hep

The House Always Wins

February 16, 2015 By Rick Nash

For over five years I went to one of the best hospitals in the nation. In that time I was on treatment twice, and unknowingly suffered from ascities. My specialist in that time had seen me a grand total of nineteen times. I primarily had to make appointments with his Nurse Practioner (NP) in his stead.

For those of you not familiar with NPs, NPs are nurses who've gone beyond what an RN can do. NPs are essentially doctors without the MD, but have a more applied and patient-related experience. An NP, however, does not necessarily know how to handle some extreme or unusual cases, nor do they have the ultimate say in a patient's treatment. For these five years I had two different NPs, neither of whom fully investigated the scope of my issues, and when they did, the specialist was scant to provide a timely remedy. He was so hard to get an appointment with. I recall waiting three months for a time during the middle of the day, in the middle of the week, which was rarely fulfilled at the scheduled time-- I often spent hours in the waiting room. This was in part due to him being the only GI allowed to treat HCV in my part of the county's clinic.

Why was this acceptable? How could a hospital be so reliant on one man for their Gastro-Intestinal department? They built a system that favored surgery. I would learn his unavailability was in part because he did operations on Fridays and Mondays. Their GIs rotate surgery within the county and because of this can handle overloads in many localities, which is amazing. However it doesn't excuse the lack of dedication to the medical office side. It also didn't help that he was often out of office at speaking engagements elsewhere.

I had been with another medical group before this, and their specialist availability was equally horrid. This is why I suspected it was the norm. It would turn out the other group had a similar issue, only their doctors worked for multiple contracts at hospitals...literally next door. And they refused to see the need to hire more.

These two groups had different reasons for their doctors being unavailable. Both ended up serving me the same options over and over again. When I would eventually be referred to transplant, I was met with a cold, bleak man who did not disguise the fact that he didn't want to work with me. He cared more about the odds than the patient, and he was an asshole. He left a little before I switched healthcare providers.

I was on interferon/ribivirin twice in my life. The odds weren't in my favor for a repeat prescription. The second time I took it was double the dosage. In hindsight, my specialist knew of several drugs in the phase II and III that I could have waited for, rather than failing a second treatment. The next treatment I was on was an expansion and included Incivek. It would cure my mother, but nearly kill each of us. When the hospital's preferred insurance at my then-work began to get more expensive I switched to a different insurance and provider.

Upon switching to Sharp, I noticed the difference. The previous healthcare group I'd been with was

Scripps, and its surgery and transplant groups are fantastic. Ironically I'd left Scripps when a new transplant doctor started working there. I say this because Sharp handles transplant through Scripps. The new transplant doc was more invested in my well being and very well versed in what was going on in the GI world.
Another delight was my new GI specialist at Sharp. She asked better questions, and within a few meetings she assessed my situation better than any of the GIs I'd had before. I had unknowingly been suffering from ascities for near six years at that point, and it had been becoming more extreme. She was also able to quickly realize that my liver deterioration had led to encephalopathy, something that was evident for near three years by this point. She worked with me and my family to get me on the next two treatments in record time. I took Sovaldi/Olysio as well as Harvoni within weeks of their approval. Her bedside manner, her cooperation with the transplant office, and her willingness to work with my family to make sure these treatments could happen were nothing short of miracles from my experience. She was not hesitant to try new treatments, and she was very well-versed on the new RXs. In combination with the new transplant doc at Scripps, I had an entirely new team of amazing people working on me.

This post however, isn't about that dramatic shift. It's about something that I recently found out, regarding my previous GI and his inclination to use Genentech meds over others. I'm an avid fan of the Daily Show, and similarly began following John Oliver's Last Week Tonight. The show does fantastic bits of journalism with lots of humor built in. Recently they had an episode on prescription drugs that caught my eye. Most of the information wasn't all that new, however this website was a big deal. It tracks payments regarding doctors and their relationships with pharmaceutical companies.

https://openpaymentsdata.cms.gov/

I looked up my doctors. My new GI was clean, no influence had been bought. My first GI wasn't on their system, I presume he's retired to a private practice at this point. My second GI, the doc who'd been so unavailable due to surgeries and speaking/conferences or other out of office things had received over $35,000 in 2013 mostly from Genentech and Boehringer Ingelheim.

Genentech is Pegasys (Interferon) and Ribivirn. The drugs he favored used both of those prescriptions. The trips he took were often at Genentech expense and were labeled as " Compensation for services other than consulting, including serving as faculty or as a speaker at a venue other than a continuing education program." Given the information available it can be concluded that he was paid by the company to speak at conferences at their behest. It's also reasonable to conclude that the over $500 in food/beverage he was given during a collective two and a half weeks were centered around those trips being all inclusive.

BI produces newgen HCV drugs with less than 50% efficacy for Genotype 1a and 1b. He consulted for them and had a number of other sporadic trips and meals. As I know people who still have him as their GI, and we talk about our treatment options and what we learn from docs, I'm certain we'll see that influence pay into preference for those drugs, given his other records.
Look up your doc, your GI, and see what influence the RX companies are having. And above all, educate yourself on your options.

If you or a loved one has HCV check out: http://www.hepmag.com/drug_list_hepatitisc.shtml

and for anything else, ask your doctor what your RX options are. If you can wait a day or two ask to make a follow-up (call) to finalize prescribing the right meds, so you can give yourself some time to look up

your options. So you can have the best odds.
Information can be your greatest asset in getting the care you need.