



photo: Olivier Asselin

## Public Policy and Advocacy

When Elizabeth Glaser discovered that the medicines prolonging her own life were unavailable to her young daughter, Ariel, because they had not yet been tested on children, she became one of the first people to champion the needs of HIV-positive children in the United States. Building on Elizabeth's legacy, the Elizabeth Glaser Pediatric AIDS Foundation works with policymakers around the world to continue the work she started, advocating for the best public policies for children, women, and families living with and affected by HIV/AIDS.

### The Global HIV Pandemic

Every day, 900 children around the world are infected with HIV—the vast majority through mother-to-child transmission of the virus. Without treatment, almost half of these children will die by their second birthdays. EGPAF is committed to eliminating pediatric AIDS through the expansion of services to prevent mother-to-child transmission of HIV, while ensuring access to comprehensive HIV care and treatment services for children, women, and families.

In 2008, when the reauthorization of the President's Emergency Plan for AIDS Relief (PEPFAR) was before the U.S. Congress, EGPAF led the call for increased access to HIV prevention, care, and treatment services for children, women, and families living with or affected by HIV and AIDS. Today, the Foundation continues to be a strong voice for women and children around the world, ensuring that effective services, including prevention of mother-to-child transmission (PMTCT) of HIV and pediatric treatment services, are prioritized by the U.S. government through PEPFAR and President Obama's Global Health Initiative. Achieving these goals requires advocacy for increased U.S. funding for global HIV/AIDS programs in order to meet the needs of children and families worldwide.

Eliminating pediatric AIDS requires an international effort. Therefore, EGPAF's advocacy is global in its scope. EGPAF partners with a number of multilateral and national institutions, including the World Health Organization; the United Nations Children's Fund; the Joint United Nations Programme on HIV/AIDS; the Global Fund to Fight AIDS, Tuberculosis and Malaria; national ministries of health; and other global organizations and donors. EGPAF works with these organizations to prioritize women and children in the global HIV/AIDS response, with a particular emphasis on the scale-up of PMTCT and pediatric HIV care and treatment.

EGPAF's HIV/AIDS work also plays a critical role in broader global efforts to improve the health and longevity of all women and children. EGPAF's PMTCT and HIV care and treatment programs help increase women's access to quality antenatal care and delivery services; strengthen child health services; and support the establishment of sustainable, integrated health systems in the countries where it works. In partnership with other global organizations and governments, EGPAF hopes to help achieve three of the eight United Nations Millennium Development Goals established in 2000, including reduction of child mortality (Goal 4); improvement of maternal health (Goal 5); and combating HIV/AIDS, malaria, and other diseases (Goal 6).

EGPAF is also working to develop country-specific advocacy plans aimed at enhancing the reach of HIV prevention, care, and treatment programs at the national level, at establishing policies that promote PMTCT services and pediatric HIV treatment, and at raising awareness of pediatric HIV/AIDS issues among national policymakers, key influencers, the media, and other partners.



## The U.S. HIV Epidemic

In addition to its work around the world, EGPAF engages in advocacy in the United States to ensure that women, children, and families living with or affected by HIV/AIDS domestically receive the care they need. As a result of long-term advocacy efforts led by EGPAF and others, pediatric AIDS has been virtually eliminated in the United States, with fewer than 200 infants born with HIV each year. To maintain this success, the U.S. government and its partners must continue to focus resources and expertise on domestic pediatric HIV prevention, care, and treatment efforts.

EGPAF is supporting these efforts through domestic advocacy work, which includes:

- **National HIV/AIDS Strategy:** Together with partners and other organizations, EGPAF advocated for the inclusion of women and children into the National HIV/AIDS Strategy, a presidential initiative led by the Obama administration and completed in 2010. The strategy focuses on reducing HIV incidence and HIV-related health disparities in the United States and on increasing access to care and treatment for those living with HIV/AIDS. As the strategy is implemented, EGPAF is committed to ensuring that women and children in the United States receive the care and support they need.
- **Ryan White Comprehensive AIDS Resources Emergency (CARE) Act:** EGPAF advocates for full funding of the CARE Act, the largest federal program focused exclusively on HIV/AIDS care, including services specifically designated for children, women, and families living with HIV in the United States. EGPAF was integral in the passage of the original CARE Act in 1990, advocating for the inclusion of HIV prevention, care, and treatment models for children.
- **HIV Testing:** EGPAF advocates for increased HIV testing as key in reducing the number of infants born with HIV in the United States. Testing women early in their pregnancy increases the chances that those women will receive the medical care and treatment they need to remain healthy and to deliver healthy, HIV-negative children. To boost HIV testing rates, EGPAF supports more robust implementation of the U.S. Centers for Disease Control and Prevention HIV testing guidelines as the most effective way to reach pregnant women and prevent mother-to-child transmission of HIV.

## Research and Drug Development

Since Elizabeth Glaser first lobbied in the halls of the U.S. Congress more than two decades ago, EGPAF has carried on her advocacy to increase HIV-positive children's access to the best available treatments. Today, EGPAF continues to advocate for strong investments in HIV-related scientific research, including the development of a pediatric HIV vaccine.

An important step in slowing the spread of HIV in children is assessing current HIV prevention and treatment approaches and identifying best practices and areas for improvement. EGPAF fights for continued global support of operations research — research into existing on-the-ground programs — to improve the delivery of HIV prevention, care, and treatment services and to replicate successful service models in the most affected regions of the world. In addition, EGPAF advocates for a pediatric focused HIV/AIDS clinical trials network through the National Institutes of Health (NIH) in order to ensure pediatric populations are being addressed in research.

EGPAF has worked with the U.S. Congress and presidential administrations to enact and implement legislation that is widely credited for dramatically increasing the number of drugs tested and approved for children, including the Best Pharmaceuticals for Children Act and the Pediatric Research Equity Act. Building on the success of pediatric drug testing legislation, EGPAF worked with the U.S. Congress, the American Academy of Pediatrics, and other children's health advocates to enact legislation that improves pediatric medical device development through the Pediatric Medical Device Safety and Improvement Act. As these bills come up for reauthorization the Foundation is committed to ensuring that children are kept at the forefront of drug development.

EGPAF also supports safe access to medical products already on the market and improved public access to information about clinical trials of new therapies.

## Elizabeth Glaser Pediatric AIDS Foundation

*Elizabeth Glaser acquired HIV through a blood transfusion and unknowingly passed the virus on to her daughter, Ariel, and her son, Jake. Following Ariel's death in 1988, Elizabeth joined with two close friends with one goal: to bring hope to children with AIDS. The foundation that now bears Elizabeth Glaser's name has become a global leader in the effort to eliminate pediatric AIDS, working in 15 countries and at more than 5,400 sites around the world to prevent the transmission of HIV to children and help those already infected with the virus. EGPAF's global mission is to implement prevention, care, and treatment; further advance innovative research; and give those affected by HIV and AIDS a voice to bring dramatic change to the lives of millions of children, women, and families worldwide.*