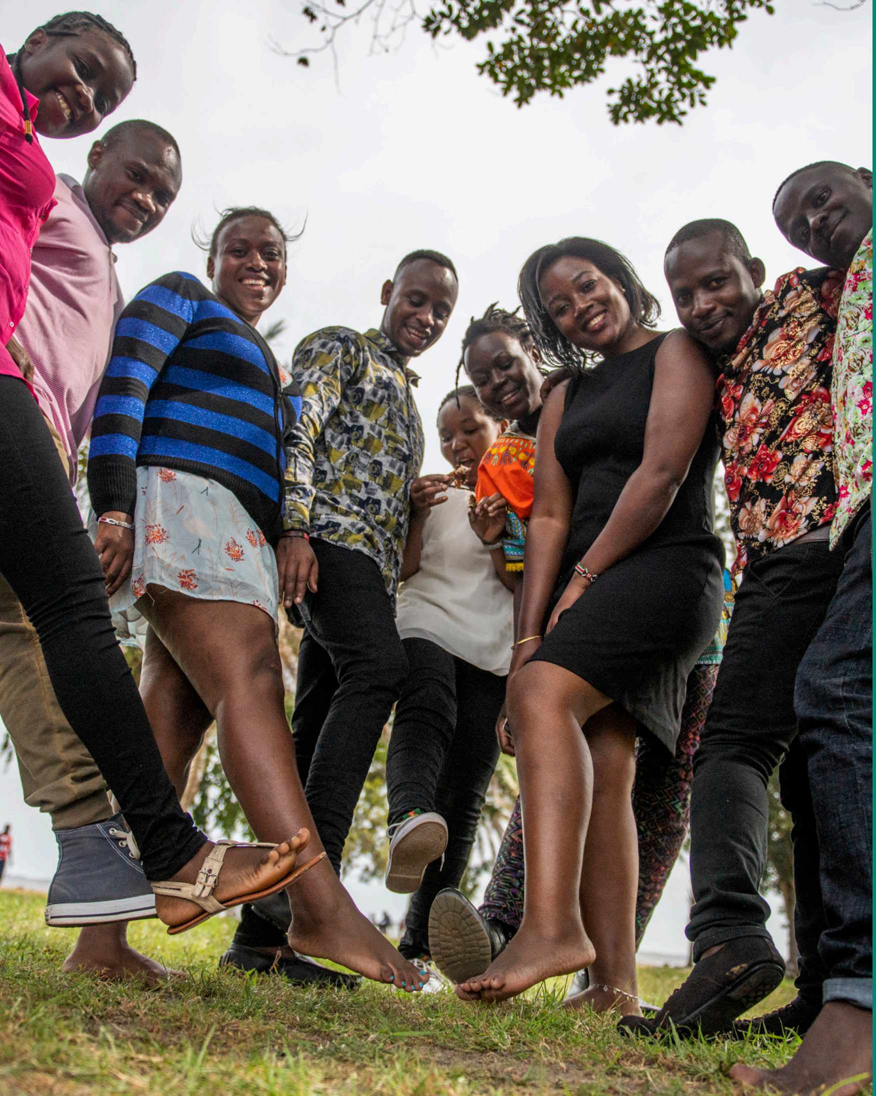
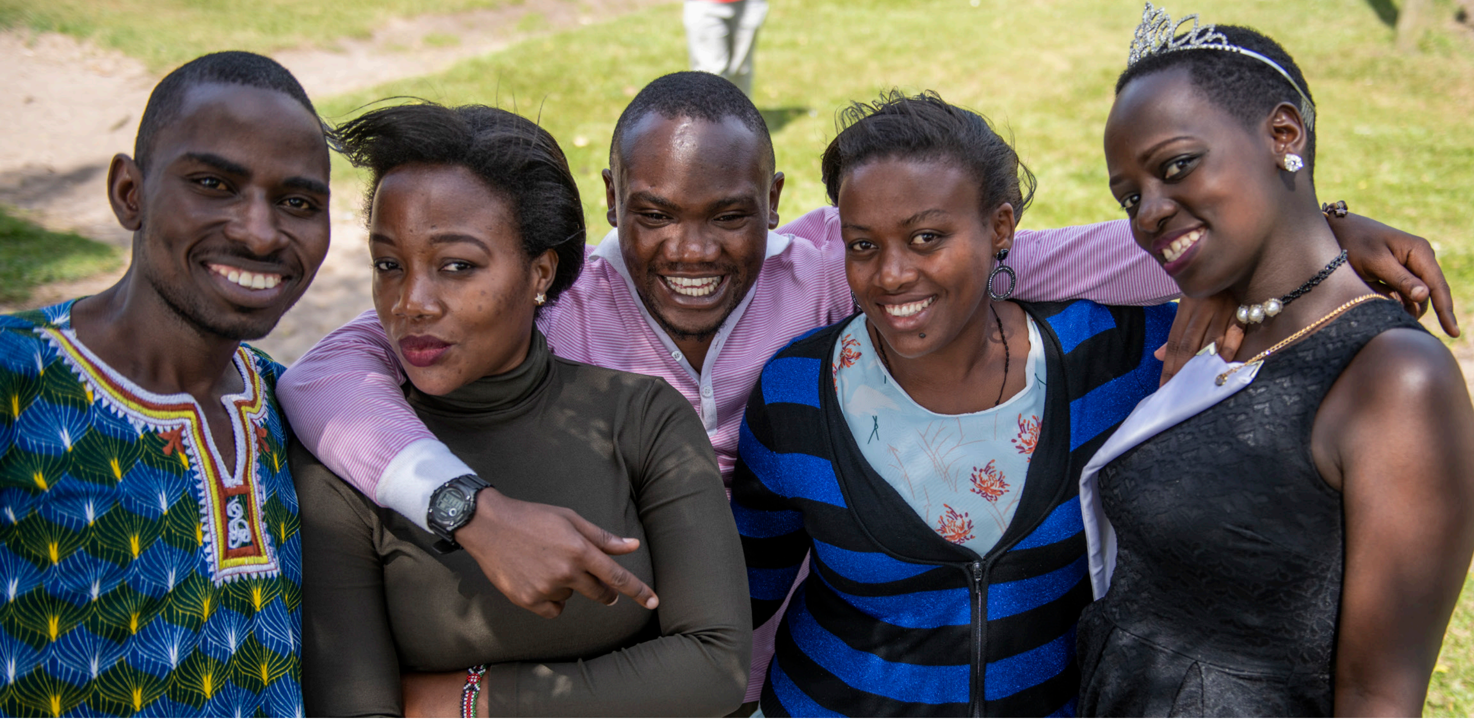


Elizabeth Glaser
Pediatric AIDS
Foundation

STORIES

Fast Forward

The Elizabeth Glaser Pediatric AIDS Foundation Empowers Young People to Support Other Adolescents and Young Persons through Their Journeys with HIV and AIDS



Cover photo and above: Eric Bond/EGPAF, 2018

UGANDANS AND AMERICANS
IN PARTNERSHIP TO FIGHT HIV/AIDS

USAID
FROM THE AMERICAN PEOPLE

THE REPUBLIC OF UGANDA
MINISTRY OF HEALTH

Globally, the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) is committed to a fast-tracked response to end AIDS among children and adolescents by 2020.[1] This guiding framework sets in place policy, health service programs, and operations research to prevent new HIV infections among children and adolescents, end mother-to-child HIV transmission, and ensure adolescents living with HIV (ALHIV) remain AIDS-free. Building upon this, EGPAF-Uganda has nurtured the opportunities to provide clinical and psychosocial support beyond HIV and co-infection, to address sexual and reproductive health (SRH), sexual and gender-based violence (SGBV), hygiene, nutrition, malaria and non-communicable diseases to adolescents and young people of the Southwestern Region.

Our approaches to connect and offer comprehensive, well-utilized health services to adolescents have included training health workers on provision of tailored and quality clinical care to this population, empowering youth to inform projects and programs that work for them and their peers, and peer support group implementation led by "expert clients" (adolescents retained on treatment).

This peer-led support enables psychosocial support to reduce effects of stigma, ensure acceptance of HIV diagnosis and resilience, enhance treatment literacy, provide home visits for follow-up in case of missed appointments, and enable active linkages to SRH services. These peer-led groups are inclusive of children and adolescents aged 8-10 years and are known as "Ariel Clubs". Ariel Club Ambassadors are young people, not only passionate about advocating for their health, but also the health and wellness of youth in their communities and around the world. These peer leaders have been solicited and trained on also increasing access to testing and have been a source for information on counseling and treatment management among those who test HIV-positive.

These leaders have an incredible ability to contribute to conversations about advancing the mission to end HIV among adolescents, whether it is promoting adherence, the possibility of staying HIV-free, or advocacy for policies that enable young people in school to stay on treatment. In fact, several of these youth leaders help inform EGPAF advocacy and programmatic initiatives through its **Community of Africa Youth Advisors**. These young ambassadors are the future of the AIDS response and their journeys toward viral suppression and stories of strength are highlighted here.

Because of the support of the United States Agency for International Development (USAID), the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), and the Government of Uganda through Ministry of Health, these peer leaders were themselves able to access antiretroviral therapy (ART), from early childhood through adolescence. These youths are working all over the Southwestern Region of Uganda through support of USAID and PEPFAR to support other children infected and affected with HIV to live healthfully.

---

[1] Joint United Nations Programme on HIV and AIDS (UNAIDS). START FREE, STAY FREE, AIDS FREE Report. 2016.

Photos: Kathleen Borgueta/EGPAF, 2018

STRATEGIST BRIAN AHIMBISIBWE

Brian is an EGPAF Ambassador, Global Health Corp fellow at Intrahealth, USAID-funded Regional Health Integration to Enhance Services in the Southwest Region Project (RHITES-SW) Young Leader, past president of Rotaract, board member of Mayanja Memorial Hospital Foundation, and master of public health student at Mbarara University of Science and Technology.

Over a decade ago, no one thought children like Brian in Uganda would make it. Brian was born with HIV at a time when the world was grappling with treating adults. Mothers who had the disease passed it on, unknowingly to their children through pregnancy, delivery or breastmilk.

In 2006, when Brian was 16, a friend noticed him taking medications and asked if they were for HIV. Brian was confused and shocked, denying the possibility—but his friend's question planted doubts in his mind. He looked into his prescription and realized it was, in fact, an antiretroviral drug.

"I imagined everyone in my class now knew about my status," Brian says. "I began to hide when taking the drugs." He even stopped taking his medications reliably and skipped a few doctor's appointments. His health began to deteriorate.

Plagued by shame and self-doubt due the stigma HIV carries within his community, Brian struggled in adolescence. Eventually, returning to the clinic where he sought treatment, he recognized three fellow students from school. They acknowledged each other, mutually recognizing their shared status. Finding solidarity in this way was comforting to Brian, as well as his classmates.

He was among the first members of an Ariel Club started at Kabale Regional Referral Hospital in 2007. Brian also began to help register other children at the clinic and follow-up with those who missed meetings. Brian explains that in his Ariel Club, he not only received psychosocial support from peers living with HIV, but also experienced "positive living interventions, just broken down for kids like me."

"In them, I found a safe place where I belonged. There were children like me and the adults 'got me;' they understood what we were going through. The friendships I developed are still strong and we hold each other accountable even to this day," says Brian.

FAST FORWARD

With the help of good doctors, relentless global advocates including EGPAF, innovations in HIV treatment, political will and Ariel Clubs, Brian is here today living a wonderful life. Brian advocates for a world where no child has AIDS and where there is no stigma attached to HIV. "I have seen too many people; my own age, mates, struggle with taking their medications because somebody out there made them feel ugly or like they did something awful to contract HIV. As part of our work as youth leaders in USAID RHITES-SW project, we confront the shame and fear which prevent people including mothers and their babies, children and youth from testing, starting treatment and adhering. When we no longer attach stigma, adherence and support for effective treatment will not be an issue, young people will be eager to get treated without any worries, leaders at all levels will genuinely.

"I will not stop telling my story until HIV is normalized and young people living with HIV are not stigmatized, have no need of hiding their status, or worry about taking their medicines," Brian asserts.

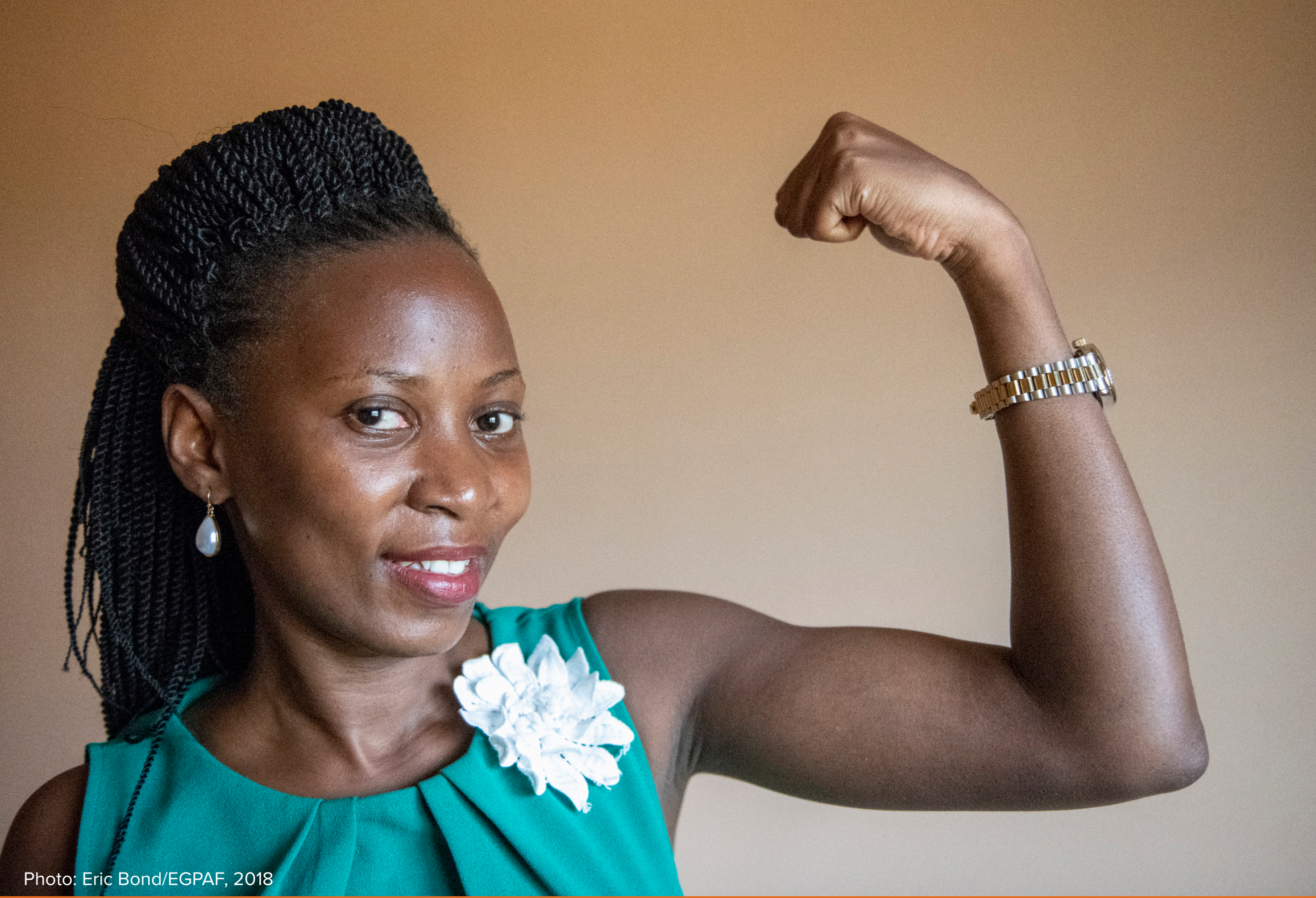


Photo: Eric Bond/EGPAF, 2018

TRAIL BLAZER: JOSEPHINE NABUKENYA

Josephine is earning her degree in Social Work from Makerere University in Uganda. She also serves as a Stephen Lewis Foundation Youth program coordinator at Makerere University Johns Hopkins University (MUJHU) and was recently awarded the Queen's Young Leader 2016 award for her advocacy work. Josephine wrote her first book, Beyond Your Status, in which she shares her life journey and encourages young people to discover their HIV status, get on treatment, and live their best lives. She is an EGPAF Ambassador, and a tireless supporter of the HIV/AIDS community.

However, like so many children living with HIV in Uganda, Josephine was not aware of her HIV status during most of her childhood. When she was eight years old, she came across a letter from her mother that revealed the devastating news—Josephine, her mother, father, and younger sister, were all living with HIV. Josephine and her sister both contracted the virus from their mother during pregnancy. Her mother only disclosed her HIV status to Josephine a few years later, discovering then that Josephine already knew.

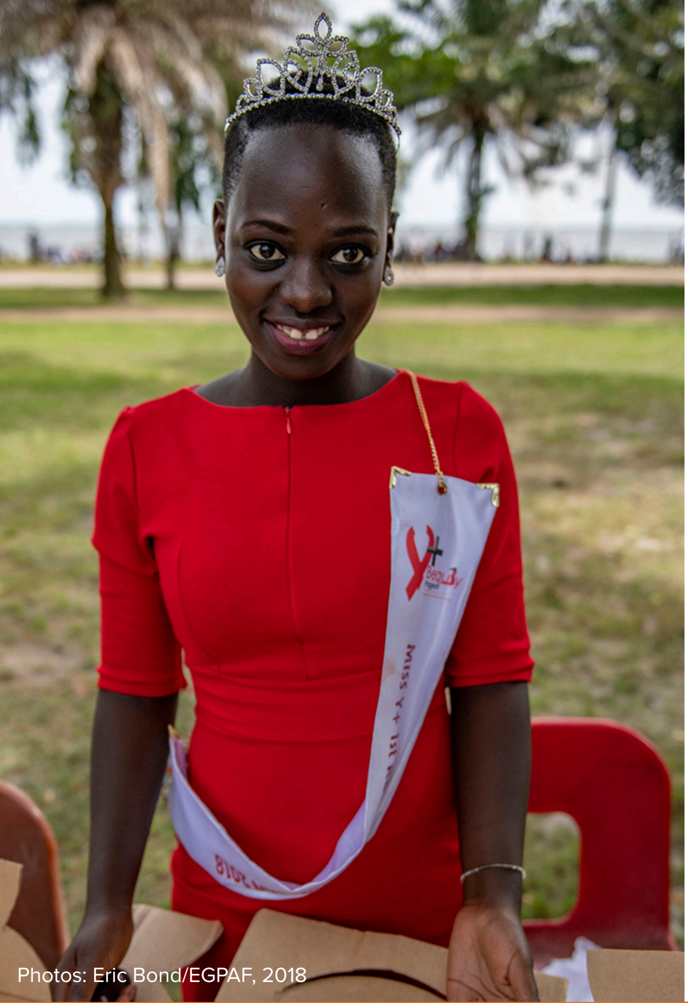
Shortly after starting ART at a local hospital, Josephine was introduced to EGPAF's Ariel Club.

"For the first time in a long while, I had hope that I could live with HIV. In the Ariel Club, we played games, wrote, sang, and read different stories," said Josephine. "We were a family and it was fun being together and sharing our stories without the fear of stigma or discrimination."

Soon Josephine became an Ariel Club facilitator, leading sessions to help other children accept their own HIV status and seek the treatment they needed to stay healthy. Through her time at Ariel, using her story to help guide others to overcome the challenges of a life with HIV, her confidence in the promise of her own life also grew stronger.

FAST FORWARD

Today, Josephine continues to speak out as an Ambassador for EGPAF. From her work with Ariel Clubs in Uganda to speaking in front of members of the United Nations or U.S. Congress, Josephine's story inspires other people to learn about HIV and fight stigma and discrimination around the disease.



Photos: Eric Bond/EGPAF, 2018

BEHOLD THE QUEEN: HAJARAH ASIIMWE

Hajarah, a 19-year-old student living in Southwestern Uganda, knows all about stigma. “I call it my dark times,” she says. “I was stigmatized at school, at home, even in the community. I would pass by someone and they would say, ‘That girl has slim’—the slang term for AIDS. “When you are in school is when it is worse. Some girls in primary [school] knew my status. So whenever I went to talk to a guy, the girls would go to him and say, ‘She has HIV, why are you wasting your time on her?’”

While battling stigma at school, Hajarah isolated herself and became depressed. “I learned to be alone. When they went for lunch, I stayed in the classroom. No one knew what I was going through. It reached the extent of not caring about anything. I stopped taking my medicine,” recalls Hajarah.

However, that changed when she met Brian Ahimbisibwe, who introduced her to the Ariel Clubs. “All those things we go through—lying, defaulting on medicine, not caring about life—when you get to share that story with your peers, you no longer feel alone,” she continues, “I began to see a bigger picture. I started to think that it is time to adhere to my medication and suppress my HIV so that I can live healthfully and cannot transmit it. I had hope of becoming like that person who reached out to [help] me.”

FAST FORWARD

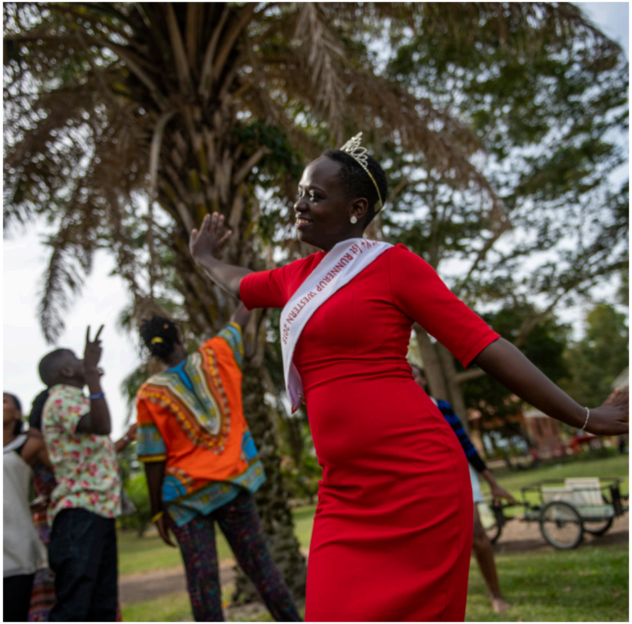
Hajarah soon became inspired to be a role model herself, initially volunteering to be an Ariel Club peer educator. “I would sensitize people [teach them about HIV and how to live with it], I would give people confidence,” she explains. As Hajarah grew older, she joined other young adults who had “graduated” from Ariel Clubs, and formed a nationwide support group called the Ariel Superstars.

Through the Superstars, she discovered a beauty pageant for young people living with HIV. Organized by the Uganda Network of Young People Living with HIV/AIDS (UNYPA), the contest aims to end stigma and discrimination around HIV. “I had a goal. I represented EGPAF and became the 2018 first runner up in the Western Region. Then I went to the finals. Though I didn’t become the national ‘Miss,’ I learned a lot.”

Hajarah uses these lessons to be a confident advocate and source of information for the people around her, with hopes of influencing the world. “In my own family, I taught them about HIV. I even told my grandmother that I am going to be a ‘Miss’ and that she should not be surprised to see me in the newspapers.”

She says her journey has inspired her to make a difference in the lives of other youth in similar circumstances, “I got involved in this because I believed in myself that I can change and make a difference in young people living with HIV,” says Hajarah. “Some can be like me—a ‘Miss.’ Everyone can have a bright future. We should be allowed to study like others, we should be allowed to dance with others.

“Now we are the AIDS-free generation,” says Hajarah as she adjusts her sash.



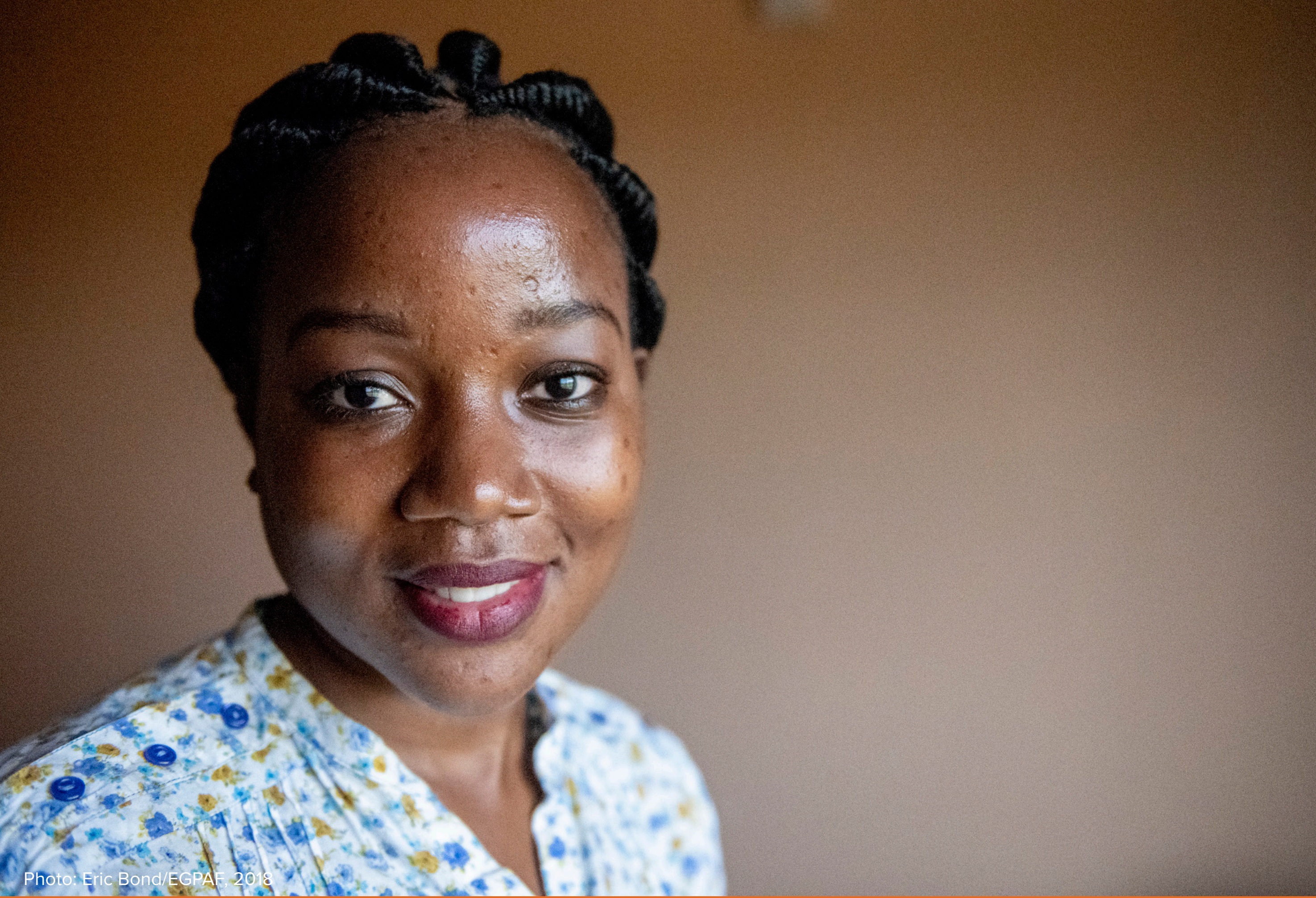


Photo: Eric Bond/EGPAF, 2018

CONQUEROR: BENA ASSIMWE

Bena is a 26-year-old nurse living in Kampala, Uganda. She dreamt of being a nurse from the time she was a young child, "When I was around 6 or 7 years of age, I nursed my mother on her deathbed," says Bena. "I used to be in the hospital with her, and I saw the nurses. They were smart and kind, and I felt that when I grow up, I need to be a nurse to help other people who need it." She eventually achieved this lifelong dream and graduated as a nurse on World AIDS Day [December 1], 2016.

However, the road to being a nurse was particularly difficult for a child such as Bena. When Bena was eight, her mother died of AIDS-related causes. Later, her father, too, died, leaving Bena an orphan. Growing up, she moved from relative to relative—and even lived with people outside of her family. Some of those guardians were hostile to Bena, and she often felt alone in the world.

Although Bena has been prescribed antiretroviral medication since she was a small child, no one told her about her HIV-positive status until she became very sick at the age of 15. Bena had stopped taking her medication regularly, not knowing what it was for.

When she learned her HIV status, Bena tried to commit suicide. The anguish was deeper than she thought she could bear. At her very first Ariel Club, Bena was chosen to attend Ariel Camp, a weeklong retreat for children and adolescents living with HIV. "When I arrived in Kampala for Ariel Camp, the story changed," recalls Bena. "I never knew that I would find people who were the same status as me and were older and had accepted their status."

FAST FORWARD

Now that she is grown, Bena is also one of the graduated, "Ariel Superstars." She reconnected with fellow Ariel Club alumni on December 1, 2018 to celebrate World AIDS Day and Bena remains close with other superstars, providing support for one another over WhatApp and other social media fora. She is also a CAYA member.

"We are the first generation of Ariel Club to grow up," says Bena. "The Superstars are those people who have accepted their status, who are willing to disclose their status, and who are role models for those other children out there who are being stigmatized, who are being discriminated against."

Last year, the Ariel Superstars met near Lake Victoria for a campfire, a club meeting, games, and a cake commemorating their HIV viral suppression as a group. "It was '#TeamViraLoadSuppression' because [of our] viral suppression. It means we are conquerors," affirms Bena. "I think I will have a reunion with these people when I am 85 years old on the shores of Lake Victoria. I don't want to lose anyone in the family—especially not because of anything related to HIV. And I want to encourage those young Ariel children to do the same."

UNSTOPPABLE: PETER NGAMBENAWE

Peter is 22 years old and lives in Kabale District where he volunteers as a peer counsellor at Kabale Regional Referral Hospital. His parents separated before he was born and after two months, his mother left him with his great grandmother. As an infant, Peter fell ill and after several tests, he was diagnosed with TB, which kept him admitted in a hospital for almost 10 months. He then faced multiple illnesses such as malaria, fever, rashes, and diarrhea, which attacked and weakened his immune system.

Finally, at age three, he was diagnosed with HIV. Growing up, his great-grandmother could not afford to pay for his education so she received funding from a Catholic charity organization. However, funding soon stopped.

At eight years old, he had a TB relapse and stopped going to school for about two years. He was constantly falling ill, and because of this, his great grandmother's children kicked him out of the house.

When Peter first encountered EGPAF, he was living on the streets, unable to attend school. However, by connecting with EGPAF workers, the Ariel Clubs, and its counseling services, he was inspired to work to go back to school. Through his hard work and continued support from EGPAF, he was not only able to pass his exams to join secondary school; he even received a housing scholarship from the school, as well as extra assistance from the head teacher who was inspired by his journey.

FAST FORWARD

After senior four, during one of the Ariel Club counselling sessions, Peter received a sponsorship from a private guest of the hospital to attend a short educational course in counseling alcohol and drug abuse. After he graduated from the counseling program, Peter was recruited to work as a volunteer at Kabale Hospital, where he counsels adolescents on positive living, and has done this for three years.

Now, Peter is an Ariel Superstar; he works with children and adolescents, attending Ariel Clubs across all the health facilities supported by EGPAF through the USAID RHITES-SW project in Southwestern Uganda, using his experience to encourage other young people to live positively.

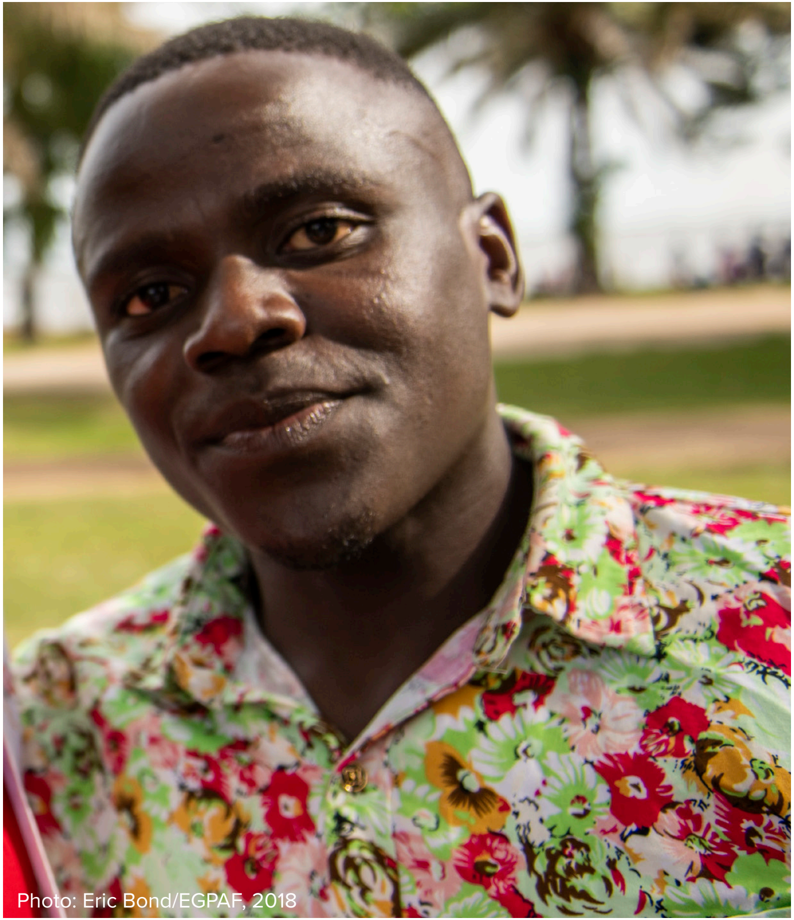


Photo: Eric Bond/EGPAF, 2018

CHANGE MAKER: ISMAIL HARERIMANA

Ismail is a 24 year-old youth peer counsellor at Kabale Regional Refferral Hospital. His main job is to support other young people living with HIV get in to care, start treatment, and consistently take their medication. Ismail knows what it means to be afraid of being stigmatized and tired of taking ARVs.

Ismail was born with HIV, and because he was very sick as a child, other children excluded and taunted him. When he started formal school and confided in teachers, they further stigmatized and shamed him. At boarding school, Ismail even hid his medication in a tin of sugar so that nobody could tell he had HIV.

Things started to get better for Ismail when he began attending Ariel Clubs. They equipped him with the psychosocial support to reverberate positivity and change in himself and other young people living with HIV. Today, Ismail supports about 330 peers and children at the Kabale Regional Referral hospital and also supports adolescents' clinics/Ariel Clubs mainly in the Southwestern Region and other districts including Jinja, Masaka and Kyenjojo.

FAST FORWARD

Recently, Ismail worked with a young man, Ali, who reminded him of his own struggles. Ali lost his parents to AIDS-related causes and grew up in an orphanage that enrolled him into care. However, he feared discrimination and dropped out of care. One day however, Ismail and the other health care providers noticed Ali was missing from their records. He had stopped coming to take his medication so they proceeded to look for him in the community. Ismael searched the streets for Ali and only returned to the health center once he found him. Back at the health center, Ismail encouraged Ali and shared his journey of overcoming stigma. He even got Ali to join a peer support group for adolescents over 18 years of age called Kabale Young Positives.

Now, Ismail is a member of CAYA who support the design and implementation of adolescent and youth programs. He is also a national trainer for the Young People and Adolescent Peer Supporters model with the Ministry of Health, AIDS Control Program.

Ismail has taken much of what he learned in the Ariel Clubs to help build the Kabale Young Positives support group. This group never lets young people like Ali give up. Today, Ali's health is better and he even supports other peers' journeys to getting care. This is what matters most to Ismail, giving back and reaching out to people like Ali.

"Ali is doing well on ART and the support from his peers has made all the difference. He doesn't have to worry about hiding. We know how he feels and we make him feel safe — that's the part of my job I like," says Ismail.

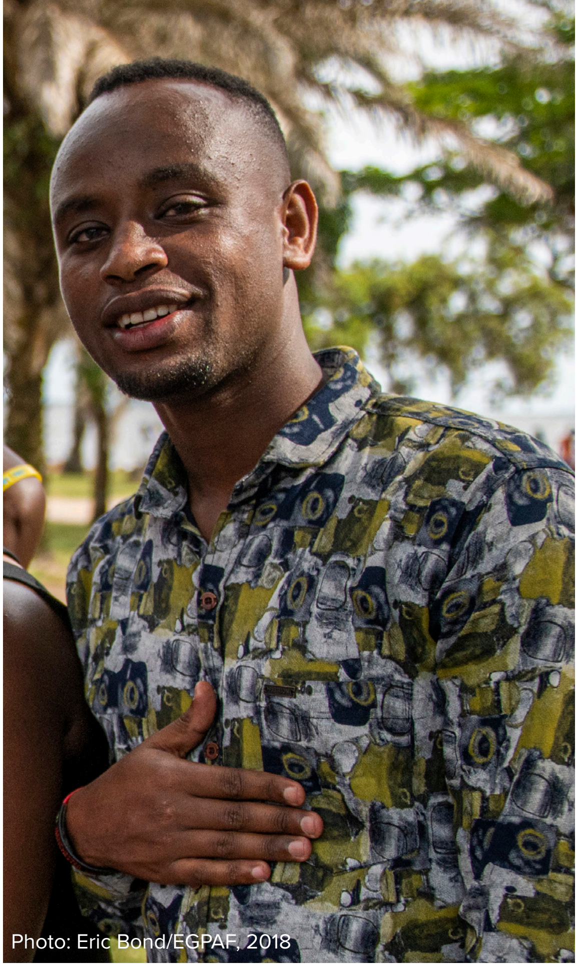


Photo: Eric Bond/EGPAF, 2018

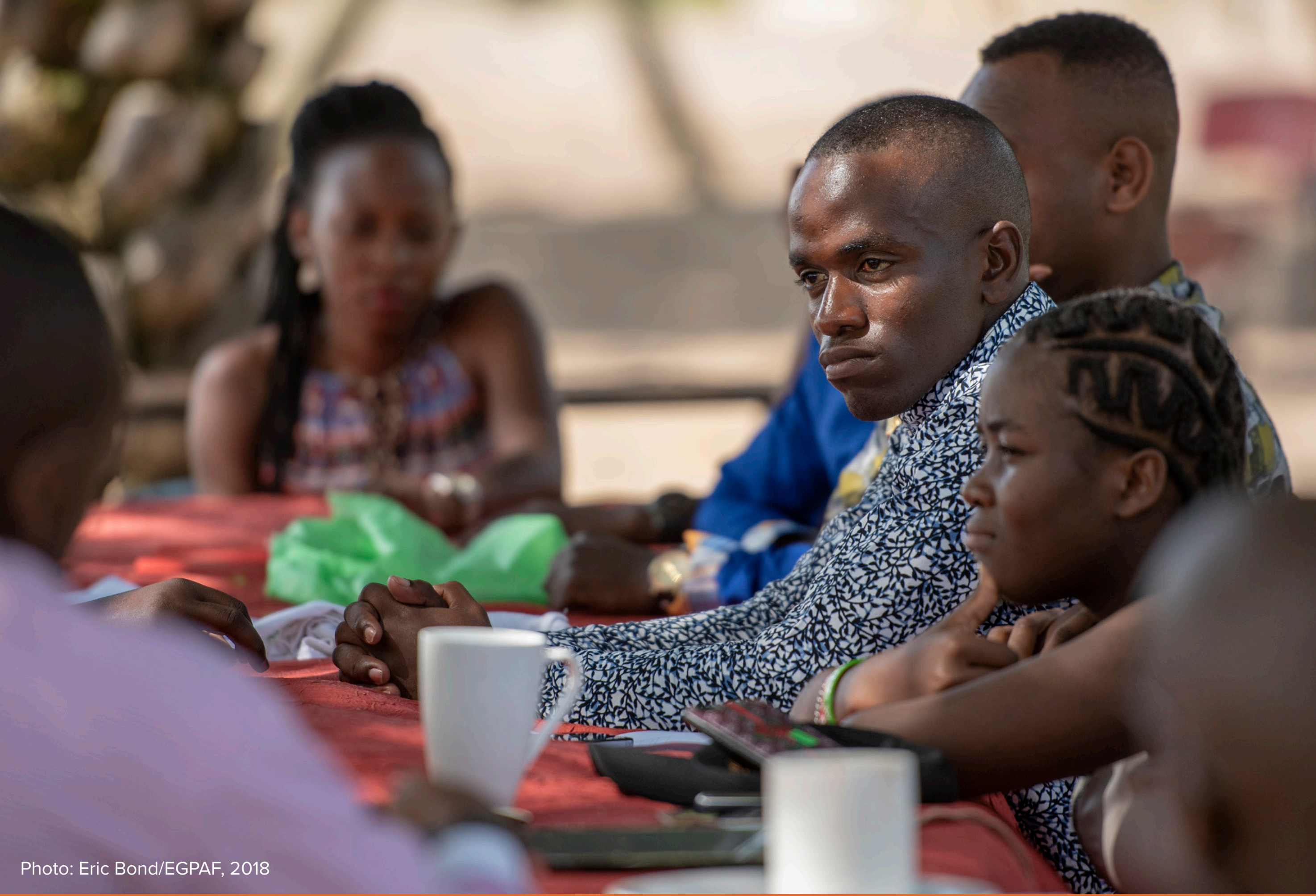


Photo: Eric Bond/EGPAF, 2018

FREEDOM: GRANT ANGAMBIIRE

Grant is 23 years old and works as a wildlife tour guide/ hotelier in Uganda. Today, he devotes much of his energy to sensitizing others about HIV. But as an orphan growing up with HIV, Grant was burdened by his HIV status and the associated stigma. Until recently, he was afraid to disclose his HIV status outside of his circle of HIV-positive peers.

Grant 's parents died of AIDS-related causes when he was only two years old. He soon began to show symptoms and was diagnosed with HIV when he was about eight or nine. Fortunately, ART was available, and although money was tight, Grant's grandmother managed to pay for his medication and enrolled him in school. However, at this time, Grant was unaware of his status. In fact, his grandmother did not disclose his positive status to him until he was 11.

After graduating school, Grant faced a new challenge, stigma in the workplace. At his first job after graduation, he lived in fear of his colleagues discovering his status. Every day he had to plot how he would take his ART in secret, always doubting if he should disclose his status. Fortunately, he developed close friends with the Ariel Superstars who understood and offered advice.

"The other Superstars keep on empowering us, aiming at ending stigma and discrimination," says Grant.

FAST FORWARD

Today, Grant is connected with the Ariel Superstars via their What's App group, which he claims has impacted and strengthened his friendships.

Grant's experience illustrates just how important support groups are to people living with HIV. At the most recent gathering of the Superstars, the group was able to announce that every member has achieved viral suppression—meaning that HIV is undetectable in their blood samples. While there is still no cure for HIV, the Ariel Superstars are showing that HIV does not have to be a hindrance to health or to opportunities.

"Surely, I am finally proud to be HIV-positive," says Grant on World AIDS Day. "This is our day. To Uganda, I say, 'We stand firm. Let's confront AIDS, HIV—and stigma as well. At this time, no one should die of AIDS."

UNBROKEN: AGNES RUKUNDO

Agnes lost her mother from AIDS-related illnesses when she was 9 years old. Two years later, her father died.

“I never got the chance to really live with my parents and be loved by them, I was taken care of by another family. Life wasn’t easy without parents but I had to persevere no matter the challenges. As I was growing up, neighbors and people from my home area always pointed fingers at us children who lost their parents to AIDS and were living with HIV. But being small children, we never got to understand what it meant,” Agnes remembers.

Surprisingly, Agnes went through school without any trouble until age 19, when she got a terrible rash. She overheard the doctor suggest to her uncle that she get tested for HIV and hearing this mortified her. People in the community already ostracized her as someone with HIV; therefore, one evening, she asked her uncle to take her for testing. “[the health care worker] broke the news to me and told me that they had found HIV in my blood and my CD4 count was 16 by then. I didn’t know what all this meant but I just broke down in tears thinking about how I am going to die and leave my siblings all by themselves.

“Aunt Hope introduced me to the Ariel Club, they saved me. I loved the camps, where we had fun and shared our experiences. I made friends with Bena and others. During the holidays and after high school we got in touch and we would meet often to talk about our lives and how we could do better. Then, through EGPAF, we were invited to talk to young children in the Ariel Clubs about our own experience. After this we got more training and became Ariel Ambassadors.

FAST FORWARD

Agnes continued with her studies and once she graduated as a nurse, she was taken up as a peer educator at Kisoro hospital under the USAID RHITES-SW project implemented by EGPAF. Agnes provides psychosocial support, facilitates play therapy groups for young children and engages teenagers in candid talks on sexuality and stigma. Agnes is especially keen on supporting young people fight stigma because she too had a difficult time in school.

“In 2012, at one of the district functions commemorating candle light memorial for HIV/AIDS awareness, I chose to do a public disclosure. The story was run by all radio stations and I received a number of phone calls asking me why I had to do this, I told them this is what I should have done a long time ago! Ever since that day I never looked back at anything as I received the strength that I never had before."

When Agnes got pregnant, she took precautions to ensure her baby was HIV-free: she attended antenatal visits, stayed on treatment, and her baby completed a nevirapine-based regimen. Now, baby Ethan is three years old, HIV-free, and the light of Agnes' life. She derives her support also from her fellow Ariel Ambassadors. She loves the WhatsApp group, through which they tackle real life challenges and hold each other accountable to adhere and live well. The group is also attended by doctors from EGPAF to support learning and offer correct clinical advice.

Agnes lives for her son and to be a good example to her siblings and other young people living with HIV/AIDS.

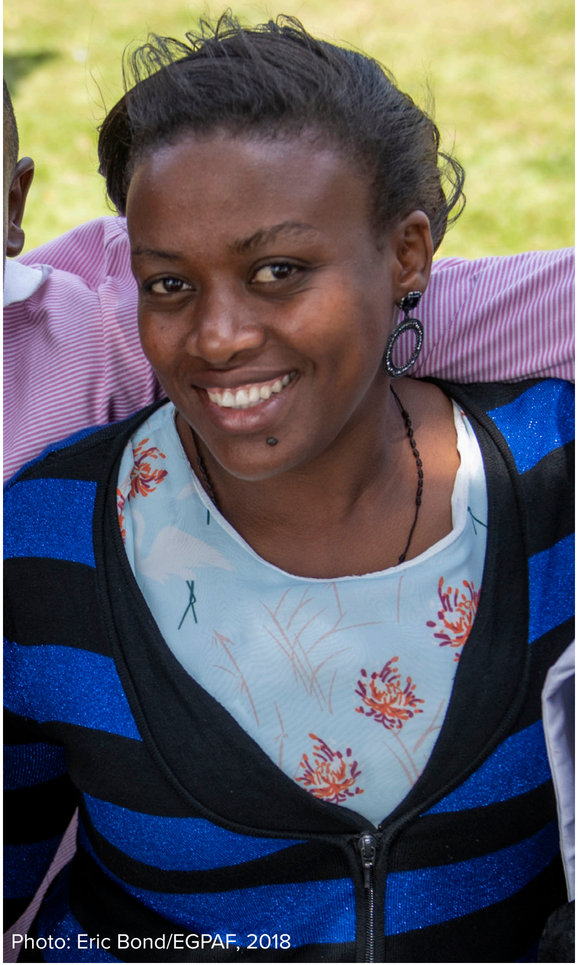


Photo: Eric Bond/EGPAF, 2018

ELIZABETH GLASER PEDIATRIC AIDS FOUNDATION
Plot 15 Kitante close,
Yusuf Lule Road
P.O. Box 21127 Kampala, Uganda

T +256 312 264 380/1
+256 414 341 219

USAID RHITES-SW PROJECT OFFICE
Plot 7 Galt Road Boma
Mbarara, Uganda
P.O. Box 881 Mbarara

T +256 485 420 160

WWW.PEDAIDS.ORG