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The Well Project's Ongoing Fight for Women's Health Rights and Inclusion in HIV Research (TheBody)

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Image



Krista Martel Courtesy of the subject

The Well Project's executive director talks about what the organization is working on now.

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by [Charles Sanchez](#)

The Well Project has been offering education, support, and community for women living with HIV across the gender spectrum for over 20 years. Their amazing work is mainly online, which has made the reach of their work go beyond the borders of the U.S., letting women living with HIV connect internationally. From their inception, they've advocated for women's inclusion in HIV research, access to accurate data about the specific needs and challenges of women, and women's right to have control over their own bodies in any situation.

Krista Martel, The Well Project's dynamic executive director, joined me for a live conversation. Krista and I talked about the current national issues surrounding abortion and women's body autonomy, the history of The Well Project, the fantastic work they are doing now, and more.

This transcript has been edited for content and clarity.

Charles Sanchez: Since women's health is such a hot button right now, and this mifepristone debate

happening, what are your thoughts and feelings about these abortion rights being taken away, challenged, all of the above?

Krista Martel: Starting off with the light [question]?

Sanchez: Well, it's your fault! [Laughs] That's one of the first things on [The Well Project] website.

Martel: I know. Credit to Olivia Ford, our editorial director, for getting out those factsheets. Obviously, it's a huge issue. Part of our core tenet is bodily autonomy, and so we are really trying to figure this out. I mean, we had a meeting recently where we were talking about the intersections of abortion access and HIV, and how it is intertwined with HIV criminalization. There are certain states where if someone, like, say Texas, for example—shout out to [The Afiya Center](#), who's doing great work there—but if someone is seeking an abortion, that automatically says that they had sex, and you can be criminalized in Texas for having sexual relations with someone while having HIV.

It's so layered. We've even been talking about the aspect of bodily autonomy as it relates to women's and other birthing parents' choice to breastfeed or chestfeed, and it's along the same lines: that women should be able to make the choices that they feel are right for them and their family. So yeah, it's a big, big deal and it's a lot to be watching. In addition to the work that we're doing specifically in HIV and women, all these other rights that are being attacked [in terms of] women and women's health, the right to access health care—is hard.

Sanchez: It's amazing too, how this current mifepristone challenge is not even really about the medication itself as much as it is about the doctors. This particular court decision is about the doctors not being able to care for the patients, and they're being deprived of that if the women can take this medication that has been safe and used for 20 years. It's a really slippery way that [the courts] can get around certain things legally. It's crazy.

Martel: It's really hard because, with all the abortion restrictions in certain states, this has been a way to ensure that women have access to safe health care. And it's just—the whole thing, it's all about controlling women's bodies, and it's completely not OK. We're hoping that they will prevail on this side because it's endangering women's lives.

Sanchez: It's controlling women's bodies, and it's also controlling poor people, because rich people will always be able to get an abortion whenever they want one by either going to some other country or paying a doctor off. But when you're poor and you have [fewer] choices, they're taking away more choices.

Martel: And it's the people with already more obstacles to access. In this meeting that we did, we were looking at a lot of recent legislation. We started with HIV criminalization, and we were talking about policy, and it's the same states that, if you layer the maps [of states] that don't have access to or don't have Medicaid expansion, so have less access to health care—and this is mostly along the U.S. South—the rates of new [HIV] diagnoses especially for Black women are also in these same states. And then it's the most difficult or harsh HIV criminalization laws, the same [states] that are restricting access to abortion, the same that have the most harsh anti-LGBTQ laws. It's all super layered, and it's penalizing [mostly] Black and Brown people.

Sanchez: Well, whew, that was a big thing to start with. I apologize! Let's go back a little bit. The Well Project has been in existence for, what, over 20 years?

Martel: Yeah, 22 years.

Sanchez: How did it start?

Martel: I was not part of the origins of The Well Project, but I began working [in HIV] almost 30 years ago. It's a long story, but it's where I met the founder, Dawn Averitt, of The Well Project. Dawn was diagnosed at the age of 19, in 1988. After being told that she had six months to live and went beyond that, she walked into a CBO [community-based organization] in Atlanta and said she wanted to get involved. At that time, it was a bunch of gay men, and they just handed her a bunch of books and were like, "Dig into the treatment."

And so she did, and she started realizing quickly that women were not engaged in research. The medications were not really tested [on women]. They weren't engaged in clinical trials, they weren't part of research protocols. That led her down this path to really start getting involved in advocating for more research for women living with HIV, and better clinical trial design so that women would be able to engage in it. One of the big things for her too was, would she ever be able to have children? She was very much pushing research around [pregnancy and HIV](#), and so all these things led up to her becoming one of, you know, a handful—as we know, there are a lot of people living with HIV who are treatment activists and work with industry or government to advance the research agenda from a community perspective. But she was one of a small handful of women that was doing this.

And so, because of that, she became asked to be in so many different places all the time, both in the U.S. and globally. And so she had this idea of creating this thing like a well: People coming to the well and then going back with the information. So, to create this resource, an online resource that had all this information that people could access and then disseminate out. The origins of The Well Project were, in 2002, it launched as this pretty new-at-the-time [type of] online resource that housed probably 100-plus factsheets on all different issues related to women and HIV. And that was the beginning of it.

Sanchez: You [mentioned] specific research being done for women. That's a challenge that women across the board have had. What are you guys working on right now at The Well Project?

Martel: What aren't we working on? I mean, we are a small and mighty team. Our five buckets: The factsheets and the information/education part were the basis, but since then we've expanded. A second program launched by Dawn and others was the [Women's Research Initiative on HIV and AIDS](#), and that was started in 2003. And that was to bring together a multidisciplinary group of people to focus on how to advance the research agenda for women. That's the second program, and that's also one of our buckets.

I started with The Well Project in 2009 and then became the ED in 2013. In 2009, I was handed the website over, like, "Here's the keys to the car, do what you want," and was given a small grant to start a blog for women living with HIV. That [blog] is called "A Girl Like Me." Shortly after I started, I was working on trying to lower the health literacy of the factsheets and get them up to date with current science, and I started social media. I was the only staff person at that time and was for quite a while until we did have someone come on in 2011. And then there was a gap again with just me, and then we hired a second staff member in 2019, Juliana [Hawawini], who then took over the website so that I could focus on other things.

In 2021, we hired Ci Ci Covin, and then Olivia Ford has been with us as a consultant, so we had this team that has been evolving. Our most recent staff hire was [Bridgette Picou](#). And I cannot forget to mention Kelly Bower, who's been part of the operations in the background and the backbone of The Well Project since the beginning, because she had known Dawn and Richard [Averitt], Dawn's brother, who was a co-founder. Also, Jenna Conley, who's also been part of The Well Project, heavily involved.

Once the blog started and we started seeing these amazing women coming and sharing their stories and having wide platforms, we then started being asked to be part of other opportunities with other organizations and entities. We started thinking, "How can we provide capacity-building and leadership development too?" One thing I started right after I became the ED was the community advisory board (CAB), which has been instrumental. It's a group of women from all over the U.S. and outside the U.S. to be part of the development of our programming, ideas that we bring to funders to get grants for.

They're also the people that, when we're asked if we know someone who might be interested in participating on a panel or speaking at a conference, we go to our CAB first to provide those opportunities and advocate both internally and externally for meaningful compensation for their sharing their expertise. That's been something that has been a tenet since the beginning. So it's information/education, community support, leadership development, and then collaborative engagement. We really like to partner with other organizations to make sure that we're not overlapping and we're lifting each other up. And then the women's research part. Those are our five buckets.

Sanchez: I imagine that the blog is really important, that women are telling their own stories. When we talk about women, we're talking about anyone who identifies as a woman.

Martel: Women across the gender spectrum.

Sanchez: When I've been talking to other women in the HIV community, that feeling of being alone is one of the first things, after the fear of being diagnosed—that, "I don't have anyone to talk to. I don't know anybody." So the blog, I imagine, is really important.

Martel: Yeah, it's huge. It was very organic too. When we first started, we tried to say, "Oh, try and blog once a month." They're volunteering their time. That part is not compensated because when we started, we just really couldn't. And so we're sticking with the original model, but it's really anyone that wants to share, they can do it anonymously or they can do it publicly. It's helped people, especially people who may be anonymous, interact with other people and share their experiences, and feel part of a community even if they're not publicly disclosing their status. And that has led to the evolution of really seeing people become advocates, whether public or not.

Because it's virtual and because it's global, it's created this global sisterhood of women who are able to share their experiences and relate to each other where they may not otherwise have been able to do so if they were geographically in one place, because sometimes it's harder to step into certain places. It's pretty amazing to watch, just through word of mouth, through our community advisory board and our team, to see how more and more people become part of that sisterhood. Someone might blog actively for years and then step off and then come back five years later. What we hear is that it helps the readers who may be out there feeling alone to see their stories, but it also is kind of therapeutic for the women who are blogging.

Also, in that leadership development part, two of our staff members, Ci Ci and Bridgette, found The Well Project and started as bloggers. Then they became community advisory board members and now are on staff. We are still pretty small, but because The Well Project is a nationally recognized organization, people will come to us and we're able to recommend people to get job opportunities elsewhere.

Sanchez: You mentioned that it was global. Did you reach out to other organizations in other countries, or was that something that happened naturally?

Martel: That is really due to having such a large online presence, and people just Googling. We did get a pretty sizable Google Ad grant from the early days of the organization, so that helps people find us. While our programming is largely focused on the U.S., the online resources have a global reach. I think about 60% to 65% of our visitors to the website are outside the U.S. Because of that, we wanted to see what it would do if we were able to provide some capacity and leadership to women outside of the U.S. So we have a global ambassador in India who is really leading the way for women with HIV in India, and also a woman in Nigeria, Abosede Olotu.

Sanchez: Do you provide things in different languages on your site?

Martel: We do have a lot of resources in Spanish. That took us a while to build back up because it

started out that way, but when we were redesigning the website, it was hard to get all the updates we were doing to English also done in Spanish and updated. But now we have some dedicated funding and resources for that. We have a couple of factsheets in Hindi and we want to do more there, but we just need to build up capacity and funding for that. We'd love to do every language if we could.

Sanchez: Well, in this country, to find things that are in English and in Spanish is a challenge. I don't know about other health disparities, but HIV specifically because I have friends who are actively trying to get everything translated into Spanish all the time. And I don't know what the problem is with that, what the resistance is. If it's just that "we're American and we need to speak English," or is it racial, or is it just financial, or what are the challenges? I just don't understand it.

Martel: I don't either. I think, again, it's funding and capacity, but we are really dedicated. We were doing it with some general operating grants for a while. Then we did get some dedicated funding to really push out even more. We translated even more of our factsheets and blogs into Spanish, and we're trying to do some events with Spanish interpretation. But, you know, it does take resources. But it's needed. Of our top 10 countries that came to the website, all of a sudden five of them were Spanish-speaking countries, so obviously there's a need. I remember when we launched our factsheet around [U=U](#) back in like 2017 or 2018. When we translated that into Spanish, it became one of the No. 1 factsheets viewed on our website. So it's definitely needed.

Sanchez: I love that you're doing that, and that you're dedicating resources and time to getting the word out in different languages to other people. You mentioned earlier that there are Southern states that are the ones that have the most challenges. Are you doing programs to specifically reach that target market?

Martel: We have been focusing increasingly more and more over the years to center Black women and other women of color in the work, and then also with a more specific focus on the U.S. South because of the disparities within the epidemic and especially with women. One of the things we've been working on is working with different women and even providers around trying to raise awareness. We have a partnership with [NASTAD](#), which is an organization in D.C. that works directly with the EHE, the Ending the HIV Epidemic, jurisdictions. They actually are giving us some funding too, to supplement some of the work that they're doing. But they have a database of all those jurisdictions and all the public health departments within Ending the HIV Epidemic, largely in the South. That's another way that we're able to disseminate our resources, get some of these public health departments to recognize some of the messaging, and hear some of the most pressing needs that we would like them to hear.

Sanchez: What is something that you're the most proud of at The Well Project, or that you're most excited about?

Martel: It's hard. One of the things that we are really proud of is the work that we've done around breast- and chestfeeding, breastfeeding for women and infant feeding. In 2018, we did a Women's Research Initiative meeting focused on U=U as it pertains to women. There's not that much research. I mean, some is starting to happen in the U.S., but the research that we really had was from 2017 and it was all in Africa. That showed that there were a few women who apparently had undetectable viral loads that were transmitted. There's still some question around that, but it's less than 1%, which is basically still what we are talking about with pregnancy.

Yet the U.S. federal and CDC [Centers for Disease Control and Prevention] guidelines said, "Do not breastfeed." The other U.S. guidelines said that if a woman chooses to breastfeed, she should be supported by her provider. And there was a lot of language around that, but a lot of people didn't see that. And so if a woman even decided to make that decision, oftentimes they would be threatened with child protective services [CPS]. Then also, the WHO [World Health Organization] international guidelines often said something completely different: They recommended breastfeeding.

So, there was all this confusion. People were saying, "Oh yeah, U=U does apply to breastfeeding." Other people were saying, "No, because we don't want someone to get CPS called." We dove in on really trying to get out accurate information and then do advocacy. Again, I'll shout out to Ci Ci. When Ci Ci came on staff, she then later got pregnant, and she had been part of some of this education advocacy that we've been doing. Because she had all this information and access to some of the experts in the field, she decided to breastfeed her baby, who's now 2 and a half, I think. She did it publicly and shared her story in a lot of different places, which actually changed a lot of people's perceptions and made people think. And all the different experiences that she as a Black woman going through this process and how that may be different for a white woman who also is doing that. That led to us being able to work with a bunch of people to actually get the guidelines updated. All the guidelines in the U.S. now say if a woman chooses [to breastfeed], it should be a shared decision-making process between her and her provider. And there's a callout: "Under no circumstances should CPS be involved."

As soon as the other guidelines were updated, [the CDC] pretty immediately changed all of their webpages to say, "These are the guidelines that we're supporting." And they recently put out a call for a proposal around breastfeeding and HIV research in the U.S. So that's a huge thing too.

For more information about The Well Project, visit thewellproject.org. To stay up to date on activities and information, follow them on social media @thewellprojecthiv. You can contact Krista Martel directly at kmartel@thewellproject.org.

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