2021 ANNUAL REPORT
# ANNUAL REPORT 2021

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While the Elizabeth Glaser Pediatric AIDS Foundation makes effort to use photos which accurately depict the actions, topics, or populations referenced, unless specifically indicated, the photographs in this document do not imply program participation, health status, attitude, behavior, or action on the part of persons who appear therein.
Every Child Has a Right to Health

In 2002, the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) answered a formal Call to Action issued by the newly established U.S. President’s Emergency Plan for AIDS Relief (PEPFAR). The Call to Action initiative was an eight-year program that EGPAF helped implement in 12 nations hardest hit by the HIV pandemic. This call to action marked a dramatic shift in EGPAF’s work as it looked beyond the United States at the global impact of HIV on children, mothers, and families. Through that initiative and others that followed, PEPFAR programs have led to 5.5 million babies being born HIV-free.

Twenty years later, many of those babies are now adults, contributing to their communities, starting their own families, and fulfilling Elizabeth Glaser's vision that “every child deserves a lifetime.”

And through programs like EGPAF’s Ariel Clubs, children living with HIV receive access to treatment and the psychosocial support necessary to suppress their viral loads and develop courage, solidarity, and hope. Many of those children are now activists and leaders, working with vulnerable populations and calling their communities to action.

It is undeniable that investments by the United States and other governments have played a crucial role in reversing the trajectory of the HIV crisis. Over the years, international funding sources like the Global Fund have likewise ramped up their investments to address HIV. And, consistent with EGPAF’s early years, private donors and sponsors are playing an increasingly important role as we redouble our efforts to achieve an AIDS-free generation.

Now is not the time to consider our work complete or continued success inevitable, especially when we consider new trends that show rising HIV rates among young people and persistent testing and treatment gaps when it comes to pediatric response. AIDS-related illnesses remain the leading cause of death of women 15-49 in sub-Saharan Africa. Worldwide, less than 1 million children (younger than 14) living with HIV are on treatment out of an estimated 1.7 million.

Simply put, this is a human rights issue. Without a voice in the global AIDS response, children have an unequal opportunity to call for solutions to their needs. It falls on us to put children forward, preventing them from once again being left behind.
At this historic moment, many global issues might cause us to take our eye off the ball when it comes to our mission to end AIDS in children. Other pandemics, war, the climate crisis, and political disruptions are grave concerns. But the reality is that these factors exacerbate the vulnerable position of at-risk children, adolescents, and families. The COVID-19 pandemic has slowed our progress, for instance, as access to HIV services was impacted. And resources for future HIV programs are not guaranteed.

Just like 20 years ago—when EGPAF became a global organization—we are now calling for collective action to protect families affected by HIV. We have the tools to ensure that every child can be born HIV-free and that any individual living with HIV can have a long and fulfilling life. But if we neglect our responsibility to prioritize and meet the needs of children in households around the world, this will not be the case.

In her memoir, Elizabeth wrote, “I want to save my family, [but] to do that, I have to change the world.” She did change the world. Together, we changed the world. Our success is undeniable. And yet we must continue to be a change agent. Too many lives are at stake. Please join us in fighting for the human right of children, mothers, and families to live long and productive lives.

Charles J. Lyons
President and CEO | Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)
OUR STORIES OF IMPACT
Detecting TB and Saving Young Lives in Malawi

Mallita Chipungu, 26, was all smiles when she gave birth to twins at Thyolo District Hospital in southern Malawi, even though they were premature. Babies Aisha and Idah spent almost a month in the kangaroo ward for underweight babies. When they did not gain weight as expected, a volunteer trained by EGPAF recommended that they be screened for tuberculosis (TB).

“We noted symptoms ranging from fever, night sweats, neck swelling, and difficulties in breathing,” says Enock Saka, a TB cough monitor. Using an advanced sample collection procedure made available through the Catalyzing Pediatric TB Innovations (CaP TB) program, the health care workers removed specimens from the children’s stomachs, which tested positive for TB.

“Immediately after my children were diagnosed with TB, they were put on treatment,” says Mallita. They gained weight and are now rambunctious 3-year-olds.

Irene is an 11-year-old living in southern Malawi. She became sick with a mysterious illness that included purulent discharge from her right ear, fever, vomiting, night sweats, and weight loss. An X-ray showed no irregularities. Clinicians initially diagnosed her with severe malaria and meningitis, but her symptoms continued.

A TB otitis media diagnosis was made after the discharge from her ear was collected for microscopy, and she was put on an eight-month anti-TB treatment.

The twins and the 11-year-old girl are among the children diagnosed through CaP TB, a Unitaid-funded project, implemented by EGPAF in nine sub-Saharan African countries, including Malawi. The project seeks to end childhood TB illnesses and deaths through increased access to models of care that are innovative for pediatric TB.

“The innovative diagnostic and care approaches have become a game-changer in childhood TB care,” says Yusuf Bhamu, CaP TB project manager in Malawi.

“TB is preventable and treatable. It is imperative that we leverage innovations effectively in our public health programs to stop children from contracting or dying from TB,” says Veena Sampathkumar, EGPAF country director in Malawi.
Operation Triple Zero: A Path to Well-Being in Kenya

“Pray for my nephew. He is HIV-positive!” These are the words that Robert John Ouko’s guardian uttered during a church service following the death of Robert John’s mother.

Robert John, then a 14-year-old living in western Kenya, was devastated to have his HIV-status disclosed to his entire community. He had known his HIV status since the age of 12 but was private about his HIV status.

“The dynamics of adolescence as a stage of life compounded by HIV challenges can lead to very poor treatment outcomes,” says Daniel Mumelo, an EGPAF senior technical officer. AIDS is the leading cause of death among young people aged 10 to 24 in Africa and the second leading cause globally.

Mumelo says that against this backdrop, “EGPAF rolled out the facility-based, adolescent-centered Operation Triple Zero (OTZ) model in Homabay County to reverse negative trends. By agreeing to be enrolled into the OTZ club through voluntary written consent, adolescents commit to zero missed appointments, zero missed drugs, and zero viral load.”

To avoid trauma and distress, parents and guardians are taken through sessions on how best to disclose HIV status to adolescents living with HIV.

“Through OTZ, we have networks of HIV-positive adolescents within health facilities, across health facilities, in schools, across schools, and in the community,” says Robert John, now 20 and an official OTZ Champion. “The older ones have social media groups where we keep in touch and encourage each other,” Robert John explains. “As champions, we also work closely with the Orphans and Vulnerable Children offices to provide financial and nutrition support to those in need as this improves drug adherence,” he says.

Robert John especially enjoys the quarterly fun days held by the OTZ Club, where they mingle with their health providers in dance and games. During these fun days, heroes (young people who have achieved the triple zero outcomes) share their stories to inspire others.

Now that he is an adult, Robert John looks back at that day when he was stigmatized publicly because of his HIV status and knows that he could have stopped adhering to medication as a result. Operation Triple Zero gave him a path, which he now shares with his younger peers.
Sharing Knowledge Across the Ocean: EGPAF-Côte d’Ivoire Helps Haiti Unify Its Lab Network

In 2021, EGPAF launched ECHO—an innovative knowledge-sharing project—in Haiti to stabilize and unify the lab network.

The ECHO model was developed in 2003 at the University of New Mexico to address gaps in healthcare in that state. It focuses on unifying a community of practitioners who can mentor and support one another to better serve their communities and goals. In 2015, EGPAF supported an HIV ECHO project in Namibia and, in 2017, led the first Francophone African ECHO project in Côte d’Ivoire—successfully transforming the national laboratory network.

As most ECHO practitioners will tell you, the strength of the ECHO model is not the technology, but rather the people who invest in the platform and the rich community they build. EGPAF was blessed to find the perfect person to lead this project in Côte d’Ivoire: Konan Assouman Alphonse. With his experience supporting ECHO programs and as a fellow French speaker, Konan could easily relate to the Haitian ECHO team that he started mentoring.

“Haiti was a challenge in itself because of the political environment when we started; we had a lot of doubts and fears,” says Alphonse. “We noticed tremendous disparities, as some parts of the country received international support and other parts of the country received nothing.”

In a typical session, a practitioner presents a real case study on which they request advice. For example, one laboratory technician recently talked about a case that stumped his lab: a client living with HIV who had an undetectable viral load for years suddenly saw a spike, even though the client had reported no medication or lifestyle changes. A few weeks later their confirmation tests showed that the client was undetectable again.
The other professionals from across the country brainstormed possible explanations. One lab tech explained how delays in transport may lead to a compromised sample, while a physician described medical anomalies that could explain the unusual test results. The practitioner was able to go back to their site to follow up on ideas brought up in the discussion to identify the cause and adjust lab procedures—improving the quality of care moving forward.

“This initiative is vital insofar as the question of continuing education remains ambiguous in Haiti—and even more so in the current situation in the country,” says Elsaïda Madeus, a technician at Hôpital Albert Schweitzer. “We made contact with fellow professionals working in the health field, which allowed us to discuss concerns related to relevant cases. This greatly contributes to the strengthening of our professional capacities.”

Through the ECHO project, EGPAF secured equipment to conduct virtual sessions and improve lab monitoring resources. Now the staff from the National Laboratory can disseminate standardized quality assurance protocols, with these methods being reinforced with peer learning through the ECHO sessions.

While there were many similarities between Côte d’Ivoire and Haiti, such as remote sites and a need for training medical staff, Haiti also faces many unique difficulties. Konan had his doubts about implementation among all the challenges Haiti was facing.

“I asked myself ‘Is this possible? Will this work in Haiti?’ And the answer is yes—because it’s not based on the political situation. The technology ‘is here: we have the internet and’ the equipment. The rest is about building a community.”

“It is working so well that I wish Haiti had adopted ECHO even earlier,” Edet says. “It had been so difficult at times for our practitioners to have access to mentoring or to send staff to the capital for training. We are seeing such positive changes here. I really do hope that those countries who do not have a community of practice like this yet will consider adopting it.”
A TIME FOR HEROES
On October 27, 2021, EGPAF convened virtually to honor and celebrate those fighting for an AIDS-free generation at A Time for Heroes. Our Heroes and esteemed experts spoke about progress in the HIV/AIDS epidemic, highlighting innovative approaches necessary to address the unique challenges facing children, youth, and families in the global AIDS response.

Our 2021 Honorees included our Corporate Hero awarded to Johnson & Johnson, who has been a steadfast partner of EGPAF in our work to end AIDS in children, youth, and families for over 30 years. Dr. John Nkengasong, Director of Africa CDC, was given the Innovation Hero Award for his leadership in the global response to COVID-19, leading the agency to achieve vaccine equity across the continent. EGPAF deeply appreciates the Africa CDC and Dr. John Nkengasong’s partnership in our work to confront HIV and COVID-19. Having lived with HIV since her teenage years, Dee Mphafi Tanka, Senior Youth Ambassador, EGPAF, uses her powerful voice to advocate on behalf of other young people, providing an essential perspective in our work to reach youth and adolescents with lifesaving HIV services in Lesotho. Dee was awarded the Frontline Hero Award at the 2021 event.

OUR COMMUNITY

UCLA
Hosted by the Pediatric AIDS Coalition at UCLA, “Take a Stand” UCLA Dance Marathon week-long events were held virtually in April 2021 to educate and inspire the community on the impacts of pediatric HIV and AIDS. Events included Zoom panels where EGPAF Ambassador Paige Rawls shared her personal story. The week culminated in a three-hour virtual event that raised over $100,000 for its beneficiaries.

BALDWIN WALLACE UNIVERSITY
Baldwin Wallace Dance Marathon raised over $3,000 to support EGPAF’s mission for an AIDS-free generation. Committee members held a month of multiple virtual events, bringing together students, faculty, staff, alumni, parents, and community members to raise money and awareness about pediatric AIDS.

COLLEGE OF THE HOLY CROSS
College of the Holy Cross held its dance marathon on December 3, 2021, where students danced all night to take a stand against pediatric AIDS. Since 2012, the event has aimed to allow students and faculty to share a remarkable dance experience to raise awareness and funds for EGPAF; the event raised $4,000 to support our mission.

ALPHA EPSILON PHI
In 2000 AEPhi adopted EGPAF as their national philanthropies and has raised funds to support our mission. In 2021, Jake Glaser spoke at a virtual presentation for collegiate leaders and alumnae volunteers about the AEPhi/EGPAF partnership and how EGPAF can help chapters in their fundraising efforts. Chapters held in person and virtual events throughout the year. Twenty-one chapters raised over $47,000 to support EGPAF.
For over 20 years, Jewelers for Children has generously supported EGPAF’s mission to achieve an AIDS-free generation. Adapting to COVID-19 and the limitations of pandemic restrictions, JFC and the jewelry community remained committed to fundraising and supporting their charity partners, including EGPAF. Last year, JFC’s fundraising culminated in the annual Facets of Hope fundraising event held in Las Vegas. Jake Glaser offered inspiring remarks at the dinner program, thanking the JFC community for their continued dedication to helping children in need.
OUR GENEROUS DONORS
DONOR INTERVIEW:

Drs. Nicholas S. Hellmann and Susan Desmond-Hellmann

Individual donors fuel our work around the globe. Drs. Nicholas S. Hellmann and Susan Desmond-Hellmann, two of EGPAF’s donors, talk about how our journey is not yet complete.

What connects you to EGPAF’s mission and cause when it comes to HIV and specifically pediatric HIV?

NICHOLAS: “Sue and I initially met in 1982, and if you’re a historian of HIV, this coincides with the beginning of the HIV epidemic. We first met before starting our postgraduate training at the University of California, San Francisco. We were thrust into this, and I still remember the first patient I admitted to the hospital as a new intern was a person with AIDS. Although we didn’t know what AIDS was at the time, we didn’t know what HIV was, either; we didn’t know how to treat it or manage it. So, we were thrust into the pandemic very early on, and it took over most of our training. And as we were finishing our fellowship training, we were offered the opportunity to go to Uganda and study AIDS. So that is where we got started and invested in the HIV pandemic from the very early stages.

My career for the past 40 years, from 1982 to 2022, has, in one way or another, been connected to HIV. Then when I was at the Gates Foundation, I met the people from EGPAF and was very intrigued by what was happening. It seemed like an excellent opportunity to commit resources to a very noble cause.”

SUE: “The thing that I always had a fondness for with pediatric HIV is you can prevent it. The thought that a pregnant woman can be treated when she knows she’s HIV infected and you can prevent transmission to her child—I think that’s why we started this job. I’ve always thought it’s such a wonderful thing that we can fix something, and therefore we should.”
There’s been such a dramatic change in the HIV world, where so many people are now living with HIV rather than dying from AIDS-related illness, and, especially in the United States, people forget or think that HIV is a pandemic of the past. Can you comment on why it continues to be an urgent issue?

NICHOLAS: “At this point, clearly, things have changed dramatically with the onset of therapies and better prevention measures with dramatic advancements in the treatment and prevention of HIV disease. It has changed things. But that being said, we’re still left in a situation where we don’t have adequate tools to optimally prevent disease, and we don’t have a cure for HIV. Right now, the latest data shows that over 38 million people are living with HIV globally. If people don’t have access to therapy, the vast majority of them will die generally within a few years. Those are sobering statistics. There are 1.7 million children infected, and even though we could say we have made great advances, deaths have plummeted because of people being on therapy. However, unfortunately, you still have 160,000 new infections in children and 100,000 deaths in children. We have the tools to prevent new infections in children and deaths in children. We have the tools, but we haven’t finished the job. It is still a major issue and a major crisis.”

When choosing a nonprofit organization to support, what do you look for?

SUE: “We start with a pretty simple question that’s unsurprising, which is, what’s a good bang for your buck? Where will the money translate into outcomes that matter and change people’s lives? What’s the integrity of the organization? Do they effectively use resources towards their mission?”

NICHOLAS: “We want to focus on areas where we feel like we can have an impact. We primarily provide unrestricted funding, recognizing that we want to give to organizations that we feel are skilled, knowledgeable, well positioned to have an impact.”

What excites you right now in the work around pediatric HIV and AIDS?

NICHOLAS: “The thing that, without a doubt, excites me the most is how close we are getting to the finish line. We can create a generation free of HIV and AIDS in children. But we’re not there yet.”
Thank You to Our Generous Donors
JANUARY 1, 2021 – DECEMBER 31, 2021

GREATER THAN $1 MILLION
Conrad N. Hilton Foundation
The ELMA Philanthropy Services
Bill & Melinda Gates Foundation
Johnson & Johnson
UNITAID
U.S. Agency for International Development
U.S. Centers for Disease Control and Prevention
U.S. Department of Defense
ViiV Healthcare

$500,000-$999,999
CDC Foundation

$250,000-$499,000
The Keith Haring Foundation, Inc.

$100,000-$249,999
Anonymous
Willow Bay and Bob Iger
Communications Workers of America
Drugs for Neglected Diseases Initiative
Estate of Anthony Alacca
Drs. Joseph M. McCune and Karen Smith-McCune
National Basketball Association
Norwegian School of Economics
Gregg and Debra Oppenheimer
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Justin B. Smith
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Bobbi and Walter Zifkin

$2,500-$4,999
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The Apatow-Mann Family Foundation
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The World Health Organization
Susie Zeegen and Dr. Peter Zeegen

FUNDRAISING PARTNERS
Alpha Epsilon Phi—Alpha Lambda at University of Arizona
Alpha Epsilon Phi—Alpha Tau at University of Florida
Alpha Epsilon Phi—Beta Eta chapter
Alpha Epsilon Phi—Beta Zeta at U of Central Florida
Alpha Epsilon Phi—Mu at University of Illinois
Alpha Epsilon Phi—Phi Kappa at Rowan University
Alpha Epsilon Phi—Phi Omega at Northeastern Univ
Alpha Epsilon Phi—Phi Sigma at Wayne State University
Alpha Epsilon Phi—Phi Theta Chapter at Temple University
Alpha Epsilon Phi—Rho at Ohio State University
Alpha Epsilon Phi—Zeta at New York University
AmazonSmile Foundation
Baldwin Wallace University Dance Marathon
Benevity Community Impact Fund
Bright Funds, Inc.
CFC
College of the Holy Cross Dance Marathon
Facebook
GlaxoSmithKline Foundation
IBM Employee Services Center
Just Giving, Inc.
Network for Good
Pediatric AIDS Coalition at the University of California, Los Angeles
United Way of Central & Northeastern Connecticut

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Becky Rogers
Beki and Luke
Bellem Santiago
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Shai Levy Kahn
Sherwood Redelick
Stephanie Thorn
Stephen Terrell
Susan J. Evans
The Glaser Family
The Hammond Rapuano Family
Thomas Fumarelli
Tim Shovan
Tracy Tastet
Tricia Mire
Yi-Ting Feng
Yolanda Williams
# Financial Summary

**as of December 31, 2021**

## STATEMENT OF FINANCIAL POSITION

### ASSETS

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<td>Prepaid expenses and fixed assets</td>
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<td><strong>TOTAL ASSETS</strong></td>
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## LIABILITIES

### TOTAL LIABILITIES

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## NET ASSETS

### NET ASSETS WITHOUT DONOR RESTRICTIONS

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### TOTAL LIABILITIES AND NET ASSETS

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<td><strong>TOTAL LIABILITIES AND NET ASSETS</strong></td>
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## STATEMENT OF ACTIVITIES

### PUBLIC SUPPORT AND REVENUE

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### EXPENSES

#### PROGRAM SERVICES

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### CHANGES IN NET ASSETS

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<td><strong>CHANGES IN NET ASSETS</strong></td>
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In 2021, 91% of EGPAF’s expenses were dedicated to programmatic purposes.

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

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