



# Elizabeth Glaser Pediatric AIDS Foundation

Fighting for an AIDS-free generation

# Hadithi Yangu

2022

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# Word from Our Country Director

#### Dear Readers,

It is my pleasure to introduce to you the Hadithi Yangu booklet, which amplifies the voices of our beneficiaries, the people that we serve in different communities of Tanzania. These voices from our beneficiaries are narrated through their testimonials and photos.

Over the past five years, we have been to have identified and initiated over 147,000 HIV clients on antiretroviral therapy, achieved an HIV viral suppression rate of 96%, identified over 93,000 new TB cases, and provided 5.7 million individuals with family planning methods. To us, these are not mere numbers; instead, they represent every girl, boy, mother, and family that has engaged with our programs.

As a health programme, we have been able to achieve these milestones by collaborating with the government of Tanzania, donors, implementing partners, the private sector, and the communities we serve—along with all of the stakeholders.



As we reflect on our work, I take this opportunity to extend our heartfelt gratitude to our partners for every support you have given us. We exist because of you, and we continue to learn from you. We are determined to strengthen our partnership with you in our effort to continue to promote an AIDS-free generation in Tanzania.

I wish you a happy reading.

Dr. Sajida Kimambo, M.D., MPH

Country Director, EGPAF- Tanzania

# Who we are

### **History of EGPAF**

The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) was born from the most powerful force of all: *a mother's love for her children*. Elizabeth Glaser acquired HIV through a blood transfusion in 1981 while giving birth to her daughter, Ariel. At the time, it was not yet widely known that HIV could be passed from mother to child in uterus or through breast milk.

Ariel lost her battle with advanced HIV disease in 1988. Elizabeth's remaining child, Jake, was also living with HIV. Fully aware that his life was in danger, Elizabeth rose to action. She approached her close friends, Susie Zeegen and Susan De Laurentis, for help in creating a foundation that would raise money for HIV research.

The Foundation, which formed around Elizabeth's kitchen table, had one mission: to bring hope to children living with or affected by HIV. Few researchers were focusing on issues specific to paediatric HIV/AIDS. There were no drugs available for children, and the infection rate was rapidly rising. By raising awareness and funding vital paediatric research, Elizabeth, Susie, and Susan changed the harsh reality by becoming a strong, unified voice for children in the fight against AIDS.







That organization is now the leading global nonprofit organization dedicated to preventing paediatric HIV infection and eradicating paediatric AIDS through research, advocacy, and prevention and treatment programs. Today, fewer children are born with HIV, and children with HIV infection are living longer and healthier lives. And while Elizabeth lost her personal battle with AIDS in 1994, her son, Jake, is now a healthy adult.

### **History of EGPAF-Tanzania**

EGPAF began supporting HIV programs in Tanzania in 2003 and established a country office in Dar es Salaam in February 2004. Through USAID's Call to Action program, EGPAF began supporting prevention of mother-to-child HIV transmission (PMTCT) activities. Towards the end of 2004, we expanded the scope of our activities to implement Project Heart, a care and treatment program funded by the U.S. Centers for Disease Control and Prevention (CDC).

EGPAF Tanzania's activities were initially implemented in the regional districts and facilities of the government of Tanzania's priority regions. However, due to the regionalization of the government's HIV/AIDS initiatives, in 2006, EGPAF-Tanzania began focusing its activities in its six assigned regions of Arusha, Kilimanjaro, Mtwara, Lindi, Shinyanga, and Tabora.

While the Call to Action and Project HEART officially ended in September 2011 and February 2012, respectively, EGPAF-Tanzania won a follow-on CDC award to continue to support care and treatment in Arusha, Kilimanjaro, Tabora, and Lindi. In consortium with Pathfinder International, EGPAF successfully applied for and won a comprehensive PMTCT/reproductive health (RH) award: the Linked Initiative for Elimination of Pediatric AIDS (LIFE) for Arusha, Kilimanjaro, Tabora, Shinyanga, Lindi, and Mtwara. LIFE programs also focused on community and home-based care in Tabora, Pwani, Mwanza, and Zanzibar.

From 2016 through 2021, EGPAF, partnering with EngenderHealth, implemented another anchor project called Comprehensive Health Service Delivery, later branded as USAID Boresha Afya North-Central Zone.

# Where we work



In 2015 EGPAF began work in early childhood development, with a grant from the Conrad N. Hilton Foundation. Through Malezi I and Malezi II, EGPAF integrating early childhood stimulation and early learning through play and communication into maternal and child health services, pregnancy care, and HIV treatment. Eventually, 86 health facilities sites provided early childhood services with health care professionals and more than 300 community health workers training caregivers with a holistic care approach.

EGPAF's is relentlessly working to ensure that childhood TB is a standing priority in Tanzania's health agenda. Through Unitaid's Catalyzing Pediatric Tuberculosis Innovations project (CaP-TB), EGPAF has increased Tanzania's capacity to diagnose and treat childhood TB through an integrated approach.

In 2021, EGPAF—with Amref, Health Africa, EngenderHealth, D-Tree International, Matchboxology, and regional and council health management teams—won the USAID Afya Yangu Northern program. This program takes a client-centred approach to address gaps in HIV, TB, and family planning service delivery, while continuously building and transferring the capacity of local stakeholders for sustainable and country-led ownership. USAID Afya Yangu Northern focuses intensely on direct service delivery across all regions, ensuring that gaps to epidemic control are identified, and tailored solutions are designed to meet the needs of vulnerable populations.

Through its various projects, EGPAF-Tanzania advocates for the development of policies that facilitate greater access to services and support those affected by HIV and TB. These services also include family planning and early childhood development.

### **Acknowledgements**

EGPAF-Tanzania implements its programs through the support of the Ministry of Health; the Ministry of Community Development, Gender, Women, and Special Groups; and the President's Office-Regional Administration and Local Government (PO-RALG) to implement the highest quality HIV services. We are grateful to our donors who have supported our programs such as the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through USAID and CDC, as well as the Conrad Hilton Foundation, Unitaid, CHAI, and the Swedish Research Council.

# **Stories from Our Programs**

# "We Have Become Free People"

It is a sunny day at Kibosho Hospital in the Kilimanjaro region of Tanzania, and a group of mothers gather on a patio of the local hospital for an HIV mother support group.

You all know we are mothers that are HIV-positive," says Rose, one of the mothers. "We were also distressed. Some even gave up trying to have a baby because you had been diagnosed with HIV." The women nod. Rose herself had vowed off bearing children after receiving her HIV diagnosis.





"But after being educated by our healthcare workers, our nurses, we learned that bearing a child doesn't have to mean bearing a child who is HIV-positive."

Rose now has four heathy, HIV-free children, including her son Joel, who plays with the other children of the group as the women talk.

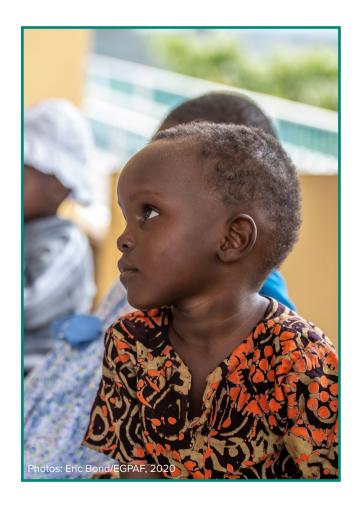
"If you continue to stigmatize yourself, you will fall sick and your children will suffer," Rose says. "But if you continue adhering to this drug, it suppresses the virus accordingly. You will live well; you will take good care of your family; and your children will study up to university while you are still alive."

One member of the group provides testimony, of both how hesitant she had been to adhere to her medication, and of how much better she felt when she took her medication regularly. The group celebrated her, and shared other experiences and tips for staying motivated to take their drugs.

"We are given enough knowledge, the knowledge to get rid of the stigma; finally we have invested in our health and we have become free people," says another mother.

As the group grew and as the mothers learned more about living healthily with HIV, solidarity expanded. For those not yet comfortable receiving formal services from the hospital, these women serve as intermediate counsellors and champions in their communities.

"This group has given me awareness and I practice what is taught to me. As a result, I am saved, and whenever I get my viral load tests, my HIV virus is undetectable!" exclaims Rose.





# "I Have Become a Teacher in the Community"

Catherine Alfonse learned about her HIV-positive status when she was tested during an antenatal care visit for her second child. Fortunately, Catherine found support at Same District Hospital, where she receives HIV services from compassionate health workers, and she participates in a peer support group of other women living with HIV. Seeing strength in Catherine, a nurse even asked her if she would be willing to work at the hospital as a community health worker.

"After I gave birth to an HIV-free baby, I found out there is no need to hide myself," says Catherine. "I thought, It's better I be a community health worker instead of staying at home to die because of anxiety. I was no longer worried that society would talk about me—they already knew my HIV status. I decided to volunteer and educate my fellows."

"When a woman has received her HIV-positive test result, I reach to her, and I hug her," says Catherine. "I quietly ask her to come, and we go for a talk. I won't talk to her right there around the health workers. I tell her, Don't be afraid; I was in the same boat as you. I was afraid, and I even cried. But after the education I was given, I no longer expected to die soon.

"What you have got isn't a problem. If you adhere to these drugs, your immunity will increase, and you will not get infectious diseases. And if you don't get infectious diseases, you will be like normal people, and you will not be known to be living with HIV.

"So for five or six months, I continue with positive messages until she can accept herself. I educate her that she is not alone."

"I have become a teacher in the community. I have become an example," Catherine says. Today, she is alive and healthy with two grown, HIV-free children.



# **Community Health Workers: Everyday Heroes**

The downpour of a summer rain patters outside as a group of women gather in a meeting room at the Saint Elizabeth Hospital in Arusha. Christina, Eva, and Ivoce have been working together for years as community health care workers, and are essential in their community's fight against HIV and TB.

"Our main duty is to provide education," Christina says. "Our role is to ensure that new HIV patients are received and connected to resources at the facility, district, and regional levels. We are very close to the patients; we follow up to remind them of their clinic visits, and we counsel and encourage them."

"I receive calls any time even at night," Ivoce says. When someone from her community living with HIV is in crisis related to her status, Ivoce shows up for them.

Despite the sporadic hours, each of these women continue to take pride in their work each day supporting their communities.

Many years ago, a woman living with HIV in Eva's community gave birth to a child. The mother was very ill, so Eva stepped in to help. She took the child to their health appointments, and when the child was found to also be living with HIV, she continued to visit the HIV clinic to get medication for the family. The child did survive, and is now in university.

"The way I managed to help this child, I felt I should help others as well," Eva explains. "This example gives me strength, and reminds me that I am important in the community."

Christina has had similar experiences that motivate her to continue her work.

"There was a baby I was servicing whose caregiver said it was no use taking her to the hospital because if she took those drugs she may die," says Christina. "But I encouraged and encouraged her. I went back and visited

her home four times, educating her about how much better the treatment has gotten. The child is now 17 years old and pursuing higher education."

"I am very proud that through my self-acceptance I've been able to encourage others to accept themselves," lvoce says. "When one accepts themselves, they feel good, and they are more willing to invest in themselves, to improve their self-awareness and continue taking drugs. I am also inspired by all the young people that I have been able to care for, or who my colleagues have been able to care for—there are so many now who are now in university, and this brings me great pride!"

"The way I see the job, I am doing really it helps the community," says Eva, one of the community health workers. "We have saved a lot of people through educating them about taking medication and testing, and many are continuing to take their drugs. I see people who have been down but they are now working and come to collect their medication and are taking care of their families. They are happy and have peace because I have managed to counsel them. At first, they were pointing fingers at us but I thank God we are able to do it."





#### **HIV Activist Turns Misfortune into Fortune**

"It all started when I was a baby," says Jane Emmanuel, a 21-year-old living in Arusha. "My mother made sure I took a pill every day and told me that the pills were for my headache. As I was young and naïve, I faithfully took the pills without any questions.

"One day, during my biology class in one of the books I was reading, I saw a pill that looked exactly like the one I was taking. I was astonished to learn that the pills were for HIV. I Googled the name of the drug and the results confirmed my suspicions. It didn't take much effort to fill the gaps and realize I was living with HIV.

"At that moment, it felt like the world had stopped for me. I confronted my mother. I remember seeing tears roll down her cheeks. She told me I am HIV-positive.

"Things took a different turn when a few months later I was introduced to the Ariel Teen Club at St. Elizabeth Hospital in Arusha. I met my fellow peers who were also HIV-positive like me. Unlike me, they oozed with positive energy and hope. I slowly began to accept who I am and refused to be defined by my HIV status."

A teen club evaluation study revealed that young people attending clubs were three times more likely to remain on treatment compared to those who were not attending such clubs.

"I remember when in secondary school a teacher announced publicly to fellow students that I was HIV-positive," Jane recalls. "My life turned hellish. I was discriminated against in the dormitory and everywhere.

"But words from my mum that told me to be strong helped me turn the misfortune into a fortune—to stand for myself and educate others so, instead of discriminating against me while they don't know their status, they too can seek to know their status," Jane says.

Jane realized that someone might be gossiping about her HIV status behind her back. She took that opportunity to talk to that person one-on-one and disclose her HIV status while also educating about HIV. Education, Jane points out, helps people understand that HIV is nothing to be ashamed of. If people understand HIV transmission, treatment, and prevention, they will find no reason to fear those living with HIV.

Now Jane is a peer leader in her Teen Club at St. Elizabeth Hospital. She also belongs to EGPAF's Committee of African Youth Advisors, which connects young leaders across several the continent to discuss HIV-related issues that young people face and work together on solutions.

"I am so proud of the model Jane has become," says Jane's mother. "She is a great role model to others and an anti-stigma champion."





# A Teen Advocate Steps Out to Fight HIV Stigma in Tanzania

"I remember one day when one of my relatives was visiting, and I prepared a mango for her, slicing it just the way she likes," says Salma, a bright 18-year-old living with HIV in northeast Tanzania. "When I took it to her, she asked 'Are you sure you have not washed all your HIV virus into this mango?' She left it and got another one. I went to my room and cried.

"Later on, she called me to eat, and when I went to the table. I saw that she had labelled my plate with my name so that I don't share it with other people—fearing that I will contaminate them with the virus. This just amplified my pain even more."

Salma, a teen advocate, says that although she is now physically healthy, thanks to her adherence to antiretroviral medication (ARVs), ongoing stigma takes a toll on her and other young women living with HIV. At a recent advocacy orientation session, she shared some of her struggles with her peers.

Advanced HIV Disease remains the leading cause of death among women of reproductive age in sub-Saharan Africa. Stigma and discrimination continue to impede the realization of human rights—including access to essential information and services to prevent and treat HIV.

Salma finds fellowship with other young people living with HIV through her Ariel Teen Club, a peer support group sponsored by EGPAF.

"Sometimes I feel neglected and alone. It is only the Ariel Teen Club members who understand me. Teen advocacy training has come for me at the right time," says Salma. "I have learned how to use my experience to influence decision makers to end HIV stigma in Tanzania. I am also learning how to work with influencers to create more space to achieve zero discrimination among people living with HIV."





# **Children Thrive with Strong Community Support**

The sky is blue and a gentle breeze rolls through the maize fields in Igambilo Village in Tabora, Tanzania. Janet Kapona, a village elder and EGPAF-supported community health worker, is visiting Zamzam, a mother of three whose youngest, Leila, is just over 1 year old. Janet is here to check on Leila as she grows, to help Zamzam cultivate a strong connection with her daughter and to link her to any resources she may need as a mother. Janet and Zamzam talk under the shade of a tree as Leila flings herself, giggling, into her mother's lap.

Janet has been trained in early stimulation and responsive caregiving using a UNICEF-tested training package on childhood development, Care for Child Development through the Malezi Project, funded by the Conrad N. Hilton Foundation. The project addresses early stimulation for infants from birth to age 3 by integrating early stimulation within health services and building capacity of facility and community health care workers.

Janet has been visiting Zamzam's home ever since Zamzam became pregnant with Leila. During her visits, Janet advises Zamzam on how to ensure that her child is engaged, healthy, and on track to reaching developmental milestones. She checks on the child's nutrition and activity level. If the child or the parents need healthcare services, Janet can provide advice on seeking medical treatment. For Zamzam, this has included referrals for family planning resources, which she says has been very helpful. Janet even takes the time to show Zamzam how to make developmentally appropriate toys, like dolls and music makers, and she plays with the family.

"When we give counselling, we help children cultivate self-awareness and self-confidence," Janet explains. "We want them to have a good life intellectually and physically so that our community and the nation have good children who are doing really well."

That is exactly what Zamzam sees for her daughter. "She's going to be a good child," Zamzam says proudly. "[She will be] a child who listens and has a deep understanding of others and the world around her."











# "Community Health Workers Are Key"

Mwamini lives in Tabora, Tanzania, a short walk away from a local health clinic. Through the clinic, Mwamini accesses her standard health care, but she is also served by an integrated early childhood development program called the Malezi Project, which builds on existing health infrastructure to integrate trainings and support for staff, community health workers, and parents on early childhood development. Community health workers reach out to every family with a pregnancy or infant up until three years of age in the area, including Mwamini

In 2018, Mwamini gave birth to a beautiful baby boy, Adam, but he struggled deeply in his first months of life. During follow-up visits, health workers noticed that it was not only Adam's health that was a cause for concern, but also Mwamini's health. Malezi-supported health workers know that successful early childhood development relies on a healthy environment. They found that both Mwamini and her son were living with HIV, and their compromised immune systems were losing the battle against opportunistic infections.

Fortunately, health workers were able to refer mother and son to comprehensive HIV care, and their support did not stop at a prescribing medication; they conduct regular home visits to check on their health and play with Adam. Now, not only is Adam truly an active and happy child, but Mwamini has a renewed sense of hope and drive to care for her family.

"Adam will grow up, and I believe that I will get grandchildren. I believe that my life will be good, and it won't end before its time."





Photos: Eric Bond/EGPAF, 2020

### The Neighbor Who Saved My Life

Kadala Said, 45, lives in the heart of rural Tanzania with her husband and eight children—a big, happy family. Thanks to a vigilant neighbour, Kadala was able to identify tuberculosis (TB) in her family and take steps to recover from it.

"Just three houses from my house lives a child who became very fond of me. She would enjoy having me around and would follow me everywhere I went, even to my house. We became very close. During our interactions, I noticed she had a cough, but it did not bother me at all because in my mind I was convinced that what she had was a normal cough.

"A few months later, I fell sick and started coughing. News about my condition reached my neighbour who was the mother of the child I was fond of. She came to see me and quickly advised me to go to a nearby health facility for TB screening, as she told me that her child whom I had been spending time with had been diagnosed with TB.

"My husband immediately took me to the Kizengi Dispensary, where I was attended very well by a healthcare worker. I tested positive for TB, and he prescribed me the right medication.

"The healthcare worker continued to constantly follow up on me and advised that my children should also go for screening. I am glad he did, because three of my children were also found to be TB-positive and were also enrolled on treatment.

"Everyone has continued treatment and recovered from TB. My family is well now, and we are happy."



Photo: Nuru Ngailo/EGPAF, 2022

# **Healthcare Staff Committed to Reaching Rural Tanzanians and Their Children**

Isabella Nyamizi, a medical doctor and project assistant working with EGPAF, walks to a client's home in Damwelu, a village in central Tanzania. Two months before, Community Health Worker Magreth Ndudumka had guided the medical team to the village to collect TB samples.

"After the screening results came out, we successfully managed to identify a 5-year-old patient named Anna," says Ndudumka, who then returned to Anna's house to follow up on her health and check on her family members. She found that the whole family was sleeping in the same room.

Now Nyamizi and the team are following up to test the other members of Anna's household for TB. They sit down with family members who are feeling unwell and walk them through why testing for TB is important, and how to provide a sample. Children are among the groups most at risk for TB and must be closely monitored for symptoms such as malnutrition and failure to thrive.

The following week, the sample analysis reveals that both Anna's mother and grandfather have TB. The team promptly returns to the household to initiate medications for the adults, check on Anna's progress, and continue to monitor other children in the household.

Anna's family is relieved to find there is real hope for good health and a prosperous future for them.

Many of those living in rural villages do not have a nearby health facility or do not have the means of reaching the closest clinic. Despite this obstacle, the district sees health as a human right and aims to reach these people with clinical services, even if it means bringing it to their homes. Community health workers help bridge the gap by providing health-enhancing communication and support in between physician visits.

"We should increase our efforts both the government and other nongovernmental organizations involved in fighting and investigating TB and help people who are infected," Nyamizi says. "But as we continue moving through the community, we should also not forget children under 15 years of age, so we can prevent unnecessary deaths that occur through TB."



# **Breaking Family Planning Myths**

"Some community members believe that contraceptives can cause infertility or cancer," says Theresia Mgulu, a community ambassador for family planning services in Tabora. "Others claim that locally produced traditional medicines can be used as alternatives to family planning contraceptive methods."

As a community ambassador, Mgulu's mission is to advocate for women to uptake family planning services for safer conception provided at the supported health facilities. Beyond combatting myths about contraceptives. Mgulu also meets women who choose to have children because they believe that it will improve their relationship with their male partners. With access to family planning resources, women can start families if and when it makes sense for them.

A wife and a mother of four children, Maulu is, herself, a beneficiary of family planning services at Tabora Referral Hospital.

Mgulu farmed to supplement the meagre income from her husband, but it was still a challenge to make ends meet. After Mgulu had given birth to her third child, healthcare workers explained to her the benefits of family planning services.

"I thought this was a solution to the health and economic challenges," says Mgulu.

Their fourth child came at a time when they had planned—four years later—and this has helped them to be a happier and healthier family.

Because of the education and assistance delivered by health workers, Mgulu was able to successfully implement family planning with her partner.

USAID-funded projects have further integrated child immunization with family planning in the region so family

planning services are also offered to women and men during vaccination days. This improves accessibility and public awareness of family planning.

"I am determined to see that I play a role in addressing these myths and have volunteered to be an ambassador to the project," Mgulu says. "I will continue to raise awareness to my community and will ensure that my community benefits from the family planning services offered at this facility."



Photo: Nuru Ngailo/EGPAF 2021

# A Vasectomy to Preserve the Health of His Partner

Among the hills of the Mbulu District in central Tanzania lives a farming couple, Martin and Rehema, along with their eight children.

When Rehema conceived her first baby, she was sick throughout her pregnancy. They both thought things would change with the other pregnancies; however, throughout all of the pregnancies, she suffered. Even during the ninth pregnancy, when Rehema was 43 years old, she was sick and could not do anything but lie in bed. Not only did Martin feel sorry that she was suffering, but she would get so ill that Martin worried her body would no longer be able to handle it and that he might lose her.

Martin was determined to find a solution to this misery. He approached a healthcare worker at Mbulu Town Council Hospital, and she explained to him the family planning options available for women and men. Martin knew he had to do something to save the life of his wife. If family planning methods were not a good option for his wife, maybe they were for him. He made a decision to get a vasectomy. After discussing it with his wife, they both agreed, and Martin went to the health facility to get the procedure in coordination with a USAID Afva Yangu Northern family planning event.

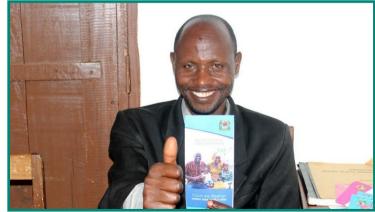
Martin explains that the procedure was relatively painless, and that the community myths were proven wrong. In addition to rumors of major discomfort, many of Martin's community members feared that after one goes through the procedure, they lose their sexual desire. Martin was happy to report that this was not true at all.

"After my experience, I am set to educate my community on family planning and curtail all these myths and negative mindsets around family planning," says Martin.



Photo: Rajabu Hassan, 2022





# EGPAF-Tanzania Wins an Award for Advancing Gender Balance in the Workplace

# By Nuru Ngailo

On March 8, 2021, I had the honour of helping to accept a Woman of the Future award on behalf of EGPAF at the Citizen Rising Woman Award ceremony in Dar Es Salaam. Sponsored by the Citizen Tanzania media outlet, the ceremony was held on International Women's Day to "bring together various stakeholders to celebrate the achievements of women in Tanzania and around the globe."

Fifty percent of EGPAF-Tanzania's management are women, led by Country Director Sajida Kimambo M.D. Additionally, EGPAF promotes diversity in the workplace; fosters a supportive and inclusive culture for all employees; and encourages respect, dignity, and openness to varied cultures. Diversity in the workplace enriches our work and enhances our impact and effectiveness. Differences in knowledge, approach, and perspective are a source of innovation and learning.

As EGPAF-Tanzania's country communication and advocacy officer, I took the initiative to submit an application for this award, and I also attended the award ceremony to cover the event. I was overjoyed that we won the second award, Woman of the Future, which recognizes "unique and impactful organizational initiatives ... that advance gender balance in the workplace." I felt proud of my organization, and it is amazing to work to promote gender equality with strong policies, systems, and structures that allow women leaders to flourish.

We dedicate this award to Elizabeth Glaser, our founder and a leader for the fight to end AIDS in children, youth, and families. When I think about women who changed the world, Elizabeth Glaser sets an example for all of us







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