

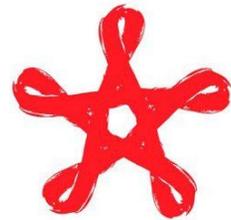
# Panel Discussion with Questions & Answers On Long-Term HIV Survivorship

Raising awareness of the  
challenges and struggles of  
those aging with HIV/AIDS



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## *Session Goals*



- Panelists Introductions with personal histories
- Overview of the affected population and projected statistics
- Examine the current special needs and challenges of consumers aging with a long-term HIV/AIDS diagnosis
- Brief discussion of clinical/medical involvement, advocacy support and community engagement
- Questions and Answers
- Take Away Thoughts and Considerations

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## **Brief Summary**

Long-term survivors; those infected prior to the introduction of HAART (1996) are an unique and growing subset of the HIV population. This population faces challenges that have not been seen in the HIV community. An HIV diagnosis in the 1980's and early 1990's was generally seen as death sentence. With the introduction of HAART, many of those infected were given a new lease on life.

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*We as medical, clinical, social, and advocacy groups for long-term survivors need to examine ways to address the issues and challenges of this group and to formulate viable solutions and treatments.*

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## Today's Panelists

### **Susan L. Koletar, MD, FACP, FIDSA**

Dr. Koletar joined the OSU faculty in 1988. She was the Fellowship Program Training Director from 1993 to 2012 and the Principal Investigator of the National Institutes of Health-sponsored AIDS Clinical Trials Unit at OSU since January 2002, and the Division Director since 2011. Her commitment to education has been recognized by a number of teaching awards, including the College of Medicine's Professor of the Year in 1995 and the American College of Physicians/American Society of Internal Medicine Master Teacher Award in 2002. In 2007 she was selected as one of the "Best Doctors of America", by Best Doctors of America Inc.

#### **Special Interests**

Dr. Koletar's clinical interests are infections in immunocompromised hosts, especially HIV-infected and transplant recipients. Her research interests are the diagnosis, treatment, and prevention of opportunistic and metabolic complications associated with HIV infection and its related therapies. She is currently working on a number of AIDS Clinical Trials Group protocols including a longitudinal study of metabolic, cardiovascular, and neurologic complications in HIV-infected patients who have had significant increases in CD4 counts in response to potent antiretroviral therapy.



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## Today's Panelists

### **Moderator: Eric Novak, 61 years old; 30 yrs HIV+; 20 yrs AIDS**

Eric first tested positive in February 1987 at the age of 31, after his partner was diagnosed with AIDS. He now knows that he was infected sometime around 1984 due to an April hospitalization that included most of the current known conversion symptoms (testing was not put into use until late 1985). His partner of 14+ years, died at the age of 41, of complications of HIV in July 1989.

In January 1998, he was diagnosed with PCP and consequently stage III HIV (AIDS). His life with AIDS has had many challenges such as depression, medication fatigue, severe side-effects of medication, chronic fatigue and inflammation, suicidal thoughts & financial and social struggles. In 2012, Eric decided he could no longer work productively full time and went on disability.

While he fortunately has not experienced another AIDS defining conditions since the PCP episode, he has had several health issues over the past few years to deal with including shingles, oral cancer, severe DVT in his leg, and breast cancer which resulted in a full mastectomy. For these reasons he wears a survivor bracelet to reinforce his resolve to overcome the health struggles that he faces as he ages.

Today, he lives with his fiancée in Victorian Village. He devotes much of his time to volunteering with HIV/AIDS boards and committees, including OSU ACTU & HPTN Community Advisory Board, Central Ohio HIV Planning Alliance (COHPA) and is the current chairman of the Equitas Health Client Advisory Committee.



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## Today's Panelists



### **Graig Cote: 56 years old; 31 years positive**

Graig was diagnosed June 15, 1986 when the life expectancy was only 2 years. He hid his diagnosis until 1990 when he started participating at the Ohio State University's AIDS clinical trials cohort. Becoming an active participant in AIDS research as time progressed, Graig became a member of consortium as well as for the Regional Advisory Group for Columbus Ohio. He became an active member of the Ohio AIDS Coalition (OAC) where he served President and Vice President.

Through his involvement with OAC, Graig became a public speaker, earning Volunteer Speaker of the Year. Through the Columbus AIDS Task Force (CATF), he became an Adjunct Facilitator at OSU. As an activist, Graig lobbied for the re-authorization of the Ryan White Drug Assistance Program for the State of Ohio. Graig has also spoken to the Bar Association for the decriminalization for HIV/AIDS.

In 2015, Graig was included in POZ magazine's Top 100 Long Term Survivors (<https://www.poz.com/article/grraig-cote>). He has been featured in other media outlets for his involvement in HIV/AIDS issues.

Today, Graig continues to impact the HIV community with his involvement.

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## Today's Panelists

### **Barbara Lebby, 57 years old; HIV+/AIDS 22 years**

Barbara is originally from New York City. She relocated to Columbus in February 2014. She was diagnosed with AIDS in March 1995 at the age of 35, seven years after the birth of her daughter. At the time, her CD4 was 34; she had PCP pneumonia, thrush, cervical cancer. In addition Barbara had to worry about having her daughter tested for HIV. She also lost her boyfriend to a brain aneurysm after being together for 15 years. Today, her CD4 is over 1300 and in her words, "...trying to live my best life."

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**Kate Schumate,**

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**AIDS in the beginning was a cultural, political and social force that changed the course of our lives and killed many of our loved ones and decimated our community. AIDS robbed us of a carefree youth while trying to kill us too. Do you know what it is like to have loaded gun aimed at your head for 25 and 35 years?**

**All of that is affecting our lives right now. And many of us rightly feel forgotten and invisible in the current HIV discussions.**



*By Tez Anderson, Founder, Let's Kick ASS <http://letskickass.org/aids-survivor-syndrome/>* 9

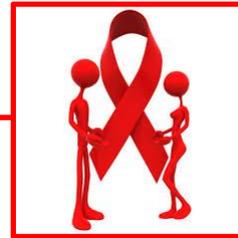
**As this population continues to grow, we must examine the special needs that arise in caring for these individuals. These needs can include:**

- Geriatrics & Gerontology medical care in conjunction with long-term HIV infection as well as an AIDS diagnosis
- Mental Health Issues such as:
  - Depression
  - Suicidal Thoughts



- Social Issues such as:
  - Loneliness
  - Isolation
- Stigma & Prejudice
- Safety & Stability Issues such as:
  - Homelessness
  - Poverty

**Our population, i.e. long-term survivors, has a history of fighting for what's best for our survival through protests and lobbying. Who will take up the baton to fight these important battles for this generation and those who follow.**



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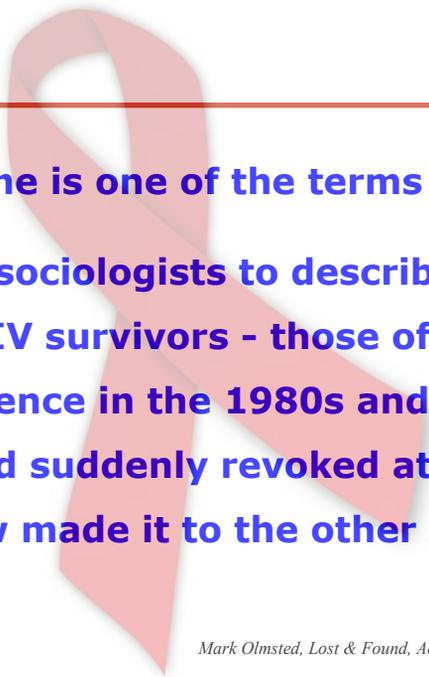
## **Who Are HIV Long-Term Survivors?**

***“ We were a group of people who were willing to stand up for ourselves and for the 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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**“Lazarus Syndrome is one of the terms coined by psychologists and sociologists to describe the condition of many long-term HIV survivors - those of us who were given a death sentence in the 1980s and '90s, only to have it unexpectedly and suddenly revoked at the eleventh hour. We somehow made it to the other side—hanging on day by day...”**

*Mark Olmsted, Lost & Found, A&U America's AIDS Magazine, 09/13/2017*

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## **The Aging HIV Population Is Growing**

**Worldwide, more than four million people 50 years and older are living with HIV (HIV+). According to UNAIDS, the proportion of older adults living with HIV continues to increase in all regions. In high-income countries, approximately three in ten adults living with HIV are 50 or over.**

*Aging and HIV, The Well Project, Aug. 25, 2016*



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## HIV and Older Adults

- In 2013, people aged 55 and older accounted for 26% of all people living with diagnosed or undiagnosed HIV infection in the United States.
- Many older adults have conditions such as heart disease or diabetes that can complicate HIV treatment.
- Life-long treatment with HIV medicines helps people with HIV live longer, healthier lives but can come with a high cost physically. The science is still being done on this.

<https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/25/80/hiv-and-older-adults>



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## ***What is the life expectancy of someone with HIV?***

**U.S. Kaiser Permanente research found that the life expectancy for people living with HIV and receiving treatment has increased significantly since 1996. This is when new antiretroviral drugs were developed and added to the existing antiretroviral therapy.**



<http://www.healthline.com/hiv-aids/life-expectancy?>

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## ***How will HIV affect me in the long term?***

**As time passes, people living with HIV may begin to develop certain side effects of treatment.**

**These may include:**

- **“Accelerated aging”**
- **Cognitive impairment**
- **Inflammation-related complications**
- **Effects on lipid levels & kidney functions**
- **Cancers**



<http://www.healthline.com/hiv-aids/life-expectancy?>

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## **Are people with HIV aging more rapidly?**

**There is no dispute that many of the diseases associated with aging occur at much higher rates in people with HIV and at much younger ages than in people not living with the virus. Here are just a few of those conditions:**

- **Weakened bones**
- **Loss of muscle mass**
- **Redistribution of body fat**
- **Cardiovascular disease**
- **Liver disease**
- **Kidney disease**

<http://www.poz.com/basics/hiv-basics/hiv-aging> <http://www.aidsmeds.com/articles>

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## **What is AIDS Survivor Syndrome?**

**AIDS Survivor Syndrome is a “syndemic” of psychosocial health problems that exist on a spectrum. It varies by degrees of intensity, and it affects HIV Long-Term Survivors differently at different times. It not a linear phenomenon.**

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### ***What is AIDS Survivor Syndrome and Why Do You Need to Know?***

**“...HIV agencies and activist are focused on “Ending AIDS” and creating an “AIDS-Free Generation.” Of course, those are worthy, admirable goals but can you imagine how the phrase an “AIDS-Free Generation” sounds to the first generation who acquired the virus during the “Plague Years”? To people still living with AIDS, most of us finish that phrase with “after I’m dead.”**

*By Tez Anderson, Founder, Let's Kick ASS <http://letskickass.org/aids-survivor-syndrome/>*

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## What signs and symptoms define AIDS Survivor Syndrome?

- Depression
- Lack of Future Orientation
- Panic from Unexpected Older Age
- Thought of Suicide
- Sexual Risk Taking
- Destructive Behavior
- Substance Abuse
- Social Withdrawal & Isolation
- Persistent Negative Thoughts like Deep Regret & Overwhelming Shame
- Survivor's Guilt
- Cognitive Impairment such as Poor Concentration & Loss of Immediate Memory
- Loss of Ability to Enjoy Life

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## What signs and symptoms define AIDS Survivor Syndrome?

- Deep Sadness
- Emotional Numbness
- Anxiety & Nervousness
- Irritability or Flashes of Anger
- Difficulty Falling Asleep or Staying Asleep
- Nightmares
- Personality Changes
- Feeling Tense, "On Guard" or Hypervigilance.
- Low Self-Esteem & Self-Worth
- Sense of Hopelessness
- Irritability
- Self-Stigma

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**“For us, AIDS was more than simply a medical diagnosis or the end-stage of a deadly disease. AIDS shaped our psyches. It also galvanized our community and gave us a sense of meaning and purpose.”**



*By Tez Anderson, Founder, Let's Kick ASS <http://letskickass.org/aids-survivor-syndrome/>*

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## **Access to services**

**Health communication and health services are not geared towards people aged 50 and older living with HIV. Clinicians are less likely to be trained on the specific needs of people 50 and older living with HIV. As a result, this population is likely to be diagnosed late in the course of HIV infection and often after their health has deteriorated considerably.**



## Stigma and discrimination

For people living with HIV aged 50 and older, the consequences of stigma and discrimination are potentially devastating. In addition to the psychological impact of being shunned by family, peers and the wider community, poor quality and delayed services in healthcare settings significantly reduce the potential for positive outcomes from HIV treatment.



[www.unaids.org/sites/default/files/media\\_asset/12\\_Peopleaged50yearsandolder](http://www.unaids.org/sites/default/files/media_asset/12_Peopleaged50yearsandolder)

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## Questions And Answers



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## Take Away

- Kicking AIDS Survivor Syndrome requires interventions that focus on **strengthening resiliencies** and creating a **sense of future orientation**.
- Beyond mere survival we have to changing the narrative to a **thriving mindset** and make Healthy Aging with HIV the goal. We need to improve those factors we have control over so aging is not so perilous and fraught with fear.
- Survivors need to be **celebrated and ennobled** like survivors of other atrocities.
- We have to battle and reject HIV-related stigma by **strengthening empowered networks** of long-term survivors aging with HIV including older gay and bisexual men, women survivors and transgender people. By increasing engagement, we battle depression and hopelessness.
- We also need **Person-Centered Health** where survivors are partners in their care.
- **Trauma-Informed Care** is also vital to understanding the full picture of health care for older adults aging with HIV.



*By Tez Anderson, Founder, Let's Kick ASS  
<http://letskickass.org/aids-survivor-syndrome/>*

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continued

- **Cultural humility training** to Health Care Providers so they aware of the possible issues affecting an aging population who never expected to be aging.
- We also know that **online social networks are helping** older survivors form community and create in person communities. Much more needs to be done to reach those who are not engaged.
- We need to explore the **role of technology** and smartphone apps in helping survivors improve their quantity of life.
- Finding ways to **overcome the financial difficulties** faced by many survivors that excludes them from participating in community when they want to.
- Helping survivors think long-term and to **see aging as something to embrace** not a barrier or limitation.
- Embrace a **mindset of Healthy Aging** with HIV not merely surviving.



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*Thank you for joining and participating in this important discussion. We hope you have a new awareness of the challenges long-term HIV/AIDS survivors deal with on a day to day basis. We will continue to have these struggles as we are living to a more normal life expectancy.*

