

Struggle with HIV: a personal experience of Bob Gerwig

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Opinion

My Stage for AIDS Dx was in June 1991. I continued to work in Microsoft's Applications Division for another 12 months so my stock options could finish vesting. At the beginning of June 1992, my doctors told me to stop driving due to rapid cognitive deterioration which proved not to be "AIDS dementia," rather "slow progressive encephalopathy" and I got into bed and was bedridden for most of the 10 years: 1994-2004.

That's when my physicians started describing the changes in my condition as a miracle, and so did I. It lasted at "full-tilt-boogy" for 2 years, then a slight decline in the third year and a sharp drop in the ninth year, 2009. After being home-bound and in bed ca. 80-95% of the time 2009-2014, it has happened again.

Starting in July 2014, it is happening again on a deeper and more profound level for me mentally, emotionally and spiritually. And my HIV/AIDS scientific profile has broken all records tracking my levels. My immune system is rejuvenating at great speed. (Some say God speed).

Summary

a. 1985.07.14: Exposed to HIV (Bastille Day) via Quaker boy friend who knew he was HIV+ but had told me he was in an HIV-control group in a clinical study for people HIV+. Not.

b. 1985.10.02: A public nurse who was a friendly neighbor got to be the one to tell me there was no HIV- control group in that study. She said everyone in it was HIV+ and they all knew it, and I needed a blood test. This was late October. I went to that same hospital the next day, and a week later found out I was HIV+.

It was 1985.10.31 confirmation HIV+ (Halloween in gay Seattle on public busses from 4-6pm. Surreal.)

c. 1986: My HIV/AIDS- related & other blood work and lab results

CD4 ca.700.

CD8 and their ratio unknown.

HIV viral load unknown.

Rx AZT in large doses.

d. 1990: pre-AIDS deterioration:

CD4 ca.550.

ratio ca.10%.

e. 1991.06.1: Dx'd w/Stage 4 AIDS

f. 1992.06.01: Permanently disabled & taken off the road by physicians for bed and "permanent disability" and by 1998, was

told I'd be taking morphine "for the duration." I asked, "The duration of what?" "Your life." And I've now taken morphine (except for 1992-93, replaced by Fentanyl) every day since then and for the duration.

g. 1994-1998: Chronic and overlapping outbreaks of h. zoster ("shingles") on my right forehead and scalp. I was on high doses of opiates: CD4 usually in the 150-250 range with dips of 3-6 months in the 50-150 range. CD8 is?, with ratios down to 8-6%. Shingles-affected area grew along nerve lines on the area from my right eyelid up along the right supra-orbital nerve under my right eyebrow where it turned upward from the top of my nose and along the right side of center to the "baby's soft spot," infected nerves around the right rim, and also branching off to the right along my right forehead hairline forming a large figure-C from my perspective running from the outer end of my right eyebrow to the nose and up to the hairline and right on the scalp to about the tip of my right ear (not infected).

h. 1998.03.1: 1st of 2 Radiofrequencies on the right supra-orbital nerve to try to knock out the frequency of the pain transmission. It worked very well but only for 3 months, then again for 6 weeks with 1-2 weekly injections of Lidocaine into my right supra-orbital nerve for a rush of cold "water" putting out fires. So we decided to make it permanent, on:

i. 1998.05.2: Neurosurgeon ablated right supra-orbital nerve, accessing it by incision along top of eyebrow. The results were an unanticipated spectacular success and received well by all. It broke the never-ending outbreaks of the previous four years. And I had the IV morphine catheter of 11 months removed in one month and have been on a maintenance dose of Morphine Sulfate ER tablets 30mg/bid. and currently am preparing to step it down to 15mg/bid. as it was before 2004. I still get small outbreaks of shingles when I'm tired, stressed and am sick with something else (e.g., cold, flu, whooping cough for 9 months overlapping with laryngitis for 6 months, a staph infection becoming an abscess to

be lanced, then it became non-necrotic MRSA, etc. - all of which I've had and much more).

- j. 1994-1996:** MS-Contin 30mg/t.i.d. My peristaltic motion in my intestines was so disrupted, I had dehydrated bowel blockages.
- k. 1996-1997.05: Fentanyl trans dermal patches:** 100micrograms/hour x 3 patches at once every 3 days. "HIV Night [& day] sweats" caused the patches to fall off sooner than 3 days in random order causing endless narcotic withdrawal and insufficient pain relief. I had other neuralgias developing in my face, arms and legs plus peripheral neuropathy in my hands, and severely in my feet (still). I also felt like I had "phantom tropical sunburn from head to toe. There was no redness, just the sensation. Any physical touching, even shaking hands and especially receiving hugs became unpleasant for me and I had to tell people no more.
- l. 1997.05.1:** Began IV morphine in saline with a baseline of 22mg/hr with 3 optional boluses/hr of 8mg each. I was on palliative care at home for 11 months of home nursing to change the dressing on the catheter in my arm and change sides when needed. I knew the password on the pump and was receiving a 10-day bag of morphine in saline every 7 days. It was very tempting, but I went into hospital to die by refusing nutrition and hydration except for morphine, saying it was insufficient to manage the pain to increase the morphine legally until I stopped breathing which would be a Dx of "complications due to AIDS" rather than "suicide." But at the last minute I pulled out of it. My daughter was in high school (class of 2000).
- m. 1998.04.1:** 11 Months after beginning palliative IV morphine averaging 30mg/hr/day. I felt despair. Several days later, still in the hospital with no options, my doctor introduced me to a neurologist and a neurosurgeon. Long story, but six months later the IV catheter was removed and I began taking MS-Contin again @ 30mg/t.i.d., then bid., then 15mg bid., but that was as low as I could go without unmanageable pain.

n. 1999-2004:	Averaged	MS-Contin/Morphine
Sulphate ER	ranging from	15mg-30mg bid
1999-2001:	CD4 in	250-350 range
2001-2004:	CD4 in	300-450 range
2004-2010: CD4 in 350-450 range.		

- o. 2010.10.10:** Moved out of condo of 19 years and neighborhood of 26 years for a condo better suited to me in a very different neighborhood, moving from Capitol Hill to Lake City in northeastern Seattle.
- p. 2010:** CD4 broke 500 for the first time since the 1980s. Then it broke 600 and I'm currently and consistently in the mid-600s with a ratio with CD8 at 12-16%. My HIV viral has been undetectable for years.
- q. 1991-2000:** HIV viral load in 2-3 million range during acute illness, then down to 100,000-300,000 and finally undetectable except for two brief spikes to 10,000 and a second time to 2,000.
- r. 2014.07.03:** 2nd major healing in 10 years began.
- s. NOW: 2015.01.10:** Current level for three years has been Morphine Sulphate ER @ 30mg bid. and I've switched to the same dose in 15mg pills to start to decrease my maintenance baseline dose as my pain is much reduced since last Summer.

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None.

Conflicts of interest

None.