



WORLD*

*WOMEN ORGANIZED TO RESPOND TO LIFE-THREATENING DISEASES

November 2006

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by, for and about HIV positive women and their loved ones

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The Beginning of Another Life

by Lisungu Chieza

I was bold enough to take the test; I could not believe it when the results showed that I was HIV positive.

My name is Lisungu and I am 36 years old. As a result of the ill health my late husband was experiencing I was mandated under those circumstances to know my HIV status I was diagnosed with HIV in 1996.

My mother is familiar with the symptoms of AIDS related illnesses, as she has witnessed best friends, sisters and brothers passing away because of AIDS. It gave her the guts to confront me to own up and know my status. "How could my own mother suspect that I am HIV positive?" I asked myself. I was bold enough to take the test; I could not believe it when the results showed that I was HIV positive. My thinking was the only people who tested positive were prostitutes or people who were promiscuous, poor, or uneducated. "It wasn't me, it couldn't be!" I guess this started the long journey of my denial and my coping with the fact that I am HIV positive.

My late husband died eight months later. He died in my arms at home. I would have taken my husband to a hospice but I did not know about this service. I had met him while I was studying at University of Zimbabwe in 1990.

I experienced a lot of emotions like depression, stress, anger, and many others as a result of testing positive and losing my husband. In African culture when something goes right the husband gets the credit but when something goes wrong it's considered the wife's fault. My in-laws blamed me when my husband got sick. They said that I'm the one who had made him sick. They said I had put



Lisungu Hazel Marion Chieza.

witchcraft on him and made him ill. When he died they said I killed him. I did not know at the time that this was stigma and discrimination at its best.

As per our African custom, people gather together in the home to make funeral arrangements. In my case, my in-laws made all the arrangements separately without any family representation from my side. They came to our house where I had stayed with my husband demanding all his personal belongings. When my mother-in-law left the house she said, "Her foot will never step in the same house again," and also warned that she will have nothing to do with the welfare of the children. She said, "If those children of yours get sick, don't even call us. We won't have anything to do with them or you." I still recall these remarks vividly.

They made arrangements to bury him without me. I tried to follow them to the burial place but they refused to let us attend.

"What do you want here? You bewitched him, you killed him, and do you want to eat the body too?" the in-laws said. We were chased away. We stood

at a distance clasping our hands. I was confused, angry and at a loss. Life became meaningless. I lost my sense of time.

Traditionally, it is important for the wife to attend the funeral. To this day, I do not know my husband's grave. He was buried while I was at a distance.

I lived in fear because traditionally there are rituals performed at funerals and I was not there to perform them. As such, I feared that something bad was going to happen to me.

I became suspicious whenever something happened; I always felt it was because I missed the ritual. I believed I was a bad person because my in-laws blamed me for my husband's death. The first years were really difficult coping with loss and my HIV status. The myth that when one loses a partner one would also die subsequently gripped me. I stopped living a normal life as a result. My dreams had come to an end. As time progressed I kept on thinking that I would die.

I had earlier registered for an MBA program but gave up. All I thought about was death. I started neglecting my children and myself. I did not take the kids out to play. I could not concentrate on anything. I would fail to go to work, as I felt unmotivated to do so.

Through the support of my mother who came to check on me constantly, I began to pull myself back together. She was already interested in HIV due to her losses. She told me about support

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groups, counseling, books she'd read, and documentaries she'd watched. She really motivated me. I joined a support group, sought counseling and began to learn about HIV. She would ask me, "Did you read this in yesterday's paper?" Or, "Did you see this documentary?"

While working as a microbiologist at a private firm in Harare seemed

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worthwhile, I knew that I wanted to be involved more in HIV/AIDS. When it came to personal development, I changed my focus to HIV/AIDS. I studied for Systemic Counseling in HIV/AIDS. This assisted me in coping, and I counseled others who were newly diagnosed. There is power in getting involved. Later I enrolled at Stellenbosch University in Cape Town, South Africa. I studied for a Post-Graduate Diploma In HIV/AIDS Management.

In my Church, I did HIV/AIDS programs with youth and adults in the community. I wore HIV positive t-shirts to break the stigma.

I left my microbiology work to concentrate full time on HIV/AIDS. The first agency I worked for was "The Center" in Zimbabwe as a training coordinator. I coordinated trainings for schools, agencies, and churches everywhere. It was needed. Then I left to work for Vital Hope as a support-workplace coordinator, empowering companies to have HIV/AIDS workplace policies. I became involved in activism, working for people in grassroots communities advocating for access to treatment. Later I left for Canada. I work for AIDS Committee of Toronto (ACT) as a women's community education coordinator. I coordinate programs for positive women and agencies working with women. In one of the support groups in Zimbabwe I met Believe Dhliwayo, also an HIV positive activist. We got married. I disclosed my status to my children. They've taken on an interest in HIV/AIDS themselves. My daughter Takudzwa will be 15 years old in October.

She's taken a leading role in the AIDS clubs at her school in Zimbabwe. In Zimbabwe they have AIDS clubs in schools just like United States schools have drama clubs. My son, Tapihwa will be turning 13 years old soon.

I'm passionate about HIV/AIDS because women from the grass roots told me that I wasn't going to die. Professional people in my country usually don't associate with grass roots people. HIV caused me to be a new person altogether. I used to go to church just to be going. When I say "Thank you God," now I really mean it! Many people did not want to have anything to do with me so when someone calls me I say thank you. HIV has helped me develop a relationship with God and a better relationship with my mother and others. I took everybody and everything for granted. Now I value all my relationships and people I meet.

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In Zimbabwe professionals who are HIV positive don't attend support groups or come out about their status. I broke this cycle. I let the whole company I worked for know I had HIV. I called everyone in my company together and told them I was leaving. They asked me if I was going somewhere to make more money. I disclosed to them and told them it would be less money but it was not about the money.

In the support group I received moral support and empowerment. I felt safe in the support group and our educational differences didn't matter. In conclusion, I would like to say to other women "It's not the end of the world. Take it as the beginning of another life. You are the first person that can help you. Come to terms with the fact that you will live with something for the rest of your life. Live with your HIV, talk to it, because you are sharing your body with it! Blaming yourself or others won't change anything. If there is something you are passionate about, do it! I wasted two years of my life just waiting to die! ♦

WORLD Turns 15

by Maura Riordan

I would like to dedicate this issue of the WORLD newsletter to them: HIV positive women who would not lay down and die, but instead mobilized, supported one another and made a profound contribution in the HIV epidemic among women.

Fifteen years ago this year a small group of HIV positive women gathered in WORLD founder Rebecca Denison's living room to write a newsletter. Despite the fear that they had all been handed down death sentences with their HIV diagnoses, these women were driven to find other women with the message, "You are not alone". Some of the women who sat in the living room are alive today and some are not. I would like to dedicate this issue of the WORLD newsletter to them: HIV positive women who would not lay down and die, but instead mobilized, supported one another and made a profound contribution in the HIV epidemic among women. We who work at WORLD today thank them for their courage, resilience and foresight and are honored to follow them in this work.

If we fast-forward the picture of HIV among women from 1991 to today, it is a devastating scenario: 20 million women infected worldwide with women soon to be the global majority. Gender inequality, violence and poverty have been fuel for the HIV fire among women. Recently, several of us at WORLD were able to attend the International AIDS Conference in Toronto. Women from around the globe who are doing amazing work with very few resources inspired us. However, there was a theme of far too many women having little power to prevent HIV on a personal level. Many of these women live in countries where life-saving drugs are not accessible, women have no power to negotiate safe sex, and revealing an HIV positive diagnosis can lead to physical violence

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and rejection by family and community. It is not uncommon for women who have been infected by husbands to be blamed and punished severely by the extended family (see Lisungu Chieza's cover story). Lack of inheritance and property rights for women mean that once the husband dies the wife is cast out of the family without resources, often while caring for small children.

On a national level, we have infection rates among African American women that rival those of some developing countries. We still have immigration laws that ban HIV positive people from entering the US, with few exceptions. Women are still underrepresented in clinical trials and pharmaceutical companies are far too slow in developing pediatric formulations for HIV drugs. For those of us who attended the Toronto conference, it was painfully clear that there is an enormous amount of work to be done by and for HIV positive women everywhere and a renewed sense of urgency is needed in this fight.

Where do we all find the inspiration and hope to ramp up our efforts in the

face of devastating circumstances for millions of women worldwide?

We can find it in Louise Binder, the only HIV positive woman plenary speaker in Toronto. When Louise was cut short in her speech about the need of HIV positive women globally due to long-running speeches by HIV-men, she refused to yield the stage until she was done. When the moderator cut the power to Louise's microphone she continued her speech, yelling it out to the 5,000 audience members. Soon the chant, "Let Louise finish!" came from the audience and the microphone was turned back on. Like the women who started WORLD, Louise refuses to be silenced.

We find inspiration in the women of Uganda who have created peer outreach and support programs for HIV positive women who cannot leave their market stalls to get tested and treated for HIV because they work 16 hour days simply to feed their families. These peers go to the market to provide support, education and testing for women and are in the process of building a childcare center for the children of these vendors. Like the women who started WORLD, the

Ugandan women are creating programs that leverage the expertise and wisdom that HIV positive women have to offer in finding solutions within the epidemic.

Hilda Perez-Vasquez and the HIV positive women of *Collectiva Sol* in Mexico inspire us. These women have refused to be ignored by their government. They have raised their voices to demand that HIV positive women be a priority and have now received funding to hold their first educational and support retreat. It was clear in meeting these women in Toronto that they face an uphill battle at home, but they will not be ignored and disregarded any longer. They find their strength in each other.

In meeting these women, hearing their stories and seeing the results of their tireless efforts we come home knowing that despite the overwhelming circumstances facing HIV positive women worldwide, there is a irrepressible human spirit among them that is growing alongside this epidemic. This is the same spirit that was present in Rebecca Denison's living room 15 years ago and it is the same one that carries us forward today. ♦

Time to Deliver

by Dawn Averitt

The International AIDS Conference took place August 13-18, 2006 in Toronto, Canada. The theme of this conference was "Time to Deliver"— and after more than a dozen years of attending this biannual meeting I am pleased to report that the theme might as well have been "Time to Deliver FOR WOMEN!" Finally! From small breakout sessions and affinity groups to a powerful opening plenary talk delivered by Louise Binder, a Canadian activist and HIV positive woman, women were everywhere. Bill and Melinda Gates, Stephen Lewis, Bill Clinton, and former President of Ireland, Mary Robinson, were just a few of the dignitaries who demanded action on issues ranging from prevention technologies, to treatment and care access, to policy and human rights issues for women living with HIV. This meeting provided a venue for women to speak up, speak out, and be heard. Now we face the

real challenge— turning all of this energy and determination into action!

Take heart that we are seeing action all around us now. Women's organizations and advocates around the globe are creating networks and

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coalitions to work together. The Food and Drug Administration (FDA) has begun to put more pressure on drug companies to research their products in women during drug development. If companies do not include women in studies, they may not receive full approval for medicine without doing a special study with women. In fact, several companies are already working on ways to include more women in clinical trials. One of those companies, Tibotec Therapeutics, is about to launch a study called the GRACE Study (which stands for Gender, Race, And Clinical Experience). The GRACE

Study will enroll 70% WOMEN and only 30% men in North America – which will be a first in the US. Perhaps most importantly, women living with HIV are becoming involved in their communities doing advocacy or peer education, and many are speaking out publicly.

It is time for women living with HIV to be heard, to take leadership, and to make sure that our needs are met as we help shape and move the research agenda forward.

So what do I ask of you? Join us. Join other women living with HIV or affected by HIV and be a part of the solution. Get involved in research – planning it, supporting it and even participating in it. Figure out what you want to know most about living with HIV and help us find answers. It is time to deliver. ♦

Dawn Averitt Bridge is an HIV positive mother of 2 girls, Founder of The Well Project (www.thewellproject.org), and a women's advocate. The Well Project convenes the Women's Research Initiative on HIV/AIDS to improve the lives and quality of care for all women living with HIV disease.



Clockwise from top: Marching through the streets of Toronto with a universal message. ♦ Mme Leontine Ouedraogo/Tougouma (left) and Mme Ouedraogo/KI Abi of the Burkina Faso group, Association Burkin Action - a volunteer group working with HIV+ women and children with no access to HIV treatment. ♦ Maria Jose Vasquez, ICW International Steering Committee Chair. ♦ Anne-christine d'Adesky and Kathryn Anastos, MD of Women's Equity in Access to Care and Treatment (WE-ACTx) ♦ Hilda Perez-Vasques of Collectiva Sol in Mexico, a group of women helping to fight for visibility and empowerment of HIV+ women in Mexico. ♦ Center: "Tonya", a 30-year old HIV+ Mexican woman. Her husband died shortly after her diagnosis and within 6 months she began co-facilitating a support group for women. She stays strong with the help of her fellow HIV+ women.



Top: Members of Stella from Quebec and Asian advocates for Sex Workers Rights gather at the Women and Girls Rally. ♦ Middle row from left: Congresswoman Barbara Lee speaking out for HIV+ women. ♦ Mary Robinson, former President of Ireland— a tireless advocate for women living with HIV/AIDS. ♦ Stephen Lewis, UN Special Envoy for AIDS in Africa, a committed and inspiring ally in the fight against HIV/AIDS among women. ♦ Bottom row from left: International Community of Women Living with HIV/AIDS (ICW) members at the Women and Girls Rally. ♦ ICW activists at the Women and Girls Rally. ♦

Violence and the Virus: IAC Women Say Hands Off

by Anne-christine d'Adesky

Chantal Mukandoli traveled all the way from Rwanda in August for the International AIDS Conference in Toronto. A short trip, she says, compared to her journey since the days in 1994 when she was repeatedly raped during the 100-day genocide there—and exposed to HIV in the process. “I suffered for years before I could begin to talk openly about this,” she recalls.

Mukandoli spoke to other conference-goers on a theme that has emerged as central in Toronto: the cruel link between sexual violence and HIV, both as an extra factor for infection and in response to the news of a woman’s diagnosis.

HIV transmission through forced sex with a positive man is as tricky to measure as it is to stop. “It’s not only rape and sexual abuse but also marital rape, which is not even recognized by some countries,” says HIV positive activist Louise Binder of Canada’s Blueprint for Action on HIV and Women.

But new studies suggest that women who have experienced violence may be up to three times more likely to acquire HIV. In the U.S., a longitudinal study by the Women’s Interagency HIV Study (WIHS) has documented a high degree of sexual violence and domestic abuse among its cohort of largely African-American HIV positive women.

Danielle Layman-Pleep, executive director of Ontario, Canada’s Voices of Positive Women, reports that, “In the last two years, four HIV positive women in our organization have died—and three of those four were from violence from their partners.”

The anecdotal evidence is worldwide. “We’re seeing this everywhere,” says Binder.

It also turns out that in many more cases than were imagined, violence enters a woman’s life the moment her husband or boyfriend learns her status. Fear of such an assault often keeps women from getting tested in the first place, and in other cases, from seeking HIV treatment.

The imbalance of power between the genders is a well-known factor in negotiating safe sex, but this goes beyond that. “A lack of respect for women’s rights both fuels the epidemic and exacerbates its impact,” write the authors of “Strengthening Resistance—Confronting Violence Against Women and HIV/AIDS,” a report just released by the Center for Women’s Global Leadership.

Then add war into the mix. Rape is an HIV-tinged weapon in conflicts in Darfur, Sudan, for instance, and the Democratic Republic of Congo (DRC). The pattern has been documented by Human Rights Watch and other rights groups, which say the situation of mass rape in the DRC goes beyond anything

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Travel and Immigrations Restrictions

by Dorothy Kleffner

While we have won many battles against discrimination, limitations on travel and immigration remains a glaring example of how countries limit human rights based on HIV status. Such laws create severe and undue hardships and continue to grow worldwide year by year.

One of the most severe limitations on such freedom of movement comes from the U.S., which does not allow any person infected with HIV to travel or immigrate to the U.S., or change planes en route to another destination. Blanket waivers are sometimes granted for a special event such as the International AIDS conference in Toronto. But anyone that accepted the offer to allow one-time transit through the U.S. was entered into the U.S. database and will now be denied entry at any U.S. border. There are also individual travel waivers that

can be applied for. These waivers are expensive and difficult to obtain, take a long time to process, and are almost always declined. People attempting to cross the border without knowledge of this law are frequently detected by the presence of HIV medications in their luggage. Such people are fingerprinted, entered into the database, and a notation is placed in their passport. With this in their passport, they frequently experience difficulty with subsequent travel to other parts of the world. Many people wishing to travel to the US leave their medications behind, jeopardizing their health.

A friend of mine, a grandmother from the Caribbean now living in Canada, was planning to visit her family this year. She was scheduled on a direct flight, but was rerouted to change planes in the U.S. Since she was required to clear customs even though she was only changing planes, her HIV medications were detected in her luggage, and her HIV status was announced quite loudly. She was interrogated, fingerprinted, and notes were made in her passport. She was not allowed to complete the trip, did not see her family, and she will never be allowed

to enter the U.S. again, even though she lives only a few miles from the border.

While travel waivers are almost always denied, waivers of the U.S. immigration restriction are occasionally approved, particularly when legal experts with experience with this law are involved. But many people are still deported simply because they are HIV positive, and I have met husbands unable to bring their wives to live with them in the U.S. We know that most women worldwide are infected because of circumstances beyond their control, poverty and a lack of power over their personal circumstances. It seriously increases the burden to deny them the right to immigrate or even travel.

Since the International AIDS Conference is always held outside of the US as a boycott of this law, GNP+NA (The Global Network of People with HIV/AIDS North America) presented a panel discussion at the IAS 2006 conference in Toronto to highlight and bring focus to this issue.

Further information can be obtained at www.gnpna.org. ♦

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the world has seen. Doctors struggle to repair women's mutilated bodies in repeated fistula operations, and a growing number of rape survivors have tested HIV positive. Women and children also make up 80% of refugees and easily fall prey to rape in and around temporary refugee camps.

The way forward, advocates argued at the IAC conference, is to put issues like rape and domestic violence front and center in global AIDS efforts and earmark the funds to make that happen. None of the major AIDS funding mechanisms—the Global Fund, UNAIDS, PEPFAR, World Bank, UNICEF—designate money to address sexual violence. “We need to get this up to the level where the policy makers begin to act,” says Sally Fisher, who runs a group called Intersect that operates primarily in Africa and Asia.

At a press conference to release a new report, the Global AIDS Alliance

called for \$2 million annually to fund a comprehensive effort to combat violence against women related to HIV/AIDS. They are urging donors to devote 10% of global AIDS funding to programs that specifically address this issue, and have asked host countries to take up a “focused effort” to fight sexual violence.

Advocates also want better documentation of the problem and money to scale up the work that grassroots groups are already doing to protect women from the virus and the violence and to care for the victims of this toxic combination.

At an IAC conference strategy session called “Building A Movement,” health care providers from the Caribbean, Africa and South America swapped strategies for empowering positive women caught up in violent partnerships or enduring other mistreatments triggered by their diagnoses—and providing supportive services for survivors of sexual violence.

Finally, there are campaigns afoot to enlist men as role models and peer educators for other men. Bukeni Tete Waruzi Beck is with a group called AJEDI-Ka/PES that works in the DRC to help former child soldiers and women who were enslaved there during the wars that have raged almost constantly in the past decade. Many have HIV.

“As a man, I am committed to fighting sexual violence against women and children,” says Beck. “I appeal to other men to join us in our efforts. This is our joint struggle.”

Women at the conference in Toronto who are pushing for funding and attention for this issue can only agree. “We need men to be our allies,” says Fisher. “They have a role to play here.” ♦

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Reflections on the International AIDS Conference from WORLD Peer Advocates

by Anna Jackson

When I found out I got a scholarship to the International AIDS Conference in Toronto, I told everyone I knew. By the time I arrived at the conference I was exhausted, but that changed upon entering the Global Village. I received renewed energy from all the activity. People were there from Aruba to Zambia.

I met a woman who shared her disclosure story and said, “I first had to disclose (HIV status) to myself.” That made so much sense. To live your life, you have to be okay in your own skin. If you're not, then this dis-ease will run your life. It took me a long time to get to that point, but my life is fuller and richer for having achieved that goal. Upon leaving the conference I had a renewed sense of commitment, empowerment and determination. ♦

by Sylvia Britt-Raven

At the International AIDS conference, I saw people and attire from many countries and faiths. There were people

in traditional African and Indian garments. There were monks draped in orange. I saw women marching for equality. Hotel workers and men marched along side the women.

I heard that it is up to women worldwide to turn this epidemic around. We must work together to end the deaths, violence and disrespect towards women and children. I heard that we must work together globally to end the U.S. ban on HIV-infected people entering this country.

The best part of the conference was meeting other women. A woman from Liberia lost her luggage and I was able to share my clothing with her. She had little money for food, but she was in good spirits and grateful. I met a woman from Sudan. She held a prestigious position and when I said “wow”, she shook her head and said, “No—no wow.” She was humble and spiritual.

One day I wore an African dress and felt so connected to my roots that I felt out of place the next day in my American clothes. One woman told me

that I looked like I could be from Nigeria. I put my fist out and yelled YES! ♦

by Sylvia Young

After the International AIDS conference, I came back home rededicated to the cause to fight for our rights as women of the world. I quote Stephen Lewis, Special U.N. Envoy to Africa “This epidemic's force will never be subdued until women are brought to the table of discussion.”

At the conference, there were plenaries and skill building workshops, but the one place where I found the inspiration and hope is in the Global Village. I met women from all over the world living with HIV/AIDS, and/or working in the field. Feelings of belonging were strong and warm, and I felt that we all had something in common. When the time came on Thursday to leave the Global Village, I had tears in my eyes from the emotion of having to leave such a heartening place. The faces of all the women I met will stay in my heart forever. ♦

National & International Calendar

November 9–12, 2006: National Harm Reduction Conference: Drug Users Health: The Politics and the Personal, Oakland, CA. For more information contact Paula Santiago 212-213-6376, ext 15, email: santiago@harmreduction.org, or visit: www.harmreduction.org/6national.

November 30, 2006: Global Summit on AIDS and the Church: Race Against Time, Purpose Driven Ministries, Saddleback Church Campus, Lake Forest, CA. Call 800-633-8876.

December 6–10, 2006: Staying Alive, National Association of People With AIDS, New Orleans, LA. Visit www.NAPWA.org.

February 12–13, 2007: National Conference on African-Americans and AIDS, Minority Healthcare Communications, Philadelphia, Pa. Call 610-417-5844

February 17–19, 2007: Positive Youth Institute/Ryan White National Youth Conference, Oakland, CA. Visit www.napwa.org/rwnyc.html.

February 25–28, 2007: 14th Conference on Retroviruses and Opportunistic Infections (CROI), Los Angeles, CA. Visit www.retroconference.org/2007.

March 21, 2007: A Celebration of Life: Native HIV/AIDS Awareness Day, National Native American AIDS Prevention Center. Call (510) 444-2051, or email information@nnaapc.org

April 6–7, 2007: Skills Building Institute, Washington, DC/Silver Spring, MD. Visit www.napwa.org/calendar.html.

May 31–June 3, 2007: American Conference for the Treatment of HIV, Dallas, TX. Call 202-973-8658, or email ACTHIV@courtesyassoc.com.

May 29, 2007: 34th Annual International Conference on Global Health: Partnerships: Working Together for Global Health, Global Health Council, Washington D.C. Call 202-833-5900 or 802-649-1340 ext. 2134, or email conference@globalhealth.org, or visit www.globalhealth.org/conference.

June 27 2007: National HIV Testing Day, sponsored by National Association of People with AIDS. Visit www.napwas.org/hivtestinfo.

WORLD's Mission

WORLD is a diverse community of women living with HIV/AIDS and their supporters working together to:

Provide support and information to women with HIV/AIDS and their friends, family and loved ones;

Educate and inspire women with HIV/AIDS to advocate for themselves, one another and their communities;

Promote public awareness of women's HIV/AIDS issues and a compassionate response for all people with HIV/AIDS.

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