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Tonia Poteat: Hearts and Minds of The Well Project

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Hearts and Minds of The Well Project is a storytelling project that shines a spotlight on some of the extraordinary individuals who have been instrumental [over the past 20 years](#) in making The Well Project the organization it is today. The series features portraits of women living with HIV, members of our community advisory board and board of directors, staff members, partners, and other allies of The Well Project. In honor of our 20th anniversary year, we released 12 new stories between November 2022 and November 2023 to highlight the diversity of our community. [Read all the stories in the Hearts and Minds of The Well Project series](#)

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Providing HIV Information and Care for 30-Plus Years

I grew up about 30 minutes from Durham, North Carolina, where I live now – which is hilarious given that I've lived in a whole bunch of different places. I grew up in a relatively small town with my parents and my brother, both sets of grandparents, and a lot of cousins. I didn't recognize it at the time, but I had a very firm grounding in my family and extended family.

Starting an AIDS hotline then wasn't like you Googled the answers to questions and read it to people. There was no Google. There was no internet. There was just us and some books.

I first heard about HIV when Rock Hudson came out about his diagnosis. I was in high school and didn't know much of anything. I got to college and volunteered at the local AIDS service organization, AIDS Project New Haven. I wanted to be a buddy, but I didn't have a car, so I couldn't drive people to appointments and things, so I worked in the office and helped type up the executive director's speeches. Doing that, I learned so much about the political nature of HIV and how it reflected social inequalities; and that HIV was a social justice issue, which I hadn't recognized before. This was 30 years ago now, so I can't remember the name of the executive director, but she had such a big influence on my life, and she has no idea.

After college, I moved to Atlanta and worked at the Feminist Women's Health Center and recognized how little information there was around women and HIV. In 1992, the Feminist Women's Health Center got a small grant to start an AIDS hotline; another advocate, the late [Alicia Culver](#), and I started the AIDS Hotline for Women. There was no space for us at the Feminist Women's Health Center, so we got space from the Atlanta chapter of the National Association of People with AIDS. [Dawn Averitt](#) worked there, and that's how I met Dawn.

I just want to put in context, for people who are young and may not know, that starting an AIDS hotline then wasn't like you Googled the answers to questions and read it to people. There was no Google. There was no internet. There was just us and some books, and whatever articles were printed out. A lot of our interaction was around, *How do I find this information? What do you have in the library?* It was literally paper things and a phone.

Dawn worked in the treatment education division, so I *needed* to know her, talk to her. Of course, she was very invested in learning whatever was out there around HIV and women. And we liked each other. That always helps, to get along. I had a lot of respect for her and what she was doing. She started a project called WISE (Women's Information Service and Exchange) and invited me to be part of it. I have been involved ever since.

I was very moved by this work and wanted to do more tangible stuff. I decided I wanted to provide care for people living with HIV. I'm also very impatient. Medical school was too long. I became a PA (physician assistant), which is two and a half years of school. I kept in touch with Dawn sort of tangentially, but not much at all until I moved back to Atlanta years later and was working at the Grady Infectious Diseases Program, the largest HIV care provider in Atlanta. Dawn told me that WISE had become The Well Project.

Image



When The Well Project's online presence started, I was the editor of the first [fact sheets](#), reviewing them for medical accuracy and using them in my own work: *Hey, there's an article about this and I can print it out and give it to you if you don't have a computer.* I was excited to have a place to direct the women that I provided care for to connect around information specific to them and to other women living with HIV – to be able to say: *You are not alone. Here's information for you, and here are people who are also living with HIV and understand your experience. It was started by a woman living with HIV. Isn't this awesome?* So many women felt alone and isolated.

In terms of The Well Project, I think there is still a need for women living with HIV to be connected and see other women with HIV thriving, telling their stories, feeling empowered, growing. [A Girl Like Me](#) is powerful for that. I access those stories myself sometimes when I do education, to say: *Here are examples of all these people from different walks of life, and their experiences of living with HIV.* The fact sheets are so important and accessible for people. I don't know any organization other than The Well Project that is filling that educational and connecting role around women and HIV.

The Subtly Transformative Impact of WRI

The WRI ([Women's Research Initiative on HIV/AIDS](#)), of course, is amazing. The first WRI meeting in 2003 blew my mind. Different kinds of people all together in one space with a common goal – it felt more like a rejuvenation retreat than work. Everybody was there because they cared, and nobody was posturing. Everybody was like, *How can we make a difference?*

At WRI, I would see people whose motivations and passions were very clear and informed how they did their work. To have those 'possibility models' was really impactful for me.

When PEPFAR (US President's Emergency Plan for AIDS Relief) happened, I talked my way into a part-time job in the newly formed Global AIDS Program at CDC (US Centers for Disease Control and Prevention). I was doing a lot of international travel and also still working clinic. I've never been able to give up working clinic; I love it too much. I realized that if I wanted to have some impact, instead of doing what other people told me to do that I might not agree with, I needed to have a terminal degree. I went back to school to get a PhD in international health – but I would still go to the WRI meetings. Those meetings were just inspirational: To have not just a vision for, but to actually see what it's like when you get bench scientists, social scientists, people who are living with HIV and not scientists at all, and activists all together in a room around a table on equal footing to address specific questions and concerns – and how important it is for the scientists' side.

One WRI meeting that stands out to me is the [2016 meeting on the cure](#). I don't do that kind of research; I learned so much about what they're doing in that arena. I also remember the panel of women living with HIV talking to the bench scientists about how they don't know that a cure is worth it to them given that they are doing well on treatment – and the bench scientists' minds being visibly blown. Like, *What!?! A cure is not something that everybody equally wants?* The importance of realizing the disconnect there, and how WRI created a space for that dialogue, is significant.

How I went from being a care provider, to doing research, and then the period where I worked for PEPFAR: All those shifts were influenced by the people I met at WRI and what I felt both capable of

and supported in doing in my own personal growth. There's an image of what it means to be a researcher or a public health person, and it's very not informed by your passions. At WRI, I would see people whose motivations and passions were very clear and informed how they did their work. To have those, to borrow Laverne Cox's term, "possibility models" was really impactful for me.

I remember a time when WRI was trying to evaluate itself and its impact, and it's so diffuse that it's hard to say, *This is the thing that WRI did*. People point to [the GRACE study](#), which demonstrated it's possible to enroll a substantial number of women living with HIV into clinical trials. But I believe the influence is so much more subtle but also powerful in that each person who comes to WRI leaves changed. I think of people like [Judy Auerbach](#), a leading social scientist: She leaves those meetings changed. Women living with HIV leave those meetings changed. There are ways it influences all of us who sit together and think deeply for a couple of days about what it would take, and what it means, to improve the lives of women living with HIV.

Continuing to Evolve for 20 Years – and Beyond

What most impresses me about the survival of The Well Project and the WRI for 20 years is not just that it is still here and has grown, but that it has also *evolved* in ways that respond to the evolving needs of women living with HIV.

I was excited to have a place to direct the women that I provided care for to connect around information specific to them and to other women living with HIV – to be able to say: *You are not alone.*

There is probably going to be the need, as we age out of what is most relevant for younger people, to make sure there is not just space, but leadership opportunity for folks who are in the moments that are changing, not just from the prior moments. Not to throw us out with the garbage, but to recognize evolving needs for different kinds of leadership and involvement and directions for the organization. It's a challenge for any entity. I think that's what The Well Project and WRI are going to have to face. You don't want to look around the WRI table and it's just the same exact people from 20 years ago. As much as I always want to be invited until my deathbed, that might not be the best thing, right? It might need to be a different person, different people, at that table – or different tables.

This narrative has been edited and condensed for clarity from a longer conversation.

Tonia Poteat, PhD, MPH, PA-C, has been a part of The Well Project and the Women's Research Initiative on HIV/AIDS since their inception. She was an early medical reviewer for The Well Project's library of fact sheets.

Read all the stories in the [Hearts and Minds of The Well Project](#) series



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