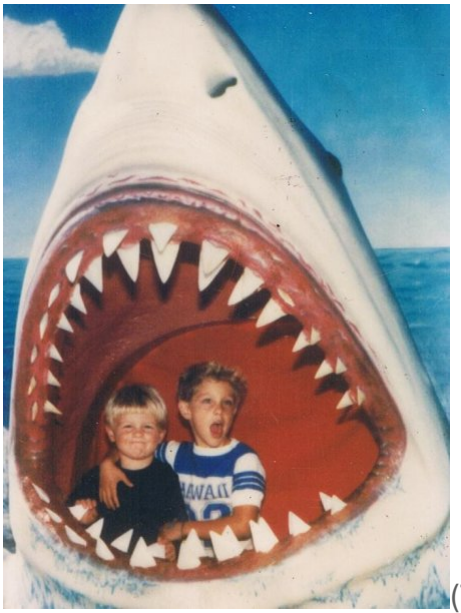
Rick Nash: An Advocate’s Journey

April 26, 2019 By Rick Nash

I told my story in Hep Stories years ago, but a lot has happened since then. If you haven’t, I recommend it, it’s wonderful to be able to share your story with the community.

It was a hot summer day in late July of 1999, Y2K was the biggest concern on anyone’s mind, but I was 12, my concerns lay in how much pizza I could get from the pizza party coming up that Friday. I was in Tennis camp, and while I wasn’t great at Tennis, I was great at eating pizza. It was still a few days away, and like most 12 year olds I’d drink Gatorade and sodas in between the class sessions. But when my dad picked me up that day, I had little clue about how much all of our lives would change from such a small series of events. Upon arriving home, I rushed to the bathroom. The color was unusual, a dark, iced-tea colored urine, alarmed, I called over my dad. Upon his inspection, we decided a visit to the doctor was in order. After that point, the pizza party seemed a lot further away. When my doctor brought my family in, he wasn’t sure what he was looking at, the blood tests were inconclusive, so he explained a biopsy would help find the culprit. I was twelve, and it was 1999, Biopsy was the standard still, and I was more excited that this Saturday I would get to watch more than my allocated 30 minutes of cartoons. They’d decided to biopsy my liver, spleen and kidney, because they weren’t sure where the internal bleeding came from, and my platelets were fine. Although I had no idea this is what was happening, I was more focused on the McDonalds at the entrance to the hospital, and the potential for Chicken Nuggets.



(That’s Me, age 9, and my brother, age 6)

My follow up appointment in September made all the chicken nuggets, pizza parties and cartoons seem completely irrelevant. The doctor explained to me and my family that I had

Hepatitis C (HCV), which was unusual for a 12 year old, so they tested the rest of my family. The doctor also explained that because of how the disease progresses, and that I likely had it since birth, and that by 30, I would need a liver transplant or die. I am glad that he was serious in his explanation, and that he didn't hold back any information. At that time there was no cure for Hep C, there was a sliver of hope though through a life-altering treatment. When my family's tests came back, we were relieved when both my father and brother tested negative for Hep C. But it had confirmed the doctor's suspicion, that my Mom was the source, as we had the same strain of HCV. My mom was devastated, I didn't understand how to feel. I knew that I was 12, and that I was potentially already at the midpoint in my life, so my goals and dreams faded. While there was no cure in 1999, there was a treatment with a less than 30% success rate. The treatment required a year of thrice weekly injections and a series of pills. Non-pegalayted Interferon and Ribavirin, when she took them, my mom began acting almost bipolar in her characteristics. It was hard to understand what she was going through for any of us. But Interferon essentially makes you feel like your worst flu, a dozen times over, and ribavirin can encourage emotional swings, skin issues and both enhance fatigue. My mom made it through nearly ten months before the treatment failed her. It took years for my family to recover, but there wasn't a lot of time for that. She found a new job, and I entered High School. My dad had made an agreement with the school to preempt anything they may do: they would pull me out of all sports, and any sports teams, and I would be barred from joining. Which meant leaving Tennis, Swimming, Wrestling and Basketball behind. I didn't know not to talk to others about my Hep C, so I freely explained my circumstances to everyone I knew. I didn't know that faculty and parents would react so negatively to something which could affect them in no way except their own misunderstandings and fear.

I was lucky in a way, 2002 happened to be the year a lot more people learned about Hep C. Mostly through gossip and rumors regarding Pamela Anderson and her former relationship with Tommy Lee. She was infected through a tattoo needle, although her status as a sex symbol meant that kids my age assumed it was an STD. By then I realized I should be more selective with whom I share my status. My mom was ramping up for her second treatment, a pegalayted version of what she'd taken before. This version only required one injection per week, but still lasted the 48 weeks. This treatment would also ultimately fail her, but we still had hope it might work for me. Once I turned 18, I was given the option to take that same treatment, but I wanted to wait for better timing with school, because I'd seen the debilitating state the treatment had left my mom. And as the magnet on my fridge reminded me: When you miss school, you miss out. So I waited until my senior year of college, while in a long distance relationship with an unsupportive fiancé. She wanted me to move out to Florida as she'd done nearly a year before, but my decision to treat while living with my family, and having friends nearby turned out the be the best decision I could have made. She was resistant and frustrated with my choice, and it was made because I knew what I would go through, I knew the risks. I also knew that when I graduated I could lose my health insurance, so it wouldn't be covered otherwise until I got a fulltime job. And even then it would be a preexisting condition, so it became even more complex, and all of this was lost in our arguments. The stress was unreal, and the treatment I thought I'd prepared for, was worse than I'd could have imagined. For three months, between my hormones pushing me to cry at doorknobs, and the daily fatigue having me miss work for the first time, I was in pieces. I walked with a cane,

because my legs were weak from the injection sites, I used a megaphone to speak to the kids I worked with because my voice would go, and I tried by best to stay in a doomed relationship which my treatment's failure would ultimately help me in realizing that maybe we weren't right for each other. When the treatment failed, I was crushed. I didn't know what to do, my mom was equally devastated, having hoped that maybe it would work for me, that maybe her pain wasn't pointless. With the help of my kids in the program I worked at, of my friends that summer, and my family supporting me, I found renewed purpose. I hit the gym, I reinvented myself, and after a few months of exploring my budding identity, I found some peace. Two years later, my doctor would suggest that I try the treatment again, only with higher dosage. This, was an unnecessary treatment, it was a year before the first DAAs would come out, and he was more interested in pushing the treatment because he was working for the company who made it. I learned of this years later thanks to OpenPayments, a searchable database of payments doctors receive. This was the beginning of my life with cirrhosis. The treatment was just as you'd imagine, a bit worse than my first, and equally devastating when my viral load stayed at 3 million. I was a wreck, and my behavior and choices reflected my depreciating attitude about life. But I put myself back into again, hit the gym, reinvented myself again, and started running a before/after school care organization. That next year, my mom would go on the single roughest treatment either of us would take. The regimen called for 3 months with the new DAA, and then 6 months additional without it. It was dubbed the triple cocktail, an ironic name as this was for liver disease. Interferon, Ribavirin and Incivek would ravage my mom's body requiring multiple units of blood and Procrit to keep her alive. Ultimately she would find that her hell had paid off, and was cured on her third treatment. While the ACA had recently been passed its stance was shaky, and I was worried about my preexisting condition preventing me from accessing insurance. And so in the two months between when I turned 26, and my new tech support job's insurance kicking in, I opted to fork over half my paycheck for two months of COBRA. Then I prepared for what I hoped would be my last treatment. I worked out for months prior, ate healthier, and tried to make the only factor, which was poorly affecting my health, the virus. My new friend at the time, who is now an RN, walked with me through the rough of it. My friends helped me deal with the unusual requirements of the treatment. I was to eat 10 grams of fat with each pill, which when one has no appetite, is rather hard. So I'd stuff my face with crumb donettes while taking my pills, or a handful of nuts, depending on which was available. The treatment was twice as hard as anything else I'd taken previous, and it would bring me to the floor in exhaustion. Three months after I'd started my third treatment, I found myself in a hospital ER asking for a puke bucket. Not a few seconds later however, missing the bucket altogether, but thankfully the floor would catch most of the nearly two units of blood which projected itself from my mouth like a font. The next few moments were a bit hazy, but needless to say, they gave me an express pass to a bed, I skipped the whole ER line. They began the process to infuse blood and figure out where the internal bleeding was coming from. Had I not recognized the signs from a previous hospitalization, I'd probably have bled out even more en route to the hospital.



This was the beginning of my symptoms manifesting regularly, as prior to treatment I'd received a MELD score, indicating the need for liver transplant. I was creeping closer to thirty, so my doc's warning was ringing in my ears. This failure was hard to accept, but like the others, I reassessed my life. I decided to leave my new job at Tech support and return to working with kids. Unfortunately over the course of the year I was building up my strength, my liver disease was making up for the treatments I'd been doing. My legs began to swell and retain fluid, an unusual manifestation of ascites, I'd been diagnosed with every symptom which comes with end stage liver disease.



(My Ascites acting up, 24 hours later with diuretics)

Hepatic Encepholapathy was the trickiest one, and one which helped get me relieved of the field I'd just reentered. My inability to do basic math proved challenging, but by using an excel spreadsheet, I felt I could compensate. The problem wasn't my health, the problem was that I wasn't who she wanted to hire, so they told me I was the best candidate they'd seen, and was welcome to reapply, however this position was determined to not be a right fit. The entire time she'd used my health as an excuse to push me out, encouraging me to take sick days during my evaluation period, planning meetings on days where I had appointments, knowing all of this would

hurt my chances to become permanent. After being let go, I was beside myself. This was the field I'd learned so well that they would ask me to come back as consultant to help fix up floundering sites. It was December of 2013, and I realized that my trajectory would have me disabled in no time. So we began the paperwork, and then, seemingly out of nowhere, something wonderful happened.

Part 2 to come 4/29 ahead of End The Epidemics

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