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

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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
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
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
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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"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
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
Poll Question
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
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
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.)
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
Poll Question
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.
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
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
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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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!
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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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
- www.facebook.com/thewellproject
- www.twitter.com/thewellproject
LTS A Girl Like Me Bloggers

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

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

Please go to
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!

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