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Long-Term  
Survivors  
of HIV





**Women's Advocacy and  
Treatment Coalition on HIV**

A program of The Well Project



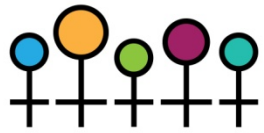
## **Surviving HIV Over the Long Term: The Past, Present, and Future - Part 1**

*Together, we can change the course of the HIV epidemic...one woman at a time.*

#onewomanatatime

[www.thewellproject.org](http://www.thewellproject.org)

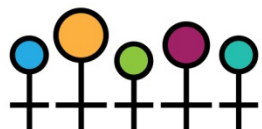
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# About The Well Project

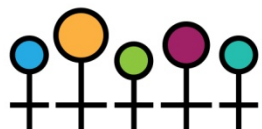
- Non-profit organization with a mission to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls
- Leverages technology to improve health outcomes and increase quality of life for women and girls living with HIV
- Provides accessible and comprehensive #information, #community support, and #advocacy building
- Access our resources and join our community at [www.thewellproject.org](http://www.thewellproject.org)



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## About *WATCH!*

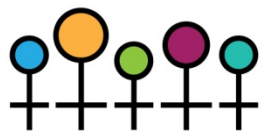
- WATCH! Women's Advocacy and Treatment Coalition on HIV is an ongoing HIV treatment advocacy and capacity-building webinar series
- The 2016 WATCH! series will take place throughout the year, and will include 5 webinars
- For certification, participants must participate in live webinar or view recording, take a pre- and post-test, and final evaluation survey (end of series)
- Webinars will be recorded and can be accessed up to one month after they take place



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# Webinar Details

- Webinar will last approximately 90 minutes with Q&A at end
- Use live chat box on left side to enter questions while someone is talking; questions will be put in queue
- If you are listening to webinar via your phone, please enter second audio pin to connect your phone to computer \* (3-digit number)#
- Participants' lines will be muted until the Q&A
  - To unmute your phone, press \*6, or click on microphone icon at the top of your screen (if using computer microphone)
  - To mute, use your phone “mute” button



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# Speakers



**Kimberly Y. Smith, MD, MPH**, Vice President for Global Medical Strategy and Head of Research and Development, ViiV Healthcare



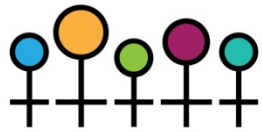
**Maria Mejia**, Global Ambassador, Community Advisory Board, *A Girl Like Me* Blogger, The Well Project



**Tranisha Arzah**, BABES Network; *A Girl Like Me* Blogger, The Well Project

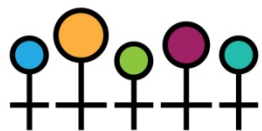


**Krista Martel**, Executive Director, The Well Project  
(*moderator*)



# Agenda

- Defining Long-term Survivors
- Perinatal Acquisition
- Concerns of Long-Term Survivors
  - Physical health
  - Treatment Challenges
  - Aging
  - Inflammation
  - Co-Morbidities
  - Menopause
  - Sexual health
- AIDS Survivor Syndrome – Intro to Part II
- Q&A



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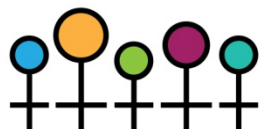
# Who Are Long-Term Survivors of HIV?

*"We were a group of people who were willing to stand up for ourselves and for others and face what the world had to offer.... Those living with HIV today can never [imagine] the horrors many of us had to endure in the early days of this epidemic. I wish I didn't remember – I wish I could forget."*



– Vickie Lynn, [Drawing Lines in the Sand](#), *A Girl Like Me*

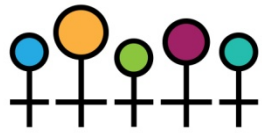




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# Defining Long-term Survivors

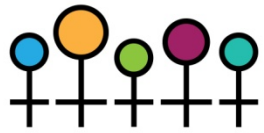
- Powerful drugs now make it possible for people with HIV to live far longer than we could have imagined in the epidemic's earliest days
- **Pre-HAART LTS:** Living with HIV since before 1996 – start of the modern era of "highly active antiretroviral therapy" (**HAART**)
  - Acquired HIV when it was usually a death sentence
  - Often spent early adult lives believing they would die young, watching many friends die
- **Post-HAART LTS:** Living with HIV for more than 10 years
  - Anyone diagnosed after 1996
  - A very different experience than being diagnosed earlier in the epidemic



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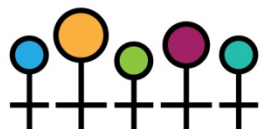
# Other Definitions

- Perinatal acquisition: People who were **born with HIV, or acquired it as young children**
  - Now in their 20s and 30s, having lived with HIV for decades
  - May have experienced loss of many loved ones
- **HIV-negative LTS:** Partners, companions, activists, healthcare providers, etc., directly supporting people living with HIV in the epidemic's earliest days
  - Many experienced tremendous losses, had their lives deeply affected by the epidemic



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# Poll Question

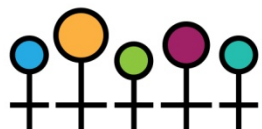


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# Perinatal Acquisition

Studies of people who acquired HIV at birth (**perinatally**) found younger LTS ***more likely to have unsuccessful HIV treatment*** than adults, in part because:

- They may have been exposed to HIV treatment in the womb
  - Increased chances of HIV drug resistance
- Treatment histories tend to be just as complex as those of older-adult LTS (including pre-HAART LTS)
- Young people may find adherence more challenging than adults



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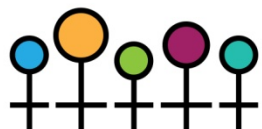
# Physical Health Concerns of LTS

Some relate to common *effects of aging*; others to the unique *realities of surviving with HIV*

- Important for LTS of all ages to have trusting relationships with healthcare providers
  - Can work together to find effective, *tolerable* treatment options

## HIV Treatment Challenges

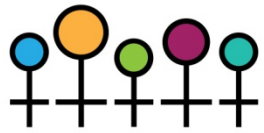
- Many LTS deal with consequences of decades of HIV treatment
- Toxicity of many early HIV drug regimens caused life-altering side effects; include but are not limited to:
  - Lipodystrophy (body fat changes) and resulting scars from surgeries, implants, and injections
  - Peripheral neuropathy



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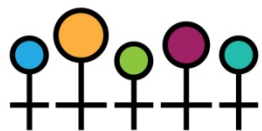
# Treatment Fatigue and Tolerability

- **Treatment fatigue:** physical or emotional weariness with taking HIV drugs
  - May cause LTS to have difficulties taking their HIV treatment regularly (**adherence**)
    - Can eventually cause HIV drugs to stop working (**HIV drug resistance**)
- **Multidrug-resistant HIV (MDR-HIV)** is reality for many LTS
  - Makes effective treatment options difficult to find
- LTS may take several pills each day for HIV and other health conditions (**comorbidities**), plus vitamins, supplements, birth control methods, pain relievers, etc.
  - More pills increases likelihood of drug interactions



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# Poll Question

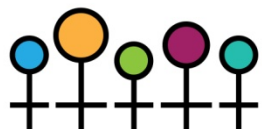


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# Inflammation

- Human body's natural response to threat or damage
- Immune system of a person living with HIV is always struggling to get rid of the virus
  - This means the immune system is always activated, or "turned on"
- After many years of being constantly activated, may produce inflammation
- Ongoing inflammation appears to be related to many health conditions (heart disease, cancers, etc.)

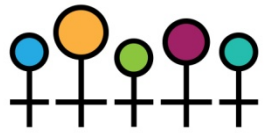




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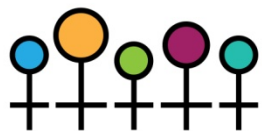
# Accelerated Aging?

- Scientists exploring whether inflammation causes people living with HIV to experience signs of aging earlier (**accelerated aging**)
- Some professionals believe that signs of 'accelerated aging' may be less about HIV, more about higher rates of **traditional risk factors**
  - Smoking and stress are examples of traditional risk factors for heart disease that are more common among people living with HIV
- Eating well, exercising, managing other health conditions, and taking HIV drugs can all help reduce levels of inflammation



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# Poll Question

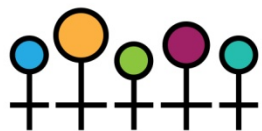


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# Comorbidities

Many non-AIDS-related health conditions are more common among LTS and other aging people with HIV, including:

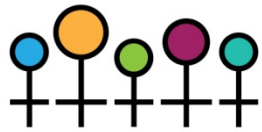
- Heart disease: LTS more likely to have taken older HIV drug regimens associated with body shape changes and increased blood fats
- Hepatitis C (HCV): Many LTS are **baby boomers** (born between 1945 and 1965); CDC recommends they be tested for HCV
- Other liver disease: Long-term use of medications can overwork the liver; certain HIV drugs also linked to liver damage



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# Comorbidities

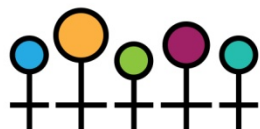
- Brain problems: HIV-associated neurocognitive disorder (HAND) may be more common among older people and LTS
- Cancers: Vital that LTS be regularly screened for AIDS-related cancers as well as others not associated with HIV (e.g., breast or lung cancer)
- Bone disease: Some older HIV medications have been linked to bone loss



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# Menopause

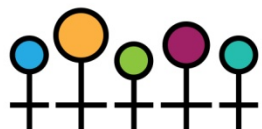
- Often called the "change of life"
- Point in time when a woman's menstrual periods stop
- Milestone that many women LTS may have thought they would not live to reach
- Effects of menopause can be treated with:
  - Hormone replacement therapy
  - Complementary treatments
  - Taking steps to stay healthy



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# Sexual Health

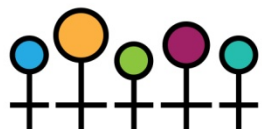
- Older women remain sexually active
  - May date and become sexually active after ending a long relationship or partner's death
  - Sexual risk-taking can be an effect of past trauma; can be a symptom of AIDS Survivor Syndrome
- Providers must talk about sexual health with their LTS clients
  - Important for women growing older with HIV to continue to visit gynecologist
  - For younger LTS and those of childbearing age, sexual healthcare should include:
    - Respectful safer conception resources
    - Conversations that affirm women's sexual expression



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# AIDS Survivor Syndrome (ASS)

- Refers to the psychological results of living through the most brutal years of the HIV pandemic
- Pre-HAART LTS especially vulnerable
- Sometimes compared to **post-traumatic stress disorder** (PTSD)
- Not many published studies
- Symptoms include, but are not limited to:
  - Anxiety
  - Nervousness, or sense of feeling constantly 'on guard'
  - Depression
  - Irritability or flashes of anger
  - Lack of future orientation
  - Low self-esteem & self-worth
  - Substance abuse
  - Social withdrawal & isolation
  - Survivor's guilt



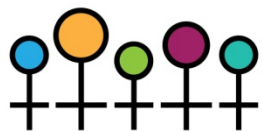
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# Long-Term Survivors: Taking Care, Kicking Ass

If you are a LTS, you can stay resilient and ***not only survive, but thrive*** throughout a long life with HIV:

- **Take charge of your health:** Learn about your medications, have a good relationship with healthcare providers, keep on top of diet and exercise
- **Get support:** A healthcare provider, mental health counselor, peer mentor, or support group can provide support, help with connections to activities and community
- **Tell your stories:** Speaking your truth is part of healing!

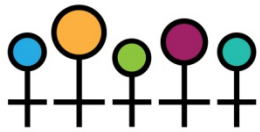




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# Long-Term Survivors: Taking Care, Kicking Ass

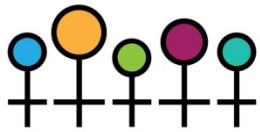
- **Find your purpose:** Commit to an activity that excites you, work or volunteer on something you believe in, rediscover your talents
- **Take your rightful seat at the table:** LTS are experts in living a long life with HIV, and should be part of the organizational and policy decisions that impact their lives
- **Commemorate June 5, National HIV Long-Term Survivors Awareness Day (NHLTSAD):** It's a call to action to keep the needs and demands of LTS front and center in the HIV community



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# Learn More!

- Please read the full fact sheets on these topics:
  - [Long-Term Survivors of HIV](#)
  - [Menopause](#)
  - [Older Women's Sexual Health](#)
  - [Mental Health](#)
- Additional Resources
  - [Let's Kick ASS](#)
  - [The Reunion Project ACRIA](#)
  - [Graying of AIDS](#)
  - ["We're Still Here"](#)
- For more information, please visit:
  - [www.thewellproject.org](http://www.thewellproject.org)
  - [www.facebook.com/thewellproject](https://www.facebook.com/thewellproject)
  - [www.twitter.com/thewellproject](https://www.twitter.com/thewellproject)



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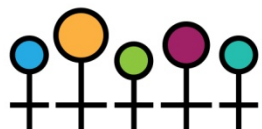
# LTS *A Girl Like Me* Bloggers

- [Angel S.](#)
- [Tranisha Arzah](#)
- [Dawn Averitt](#)
- [Maria T. Mejia](#)
- [Robin Barkins](#)
- [BornHIVPoz89](#)
- [Angelena Cortello](#)
- [Nancy Duncan](#)
- [LovingLife101](#)
- [Sara Thapa Magar](#)
- [Wanda Brendle Moss](#)
- [MumbaiyyaGal](#)
- [Neen](#)
- [Sandra](#)
- [Ieshia Scott](#)
- [Stigma Warrior Princess](#)



# Questions & Answers

The Q & A will come from the questions submitted to the presenters through the chat box during the webinar session.



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# Thank you!

**Please go to**

**[https://www.surveymonkey.com/r/WATCH2016\\_Posttest4](https://www.surveymonkey.com/r/WATCH2016_Posttest4) to  
take today's webinar Post-Assessment Test**

An email message will be sent out on in the coming days, with the link to the webpage for today's webinar that has links to pre- and post-assessment tests, the webinar recording, and additional resources on this topic.

Thank you for your participation!

**[Register now for Part 2 of this webinar series!](#)**

[www.thewellproject.org](http://www.thewellproject.org)