Hepatitis C and Your Future: Make Your Voice Loud and Clear

August 27, 2014 By Lucinda K. Porter RN

In my recent blog, *The Latest Hepatitis C Recommendations: Who Decides Your Future?*, I expressed my concern about the latest hepatitis C recommendations. For details, you can read my previous blog or the recommendations, but the short version is that patients with stage 1 or 0 fibrosis were assigned the lowest treatment priority. Insurance companies, state Medicaid programs, and health maintenance organizations can use this to deny treatment to patients in early stages. To me, this is sort of like saying to someone who has stage 1 cancer, "Come back when you have stage 2--then we'll treat you."

We need to fight back. It is time for hepatitis C patients to say, "This is unacceptable. Everyone deserves treatment." Here are some suggested actions you can take:

- Document your hepatitis C symptoms, especially fatigue and brain fog. Don't hold back. Doctors want us to feel better. Patients who have severe symptoms are more likely to be treated.
- If you want to do hepatitis C treatment, don't postpone it unless you really have to - January 2015 is when the United States Prevention Services Task Force/CDC's hepatitis C screening of Baby Boomers should begin. If there is an increase of referrals to liver specialists, it will be harder for you to get an appointment. Beat the rush and get your treatment taken care of soon.
- Speak up - Join the National Viral Hepatitis Roundtable (NVHR) or an organization that belongs to it.
- Sign NVHR's community sign-on letter.
- Contact elected officials, especially your U.S. Congressional Representative and Senators.
- Find out what your state is doing, and what groups are working to make a difference.
- Don't just get mad - get active. Write opinion letters (op-eds) to your local paper. Let the drug company know that you are angry about the price they set.
- Donate money to organizations that are fighting to make a difference.
- Strategize with other hepatitis C patients. You can find patients on the Hep Forum.

- Spread the word, especially with social media - we need an ice bucket challenge, preferably something drought-friendly.
- Take good care of your health. The best way to keep from progressing is to abstain from alcohol, keep your weight in check, and exercise on a daily basis.

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