UNTIL NO CHILD HAS AIDS

25 YEARS

A COMMITMENT TO WOMEN, CHILDREN, AND FAMILIES

ELIZABETH GLASER
PEDIATRIC AIDS FOUNDATION
—25 YEARS—

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A COMMITMENT TO WOMEN, CHILDREN, AND FAMILIES
TWENTY MILLION WOMEN

One ordinary spring day in 2014, in one of the countries supported by the Elizabeth Glaser Pediatric AIDS Foundation, a health care worker provided a woman with HIV counseling, HIV testing, or antiretroviral medicines.

Perhaps it happened in a one-room private clinic along a quiet dirt road in Swaziland. Or it might have happened on the second floor of a government hospital in Harare, Zimbabwe, to the din of car horns and rumbling trucks. It might have occurred in any of the 7,000 facilities that the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) supports.

There was nothing particularly special about that moment for the dedicated health care worker, who every day provides services to prevent mother-to-child transmission of HIV. But it was a hugely important encounter for the client, nearly ensuring that she will not infect any children that she bears. And if she lives in an area that has implemented the most effective prevention regimens, that woman, if infected with HIV, was given the choice to enroll in lifelong treatment so that she, too, can live a long and healthy life.

Although there was no fanfare, that woman represents an EGPAF milestone. She was the 20 millionth woman that EGPAF has reached with prevention of mother-to-child transmission (PMTCT) of HIV services. Myriad actions and resources over the past 25 years have contributed to that hope-filled moment.

That woman, wherever she might be, brings to mind the origins of EGPAF. In 1988, another woman, Elizabeth Glaser, gathered her best friends, Susie Zeegen and Susan DeLaurentis, around her kitchen table to find a way to save her HIV-positive son, Jake.

Jake Glaser—alive and healthy today—is a living tribute to their success.

By 1998, the end of the first decade of the Elizabeth Glaser Pediatric AIDS Foundation, the threat of pediatric AIDS had been nearly eliminated in the United States.
And by the end of 2013, programs supported by EGPAF had reached 19 million women around the world with services to prevent the transmission of HIV to their babies.

In the following pages, you will read the words of some of the people at the center of the effort to end pediatric AIDS over the past quarter century. All have been touched by the legacies of Elizabeth, Susie, and Susan—from a virologist in San Francisco trying to understand the impact of HIV on young immune systems to a mother in South Africa desperately trying to avoid transmitting HIV to her unborn son.

This organization of three mothers has grown into an international staff of more than 1,000, most working in sub-Saharan Africa, where 25 million people are estimated to be living with HIV. Every day, the lives of children and mothers are saved because of the work of EGPAF in the places where the AIDS epidemic remains a significant threat.

The work of Elizabeth, Susie, and Susan continues.

Worldwide, one-third of expectant mothers living with HIV still do not have access to PMTCT services. Nearly 700 children continue to be infected with HIV each day. Parents continue to bury their children each day. And mothers continue to sit in their kitchens each day, wondering if their HIV-positive sons and daughters will live into adulthood.

As we reach our 20 millionth woman with PMTCT services, we find satisfaction in the extent to which we have fulfilled the mission of our founders.

But we also immediately think of an HIV-positive woman whom we did not reach. What were the circumstances that prevented her from receiving lifesaving treatment?

Does she live too far from facilities that test and treat for HIV? Did a stock-out prevent her from receiving antiretroviral medication? Did stigma and poor information in her community deter her from seeking testing? Our job is to reach that woman and her son or daughter.
Children attend a STAR-SW Project launch event in Uganda, 2011. (Photo: James Pursey)
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Thanks a Million
In 1981, with a baby on the way, Elizabeth and Paul Glaser were enthusiastic. The coming baby would fulfill their greatest wish. "All the goodness in the world seemed to be ours," Elizabeth later recalled.

The joy of Elizabeth’s pregnancy was overshadowed by health complications that required bed rest during the final three months. On Aug. 4, 1981, Elizabeth began hemorrhaging and was rushed to Cedars-Sinai Medical Center in Los Angeles, Calif., where she delivered a healthy daughter, Ariel. During the delivery, the young mother was transfused with seven pints of blood. Fortunately, Elizabeth was at a world-class hospital with resources unavailable to many mothers around the world. Unfortunately, the blood that saved her life contained a viral time bomb.

Ariel—Ari to friends and family—grew into a bright child, with a love of drawing and painting. Elizabeth and Paul doted on their daughter and, like all parents, shared her wonder at the world. Three years after Ari’s birth, the Glasers welcomed a son, Jake, into the family. Life seemed perfect for the young family cocooned in their quiet Santa Monica home.

Then, shortly before her fourth birthday, Ari began to experience painful stomachaches. Her pediatrician suggested that it might be caused by a parasite, but as Ari’s red blood count plummeted, medical specialists began to think that the problem might be more dire. Over the next year, Ari’s symptoms increasingly pointed to an immune deficiency. Finally, in May 1986, a pediatric kidney specialist at the University of California, Los Angeles (UCLA) Hospital confirmed their greatest fear—Ari was HIV-positive.

I WANT TO SAVE MY FAMILY,
but to do that I think that I have to change the world.

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“Why should I bother going on?” thought Elizabeth. “The most important thing in my life, my daughter, is going to die.”

The next day, Elizabeth and Paul met with pediatric immunologist Richard Stiehm, M.D., and were hit with more shocking news. From blood tests run on every family member, Dr. Stiehm confirmed that Elizabeth and toddler Jake were also HIV-positive. Dr. Stiehm helped Elizabeth and Paul understand how their family had been infected: the virus had been transmitted to Elizabeth during the blood transfusions at Ari’s birth. Elizabeth had passed the virus to Ari during breastfeeding. And Elizabeth had transmitted it to Jake while she was pregnant.

“The most horrible part about it was, within three minutes of the time that our doctor said to us, ‘Your daughter is infected and she is diagnosed as having AIDS, your son is infected, and you are infected,’ he also said, ‘Don’t tell anyone. Because the world is not ready for your family,’” Elizabeth said.

By that time, AIDS hysteria had reached its peak. Nearly 12,000 Americans had died from AIDS-related illnesses, and the number was climbing. No cure was in sight; misinformation, however, was plentiful. Poorly worded news releases from health officials had suggested that HIV could be transmitted through routine contact. A 1985 *New York Times* poll had shown that a majority of Americans favored a national quarantine for people living with HIV.

This was the reality that the Glaser family faced: a fatal disease under a cloud of stigma. “It was a time that would almost be unimaginable if we hadn’t lived it,” Elizabeth later wrote in her memoir, *In the Absence of Angels*.

For the sake of her children, Elizabeth had only one choice: find hope. She was fortunate enough to live in metropolitan Los Angeles, home to UCLA immunologist Michael Gottlieb, M.D., one of the doctors who had identified the first cases of AIDS. Gottlieb quickly became her personal physician. But neither Gottlieb nor Stiehm could tell her how she was going to save her children.

“In May 1986, answers were in short supply and there were no guarantees,” Elizabeth wrote.

In her search for treatment for Ari, Elizabeth was shocked to discover that drug companies and federal health agencies had no idea that pediatric HIV was prevalent. By the spring of 1987, a new antiretroviral drug, azidothymidine (AZT) offered hope. AZT was the first U.S. government-approved treatment for HIV. Although it did not cure HIV, AZT slowed replication of the virus, potentially adding years to those living with the disease.

But it had not been approved for children.

Elizabeth knew that she could not wait. A study by the National Institutes of Health (NIH) had been conducted on children, and doctors suddenly knew a lot more about AZT dosages.

**WHAT IS HIV?**

The human immunodeficiency virus (HIV) causes acquired immunodeficiency syndrome (AIDS). When the virus enters the body, it inserts itself into vital immune cells called CD4 cells. HIV can be transmitted during sexual intercourse, pregnancy, childbirth, breastfeeding, blood transfusions, and intravenous drug use. In the absence of treatment, HIV continues to replicate itself within the body, eventually leading to chronic illness and death.
Through Elizabeth’s insistence, Ari finally started on AZT by the end of 1987 even though it would not be given Food and Drug Administration approval for children until 1990.

But it was too late. In the early months of 1988, weakened by illness and suffering from brain atrophy, Ari lost her ability to walk and talk. When asked what she was going to do, Elizabeth replied, “I don’t know exactly... I want to save my family, but to do that I think that I have to change the world.”

On Aug. 4, 1988, Ari Glaser celebrated her seventh birthday suffering from an unrelenting fever in a bed at UCLA Hospital. One week later, on Aug. 12, with no change in sight, Elizabeth and Paul decided to at least bring her home.

As they packed up her belongings in the hospital room, Ari suddenly spoke: “Mom, I’m going to walk home.” Then she began breathing heavily.

“And then very quietly, but very quickly, she died,” Elizabeth wrote.

“Nothing will make her death acceptable to me.

—Elizabeth Glaser—

WHAT IS AIDS?

Acquired immunodeficiency syndrome (AIDS) represents an advanced stage of HIV infection. AIDS is characterized by a diminished immune system, leaving the body highly vulnerable to illnesses that a healthy body typically fights off.

A person living with HIV is considered to have AIDS when the virus has drastically reduced his or her CD4 cell count, indicating a severely weakened ability to fight infection.

WHAT IS AZT?

Azidothymidine (AZT) is an antiretroviral drug used for the treatment of HIV infection. Originally developed to fight cancer, AZT was the first U.S. government–approved treatment for HIV and the first breakthrough in AIDS therapy. AZT did not cure HIV, but it significantly slowed the replication of the virus. It later became a key component in drug cocktails that slowed the virus even more. The U.S. Food and Drug Administration approved use of AZT for adults in 1987. Approval for children came in 1990.
INTRODUCTION

AN EPIDEMIC OF FEAR

1981
The U.S. Centers for Disease Control and Prevention (CDC) reports the first five cases of a rare pneumonia in Los Angeles, Calif., followed by diagnoses of a rare cancer. These are later understood to be the first reported cases of AIDS.

Elizabeth Glaser receives a transfusion of seven pints of HIV-infected blood and unknowingly transmits the virus to her daughter, Ariel, through breastfeeding.

1982
The CDC establishes the term acquired immunodeficiency syndrome (AIDS).

Despite CDC clarification, many media and health care professionals increasingly refer to AIDS as gay-related immune deficiency (GRID), mistakenly suggesting a link between homosexuality and the syndrome.

1983
The World Health Organization (WHO) holds its first meeting to assess the global impact of AIDS.

The CDC adds female sexual partners of men with AIDS as a risk group.

1984
Elizabeth Glaser gives birth to her son, Jake, having unknowingly transmitted HIV to him while pregnant.

The U.S. Department of Health and Human Services announces that it has identified a human retrovirus as the probable cause of AIDS. In 1986, the retrovirus will be officially named human immunodeficiency virus (HIV).

1985
The Glaser family discovers that Elizabeth, Jake, and Ariel are living with HIV.

Ryan White, an Indiana teenager living with HIV, is barred from school. Ryan speaks out against AIDS stigma and discrimination.

The American Foundation for AIDS Research (amfAR) is founded by Mathilde Krim and Michael Gottlieb, M.D. Gottlieb will later become Elizabeth Glaser’s personal physician.

1986
Ricky Ray, a 9-year-old hemophiliac living with HIV in Florida, is barred from school and his family’s home is burned by arsonists the following year.

Anthony Fauci, director of the U.S. National Institute of Allergy and Infectious Diseases (NIAID), announces that 1 million Americans have been infected with HIV.

1987
Azidothymidine (AZT) becomes the first drug approved to treat HIV infection among adults.

Researchers from Case Western Reserve University join doctors in Uganda to research and treat the AIDS crisis ravaging that country.

Several researchers involved in this work later come to work for the Elizabeth Glaser Pediatric AIDS Foundation.
In September 1988, three mothers gathered around a kitchen table to save a boy. Elizabeth Glaser’s son, Jake, was infected with HIV, and death seemed inevitable; AIDS-related illnesses had taken Elizabeth’s 7-year-old daughter, Ariel, the previous month. Elizabeth and her husband, actor Paul Glaser, had access to some of the best medical care in the world. Their home in Santa Monica, Calif., was only a short drive to reputable doctors and well-stocked health facilities across Los Angeles. But they could not buy medicine that had not been developed. Still grieving for Ariel, Elizabeth called her best friends, Susie Zeegen and Susan DeLaurentis, to her kitchen to brainstorm. The Pediatric AIDS Foundation was born as the three mothers quickly developed a plan to raise money for research and identified key scientists, policymakers, and celebrities to take up their mission.

“I couldn’t wait six months or six years to recover from Ariel’s loss,” Elizabeth later wrote in her memoir, *In the Absence of Angels*, “because those six months might be the ones that could save Jake’s life.”

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.”
As the three mothers investigated, their worst fears were realized when they discovered that virtually no one was conducting research into pediatric AIDS and that drug development for children significantly lagged behind that for adults.

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, and 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.

As important as providing funds for research, the Pediatric AIDS Foundation encouraged doctors and scientists to work together at a time when collaboration was rare. “You would think that these people talk to each other, but they don’t,” wrote Elizabeth, astonished.

So the Pediatric AIDS Foundation launched think tanks, with the first at the National Institutes of Health in Bethesda, Md., in 1988. With an emphasis on substance over style, collaboration over virtuosity, the think tanks encouraged scientists to approach research creatively and collectively.

By 1991, Elizabeth, Susie, and Susan had managed to raise more money than they had thought possible. They had educated senators and presidents about pediatric AIDS. And they had gotten scientists to talk to each other. Most importantly, Jake was alive and healthy.

But Jake’s life remained in danger. Treatment for children with HIV was unreliable and far too expensive for most families. Children continued to be born with HIV—and children continued to die from AIDS-related illnesses. Pediatric AIDS remained a low priority in the United States.

“Becoming active in the fight against AIDS made me realize I’m not a victim. I have power and I can work for change.”

—Elizabeth Glaser—
Elizabeth Glaser (then Betsy Meyer) and I grew up together in New York on Long Island—we were Brownies together. Years later, she and I rekindled our friendship when, by happenstance, we found ourselves working together at the Los Angeles Children’s Museum.

One afternoon, we went outdoors to eat our lunch, and she asked, “Where are you from?”

I said, “Oh, I’m from this little town on Long Island that if you don’t know it, you don’t know it.” She said, “Oh my god; that’s how I always refer to where I’m from.” So I looked at her and said, “Betsy Meyer! I’m Susie Bernstein.” From that moment, she and I rekindled our friendship and had a stronger and closer relationship than ever.

On the night that Ariel Glaser was born in 1981, my husband and I were at the hospital with Elizabeth and Paul.

After Ari died in August 1988, Elizabeth was determined to figure out how to save the life of her second child, Jake—and she knew that she was going to need help. Susan DeLaurentis and I became the outside faces of the Foundation, and Elizabeth worked behind the scenes. We had our first fundraiser in Washington, D.C., in June 1989 and raised a million dollars.

From there we became a major force.

Susie Zeegen is a co-founder of the Pediatric AIDS Foundation.

Elizabeth Glaser and I met at the public swing set when my daughter, Francesca, and Elizabeth’s daughter, Ariel, were just 2 years old. We became close friends from that moment.

Four years later, Elizabeth and her husband, Paul, were told by their doctor that Ari was not going to make it. In the midst of that devastating news, Elizabeth found me sitting on the steps outside the hospital, and she said, “I’ve got to do something about this.”

After Ari died, Elizabeth’s attention turned to her young son. She called me and said, “I’ve decided.

I really want to start a foundation to save Jake—but I can’t do it without you.”

I started making calls to the National Institutes of Health, trying to track down more specific information about pediatric AIDS research. Finally, after months of pestering, they sent us a printout of their projects, and it turned out that it was all being done with adults. Our scientific advisors determined that none of it would help kids with their specific AIDS-related issues.

I was shocked.

Susan DeLaurentis is a co-founder of the Pediatric AIDS Foundation.
CHAPTER 1


(Photos: EGPAF)
FUNDRAISING IS FOUNDATIONAL

“I would have to raise money now for the child I still had.”

—Elizabeth Glaser—

A Night to Unite
Elizabeth, Susie, and Susan knew that funding was desperately needed to jump-start research into pediatric AIDS. To kick off the effort, in June 1989, the three mothers hosted a black-tie gala in Washington, D.C., bringing together members of Congress and policymakers from both sides of the aisle. The event was hosted by Sens. Orrin Hatch (R-Utah) and Howard Metzenbaum (D-Ohio), with headline entertainment by Cher and Alan Alda. This gala, A Night to Unite, was the first bipartisan HIV/AIDS fundraiser in the nation’s capital. It raised more than $1 million, far exceeding the original goal.

This bipartisan event was hosted again in 1999, 2001, 2002, and 2003.

A Time for Heroes
A year after the success of A Night to Unite, the Pediatric AIDS Foundation hosted A Time for Heroes, a family-friendly celebrity picnic held in the Hollywood Hills. “Heroes” referred to all of the donors and attendees, but especially celebrity supporters. Originally sponsored by People magazine, the event attracted prominent celebrities who brought their families and participated in arts and crafts activities, dunking booths, reading to children, and sports. Nearly $1 million was raised at the first picnic, held on the estate of movie and record producer Ted Field. For more than two decades, this annual picnic remained one of EGPAF’s most successful fundraising events. Over the years, more than $34 million has been raised through A Time for Heroes.

Kids for Kids
In March 1993, Pediatric AIDS Foundation board member Alexander Vreeland organized the first Kids for Kids street fair and carnival in New York City. Mirroring the successful A Time for Heroes in Los Angeles, Calif., Kids for Kids drew celebrity supporters from television, movies, the arts, and sports for a day of celebration. This annual fundraiser focused on kids helping kids—emphasizing the role that children and families can play in the fight against AIDS. Like A Time for Heroes, this annual event consistently raised $1 million or more each year. To date, more than $26 million has been raised through Kids for Kids.

UP 4 THE FIGHT Dance Marathons
As the Elizabeth Glaser Pediatric AIDS Foundation expanded internationally, college students in the United States became more involved in the fight against pediatric AIDS by staying up all night dancing. The first dance marathons were held in 2001 at Northwestern University and Columbia University. Since then, students at 36 colleges and universities have invested time, dollars, and rhythm—raising more than $6 million. Of that, students at UCLA have contributed more than $3 million.

Special Events
These are just some of the events that have brought together donors to join the mission of Elizabeth, Susie, and Susan. Other memorable events over the years have included the Celebrity Golf Classic, AIDS Walk Africa, Nautica Malibu Triathlon, Celebrity Dodgeball, Global Champions of a Mother’s Fight Awards Gala Dinner, Global Impact Award Gala Dinner, and many other events—movie debuts, television specials, and athletic competitions.
ABOUT THE LOGO

Shortly before she died, Ariel Glaser painted her vision of the world—as a beautiful garden, bright with sunshine and surrounded by love. Her inspiration served as the logo of the Pediatric AIDS Foundation and continues to represent the Elizabeth Glaser Pediatric AIDS Foundation (as it was renamed in 1996).

Today, this image means hope to millions of people.

“
You can show that painting by Ariel to officials, ministers of health, first ladies, health care workers, and ordinary people across the continent of Africa, and they will look at it and say that it stands for kids and moms; it stands for health. That’s Ariel’s legacy.

—Charles Lyons, EGPAF president and CEO—
Jake Glasser displays Ariel’s original painting, which inspired the EGPAF logo. (Photo: EGPAF)
In 1981, I reported the first cases of what we now call AIDS. 

But by the late 1980s, no individual or organization had taken up the cause of children with the virus. Pediatricians administered gamma globulin infusions [to temporarily boost a patient’s immunity] with limited benefit. The prevailing medical opinion was that treatment for HIV-positive children could only be palliative [treating symptoms] because the virus quickly decimated immature immune systems. The prognosis was bleak.

One woman, Elizabeth Glaser, changed all that. As her doctor, I witnessed how much Elizabeth wanted to live and wanted her children to survive. Elizabeth was furious that drug development for kids always lagged far behind drug development for adults. Determined to make a difference, she harnessed her deeply competitive instincts, enlisted her friends and family, and tapped her connections in politics and Hollywood to shake up the status quo.

The Pediatric AIDS Foundation became the first organizing and funding body for scientists around the world studying pediatric AIDS. For me, the early days of EGPAF were reminiscent of Camelot, a golden age of collaborative research, with think tank retreats and tequila toasts. The most striking outcome from that scientific effort was the ability to routinely prevent mother-to-child transmission of HIV.

Michael Gottlieb, M.D., is often referred to as one of the first responders to AIDS because of his identification of the syndrome in 1981. He was also Elizabeth Glaser’s physician.

Dr. Gottlieb is an associate clinical professor of medicine at the David Geffen School of Medicine at UCLA and serves on the medical staffs at Cedars-Sinai Medical Center and Olympia Medical Center in Los Angeles.

“

We owe it to her to sustain the momentum toward a world where children have a chance to be healthy and live lives free of HIV.

”

—Michael Gottlieb, M.D.—
Elizabeth, Susie, and Susan were three people who had probably never thought about the fact that they would change the world—but they did just that.

My first connection with Elizabeth happened when a colleague of mine on the West Coast was involved in the care of both Ariel and Jake. Dick Stichm [Ariel’s physician] was one of the world’s most notable immunologists and was aware of the work that we were doing with AZT at the National Cancer Institute. He suggested to Elizabeth that she reach out to me.

Elizabeth was one of the most charismatic and engaging people the world has ever seen. She had a charm about her that made everyone feel accountable: you wanted to help her; you wanted to help her family; you wanted to help the community that she was serving. Everyone kind of came along.

The Foundation also began to engage members of Congress on both sides of the aisle to come together and support pediatric AIDS. And that brought in more money and more resources that allowed more trials to take place, which led to results.

Because of the great need, the Foundation served many different roles. It served as a catalyst for change; it served as a broker for change; it served as an advocate for change. It was sometimes behind the scenes and sometimes very much front and center. But its hands reached far and wide.

While Elizabeth lived, the success was almost wholly attributable to her voice—her ability to so eloquently speak to the issue and, frankly, to make everyone feel that they had a job to do on behalf of her and her children.

And I don’t just mean her children personally—I mean the children that the Foundation advocated for.

Philip Pizzo, M.D., served as head of the National Cancer Institute’s Infectious Disease Section and was chief of the Pediatric Department during the late 1980s and early 1990s. Dr. Pizzo was one of the first members of the Pediatric AIDS Foundation’s health advisory board and was later a member of its board of directors.

How Does HIV Affect Children?

Because children’s immune systems are not fully developed, children living with HIV get more severely ill than adults. They may experience the same common pediatric infections as HIV-negative children, but their bodies cannot fight these infections as effectively. Common infections in HIV-positive children include ear and sinus infections, pneumonias, urinary tract infections, intestinal illness, skin disease, and meningitis.

These infections can become fatal for children living with HIV.
Clockwise from top left: Susan DeLaurentis and Elizabeth Glaser participate in a tequila toast; Susan DeLaurentis, Elizabeth Glaser, Susie Zeegen; friends and supporters ceremoniously jump into the pool to celebrate the Pediatric AIDS Foundation’s accomplishments.

(Photos: EGPAF)
Pediatric AIDS Foundation think tanks were widely known as high-caliber brainstorming events at which researchers exchanged ideas, identified research priorities, and planned rapid courses of action.

“The think tanks that we started with Elizabeth are a perfect example of her tenacity and willingness to take a new approach,” says Pediatric AIDS Foundation co-founder Susan DeLaurentis. “We would have no more than 30 scientists, from all different disciplines, working together to answer a particular question, like how to address opportunistic infections.

“No one was allowed to use slideshows because we never wanted the room to be dark. We wanted the scientists to always be talking with each other in a more informal way than was the norm at a scientific meeting.

“We made sure the meetings were in a beautiful location, with delicious food and plenty of free time when they could discuss ideas with each other.”

“The gatherings were unique in the sense that people shared thoughts inside the proverbial tank,” says Mike McCune, M.D., a stem cell researcher who attended nearly all of them. “And the secrecy and competitiveness that sometimes shrouds scientific research was not evident. I think that, in part, that had to do with the way that Elizabeth and her team chose to run them—not as scientists, but as people able to engage with people and to get them to work together.”

The think tanks also included a unique tradition. At the closing session, Elizabeth led the group in a tequila shot to remind those gathered that even in the face of life and death, it is important to have fun.

“I’ve had many scientists tell me that to this day they continue to use that format. We really insisted on collaboration, insisted on openness.

To us, how would you do it any differently?

Our naiveté is what allowed us to make that happen.”

—Susan DeLaurentis—
Elizabeth and Ariel Glaser
( Photo: EGPAF)
CHAPTER 1

A MOVEMENT BEGINS

1988
Ariel Glaser dies from AIDS-related illness.
Elizabeth Glaser, Susie Zeegen, and Susan DeLaurentis launch The Pediatric AIDS Foundation (PAF).
PAF hosts a think tank at the National Institutes of Health, foreshadowing the organization’s role in fostering collaboration.
AZT helps thousands of adults living with HIV but is not approved for pediatric use.

1989
PAF gives its first research grant, $60,000, to Dr. Richard Stiehm of UCLA and its first Scholar Award to Dr. Richard Koup of the University of Massachusetts.
Sens. Orrin Hatch (R-Utah) and Howard Metzenbaum (D-Ohio) host the first PAF fundraiser: A Night to Unite. The event raises $1 million for research and unites people across the political spectrum.
On Aug. 25, the Los Angeles Times runs a feature story about the Glaser family, “Breaking a Silence: ‘Starsky’ Star, Wife Share Their Family’s Painful Battle Against AIDS.”

1990
Nearly $1 million is raised at PAF’s inaugural A Time for Heroes celebrity carnival in Los Angeles.
The Communications Workers of America adopts PAF as its charity of choice.
The U.S. Food and Drug Administration approves AZT for pediatric use.
Adolescent AIDS activist Ryan White dies of AIDS-related illness at age 18.

1991
Ten years have passed since the first AIDS cases were reported and since Elizabeth Glaser was infected.
Disney releases an album inspired by a tape that James Taylor made for Ariel Glaser. For Our Children—featuring Paul McCartney, Elton John, Ziggy Marley, and other stars—raises $4 million for PAF.

Elizabeth Glaser, with Laura Palmer, publishes her memoir, In the Absence of Angels.
Elizabeth Glaser is featured on the cover of People magazine, with an excerpt of the book inside.
NBA star Earvin “Magic” Johnson announces that he is living with HIV and retires from basketball. Johnson credits Elizabeth Glaser with giving him hope.
A NATIONAL CHALLENGE

"I started out just a mom fighting for the life of her child."

On July 14, 1992, a mother from Los Angeles, Calif., with a determined look walked onto the stage of the Democratic National Convention in New York City and introduced herself to the United States and the world.

“I am here because my son and I may not survive four more years of leaders who say they care, but do nothing....” said Elizabeth Glaser. “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 brought the reality of HIV into living rooms across the United States, and in so doing delivered one of the most remembered speeches of the 20th century. With measured words, she reminded politicians and delegates in the convention hall—and millions of television viewers—that lives hang in the balance when policies are made and budgets are set.

By 1992, the Pediatric AIDS Foundation had succeeded beyond its initial dreams of sparking research into pediatric AIDS. But many families across the United States were still being visited with illness and death because of lack of treatment for children living with HIV.

Among other issues, Elizabeth pointed out that the antiretroviral medication that she took cost her $40,000 per year. So not only was treatment limited in its effectiveness; it was beyond the means of many people. Eliminating pediatric HIV would require better medication and better access to it. Drugs had to be effective, accessible, and affordable to all families. A crisis this big required a national response.
During that same election year, Mary Fisher, another mother living with HIV, spoke at the Republican National Convention. Together, their speeches helped bring HIV out of the shadows and cut stigma about those living with the virus. And they set the stage for increased funding and outreach from the government.

But Elizabeth, Susie, and Susan knew that ending pediatric AIDS would require more than treatment for children already infected. They needed to find an effective way to block the transmission of the virus from an HIV-positive mother to her child.

At the end of one think tank devoted to mother-to-child transmission of HIV, Elizabeth Glaser stood up and said, “Clearly this is something that one person can’t do alone. We have to do it as a group. Who’s in?” One by one, leaders in this emerging field of research raised their hands. This led to the Ariel Project, a five-year study on HIV transmission from mothers to infants.

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 Glaser had lived with HIV. But by the end of 1994, her body was too weak to continue its own fight.

Elizabeth Glaser passed away on December 3, two days after the sixth World AIDS Day.

“...

We all need to hope that our dreams can come true. I challenge you to make it happen, because all of our lives, not just mine, depend on it.

—Elizabeth Glaser—
I’m Elizabeth Glaser. Eleven years ago, while giving birth to my first child, I hemorrhaged and was transfused with seven pints of blood. Four years later, I found out that I had been infected with the AIDS virus and had unknowingly passed it to my daughter, Ariel, through my breast milk, and my son, Jake, in utero.

Today, I am here because it’s a matter of life and death. Exactly four years ago my daughter died of AIDS. I am here because my son and I may not survive four more years of leaders who say they care, but do nothing.

I started out just a mom fighting for the life of her child.

I understand the sense of frustration and despair in our country, because I know firsthand about shouting for help and getting no answer.

When you cry for help and no one listens, you start to lose your hope. I was raised to believe that others’ problems were my problems as well. But when I tell most people about HIV, in hopes that they will help and care, I see the look in their eyes: “It’s not my problem,” they’re thinking. Well, it’s everyone’s problem.

Do you know how much my AIDS care costs? Over $40,000 a year. Someone without insurance can’t afford this. Even the drugs that I hope will keep me alive are out of reach for others. Is their life any less valuable?

Once every generation, history brings us to an important crossroads. Sometimes in life there is that moment when it’s possible to make a change for the better. This is one of those moments.

We are just real people wanting a more hopeful life. But words and ideas are not enough. Good thoughts won’t save my family. What’s the point of caring if we don’t do something about it?

My daughter lived seven years, and in her last year, when she couldn’t walk or talk, her wisdom shone through. She taught me to love, when all I wanted to do was hate. She taught me to help others, when all I wanted to do was help myself. She taught me to be brave, when all I felt was fear.

We all need to hope that our dreams can come true. I challenge you to make it happen, because all our lives, not just mine, depend on it.
Susie Zeegen and Elizabeth Glaser in New York City
(Photo: EGPAF)
When Elizabeth Glaser died in December 1994, 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 Elizabeth’s kitchen.

In the year that Elizabeth died, the Pediatric AIDS Foundation had launched a Long-Term Survivor Study to examine reasons that some individuals—including children—can remain symptom-free without taking antiretroviral medication. The results of the study, published in the journal *AIDS Research and Human Retroviruses*, suggest that the overall preservation of the immune system correlates with long-term survival.

In that same year, a significant trial (ACTG 076) showed that when pregnant women with HIV take AZT, the likelihood of them passing the virus to their unborn children is significantly decreased. This was the first breakthrough in prevention of mother-to-child transmission of HIV.

In response, the Pediatric AIDS Foundation, partnering with the White House, crafted a public awareness campaign to encourage every pregnant woman in the United States to be tested for HIV. Once tested, an expectant mother could receive treatment to prevent transmission of the virus to her baby.

In the ensuing five years, new cases of HIV in children dropped by more than 90 percent in the United States.

In 1996, the Foundation honored Elizabeth’s legacy by naming the organization for her. The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) continued to be a prime advocate and funder of research. That year, EGPAF introduced its Elizabeth Glaser Scientist Award (EGSA), 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.

As the 1990s came to a close, fewer than 200 children in the United States were being born each year with HIV.

In other parts of the world, however, where those resources and opportunities were not available, the numbers of cases of pediatric HIV towered.

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. But thanks to the Elizabeth, Susie, and Susan, critical trials were done, and transmission of HIV was blocked.

—Phillip Pizzo, M.D.—
CHAPTER 2

THE ELIZABETH GLASER SCIENTIST AWARD

Through its Elizabeth Glaser Scientist Award program (1996–2006), EGPAF supported the groundbreaking research of 36 scientists and clinicians with more than $24 million in research funding. 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.

By providing research funding over a five-year period, this award enabled recipients to focus their long-term efforts on issues specific to pediatric HIV/AIDS. In typical EGPAF fashion, the award fostered a spirit of collaboration among the scientists. Each year, all of the Elizabeth Glaser Scientists would convene with EGPAF’s internationally renowned advisory board to stimulate ideas, report on current programs, and plan collaborative research.

In 2005, through her Elizabeth Glaser Scientist Award, Deborah Persaud, M.D., conducted the first studies in young children on how HIV hides in the body to avoid elimination. More recently, Dr. Persaud and Katherine Luzuriaga, M.D., another EGSA awardee, were part of the team that documented the “Mississippi baby,” the first case of a functional HIV cure in an infant.

HOW IS THIS GOING TO PREVENT INFECTION IN BABIES?
—JOSEPH “MIKE” McCUNE, M.D., PH.D.—

In 1996, the newly renamed Elizabeth Glaser Pediatric AIDS Foundation introduced its Elizabeth Glaser Scientist Award (EGSA). Mike McCune, M.D., was one of the first EGSA recipients.

All of the scientists who received the Elizabeth Glaser Scientist Awards were doing research on a basic level that was applicable to the prevention and/or treatment of HIV infection in newborns.

Everything we were learning was brand new, and most of the work was coming out through the Pediatric AIDS Foundation.

It wasn’t just the research that was going on. It was the advocacy as well—so that by 1995 in the city of San Francisco, it was very rare for babies to be born with HIV because aggressive therapy was being provided to pregnant women and their children. Then work fanned out across the United States, so that it is now very rare for a baby to be born in the United States with HIV.

Since that time, this work has been extended around the world, and the lives of millions of babies have been saved by the efforts of the Pediatric AIDS Foundation. The end result has been nothing short of amazing.

Elizabeth was very smart and extremely focused. She was clearly driven to do something about pediatric AIDS and there was no deviation from that focus. Whenever we had a discussion about the science that we were doing it would always come back to the same question: how is this going to prevent infection in babies or to make babies who are infected better?

She wasn’t from a scientific background, but she knew what she wanted to do, she set out to do it, and she was smart enough to engage the right people to help her do it.

Mike McCune, M.D., Ph.D., is the chief of experimental medicine and a professor of medicine at the University of California, San Francisco. He has served for many years on EGPAF’s board and continues to work on issues related to the eradication of pediatric HIV.
Ben Banks, his daughter, Finley, and his wife, Kasiah
(Photos: Piedmont Photography, Palmyra, Va./Rachel Taylor)
I was 2 when I was diagnosed with cancer in both kidneys—and it had spread to both lungs. I had two surgeries, each of which required blood transfusions. Then I received my third transfusion when my platelet count was so low that I started to bleed through the pores on my face, feet, and hands.

Ten years later, I celebrated a decade of being cancer-free. My doctor was excited when I checked in with him. I had grown. My complexion was normal. I had hair!

A few days later, I came home from school to see my mother crying on the edge of her bed. With tears streaming down her face, she told me that the doctor had called. I was HIV-positive. I had to face the reality that the blood that saved my life from cancer ten years earlier had given me HIV. I collapsed into my mother’s arms; she held me, rubbed my head, and kept repeating that everything was going to be okay.

I returned to the hospital and went to the infectious disease doctor instead of the oncologist that I usually saw. He immediately put me on AZT.

AZT was available to children because of Elizabeth Glaser. Elizabeth demanded that medications, doctors, research, and treatment be available for children.

My diagnosis came early in the 1990s, when being HIV-positive was tinged with stigma and discrimination. Shortly after being diagnosed, the thought crossed my mind that because of my HIV status, I might never find someone to love me without reservation. I prepared myself for the worst, but what I got was the best—my loving wife, Kasiah. We have been together for more than 15 years, and we have been blessed with our first child, Finley Elizabeth Banks—named in honor of Elizabeth Glaser.

Elizabeth Glaser paved the way for many medical miracles. I am alive today because of the work Elizabeth did so many years ago and the people she inspired to keep fighting.

Both Finley and Kasiah are healthy, and most importantly, they are both HIV-free.

Ben Banks is an EGPAF ambassador who travels around the country to raise resources, awareness, and hope for children living with HIV. He lives in Virginia with his wife, Kasiah, and daughter, Finley.

EGPAF AMBASSADORS

To spread awareness about EGPAF’s mission to eliminate pediatric AIDS, the organization relies on individuals and families infected with or affected by HIV. Like Elizabeth Glaser herself, these ambassadors lend their voices and personal experiences to engage people and promote action by speaking at events, writing articles, posting stories and information on social media, and advocating on behalf of families affected by pediatric AIDS.
When I was newly born, I was abandoned at a hospital in southern Nevada. Later, I was adopted. It wasn’t until I was 3 years old that my family learned that I was living with HIV. The prognosis wasn’t good. Doctors told my parents that I had two years to live—if that. They were shocked and began the hunt for information on children living with HIV.

On a quest for answers and for hope, my mom started attending events and conferences related to HIV and pediatric health. It was at one of these events that she and I met Elizabeth Glaser, who was experiencing a similar, devastating reality.

Elizabeth refused to accept her diagnosis as a death sentence. She stood up and shared her story. In doing that, she not only fought for the lives of her children; she gave hope to all children infected with HIV. Because of Elizabeth and other advocates, pediatric AIDS research was available for me.

My parents signed me up for HIV treatment trials. The medicines I was exposed to brought me back to life, and because of my participation and the participation of other children, those treatments soon became available to other children suffering from AIDS. While participating in the treatment trials, I joined support groups and made friends with other kids living with the virus.

Many of these children who attended my hospital kept their status a secret; some were not even allowed to tell their grandparents. This didn’t sit right with me. I thought of Elizabeth, and at six years old I began to share my story. I wanted my friends to know that we shouldn’t be ashamed of our status. I wanted the world to know that our HIV-positive status didn’t make us any less deserving of healthy lives.

My advocacy efforts gave me the opportunity to work with Elizabeth. Her warm spirit and welcoming demeanor made it hard for anyone not to like her. Elizabeth, and other advocates who followed, helped me to discover my passion for AIDS advocacy and gave me motivation to fight for others affected by HIV/AIDS.

Hydeia Broadbent is an EGPAF ambassador who travels around the country to raise resources and awareness in order to help bring hope to children.
Hydeia Broadbent
(Photography: Michael Collopy)
A NATIONAL CHALLENGE

(Photos: Getty Images Entertainment/Gary Gershoff)
WE ARE THE SOLUTION
—JAKE GLASER—

“
My life has certainly not turned out the way I expected.
But while tomorrow will bring what it will,
today was glorious.
”

—Elizabeth Glaser—

These are words that my mother passed on to me. I live every day of my life by them.
At 29 years old, I have surpassed my own life expectancy of ten years by a long shot, and as I see it, my life is just beginning.
Being HIV-positive has taught me some of my greatest lessons.
It has taught me to love others and myself, and to embrace adversity. It has given me the opportunity to stand up for what is right, and the privilege to do so alongside amazing people. It has given me the chance to share my voice and the voice of a global community in front of tens of thousands of people.
Twenty-five years ago, my mother started what is now the Elizabeth Glaser Pediatric AIDS Foundation.

She started the Foundation to save my life, and in turn, ended up saving millions of other lives. It was her courage, her connection as a mother, and her love for others that inspired all of us to live by her example, and in turn, be an indispensable part of the solution, because we are the solution.
I view my life as a continuation of our story.

My mother gave the average person the opportunity to look inside and realize that “I have the ability to make things better.” We honor her memory by doing just that.

Jake Glaser is an EGPAF ambassador, the founder of Modern Advocate, and Elizabeth Glaser’s son.
I was made aware of the then–Pediatric AIDS Foundation in 1994 when I was a postdoctoral candidate looking for funding opportunities. I was fortunate to get a basic research grant looking at the early immune response to HIV in pediatric cases.

My advisor, Dr. Richard Koup, and my collaborators, Dr. Steven Wolinsky and Dr. David Ho, were all involved in the early Pediatric AIDS Foundation think tanks that were helping determine important questions about pediatric AIDS research. At that time, there were questions about everything with respect to HIV. We desperately needed research to understand how HIV affected infants and children differently than adults.

The Ariel Project and the Long-Term Survivor Study were both created in this time period. The Ariel Project was created to investigate the mechanism of mother-to-child transmission of HIV, which wasn’t really understood at the time. The Long-Term Survivor Study aimed to determine how people who had lived with HIV for a long time were able to do so without treatment.

These studies were the first large multicenter studies supported by the Foundation and were instrumental in the early fight to better understand pediatric HIV.

By 1999, there was a lot of soul searching going on with the direction of the Foundation. After the 1994 clinical trial that showed that AZT could block transmission of HIV from mother to child by 68 percent, it was clear that there were going to be fewer and fewer cases of pediatric AIDS in the United States. At around that same time, because of advances with the drug nevirapine, EGPAF started a new chapter with its first prevention of mother-to-child transmission programs in sub-Saharan Africa.

Our international work was just beginning.

Jeffrey Safrit, Ph.D. is the director of clinical and basic research at EGPAF.

EMERGENCY ASSISTANCE PROGRAM

The EGPAF-funded Emergency Assistance Program (1990–2002) awarded grants of up to $10,000 to hospitals to assist families of HIV-infected children who were living at or below the U.S. poverty line. The grants helped provide urgent basic needs—food, transportation, child care, and medication not reimbursable from other sources—so that families would have access to state-of-the-art treatment that would be otherwise out of reach. EGPAF distributed more than 820 awards totaling $3.5 million during the fund's 12 years.
CHAPTER 2

THE ARIEL PROJECT

The Ariel Project for the Prevention of HIV Transmission from Mother to Infant was a five-year $10 million project started in 1992 to bring together key researchers and clinicians to identify new ways to block HIV transmission. Pediatric AIDS Foundation associates collaborated with 15 institutions across the country to better understand the factors that increased the risk of transmission of HIV from mother to child.

“

Clearly this is something that one person can’t do alone.
We have to do it as a group. Who’s in?

—Elizabeth Glaser—

LONG-TERM SURVIVOR STUDY

The Pediatric AIDS Foundation’s Long-Term Survivor Study (1994-1999) examined the factors that may inhibit HIV progression, including a child’s genetic makeup, the immune system, and the nature of a particular HIV strain. The 13 research groups who participated in the study presented their findings to the U.S. Centers for Disease Control and Prevention, the U.S. National Institutes of Health, and the Pediatric AIDS Clinical Trials Group.

The results of the study, published in the journal *AIDS Research and Human Retroviruses*, suggest that the overall preservation of the immune system correlates with long-term survival. Data showed that the most important time period for predicting the progression of HIV is during the short period of time immediately following infection—with higher viral loads appearing in infants.
Elizabeth Glaser is featured on the AIDS Memorial Quilt.

(Photo: EGPAF)
CHAPTER 2

RAPID PROGRESS IN THE UNITED STATES

1992
The Pediatric AIDS Foundation (PAF) launches its first multicenter research study, the Ariel Project, to investigate the mechanisms of mother-to-child transmission of HIV.

Elizabeth Glaser speaks at the U.S. Democratic National Convention, bringing national attention to HIV/AIDS and pediatric research needs.

1993
PAF’s Kids for Kids celebrity carnival makes its debut in New York City. For many years, this event will be the organization’s leading fundraiser.

1994
AIDS is the leading cause of death for Americans ages 25 to 44.

PAF launches a second multicenter research project, the Long-Term Survivor Study, to examine reasons that some individuals, including children, can remain symptom-free without taking antiretroviral medication.

AZT is shown to reduce mother-to-child transmission of HIV by 68 percent in the landmark AIDS Clinical Trials Group (ACTG) 076 study.

Elizabeth Glaser dies of AIDS-related causes on Dec. 3.

People magazine displays Elizabeth Glaser on the cover. With the feature article “The Defiant One,” the magazine sells more than 1 million copies.

1995
All pregnant women in the United States are urged to get an HIV test by PAF’s national public service campaign.

1996
PAF creates the Elizabeth Glaser Scientist Awards, which would go on to provide 36 scientists and clinicians with more than $24 million in research funding over the next ten years. These individuals would use these awards to leverage more than $250 million in additional research funding.

1997
In honor of Elizabeth Glaser’s passion, dedication, and commitment, the Pediatric AIDS Foundation is renamed the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF).

Kate Carr becomes CEO of EGPAF.

The first EGPAF Commitment to Children Award is presented to First Lady Hillary Rodham Clinton on Dec. 1, World AIDS Day.

1998
Ten years have passed since Ariel Glaser died of AIDS and the Pediatric AIDS Foundation was started.

The first large-scale, multicountry HIV vaccine trial begins.
By 1999, the rate of pediatric HIV infections in the United States had dramatically fallen—due primarily to the effectiveness of AZT in subduing the virus and reducing HIV transmission.

HIV-positive pregnant women were routinely given antiretroviral medication during pregnancy and at childbirth. Newborns of HIV-positive women were also routinely given AZT as a preventive therapy for six weeks after delivery. People living with HIV now had access to affordable medications that maintained their long-term health.

The mission of the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) to end pediatric AIDS appeared to be within reach—in the United States.

Around the world, however, the AIDS epidemic 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, in some countries, as many as 35 percent of adults were living with HIV. Most women in low-resource countries did not have the means to be tested for HIV or to prevent transmission of the virus to their babies.

“The scope of this epidemic is unparalleled and its impact on families ... and future generations is immeasurable,” wrote Cathy Wilfert, M.D., EGPAF’s scientific director in 1999. “Given the magnitude of the global crisis, we must expand and export the knowledge and technology from the developed world to the international community, particularly in the developing countries that are home to more than 95 percent of the world’s 33 million HIV-infected people.”
Without intervention, this virus looked like it might devour nearly an entire generation of children. But a new drug—which could be administered in a single dose—offered hope.

“The biggest milestone that occurred over EGPAF’s 25 years was when the results of the nevirapine trials were announced in 1998,” says EGPAF co-founder Susie Zeegen. “Until then, most of our work had been about funding research and researchers. But when nevirapine was given to pregnant mothers in Uganda, we found that we could cut in half the transmission of HIV from mothers to children. That still left a thousand children a day being born with HIV—which was unacceptable—but it was the turning point.”

EGPAF’s international expansion began with the Call to Action project in 1999, which provided grants for programs to prevent transmission of HIV from mothers to their babies. The first recipients were in Thailand, South Africa, Kenya, Cameroon, Rwanda, and Uganda.

“The grantees set up a system in the local clinics or public health system with the approval of the minister of health to prevent mother-to-child transmission,” says Cathy Wilfert. “We didn’t have international offices at the time.

“We just had clinical investigators who were willing to work within systems in countries.”

Soon after the creation of the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) in 2004, EGPAF applied for and was selected as a partner to provide care and treatment in resource-limited countries: Côte d’Ivoire, Mozambique, South Africa, Tanzania, and Zambia. This PEPFAR-funded project was eventually called HEART (Help Expand Antiretroviral Therapy to children and families). It was a large leap from the work that the organization had done before.

“We thought we had the system in place to set up care and treatment in a similar way to setting up PMTCT [prevention of mother-to-child transmission],” says Wilfert. “It was easier said than done, but we managed to equal or surpass all other funded U.S. government partners. Maternal and child care is delivered by all of the rural clinics in the developing world, so PMTCT services can be delivered within established, routine antenatal care and maternity services.”

“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. It was a sea change and the high point of my work with the Foundation.”

A CALL TO ACTION

The Call to Action initiative (1999-2010) allowed international health care sites, nongovernmental organizations, and community-based organizations to apply to EGPAF for funds to help reduce mother-to-child transmission of HIV in resource-limited countries. It provided funding for community mobilization and training of health care workers, HIV counseling and testing, and building capacity to deliver antiretroviral medication.
Twenty years ago, I took a job at a small nonprofit in Santa Monica, Calif., now known as the Elizabeth Glaser Pediatric AIDS Foundation. The co-founders, Elizabeth Glaser, Susan DeLaurentis, and Susie Zeegen, hired me. We were a team of eight people at that time.

Soon after I was hired, in 1994, research showed that giving antiretroviral medication to HIV-positive pregnant women could cut transmission to newborns by two-thirds. It was a massive breakthrough, and the research was in part funded as a result of Elizabeth’s tireless advocacy.

Sadly, at the end of that year, in December of 1994, we lost Elizabeth. We had lost our leader and risked losing the story that has inspired so many, but we had an opportunity to get treatment to the women and children around the world who needed it.

In the next five years, we saw that potential realized. New cases of HIV in children dropped by more than 90 percent in the United States. The number of deaths in the United States was declining. Treatments were improving, and children were getting increased access to medicines. Stigma was reduced.

While the story improved here in the United States, resource-poor countries around the world had nothing. Ninety percent of the new HIV infections in children occurred in Africa. And the question came to the Elizabeth Glaser Pediatric AIDS Foundation: what were we going to do about it? Reflecting on what Elizabeth wanted, how could we look at the success in the United States and declare victory?

We had no Africa experience. Most of us had never even been to Africa. Health care infrastructure was minimal. Few people in the most affected countries knew their HIV status. On average, pregnant women came for only one prenatal visit, and only half of them delivered in a health facility. How could we encourage women to be tested, and—if found to be HIV-positive—to accept treatment and disclose their status to their families? Also, what would international expansion mean for our systems, staffing, and structure?

In early 2000, with help from the pharmaceutical company Boehringer Ingelheim, we funded our first eight health facilities in six countries in Africa. In some of the facilities we supported, as many as 30 percent of the pregnant women were living with HIV, with no treatment access.

PMTCT, THE LIFE SAVER

Prevention of mother-to-child transmission of HIV, or PMTCT, is a long phrase for a simple hope—that an HIV-positive woman can give birth to a healthy, HIV-negative child. More than 90 percent of HIV infections in children result from mother-to-child transmission, in which the virus passes to a baby during pregnancy, childbirth, or breastfeeding.

The first breakthrough in blocking those transmissions occurred in 1994 when researchers proved that administering AZT to an HIV-positive pregnant woman could reduce transmission of the virus to her child by 68 percent.

Now, thanks to the development of other drugs, nearly all of these infections are preventable.
Women and children wait at an EGPAF-supported clinic in Côte d’Ivoire.

(Photo: Olivier Asselin)
It seemed overwhelming and hopeless. But the programs began to grow, and services were delivered. EGPAF was very fortunate to get an additional investment from the Bill & Melinda Gates Foundation to expand these services worldwide. Soon, we were in several hundred facilities throughout Africa, India, and Russia, working within the existing public health system to build capacity.

The international community was beginning to shine a bright light on the pandemic in Africa. 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 support of the U.S. government, we were able to further expand, including placing more than 1 million people on antiretroviral treatment. Today, we are in 7,000 facilities and have reached 20 million pregnant women with services. Reflecting back on EGPAF’s growth reveals that we have always tried to step up to fill key gaps for women and children. It is important to take that first step, even in the face of so many challenges. To date, there has been a 51 percent decline in the number of new infections in children globally, and EGPAF is a big part of that achievement. We will keep fighting until no child has AIDS—and finish the job Elizabeth started.

Trish Karlin is EGPAF’s executive vice president of communications, marketing, and resource development.

THE 13TH INTERNATIONAL AIDS CONFERENCE

The 13th International AIDS Conference 2000 in Durban, South Africa, marked a change in the fight against AIDS. It was the first to be held in a low-resource country, and it was held in a country that was particularly hard hit by the HIV pandemic.

The conference theme, Breaking the Silence, was a poignant commentary on the stigma that persisted in keeping people living with HIV from accessing lifesaving services, as well as the need for equal access to HIV prevention, care, and treatment services in all communities.

It was at this conference that Professor Jeffrey D. Sachs, then chair of the World Health Organization’s Commission on Macroeconomics and Health, called for the creation of a global fund to fight AIDS. The Global Fund to Fight AIDS, Tuberculosis, and Malaria was created the following year, to invest in lifesaving health programs.
Founded in 1909, the Alpha Epsilon Phi (AEPhi) sorority is known to foster lifelong friendships and promote community service. Co-founders Elizabeth Glaser and Susie Zeegen were AEPhi sisters at the University of Wisconsin and the University of Southern California, respectively. Today, across the country, the young women of AEPhi carry on the legacy of EGPAF’s founders by raising awareness on their campuses and donating funds in support of EGPAF.

In 2000, EGPAF was able to vastly expand its international PMTCT efforts through a multi-million-dollar grant from the Bill & Melinda Gates Foundation.

In 2000, EGPAF was able to vastly expand its international PMTCT efforts through a multi-million-dollar grant from the Bill & Melinda Gates Foundation.

From 1995 to 2012, Boehringer Ingelheim provided EGPAF with critical support to scale up services for PMTCT and strengthen the quality and comprehensiveness of maternal and child health services.

EGPAF’s relationship with the Communications Workers of America (CWA) stretches back to its earliest days, when little was known about HIV/AIDS and its effect on children. CWA designated EGPAF as its charity of choice in 1990 after Elizabeth Glaser passionately spoke at the CWA convention. Over the years, CWA members have raised more than $7 million for EGPAF.

The Walt Disney Company is a valued partner of EGPAF, serving as the title sponsor of the A Time for Heroes celebrity picnic from 2006 through 2011. As importantly, countless VoluntEARS with the Walt Disney Company have helped staff the signature fundraiser.

Jewelers for Children (JFC), the official charity of the jewelry industry, has supported EGPAF’s global programs since 1998. JFC has supported EGPAF’s core initiatives to eliminate pediatric AIDS and has contributed $9.1 million toward those efforts.

Johnson & Johnson is a leader in fighting for mothers and children infected with and affected by HIV/AIDS in the United States and around the world. The company’s recent support of the Global Plan to Eliminate Pediatric AIDS by 2015 and its ongoing commitment to EGPAF will help to ensure that every mother has access to the knowledge and resources she needs to keep herself alive and her baby HIV-free. Contributions to EGPAF have exceeded $15.5 million. Johnson & Johnson was recognized with the Corporate Champion Award in 2013 at the Global Champions of a Mother’s Fight gala in New York City.

Please see the appendix on page 68 for a list of EGPAF’s donors who have contributed a million dollars or more.
Lehema and Bashil get an HIV test, Uganda, 2011.
(Photo: James Pursey)
CHAPTER 3

IT’S AMAZING TO SEE PEOPLE WHO LIVED THROUGH LIFE-THREATENING INFECTION
—EDWARD BITARAKWATE, M.D.—

Uganda was one of the countries hit earliest by the AIDS crisis. The country was also the location of groundbreaking research on the prevention of mother-to-child transmission of HIV.

The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) began working in Uganda in 2000. Today, EGPAF is increasing access to a broad range of comprehensive and integrated HIV services for children, women, and families. Fifty-three percent of HIV-positive pregnant women are now receiving antiretroviral treatment to prevent mother-to-child transmission.

When I was doing my undergraduate training in medical school, not much was understood about HIV—and HIV was everywhere. Up to 90 percent of the patients in the inpatient wards were being treated for severe AIDS-related conditions. The crisis was close to me because I had several uncles and aunts who got HIV and died.

I was working with children. There was a specialized clinic for children. Because of the stigma, it was called the Pediatric Infectious Diseases Clinic—but it was basically an AIDS clinic.

Some of the health workers were infected as well, and they did not want to come forward as people with a bad illness—because HIV was associated with immorality. It was a more sensitive case for children because if you had an HIV-infected child, then it implied that Mom was infected and that Dad was probably also infected.

At that time, we didn’t have a national treatment program. There were no antiretroviral drugs. It was too expensive.

When I was doing my residency in pediatrics, things were changing. That’s when it was discovered that a single dose of nevirapine could prevent transmission of HIV. It became clear that we could save all these children who were dying in the wards.

Soon after that, I was made head of the pediatrics department in a rural hospital, about 400 kilometers from Kampala. The first thing I did was set up services to prevent mother-to-child transmission of HIV. I met the staff of the Ministry of Health, and they trained us and gave us medicines. The first medicines we got I carried back from the Ministry of Health in a backpack on public transport.

But the Ministry of Health didn’t have enough resources, so the staff pointed me to the Elizabeth Glaser Pediatric AIDS Foundation, which had an office in Kampala. That was in 2001.

Then in 2004, I received an email message from EGPAF telling me that I had received a grant. A few weeks after that, Cathy Wilfert, EGPAF’s scientific director, visited me. This was just after PEPFAR started, so EGPAF’s country programs were still being formed. There were fewer than 20 EGPAF sites in Uganda. Over the years, we grew. By the end of the Call to Action award, EGPAF was basically supporting about one-third of the national PMTCT program in Uganda.

One of my favorite young people today was once a little boy I had treated. Now, as a young man, he has completed his undergraduate studies and is a social worker. It’s amazing to see people like him who lived through life-threatening infection after life-threatening infection. It has helped strengthen my resolve to work harder to prevent mother-to-child transmission and to treat children living with HIV.

Edward Bitarakwate, M.D., M.P.H., is the EGPAF country director of Uganda.
In August 1988, Laura Guay, M.D., arrived in Uganda at the height of the AIDS pandemic. She was not affiliated with EGPAF at that time. Dr. Guay’s team, supported by Case Western Reserve University, was conducting research to help understand AIDS in Uganda. But first it had to overcome a pervasive health barrier—poor infrastructure.

When I got there “everything was sort of decimated from the various coups and civil wars,” Dr. Guay says.

It took years to build the infrastructure needed to provide HIV care, treatment, and prevention services, but slowly, Uganda became the African paradigm for how to respond to the AIDS pandemic.

“Uganda started the first HIV testing and counseling center. They had huge education programs in schools and rolled out their national ABC Campaign—Abstinence, Be Faithful, Condoms—in terms of prevention,” she says. “Huge amounts of HIV-related research and knowledge comes out of Uganda because they established research infrastructure very early on.”

With the mechanisms in place to screen and test patients for HIV, Dr. Guay and her colleagues were able to shift their attention to finding ways to prevent new infections.

By 1994, researchers knew it was possible to prevent mother-to-child transmission of HIV, but the high cost of antiretrovirals (ARVs) made it hard to implement on a global scale.

“In Uganda, the average annual health care expenditure was $3-4 per person, and you were talking about $1,000 [to provide ARVs] for a mother-infant pair,” Dr. Guay says. “It just wasn’t feasible.”

So while the number of pediatric HIV cases fell sharply in the United States, it continued to climb exponentially in resource-limited settings, including Uganda. Frustrated, researchers began searching for a lower-cost alternative. The result was the HIVNET 012 clinical trial in Uganda, which was designed to find an inexpensive, simple, and effective drug for expectant mothers living with HIV. The team settled on a drug called nevirapine.

“The short course of nevirapine worked so much better than the short course of AZT,” Dr. Guay says. “We were able to demonstrate the difference, but we didn’t really expect that it would work as well as it did, or that the data would be statistically significant.”

Nevirapine was the drug the global health community needed to launch PMTCT programs in Africa.

“At the time, the results showed that we could do this—even in Africa—with limited resources, and limited amounts of money,” Dr. Guay says. “You can make a difference with this very simple regimen and now is the time to do something about it.”

Laura Guay, M.D., has served as EGPAF’s vice president of research since 2008.
Laura Guay, M.D., at work in the pediatric AIDS clinic at Mulago Hospital around 1990. Dr. Guay worked on the HIVNET 012 clinical trial, which proved the efficacy of nevirapine in preventing mother-to-child transmission of HIV.

(Photo: Laura Guay, M.D.)
EGPAF Ambassador Florence Ngobeni-Allen with her son, Kulani, Johannesburg, South Africa 2011
(Photo: James Pursey)
WHAT AN INCREDIBLE GIFT IT IS TO HAVE A HEALTHY BABY

—FLORENCE NGOBENI-ALLEN—
SOUTH AFRICA

“I can tell you that losing a child to HIV is the worst thing a mother can go through. When I lost Nomthunzi, I cried for a long time. Then I decided to stand up and try to make a difference.”

I gave birth to my daughter, Nomthunzi, in September 1996. Then my husband suddenly fell ill and died. Nomthunzi had also become ill, so I took her to Chris Hani Baragwanath hospital in Soweto, South Africa. We were both tested for HIV, and we both tested positive.

Nomthunzi fought her illness for several more weeks, but there were no antiretroviral medicines available for children at that time in South Africa. She passed away when she was only five months old.

After I lost Nomthunzi, I cried for a long time. During the first few years after Nomthunzi’s death, I worked as an HIV/AIDS counselor at the hospital. HIV was not a disease that most people in Africa talked about. In many areas, they denied that it even existed. There were no HIV prevention programs. It was a very difficult time. After I counseled someone who lost a child to HIV, I would just run to the toilet and cry. We were seeing so many lost, and it felt like it was only getting worse.

But then, thanks to the work of so many, there was finally a way to stop the transmission of HIV from a mother to her child. I found that there were fewer and fewer days for me to cry about someone infecting her child. Instead, I would bring smiles by delivering the news to HIV-positive mothers that their children were HIV-negative.

Then, I experienced that incredible joy myself. After watching so many other HIV-positive mothers give birth to healthy, HIV-negative children, I began to think to myself, “What am I waiting for?” I was married again, and for the first time considered it possible for me to have a family.

I became pregnant again. But this time, I had access to antiretroviral medication to stop the transmission of HIV. My son Alex was born healthy and HIV-free.

Today he is a healthy, beautiful boy. A few years after Alex was born, I gave birth to a second son, Kulani, who is also HIV-negative. What an incredible gift it is to have a healthy baby, free of HIV. It’s a gift that every mom deserves. And that’s why we have to keep going until we end pediatric AIDS once and for all.

I dream of a generation free of HIV. I know it’s real, because my children are a part of it.

Florence Ngobeni-Allen is an EGP4F ambassador living in Johannesburg, South Africa. She considers it her life’s work to give a voice to the millions of women who, like her, are living with HIV.”
PROJECT HEART

In 2004, EGPAF launched Project HEART (Help Expand Antiretroviral Therapy to children and families), an eight-year, five-country project to extend lifesaving HIV treatment to millions of people living with HIV. The project was funded through a grant from the U.S. Centers for Disease Control and Prevention.

Administered in Côte d’Ivoire, Mozambique, South Africa, Tanzania, and Zambia, Project HEART also helped strengthen health systems to improve service delivery.

Between 2004 and 2012, EGPAF served as an antiretroviral therapy care and treatment partner in those countries, working to increase and improve delivery of antiretroviral therapy and other HIV services in those countries.

More than 1 million people received HIV care and support services through Project HEART, and more than 2.5 million pregnant women received services to prevent mother-to-child transmission of HIV.

“Our success was that we got up every day and looked at the problems that kept kids from getting treatment—whatever the problems were—and we worked to solve them.”

—Susan DeLaurentis—

EGPAF AFFILIATES

In 2011, three national organizations were created as affiliates of EGPAF to continue the sustainable service delivery of Project HEART: Fondation Ariel Glaser pour la Lutte contre le Sida Pédiatrique in Côte d’Ivoire, Fundação Ariel Glaser Contra o SIDA Pediátrico in Mozambique, and the Ariel Glaser Pediatric AIDS Health Care Initiative in Tanzania.

“We have a unique understanding of the reality of HIV/AIDS in our countries,” says Paula Vaz, M.D., executive director of Fundação Ariel in Mozambique. “By tackling the AIDS epidemic locally, we can lead the way to global change.”

“Country ownership is essential to ending the AIDS epidemic,” says Charles Lyons, EGPAF president and CEO. “Through this model, EGPAF provides comprehensive capacity building and support to locally based organizations.”

Collectively the three EGPAF affiliates support more than 650 public and private health facilities that have tested more than 895,000 pregnant women for HIV and have started more than 180,000 clients on HIV treatment.
EGPAF supporters participate in AIDS Walk Africa, which aimed to shed light on the AIDS pandemic while raising funds to benefit EGPAF’s Call to Action sites throughout Africa. AIDS Walks were held between 2003 and 2008, with excursions to South Africa, Tanzania, and Swaziland.

(Phot: Jon Hrusa)
Manga Devi Tharangini with her daughter, Keshava, Hyderabad, India, 2013
(Photo: Ann Summa)
I WANT TO USE ALL MY OPPORTUNITIES
—MANGA DEVI THARANGINI—
INDIA

Our work shows that when women have the means to receive proper health care, pediatric AIDS can be virtually eliminated.

—Charles Lyons, EGPAF president and CEO —

Manga Devi Tharangini is willing to talk about her HIV-positive status, but not at her job in an Internet café or around the apartment building where she lives. Her daughter, Keshava, is HIV-negative, but the school where the child is attending doesn’t know about Tharangini’s status. She wants to keep it that way.

So Tharangini asks to meet at her parents’ rented house, a half-hour on a dusty road from the center of Miyagluda, a town in central India. Her parents live in a spare two-room structure with a small cottage garden of well-tended tomato bushes and stalks of green onions poking above the dirt.

“I cried for a week when I found out about her status,” says Tharangini’s mother. “We had a house at that time, but we had just sold it for her dowry.”

Tharangini did not find out that she had been infected with HIV until she was in her eighth month of pregnancy.

“I felt very sad when my husband told me he had HIV,” says Tharangini.

“First I went to a private hospital, and there I found out about my status,” says Tharangini. “Then I went to a community hospital where they referred me to a hospital where they deliver HIV-positive pregnant women.”

At the hospital Tharangini received antiretroviral medication to prevent transmission of HIV to her unborn daughter.

“There were no complications in my delivery,” Tharangini continues. “And the baby was born [HIV-] negative.”

Tharangini has managed to keep the virus at bay through the antiretroviral therapy that she receives. However, her husband eventually died from AIDS-related illness.

Tharangini explains that she feels safe when she visits her parents, but that life as a single mother with HIV is more challenging in her own neighborhood.

“She I don’t have any problems with the neighbors. But in the city where I am living alone and working, I’m not disclosing my status.”

Still, with the help of treatment and a 7-year-old daughter to raise, Tharangini is hopeful, resourceful, and independent.

“I don’t want to get married again. I want to build up my career. I want to live with my baby and to use all my opportunities,” she says.

Since 2002, EGPAF has partnered with Solidarity and Action Against the HIV Infection in India (SAATHII). As of December 2013, EGPAF-supported programs in India have provided more than 1.6 million women with critical PMTCT services.
1999
Nevirapine is shown to reduce mother-to-child transmission of HIV by 50 percent with single doses given to the mother during labor and to the infant following birth in the landmark HIVNET 012 study, led by Laura Guay, M.D., now a researcher with the Johns Hopkins University and EGPAF’s vice president of research.
EGPAF begins the Call to Action prevention of mother-to-child transmission (PMTCT) program in eight clinics in six countries, focused on implementing the HIVNET 012 intervention.

2000
The Glaser Pediatric Research Network is launched as an affiliate organization to EGPAF. Researchers in the network expand their work into other serious and life-threatening pediatric diseases.
EGPAF receives its largest donation to that date when the Bill & Melinda Gates Foundation awards a $15 million grant to the Call to Action project.

2001
Twenty years have passed since the first AIDS cases were reported and since Elizabeth Glaser was infected.

2002
AIDS is the leading cause of death worldwide among those aged 15 to 59.
The Joint United Nations Programme on HIV/AIDS (UNAIDS) reports that women account for half of all adults living with HIV worldwide.
EGPAF introduces the International Leadership Award, which is given to three up-and-coming researchers in resource-limited settings.
Dr. Jeffrey Stringer of the University of Alabama and Center for Infectious Disease Research in Zambia becomes the first Elizabeth Glaser Scientist awardee to conduct research in a resource-limited setting.

2003
During the 2003 State of the Union address, President George W. Bush proposes creation of the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR).
EGPAF’s first AIDS Walk Africa begins with a 100-mile, seven-day walk through the heart of the pandemic in Africa to raise funds and awareness.
The Pediatric Research Equity Act is enacted, requiring drug companies in the United States to test their products to ensure that they are safe and effective for children.

2004
Tom Hope, Ph.D., of Northwestern University and Grace Aldrovandi, Ph.D., of Children’s Hospital, Los Angeles are awarded Elizabeth Glaser Scientist Awards to study how viruses are transmitted from mother to child in utero and during breastfeeding.
EGPAF launches Project HEART.

2005
Jake Glaser, an EGPAF ambassador and healthy young adult, celebrates his 21st birthday.

2006
EGPAF receives funding from the Bill & Melinda Gates Foundation for enhancing PMTCT through implementation and operations research.
Pamela Barnes becomes president and CEO of EGPAF.
CHAPTER 3

GLOBAL MOVEMENT TO END PEDIATRIC AIDS

2007
EGPAF launches its Pediatric HIV Vaccine program with funding from the Bill & Melinda Gates Foundation.
EGPAF funds its first operations research project to enhance PMTCT.
EGPAF launches its first internal operations research project in Swaziland to look at the impact of specific health care worker training for HIV testing in labor and delivery.

2008
Twenty years have passed since Ariel Glaser died of AIDS and the Pediatric AIDS Foundation was launched.
EGPAF funds the first round of Pediatric HIV Vaccine Program basic research grants.
Laura Guay, M.D., joins EGPAF as vice president of research.

2009
EGPAF holds its first operations research think tank in tandem with its first operations research training in Kampala, Uganda.

2010
President Barack Obama launches the Global Health Initiative, a six-year effort to develop a comprehensive approach to addressing global health in low- and middle-income countries, with PEPFAR as a core component.
To mark its 20th anniversary, EGPAF launches Join the Movement, a new effort to create a generation free of HIV.

2011
Thirty years have passed since the first AIDS cases were reported and since Elizabeth Glaser was infected.
EGPAF affiliates are established in Mozambique, Côte d’Ivoire, and Tanzania.

2012
Project HEART concludes. Through this project, started in 2004, more than 1 million individuals in Côte d’Ivoire, Tanzania, South Africa, Zambia, and Mozambique received HIV care and support, and more than 500,000 individuals were started on antiretroviral therapy.

In addition, more than 2.5 million pregnant women were tested for HIV—and as a result, more than 66,500 pediatric HIV infections were averted.

2013
Twenty-five years have passed since Ariel Glaser died of AIDS and the Pediatric AIDS Foundation was started.
Elizabeth Glaser Scientist Award recipient, Deborah Persaud, M.D., announces that a baby has been functionally cured of HIV in Mississippi.
U.S. Secretary of State John Kerry announces that 1 million babies have been born without HIV because of the work of PEPFAR. One quarter of their mothers received PMTCT treatment through programs supported by EGPAF.
EGPAF remains committed to eliminating pediatric AIDS, working in 15 countries and more than 7,000 sites around the world.
NOW IS THE TIME TO ELIMINATE PEDIATRIC AIDS

The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) started because a mother with access to the best resources in the world was not able to save her daughter, Ariel, from a mysterious illness. With the help of her friends Susie Zeegen and Susan DeLaurentis, Elizabeth Glaser sparked the research and policies that ultimately saved her second child, Jake.

But the vision of the three founders went beyond the life of one boy.

“Much has changed for the better since those early days,” says Jeffrey Safrit, Ph.D., EGPAF’s director of clinical and basic research. “In the United States, mother-to-child transmission of HIV is now exceedingly rare. I think that Elizabeth Glaser would be in awe about what the Foundation has achieved.”

Every day, hundreds of women who are living with HIV safely deliver HIV-free babies. But work continues to make those resources available worldwide.

“Complete eradication of HIV—this is the goal now,” says Mike McCune, M.D., an EGPAF board member and past Elizabeth Glaser Scientist. “Around the world, among the 34 million people who are infected, roughly half are women and many are women of childbearing age. To eliminate pediatric HIV, we have to get rid of HIV among those women.”

Today, 65 percent of HIV-positive women around the world have access to services for the prevention of mother-to-child transmission of HIV. This shows the success of EGPAF and its partners.
Yet more than 700 children are newly infected with HIV each day. More than 90 percent of those children live in sub-Saharan Africa. While they carry a huge burden of disease, children are treated at half the rate of adults—34 percent of children needing HIV treatment currently access such care, while 64 percent of adults do.

“We have to make it as simple and convenient and affordable as possible for families to get the antenatal treatment, the birthing care, and the postnatal support that they need,” says Charles Lyons, EGPAF president and CEO.

“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,” Lyons continues.

“Health systems are now the essential element of a sustainable HIV/AIDS response,” says Francesca Celletti, M.D., EGPAF’s director of health system strengthening and sustainability. “Strengthening health systems means increasing access to quality health services.”

“It is also the path to country-owned sustainable programs.”

Success of those efforts can be measured by the announcement in June 2013 that 13 new countries had reached a tipping point in the fight against HIV/AIDS—meaning that the annual increase in the number of patients on treatment exceeds the annual number of infections.

“Success breeds success,” says Lyons. “It draws attention and it builds confidence that the ministers of health and the health care workers in a country with a high HIV burden can set a goal and move methodically toward that goal—and achieve it.”

The scope of EGPAF’s work has changed dramatically from that evening in September 1988 when Elizabeth Glaser gathered her close friends to figure out how to save Jake, but the mission has not changed.

“Moving into the future, it is important that EGPAF doesn’t lose the problem-solving attitude that we began with,” says co-founder Susan DeLaurentis.

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“We were moms who saw a crisis and knew that we couldn’t sit by and let that crisis continue.”

“We have the science. We have the medicines.
Now is the time to eliminate pediatric AIDS.

—Charles Lyons, EGPAF president and CEO—
The prevention of mother-to-child transmission (PMTCT) program was introduced in Zimbabwe as a pilot program at three sites supported by the United Nations Children’s Fund (UNICEF) and the World Health Organization in 1999. When the pilot ended in 2001, the Zimbabwe government decided that PMTCT was a priority area, and it wanted to move forward with a national program. EGPAF stepped up with the resources to fund and support it. Until that moment, although everybody was extremely worried about HIV/AIDS, the focus was mostly on adults, with no one quite knowing what to do with children.

I worked with the Zimbabwe Ministry of Health and Child Care as the national PMTCT coordinator, managing the expansion of the program. While my main focus was increasing coverage and reach, I became more and more attached to the individual mothers and children who would come to the national program events thanking us, saying, “My god, you saved my family; you saved my child.”

I have found great fulfillment in hearing their stories, knowing that this work has made such a difference.

In Zimbabwe, our culture places a lot of importance on preserving our clan. With the onslaught of the HIV pandemic, people truly felt that whole clans would be wiped away. Seeing those women coming and thanking us, saying how much the program had changed their lives, made me think again that when you talk about a generation free of HIV—or a nation continuing to exist—you have to really start with the little ones first, the children.

Yes, we could get more people on treatment, but what we really wanted to prioritize was turning off the HIV tap by ending transmission of HIV to children.

There has been such massive progress with the rollout of the national PMTCT program. When we started, the mother-to-child transmission rate was near 30 percent because there was nothing happening, no intervention. By 2009, we found out that the mother-to-child rate was down to 18 percent. Then in 2011, it was at 8.8 percent. Now it is even lower.

While EGPAF-Zimbabwe started as a PMTCT program, our work has evolved so that now we don’t just focus on mother-to-child transmission. We are working with the Zimbabwe Ministry of Health and Child Care to support an integrated and comprehensive program to make antiretroviral treatment available in all maternal, newborn, and child centers. We are working to ensure that all women are tested for HIV at any antenatal care clinic and are put on lifelong antiretroviral treatment if they test positive. And we are working to identify and test HIV-exposed children—and putting them on antiretroviral treatment if they are HIV-positive.

We also do quite a lot of work in the community, so that women know that they need to come for treatment and that babies who have been put on treatment must come back with their mothers—what we call retention and follow-up. We work very closely with community leaders to educate and raise awareness.

We are turning off the tap.

Agnes Mahomva, M.D., is a physician specialized in public health and has been EGPAF’s country director for Zimbabwe since 2007. Today, EGPAF supports PMTCT at a total of 1,445 sites, accounting for approximately 93 percent of coverage throughout Zimbabwe.
A health care worker administers a rapid HIV test to a mother at an EGPAF-supported clinic in Zimbabwe, 2010.

(Photo: James Pursey)
I am trained as a physician specializing in infectious diseases. I started my postgraduate experience in San Francisco in 1982, when the AIDS epidemic was still very young. It was pretty grim.

Then in 1988, I went to work in Uganda. In a sense, it was moving from the frying pan to the fire. Things were bad in San Francisco, but they were much worse in Africa.

One of my most vivid recollections when we first arrived in Uganda was taking the drive from Entebbe into Kampala. I remember seeing all these shops on the side of the road, especially as you got closer to Kampala. If you can imagine, the single largest growth industry in Uganda when we arrived in 1988 was coffin making. You just saw all these little shops with stacks of caskets there. During our first year in the sexually transmitted diseases clinic, one out of two people who walked through the door of the clinic were HIV-positive.

It’s telling that when you go there now, you don’t see much casket making.

The number of women who have access to PMTCT services has skyrocketed, so the number of new infections in children is decreasing incredibly.

**A Vaccine and a Cure**

EGPAF has a big role to play to continue to push the agenda forward, not only for the sake of children but to also help point the way to potentially big benefits for adults. The nuances of a child’s immune system may permit us to identify a protective vaccine in children before we do in adults.

Even though we changed AIDS from being a uniformly lethal disease to a manageable chronic disease—and people can live long, productive lives with it—the bottom line is that health care workers still need to treat people for life with complex and somewhat toxic therapies. And AIDS is still a disease that causes significant morbidity, so we still desperately need a vaccine and/or a cure to truly end the scourge of AIDS. And vaccines may also be used therapeutically to reduce the impact of the virus on people who are infected.

We also need to continue to push hard at eradicating the virus in people who are already infected—because even if tomorrow I could wave a magic wand and have a vaccine that could prevent all new infections, there are currently still about 35 million people in the world living with HIV.

**PEDIATRIC CURE CONSORTIUM**

In 2013, EGPAF established the Pediatric Cure Consortium to focus the research agenda on children and to drive progress to find a cure. The Consortium—led by EGPAF staff and an international group of scientists from the Pediatric Cure Consortium advisory board—promotes collaboration to determine research priorities and to garner resources for the cure of HIV infection in children. Through this forum, EGPAF will provide seed funding for the most promising ideas, support think tanks, and ensure the sharing of key data and research results.
Health System Strengthening

Everyone knows EGPAF very well because of our successful efforts to scale up PMTCT—especially in sub-Saharan Africa. We really have also been from the very earliest stages one of the largest implementers of HIV care and treatment. If a cost-effective and cost-appropriate curative or vaccine intervention could be implemented, we would be a prime candidate to manage it because we have the structure, we know how to support the programs and work with the national and local agencies, we know how to integrate programs into existing health systems, and we know how to strengthen health systems.

Remember that there is no such thing as an HIV health system. Health systems throughout the world do not deal with individual diseases; they deal with patients or clients. Sustainable systems and programs to eradicate HIV have to be integrated within existing health systems.

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Maternal and Child Health

Most of the work we do is related to maternal, child, and reproductive health. So we have to continue to focus on strengthening those systems.

As part of that we have to build more capacity in the countries where we work, building up local organizations. We have to continue to reach out to communities and make sure that they are engaged with maternal and child health services—and that families are retained within those services over time.

Elizabeth Glaser was instrumental in putting children on the map, and subsequently, the benefits that have been derived for children during this epidemic have been fantastic. People still forget the first major HIV prevention success in any population was the prevention of new infections in children.

Nicholas Hellmann, M.D., is EGPAF’s strategy and science advisor and former executive vice president for medical and scientific affairs.

PROGRESS TOWARD A CURE: THE MISSISSIPPI BABY

In March 2013, the world was stunned by news of a baby in Mississippi who was functionally cured of HIV. The lead author of the case study was Deborah Persaud, M.D., a 2005 recipient of the Elizabeth Glaser Scientist Award and a pediatric infectious disease specialist at the Johns Hopkins University. Dr. Persaud learned of the case in Mississippi from another Elizabeth Glaser Scientist Award winner, Katherine Luzuriaga, M.D., of the University of Massachusetts.

“This study has huge implications for treatment of HIV-infected infants globally,” says Dr. Persaud. “If this can be replicated, this can be scaled up very quickly.” Dr. Persaud adds that the case in Mississippi “culminates what Elizabeth Glaser really wanted for children with pediatric HIV—including her own kids.”
Chris is a beneficiary of an EGPAF-supported clinic in Zambia, 2011.
(Photos: James Pursey)
Adolescence can be a difficult period in anyone’s life, but that struggle is amplified for adolescents living with HIV. The challenges of growing up are made even more difficult by the physical, social, and emotional toll taken by the virus. In Zambia, EGPAF works with local partners on a mentor program to support adolescents dealing with the everyday struggles of HIV.

“When I found out I was HIV-positive, I had mixed feelings because that was the time I was applying for school,” says Chibesa, a young woman who studies at Zambia’s National Institute for Public Administration. “I was about 19. The first thing that came to me was shock. I was like ‘How is that possible?’ I was sad and I wanted to convince myself that it was not happening.”

EGPAF-Zambia’s Tisamala Teen Mentors program—in Nyanja, a local language in Zambia, tisamala means “we take care”—offers psychosocial support to teens living with HIV. Adolescents have the opportunity to be part of a support group led by HIV-positive peer mentors. Through these support groups, adolescents can ask questions about their health in a safe and understanding environment.

“Some of them [teens in the group] have problems from home. Aunties and others stigmatize them about the disease,” Chibesa says. EGPAF trains HIV-positive teen mentors who either volunteer for the position or are nominated by members of their local support groups. Each mentor is 17 or 18 years old, knows her or his HIV status and is comfortable talking about it, and has received consent to participate from a parent or guardian. Chibesa, though older than other Tisamala mentors, has experience mentoring teens from being a peer counselor with Tiny Tim and Friends, the nongovernmental organization where she first started receiving her HIV medication.

“The guidelines are about relationships, multiple partners, and adherence,” she says. “We also give our own experiences. We share our life story and advise what can be done about [HIV]. I advise people what I do to adhere to my medication.

“The Tisamala program is helping me accept [being HIV-positive] and just encourage other people. I feel normal like every other person. In fact, I think I am even more strong. When people are talking negatively about HIV-positive people, I tell them not to say that, even if I don’t tell them why.

“Most of them, at first, are stigmatizing, but then, later on, they change. They come back and say, ‘you know ... what you told me is making sense.’”
LIFELONG TREATMENT (OPTION B+)

In 2012, a groundswell of support arose to introduce a new prevention of mother-to-child transmission (PMTCT) protocol, which the World Health Organization has designated Option B+. In essence this option provides lifelong treatment for pregnant women who are living with HIV. Lifelong treatment programs are being rolled out in many of the countries that EGPAF supports.

In Rwanda, EGPAF is researching the ramifications of Option B+ through a three-year project funded through the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) called the Kabeho study. It examines the survival and health of infants born to HIV-positive mothers who participate in Option B+.

It is also analyzing the diets of children from birth to 18 months to see how drugs and nutrition interact to affect the child’s HIV status.

“The findings from this study are going to help us understand what is happening in terms of feeding the babies and anything we can do to anticipate what the babies’ needs are,” says Jeanine Chondo, M.D., the deputy dean of Rwanda’s School of Public Health. “Many, many people are watching this study.”

If the Kabeho study shows that Option B+ is more effective than other methods of preventing HIV transmission from mothers to babies, it could mean a revamping of public health policies around the world and thousands more children living HIV-free.

GLOBAL PLAN TOWARDS THE ELIMINATION OF NEW HIV INFECTIONS AMONG CHILDREN BY 2015 AND KEEPING THEIR MOTHERS ALIVE

EGPAF played an integral role in the development of the Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive (the Global Plan). This plan was developed in 2011 to help countries most affected by the HIV pandemic lead the effort to eliminate pediatric HIV.

The Global Plan consolidates buy-in from many stakeholders for the purpose of eliminating pediatric HIV by 2015. While the plan applies to all low- and middle-income countries, it focuses on 22 countries with the highest number of pregnant women living with HIV.

The plan aims to reach HIV-positive women and their children from the time of pregnancy through breastfeeding to prevent transmission of HIV from mother to child. HIV prevention, care, and treatment services are also a priority to ensure that women and children living with HIV maintain their long-term health.
MOBILE CLINICS REACH COMMUNITIES IN MOZAMBIQUE

Outside a health post in Mazivila, Mozambique, a large white truck sits, surrounded by what appears to be about 80 people. The action has already begun. Today, the health workers moving in and out of the truck will be providing the people of this community with services they normally do not have access to: HIV testing and counseling, CD4 (white blood cell level) testing, gender-based violence education, and pharmacy services. In Mozambique, EGPAF has started an initiative to bring health services to people in communities far away from large hospitals and clinics. There is a health post in Mazivila, but that facility is limited compared with other clinics and hospitals. With mobile clinics, Mozambicans in remote locations can access the same health services that exist in larger health facilities.

A tent has already been set up alongside the van, where a health care worker is providing HIV counseling and testing. A nurse inside the van calls the names of patients she has written on slips of paper. About 12 people wait to be tested for their CD4 count. A CD4 test shows how many white blood cells are in the blood stream, an indicator of the body’s ability to fight infection.

The process moves quickly. Once all testing is complete, the clinic turns into a pharmacy.

A door in the back of the truck opens, with a ladder leading to the ground. Maria, one of the nurses, sets up a table in front of the door, pulls out medications, and begins filling prescriptions from health records kept inside the truck. Clients climb the stairs for their prescriptions as their names are called. Technicians inside the truck go through each patient’s record to ensure that he or she is receiving the correct drug regimen.

Outside, Almira Nhamtumbo and Anatercia Gilberto speak to a crowd of women and men about gender-based violence. This particular event is part of six days of activities that EGPAF has developed to educate communities. Anatercia is a police officer tasked with supporting victims of gender-based violence and following up the cases.

“We are helping many people.”

—Moses Mussane—

EGPAF mobile clinic technician
COMMEMORATING OUR FOUNDERS
BY RECOGNIZING OUR ALLIES

—GLOBAL CHAMPIONS OF A MOTHER’S FIGHT—

On Feb. 20, 2013, the Elizabeth Glaser Pediatric AIDS Foundation held the Global Champions of a Mother’s Fight Awards Dinner in New York City, highlighting the momentum of the Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive. Johnson & Johnson received the Corporate Champion Award, which was accepted by CEO Alex Gorsky. Amy Robbins Towers, founder of the Nduna Foundation, received the Humanitarian Award. Cookie Johnson, board member of the Magic Johnson Foundation, received the Global Advocate Award. All three awardees participated in a panel discussion moderated by Arianna Huffington, president and editor-in-chief of The Huffington Post.

“Elizabeth was a loving mother, a devoted friend, and an eloquent, passionate, unstoppable woman. [She] turned her personal loss into a public campaign on behalf of children with HIV/AIDS, founding this Foundation and inspiring so many of us to join the fight.”

—Hillary Rodham Clinton—
Former U.S. secretary of state and recipient of EGPAF’s 2013 Global Impact Award

—THE GLOBAL IMPACT AWARD—

The Global Impact Award Gala Dinner was held in New York City on Dec. 3, 2013, the 19th anniversary of Elizabeth Glaser’s death. The event honored Sec. Hillary Rodham Clinton and celebrated the 25th anniversary of EGPAF’s founding. ABC World News anchor Diane Sawyer presented Sec. Clinton with the unique Global Impact Award, a Lego representation of an iconic photo of Elizabeth Glaser and Sec. Clinton at EGPAF’s 1994 Kids for Kids carnival in New York City.
CHAPTER 4

Alex Gorsky, CEO of Johnson & Johnson; Amy Robbins Towers, founder of the Nduna Foundation; and Cookie Johnson, board member of the Magic Johnson Foundation at the Global Champions of a Mother’s Fight Awards Dinner. (Photo: Getty Images Entertainment/Bryan Bedder)

President and CEO of The Huffington Post Arianna Huffington (left) leads a discussion about pediatric HIV and global health with Alex Gorsky, CEO of Johnson & Johnson; Amy Towers, founder of the Nduna Foundation; and Cookie Johnson, board member of the Magic Johnson Foundation. (Photo: Getty Images Entertainment/Bryan Bedder)

Former Secretary of State Hillary Rodham Clinton receives the unique Global Impact Award, presented by EGPAF board member Nigel Barker, ABC World News anchor Diane Sawyer, and EGPAF board co-chair Willow Bay. (Photo: Getty Images Entertainment/Cindy Ord)

Former Secretary of State Hillary Rodham Clinton speaks at the Global Impact Award Gala Dinner. (Photo: Getty Images Entertainment/Cindy Ord)
A mother holds her newborn in Tanzania, 2012.
(Photo: James Pursey)
Some of the most poignant moments I have experienced have been when I have attended graduation ceremonies at which 18-month-old babies of HIV-positive mothers have been tested and it is confirmed that most of the children are HIV-free. I have been in clinics where there are 45 HIV-positive moms holding their young children, and 43 of the children are HIV-free. Without the actions and support of the Elizabeth Glaser Pediatric AIDS Foundation and our partners, as many as half of those babies might have been HIV-positive.

In early 2013, I was privileged to attend a graduation ceremony at a dispensary in Ngegu, Kenya, on the south shore of Lake Victoria, at which 19 of the 20 babies were confirmed to be HIV-free. This was particularly impressive because the entire site is managed by only a handful of health care workers.

The nurses at that clinic administered prevention of mother-to-child transmission of HIV (PMTCT) treatment with incredible competence and sustainability. They are determined that no woman within their community who tests positive for HIV misses out on antiretroviral treatment.

And those nurses are doing so much more. They are bringing HIV services closer to the people and following up with families—resulting in higher retention and greater efficiency in meeting our goal to prevent mother-to-child transmission of HIV.

In addition, the Ngegu dispensary is capable of responding to malaria and is distributing bed nets to prevent people from becoming infected with that often-fatal disease. Those nurses have vaccinated 90 percent of their community for routine childhood diseases. And they are able to identify and respond to moderate to severe malnutrition with a child running a high fever or with chronic diarrhea—potentially deadly situations.

These health care workers have created a model of what we are talking about, which is the full integration of PMTCT and maternal and child care and treatment in a community site where ALL of the most immediate health needs of the clients are being addressed.

The nurses have been through various training opportunities. They are smart. They are upbeat. They are energetic.

Their goal is this: no new infections. “We want to get 20 out of 20 next time,” they told me after the graduation ceremony.

It’s worth noting that the Ngegu dispensary is in the region in Kenya with the highest prevalence of HIV and that Kenya has the fourth-highest prevalence of HIV in the world. If those three nurses in that tiny clinic can bring down pediatric AIDS so substantially, it can be done everywhere.

Charles Lyons is president and CEO of the Elizabeth Glaser Pediatric AIDS Foundation.
APPENDIX

THANKS A MILLION

The following partners and donors have contributed $1 million or more to the Elizabeth Glaser Pediatric AIDS Foundation over the past 25 years. Through their generosity—and the generosity of all of our donors—EGPAF has been able to save millions of lives.

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The World Health Organization

While we cannot list all of our generous partners and donors, we are grateful for every donation, no matter the size.
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2005
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2006
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Harvard Medical School
Margaret Feeney, M.D.
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Alexandra Trkola, Ph.D.
Institute of Medical Virology

THE ELIZABETH GLASER PEDIATRIC AIDS FOUNDATION

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Pamela Barnes (2006–2009)
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Russ Hagey (2012–present)
Children play outside an EGPAF-supported clinic, Zimbabwe, 2010.

(Photograph by James Pursey)
The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) is the global leader in the fight to end AIDS in children. To date 20 million women have been reached with services to prevent mother-to-child transmission of HIV through EGPAF-supported programs. With a global footprint reaching more than 7,000 sites and work in 15 countries, our programs reach more than 2.5 million pregnant women and families each year. But every day, 700 babies are infected with HIV because their families lack access to the health services they need to prevent transmission.

Together, we will make that number zero. We will do whatever it takes until no child has AIDS. Elizabeth Glaser’s promise to her own children is now our promise to all the children of the world.