Six-Month Anniversary On Disability

May 30, 2007 By Mark de Solla Price

I love the Memorial Day holiday here in the US. It is the unofficial beginning of the summer, especially in New York City. The bulky Winter clothes are replaced with skimpy Summer fashions and everyone seems to plan frequent escapes to the beach, mountains or “their country place.”

This week is also the six-month anniversary of my having to stop working at POZ Magazine and having to go out on disability.

As those of you have been reading along, you’ll know from my description of my experience with Pegasys/Ribavirin treatment, it’s been pretty brutal for me. I take my shots on Tuesday night, and then spend about 70% of the rest of my week -- sleeping, aching or waddling through with my scrambled brains and precious little strength, stamina, or focus.

It’s been two months since I was last able to post to this blog. Frankly, these two months from end of February through the end of April are one long blur. Each week’s treatments knocking me down just as I started to be human again.

But from the end of April and May, things got a LOT better, with a whirl-wind of good things filling my precious few good days, so there just wasn’t the time left to blog. I apologize for posting such a long and fact-filled entry, but there’s so many details I’ve been wanting to share as soon as I was able, and that’s now!

Back in October, when I was first diagnosed with hepatitis C, we ran an RNA analysis that showed that my hepatitis C is genotype 1a/1b. This type is the most common with gay men in the US but unfortunately it’s the least likely to respond to treatment.

I’ve heard that as many as 80% of folks like me are kicked out of Pegasys/Ribavirin treatment after the 12-week lab-tests because the treatment just isn’t doing enough good to be worth all the pain, suffering and other ill effects. Naturally, I was worried as there aren’t really any other good options for treatment.

Before treatment my hepatitis C viral load was 42,900, after 12-week of Pegasys/Ribavirin treatment my hepatitis C viral load was measured as (drum roll, please) UNDETECTABLE.

Clearly good news. Most of my other blood tests were keeping about the same -- my CD 4 T-cells

did drop of 304 to 154, but the probably bounce back after treatment.

Being a math geek, I had brushed up on the math formulas I'd need to understand the relative meaning of the test results.

Please feel free to skim over the next section, How To Compare Viral Load Test Results, which is more of a technical tutorial and pick up my story again at Mark's Treatment A Spectacular Success!

How To Compare Viral Load Test Results

One can't just compare viral load numbers (of hepatitis or HIV or any other virus), as the significance of viral load is not linear but logarithmic.

If the relationship were linear (which it's not) 100,000 would be twice as bad as 50,000, three times as bad as 33,333, and four times as bad as 25,000.

Since significance of viral load change is logarithmic 100,000 is twice as bad as 10,000, three times as bad as 1,000 and four times as bad as 100.

As a math geek, I'd write the formula as:

Measure of Improvement = log (starting value) - log (ending value)

Luckily, anyone who has access to a computer with Google Documents (or Excel) can use a spreadsheet to do the math for them. You can even do all the math from the Google search window in any web browser, as it has a built-in calculator. I'll show both ways. First the spreadsheet method, so you see all the steps.

Since my starting value for hepatitis C viral load was measured as 42,9000, I typed the following into the spreadsheet cell:

Then by hitting the enter key, it will calculate what the log of that number is:

My current ending value for viral load was measured as "undetectable" which (for my lab) mean the value is less than or equal to 50. Assuming the worst case, I used 50 as the ending value:

And hitting the enter key and have it do the subtraction:

Now let's do it again in one-step using the Google search page from any browser:

Type in the full calculation log(42,900) - log(50) and hit enter (or click Google Search). The result is displayed as follows. Pretty cool.

My treatment has given me about a 3 log improvement in the first 12-weeks.

Had the log improvement computed a negative number, my infection would have been worse.

For hepatitis C treatment, had the log improvement been between zero and one, most doctors would probably say that you're getting some improvement but not enough to justify all the torture and side effects.

A log improvement of closer to two or more would be considered a success.

Mark's Treatment A Spectacular Success!

Hitting a 3 log improvement resulting in "undetectable" is like batting a home run in base ball or a golf hole-in-one.

I'll still have to be on the brutal treatment regime until about Christmas (the full 48 weeks) and then I'll have some months of rehab, but studies show that with this level of response, there is a really good chance that I could actually be cured of hepatitis C.

Spring Retreat in Warwick

With that news under my belt, I felt up for a two-day weekend retreat sponsored by our local Community Church of NY Unitarian Universalist. I had very limited stamina, but boy was it great to be outdoors in Warwick in upstate New York on a picture perfect weekend. We have a few photos from that weekend, plus the funny results of our "art therapy" -- as always in MarkandVinny.com/gallery

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Mark's Birthday Party

Because that outing went so well, in turn, made Vinny feel that I should have a few friends over to celebrate my 47th birthday on May 17th - actually, my birthday was on a Thursday this year, so Vinny smartly pushed the party to the Tuesday, catching me at my best.

I had such a great time (check out the photos in the gallery), and it made me feel that there really was going to be a life AFTER Pegasys/Ribavirin.

At the party, I showed the really stupid way they ship Pegasys in refrigerated glass syringes with glass necks that you have to push a needle on to - twisting it just right to get the fit without breaking the glass.

After the guests left, I gave myself the injection and -- for the first time -- half the drug sprayed on my leg. I guess I didn't show the correct way to put it on . Not good. Pegasys is about $550 per shot, so that's a costly error, plus Pegasys is one of those drugs you really don't want to have a double dose of, so Vinny and decided that I probably got close to a full dose.

Based on my side effects that week, I did NOT - but if there is any good time to take a little semi-break, it's for my birthday week. Still some aches and pains, but nothing like a normal week.

Mark, Vinny and Troika in picturesque Milford, PA

We had also somewhat overly ambitiously planned a weekend get-away to visit Sean Strub in Milford, PA from Saturday through Tuesday. Milford, PA is a picturesque town 90 minutes from NYC and Sean has been instrumental in the it's new-found renaissance. Check out the 8-page story in Instinct Magazine's May issue.

Since I had such an easy week, it made the whole trip that much better. As always, check out the photos in our gallery. We ate great food in Sean's wonderful new Hotel FauchÃ¨re, Troika (our Doberman-mix rescue dog) loved bounding though the woods for half an hour at a time. We played with horses and watched Bald Eagles nest and ate at the other two good restaurants in town - the Water Wheel Cafe and the Dimmick Inn.

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