



Aging With HIV

Long-term survivors
persevere against
the virus



Pat Kelly

What is it like to start an infused treatment for HIV?

Discover Nelson's Trogarzo[®] Experience

This is the experience of one patient and may be not representative of all Trogarzo[®] patients. Please find complete safety details at the end of the article. For more information about Trogarzo[®] go to Trogarzo.com.

Hi Nelson, could you introduce yourself?

My name is Nelson Vergel, and I live in Houston. I have been HIV positive for over 34 years. I have been a long-term survivor. I am also a long-term HIV activist and patient. I run a non-profit call Program for Wellness Restoration, and the website is powerusa.org.

How has your journey with HIV been?

Well, most of us in HIV that have been long-term survivors are long-term survivors for a reason.

For some, it is luck, but for most of us, it is because we are exercising, trying to eat well and trying to manage stress. Most of long-term survivors have been positive for over 25 years and have developed many resilience skills.

And I'm one of them. Ever since I found out that I was HIV+ when I was in my early twenties, I started to exercise. I knew I was in control of that and of eating better and trying to avoid unintentional weight loss. That helped me live a better life, but with detectable viral load, I knew there was nothing I could do back then to avoid eventually getting sick and dying.

Would you tell us more about how you eventually started treatment with Trogarzo (ibalizumab-uiyk)?

My doctor told me there was a new option in a study. I needed a new option because I was struggling with getting my viral load undetectable for 27 years, and my T cells were already dropping. I was in constant worry, so I jumped at the opportunity.



I started Trogarzo six and a half years ago, as part of a study, a phase 2 b study, here in Houston.

I'm a director of a non-profit called Program for Wellness Restoration, and I lectured around the country every week about health. I was the only one or one of the few in the room that was still worrying about viral load. So that was the irony of everything. I was taking care of myself by taking all my pills. I never had a problem with adherence, and yet I was struggling still with controlling my viral load. We now know that we need two to three active agents to control our virus.

I had the luck to have two other active agents that could be combined with Trogarzo. That regimen did it.

Within two months, for the first time I had undetected viral load. I didn't believe it at first because you never know it's always like: "Well, how long is this going to last? And don't get too cocky!" So you get excited but not really.

But as months went by, I started feeling more secure that maybe I wasn't going to die of this thing and now we're talking six and a half years, and I'm like: "Wow!"

My life has changed dramatically because, for the first time I have had an undetectable HIV viral load for over six years now.

So, I was able to restart my life again. I had put my life on hold for easily 27 years doing some non-profit work, educational work, but now I am running two businesses plus my non-profit. I don't have that anxiety that I used to have; I had constant daily worry about what was going to hit me next.

So, Trogarzo gave me that peace of mind.

What do you know about Trogarzo?

It is a monoclonal antibody, very different from all the oral medications. It's the first long-acting medication that lasts that long in the body.

Actually, it works on a receptor on the CD4 cell.

"The big difference about Trogarzo is the fact that it is a new class of medication."

It's not a drug that works by itself; no HIV drugs do. It needs a combination of other active agents.

I get it via an IV every two weeks. I have done this 156 times which hasn't been a problem for me. It doesn't hurt really. When the drug goes through your veins, it's like saline. I do not feel any difference. I never had a bruise.

There are really no side effects. Basically, the drug is like saline with no gut side effects, no fatigue, no flushing, nothing! (experience may vary from patients to patients, please read complete safety information at the end of the interview).

So, yeah, I am willing to keep doing this drug until I die because it is keeping me here and healthy. I am working out. I take care of myself. But nothing you do while you have detectable viral load really will save your life. You can delay

your death, but it does only controlling your virus, and taking care of yourself can save your life.

As an activist, I follow this field very closely. I was thrilled to see this drug finally approved. I want people to have access to it because it changed my health; it changed my outlook on life. So that's why I tell physicians: "Please don't make assumptions about what the patient wants or not. Don't make assumptions about the fact that we are adhering to our medications or not".

What are the benefits for the patient in its daily life?

Well, for me, the most significant benefit, the biggest change in my life is removing the fear of death. I know everybody is afraid to die, the HIV negative, positive, cancer or not or whatever. But we have a daily conscious presence of death and illness in HIV when our viral load is not undetectable.

All of us, I've been around for so many years as an activist, as an educator and all of us, when the viral load is not undetectable, we all have this anxiety inside. Some of us suppress it; some of us don't. Some of us live with this anxiety and depression.

Once you get a new drug like Trogarzo, you remove that anxiety and then people, like me, start being productive and happier. If you are not worrying so much about being sick, you have a lot more time. I have a lot more time to spend, to be present with my family and develop relationships.

Say that you've always had this fear and then after a few months of having undetected viral load, you realize "Oh my god, I have this much freer mental space to do a feast (laugh) with my life rather than worrying about my next illness, my next challenge."

I'm looking forward to the day when all patients like me know all of their options and make their own choices.

Can you walk us through how you integrate Trogarzo in your routine?

Every two weeks, I leave the house at around 10:15. I have my appointment at 11. They call me in and by 11:30 I'm gone. I'm going back home and work.

So basically, it takes an hour and a half of my time every two weeks. That's a very low price to pay for surviving!

For me, it's not a big deal. I am looking forward to seeing the nurses as I get to chat a little bit. Sometimes, I bring my laptop or my cell phone.

"I am able to see my doctor more frequently because of that, and that actually has a lot of advantages as you get even better care. Even when you have the flu or cold you get medication faster and treatment faster because you see your doctor or the nurse more frequently."

The only thing that may be a problem is traveling overseas for more than two weeks but I have managed over six and a half years. I have travelled. I take 13 days vacations, and that's fine. I mean, nobody can really afford any more than that (laugh), so it's not inconvenient at all.

What would you say to somebody who is hesitating to prescribe or take that treatment?

Well, some physicians may have some reservations about prescribing a medication that is provided by intravenous administration because they assume that a patient may not like it or that it may be too much trouble.

But I think those are assumptions and you have to be careful because some of us, we want to be asked.

"So, all of us as patients, we deserve to be provided all the options, all the menu in front of us and allow us to make the decision. A physician should not be deciding for us when it comes to assuming that an IV is too much trouble for us, ask us."

I would say most patients like me want to live. Most patients like me don't want to worry about their health. So, when there's an option that can do that, in combination with other active agents, then we should be provided the option. It's up to us whether to say yes or no.

INDICATION:

TROGARZO[®], in combination with other antiretroviral(s), is indicated for the treatment of human immunodeficiency virus type 1 (HIV-1) infection in heavily treatment-experienced adults with multidrug resistant HIV-1 infection failing their current antiretroviral regimen.

IMPORTANT SAFETY INFORMATION:

Before you receive TROGARZO[®] (ibalizumab-uiyk) Tell your healthcare provider about all of your medical conditions, including if you are:

- Pregnant or planning to become pregnant. It is not known if TROGARZO[®] may harm your unborn baby. Tell your healthcare provider if you become pregnant during treatment with TROGARZO[®].
- Breastfeeding or planning to breastfeed. Do not breastfeed if you are receiving TROGARZO[®] or have HIV-1. Talk with your healthcare provider about the best way to feed your baby during treatment.

Also tell your healthcare provider about all the medicines you take, including all prescription and over-the-counter medicines, vitamins and herbal supplements.

Possible side effects of TROGARZO[®]

The most common side effects of TROGARZO[®] include:

- Diarrhea
- Dizziness
- Nausea
- Rash

TROGARZO[®] may cause serious side effects, including changes in your immune system.

Immune Reconstitution Inflammatory Syndrome is a side effect that can happen when you start taking HIV medicines. Your immune system might get stronger and begin to fight infections that have been hidden in your body for a long time. This may result in an inflammatory response which may require further evaluation and treatment. Tell your healthcare provider right away if you experience any new symptoms after starting TROGARZO[®].

Tell your healthcare provider if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of TROGARZO[®].

For more information or medical advice about side effects, ask your healthcare provider. You may report side effects to the FDA at 1-800-FDA-1088 or the THERA patient support[™] program at 1-833-238-4372.

For full product information go to trogarzo.com.

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Pat Kelly has been living with HIV for more than three decades.



Living to Tell

Having learned to cope, connect and dream again, long-term survivors aging with HIV prove they're resilient.

By Tim Murphy

In early August 2019, Pat Kelly, of Orangeburg, South Carolina, was busy packing for a trip to Las Vegas. It would entail shopping, a visit to the Hoover Dam and a night out to see comedian Eddie Griffin. She would be one of a group of friends—all women living with HIV—making the trip, and, most important, it would mark her 65th birthday. “I never thought I would make it this far,” she says.

Tested for HIV without her consent and diagnosed positive in 1985 while serving one of several drug-related prison sentences, Kelly has now been out of prison and drug-free for two decades and has lived with the virus for nearly 35 years. That makes her one of the roughly 50,000 Americans commonly referred to as long-term survivors of HIV.

These folks were diagnosed with HIV before 1996, the year that effective treatment emerged. Some of them were diagnosed (based on such metrics as low CD4 counts) even before the actual HIV test became available in 1985.

That means such individuals often endured many years without effective HIV treatment—not to mention they lived with the ever-present fear that they might die within months. No wonder, then, that many of them—like Kelly—consider it a near-miracle to still be alive.

Today, 47% of all Americans living with HIV are over 50; by 2030, it's estimated that figure will be 70%.

“I'm still here,” declares Kelly, the founder of A Family Affair, a South Carolina-based group that provides support and organizes knitting circles for women living with HIV and their families. “I'm surviving and thriving, the grandmother of eight and great-grandmother of seven!”

That's not to say the road to elderhood has been easy for Kelly—or for most long-term survivors. Many of them already identified as gay, people of color, people who use drugs, transgender or some combination thereof before they were diagnosed, meaning that being HIV positive in the 1980s and '90s only added to the stress, stigma and discrimination they might have already been experiencing.

Back then, knowing that one might die at any time as a result of an untreatable virus often contributed to years of depression and anxiety that sometimes manifested in escapist drinking or drug use, a tendency to isolate or an understandable indifference to one's well-being.

Further complicating matters was the sudden realization, in 1996, that one might live a long life—with all its accompanying bills, career challenges and other hassles—after all. That's a lot of emotional whiplash, especially for the many survivors who buried friends and lovers lost to the virus along the way.

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Health Concerns

Fast-forward to today, when it often seems that the culture has moved on and that—between pre-exposure prophylaxis (PrEP) to prevent HIV and effective treatment to keep people diagnosed with HIV healthy and unable to transmit the virus sexually—the virus just isn't a big deal anymore.

“We long-term survivors are facing invisibility,” says Tez Anderson, 60, who was diagnosed with HIV in 1986. He's the founder of the support group Let's Kick ASS (AIDS Survivor Syndrome). Started in San Francisco, where Anderson is based, the group now has chapters in other cities, including Palm Springs, a mecca for long-term survivors in the middle of the California desert.

“We're living in an age where we're taking on ending the epidemic and creating an AIDS-free generation, and most survivors I talk to feel like we're forgotten, relics of a bygone era who have no right to complain because now we've got good medications,” he says. But that attitude, he notes, denies the trauma that comes with having lived for years in a state of fear, uncertainty and depression.

Of course, the flip side to the challenges of being a long-term survivor is the tremendous coping skills that many have developed over the years. “For many years, I focused only on how many times I was sick or how many people I had lost, and I wasn't focusing on the fact that I always got up,” Anderson says. “Then I started thinking, ‘Maybe I'm resilient.’ And then that changed to ‘I am resilient.’”

Indeed, the landmark 2006 Research on Older Adults with HIV (ROAH) study, by the ACRIA Center on HIV and Aging at GMHC in New York City, found significant levels of depression, posttraumatic stress disorder (PTSD) and social isolation among its nearly 1,000 participants.

But, according to ROAH researcher Mark Brennan-Ing, PhD, both ROAH and its follow-up, a study of a smaller group of older San Franciscans living with HIV, found high levels of resilience, the ability acquired over decades of adversity—via community building—to roll with the punches and make the best of things.

For people with HIV, the very opportunity to age is cause for celebration—because it means today's treatments are allowing people to enjoy much longer lives. However, aging also brings much more complex challenges to those living with HIV compared with their peers without the virus.

Even well-treated HIV is associated with a number of age-related health conditions that can greatly interfere with well-being and physical function and tend to affect those with the virus at younger ages than the general population. In addition, antiretrovirals themselves are associated with various health risks, such as bone and kidney toxicities. The older drugs that many long-term survivors took during the 1980s and '90s were especially toxic.

The biggest health concerns as people with HIV age include cardiovascular disease, cancer, diabetes, chronic kidney disease, liver disease, arthritis, osteoporosis (bone loss) and cognitive decline.

A recent analysis found that between 2003 and 2013, as the U.S. HIV population aged, the prevalence of cardiovascular disease increased from 3% to 7%, while the proportion of people with kidney impairment rose from 5% to 11%. In the same period, the prevalence of osteoporosis increased from 5% to 6% and that of diabetes jumped from 9% to 19%.

The upside is that many of these health conditions need not be life-threatening or put a significant damper on quality of life. Conditions such as diabetes are manageable with proper care, including medical treatment and lifestyle changes such as diet and exercise.

Factors that likely drive such health problems include HIV itself, particularly the state of chronic inflammation that occurs with even well-treated virus. What's more, compared with the general population, people with HIV are more likely to have various risk factors linked with negative health outcomes, including smoking, hepatitis B and C viruses (HBV and HCV) and problems with drug and alcohol use.

A 2016 study found that lacking these key risk factors and having a CD4 count above 500 significantly narrowed the existing 14-year gap in life expectancy between people with and without HIV.

These days, people with HIV are more likely to die of smoking-related diseases than of virus-related causes. One recent study found that among those with well-controlled HIV, 25% of smokers and 30% of heavy smokers will die of lung cancer. Smoking, which drives harmful inflammation and immune-system dysregulation, is linked to emphysema and cardiovascular disease and is further associated with a host of other cancers, including those of the mouth and throat, liver, colon, kidney and cervix as well as leukemia.

The burden of cancer in the HIV population has been shifting away from AIDS-defining cancers and toward those associated with aging, most notably prostate and lung cancer. That said, the number of HIV-positive U.S. residents projected to receive a cancer diagnosis each year is expected to decline over the next decade, thanks in large part to continued reductions in AIDS-defining cancers.

Frailty, which is associated with cardiovascular disease, diabetes and death, is also a risk as people with HIV age—even before they reach age 65. Frailty is defined as having three of the following conditions: weak grip, slow gait speed on a four-meter walk, unintentional weight loss, exhaustion and limitations in the ability to engage in vigorous physical activity.

—Benjamin Ryan

“I walked into a focus group of older HIV-positive transgender folks the day after Trump was elected,” Brennan-Ing recalls. “They were scared, but many said, ‘We’ve been through so much worse—we’re going to get through this.’ They recognized the need to be there for one another and as a community.”

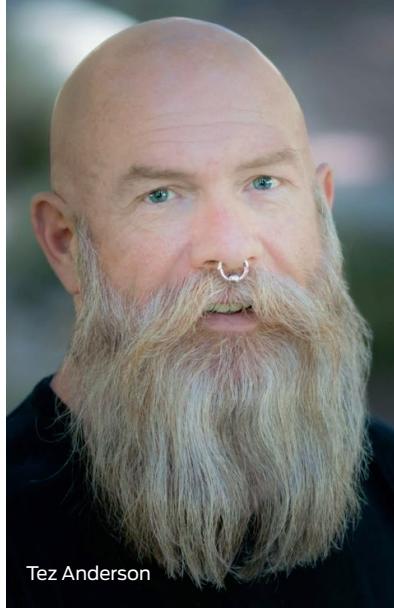
Aging is hard enough, but aging with longtime HIV can present special challenges. Folks with HIV have now lived long enough for researchers to observe that they tend to experience age-related health problems—such as bone weakening, muscle loss, cardiovascular disease and a host of cancers—a decade or more earlier than HIV-negative people, even if they are on HIV meds and have an undetectable viral load. In part, this is likely related to inflammation, the overactivation of the immune system as it constantly wages a battle against HIV.

“It’s also called ‘inflammaging,’” says Brennan-Ing. Nonetheless, he notes, “we still don’t have a great understanding of how HIV affects the aging body. People aging with HIV tend to blame everything [going wrong physically] on the HIV, whereas, in fact, the jury’s still out on that.”

One thing is certain: As with HIV-negative people, the six factors that play the biggest role in the health and longevity of folks with HIV are exercise, a healthy diet, not smoking, minimal alcohol intake, staying in regular medical care and social and emotional support. So it’s wiser to focus on what can be controlled than on what cannot.

The importance of quitting smoking cannot be overstated. HIV aside, it’s the single greatest factor in reducing or avoiding a variety of bad health outcomes, including heart disease and many kinds of cancer.

For Enrique Menendez, 54, a New York-based entertainer and casting director diagnosed with HIV in 1989, a major part of his acceptance that he was going to live longer than he thought was kicking the butts—in his case, with the help of a smoking-cessation drug. “I’ve had one cigarette in the last three months,” he says, “and I’m OK with that. I never planned for a future, and now I’m having one,



Tez Anderson

so it’s kind of weird to me.”

Beyond that, regular exercise (especially including some form of weights or resistance training) and a diet rich in fruits, vegetables, whole grains and lean protein (chicken, turkey and fish) and sparing in sugar, white flour and processed and fried foods are all essential. Menendez says he hits the gym three to five days a week, plays softball in a gay league and maximizes his intake of produce while minimizing white bread, rice and pasta.

For San Francisco’s Patti Radigan, 62, a part-time accounts payable manager diagnosed with HIV in 1992, her physical and mental health savior over the past 20 years has been yoga. Not just practicing it but also teaching it once weekly to other Bay Area HIV long-term survivors via Anderson’s Let’s Kick ASS network.

“I was so depressed, all by myself, and had toyed with the idea of suicide,” she says. “Then I went to Let’s Kick ASS and found there’s a community of people who felt the same way.” Her yoga classes began shortly after that. “It’s given me a purpose,” she says.

Long-term survivors often talk about the existential challenge of figuring out what to do with the rest of their lives once they realized they likely weren’t going to die anytime soon. For Billie Cooper, 61, a transgender San Franciscan diagnosed with AIDS in 1983, for many years, the answer came in the form of drugs.

“They helped me forget about the HIV, about my fear and stigma over my status,” she says. But, she continues,

“I got tired of having nothing—not having a life, not being a human, people calling me a drug addict and avoiding me, not taking care of myself.”

One morning in the early 2000s, while in her room in a single-room occupancy building in the Tenderloin District, she decided she’d had enough and checked herself into Walden House, a residential treatment center. There, she says, “I found my purpose: to be a productive human being, a Black trans woman whom people don’t look down on. I realized I had a voice and could make a difference.”

At the San Francisco AIDS Foundation, Cooper started TransLife, a support group for trans women. Now, she says, she derives strength and joy from “waking up in the morning and going to sleep at night knowing that if a trans woman needs help, she can come to me. I’m finally giving back.”

Before he started Let’s Kick ASS, Anderson, too, experienced the same crippling depression Radigan and Cooper describe. “I was angry, depressed and couldn’t sleep,” he says. “I wasn’t even doing drugs or drinking. Then I saw a TV show on PTSD and realized that I was dealing with trauma. I started looking into it, but I could find nothing about the trauma of surviving HIV for so long. So I coined the phrase ‘AIDS Survivor Syndrome,’ and talking to other long-term survivors, to a person, they had the same feelings as me.”

This all led to a town hall in San Francisco in September 2015 that launched Let’s Kick ASS and kick-started HIV Long-Term Survivors Awareness Day, observed every year on June 5. This awareness day follows in the footsteps of National HIV/AIDS and Aging Awareness Day, which was started in 2008 and is marked each year on September 18.

The group now has 2,700 members worldwide on its Facebook page and holds events all over the United States, Canada and Europe. Anderson says he wants to organize a conference in 2021.

Pat Kelly started A Family Affair to bring together all the long-term survivor women in her region for mutual support. “We’ve survived so much,” she says. “We all have a purpose.” ■

Health Tips



1. ADHERE TO YOUR MEDS

Taking your antiretrovirals as prescribed and maintaining an undetectable viral load not only help protect your immune system but also prevent transmission of the virus. What's more, fully suppressing HIV helps reduce chronic inflammation, which is associated with various negative health outcomes, such as cardiovascular disease.

For those who have multidrug-resistant HIV, the biweekly injectable antibody Trogarzo (ibalizumab) hit the market in 2018. In addition, the investigational attachment inhibitor fostemsavir recently performed well in a clinical trial.

2. QUIT SMOKING

Two medications can help you kick cigarettes to the curb: Chantix (varenicline) and Zyban (bupropion). Complementing such treatment with smoking-cessation behavioral counseling may boost your chances of success.



If you use e-cigarettes, it's important to note that there has been an outbreak of severe lung illness among users, including several deaths. The Centers for Disease Control and Prevention (CDC) has recommended that people abstain from vaping until investigations into the cause of the outbreak can be conducted. In particular, the CDC has advised against using bootleg vaping products, including those containing THC, the active ingredient in marijuana.



3. TREAT VIRAL HEPATITIS

Hepatitis B virus is treatable with medications such as Vemlidy (tenofovir alafenamide) and Baraclude (entecavir). Hepatitis C virus is now readily curable with a number of well-tolerated regimens—typically taken for just six to 12 weeks.

4. CONTROL ALCOHOL USE

Three or more daily drinks for women and four or more for men is considered heavy drinking and is associated with health problems.



For those with hep B or C, physicians tend to advise totally avoiding alcohol because of its potential harm to the liver.

Many heavy drinkers have benefited from programs such as Alcoholics Anonymous and SMART Recovery. In a recent study, monthly injections of extended-release naltrexone helped HIV-positive heavy drinkers cut back.

5. ABSTAIN FROM DRUGS

Three meds are available to help those with opioid use disorder: methadone, buprenorphine and naltrexone. Counseling and abstinence-based programs, such as Narcotics Anonymous, are other options.



6. GET REGULAR CHECKUPS

These days, keeping HIV well controlled may require seeing a doctor only twice per year. But as you age, you may need to see health care providers more frequently. Clinicians should assess cancer risk, cardiovascular disease, bone loss, mental health and quality of life; they should also provide any necessary vaccines, including boosters. Routine testing for hep B and C and for sexually transmitted infections is recommended.

7. SEE A GERIATRIC PHYSICIAN AND OTHER SPECIALISTS

Ideally, medical care for older people with HIV should involve a team that includes various specialists, including geriatricians. In particular, clinicians should assess physical function, frailty and nutrition and ask about falls, incontinence, sleep disorders, vision and hearing problems, confusion and aging-related muscle loss.



8. EAT WELL

Research involving HIV-negative people with a high risk for cardiovascular disease shows that the Mediterranean diet is associated with a lower risk of heart attack, stroke and death. Eating plenty of lean protein helps maintain muscle mass, while highly processed food is associated with a shorter life span.

9. EXERCISE

Maintaining a healthy body weight can help reduce the risk of cardiovascular disease, including by lowering blood pressure and preventing diabetes. A healthy weight also lowers cancer risk. Strength training can help ward off aging-related muscle decline. Aerobic exercise may mitigate depression in people with HIV. Staying active can also help prevent frailty.



10. MAINTAIN YOUR MENTAL HEALTH

Seeing a mental health professional and possibly taking medication to treat conditions such as depression and anxiety can help not only with mental health but also with overall health. Reducing social isolation is another vital step for people aging with HIV.

—Benjamin Ryan

“HIV, my life revolves around the people I love. Not around you.”

Chris – Minneapolis, MN

Living with HIV since 2010.



HIV TREATMENT WORKS

Diagnosed as a young college student, my first fears were of rejection and death. But, I was wrong about both. Instead of rejecting me, my grandmother immediately began to learn about the disease. She helped me see that, with HIV meds, I could live a long, healthy life. Now that I understand what it takes to live well with HIV, I take care of myself so I can spend time with the people who matter most.



Get in care. Stay in care. Live well.

cdc.gov/HIVTreatmentWorks