Positive Impact

The executive director of The Well Project shares what motivates her to stay in the fight against HIV/AIDS.

February 24, 2020 By Oriol R. Gutierrez Jr.

Krista MartelCourtesy of Krista Martel

Krista Martel is executive director of the Well Project, a nonprofit organization founded in 2002 whose mission is to change the course of the HIV/AIDS pandemic through a focus on women and girls. She joined the group in 2009 as director of online services. When the founder, Dawn Averitt, stepped aside in 2013, Martel took on her current role.

Before The Well Project, Martel was vice president of Visionary Health Concepts, an independent, community-based medical education company. Before that, she was an account executive at World Health Communications, an international medical education agency. She has been working in HIV education since 1995.

What is the origin of The Well Project?

Diagnosed with HIV at age 19 in 1988, Dawn Averitt quickly realized there was very little women-specific information about the virus. That was even more the case when it came to research. The lack of women in clinical trials prevented knowledge of basic things, such as how HIV treatment may affect women differently than men.

So it became her mission to advance research about women and to increase participation in research and clinical trial design by women. She soon became one of the leading female HIV treatment activists in the United States and around the world.

After being asked repeatedly to be on advisory boards, attend conferences and make presentations, she realized there was a need for a centralized place for all this information. That's how The Well Project was born. She remains an emeritus board member.

What are The Well Project's focus areas?

We have five focus areas—education and information, community support, advocacy and leadership, collaborative engagement, and women-focused research.

One example under education and information is our fact sheets. We have them medically reviewed regularly. We have over 120 fact sheets now. We add new ones as our advisers identify gaps.

An example under community support is our blog, A Girl Like Me, which we added when I joined the organization. This blog of women's voices has become an online community, a sisterhood and a support network. We have published more than 1,000 posts by over 80 bloggers from around the world.

Our advocacy and leadership focus area evolved from seeing how these women's voices were having such a large reach through the blog and social media. We believed it was important to equip our women with the latest information about HIV treatment. That's when we developed our webinars, which have grown to become a platform for us to help develop leadership.

We've accomplished that by asking our women to participate as speakers. That evolved into having them do presentations at conferences for us, which has expanded our presence as an

organization and has helped them grow.

Under collaborative engagement are our community partners. In 2014, when we relaunched our website, we wanted anyone who came to us to be able to access other respected organizations. Each group gets a page. We have over 30 community partners [including POZ].

In addition to HIV groups, we are also establishing partnerships with more women-focused groups, including those focused on sexual and reproductive health, to help women living with HIV connect to other resources.

As for the women-focused research, much of that is accomplished through the Women's Research Initiative on HIV/AIDS (WRI), which is now essentially an annual meeting. Founded in 2003, it started as kind of a think tank.

The idea was to be interdisciplinary with different people working on a topic from various angles. Participants included clinical researchers, social scientists, activists, clinicians, government folks and pharmaceutical industry representatives.

For a while, WRI became independent, but it is definitely back in-house.

Tell us more about the influence of WRI.

During one of the WRI meetings, a question about women's participation in HIV cure trials came up. Rowena Johnston, PhD, vice president and director of research at amfAR, The Foundation for AIDS Research, was there and heard the question. She looked into it further.

She did an assessment of trial research and realized that in some places, the rate was zero, and in most places, it was 10% or less. This awareness of the huge gap sparked her to change a lot of the grants amfAR was funding to make sure that women were more involved.

After that, we held an entire WRI on cure research in women. That meeting led to a study, which we participated in, to find out what women living with HIV would or would not do in terms of participating in cure research.

The study was led by Karine Dubé, DrPH, of the Gillings School of Public Health at the University of North Carolina, and David Evans, of Project Inform. The data show the differences between what men and women are willing to do.

There are many other examples, such as changes to how clinical trial research is conducted through the Food and Drug Administration. We have had an impact.

In recent years, we dove into topics such as long-term survivors, including women born with HIV, and aging.

A major topic we've explored is U=U [Undetectable Equals Untransmittable] in women. That has led to us trying to be the lead on the issue of breast feeding and U=U, which is increasing in interest.

We cannot say definitively that U=U applies to breast feeding. Currently, U=U is for sexual transmission only. Part of the reason why is that there is so little research on breast feeding and HIV, due to a lack of research on women.

However, the topic is not that simple. The U.S. guidelines say that formula feeding is recommended and not to breast-feed, but there is a secondary condition that if a woman chooses to breast-feed that she should be supported.

In real life, we don't ever hear about women receiving that type of support. Most often, we hear that they face some sort of HIV criminalization charge or that they fear having their babies taken away if they choose to breast-feed.

As a result, we are digging deeper into the topic to advocate for more research.

How much of the work is international?

The Well Project definitely started out as a U.S. resource, but our online presence has given us a global reach. Most of our site visitors are now from other countries.

However, organizationally we continue to focus on the programs we're committed to in the United States.

We do feel a responsibility to our global audience. One of our responses has been creating fact sheets in Spanish.

How did you get into HIV advocacy?

In college, since I was studying economics, I had written some papers about the Ryan White program. I also specialized in developing countries and worked on issues in Africa related to women, HIV and the economy. So when my sister was diagnosed with AIDS in 1994, I was grateful to have that background.

When I had the opportunity in 1995 to work for a medical education company that specialized in HIV, I took it.

I worked on a program from WORLD [Women Organized to Respond to Life-Threatening Diseases] called HIV University. It was a peer-based treatment education program for women. We did several trainings over four years.

In 1996, Dawn Averitt was one of the women I met who was part of a training. Over time, we built a friendship and worked together in various capacities.

During that time, my sister struggled with AIDS. She was often the only female in support groups. She was her doctor's first patient living with HIV. This was before effective treatment, so she also went through a series of toxic drugs. She passed away in 1998.

At that point, I almost fell out of HIV advocacy. I didn’t know if I could continue the work, but I’ve stuck with it to this very day. Fighting HIV stigma is what keeps me motivated.

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