Surviving HIV Over the Long Term: The Past, Present, and Future - Part 2

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

Theresa Mack, MD, MPH, Mt. Sinai Doctors Faculty Practice; Medical Editor, The Well Project

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

• About The Well Project
• Recap of Webinar Part 1
• Mental Health Issues
• Isolation
• Sexual Health
• Financial Considerations
• Long-term Planning
• Q&A
Long-term Survivors (LTS): individuals who have lived with HIV for many years

- Pre-HAART LTS: Living with HIV since before 1996
- Post-HAART LTS: Living with HIV for more than 10 years
- Perinatal acquisition: Born with HIV
- HIV-negative LTS: Partners, family, activists, healthcare providers, etc., directly supporting people living with HIV in the epidemic’s earliest days

Physical and treatment-related concerns of LTS include

- Physical health
  - Co-Morbidities
- Treatment Challenges
  - Menopause
- Aging
  - Sexual health
- Inflammation
Poll Question
AIDS Survivor Syndrome (ASS)

- Refers to psychological results of living through 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:
- 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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"Why am I still here and my friends are gone!? Not a few, THOUSANDS!!! MILLIONS!!!!" Maria Mejia, Survivor’s Guilt/PTSD/Anxiety/Depression, A Girl Like Me

**Depression:**

- A significant concern for all people living with HIV, particularly older women
- Prevalent among HIV LTS, along with other serious mental health issues
- High rates of depression also found among young people born with HIV

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Mental Health Issues

- **Isolation** from community and family can have numerous negative health effects, including higher rates of death from chronic health conditions.
- Working with mental health providers, social support, and a sense of purpose in life are key to decreasing isolation and improving mental health.
Poll Question
Contributors include:

- Multiple losses
- Trauma
- Decreased ability to leave home or get around town
- Substance use
- Financial concerns
- Caregiving duties (especially for women)
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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Poll Question
Financial Considerations

• Faced with much longer life expectancy, LTS now find themselves asking "What's next?"
  – Panic about the future/inability to plan for future, are symptoms of AIDS Survivor Syndrome
  – Many LTS may have once had no need to save money; now face financial challenges as they age
  – “Retirement:” a euphemism for being on permanent disability
  – Eligibility requirements for some public assistance force people living with people to keep incomes low
    • Makes it hard to save
  – Long gaps in work histories/ageism pose challenges for LTS returning to work
Unexpected Long-Term Planning

LTS need to imagine the future, despite not thinking they had one for years or even decades

End-of-Life Planning

- Likely to be much farther off than once expected
- Can be an empowering process
- Means deciding not just where belongings will go, but how a person wishes to be treated, if a time comes when they are unable to make such decisions on their own

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“How will we be treated as elders in our twilight years? It's coming, for so many of us who were told we had 6 months to live. Now it's 25 years later and I am left to wonder, ponder and worry about the people who will tend to our needs as we start losing the ability to tend to them ourselves.”

— sologirl, Surviving into an Unknown Age, A Girl Like Me
“An ordinary woman, who has lived an extraordinary life... My attitude is of gratitude, for this life I have been given. The more I can share gives my life meaningful purpose. It is my daily mission to help inspire and motivate others to be kind, compassionate and above all, hopeful.”

– honeysplace2, An Ordinary Woman, A Girl Like Me
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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"Ours is not a movement simply about nostalgia, pain and grief. It is also a testament to the resilience of the human spirit, to humans who rolled up their sleeves and refused to accept our death sentences."

• Please read the full fact sheets on these topics:
  – Long-Term Survivors of HIV
  – How to Be an Advocate for Yourself and Others
  – Aging and HIV
  – Depression
  – Stress Management
  – Understanding your Rights and Responsibilities in the Workplace (U.S.)
  – Public Benefits and HIV (U.S.)

• For more information, please visit:
  – www.thewellproject.org
  – www.facebook.com/thewellproject
  – 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

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Resources for LTS

- Let's Kick ASS
- The Reunion Project ACRIA
- Graying of AIDS
- "We're Still Here"

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Thank You!

Questions & Answers

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_Posttest5 to take today’s webinar Post-Assessment Test.

An email message will be sent out 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!