Stigma: It’s not me, it’s you

September 13, 2017 By Rick Nash

When I turned 20 I started seeing a new doctor. He was my mom’s doctor, and this was our third meeting, at a little after age 21.

“I’m surprised to see someone of your age in here with Hep C.” My GI doc began. “Before we even talk about treatment, it’s important that you stop any drugs you’re doing.”

“Done. I’ve stopped all of them, what do I do now?” I quickly replied.
“When did you stop?” He probed
“That’s a hard question, because it implies I started at some point.” I remarked.
“I’d appreciate it if you answered the questions appropriately.”

I told him that he literally just had an appointment with my mother, that she disclosed to him my existence. That in previous appointments with him I’d explained that I’d never done any drugs outside of a medical setting and that my mother was the source of my Hep C.

This doctor was one of the foremost researchers with Hep C. This was one of the best doctors in one of the best hospitals in the nation.

Stigma.

When I was around that same age I started looking online for advice, for others. In 2007, I came across a few blogs, a few forums but what I found was just as disheartening.

I found chat rooms and forums of depressing posts filled with self hate and this repugnant idea that many with Hep C brought this upon themselves. Tigers earn their stripes, a notion that they should sit with pity.

I couldn’t keep reading.
I couldn’t participate in an echo chamber of pity and shame. Thankfully there was one large voice which would carry a torch to newer communities by being a positive source of accurate information: HCV Advocate

Things have shifted a lot since then, our communities are warmer and the repulsive word those old communities created to call themselves is by and large disappearing.

New forums started with some familiar faces but lots of new ones trying to learn more about DAAs (Direct Acting Antivirals like Victrellis (Discontinued) to Sovaldi which brought hope to many who'd been waiting for an oral treatment.
Those new and growing forums like HepMag and HepatitisC.net have helped to shift to the landscape of positivity in 2017.

What had changed was an important shift in opening our arms to newcomers: it doesn't matter where you came from, what matters is you're here.

It's something that is core to our success, because we can raise each other up rather than put each other down.

In my more recent hospital interactions, I find that when people assume I'm a former/active person who injects drugs (PWID), I politely correct them and ask them if it's relevant.

When speaking with others in my area with Hep C who are/were PWID I've found that some still blame themselves.

But if you're among them and you still believe that, you're missing the bigger picture.

It's not your fault, you are not that powerful.

It sounds weird, right? But thing is... If you have HCV (Hep C), nothing you did is why you have HCV. Something is, but even if you probably know the vector, and how is that useful now?

There is a mentality that helps deal with stigma:
I have HCV, and I want to be cured.
I am still me. HCV is my dragon.
I did not bring this upon myself.
No one chose this and no one earned it.
It is a chance to face my dragon.
It's time to become a dragonslayer.

Get tested. Get treated. Get cured.