
The Kick ASS Manual

Let's Kick ASS Palm Springs Reference on
aging with HIV and AIDS Survivor Syndrome



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Introduction

The Kick ASS Manual was originally conceived as something useful to front-line providers. The project has shifted in composition, away from journal-type articles and towards personal stories, always with the goal of informing, increasing the body of knowledge around HIV and thereby improving quality of life for people living with HIV. Most of the pieces are short. We want them to be approachable and useful to a diverse audience, ranging from professionals and caregivers dealing with people who might have HIV, to people living with HIV, to people who don't have HIV but want to learn more. The Manual can answer questions directly, and suggest sources for further information. It puts a face to aging with HIV, raises awareness around some of the issues that can trouble our lives, and provides ideas about how to improve them.

A more complete version will be available online, at the Let's Kick ASS Palm Springs website lkaps.org. In particular, this is where we will post links to other organizations and scientific literature, articles that highlight local opportunities for care, and stories submitted after our print deadline. Our intention is to maintain this as a living document. Medical information can be expanded and brought up-to-date. More stories can be added.

Advocacy has been crucial to the story of the HIV epidemic. Always a disease of stigma, it was easy for the powerful to turn away. Now there are many agencies dedicated to helping people with HIV, founded by noisy determined people who decided something needed to be done. The Manual continues that tradition, hoping to bridge, unite, educate.

The National Minority AIDS Council (NMAC) gave the needed nudge to set this project in motion through a mini grant provided by their HIV 50+ program. This program aims to raise awareness and educate about the issues people living with HIV face as they age- so it is a natural match for LKAPS. The print version of the Manual will be delivered to area service providers by LKAPS members. People living with HIV are first of all people. In-person delivery helps to empower our members and to very directly put local faces to this enduring epidemic.

Let's Kick ASS Palm Springs is a grassroots organization run entirely by its volunteer members. ASS is the catchy acronym for AIDS Survivor Syndrome- a version of complex post-traumatic stress. Survivors of long-term trauma can struggle to fit in with a society they formerly navigated with comfort. We create social events for long-term survivors, regardless of their HIV status. We advocate, we educate- ourselves and hopefully others.

As editor, I could not have managed the project without continued encouragement and support from friends, all profoundly affected by the epidemic. I asked, and people gave. They dug deep, finding words for things painful to explain, providing clear medical information, concise summaries of available treatments. I am grateful to be part of such a supportive and compassionate community.

Eric Jannke

April 2018, Palm Springs, California

Behavioral Health

Therapy for Long-term Survivors Living with HIV

Jill Gover, Ph.D.

For long-term survivors, the AIDS epidemic has been a series of traumatic events. The effects of sustained trauma may present a combination of symptoms such as: depression, anxiety, emotional numbness, anger, survivor guilt, insomnia, nightmares, hypervigilance, hopelessness, substance abuse, sexual risk-taking, emotional numbness, low self-esteem, social withdrawal and isolation, and/or a lack of future orientation. Effective treatment for this type of sustained trauma requires interventions that focus on strengthening resiliencies and creating a sense of hope for the future. Therapy techniques focusing on developing a new, positive “internal narrative” of self-talk that emphasizes healthy aging with HIV is crucial to combatting the challenges and fears that overwhelm so many long-term survivors. Just as survivors of war and other atrocities need to celebrate their courage and resiliency, so too do long-term survivors living with HIV (LTS). Therapy that helps LTS reframe their perspective so that they can view aging as something to embrace rather than fear will help them overcome the symptoms of sustained trauma and allow them to thrive in their later years.

There are several evidenced-based therapies that have proven to be efficacious in treating sustained trauma. The following are some specific technique and models currently being used with great success to improve quality of life for LTS:

Post Traumatic Growth (PTG) emphasizing a resiliency model that builds on strengths

Mindfulness Based Stress Reduction (MBSR) adapting Buddhist principles of mindfulness to reduce stress

Cognitive Behavioral Therapy (CBT) identifying and challenging unhelpful thoughts to construct a more accurate and hopeful belief system

Eye Movement Desensitization and Reprocessing (EMDR) processing past trauma through neurocognitive desensitization

Pain Management Treatment (CBT for Chronic Pain) to cope with chronic illness

In addition to these therapeutic models, evidenced-based group therapy that incorporates a structured psychoeducational component has been proven by research to be very effective in addressing the myriad issues facing LTS, and providing a safe space to explore solutions. The Scott Hines Mental Health Clinic offers a free LTS therapy group for gay men over the age of 50 living with HIV for a minimum of 10 years. This is a very specific group that acknowledges the unique experience of gay men who were coming of age in the 1970's and 80's, and are now aging with HIV after having suffered decades of multiple losses and sustained trauma. This is an evidenced-based 12 week structured closed group that creates bonding around shared past trauma, and provides psychoeducation on topics that are specifically relevant to LTS. Just as veterans need to talk with other veterans (and sometimes veterans from the same war), gay men aging with HIV need to talk with each other to break out of their isolation and not feel so alone. The participants create their "topics" for each group session, and the therapist provides therapeutic exercises for the group to explore those topics. Topics may include: healthy aging, coping with ageism, dating as an older HIV+ man, shame @ HIV stigma, reducing survivor's guilt, breaking out of isolation, grieving multiple losses, finding purpose, planning for the future, living with chronic pain, etc.

In the 1980's an HIV+ diagnosis was a death sentence. No one could imagine aging with this disease. However, now there are many ways for therapists to help long-term survivors to age well, despite the challenges. We have available to us researched, evidence-based interventions, models, and techniques that focus on developing strengths and resiliencies. Today, with the help of a well-trained, culturally competent therapist, long-term survivors can overcome past trauma and thrive in their golden years.

Isolation and Sensing Happiness

Leif Wauters

Isolation numbs us. All the facets of the wild world fade into unused memories and we forget our vibrant potential when we stop connecting. The same way being sedentary can facilitate physical issues, so does allowing one's self to be alone too much can dull our mental wellbeing. We can all enjoy our own company or want to catch up on our favorite show from time to time, but the lack of connection with others can have untold negative effects unless we take a few small steps towards happiness.

Just the act of conversing face-to-face with someone stimulates thoughts and neural pathways, leading the state of mind for everyone involved in unique directions. And by seeing others' facial expressions and body language, an entirely undervalued form of communication steps up where volumes of unspoken honesty is subconsciously absorbed.

Talking with someone by phone is a good start – you can actually hear them smiling and be lifted by their laughs – but seeing someone smile genuinely breeds a smile in others. Smiles are wired into us as a positive physical response, so the act of smiling can reversely prompt the mind to think positively.

We know about the monumental value of the olfactory sense – smell – but just consider all the emotions that come from the wafting aroma of great food, fresh coffee, body odors or pheromones, cut grass and flowers for those not allergic, on and on down an endless list. But variety sparks fresh connections in your brain and body. Take snow blindness for instance.

White upon white upon white bleaches your vision and it takes a long time to reset. So it is with smells (and every other sense). You may have a little garden that feeds you the same sweet smells day in and out. Although caring for these plants is invigorating, getting out and about to smell new sweet and savory odors awakens memories or prompts fresh thoughts. It encourages us to think more broadly and can stimulate creativity.

Taste, sight and sound – all need to be fed diverse meals to round out their health. We may know what we like but we don't know what we don't know, so why not stretch out towards something new. Experimenting with a meal you either never tried or perhaps didn't like in the past could start you thinking of ways build upon your regimen at home. That latter part is especially important. You are not the person you were ten years ago when you hated Thai food, nor are the restaurants around you the same as they were then. You've evolved and allowing yourself to give it a fresh go could lead to a favorite new joint you'll start sharing with friends or it might even become a place where you make new ones.

Serendipity is the gold that comes from getting out and exposing yourself to other people, places and experiences. Okay, I'll admit the word kindles some hippy dippy hesitation in some, but maybe an algebraic view would help: $X + Y = Z$. Given that X is your mindset at that exact point in time and Y is the entire event you are confronting (a person, place, concert, movie, hike), then the outcome of Z is the unpredictable sum of those variable thoughts and emotions in that moment. It is entirely unique and potentially brilliant. Sure, it may be shit too, but the value of X + Y each and every time is that even though it may not seem it, the Z belongs to that precise combination. It's actually the SUM of countless variables, so although this basic analogy doesn't do it justice I think you get the picture. There's no knowing that can come of saying hello to someone and sharing a bit of you with them. That mystery Z is what life is really all about, eh?

Touch can be the most complicated and scary sense to embrace. Maybe you weren't raised in a hugging family or there was more hurt than hugs going on that you've struggled to reprogram over the years. Your body may also have been dragged through the coals to survive HIV and along the way you cut yourself off from giving and receiving the gift of

touch. Distrust takes seconds to root and can fill our mind with a forest of darkness you don't deserve to live in.

Small steps towards reconnecting physically with others can reap massive returns, most of which you may never see. When I call touch a 'gift', I mean it. Put your hand on someone's shoulder, hold their hand or even hug someone when you meet them. You're entering their personal compound, overcoming their defenses and showing them what is possible. In so doing it, your body re-learns what it feels to be touched by others. After that tactile connection is made, they may go forth and hug the next person they meet because they now realize they can. And this doesn't even tap the enormous cerebral benefits that come from touch, of which volumes have been written.

Remember, as hard as it is to, that other people's filters are not yours and vice versa. In the words of Madonna: "I'm not your bitch, don't hang your shit on me." That comes in many forms, the unspoken ones where we project our filters on how we believe someone sees us can be the most damning. We're doused the flame of a new friendship before it's been sparked. Each time you meet someone, allow that connection to be a blank slate. They have their own method for exposing their identity, which shouldn't be pre-judged. Of course first impressions are golden so trust your gut, but one person is not the next so keep saying hello. And if you feel unsafe or unable to on your own, line up an 'accountabilibuddy' – a term born on South Park that can be the difference between facing the world alone or having a running buddy to get you out the door or share laughs together when you can. Start with one person who gets you out and return the favor. Once a week or whatever works for a stroll, a dinner, a drink, a trip to the park. Smell the flowers, share ideas and see where it leads... it can begin to sharpen those many senses that isolation has dulled and the potential positivity is endless.

Facing Addiction

Wade Cook

If you had told me that I would go from art teacher to homelessness, I would never have believed you. But, there I was, stuffing a few things into a backpack and heading off to live on the street. I just wanted to be able to use meth and nothing else mattered. I, indeed, am an addict and have been a long time.

Addiction can occur in many forms and is defined by physical dependence characterized by withdrawal symptoms. Especially for long term HIV survivors, issues like isolation, loss of purpose, financial worries, fatigue and health issues can lay the groundwork for addictive behavior. Addictions can be broken down into two subgroups: substance and process. Substance addictions include: alcohol, amphetamines, nicotine, solvents, opiates and

barbiturates. Process (behavior) addictions include: bulimia, sex, crime, gambling, exercise, food, isolation (tv), internet, pornography, electronics (phone), perfectionism, shopping, cutting and video games¹ in 6 of those with a substance problem have multiple substance disorders. (Center on Addiction, April 14, 2017) Approximately 16% of the U.S. population ages 12 and over has a substance problem. This includes:

Nicotine (approximately 9%)

Alcohol (approximately 7%)

Illegal drugs (approximately 2%)

Prescription drugs (approximately 1%)

According to the National Institute on Drug Abuse, a third of the 1.2 million Americans with HIV currently use drugs or binge on alcohol. It's estimated that 24% of all persons with HIV are in need of substance abuse treatment. Over 60% of 100 DAP clients surveyed in March 2016 said that they'd used crystal methamphetamine. (DesertAidsProject.org) In addition to the life factors that contribute to increase in addiction, the Coachella Valley and Riverside County have become known as America's drug pipeline. "Over a three-year period that ended in September 2015, the Riverside DEA Office, which also covers San Bernadino County, has seized about 6,500 pounds of meth and 770 pounds of heroin. That's nearly one fourth as much meth, and one tenth as much heroin, as was seized by the entire DEA—nationwide—from 2012 to 2014", states Alejandro Gonzalez, Drug Enforcement Administration. (Brett Kelman The Desert Sun 2015). Palm Springs, rich in resort and vacation destination tourism, can also be the setting for a deep dive into a meth- induced nightmare and endless supply of the drug.

For people living long term with HIV, an escape from fatigue, loneliness, stress, boredom, survival guilt, internalized homophobia, prejudice and side effects of medications are common reasons for using meth. Other reasons include enhanced libido, energy, alertness, confidence and euphoria. With long-term use, however, meth can damage cognitive functioning, create hallucinations, ravage the body, and increase the likelihood of violent behaviors. Meth's ability to increase energy, sexual libido and disinhibition leads many users to have sex for hours. (HRSA Care Action June 2007)

Other consequences people experience are resistance to HIV medications, dental problems, weight loss and wasting, financial loss, bankruptcy, suicide, rejection by family and friends, divorce, violence, domestic abuse, homelessness, job loss, legal issues, incarceration, physical tics, isolation, mental institutions, loss of interest in life as well as toxic shame.

Helping people face and cope with addiction includes strategies such as intensive collaboration among mental health specialists, dentists, pharmacists, social workers, primary

care phsicians, substance abuse counselors, etc. Personal and family therapy, support groups as well as alternative therapies such as sports and adventure therapies, nutritional therapy, journaling, psychodrama and somatic techniques can also be effective in working with those dealing with addiction. (American Addiction Centers) A strong support system has been one of the most important factors in healing from addiction. Many of those that have struggles with addiction have experienced significant trauma and abuse at some point in their life and it is important to address those wounds.

My story continues with an intervention by caring friends, treatment and lots of work in 12 step groups like Crystal Meth Anonymous, Sex and Love Addicts Anonymous and working with therapists who deal with trauma. October 7, 2007, I stopped using meth. I began to experience many of the benefits that others have experienced as they stop their addictions such as nurturing healthy relationships, sorting out financial matters, finding forgiveness from loved ones as well as self-forgiveness and self-compassion. It's possible to find freedom, even joy.

Diverse Voices

An Immigrant Speaks

Jesus Guillen- Founder of the HIV LONG TERM SURVIVORS group

How many of us come to this country following the dream?

How many of us, hardly speaking English?

How many alone?

How many young, "fresh meat"?

How many of us trying to survive, trying to get any possible job, washing dishes, cleaning houses, anything, sometimes in almost slave positions?

How many of us left everything behind, to start all over again?

And then...

And then suddenly have an unexpected welcoming from a virus....

WELCOME TO THIS COUNTRY, YOU ARE HIV POSITIVE.

To be told you might die soon, and to don't have anyone to tell,
to feel you're dying already, and feel literally on fire,
to have a death sentence riding in a wild horse every minute on your head,
without a breathing moment.

To feel like you want to scream, but to know you simply can,

NO WAY, NO HOW.

To don't know where to get help, where to talk, where is, what is support?

To hardly understand what is going on....

That was me, in 1984.....for some strange reason, I became part of a study, not sure why,
maybe after hearing some rumors about a strange disease, maybe I felt something
weird...maybe my empathy.....maybe, who knows....

maybe...it does not matter anymore.

In those days, it was impossible to try to become a legal resident of this country or immigrate
if the person was HIV positive (or whatever the terminology was in those days, I forgot, my
memory is braking apart, falling apart, fading away...LOL)

Even if I did my HIV transition in this country, because in my case, I knew exactly who and
how gave me the present of "EL BICHO" , this is how they still call it in Mexico, naming the
virus.

The beautiful man who passed me the virus, in a sexual encounter that I wanted very badly,
died one year later...almost like hammering more that consciousness of me dying soon.

Now I am an American citizen, the details of my journey to this present moment, are another
story; for now, I want to focus the attention in the immigrants, because even if you come
here "legally" many of the factors are the same, but without "papers", it is a lot of worse, at
least in the uncertainty.

I can not tell you, what is worse or better, to see your friends and lovers dying, or to not have them; to see your community melting one by one, or even by many, or to don't have that community. All that I can tell you, is that been alone, SUCKS!!!

There is so much more that we can talk about this issue, and the HIV story tell us these days, that most of us, or /and specially the newly infected, might get to live a normal full life - whatever that is- but many of the parts of the equation of been an immigrant are the same, or almost the same. All that I'm asking you, is that we should not forget them, because every day we have newcomers to this country that get an unexpected welcoming.

Being an immigrant is part of who I am, but as an advocate and activist, I fight for all the colors of the survivors' rainbow.

What does U=U mean to an HIV long-term survivor?

Fausto Perez

The scientific evidence is clear: People living with HIV who adhere to effective Antiretroviral Therapy (ART) achieving and maintaining viral suppression (undetectable) for a minimum of 6 months, are less likely to develop HIV-related complications and **cannot transmit** HIV to others. Conversations have begun about ending the HIV epidemic or dramatically curbing its impact in the United States and around the world, in large part due to the effectiveness of biomedical HIV prevention methods (PEP, PrEP & TasP). The unprecedented international scientific consensus that “**Undetectable equals Untransmittable**” (U=U) has significant public health implications solidifying HIV treatment as a powerful tool for preventing new seroconversions. It also presents a historic opportunity to improve the quality of life and sense of wellbeing for people living with the virus by promoting early HIV treatment, improving medication adherence, raising survival rates, restoring morale and reducing decades of stigma, discrimination, and HIV criminalization.

Every person living with HIV would tell you that the most difficult part is surviving stigma. Transmission risk not only fuels stigma but has always been a concern for us, people living with HIV, our sexual partners and even our families. “U=U” promoted globally by the Prevention Access Campaign, is based upon the same scientific premise as TasP (Treatment as Prevention). The interpretation from “less likely to pass the virus” to “Untransmittable” is a **game-changer** with the potential to affect the way HIV is perceived by everyone –

specifically what it means to live with HIV now, in the new millennium. The knowledge of this fact empowers us, people living with HIV, like nothing ever before. It shows that we are part of the solution and not the problem. For too long we have been told by our physicians and lawmakers that our bodies are dangerous, making us feel like vectors of disease or even biohazards. The fear of exposing our loved ones to the virus has been a heavy burden difficult to bear. Internalized stigma, shame, and fear has prompted many of us to live lives of social isolation, depression, anxiety, and even suicide ideation. HIV survival has not come without a price.

Meanwhile, at the 2016 International AIDS Conference in Durban, South Africa data were released from the most recent and compelling study on the subject: **the PARTNER Study**. Between September 2010 and May 2014, the study enrolled 1166 serodiscordant couples at 75 clinical sites in 14 European countries. The criteria included one partner living with HIV and having an undetectable viral load on ART and that the couples were not always using condoms when they had sex. The study included both gay and straight couples in the final analysis when the most recent viral load for the positive partners was undetectable – defined as <200 copies/mL. The results are simple

to understand: **zero transmissions** from over 58,000 reported condom-less acts of intercourse among serodiscordant couples participating in the study.

Notably, ten years ago on January 30th, 2008, the Swiss Federal Commission for AIDS-related Issues published similar conclusions on what became known as “**The Swiss Statement**”. Despite the lack of results from large randomized studies, the Commission felt, based on an expert evaluation of HIV transmission risk under therapy, that the risk of HIV transmission in such a situation was negligible. The risk was compared to the risk of transmitting HIV from kissing! Reactions from around the world’s medical and public health fields came with relentless condemnation and sensationalistic headlines. Today, the Swiss Statement is fully vindicated: Still no documented transmission under ART, ten years later! This remains the most compelling argument supporting the Swiss Statement: Undetectable people living with HIV “ne transmettent pas le VIH par voie sexuelle”. There were three main issues that motivated the publication of the Swiss statement in 2008, and these issues remain relevant in our own country today: **Criminalization, Conception, and Ethics in Medical Practice**.

Now that the United States has finally joined other nations on the U=U consensus, it is imperative that the message be disseminated loud and clear so it is heard and understood by everyone. The preventative impact of effective HIV treatment underscores the importance of expanding access to treatment by eliminating barriers to care, improving uptake and adherence, and eliminating HIV-related Stigma as we know it. We have the tools needed to end the HIV epidemic, but lack the political will! Central to this, we must fight for evidence-

informed, human rights-based policies and programs that support individuals living with HIV to make choices that address our needs and allow us to live healthy, dignified lives free from stigma and discrimination. The understanding, acceptance, and implementation of these facts in our public health and justice systems is long overdue. It is time that we all – agencies working in the HIV field, activists, advocates, people living with HIV and our allies – **unite in demanding sound policies that conform with current scientific and medical evidence.** Our community of people living with HIV and our loved ones deserve to enjoy the benefits of these implications, which should never be underestimated as we strive to end the dual epidemics of HIV and HIV-related stigma.

So, what does U=U mean to me, an undetectable HIV long-term survivor? After 30 years of thriving with HIV, simply put, this is my “cure”. I can’t develop AIDS and I can’t pass HIV to others. It also means I can truly have a normal life, and therefore, **I’m not dirty!**

Defining Long-Term Survivor

Jax Kelly

Recently I attended a conference on HIV and Aging where I heard that several of the participants had a discussion about “Who is a Long-Term Survivor?” This gave me pause to think about all of the ways people could identify as long-term survivors.

Of course, I first think about anyone who has been HIV-positive since 1981 when the NY Times first wrote about a disease causing the death of gay men. Anyone from that era -- positive or negative -- attended the funerals, raised money in cans at bars, and tended to the sick and dying.

Then there are those who have been living with the disease since 1996 when the antiretroviral medications became available and death could be averted. Those newly-infected at that time benefited from a class of drugs that kept their T-cells high and avoided many side-effects from earlier medications.

I was diagnosed with AIDS ten years later, in 2006. That being a over a decade ago, I consider myself a long-time survivor. And the rest of my bio has been touched by the history of AIDS. I was in college during the early 1980’s. My first long-term relationship was as the negative partner in a sero-discordant pairing in the early 1990’s. And I later learned what it felt like to be hospitalized with pneumocystis carinii pneumonia (PCP) and rebuild my T-cells from a low of 44.

The conference decided to let people self-identify. I trust people who are willing to share their stories candidly and let them tell me who they are.

Currently I wear a red AIDS ribbon with the symbol “U=U” across it for “undetectable = untransmittable.” The ribbon is to remind people of those who didn’t survive, while “U=U” gives hope for HIV-positive people that stigma will be reduce as people learn that adhering to medications and achieving a continuous status of an undetectable viral load will keep them and their partners healthy.

Shame & Stigma

This is an edited interview, with follow-up email and text messages. We spoke at length on a wide range of topics. Some of our conversation was narrative, other parts were an attempt to better understand concepts. ej

Hi Eric, Sorry for the confusion: Right off the top I turn 76 next month!

Short timeline:

1983 got HIV

1985 tested positive

1986 boyfriend died

1988 sold house and moved to Silverlake/Los Feliz/ Hollywood for own condo

1995 AIDS diagnosis, SSI Disability

2007 Off disability, moved up to second home in Apple Valley, CA

2014 retired to Palm Desert home

You ask about my decision to move to West Hollywood, about stigma and gay ghettos.

I did not think in terms of stigma (I told very few people at that time) and ghettos. Yes, gay people lived in gay communities, but not always. I had gay employees at the hospital and never thought of them as gay per se, just part of our lab team. I felt distraught, isolated and alone with my diagnosis. My first step was to find and join the support group on my side of town. The next step was the POZ workshops on weekends and Louise Hay on Wednesday nights.

I managed to keep working for a few months, then took a four month sabbatical to travel around US and tell my family. I had an incredible time. When I came back I knew I wanted to survive and live to see my kids as adults. For me it became about what I could do to survive! When I was in Whittier I never felt as relaxed (headaches, stomach aches and body quivers, isolation) as I felt in the gay community. My spirits were always uplifted in the gay

community. I began to feel true anguish as I lost friends, but going through that process made me stronger and even more grateful, and more accepting of my own fate.

At that time, the late 80's, there wasn't much hope. Because I could pinpoint when I got it, living even 10 years was important and I felt I would be better in the gay ghetto than in Whittier. I wanted to live and fight the stigma of HIV! I was vocal in West Hollywood, I was seen. I found camaraderie, understanding and loving people! I would drive to Whittier to the job I loved and then go to support groups and meetings and hang out with new friends in WH.

I don't think the term ghetto entered my mind. I was aware of the stigma of HIV but survival was primary and I would only do something so radical as move, a single woman in the neighborhood, because I wanted to survive. And- I found a whole new way to live. In the ghetto I found acceptance, understanding, friends, love, activities, Reiki, support, marches, quilt making, gay pride, and growth and survival! The choice to move was indeed a life prolonging option for me! It was my path...

Let me stop right here and define two words. By definition stigma is a stain or reproach on one's reputation or a character defect or disease.

The definition of shame is the painful feeling of having done or experienced something dishonorable, improper or foolish.

HIV for me was mostly about shame. So for me HIV equaled shame, not necessarily stigma. It did not affect my identity; I really experienced shame when I had regrets about what I had done to get the virus, and when I told my children and family.

I definitely do not feel as much shame today but I choose to stay quiet when it comes to stigma- I can by choice reveal or not reveal my HIV status. It is my right to disclose or not (and I can do that pretty safely as a woman). I have already modified my sexual behavior and I will stay in the closet and hide my HIV status as much as I need to feel safe and happy. But- I have experienced and do know for a fact that if I feel safe in disclosing it feels good and down the line benefits my physical and mental health.

I didn't want to know

JB

I went to my San Francisco doctor to get a blood test for HIV back in early 2000. I had been participating in risky behavior and having multiple sex partners. I didn't talk about HIV, and neither did my sex partners.

I went through a five year pattern of this type of behavior and assumed I was very likely positive for HIV, but I was scared to death to get a blood test and hear the results. Back then there was no instant testing. Usually you had your blood drawn and find out the results in 2 weeks. Two weeks went by and I just couldn't find the strength to pick up the phone and make an appointment to see my physician. I waited another two weeks and decided I would never call and they would forget that I had been tested. I was wrong about that thought. After about six weeks my doctor called me at work and asked if we could talk. I said yes and walked to a corner of the office. Finally I heard the words I had been dreading. "You are HIV positive." My doctor asked me why I seemed to not be reacting to this diagnosis. I stood in my safe corner and felt my stomach drop. It was not a total surprise to me. I told my doctor that I had been meaning to call, but just kept forgetting. He told me I needed to make an appointment so we could discuss my viral and t-cell numbers. After hanging up, I slowly walked back to my desk and a close friend who sat close by, looked over at me and signaled a "what's wrong?" expression. We met outside on Geary Street and I told him I was HIV+. He had been positive for over ten years himself and knew the routine of checking on his disease by quarterly labs. He looked at me and said, "You're so stupid. You are in your 40's and dodged the virus from the 80's and all throughout the 90's." I said I knew I had been living a risky lifestyle and I was to blame. He told me he was mad at me and to know from this point on, my life would never be the same. He was right. I had to take drugs that were very hard on the body with terrible side-effects and had to go in every 4 months to have my vein poked by a needle. I hate needles.

I told no one else and then it became impossible to maintain an 8+ hour a day job. I was fatigued and suffered diarrhea from the medications I was taking. I grew depressed and feared how I would manage quitting my job and paying rent, plus buying the drugs without my employers insurance. Thankfully, San Francisco has a great resource for people with HIV/AIDS called Positive Resource Center. I went down and the case managers and lawyers helped me with my disability insurance and getting myself started on Medicare and Medi-CAL. All this was overwhelming, but they held my hand and guided me through the process.

Today, I have good health and security with SSDI. I occasionally have questions involving the new Affordable Healthcare Act, but PRC taught me the ropes of getting the answers I needed.

I never saw the actual HIV diagnosis report. I still didn't want to see the words, "Results: HIV Positive." I have had bouts of deep depression in which I have tried to do self-induced harm to my health by not taking my pills and my viral load spiking from undetectable to 500,000 copy cells. I've had stern lectures by my doctor to not do this type of acting out. I am not perfect in keeping my health the best I can, but I am alive. Yeah, I am still alive, but my life changed forever.

You're not going to die.

Bridgette Picou

You're not going to die.

The good news is you're not going to die.

You are going to be just fine.

As long as you realize you're not going to die.

People can live long healthy lives with HIV.

You can survive this like the millions before you.

In one way or another in various tones from forced to cheer to seriousness, at four out of five of my initial appointments after learning that I had HIV, someone made it a point to tell me that I wasn't going to die. People who were trying to give me resources made sure to remind me I wasn't going to die, and that I was looking at a very different disease than some years ago. I was told about medications that would not only help me live longer, but that were kinder, gentler medications than ones from past years. Rather than finding that comforting, it actually only served to heighten my anxiety and worry me more. If someone is trying so hard to convince you of something might the opposite actually be true? Are they trying to convince you or themselves? Who the hell lives a fulfilling life worried about not dying? I've always believed that if something was a fact, or true, I didn't need to spend a lot of time trying to convince anyone of it. It just IS. You can believe it or not.

Let's say I believed them. I'm not going to die, but even if I take you at your word, how am I supposed to live? No one was telling me that. Other than to tell me to take my medication every day, no one was going out of their way to tell me how to LIVE with HIV. I have always been a person that believed life is not just meant to be survived or endured. I'm not going to die but how do I do daily life? Please, do tell, how exactly is everything going to be just fine? I have this... this...what? Virus? Condition? Disease? If I can't even decide what to call it, how do I live with it? How do I thrive? Was someone going to tell me how not to die a little everyday living with uncertainty and a vague sense of shame? Somehow, this idea of "not dying" wasn't comforting in light of figuring out how to function with fear and social stigma. I still knew people that were worried about getting AIDS from kissing, let alone understanding the difference between HIV and AIDS. How do I live with that?

You know how you get an idea in your head and can't get it out? Sometimes its anxiety manifesting. Sometimes it's there as a distraction from a thing you don't want to deal with on

a subconscious level. This concept of not dying vs. living became a combination of those two things. Anxiety as I tried to figure out the ins and outs of HIV as a disease and a distraction from actually dealing with having it. It was maddening and distracting. Gradually, I learned more about the how and what of HIV/AIDS. I started learning that how I felt about myself within my status had everything to do with how my loved ones and potential loved ones felt about my status. I was in the beginning stages of exploring who I was within my disease and process. Discovering what I was going to allow it to change about me. Shoring up the weak places I found, reveling in the strong, positive ones. I decided to go back to school and become a nurse. I got used to taking medications daily. I studied in school. I dealt with and got help for my depression. Started redirecting emotions and getting rid of guilt and shame. I was very busy not dying. At one point I had to change my HIV medications, and went through a stage where I felt resentful towards having to take pills every day to stay healthy. It felt like my pill was taunting me a little. "The good news is, as long as you take me you'll be just fine." Or "Take three every morning, and live a long healthy life." This was that reminder (as if I had forgotten), that I was not going to die. Thank goodness I got past that stage fairly quickly. Life was doing its thing. Ebbing and flowing. Bills still had to be paid. Relationships had to be navigated. People died, and babies were born. I started dating again. Like a lot of people, I forgot to go to the grocery store and occasionally only washed one sock when doing laundry. I even got busy enough to forget to be distracted by not dying.

One day, I was talking to a patient. He was newly diagnosed, and I was trying to encourage him, and let him know he was going to be okay. I made it a point once I became a nurse and starting working with HIV patients to not say "You aren't going to die". I always express the sentiment, but I don't use those words. It gets tricky. I don't disclose my status to everyone. Not out of shame, just because not everyone needs to know, or it's not appropriate for them to know. However, when I feel like it matters or a person needs to hear it, I disclose a bit of my journey, sharing where I am with my status. In this particular case, he was crying and he said to me "How am I supposed to live?" In that moment, without fanfare and horns, without lightning or rainbows, I realized you just live. I had been living for quite some time without worrying about my HIV. I was just living life. Once I educated myself on managing my status, and more importantly realized I was still me, I forgot to live worried about trying not to die. No tricks, no gimmicks, no blueprint. That's what I told him. What I would say to you. Remember who you are, or figure out who you want to be. Take care of your body and love yourself. Know that how you feel about yourself, will affect how others feel about you. Not only are you not going to die, you can live amazingly well.

Medical

Inflammation

Ken Lichtenstein, M.D.

Inflammation is the activation of immune cells with the production of molecules (cytokines) that stimulate activation of more immune cells in response to an infecting organism or other stimuli that are perceived as “foreign” to the body’s tissues. The inflammation is terminated when the organism or foreign protein has been eradicated. At that time, the activated cells are programmed to die (apoptosis) and be replaced by new immune cells. The loss of CD4 cells (T-cells) in advanced AIDS is, in part, due to apoptosis at a faster rate than the replacement of T-cells plus destruction of the lymphatic system that harbors these cells.

With HIV infection, there is chronic inflammation due to continuous activation of the immune system. Treatment with antiretroviral medications reduces the level of chronic inflammation and permits repletion of T-cells, but it continues to persist. Chronic inflammation in HIV infection has been the underlying process driving many antiretroviral drug side effects as well as the higher incidence of age-related illnesses (co-morbidities) in HIV-infected individuals.

Examples of drug related side effects include peripheral neuropathy, anemia, and some forms of kidney failure. In these situations, the active forms of drugs were elevated to toxic concentrations by high levels of inflammation. In addition, those individuals with advanced AIDS had exhausted their immune systems. When antiretroviral drugs were introduced and the immune system began to recover, it became immediately activated with an enhanced inflammatory response to the virus and other acquired opportunistic organisms resulting in the Immune Reconstitution Inflammatory Syndrome (IRIS). IRIS resulted in symptomatic infections (fever, swelling, fluid in the lungs, etc) rather than dormant, asymptomatic infections. This response is also likely one of several processes (e.g. increasing age, medications, and genetics) that resulted in lipodystrophy. Since HIV infection is being diagnosed earlier in its course and treatment is started before depletion of the immune system, IRIS and all of its complications is now, thankfully, a rare event.

As part of the normal aging process, the levels of chronic inflammation increase. Most of the diseases of aging are driven by chronic inflammation. These co-morbidities include cardiovascular disease, osteoporosis, kidney and liver failure, and several cancers. Adipose

tissue (fat) also contributes to chronic inflammation because it is the second most inflammatory tissue in the body next to lymphatic tissue.

Although we don't yet have specific medications to regulate or control chronic inflammation in individuals infected with HIV, several studies have shown a reduction in markers of inflammation when body weight is reduced to ideal body weight (a body mass index or BMI of 20-25). Other studies have demonstrated that cardiovascular exercise will also reduce markers of inflammation. The American Heart Association recommends at least 40 minutes of moderate to brisk exercise 3 times a week. Finally, cigarette smoking not only increases inflammation but introduces carcinogens into the body. It has been shown that HIV infection plus smoking will shorten an individual's lifespan by 12 years.

Therefore, for the HIV-infected population, achieving or maintaining a normal body mass index, exercising, not smoking, and avoidance of most recreational drugs and excess alcohol consumption can contribute to a healthy quality of life with greater longevity.

Letter to a Physician

"Several years ago I complained that after meals I had an unusual response of extreme fatigue. The doctor did usual blood work but nothing stood out. He suggested a sleep study. I did their home version, where I wore a device that recorded me. Nothing conclusive came of that. He suggested I add otc essential enzymes to be taken with each meal, which I did. Life went on - nothing much changed, but I managed.

I complained to new doc of the same thing, along with a general lack of energy, but within 30 to 60 minutes of every meal I could barely hold my head up. I've since realized that I neglected to add a few other symptoms that happen at the same time. My throat constricts some and I get vaguely nauseous without production. My eyes become very light and correction sensitive, to the point of needing to take off my glasses and close my eyes. My pulse feels very rapid and I must lie down. Before I elaborated on the symptoms, he first thought of chronic fatigue. We tried Provigil. It seemed to work for a week or so, and then I was back to the same. Unbeknownst to us, the Provigil also appears to have nullified the action of my duloxetine, and I got progressively more depressed and experienced far more pain in my hands and feet. We cleared the Provigil and tried adding Adderall. It gave me energy at first, but I still had the symptoms post eating, and after a month mostly what I felt

was anxious, so I stopped and found a new psychiatrist who added Abilify to the duloxetine which has helped with depression, but that's a separate issue/story.

When I cleared the Adderall, we ordered a ct of my pelvis and abdomen and a glucose tolerance test. Both came back "normal". My lesson from the tests was that the glucose tolerance test seemed to mimic what happens to be after every meal- within 20 minutes of drinking the test drink I needed to be assisted to recliner, have the lights turned off and left to rest for nearly an hour. While the test was normal they said, to me it highlighted my 3 times a day life.

Back in January we also ordered an overnight sleep test at the sleep center. When we filled out the paperwork, my partner and I determined (without any medical knowledge of course) that sleep apnea is highly unlikely.

Two weeks ago when I went in the doc decided I should see a gastroenterologist. Her office called yesterday and scheduled me for May. It seems a long time.

Does this pattern of symptoms leap out at you as anything you've seen? Do you have any questions?

One other thing, possibly unrelated - my rheumatologist has been puzzling for over a year at the elevated level of ammonia in my blood. He diagnosed and is treating me for Reactive Arthritis.

That's all I've got - thanks very much for reading."

Cognitive & Co-morbid Challenges of HIV

RB

March 13 1989 I was diagnosed. My partner drugged me stupid while he drained my bank account. He committed suicide because he didn't want to die a horrible death from AIDS.

I was diagnosed with major depression. I took Prozac til it stopped working, by then I had learned how to cope. It took me 7 years of therapy and almost ten years of pharmaceuticals to get my life back.

1998 My t-cells were at a low of 7. I finally agreed to take the new medications.

In the year 2000 I had just lost my dogs, I figured my chances of not losing them were better than actual friends...they gave me good reason to carry on. In San Francisco, I'd lost almost 15 friends and close allies. Corky died after Thanksgiving, Ben after Christmas.

January 2001 I hadn't felt at all well. I've always felt lucky. No side effects. No real illnesses other than colds but now fatigue was my middle name. My Hepatitis C co-infection was still dormant. So I just reasoned it was naturally my HIV.

I was replacing the tile floor in my bathroom and couldn't figure out why I had such a foggy mind. My reasoning was so off. I decided to take a nap and return to it refreshed. I was lying next to my bedroom window because I like the cool breezes. Suddenly I felt horrible anxiety. A sense of danger of something outside. I went to turn over and move. That's when I realized I wasn't in control of my body. I lay there frozen but wide awake, unable to speak. I lay there all afternoon unable to call for help. Thank God for my open window and my nosy neighbors.

Rushed to the nearest hospital, I was mis-diagnosed with end stage of AIDS. Hospice was called. By next day I was sitting up in the chair next to hospital bed. My nurse informed me my blood sugar was over 700 and I had almost died while in a diabetic coma. The truth was they assumed the worst because I was a gay HIV/AIDS patient.

Mesa Hospital made a major mistake. The following week they were closed down. Evidently I wasn't their only mistake. They told me to go to my library and learn how to take care of myself.

This March is my twenty-ninth anniversary living with HIV/AIDS. Seventeen of those years I've lived with diabetes.

I've learned I can't control what I can't control.

Yes, my numbers are good. Yes, I'm on insulin. But still my sugars change change without notice.

I live on a narrow edge.

Diabetes doesn't always show itself on the outside. Normally the public assumes just overweight folk are the target. But more often than not heredity, medication and today's unhealthy processed foods are the culprits. The diabetes shows it head in different ways. Usually when I least expect it.

Equilibrium issues, confusion or foggy brain seem the most common. Memory issues seem an everyday occurrence. Not able to remember names & places you know continues to frustrate me.

Sexual dysfunction is my norm. But at 64 years of age I believe some of it may be normal aging.

The most concerning side effects for me have always been fatigue and neuropathy- pain in my legs and feet. Also the fear of losing them if not cared for correctly.

It is also responsible for most of my equilibrium issues. Medication usually works pretty well at controlling the pain, and pins & needles. Just finding the one that works for me, seems to be the issue that we all share.

2017 was the year my Hepatitis C reappeared. A routine Drs. Appointment turned into a week stay at Eisenhower Hospital. They thought it something else as 5 doctors rushed to diagnose the problem. Two exploratory surgeries canceled when they realized it may be the liver. I'd put off the liver biopsies too many years for the fear of the ice pick! How many times has the fear been worse than the actual procedure. Too many.

Being diagnosed was the beginning of the end. After four weeks of wrangling with insurance I was approved for Harvoni. At \$1000 a pop everyday for 12 weeks, I could have bought a permanent abode. After nearly a year and a half, the results are quite amazing! Fatigue is at least cut in half from where I was. My strength surprises me. I use to wear myself out just doing a load of laundry, of course a flight of stairs was part of it.

Now I have no problems carrying my groceries from the car to the house. I'd usually have to rest between runs and it would be quite the chore. Sweeping & washing my floors, it took hours. Trying to stand up off the floor, took too much of my energy. Then, I felt like I was 84.

Today I feel like a miracle. I still rest a lot. Take naps. But when I'm exerting energy, I can do the job! No more straining to get it done. I am cured of Hepatitis C and I am very thankful to medical science and the doctors who are of service.

I have volunteered most of my adult life. It gives me purpose. I believe it has the power to heal oneself. Giving and sharing your time & energy to another helps others but the real work is, it heals you.

Food

Many of us have relied on others to manage the challenges of living with HIV. Food is necessary to live, but can be so much more. It can nourish the soul as well as body, help a person to feel cared for. Project Open Hand in San Francisco started delivering meals to people in 1985, regardless of ability to pay, when they were too ill to prepare food for themselves. It was a small moment of human contact each evening. We each got to know the

people who delivered for our area. Years later, we remember the good feelings from them, the compassion and friendliness. Many days they were the only people we saw. ej

<https://www.openhand.org/about-us/history>

https://www.washingtonpost.com/news/wonk/wp/2018/04/02/study-suggests-home-delivered-meals-might-reduce-er-visits/?utm_term=.d7ed7db85646

Housing

Housing for long-term survivors with HIV can be a challenge for many reasons. It is crucial to well-being, and to controlling the spread of HIV. AIDS United has for some years now lobbied with the slogan “Housing is Healthcare.” Indeed it is. People are far more likely to stay on their medications, in care, to get rest and food, when they are housed. ej

R. C. Doyle

Like many long-term survivors, I moved to the Coachella Valley because it is an accepting community with good healthcare, good climate and a demographic favoring older gay men. I left the Pacific Northwest because of the high cost of living in Seattle and a lack of assistance in paying for my HIV medications. I was priced out of my home.

At first impression, housing seemed affordable and well placed to access services and care. But like nearly every place in California, the cost of housing is rising in all categories. The Coachella Valley Association of Governments expects the population of the Coachella Valley to double by 2035 to nearly 800,000 residents.

The pressures of increased population as well as the desirability of living in the valley is forcing the cost of housing of all types to rise making housing an unpredictable expense for people like me who live on a fixed income. The impact can be seen already with long-term survivors moving out of the west end of the valley into less expensive communities to the east.

Added to this problem is the lack of new affordable housing, it has been several years since any new housing has been constructed in the west end of the valley for people on disability with fixed incomes and persons who work low wage jobs either full or part-time. The west end of the valley has a prospering tourist and vacation industry that pays low hourly wages. The valley as a whole lacks diversity in employment opportunities, jobs where higher wages would be paid so that employees would have greater choice in where they lived in the valley.

HUD (Department of Housing and Urban Development) estimates there are slightly more than 1,000 apartments in the city of Palm Springs that qualify for Section 8, HOPWA (Housing Opportunities for People with AIDS) or other federal programs. Access to these apartments is determined by income. Unfortunately, a large number of long-term survivors exceed the income limit and do not qualify for assistance. Some new low-income housing is planned for Palm Springs but what is in the pipeline won't address all of the need for affordable housing.

The long-term survivors who do not qualify for housing assistance must compete in an increasingly competitive housing market in which their fixed incomes limit their ability to afford housing. Long waiting lists are nearly universal for the limited number of HUD apartments.

Some long-term survivors who were able to work uninterrupted by HIV disability or have other sources of income have been able to purchase homes or keep up with rent increases and while they are less affected than others they too must deal with rising costs related to maintaining their homes and paying expenses such as state and local taxes as well as the uncertainties of aging with HIV.

The federal government recognizes that stable housing is one of the cornerstones of being successful in living with HIV. The increased costs of housing, the existing limited supply of low income housing and the lack of plans for a substantial increase in housing of all types is creating instability for many long-term survivors. Unless something is done very soon this situation will only get worse.

Added to housing instability is the growing need for care services in the home; assisted living facilities that understand the rights and needs of the LGBTQ community; lack of traditional family-based support systems; loss of family and friends as long-term survivors live longer lives as well as the unpredictability of the impact of aging with HIV.

All of these factors increase the potential for instability which can lead to a failure to be able to maintain a stable household and meet the demands of living with HIV. When you consider the large population of aging long-term survivors in the Coachella Valley the potential is there for crisis in the lives of the survivors.

Sadly, it is very possible that the next group of persons who will find themselves homeless will be those long-term survivors who can no longer compete in the housing market, along with those waiting on lists for access to affordable housing. Added to the loss of stable housing will be the other factors related to aging with HIV as a LGBTQ person. Unfortunately, it doesn't appear that enough is being done to address housing or the other issues listed above which are part of surviving long term with HIV.

Resiliencies

Resiliencies are behaviors that help us get through life with (or without) HIV. Sometimes they allow us merely to survive, then having survived, they can help us to thrive. They come in many forms, and vary with the individual. There are recurrent themes: Friends, family, supportive health care often including non-Western approaches. Faith of whatever stripe. Contemplation. The gym. Creating art. Motorcycling. These are things we love that give us strength. I asked a friend of several decades to write briefly about the importance of his family. More about resiliences can be found in the online version of this manual at lkaps.org. Ron Stall, PhD., has kindly allowed use of his pioneering work on this topic. ej

HIV and Family

Doc Duhon

I remember feeling body slammed when I read the report from the insurance company denying me life insurance. I had tested positive for HIV. After testing negative at Health Center Number One in San Francisco, I believed it was safe to take the insurance company's blood test. Apparently, in the intervening five weeks, I had sero-converted. It was a time before effective meds. Treatment for HIV was for symptoms only and the presence of the virus was considered an automatic death sentence. I was in a daze for weeks, not knowing where to turn.

I have a loving family. They are good people. However, the stigma attached to HIV at that time was profound. My parents had long been fearful about the possibility that I might sero-convert. My siblings were likewise afraid. The information then available to the general public was limited and sensationalistic. As a result, I chose to forgo sharing my sero-status with my family of origin. Complicating my situation further, I was the custodial parent of a preteen daughter. My daughter was a happy child. Her one great fear in life was that she would be forced by circumstance to live with her mother. As a small girl, she had fretted every time I was away on business, afraid that something might happen to me. I decided that I would withhold the information about my sero-status from her until she was older or until faced with the necessity of telling her due to illness.

So where do you turn when you are faced with your own mortality and traditional support systems fail you? For me, it was to my community. They became my family of the heart: close friends, AIDS activists, people in my recovery community, brothers and sisters of the leather

community, and my partner. They were already the foundation of my social and personal identity and so became my chosen family in a way my blood family could not. At a time when they were literally fighting for their own lives, my chosen family circled around me to provide love, emotional support, sounding boards, and mentorship. They helped guide me as I found my way through mountains of medical information. They buoyed my spirits when it became obvious, a few years into my diagnosis, that I was a “rapid progressor,” somebody who would likely not make the average of 11.3 years from infection to death.

Many in my circle passed during those years. The rest of us drew tighter in order to provide one-another stronger support – out of both love and necessity. Men and women, both HIV positive and negative, stood together to fight for recognition, funding, research, and medicines. We tended our ill, and buried our dead. Our work and mutual support gave us focus in dark times and brought us together as a family like nothing else could.

My immune system began to show the initial signs that it was failing at the same time that the test trails for the first protease inhibitors got underway. I was lucky enough to be included as a participant in the Crixivan study. My body responded incredibly quickly to this med and, while my CD4 T-Cells took decades to return to a close-to-normal count, my detectable viral load disappeared seemingly overnight.

It was early 1996 and well informed members the general public had begun to understand the facts about transmission. The stigma associated with the virus had waned a bit among this group, my family included. With an undetectable viral load and the possibility of living for a while, I told my daughter (then 16) and my family about my diagnosis. My daughter was sad and a bit angry that my partner and I had withheld my HIV status from her but acknowledged that knowing would have burdened her childhood with unnecessary fear. My birth family came to terms with my HIV status and eventually proved supportive, but by then the term family had come to have a much broader and deeper meaning for me. My family of the heart had supported and loved me through those fear-filled and tumultuous years as we nursed our sick, buried our dead, fought for our rights, and gave each other comfort. They had become part of my very being.

The relationships that formed during those years persist. We survived the dark years. We are the lucky ones who were strong enough to come back from the brink after the arrival of meds. We stay in touch and we are there for each other to this day. We are family and will always be, but developing these connections cannot be a thing of the past. Our community must continue to foster this caring spirit and we need grow these connections to provide family to all who desire it.

Calls for Research

Timothy Ray Brown's Tenth "Cure Birthday"

My name is Timothy Ray Brown. I am the first person in the world to be cured of HIV and hopefully not the last. In 2017, I celebrated the 10th-year anniversary of the bone marrow stem cell transplant that cured my HIV infection. Much has changed and much has stayed the same since that time. There have been both failures and successes in the search to cure HIV during the past 10 years. Challenges remain in the funding of innovative ideas, scientific research, and in the education of the public and the social roadblocks to finding a cure for HIV. Although I remain ever-optimistic that the scientific and medical communities will find a cure for HIV, if properly funded, I am still concerned about the general public opinion in support of this important work.

We recently had a close call with efforts to cap individual funding levels that would have crippled HIV Cure Research and the Delaney Cure Consortia.¹ However, a strong negative response to this cap, including an open letter from me to raise awareness of this issue, prevented this change.² Now that this catastrophe of funding has been averted, I see now how it happened in the first place—apathy in public opinion. Although I sometimes feel lost when I meet with scientists to discuss their research, I see their excitement and optimism at the progress being made toward a cure. We must protect this progress!

In the past 4 years, I have traveled the country and parts of the world challenged by HIV and have talked to medical scientists, activists, researchers, and people living with HIV (PLWHIV) about their hopes and concerns. As 2017 was my 10th-year anniversary of being cured of HIV, I had an exceptionally action-packed year. Because bone marrow stem cell transplants replace the entire immune system of the patient, thus making a person with a new immune system (almost a fully new person), each year that the patient survives after the transplant is a "birthday" worth celebrating. For this reason, I like to refer to my rebirth after being cured as my "cure birthday." I was able to officially celebrate this 10th birthday multiple times in 2017.

The most memorable celebration was in my birth city of Seattle. HIV activist, Michael Louella, along with his employers, "Defeat HIV" and Fred Hutch "Cures," invited me to a celebration where I received a cake to share. Delightfully, my partner, Tim, and my mother were able to attend. I was overjoyed that they could be there. A room full of HIV cure researchers also celebrated with me because they were there for a conference at Fred

Hutchinson Cancer Research Center happening the following couple of days. The day after the celebration, the conference on HIV cure started. Many ideas were presented. Since I am not a scientist, I often find it difficult to understand the presentations. The great thing about this conference was that each presenter added a “community slide” at the end of his or her presentation, which was a summary of each presentation for lay people like myself. The one presentation that I found the most promising was on combining CRISPR/Cas9 technology with some of the current ARVs.

I also attended multiple conferences including the 2017 International AIDS Society (IAS) meeting in Paris and the Reunion Project for activists and patients. I visited a few research centers such as Fred Hutchinson Cancer Research Center. A highlight of the year was a trip to South Africa with my partner Tim to share the message and importance for a cure for HIV. I had been invited to speak at the South African Infectious Disease Symposium in September. We had a couple of days to acclimate before I spoke. The day I arrived, a journalist from a major South African newspaper interviewed me. The article was published in the Sunday paper and raised awareness about the possibilities of a cure for HIV. People told me afterward that my speech went well, although I am always my worst critic. I always think I did poorly. The hotel was beautiful and it was easy to buy espresso there, which is always very important to me, particularly when I am having to think.

However, by Friday, we were ready to leave and happy to be picked up by a very bright and nice young man who took us to the Gugulethu Township in Cape Town. He and a clinic director gave us a tour of the Desmond Tutu Health Clinic there. Then I was asked to speak to the patients sitting in the waiting room. Most importantly, I had to make sure I refrained from presenting the patients false hope. Before I began, I made sure that they realized that my case only proves that HIV can be cured but that it was very difficult; I had come extremely near dying several times. Our driver translated from English into Xhosa, the language used by most black South Africans in Cape Town.

One of the directors explained that there is the health clinic and the HIV clinic. People requiring care from the HIV clinic generally do not want people to know because the township is small enough for other people to know and gossip about their business. There is still much stigma toward PLWHIV in South Africa even though the rate of those infected is very high there (estimated to be greater than 12% of the population).

After getting some lunch at a sandwich shop, we went to the headquarters of the Desmond Tutu HIV Foundation where we met Professor Linda Gail-Bekker, chief operating officer of the Foundation and president-elect of the IAS. Linda and I along with an HIV-positive South African woman, Nombeko, spoke to a group of mostly HIV-infected young people. Our presentations went over very well.

For the weekend, we went sightseeing, experiencing the beauty of the city and surroundings. A wonderful gay male couple hosted us in their nice condominium and made dinner for us Friday evening. We saw great views of the city and Atlantic Ocean from the base of Table Mountain and African penguins at a beach outside of the center on Saturday. Sunday we went to a gorgeous botanical garden and to a bird and wildlife sanctuary where we walked around a monkey cage with small monkeys that ran around and would jump up on us when we sat down. We ate at fantastic restaurants both Saturday and Sunday evenings. The restaurants were incredibly inexpensive and the food was delicious!

Late afternoon on Monday, we toured the HIV laboratories at the University of Cape Town and I did a couple of interviews for the student newspaper. Several HIV researchers and I spoke in front of university students, government healthcare officials, activists and patients. The last day, Tuesday, we visited downtown and the waterfront and then were taken to another township where we toured the Desmond Tutu HIV Centre's youth center where I spoke to the high school youth group. The full group of about 40 kids was divided into four groups and they came up with questions to ask me after I had given a speech to them. I enjoy talking with high school kids. These kids seemed more knowledgeable about HIV than the high school students I talk with in Riverside County in California, United States.

The entire experience in Cape Town, South Africa, was amazing. I felt that it was successful in giving my hosts what they wanted from me. I was able to give PLWHIV and their friends and families hope without giving them false hope. Furthermore, I think my story continues to be an inspiration to researchers including students and faculty at universities and perhaps pharmaceutical companies. Although our current U.S. President does not find that further HIV cure research is important enough to continue funding it, I am still playing my small role, doing what I can to make sure research continues until HIV can be cured in easier ways through the hard work of brilliant medical scientists.

In my "10th Cure Birthday" year, I also participated in the Steven Deeks San Francisco General Hospital's SCOPE study in an attempt to further answer the question of how I was cured. As it was explained to me, a procedure called leukapheresis was used to isolate cells from my blood that can harbor HIV. Leukapheresis is a laboratory procedure in which white blood cells are separated from the blood, without removing any red blood cells. It is a specific type of apheresis, the more general term for separating out one particular constituent of blood and returning the remainder to circulation (Wikipedia). I am hopeful that this experiment will bring us one step closer to a cure. Medical scientists dealing with my case are not really certain what actually cured me of HIV. I think it was the lack of CCR5 protein in the donor stem cells, but I am not a medical scientist so I realize I could be wrong. One medical scientist, Tim Henrich (known for his work on The Boston Patients),³ who is now at University of California, San Francisco (UCSF) and San Francisco General Hospital,

explained to my partner, Tim, and myself that this procedure should clear up this controversy as to why I am cured. They were planning to look specifically at CD32 cells. A 2017 article in the journal Nature suggested that these cells are a major hiding place for HIV. I have not seen any results yet. I think the most important thing is that I no longer have to take ARVs, that I am healthy and noninfectious. I take daily Truvada as PrEP to be certain that I do not contract HIV again. I am hoping to hear good results soon. I have learned many new things and remain confident in the scientific progress toward a cure.

Unfortunately, I learned a few things last year that I found disappointing. Michael Louella invited me to the Reunion Project, a conference for activists and patients. I participated in two HIV cure seminars. He started each seminar by asking the participants what an HIV cure means to them. The responses surprised me. Many suggested that a cure was accompanied by fear- fear about how they would support themselves if suddenly cured and cut off from current income and healthcare sources. It seemed to me that they felt that their lives were stable and predictable, if difficult, as things are now. I understand this unease and have had negative experiences myself. If a cure were found, then their lives would be upended and they would have to start all over again. The USA is not an easy place to do that. I told them I am grateful for my new lease on life- being happy, healthy, and noninfectious. In my Reunion Project presentations I mentioned that I had tried to get reduced housing costs in a HIV housing complex. Ironically, I was refused because I no longer have HIV. Furthermore, the main HIV organization in the Coachella Valley, where I reside, initially refused me membership- again, because I am cured. That has since changed and I am now a volunteer there. Everything worked out fine but I wanted to describe how I understand their fears, yet I argue that being cured of HIV definitely has advantages. I have made a life for myself despite my physical defects and disabilities.

The audience reaction was a disappointment to me because I thought everyone, particularly PLWHIV, would want HIV to be curable. I am in a group on Facebook called the “International place for people with HIV/AIDS, and the people who love us.” I always had the feeling from the members of that group that PLWHIV still want to be cured; that is however an international Facebook group and not specific to the United States. Furthermore, that group seems to want the HIV/AIDS crises to come to a final end. Despite this support for a cure, others remain skeptical. I was again disappointed when a friend asked why I was putting so much effort into making sure other people with HIV are cured. He told me that he did not understand why a cure was necessary because he was happy to take his ARVs and was doing just fine on them. That hurt my feelings. I have found this opinion growing among younger generations who do not know what it was like before. Of course, this attitude might “work” in the United States and most of Western Europe where ARVs are readily available and relatively affordable. What about all the PLWHIV outside the United States and Western Europe? I continue in my resolve to keep advocating for an HIV

cure by supporting medical researchers working to find cures for HIV and trying to give PLWHIV hope that an HIV cure is possible, while not necessarily easy. Especially given the current attacks on the integrity of the scientific research community, we all must actively support widespread public education and scientific and medical research to finally find a cure for HIV.

Reference

Hope TJ: Upcoming implementation of NIH funding caps invites researcher feedback. AIDS Res Hum Retroviruses

Growing Need to Revolutionize Clinical Research Enrollment Criteria for Aging People Living With HIV

By Carlos Martinez, MD, Nicolas Milligan, MD and Shayna Phillips

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As the percentage of older adults living with HIV continues to rise, physicians and health-care professionals are faced with new challenges. How are we going to treat advancing comorbidities that are the result of HIV or antiretroviral therapy? How are we going to treat new age-related conditions in the setting of HIV? Chronic diseases unrelated to HIV, and more a consequence of simply getting older, are becoming more common. Hypertension, diabetes mellitus, COPD, heart disease, and cancer are conditions growing in older HIV populations for which we have limited research data, a limited ability to initiate clinical trials, and a lack of evidence-based guidelines of management for our health care providers.

The medical and research communities are increasingly aware that well-designed research trials are needed to provide appropriate care specifically catered to this aging HIV+ population. Advancing HIV-associated comorbidities, polypharmacy and the problem of compounding medications, emerging chronic diseases that are new to HIV, and the lack of literature on these topics increase the challenge to our health care providers.

But just how do we initiate clinical trials, or gain acceptance into existing clinical trials, for a population that often has significant barriers to safety and inclusion? In trials for non-HIV specific disease it can be HIV or advanced age by itself that limits participation. Additionally, there is often a long list of strict inclusion and exclusion criteria which a person aging with HIV and often co-presenting cardiovascular disease, kidney problems, bone problems, or frailty (to name a few) will not be able to meet in order to qualify for acceptance into the trial.

The clinical research community has observed these growing developments and identified key areas for change. In order to properly address HIV and aging issues in a timely manner, it is important for the pharmaceutical research industry and HIV community to do their parts. A collaborative effort to challenge the current research standards will help our friends and patients gain access to innovative therapies, not only in HIV research, but also in new and emerging HIV and aging associated diseases. New clinical trials specific for aging HIV conditions have not yet gained the full support needed.

Gathering high-quality data for people with HIV and advancing age will not be easy and will require more time, more resources, and more oversight to renovate research standards and realign how patient safety is managed.

Scientists have already begun to debunk the age limits for clinical research trials. In the article “Elderly patients’ participation in clinical trials,” [{article link}](#) authors highlight how under-represented the older population is in research and how existing common barriers are not convincing reasons to exclude an older population from research. In fact, the USFDA and The International Conference of Harmonization (ICH) actually encourages researchers to eliminate upper age limit exclusion criteria and urges them to focus on new safety parameters in older populations. [{Click here FDA guidance}](#) or [{Click here ICH E7}](#) The ICH encourages inclusion of participants with concomitant illnesses to best capture data on multiple drug and disease interactions, improving its application in this population. In fact, if previous research enrolled participants within subcategories such as advanced age and/or HIV, the research communities could already have the needed data.

One area that highlights unacceptable restriction of people with HIV is cancer and cancer treatment research. Venturelli, Serena, et al., 2018, [{article link}](#) identified 56 multicenter open clinical trials involving lymphoma in the United Kingdom in January 2015. Oncological trials in this area are essential since PLWH have an increased risk of non-hodgkin and Hodgkin lymphomas. The findings were alarming because 70% of the open clinical trials excluded PLWH. Furthermore, they found no scientific or safety justification for this type of exclusion criteria. In this same report, it was mentioned that the US National Cancer Institute tried to regulate cancer-related studies by stating, “individuals known to be HIV-positive should not be arbitrarily excluded from participation in clinical cancer treatment

trials” and justifiable scientific rational needs to be specified for excluding PLWH. One actively recruiting clinical trial in the US for tandem stem cell transplantation for Non-Hodgkin’s lymphoma, {study link} excludes subjects >70 years old and subjects that have an HIV diagnosis, but a rationale was given for the latter stating that this population had a higher risk of opportunistic infections and significant hematological changes.

Other scientific justifications that have been reported to exclude PLWH is a study performed by Perez-Matute, P. et al, 2013. {study link} It stated that mitochondrial disorders are some of the many issues faced by PLWH. The mitochondria are fundamental structures in a healthy cell, producing cellular energy via oxidative phosphorylation, and are responsible for the process of programmed cell death. Mitochondrial disorders lead to premature aging and metabolic disturbances that have repercussions on the heart, nerves, muscles, pancreas, kidneys, and liver. Several factors causing mitochondrial damage have been reported including aging, infections, and certain antiretroviral drugs. Aging PLWH who have been exposed to multiple ARV therapies such as NRTIs and PIs are at particular risk. Past studies have reported significant mitochondrial toxicity with these HIV ARV drug classes. With this knowledge, it can be speculated that the exclusion criteria for PLWH older than 65 years old may affect the data collected, adverse events may be reported at a higher frequency, and the pharmacokinetics and pharmacodynamics of the investigational drug may be miscalculated.

With regulatory guidance favoring the elimination of upper age-limit criteria and encouraging the inclusion of study participants with additional illnesses within Phase 2/3b and Phase 3 studies, an aging HIV population provides a novel arena for new clinical research. By sharing this responsibility, academia and pharmaceutical research can collect larger volumes of information designed to improve a vast array of conditions developing in this population. We are already noticing a less restrictive age limit in HIV clinical trials and the National Comprehensive Cancer Network (NCCN) just released a new guideline addressing their intention “to help make sure (PLWH) who are diagnosed with cancer receive safe, necessary treatment ... to cancer research” {NCCN article link}. However, there is still room for improvement. Greater strides must be taken to revolutionize enrollment criteria to ensure those aging with HIV who need access to innovative research therapies gain it, not only within HIV research. Eliminating barriers will increase opportunity for more individualized enrollment based on the combined medical assessment and knowledge of the sponsors and principal investigators, fostering a safe environment for subjects to receive necessary treatments. It will allow additional data to be analyzed applicable to a larger scale population, promoting the development of a broader body of knowledge that can guide treatment decisions for our health care providers and PLWH.

