Mother’s Day with Hep C

May 8, 2020 By Rick Nash

Happy Mother’s day!

Mother’s day is special day for millions of women around the world. But for those of us in the Viral hepatitis community, mother’s day can be more complicated. For people like myself who got Hepatitis C at birth, through vertical transmission from my mother, this holiday pulls at a sometimes strained but now strong relationship. For people with Hepatitis B, vertical transmission is one of the most common forms of transmission outside the United States due largely to a lack of access to the Hep B vaccine. But unfortunately that’s changing in the US.

In the US Viral Hepatitis due to vertical transmission is on the rise. In an Ohio study From 2012 to 2015, Hepatitis C on the birth certificate nearly doubled[1], and that’s about par for the country. Each year the number of people born with Hep C on the birth certificate rise. That being said, for the expectant mothers reading this: HCV has a low rate of vertical transmission, about 5.8%, this rate nearly doubles with co-infection with HIV, at 10.8%. It is also suspected that acute hepatitis C during pregnancy may increase the risk of vertical transmission.[2]

While follow-up is equally abysmal, one study found as high as 55%[3] were lost to follow up and did not receive more information regarding their care.

I was lucky, my diagnosis of Hep C, was actually how my mom learned of hers’. At age 12, my family learned of our situation. At the time there were treatments, but not cures. The treatment had a low chance of Sustained Viral Response (SVR essentially means cured) and was 48 weeks long. Interferon is still used as a treatment worldwide, and also for Hepatitis B and D (what there’s a D? Yea, it’s actually a superinfection(or coinfection) with Hep B, It’s super trippy and affects millions.)

In the United States, this all is going to change soon for Hep C. Two major changes in the past few years have created a landscape which only needs one more element to start reducing the number of people who have Hep C, and the children who acquire it at birth.

The first change is new treatments, treatments are available as young as 3, although 12%-64% of vertically infected children spontaneously clear HCV[4] It’s important to consider treatment sooner rather than later to prevent the decline into end stage liver disease and permanent damage. Trust

me on this one, I've got the scars to prove it.

My decline began after high school, at age 18, my liver fibrosis had begun. By that point I'd watched my mom go through two treatments, and the intense failure of those treatments affected her, our family and her and my relationship. Because to her, successful treatment and cure for her, meant it could also do the same for me. We both saw the reality of her journey walking in step ahead of mine. Until 2011, when she tried one of the most intense treatments either of us have ever taken, and after seven grueling months, including three with bi-weekly blood transfusions and anti-cancer drugs. She made it through, and she'd hoped the same for me.

But when that didn't happen, and I nearly died while on it, our relationship hit another hard point. Because she'd felt an intense guilt, for "giving me" Hepatitis C. But as I still say to the day, it had nothing to do with her, and she had no control in the matter, and even if she'd known she had Hep C it still wouldn't have been her fault. I can't see this as forgiveness, as there was nothing to forgive, except for our mutual grief.

It is a virus, it does whatever it can to survive, we cannot be held responsible for the actions of another independently acting being, even if it feels like it's part of us. It is an agent of change and nature, like the wind. We must adapt and grow as best we can. It doesn't matter how we got here, what matters is we're here.

Thankfully, we're both alive have an outstanding relationship and are cured thanks to new the Direct Acting Antiviral treatments. Those new treatments have a 90%+ rate of efficacy, minimal side effects and can be as short as 8-12 weeks depending on liver damage, 24 weeks for higher amounts of liver damage.

But these new treatments are not the only cause of celebration. The CDC expanded their testing recommendations! Now they not only recommend universal screening, and rescreening for high risk groups. (thank you for all who publicly commented by the way, YOU helped make this happen)

More contextually important, they also expanded pregnancy screening recommendations: "Hepatitis C screening for all pregnant women during each pregnancy" This is huge, because one of the biggest losses for screening was prior to pregnancy, because it's double duty as a screening method.

These core changes will help us reduce the number of people who struggle with Hep C unknowingly.

And they will help us all Eliminate Hep C.

References

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[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6512319/

[2] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6312659/#hep41282-bib-0004

[3] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6252153/

[4] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6312659/#hep41282-bib-0004

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