What it’s 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.

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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 been your journey with HIV?

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. It 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. I was one of those patients who had joined several HIV studies only to develop resistance to the study drug because they would give us one new one at a time. 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.

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

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

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.

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.

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