



Webinar in honor of National Women and Girls HIV/AIDS Awareness Day (NWGHAAD)

The Well Project Unplugged: Let's Talk About Women and HIV

Tuesday, March 10, 2020 | 12:30 PM - 2:00 PM ET

Featuring several members of The Well Project's Community Advisory Board

**Gina Brown, MSW, Ciarra Covin, Porchia Dees, Arianna Lint,
Maria Mejia, Bose Olotu, and Wanona Thomas**

And moderated by Krista Martel, Executive Director, The Well Project

Visit www.thewellproject.org for a link to register



Chat Log (Abridged)

- 12:33:02 From Olivia Ford: Welcome everyone! We will be discussing some key topics with our Community Advisory Board members
- 12:33:16 From Olivia Ford: You'll also get to participate via a few poll questions ;-)
- 12:33:23 From Maria Mejia: welcome everyone ❤️🙏🦋
- 12:33:34 From Olivia Ford: You can ask questions here in the chat box or via Q&A function
- 12:34:52 From Olivia Ford: Feel free to say hello and where you're from here in the chat box as we get going! No pressure but always great to see who's here!
- 12:36:11 From Vanessa Leja: Hi All! I'm Vanessa Leja, HIV planning coordinator for WA DOH. I'm also a WLWH
- 12:36:13 From Olivia Ford: Many of our CAB members began as bloggers on A Girl Like Me - that's how they first got engaged with The Well Project's community
- 12:36:47 From Jyoti Dhawale: true that, Olivia
- 12:37:43 From Michael Louella: Good morning from Michael in Seattle, WA
- 12:37:52 From Olivia Ford: Hi Vanessa! Welcome! And hey there Michael!
- 12:37:57 From Maria Mejia: good morning 🙏
- 12:38:02 From Michael Louella: :)
- 12:38:21 From Evelyn Scalice: hi! I'm Evelyn Scalice, from NYC
- 12:38:27 From Wanona Thomas: Good afternoon to some and Good morning to most
- 12:38:56 From Carmen Valentin: Thank you I love that you are aware of that
- 12:39:30 From Maria Mejia: welcome Evelyn

- 12:40:09 From Thamicha Isaac: hey Everyone 🙌
- 12:40:23 From Olivia Ford: Speaking now is Krista Martel, The Well Project's awesome Executive Director - our panelists are up now!
- 12:41:26 From Nancy Duncan: Hi everyone, glad to be on with you all!

CAB/PANELIST INTRODUCTIONS

- 12:41:29 From Olivia Ford: *The phenomenal brilliant Gina Brown is speaking now - reflecting on the fact that after so many years, we still need awareness days*
- 12:41:38 From Thamicha Isaac: yesss ladies let's get the education out stop stigma
- 12:42:06 From Krista Martel: Hello all! It's so great to see you all! <3
- 12:42:39 From Gina Brown: Welcome sisters! So glad you could all join us :)
- 12:42:51 From Maria Mejia: welcome !!!!
- 12:43:04 From Olivia Ford: *Ciarra "CiCi" Covin, rad new CAB member, believes that HIV is more of a psychological thing - her own blog is called Healing Is Voluntary (H.I.V.)*
- 12:43:06 From Maria Mejia: our sisterhood is strong and beautiful
- 12:43:58 From Maria Mejia: stigma continues and us women are always left out
- 12:44:03 From Olivia Ford: *Porchia Dees is another Fab new member of our CAB! Porchia was born with HIV - she believes if there were more support around her birth, her mom might still be here - but there are *still* not enough services or support for women even today*
- 12:44:12 From Meta Smith-Davis: Hey sisters. So glad to be here.
- 12:45:56 From Olivia Ford: *Visionary Arianna Lint is up now! She's glad to be here standing side to side with women committed to Fighting HIV - as a trans Latina she is among the First U=U campaign ambassadors - U=U is just one tool to empower PLHIV and Fight stigma*
- 12:47:32 From Thamicha Isaac: thank you ladies
- 12:47:45 From Thamicha Isaac: you ladies inspire me 🙌❤️
- 12:47:45 From Katie Willingham: Hey everyone, love !!!
- 12:48:09 From Olivia Ford: *Veteran A Girl Like Me blogger, global ambassador and all-around maven Maria Mejia thinks NWGHAAD needs to be *every day* - so important to keep showing our faces to take stigma away, just as she's been doing for 10 years now with The Well Project - she is also a cofounder of Latin+ and on U=U steering committee*
- 12:51:56 From Olivia Ford: *Truly amazing Nigeria-based activist and CAB member Bose Olotu has been an HIV advocate almost 20 years - and another veteran with The Well Project / A Girl Like ME!*

- 12:53:49 From Olivia Ford: *Young/adolescent women in Nigeria/Africa at large are extremely vulnerable to HIV - Bose is committed to reaching out to and connecting with these young women*
- 12:53:57 From Brielle: Arianna I'm here girl
- 12:55:25 From Vanessa Leja: Can Nunu share her blog? I'd love to check it out.
- 12:55:31 From Vanessa Leja: blog/website
- 12:55:47 From Olivia Ford: *Wanona "Nunu" Thomas is up now! Trauma survivor, newly diagnosed, tirelessly working with other young people to share healthy sex practices and knowledge about HIV <3*
- 12:57:26 From Olivia Ford: Join the *A Girl Like Me* group on our website to get the latest from this fierce, vast community of women! <https://www.thewellproject.org/groups/girl-me>

DISCUSSION: HIV STIGMA IN PERSONAL LIVES

- 13:01:16 From Olivia Ford: *Porchia was raised by her aunt and uncle because her mom was on drugs - she has been blessed with their support <3*
- 13:01:43 From Wanona Thomas: are you on Facebook if so you can find me at Wanona Thomas or LIVE IN YOUR TRUTH
- 13:01:54 From Olivia Ford: *Porchia didn't experience stigma until she got older and started learning about sex*
- 13:02:05 From Tyra FLEMING: it is not surprising that family would be the highest percentage because people turn to those they believe love them unconditionally
- 13:03:54 From Olivia Ford: *Porchia went to a great children's hospital and got positively framed sex ed - not so in middle school, where the learning was stigma-based, negative, and students picked up on that*
- 13:05:12 From Tyra FLEMING: Stigma makes more sense when considering the initial response from family is not compassionate, how could the rest of the world
- 13:05:15 From Olivia Ford: Vanessa! Also, here's Nunu's blog since you asked: <https://www.thewellproject.org/users/forevertrue24>
- 13:07:26 From Olivia Ford: Maria: *With all the campaigns she is an ambassador for, so many cisgender women and heterosexual-identified men living with HIV do not want to show their faces and be connected with HIV*
- 13:07:30 From Thamicha Isaac: you better Speak on it Maria 🙌🙌🙌🙌🙌🙌🙌🙌
- 13:07:59 From Krista Martel: Thank you! We are going to move soon to the next poll!
- 13:09:34 From Tyra FLEMING: It is so true that HIV does not discriminate it will and can affect anyone

- 13:09:44 From Olivia Ford: *Maria: Campaigns often fuel the practice of putting people in boxes (gay/MSM, etc) even if they don't identify as such - this does a disservice to the broader, more diverse HIV community - and contributes to the untrue notion that HIV affects certain groups exclusively*
- 13:10:44 From Olivia Ford: *Porchia: As a sexual health educator, so important to uplift and celebrate both facts *and* the sexuality of people living with HIV - critical to battling stigma!*
- 13:10:47 From Evelyn Scalice: I feel like a lot of stigma comes from lack of education and misinformation. it also gets passed down from family and friends
- 13:11:59 From Porchia: "@evelyn scalice Right!"

DISCUSSION: HIV STIGMA IN HEALTHCARE SETTINGS

- 13:13:00 From Olivia Ford: Almost 60% of people polled say they have experienced stigma in a healthcare setting
- 13:13:52 From Tyra FLEMING: My answer reflected the care and access that was available 20+ years ago.
- 13:14:21 From Jyoti Dhawale: I still face stigma at the dentist
- 13:14:26 From Olivia Ford: These stats have been consistent across other surveys
- 13:14:36 From Jyoti Dhawale: until I found one who is able to treat me
- 13:15:19 From Olivia Ford: *Gina: Diagnosed while pregnant, experienced awful stigma while in labor and delivery - HIPAA violations, having her status disclosed multiple times in appropriately*
- 13:15:43 From Olivia Ford: *She was on a room at the end of the hall, no one came in or cleaned it - they would put the food outside:-(Awful*
- 13:15:47 From Jyoti Dhawale: what is HIPAA
- 13:16:03 From Olivia Ford: *Only one nurse treated her with care, as human*
- 13:16:17 From Tyra FLEMING: I can relate so closely to Gina story.
- 13:16:18 From Maria Mejia: same here 🙄
- 13:16:52 From Maria Mejia: I'm so sorry sister Gina
- 13:17:07 From Maria Mejia: virtual hugs in this battle
- 13:17:13 From Olivia Ford: Ah, I am so sorry! HIPAA - pardon my US-centric acronym use:-P In brief, protects the privacy of people's medical information from providers
- 13:18:51 From Olivia Ford: *Gina was on her own with her tiny baby - not the love and care a new mom and baby ought to have. She still feels the effects of that today, 25+ years later.*

- 13:19:26 From Mary Prim: what is the biggest theme in the HIV-related stigma that you experience in the medical setting?
- 13:19:28 From Bose Olotu: This why impacting knowledge is very important.
- 13:19:30 From Olivia Ford: *Gina: The way to keep people mad is to keep living! So I'm going to do that! :-D Gina has also witnessed others experiencing stigma even at ASOs*
- 13:19:34 From Maria Mejia: 😊
- 13:20:31 From Bose Olotu: because lots of people are aware of HIV/AIDS but lots still do not have the knowledge and impact of the virus. this why I take HIV and health education and sex education to Schools.
- 13:20:42 From Tyra FLEMING: I did walk out of care for a while after my first interactions, but had the courage to go back and have been trying really hard ever since.
- 13:21:26 From Porchia Dees: @Gina Brown Thank you so much for sharing that... That's what happened to my mom... She never got back engaged in care after that... Even when she finally got off the streets and stopped using
- 13:21:43 From Wanona Thomas: thanks Gina
- 13:22:03 From Wanona Thomas: I too hate the experience I had once getting diagnosed while pregnant
- 13:23:36 From Olivia Ford: Tyra, Gina, Wanona, Porchia - thank you so much for sharing your experiences - devastating, and incredibly powerful <3

DISCUSSION: HIV SELF-STIGMA

- 13:25:22 From Olivia Ford: *For CiCi, self-stigma comes in the form of beating herself up, feeling she knew what to do to stay HIV-negative and didn't do that for herself. It is a daily struggle - and every pill is a reminder of being different*
- 13:25:40 From Maria Mejia: exactly
- 13:25:45 From Maria Mejia: this is a bitch!!!
- 13:25:50 From Gina Brown: CiCi, you are not alone.
- 13:25:58 From Vanessa Leja: Ce-Ce - thank you for being so raw and open. I can completely relate to your story and your experiences.
- 13:26:23 From Wanona Thomas: omg yes cici same here I self stigmatized for so long and still kinda do
- 13:26:26 From Maria Mejia: I am the same
- 13:26:46 From Thamicha Isaac: CeCe you got this 🙏❤️👉
- 13:26:52 From Vanessa Leja: Hell yes! Preach!

13:26:54 From Maria Mejia: yup

13:26:55 From Olivia Ford: *The Well Project has helped CiCi know she is not the only one to feel that way - that even with all the education and knowledge she has, getting a cut in public or at the nail shop, the pressure to disclose may come up <3*

13:26:58 From Thamicha Isaac: sending you love and light baby girl

13:27:05 From Maria Mejia: it's not easy no matter how strong we are

13:27:05 From Courtney Biddulph: CiCi you definitely not alone!

13:27:05 From Thamicha Isaac: you're not alone

13:27:37 From Tyra FLEMING: I can relate with the constant stress of thinking about if I am being safe with myself and others

13:28:48 From Olivia Ford: *Porchia: My aunt used to say be careful of who you share your business with and of course as a young person it was hard to listen - disclosed to someone who she then split with, and they shared her status throughout her school*

13:28:48 From Evelyn Scalice: Thank you for sharing cici. I can relate 100%

13:29:49 From Maria Mejia: some people are horrible

13:30:27 From Tyra FLEMING: I have had men threaten to kill me in the past because someone else (my mother) disclosed my status. I had to move out of the state to keep my children and myself safe. These things still sit with me today

13:30:44 From Olivia Ford: *Porchia: Even some very close friends started to look at her differently - she knew she was beautiful and pretty, but when someone regarded her as less attractive because she's living with HIV, she would start to internalize that*

13:31:18 From Olivia Ford: Porchia is beautiful!!!!

13:32:34 From Tyra FLEMING: It created serious trust issues with how I see myself in the world around me and how I fit in it

13:33:27 From Olivia Ford: *Wanona consented to have her tubes tied after being diagnosed while pregnant - she assumed and was afraid the baby would be born with HIV - had made arrangements for her child if she couldn't take care the little one (though by the time she delivered she knew she probably wouldn't need her) - providers did not inform her about U=U!*

13:34:05 From Olivia Ford: @Tyra: I totally hear you, about trust issues after such a horrible experience. Many, many thanks for sharing <3

13:34:22 From Maria Mejia: I feel the same

13:34:26 From Maria Mejia: absolutely

13:34:30 From Maria Mejia: it's scary

- 13:35:04 From Tyra FLEMING: The lack of knowledge is so powerful and life changing. Makes educating so much more significant
- 13:35:49 From Olivia Ford: *Wanona still self-stigmatizes, including around thinking about how she might Feel about dating someone who is also living with HIV*
- 13:36:58 From Olivia Ford: *Krista shouts out the positive impact of women supporting and learning from one another! (and it's happening right here right now! <3)*

DISCUSSION: BARRIERS TO ACCESSING MENTAL HEALTH

- 13:39:13 From Gina Brown: I think Menopause causes Mental Health issues....depression, mood swings, and forgetfulness.
- 13:39:32 From Maria Mejia: yes Gina !!!! I believe that
- 13:39:38 From Maria Mejia: our hormones
- 13:39:48 From Maria Mejia: hiv and meds affect that as well
- 13:39:55 From Tyra FLEMING: when I lived in San Francisco many years ago most treatment options were geared towards the LBGTQ community. So being a heterosexual woman was not fully supported with resources
- 13:40:05 From Bose Olotu: oh wow!
- 13:40:10 From Gina Brown: Maria, I totally agree!
- 13:40:20 From Maria Mejia: 😊
- 13:41:48 From Olivia Ford: *Maria: There is stigma around seeking mental health support in her Latinx community - especially older folks - and at the same time, many in the community have experienced trauma - she herself was diagnosed as a teenager and also survived sexual abuse*
- 13:44:15 From Olivia Ford: *People who have experienced so many layers of trauma, plus HIV which in itself is traumatic, and are unable to access mental health care are at high risk of self-medicating through addiction*
- 13:44:52 From Ciarra Covin: yaaaaaaaaay Maria!
- 13:44:53 From Porchia Dees: @Maria Mejia 🙌🙌🙌
- 13:45:00 From Tyra FLEMING: mental health and the stigma associated to it could also fill another webinar
- 13:45:09 From Bose Olotu: Speak Maria
- 13:45:16 From Bose Olotu: Thank you
- 13:45:52 From Maria Mejia: Thankyou my dear sisters ❤️🙌🦋

13:46:09 From Olivia Ford: *Maria: Being unable to stay on meds and take care of oneself is tied into that lack of access to mental health support. So important to care for our minds that have been through so much. We have to help each other and support those who are struggling - if we don't, we're lost <3*

13:46:46 From Jyoti Dhawale: mental health care associated with HIV is a total ZERO here

13:46:51 From Olivia Ford: *Arianna: SO important for us to educate those working in mental health, other providers, the whole system*

13:46:56 From Jyoti Dhawale: Zero as in - unheard of.

13:47:16 From Maria Mejia: so sad 😞

13:47:50 From Tyra FLEMING: I totally agree with the connection. between mental health contributing to physical health

13:48:10 From Jyoti Dhawale: regarding SELF CARE - In India, many can not afford to have proper balanced meal because of financial issues. HIV here doesn't have insurance

13:48:36 From Olivia Ford: *Other communities experience stigma and challenges to mental health access - this is compounded for transgender folks, a high percentage of whom do not have health insurance, have left HIV care within one year, and also experience profound stigma and discrimination just for being who they are*

13:48:49 From Ciarra Covin: o, if my mental wasn't addressed ... screw all the HIV care

13:49:05 From Krista Martel: Jo, that's also an issue here--good nutrition is more expensive and hard for many to access

13:49:26 From Olivia Ford: *Arianna: Ryan White providers need to be educated on working with clients of trans experience - and programs that are working need to be uplifted, as with the COMPASS Initiative*

13:49:50 From Gina Brown: We love you Arianna!

13:50:09 From Jyoti Dhawale: whoa, that's new to me Kris. I thought USA is better off than India or Africa. I will look up at COMPASS initiative, Arianna

13:50:46 From Maria Mejia: I was going to be a talk back host in an off Broadway show and they cancelled because of the corona virus

13:50:56 From Maria Mejia: we will have a next time

13:51:06 From Maria Mejia: our lives are more important

13:51:11 From Olivia Ford: *Arianna: in our present moment, events and in-person gathering are being cancelled due to coronavirus - will complicate people getting support and doing their work*

13:53:25 From Olivia Ford: *CiCi: Has been powerful coming to realize HIV was a symptom of something larger - we all have things we're going through, and if she didn't have mental health support, the HIV care piece would go out the window*

13:53:47 From Tyra FLEMING: I have definitely fell into the self harm of not taking medicine at points in my life and mental health services were definitely significant in helping with these issues

DISCUSSION: SELF-CARE

13:55:05 From Olivia Ford: *Krista has seen self-care have a ripple effect - when people share their techniques, it inspires and helps others find their own strategies for caring for themselves!*

13:55:25 From Porchia Dees: Massages, Spa Days, Mani's & Pedi's... Going to the beach... Taking a bubble bath

13:55:47 From Porchia Dees: Mary Jane lol 🤪🤪🤪🤪

13:55:55 From Courtney Biddulph: I have fell into the self harm mental health issues and a lot of therapy places do not have night appointment. so I was discharged because of my work schedule

13:56:00 From Gina Brown: I love BathFizzies!!!

13:56:45 From Porchia Dees: @Gina Brown Me too... Bath Bombs are everything!

13:56:52 From Gina Brown: I am so sorry but I have to run to another meeting. Thank you all for an amazing webinar!

13:57:04 From Maria Mejia: massages too 😊

13:57:51 From Jyoti Dhawale: massages 😊

DISCUSSION: U=U

13:57:51 From Evelyn Scalice: the First time i heard of U=U was about two years ago when i started taking trainings

13:57:53 From Cameron Kinker: I checked N/A, but as a PrEP user I believe my provider should still tell me about U=U even though I am not living with HIV!

13:59:02 From Olivia Ford: @Cameron: Agreed!

13:59:15 From Vanessa Leja: keep going - this is one of the best webinar's I've seen with regard to HIV and women

13:59:26 From Evelyn Scalice: my doctor had talked about undetectable in terms of my viral load count and in terms of how that protected my baby. (I was pregnant) but not in regards to not being able to transmit

13:59:29 From Tyra FLEMING: what is U=U

13:59:35 From Gina Brown: Thank you, Vanessa!

13:59:55 From Maria Mejia: Undetectable equals Untransmittable

14:00:11 From Vanessa Leja: I'd love more information about how I can be active with The Well Project

14:00:13 From Olivia Ford: @Tyra and anyone who may be new to the concept of U=U - so glad you are here to hear about it! Here is The Well Project's very comprehensive fact sheet about it: <https://www.thewellproject.org/hiv-information/undetectable-equals-untransmittable-building-hope-and-ending-hiv-stigma>

14:00:16 From Tyra FLEMING: thank you

14:00:43 From Maria Mejia: you can email me mariahiv1111@yahoo.com

14:00:59 From Vanessa Leja: Will do, Maria!

14:01:01 From Vanessa Leja: Thanks.

14:01:14 From Olivia Ford: *Bose became undetectable months after being diagnosed and starting meds - when she first heard about the U=U campaign, she began by sharing that information at her clinic and was shut down:-{*

14:01:15 From Maria Mejia: my pleasure sister

14:02:03 From Olivia Ford: *Staff thought it would lead to people having unprotected sex (but sex with a person living with HIV who is on treatment IS a form of protection!!!!)*

14:02:16 From Tyra FLEMING: it is so frustrating to hear people blocking progress. so sorry Bose

14:02:18 From Meta Smith-Davis: Courtney, don't give up. there is some place out there that will work with your schedule...don't give up beloved. Thanks my sisters for sharing your truths with us...I really appreciate you all

14:02:38 From Olivia Ford: For those who have to step off - many many thanks and much love!!!

14:02:54 From Krista Martel: I know we are wrapping up so I just want to be sure to thank all of our amazing panelists! I could listen to them all day! We hope this is just the beginning of many discussions with you all-and thanks who participated! xxxx

14:03:42 From Tyra FLEMING: it has been a pleasure to be a part of something so personal

14:04:43 From Olivia Ford: We're addressing a question now from a participant! From Mary Prim: "what is the biggest theme in the HIV-related stigma that you experience in the medical setting?"

14:05:36 From Tyra FLEMING: Was in a car accident in the later 90s and the doctors were slow to address my issues because of my status and the fact that I was bleeding. It was very disheartening

- 14:05:37 From Krista Martel: *One person mentions "As HIV negative woman I was treated very badly when asking to access PEP"*
- 14:06:40 From Olivia Ford: *Maria: In Colombia in the early days, providers would say terrible things, not want to treat her, leave her sitting in the doctor's office because they couldn't "deal" with HIV*
- 14:07:11 From Olivia Ford: *She knows providers living with HIV who don't disclose because of stigma, use universal precautions*
- 14:08:06 From Olivia Ford: *U=U is not just about being undetectable but really knowing the truth that it means a person living with HIV CANNOT TRANSMIT HIV with an undetectable viral load - she can't go against science and the science is on our community's side - but to this day, a provider has NEVER talked with her about U=U*
- 14:08:33 From Tyra FLEMING: *I still do not disclose in most instances such as dentist and other such services. Then I worry if I am wrong. It is Frustrating*
- 14:08:41 From Olivia Ford: *Maria: I have seen with my own eyes that U=U is an incentive to take meds -For providers not to share that information is NEGLIGENCE*
- 14:08:43 From Jyoti Dhawale:  Love the chat session and webinar
- 14:08:59 From Maria Mejia: *same here believe it or not*
- 14:09:37 From Tyra FLEMING: *Thank you for all of the wonderful information and sharing*
- 14:09:57 From Maria Mejia:  join our sisterhood
- 14:10:14 From Vanessa Leja: BEST webinar I've seen in a LONG time with regard to WLWH**
- 14:10:24 From Olivia Ford: *Krista: U=U is one of our biggest tools to fight stigma and fight for better access to medications for all*
- 14:10:49 From Olivia Ford: *Signing off now! Abundant gratitude presenters and panelists or showing up and sharing so beautifully! <3*