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Seattle, Washington

Diagnosed With Hep C in 2015

May 23, 2016 marks the one-year anniversary of the letter. The letter that changed everything. The letter that divided my life into BHC (before hep C) and AHC (after hep C).

The letter came a month after I donated blood for the first time. It arrived from the blood bank in a nondescript envelope with a mail-merge address label. I found it in my mailbox a week before my brother's wedding. I almost put it directly in the recycling with the other junk. I assumed it was a form letter, stating simply, "Thank you for donating."

Eventually, I opened the unremarkable envelope and read: "Your blood tested positive for hepatitis C antibodies (anti-HCV). A nucleic acid test (NAT) for hepatitis C virus (HCV) was also positive."

The letter was a whole-body shock. The acronyms, NAT, HCV, anti-HCV, froze me to the floor with cold waves of fear. The words shot me forward instantly, shattering my old life BHC and throwing me into my new life AHC.

At the time, I knew very little about hep C. I thought I had no risk of contracting a blood-borne virus. I later learned two critical pieces of information. First, blood donations were not screened for hep C until 1992. Second, I received multiple blood transfusions when I was born in 1981. Since I have no other risk factors, it is most likely I was infected with hep C via the blood that saved my life, possibly on the day I was born.

Follow-up viral load testing revealed that I had 4,412,972 viruses in every milliliter of my blood. That's 22 billion virus particles circulating my body, destroying my liver, replicating a trillion times a day. I had hep C for 34 years, and I had no idea.

In retrospect, I now know I have several extrahepatic manifestations of hep C, conditions related to hep C that affect body systems other than the liver. Each of my symptoms was diagnosed as its own separate thing, unrelated to each other and never linked to an underlying cause.

In 2003, I was diagnosed with Gilbert's syndrome and told not to worry about this benign condition. Gilbert's syndrome just means your body naturally produces more bilirubin than normal. Unfortunately, it turns out I never had Gilbert's syndrome; I had hep C.

Over the years, I was also diagnosed with dermatitis (itchy skin, rashes), Raynaud’s phenomenon (a condition where you lose blood flow to your fingers and they turn cold and numb) and nausea with no apparent cause. At least once a month, I spend a few days sick to my stomach and often throw up. This has been going on since 1998. I was used to it; it was my own normal.

In 2012, doctors tested me for multiple sclerosis. My constellation of symptoms can suggest autoimmune diseases like MS. They can also suggest hep C. But because I don’t “look like” a person at risk for hep C, once the MS tests came back negative, no one looked any further. No one asked if I had a blood transfusion before 1992. Only with hindsight do these pieces point to hep C.

If I had not donated blood, I wouldn’t have discovered my hep C until my liver started to fail. I would not have been tested at any routine medical visits. Because hep C is not considered a sexually transmitted infection, I was not even tested during STI screenings. I encourage everyone to donate blood. If you have an infection, you will find out and can start taking care of yourself. If you don’t, your blood will help others. Either way, you will save at least one life, maybe your own. Editor’s note: Donating blood can save lives, but blood donation is not recommended as a substitute for hepatitis C screening. Look for a testing site in your area or ask your primary care provider to test for hepatitis C the next time you go for a physical or get blood work.

After Hepatitis C

I spent most of the summer in my apartment, in a red IKEA chair. I was afraid to move, afraid for my life, afraid of losing my job. I was afraid of rejection by friends, family and colleagues. I was afraid I would die young, painfully and alone. I was afraid of infecting others. Most of all, I was afraid that even though there was now a cure, I would not be able to get it.

Like thousands of patients, the next life-changing letter I received in the mail was from my insurance company, denying my doctor’s prescription for Harvoni. They decided that treatment was not “medically necessary.” I was not yet ill enough. My liver had not reached stage 3 fibrosis, and therefore, they told me to wait. Wait to get sicker. Wait for deeper liver scarring. Wait for cirrhosis or cancer. Wait to develop worse extrahepatic manifestations, such as diabetes or vasculitis, kidney disease or lymphoma. If they were very lucky, maybe I would die before they needed to do anything to help me.

I sat in my chair. I waited. I felt like my life was over, both because I would die and also because I was now “other,” different from everyone else. I was infected, dirty, scum. I was not medically necessary.

I was afraid. I was also angry. I felt betrayed. I cut myself off from people, hobbies, community. I stopped playing music. I stopped seeing friends. I stopped leaving the house, except to go to work. I couldn’t sleep for months, awake in a sea of insomnia, fear and fury. Eventually, my doctor prescribed sleeping pills and antidepressants.

My health maintenance organization (HMO) refused to cure my hepatitis. But they paid for drugs to treat the mental health issues I developed because they wouldn’t cure me.

I had always done everything I was supposed to do. I earned perfect grades through college. I went to grad school. I got a job with insurance. I worked hard, volunteered in my neighborhood and was kind, helpful and nice. Despite all that, I got hepatitis. Despite my insurance, I could not get the medicine I needed. I lost fundamental trust in the world. I nearly lost myself.

Four things saved my life: the love of my steadfast friends and family; the work of organizations seeking to connect patients to care; and, finally, science and art.

With the encouragement of my friends and family, I fought. With the help of the Hepatitis Education Project and the Caring Ambassadors, I became my own advocate. I learned to demand what I needed, do my own research and not take no for an answer.

When my HMO denied Harvoni, I researched clinical trials, assistance programs and drug prices abroad. When my HMO said I could not see a hepatologist, I called every day until my referral was approved. When the hepatologist wrote an order for a biopsy with a one-month deadline and the phone scheduler said I could not get in for two months, I went to the office in person and wouldn’t leave until they fit me in before the order expired.

I navigated the convoluted process required to access treatment. I appealed my HMO’s Harvoni denial and called daily until they denied the appeal so I could apply to Gilead’s patient assistance program. In a cruel bit of timing, Gilead changed their patient assistance criteria on July 1. Because I had insurance, I was no longer eligible for that program either.

I had gone too far to give up. I had raised my voice too loudly to stop shouting. With guidance from the Hepatitis Education Project, I asked my hepatologist to prescribe Viekira Pak instead. She refused and told me to wait and check my liver every year. So I got a different hepatologist—and the new prescription. My HMO denied it. I appealed their denial, and they denied my appeal. Finally, I was eligible to apply for AbbVie’s Viekira Pak patient assistance. In October, I was accepted.

FedEx delivered my first box of Viekira Pak and ribavirin in November 2015. I took my last dose on February 6, 2016.

During treatment, I was nauseous and had bad heartburn. I became what I can only describe as “very burpy.” Ribavirin gave me hemolytic anemia, and I spent the winter cold and short of breath.

I have never felt better.

I got treatment.

I was being cured.

My side effects were nothing compared to what patients endured on interferon. I count myself extremely lucky that all I had to do was take pills and occasionally apologize for burpiness and fatigue. The scientists who found this cure saved my mortal life.

Hepsie the Wonder Liver Maggie McGehee

While all this happened, as I was finding my voice, to my surprise I started drawing a comic. I was overflowing with hepatitis information, bursting with raw emotions and thinking 24/7 about fighting for care. When I finally got out of my chair, I started pouring that knowledge and those feelings onto paper. What were initially just sketches to organize my research and vent fear and anger in dark humor eventually became “Life with Hepsie: The Wonder Liver.”

I had never drawn comics before. I had always been a musician. Music was a daily habit and source of joy. I played in ensembles ranging from rock bands and musical theater orchestras to classical trios and piano ensembles. After the letter arrived, I could no longer bring myself to the piano. When I needed music most, I couldn’t get near it. Instead, my creative outlet became writing a comic.

I hope “Hepsie” will become a book. I hope it will help other patients know you are not alone. You are not lost. Your life is not over. Everything you feel is perfectly normal, even if nothing you are facing makes sense. You can do this. It sucks. It is unreasonable. It is ludicrous. You do not deserve it. But you can do this. If I can, so can you.

I would never have predicted I was at risk for hep C. I would never have guessed I’d write a comic book. A year ago, I had no idea what hep C was. Now, in just a few days, I’ll be starting an entirely new career. I am going to work full time for the Hepatitis Education Project, one of the groups that helped me save my own life.

My first day of work is May 23. The one-year anniversary of the day I got the letter.

As I type this, I am waiting for my three-month post-treatment viral load test. If it comes back undetectable, I will be able to say, “I had hepatitis C.”

I am no longer fighting for my treatment. We are no longer just talking about curing everyone with hep C; we are talking about eradication. Hep C can be a thing of the past, a distant memory, an ancient horror like polio or smallpox. We have the opportunity to wipe hep C off the earth.

Let’s move our planet into life after hep C.

What three adjectives best describe you?

Inquisitive, creative, determined.

What is your greatest achievement?

Returning to music after a five-year hiatus and learning 13 Ben Folds covers to perform on my 30th birthday (even though, or maybe especially because, I didn’t finish this goal until after my 31st birthday).

What is your greatest regret?

Losing a year of my life to worrying, fearing and being angry about hepatitis C. However, if it weren’t for that year, I wouldn’t be the stronger, more compassionate, driven person I am today.

What keeps you up at night?

Knowing that I was cured of hep C because I have every privilege in the world: computers, a job, insurance, a strong community, time. It is not fair that I was cured and others are still waiting.

If you could change one thing about living with viral hepatitis, what would it be?

I would take away the fear and the self-stigma; I judged myself more harshly than anyone else ever did.

What is the best advice you ever received?

Early on, Jill Wolf of Caring Ambassadors told me, “You will be cured. It will take time. It will be hard. You will have to fight for yourself. No one else can do it but you. But you will be cured.”

What person in the viral hepatitis community do you most admire?

Patients who have faced challenges I can’t imagine, such as addiction, losing family and jobs, interferon, cancer, cirrhosis. Those who have been cured but still go to support groups to give hope to others.

What drives you to do what you do?

I believe the purpose of life is to create joy. Health is a fundamental requirement of being able to spread joy. I know we can eradicate hepatitis.

What is your motto?

Make no little plans.

If you had to evacuate your house immediately, what is the one thing you would grab on the way out?

My cats. If they evacuate on their own, then I would also grab my Rain City Rock Camp for Girls hoodie (though I’d likely already be wearing it anyway).

If you could be any animal, what would you be? And why?

A narwhal. I can’t believe they’re real and not magical, a unicorn in the sea. During treatment, I envisioned narwhals attacking my viruses. Plus, you’d get to swim and poke stuff with your head tooth!

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