



**Elizabeth Glaser
Pediatric AIDS Foundation**
Fighting for an AIDS-free generation

STORIES

A PILL A DAY KEEPS HIV AWAY

How The Elizabeth Glaser Pediatric AIDS Foundation, through United States Agency for International Development Support, is Scaling up Use of Daily Oral Pre-Exposure Prophylaxis in Uganda





USAID
FROM THE AMERICAN PEOPLE



THE REPUBLIC OF UGANDA
MINISTRY OF HEALTH

Uganda has made strides in controlling the HIV and AIDS epidemic, as seen by a 58% decrease in the number of AIDS-related deaths and a drop in new infections from 92,000 to 53,000 since 2010. However currently, Uganda has an HIV prevalence of 5.7%, with key populations including adolescent girls and young women, men who have sex with men (MSM), female sex workers (FSW) and migrant fishing communities particularly vulnerable to HIV.¹

Daily oral pre-exposure prophylaxis (PrEP) is an antiretroviral (ARV) medication that can help HIV-negative individuals remain HIV-free, when taken properly. In fact, some studies have suggested a reduced risk of HIV acquisition in all high-risk key populations by 70%.² The World Health Organization (WHO) recommends use of PrEP in populations with an HIV incidence of above 3%.³ Uganda's Ministry of Health, in 2018, produced guidelines on use of PrEP in-line with the WHO's recommendations, illustrating that anyone who engages in sex with multiple partners, transactional sex, injected drug use, who may be in a HIV discordant relationship should be counselled on and offered PrEP.⁴

Since the release of these guidelines the Elizabeth Glaser Pediatric AIDS Foundation's Uganda (EGPAF-Uganda) program, which supports comprehensive health care programming including HIV and AIDS prevention, care, and treatment across over 800 sites in Uganda's Southwestern Region with support from the United States Agency for International Development (USAID), has scaled up use of PrEP among high-risk groups in all supported clinic settings. Both the community and facility delivery model were used


to reach individuals who were at substantial risk of HIV with PrEP services. In the communities, health education and sensitization on what PrEP is, its benefits, and where it can be accessed was disseminated, including training peer educators who were used to create demand and address misconceptions around PrEP. At the facility-level, training of clinical service providers, laboratory technicians, and community health persons were implemented, as was support to address the demand and supply challenges. Our trainings focused on accurate understanding of benefits and limitations of PrEP, how to manage and correctly administer this drug to clients along with counsel around dual protection to reduce transmission risk of other sexually transmitted infections and/or unwanted pregnancies.

Currently, nearly 40 EGPAF-supported facilities support mobilization, onsite counseling of eligible clients, along with follow-up and adherence support for PrEP. To date, over 4,600 individuals have been reached with or received PrEP with the support of EGPAF and USAID.

Community support cadres conduct outreach to educate whole communities about PrEP, initiate those eligible on PrEP, and offer refills and adherence counseling. For example, a community support mechanism in Rubaare has enabled scale-up of PrEP use by many high-risk individuals in a universally high-risk community. In this book, you will read stories of how PrEP is changing the lives of Ugandan's living with an increased risk of HIV and how EGPAF and community members are working together to reduce these risks and create an HIV-free future.



Clinical Officer
Sherina Amutuhair
Shares Her Tips on
Reaching Most-At-Risk
Minority Groups



The Rubaare Trading Center seems like an ordinary commerce site: people walking up and down the dusty roads to buy supplies from markets, boda-boda riders at their pick-up corner chatting with passers-by, and women carrying jerry cans on their way to fetch water. But in the middle of the center stands a little, orange building with a unique purpose. Called the Knowledge Room, a bright, refurbished shipping container, this building serves members of key populations, including MSM and FSW. It is supported by EGPAF through the U.S. Agency for International Development (USAID), RHITES SW project. The room is equipped with a pool table and a television, making it an ideal hang-out spot. It is staffed by health workers and social workers who provide HIV services. The center also provides free condoms, lubricant, and PrEP.

Knowledge Room staff, Sherina, Humphrey, and Alice, sit at the entrance, greetings hail from the road.

“My doctor, my doctor, hello, hello; let me come in,” says a young builder, who is clearly tipsy. Sherina reaches out with her fist to bump his—a type of high-five referred to as *bonga-wo*. He cracks several jokes and then asks for an appointment to bring in his new girlfriend for HIV testing before the market day.

“It is common for people to have multiple sexual encounters on market day,” Sherina says after he leaves. “It is our busiest day with couples for the day coming in to get contraception and testing services. We also do moonlight outreaches in difficult neighborhoods where drug use is prevalent and at bars and brothels where several young girls work.”

How does Sherina foster her approachability, given the sensitivity of her work?

“This community is very special,” says Sherina. “Rubaare is not like any other place I have ever worked,” she says.

“It is a hot spot for HIV and other sexually transmitted illnesses—with a large Rwandan migrant population, truckers, and sex work.”

It has been this way for ages. Food crops thrive in Rubaare and people camp here for the market day waiting to buy produce at low prices. The nightlife is busy and attracts people from all corners. Sherina says the only way she is able to reach out to so many people who are at risk of HIV is by remaining relevant, “speaking their language,” she says.

“As you can see I try to dress up cool and smart, otherwise if I look old and boring, none of these young girls, sex workers, and the truckers would be open to me,” says Sherina. “I adapt the slang so that my clients feel understood. I am amazed that everywhere I go, I find people who know me because of the Knowledge Room. Young girls in the bars will even stop me to tell me that their workplaces are out of condoms or that they need a talk because they have new arrivals. I respect my clients and also make sure that my body language demonstrates the same.”

“We receive clients from the health center, from self-referrals, and through the outreaches that target those most at risk for HIV, including key populations [KPs] and priority populations [PPs],” says Alice Berigija, Knowledge Room Team Leader. “The Knowledge Room is a recreational facility that provides health education and information. For example, young people will come and play games, watch movies—and, in between, we start health talks on HIV and AIDS, about who is at risk and how they can receive services including confidential counselling, testing, treatment, and how and when to use PrEP to remain or keep their sexual partners HIV-negative.”

Maureen Kengabi is the ART Director at Rubaare Health Center, which frequently liaises with the Knowledge Room. Kengabi has seen it all—the various efforts to fight HIV and AIDS. While she admits prevention of mother-to-child HIV transmission is a miracle, she votes PrEP the number one innovation in HIV care and treatment so far.

“You see it used to be hard to offer counsel to a discordant couple. Fine, we would give ARVs but here in our culture, it was a real challenge for a couple to stay together and adhere to correct consistent condom use. But PrEP immediately makes people hopeful because they can take control and protect themselves in a practical way. In fact, they are even more willing to encourage each other to stay on track.”

“It is a small community, so we are careful about how we handle each individual. If a client needs to go to the health center, we make sure they are escorted to reduce waiting times and to counter stigma. A sex worker, for example, may be nervous about running into their clients at the health center. They are worried about being discriminated against by health workers. And MSMs cannot even begin to be honest in their conversations, because of the stigma and phobia around them. But we protect them, as best we can”





The Nuwagabas:
Taking Precautions
For the Health
of the Family

The Nuwagabas are a handsome couple in their 20s, with two children they adore. Sezi works on a ranch in Rubaare. His wife, Jovita, and their children live in Nyarushajja, a neighboring sub-county. Sezi bought land this year and soon they will all move to Rubaare.

In 2018, Sezi began feeling unwell and decided to go to Rubaare Health Center IV for a checkup. He tested positive for HIV. The diagnosis was a hard blow because he had tried to be safe in his sex life and could swear that he used condoms almost every time.


“I was always careful,” says Sezi. “When I found a girl I liked, I would first take her to test for HIV at the health center.”

With the counselor’s support, he accepted the results and disclosed his status to his wife.

“I was struck with fear,” Jovita says. The couple went for counseling at the health center and Jovita and the children were tested for HIV. All are HIV-free. This was a great relief for Sezi.

The nurse at the ARV clinic relayed good news—about a pill that Jovita could take to stay HIV-free. Sezi was initiated on treatment and the couple referred to the Knowledge Room for PrEP. They did everything the clinicians told them to do. PrEP is a potential game-changer for preventing HIV transmission in HIV discordant couples, as it can reduce the risk of sexual transmission of HIV by almost 90% in this high-risk population.

The couple admits it hasn’t been easy to come to terms with HIV and how it came into their lives, but they are determined to keep each other on treatment to stay well. All Sezi wants is for him and his family to be healthy and PrEP gives him assurance of this.



Local Council
Chairman Becomes
a PrEP And HIV
Prevention Champion

Jamiru Kanyarutooky, a council chairman in Rubaare, met his wife in a bar. It was love at first sight. Things moved fast and the couple started living together. Then Jamiru came across a bag of ARV medication. When he asked his bride about it, she said it wasn't hers. The hiding games began. Jamiru would move the medicine. Then Hajara would find it and Jamiru would move it again. The newlyweds were both afraid to talk openly about HIV even though they knew it existed somehow in their lives.

When the couple conceived, they went together to the EGPAF-supported Rubaare Health Center IV, and they asked to be tested for HIV. The counselor talked to them about possible outcomes and answered their concerns before they were tested. Hajara tested positive for HIV, but Jamiru tested negative. Hajara was distraught and asked to get retested. According to Jamiru, "Hajara was afraid about having to explain that she had HIV all along."

The couple was referred to the Knowledge Room, where the counselor explained discordancy in more detail. Initially, they were not using PrEP, Jamiru says. Jamiru and Hajara were overjoyed when the counselor explained the option of using PrEP to limit transmission of HIV in discordant sexual relationships. Jamiru says the first tablet was so huge it made him sick to swallow. The new one is smaller, and the couple is accountable to each other to take their medication on time.

"It's like my food. Every day I make sure I take it. I am watching Hajara, and she is watching me." Together, they're watching their daughter, now a kindergartener, grow.

As a local council chairman, Jamiru uses his story to encourage the community he serves to test for HIV and prevent its spread. Jamiru has brought several couples for testing and supports them through starting treatment.



A Female Sex Worker
is a Peer Leader,
Set on Ensuring Every
Girl on Her Street
is Protected

Ninsiima knows everything about Rubaare. She has worked here for more than 10 years. Ninsiima calls herself a “Neyko,” which is short for “I do my own thing” in the local language. Ninsiima is a bright energetic lady, praised for her honesty and care for other FSW. She has had a steady partner for eight years who is currently working in Kenya.

They are a discordant couple. Ninsiima is living with HIV. She is a walking encyclopedia of information related to HIV. “I speak in specifics and I know the reality,” says Ninsiima. She opens her purse to point out the condoms and lubricator she shares with other girls.

“You see if someone gives you 10,000 shillings (equivalent to about 2 dollars) how will you say no? That money can help you. But it means that you may not use a condom,” says Ninsiima.

“Everyone knows me. I go to the bar to see that the girls have the supplies they need. I check that they are getting their medicine. And I escort those who are afraid to come to the Knowledge Room. For me I speak the truth. I tell them to come to the Knowledge Room to use condoms, but also to start PrEP and protect themselves.”

Ninsiima’s dream is that all girls could learn occupational skills and make another living. Her reality is different, but her honesty and concern for the health and wellbeing of her peers and clients is creating a better world around her.



19 Years Old,
Determined,
In Control and
Unstoppable

During a visit with her cousin, who is serving in the military in Rwemitalo (a nearby subcounty), Mutima was befriended by a soldier. A relationship developed, and she and he eloped. They had a baby. After two years, Mutima took her son to visit her family in Rwanda.

Mutima's parents wouldn't let her return to her partner because they hadn't given her permission to get married. Her parents felt that she was too young. She started a vegetable selling business and put her son in school. Mutima needed more money to expand her business and make a home for her son. One day in the village she heard about hotel work in Uganda and signed up immediately.

"I thought I was coming to work in a hotel, but I ended up here in a bar [brothel] and work as a bar girl." Mutima is a FSW at the brothel. She is also in charge of cleaning up the rooms behind the bar, and stocks every room with condoms. Mutima insists on condom use. If a customer refuses to use a condom, she returns his money and reports him to her boss. Mutima's boss is protective of the girls who work at the brothel and wants them to protect themselves from HIV. She is also open to the Knowledge Room health workers advice and support in this regard.

"Humphrey and Serina would pass by and tell us we could come and get condoms any time at the Knowledge Room," says Mutima. "So I would tell my boss and get permission to come here. This is where I learned about PrEP and started on it.

"I have worked hard and saved a lot of money. I send it home and am buying many goats I am going to go back. I can't do this work much longer, and I will do the goat business." Mutima is on schedule with her savings. Her new life begins in 2020.



No Lines Crossed: Peter's Principles

By the end of his O levels, the first stage of high school, Peter knew he had what it takes to start and succeed in business. Peter talked to his family and got start-up capital for a boutique, stocking modern and new clothes for young people. His eye for style is undeniable and Peter soon had a thriving business.

Peter is serious about saving money and does this through a local savings club. He is in a relationship, but his partner doesn't live in the area. While Peter uses condoms consistently, and gets these and lubricants through the Knowledge Room, he admits that "you can't be sure about what happens when people go out to a party. Your partner might also not always want to use a condom."

As such, Peter does his best to bring his partner for testing when they visit. Peter takes PrEP and for this he is grateful to the Knowledge Room.

"When we were in school, all the students couldn't wait to come to the Knowledge Room to play pool, but we did not know that it would save us," says Peter. "I take PrEP and am not going to stop I have told others—I have so many friends like me and we talk a lot about sex and protecting our lives. I just tell them to come over because it's not like a hospital. The staff is always friendly, and you can just come and watch a movie and have fun. I know when they come, they will get tested, get condoms, and PrEP."



Meet Dickens, The Peer Leader

“I make friends with everybody. Even the police. So that people like me and my friends don’t get hurt,” says Dickens. He is the peer counselor for MSM, a distinct minority in Uganda.

For years, Dickens has brought together young men for HIV services. Now he does so at the Knowledge Room.

“It is a small community, so we are careful about how we handle each individual,” says Alice Berigija, Knowledge Room Team Leader, again. “If a client needs to go to the health center, we make sure they are escorted to reduce waiting times and to counter stigma. Alice emphasizes that the Knowledge Room staff work closely with the local health center to ensure clients are well served. They conduct outreaches together and document and share data.

Dickens likes the Knowledge Room because he can refer young men there, and they don’t have to worry about being discriminated against. They can have fun and learn about how to stay safe. For those who are not able to come to the Knowledge Room, Dickens arms himself with all forms of protection, condoms and PrEP, to distribute in the community.

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