

## 2023 Annual Report





People say that they care, but actions are what save lives.

**—Elizabeth Glaser** 

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# 2023: Advancements and Persistent Challenges Shape EGPAF's Mission



For more than 35 years, Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) has been a critical voice speaking on behalf of children who have been overlooked. Founded on the commitment of Elizabeth Glaser, Susie Zeegen, and Susan DeLaurentis, our mission remains laser-focused on ending the HIV epidemic for children, youth, and families globally. 2023 brought exciting progress and also stark reminders that our mission remains vital.

The global community is advancing towards achieving control of the AIDS epidemic by 2030. We have seen significant progress in reducing new HIV infections and deaths due to AIDS. Each year more countries are succeeding in ensuring communities have access to testing and effective treatment. This achievement is a cause for celebration and a testament to the impact of coordinated global efforts, including those supported by our generous donors.

Unfortunately, not one high burden country has achieved epidemic control for children. We cannot control the AIDS epidemic by leaving children behind. Recent reports from UNAIDS alarmingly indicate that the disparity between adults and children in access to treatment is widening rather than diminishing. Continued investment in children is crucial.

Advancements in research have given us the tools to prevent HIV transmission to children and offer effective lifesaving treatment. It is up to all of us to ensure that prevention and treatment tools reach all children in need, and their families. EGPAF is working with ministries of health to strengthen health systems to reach the most marginalized communities. By leveraging new tools, such as electronic medical records and data analytics, we are able optimize approaches to reach more people with essential health services.

The value of your support of EGPAF has never been more crucial at this moment of such significant promise and pressing need. Lacking a political voice, children rely on partners and allies such as you to advocate on their behalf. At this critical time, we invite you to stand with us. Your support gives voice to those who cannot speak for themselves and accelerates our mission to end HIV and AIDS in children, youth, and families around the world for good.

Charles J. Lyons
President and CEO

Elizabeth Glaser Pediatric AIDS Foundation

## Why it Matters



because their families lack access to the health services they need to prevent transmission.



Without diagnosis and treatment, 50% of infants with HIV will die before their second birthday.



76,000 children died from AIDS-related illness because their families lacked access to care and treatment.

## Our Mission

The Elizabeth Glaser Pediatric AIDS Foundation seeks to end HIV and AIDS globally in children, youth, and families.

## Our Work

To date, our work across countries has:



#### PROVIDED

**OVER 33 MILLION** pregnant women worldwide with services to prevent transmission of HIV to their babies.



#### SUPPORTED

**OVER 15,000** sites to offer HIV counseling, prevention, diagnosis, and treatment services alongside high-quality family healthcare.



#### AVERTED

**OVER 410,000** new HIV infections in children since 2000 by offering prevention of mother-to-child services to pregnant women.

In 2023, EGPAF was engaged in 56 research studies across 12 countries. Sixty percent of our research involved adult and pediatric/ adolescent HIV testing, care, and treatment. Other studies looked at tuberculosis; maternal, newborn, and child health; COVID-19; and prevention of mother-to-child HIV transmission.

## Optimizing Treatment for Children in Mozambique

## Little Esmeralda Returns to Health Through Optimized Treatment and Focused Care

Esmeralda is a five-year-old girl. Cheerful, restless, and hopeful, she asks questions about everything she sees in the doctor's office when she goes for a consultation at the Chaimite Health Center in Gaza Province. Anyone who sees her today would immediately think she was always a strong and healthy child, but that was not always the case.

Esmeralda lived with her father, who was a miner; her two brothers; and her mother, Admira, who was diagnosed with HIV when she was five months pregnant.

When Esmeralda was born, she was immediately put on HIV prophylaxis. At one month, she tested positive for HIV. Admira received the news with grace, but when she arrived home, her husband refused to accept the medication, claiming that none of the children were sick because he was fine, and he threw the pills away.

Desperate, the mother returned to the health facility and reported the situation. The technician asked a <u>mentor mother</u> to accompany Admira home to sensitize the father. After some counseling, he accepted the diagnosis and allowed Esmeralda to start antiretroviral therapy (ART).

Sometime later, Esmeralda's father passed away. Even with the pills, Esmeralda's health worsened as her mother struggled to give her the medication consistently as she would go to work in the fields. Admira left Esmeralda with her sons, who had no experience caring for a child, while she was away for work. Esmeralda's health became increasingly fragile.

When Esmeralda was tested in February 2022, her viral load was dangerously high.

"Esmeralda and her mother came to the consultation, and I welcomed them with a hug, as was customary with all children," says Muhlavasse David, the care and treatment focal point clinician with EGPAF. "At the consultation, I asked about the reason for those results, and we found ways to overcome the situation [once again] through mentor mothers."

With this intervention, things started to improve. In March 2022, Esmeralda's regimen was switched to a <u>pediatric formulation of dolutegravir</u> (pDTG 10mg), per new Ministry of Health regulations. This is supported through the <u>CHAI</u> Optimal Project implemented by EGPAF through Unitaid funds.

Six months after starting dolutegravir, Esmeralda had another viral load test, and HIV was undetectable in her body.

"We celebrated the work done and to see her healthy and very happy," says Muhlavasse.

Today, Esmeralda is attending first grade. Her mother is happy to see her daughter healthy and playing with her friends.

"In terms of health, I have nothing to complain about. My family is well, and my dream is to remain strong, to build a house, and educate and raise my children. I want to see Esmeralda grow and study," says Admira.







## Camp Care-A-Lot

#### **Ariel Camps Care for Peer Leaders**

Jalia Nabukenya, 23, breathed the refreshing breeze drifting over Lake Bunyoni in southwest Uganda. She was ready to be joined by 29 other young HIV activists to learn how to better support their peers and advocate on their behalf. The 2023 Ariel Camp, "Caring for the Carer," would be five short days of intense learning, reflection, and caring.

"I'm looking forward to catching up with old friends, making new friends," Jalia exclaimed, looking across the smooth lake.

#### **Ariel's Legacy**

Day one started with a wholesome breakfast of omelets, pan-fried potatoes, and matoke (a banana starch), followed by introductions among the peer educators, who represented nine districts of Uganda and ranged in age from 16 to 23. The Ariel Camp is named after Ariel Glaser, Elizabeth Glaser's daughter. Ariel died from AIDS-related causes in 1988 at the age of 7 and was her mother's inspiration to start a foundation to end AIDS in children.

The Elizabeth Glaser Pediatric AIDS
Foundation (EGPAF) collaborates with the
ViiV Pediatric Breakthrough Partnership to
improve the quality of care among children
and adolescents living with HIV. It also offers
psychosocial support through the EGPAF
Ariel peer program in southwestern Uganda.
As part of the project, an annual Ariel peers
camp provides a platform for leadership
development, capacity building, and emotional
support for young leaders.



L-R: Ampeire Derrick, Atwijuka Shallot and Arigaba Brendah

"Nice to see that you are all vibrant, just like the last time I saw you," said Dr. Edward Bitarakwate, the director of EGPAF-Uganda. "Remember, when we work as a team, we achieve more. These next few days are an opportunity for deep reflection, but I also encourage you to indulge in some edutainment."

Mr. Denis Adoa, the program officer of adolescent care and treatment at the Ministry of Health emphasized the importance of young people providing support to other young people: "The Ariel program is deep-rooted in the community, which makes it different from other programs," he said.

#### **Caring for Carers**

For many participants, the retreat provided a chance to enjoy a break from ordinary life.

"I have come for camp to mainly eat chicken and sleep in a nice bed," said Joash Muhimise, 17. "And also to learn more about reporting standards and the champion advocacy toolkit," he added.

The toolkit, designed by some of the peer educators, serves as a training manual for the adolescent champions to develop advocacy skills and gain knowledge about HIV treatment gaps and offering of services according to the needs of the different groups of clients instead of a one-size-fits-all approach.

On the first day, the Ariel peers became acquainted with the advocacy toolkit. They spent time developing elevator pitches so that they could better connect with potential partners in the fight to end AIDS in children.

On other days, psychologists conducted sessions to equip Ariel peers with counseling skills to help them provide effective psychosocial support to other young people. Special sessions covered self-awareness,

Brian Ahimbisibwe with a group of Ariel Peers. Photo by Masereka Joseph/2023





Dr. Happy Betty Paul, Senior Technical Advisor Care and Treatment at EGPAF-Uganda. Photo by Masereka Joseph

supportive friendships, personal hygiene, and personal and interpersonal relationships. The campers also participated in a session focused on sexual and reproductive health.

Of course, the time was not only filled with training. Every afternoon, the group broke for games, dancing, and chatting among new friends—conversations that were both playful and deep.

"The camp ... provides me with a sense of calm and helps me reconnect with a part of myself that I may have lost," said Shallot Akanyijuka, an Ariel peer serving at the Bushenyi Medical Center. "The motivational sessions have had a profound impact on me. [I am filled] with encouragement and a feeling of being supported, both by the caring mentors and my fellow campers. Witnessing the good health of my Ariel peers brings me immense joy and further strengthens my determination."

Mukama Emmanuel, an Ariel peer serving at Kasheshero Health Center III, agrees: "The Ariel camp provides an opportunity to meet and bond with new friends, fostering a sense of camaraderie and enabling the free exchange of experiences and emotions."

#### **Boundless Potential of Young People**

Brian Ahimbisibwe, a young EGPAF program officer and ambassador, mused about the importance of these young people finding their purpose: "As someone who was once an Ariel camper and has now transitioned into a practitioner role, the Ariel camp holds immense sentimental value for me. Above all, it serves as a powerful testament to the boundless potential of an empowered young individual."

The older generation also came away heartened by their time with the young people.

"When I look at the Ariel peers, I see the leaders of tomorrow, the individuals who can make a significant impact and become stakeholders in our pursuit of an AIDS-free generation," said Happy Paul, EGPAF senior technical advisor. "It is crucial to increase investment in these young people because they are highly responsive, well-informed, and dedicated."

Five days after her hopeful arrival at the Ariel Camp, Jalia participated in tearful group hugs and smiling selfies with her colleagues, promising to continue the conversations and the fun via WhatsApp. She and the other 29 young leaders then scattered to their communities to spread the care.



## 35 Years of Impact

#### 1988

The Pediatric AIDS Foundation (PAF) is launched by founding board members Elizabeth Glaser, Susie Zeegen, Susan DeLaurentis, Lloyd Zeiderman, and Peter Benzian to raise money for pediatric AIDS research.

#### 1990

Elizabeth and Paul Glaser ask the U.S. Congress to fund testing of HIV drugs for children because they still do not have access to effective drug treatment, despite the fact that azidothymidine (AZT) has already been approved for adults by the U.S. Food and Drug Administration.

#### 1992

Elizabeth Glaser's passionate address at the U.S. Democratic National Convention rivets the nation as she shares her story and declares that "people say they care, but actions are what save lives."

#### 1994

Elizabeth Glaser dies of from HIV-related illness on December 3, and PAF is renamed the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) in her memory.

#### 1999

EGPAF begins the Call-to-Action Prevention of Mother-to-Child Transmission (PMTCT) program in six of the countries hardest hit by the HIV pandemic. Through Call-to-Action, EGPAF begins one of the first global programs to bring antiretroviral therapy to pregnant women to reduce transmission to newborns.

#### 2000

The rate of mother-to-child transmission of HIV declines to less than 2% among mothers in the United States who are living with HIV.

#### 2003

The U.S. Congress passes the Pediatric Research Equity Act. This new law dramatically increases the number of drugs tested and labeled for use in children.

#### 2003

The creation of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) expands access to HIV treatment for millions of children, women, and men in the countries most impacted by the epidemic.





Photos by Felix Filipe/EGPAF 2022; EGPAF 2022; Adelaja Temilade/EGPAF 2023

#### 2008

EGPAF helps to renew PEPFAR, authorizing \$48 billion in global health programs.

#### 2013

One million babies have been born without HIV because of PEPFAR, a primary donor to EGPAF. In addition, one-quarter of the mothers received treatment for PMTCT through programs supported by EGPAF.

#### 2014

EGPAF announces that it has reached 20 million women with lifesaving services such as HIV testing, counseling, and treatment to prevent HIV-positive women from passing HIV to their babies.

#### 2017

EGPAF begins administering large-scale programs to reach adolescents living with or at risk for HIV in the most affected regions.

#### 2019

EGPAF launches Delivering Technical Assistance 2 (DELTA2). This program offers specialized technical assistance, that include health worker and health care program management training, mentorship, expert consultations, and e-learning opportunities, which is essential to ensuring sustained momentum and progress toward achieving an AIDS-free generation by 2030.

#### 2022

5.5 million babies are born HIV-free. EGPAF has worked tirelessly over the years to end mother-to-child HIV transmission. Since 2000, EGPAF and its Ariel Affiliates have reached more than 33 million pregnant women worldwide with services to prevent the transmission of HIV to their babies.

#### 2023

Achieving an AIDS-free generation means that other public health challenges must also be addressed. With this in mind, EGPAF deliberately focuses on addressing tuberculosis, cervical cancer, family planning, early childhood development, and other issues that at-risk families face.



## Co-founders Reminisce About the Revolution They Started with Elizabeth Glaser

#### A Chat with Susie Zeegen and Susan DeLaurentis

What are your thoughts when you look back to the founding of the Elizabeth Glaser Pediatric AIDS Foundation—then known as the Pediatric AIDS Foundation?

**Susie:** When we started, Elizabeth was the face of the organization, and her story was so important to share. Earlier this year, at an L.A. fundraising event, we were joined by Rosa Mahlasera, who is a young woman living with HIV in Zimbabwe, and listening to her tell

her story, I thought that she is the face of the Foundation, along with all of the individuals who are alive and healthy because of what we started with Elizabeth.

EGPAF has always been about young people, and that's our primary goal—to eventually, finally bring about an AIDS-free generation. Rosa is alive because of what we started with Elizabeth, and now she carries on Elizabeth's work.

**Susan:** When I think that three women started this organization at a time when there were not as many women-led organizations, I think about the fact that we were ahead of our time. But, you know, also, we always felt that three mothers were the only ones that could really do this.

We didn't have any experience, but as mothers, we just used our intuition and just did what we thought was right and what we thought was the best way to do things. And it turned out that it was successful.

## What kind of an influence has Elizabeth had on your life?

**Susie:** I think about Elizabeth every day. We grew up together. We're the same age, so Elizabeth would have been 76 years old, but she died when she was 47—so a lifetime has passed since then. But I think about Elizabeth as the young woman who did pretty miraculous things and brought Susan and me together.

I have pictures in my bedroom and at my desk of [Elizabeth's daughter] Ari when she was still healthy. And I have photos of [Elizabeth's son] Jake, who is still with us. He's the reason the Foundation started, so it's heartwarming and gratifying to know that what we really started out to do in the very, very, very beginning was to save Elizabeth's second child. And we did. Jake is now in his 40s.

**Susan:** My daughter, Francesca, was Ari's best friend. They knew each other from the time they were 2 years old until Ari died right before her 8th birthday. We met the first day of toddler group at this preschool. The girls were on the swings, and we started talking. We both had our first children that were daughters that were the same age. Elizabeth's daughter, Ari, was already living with HIV, of course, but nobody realized it.

There was a period when Ari was around 4, and she started being sick a lot. We just thought it was regular childhood stuff until she got really sick, and that started their journey to a diagnosis. Later, when Ari was in the hospital a lot, we used to sneak Francesca in to play Old Maid with her.

You can imagine what kind of an impact that continued to have on [Francesca]. My children

are so empathic and so aware of what people go through. And I don't think they would have been if they hadn't grown up with this.

### Tell me about the early days of the organization.

**Susie:** Elizabeth was the face and the story and the force behind everything we did. Susan did all of the political scientific outreach and, lucky me. I got to be the fundraiser.

None of us knew what we were doing, but we knew why we were doing it. I think that's the reason we were so successful. You know, Diane Sawyer's piece, "Three Moms on a Mission," is exactly what happened. We were three moms, and we acted like lion moms. There was nothing that was going to stop us. We didn't have the time to spare.

We worked out of a scrappy little office in Santa Monica. I don't know how many people we had working with us, maybe 10. I can't imagine how many square feet it was, but we all jammed in together—it was a very close-knit group. I don't think we had computers until we moved into a larger space.

It's hard to believe that from those beginnings, millions of lives have been saved.

Susan: When we first started, before the office space was donated to us, we were doing it all at my kitchen table because I had the youngest child that was not in school. We split up the jobs. I would do the research side. It turned out that there wasn't anything being done in pediatrics. They just allocated percentages of the adult research that it might impact kids. That's when we really realized that we had to go to Washington and try and get money allocated for pediatric AIDS. We got the first money ever for pediatric AIDS, for the clinical trial units.

I remember how divided Washington was even back then, but it was a period when it was much easier to find consensus and bipartisanship on an issue, especially, especially about children's health. For instance, [Republican Senator] Orrin Hatch and [Democratic Senator] Ted Kennedy had a really good relationship, and so, they partnered on stuff and helped us and came up with some great ideas, like doing a fundraising

event in Washington called A Night to Unite. That's how we raised our first million dollars. Cher headlined the event! Elizabeth asked Cher personally to perform because Elizabeth had taught her child in school.

And we had the first think tanks where we invited scientists from all different areas, not just pediatrics, not just HIV, because we felt like a group of them together would have new ideas, which is exactly what happened. We saw success marginally in everything we did. And we celebrated every success.

I have this vivid memory of Elizabeth and I walking down one of the halls of Congress, and we were laughing. Because we were always having so much fun, and that was part of who Elizabeth was. You had to have that aspect of fun when you are working so hard on such a grim reality. And we did have fun in everything that we did.

### How do you feel when you look at EGPAF today?

Susie: I'm beyond proud of the Foundation's work and that what we do today is different than what we did 35 years ago. We are taking our expertise and making the world better. We've evolved and will continue to evolve. But children will always be at the center of the Foundation, and that is something that fills me with pride.

**Susan:** EGPAF has always been an organization of problem-solvers, starting with the three of us who founded it. We would see a problem and we would figure out what we could possibly do to change it. There's that Margaret Mead quotation about how a group of committed people can change the world. It means a lot to me that the three of us did that.



## Thank you to our Donors

#### January 1, 2023 – December 31, 2023

#### **GREATER THAN \$1 MILLION**

Bill & Melinda Gates Foundation

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LVCT Health

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#### \$500.000-\$999.999

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at Wayne State University

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Benevity Community Impact Fund

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The Bat Mitzvah of Leah Polien

The Sisters
Theresa Ridings
Travis G Looper
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Wallace Anne Cloud

Walter Sherr's 85th Birthday

## Financial Statement Summary

as of December 31, 2023

#### **Statement of Financial Position**

December 31, 2023

#### **ASSETS**

Cash and cash equivalents  Cash held at foreign offices  Investments  Cash and investments	\$5,464,347 \$1,703,109 \$8,256,578 \$15,424,034
Due from government agencies  Contributions receivable  Other receivables  Charitable remainder trust contribution receivabes  Total Receivables	\$249,376 \$12,453,471 \$222,938
Prepaid expenses and other assets  Property and equipment, net  Operating lease right of use asset, net	\$910,261 \$7,388,504
Prepaid Expenses and Fixed Assets  TOTAL ASSETS	\$41,655,184\$

#### **LIABILITIES AND NET ASSETS**

#### Liabilities

Accounts payable and accrued expenses	\$14,688,969
Grants payable—federal	
Due to government agencies	
Refundable advances—non-U.S. government grants	
Operating lease payable	
Deferred rent	

#### TOTAL LIABILITIES \$32,221,840

#### **Net Assets**

Without donor restrictions	.\$8,621,929
With donor restrictions	\$811,416

#### TOTAL NET ASSETS \$9,433,345

#### **TOTAL LIABILITIES AND NET ASSETS**

\$41,655,185









EGPAF's financial performance and accountability are recognized by leading charity rating organizations.

#### **Statement of Activities**

December 31, 2023

Contributions	\$1,532,953
Contracts and Grants	\$160,339,930
Investment return, net	\$877,562
Change in beneficial interest	\$9,036
Contributed goods and services	\$193,941
Net assets released from restrictions	

#### TOTAL PUBLIC SUPPORT AND REVENUE

\$162,953,422

#### **EXPENSES**

Program Implementation	\$139,104,392
Research	\$2,576,448
Communications	\$2,377,632
Public Policy	
	, , , , , , , , , , , , , , , , , , ,

#### **TOTAL PROGRAM SERVICES**

\$145,706,344

#### **Supporting services**

Management and general	\$13,533,959
New business development	\$2,085,178
Fundraising	\$1,133,256

#### **TOTAL SUPPORTING SERVICES**

\$16,752,393

#### TOTAL EXPENSES

\$162,458,737

#### **CHANGES IN NET ASSETS**

\$494,685

Net assets at beginning of year\$8	,938,659
Net assets at end of year\$9	,433,344

#### IN 2023, 89.69% OF EGPAF'S EXPENSES WERE DEDICATED TO PROGRAMMATIC PURPOSES.

The complete audited financial statements may be viewed on our website (www.pedaids.org)

## **Board of Directors**

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