services and the distribution system to cope with the considerable complexity of covering many sites spread out over long distances. In addition, the government would have to implement even broader centrally coordinated education and communications efforts, as well as a program to monitor patients to measure and ensure their adherence to the therapy.

#### **Who pays?**

Our analysis of the price sensitivity of demand suggests that treating 50,000 Ugandans with HIV/AIDS would require the cost to the patient of ARV treatment to drop by upward of 90 percent. Since the gross margins of pharmaceutical companies are reported to be about 64 percent, and they might have to invest in additional manufacturing capacity to meet higher levels of demand, it is inconceivable that they could support such a reduction in out-of-pocket costs to patients on their own.

If ARV treatment is to expand to that extent, other organizations will have to play a role in subsidizing the cost of treatment. International agencies, charitable foundations, and donor governments must agree to subsidize drug purchases and to go on investing in the significant but necessary expansion of infrastructure.

### Public-private partnership

The Accelerating Access initiative was created in response to a call from leaders of the UN and other international organizations—including UN Secretary General Kofi Annan, WHO Director-General Dr. Gro Harlem Brundtland, and World Bank President James D. Wolfensohn—for a multi-sector response in the global fight against AIDS. The potential benefits of a successful partnership are tremendous.

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Some see access to medicine as **a human right**; others think that pharmaceutical companies have a right to a return on their investment

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In practice, however, bringing the pharmaceutical companies and international agencies into partnership is difficult. Many people in the field mistrust the motives of

the companies and believe that they are trying to maximize the profits they make from sales to African countries. Practical action is hampered by stark philosophical disagreements between those who regard access to medication as a universal human right and others who argue that the shareholders of pharmaceutical companies are entitled to a return on their investment in research.

As for the pharmaceutical companies, they feel aggrieved that they get no credit for the hundreds of millions of dollars they donate each year in the form of grants, services, and free products. In their view, the consensus and consultative processes that characterize many international agencies are an obstacle to efficient decision making and the idea that access to all pharmaceuticals is a universal human right undermines the basis for investment in scientific innovation.

For the Accelerating Access initiative to work, everyone must set these issues aside and contribute actively to a solution. An important first step was taken when all participants agreed to a set of underlying principals.<sup>3</sup> The pharmaceutical companies have agreed that the affordability of their products is a problem and that they must individually reduce prices. The aid agencies, foundations, and donor governments need to invest in infrastructure and to help further reduce the cost of treatment. National governments must not only build up the medical infrastructure but also tackle some of the social, educational, and cultural problems that fuel the epidemic.

Furthermore, the partnership must add up to more than the sum of its parts. The pharmaceutical industry and the private sector more broadly have a

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<sup>3</sup>See the joint statement of intent signed by all participants at [www.ipms.org/pdf/ipms/AIDSstatement.pdf](http://www.ipms.org/pdf/ipms/AIDSstatement.pdf).

greater role than merely discounting drugs. Many companies have expertise, beyond their specialized medical knowledge, that could help control AIDS in developing countries: the distribution capacity to reach remote areas, the mass-marketing capabilities to improve awareness and overcome the social stigma associated with prevention, and the project-management and planning skills to establish and maintain access programs. In nations wracked by AIDS, these business strengths can literally be lifesaving. *MQ*

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