Why I Am Passionate About Hepatitis C Support Groups

August 27, 2018 By Lucinda K. Porter RN

Recently, a member of the Hep Forum posted that after nearly three years since his successful hepatitis C treatment, the virus is back. It was shocking. This had to be a mistake. And although the member and his physician are sorting this out, this experience showed once again how amazing hepatitis C support groups are.

Science tells us that support groups work. You can read more about this in my general blog at www.LucindaPorterRN.com. We know that support groups help people with grief, health, disease, divorce, addiction, and so on.

In this blog, I want to go further, and discuss some unmeasured, intangible benefits that I noticed while reading the post about this member who tested positive for hepatitis C virus (HCV RNA). It was a powerful experience for me and underscored the reasons why I stress the value of support groups, especially for hepatitis C.

I'll start by saying that the Hep Forum member still doesn't have all the information yet in order to know how it is that he has hepatitis C after having a sustained virologic response 12 weeks after treatment ended (SVR-12). That's something he and his medical provider will sort out. But here is what we know as a group of Forum users: we pooled our collective experience and gave him valuable information to take to his medical visit.

Here is what else we gave him: support, compassion, and hope. These are not small ideas; these are the stuff that help us get up in the morning.

But the giving was not by any means one-way. I felt like I received more than I gave. I am eternally humbled by the courage it takes to be in a support group. It means being vulnerable, and who the heck wants to do that? I don't like to be vulnerable, but when I do, my pain is usually transformed. It's paradoxical – there is great strength to be found in our weakest moments.

Starting a support group was the first thing I did to try to change the way we were dealing (or not dealing with) hepatitis C in the United States. That was more than 20 years ago. And although I've been free of hep C for 5 years, I have never stopped participating in a support group. I believe that when we join with others, we defy stigma, we challenge the status quo, and eventually the power this virus has over us begins to loosen its grip.

This recent experience revealed another benefit. When I participate in the Hep Forum, and in this case in particular, I feel like the world works how it is supposed to. It’s not the world of the news; it is the real world. A place where people are kind and funny and don’t shoot the wounded. It’s not always perfect, but it knows how to right itself.

I don’t post as much anymore on the Forum. These days, most of what other members have to say is better than what I can contribute. But I stay close so I never forget what it was like. Also, I get a contact high from the love that’s shared there. It’s odd to care about people who I’ve never met, but that happens to many of us. And in that process, the caring lifts me up, carrying me far beyond the cyber world, and in to my daily life. That’s a good deal.