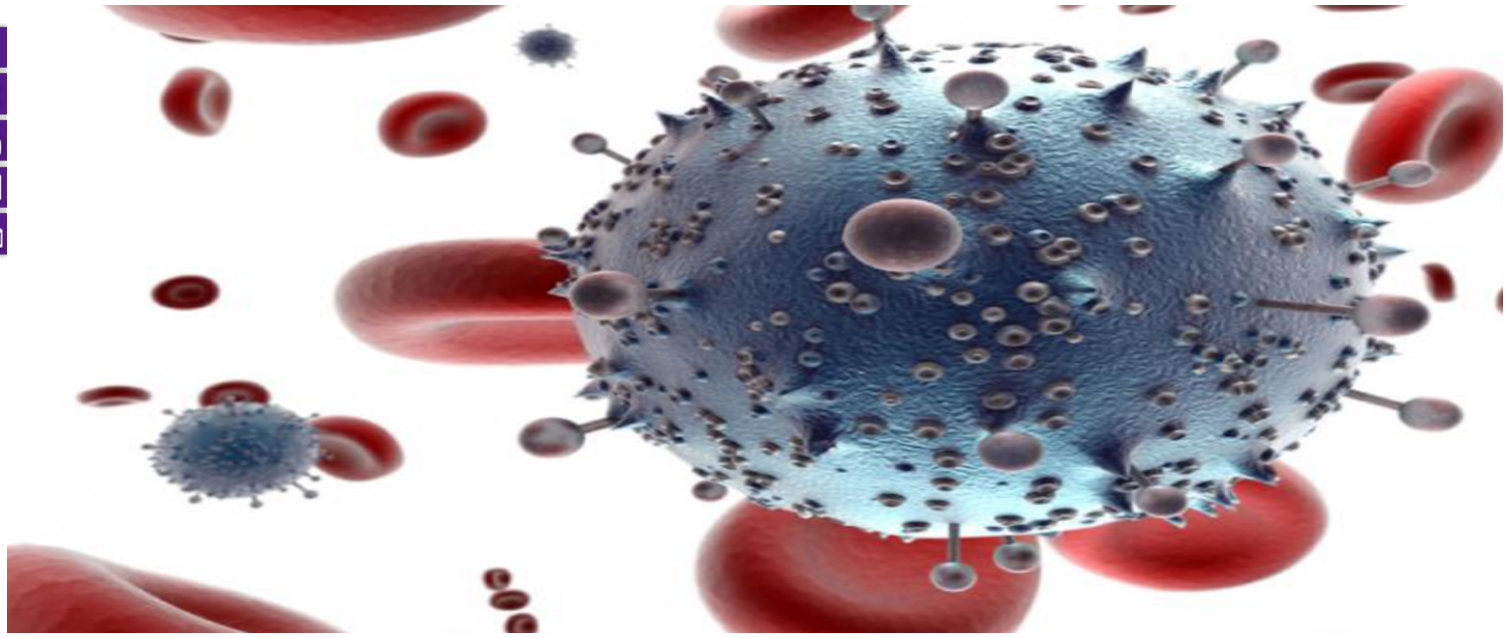
WORLD AIDS DAY 2017

WHY WOULD ANYONE SUCCESSFULLY MANAGING THEIR HIV WANT TO ENROLL IN A CLINICAL HIV CURE STUDY?



I am an HIV-positive gay man with a manageable illness. A year ago at an AIDS Law Project fundraiser, I had t good fortune to meet Dr. Luis Montaner, a leading HIV scientist at The Wistar Institute. Through Dr. Montaner learned about BEAT-HIV (beat-hiv.org), and an important new study looking for clinical study participants — interesting possibility I had not considered before.

I tolerate my meds and manage my HIV. So why was I asking myself if I really wanted to participate in an HIV cu study? The study would involve an experimental drug called Vedolizumab, and participation would mean I had temporarily stop all my HIV medications, as treatment interruption was necessary to determine if the experiment drug works. At the time, I was stable, on combination antiretroviral therapy (ART) and had an undetectable viral loa

My big reason is altruism. I would not be contemplating this decision if it wasn't for the brave people who participat in the early studies that gave us protease inhibitors and all the treatments that followed. I saw the epidemic in the la '80s and early '90s. My friends and I were responsible to clean out the houses of loved ones who had died from t disease — to hide the fact they were gay and died from AIDS — before their parents arrived. I remember the face AIDS. Because of this, I feel we must pay back — as a community — and test new drugs to get closer to a cure f HIV/AIDS.

Remember the early '90s, when there were no drugs and people were willing to jump on any study? Remember a tir before protease inhibitors, where AZT was the only drug and was very harsh to tolerate?

We can't forget the treatment advances we benefit from were borne on the backs of others before us. Yes, because many before me, I can now take one pill a day and live with a manageable illness.

I broached taking part in this clinical study to my husband and doctor and they both asked why "rock the boat?" W stop medications that suppress my virus and exchange them for an unproven drug? Why risk becoming viremic — a no longer have an undetectable viral load?

Being undetectable is my gold standard. Undetectable equals untransmittable. My own questions flashed before m
Will I become viremic and how quickly? How long will I be off my meds? Will I be able to go back on my meds after t
study? Will I have drug-resistance issues? How could treatment interruption and a potential spike in my viral lo
affect me and my spouse?

Basically, how could this affect my life?

Weighing the negatives, I also saw positives. The new study has 15 participants, so I'd get much more attention a
face time with doctors on the cutting edge of HIV research and practice. If the study was successful, I'd be at the he
of the line of people receiving it. I'd also receive compensation for many of the study procedures.

I decided to give clinical-study research a chance.

Before enrolling, I signed an informed consent, which was very helpful and detailed study procedures, associated ris
and risks of treatment interruption. It outlined any benefits associated with the study, alternatives to participating
the study and how to withdraw.

In the past, there have been significant ethical lapses in clinical studies discouraging people from enrolling, but I ho
and believe that those days are behind us.

My study will last about a year and requires 24 visits to the National Institutes of Health (NIH) in Bethesda, Md
receive the Vedolizumab infusion through an IV placed in my arm, which is painless, and I've had no side effects or b
reactions. I've also had leukopheresis performed, in which white blood cells are isolated and stored for research.

After six months, and seven Vedolizumab infusions, I stopped taking my ART. This was exciting, but scary. I return
to the NIH for testing and examinations every two weeks. If my viral load became detectable, staying above 1,000 f
longer than four weeks, I'd have to restart ART.

The first blood draw was reassuring — I was still undetectable. Maybe this would work and I wouldn't ever have to ta
pills again!

Two weeks later, my bloodwork showed a viral load of 828. Though not horrible, it was worrisome. At six weeks, r
viral load hit 10,170 and triggered the start of my four-week "watch" period. After being undetectable for so long, I w
now viremic. Two weeks later, my viral load reached 12,998. I was two weeks into my watch period with an uptrend
my virus. I had almost forgotten the fear of transmission and becoming sick again.

Ten weeks after stopping all my HIV meds, I had another blood draw showing a drop in my viral load to 7,202. M
viral load was now decreasing — so did the treatment work?

I proposed to wait another two weeks to see what happens, but this would not be an option. Study guidelines were
place for my protection. Though I was disappointed, I was relieved. It's scary to be viremic.

I restarted ART with no problems, and after consulting with my study and personal doctors, I resumed my pre-stu
regimen. My first follow-up visit was the same routine, except no more infusions of Vedolizumab. Would I
undetectable again? I knew it could take a few months to get there, but was happy to learn my status had quickly go
back to undetectable! After three more visits, my clinical study will be over.

A major benefit of being on a study is making suggestions to the scientific and medical communities — and o
community — for improvements in how studies are conducted. We must ensure all members of the community a
represented in clinical studies. When a study involves treatment interruption, consideration should be given
transmission education, PrEP and contraceptives. Most importantly, clinical studies including treatment interrupti
need to be on the forefront of developing faster, easier viral-load tests. During the study, when I went off my meds
was tested every two weeks. That, coupled with the wait time for results, is too long. A home test would be ideal, so le
strive for something better!

As part of this study, I have a voice in insisting all treatment-interruption studies accumulate and distribute data participant success rates, and the time it takes, to return to undetectable status. I am excited and proud to be a part this research and better understand the incremental steps we are making in our progress towards an HIV cure.

Let's keep moving forward! I trust my experience will make it easier for you. Consider participating in an HIV cure, several are about to start recruiting right here in Philadelphia.

The Delaney Collaboratory

The Delaney Collaboratory to Cure HIV-1 Infection by Combination Immunotherapy (BEAT-HIV Collaboratory) is consortium of more than 50 top HIV researchers from leading national and international academic resear institutions who are working with government, nonprofit organizations and industry partners to test combinations several novel immunotherapies under new pre-clinical research and clinical studies.

The BEAT-HIV Collaboratory has three main goals:

Find where and how HIV hides

Even after treatment with current medications that render viral load undetectable, there are still a few cells in the bo where the virus hides. In order to get rid of the virus, we need to find where and how it hides; then we can try to force out and destroy it.

Make the immune system stronger against HIV

By using a medication called Pegylated Interferon Alpha 2b, which may help control viruses, in combination wi antibodies that can neutralize HIV, we may be able to reduce the number of cells containing hidden HIV. This cou bring us much closer to developing a cure.

Introduce new HIV "killer cells"

What if we were able to give a patient special cells that would actually seek out and kill the cells in which HIV hide Some previous studies have already done something similar, but these "killer cells" became infected themselves. Wi the BEAT-HIV project, we will remove a protein that facilitated HIV infection before giving these cells to the patie making them resistant and able to destroy cells with hidden HIV.

For more information, visit www.beat-hiv.org.

If you are interested in learning more about local HIV-cure clinical studies, please conta Kenneth.lynn@uphs.upenn.edu.