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Spotlight on Katie Willingham: Women Making a Difference

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The Well Project interviews Katie Willingham, Community Advisory Board member and A Girl Like Me blogger, for our "Spotlight: Women Making a Difference" series.

How did you get your start in HIV advocacy? Are you particularly passionate about a specific topic or demographic?

After 15 years of living with HIV, 10 of which I spent in terror waiting for death to catch up to me (after being given one to five years to live), I was invited to attend an HIV conference where I met some amazing advocates who impressed me very much. It planted the seed of interest and passion to get involved but I didn't know how, or where. The following year I went back to that conference, but this time I met a group of women called the Positive Women's Network USA, a passionate group of women dedicated to advocating for the HIV community for social, racial, gender, and reproductive justice, I also heard Bruce Richman of the Prevention Access Campaign share the U equals U message for the first time. These people ignited a fire in me that would change my life. I found my place, my passion, and knew I could not sit on the sidelines any longer. I became passionate about sharing the U equals U message because it changed everything about how I felt about myself. The following year I met The Well Project, where I learned the power of sharing my story, and where I really started to develop my own voice.

I want to fight for the rights of the disenfranchised and under-represented communities, including: women, people of color, LGB and particularly transgender communities, because someone else did it for me. I want to educate people about the modern realities of HIV, especially youth, as I think they're the key to ending stigma and the epidemic.

Do you think women living with HIV face unique challenges? What are they?

Absolutely, I think for most of the nearly 40 years of the HIV epidemic, women have been overlooked and underrepresented. Since the early days, HIV has been surrounded by stereotypes, misinformation, and stigma. For years women were left out of the conversation because it was mostly seen as a gay men's disease. Women, Black people and other people of color, and transgender communities are more likely to be afflicted by mental illness such as depression and anxiety, homelessness, food insecurity, comorbidities, and/or forced into sex work for survival, yet disrespected by healthcare professionals, and underrepresented in research and decision-making tables. It's long past time that we be truly seen and heard.

Do you work to address those challenges through your work? If so, how?

I think education and awareness is key, that's why I started Facebook groups (Alabama Poz Life and Alabama Transgender Coalition) to try to educate others, raise awareness, and build community. I also try to build my networks, affiliations, and reputation. While it goes against my nature as I'm not a braggy or egotistical type of person. I heard a great woman say something that changed my views about it, she said (paraphrasing) "Don't be shy about building yourself up and making yourself big, share your accomplishments, accolades, and affiliations, make yourself big, because big voices get heard." Most of us women don't like to brag, but she showed me how it can be a useful tool to help you in your work in representing others, so don't be afraid to brag a little ladies, big voices get heard!!

Can you share a story that illustrates how you've been successful in working with women living with HIV?

I had been in advocacy about two years, just doing my thing, I didn't really think anyone even noticed really, when I went to a conference where a woman walked up to me and she knew who I was, she hugged me almost in tears and proceeded to tell me that she had been watching my work for a while and I was one of the reasons she got into advocacy herself. My mind was blown and I was so extremely touched. I was awakened to the fact that you never know most of the time who is watching you, how many people you're really reaching, they don't usually come walking up to you, but you ARE reaching somebody, lots of somebodys. Always keep that in mind.

What advice would you offer a woman who recently learned that she has HIV?

Please don't waste your time living in fear like I did for 10 years, you can live a long, healthy, productive, and dignified life with HIV, and with an undetectable status you can even have unprotected sex and even have children, SAFELY!! So life isn't over, it's just beginning. I think my life is better now than before my diagnosis, no lie. Just stay adherent to your meds, if you can take a vitamin every day, then another pill is really no big deal, it's just a pill that saves your life. Keep your doctor appointments and be proactive with your healthcare, ask questions, research, etc. Build a supportive network of friends, family, therapist, etc. and keep your status close to the vest until you've had time to think about the ramifications and whether you're fully prepared for to disclose, because unfortunately stigma is still a very real thing, but know that you're not alone.

What advice would you offer a woman who wants to get started in HIV advocacy? Any specific guidance about getting ready to publicly share her HIV status for the first time?

I would say AWESOME!!! Advocacy can be very rewarding and fulfilling, and in truth it helps you as much or more as anyone else, you learn things you might not have otherwise, you connect with amazing people, get access to great resources, and enjoy the fulfilling rewards of knowing that you're helping others. It gives a sense of purpose, accomplishment and pride, and the HIV advocacy community very much shares a close bond very comparable with that of family, and for some like me even closer than family. But advocacy often (not always) means disclosing one's status. This never bothered me personally, I've always found it to be very liberating and empowering, but you also have to take into account your loved ones and how they feel about that, because they often pay the same price as you by association. If you decide against disclosing, that doesn't mean you can't advocate, many advocates do great things without disclosure of their status. So just take the time to consider all things, talk to advocates, a therapist, your family before choosing your path.

Can you describe an experience in your advocacy or personal life of which you are particularly proud?

I'm proud I finally gained the courage to come out as a woman of transgender experience and live in my truth, knowing that my visibility and openness in a state like Alabama is making it easier for others to come out too. I'm proud to be an advocate, completely open with my status and my life, and knowing that I'm helping others in some way. I'm proud every time I can overcome my fears and insecurities, face my anxieties and work through bouts of depression, which is often a daily accomplishment lol.

What impact has COVID-19 and physical distancing had on your life and work? What coping mechanisms are helping you?

Personally, I'm an introvert by nature so the isolation hasn't been a very negative experience for me; most of my advocacy is already virtual and online, but I do very much miss traveling and seeing my advocacy family. Living with mental illness (severe depression and social anxiety), I know the importance of self-care. My puppies are my world and amazing soothers, I have a great therapist, an amazing network of sisters to reach out to if I need to, and it's important to have hobbies. I like to draw, and write, and I'm learning to play drums and I want to learn another language. I want to learn Spanish to have that skill in my advocacy toolkit and Cherokee to learn and connect more with my own heritage. Wish me luck lol.

How did you learn about The Well Project? How long has it been

part of your life?

I first learned about The Well Project September 2017 at a conference, I attended their workshop about writing and sharing your story, they talked about their *A Girl Like Me* blog and I loved it, I was sooo interested in it, but I didn't join at that time. I don't know why, maybe I thought I was busy or something. I honestly can't remember, but about six months later it crossed my memory again and I decided to look them up and applied to join and I'm so glad I did because it's such an amazing and supportive organization. I've been blogging with The Well Project now since March 2018.

What impact has The Well Project had on you?

The Well Project was not the first advocacy organization that I got involved with, but I could argue that it was one of the most personally consequential, because when I was honestly too afraid to reveal too much about myself elsewhere. I found in The Well Project a space where I felt safe to share all my inner truth. Writing was kind of a form of therapy for me where I found healing and wholeness in sharing my story and my thoughts. I wasn't afraid to reveal my struggles and insecurities, my past traumas or present struggles, and I got the added benefit of knowing that in doing so I could help others who may have been through something similar and feel the same way. This healing and wholeness has allowed me to bring a stronger and more complete self to all of my endeavors wherever they may be.

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