



#IASONEVOICE

# Growing Up HIV-Positive: From Diagnosis to Activism

By Juliana Odindo, IAS member and  
youth advocate

**Juliana Odindo** is an Advocacy Officer at The International Community of Women Living with HIV Eastern Africa (ICWEA), a regional advocacy network and membership based organization in Uganda that unites and supports girls and women living with HIV. Juliana became an International AIDS Society (IAS) member in 2016 and is an IAS Youth Voice. After struggling with her health for many years, Juliana was diagnosed with HIV at the age of 11. Motivated by her experience, Juliana is now a passionate advocate for the rights of young people, especially girls and women living with HIV. Today, Juliana shares the challenges young people, especially young women, face when living in a resource-limited country with high rates of HIV, poverty, unemployment, and limited educational opportunities. This is her story...



**“It’s all here. Why didn’t anyone  
ever help this girl earlier?”**

I was born in 1992 in Kisumu, a city by Lake Victoria in Kenya. The youngest from a family of seven, at only three years old I lost my parents to what I later came to understand was AIDS. I was brought up by my eldest brother and growing up my health was never good. I spent most of my childhood admitted to hospitals for various illnesses that I later learned were opportunistic infections.

When I was 11 years old, I was admitted to hospital and a paediatrician doing routine rounds was curious about my file; it was the size of an encyclopaedia. She reviewed my file and shook her head with sadness and anger. I remember her saying to herself, “It’s all here. Why didn’t anyone ever help this girl earlier?” As she walked over to my hospital bed, my eldest brother came to visit me. The doctor suggested an HIV test was necessary, but my brother did not agree and he was angered by her suggestion. To his knowledge at the time, HIV was a sexually transmitted infection (STI) and there was no way I could have it at the age of 11. After their argument, the doctor did the test anyway; I was HIV-positive. My brother was upset and he was given instructions by the doctors, but he was too shocked to deal with the situation.





Picture taken during IAS Youth Voices focus group discussion in Lusaka, Zambia

The hospital counsellor struggled to find the words to tell me, an 11-year-old, that I was HIV-positive. He told me that there was medicine the doctor would give me that would make my wounds go away. My dress was covered in dry blood and pus. I thought my wounds would never heal because each time I undressed, they bled again and again. The doctor then asked me if I knew about HIV. I had heard people, the news and teachers talk about it - at that time everybody was terrified about it. I asked him if I would die but he assured me that scientists were studying the virus and finally they had a medicine that would help. Although he said I would have to take it for a long time, he never mentioned that I would have to take medicine for the rest of my life. The medicine however was too expensive but my head teacher persuaded my brother to seek financial support from a local AIDS organization. I was then able to start and maintain antiretroviral (ARV) treatment and my health stabilized.

**“For as long as I can remember, I have never been ‘normal’.”**

As a woman living with HIV I have faced discrimination, stereotyping and stigma. Sometimes it was out of ignorance, sometimes out of genuine concern and other times it was just out of meanness. I had a close friend tell me that they admire my life and strength but if they were in my situation they would not have a baby because preventing mother to child transmission (PMCT) is not 100% effective. The risk of mother-to-child transmission of HIV can be reduced to less than 5%. I also remember the time a nurse at a family planning clinic said to me, “Juliana, I am not sure of the best way to say this without you feeling discriminated against, but when you ask for family planning I get scared, because that means someone’s son is likely to get infected.”

Self-esteem has played a central part in my life living with HIV. For as long as I can remember, I have never been “normal”. I was always sick and weak with fresh wounds all over my body. Children used to call me a leopard because I had brown skin with ugly huge black wounds. Sometimes I would try to play with other children, but they would leave because they said I brought flies with me. In school, nobody would sit next to me and my teacher would use me as a physical reference of what HIV is. I felt like less of a person every day and people looked at me and laughed, saying I was ugly. I looked like a scarecrow and my family members would not let me near their babies. After I started ARVs my wounds healed, but left spotted scars that would not disappear.

Relationships are some of the best stories of my life; a combination of sadness, drama, happiness, fear and much more. I started dating in high school, I guess I was around 18 years old. There was a boy in my school who was my dream guy but I thought he was out of my league. He started talking to me one day and after a while he became my boyfriend. The relationship was amazing and I did not want to ruin this feeling so I did not disclose my status, but somehow he found out and I ruined everything. He was so mad, not because of my positive status, but because I lied and he thought we were in a place where we could tell each other everything. He was so hurt, he cried every time he saw me. I felt guilty and mean, and from then on I made the decision to always disclose my status. So many guys took off when I told them I was HIV-positive but some also became friends. Some were curious about what it is really like to live with HIV and how it is transmitted. I was even asked if I cut my finger and bled would they be able to see the HIV virus. I realized that with all the awareness done, young people only take a keen interest in HIV when they are directly faced with the situation.

**“It was like our safe haven, it was the only place where we felt free, accepted and understood.”**

To share my experiences and gain strength from others living with HIV, I joined a support group. The support group met once a month on every last Sunday of the month. It was like our safe haven; it was the only place where we felt free, accepted and understood. I cannot describe how excited I was for each group session. I would wake up very early if I had to, or walk if there was no transport—just to attend. I felt this support group was invaluable for me and I want other young people living with or affected by HIV to have access to similar services as well. Connecting with other HIV-positive people builds confidence and strength.

Together with my friends, we created the Youth Caffe, a youth-centred organization that caters to the urgent and unmet needs of vulnerable and disadvantaged youth living in Kenya. Our target group is youth aged 14 to 25, and our programmes focus on sexual and reproductive health education, information technology and multimedia skills and entrepreneurship. I realized that if I am doing well health-wise, the community accepts me, I have a job and a stable relationship, it gives other girls and women living with HIV hope.

There is more we can do to make girls less vulnerable to HIV. We need mentorship and good programmes that speak about female sexuality to reduce risk-taking behaviours. We need to raise awareness, and have proper follow-ups. We need engaging activities and micro-enterprise programmes for women. After some time, I felt that someone other than us needed to hear our challenges and bring the changes we desired. I saw that women were rarely included in policy-making with regards to HIV, something that I strongly feel we can change. I wanted to tell judges, magistrates, schools, hospitals, parents and guardians how we felt, so I started to speak out.

I am now working for ICWEA which exists to give visibility to women living with HIV in Eastern Africa who face gender inequalities and lack access to sexual and reproductive health services for women, which are at the heart of the HIV epidemic. I joined ICWEA because I want to see a change in social attitudes and an increase in the public availability of the latest information on HIV, including research.

I believe that women and girls must not be raised to be scared to engage in sexual relations or to consider it a bad thing. If I had a daughter today, I would tell her that she should always practise safe sex by using protection and being monogamous. But most importantly, I would talk to her at an early age (12-14) about her sexuality and make her feel safe talking about it with me. Being a friend and creating a good atmosphere where she can express her feelings without fear or intimidation would be key.

There are so many barriers for women and girls to access HIV care and treatment services. Most of the service centres are women-administered, and sometimes women shy away from expressing themselves with the same sex. Low self-esteem is a big issue among women and girls who do not pursue the right medical care out of fear of being blamed. There is a strong cultural fear of intimidation and blame that hinders access to health services for women in too many cases.

**“African culture plays a big role in HIV prevalence among women.”**

Women have become the face of HIV and AIDS in sub-Saharan Africa, comprising 61% of adults living with HIV in the region. HIV continues to disproportionately affect girls and young women in Africa, with 74% of new infections

occurring among African adolescent girls in 2013. African culture plays a big role in HIV prevalence among women.

Expectations about women's roles in relationships and at home can limit their ability to control their health. Early marriages are still common, which put girls at risk of being sexually active earlier and acquiring HIV. The practice of female genital mutilation can also increase the risk of HIV transmission among girls when the surgical instrument is not sterilized. With over 15.7 million AIDS orphans living in sub-Saharan Africa, orphan girls are more likely to drop out of school to take care of their siblings, and with no trained skills, they often resort to prostitution.

Girls and young women generally know less than men about how HIV is transmitted and how it can be prevented. Many girls drop out of school once they become pregnant or because their husbands and family insist they stay at home to take care of the household. Girls who drop out of school are less likely to access comprehensive sex education, which is critical for awareness of HIV. Outside of the classroom, there is a general lack of adequate HIV and sex education services available. Women are the most at risk of HIV infection and men have an important role to play in reducing HIV prevalence among women. They should protect women against a culture that places them more at risk of HIV infection. Men can help reduce HIV prevalence among women by using protection during sex, practising monogamy, and changing their views on traditional prescribed gender roles for women.

**“If current trends continue, the AIDS epidemic will be the biggest killer of my generation.”**

AIDS is the second most common cause of death among adolescents worldwide and the leading cause of death among adolescents in Africa. If current trends continue, the AIDS epidemic will be the biggest killer of my generation. But the good news is that it is not too late to take action. Join me as an IASONEVOICE to call for youth-inclusive initiatives to increase youth participation in education, health services and employment. Together, we can empower youth to better protect themselves and make informed choices so the AIDS epidemic will not devastate another generation like it did to mine.

