Rick Nash: An Advocate’s Journey Part 2

April 29, 2019 By Rick Nash

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A new treatment came out, one with a 90%+ efficacy. For the first time in my life I had real hope. I pumped up my advocacy efforts and began writing for HepMag at the invitation of Lucinda Porter, after she’d read my heart wrenching story submission and subsequently my blog I’d started during my third treatment. The treatment had to be off label, and combined with another DAA called Olysio, the combo was the first treatment to bring me to zero. And not only that, it had almost no side effects, it was life changing. My family and friends were excited for me, but this isn’t it. This isn’t the good part. It’s not even close. It was a high moment, where my family and friends enjoyed a month and a half of knowing I would live beyond thirty and maybe have a more typical life after I hit SVR12. These treatments all have a waiting period, for when one can be cured. Because it takes time to know if the treatment has been effective. That date is called Sustained Viral Response at 12 weeks or SVR12. I never hit SVR12, in fact not six weeks later I was hospitalized for C.Diff. The infection I’d acquired at a diner gave my remaining HepC the chance it needed, the jaundice was so bad, my eyes were golden yellow, and I was bumped up on the transplant list. I spent the week at the hospital, wondering when, and how I would leave. Transplant scared the hell out of me even though I knew it would ultimately save my life. Two days in they explained that my Hep C had returned. I wasn’t allowed to leave my room alone, but thankfully I had lots of friends and family come to visit. Even an old co-worker who I hadn’t seen is almost two years heard about it and stopped by. Also coming into the hospital with C.Diff is awful, but as I was spending a week there, at least I got my own room. I also wanted to confuse the CNAs so I had everyone bring in stuffed animals and “congrats on your baby” things, because humor is great medicine. Upon my release I was informed of a new treatment, and was slotted to take it by the end of the next month in November. It had a higher success rate at 98%, Harvoni also required 24 weeks, due to extent of damage done to my liver. But it was just as successful as the prior treatment, by six weeks I’d hit zero, and I’d maintained it up until May. Then, as we prepped for the annual Liver Life Walk, I received the news that my last week on treatment, the virus had rebounded, and failed again.

(Showing off the jaundice in my eyes during my C.Diff hospitalization)

The walk was tough, and my body was starting to have trouble dealing with the symptoms even with medication. The cascading failures, put me into a deep depression, and my girlfriend at the time, felt equally depressed. Months afterward, our state had degraded to an untenable point, the breakup though was fuel for change. Sometimes it takes a kick to see a different perspective to push someone out of a funk. I redoubled my efforts, crafted a routine to help me maintain my strength and fortitude, and told all of my friends to help watch for my HE symptoms, to tell me when I should take Lactulose to help ease it. I jumped back into things and began a search to find out exactly why the treatments failed and to see if there were any treatments which could match my specific situation. I found the specific mutations and why my treatments didn't work, so I proposed a combination of two treatments, combining Zepatier with Harvoni. My doc took it under advisement, but before anything could happen, my liver hit the point of no return. My liver, as my transplant doc described it best, was an old shoe, and it needed to be replaced before I could go on another treatment. My three year wait for a transplant had so far, gone without a call for a full healthy liver, so I knew it would be challenge going forward. To keep my mental faculties, and physical state intact I followed a friend to Dance class. There I found the perfect outlet to work around the temporary memory loss caused by HE, by introducing muscle memory to my memory castle techniques for memorization. Dance was at my own pace, and I kept a bag of intentionally chosen mixed nuts (the combo helped balance my electrolytes which would constantly be a wreck because my body would purge the retaining fluid or expelling fluid from diuretics.) Dance gave me a lot of my world back, but as my jaundice became impossible to hide, sunglasses at night were harder to pull off. I started working with a newly formed coalition of non-profits called CalHep, and helped them pass a pilot program by speaking with the assembly subcommittee. I was committed to ensuring no one else go through the hell I had, because it wasn't unnecessary if they can get treatment. At that time, there were restrictions on access, so that you needed to be F3, which is when permanent damage begins, to start treatment. While that's no longer the case in California, other states still have these heinous restrictions. I dedicated myself to helping in the fight to the best of my ability. But in September, I began a series of monthly hospital visits which could eventually lead to my death or maybe a transplant and everyone around me knew it. It was the most intense period in my life, and it also happened to be October of 2016.

So everything was becoming politically charged, and tribalism was making the fight for healthcare even harder. In September of 2016, I moved, along with my friends from the apartments we'd lived in for three years, into a four bedroom house. It was nice, and I'm thankful that my friends were able to do this with me, especially in the condition I was in. But in my shape, setting up for the move was hard, and during the process I passed out while explaining "no, I just need a double double from innout." What I didn't realize is that craving came from a complete lack of sodium in my body. In addition to that, I happened to be Hypocalcaemic, so when I arrived at the hospital they quickly assessed the situation and were more surprised that I wasn't in a coma, based on how low my sodium was. I spent the week in the hospital recovering, while my friends packed up my remaining things and moved me into the house. When I got home I started to organize things, and pack for a trip. My mom had decided that we should take a cruise ship to Mexico, so she invited me and even paid for a friend to come along. I understood why she was doing this, she wanted to have some good last memories if things should come to that, and she wanted me to have some enjoyment in this rather literal hell. I wish it would have had that.

The trip was made more challenging by an odd bit of advice. Counter to literally every other doctor I've had, the attending doctor, during my last trip to the hospital, told me that to beat Hepatic Encephalopathy I should really be consuming less protein and more salt. (just so we don't spread this around, that's TERRIBLE ADVICE, it's the exact opposite of what should be done, low salt, high protein is correct.) But the thing is, when you have HE, memory is tricky and confusing thing, so I followed his advice for a few weeks, including this trip. Needless to say I looked straight up pregnant, my ascites were such that my stomach actually started to hurt on its own, and I spent most of the trip vomiting and walking in circles to avoid leg cramps because I didn't pack my mixed nuts combo. When we returned from the trip I found myself in so much pain, I couldn't put on socks. The trip to the hospital had become so routine, I prepped my doc en route and told her what was going on. She confirmed what I'd suspected, I'd need a peritoneal tap. Thankfully they were ready for my arrival, and they rushed me into triage and started work right there. The reason for the concern was that peritoneal fluid can become septic if left for too long. And the pain was indicative, of just that: sepsis. My heart rate was such that the only pain med I could take was Ketamine. As they drained twelve pounds of fluid from me and placed an Internal Jugular port in my neck, to administer to anti-biotics, in an attempt to knock out the sepsis. I was lucky in that within 18 hours the antibiotics were working and I could slowly get better. This had also raised my MELD from 26 to 35. My higher MELD meant it was more likely that I could get a transplant, but I would wait and be denied not one, but three potential transplants while the election day would frustrate my television set in the background. Going home with a PICC line in, I didn't know how long I'd have left, I felt better, but I knew it was relative. I'd accepted, and come to terms with my death should it come to that.

(my transplant before/after and my amazing surgeon)

About three weeks later on December third, 2016, I received the call for my transplant. That day is one of the most vivid blurs, because only shortly after I arrived and cleaned up, I was prepped for transplant and put under. Five hours later, I was out. Everything had gone right, and within two days I was farting! Okay, yea, I get it, it doesn't sound impressive, but it's the first step in knowing that everything is hooked up and working properly. Within three days I was out of the hospital and kinda walking, I had to do a rollout method to get out of bed, because well, my abs were cut in half, but one adjusts. I was back on the elliptical within the week, and ready to get back into life. My friends and family all wanted to visit, but because of my fragile immune state, everyone had to wear masks and gloves, and no one who was sick could come over. Once ready, I returned home, and prepped for the next step in my recovery: treatment. Again. Because if this treatment didn't work, the virus would infect my liver, and I would be reliving the last three years of my life as my new liver slowly failed. But thankfully, my doc expanded on what I'd suggested a year earlier, prescribing me twelve weeks of Zepatier, Sovaldi, and Ribavirin. An off-label treatment designed to target my specific situation, and it was approved by insurance (every previous medication had been denied and required multiple appeals to push through, but this one was on Medicare.)

It too had its bumps, as I didn't zero out until eight weeks, my team was concerned I might not reach SVR24 because four weeks isn't a lot of time to stay zero while on treatment when you have the history I do. After weeks of stressing, calling lawyers offices and preparing for a large lawsuit should it need be done, I was relieved to get to SVR12, I wasn't quite cured, but it was a good sign. Then, 18 years after my initial diagnosis I was cured of HCV, in early September of 2017, I reached SVR24.

Reaching SVR, isn't the end of this journey, this experience emboldened me to help prevent others from having to experience it.

(Advocating for Patient care at a pres conference in summer of 2017)

In 2017 I was already writing for HepatitisC.net, working with CalHep, the American Liver Foundation and HepMag.com, but I needed to do more. In 2018 I started working with Help4Hep as a Peer counselor, I stepped up at HepatitisC.net as a moderator as well, I stepped up my volunteering, speaking with ALF and Lifesharing, doing TV interviews to promote organ donation, assisting CalHep in attempting to expand the pilot program I'd helped promote in 2016, and at the close of 2018 I was offered to be the Chair of the Consumer Committee at Eliminate Hep C San Diego. This year I started with a brand new nonprofit. Having been a patient advocate and a part of NoHep 2030 since it started, I knew that given our current prescription drug system, the goal is near impossible. Which is why I started working for this new nonprofit, Open BioPharma Research and Training Institute. I realize that the holistic drug marketplace has a lot of holes which increase prices, and one of those holes is manufacturing training, as there are drug shortages and lost development costs. So in an attempt to help smooth that process, I jumped at the chance to join Open BioPharma as their Outreach and Communications. It's been a while since I've written a whole cohesive outline piece of my story, I feel I should update all my fellow Hep C warriors and survivors about my progress over the years in one piece. If anything I hope my story inspires you to help someone close to you who has Hep C, who you may have not understood the potential for their plight, or to help yourself remind you that you have so much more potential than you know.

TLDR; When it comes to Hep C: Get Tested, Get Treated, Get Cured.

Also 4/30 is #EndTheEpidemics Day and I will be joining a large coalition of advocates in educating lawmakers on the hardships of living with HCV, our focus is to End the HIV and HCV epidemics, because we have the tools! so what are we waiting for?
