We've Come a Long Way Baby

October 6, 2016 By Karen Hoyt

Karen Hoyt is a blogger who has a story about hepatitis C, cirrhosis, end-stage liver disease, liver cancer, and liver transplantation. This excerpt from Karen's blog was originally written in observance of World Hepatitis Day, is just as timely during Liver Awareness month, observed in October. The original first appeared on Karen's I Help C blog.

Look at us! There was a time when we didn't know what HCV meant. In fact, World Hepatitis C Day did not exist. There was not even a cure for Hepatitis C. The old Interferon and Ribavirin treatment didn't even come close, but it's all that many of you had. Some people cleared HCV on those drugs, but others were left to wait. Warehoused. Watching for the FDA approval.

Even when the first protease inhibitors were approved in 2011, everything was so dang iffy. It was all brand new, and the trial results weren't even public. If you had a "detected" viral load within the first month, they kicked you off of treatment. Information was scarce. Lucinda Porter and Alan Franciscus at hcvadvocate were putting out information as quickly as they could. But it was bleak. We were a scared bunch. Pam and her friends were advocating, and the forces grew stronger.

Advances came quickly:

Finally, the new triple therapy was available to the public. Heck YES! Many of us signed up to lose hair, throw up, have diarrhea, and eat protein at odd hours with our meds. We were like a bunch of lunatics! We got on forums and described every symptom that we experienced. We waited to see if our labs showed the virus was not detected. We honestly waited to die from the side effects. We shared "Shot Night" many times with strangers who had become virtual best friends.

We grudgingly embraced the side effects of anemia, killer skin rash, and suicide. (There were people that took their own life during trials) Freaking Brave we were – armed with anti-depressants, we dove into the cure.

Some of us made it through treatment with little or no cirrhosis. We jumped back into life with zest. Some of us felt the call and became supporters for the newbies. Many of you became advocates using your experience to help others link to care. Together, we learned about the new treatments. We were frustrated by the pharma wars. All we really wanted was to see the next round of treatments be easy and affordable.

Some of us were cured and felt relieved. Sadly, some of our livers had begun to fail. Even to this day, we huddle together against liver disease like puppies in a thunderstorm. I think we all know

that it’s not a perfect world. It never will be until it’s a Hepatitis C free world, but it’s a better place now because of the cure.

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