



Elizabeth Glaser
Pediatric AIDS
Foundation

STORIES

Fighting the Double Threat

The Elizabeth Glaser Pediatric
AIDS Foundation Takes on TB



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THE REPUBLIC OF UGANDA
MINISTRY OF HEALTH

Tuberculosis (TB) is a major public health problem in Uganda. In 2017, there were an estimated 86,000 individuals infected with TB in the country.¹ According to some reports around 40% of active TB cases in Uganda are never reported to the national registry; this means many more individuals living with TB are unaware of their status, out of care, and potentially transmitting the bacteria to others.² Increasing levels of drug-resistant TB in the country is a growing worry and attributed to suboptimal treatment success rates.* The World Health Organization (WHO) ranked Uganda among the 30 TB/HIV high burden countries.³ The HIV prevalence in the general population is 5.9%. It is estimated that about 45% of the TB patients are co-infected with HIV/AIDS. TB stands as the number one killer of HIV/AIDS patients. The clinical presentation of TB among the dually infected persons has a bearing on the clinical management and design of public health interventions to respond to both epidemics.

It is for this reason that Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) with the support of the United States Agency for International Development (USAID) prioritized a strong response to TB in Uganda. Identifying, treating, and managing TB successfully requires an integrated approach, inclusive of HIV prevention and treatment, family-focused counseling, nutrition, and the testing and treatment of other infections common in the immune-suppressed.

EGPAF has been working in Uganda since 2000 to eliminate HIV and AIDS. Under the United States Agency for International Development (USAID Regional Health Integration to Enhance Services in South West Uganda (RHITES -SW) project, EGPAF works with the Ministry of Health to provide technical support to 808 health facilities in 18 districts. Of these, the project supports 253 TB diagnostic and treatment units including strengthening diagnosis and treatment skills of health workers to save the lives of co-infected individuals..

The project has increased access to effective TB testing using the GeneXpert from 4,254 in 2015 to 51,203 in 2019. To date, the project has also strengthened staff skills and supports the use of the GeneXpert in 26 sites. Further, in order to increase access to effective TB testing in rural areas, especially health centers located in far to reach places, the project set up a network of 29 motorcycle transporters (hub riders) who pick up samples from over 250 sites and take them for testing at GeneXpert hubs. EGPAF has steadily worked to increase community awareness of TB in children; improve health worker skills; strengthen capacity to manage TB diagnostic infrastructure and innovation; roll out contact investigation†; and conduct screenings in high-burden settings.

* only 75% of those treated for TB take treatment as recommended; resulting in decreased responsiveness to ongoing TB treatment and increased risk of TB-related morbidity and mortality among the rest (Ministry of Health (2018). National TB and Leprosy Division: July 2017-June 2018 Report. Kampala, Uganda).

† asking a person who is diagnosed with TB to identify contacts with whom he or she has had close contact within the proceeding months for their name and contact information, then reaching out to those contacts to counsel, test, and care for them.

THE RESPONSE



Health workers training: EGPAF trained 83 health care workers in existing supported sites as trainers in comprehensive clinical TB management in May 2019. This training of trainers cascaded down to all staff of the 253 TB units, with each facility having around 15 health workers trained on TB identification, care and, treatment. EGPAF also trained six village health team (VHT) members at each of the 253 sites on signs, symptoms, and risks of TB, ensuring that these community cadres knew when to escalate presumptive TB cases to clinicians. To support health workers in managing TB, reporting tools were corrected to reflect contact investigation and Isoniazid Preventive Therapy (IPT) initiation and duration.



Contact Tracing: VHTs followed up with contacts provided by those diagnosed with TB in homes and communities for screening. Of the 2,629 individuals with bacteriologically confirmed pulmonary TB in 2019, 1,070 had their contacts investigated. From 3,241 contacts, 777 (32.97%) were found to be presumptive. On testing the presumptive cases for TB, 94 were confirmed to have TB a yield of 12%. During the contact investigation, 973 contacts were found eligible for an HIV test. When they were tested, 40 (4.11%) were found to have HIV.



Infrastructure and Innovation: EGPAF helped the Ministry of Health equip over 26 sites in Uganda with functional GeneXpert machines (molecular test for TB and drug resistant TB that runs a sample on site and provides a result to patient on the day of their testing visit) for effective and fast TB diagnosis. EGPAF also helped to scale-up use of urinary TB-LAM , a point-of-care test that has been recommended for the diagnosis of TB in adult and children living with HIV who are severely ill and/or have a low CD4 count (< 200). EGPAF has scaled up use of TB-LAM in all 253 TB units.



Community awareness: In collaboration with community partners, a communication strategy was devised. This involved using interpersonal communication strategies to reach communities with messages on signs of TB, importance of identification, diagnosis, treatment and prevention. EGPAF also used mass media to reach diverse audiences through radio spots in addition to collaborating with the Ministry of Education to educate school administrators and students on the importance of prevention, screening, and treatment of TB.



Prioritizing high-burden settings: EGPAF provided testing and treatment services to multiple prisons and employment agencies, including mining companies. This focused case-finding resulted in TB testing of over 3,500 individuals with 30 active cases identified, 740 individuals tested for HIV, with 55 HIV-positive persons identified.

In 2019, EGPAF has progressed comprehensive TB and HIV screening and treatment access and counseling. We've also seen the lives of the individuals affected touched in a very critical way. This booklet intends to shine a light, not just on this work, but how this work can create a lasting impact on its beneficiaries.



GETTING TB DIAGNOSIS RIGHT: SAVING NYAKATO

“If you don’t come soon, you may never see me and the baby alive again!” That is all Nyakato could say over the neighbor’s cellphone to her older sister Beatrice.

Nyakato and her two year old daughter, Ahabwe, were in the grip of a debilitating illness that was causing both to waste away. Ahabwe was so weak that she could hardly hold her head up.

Nyakato’s husband had recently died from an AIDS-related illness. As a person living with HIV, Nyakato knew her health was a priority and orphaning her remaining children was not an option. Nyakato was prescribed antibiotics at a clinic near her home in rural Southwest Uganda, but she didn’t feel any progress, in fact her symptoms worsened.

“I would feel something grab me in my chest, and then I would cough and cough and all the stuff inside was so bad,” says Nyakato. “I could hardly walk. In the evening I just lay there—I was sure I would die.”

In the bustling city of Mbarara, Nyakato’s sister, Beatrice, heard a message on the radio about TB—that it started with a persistent cough and that people living with HIV were vulnerable to TB. Beatrice thought that perhaps this was the illness attacking her sister and niece. Beatrice figured that the Mbarara Regional Referral Hospital might

be able to save Nyakato. It is one of the 235 TB diagnostic and treatment centers supported by EGPAF.

The family pooled resources to transport Nyakato to the hospital, where she was diagnosed with TB and referred to a supporting rural clinic—Rwashamaire Health Centre, which is close to her home. The hospital clinician used Xpert MTB/RIF to confirm her diagnosis. Nyakato started her medication and her health rapidly improved. The clinicians also started the tracing process, figuring out who in Nyakato’s life might be exposed to TB.

Sure enough, her baby, Ahabwe, tested positive. “This was no simple achievement [to diagnose the baby],” says Sister Marion Nahabwe, TB Focal Person. “Little children are harder to diagnose because they don’t cough up sputum easily, and even when they do it’s not enough to test with and you may easily misdiagnose. So we checked her urine, using TB-LAM diagnostics, to screen for active TB.” Now Ahabwe is on her third month of anti-TB drugs.

Recently, Nyakato reached out to one of her friends who has been coughing for a while, urging her to see the doctor and check for TB. She tells anyone who cares to listen about how her life was saved as she watches her baby holding her head high, interested once more in everything around her.

A CLOSER LOOK AT COINFECTION: RITA'S FIGHT

Rita is a young woman in Southwest Uganda who has been living with HIV since birth. Both of her parents have died from AIDS-related illnesses. But with the support of her grandmother, Rita has adhered well to her prescribed antiretroviral (ARV) medication, which has reduced her viral load and maintained her health. She was thriving—until a terrible cough started.

Her grandmother, Betty, was puzzled by Rita's cough, rapid weight loss, and swollen lymph nodes. She asked Rita to sit in the sun on the top of a hill every day in hope that the warmth would improve her health. But Rita just got sicker.

Health workers at local clinics were unable to diagnose the cause of the illness. They believed that Rita's health problems were related to her ARVs—perhaps she was suffering because of poor adherence to medication. Rita and her grandmother knew that that was not the case. So they eventually found money and hired a motorcycle taxi (boda-boda) to Rwashamaire Health Center IV, which is supported by EGPAF.

“We didn't know if Rita would make it,” says Sister Marion Nahabwe, a nurse at the facility. “She was so thin, and could barely breathe.”

Upon initial clinical assessment, these health workers also believed that Rita's illness was related to her ARVs. “However, because we had been trained to diagnose and treat HIV/TB co-infection, nurses on the wards were quick to request a TB test before any ARVs adjustments were considered,” says Marion. A sample was sent for testing with the Xpert MTB/RIF, which is an effective test for TB and can also identify drug resistant TB. Rita tested positive for TB.

Rita is one of the many patients who is coinfecting with HIV and TB—and whom TB diagnosis is missed. HIV is the leading risk factor for development of TB, and TB is the leading cause of death among people living with HIV. Ntungamo District where Rita lives, has the highest number of drug-resistant TB cases in the region.

Her grandmother cried with relief. While TB is usually fatal if untreated, a medication regimen made of 4 drugs, taken properly every day, can completely cure TB. The clinicians made sure that Rita's grandmother was also tested. This is known as contact investigation, whereby all people who may have come into contact with the patient are identified, tested, and treated if active TB disease is identified. Rita's grandmother tested negative.

TB is responsible for 30% of deaths in people living with HIV in Uganda. Working with the Ministry of Health through the USAID RHITES- SW project, EGPAF is strengthening diagnosis and treatment skills of health workers to save the lives of affected individuals, like Rita, and their families.

Rita became a favorite at the health center,” says the health center clinician, Charity Asingwire. “She was strong-willed, and we all wanted her to make it. We made sure she got nutrition therapy to help build her strength up. She was already sleeping under a net to protect her from getting malaria.”

Today Rita is one of the 439 HIV/TB co-infected children and youth who have been identified and treated through the support of the USAID RHITES-SW project within the last four years (2015-2019). Rita is feeling better. She looks forward to returning to school and helping out her grandmother take care of their garden and home.

Ntungamo district, where Rita lives, has one of the highest number of drug-resistant TB cases and low case detection levels in the region.³ The World Health Organization (WHO) ranked Uganda among the 30 TB/HIV high burden countries. It is estimated that about 45% of the TB patients are co-infected with HIV/AIDS. TB is the number one killer of HIV/AIDS patients.^{1,2,3}





GRANDPA DAVID KEEPS HIS FAMILY TB FREE

David called his little grandson over the phone every week or so. A few weeks had passed, where he could tell little Robert couldn't stop coughing. Auntie Rose, who Robert was staying with over a school holidays, sounded to have a similar cough. Rose was taking herbs from her local traditional healer and picked up antibiotics at the pharmacy. However the cough persisted.

David asked for Robert to be brought to him. When David saw how much weight Robert had lost, he rushed him to the Rwashamaire Health Center (IV), which is supported by EGPAF through USAID and Unitaid funding.[‡] Testing Robert was difficult because he could hardly produce the amount of sputum needed for conventional TB diagnosis. Children below 6 years cannot produce a sputum and if they can produce a sputum, it is usually paucibacillary (very few bacilli) which can easily be missed by conventional methods. The clinicians had to look at all the signs and symptoms to make an accurate clinical diagnosis.

Robert tested positive for TB and was started right away on an anti-TB drug therapy. Robert's recovery was speedy. He was treated with dispersible, fixed drug combination (FDC) medicine. These FDC are flavored and dissolve easily when added to water for easy consumption by

children. The health center staff asked Grandpa David who else in the family was coughing and they made an appointment to visit the family's home. They explained that Robert likely contracted the disease from someone living with him. During the home visit, the other children tested negative. Then David remembered Auntie Rose and her persistent cough and he called her home. He pleaded with her to go for a test. She tested positive for TB and was immediately started on treatment. Robert is TB free, back in school and Auntie Rose is doing better, too.

[‡] With Unitaid support, EGPAF has been able to further expand its work in TB and pediatrics to implement stronger child case finding practices, and scale up newer to market diagnostics and palatable effective pediatric TB treatment regimens.

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