

# WATCHDOG



## youth coalition

### FEATURED ARTICLES

### World AIDS Day 2015

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27 años de VIH  
 L'Orangelis Thomas Negrón  
 27 | Puerto Rico, USA



**DO YOU  
SEE HIV?**

**ICW**



INTERNATIONAL COMMUNITY OF  
WOMEN LIVING WITH HIV

# World AIDS Day 2015 Watchdog

The Youth Coalition for Sexual and Reproductive Rights, in cooperation with the Women's Global Network for Reproductive Rights, the International Community of Women Living with HIV, and members of the "More Than Our Status" initiative, is pleased to release this special edition of the Watchdog on December 1st 2015, World AIDS Day. This publication marks this important occasion and serves to renew our call to end stigma, violence and discrimination against young people living with HIV.

Entirely youth-authored, edited and designed, this edition of the Watchdog features the voices of young women and adolescent girls living with HIV, including lesbian and bisexual women and girls, trans and gender nonconforming people, people with disabilities, and others from marginalized groups. Young people living with HIV are still silenced and made invisible in their communities. These are young people who face multiple forms of oppression, disproportionate discrimination, violence and lack of respect for their rights, including their sexual and reproductive rights, because of their HIV positive status.

Within these pages you will get a glimpse of the stories of young women and girls from diverse parts of the world, and their everyday lives as people living with HIV and/or affected by HIV. We appreciate the courage and generosity of the authors and artists who have shared their work, as we understand the difficulty in sharing personal experiences that are so often politicized.

In addition to the powerful narratives, we also celebrate projects carried out by young people to fight stigma and empower young women and girls. From a photography workshop for girls living with HIV in Delhi to the body mapping activity held in Puerto Rico, we are inspired by the initiatives of these young leaders in advocating for the rights of people living with HIV/AIDS, especially young women and girls.

We dedicate this publication to all young people living with HIV and still facing oppression and discrimination in their communities. Thank you for sharing your stories and your voices.

Youth Coalition for Sexual and Reproductive Rights

## On the Cover 27 años de VIH

L'Orangelis Thomas Negrón  
27 | Puerto Rico, USA

The purpose of this photo blog is to share how HIV can influence the different areas of your life, for good or bad. With these pictures, I wanted to share how a body can look after 27 years with HIV, with or without lipodystrophy (changes in body fat that affect some people living with HIV). But it is also a way to break with the things I don't like about my body and embrace them.

The photos can be found here: <https://rojavidawordpress.com/2015/05/31/27-de-vih/>

# My Story

**Bright Bee**  
27 | Zimbabwe

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My name is Bright Bee. I am a 27 year-old Zimbabwean woman living in Johannesburg and I am HIV positive.

Like many teenagers, I fell in love when I was fifteen to a man eight years my senior, who I thought was my true love. Two years later I became pregnant and had a baby. After giving birth, my boyfriend began to disappear and only came back when he wanted sex. I was naïve and I always gave in. I continued to have unprotected sex because I was ignorant when it came to HIV and sexually transmitted infections (STI). I believed that only promiscuous people got infected and thought I was safe since he was the only man I ever slept with.

I remember one day after having sex with him, I noticed he had blister like sores on the tip of his manhood. When I asked him what it was, he said, "I get these when it's hot and I've been wearing jeans the whole day." Surprisingly I believed him, but a few weeks later I saw the same blisters on me and noticed I had a smelly discharge. I'm an introvert and I've somehow always believed I can solve things on my own, so I went to the local clinic. The nurse who examined me told me I had an STI for which she gave me antibiotics and told me to come the next week to get more medication. I chose not to go back and continued sleeping with my boyfriend as if nothing had happened. The blisters would go away and come back after weeks but I chose to ignore them.

Two years later I relocated to South Africa to be with my parents. I began to notice huge changes in my body: my skin was flaky, my hair not the same, and my appetite had deteriorated. One day I came across a magazine article about HIV and antiretroviral therapy (ART). I asked myself, "What if I am HIV positive?" I thought to myself that if this were true, it would get better because I could take medication and get back to my old self. I thought about this for months and in that time developed a cough that lasted for a month. I braced myself and told my mother I wanted to do an HIV test. It came back positive. The doctor told me my CD4 count, indicating how well my immune system

was working, was at 194 and that I had to start ART immediately.

"God this is another journey, please walk with me," I said as I held a pill in my hand ready to begin a new life. I stayed in bed for two weeks because the side effects were severe. The medication would cost me about 800 rand a month because I wasn't ready to go to a clinic. But due to financial strain my parents decided I should start going to a clinic. I chose one faraway from my neighborhood in case I met someone I knew at the local clinic. My CD4 count was now 380 after a year. I hated long clinic queues, and it was there that I broke down and cried for the first time. They gave me 3 months of medication but the nurses were not friendly so I decided I was going to stop taking my antiretroviral drugs when I finished it. Stupidly, I believed I was healed because I felt fine and restored.

I stayed in remission for about 11 months and during that time I was free from carrying pills wherever I traveled. I felt lighter. After a few months, though, I realized I was getting sick again. The cough came back with a vengeance, intense this time and accompanied by fever. I realized that I could die if I didn't take action fast. My CD4 count was below 100 this time.

I went back to the clinic and made a life long commitment to the one pill per day regimen. The side effects were not so bad and now, less than two years later, I'm healthy. My CD4 is at 490 and I'm content with what I have. Apart from my parents, I decided to tell my three best friends about my status, and they make up my support system.

I am not living openly with HIV. The stigma and discrimination towards people with HIV still exists and some people still say the word "AIDS" with disgust. I am silent because I choose to be, and because I don't want to be defined by the disease. Am I in denial? No. I've accepted HIV. I keep hoping for a change, a change where I see myself on top of Mount Kilimanjaro telling the whole world about my status, a change where HIV can be seen just like the flu.

# Every Minute is a Gift

**M.UWASE Nadège**  
25 | Rwanda

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My name is M. Uwase Nadège.

I was born in 1990, a native of Rwanda in a family of three: two boys and me. In 1994 our family survived the genocide against the Tutsi. In 2007 at 17 years of age at our neighborhood's health center I tested HIV+ after suffering from a severe cough, skin rushes and headaches. I was too young to go for an HIV test, according to the law, which requires that those under 18 years of age must be escorted and given consent to have the test by a parent or guardian. But the doctors were suspicious of my symptoms and the duration of my cough and thus advised me to take an HIV test.

Believing what was in the test results was hard for me. I was confused! The nurses at the health center advised me to start medication as soon as possible due to my low CD4 counts -I only had 300. I shared the news with my family later that day and found out from a close Aunt that my Mom had died of AIDS in 2001. I took the initiative to take my two brothers for an HIV test and luckily both of them tested negative. All along, my Dad was HIV+, but none of us knew because he never told us about his status and made sure he took his medication in a private place; we only learned about this through our relatives that knew about my father's condition.

I started medication and carried on with my education. This was not easy as I lived every single minute questioning God why it had to be me, out of all my siblings, and why my father or other relatives that were close to my mother had never told me about my condition.

Even as I was struggling with accepting the fact that I was HIV+, I faced more hard times with my family and friends when I told them about my condition. I was hopeless and needed someone to talk to, someone to console me, someone who would make me believe that I wasn't going to die! But alas, those that I trusted instead chose to discriminate and stigmatize me. I started joining support groups at the health center where other young people like me met to talk about the issues they were facing in their lives. We talked about issues like how it felt to be HIV+, about stigmatization, the medication, and how it changed our lives, our love lives, and our hopes and dreams for the future.

I always woke up thinking that I was going to die very soon due to the physical and mental torture that I was experiencing. But this did not happen and instead my health condition improved with each day that passed. With these support group meetings, I came to realize that I was not the only one living with HIV, that I had brothers and sisters, and that we could all hold each other's hands and stay strong even through the hardest times. These meetings taught me to love myself. And as time passed, I came to realize that no one would love me if I did not love myself first, that my condition did not define who I was deep inside.

It did not take long for my family to notice the changes in my life as I was developing so fast, accumulating different achievements year after year. This drove most of them close to me again. Some still do not understand how I overcame the stigma, but my achievements can speak louder than my words!

The word of God has also helped me to understand that I was created in God's image, that there is a reason for everything that is happening in my life. Therefore I have decided to use my testimony to change the lives of other people who are also living with HIV. Young people have become the focus of my work, where I now feel devoted to advocate for their rights for different youth friendly SRHR and HIV services, HIV/AIDS treatment and prevention, and capacity building and awareness raising through various positive change projects that I have designed. I want these young people to have comprehensive sexual and reproductive health services that are affordable, accountable, acceptable, appropriate, physically accessible, of high quality and non-stigmatizing. Only this will enable young people to make informed, safe and healthier choices in their lives.

If I had chosen to sit down and give up back then, I would have chosen the path of failure in my life. But I chose to stand and fight back, to fight for my rights and freedom because I felt that I deserved them. Today many young women around the world are still having a hard time accepting their status and disclosing it to their families because they are afraid of rejection and losing their loved ones. Finding love and acceptance from the people close to you is vital in building determination and taking the first step in accepting yourself and making a change.



# "We Were More Than our Status and Wanted to Dream More"

Jasmine Lovely George, Hidden Pockets  
27 | India

Young people need to be more active in movement building within the HIV and AIDS discourse in India. Though many of us are very active in different capacities, there seems to be silence around reproductive and sexual health. Young people often lack the language and channels to speak about their sexualities, and they perceive sexual and reproductive health and rights as limited to their right to better access to treatment.

Hidden Pockets recently conducted its first workshop on photography and young girls living with HIV and AIDS, with support from the International Community of Women Living with HIV and the Women's Global Network for Reproductive Rights. There were young HIV positive girls, who wanted to spend time with us discussing their aspirations and dreams, and have conversations that go beyond their HIV status. As one of these girls rightly put, "We were more than our status and wanted to dream more". In order to capture their aspirations, we provided them with cameras to capture, create, and show us what they saw and aspired to create.

When we started thinking about connecting with these young girls, we didn't realize how difficult it would be to find young girls living with HIV in the city of Delhi. Even though we were working with Delhi Positive Women's Network, there were no coalitions of girls living with HIV where we could go and meet these girls. In most of the scenarios it was necessary to understand that all of the girls were completely dependent on their parents, be it financially, emotionally or physically. Some of the girls had access to education in schools, but many of them did not go to school. Some of them were drop outs, forced to leave their education. Most of the parents were not willing to send the girls to the workshop. They had various reasons to cite: some suggested financial difficulties, some found the location too far to commute to, some of them did not want to bring the girls outside. Though we had been introduced via the network, there was also a lack of trust.

While we negotiated with parents, it was heartening to see that most of the girls pleaded with us to convince their parents to allow them to participate in the workshop. It took follow-ups and pleading to convince some parents to agree.



Most of the girls had some experience with workshops, but mostly within a medical framework. The girls were aware of their rights to get medical treatment, and since most of the girls were born with HIV, they were conscious of their treatments. Most of them hid their status and found it to be an extremely scary experience to talk to strangers about their HIV positive status. They were young girls with dreams, and we wanted to focus on that aspect of their lives. Some of them wanted to become models, some wanted to be dancers, and some just wanted to be able to go to school. We all discussed our own aspirations and where we saw ourselves in the next 5 years. The girls with cameras reversed the gaze and made us their muses. They were running around trying to capture the best shots, and were excited to be able to negotiate their lives in this capacity.

They were excited to be able to create art and be owners of their dreams, dreams that they could share with others. We shared their photos in exhibitions and they were happy that the photos were out there for people to see and reflect on. We learned a lot from these girls and were even forced to think about our own limited understanding about young girls who live with HIV and AIDS. What we were able to create in the end was a friendship which they valued as they were able to talk to us without the need to hide their status. With us, they did not have to live dual lives and lie about their dreams and aspirations.





# HIV/AIDS Stigma and Discrimination: What's Wrong with our Societies?

Yunah Bvumbwe  
24 | Zimbabwe

A popular adage states that “to err is human and to forgive is divine.” We are all human beings and don't lead perfect lives, and that is why words like “mistake” and “forgiveness” exist in my vocabulary. However, in my society, where people don't forgive easily, they often stereotype and show no feelings of remorse.

As I was committing ink to this paper, I tried really hard to fight back my tears, which were obviously betraying me as I was unfolding this story. Growing up, I used to hear many stories about people dying of HIV/AIDS, how people would discriminate against you if they found out that you were infected and say there was no cure and you would surely die. This made me shiver as a child. People like my grandmother - who, like many women of her age, hadn't gone to school - would say all sorts of things that were discriminatory about people living with HIV/AIDS, but because I was still a kid, it didn't matter to me. After all, I had not come across anyone who had opened up about their HIV status.

A few years later, my aunt, who was the family breadwinner, got pregnant with another man after having three boys with different fathers. She did not register her pregnancy at any clinic or hospital until the day she gave birth. I was really shocked and I couldn't understand why she would do that.

Nevertheless, she gave birth to a baby boy and named him Pride. I liked him so much. He was cute and handsome and I could tell by the way he smiled at me when I held him that he liked me too. However, when he was only a few months old, baby Pride died after suffering through a long week of coughing and fever. We were all devastated. I cried that day and refused to eat. I felt something was not

right. It was like a heavy cloud over my family.

Later, we found out that Aunt Elizabeth hadn't taken Pride to the clinic for a check up after giving birth to him. Now, she too was sick, but refused to seek



## An Experience of a Young Woman Living with HIV in Uganda

Full video can be found at: <https://vimeo.com/142628841>

Uganda Network of Young People Living with HIV&AIDS (UNYPA)  
<http://www.unypa.org/>

medication. I still remember one day, when granny shouted at her, "You are now a moving skeleton, but you still refuse to go to hospital!" She was speaking with utter rage.

But why did Aunt Elizabeth refuse to go to the clinic? That question kept on crawling through my head. Her only action was receiving holy waters from a prophet of some sort who lived close to us.

The longer Aunt Elizabeth refused to visit the clinic, the faster her health deteriorated. She was now very thin and sickly looking. She agreed that she used to be an attractive woman, a woman who attracted the eyes of men whenever she passed. Now, she drowned in her clothes.

I shared a bed with her when she was sick. One midnight, my grandma woke up to check to see if Aunt Elizabeth needed anything, but when grandma opened the door, she screamed, "Eliza! Eliza!" My aunt did not respond.

Grandma then shook me vigorously from my deep sleep and I jumped. She said I should go and wait in the sitting room. I didn't understand what was happening. Suddenly, I heard a hysterical cry from the room where Aunt Eliza was. I didn't cry that time. Nor did I speak. It was too hard for me to believe that Aunt Elizabeth had breathed her last breath.

The following morning her body was taken to the mortuary and all relatives and neighbors gathered to bid her farewell. It was at that moment that my conscience told me everything was really happening. My best friend, Aunt Elizabeth, had really died.

It has been six years since my Aunt Elizabeth's death. One day, I was going through a pile of papers in my grandma's room, and I found a letter addressed to a man who I suppose was the father of Pride. However, the letter was never sent to the recipient. It remained in the envelope with all the stamps.

I read the letter and it broke my heart. It made me

hate the society I live in and hate how people's minds and prejudices refuse to change. The letter stated that she was tested and found to be HIV positive. She was too scared to tell grandma or anyone else in the family, and worst of all, she said she was never going to seek medication because she feared she would be found out by members of the community. She feared she would be chased away from the family house. She feared she would be discriminated against by her friends.

I was really disturbed by this. Why did my aunt choose death over life all in the name of fear? She could have stood up for herself and denounced discrimination and stigma.

But she didn't - and now it is 2015 and these are still huge problems despite the many new interventions to tackle HIV/AIDS. People are still scared to say, "Hey, I am HIV positive and I have been living positively for so and so years."

Just recently I heard a young boy say he would rather die unmarried than love a girl who would coerce him into getting tested before marriage. That is why there are still issues of willful transmission, because there are a lot of people who don't want their HIV statuses known but want to have sexual partners.

As a young woman who wishes to get married one day, I think ending HIV/AIDS is possible only if we go to our communities, socialize with members, engage them collectively and listen to their diverse views, because all cultures are different.

The United Nations Sustainable Development Goals were adopted this September and ending HIV/AIDS is part of the goals. UNAIDS unveiled its ambitious target of ending AIDS by 2030, but if a "one size fits all approach" is used, I am scared this may not help reach people we are trying to influence so they can come on board and speak with one voice on stigma and discrimination. Let's learn from our mistakes by engaging our societies to bring about positive results.



# My Past Does Not Define Me

Story by Sarah Kutahi  
25 | Kenya

Written and Compiled with Kelvin Mokaya, 22  
Youth Advocate at NAYA Kenya and dance4life Kenya

**Content warning: this article contains accounts of domestic violence, sexual violence and rape**

Just the other day I asked my mother why she never allowed me to play outside and enjoy my childhood like the rest of the kids in my neighbourhood. The answer she gave me made me appreciate the sharia culture that I was brought up in.

I was raised in one of Nairobi's biggest slums but I made it out without being subjected to sexual violence and without getting pregnant at a young age. This is not because I was special or I had superpowers but because I had the toughest mother in the world.

My mother was a Muslim before she got married to my Christian father. She was brought up to be very obedient, reserved and respectful. It is in this same manner that I was raised, and even more so because I was the first-born child. As unpleasant as it may have been, it played a major role in giving me a chance to tell this story.

My younger sister and brother would often go out to play leaving me alone in our one room iron sheet shelter that we called a home. In the evening everyone would come home with stories of what had happened during the day. Even I had stories to tell despite my sheltered existence. Stories would present themselves at my doorstep with evidence written all over my friend's faces. One friend lamented at how her relative had taken advantage of her and how she did not know what to do. Another friend complained about her mother's business of selling chang'aa (illicit brew) and taking part in commercial sex work and how it was keeping her awake at night such that she would be forced to drop out of school. Her mother contracted HIV/AIDS and passed on when it became tough to get a hold of the anti-retroviral drugs, leaving my friend as the breadwinner for the family and forcing her to take up her mother's job in raising her sisters.

There were other stories that awakened my rage and fear of the neighbourhood such as those of gang rapes and early marriages to violent men.

One day in the middle of the night there was a shrill cry heard throughout our neighbourhood. People assumed it was one of the neighbours who was of the

habit of coming home drunk and "expressing his love" by handing his wife heavy blows to the face. The woman would often boast to her friends of how she is loved by her husband and that he had expressed it by beating her. The next day we woke up expecting to hear boasting from our neighbour, but surprisingly she was not in the mood that morning. So we went about our business only to be visited later by my schoolmate Maureen, whose two black eyes were evidence of a thorough beating. Maureen was in tears as she told us that she had been pulled out of her house, where she was sound asleep, and was raped by several men during the night.

Maureen was older than me by five years and had started to bloom. Her breasts were quickly coming out of hiding and as an early bloomer she had hips and a butt that attracted men of all ages. She was very attractive for her age and vulnerable to all kinds of negative emotions from boys her age, women who felt threatened, and dangerous gangs in the neighbourhood. The gangs would sit on a corner surveying the area and making note of every woman while abusing drugs. In the evening they would make their move, violating women in the community. They would disappear for a while to allow the dust to settle but would just continue with the same somewhere else.

After this incident, I accompanied Maureen to the nearest missionary clinic where she could not get emergency medical assistance as the hospital was not equipped for her case. Because of the judgement and condemnation on the health workers' faces, she decided to forego the idea of going to any other clinic. After some time, she started noticing changes in her physical appearance. After sharing her story with a visiting aunt, her aunt advised her to visit an HIV Testing and Counselling centre. She tested positive and locked herself away, where death eventually found her.

Stories of school dropouts, and sometimes deaths from early childhood pregnancies and unsafe abortions filled the streets of the slum. Looking back, only a few of us made it. I wish something more had been done to rescue my friends -young women with bright and promising futures.

# Body Mapping Workshop

L'Orangelis Thomas Negrón  
27 | Puerto Rico, USA

Not knowing if we required permission, and not caring if we did, this past August we took over a magical corner in the Luis Muñoz Rivera Park of San Juan. Eight young women, each HIV positive, showed up to take part in our "BodyMapping" workshop.

The workshop consisted of an informal, open and honest conversation about sexuality, reproduction, our experiences, and the concepts around them. Using these ideas and conversations, the task was to paint our uteruses as we felt them. We started very simply, presenting and sharing what motivated each of us to be at the workshop. Responses included feelings of loneliness, the need for learning and growth, and the logistics of being able to bring our daughters along and whether or not we had transportation to the park. Before we moved on, we each shared a word that we felt defined every one of us. In unison and saying "I am because you are," we defined ourselves collectively as "extroverted, committed, happy, hardworking, strong, friendly, outgoing, sincere, sexy, challenging and grateful."

We talked about womanhood and how each of us expresses it and experiences it, and how it intercedes in our health and vice versa; the meaning of sexuality that we have freely built and the sexuality imposed on us by society; the integration of "soul and spirit" and how we relate to what is and those around us; the perception of gender roles, motherhood, menstruation and pleasure.

Next, we discussed how we feel when we are subversive, and the messages and treatment that we receive. We talked about the emotional and psychological burden of religion, and the guilt we can feel about how we act and what we choose to do with our bodies; about the permission that we give to ourselves to assume autonomy, control and power, from something as simple as getting a tattoo, a piercing or cutting our hair, to the most complex, on rights and sexual and reproductive health, on being coerced into abortion for being HIV positive.

We discussed the experiences of disclosure, of diagnosis and the types of stigma we face, including the route of infection. Space for diversity of thought was given in this workshop, and in short, it was a day of learning, growth and horizontal exchange, respect and appreciation.

For me it was a tremendous learning opportunity,



especially as I look at the things that I need to improve upon to be able to facilitate this kind of rich discussion again. It was an experience in which I could reflect on my local work and activism, as well as participate as a young woman living with HIV. Together, we went back to basics as we talked about what happens to us, how it happens, and how is repeated with other girls.

Thanks:

My deepest appreciation to those persons who helped to promote this workshop and gather participants, Also to those who supported with transportation, food and childcare.

I would especially like to thank the girls for trusting the process, being open, and sharing their experiences to make for a spectacular day. We continue spinning thoughts and constructing networks.

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The International Community of Women Living with HIV offers a supportive space for peers and allies specifically for young women, adolescents and girls. You can contact the ICW Chapter for Young Women, Adolescents and Girls at [cywag@iamicw.org](mailto:cywag@iamicw.org).

Learn more about the "More Than Our Status" Campaign at <http://doyouseehiv.org/>.

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