Hepatitis C: Looking Behind, Looking Ahead

December 29, 2014 By Lucinda K. Porter RN

I was reading Hep's *2014 Top Treatment Stories*, and concluded that from a hepatitis C standpoint, 2014 was quite an amazing year. Here is my list of a dozen important events relating to hepatitis C:

1. FDA approval of Gilead Sciences' Harvoni (sofosbuvir/ledipasvir)
2. FDA approval of AbbVie's Viekira Pak (ombitasvir, paritaprevir and dasabuvir, along with the previously approved drug, ritonavir)
3. Approval of Olysio/Sovaldi (simeprevir/sofosbuvir)
4. Report of three patient deaths related to Olysio use in Japan
5. The outrageous problems consumers are having getting insurers to pay for hepatitis C treatment
6. The amazing job Gilead Sciences' Support Path has done with serving the hepatitis C community (Oh Gilead, if you would only lower the price, you might reach superhero status)
7. Express Scripts' announcement that it will cover hepatitis C treatment for people at all stages of liver disease, except those at very advanced stages of cirrhosis. However, Express Scripts will discontinue use of Harvoni and Olysio and will limit access to Sovaldi. (Oh Express Scripts, if you only knew how hard ribavirin is you might rethink this)
8. Hepatitis C rise in young people and nursing homes, including an outbreak in North Dakota
9. A Michigan bill that would make it a felony to not tell a sexual partner about hepatitis C infection passed the Michigan Senate
10. Medicare backing off Olysio/Sovaldi treatment restrictions
11. Availability of Sovaldi in Egypt and India
12. The updated **HCV Guidelines** by the American Association for the Study of Liver Diseases (AASLD) and the Infectious Diseases Society of America (IDSA)

Looking Ahead

This past year can be summarized using the expression "two steps forward, one step back."

- Step forward: Three new hepatitis C treatment combinations were approved. Step back: Access to hepatitis C drugs is restrictive.
- Step forward: Express Scripts opens the door to hepatitis C treatment to people with early stage of liver disease. Step back: Many Express Scripts users will be restricted to hepatitis C treatments that use ribavirin, a drug that has many side effects.

- Step forward: We can cure hepatitis C. Step back: More people are dying from hepatitis C, and hepatitis C is on the rise in young people.

How do we change the momentum, so that we keep stepping forward without going back? We need to claim our right to humane treatment. It is time to get past the stigma of hepatitis C and concentrate on curing everyone. How do we do this? Here are a dozen ways:

1. Speak up. Alan Franciscus, founder of the Hepatitis C Support Project and the HCV Advocate suggests this, “There are too few people who understand hepatitis C. I challenge people to commit to telling 10 people about hepatitis C and ask those they tell to tell 10 others.”
2. Tell your story. Ryan Clary, Executive Director of the National Viral Hepatitis Roundtable (NVHR) said, “The only way to make sure that elected officials, the media, and the general public are aware of hepatitis C is for everyone to tell their story and show the face of those affected by the epidemic. Members of Congress need to know that their constituents are affected. The public needs to know that their family, friends, and neighbors are affected. The media needs to see the diversity and broad range of affected individuals. By telling our story, we can change the story.” HepStories makes it easy to tell your story.
3. Stay informed. Hep brings the latest hepatitis news, helping readers to know the hot topics.
4. Join NVHR or an organization that belongs to it.
5. Sign community action letters when you have the opportunity.
6. Contact elected officials, especially your U.S. Congressional Representative and Senators. For more ideas, check out the Viral Hepatitis Advocacy Toolkit
7. Find out what your state is doing, and what groups are working to make a difference. For instance, Project Inform offers both local and national opportunities for making a difference.
8. Don’t just get mad, get active. Write opinion letters (op-eds) to your local paper. Let the pharmaceutical industry know that you are angry about the prices they set. Inform the insurance industry that their policies are inhumane.
9. Donate money to organizations that are fighting to make a difference.
10. Strategize with other hepatitis C patients. You can find patients who are making a difference on the Hep Forum.
11. Spread the word, especially with social media. Anyone with email can include an automatic signature with a hepatitis C advocacy message. Here are some lines to consider: a) *Be an organ and tissue donor. Check out* ***donatelife.net,*** b) *75% of those with hepatitis C were born from 1945 through 1965,* c) *The CDC recommends testing all Baby Boomers for hepatitis C.Hepatitis C causes more deaths in the U.S. than HIV does,* d) *Hepatitis C: Don’t get scared--get tested,* e) *Hepatitis C is preventable and curable.*
12. Take good care of your health. Being healthy is a radical act and inspires others to do the same.

Looking forward to changing the world with you in 2015.

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