

## In Memory of Jacques Chambers

—Alan Franciscus, Editor-in-Chief



On January 11, 2016, we lost a friend, colleague and long-time contributor to the HCV Advocate—Jacques Chambers. Jacques died after a brief illness.

Jacques started as a volunteer with HCV Advocate. Soon thereafter he joined us as a regular columnist with the HCV Advocate Website for over 13 years.

Jacques wrote about disability, insurance issues, discrimination, Medicaid, Medicare, Social Security, and just about anything we would ask him to write. His command of the issues was extraordinary. If he did not quite understand an issue, he would research it, and if Jacques felt that he could write it, he would cover it in depth.

Jacques also had a big heart, a lot of compassion and patience. We would get emails from people all over the country, and he would patiently answer all of their questions. Not only would Jacques receive emails about hepatitis C he would receive emails from people with other diseases and conditions. Jacques was always there to answer their questions. Some emails were so confrontational and rude that I would advise him to ignore if he should so choose. Jacques, however, took his time to answer even these emails with his usual grace and expert knowledge.

I always learned from his articles. He was a superb writer. He also had an excellent sense of humor. I remember once after reviewing one of his articles, I sent it back to him and commented that I always learned something from reading one his articles. The next day he sent his invoice and he wrote: “learning ain’t cheap.”

Jacques lived a wonderful life full of service. He helped so many people, and we should celebrate all that he accomplished during his long life.



APLA posted a moving tribute to Jacques at <https://www.frontiersmedia.com/frontiers-blog/2016/01/21/apla-tribute-to-jacques-chambers/>

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 **Health Wise****Generic Hepatitis C Drugs**

—By Lucinda K. Porter, RN

Hepatitis C was destroying Australian Greg Jefferys' liver. In 2015, Sovaldi and other new direct-acting antivirals were unavailable in his country. Greg could die or fly to India, and obtain hep C treatment using generic medications. He chose the latter and is now cured. However, that is just the beginning of the story. Greg used his experience to help countless others in the world, starting a cascade of events that opened the door to treatment for all Australians.

This month I provide information about obtaining generic hepatitis C drugs from outside the U.S. This is the most controversial subject I've ever discussed in my *Healthwise* column. The opinions expressed here are strictly my own and not necessarily shared by the HCV Advocate or its staff.

I am risking my reputation. However, it's a risk I am willing to take as long as physicians, state Medicaid programs and insurance companies continue to deny hepatitis C treatment to their patients. My reputation seems small compared to the health of my fellows with hepatitis C.

Before you compose hate mail or type "generic hep C drugs" into your search engine, please read the following:

- Hepatitis C treatment should always be medically supervised, regardless of where you purchase the medication.
- My remarks only pertain to hepatitis C generics, and should not be generalized to other medicines.
- I am not endorsing the use of a particular hepatitis C drug, generic or brand name.
- Never buy medication from a source unless you completely trust it.

- Generics should be a last resort option. If you have health insurance, pressure that plan to pay for your treatment. It's wrong of insurers to deny treatment, and as wonderful as a trip to India or Australia sounds, you have the right to get these drugs in the U.S. from the company who covers you. If treatment is denied, pester them with appeals before accepting a final refusal. If treatment was denied last year, try again this year. If you don't have medical coverage, get help from a patient advocacy program. Resources to help you fight for coverage are provided at the end of this article.

The reason why I want you to fight for coverage is that if everyone gives up, the situation won't change. If insurance companies have to pay for hepatitis C treatment, they will complain about the price to the drug companies. If insurance companies keep denying treatment, the drug companies won't sell their drugs. Either way, the price is likely to drop, and access to treatment may



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improve. Australia is a beautiful example. A year ago, Australians didn't have Sovaldi, let alone Harvoni. Beginning in March, the latest drugs will be available without restrictions to all Australians, including the incarcerated. It will cost up to \$37.70 per person. Access is granted regardless of level of liver damage and substance use. Australia wants to eradicate hep C in one generation.

**My Fears about Generics**

People die while taking hep C drugs. These deaths may be unrelated to their treatment, but nonetheless, it leaves one to wonder. I am afraid that someone is going to die while taking generics. However, I also fear that people will die or suffer needlessly because they aren't able to get treatment. On average, more than two people die every hour in the U.S. from hepatitis C. We have to do something.

I am concerned that people will take phony hepatitis C medications, or even worse, contaminated ones. All generics are not equal. If you go down this road, it is critical that you purchase from a reliable source, test before you ingest, and take your medication as prescribed. In addition to being medically monitored, you need to know:

- That the hep C drug is appropriate for you and not contraindicated
- What medications can interact with your hep C drugs
- How to take the medication prescribed for you

**Importing Generic Hepatitis C Medications**

**Is it legal?** It depends on your interpretation of the [FDA regulations](#), but my sources say yes. Here is what the FDA says:

*...it typically does not object to personal imports of drugs that FDA has not approved under certain circumstances, including the following situation:*

- *The drug is for use for a serious condition for which effective treatment is not available in the United States*

*(my note: if you can't get it, then it isn't available);*

- *There is no commercialization or promotion of the drug to U.S. residents;*
- *The drug is considered not to represent an unreasonable risk;*
- *The individual importing the drug verifies in writing that it is for his or her own use, and provides contact information for the doctor providing treatment or shows the product is for the continuation of treatment begun in a foreign country; and*
- *Generally, not more than a 3-month supply of the drug is imported.*

**All generics are not equal**

**How do I know that I am getting quality medication?**

As of this moment, the only source I trust is the FixHepC Buyers Club. They don't sell medication directly, but they help you buy it, have it tested, and then delivered. I have communicated directly with people who have used the Buyers Club, and I have not heard anything negative.

**Note:** Treatment with generics is likely to have the same response rate as brand name drugs, which means that some people will fail treatment. Dr. James Freeman of the Buyers Club is conducting research using generics.

**How much will it cost?** Depending on what you need, and for how long, between \$1050 and \$1700 USD.

**How do I do it?** Contact the FixHepC Buyers Club and follow instructions.

- Get a prescription for the required medication from your doctor. You can use the online doctor service

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GP2U Telehealth in Australia, but I am adamant about having a U.S. doctor too.

- Send the prescription, the authorization agreement, and your payment to the Buyers Club.
- Your tested medication will be shipped to you.

### Medical travel

Perhaps like me, you don't want to fork over your credit card to a stranger and trust that Fed Ex will deliver the precious medication. You would rather fly to Australia or India, and return with the goods. India is cheaper to visit than Australia is. If travel to India is your first choice, contact Greg Jefferys (*see Resources*).

*A Doctor who prescribes generics may be hard to find*

Here is how medical travel to Australia works: contact the Buyers Club and tell them you are interested in travel to Australia. Likely they will suggest you go to GP2U on the web and make an appointment with Dr. James Freeman, an Australian online medical consultant. Freeman has been doing telemedicine for a long time, and this service will walk you through the steps. Again, I can't overstress the importance of also having a U.S. medical provider who will follow you when you return.

When you book a flight to Australia, plan on a 5-day stay. Australia requires a [visa](#), called an ETA. Australia is a wonderful country, and personally, if I was traveling that far, I would go for at least 3 weeks. However, if you are really pressed for time then you can speed this process up to 3 nights.

### Working with Your Doctor

This may be your biggest obstacle. Doctors are uncomfortable with unknowns, and they have taken an oath to "Do no harm." If you are injured or die, they don't just worry about being sued; they worry about you and your family. If they work in a group practice, they could lose their job. A doctor who prescribes generics may be hard to find.

However, your doctor may be frustrated by insurance denials and worried about you. If your doctor is unwilling to write a prescription, ask if he or she will follow you if you obtain a prescription outside the U.S. If they need more information, give them a copy of this article. Mike Galbraith, a high school teacher in Arkansas took generics with the support of his physician. It's too soon to know if he is cured, but so far, he's on track. Fortunately, he had the resources to obtain generics, which is not a choice for those with limited incomes. However, it horrifies me that it was his only option. There is something deeply wrong when a person can't get treatment for a curable disease because health plans decide who can and who can't. However, we wouldn't be in this position if hep C medications were more reasonably priced. Maybe insurance companies should think about branching out into travel medicine?

#### Resources to Help You Obtain Generic Hepatitis C Treatment

FixHepC Buyers Club <http://fixhepc.com/blog.html>

Greg Jefferys <http://blogs.hepmag.com/gregjefferys>

Patient Advocate Foundation's Hepatitis C CareLine <https://hepatitisc.pafcareline.org>

Lucinda K. Porter, RN, is a long-time contributor to the *HCV Advocate* and author of *Free from Hepatitis C* and *Hepatitis C One Step at a Time*. She blogs at [www.LucindaPorterRN.com](http://www.LucindaPorterRN.com) and [HepMag.com](http://HepMag.com) 

## SNAPSHOTS

—Alan Franciscus, Editor-in-Chief

**Article: Influence of female sex on hepatitis C virus infection progression and treatment outcomes—D J Tasi et al.***Source: Eur J Gastroenterol Hepatol. 2016 Jan 7. [Epub ahead of print]***Study Aims and Results**

The purpose of the study was to understand the effect of female sex and socioeconomic status on hepatitis C—specifically, disease progression and HCV treatment.

The study was conducted at the Ottawa Hospital and Regional Viral Hepatitis Program. The data was collected on 1,978 people with chronic hepatitis C—630 (32%) were women.

**Conclusions**

Women were more likely to be non-genotype-1, Black or Asian, and immigrants from Africa and Asia. The women had lower liver enzyme levels, lower HCV RNA levels, and lower weight compared to men.

In women under 50 years of age, the average fibrosis score was lower than in men. In the women over 50 years old the average fibrosis score were similar to men—the authors noted that the disease progression of women accelerated after 50 years old to match the progression of men.

Compared to men, the women in the study with lower socioeconomic status were more likely to be coinfect

with HIV and hepatitis C and have a higher rate of fibrosis progression.

The women were less likely to have started interferon therapy. The cure rates were higher in the women when compared to the men in the study. However, the women who lived in low-income neighborhoods were less likely to achieve a cure than women living in higher income areas.

**Editorial Comment**

Previous studies have shown that, in general, pre-menopausal women have a slower degree of disease progression and higher cure rates with interferon-based therapies. This would suggest that pre-menopausal women should be treated before menopause to decrease the chances of increased liver disease progression.

This study highlights how gender can affect the progression of fibrosis. The other outcome highlights how socioeconomic status can have such a significant influence on both disease progression and HCV treatment outcome at least on interferon-based therapies.

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***This would suggest that pre-menopausal women should be treated before menopause to decrease the chances of increased liver disease progression.***

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## Article: Interferon-free treatment with sofosbuvir/daclatasvir achieves sustained virologic response in 100% of HIV/HCV-coinfected patients with advanced liver disease—M Mandorfer et al.

Source: AIDS DOI: 10.1097/QAD.0000000000001020

### Study Aims and Results

This was a retrospective study—looking back at a study that had already been conducted. The study involved the treatment of sofosbuvir plus daclatasvir to find out if treatment was effective in HIV/HCV coinfected people with advanced liver disease and/or portal hypertension (a symptom of advanced disease). A total of thirty-one patient records were accessed from the study. Liver stiffness was evaluated—94% of patients had fibrosis F2 (45% F4 or higher (fibrosis scale is F0 to F4 with F0 being no fibrosis)). The genotype distribution was HCV genotype 1 (68%), genotype 3 (23%) and genotype 4 (10%). Fifty-two percent were treatment experienced.

*Treatment Duration: Genotype 1 & 4—without cirrhosis: 12 weeks; with cirrhosis 24 weeks. Genotype 3: 24 weeks. Interestingly, if viral load was detected 4 weeks before the end of treatment, treatment was extended for an additional 4 weeks.*

The cure rate was 100% (31 of 31 patients). There was also an improvement in the health or histology of the liver. The treatment was safe and well-tolerated.

### Editorial Comment

This is an interesting study. A retrospective study is not the gold standard in clinical studies since it was not designed from the beginning looking for outcomes. However, this study has some important implications. What I thought was impressive about the study was the degree of advanced disease and, of course, the 100% cure rate. There was another remarkable result of this study. At the 4-week mark prior to the completion of treatment, the viral load was checked. If it was detectable, the treatment period was extended for an additional four weeks. This approach is dead-on! If only we could get insurance companies to think outside of the box and approve this approach. What a fantastic way for patients and medical providers to approach managing and treating patients.

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***The cure rate was 100% (31 of 31 patients). There was also an improvement in the health or histology of the liver.***

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## Article: Prevalence of HIV, hepatitis B, and hepatitis C in people with severe mental illness: a systematic review and meta-analysis—E Hughes et al.

Source: *Lancet Psychiatry*. 2016 Jan;3(1):40-48. doi: 10.1016/S2215-0366(15)00357-0. Epub 2015 Nov 29.

### Study Aims and Results

This was a meta-analysis—a study that searched databases for studies that had similar criteria—about the prevalence of HIV, hepatitis B and hepatitis C among people with severe mental illness. The databases searched were published between January 01, 1980 and January 01, 2015. The search included studies published worldwide. A total of 91 clinical trials met the authors criteria for inclusion into their meta-analysis. Forty-four studies were identified for human immunodeficiency virus (HIV); 19 were identified as hepatitis B (HBV); 28 studies were identified for hepatitis C (HCV).


### Conclusions

I am only including the pooled data from U.S. studies—the prevalence of HCV—4-17% and the prevalence of HIV—6%. HBV only had the pooled prevalence for North America—2%. The authors noted that there were three common factors that increased the risk of blood borne infections (HIV, HBV, HCV) “first being black and female, second injection drug use, and third engaging in risky sexual behavior, including not using a condom, having multiple partners, sex trading, and unprotected sex with a partner who is infected with a blood-borne virus.”

### Editorial Comment

The results in the study were not reaffirming. Some of the numbers in the studies outside of North America had very low prevalence numbers which means there was very little testing. Obviously, more testing of HIV, HBV and HCV is needed in people with severe mental illness. In North America the rates for HIV, HBV and HCV were high which is not surprising because of the similar transmission routes.

Regarding HCV, the biggest barrier to treatment of people with severe mental illness was that interferon-based therapy was wrongly perceived as an obstacle to treatment. Now that we have an interferon-free therapy we should be treating this vulnerable patient population.

Another important issue with mental health and hepatitis C—we know that the hepatitis C virus can cause depression and worsen mental health problems. It might be helpful to study if curing hepatitis C improves severe mental health issues. 

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***Now that we have an interferon-free therapy we should be treating this vulnerable patient population.***

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## HCSP Training Workshops – 2002 – 2015

—Alan Franciscus, Editor-in-Chief



*A 2015 training workshop co-sponsored by Andrea Lombard Connecticut's Adult Viral Hepatitis Coordinator and Sue Dubb, PHN Uncas Health District.*

It is with some regret that the Hepatitis C Support Project (HCSP) Train-the-Training Workshops have been discontinued. We have stopped the workshops for many reasons. One of the reasons is that there are many more national, state, regional and local resources and advocates available to provide these services to the hepatitis C community. We thought it was time to retire the program, and hopefully, people in their communities will continue to provide and expand these vital services.

Now that I am not constantly traveling and conducting training workshops I will be able to concentrate my time and energies on our Website—[www.hcvadvocate.org](http://www.hcvadvocate.org). I have many plans to increase the amount of information we provide to help educate the HCV community.

**History:** Hepatitis C was my second real career. When I was able to work full time in hepatitis C, it was a dream come true. Conducting the workshops was my ultimate dream job. In 2001 the Hepatitis C Support Project (HCSP)/HCV Advocate started our hepatitis C training workshops in Northern California. The Northern California training workshops proved so successful that we were able to secure funding to 'go national.'

The training workshops started out as 2-day workshops that covered the liver, viral hepatitis (hepatitis A, B, D, E and more) but we mainly focused on hepatitis C. About ten years ago we condensed our training workshop from 2

days to one day (8 hours) and recently down to 6 ½ hours. We were able to condense them because the general overall public knowledge about hepatitis C had increased.

We have conducted many, many workshops around the country and multiple ones in most states. In fact, I have personally conducted numerous workshops in every state—even one in Canada and Mexico. By the end of 2015, we have trained about 16,000 people. Lucinda K. Porter, RN was our other main trainer and loved the training workshops as much as I loved them. People often ask me what the best and the worst of the training experiences.

There were very few 'worst' experiences or states that I visited. Every training and state had something positive about it. It was a gift to be able to see our country and meet some of the most amazing people working in hepatitis C. There were a couple of years traveling around the country that I built in a day or so to do some sight seeing. If I had to drive to a workshop site, I would pull over or drive to a hiking trail to do a bit of hiking. Nature was a great respite from all the stress of the travel. During the last five years, however, all I wanted to do was get to the city of the workshop, do the training and get home. I still enjoyed the training workshops, but the traveling took its toll. One year I traveled 150,000 air miles, and that's not including the miles I drove.

**Best State:** The most beautiful state that I've traveled to is Alaska. Visually it is breathtaking. I had just conducted a training workshop with another trainer (Carol C), and we decided to rent a car and blitz the state in 4 days. It was a perfect time to visit—summer was transitioning to fall. The leaves had changed, and it had just snowed. We visited up north, took a two-propeller plane ride over the southern portion of Alaska (and saw a couple of black bears), took a boat



**HCSP Training Workshops – 2002 – 2015 – CONTINUED FROM PAGE 8**

ride out of Seward, AK and saw wildlife and glaciers. All of this on interferon therapy and I still remember it as an enjoyable experience.

**Worst State:** There is no state I considered to be a horrible or ugly state. Every state has some beauty in if you plan for it and talk to the local people for advice. I used to think that this state or that state would be terrible to visit, but every state has something for everyone. There are so many kind people all over the country.

**Best Experience(s):** The best part was meeting the people at the workshops. The people that do our work always inspired me. These people are out there doing the important work, and many don't get any acknowledgements of the good job they do.

One of the best experiences was working with the Adult Viral Hepatitis Coordinators (AVHC). The AVHC's was a perfect partnership with us. Thank you to all of the AVHC's who worked with us and helped us to make the HCSP training workshops successful.

**Worst Experience:** Anyone who has traveled and conducted training workshops can tell you that it is a grueling experience. It takes an enormous toll on your health—physically and emotionally—you lose track of friends, you may not be able to have all the experiences you can have with your family and friends. You start to have health problems from eating unhealthy food; the stress is continual...blah, blah, blah.


However, probably the worst experience I had when I was treated with pegylated interferon plus ribavirin therapy for 70 weeks. I was dragging my butt all over the country – I conducted 65 training workshops in one year, reported on two major conferences, published 17 newsletters (and wrote articles), wrote educational materials and much more. To tell you the truth I do not know how I did it – what I mean to say is that I remember very little about that time.

I had a bunch of help during this period that got me through the worst of it and best of all **I was cured!**

**Rose Christensen:** While I was the person out traveling around and conducting the training workshops—Rose Christensen—our office manager and training coordinator was behind the scenes taking care of the planning of the training workshops and conducting the day-to-day office duties that kept everything running. This was no small feat. I would frequently hear back from people how Rose made the workshop planning and implementation a professional, pleasant and easy experience. She deserves a lot of the credit for the success of the workshops and HCSP over the many years.

**Final Run:** The last two workshops were held in December 2015 in Texas. I worked with Larry Cuellar—Adult Viral Hepatitis Coordinator for Texas—and we finished 2015 and my career of training workshops.

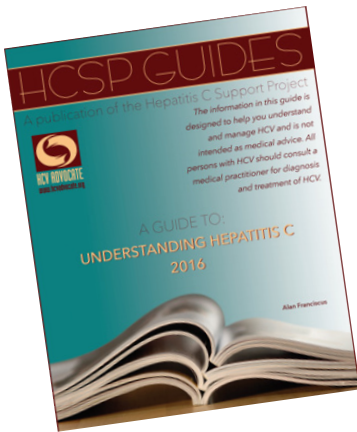
Larry presented Rose Christensen and me with commendations for providing services to the Viral hepatitis communities in Texas.

It was a fantastic way to end the year and my career as a National HCV trainer. 



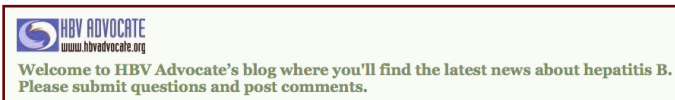
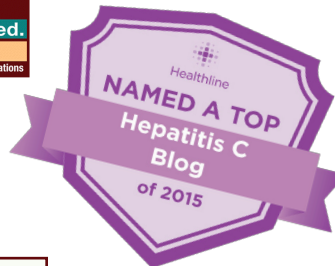
*Larry Cuellar presents Alan Franciscus and Rose Christensen with a commendation.*

# WHATS UP!



## A GUIDE TO UNDERSTANDING HCV 2016

We have updated our most popular publication to include information for 2016. Please feel free to download, read, print and distribute.



On January 31st, our blogs are changing! For simplicity and consistency, we are moving all of our blogs to the same host and the Wordpress platform. The old addresses will permanently redirect to the new ones, for sites that may still point to the old address. The new blogs will look very similar to the existing blogs, except for slight look and feel differences. The new blogs do have really one noticeable enhancement: instead of a tiny pencil icon at the bottom of a post that you could click on to make a comment, you'll see a large bubble on the top right side of a post that clearly suggests you can "Make a Comment".

If you are a "Follower by Email" of any of these blogs, you have been getting emails containing our posts. The look of those emails will be changing a bit with the new blog. It will have the same header picture that the blog has, and will have slight look and feel differences as well. If you are not yet a Follower, please wait until we have cut over to the new blog to sign up to Follow by Email, as we have already moved the existing followers over.



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The HCV Advocate offers information about various forms of intervention in order to serve our community. By providing information about any form of medication, treatment, therapy or diet we are neither promoting nor recommending use, but simply offering information in the belief that the best decision is an educated one.

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