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Karine Dubé: 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

Table of Contents

- An Interdisciplinary Life
- A Space to Shape Your Work and Worldview
- Bridging Science and Advocacy
- Transforming the Field with WRI's Approach

An Interdisciplinary Life

Growing up in Canada, I took a lot of things for granted in terms of what is considered a right versus a privilege – for example, a comprehensive sex education, or basic healthcare.

I spent the first 19 years of my life in the French part of Canada. I was accepted to medical school right after completing the International Baccalaureate program, which is possible under the French system. But instead, I took a big chance and moved to Chapel Hill, North Carolina, to study at UNC (University of North Carolina). I have been in the US since then, although I have traveled quite a bit. I became a dual citizen in 2011.

My life has always been about bridging different worlds. First, I had limited English when I came to the US. I learned to speak English in my late teens and became bilingual. When I moved to the US, it was about bridging languages and countries. I moved to San Diego last year to work at UCSD (University of California – San Diego), so now it's about bridging two coasts of the US. I am also an interdisciplinarian, constantly trying to bridge different disciplines and to integrate different fields of research.

Growing up in Canada, I took a lot of things for granted in terms of what is considered a right versus a privilege – for example, a comprehensive sex education, or basic healthcare. As a sophomore in college, I had an asthma attack and it ended up costing me a fortune, even though I had health insurance. That was my first encounter with the US healthcare system, where I witnessed the discrepancies. The healthcare system is definitely more advanced in the US, but in Canada, at least everyone has access to it. You can always fall back and rely on the system. The value of solidarity, viewing issues from the perspective of the most disadvantaged communities, and advocating for access to things that *should* be taken for granted, have greatly influenced who I am today.

I graduated from UNC and went to England to study international development and global health, then spent six years in and out of Mozambique developing clinical research capacity for HIV prevention trials. I learned Portuguese – again, bridging different worlds, different realities. Learning a new language gives people a different consciousness.

Prior to going to Mozambique, I worked with amfAR, the Foundation for AIDS Research. I met <u>Judy Auerbach</u> at the <u>Women's Research Initiative on HIV/AIDS (WRI)</u> annual <u>meeting in 2007</u>. WRI 2007 was my very first WRI meeting and there was Judy, the legendary socio-behavioral scientist everyone spoke about so highly in the amfAR office. Judy had just left amfAR to go work for the San Francisco AIDS Foundation. I remember sitting next to Judy at a WRI dinner; she put a yellow pashmina on my shoulders as it was pretty cold outside. I didn't realize the impact she, and WRI, would have on the rest of my life.

I quickly witnessed the lack of socio-behavioral science, ethics, and community engagement in the field of HIV cure research at the time.

Being invited to the WRI meeting in 2007 was kind of by chance. My amfAR supervisor at the time, Monica Ruiz, asked me if I wanted to go, and transferred her WRI invitation to me. I ended up meeting Dawn Averitt, Judy, and all these amazing WRI women.

A Space to Shape Your Work – and Worldview

WRI stayed in the back of my mind after 2007. I worked in Mozambique from 2008 until 2013, when I came back to UNC for my doctorate while working for an <u>HIV cure research</u> collaboratory. I quickly witnessed the lack of socio-behavioral science, ethics, and community engagement in the field of HIV cure research at the time.

WRI has defined who I have become as a scientist, as a practitioner, as an advocate.

Three years later, I felt so fortunate to present the results from my doctoral work at <u>WRI 2016</u>, which focused on <u>HIV cure</u>. That meeting gave me so much inspiration and direction. There was a panel of women with HIV talking about cure research and all their concerns about it. That panel has shaped so much of who I have become as a social scientist, and how I frame questions. It made me a better researcher.

After meeting Eileen Scully at WRI, I started working with Eileen on the <u>first HIV cure-related trial</u> <u>focused on women</u> in the US, and led the socio-behavioral component. As a result of WRI 2016, I also worked with Project Inform on a survey with The Well Project, which became a <u>paper co-authored by many WRI colleagues</u>. I also started working with <u>Tonia Poteat</u> on a transgender study. I am now working with Amaya Perez-Brumer on some other work.

WRI 2022 was about increasing meaningful representation of women in research, which led to a paper we just published on the topic with many The Well Project and WRI collaborators. With John Sauceda at UCSF (University of California – San Francisco), we also invited The Well Project to collaborate on a grant focused on HIV cure research. In collaboration with the FRESH (Females Rising through Education, Support, and Health) cohort in Durban, South Africa, we are also integrating trauma-informed, healing-centered concepts into the design of a cure-related trial done with African women based on inspiration from talks at the WRI 2022 meeting.

There was also <u>WRI 2018</u>, focused on <u>undetectable equals untransmittable (U=U)</u>. The meeting was always at the back of my mind, percolating, and has left such a big impression on my research as well. Looking at the tensions in the field of HIV cure research and the need to interrupt HIV treatment – and essentially risk breaking the U=U equation – we need to conduct HIV cure research in a way that is equitable and accounts for the intersectionality of people's lives, including the health of participants' sexual partners. WRI 2018 inspired some work with <u>HIV serodifferent couples in the US</u> and also led me to create the Partner Protection Working Groups in the ACTG (AIDS Clinical Trials Group). We also just published a <u>paper on partner protection in HIV cure trials with HIV treatment interruption</u>. As a result of WRI 2018, I have become a fervent advocate of partner protections in HIV cure trials with treatment interruptions.

The most recent WRI was focused on mental and behavioral health and is also influencing where I'm going right now with my research. Every WRI meeting has been part of my journey and has shaped my research. It's almost become my "WRI subconscious." WRI highlights the value of lived experiences, which has changed how I work, starting with *put people first* – preferably *put women first*. If you start

there, you can reach everyone.

Bridging Science and Advocacy

I'm a social scientist, but I engage in advocacy as well. I've learned so much from the way Judy Auerbach does this. Judy is always on point and so impactful. She is a very elegant advocate. I feel very clumsy, but I'm trying to become a better advocate for the issues that matter most, particularly around women in HIV cure research now. WRI has defined who I have become as a scientist, as a practitioner, as an advocate.

As HIV cure trials are scaled up in Africa, we will need to have more woman-centered conversations.

I also have a lot to learn. I'm so grateful for the chains of mentorship that exist within WRI – for Judy, and for other amazing WRI participants who show us how to make good change, and sometimes good trouble, happen in the world.

It's almost like I am coming full circle now, from working on HIV prevention in Mozambique to going back to Africa to work on HIV cure research, again working with young women, and being able to bridge the HIV prevention, early treatment, and cure-related or post-intervention control research continua. As HIV cure trials are scaled up in Africa, we will need to have more woman-centered conversations. We are going to have to pay attention to issues of reproductive justice, human rights, and mental health. The issue of partner protection is going to become so important as well, to implement these trials ethically.

Being at that intersection of different disciplines, we must be brave to have these difficult conversations and consider others' points of view. WRI provides that safe space, and that courage, to break down silos. For me, it's almost like the story of *The Wizard of Oz*: WRI has given me the courage, the heart, and the brain to keep going.

Transforming the Field with WRI's Approach

WRI is the only space where I have felt truly safe to have these interdisciplinary, multidisciplinary, and even transdisciplinary conversations. A lot of HIV research, particularly in HIV cure, is very biomedical. WRI is always so careful about who is around the table, and values every single voice that's represented. That is so precious in our field.

HIV trials are usually designed with older white cisgender male participants in mind. They've contributed a lot to HIV research, and we are extremely thankful for their involvement. At the same time, what if we started with a young African woman, or a transgender woman in the US or anywhere in the world? If we designed a protocol around that person and centered the person instead of the product, what would the trial look like? WRI represents a model for having these types of difficult discussions safely, which should probably be replicated in other spaces.

There is a problem-solving mindset in WRI that we need more of in the field, instead of being fatalistic about how things will never change. Well, how do we change things?

It sometimes feels like we're preaching to the choir. It might be nice to bring in other people to experience the value of a safe, interdisciplinary space – and to have similar conversations internationally, particularly on the African continent where the majority of people with HIV live, and are

female. We still have a lot of work to do in the US and in Africa on some critical issues. WRI could be a great framework for addressing them, and even reshaping some of the research infrastructure along those lines.

The field of HIV research probably needs reform in the long term, especially if we want to see women represented, but it would require changing a lot of the power dynamics in our field, particularly in terms of acknowledging the role of socio-behavioral sciences and lived experience. WRI is a unique space where we are encouraged to think in terms of, *How do we solve this?* There is a problem-solving mindset in WRI that we need more of in the field, instead of being fatalistic about how things will never change. Well, how do we change things?

Knowing how to ask those tough questions is not always easy. Sometimes I get myself in trouble for asking too many questions. But some questions need to be asked, and we need to be able to appreciate a range of viewpoints.

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

Karine Dubé, DrPH, is a Women's Research Initiative on HIV/AIDS member and past presenter, and a frequent collaborator with The Well Project.

Read all the stories in the Hearts and Minds of The Well Project series



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