Every child deserves a lifetime.

Public Policy and Advocacy

The Elizabeth Glaser Pediatric AIDS Foundation has a long history of advocating for children's access to the best of science and medicine. Elizabeth Glaser was one of the first to champion the needs of children with HIV/AIDS after discovering that the same drugs prolonging her own life were unavailable to her daughter because they had not yet been tested for children. Building on Elizabeth Glaser's legacy, the Foundation has played a lead role in enacting legislation that has expanded the participation of children in cutting-edge clinical research, significantly increased the number of drugs tested and labeled for children, improved care for families affected by HIV in the U.S., and launched an unprecedented effort to fight HIV/AIDS globally.

Presently, the Foundation largely relies on the expertise of public policy professionals to create a voice for children with HIV/AIDS on Capitol Hill, with the Administration, and with other key decision makers. Largely through technical and policy analysis and advocacy, the Foundation has had significant success in advancing public policy for children both domestically and in the international arena by leading coalition efforts with other public health organizations and forming important partnerships with the World Health Organization, national Ministries of Health, and other global entities.

A Foundation Based on Research

At the time the Foundation began, it was not yet widely known how HIV/AIDS affected children. While meeting with lawmakers, Elizabeth realized that targeting federal funds specifically to pediatric HIV/AIDS research was key to saving the lives of affected children and preventing new infections. One of the Foundation's first significant advocacy accomplishments came in October 1989, with the procurement of $10 million for basic pediatric HIV/AIDS research at the National Institutes of Health (NIH). The Foundation's legislative success marked the first time tax dollars were specifically targeted toward research for children with AIDS. One year later, the Foundation successfully advocated to double this amount, securing $20 million for pediatric HIV/AIDS research.

Pediatric HIV/AIDS research remains a Foundation priority today. In addition to advocating for increased funding for important areas of research, the Foundation has launched a pediatric HIV vaccine program to conduct clinical trials and promote research to develop a better understanding of how HIV behaves in breastfeeding infants and ultimately develop a protective AIDS vaccine that is safe and effective for children.

The Domestic Pandemic

At a time when the HIV/AIDS epidemic was gaining strength in the United States, the Foundation recognized the importance of quickly matching resources to research and health care programs to provide care for the most vulnerable victims of HIV – women and children. In 1990, as part of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, the Foundation successfully advocated for a program to help women and children participate in cutting-edge HIV/AIDS research in the U.S. Years later, the Foundation spearheaded support for additional legislation to assist families living with HIV/AIDS across the nation. Today, thanks to Foundation efforts, a reauthorized Ryan White CARE Act includes provisions to improve prevention, care, and treatment services for children living with HIV/AIDS.

Children's Health

Although Elizabeth Glaser died in 1994, her vision and passion for children's health live on in the Foundation's advocacy work. In November 1997, the Foundation's efforts to ensure that critical

medicines are tested for their safety and efficacy in children culminated in enactment of the Better Pharmaceuticals for Children Act (BPCA), which provides market incentives to drug manufacturers that study their products for use in children. After continued advocacy, including congressional testimony by Elizabeth's husband Paul Glaser, in 2002 the Foundation celebrated the passage of an expanded version of this legislation, known as the Best Pharmaceuticals for Children Act.

Concurrent with its efforts to get drug manufacturers to voluntarily study their products for children, the Foundation has advocated for a critical regulation, known as the "Pediatric Rule," to require that certain products be tested for pediatric use. The regulation triggered judicial disagreement and a court battle ensued. The Foundation's efforts were rewarded in 2003 by enactment of the Pediatric Research Equity Act (PREA), which restored the protections of the previous Pediatric Rule.

Together PREA and BPCA have established requirements and incentives for pediatric drug testing that have been extraordinarily successful in generating important new information about the safety and efficacy of drugs used by children. In 2007, the Foundation worked closely with Congress to strengthen and renew both BPCA and PREA and ensure that the two act in greater partnership.

Building upon the success of the pediatric drug testing laws, the Foundation worked with Congress in 2006 to create new legislation to spur the development and safety-testing of medical devices for children. Pediatric device provisions were later included as part of broader legislation to reform the Food and Drug Administration (FDA) in 2007. Because of the Foundation's efforts, the *Food and Drug Administration Amendments Act of 2007* also included important safety reforms to better protect the health of both pediatric and adult patients. The Foundation also worked to ensure that the legislation included the establishment of a clinical trials database that will give patients access to information about important ongoing research and subsequent results.

The International Pandemic

The Foundation has made remarkable achievements in its international advocacy efforts, supporting programs to prevent mother-to-child transmission of HIV and provide care and medical treatment to children and families living with HIV/AIDS around the world. The Foundation was a strong advocate for the U.S. Leadership Against AIDS, Tuberculosis and Malaria Act of 2003, which built the framework for the President's Emergency Plan for AIDS Relief (PEPFAR) and its subsequent launch. In addition, the Foundation has worked to ensure that global AIDS programs receive substantial funding each year with special legislative focus on children. The Foundation successfully advocated for the passage of the Assistance for Orphans and Other Vulnerable Children in Developing Countries Act, signed into law by President Bush in November 2005, which addresses the unique medical needs of HIV-infected children, including access to pediatric-friendly antiretroviral drugs, diagnostic equipment, and specially trained health care workers.

You Can Help!

Today, the Foundation continues its advocacy efforts to prevent mother-to-child transmission of HIV, increase care and treatment for children and families suffering from HIV/AIDS, and promote children's access to new treatments. For more information about the Foundation's advocacy work and how you can become an advocate for children, please visit www.pedaids.org.

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