



WORLD*

*WOMEN ORGANIZED TO RESPOND TO LIFE-THREATENING DISEASES

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

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This Issue: Older Women

This issue of the WORLD newsletter focuses on the lives of older women living with HIV. We are defining “older women” as those who are 50 years of age and older. As the HIV/AIDS epidemic moves past the twenty-five year mark, a growing number of women are living positive and vital lives longer. Additionally, women continue to acquire HIV during their senior years. In the U.S., 18% of women living with HIV are over the age of 50. It is important to note that these women have unique healthcare and psychosocial needs that sometimes get left out of program and policy discussions. To kick off this issue, we are thrilled to re-visit Alba, who was featured on the cover of WORLD’s first newsletter in 1991. She is now 80 years old and living a full and inspiring life. To all of the older women living with HIV, we say to you, “You are not alone.”

Alba: “I think I’m the oldest woman living with HIV!”

At first I was scared to death about HIV. I was trying to get my life back again, plus, I had an emotional rupture with my boyfriend. It was so hard for both of us to accept HIV. I got to acceptance, but he did not. He left me and said I was the person who infected him. I was alone to be with the emotional difficulty. My family supported me well, and my human family of friends also supported me. In the beginning, I did not want western medicine and I stuck with eastern care for 10 years. Later someone convinced me to follow both, but it was so hard. My stomach was so delicate with the meds. I had no appetite and was vomiting from them. I am still healthy but I got sick in October and decided to go off meds. I want to live my last years relaxing with a good stomach, enjoying my life—I want to be me. I went back to eastern treatment—herbs and vitamins, and I am okay. Doctors could not tell me what was wrong. They tested everything on my body and I’m healthy everywhere. My family was so worried. My t-cells have come back up after my sickness and I am getting better.

In the beginning, I did not see the full picture of my life with HIV. But life has not changed with HIV. I am the same person with the same essence—it does not change. I have the same values and the same strong faith in the Creator. My message is that your essence, your spirit

You cannot carry the destiny of another one, it's enough to carry your own.

has to be really together and strong. If you are strong inside, you are strong from the outside. I don’t think anything will help you if you do not have faith, not medicine or anything. I believe in the Creator, the metaphysical. We are here for some reason. In the beginning, I tried to help so many people. I worked on the WORLD newsletter, a Spanish newsletter, and helped people with HIV in a group and at clinics. All my life I was very involved. About five years ago I stopped and said I will now dedicate more of my energy to myself. I am still happy to talk with people and share my knowledge. This is the meaning of life, whether you have HIV or not.

For 10 years I tried to help my ex-partner with his sickness but he was in denial. He got very sick and toward the end of living here he had dementia. I tried to help him to get back to Chile since he wanted that. I told him it would be best to stay here but he did not listen. Now he is back there but does not have help. It was a heavy load for me to carry. I carried him for 10 years, every time he was sick he called me. I would get him appointments with specialists and he would not go. I finally said “I don’t want to help anymore,” I did not want to push him anymore. I stayed close to him until he called me from Chile with collect phone calls. I stopped accepting the calls. I made connections for him in Chile and said goodbye last year. I feel

HIV has been a chance to learn things in a hard way.

so relaxed now because I did for him what I needed to do. You cannot carry the destiny of another one. It’s enough to carry your own. People need to learn for themselves. Some people never learn.

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He never saw me in the world as I am; he never loved me as I am.

HIV stigma has not changed in my country. I love my country but I do not like parts of the culture—the prejudiced part of it. My country is a beautiful country but there is not enough trying to help each other. My children and grandchildren born here know about my HIV, they love me so much, they don't worry about it and they don't care. My friends also know and nobody cares about it! I have had no bad experiences. The people I got close to saw my inside, not outside. Everything is a gift from heaven. I am blessed. I do not care about my HIV, if I do not care, who else should? HIV has been a chance to learn things in a hard way. People with HIV are more open souls—they understand life better. They have to learn to live with it. It is one more thing to carry in your life, it is part of you. You can help and teach people about this. I am grateful to be alive and have life as it is, full of people who love me.

No one wants to believe that I have HIV. People say, "That's not possible!" I think I'm the oldest woman in the world with HIV! I never feel my age and only began to realize how old I am when

*Your life is like a river,
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I got into my 80s. I feel what it is in my body to be old. Before this, I did not feel it. I never had older people around me, I always had young people, and I did not understand about being old. I did not fear it; I was just in my life. People look at me like I am a miracle. I feel I am not better than anyone else. For some reason I am alive, the Creator has some reason to keep me alive. My sick time has not been about HIV. When I got sick recently I saw a doctor and I told him I have HIV. He asked how long and I

told him. He could not believe it! I do not feel the HIV, but I do know I'm getting older. Older people I know have the same symptoms I have. It's aging. My friends were always younger than me. Inside I am young. Being old is new—I have to accept it. My physical body is getting old, but not the rest of my body.

With the rest of my life, I will help myself and others who need my help. I have always been taken care of by someone in my family and my family of friends. My faith has helped me be alive and also help others. I'm getting old because I'm supposed to. Now I take no more than the vitamins and herbs. What really helped me for years was the breathing and movement of yoga. Moving still helps me - everyday I go down and up my stairs. I love going outdoors and being alive. I will see how my body works and I will not push life. Your life is like a river, you have to let go to the current to get where you are going. You swim against the current and you get hurt. ♦

Taking it Step by Step: An Interview with Dorothy and Lizabeth

Dorothy and Liz are both HIV-positive. They are both over 50. Their risks for HIV were the same, regardless of the fact that when diagnosed, one was married and one was single.

"We came from the same era," explains Liz. "We believed that our men were there to take care of us. We had the expectation that when you're going out with me it's just me." Dorothy adds, "Now we know that's not true. When you're married, you don't think about condoms. You're not thinking about what he's doing when he goes out with the guys."

Dorothy was married when she found out she was HIV-positive. "If I had caught the clap [when I was young] I might understand. Then in my elderly age I get *this*. I catch HIV! That was a shock," says Dorothy. "At first for me it

*...and that's the hurtin' thing—
when you know you were
faithful to only one man."*

was disgust," says Liz. "But I know that I had a healthy sex life and it was about expressing my love. Maybe I could have put on a condom more—but we don't have the power to wear a condom or even negotiate it with our men." Dorothy adds, "And when you're married, what's there to negotiate! I got it from my second husband and that's the hurtin' thing—when you know you were faithful to only one man."

These are not uncommon stories for any woman who acquires HIV. Yet, for women who are over 50 there are other issues that they face that compound an

HIV diagnosis. Dorothy and Liz share that the primary emotional and spiritual challenge faced by HIV-positive women over fifty is isolation. "If you're single and over 50, it is hard to go out and look for someone, even more so if you are HIV positive," says Dorothy. "Yeah, if you're single it's tough," confirms Liz, "and if a woman is with someone, then the disclosure part is hard. Then there is the self-blame, the guilt, and the shame." Dorothy goes on to suggest, "If an HIV-positive woman is over 50 and has a man, she'll do whatever she can to keep that man. These women are scared of losing their men. Especially if this man already knows about her status. Sometimes a woman will go through hell just to keep that man."

For women who are HIV-positive and over fifty the sense of stigma is also compounded because of age. "Stigma is different for women—and for older women especially," says Dorothy. "There's more shame." While the stigma older woman experience may be similar

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OLDER WOMEN AND HIV/AIDS FACTS

- About 18 percent of AIDS cases in the U.S. female population are said to be in women older than age 50; and numbers of cases are expected to increase as women of all ages survive longer due to improved drug therapy and other treatment advances.
- In the last decade, AIDS cases in women over 50 were reported to have tripled, while heterosexual transmission rates in this age group may have increased as much as 106 percent.
- “Older women,” according to UNAIDS, “appear to have higher incidence than older men, and during a recent 5-year period, the number of new cases in this group increased by 40 percent. More than half of the infected over 50 are of African-American and Hispanic origin, indicating greater risks among minority groups.”
- In the U.S., elder African American women are disproportionately affected; in 2001 they comprised 11 percent of the population of women older than 50, but accounted for more than 50 percent of the AIDS and 65 percent of the HIV cases in this age group.
- While all older individuals with HIV infection or AIDS usually are invisible, isolated and ignored, this is particularly true of women, who often feel unable to disclose their HIV status due to stigma, even to family and friends and, certainly, not their community.
- Despite myths and stereotypes, many senior women are sexually active and some are drug users; therefore, their behaviors can put them at risk for HIV infection.
- Health care and service providers— and older women themselves— do not realize that they are at the same risk as other age populations; professionals often are reluctant to discuss or question matters of sexuality with their aging patients/clients.
- Most women (and all older persons) are first diagnosed with HIV at a late stage of infection, and often become ill with AIDS-related complications and die sooner than their younger counterparts; these deaths can be attributed to original misdiagnoses and immune systems that naturally weaken with age.
- Older people, especially women, with HIV/AIDS face a double stigma: ageism and infection with a sexually or drug-injecting transmitted disease; in addition, they are sensitive to a cultural attitude that assumes: “Elderly people have lived their lives— so what if they die from AIDS?”
- Seniors of both sexes are unlikely to consistently use condoms during sex because of a generational mindset and unfamiliarity with HIV/STD prevention methods.
- For older women, there are special considerations: After menopause, condom use for birth control becomes unimportant, and normal aging changes such as a decrease in vaginal lubrication and thinning vaginal walls can put them at higher risk during unprotected sexual intercourse.
- As HIV symptoms often are similar to those associated with aging (fatigue, weight loss, dementia, skin rashes, swollen lymph nodes), misdiagnosis is frequent in older women/people who are, in fact, infected.
- Women and older males may confront social and professional bias regarding the allocation of limited health care services and resources available to the AIDS community (i.e., “Why waste money on the elderly?”)
- Because the aging process itself lowers energy levels and results in restrictions in social routines which can cause emotional/psychological problems, the older woman/adult additionally infected with HIV may feel another “loss” and endure more severe depression.
- Senior women often are less likely to find support and comfort among family and friends, and because they are traditionally not comfortable in support groups, they may be less inclined to join them, citing lack of shared experiences concerning different issues.
- Due to the general lack of awareness of HIV/AIDS in older adults— in particular, women— this segment of the population, for the most part, has been omitted from research, clinical drug trials, educational prevention programs and intervention efforts.

SPECIAL CONSIDERATIONS

- HIV/AIDS educational campaigns and programs are not targeted at/to older women (and men); how often does a wrinkled face appear on a prevention poster?
- Rates of HIV infection (not AIDS) in all seniors, including women, are especially difficult to determine because older people are not routinely tested.

NECESSARY ACTIONS

- Specific programs must be implemented for older adults, especially women, who need to be informed about the transmission and prevention of HIV.
- Outreach should include workshops and trainings devoted to basic HIV/AIDS information, “safe” sexual and drug-using practices, testing, negotiation skills— all in relationship to aging.

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- More research is needed to study seniors' sexual and drug-using behaviors and to determine HIV disease progression and treatments in the over-50 population.
- Health care and service providers on all levels should be educated on HIV risk behaviors and symptoms of HIV infection; they need to conduct thorough sex and drug-use risk assessments with their older clients/patients.
- Programs aimed at reaching health care and service providers should cover misdiagnoses, testing technologies, treatments, support groups, case management and the importance of being actively involved in the health and well-being of their older clients/patients.
- Successful media and social marketing campaigns can raise awareness of HIV/AIDS in older people and reinforce the need for educational programs, while promoting respect and validation for the elderly as a group.

Jane P. Fowler compiled much of this tip sheet, based primarily on personal perspectives and experiences of consumers and professionals, while she was co-chairperson of the National Association on HIV Over Fifty. Now director of the national HIV Wisdom for Older Women program, she can be reached at: jane@hivwisdom.org. The web site is: www.hivwisdom.org

Resources

The Body: HIV/AIDS Resource Center

www.Thebody.com/index/whatis/older.html

HIV Wisdom for Older Women

www.Hivwisdom.org

The Women's Collective

www.Womenscollective.org

Columbus AIDS Task Force

*Extensive resource library—
link to resources over 50*

http://www.catf.net/
LIBRARY_BIB.html

International Community Of Women Living With HIV/AIDS

www.icw.org

AIDS Meds

*(Founded and Operated by
People with HIV)*

http://www.aidsmeds.com

ACRIA (AIDS Community Research Initiative of America)

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www.acria.org

AARP

*(Membership Organization for
People Over 50)*

www.aarp.org/family/love/
articles/hiv_over50.html

Lesbian and Gay Aging Issues Network

(Sub of American Society on Aging)

http://www.asaging.org/
networks/LGAIN/lgainlinks.
cfm?category=aids

Legal Assistance for Seniors

www.lashicap.org

Sisterhood Mobilized for AIDS Research and Treatment

www.smartuniversity.org

The Well Project

www.thewellproject.org

HIV + Women over 45 Support Group @ UCSF

415-353-2414

New York Association on HIV over Fifty

www.Nyahof.org

SAGE

*Agency Dedicated to Serving
Lesbian, Gay, Bisexual,
And Transgender Seniors*

www.sageusa.org

Needy Meds

*Disease based assistance guides for
medication assistance*

www.needymeds.com

Copasetic Women

*A support group for HIV positive
older women in New York*

(212) 864-6978

WORLD Program Updates

For more information about all of WORLD's programs, check out our website at www.womenhiv.org.



Shailey Merchant, Lotus Project Manager; Alejandra Cano & Anna Jackson, Lotus Project Trainers; Shalini Eddens, Director of Education & Training; Pat Kelly, Lotus Grad ATL; Christine Gordon Regional Dir. Hope Health; Nitti Champaneria Lotus Project Asst.; and Mulamba Lunda, Dir. Of Program Services Hope Health.

The Lotus Project

The Lotus Project, a collaborative program between WORLD and the Center for Health Training, continues to grow and blossom. The goal of the program is to increase and strengthen peer advocacy for women living with HIV throughout the U.S. The Lotus Project is funded by the Health Resources Services Administration (HRSA) for five years. At the heart of the project is the belief that Peer Advocates are the key to empowering and supporting women living with HIV. The project takes a community-centered approach partnering with women's agencies around the country to provide trainings to women. These organizations are a vital link to support, information and advocacy for women living with HIV in their community. Many of them are very grassroots with only 2-3 staff members. So far, Lotus has traveled to South Carolina, San Diego, Atlanta, New York, San Antonio, and Seattle, as well as right here in our own backyard of Oakland and San Francisco providing training in English and Spanish. 150 women from ages 19 to 67 have participated in Lotus and are blossoming in their journey towards growth. For some women, the Lotus training leads towards volunteer paid work, or simply educating others about HIV.

WORLD's Positive Women's Network

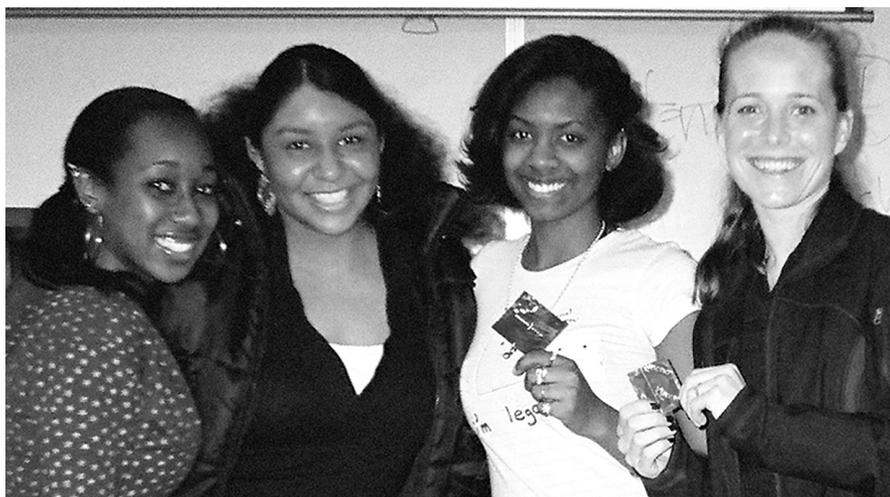
We are excited to announce the formation of a new national program! WORLD's Positive Women's Network is a national membership body of HIV-positive women designed to strengthen our power at a national level to create and demand policies and programs that fit the realities of our lives. All women living with HIV are welcome to join to ensure that their voices and issues are heard! PWN membership forms can be found on our website. All information is confidential. More information about the Network, as well as regionally based PWN caucuses, will continue to become available as the Network develops.

WORLD's HIV University goes to South Africa

In the small township of Mpophomeni, South Africa a group of about 15 HIV positive women are coming together to learn about WORLD's HIV University program. HIV University is an HIV/AIDS treatment and advocacy course established by WORLD in 1995, by and for HIV positive women. HIV positive women meet in private and decide on the structure of their HIV University, including what topics they want to learn, who they want to teach them, and who else (besides women with HIV) they would like to attend- such as family members, partners, friends. The students also decide what criteria will be used for graduation, and set their own ground rules.

In 2005, WORLD Board Member Moher Downing visited Mpophomeni with Professor Jane Salomonsen from the University of Oslo in Norway and talked about WORLD and HIV University. HIV has heavily impacted this community, with about 50% of the population being HIV positive. Earlier this year WORLD received an invitation from Professor Salomonsen to work with HIV positive women leaders in the community to launch their own HIV U.

WORLD Staff member, Shalini Eddens, arrived in Mpophomeni in early April to begin work with a small group of positive women. "The women we are working with are incredibly resilient. Many of them are open about their status, but there is also so much silence about HIV in this community, even though there are many organizations and a testing and counseling site in the community. The women are so excited to be able to create something of their own—they have already chosen some classes and teachers and have great momentum toward getting HIV U running," reports Eddens.



POWERRful Girls: Teju Adisa-Farrar and Sheena Castrejon, WORLD Peer Health Educators; Surita Allen, WORLD Volunteer; Piper Hyland, POWERR Facilitator & Outreach Coordinator.

POWERR (Prevention Outreach with Women Empowering Risk Reduction)

The POWERR Project just had its first birthday! POWERR is WORLD's first foray into an official prevention program targeting young women, and was born from a focus group held in 2006 with HIV-positive women, who indicated they would like to be more involved in prevention work with young women in their communities. We talked to young women (14 to 19) to find out what information they need about HIV, and how, where, and from whom they would like to receive it. From there, the POWERR Project was born. POWERR is a seven-part workshop for teenage girls in Alameda County, CA co-facilitated by a youth Peer Health Educator and an adult ally living with HIV. The workshops address Gender, Stages of Relationship, Communication, HIV and STI's, Safer Sex, and Visioning the Future. POWERR is funded through the *GENERATIONS: Strengthening Women & Families Affected by HIV/AIDS Initiative*, a project of the National AIDS Fund and Johnson & Johnson.

WORLD Summit

To commemorate World AIDS Day 2007, WORLD hosted the first-ever Bay Area Community Summit on Women and HIV. It was a powerful day, with almost 300 attendees from around the U.S., half of whom were women living with HIV. The day opened with

a panel profiling HIV-positive women leaders from around the U.S.—Cecilia Chung from Transgender Law Center, Vanessa Johnson from NAPWA (the National Association of People With AIDS), Dawn Averitt Bridge from The Well Project, and our very own founder, Rebecca Denison. The day consisted of breakouts in English and

Spanish along three tracks: Emotional Wellness, Treatment Updates, and Advocacy. Participants and staff left feeling **inspired, empowered, and involved** in a larger movement of HIV-positive women and their allies. We can't wait to host another Summit, or better yet, a National Conference on Women and HIV! Look out 2009!

Peer Advocate Program

The Peer Advocate Program is perhaps the oldest program at WORLD, and we continue to grow to address the needs of the WORLD community of women. Today, WORLD has six paid Peer Advocates on staff: Margaret Giordano, Sylvia Young, Anna Jackson, Sharon Gambles, Liz Bates, and Felecia Greenly. Liz was part of the LINC's program at WORLD

and now serves the same clients through the Peer Advocacy Program. Felecia has joined us temporarily to assist with our services. Sylvia works specifically with WORLD's Latina community. She has also recently taken on a new role as Peer Advocacy Coordinator, assisting the Program Director with administrative tasks. Janie Riley, MFT, serves as Program Director, and provides clinical support and supervision to the Peer Advocates.

Speaker's Bureau Update

The Speaker's Bureau continues to expand and reach out to new places to raise the issues of women living with and at risk for HIV locally, nationally, and internationally. Over the past year, WORLD has sent plenary speakers to HPLS (HIV Prevention Leadership Summit) and Staying Alive, presented a workshop at VOICES2007, presented a workshop in Kenya, participated in a Congressional Briefing, spoken at San Quentin State Prison, numerous faith-based institutions and health fairs, and spoken to students at colleges, high schools, and middle schools around the Bay Area. WORLD's Speakers Bureau consists of HIV+ women and allies—those who want to advocate for HIV-positive women and prevent new infections in women and girls. As part of our commitment to working more with the affected community, WORLD recently held a training for speakers which included both HIV-positive women and the affected community. Participants ranged from age 22 to 55 and included an HIV-positive woman with her negative male partner as well as the daughter of a woman who died from AIDS.

National & International Calendar

June 8, 2008: Caribbean American HIV/AIDS Awareness Day (everywhere)

June 25–29, 2008: Campaign To End AIDS (C2EA) Youth Action Institute, Albuquerque, NM (www.c2ea.org)

June 27, 2008: National HIV Testing Day (everywhere)

July 11–14, 2008: HIV Prevention Leadership Summit, Detroit, MI (www.nmac.org)

July 28–29, 2008: National Conference on Latinos and AIDS, Miami Beach, FL (www.minority-healthcare.com)

August 3–8, 2008: International AIDS Conference, Mexico City, Mexico (www.aids2008.org)

September 18–21, 2008: United States Conference on AIDS, Miami Beach, FL (www.nmac.org)

October 13–16, 2008: AIDS Vaccine 2008, Capetown, South Africa (www.hivvaccineenterprise.org)

October 15, 2008: National Latino HIV/AIDS Awareness Day (everywhere)

December 1, 2008: World AIDS Day 2008 (everywhere)

December 3–7, 2008: 15th International Conference on AIDS and STIs in Africa, Dakar, Senegal (www.icasadakar2008.org)

January 14–16, 2009: 12th Bangkok International Symposium on HIV Medicine, Bangkok, Thailand (www.hivnat.org)

WORLD now has added a way you can subscribe to the newsletter or make a donation on our website: www.womenhiv.org. Check it out!

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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