

Peter Mugenyi

Kampala, Uganda

Peter Mugenyi is late. A traffic jam has snarled vehicles for blocks around the hotel where we are scheduled to meet. He arrives an hour behind schedule. He is apologizing even before he takes a seat. Years before, he would have left his driver to wait out the gridlock and hopped on one of the motorcycle taxis that clog the Kampala streets. In his retirement, though, with a sick wife and an anxious daughter, he is less adventurous.

He chucklingly acknowledges the change from a career defined by risks. He gave up a comfortable pediatric position in Saudi Arabia to return to Uganda in 1989, returning to his country at the height of the AIDS crisis. He then set about transforming the new Joint Clinical Research Center into one of the most advanced HIV treatment sites in Africa. He accomplished this, in part, by orchestrating the illicit smuggling of anti-retroviral drugs into Uganda.

There are tales of Mugenyi rushing to Entebbe International Airport to demand the release of confiscated ARVs. He downplays the drama, though he seems to enjoy the legend that has built up around his efforts.

“ Some of those are a bit exaggerated, overdramatized. The scene was much more simple and down to earth than that. People were dying and I just had to go and get the medicines. Really there was no drama. It was a desperate situation. Anybody in my situation would have done exactly the same kinds of things.

What was really wonderful was the understanding of people. The vast majority of Ugandans knew their own relatives, knew their own friends, parents, who were dying. The moment those people realized these medicines that were stuck at the airport were for treatment of AIDS, those people who were doing their jobs would turn out to be your partners in trying to get the treatment into the country.

With the ARVs, Mugenyi built one of the largest treatment programs in Africa.

Patients who are coming to me every day, whom I saw dying every day, dying of preventable death, was just unbearable. I am not a confrontational person. I was not out to prove anything. I just wanted to treat patients and to bring something that could at least alleviate their suffering.

I was the pioneer of anti-retroviral treatment in Africa. It was the biggest number being treated in any clinic anywhere on the continent. But it was a tiny, tiny drop of the people who really needed treatment. That's the perspective that should be looked at.

The program's success put Mugenyi in a position to counter a line of argument made by some in former U.S. President George W. Bush's administration. They claimed Africans were incapable of the daily regimentation required for the ARVs to be effective.

That was really a very sad time. Some people were quite cynical, trying to give excuses for their failure to help Africa. Indeed, someone did say that Africa could not manage treatment using anti-retroviral drugs. That they were too complicated. That they were beyond the capacity of Africa to use them. And that therefore the deaths were nobody's fault. That was cynical. That was very sad.

In early 2003, Mugenyi was flown to Washington, D.C., tasked with helping Bush's team draw up the blueprint for what would become the President's Emergency Plan for AIDS Relief.

I was very anxious, extremely anxious that some sort of result materialized. I wanted desperately to get people to listen to us, that we needed help. That the carnage in Africa must stop. That life-saving treatment was available. And that it was a shame that the rich world abandoned the poor to just die a preventable death when the treatment was available, but just out of reach of the capabilities of the developing countries.

I spent several days working with Tony Fauci and advisors of President Bush, looking at the details, looking at the feasibility of the program, and mapping out how it could be successfully*

¹ The AIDS Support Organization (TASO) is an indigenous HIV and AIDS service initiative, registered in Uganda as a non-governmental organisation.

implemented across southern Africa. And addressing concerns that they had. Reassuring various skeptics that this program would actually succeed, it wouldn't be a waste of their money. It would be one of the most successful programs that was needed at that particular time.

I was asked a question: Dr. Mugenyi, we have experts here who are saying treatment is impossible in Uganda and Africa. We even have people who have worked in your own country here with us who are saying treatment is impossible because so many people are already sick and drugs cannot be found. Technical skills cannot be raised to be able to handle this problem. Why is it that you are insisting that in fact it is possible, contradicting so many other experts? My answer was, We are doing it. Full stop. Indeed, some had to come and see for themselves that treatment was being successfully carried out at JCRC.

When Bush announced PEPFAR's creation days later at the 2003 State of the Union address, Mugenyi was seated in a viewing box alongside First Lady Laura Bush. At the moment of the announcement, she turned and gripped his arm as the rest of the audience broke out into applause.

Now retired, Mugenyi has watched with alarm as the Trump administration has moved to dismantle PEPFAR.

The impact has not been fully felt. I think it is still unfolding. If it continues, I think it is going to be devastating. Before PEPFAR, in Africa, we had millions of people die. When PEPFAR started, the death came to a standstill. The people who were in hospitals, overcrowding the wards, just disappeared. The burials, which were taking place every day in the villages, came to a standstill. The people who were on their death beds started recovering and resuming their work. And the orphans that were being created every day just stopped. Now, I am very worried that this kind of situation might reoccur.

There is also uncertainty as to what extent the cut is going to go. It has not been announced specifically what is going to be cut, what is going to remain. The unclarity is another disruption.

PEPFAR was so successful. It is one of the most successful programs ever in health. In fact, maybe within other sectors. Not so many lives have been saved by a single program ever in history that I know of. And with such success, I never imagined that there could be a situation when it would suddenly come to a stop without phasing it out, giving a chance to countries, to governments, to sort of gradually take it over so that people's lives are not affected.

He can predict what is coming.

You remember at the end of President Bush's presidency, the economy seemed to collapse. At the time, some people wanted to drop PEPFAR. It was a very serious threat. We were told at the Joint Clinical Research Center to immediately stop recruiting new patients and support only those who were already on the treatment.

Yet, at the time, so many new patients were still coming in. Within weeks of their announcement that no new patients would be supported, the bad situation started coming back. Queues of patients started descending on us. The scenes that had become rare, started reoccurring. Death started rising because people were not getting treatment.

I was back in Washington. And this time it was a protracted campaign. I met senators in their offices. I met influential congressmen. I worked with some activists in the U.S. to explain our plight. I even had a presentation in Congress to explain that that was a wrong time to stop. That in fact what was needed was to strengthen it. That we are winning, we are on a winning path.

Funding was sustained, if not increased, under the incoming Obama administration. It was enough to develop the program beyond anything Mugenyi ever imagined.

There is a huge number of people who are involved in PEPFAR problems. It's a big number of people. They are in every part of Uganda. And they are carrying out various services around

AIDS. AIDS is not just giving people pills. It is also linked to health education, to prevention and, by extension, to prevention of so many other diseases. In Uganda, when COVID came, it was relatively easy to mobilize people to be able to address the new disease because they were used to mobilizing to address another disease.

Given PEPFAR's obvious importance, I ask if the current disruption could have been tempered if the Ugandan government had made an effort to adopt more of the program.

I think there are two phases to that. The first one is the suddenness, the abrupt stop that does send everything in disarray. The current arrangements coming to a sudden stop will inevitably be very disruptive. And then the second phase is that building up capacity does take time. So not being given the time to take over this program in an organized manner in itself is the second disruption. That's a definition of chaos.

In many African countries, over the last decade, capacity has been built, gradually. More and more responsibility for the healthcare were being taken over by various countries in an organized manner. What is quite worrying is the abrupt nature. The interruption of a smooth process.

Mugenyi is not now in a position to wage another campaign for PEPFAR, but he has advice for those who are.

What needs to be made abundantly clear is that the problem of AIDS is not over. Millions of people are still being infected. It is nowhere near the devastating levels that it was way back in the 1990s, in the early 2000s, where it was being described as a carnage. I hope the program that changed that desperate situation and that allowed the countries to progress and start preparing for their own development and eventually take over, that it is not suddenly disrupted.

It is a successful program, and we should not snatch failure out of it. We are at the last stages of seeing what has been a devastating epidemic being ended and then we sort of allow it back. It is inconceivable.