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Long-Term
Survivors
of HIV





A program of The Well Project



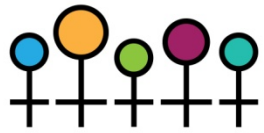
Surviving HIV Over the Long Term: The Past, Present, and Future - Part 2

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

#onewomanatatime

www.thewellproject.org

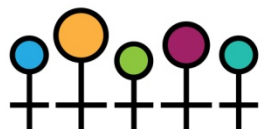
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About The Well Project

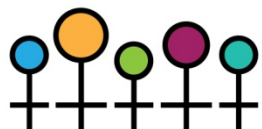
- Non-profit organization with a mission to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls
- Leverages technology to improve health outcomes and increase quality of life for women and girls living with HIV
- Provides accessible and comprehensive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



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About *WATCH!*

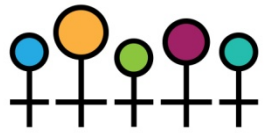
- WATCH! Women's Advocacy and Treatment Coalition on HIV is an ongoing HIV treatment advocacy and capacity-building webinar series
- The 2016 WATCH! series will take place throughout the year, and will include 5 webinars
- For certification, participants must participate in live webinar or view recording, 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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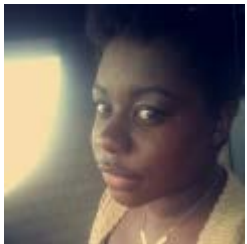
Speakers



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



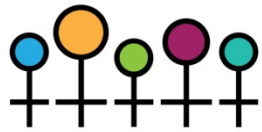
Maria Mejia, Global Ambassador, Community Advisory Board, *A Girl Like Me* Blogger, The Well Project



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



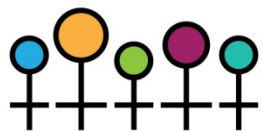
Krista Martel, Executive Director, The Well Project
(*moderator*)



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Agenda

- About The Well Project
- Recap of Webinar Part 1
- Mental Health Issues
- Isolation
- Sexual Health
- Financial Considerations
- Long-term Planning
- Q&A

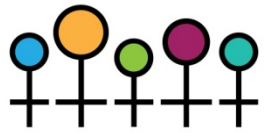


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Recapping LTS Webinar

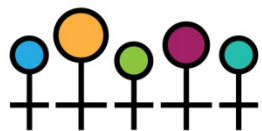
Part 1

- 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
 - Treatment Challenges
 - Aging
 - Inflammation
 - Co-Morbidities
 - Menopause
 - Sexual health



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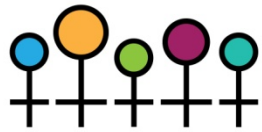
Poll Question



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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



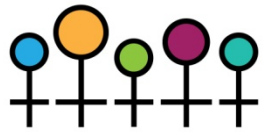
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Mental Health Issues

"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:

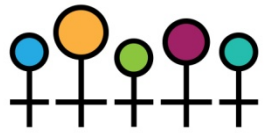
- A significant concern for all people living with HIV, particularly older women
- Prevalent among HIV LTS, along with other serious mental health issues
- High rates of depression also found among young people born with HIV



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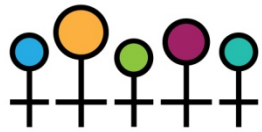
Mental Health Issues

- **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



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Poll Question

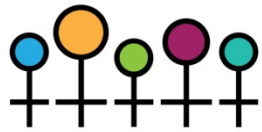


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Isolation

Contributors include:

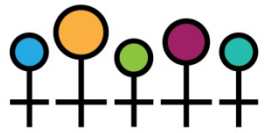
- Multiple losses
- Trauma
- Decreased ability to leave home or get around town
- Substance use
- Financial concerns
- Caregiving duties (especially for women)



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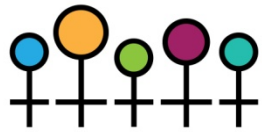
Sexual Health

- 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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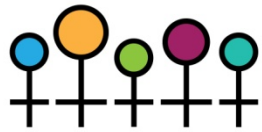
Poll Question



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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



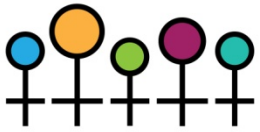
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Unexpected Long-Term Planning

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

End-of-Life Planning

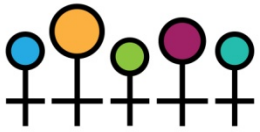
- Likely to be much farther off than once expected
- Can be an empowering process
- Means deciding not just where belongings will go, but how a person wishes to be treated, if a time comes when they are unable to make such decisions on their own



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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.”

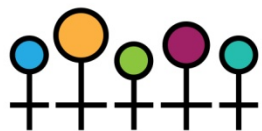
– sologirl, [Surviving into an Unknown Age](#), *A Girl Like Me*



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*“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

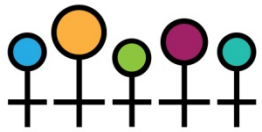


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Long-Term Survivors: Taking Care, Kicking Ass

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

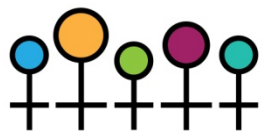
- **Take charge of your health:** Learn about your medications, have a good relationship with healthcare providers, keep on top of diet and exercise
- **Get support:** A healthcare provider, mental health counselor, peer mentor, or support group can provide support, help with connections to activities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



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Long-Term Survivors: Taking Care, Kicking Ass

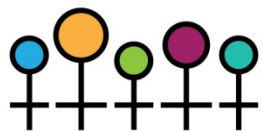
- **Find your purpose:** Commit to an activity that excites you, work or volunteer on something you believe in, rediscover your talents
- **Take your rightful seat at the table:** LTS are experts in living a long life with HIV, and should be part of the organizational and policy decisions that impact 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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"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."

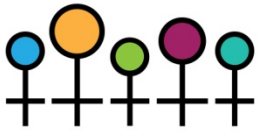
– From "[A Vision of Our Future: HIV Long-Term Survivors Declaration](#)," by Let's Kick ASS



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Learn More!

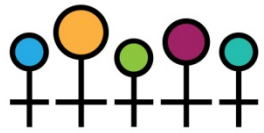
- Please read the full fact sheets on these topics:
 - [Long-Term Survivors of HIV](#)
 - [How to Be an Advocate for Yourself and Others](#)
 - [Aging and HIV](#)
 - [Depression](#)
 - [Stress Management](#)
 - [Understanding your Rights and Responsibilities in the Workplace \(U.S.\)](#)
 - [Public Benefits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

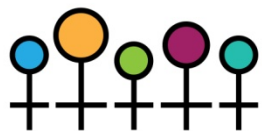
- [Angel S.](#)
- [Tranisha Arzah](#)
- [Dawn Averitt](#)
- [Maria T. Mejia](#)
- [Robin Barkins](#)
- [BornHIVPoz89](#)
- [Angelena Cortello](#)
- [Nancy Duncan](#)
- [LovingLife101](#)
- [Sara Thapa Magar](#)
- [Wanda Brendle Moss](#)
- [MumbaiyyaGal](#)
- [Neen](#)
- [Sandra](#)
- [Ieshia Scott](#)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



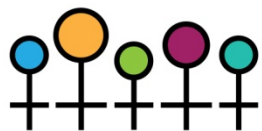
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Thank You!



Questions & Answers

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



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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 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!