# Fierce Advocacy

After 25 years, WORLD (Women Organized to Respond to Life-threatening Disease) meets the challenges ahead.

February 13, 2017 By Oriol R. Gutierrez Jr.

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Cynthia Carey-Grant is executive director of WORLD (Women Organized to Respond to Life-threatening Disease). In 2016, WORLD marked its 25th anniversary. Carey-Grant has led the Oakland, California–based group since 2009. She has nearly three decades of experience in women's health leadership and advocacy.

Prior to WORLD, Carey-Grant was executive director of Common Counsel Foundation, a consortium of family foundations and individual donors committed to funding economic, environmental and social justice initiatives. She was also executive director of Changemakers, a national public foundation dedicated to expanding and transforming philanthropy.

Carey-Grant developed her expertise in women's health with such roles as Western regional field manager in the public policy division of Planned Parenthood Federation of America, project manager for women's health at The Permanente Medical Group within Kaiser Permanente and executive director and then board chair of California Abortion and Reproductive Rights Action League.

Tell us your thoughts about women's health and reproductive rights in 2017.

President Trump is not a friend of women under any circumstances. In much of the postmortem of the election, many people were shocked at the number of women who voted for him, but I wasn't shocked because I've seen this before.

As a society, we talk a lot about culture and racism and our need to understand, with a level of humility, different people's experiences based on their ethnicity. But we don't talk a lot about classism. People are afraid of losing their status in society or not being able to see something better than what had been for their parents, etc.

I understand that, but I see the fear showing up and the acting out against people less privileged. I'm really concerned about that. That has always been the case in reproductive rights and justice for women. That's what the Hyde Amendment [a legislative provision barring certain federal funds to pay for abortion] is all about.

Sort of like, "Oh yeah, we all agree women should have body integrity and women should have a

right to determine their own future, whether they'll be mothers or not, etc., unless you're poor, unless you need some help." And I see that happening again, and that's of special concern to me.

A lot is at stake. It's about the right to accurate and age-appropriate information about sex, sexuality and biology. It's about contraception, but it's also about health care, the right to be healthy, the right to have healthy babies and the right to have intimate partners that other people don't have any say over.

That's why, particularly for women, HIV is a reproductive justice issue. It's a reproductive justice issue all around the world. At the root of it—and what makes it so icky for people—is that it's about sex and sexuality. So we don't want to just deal with it like cancer or any other life-threatening disease.

If you want to get attention and justice, you have to be very loud, very diligent and very engaged. That's what we're going to do in 2017 at WORLD.

Please share more on WORLD's goals and your 25th anniversary.

Our mission is to improve the lives and health of women, girls, families and communities affected by HIV through peer-based education, wellness services, advocacy and leadership development.

There were four major accomplishments in 2016 that marked our 25th anniversary: We opened WORLD House, we opened the women's clinic, we began our anti-stigma campaign and we expanded many of our services.

The dream of having WORLD House had been around for a while. We wanted to have a safe and comfortable place for women that was clearly women-focused and women-friendly. We shared this dream with the AIDS Healthcare Foundation when we affiliated with them, and they helped us make it a reality.

The idea for the women's clinic was a result of our national project funded by Kaiser Permanente to look at how we can retain women in care. We hear a lot about outreach and linkage to care, but it's about retention. You can't get people to be undetectable if you can't keep them in care. So the clinic was born.

We also realized that too many women would still rather become ill and even risk death before they would disclose their status. In response, we initiated our "Rise Above HIV" campaign. We consider stigma one of the biggest challenges that women have to deal with in trying to live well with HIV. Addressing it has become paramount.

As for expanding services, that was in response to several needs. Just two or three years ago, we didn't do much prevention work. We were focused on women with HIV, but they were telling us they needed more. They needed help in a more holistic way. So we expanded prevention and extended partnerships with other organizations and agencies.

That said, we have never been about just providing services. We've always understood that if you

want to be able to provide services, then you have to have some kind of program to advocate on behalf of those services.

As an HIV-negative leader of an AIDS service organization, what led you to this field? What motivates you to stay?

This was not my chosen career path, but it is the culmination of a lot of different experiences. I lost my younger brother Garrith to AIDS-related complications. But I feel like I was called to do this work. Sort of the way that people who've had religious callings feel.

You see, I know it's only luck or God or circumstance that I'm not HIV positive. So whatever it is, it's beyond me—I know what my behavior was, just being honest. But having said that, I'm not HIV positive, so I don't know firsthand what that feels like. What I do know is that it's going to take all of us—positive and negative—to make real change.

My motivation to keep at it also comes from having worked in women's health and reproductive rights for so long. When I realized the outrageously disproportionate impact HIV was having on Black women in particular, you could have picked me up off the floor. The numbers are too high.

When it comes to advocacy, what are some of your priorities in 2017?

We need more advocates. Late last year, we lost Gina Quattrocchi, the longtime CEO of Bailey House, which provides housing and services to homeless people living with HIV/AIDS in New York City. She died after a long battle with cancer. Her loss affected me so deeply because we are in need of many more fierce advocates for women. She totally understood the intersectionality of all the issues that make living with HIV so difficult for women.

We need more bridging between people and movements in 2017. We can no longer afford these abstract divisions that sometimes occur between HIV-positive men and women, gay Black men and heterosexual women. This is the time to come together, particularly for African Americans. We can no longer wait for some other leader to come and show us the way.

In terms of women and WORLD's role, we're going to be actively involved in helping to continue the empowerment of women living with HIV. Not just in relationship to having the virus, but in relationship to all the intersectionalities between poor women and women who are in the margins of society in general. That means using initiative to contact allies and unlikely allies.

We're talking about people who we may not have prioritized working with before, but we're going to have to change that in 2017 when it comes to advocacy.

It is different for women living with HIV versus men who have the virus—there is a different kind of stigma, sexuality issues, the impact of trauma. But we need to talk with each other and not do this Oppression Olympics. We have to be as compassionate as we can be with each other and lift each other up. That's what I want in 2017.

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