

MEDICAL ACCESS UGANDA MARKS 20 YEARS OF PROVIDING LIFE-SAVING MEDICINES NATIONWIDE

The AIDS epidemic was a global public health crisis that would come to define the last century. The deadly HIV virus, first diagnosed in East Africa in the early 1980s, fiercely took hold in Uganda, its rampant spread fueled by a combination of labor migration, lack of safe-sex practices, and a high prevalence of sexually transmitted diseases.

Physicians across the country began to see a surge in a severe wasting disease and other rare conditions, but there were no drugs to treat the disease, making an HIV diagnosis essentially a death sentence. And due to a pervasive stigma, people with HIV were often shunned by family, friends and even entire communities.

By the late 1980s, an estimated one in every three Ugandan adults was infected with HIV/AIDS. Given that the virus could be transferred to an unborn child, generations of babies were being born already infected. Initial approaches to protect against AIDS promoted abstinence, being faithful to partners and the use of condoms, but this approach had limited impact on the mushrooming epidemic.



Professor Ely Katabira, Makerere University

"AIDS had become a very big problem in Uganda," said Professor Ely Katabira, a professor of Medicine at Makerere University and one of the first physicians to diagnose and treat HIV/AIDS in Uganda. "People were very scared and didn't want to talk about it. And even many doctors

and healthcare workers didn't want to deal with these patients because here was a disease, we couldn't do anything about."

Fast forward to today – Uganda is heralded as one of Africa's greatest success stories. HIV infection rates hover around six percent – compared to double-digit rates in some African countries – and over one million people are on a combination of medicines known as antiretroviral therapy (ART), which is allowing them to live long and productive lives.

During this time, the world's leading pharmaceutical companies were working tirelessly as the AIDS epidemic waged on to discover and develop the drugs that would eventually tame the disease. Much of Uganda's success centered on increasing access to HIV/AIDS treatment, and over the past two decades, a part of this effort can be traced to Medical Access Uganda, Ltd. (MAUL), the not-for-profit organization that is responsible for negotiating with and acquiring life-saving medicines from the drug companies that make them, storing them, and then delivering them to clinics and hospitals all over the country.

Each month MAUL provides medicines to over 300,000 patients throughout Uganda, many living in hard-to-reach areas. And where the organization's trucks cannot go because of poor roads – no roads at all – MAUL relies on a fleet of nimble motorcycles specially outfitted to carry medicines in a box fixed above the rear wheel or specialized off-road trucks.

From its humble beginnings, MAUL today is a model of success among countless programs throughout Africa designed to help treat patients and stem the spread of HIV/AIDS. As MAUL celebrates its 20th anniversary, this year the organization opened another state-of-the-art warehouse equipped with the most sophisticated technology to manage every kind of medicine, including those that require not only cold storage, but very, very cold storage.

MAUL now obtains and distributes more than 500 different drugs, rapid-testing kits for HIV and tuberculosis, male circumcision kits and other supplies that are essential for a top-line medical laboratory. In 2017 alone, more than 300,000 patients receiving care at more than 200 health facilities across the country received an uninterrupted supply of medicines valued at over US\$160 million.

This is a far cry from MAUL's early days. Twenty years ago, there were just a few HIV medicines available and almost no money to purchase them. Before pharmaceutical



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companies would provide any medicines to Uganda, "they had to be sure about the security of the drug supply and the distribution of the medicines. They had to be assured that patients would get the drugs, and get them on time," said Brian Elliott, former Chief Executive Officer of Axiom International, a global healthcare organization committed to designing and implementing sustainable solutions to drive access to healthcare across developing countries and emerging markets. "We had to establish an organization that would manage and be accountable for the drug supply; and this resulted into the establishment of a non-governmental organization that would be known as Medical Access Uganda, Ltd."

With limited money from a few international funders, MAUL under the leadership of Muyingo was able

to purchase small supplies of the three medicines that were available at the time. Mr. Muyingo set about delivering them himself to clinics in Kampala in an old Nissan Primera, which was loaned to MAUL by the British pharmaceutical giant GlaxoSmithKline (today known as GlaxoSmithKline) and later sold to the organization for US\$1.

"I was my own secretary," Muyingo recalled. "I was the accountant. I was the General Manager. I would drive to the airport to pick up drugs and then deliver them to clinics and hospitals in Kampala," said Muyingo, who continues to serve as MAUL's Executive Director. But he did much more than that.

MAUL was described by The Wall Street Journal in a 2000 article as "an efficient two-person operation that negotiates prices with drug makers, imports the drugs, and keeps track of every physician who prescribes and every patient who uses the medicines. This all happens out of a tiny one-room office on the second floor of a medical supplies warehouse."

Still, these critical drugs were not widely available. The problem was that only people who could afford to buy the drugs out of pocket could get them, and there just wasn't enough money for the country to buy drugs for all the people who needed them. Indeed, per capita income in Uganda was under US\$300 annually, while AZT, the first antiretroviral drug available, carried a price tag of US\$8,000 per patient per year in developed countries.

But everything changed in 2003, when President George W. Bush established the President's Emergency Plan for AIDS Relief – commonly known as PEPFAR – a U.S. government funding initiative created to save the lives of people suffering from AIDS, primarily in Africa.

Because of the high prevalence of HIV/AIDS in Uganda and the country's limited resources, Uganda was one of the program's first beneficiaries. For the first time, money was available to buy medicines for a broad population of people suffering from HIV/AIDS.

"It was on the 19th of February in 2004 that we received the letter that stated we had access to money now to start patients on antiretroviral drugs for free," said Dr. Luyirika, former Executive Director of Mildmay Uganda. And the results were nothing short of miraculous. "Within six months, all the patients who had been lying on small pillows and mattresses in the waiting rooms of health facilities were now all sitting up. It was like people had died and now they were resurrected," he said.

Since it began, PEPFAR has been responsible for saving more than 11 million lives globally and is considered the largest health initiative ever undertaken by one country to address disease.

However, there were still challenges. Stigma remained a big barrier for many patients. "In 2006, I started talking to my patients in this clinic because they were not adhering to the treatment regimen because of stigma," said Dr. Steven Watiti, HIV/AIDS Specialist and Founder of The Watiti Foundation. He had to find a way to make an impact. "So, I started talking about myself and my condition to these patients. I would tell them that I'm on these drugs myself. And this would help them to see that I used to be someone who was very sick with AIDS and now I am okay." It was an effective way to help patients feel comfortable with their treatment.

For patients who go on treatment, the daily dosing schedule must be strictly followed so that the drugs continue to be effective and resistance to the medicine does not develop. This can be a particular

challenge in remote areas like Karamoja region, where clinics treat nomadic populations. "We have a very mobile group of patients here," said Sarah Oria, Associate Supply Chain Technical Advisor, MAUL. "They have to ask themselves – 'Do I take my ART, or do I take care of my cattle?' Taking care of cattle may be their best means of survival, so they travel to look for water and ART is a second option. We want them on drugs for the rest of their lives."

"Ensuring compliance and reducing stigma requires education and flexibility. Remote clinics that serve these cattle herders can be isolated due to seasonal flooding. This has meant that MAUL had to adapt its forecasting models so that six-month supplies of drugs could be provided to these clinics rather than the usual three- to four-month supply," Sarah added.

Over time, more and more patients were receiving ART from MAUL. And with this increase, MAUL was transporting, storing and managing more and more medicines. The fleet of transportation vehicles was growing. "We decided we needed a home of our own and a state-of-the-art warehouse," said Ashraf Kasujja, MAUL's Director of Technical Operations. MAUL's first new warehouse opened at Nakasero Road, and two additional warehouses would follow.

"These facilities have 24-hour security, cold-chain systems for medicines that need refrigeration, and very large back-up generators," Ashraf said. "The benefit is to enable us efficiently receive and warehouse drugs in the shortest amount of

time. We can trace products electronically to prevent shortages and stock-outs."

Over time MAUL began taking a more holistic view of health and the communities it serves and moved beyond simply supplying medicines. MAUL has implemented a rigorous program for training healthcare workers in the appropriate use

and storage of drugs and medical supplies. In the last 10 years, MAUL has trained more than 2,000 healthcare workers across Uganda through its Centre for Health Systems Strengthening.

MAUL saw other problems in the healthcare system that impeded progress even when medicines were widely available. The clinic in Buyege, for example, was lit with kerosene lanterns, which proved to be hazardous. "The corridor was always filled with fumes from the kerosene as it burns," said Dr. Godfrey Sekabira, Medical Officer at Buyege Health Centre III.



Managed Price reductions for firstline HIV treatment from US \$6,450 per patient per year in 1999 down to US \$82 per patient per year in 2018 in Uganda.

channeled to local organizations. Over the years, staff have donated recreation items and basic material needs for orphanages and facilities that care for children, including the Divine Mercy Babies Home in Mbarara, the Jajja Children's Home in Mildmay, and the Moyo Babies Home, among others.

Despite all this success, achieved in just two brief decades, much remains to be done, and MAUL is planning to expand – adding more medicines to treat other chronic conditions and pushing into geographies beyond Uganda.

"We have thought a lot about shaping the long-term future of MAUL," Muyingo said. "We want to diversify our product portfolio and have chosen a number of additional areas to build upon beyond HIV, where we have achieved excellence."

Using HIV as the model, MAUL is now looking at cancer. "Today cancer kills more people than HIV, tuberculosis and malaria combined, so we are looking at oncology as an area where we want to improve access to medicines."

"We are also looking at hepatitis, and we are talking to pharmaceutical companies to widen access to new drugs that actually cure the disease," he said. Four years ago, the U.S. pharmaceutical company Gilead Sciences, Inc., introduced Sovaldi, the first medicine that actually cures chronic hepatitis C, a viral infection that may affect as much as 2.7% (Sonderup, et al., 2017) of the Ugandan population. MAUL has partnered with Gilead to provide the drug at a cost of US\$300, compared to US\$1,000 per pill, or US\$94,500 for a full course of therapy, in developed countries.

At the end of the day, there are still 300,000 Ugandans who are infected with HIV and do not know it. These are people who, for whatever reason, have fallen through the cracks. "We must find them," Muyingo said, "and we won't stop until they are all on treatment."

The work of Medical Access Uganda, Ltd., continues. ■



MAUL has had to traverse the country even to difficult to reach zones to reach the final client – the Patient