



WORDS OF RESILIENCE BY LUCCA MUNNIK

(AIDS 2020 YOUTH FORGE CO-CHAIR OF COMMUNICATIONS)

When we speak about transformation, we do not refer to a process that is easy. Instead, we refer to a process where we confront our trauma and use this confrontation to rewrite our narratives. 'Resilience' is the reason behind why we rewrite our stories; it helps us uncover the positivity in our transformation and enables us to overcome the trauma that has impacted us for so long. Often it is hard to do this, but it is almost always worth it.

This connection between resilience and transformation is vividly expressed in the artwork presented at this exhibition as well as throughout the Stories of Resilience (SOR) Campaign. SOR was a social media campaign that aimed to share visual and written stories told by young people living with HIV (YPLHIV) and young communities responding to HIV. The stories shared during SOR demonstrated how young people affected by HIV overcame hardships by rewriting their narratives. This allows us, as the audience, to not only understand the personal meanings of resilience but also commemorate the bravery displayed by these young people.

The stories presented at this exhibition are summarized below:

Ismail Harerimana – Ismail's story is presented with passion and determination. Through his personal experience, he indicates the profound impact that certain HIV messaging has on YPLHIV, similarly to how it impacted him.

Amit Mohite – This piece is a reflection of Amit's experience of overcoming HIV-related stigma. His story gives hope to YPLHIV and encourages them to challenge stigma through personal growth and achievement.

Adelaide Hamese – In this story, Adelaide describes how she uplifts herself by recognizing the truth of living with HIV and through this, owning and redefining her story.

Martha Clara Nakato – This is a short prose that covers how Martha Clara empowers herself and as a result, empowers others.

Noah Junior Tiago – This piece tells the story of Noah Junior's journey towards becoming open about his status. It emphasizes how one's friends, family and community contributes to one's resilience.

Helen Lonn – This piece tells the story of a young woman that Helen has counselled. It touches on Helen's perspective of this woman's journey and how she empowered herself to accept her status and begin treatment.

Ruth Akulu – This poem aims to demonstrate Ruth's perspective of what it is like living with HIV and this is important when helping others understand.

Precious Kaniki – This piece reflects on precious' journey to accepting herself as well as her HIV status.

Cindy Akinyi Lupah – This video describes Cindy's experiences; the hardships involved and how she remains resilient.

LEARNING RESILIENCE BY ISMAIL HARERIMANA

Eleven years ago, I discovered that I was HIV positive after I was disclosed to by one of my fellow adolescents. I had thought I was taking drugs for my kidneys because that is what my parents had told me. At the age of 15, I knew little about HIV & AIDS except for the information I received from the presidential initiative of AIDS strategy for communication to youth (PIASCY). This is where various speakers would attend schools to educate learners about HIV & AIDS, treatment, prevention and HIV transmission.

Due to my little knowledge about HIV, the truth about my status was difficult for me to process and so life became very hard for me. I did not disclose my status to my friends at school. I would take my drugs each day at 7am while I was still on AZT/3TC/NVP. When people asked me why I was taking drugs, I would tell them that I'm taking it for my kidneys and eyes and they believed this. My Head School Principal also did not know that I was HIV positive so this made getting permission to leave school to get my ART medication refills difficult. I would often leave school without permission and because of this, I would face school punishment nearly every month. At this point, I thought about dropping out of school because it had become too much for me to handle and my academics were also not spared. Because I had lost hope and thought I was going to die, I started performing poorly. Instead of revising during school classes, I would think about what I would tell God upon my death and how I was going to miss my friends. At the end of every school term, I would bid farewell because I thought I would not return the following term. I used to ask my friends to attend my burial in case they heard I died. To address their suspicions, I would tell them that my family had many misfortunes. I also had no future plans, especially not with partnerships, because I feared spreading the virus to other people. Despite all this and my fears, I persisted and completed my secondary education.

As time went along, I eventually stopped pitying myself and instead, started using my status to encourage fellow adolescents and young people to live positively. I initiated a group to unite young positives together to fight AIDS. This group is called Kabale Young Positives (KYP) and it involves 30 HIV positive youth, all of whom have accepted their HIV status. I lead this group by visiting, supporting and counselling many adolescent and young people who are not adhering to their drugs. I also use my social media handles where I post about risk reduction and other positive messaging.

It was as if one day, I found my voice and used it to empower my peers which is also seen in the various roles to which I commit. I have completed short courses in HIV counselling and I am now volunteering as a youth peer at Kabale Regional Referral Hospital. I am also an Ariel Ambassador supporting the Elizabeth Glaser Paediatric AIDS Foundations (EGPAF)'s ariel clinics in all their supported districts in Uganda as well as a national Young People and Adolescent Peer Supporter Trainer (YAPS). I was also selected as one of the Uganda members of a Committee of African Youth Advisors.

When comparing my experience of HIV to what I learnt about HIV in school awareness campaigns, there is one major aspect that I notice and it is something I wish to advise to policy-makers: It is essential to change provoking messaging about HIV awareness from "AIDS KILLS; AIDS HAS NO CURE; THE ENDING RESULT FOR SOMEONE WITH HIV IS DEATH" to something more positive and accurate. I question how this kind of messaging makes a school learner, who has just been fully disclosed to, feel. Similar to how I felt, I think it would make the school learner not adhere to their ARVs and think life is pointless.

This negative dialogue needs to be changed to focus on more positive and less stigmatizing language because this does not motivate youth to stay adherent but rather does the opposite and has a profound impact on their mental health. I believe that positive encouragement and making people aware that they can live healthy and happy lives despite being HIV positive is very important; it would help people living with HIV as it would have helped me.

TRANSITIONING POSITIVELY

BY AMIT MOHITE

For me, HIV is not an ailment, it is an opportunity. My positive status is just a part of my identity – I am much more than that.

I was seven when my parents died in a car accident. I lost everything that night – not only my parents but also my school, my friends, my home and everything that constituted my little world. My sister and I were shunted amongst our relatives. It was only until 2002, when it was decided that I should be admitted to a hostel. As part of the routine admission procedure, I had to undergo an HIV test. I tested positive and entered a new world; a world of stigma and discrimination, bewildering to a child of my age.

The hostel denied me admission, and this pattern was repeated over and over again. My excellent academic record meant nothing because no school or hostel would admit a child with HIV. By some good fortune, my uncle came to know about Manavya in Pune, which was the only orphanage in India at that time for HIV positive children. At first, along with the other orphanage children, I was sent to the village school, but we faced so much hostility there that it became impossible to attend. We were abused, spat on, our bags were trashed, and our books were torn by the village children who were encouraged by their parents. Eventually Manavya started an in-house school but my education came from weekend tuition in math and science by volunteers from Pune. When I was 14, I won a prize in a science exhibition at the prestigious Inter University Center for Astronomy (IUCAA) which inspired me to take my studies more seriously. I was the first student from Manavya to clear the 12th standard board exams but despite good scores, I struggled to find a college that would accept me.

I worked at odd jobs as a gardener, watchman, computer teacher and in pest control to fund my education and that of my sister's. My efforts were rewarded in 2015 when I became the first student from Manavya to graduate. In 2014, I started MyRaddi.com, an online portal to collect old newspapers that would help destitute women make paper bags to earn a living. I joined an NGO working with AIDS affected people as a group coordinator of the YPLHIV group. Through this work, I created a district level support group to provide a safe environment for adolescents living with HIV.

I have recently completed my Master's in Development Studies at Azim Premji University in Bangalore. I engage with the HIV positive community through various NGOs as a youth advocate. I travel abroad frequently as an advocate for youngsters with AIDS and speak at conferences and public events. I have come a long way from the child who was spat on for no fault of his own. I love challenges. I have no fear in disclosing my status anymore and I speak publicly to motivate people like me.

My positive status is just a part of my identity – I am much more than that. This story is for all the children, adolescents, men and women who have been diagnosed with HIV to tell them they can live a normal life and that it is our responsibility to make life happier and safe for future generations.

THE TRUTH ABOUT LIVING WITH HIV

BY ADELAIDE HAMESE

I grew up in a country where if you are living with HIV/AIDS, you are considered to be dying. It is a country where PLHIV don't disclose their status in fear of being the laughingstock of the community and where they are considered disgraceful to the family; basically speaking about HIV is taboo. So one would ask me how I did it at such a young age? Here is how the story goes...

My parents found out I am HIV positive when I was five years of age. This was after I became ill and admitted to hospital where I was diagnosed with meningitis which nearly took my life. At that point, I was too young to understand what was going on. I started taking ARVs at age five and would go for check ups every month. This obviously meant I was missing school every month and because I did not understand what was going on, I would ask my mom why I go to hospital every month and she would tell me I have a teeth problem. I honestly believed her although no one ever checked my teeth.

When I was in Grade 5, a friend of mine whose parents knew my mom, told everyone at school that I am HIV positive. The next day when I went to school, my other friend told me what had been said. At that time, this was news to my ears and so I said that there was no such thing with confidence. I thought to myself; how can a girl with such curves be HIV positive? And as for my skin? It is popping and clear. I thought this because where I grew up, if someone is slim with pimples, we think they are HIV positive. That day, I got home and asked my aunt if what I had heard at school was true. She didn't answer and instead, told my mom, whose reaction confirmed everything for me.

That's how I discovered I am HIV positive and nothing was ever the same since that day. I started battling with myself and the people around me. I sometimes felt worthless, useless, ugly and I never understood why God would give me HIV at such a young age. I had thousands of unanswerable questions to the universe. I bottled so many emotions inside for a very long time. This then led to a battle with suicidal thoughts, anxiety and depression for three years. During this period of my breakdown, I learnt so much about the virus and about myself which helped me become stronger. Although I felt broken, I managed to convince myself that I am bigger than HIV and reminded myself that my story is for people to hear. The belief that kept me going was, if not me, then who?

At some point I decided to share my story with my close friends and I told them how I managed to survive. Not all of them responded the same way and I lost friends in the process. Despite this I kept going, owning and telling my story which made me more resilient to HIV-related stigma and discrimination. The stigma and fear that I faced made me wake up one day and say: I am ready for the world to know about my journey with HIV. I realized that living with HIV is not a doorstep into heaven but it doesn't make you less of a person. Living with HIV does not define your life journey so do not let it define you. Instead, you have to define it.



LIVING IT UP – BOLDLY CONFRONTING HIV/AIDS


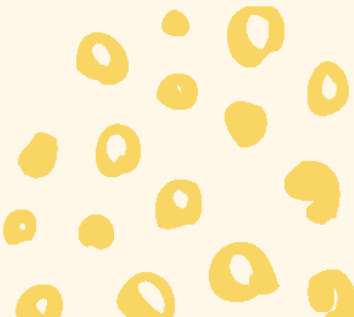

BY MARTHA CLARA NAKATO

I thought I was cursed and that I had the worst problem in the world, but when I reflect, I recognize that what I was going through was nothing compared to what our past friends experienced at the verge of the AIDS epidemic, where millions of lives were lost. It was not by choice but because of fear, ignorance and no access to the right treatment.

I'm confident that my HIV Positive status was nothing close to the worst. Since then, my attitude towards living with HIV has changed and I am using my voice and beauty to inspire and change the face of HIV by speaking against stigma, discrimination and empowering young people to embrace positive behaviours that don't put them at the risk of contracting HIV. And I aim to inspire my fellow Positives to love life, adhere to their treatment and commit to fight HIV.

I am unapologetically open about my HIV+ status and there's no shame about it because I have saved lives and inspired millions. This motivates me but I don't want to see any other child born with HIV in such a biomedically developed era.

“BE THE CHANGE”



FINDING MY RESILIENCE

BY NOAH JUNIOR TIAGO

When telling my story, I always start from the beginning. I am an orphan who lost both parents due to HIV/AIDS. My mother left both my brother (who is HIV negative) and me. After my father passed away in 2005, my brother and I were taken to our grandmother. But by then, she was very old and couldn't help herself. She couldn't manage the monthly medication refills and could not afford food. Due to this, my aunt decided that she should look after me and so I was adopted by her. My aunt was a widow who had lost her husband and therefore she lived alone. She was a hard-working woman that ran rental houses. My aunt's brother, my uncle, also lived in one of these houses with his wife. Now having moved areas, I had to be transferred from my original healthcare facility to TASO Mbarara. This healthcare facility was great, and I easily received my medication refills every month. It was also only a few kilometers from where my aunt's home so I would pay less money when traveling and sometimes I would even walk there. Back then, I was still young and therefore my uncle's wife accompanied me whenever I collected my monthly refills. One day on a sunny Wednesday, I arrived at TASO and was told that I was HIV positive. I was horrified and in that moment, I replayed the terrible statements that my primary school had said about the virus; AIDS HAS NO CURE, YOU WILL DIE. I remember my uncle's wife telling me that I would die if I didn't take my medicine. After I arrived home and told my aunt about my status, she also said a similar thing to my uncle's wife.

Due to only being 13 years old, I didn't know how to use the medication. I had to take them every day at home and often I was alone when taking the medication. I felt isolated - I hated myself and everyone around me. Whenever I took my ARVs, I would remember what people said to me, "take your meds otherwise you'll die". I would then take them quickly so that I could get better faster. I wanted to take more because I thought this would speed up the process. I eventually took double the dose. This caused horrible side effects, such as loss of appetite, fever, dizziness, and vomiting.

One day, after arriving at TASO, my counselor noticed something wasn't right and so she asked my uncle's wife what was wrong with me. My uncle's wife could not tell the counselor what happened to me, so the counselor gently pulled me aside and asked me directly. I remained silent and she asked again. Finally, I managed to find the words to tell her, "I take my drugs alone without any supervision. My aunt tells me I will die if I don't take them. I feel like I should die or live alone in this life." This was a ground-breaking moment for me because I realized how alone I felt.

After arriving home, my aunt reassured me that now she would be the one who would supervise me while I took my ARVs. After this, we became very close and today, I still feel as if I am her biological son. I always felt supported by her and found she was often there for me by providing me with things that I needed. However, as I grew older, things became more difficult. When I reached secondary school, I lived in the boarding section of the school. Now that I was an adolescent, I started seeing girls and became responsible for my actions. I would go to TASO alone to receive my ARVs refills and I made decisions for myself, even if they were reckless ones.

Due to staying in the boarding house section, I was forced to take my ARVs in the school dormitory hall. This made me anxious and afraid of judgment from my peers. I was also a school prefect and so I didn't want people knowing about my status in fear that it would tarnish my popularity. Due to this fear, I would sometimes skip days of taking my medication, and taking the ARVs strictly depended on whether people would see.

One day, I got a call from my aunt asking me to come home because she had something important to tell me. After arriving home, my aunt said, "You are now older and can take care of yourself. The fact that your parents died from HIV doesn't mean that you have to die. You can still live for many years because nowadays, PLHIV lives the same amount of time as an HIV negative person". I didn't understand why she was telling me this until she added, "Someone at TASO has told me you are not taking your ARVs at school. TASO is worried and they want to see you."

The following day at TASO, I was told that my viral load was too high. I was so surprised and shocked too. Despite this, it still didn't make me understand the importance of adherence and so I still avoided taking my medication. My friends were also beginning to suspect that I was taking something. One evening, my friend saw me opening the bottle of ARVs and asked me what they were. I didn't know what to say in embarrassment and from then on, I stopped taking them completely. Luckily, I eventually told my counselor this who then told my aunt.

Once my aunt and counselor knew about my fears, things became better and I also started receiving support from my school headmaster. Eventually, I became open about my status and despite my previous fear, my friends were actually supportive. I became a youth peer leader who taught my fellow peers about HIV. In 2017, I was tested with a low count and since then, I have never been tested with a high count. I am now undetectable. This achievement had a lot to do with the support I received from those around me.

Due to my leadership skills, the TASO community allowed me to take part in the trainers for the TOT which was held by Elizabeth Glaser Pediatric AIDS Foundation (EGPAF). Thereafter, I was recognized as an Ariel Youth Ambassador. In 2019, I took part in the Ambassadors Reunion and I was able to tell my story to many PLHIV. I also heard their stories which made me feel I wasn't alone. I want to give thanks to EGPAF for giving me a platform where I could tell my story to many other PLHIV in different areas. Working as an Ariel Ambassador is honestly the greatest achievement for me because it gives me hope that we will end HIV/AIDS.

Looking back on my story, I realize my resilience came from within but also from those around me, especially my aunt. I will always be grateful to her for teaching me to be strong in the face of adversity. She and many others showed me that HIV doesn't determine my potential and that I should always respect myself. And when I started to believe this, I slowly began to help myself; resilience comes from within and I am especially grateful to myself for realizing this.

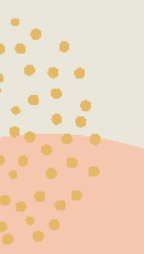


HER STORY BY HELEN LONN

Pain, frustration and uncertainty sank deep into Josephine's bones the day she was declared HIV positive. Her pain could not be explained merely by words. In one minute, she lost the true meaning to life – her personality, self-esteem and future shattered.

"I thought I was having a bad dream yet it is gradually becoming a reality. Oh God, when will I wake up from this bad dream? Who will save me? The stars seem to have disappeared from the sky, the night seems to be too long, and the blue skies seem to have turned red. Even though it seems I am living, I feel the cold hands of death right deep in my bones," decries Josephine.

While I watched the hot tears run down her cheeks, she concluded, "I know this is witchcraft". I gave her my arms to undergo catharsis. Some days later, she accepted to begin her treatment and I was relieved. The next appointment, she changed her mind and during my home visit, she said "I went for a crusade and a 'Man of God' declared me healed so I am not in for any drugs again". Then I knew that I must change my strategy. I engaged her in an empathic relationship as she walked through the 'valley of depression' and denial.



A long-term empathic relationship became imperative and through this, she was able to disclose her status to her support system. Together, we lifted the young woman's shoulders, sparking the flicker of a smile on her face and breathing fresh fire into the fading embers of a smoldering dream. We helped change the course of another human being's day, week and life as she embarked on chronic treatment. Today, she stands as an advocate for many who still live with uncertainty and who have lost hope due to their HIV status. Her life has improved that she has attained viral suppression and that she stands to encourage many others to take their test.



DO YOU KNOW WHAT IT'S LIKE BEING ME?

BY RUTH AKULU

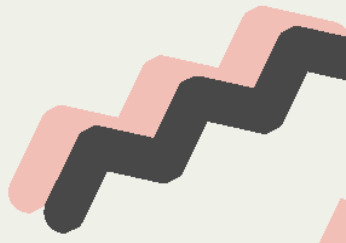
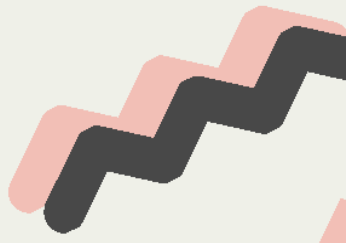
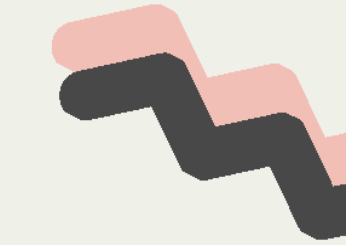
Do you know what it's like being me?
I am poked, labelled and analyzed.
I am weighed and found wanted by forces beyond my control.
I have been judged and found guilty: case closed.
Who can subscribe to that?
My freedom must be a self-fulfilled prophecy.
I choose not to carry the pain in my heart, sweat or tears.

Do you know what it's like being me?
To notice people looking at you,
Concerning themselves with the version of the life you could potentially live!
Presuming that they are afraid of you and that you are a threat to them!
Apathetic about what they say behind your back;
"She is good for nothing, worthless, not deserving of love, cursed."
"Refrain from her," they say.

Do you really know what it's like being me?
I'm constantly at war with the world and myself.
I want to stop hurting but I can't.
What's the fee to freedom if resentment is for free?
The only advice I get from folks is "take your meds, Ruth, take your meds!"
But the pain never leaves,
I want,
no,
I need to be set free.

Do you know what it's like being me?
For now, I have finally set free
I am dressed for war;
I am Desmond Doss;
The amour of love and compassion keeps me alive.

I made it. I am alive.
Or should I say I live every day;
Carefully, cautiously and purposefully.
I lower my comrades off the cliff of stigmatisation into safety,
One at a time I bring them hope
For they know what it's like being me.



MY STORY TOWARDS SELF-ACCEPTANCE

PRECIOUS KANIKI

I found out that I was HIV positive twelve years ago and back then, it felt like all my dreams were shattered. The only thing that came to my mind was to kill myself which I almost managed to do by not taking my ARVs for seven years where I only took them when I felt like taking them. I withdrew from family and friends and I stopped studying. I waited upon my death and I couldn't manage to take my medication every day. I lost self-esteem and all self-confidence. I had a fake smile to the world, and I pretended to be okay when I wasn't. I lost interest in everything. At one point, I remember when I was told I had a CD4 of 19 - I was the happiest person knowing I only remained with 18 counts to die. At the same time, I was failing treatment and so I was transferred to Didanosine Stavudine Abacavir, which meant taking twice the dosage of medication I was previously taking. This made me feel hopeless.

I enrolled in college where I was doing a diploma in Social Work and in my final academic year, I developed stomach pains. Within two months, I got sick to the point where I wasn't even drinking water. I was 23 years old and I weighed 37kg (81lbs). It was in that moment where I was able to reflect on all the seven years since my diagnosis and I concluded that I was indeed difficult; full of anger and tears, and I had even attempted suicide. I reflected on how I hated myself for all those 7 years. After this, I remember going to the clinic and telling my doctor to do what they had to do, and I would do the same. It felt similar to when I had first started treatment. I was angry at myself for all the opportunity I missed because I didn't accept myself. I could have been an electrical engineer. I could have made my parents happy by passing with distinction during high school.

Regardless of that, all I wanted was to make the most of my life, to be happy and help other adolescents and youth who share a similar experience to mine. When I was volunteering at the clinic in 2015, I saw a 19-year-old girl who had tested positive for HIV, crying while not caring that people were watching. I saw this girl in me, and I knew that if no one would be there for her, she would end up thinking life is cruel and bad. From then on, I started getting numbers from youth on treatment and told them that I am also HIV positive. I created a WhatsApp group for young people living with HIV and this group has been my true source of courage. It is a group with which I relate and where I'm able to share my struggles without being judged. I have come to know many young people striving every day to live their lives to the fullest despite their challenges with disclosure to potential partners and peer pressure.

I give thanks to everyone who was there and has always been there: family, friends and my mentor who helped me through recovery and towards accepting my status. Today, I am a co-founder of the Phenomenal Youths Association which focuses on the well-being of young people living with HIV after they start treatment, including their mental well-being. I advocate for good treatment adherence, for self-acceptance, self-love and for undetectable = untransmittable.



