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How HIV positive women #PressForProgress



PRESS FOR PROGRESS

By Christabel Millar



Pictured: Living Positive Victoria President Christabel Millar stands with Bruce Richman, founder of the U=U message and executive director of Prevention Access Campaign.

This year's theme for International Women's Day—Press for Progress—reminds us to continue pushing for women's participation in the advances we're making in the Australian HIV response.

The night before International Women's Day, I was part of a panel discussion for the U=U speaking tour presented by The Institute of Many (TIM), a grassroots social movement of people living with HIV, and a number of HIV organisations from around the country. Together, world-renowned HIV activists, researchers and community members watched the *In Bed with U=U* video campaign before unpacking the U=U message that has brought down barriers, and promotes the game-changing news that people living with HIV with an undetectable viral load cannot transmit HIV through sex.

Abby Landy is one of the faces of the TIM U=U campaign. In her video, she describes how lucky she feels to not have to worry about transmitting HIV to her partner. Her message to other women living with HIV is that "you're not alone, we're in this together, and HIV doesn't discriminate." For as long as HIV has been in existence, people living with HIV have feared harming our loved ones and have carried an unequal burden for preventing HIV transmissions. Now we know that those of us who live with HIV and have achieved an undetectable viral load cannot transmit HIV through sex. That is extraordinarily freeing! Yet Abby also touches on another home truth: living with HIV can be an incredibly isolating experience for women.

As a minority within the HIV positive population, it is important that there is appropriate and accessible peer education and support services for women in Victoria.

Services such as Living Positive Victoria's newly announced Peer Navigation program will provide a much-needed access point to minimise social isolation and help women navigate complex care needs. Other services, like the Phoenix workshops for women newly diagnosed with HIV, provide peer support and education, and capacity building which enable participants to address many of the challenges unique to women living with HIV.

For example, when a woman is diagnosed with HIV it is far less likely that she, her partner, friends, and family will have access to, and have an in-depth understanding of modern HIV in Australia. This means that the burden of personal advocacy weighs heavily on women who can rely far less on mutual and community responsibility for HIV education and prevention. This also highlights the need for more wide-reaching education campaigns that promote U=U and the visibility of women and their experiences.

Another issue unique to women living with HIV is pregnancy. While U=U provides us with strong tool for negotiating transmission risk with sexual partners, preventing vertical transmission is more complex. The viral load of a woman with HIV is the most important factor to determine the risk of vertical transmission. However, a combination of prevention approaches including prenatal HIV counselling and testing, antiretroviral therapy, scheduled caesarean delivery when indicated, and avoiding breastfeeding has reduced the risk in Australia to less than two percent. Managing these risks can be challenging and emphasises the importance of early diagnosis and protecting the high quality of specialised medical care and support services available for women living with HIV to navigate pregnancy.

There is lots to celebrate about HIV in Victoria. The *In Bed with U=U* videos and speaking tour comes off the back of the Victorian government's endorsement of the evidence behind the campaign late last year and adds to the growing acceptance of this knowledge within our community. Earlier this year, the Pharmaceutical Benefits Advisory Committee recommended that Truvada as PrEP be listed on the Pharmaceutical Benefits Scheme, paving the way for greater legitimisation of biomedical prevention and hopefully better access and shared responsibility for the prevention of HIV within affected communities.

Let's continue to push to identify and find ways to ensure that women can also participate and benefit from this progress.

You can find out more about the U=U campaign and watch the *In Bed With U=U* videos at theinstituteofmany.org

ACHIEVING WHAT I NEVER DREAMT WAS POSSIBLE

Jackie Roberts shares her story of self-discovery, achievement and living with HIV.



I was diagnosed three years ago at my local GP in Sunshine, west of Melbourne. My diagnosis did not come as a shock. I prepared myself for the worst after finding out my previous partner was HIV positive for several years. I was lucky enough to have strong ties to the LGBTIQ community for most of my life, so I knew HIV was not a death sentence.

My biggest worry as a young mother living with HIV was the stigma associated with HIV for my daughter Ella and me. How would I tell my family? Would it affect my ability to work if employers knew? Would Ella be bullied at school if people knew? Would she understand? Unfortunately, my fears were realised when I disclosed my status to my mother who we were living with at the time. Her response was to throw us out and threaten to have Ella removed from my custody. Her lack of education caused her to react with anger and disgust. I felt dirty and rejected and Ella and I were forced to move into emergency accommodation.

I was initially linked in with Positive Women Victoria and Living Positive Victoria by attending a pamper day about three weeks after receiving my diagnosis. The impression I got from the women I met that day was one of overwhelming strength and unity. To use the term sisterhood feels a bit naff, but I immediately felt welcomed into the fold. These women were smart, capable and amazingly funny. Looking back, I do not think it would be an exaggeration to say that attending that pamper day was what stopped me going off the deep end after being diagnosed. If these women could do it then so could I. Ella and I were going to be okay.

Due to our housing situation, I could not process or deal with the reality of life as a HIV positive woman for almost a year. During this time we attended retreats and family days put on by Living Positive Victoria. These events were an invaluable break for us and were bright spots in what was a very dark time. My priority was finding Ella and I some stability so I could build us a life together. Our housing service was fantastic during this time and we secured our forever home in 2016. I was finally able to get things back on track and shape our futures.

I began volunteering as a receptionist at Positive Women Victoria and Living Positive Victoria early last year. It felt amazing to be around such passionate people and it truly gave me a sense of purpose that I had not had in a long time. I felt encouraged and supported and decided it was time to deal with the crippling self-stigma that was in the back of my head.

With the knowledge that I had the unconditional support of my peers, I made the decision to disclose my HIV status on a Facebook women's support group called The Den, which has approximately 5000 members across Australia. After typing out the post, I did a nervous little dance around my apartment and clicked 'share'. I was too anxious to wait for the first comments to appear so I turned my phone off and went to bed. I was utterly floored the next morning. More than 1000 people commented and every single message was supportive. People were telling me I was strong, brave and inspirational. I sat in tears and read the messages over and over again.

Since then my life has been nothing but amazing. I joined the Board of Positive Women Victoria, which has been a fantastic experience; I am currently studying my Diploma in Community Services; and I am about to start my student placement at Fitted for Work, an organisation that helps disadvantaged women return to work. I am very open with my classmates about my HIV status and am proud to educate some of them about HIV – especially that people living with HIV with an undetectable viral load cannot transmit the virus through sex. This is such an important message as many of them will be future social workers.

I was also selected to attend the Positive Leadership Development Institute (PLDI) Australia and New Zealand workshop. It was a privilege to attend and the weekend was invaluable to me. I came away from it even more motivated and inspired. I have learnt that I am not my diagnosis, I have a special opportunity to inspire women and single mothers living with HIV, and that I am capable of achieving things I never dreamt were possible.

I look forward to finishing my Diploma, continuing my volunteer work and joining Living Positive Victoria's Positive Speakers Bureau later this year. I am incredibly thankful to everyone that has been a part of my journey, and I look to the future with nothing but excitement and positivity.

NAVIGATING HIV AND PREGNANCY

By Heather Mugwagwa



Heather Mugwagwa is a Peer Support Coordinator for Positive Women Victoria

I am lucky in my role as the Peer Support Program Coordinator at Positive Women Victoria because I get to hear unique stories of women living with HIV firsthand. This helps me to better understand women and their diverse needs.

Pregnancy is a huge topic for women let alone women living with HIV. It underscores the unique biological difference of the HIV lived experience between men and women, presents a new set of challenges, and almost always brings out fear for women living with HIV. From the day a woman is diagnosed, the first thing she wants to know is whether or not she will be able to have children. What extra precautions will she need to follow to reduce transmission to her baby? Can she conceive her baby naturally? Can she have a natural or vaginal birth? All these questions will be ingrained in a women's fear of vertical HIV transmission to her future offspring.

Sharing my experience as a mother living with HIV can be reassuring for a newly diagnosed woman who wants to know more about having babies. It is also important to have her feelings heard and validated. In my experience, these anxieties are normal and there is a number of ways peer support can help women to overcome the challenges that come with living with HIV and pregnancy.

From experience it seems women living with HIV get excited at the thought of meeting a partner who is accepting and would like to have a family with them. According to women I have supported through peer support, getting pregnant is the easy part! However, pregnancy often means that a woman faces the possibility of disclosure. This can be to a health practitioner, a potential partner—where they will have to discuss the risks associated with conceiving a baby naturally or through artificial insemination—and sometimes family. We now know that there is zero risk for women with an undetectable viral load to transmit HIV through sex. Campaigns such as U=U have made discussing risk for conception less complicated, however, there are varying levels of education and it does not come close to the fear of potentially passing HIV to your baby.

This fear almost robs women from the joy of pregnancy. The 1-2% risk of transmission from mother to child¹ is sometimes viewed as a huge number. Unlike their partners, pregnant women living with HIV often feel the responsibility of bearing an HIV negative baby is on them. It does not matter if a woman is ready to start HIV treatment, now she must

to reduce the risks of vertical HIV transmission. She also has to make sure she is undetectable, keep her doctor's appointments, eat well and do all the healthy things that pregnant women do. Women living with HIV feel and know that their status adds another layer of worry, fear and anxiety when it comes to having and raising children. There are women who have decided not to have children because of these real issues.

There is also the issue of stigma and discrimination women living with HIV experience. Like one of my peers explains, it never ends from the time you conceive to the time the child is born and raised. "There are rules that only apply to us women living with HIV," she said.

“You have babies and they are all negative, but it doesn't stop there! You have to worry about disclosing to them, what their reaction will be and how society will treat them if they find out. It is a scary thing to bring a child to this world where stigma and discrimination are still very prominent.”

There is still a tendency for people to judge the right of a women living with HIV to have children as secondary to the risk to her child, despite advances in perinatal care and the reduction of mother-to-child transmission in Australia.

In fact, there have been no mother to child transmissions since 2013². For women living with HIV there is also the difficulty of encountering many of the societal norms that come with raising children. For example, it is challenging for most women to explain to their friends and family why they are not breastfeeding their baby. This clearly shows that HIV affects women differently, not only due to biological differences, but also because of dominant structural and social norms.

We have been talking a lot in the office about the challenges women face to be heard in the HIV sector. Part of my work is to make sure that I can always keep the unique needs of women at the heart of what we do and in the sector at large. For women living with HIV, their HIV status is superimposed on the existing disadvantage women experience within a gendered social system. These gender inequities limit a woman's ability to achieve decision-making power when enacting her sexual and reproductive rights. The theme for International Women's Day is 'Press for Progress' and I am hoping that we are going to carry this within the sector and achieve greater visibility for women living with HIV.

1 AFAO. (2017) HIV Prevention Mother-to-child www.afao.org.au/about-hiv/hiv-prevention/mother-to-child/

2 The Kirby Institute. (2017). National BBV & STI Surveillance and Monitoring Report 2016