



WORLD*

*WOMEN ORGANIZED TO RESPOND TO LIFE-THREATENING DISEASES

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



Former Executive Director, Maura Riordan and Cynthia Carey-Grant, WORLD's new Executive Director

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Greetings WORLD readers

by Cynthia Carey-Grant, Executive Director

I would like to take this opportunity to introduce myself as the new Executive Director of WORLD. I am particularly humbled to follow in the steps of Rebecca Denison and Maura Riordan who grew WORLD into a local and national leader that provides innovative programs to support, inspire and empower women living with HIV.

As an African-American woman over 50, I am acutely aware of the challenges and risk for marginalized women with poor health indicators. Joining the diverse team of passionate, talented WORLD women brings me back full circle to my life calling – advocating for the improved quality of health and life for all women, particularly the most vulnerable. In my first months, I have witnessed first hand the energy, commitment and courage fueling this dedication. It was heartwarming to learn of their inspiring stories of commitment to its cause. They helped me appreciate the powerful potential of WORLD as an advocate for culturally appropriate community based healthcare for HIV positive women. As someone whose life has been personally touched by HIV, I know that HIV and AIDS affects us all. I also know that far too often, the health needs of women, particularly women of color, are ignored or minimized – and HIV is no exception. My experience as an advocate for women’s health has shown me the urgency of addressing the HIV epidemic among women. My life’s work and passion includes over 25 years as an activist in civil and women’s rights and social justice issues. I am returning to the arena of women’s health advocacy after working for several years in the social justice philanthropic sector. During my career, I served in leadership roles in several prominent women’s health and reproductive rights organizations with missions

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Welcome Cynthia

by Maura Riordan

As the former Executive Director of WORLD, I want to share my excitement and extend a warm welcome to Cynthia Carey-Grant. Cynthia joined WORLD in June and has hit the ground running. After nearly 7 years at WORLD, during which I cultivated a true love for this organization and its mission, I felt so good handing the torch to such an inspired, competent and creative leader.

Cynthia has spent much of her career dedicated to improving women’s health and their access to care and information. She has a strong track record in the field of sexual and reproductive health, and brings deep experience in management and grassroots organizing that will complement the work of WORLD. Most recently, Cynthia served as the CEO for a consortium of family foundations and brings the perspective of a former funder into this work. It was clear to

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WORLD ALL Stars at the SF AIDS Walk Summer 2009

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dedicated to creating positive social change like WORLD's. I am pleased to bring my experience and skills to further WORLD's mission and promote our nationally recognized peer-based education, support, advocacy, and leadership development by and for HIV-positive women.

As the new Executive Director of WORLD, I am committed to further strengthen our programs and build new bridges with allies in the women's sexual and reproductive health and rights arena. My goal is to leverage my background in women's health, particularly reproductive health rights, to serve the mission of WORLD. We have achieved much at WORLD over the years, but much work awaits our community if we are to overcome the issues and dynamics that keep women from getting the care they need and deserve. In a time when many community non-profits are drastically cutting services or worse, closing their doors, it is important that WORLD remains a place of hope for HIV positive women.

Thank you for your support of this incredible lifesaving organization. We look forward to continued partnerships in what I believe will be a new era of positive growth and continued service for WORLD. ♦

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me, as I spent time with Cynthia during our training overlap, that she was the right woman for the job.

Having a leader who is the right "fit" is critical. WORLD is a unique and powerful organization with a rich, inspiring history and a legacy that must be honored. Cynthia understands what the women of WORLD have achieved and how much work still awaits our community. She understands the issues and dynamics that put women at risk for HIV and the stigma that keeps them out of care. She said recently, "As someone whose life has been personally touched by HIV, I know that the face of women most at risk for HIV looks like my daughter, my sister, and myself. I believe we must make the change we want in the world."

It is my hope that the community, including our wonderful newsletter readers, will support WORLD and Cynthia as the new Executive Director. She has come into this leadership role at an incredibly difficult moment. WORLD funding has taken a severe hit and maintaining current services is a challenge. We will need your help. As I move to the East Coast, I now become a long-distance WORLD fan. Perhaps more importantly, I now become a financial donor. I have seen from the inside what this amazing organization accomplishes with too few resources. I hope you will join me, not only in welcoming Cynthia, but also in supporting the work of WORLD. ♦

After 26 Years - Starting Treatment

by Rebecca Denison

Six weeks ago—after living with HIV for 26 years, and being diagnosed for 19 of those years—I started treatment with HIV meds. For years I was a "nonprogressor." (An HIV+ person who shows no signs or symptoms of disease progression for over 12 years is called a nonprogressor or a long-term nonprogressor, LTNP.) But as my CD4 cells drifted down to 400, I got tired. As the news began to report a new H1N1-flu pandemic, I got scared.

The national treatment guidelines (www.aidsinfo.nih.gov/Guidelines) say that someone with fewer than 350 CD4s should be on meds; but advice is mixed for people with 350 to 500. I was afraid of side effects, but I also wanted to feel better and give my immune system a break.

I talked to my doctor, researched drugs on the internet with my husband, and talked to HIV+ women. We chose a combo that rarely has side effects. Then I set a date (the 19th anniversary of my HIV diagnosis), invited some friends, and organized a party. I bought a watch with a timer, and practiced adherence with my vitamins. My daughters, now 13, learned about drug resistance in science class, so they also helped me remember.

As I got ready for my guests to arrive, my mind flooded with images of the people I have loved who never got to take meds that work. This made me really sad, and grateful for what we have today.

The first week I felt kind of "off." Then, on day 11, I woke up feeling fabulous... until I discovered my body was covered in angry red spots. A trip to the emergency room confirmed that I was allergic to my meds. Scary!

My doctor and I agreed to see if I could "treat through," by taking antihistamines until I got used to the meds. It worked. Eventually, the spots went away and I felt fine. Remembering to take my meds has been inconvenient, but easier than I expected.

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Six weeks later, my energy is not great, but it's better. My viral load has dropped from 7,000 to undetectable and my CD4% (the percent of my white blood cells that are CD4 T cells—the conductors of our immune system) have gone from 24% to 33%. I am grateful to all who made this possible. In 1990 there was only 1 drug. Then there were several but they were very hard to take. Now I take 3 pills once a day and feel fine.

The change was scary. It required accepting that I needed help and committing to make it work. But now that I'm starting to feel better, it feels like a small price to pay. Fear can be paralyzing; action brings relief. ♦

Happily Ever After... Or Not

Thoughts on Relationship Change

by Cathy O

At first I was hesitant to write about changes in personal relationships. I knew that I would have to put some hard thought into my own experiences over the past twelve months—particularly the loss of my eight-year marriage, and how I have coped with the drastic change brought about by ending this unhealthy relationship.

As a little girl, every Halloween I wanted to be a bride. I loved the veil and the flowers, and basically the whole concept. In fact, I was sold on this lovely fairy tale: Meet the handsome guy, he whisks you off your feet, you have a bunch of kids and, supposedly everybody lives "happily ever after."

My path in life became derailed with drugs in my 20s, and I thought I could never have a real wedding, a family, or even meet a decent guy. Yet I never gave up on the hope of one day being able to wear the big white dress "for real." In 2000, five years into my HIV diagnosis (and after a considerable amount of time getting my life together once I gave up drugs for good), I met Prince Charming at a heterosexual

HIV support group. He was tall and handsome, and I fell hard and fast. His previous life experience was not that different from mine, so I felt a level of acceptance about my past. Eleven months later we got married—with the white dress, a gaggle of bridesmaids, lots of family and friends, and big reception. The Prince had two teenage sons from a previous marriage who were without a mom and it was perfect for me: a ready-made family!

The first six years were great; we put our energy into building a life together. We bought a house, went back to school, and focused on a future—all things I once thought I could never do because of my past and the disease that I now carried. Don't get me wrong, there were lots of ups and downs, but I took the marriage vow thing seriously—especially the "for better or worse" part. At the six-year mark, and in the middle of my transfer to a university to finish a bachelor's degree, my Prince strayed from our marriage. He said it was just about sex, but that didn't do much to help quell the anger and betrayal I felt. Because of the "for better or worse" vow I took, I chose to stay and give it a second chance. Unfortunately two years later it happened again, and in an ugly way that I never anticipated, leaving me with no choice but to make a hasty and final exit.

So here I am, single once again and not sure if I like it. Being single at my age (45) either sucks horribly or is absolutely fabulous, depending on what day you catch me. Dating is a huge change for me, and for the first time in my life I'm meeting men on the internet (on HIV sites as well as non-HIV sites). So far no one has run out the door when I disclosed that I had HIV, but it is definitely an experience. Between the alternating bouts of anger and resentment, and the counseling with a therapist (a must if you're going through any kind of traumatic relationship changes), I now mostly try to focus on myself. I wish I could say that I'm a strong woman and I've gotten past the betrayal. But I still very much mourn the loss of what could have been. I know my experience is not that different from other women so I feel comforted in that. And I would like to give a shout-out

to all my amazing beautiful female friends who helped to get me through the worst days after the break up. On the bright side, if the Match.com stuff works out, perhaps I will get to plan another wedding someday—I would soooo wear a different dress next time. And if not, well heck, I may just buy a new dress anyhow! ♦

The National HIV Treatment Hotline

Connecting people to information, care and resources

by Alejandra Cano, Project Inform Hotline Manager

Starting HIV meds for the first time can be an uneasy time for some. Take "Sonya," who has lived with HIV for 11 years and is just starting to take HIV medications. She called Project Inform's National HIV Treatment Hotline recently, worried about how those first few doses affected her. Although Sonya had talked to her doctor, who eased her mind, she still had other questions she hadn't had time to explore with him.

The Hotline is a group of staff and volunteers who have the personal experiences and outside connections to answer questions about living healthfully with HIV. Many of our operators have lived with HIV themselves for 10 or more years, so they can help many people sort through issues that most have had to face at some time in their lives. We have the time to talk through people's concerns and to help them figure out answers to sometimes difficult questions.

The National HIV Treatment Hotline has provided hope, information and resources to those in need for the past 25 years. We can do the same for you. Call toll-free at 1-866-448-4636, or email questions at www.projectinform.org/questions. ♦

"One Sister at a Time: Positive Women's Stories"

A Documentary

by Deborah Craig

In 2007/08, through a documentary film class I took at San Francisco State, I worked on a short documentary film about HIV positive women in New Orleans. I'm not HIV positive myself and hadn't had much contact with positive women before, so I guess I assumed they might be downtrodden and struggling—especially in New Orleans where so many folks were and are still recuperating from Hurricane Katrina. Well any stereotypes I had were soon shattered! I had never met women with such eloquence about the challenges in their lives, and such strength and bravery to deal with and overcome those challenges. So much so that I was inspired to do another documentary project about HIV positive women in the Bay Area. Luckily I heard about WORLD and was fortunate enough to be able to use the organization as "home base" and to work with some of their

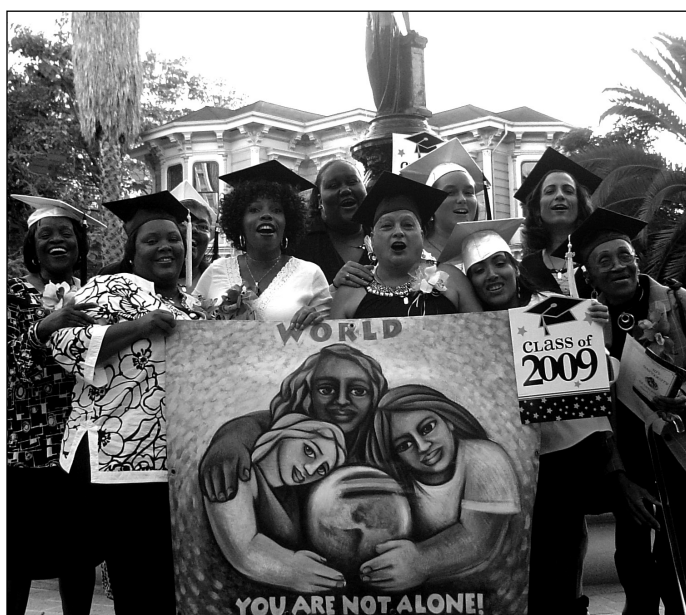


Janelle Dozier, featured in the movie "One Sister at a Time"

awesome staff members and clients. The end result was "One Sister at a Time," which both emphasizes the strengths of HIV positive women and tries to debunk some stereotypes: Women of all races are affected, monogamous and married women are affected, middle-class women are affected, none of us are immune. We showed the film at SF State, at Center for AIDS Prevention Studies, at WORLD, at the Faith Summit in Oakland, and more. Recently, it

even won best documentary at the International Student Film Festival Hollywood. (Yeah!) But, I don't feel very comfortable boasting about the project because it doesn't just belong to me. Instead it belongs to the women of WORLD who educated me about women and HIV, trusted me with their stories, supported and reassured me through the process, and in fact are some of the most "seriously bad ass" and inspirational women I have ever met. ♦

HIV University Has Returned to WORLD! by Dori Sproul



Summer 2009 HIV U Graduates

In 1994, a group of HIV-positive women from WORLD came together to create an HIV/AIDS treatment education "school." They wanted information about the disease process, treatment options and what they could do to feel better and live longer. After attending educational seminars where doctors and scientists presented information in language that was not understandable, the women became frustrated and wanted to do something that was accessible to all. They created their own school and called it HIV University. Women worked together to plan everything: the topics to be taught, the teachers, recruiting students, food, childcare, and a final graduation ceremony.

As women took on leadership roles in planning and implementing HIV-U, they took on ownership of the program as well, proudly standing up at graduation wearing their caps. HIV-U evolved into a life-changing course empowering women to take charge of their health and their lives, and to build community and personal connections with each other in a safe and confidential environment. Word began to spread about HIV-U, and ten years ago women from around the country came to a training at WORLD to learn how to do HIV University

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China's Story - Giving Birth HIV+

by "China"

I am excited about living my life as a positive women and having three beautiful sons who are HIV negative. I was only recently diagnosed with HIV, and I make sure to live a normal life. I do my best not to think about or question "am I going to die"? And I do my best to take care of my children and be happy. One challenge while pregnant for me was wondering whether my baby was going to be born with HIV. He was born negative and healthy, and is still negative. I am not concerned that he will come up positive because I took care of myself while I was pregnant by taking the HIV medications and praying. At this time, I am taking the medications Reyataz, Combivir, and Norvir. My baby is on AZT, and it's a challenge to wake up and have to wake him up to make sure he takes it properly. I have tasted it and it doesn't taste bad. It's sweet and tangy. I have not been adherent with my own medications for about a month, but do plan to go back on as soon as possible.

One thing I want to share with other HIV+ women is that your baby is very important, and to take your medication and make all your doctor's appointments to make sure your baby is negative. WORLD has changed me completely. After being diagnosed in the beginning of 2009, I felt so all alone. But WORLD has helped me change my life, especially my peer advocate Sharon Gambles. She has been there for me emotionally, especially in dealing with the diagnosis. I trust the fact that she experienced pregnancy and living with HIV. Talking with Sharon helped me understand that my baby could be healthy and negative. One thing I have which keeps me centered is my "China Wish Box." It is full of little prayers which I put into the box after praying. Once an accomplishment is finished, I take it out of the box. My concerns are not huge anymore, due to my kids being healthy and my knowing that all is fine. ♦

"If nothing ever changed, there'd be no butterflies."

– Anonymous

Going Back to Work

by Dori Sproul

Nine years ago I left a full time job in HIV/AIDS services to accept a job that would change my life in profound ways. I adopted two boys and became a "domestic goddess" ("stay-at-home mom"). I waited and longed for the role of parent, and looked forward to devoting myself to a 3 and 4 year old who needed much love, support and time, having experienced great upheaval in their first years. I was married, and my then-husband and I were able to live on his salary alone.

Having lived with HIV for 16 years, I was confident the meds were working. I'd be around a long time to raise my boys. Staying home was a huge change, having worked all my adult life. When my boys started pre-school, I kept active as a school volunteer, joined WORLD's board, and embraced domestic life. I finally had time to grocery shop regularly, cook more, and work on home improvement projects. The joy I felt in parenting was tempered by a feeling of isolation. I missed having co-workers to connect with during the day.

One year into my job as a mom, I experienced a life changing health crisis. I developed a case of strep pneumonia that resulted in three weeks of hospitalization, two in intensive care. That was my first medical crisis since contracting HIV; it affected my health for the next three years. I had considered going back to work once my sons started school, but ill health had me struggling to balance caring for kids and caring for myself. Then, new medications brought positive changes in my health for the past few years, and renewed optimism about my future.

The only constant in my life is more change. My husband and I are divorcing, requiring my family to

adjust in so many ways. Returning to work became a financial necessity. After an eight-year sabbatical, I accepted a job at WORLD in February. Two weeks later, I experienced a heart attack, an event bringing emotional and life-style changes that I am only beginning to embrace. I must now juggle motherhood, work, and self-care as a single parent, not an easy feat. My life has forced me to accept change, to embrace it, good or bad, and learn as much as I can from the experience. This is an imperfect process; one that presents new challenges every day. I left WORLD at the end of September when the organization restructured programs and services. I am currently working temporarily with a child advocacy agency, while looking for somewhere to land again. I watch my sons grow into long-legged adolescents, while chores go undone. I learn to prioritize, find joy where I can, and wait for more change. ♦

Hope for Preventing HIV with a Pill

by Matt Sharp, Director of Prevention & Treatment Advocacy, Project Inform

PrEP stands for *pre-exposure prophylaxis* or prevention, one of several bio-medical prevention strategies being tested today. It means taking a pill before sex to prevent HIV exposure from one infected partner to an uninfected partner. PrEP has not yet been proven to work, but the hope is it will at least be partially effective in preventing HIV exposure and therefore lowering the overall incidence of HIV. In light of the growing infection rate and problems with standard HIV prevention models, PrEP is really encouraging.

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National & International Calendar

January 21–24, 2010: National African American MSM Leadership Conference on HIV/AIDS and other Health Disparities, Atlanta, Georgia (www.naesm.org)

January 25–27, 2010: Latino/Hispanic HIV/AIDS Leadership Summit, Washington, DC (www.latinoaidsagenda.org)

February 7, 2010: Black HIV/AIDS Awareness Day

February 22–23, 2010: National Conference on African–Americans and AIDS, Baltimore, Maryland (www.minority-healthcare.com)

March 4–7, 2010: 6th Canadian HIV/AIDS Skills Building Symposium, Montreal, Quebec, Canada (www.hivaids-skills.ca)

March 8–11, 2010: National STD Prevention Conference, Atlanta, Georgia (www.cdc.gov/stdconference)

March 10, 2010: Women and Girls HIV/AIDS Awareness Day

March 20, 2010: Native American HIV/AIDS Awareness Day

May 15–17, 2010: Voices Conference, Washington DC (www.aids-alliance.org/education/voices)

May 18, 2010: Advocacy Day, Washington DC (www.aids-alliance.org/policy/advocacyday)

May 18, 2010: HIV Vaccine Awareness Day

May 19, 2010: Asian/Pacific Islander HIV/AIDS Awareness Day

June 8, 2010: Caribbean American HIV/AIDS Awareness Day

June 27, 2010: National HIV Testing Day

July 18–23, 2010: XVIII International AIDS Conference, Vienna, Austria (www.aids2010.org)

September 12–15, 2010: U.S. Conference on AIDS, Orlando, Florida (www.nmac.org/index)

October 15, 2010: Latino HIV/AIDS Awareness Day

December 1, 2010: World AIDS Day

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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