



ELIZABETH GLASER PEDIATRIC AIDS FOUNDATION

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December 11, 2008

President-Elect Barack Obama
Presidential Transition Team Office
Washington, DC 20270

Dear President-Elect Obama:

On behalf of the Elizabeth Glaser Pediatric AIDS Foundation, I would like to offer my congratulations on your election. I have been particularly appreciative of your ongoing support for the President's Emergency Plan for AIDS Relief (PEPFAR) as well as for domestic efforts to combat HIV/AIDS, and look forward to being of service as you and your Administration continue, and I hope expand on, existing efforts.

As President and Chief Executive Officer of one of the world's leading organizations in the fight against pediatric AIDS, I am writing to outline key domestic and international policy recommendations that will advance the prevention of pediatric AIDS and expand care and treatment for children and families affected by HIV and AIDS. In the weeks ahead, I would be delighted to provide you and your transition team members with further information on any of the issues discussed in this document, and look forward to hearing from your team.

As you know, across the globe, approximately 2 million children are living with HIV/AIDS. Sadly, in 2007, children were infected at a rate of 1,000 a day. While large-scale efforts from the U.S. Government, the United Nations, various international organizations, and civil society have made critical progress in the battle against pediatric HIV and AIDS, the tide has not yet turned. Expanding current U.S. efforts to move the world closer to a generation free of HIV will be a critical mission for the next President and Congress.

The crucial thing to understand about pediatric AIDS is that the vast majority of cases are preventable with tools that already exist. In most cases, HIV is transmitted from mother to child, usually during pregnancy or birth, or in the first few months of life through breast-feeding. In that respect, AIDS is very different in children than in adults. Medical researchers have found drugs and methods to prevent mother-to-child transmission in almost all cases. That is why the number of cases of mother-to-child transmission of HIV in the United States has fallen to approximately 200 per year.

Much of our service-delivery work is focused in PEPFAR countries, and indeed, the Elizabeth Glaser Pediatric AIDS Foundation is the largest provider of prevention of

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mother-to-child transmission services under PEPFAR. What three mothers began around a kitchen table in 1988 has grown into a leading global nonprofit organization working in more than 3,200 sites and in 18 countries to stop the pandemic and help those already infected with HIV. The Foundation is dedicated to preventing pediatric HIV infection and eradicating pediatric AIDS through research, advocacy, and prevention and treatment programs. Drawing on our 20 years of experience fighting the pandemic, I would like to recommend a number of specific domestic and international policy positions for your consideration:

Global AIDS Policy: Arresting the Pandemic

In the developing world, and particularly in sub-Saharan Africa, the AIDS pandemic continues to claim lives by the millions. The President's Emergency Plan for AIDS Relief (PEPFAR), the centerpiece of the U.S. response to the global HIV/AIDS pandemic, has already reached millions of individuals around the world with critical prevention and treatment services. Working together, we can continue the battle to arrest the spread of the disease, and make real progress in our goal to eliminate pediatric HIV and AIDS.

PEPFAR Funding

By near universal agreement, PEPFAR has been an historic success. By significantly expanding U.S. AIDS relief assistance for the nations hardest hit by the pandemic, the United States has at once transformed the nature of the battle against AIDS and reminded the world of the humanitarian values that unite the American people. In 2008, Congress and the President reauthorized PEPFAR. Recognizing both the success of the program and the still vast, unmet need for HIV prevention and treatment, Congress increased funding for the program to \$48 billion over the next five years. For that bold expansion to be more than an empty gesture, however, Congress and the President must appropriate dollars up to the authorized level. And to maximize the effect of this funding, PEPFAR should continue to better integrate with more global health sectors and existing public health infrastructure.

- *For the much needed expansion of PEPFAR to have the greatest possible impact, it is critical that the newly authorized funds be appropriated. The Elizabeth Glaser Pediatric AIDS Foundation urges your administration to support full funding for the PEPFAR program, to enable continued prudent expansion of critical prevention and care and treatment programs. In addition, we believe it is vital for PEPFAR to strengthen existing healthcare systems, operating in a more integrated manner with other public health interventions, such as those addressing maternal and child health, family planning, nutrition, clean water, and other diseases. Such integration will maximize PEPFAR dollars and reduce mortality across the globe.*

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Making Women and Children a PEPFAR Priority

The PEPFAR reauthorization puts special emphasis on caring for women and children because they are uniquely vulnerable to HIV, particularly in resource-limited countries. PEPFAR's increased funding will allow for the expansion of efforts to prevent mother-to-child transmission of the virus, and provide antiretroviral treatment to more children in need. One of the most significant challenges for the next five years, therefore, is the scale-up of PMTCT services and concurrent efforts to ensure that all infected children receive urgently needed antiretroviral treatment. Despite the dramatic growth of PMTCT services under PEPFAR, we are still only reaching one-third of pregnant, HIV-positive women with the medicine they need to keep their babies HIV-free. The reauthorization establishes the goal of reaching 80 percent of these women in the next five years.

In addition, more than 1,000 children are infected with HIV each day, most from mother-to-child transmission, and children account for a disproportionate number of deaths from the virus. While children represent 17 percent of all new infections, they represent only 9 percent of individuals receiving antiretroviral treatment under PEPFAR. Without swift access to treatment, half will die before their second birthday. The new legislation wisely sets aggressive targets to ensure that the percentage of children on treatment is commensurate with their infection rate, underscoring how critical it is that we reach all HIV-infected children as early as possible with the medicines that will allow them to lead full and healthy lives.

To be most effective, HIV prevention, diagnosis, care, and treatment should be integrated within existing health infrastructure for maternal, neonatal, and child healthcare services and antiretroviral treatment sites. Integration allows for reaching more children and women with interventions, is seen to reduce stigma attached to HIV-only facilities, and can strengthen health systems.

- *The Elizabeth Glaser Pediatric AIDS Foundation urges your administration to support efforts under PEPFAR to make women and children a centerpiece of PEPFAR programs, and to aggressively pursue the legislation's targets of reaching 80 percent of pregnant, HIV-positive women with the medicine they need, and of significantly expanding care and treatment for children. Moreover, the Foundation recommends integrating prevention and treatment services within existing maternal, neonatal, and child healthcare infrastructure and antiretroviral treatment sites.*

Domestic Policy: Pediatric AIDS at Home

On the domestic front, your administration and Congress will face a number of specific challenges, including continuing and expanding programs that have been critical to the

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success of the fight against pediatric AIDS at home, continuing research toward improved treatments and an eventual cure, and implementing reforms that will help ensure that devices and drugs are tested for safety and efficacy in children, not just in adults.

Domestic HIV/AIDS and the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act

Elevating the U.S. response to the domestic HIV/AIDS pandemic continues to be an urgent yet neglected need. A renewed effort at prevention should be a key priority, particularly in light of recent data from the Centers for Disease Control and Prevention (CDC) showing a dramatic increase in new HIV infections domestically, particularly among women and certain minority groups. For people living with HIV/AIDS in the United States, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is the largest federal investment in care and treatment after Medicaid, yet it continues to suffer from inadequate funding. The program provides vital services to approximately 533,000 low-income, HIV-positive individuals, including medical care, support services, case management, outreach, and other services to women, children, and families affected by HIV/AIDS. Its family-centered approach to providing care and treatment saves lives, improves quality of life by keeping people healthier, and saves money by reducing hospitalizations. In addition, the Act helps link women and children to opportunities to participate in cutting-edge HIV/AIDS clinical research.

- *There must be a renewed commitment to combating the domestic pandemic, with an emphasis on prevention and a focus on caring for children, families, and individuals living with HIV/AIDS. Adequate funding for the Ryan White CARE Act is critical to its continued success. The Elizabeth Glaser Pediatric AIDS Foundation urges your administration to support the development of a national HIV/AIDS strategy, as well as increased funding for Title IV of the Ryan White CARE Act, which helps fund services for women, children, youth, and families living with HIV/AIDS.*

FDA and NIH Funding

Despite significant progress in developing medicine to prevent and treat HIV/AIDS, children still lag behind in access to HIV/AIDS medicines that are properly formulated for their use. As a result, pediatric HIV/AIDS research must remain a priority. Adolescents and young adults can become resistant to existing medications and need new drugs to keep the virus in check. In addition, because AIDS medicines may be taken for life, research into the long-term health implications of drug treatment on these children and young adults as they continue to grow up with HIV is needed.

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Because of the use of effective, preventative drug regimens, many children born to HIV-positive mothers are uninfected. But more research is also needed into the long-term health effects of the exposure of these children to preventive drug regimens.

In addition, the majority of drugs and devices now on the market are not manufactured specifically for children's use. Children differ from adults in growth, metabolism, and physical activity levels, and need products that are formulated and designed for their special needs – including antiretroviral drugs (ARVs) to treat HIV/AIDS.

Finally, despite recent setbacks in testing of HIV vaccine candidates, the search for a vaccine to prevent HIV infection must continue. In particular, that search needs to include continued research into a vaccine for infants and children.

- *Continued vigorous research, including the search for an HIV vaccine, is critical to the effort to defeat HIV/AIDS, and it is vital that some of that research focus on the particular needs of children. The Elizabeth Glaser Pediatric AIDS Foundation urges your administration to work to increase the number of drugs and devices tested for children and support increased funding for the Food and Drug Administration (FDA) and the National Institutes of Health (NIH).*

Again, my staff and I would be delighted to provide briefing materials on issues related to pediatric AIDS. Please contact Clare Dougherty at (202)-448-8483 if you require more information. Thank you very much for your consideration.

Sincerely,

Pamela W. Barnes
President and CEO
The Elizabeth Glaser Pediatric AIDS Foundation

cc: John Podesta
Gayle Smith
Aaron Williams

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