WORLD AIDS DAY

Ambasáid na hÉireann
Embassy of Ireland

AN EXHIBITION

SATURDAY DECEMBER 1, 2018

UGANDA'S JOURNEY OF PROGRESS TO ENDING AIDS

"You were either infected or affected" - Namubiru Priscilla

This quote has inspired the title of the exhibition and the stories that you will experience. Priscilla is one of the many we interviewed for this undertaking.

Over a short few months the Ugandan Academy for Health Innovation and Impact at the Infectious Diseases Institute in Makerere University, The AIDS Support Organisation (TASO) and the Uganda AIDS Commission (UAC) team joined together to try and capture a snapshot of Uganda's story of HIV/AIDS from the era of 'slim' to the current fight against the epidemic.

A drama show by the TASO Mbarara team

Millions of Ugandans have been infected and millions further affected by the virus and its consequences. To unshackle ourselves from the burden of such profound experiences we must first look back. Through the stories and materials donated to this effort, we are able to see Uganda's journey from the unknown to the load of information on the virus available today.

From film, to newspaper, archives and personal artifacts, this is a mosaic of stories to get us closer to a better understanding of the journey of HIV/AIDS in Uganda.

To curate in this way is a challenge, but with the support of the Embassy of Ireland, which has played a major role in the fight against HIV in Uganda, with a strong stance on prevention, the narration has come to life.

Seeing the scale and depth of such a story our team was tasked with collecting iconic experiences and following patterns of narration to draw out themes and facts.

The storyboard, which you will find on **pages 10-11** follow with an experience that is both the country's and an individual journey.

We invite you to interact with the exhibits and be united in the struggle to end HIV/AIDS in Uganda.

Kara Blackmore,
Curator

Uganda (2017)

1.3m people living with HIV

5.9% adult HIV prevalence (ages 15-49)

50,000 new HIV infections

26,000 AIDS-related deaths

73% adults on antiretroviral treatment*

68% children on antiretroviral treatment*

*All adults/children living with HIV

Source: UNAIDS Data 2018

Highlights

Foreword from the Irish Ambassador

Strong Government leadership and impressive progress

HIV and AIDS have long been at the heart of Ireland's development programme. We are extremely proud to have supported efforts that saw prevalence in this country reduce from a high of 18% to 6%. Today, Ireland invests almost a quarter of its 5-year budget (€20 million) to support the Government of Uganda in its fight against HIV, which is more important than ever.

Before coming to Uganda and as former Ambassador of Ireland to Mozambique, I was very aware of the high level political leadership and commitment to the HIV response in Uganda, still very much alive through the Presidential Fast Track Initiative. However, success can lead to complacency and with 950 new infections every week, complacency can be a very dangerous thing. While yearly infections have reduced dramatically 90,000 - 46,000, the number remains the sixth highest in the world.

Since 2006, Ireland has invested over 20 million Euros to support the fight against HIV in Uganda, funding both the national and district local governments. The role of civil society has also been a critical component of our investment into prevention through the Civil Society Fund from 2008 to 2016. Today, we continue to work closely with UNAIDS and nine other UN agencies to support the HIV response in Karamoja and we also fund the Uganda AIDS Commission to coordinate and strengthen the multi-sectoral approach to the response.

As a founding member of the Global Fund to Fight AIDS, TB and Malaria, Ireland is also a strong advocate for increased investment in the HIV response and health systems at a global level. The

Ambassador William Carlos

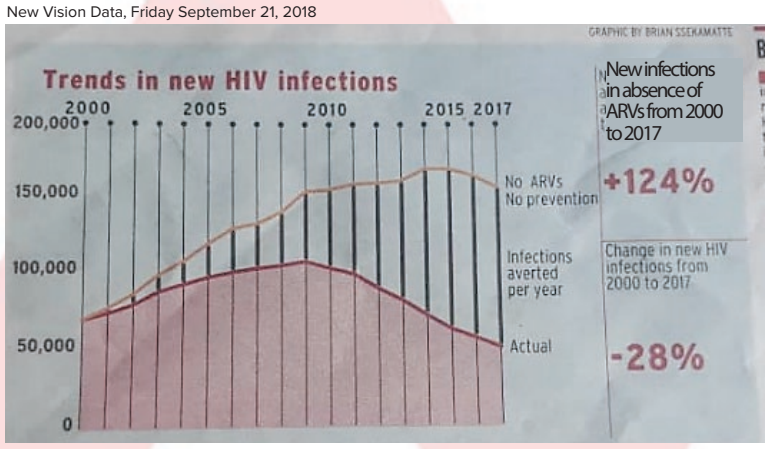
Global Fund has so far provided over $530 million to Uganda. Ireland remains an active voice in the Global Fund board to ensure funding goes where it is needed and in Uganda, we support the Global Fund Country Coordinating mechanism (CCM), where we are an active voice as board alternate.

Ireland has always been a strong voice on prevention and we are concerned that efforts to tackle structural factors have reduced in recent years. These include forced and early marriages, gender-based violence, alcohol consumption and economic

"Success can lead to complacency and with 950 new infections every week, complacency can be a very dangerous thing."

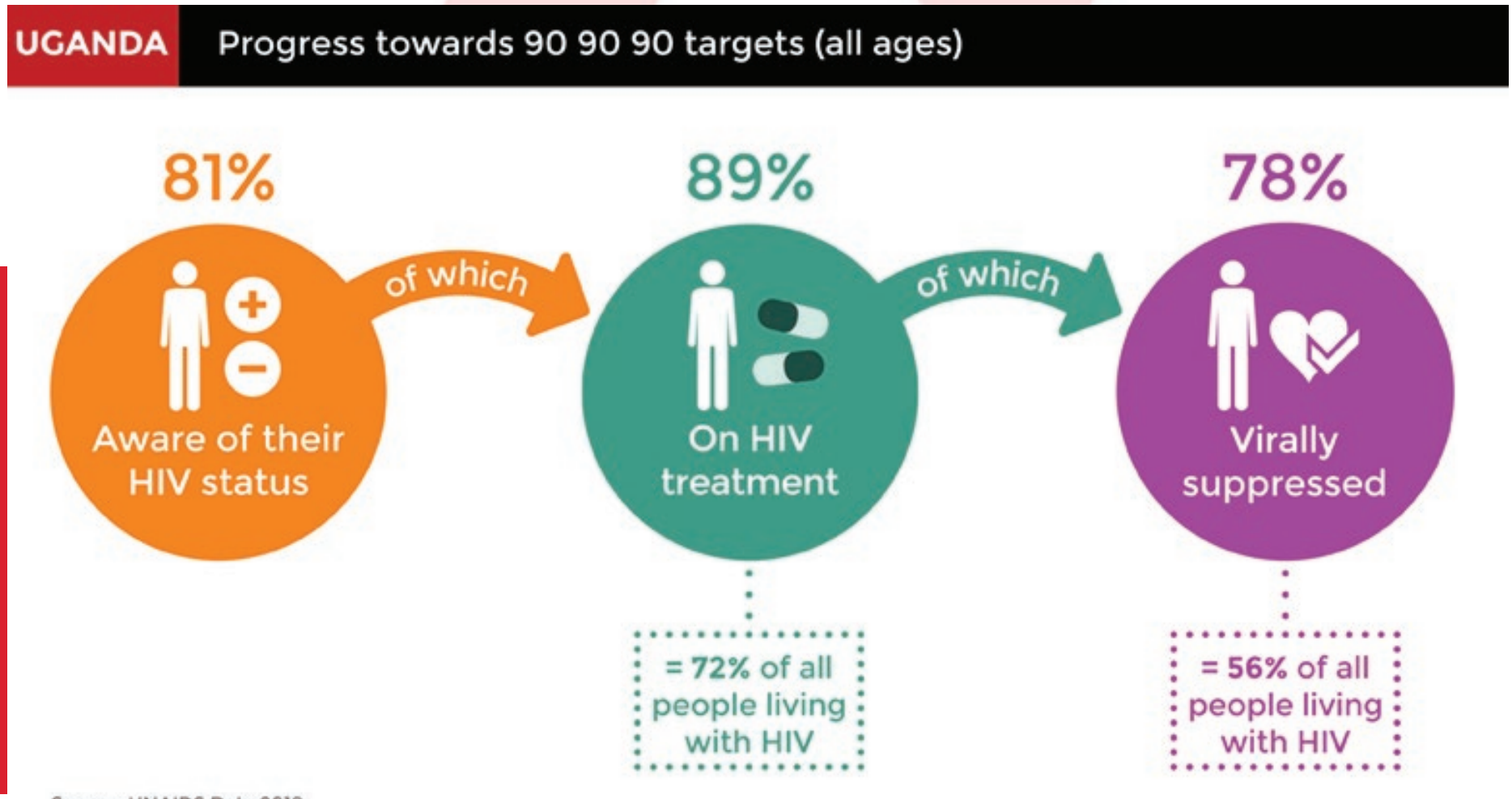
vulnerability. Prevention must include both bio-medical interventions and actions to address socio-cultural barriers. Ireland believes that a successful response to HIV requires a multi-sector approach. To give one example, a key driver to counteract the epidemic remains education. Girls with post-primary education are five times more likely than illiterate women to be educated on the topic of HIV and AIDS. There are many drivers of the epidemic which require us to have a comprehensive, multi-dimensional response. Through our engagement in Karamoja, we also observe a rise in alcohol consumption, which could cause a resurge in infection rates and so we must invest on many fronts.

New Vision Data, Friday September 21, 2018



As the epidemic landscape has changed, so too must our response. We need to work harder to reach the youth of Uganda, where coverage of prevention efforts is most uneven. With over 70% of Uganda's rapidly growing population made up of young people, harnessing demographic dividends is key and that means ensuring a healthy, educated population. Through a partnership with NGOs Straight Talk Foundation, TASO, AMICAAL and NAFOPHANU, Ireland supports specific interventions to reach adolescents through youth friendly corners in health facilities to reduce HIV infections. I have been inspired and impressed by so many individuals in Uganda, who are living positively and remain engaged in community mobilization and resource mobilization. However, I am also aware that levels of stigma among young people remains high and can be a barrier to getting tested and seeking treatment.

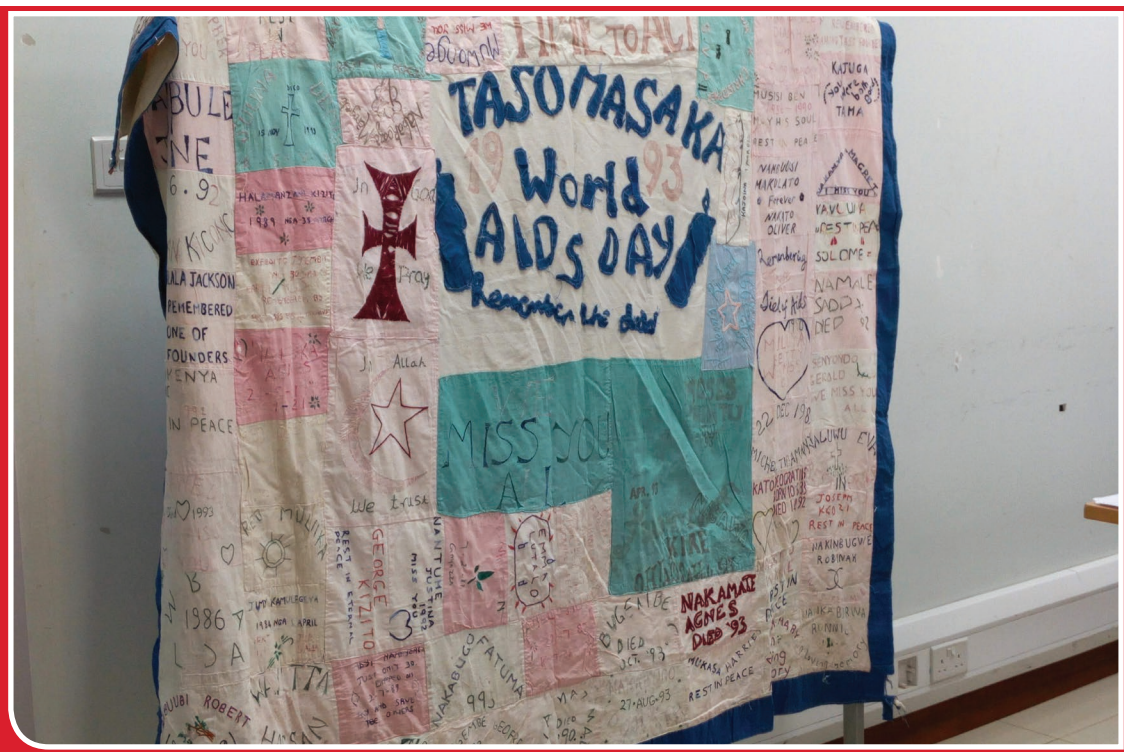
As we mark thirty years of World AIDS Day, it is important to take stock and see how we as partners can get to zero new infections, building on our successes but mindful of the remaining challenges. 90% of the HIV response in Uganda remains externally funded and so it is critical we make progress on domestic resource mobilization to ensure sustainability of the approach. We must also continue to strengthen the synergies in a multi-sector response, seek efficiencies and coordinate better to achieve more. Ireland will continue to support the Government of Uganda and its partners to achieve our shared SDG ambition of ending the HIV epidemic by 2030.



Years of The AIDS Support Organisation

Dr Michael B. Etukoit

Executive Director, TASO



President Yoweri Museveni, pictured at the openning of a TASO centre. The quilts were made by families in memory of loved ones lost

The history of HIV in Uganda, is interwoven with the history of The AIDS Support Organisation (TASO). For the past 31 years TASO has worked with individuals, families and communities infected or affected by HIV and AIDS, AIDS Development Partners and the Government of and beyond the borders of Uganda.

The Beginning

In 1987, while Uganda was recovering from a protracted war, with a new Government in place, a group of people, some of whom were infected while others had lost friends and family to AIDS, came together to form a support group. This group was registered as a membership organization in 1991 and The AIDS Support Organisation (TASO) was born. The first clients were patients abandoned by their relatives either on a hospital bed or laying on the grass in the hospital compound. While these patients had different faces, family history and cultural background, they had one thing in common; they had a disease which nobody could identify.

From a small family support group, it expanded into an organisation with 11 Centres of Excellence in 11 districts; Gulu, Jinja, Kampala, Masaka, Masindi, Mbale, Mbarara, Rukungiri, Soroti, Tororo and Wakiso, with a high disease burden in relation to AIDS. These districts were located in major transport corridors and because of the subsequent creation of new districts from all of them, they have grown from the original 11 to over 30 districts.

The TASO philosophy

TASO was built on the philosophy of living positively with HIV and AIDS also referred to as Positive Living. This means that all people should have a collective and positive attitude towards HIV and AIDS and understand that it affects anyone, regardless of age, race, religion or sex. TASO has a vision to see a world without HIV or AIDS and is on a mission to contribute to a process of preventing HIV, restoring hope and improving the quality of life of people, families and communities infected and affected by HIV infection and disease.

After partnering with the World Food Programme and the US funded ACDI/VOCA to provide food supplements to its clients and realizing that this was not a sustainable intervention, TASO developed an exit strategy and introduced the Sustainable Livelihood Programme. Under this programme, clients were equipped with different income generating and entrepreneurial skills.

Hope at the end of the tunnel

Uganda adopted the Global UNAIDS vision of Fast tracking ending AIDS by 2030; this includes Zero New Infections, Zero HIV related deaths and Zero discrimination. Uganda also adopted the UNAIDS 90:90:90 treatment targets i.e. by 2020, 90% of all people living with HIV will know their HIV status, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and 90% of all people receiving antiretroviral therapy will have sustained viral suppression. I would like to say that Uganda is on course to achieve these targets by 2030.

According to Uganda AIDS Commission, after the rigorous implementation of the HIV combination prevention approach, the number of new infections dropped from 99,000 (2010) to 52,000 (2016).

What next after the exhibition?

In January 2018, The AIDS Support Organisation (TASO) began implementation of a new strategic plan 2018 - 2022. In this strategic period TASO will operate under the guidance of three major goals. This exhibition falls right into goal number 3 of this strategic plan which is; Develop an Effective Knowledge Management Hub: TASO has gained a wealth of knowledge and experience over the last 3 decades. It intends to optimize this knowledge to empower others in the fight against HIV/AIDS and to seek new and better methods of preventing, caring and treating others, supporting families and communities and strengthening health infrastructure; TASO is working to establish a Museum of HIV/AIDS through which it will share its models of service delivery, lessons learned and challenges faced.

A preservation of the hard earned lessons of decades combating HIV/AIDS could in future be used to shorten the pain and anguish of new epidemics by containing them in a shorter period of time or achieving a quicker elimination.

Appreciation

TASO would like to express its sincere and heartfelt appreciation to all its donors past, present and future who have enabled it to keep the candle of hope burning.

OVER THE LAST THREE DECADES STRIDES TOWARDS ENDING THE EPIDEMIC BY 2030

1980s This was a time of great fear, denial, mistrust and stigma in Uganda. While the political arm was battling with the unknown disease killing off those who had survived the war, the medical fraternity was trying to find a cure and the population was ripe for any solution.

The Ministry of Health HIV Testing Policy (November 1990), reported that all districts in Uganda had reported cases of AIDS by the end of 1989. In only 7 years, the disease had spread from the first cases identified at Kasensero Landing site – Kyotera (in 1982) to the rest of the country. These statistics were collected from only women at the Antenatal clinics. The number of men infected could only be estimated. Cases of AIDS related death were reported in the communities either as death due to “witchcraft” or due to an unknown disease. It is upon this background that TASO founders decided not only to care for those infected, but also their family members who were affected by HIV and AIDS and facing very high stigma and discrimination.

During this time, TASO extended its services from Kampala to other districts in the country. It also began conducting training for HIV Counselling.

1990s Since seven of the founders were themselves living with AIDS, TASO decided to employ them to offer services within their field of expertise such as management, psychosocial support, finance and administration. This led to the myth that all those working in TASO are HIV positive. Most people do not know that most of the 16 founders were NOT HIV positive.

After the late Philly Bongole Lutaaya visited TASO, clients were trained in Music, Dance and Drama for community sensitisation. TASO expert clients have travelled across the globe to speak to high level decision making bodies and give a face to HIV and AIDS. Notable among these were Olivia Nantongo (RIP) who addressed the US Congress. Many have made presentations during the various international AIDS conferences.

A group of adolescents and youth, whose parents had died or were living with HIV, set up a peer support group with support from TASO. This was called the AIDS Challenge Youth Club. This club encouraged formation of school chapters within different schools and information material was provided by Government PIASCY programme. It also laid the foundation on which the Straight Talk Foundation was built.

2000s The earlier part of this period saw the introduction of Antiretroviral Therapy into Uganda. This is the time when more people with typically non-medical training began serving in the medical field. For example, TASO trained family members as medicine companions, it recruited and trained social workers to deliver ARVs to bedridden patients and to conduct HIV testing and counselling together with clinicians.

Lest we forget: Let us emulate our pioneers and heroes in the HIV response

Dr. Andrew D Kambugu
Executive Director, Infectious Diseases Institute, Makerere University

Innocent Kwebiha aromatherapist at TASO administering the a massage with essential oils to a patient. During this time many medical workers were not known to touch patients

The image of an emaciated, deathly pale man with curly hair and thick sunglasses is firmly etched in my memory to this day. It was a warm afternoon in 1989, at a leading school in Uganda, and I was one of the terrified teenagers listening to the strong voice of this forlorn figure, warning us about the reality of AIDS based on his personal experience. The man identified himself as Philly Bongole Lutaaya. He had hit the Uganda music scene thick and fast in the mid-eighties and most of us in the audience were in awe of his musical genius. In that moment, HIV/AIDS ceased to be a notion, a headline in the news, a story. HIV/AIDS was a reality, personal and terrifying.

With hindsight, it is not hard to imagine what great courage and selflessness Philly summoned in order to translate his personal trials and tribulations related to his AIDS diagnosis into a powerful national awareness campaign. How many did he encourage to be strong and to face a certain death with dignity? Have we fully appreciated his contribution to bring home the reality of a dreadful disease that could be thwarted by making informed choices?
This and many other stories, of courage, vision, selflessness and of challenging the standard narrative, may be lost to current and future generations unless me make concerted and deliberate efforts to preserve them.

Uganda is one of the youngest countries. With a median age of 15.5 years, more than half of the country population have no personal recollection of the beginnings of the HIV/AIDS in Uganda and the initial response to this deadly threat. Many have not witnessed the horror of a slow, excruciating, and dehumanising death that millions of Ugandans experienced at the hands of HIV/AIDS. And these were no strangers; they were cherished sons and daughters, dedicated fathers and mothers, dear friends and colleagues, classmates and workmates with great promise, teachers, health professionals, farmers, uniformed service personnel, rich, poor, hardly any family or segment of society was spared from this nightmare.

If Philly Lutaaya and countless others who lost the battle to AIDs were to somehow be transported back to the present time, they would be pleased to note that a diagnosis with HIV infection is no longer a death sentence. They would be hard-pressed to find emaciated deathly figures covered in sores and confined to dark spaces waiting for the inevitable end to come. With over a million Ugandans on antiretroviral therapy, HIV has become a chronic manageable condition. And the icing on the cake is that on top of enabling the recovery of the protective immune system, antiretroviral drugs once taken appropriately will make one much less likely to transmit the virus to another. Effective HIV treatment for the individual is also prevention for that individual's sexual network.
We thus have a generation that, having not had first-hand experience of the deadly devastation occasioned by AIDS, may effortlessly take for granted the great progress that has been made in HIV prevention and treatment. It is not hard to imagine that in this context, complacency may set in, setting up a recipe for disaster. This is not far-fetched as we see glimpses of it in other settings.

"We thus have a generation that, having not had first-hand experience of the deadly devastation occasioned by AIDS, may effortlessly take for granted the great progress that has been made in HIV prevention and treatment."

A vivid example of the consequences of complacency is the recent resurgence of another sexually transmitted disease (syphilis) in young populations in urban Western communities when effective measures for HIV prevention including pre-exposure prophylaxis become readily available and accessible.
With no credible solution for AIDS in sight in the eighties and nineties, Ugandan society, like other societies, responded by isolating and stigmatizing individuals, families and communities affected by AIDS. This dark episode was soon challenged by pioneering spirits, individuals and communities, who sought to make a difference and who were determined to change the narrative. Their stories need to be told, preserved and venerated.

Having immersed myself in the HIV/AIDS response over the past decade and a half, I am aware of countless stories that need to be told. My mentor over the years, Prof. Elly Katabira, the pioneer in providing HIV care and treatment and who inspired many of the HIV/AIDS care and treatment efforts in Uganda and the African region, has a great story to tell. As the Co-Chair of the advisory board at the Ugandan Academy for Health and Innovation and Impact at the Infectious Diseases Institute in Makerere University, Elly has continued to contribute to that story. As the current IDI Executive Director, I am extremely delighted and proud that The Ugandan Academy is working with TASO and Uganda AIDS Commission to host an exhibition on the HIV response over the past 30 years at the Uganda Museum from the 1st of December 2018 (World AIDS Day).

Like Prof. Katabira, who is one of its founding members, the IDI is a pioneering effort that currently serves one in three Ugandans living with HIV and is a leading implementing partner of the Ministry of Health in the area of comprehensive HIV/AIDS programming. IDI provides district-based HIV programming for 3 specific regions (Kampala/Wakiso, Mid-Western and West Nile Regions) using US government resources (PEPfAR) through the US Centres for Disease Control and Prevention (CDC). The IDI, a brainchild of the Academic Alliance for HIV/AIDS Prevention and Treatment in Africa — 9 Ugandan and 5 North American physicians- has emerged as a credible model for utilising the considerable academic capacity at a leading institution of higher learning to meet significant real-world societal challenges.

In my view, we need to deliberately commemorate, recognise, celebrate and emulate these pioneers and their concerted efforts. There is no shortage of ideas on how we could do this. From naming opportunities for buildings, roads and other infrastructure, to invited annual lectures and events and to coveted university professorships and chairs.

As we approach the 1st of December, let me use this opportunity to salute these pioneers in the Ugandan HIV response and to voice my profuse appreciation to all our partners in this great documentation effort of the History of HIV/AIDS in our country. We are grateful to the Embassy of Ireland that has provided the funding which made this initiative possible. We are greatly indebted to Dr Chrisine Ondoa, Former Minister of Health and Executive Director Uganda AIDS Commission, as well as Dr Michael Etukoit who envisioned this project at an Academy brainstorming session. The team including colleagues at The AIDS Support Organisation (TASO) and Uganda AIDS Commission (UAC) and our curator Kara Blackmore have worked extremely hard to collate this extensive and rich repository of reference materials. However, this would also not be possible but for the generosity of time and loan of materials from many of our other HIV implementing partners, NGOs, researchers and "Icons" of the HIV response who have supported this initiative.

+On behalf of all my co-workers in the HIV/AIDS response at the Institute, I would like to reaffirm our collective pledge to tirelessly continue investing in the future and impacting real lives; and as part of the Makerere University community to echo our commitment to Build for the Future.

For God and My Country

Take some time to reflect on your personal journey

Dr Rosalind Parkes-Ratanshi
Director at The Ugandan Academy

In my interview to enter medical school I was asked to talk about a medical problem that fascinated me. I chose to talk about HIV. It was 1991, 7 years after the HIV virus has been isolated. It was 4 years after the first HIV drug had been developed and Princess Diana has visited AIDS patients in a London Hospital. There had been a massive and controversial TV advertising campaign with tombstones and icebergs that a generation of young people in the UK have never forgotten. Much was still unknown about transmission and there was no effective long term treatment. In the UK we were just starting to learn about how bad the problem was in sub-Saharan Africa, but in Uganda people who are now friends and colleagues were already losing their loved ones to HIV. Despite having never met a person living with HIV, HIV was firmly embedded in my future career plans.

My first patient
I looked after my first HIV patient at the Royal London Hospital in 1997. He was a young man terrified of us even writing that we were testing him for HIV in his medical records. The stigma, rather than his illness, is what I remember most about trying to look after him; as a junior doctor I felt helpless in calming his anxiety.

Uganda
When I first came to Uganda in 2003, I was privileged to be working at the Medical Research Council Unit in Masaka where we set up a research clinic alongside TASO Masaka. TASO's first ARVS came to Masaka and it was incredible to see the recovery of those first patients. Unfortunately, some people were too ill to be saved. We had just started testing for CD4 counts and I remember the sinking feeling in my stomach of opening results with CD4 counts of 1, 4, or even 0, knowing that even with ARVs these people would struggle to make it. (CD4 cells are white cells that are an essential part of our immune system but are killed by HIV. CD4 counts are the marker of how severe and late the HIV infection is.) With those low CD4 counts the first few months of ARV treatment were really tough and people died. On the other hand ARVs were so rationed that you found yourself hoping that someone had a low CD4 count so that you could get them on treatment as soon as possible. But even starting people on ARVs was scary. I remember terrible side effects – allergic reactions where people's whole skin became red and angry and their eyes closed up, painful peripheral neuropathy making walking difficult. We were studying how to prevent cryptococcal disease, which killed people with horrible headaches.
Occasionally there was time to reflect and remember; I will never forget standing on the grass between our clinic and TASO Masaka hearing the TASO anthem for the first time. It was so haunting and moving but still hopeful. With drama groups becoming rarer these days we must not forget how dance and drama can be such a powerful tool for the group members, PLHIV and their relatives as well as health workers. Dance and drama communicates, it inspires, it helps us to grieve and to survive.

Luckily, with really effective ART and a massive country response we are in a very different place to the start of the epidemic 30 years ago or even the start of the ART roll out 15 years ago. However, we must never forget how fragile our gains are. We have 1.1 million people on treatment, but we are still missing over 200,000 people who are at risk of deaths that we are able to prevent.

40,000

People – including many young women and girls to get infected every year

"It felt like a war against HIV, and we lost many brave people who fought so hard along the way. Unfortunately, some people were too ill to be saved"

We still are allowing over 40,000 people –including many young women and girls to get infected every year. If we lose international support for HIV programs people may not be able to access life-preserving ART. We must keep working to reach those not on treatment, to prevent new infections and sustain the treatment for those that are doing well.

The exhibition
When this exhibition was suggested by the Ugandan Academy of Health Innovation and Impact advisory board members (especially Hon. Dr Christine Ondoa and Dr Michael Etukoit) I was really excited. On a personal level, I am happy to be working with the Uganda Museum, which I feel is an often overlooked national treasure that I spent many happy hours in with my children when they were small. More importantly I feel that understanding our HIV journey is important for our young people.

Over 50% of our population are young, but many do not remember seeing people with "Slim". The horror stories such as whole families being wiped out, or using all your money to buy ARVs week by week to survive are in the past. But we must preserve these memories, so that we understand what it took to make these gains. The Academy social scientists, Dr Rachel King and Dr Phoebe Kajubi will be undertaking some research to capture the responses to the exhibition of over 500 young people we hope will visit over the month of December.
We also urge you to bring your family and friends – the exhibition is here until 21st December and is free to enter.

Thank you
We would like to give thanks to the Embassy of Ireland especially Aine Doody, Jackie Katana, Lorraine Gallagher and Eimear McDermott who listened to our wild idea and made it a reality. To Sylvia Matovu from TASO for her patient and dogged hunting down of all the people and objects she could find, and to Dr Etukoit and the TASO board for offering permanent space for the exhibit in the long term at TASO, for the Academy team (Diana Asimwe-Bena, Tracy Ahumuza and Ruth Nalunga) for their co-ordination and perseverance. Especially, thanks to Kara Blackmore for her expert curatorial skill and insight; without her this exhibition would be a random collection of bits of paper rather than the coherent and moving experience it is.

Finally, we would like to thank all the many people and organisations-both icons of the fight and those living with HIV everyday who have contributed their time, items and memories to this collection. We thank you as visitors for joining us at the exhibition and we hope you learn something new. Most importantly we request that you use the exhibition to take some time to reflect on your personal history with HIV.

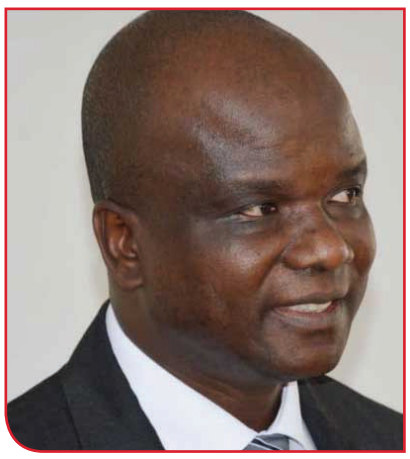
Coordinating the HIV response over years

Uganda is reputed all over the world as a pioneer and leader in the fight against HIV and AIDS. This reputation was attained due to the leadership of H.E Yoweri Kaguta Museveni who personally led the national campaign against HIV and AIDS in the late 1980s and 1990s that significantly shaped the story of the HIV epidemic in Uganda, in an era of limited HIV treatment. By his example, the President inspired other leaders- political, religious, cultural or civic, at all levels, to show leadership in the fight against HIV and AIDS in their constituencies.

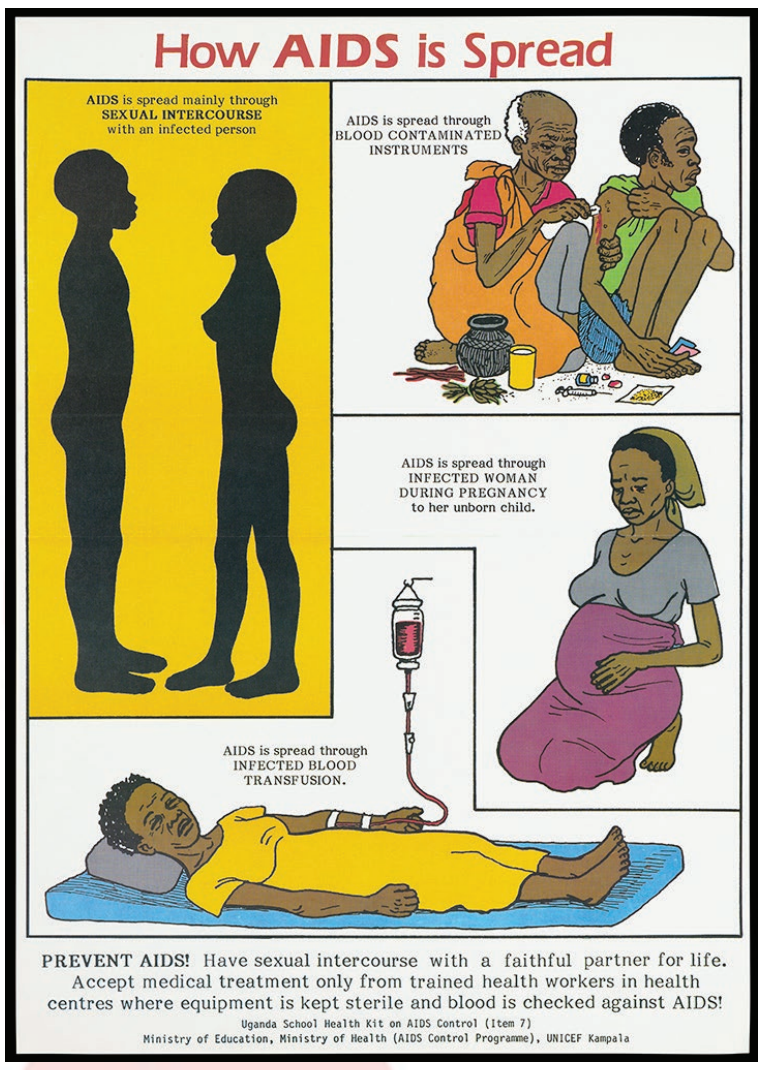
In 1992, the Uganda AIDS Commission was created by law of Parliament to coordinate HIV/AIDS multi-sectoral response. Many representatives from countries all over the world came to Uganda to learn and be inspired by our experience. Indeed, HIV prevalence had markedly reduced from 18% in 1995 to 6.4% by 2005.

However, between 2005 and 2011, several of the gains were reversed due to complacency. Uganda lost its focus on behaviour as the centerpiece of our efforts to reduce new infections. The population became complacent probably due to the advent of ARVs and as a result, the number of new HIV infections in Uganda increased by 21% between 2005 and 2011.

HIV and AIDS continue to pose a big challenge in Uganda. Approximately 1.32 million people are living with HIV today with 1,141,489 on antiretroviral therapy. Although markedly reduced, 50,000 new HIV infections were registered in 2017 and 20,000 people also died of AIDS-related causes in the same period. Of concern is the disproportionate number of new infections among young people and, in particular young women and girls. The impact of HIV has also spread across to the economy. Analysis shows a reduction of the Gross Domestic Product (GDP) growth rate as a result of HIV. Without HIV, the GDP was projected to grow by 6.5% per year until 2025. With HIV, the annual growth rate is reduced to about 5.3% over the same period. Overall, with HIV, the economy will shrink by 39% by 2025 (Macroeconomic Impact of HIV study, 2007).

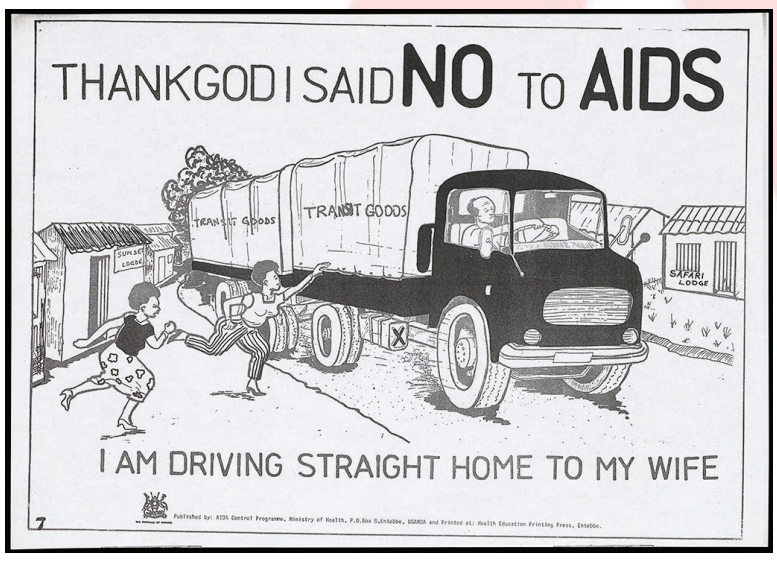


Dr Nelson Musoba
Director General, Uganda AIDS Commission



In June 2017, His Excellency launched the Presidential Fast-Track to end AIDS as a public Health threat by 2030. This was intended to act a catalyst to the various interventions being implemented by stakeholders.

Uganda, like the rest of the world is committed to ending AIDS as a public health threat by 2030. This calls for acceleration of efforts to combat the epidemic at an adequate scale of interventions that have been known to produce desired results.



Among so many factors drive the HIV epidemic including: gender inequalities, cultural and traditional factors, marriage and family values, poverty and wealth; concurrent and multiple sexual partnerships, discordance and non-disclosure, transactional and commercial sex, low, incorrect and inconsistent condom use, alcohol, substance and drug abuse, stigma, limited powers to negotiate safe sex, human rights and discrimination, permissiveness and moral decadence as well as limited male involvement, among other factors which have provided a fertile ground to sustain the epidemic in Uganda.

"The fight against HIV/AIDS will be easier if people know their HIV status."

The fight against HIV/AIDS will be easier if people know their HIV status. We can only end AIDS if we know our HIV status and the only way to know is to take an HIV test. Through taking an HIV test, an HIV positive person will be started on medication, taken effectively to reduce viral load and therefore less likely to infect an HIV negative partner. On the other hand, a negative person should guard against getting infected. Mothers have done a lot in preventing mother-to-child transmission of HIV, but of what use is it to bring children up only to lose them when they become sexually active?

HIV is around and it still kills. It is the responsibility of each individual, especially those below the age of 18 years to abstain from sex until they are ready for the consequences and responsibilities that come with sex. It is also important to note that just because your friends are having sex does not mean you should have sex because the consequences are not shared among friends.

It is a responsibility and should be in the interest of every adult to be faithful to their sexual partner. Every adult should protect themselves and their partners by testing, knowing their HIV status and using a condom. Everybody should refrain from discriminating against persons living with or affected by the AIDS disease.

Voices on positive living

"Before I had multiple sexual partners but now ever since I was taught I realized that it is my life that I am wasting then I stopped. Even if a man comes to me with money I still say no. but before (haha) I used not to refuse, I would think "after all I am already infected"

(Female, 23 years).

"Some HIV positive people should be explained to. When they find out they are HIV positive, they think it is the end of the world for them, yet they are healthier than one who has not yet found out their status. I want to encourage them so that they remain strong and know that they are still alive. Because someone who is sick is bedridden, but you are alive and well and able to work, which means you are not sick.

(Male, 24 years).

Before, I hated my life. I did not care about taking my pills. I did not matter whether I skipped my pills for the day or spent a week without swallowing. Sometimes it is hard to get food so I end up not swallowing them. But now, even if I have just water, I take my dose knowing I will get some food in the morning."

(Male, 22 years).

The Genesis: Digging into the archives

Sylvia Matovu
Librarian, TASO

Sylvia, during the collection of materials and plotting of the timeline at a stakeholder meeting in August, 2018

The journey for this project began in January 2017 while I was doing some short term assignments for The AIDS Support Organisation (TASO). I was assigned to set up a TASO museum. In addition to that assignment, I requested to re-organise the now TASO College of Health Sciences library and to set up an information archive. My idea was that the old library material would be archived and the information in storage used to set up the historical museum.

While doing this, I was asked by the TASO Executive Director - Dr Michael Etukoit, to contact the Ugandan Academy for Health Innovation and Impact, based at the Infectious Diseases Institute (IDI). We were to write a joint proposal to organise an exhibition on old IEC/BCC material developed in Uganda or for Uganda during the 1980s and 1990s. As a member of their advisory board, he had mentioned that TASO was going to set up a museum. The other members, had suggested that an exhibition would be a great prelude to the museum.

I contacted the Ugandan Academy and was asked several questions as to why TASO wanted to set up a museum. Top on my list, as an information scientist, was to share information from TASO that has never been made public or that has been forgotten by the public, information I felt could enable people and organisations to learn more from TASO. It would provide a great educational place for all things TASO and HIV-related. Dr Etukoit's public health and managerial point of view was that, if HIV was expected to end as a health epidemic in 2030, then TASO was the right organisation to showcase what has been done over the last 31 years of its existence. These answers and many more ideas shared during the subsequent meetings, were the foundation upon which this exhibition was built. Our first proposal was not successful but the second one, submitted to the Embassy of Ireland, came through. For this amazing journey so far, I say thank you to the Embassy Ireland for this great opportunity.

What made my work easy?

Several things. While we were re-organising the TASO Library, we had put aside several items that could be used for the museum. Therefore, by the time I had to identify material for the exhibition, nearly all of the old material had already been identified and put aside.

I thought back to the AIDS sensitization I received while in primary and secondary school; the drama competitions for "The Riddle" and "The Hydra", the posters, the sounding of the drum on radio and plays like 'Gampisi' and 'Ndiwulira'. I knew that for generations younger than I am, these were myths.

My parents have both supported the fight against HIV in different capacities. However, it is because of my father, a former politician who began this work in the 80s as a Resistance Committee Chairperson that I remembered the handbooks, manuals and posters he had to carry around for community sensitization. I looked for and found copies of these at the ministries of Health and Education libraries. My father had also worked with the Uganda Virus Research Institute in Entebbe and as a biologist, health is his interest. I asked him to tell me specifically about the setting up of the parliamentary committee on HIV and establishment of Uganda AIDS Commission.

I had also had a chance earlier, while doing my post graduate in London, UK, to visit the Wellcome Library. Our host used examples of posters on HIV from Uganda. Imagine my joy when I saw that someone had kept what I did not even know I would need several years later.

As a health librarian, I used my network of other health librarians to search for possible sources and contacts. My 14 years of service with TASO meant I knew most of the people, organisations and the material that was used for communication on HIV and AIDS. One of those people is Ms. Susan Candiru who is in charge of information and knowledge management at the Uganda AIDS Commission. The other was Ms Sylivia Nabakka at the TASO College of Health Sciences in Kanyanya.

A lot of the information was also drawn out during the two stakeholders' meetings, visits to veteran media personnel such as Bart Kakooza (MediaPlus) and David Mutu (Uganda AIDS Commission) as well as informal talks with people who preferred to be interviewed off-the-record.

What was it like putting together all this material?

In no particular order it was fun, hectic, exasperating, inspiring and generally worth it. I never thought I would have reason to collect old material. I did not think that I would be excited over an old records book showing people who tested for HIV in 1989 regardless of their sero status. Neither did I think I would have to interview my parents' contemporaries and my former bosses. But there we are. Video interviews with them gave us invaluable insights into the challenges and lessons they learnt when HIV/AIDS, which would quickly spread like a wild fire, had just been discovered in Uganda. They also gave us the historical background of many of the lead organisations in Uganda in the field of HIV.

During the stakeholder dinner, many pictures like this of a group of HIV positive members of a drama group that dramatised the scourge. The picture was taken by Michael Jenssen

Working with the team

On the team of organisers are some of the best "databanks" in Uganda as regards to HIV/AIDS. They have names, contacts, networks, history, background, ideas, motivation, skills.

We started out only three people doing the brainstorming and leg work. We had only one gentleman, Dr Ronnie Kasirye, who sadly left before the project was completed. He was replaced by Mr Ivan Katwesigye who came in as a volunteer for records management. This still left a team of about ten (10) women to organise what you see today.

Along the way, I have witnessed some really fancy ideas, some of which have evolved to what is in the exhibition. Our only limitation thus far has been practicability in terms of resources, time, accessibility to material and individuals with stories to allow us to present what we have on display today. Rather than trace the history of HIV in Uganda, we collected as much material as possible and let it guide us on what to do.

How many people have listened to the personal stories of the doctors who treated HIV patients when they did not know what they were treating and that the patient had no hope of survival? We tend to look at the professional side and forget that as human beings, they too are affected.

We have been to organisations, met people, collected material, listened to some really personal stories that might never had been shared and hopefully what we have put together compels you to go take an HIV test or encourage others to ensure that Uganda is not among the countries still reporting HIV-related deaths.

Appreciation

A big thank you to all our donors, these include those we interviewed or planned to interview, those who emailed, those we visited, those who sent material and those who called or made a verbal contribution. Every bit contributed to the final picture.

To the team I have worked with on this, thank you for letting me be part of such a creative, dynamic and all round inspirational team. I make special mention of the curation team led by Ms. Kara Blackmore and including Ms Candiru, Ms Carol Nansumba, Mr Katwesigye. I cannot leave out the "lone ranger" on the communication and media team Ms. Tracy Ahumuza, because we also worked closely together in that area.

To the TASO family, thank you for enduring my constant requests for information. We have made huge strides towards our museum. We are not there yet, so do not relax, more work is coming to us.

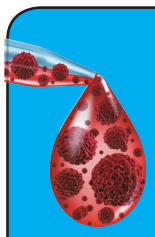
To you dear reader or visitor to the exhibition, thank you. Neither the war nor the victory belong to an individual or single organization; they both belong to all of us as Ugandans and people of the world. Let us continue this conversation and action until we are free of HIV and AIDS.

MAJOR THEMES IN THE 30

UNKNOWN

There was a time when a strange disease crept into the borders of Uganda. Many didn't know how or where such painful death was coming from. Perhaps people were being cursed? Perhaps the war with the Tanzanians had infected the people on their path? In this moment of the unknown, people would see their loved ones wasting away, becoming slim until they were no more.

TESTING



The first HIV Test came to Uganda in 1986 through special research programs. People remember in 1995 that you could pay 1,000 Uganda Shillings for a test. Then, it could take two weeks until the results arrived. It took nearly a decade to have testing widely and freely available to Ugandans. Now the test takes just a few minutes and can be done under a tree anywhere in the country. There was a time that expectant mothers were tested in a mandatory clinical setting. By 2015, Dr Christine Ondoa, the then Minister of Health confirmed that Uganda had reduced Mother to Child Transmission by 86%. The technology has advanced so much that today there are saliva tests that can detect HIV.

KNOWING

To know you and your nation have AIDS can be a shock. Moving towards a better understanding of the disease took time. The Government, organizations and individuals aggressively tried to make sense of what was happening. Why had so many people died in such a difficult way? Who would be next? Through openness and vocalizing peoples' status, Uganda came to know that we were facing a major problem with tens of thousands showing symptoms of "Slim" in the 1980s and 1990s. To tackle the epidemic key individuals spoke out as persons infected with HIV. Teams identified sources of transmission and promoted campaigns to create behavioral change. The country had to come to terms with a killer in our midst.

CARING

Caring for people with AIDS in the beginning was extremely difficult. They were considered as outcasts and contagious. Seeing how stigma alienated people, organizations and medical professionals set up clinics, outreach programmes, drama groups and other strategies to demystify the disease. The dedicated individuals and groups wanted to show that people with AIDS were not to be feared but embraced, loved and cared for. The field of counseling emerged from this work and is now a key aspect of all HIV/AIDS work.

To survive was both about hope and about caring. At first, many people did not survive the disease, they perished in large numbers. In the late 1990s more than one million orphans were documented to have been victims to losing their parents to AIDS. Caring for these young ones was often the primary goal of dying parents. Yet over time treatments and testing helped to make survival something more than a mental state of being.

A number of organisations grew up from people wanting to help and make a difference. The AIDS Support Organisation (TASO) is the greatest example of this, a home grown organization established by people directly affected by HIV/AIDS. These have now grown to hundreds of National NGOs and community based organisations we see today.

BELIEVING

Believing that AIDS was real in Uganda took courage and deep understanding. People did not want to recognize the realities around them. Voices spoke out, despite the shame and criticism, to claim back their dignity. Scientific advances in understanding HIV supplied the religious institutions, the army and the Government, ammunition that enabled Ugandans to take a leap of faith. President Museveni showing strong leadership and individuals spoke out for a better chance at survival.

REMEMBERING

Remembering those who have lost their lives to AIDS is not an easy task. They have been taken, like many, since the early days of the unknown. Most times the last funeral rites do not acknowledge the cause of death, for fear of speaking ill of the deceased. However, being honored, and remembered for the struggle is part of the heroic journey of HIV/AIDS in Uganda. Through memory books, candlelight memorials and vigils, quilted blankets and personal mementoes, those who lost their lives to AIDS are kept alive.

YEAR FIGHT AGAINST HIV

MUSIC, DANCE AND DRAMA

Music and drama were used to educate people and transmit information about HIV/AIDS into communities across Uganda. Groups tried to warn their fellow Ugandans about the dangers of AIDS. Through competition and public displays the message about the epidemic was spread. One of the most popular plays, Ndiwulira (1991) was formally supported by the Government to capture the cultural form of communication. The Hydra and The Riddle were also part of school drama competitions.

TREATING

There were no treatments for HIV/AIDS in the beginning. Doctors and herbalists could only treat the opportunistic infections. Provision of Antiretroviral drugs (ARVs) was pioneered by Joint Clinical Research Center (JCRC) in 1992 using a single drug (zidovudine). More drugs became available through the JCRC as soon as they were discovered in the USA and Europe. These treatments were intended to suppress the viral load (amount of the virus) that was in peoples' bodies. Some of the ARVs came via the country's borders and were expensive. Supply was erratic and they were only available for a few of the patients. They also had bad side-effects. In the early 1990s it would cost a patient nearly one million shillings for a monthly dose of ARVs. By the end of the 1990s that amount had been reduced to nearly 600,000. In 2002, when the JCRC imported generic drugs from India fro the first time, many working class HIV infected patients were able to access much cheaper ARVs with about 9,000 patients receiving ARVs at the time. In 2003, the first US Presidents Emergency Fund for AIDS Relief (PEPFAR) established by President George W. Bush provided funding for ART. This has transformed HIV care, allowing over 1.1 million people to access free antiretroviral treatment (ART) at government and faith based health facilities. Taking treatment for HIV has been stigmatized here in Uganda. People have been forced to hide their medications from fear of social criticism. Today we encourage medicine companions who support the family member in taking their medications regularly and correctly.

PREVENTING

In the 80s, information, education and communication through music, dance and drama led the approach to prevention and in 1986 President Museveni launched the 'Zero grazing' campaign to encourage people to stick to one sexual partner. However, it was realised that communication alone could not change the ways, mindset and attitudes of people to influence behaviour. Condoms became a key part of the ABC response – Abstinence, Be faithful, use a Condom. Today prevention includes a combination of actions to address both socio-cultural barriers and bio-medical interventions including prevention of mother to child transmission, Pre-exposure Prophylaxis (PreP), and voluntary medical male circumcision. The combination strategy led to a reduction of HIV but today there is a worrying increase in infection among adolescents and young people. With 950 new HIV infections every week in Uganda, prevention must remain a key focus.

MILITARY IMPACT

The army has a significant place in the history of HIV/AIDS in Uganda. In the early years, people thought AIDS was a curse brought on by the war with the Tanzanians. People believed that soldiers had committed crimes and were paying for their wrongdoings. Prof. Elly Katabira remembers that the very first AIDS patient in Mulago Hospital's AIDS clinic was a soldier. In 2001, the Uganda Peoples Defence Forces (UPDF) set up a special task force to treat and educate soldiers with HIV/AIDS. The militant approach taken by the National Resistance Army and President Yoweri Museveni has set a clear mission for citizens of Uganda.

ADVOCATING

More than thirty years of HIV/AIDS in Uganda has brought us to a place of advocacy. To advocate is to be a partner in understanding, testing, treating, and counseling. Many people live positively and guide us into meaningful ways of seeing life with HIV.

We know that young women and girls are the most vulnerable to infection. Their voices showcase a way to navigate the next era of struggle against the epidemic. These messages from social media show us a way in which people live positively. They find love, comfort and facts through forums and messages. We invite you to enter the boxes to see what the current issues are.

THETA

"Every Ugandan has lost a relative or friend because of AIDS. Economic hardships have not enabled people to access expensive modern medicine. However, healers have herbal treatments for specific HIV/AIDS symptoms for which few or no modern therapeutic alternatives are available in the region. The organization of Traditional and modern Health practitioners together against AIDS and other diseases (THETA) was established in 1992 to incorporate scientific practices into the traditional medical knowledge through promotion of research into traditional herbal treatments, training of traditional healers, documentation and dissemination of traditional medical knowledge." -THETA 1998. Since the availability of Highly Active Anti-retroviral Treatment (HAART or ART for short) PLHIV are advised that the ART drugs are highly effective and work well without the need for herbal medication. PLHIV are advised to tell their HIV doctor if they would like to use herbal medication alongside their ART as there can be drug interactions.

ACKNOWLEDGEMENTS

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Implementing partners
- Mildmay Uganda
- Uganda Virus Research Institute
- Rakai Health Sciences Program
- MUJHU Research Collaboration
- PEPFAR Uganda
- AMICAALL
- Straight Talk Foundation
- IDI Academy board members
- Uganda Museum
- Makerere University Department of Fine Art
- Save the children UK in Uganda
- IHK
- KCCA clinic
- Reach out Mbuya Parish HIV/ AIDS Initiative

Associations in Uganda
- Islamic Medical Association Uganda (IMAU)
- THETA
- NAFOPHANU
- Philly Lutaaya Foundation

Government ministries and agencies
- Ministry of Education and Sports
- Ministry of Health
- National Archives of Uganda
- AIDS Information Center
- Uganda Broadcasting Cooperation (UBC)
- Vision Group
- Parliament of Uganda
- Uganda Printing and Publishing Press
- Makerere University
- Uganda AIDS Commission
- Ministry of Gender, Labor and Social Development
- The Office of the President

Associations in Uganda
- World Health Organization
- UNAIDS
- UNESCO
- Joint Clinical Research Center
- Communication for Healthy Communities (CHC) | FHI360
- UN Women

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- Dr Donna Kabatesi
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- Prof. Sam Okware
- Major Ruranga Rubaramira
- Canon Byamugisha
- Mrs Mary Oduka Ochan
- Moses supercharger
- Founder JCRC
- Widow of Bishop Misaeri Kawuma
- Dr Christine Ondoa
- Prof. Elly Katabira.
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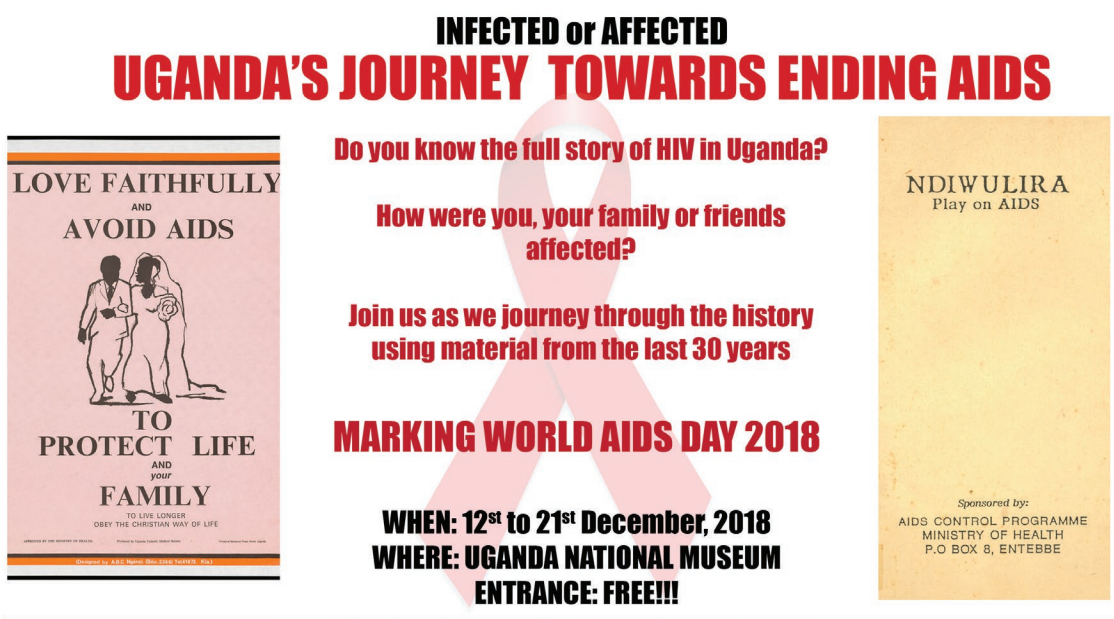
- Ms Vivian Namara
- Ms Fatuma Nalubwama
- Ms Regina Kamoga
- Dr Cissy Kityo
- Cannon Gidion Byamugisha
- Dr David Matovu Welcome Trust
- Prof. Pontiano Kaleebu
- Mrs Florence Erugudo



Mwebale nyo...Apwoyo matek...Thank you...Eyalama noi...Mwebare munonga

Design and Layout by Tracy Ahumuza, George Mukasa

Ambasáid na hÉireann
Embassy of Ireland

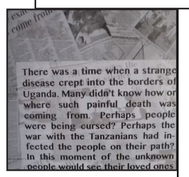
Ugandan Academy for Health Innovation and Impact

Janssen
PHARMACEUTICAL COMPANIES OF Johnson & Johnson

HIV/AIDS THROUGH THE YEARS

1968

- Dr Anthony Lwegaba, then working as a Medical Officer in Kalisizo Health Centre, Rakai District, described the first cases of HIV disease in Uganda
- AIDS was associated with witchcraft.
- New Vision publishes about a new disease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- "A neighbour and later her boyfriend die in Makindye after suffering from a strange disease
- 'Slim'. People got thinner and died

1978

- President Amin refers to AIDS as 'funny disease' brought by the soldiers from Tanzania
- Community involvement in the struggle against AIDS started.
- AIDS called "Mukenenya", "Nabwokeera", "Kattira"

1982

- ELISA test, first HIV test available in Uganda

'Slim' has an official name — HIV/AIDS

1984

1986

- Uganda soldiers went to Cuba for training and when they were tested, 30% were HIV positive. President Fidel Castro told the president about the issue.
- Doctors would not touch AIDS patients

1987

- Founding of TASO and the Immune Suppression Syndrome (ISS) clinic was started by Prof. Elly Katabira
- TASO treats opportunistic infections
- The key mode of transmission was discovered as sex
- "TASO HUG" by counselors born
- Philly Lutaaya came out publicly about his status. However, after Philly's testimony people who had AIDS were classified as promiscuous people

1988

- Nsambya Home care started with palliative care for HIV/AIDS patients
- Dying with dignity
- First counselling manual released

1989

- Recognition of counselling and as a core activity in the HIV care
- Launch of Philly Lutaaya Initiative to train in public speaking and offering emotional support to people living with HIV
- Drama becomes central to HIV behavioural change messaging
- Medications imported from Kenya but too expensive

1990

- HIV/AIDS term started being used and HIV challenge clubs in schools were formed sensitized by Philly Lutaaya
- JCRC started trials on ARVS AZT-Zidovudine
- AIDS Information Centre started
- Tuberculosis was killing many People living with HIV/AIDS (PLHA)
- Research intervention JCRC set up as a research institute.
- Publication of Uganda as the best country in fighting against HIV aired on Uganda Television UTV (Now UBC)

National prevalence of HIV estimated at 14%

1992

- First mass launch of red ribbon
- The Uganda AIDS commission born in parliament
- Canon Gideon came out as first religious leader to come out as HIV positive, by then a Reverend. People were encouraged to test because of his courage
- School drama competitions, The Riddle 1992-93 for Primary schools

1993

- TB associated with HIV
- DOT (Direct Observation Therapy) was started in response to poor adherence to the anti-TBs due to stigma
- Radio Uganda scares tactics programs of sounding of the drum, "Gwanga mujje" to alert people for HIV messages on Radio Uganda.

1994

- Many PLHAs were claiming to have been healed and many went for prayers to be healed
- PLHAs started their Networks to protest against being used and fight for their right to get drugs
- UAC introduced the multi-sectoral approach, involving churches, mosques, and cultural leaders
- Nanyonga Miracle Soils. She declared that she discovered the medicine that could cure AIDS and crowds went to her place to get the miracle soils

1996

- The Condoms use campaigns was at the peak
- Treatment transitions from monotherapy to Dual therapy in 1991 then optimal triple to date.
- ARVs required refrigeration

1998

National HIV prevalence at 10%

2000

- Evolution of counselling since 1987 from "wait to die" to "adhere to your treatment"

2001

- South Africa court case brings the ARV access issue to the global stage
- WTO adoption of the Doha declaration on public Health to increase access to medicine
- HIV workplace policy was put in place to reduce stigma

2002

- The International AIDS Society Conference in Durban highlighted the inequality between PLHIV receiving ART in resource rich settings and hardly anyone in Africa receiving ART
- The Global Fund to Fight AIDS, was established
- First Ugandan Ministry of Health Voluntary Testing and Counselling (VCT) guide-line released
- PMTCT was initiated by the first lady of Uganda to reduce the number of babies getting HIV from their mothers

2003

- Diagnosing HIV in infants in Uganda 2003 at JCRC
- National forum for people living with HIV networks in Uganda launched (NAFOPHANU)
- WHO launched the 3million people on treatment by 2005 initiative- 2% of PLHIV in Africa were on treatment
- The Presidents Emergency Fund for AIDS Relief (PEPFAR) was established by President George W Bush

2004

The national prevalence of HIV at 8%

- TASO distributed first ART under donation programmes

HIV National Sero-behavioural survey found: Six percent of Ugandan adults aged 15-49 are infected with HIV and prevalence among women is higher (8%) than among men (5%)

2005

- Ugandan MOH ART scale up begins
- UNAIDS introduced the three (3) zeros that is, Zero news infection, Zero HIV stigma and discrimination, and Zero AIDS-related deaths
- Clinton Foundation announces deal for Indian companies to make generic ARVs for Africa – dropping the price from around $1500 to $15 per month

2007

- Rakai Health Science programme showed that circumcision reduced the spread of HIV (published in The Lancet)

2008

- Second National HIV treatment guideline was released
- 300 government health centres were providing medication; 100,000 people getting medication
- CD4 count testing and monitoring included in guidelines
- Expansion of treatment for people who had a CD4 count <350cells/ul

2011

- **Free drugs for Ugandans**
- **Babies born with HIV 28,000**

2012

- Partners Prep study including Ugandan researchers shows that in HIV negative partners taking ART can prevent them becoming infected (Pre-exposure prophylaxis – PREP)

2013

- Updated guideline recommended starting people on treatment much earlier (with a Cd4 count <500cells/ul)
- Test and Treat - All pregnant women and children and those with TB or Hepatitis B should start ART for life as soon as diagnosed with HIV

2014

- 750,000 PLHIV on ART countrywide
- Voluntary medical male circumcision programme established
- UNAIDS and partners launched 3 ambitious 90-90-90 targets for 2020

2015

- Number of children infected in pregnancy/ childbirth dropped by 89% to less than 3,000 per year

Babies born with HIV 3,500

2016

- Test and treat for all with HIV policy launched in Uganda (December 1st) as part of global goal of ending HIV by 2030
- Monitoring of HIV by viral load (which can also measure how infectious someone is) started
- SDGs launched-SDG3 targets and end to the AIDS epidemic by 2030

The national prevalence of HIV among adults aged 15 to 64 in Uganda is 6.2%

2017

- PFTI (presidential fast-track initiative) to end AIDS by 2030 June was formed
- Dreams programme set up to help young women and girls avoid HIV

2018

- **Total so far - 3.6 million Voluntary medical Male Circumcisions performed**
- **PLHIV on ART = 1.1 million**

THE FUTURE

LONG ACTING INJECTABLE ANTI RETROVIRAL

CURE FOR HIV

HIV VACCINE