

THE HEALTH AND WEALTH OF HIV LONG- TERM SURVIVORS

Jeff Berry

Director of Publications, TPAN

Editor, Positively Aware

Ageing with HIV, Berlin

31 March-3 April, 2016

Disclosures

- Community Advisory Boards
 - Bristol-Myers Squibb
 - Gilead
 - Janssen/Tibotec
 - Merck
 - Pfizer
 - ViiV/GSK
- Consultant
 - Bristol-Myers Squibb

A little about me...

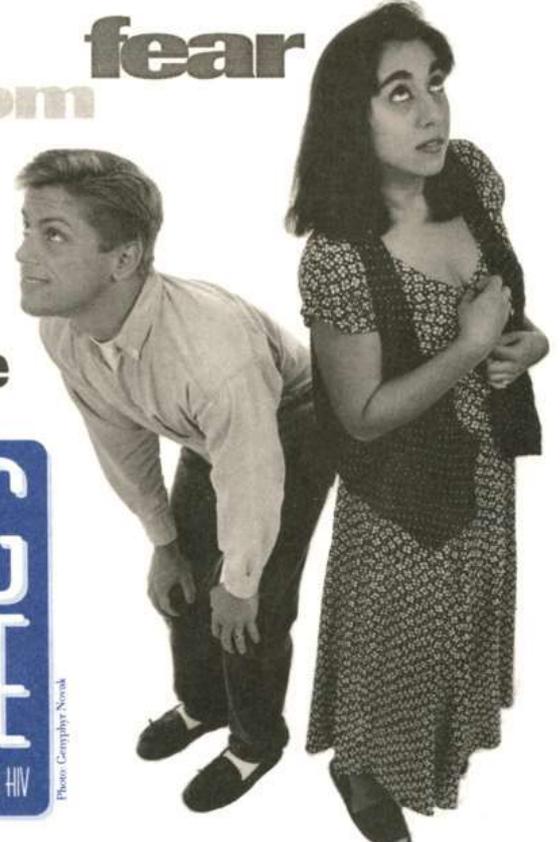
- Diagnosed HIV+ 1989
- Started at TPAN in 1992
- Since 2005 editor of Positively Aware
- ATAC and FPC member
- Co-organizer of The Reunion Project

P O S I T I V E L Y

AWARE

THE MONTHLY JOURNAL OF TEST POSITIVE AWARE NETWORK

disclosure
support stress
drugs
fear
mom
SEX
testing
health care



LIVING POSITIVE

LEARNING TO LIVE BETTER WITH HIV

Photo: Campbell Novak

OCTOBER 1993

312-404-TPAN

The Health and Wealth of HIV Long-term Survivors

- Defining HIV long-term survivors (LTS)
- Some of the challenges facing LTS
- My own story of survival
- Potential areas of research
- Opportunities for LTS

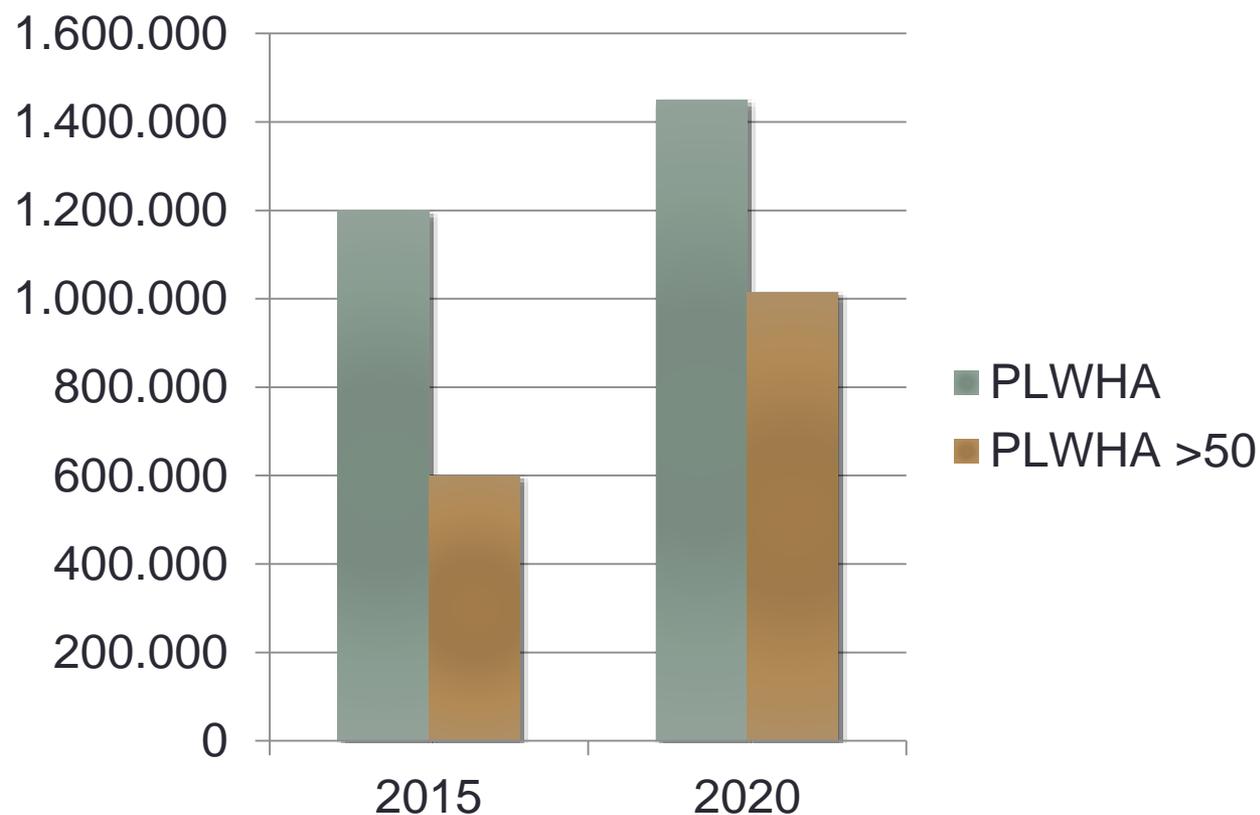
WHAT IS A LONG-TERM
SURVIVOR?

Defining long-term survivor

- Diagnosed before 1996
- Subgroups within LTS
- Definition is not static



People in the U.S. living with HIV >50¹



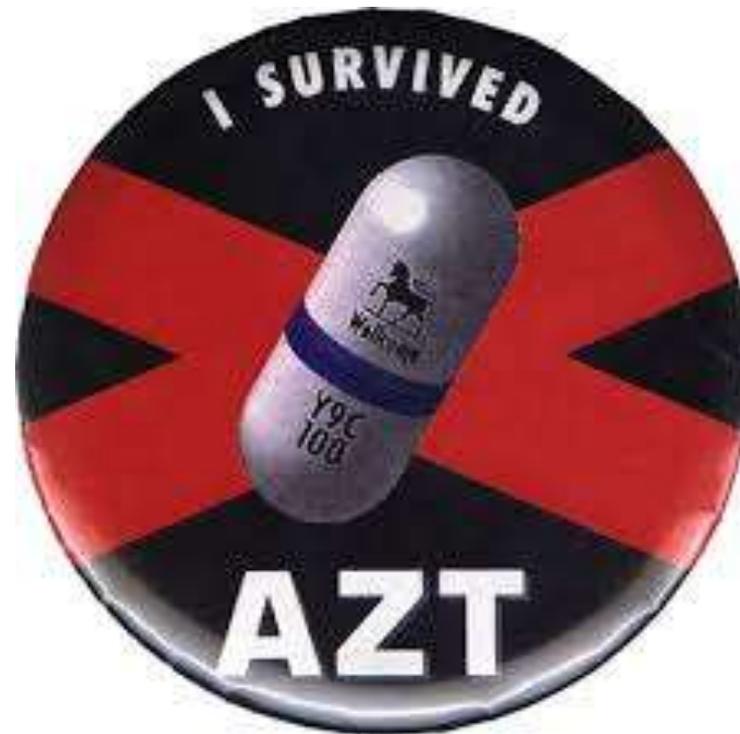
¹www.sageusa.org/issues/hiv.cfm. Accessed March 2016.

CHALLENGES FACING LONG-TERM SURVIVORS

Challenges facing long-term survivors

“I’ve already had both hips replaced, at age 52 from Crixivan [indinavir] and have kidney failure from Truvada...wh at next?”²

Consequences of long-term medications and early regimens



²Readers poll, Positively Aware (2015).

Consequences of long-term medications and early regimens and HIV

- Metabolic syndrome, body fat redistribution
- Peripheral neuropathy (PN)
- Chronic kidney disease (CKD)
- Osteoporosis, osteopenia
- Multi-drug resistance due to sequential monotherapy

Other health issues facing LTS

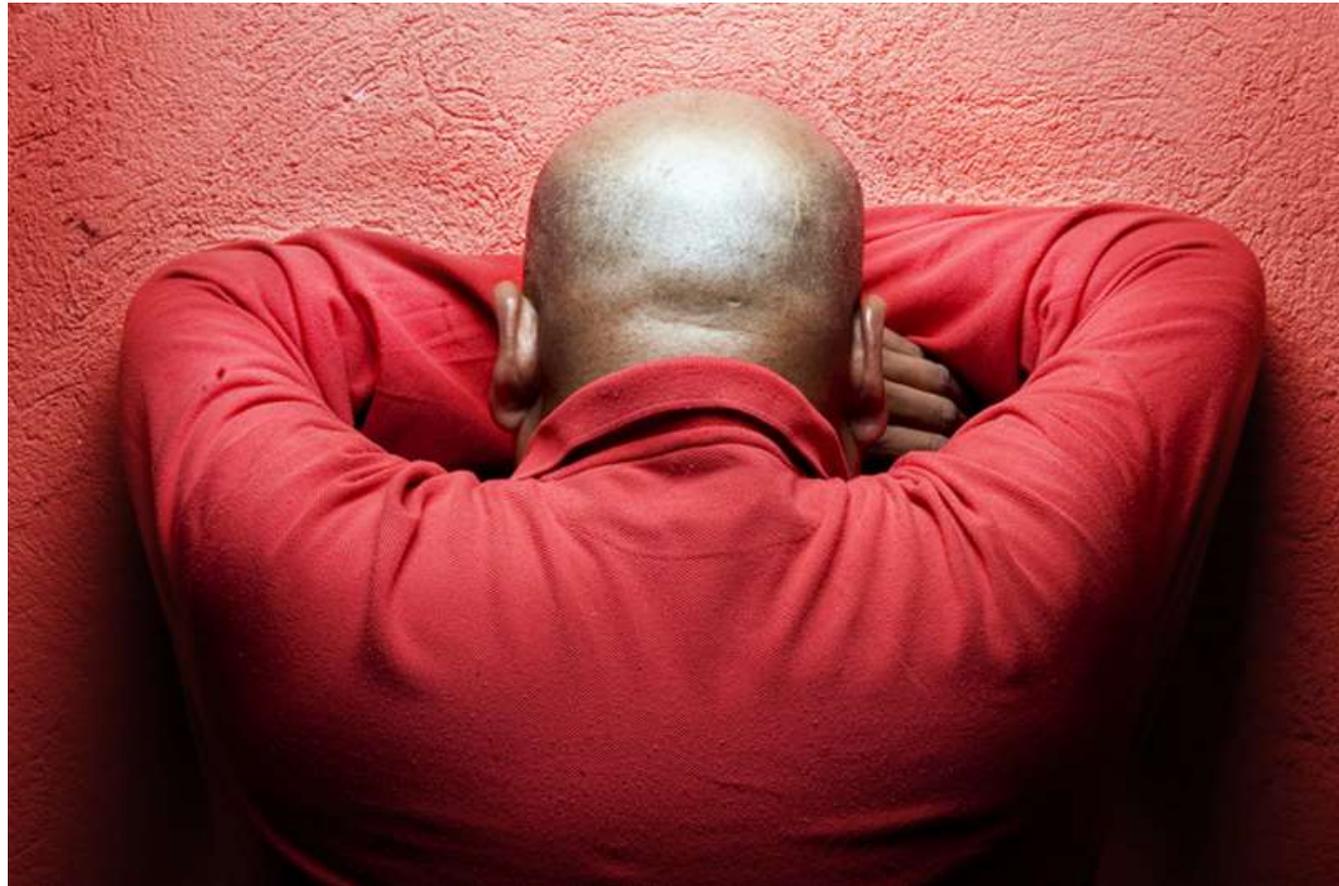
- HIV-associated neurocognitive disorder (HAND)
- Effects of long-term chronic inflammation
- Increased risk for CVD and non-AIDS cancers
- Co-morbidities and co-infection

Challenges facing long- term survivors

“Stigma is tops on my list, for it keeps some from seeking care.”

“Stigma can get worse when [you’re] older, some seem to forget you were young once and like everyone have sex. And if you are lucky still do.”²

Stigma



²Readers poll, *Positively Aware* (2015).

Additional challenges facing long-term survivors

- Lack of support, loss of family support
- Medical care/coordinated long-term care
 - Few trained in both HIV and geriatrics
 - Assisted living, nursing home, and hospice staff have no formal training and little experience in HIV
- Long-term financial planning
- The disability trap
- Independent living/housing
- Unique challenges facing women, POC who are LTS

Challenges facing long-term survivors

"I was planning to die, but I lived. Now what?"

"I thought I was dying for so long it became a habit."²

Long-term consequences of living with the trauma of the early AIDS epidemic



²Readers poll, *Positively Aware* (2015).

Long-term consequences of living with the trauma of the early AIDS epidemic

- Post Traumatic Stress Disorder (PTSD or PTS)
- Survivor's guilt
 - “Why did I live, when so many better people died?”
- Depression
- Isolation, loneliness
- Suicidal ideation
- Substance use disorders

MY OWN STORY OF SURVIVAL

OPPORTUNITIES— WHAT'S NEXT FOR LTS?

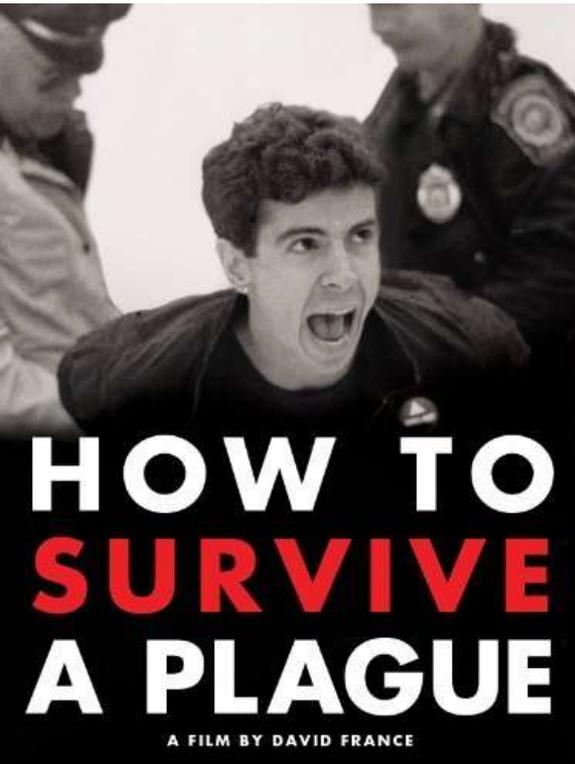
Opportunities—what's next for LTS?

“Spencer [Cox] was really the first person to speak up for long-term survivors.”—Matt Sharp, *Positively Aware* (2016)



NO ONE ARRIVES IN THE DESERT WITHOUT A STORY

DESERT MIGRATION



HOW TO SURVIVE A PLAGUE

A FILM BY DAVID FRANCE

Recent years have seen an increased interest in plight of long-term survivors and early days of the epidemic



San Francisco Chronicle PRESENTS
**LAST MEN
STANDING**

SFCHRONICLE.COM/LASTMENSTANDING

APRIL 8, CASTRO THEATRE

#SURVIVINGAIDS

A PRODUCTION OF THE SAN FRANCISCO CHRONICLE. WRITTEN, DIRECTED AND PRODUCED BY ERIN BRETHAHER AND TIM HUSSEN. ORIGINAL REPORTING AND WRITING BY ERIN ALLEAY.

Potential areas of research

- The use of ADHD drugs to improve HIV associated cognitive dysfunction.
- The use of tesamorelin plus Metormin to decrease HIV associated visceral fat increase.
- Assessment of current mitochondrial DNA in PBMCs, muscle and fat tissue in patients with history of thymidine analog exposure.
- Whey protein effect on CD4 cells in immunological non responders.
- Assessment of incidence of hypothyroidism and Hashimoto's disease in LTS.
- Assessment of adrenal insufficiency in LTS.
- Resiliency as a teachable skill: Potential methods.
- The use of Sangamo's zinc finger technology to improve CD4 cells in LTS immunologic non responders.
- Pain and LTS: Incidence of high CPK in the current ARV era.
- The use of nandrolone plus or minus exercise for improvement of frailty in LTS.
- Incidence of sleep apnea in LTS
- Effect of JAK inhibitors PLUS ARV used for RA on HIV associated residual inflammatory markers in LTS
- Does early menopause occur in HIV LTS women?
- Incidence of testosterone deficiency in LTS women.

Opportunities—what's next for LTS?

- Creating support and information networks
- Training for HCP—HIV and Aging Toolkit (<http://aidsetc.org/toolkit/aging/home>)
- Research
- Advocacy



"Aging is an extraordinary process whereby you become the person that you always should have been." - David Bowie



Conclusion

- Challenges exist, but not insurmountable
- We need to take a holistic approach
- Identify models of resiliency
- Research opportunities
- A call to action



Thank you!

Jeff Berry

@PAeditor

j.berry@tpan.com

+1 773-454-5333