



Elizabeth Glaser  
Pediatric AIDS  
Foundation

# Every Child Deserves a Lifetime

The Elizabeth Glaser Pediatric AIDS Foundation:  
30 Years of Impact





THE ELIZABETH GLASER PEDIATRIC AIDS FOUNDATION

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Above photos: EGPAF (left), Eric Bond/EGPAF, 2016 (right)



Being active in the fight against AIDS made me realize that I am not a victim. I have power and I can work for change. — **Elizabeth Glaser**



## A Mother's Instinct

In September 1988, a grieving mother and two of her friends formed an alliance around a kitchen table. Still deeply shaken by the AIDS-related death of her 7-year-old daughter, Ariel, the month before, Elizabeth Glaser came to that table with an urgent mission to save her 4-year-old son, Jake—who, like his sister and his mother, was living with HIV. Elizabeth had been infected with HIV during a blood transfusion in childbirth and had unknowingly transmitted the virus to Ariel and Jake.

At that time, death seemed the inevitable fate of any person infected with HIV—particularly when it came to children, for whom treatment was nearly nonexistent. How could a mother stand by and watch her second child die? How could her friends stand by and do nothing?

“I felt like I had no choice in what I was doing,” Elizabeth later wrote in her memoir, *In the Absence of Angels*. “I was following a mother’s instinct to try and save her child.”



Arick  
Newborn







Ariel  
3 mo







## Mothers on a Mission

In Elizabeth's kitchen, Elizabeth and her friends Susie Zeegen, and Susan DeLaurentis dared to believe that with the support of the best scientific minds and through nonpartisan political will, pediatric AIDS could be treated—and one day vanquished.

Susie Zeegen remembers their sober sense of responsibility: "Although we were three moms sitting around a kitchen table, it seemed more like we were standing at the base of a mountain staring up toward a peak. We were equipped only with an urgent maternal instinct to save one child."



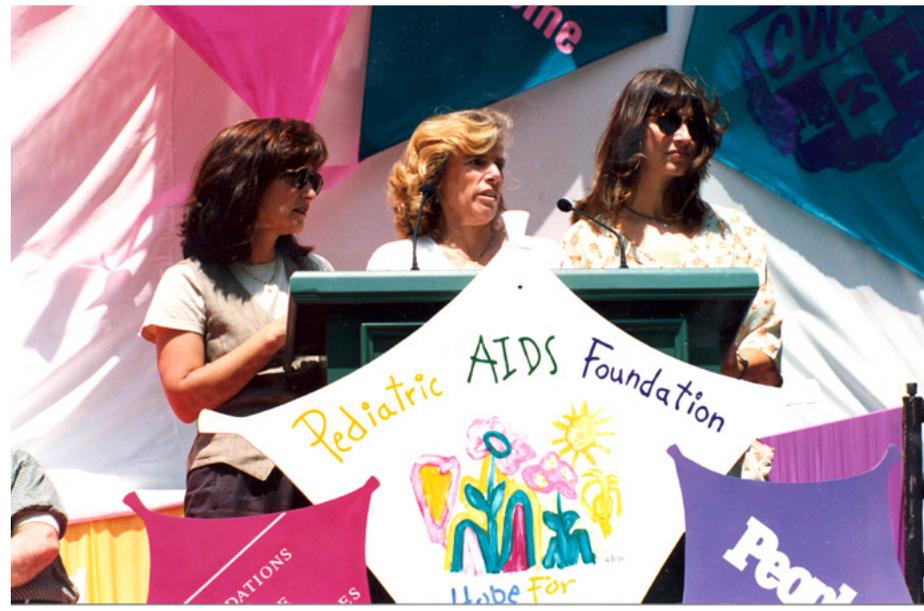
Within months, the Pediatric AIDS Foundation (PAF) had launched its first of many think tanks at the National Institutes of Health (NIH). These gatherings quickly gained fame as high-caliber brainstorming events at which leading researchers exchanged ideas, identified research priorities, and planned rapid courses of action. PAF convened doctors and scientists to work together at a time when collaboration was rare.

“The [think tanks] were unique in the sense that people shared thoughts inside the proverbial tank,” says Mike McCune, M.D., a stem cell researcher. “And the secrecy and competitiveness that sometimes shrouds scientific research was not evident. I think that had to do with the way that Elizabeth and her team chose to run them—not as scientists, but as people.”

As the wife of Paul Michael Glaser, a Hollywood celebrity, Elizabeth knew that she was in a unique position: “I use my access to pry open doors and make people care. Jake might die if I don’t.” wrote Elizabeth. “Being active in the fight against AIDS made me realize that I am not a victim. I have power and I can work for change.”

By June 1989, Elizabeth, Susie, and Susan were hosting their first major fundraiser, A Night to Unite, in Washington, D.C. Hosted by Sens. Orrin Hatch (R-Utah) and Howard Metzenbaum (D-Ohio), the black-tie gala brought together policymakers from both sides of the aisle. The event raised more than \$1 million. Success continued the following June with nearly \$1 million raised at A Time for Heroes, a family-friendly celebrity picnic in the Hollywood Hills. The funds from those events and through other donations were quickly channeled toward research to understand and defeat HIV.









## A National Challenge

By 1992, PAF had succeeded beyond its initial dreams of sparking research. But many families across the United States were still coping with illness and death because of lack of treatment for children living with HIV. Not only was treatment limited in its effectiveness, it was beyond the means of many people. Eliminating pediatric HIV would require drugs that are effective and also accessible and affordable to all families. A crisis this big required a national response, so Elizabeth Glaser took her cause to the nation with an address at the Democratic National Convention. (Mary Fisher, another woman living with HIV, addressed the Republican National Convention.)



I started out just a mom fighting for the life of her child. I am here because my son and I may not survive four more years of leaders who say they care but do nothing. This is not about being a Republican or an Independent or a Democrat. It's about the future—for each and every one of us.

— **Elizabeth Glaser**

This speech helped motivate lawmakers to accelerate funding and advance public policy for children living with HIV. But even as national support grew for the Pediatric AIDS Foundation, Elizabeth seemed less likely to win her own battle with AIDS. For 13 years, Elizabeth had lived with HIV. But by the end of 1994, her body was too weak to continue its fight. Elizabeth Glaser passed away on December 3, two days after the sixth World AIDS Day.

After Elizabeth's death, Susie Zeegen and Susan DeLaurentis knew that the only way that they could adequately honor their friend was by continuing the mission that the three had started together in her kitchen. They intensified their advocacy for federal research funding and continued to sponsor collaborative projects like the Long-term Survivor Study, which examined how the HIV virus interacts differently with different people.

In the year that Elizabeth died, the National Institutes of Health (NIH) initiated the groundbreaking AIDS 076 trials at the urging of PAF. This trial demonstrated that when a pregnant woman with HIV takes the antiretroviral drug AZT, the likelihood of her passing the virus to her unborn children is significantly decreased. This was the first major breakthrough in prevention of mother-to-child transmission of HIV.





In response to this game-changing discovery, PAF partnered with the White House to craft a public awareness campaign encouraging every pregnant woman in the United States to be tested for HIV. Once tested, an HIV-positive expectant mother could receive treatment to prevent transmission of the virus to her baby and enroll in treatment for her own health.

“If it were not for the intervention of the Pediatric AIDS Foundation, the number of children infected with HIV in the United States would have outpaced other disorders,” says Philip Pizzo, M.D., the former Harvard chair of pediatrics. “But thanks to the Elizabeth, Susie, and Susan, critical trials were done, and transmission of HIV was blocked.”

In 1996, the renamed Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) launched the Elizabeth Glaser Scientist Award to directly support groundbreaking clinical research. Over the next ten years, EGPAF awarded more than \$24 million to 36 scientists and clinicians. These individuals would use these awards to leverage more than \$250 million in additional research funding. This was the first named research award developed exclusively for work in HIV/ AIDS.



As drugs became more effective, EGPAF expanded its educational efforts, reaching out to children and families to help them cope with and understand HIV better. EGPAF scored a tremendous victory for children in 1998 when the Pediatric Rule was put in place, thanks to EGPAF's advocacy efforts. The Pediatric Rule is an essential regulation requiring drug companies to test their products for use in children, just as they do for adults.

By 1999, the rate of new pediatric HIV infections in the United States had dramatically fallen to fewer than 200 per year—due primarily to the effectiveness of AZT and the EGPAF-led public awareness campaign. And research supported by EGPAF had yielded improved treatments for children living with HIV. In the United States and other resource-rich nations, an HIV diagnosis was no longer a death sentence. Elizabeth had saved Jake's life.





## A Call to Action

Even as rates of pediatric AIDS decreased in the United States, around the world the AIDS pandemic was in full force, especially in resource-limited countries. In 1998, seventeen hundred children were being infected with HIV each day across the world. The situation was most dire in sub-Saharan Africa, where as many as 35 percent of adults were living with HIV in some countries.

“Few people in the most affected countries knew their HIV status,” says Trish Karlin, EGPAF’s executive vice president of External Affairs and Business Development. “On average, pregnant women came for only one prenatal visit, and only half of them delivered in a health facility.”



EGPAF heard the Call to Action and funded eight health facilities in six African countries in 2000. Shortly thereafter, EGPAF received additional investment from the Bill and Melinda Gates Foundation to expand these services. Soon EGPAF was supporting several hundred facilities throughout Africa, India, and Russia—working within the existing public health system to build capacity for HIV services and drive down transmission rates.





In 2003, President George W. Bush announced an unprecedented \$15 billion commitment to addressing AIDS globally, known as the U.S. President's Emergency Plan for AIDS Relief (PEPFAR). With the support of the U.S. government, EGPAF was able to dramatically expand its scope.

PEPFAR selected EGPAF as a partner to provide care and treatment in resource-limited countries: Côte d'Ivoire, Mozambique, South Africa, Tanzania, and Zambia. This project was eventually called Project HEART (Help Expand Antiretroviral Therapy to children and families). It was a large leap from the work that the organization had done before.

“We went from being national to being international,” says Zeegen. “We went from being funders of research to being implementers of public health care and treatment.”



As one of PEPFAR's first implementing partners and one of the largest global providers of prevention of mother-to-child transmission of HIV and care and treatment services, EGPAF is committed to achieving an AIDS-free generation. And we're pleased to see women and children at the core of this strategy.

**— Charles Lyons,  
EGPAF's president and CEO**

EGPAF became the global leader in ending AIDS in children. Today the organization is working in 19 countries and supporting more than 5,000 health centers. To date, more than 1.9 million people have been enrolled in antiretroviral treatment through EGPAF projects, and more than 27 million women have received HIV services.

New HIV infections in children have declined by more than 70 percent worldwide since 2000.

“At 30, EGPAF finds itself in its most hopeful position to date,” says Charles Lyons, EGPAF’s president and CEO.







I want to save my family,  
[but] to do that, I have to  
change the world.

— **Elizabeth Glaser**



## Our Work Today

EGPAF continues Elizabeth's mission to end AIDS in children, weaving together national and international advocacy for children with programmatic research and integrated and comprehensive programs in countries hit hardest by the AIDS pandemic.



# Prevention of Mother-To-Child HIV Transmission (PMTCT)



I have HIV, and I have a home full  
of healthy, HIV-free children.

— Leah, Malawi

Mother-to-child HIV transmission accounts for almost all HIV infections in children. But this threat can be virtually eliminated by providing HIV-positive mothers access to effective antiretroviral therapy (ART) and support services during pregnancy, delivery, and breastfeeding.

As the global leader in ending AIDS in children, EGPAF has reached more than 27 million women with services to prevent transmission of HIV to their babies through sustainable, high-quality programs.









# HIV Testing and Treatment



When our neighbor told us that a mobile clinic had arrived and was administering HIV tests, I told Nelly, 'Let's go get tested.'

— **Peter, Kenya**



For women who are pregnant, HIV counseling and testing is the first and most critical step in eliminating mother-to-child transmission. EGPAF works with local health facility staff and ministry of health officials to provide each woman with counseling and testing services.



Women who test HIV-positive during their prenatal visits at EGPAF-supported sites are immediately linked to lifelong ART and counseled about the lifesaving benefits of adhering to treatment—for their children and for themselves.





## Safe Childbirth



We are excited about being parents again. We feel that it is because of the grace of God, so we named her Chisomo, which means grace.

— **Dina, Malawi**



Safe childbirth is an important consideration for all expectant mothers and particularly for HIV-positive women. Yet many women around the world still lack access to adequate health facilities. EGPAF works with clinicians to counsel women on the importance of facility births and equips supported facilities to manage obstetric emergencies.





# Postnatal Care



Do not be too scared to conceive and have children because of your HIV-positive status. Just follow the advice from nurses and doctors and adhere to HIV care and treatment as I did. Then you will also have children who are free from HIV.

— **Linda, Zimbabwe**



Without treatment, more than half of HIV-positive children will die before their second birthdays. To reach those children, EGPAF has expanded early identification of HIV in infants through rapid testing technology. We also work with child health clinics to offer early and repeat HIV testing and access to treatment in addition to routine child wellness services—including immunization, nutrition, and growth monitoring.







## Children and Adolescents



“

They lift me up, make me feel like I can live like anyone else.

— **Michel, Cameroon**

EGPAF was founded by a mother on a mission to ensure that her child—and HIV-positive children everywhere—would receive the necessary treatment and support to live a long and healthy life. This remains at the core of EGPAF’s work.

Despite decreasing rates of mother-to-child transmission of HIV, each day millions of children worldwide still require access to HIV treatment and age-appropriate counseling and support. We promote active treatment monitoring to ensure that children and adolescents in our supported services sustain full viral suppression. EGPAF trains and supports health workers in early identification of treatment failure, provision of necessary support and prompt transition to second-line and third-line HIV treatment regimens.

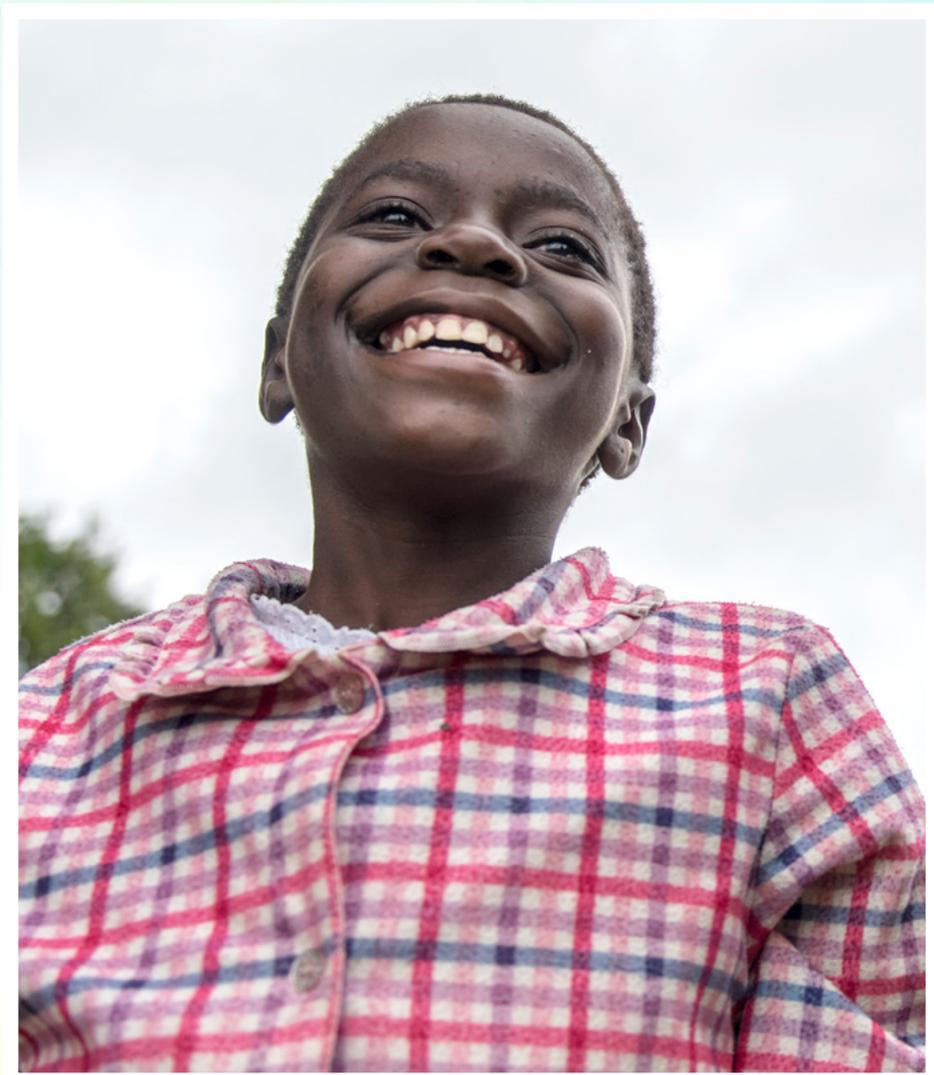
In each of our supported health care settings, we train facility staff to respond to the special emotional needs of children and adolescents, and we work with communities to reduce HIV stigma and discrimination. EGPAF’s psychosocial support model provides a safe space for children and adolescents living with HIV to learn about the virus, to express their complex feelings about it, and provide support for each other.



















# Community Engagement



Since we started the family support group, we've never had a mother with an HIV-positive result in her baby.

— **Nurse Dina Kisimi, Uganda**

Ending AIDS in children requires more than individual responses. It requires a united effort within communities to meet the needs of women, children, and families affected by HIV.

EGPAF strengthens community health structures and promotes health-seeking behaviors through various community-based programs, working with community leaders, organizations, and volunteers—and utilizing channels of communication, from the village level to the national level. Working with local leaders, we help organize community health days, which offer HIV education and community dialogues—along with mobile services for HIV; maternal, newborn, and child health; and linkage to services.





In addition, EGPAF supports community health workers, who link health facilities to the wider community. EGPAF builds the capacity of these staff and volunteers—through training and ongoing mentorships. These counselors provide HIV education, counseling, and testing. They also support partner disclosure, treatment adherence, and retention in HIV services. We also help develop community health committees to improve collaboration between communities and health facilities.

Whether at the village level or globally, ending AIDS in children is truly a group effort.





## No Time to Waste

When Elizabeth Glaser was fighting for the life of her son, she wrote that she did not have time to waste: “I couldn’t wait six months or six years ... because those might be the ones that could save Jake’s life.”

Every HIV-affected family without access to HIV services today experiences that same desperation. Setbacks and delays in implementing effective HIV programs mean that fewer women will be reached with HIV services, more children will be born with HIV, more children will die from AIDS-related illnesses, and more parents will grieve for a life that could have been.





Today, despite our tremendous strides, 400 children are newly infected with HIV each day. Nearly a quarter of the women living with HIV do not have access to antiretroviral medication (ARVs) to prevent transmission to their infants. As many as two-thirds of HIV-positive children under age 2 are diagnosed too late, making them vulnerable to infections that prey on weakened immune systems. Missing diagnoses during these early years can be fatal: without treatment, half of HIV-infected children will not live to see their second birthday.

Yet, mother-to-child transmission of HIV is entirely preventable. When families have access to HIV testing and treatment, along with other basic health services like antenatal care, pregnant women can deliver healthy HIV-free children. Children and other family members already living with HIV can get treatment and live long, productive lives.

International leaders agree that the global response to pediatric HIV/AIDS is insufficient, and that we have a strategic and moral imperative to better serve infants, children, and adolescents. Now is the time to close these gaps.



Thirty years after three mothers met around a kitchen table to save a child, the organization that they founded is pushing hard to fulfill their vision. We are collaborating with key partners to scale up early infant HIV diagnosis, to put child-friendly ARVs in the hands of more children, and to amplify country-based policies that increase access to HIV services. There is still so much to be done, but if a coalition of caring leaders follows through on these initiatives, we soon could—and should—usher in the first AIDS-free generation.

**We have no time to waste.**



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