

Failure Was Not an Option

Trust has many faces, including family, colleagues, doctors and most importantly, myself.

I always wanted to be a father, but at 42 years old, with no children, I felt it wasn't written in my cards. The girl I was living with had moved back to New York. My consulting position with Technology Management and Analysis Corporation (TMAC) required considerable travel, so at the time, not having children fit perfectly in my hectic travel schedule. I was scheduled to go to Honolulu for an Oracle Application User Group conference for a week and I was going to take another week in Maui.

My dog Hunter, a 110 lb. Husky Shepherd mix, was very protective of both me and my ex-girlfriend, Jenny. I knew she would be the only one that Hunter would be comfortable with over those two weeks. I called Jenny to see if she would watch Hunter and she jumped at the opportunity. I drove him to NY to drop him off and he was very excited to see Jenny again. A couple weeks later, I picked him up and went back to Virginia.

About 2 months had passed, when I got a phone call from Jenny saying she thought she was pregnant. I suggested she go to a doctor and get tested for sure, since home pregnancy tests could be wrong. About a week later, Jenny called and said, "Yes, I am pregnant with twins!" OMG, I am going to be a father of twins!! It was a dream come true. Jenny and I had parted friends so when I suggested she come back to Virginia she said yes.

My excitement of being a father was off the charts. I had a great job, and at my age, all of my oats had been sowed. The week following the news I was going to be a father, I prepared to go to NY and pick up Jenny to bring her back to Virginia. When I started with TMAC, I had applied for life insurance above the company provided coverage. This larger amount required me to give blood. I got a call from my agent and he said my policy was "rated," meaning there was something wrong. He said that they would issue me the policy, but it would be double the premium.

I called the doctor and found out I had tested positive for the Hepatitis C virus. The doctor informed me there was no cure at that time but reassured me I would probably die with it, rather than from it. Thanks a lot Doc!

My mind was reeling; how do you process this type of information at the same time wanting so much to be a father.

I went from one week learning the most exciting news of my life, to how much time do I have to spend with my twins before I die. When will the liver deterioration begin? It was a very dark time for me. Hepatitis C was dubbed 'the silent killer' because it progressed without symptoms;

you were unaware you were infected until the condition was very serious. Hep-C damaged the liver slowly over many years, often moving from inflammation to scarring (fibrosis) to permanent, irreversible scarring (cirrhosis).

How long had I had it, how bad was my liver? You name it, I thought about it. Additionally, who could I tell? No one! I obviously was not going to tell Jenny, the last thing she needed was to learn I had an incurable disease while she was pregnant. I had to deal with it alone and in total secrecy. On top of that, Hep-C was a communicable disease. Blood to blood. In 1999, the AIDS epidemic was well-known and the stigma associated with a communicable disease made the silence on my part even more necessary. I had to fight this alone. But how? All I knew was that I was willing to do anything to prolong my life expectancy.

I began searching for any information I could find about Hep-C. Were there any clinical trials underway to find a cure or an effective treatment? Since the Hep-C strain was discovered relatively recently in 1999, finding useful information about the virus was difficult. There were vaccines for Hep-A and B, but none of them were effective with Hep-C. Everywhere I looked for help ended with little or no information. I was going crazy in plain sight. I had to cloak my nightmare at work, keep the diagnosis from Jenny, and pretend I was this happy expectant father when in fact I felt I was a ticking time-bomb.

As my life has always been, God has either placed me in the right place at the right time or put someone into my life to change my trajectory. This time He did both. Being in Northern Virginia, I learned that the National Institute of Health (NIH) main research facility was located in Bethesda, MD. NIH was the world leader in researching incurable diseases. I learned NIH had several clinical trials underway and they were recruiting Hep-C patients for their research to find a cure for Hep-C. Finally, good news. The bad news was I had to qualify for a trial. NIH does not take any Tom, Dick or Harry who has Hep-C, you had to be physically healthy, which seems like a true oxymoron, I had Hep-C but they wanted someone healthy?

As I would learn later, the experimental protocol in the clinical trial would cause devastating side effects. Being healthy from the NIH perspective was, at a minimum, were you healthy enough to handle the side effects. Dang, you talk about heaping on worse news to worry about, and now its side effects. Little did I know the side effects were a piece of cake compared to getting into the clinical trial.

One of the acceptance criteria was to have a liver biopsy performed. I was sitting in the doctor's office at NIH when he casually described the liver biopsy procedure. He would insert a 1 ¼ inch hollow needle between my ribs and extract a sample of the liver. From this sample they could determine how advanced the scarring was in my liver. I asked, "Will I be put under to perform this biopsy?" His response was, "No, we have to have you awake but we will give you pain medication during the procedure." It's funny how when faced with an incurable virus, and twins on the way, the decision was simple. Let's go for it. I won't go into the procedure except to say

it hurt like hell. My liver scarring score was a 7 out of 16. I was a good candidate for the trial and was accepted into NIH Hep-C clinical trial. I was about to become a 6'4" lab rat.

I want to take a moment to talk about NIH and the amazing people I had the pleasure to interface with. Ms. Park was my guardian angel; she managed my entire experience at NIH. My doctor, Dr. Jordan Feld, was a Canadian hockey player with long, curly black hair and didn't look more than 25 years old. Turns out he was older *and* brilliant. I formed a great relationship with these wonderful people. The staff at NIH, on a regular basis, dealt with people whose only hope of survival was NIH. Their grace, compassion and unrivaled knowledge provided people like me with a sense of hope. They were truly God's angels on earth.

Eventually, Jenny was placed into the hospital for the remainder of her pregnancy due to her going into early labor. You can imagine her state of mind, not good. During this hospitalization time, I began preparing to begin the protocol. I would have to give myself a shot of Alpha interferon every other day as well as take Ribavirin once a day. Imagine taking an injection and a pill that made you feel, every day, worse than any illness you had experienced in your entire life.

There were two major NIH milestones I needed to overcome, the first was staying at NIH overnight the first 2 days, where I would be given the cocktail of drugs and the second was in front of a nurse could I give myself a shot with a hypodermic needle. These two factors had led to a 50% dropout rate among people in the trial. Now for the night from hell. A nurse gave me the first shot of Alpha interferon and I took two of the Ribavirin pills. About an hour later the fever began and continued for about 2 – 3 hours, then as I called it, the eye of the storm came, where I felt pretty good. Then the worst chills started, followed by uncontrollable shivering. I remember I was so cold, I curled up into a tight ball. When the shivering finally subsided, my testicle hurt so bad from squeezing my body so tight. Is this horrid feeling what I would feel for the next 6 months? I couldn't maintain this level of spasms. The doctor said the first night was the worst, but by the end of the first week, my body would have adjusted to the medication and I would only have flu-like symptoms.

I went home with a two weeks supply of meds, all of the needles, and other medical supplies I would need. The date was June 5, 1999, and on July 8th, 1999, twin boys were born 5 weeks premature. Jenny was doing well but the boys were in a neo-natal intensive care unit. My boy Matt stayed in the NICU for a week and Erik two weeks. When I picked Jenny up from the hospital, I had to tell her about the Hep-C, that I was in good hands and inside the refrigerator there were vials of medicine that must be kept cold. I showed her the needles and where I kept the medical waste container NIH provided for the used needles. I put the medical waste container on the top shelf of my closet.

As part of the trial, I had to go to NIH every two weeks to give blood so they could track the effectiveness of the drugs on the virus. When I went there for my biweekly blood draws, the doctor would tell me what my viral load was. To give you an idea of Hep-C viral load, when

they first analyzed my blood, I had a viral load of 800,000. Eight hundred thousand of *what*? The doctor said that when a patient reached 2 million, that's when they were in trouble. He assured me, my viral load was manageable.

With the boys' home and me 3 months into the trial, the doctors recommended that I take the protocol for 9 months. They were seeing a drop in the viral load, but the virus was still detectable. During this time, the boy's mom and I were having issues. It was the combination of Jenny staying home with the twins and lack of freedom combined with my side effects of the drug. It was a difficult time for both of us.

I was successful in keeping it from work until another colleague and I had finished a sales call in Toronto and were waiting for our flight back to Virginia. My backpack spilled open and two used needles fell onto the floor. My colleague looked at me like 'WTF dude.' I explained the clinical trial to him and that I was bringing these used needles back to be disposed of properly because I was being treated for Hep-C. He was so supportive of me from that point forward. I would later find out how supportive he would be.

I had arrived home from work and Jenny came to me, sat on my lap and told me she had filed a restraining order on me for leaving needles around the house and the police were on the way. It was around 7 p.m. when there was a knock at the door. I answered it to see 4 Fairfax County police officers standing there. They asked me my name and said they had a restraining order brought by Jenny and that I was to immediately leave the property. WHAT? Jenny had told the person we were seeing at couples therapy, that she had found used needles around the house. There were none. I found out later from my neighbor that Jenny had been inquiring what the child support payments would be for someone making the money I did. I was escorted out of the house. With my meds and a few clothes, I went to my office and slept there. The next day I told my colleague about what had gone down and he offered his place to me to live until court.

Again, what I am about to tell you really hits home. When the senior executives of the French company I was working for heard what was happening, they offered or I should say demanded that I stay in the corporate apartment they had. I had incredibly bad things happening to me followed by these amazing gestures of kindness. How lucky was I. Let's recap, I had Hep-C, a restraining order against me, needed to find an attorney, could not see my boys, and had side effects from the protocol that would make most people cry, all while working full-time.

Fast forward two weeks when my attorney got an emergency hearing with the judge. It was in court where my attorney and I learned that Jenny had a tape recorder hidden in her pants. I learned later from Jenny the person we were seeing for couples counseling told her to do that and provided her with the recorder. When Jenny's attorney divulged the recording of me being told I was going to be removed from the property, my attorney said he could stop it from being heard by the judge. I told him to let the judge hear it. When the judge heard the recording, she said, "This is the most passive argument I have ever heard given the circumstances. Motion to extend the restraining order denied. Mr. Cronin you can see your boys today." Wow, relief, but now I

had to live with the person (Jenny) who tried to have me removed from my boys so she could get money. Can this story get any crazier? Oh yeah, what was about to happen makes everything you've read so far seem like a walk in the park.

The Hep-C protocol did not eliminate the virus so NIH stopped it. They said that when they developed a new protocol, they would contact me. Fast forward the events up until the WTF-just-happened-event. I went to Rome on business and when I came home there was a note from Jenny that she had taken the boys to her sisters. No biggie. Then at work the next day I received a fax from her attorney saying she had taken custody of the boys and would see me in court. The same judge we had for the restraining order was the presiding judge for the custody hearing. The judge appointed a guardian ad litem to represent the boys. He asked for both Jenny and I to give 3 references for him to contact about "us." I gave my niece, who at that time was doing her internship at a hospital in New York, as one reference. When she was a freshman at the University of Virginia, my sister asked me to go visit her. My niece was an introvert, so I visited her probably 3 times her freshman year. When she graduated and was accepted into medical school, I loaned her money to go to Europe.

On the day of the custody hearing the guardian ad litem asked Jenny and I to meet with him so he could tell us who he recommended to the judge to be custodial parent. He turned to me and said, "I recommend Jenny to be the custodial parent and it was based on what your niece said about you and your lifestyle." BAM, my f-ing family, did the dastardliest thing possible. My flesh and blood, my 2-year-old boys were the most important thing on this earth. Why didn't she just say she didn't want to be a reference? Who cares; from that point on I never saw any of my family again. With family like that, who needs enemies.

Again, let's fast forward. I had met someone from Illinois; we got married and she came to Virginia to live. Around the same time, I received a call from NIH, my guardian angel, Ms. Park. She informed me that NIH had a new protocol and would I be interested in participating. I jumped at the opportunity. It was the same startup steps as the last one, staying at the hospital overnight, then beginning the protocol at home. To say I was "gun shy" about anyone knowing about this new protocol, needles, etc., would be an understatement. Since my work required me to be on business trips overnight, it was easy to have the NIH overnight, disguised as a business trip from my wife. Thinking my wife would be a little more understanding than anyone I had dealt with so far, I thought I would test the waters before I told her anything about the drugs and the needles, etc. Nope, when I told her, she proceeded to explode and say I should have told her this before our wedding since I knew I had Hep-C. She was correct, I should have told her. She then proceeded to tell her friends that I had Hep-C and went to the hospital to get tested for every communicable disease possible. For me, it was business as usual with the people in my life, being the worst people in my life when it came to Hep-C.

Of course, the test results came back negative, but more importantly, I knew that I had to keep the treatment for Hep-C a secret. This decision to go about my treatment in secrecy was validated

when we had a party at our house and many of our neighbors came over. At the dining room table, out of nowhere, she said, "Tom has Hepatitis C." Wow, really!!

It was easy to hide everything. I had a finished basement with a bar that had a small refrigerator. It hadn't been used and no one ever went into it. I hid the Pegylated interferon in the back of the fridge. I hid the needles and the waste containers in the rafters. Since it was a finished basement with a bathroom, I would give myself a shot as needed. My soon to be ex-wife never knew.

About 2 months into my new clinical trial for Hep-C, my doctor told me my virus was undetectable. ARE YOU KIDDING ME!!!!!! Dr. Feld and I gave a high 5 and hugged. He kept me on the protocol for 9 months total. When I was finished, the big test would be three years later when I retested for the virus. Thank God, my virus was gone.

And a cure for Hep-C was found. Unfortunately, the side effects, giving yourself a shot, giving blood every 2 weeks was not a viable solution for the "masses." It wasn't until 4 or 5 years later that a pill form of the Hep-C cure was developed. For me and the second NIH trial I was in, they found the correct medicines to eliminate the virus from an infected person. How lucky was I.

Follow up on the custody of my boys. Jenny was a person who earned pennies and spent dollars. She got into financial difficulty when the boys were 4 years old and moved in with me and gave me custody of the boys. Eventually, she moved out and I was a single dad for the boys. As I look back on that tumultuous time, failure was not an option. In life many negative things and people can beset you. Forget them, keep on driving to the goals you have set for yourself. Eliminate from your life the negative people who have proved they can't be trusted. Trust me, I would not be who I am today, if I cared one bit about the negative people in my life. You have no idea the power you have inside until you are tested in the way I was.