The Hepatitis C Support Project (HCSP) and the HCV Advocate website have been providing services to the hepatitis C community for more than 20 years. Our mission has been to educate and support hepatitis C (HCV) patients and their medical and service providers. Our goal is to help patients make informed decisions about their medical care. Lucinda Porter’s article on the following pages provide a snapshot of the services that we have provided over the many years.

As I mentioned in last month’s newsletter, this will be our last one. Also, we will be closing our website—HCV Advocate and the majority of our services. The target date to close our website is the end of August 2019. We will put our website on the internet so that the fact sheets, guides, and other information will be available, but the information will not be updated.

However, I will continue to provide information about HCV on our HCV Advocate Blog, Facebook and Twitter.

Thank you to the thousands of people who have followed and encouraged us through the many years.

—Alan Franciscus, Executive Director
accounts. Through these media, I will update our readers on current HCV-related news. I also plan to write original articles and provide some conference coverage. I hope you will join me to stay current on news and information about HCV.

Thank you to the thousands of people who have followed and encouraged us through the many years. It has been the experience of my life to work in HCV over the years. I have met and worked with amazing people who lived with and who have provided services to people with hepatitis C. Now, many people are living without hepatitis C, but there are still many more people who should be tested, treated and cured.

There are many people to thank who have supported me throughout the years. There are too many people outside of HCSP to thank. Within HCSP there are a lot of people I would like to acknowledge. Lucinda Porter, RN has been with us/me from the beginning, always ready to lend a hand when needed and a good friend and confidant. Lucinda has contributed with articles, publications, editing, and other duties. David Mazoff was instrumental in upping our A-game to take our organization to a level that I had not even thought we were capable of reaching as webmaster, editor, writer, and production of our materials and newsletters. Judith Barlow has kept our website going strong since taking over the Webmaster duties from David. Leslie Hoex helped us achieve a high level of sophistication with her awesome design and production of our educational materials and newsletter. But the person who was with us/me from the beginning and throughout the years is Rose Christensen. Rose is currently our Office Manager but has also held many different responsibilities throughout the years such as training manager, editing, proofing, supervising, organizing and just about every position at the Hepatitis C Support Project. We would never have achieved what we have without her dedication and her many talents. Rose has become a very close friend, and I have come to rely on her opinion, advice, and friendship. Thank you, Rose, for your dedication and friendship.

I hope you will continue to find the information I post on our blog and social media accounts relevant. Please see the links below if you would like to sign up.

Visit our blog: http://hepatitisc.hcvadvocate.org/

As they say... ‘That’s All Folks’ at least for the newsletter!

Alan Franciscus is the Executive Director of the Hepatitis C Support Project and the Editor-in-Chief of the HCV Advocate Website.
This is the last issue of the HCV Advocate and my Healthwise column. The decision to stop publishing the HCV Advocate is the right one, but I am sad about it. HCV Advocate occupies a huge and special place in my heart. Meeting Alan Franciscus was a life-changing milestone on the map of my world. Alan has been a friend like no other, and although we will continue our friendship, this column is a tribute to him, the HCV Advocate, and all who helped to build it these past 21-plus years.

"Alone we can do so little; together we can do so much."
—Helen Keller

The History of the HCV Advocate
Alan Franciscus is the founder of the Hepatitis C Support Project (HCSP) and its newsletter, the HCV Advocate. The project came about after Alan looked for support when he was diagnosed with hepatitis C (HCV) in 1996. At that point, hepatitis C was incurable. Finding no hep C support groups in San Francisco, Alan started his own. The rest, as they say, is history.

In 1997, Alan's first publication was the HCSP Information Packet. It is now titled, A Guide to Understanding Hepatitis C. It keeps company with hundreds of other HCSP publications, many translated into multiple languages.

The first issue of the HCV Advocate appeared in January 1998. It had five pages of text and was distributed via postal mail. The website would come much later. Every month, a few people met at Alan's tiny San Francisco apartment in order to assemble and send it out. By the end of that first year, the HCV Advocate had doubled in size.

The inaugural issue included a note from Ron Duffy of the now defunct HCV Global Foundation. Ron died two years later. He was the first of our colleagues we would lose to hepatitis C. His death fortified our resolve to increase our efforts. Sadly, Ron would not be the only friend we would lose to this disease.

The launch of www.hcvadvocate.org was a game changer. Free from the burden of paper, we could publish resources for everyone. Alan was always looking for an unmet need, and published information for the entire spectrum — from the newly diagnosed to medical professionals. He also made sure that the material varied in literacy levels, so that someone who could not read or not read well was being served.
**HealthWise**  A Farewell to the *HCV Advocate*  — CONTINUED FROM PAGE 3

Other highlights in HCSP’s history were:

- A national HCV program that trained more than 15,000 people, who in turn reached thousands more in their communities.
- Information about HCV/HIV co-infection.
- The Medical Writers’ Circle – a collection of 70 articles written by more than 40 experts in their fields.
- A column about work and disability issues.
- Creation of multiple related websites, offering information on topics such as hepatitis B, tattoos, and hepatitis C treatments in the research pipeline.

Additionally, there were numerous awards and flattering comments. As laudable as these accomplishments were, the real rewards came from readers. There were many thank you messages sent over the years, often written when someone’s despair had since been transformed in to hope. These messages were often gut wrenching, but always appreciated.

**“He who has health, has hope; and he who has hope, has everything.”**
— Thomas Carlyle

**Hepatitis C Treatment in the Time of the *HCV Advocate***

When the first *HCV Advocate* was published, hepatitis C treatment was tough to endure, and the results were discouraging. The response rates were around 8 to 9 percent for genotype 1; 30 percent for genotype 2 or 3. The only treatment was interferon. It was not yet pegylated, and injections were 3 times weekly. Ribavirin was not yet in the picture.

This changed around the turn of the century when ribavirin was added. The average genotype 1 patient achieved a response rate close to 30 percent; genotypes 2 and 3 jumped to over 60 percent. The biggest gains occurred when interferon was modified to the pegylated form. The response rates for genotype 1 patients jumped to around 50 percent; genotypes 2 and 3 averaged around 80 percent. Now hepatitis C is largely curable with all-oral medications. More than 90 percent of the time, people are cured in 8 to 12 weeks with drugs that tend to have mild side effects; some have none at all. If they aren’t cured with the first treatment, there are other medications to try.

HCSP’s staff had first-hand experience with HCV treatment. Nearly everyone had hep C, and nearly all of us tried treatment—some two or even three times. In the interferon days, it was amazing that we could continue to complete our work. Alan did a great deal of travelling, and I did a fair amount as well. Some days we could barely get out of bed, let alone on a plane. However, when you fight for your own life and the lives of those who share your disease, you find a way to get out of bed and on to a plane. Eventually, we were all cured.

Diagnostic testing is better too. Antibody and viral load tests are more accurate. Genotype testing is the norm. Liver biopsy procedures are being replaced with non-invasive procedures. We have come a long way.

**“If you think you are too small to be effective, you have never been in bed with a mosquito.”**
— Betty Reese

**The HCSP Team***

Over the years, more people than I can list have kept HCSP alive. I will name a few who were with us the longest. Rose Christensen began with the project practically from day one. She wore many hats during her years with HCSP, including business manager, trainer and board member. She is an integral part of the project, and I can’t imagine a world without her.

— CONTINUED ON PAGE 5
Since 2006, Leslie Hoex did the graphic design for the project and made the HCV Advocate into the lovely newsletter you are now reading. She never failed to deliver anything less than incredible.

David Mazoff was another vital force. HCSP soared into a new dimension when he became the webmaster and managing editor. Judy Barlow took his place, and is guiding us through the HCV Advocate’s final flight. Liz Highleyman was The Advocate’s first “real” writer. Although Alan and I wrote articles, Liz was the professional. She taught us a lot.

And finally, and sadly, there was Jacques Chambers. Jacques was an expert on the topics of disability, Medicaid, the Affordable Care Act (aka Obamacare) and health care navigation. He simplified these subjects, so that anyone could understand them. Jacques died in 2016. He did not have hepatitis C, and yet he helped to empower so many of us so that we could have healthcare.

There are the many more who contributed. You know who you are. Thank you for making a difference.

HCV Advocate’s Legacy

I believe that the HCV Advocate changed the world and made it a better place. Although we can’t claim to have found the cure for hepatitis C, we can honestly say that we helped people stay alive so they could be cured. We kept the light of hope burning.

However, the past is past. The only meaningful legacy is one that continues to live and grow. Hepatitis C is a curable disease but if awareness, prevention, and treatment remain low, hepatitis C will continue to replicate its treacherous viral self. At a replication rate of a trillion times a day, can we afford to wait any longer? The opioid epidemic is putting our progress in peril. We need to keep applying pressure to those who make health care policy. Do not turn your back on the progress we made together. Exercise your right to vote. Speak to lawmakers. Tell your story.

Life’s most persistent and urgent question is, “What are you doing for others?”

—Martin Luther King, Jr.

Thank You

I’ve come to the hard part, the place where I say farewell. The phrase, “thank you” says it best. Your courage and stories sustained me these 21 years. You inspired me, and for that, I am grateful. Thank you.

P.S. Although I won’t be writing for the HCV Advocate, I will continue to blog on www.LucindaPorterRN.com and HepMag.com. I am active on the Hep Forums and occasionally pop up at Hepatitis C Family and Friends on Facebook. In short, I am not retiring from hepatitis C work. Please keep in touch.

Lucinda 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 and HepMag.com
The first publication of the Hepatitis C Support Project was the HCSP Information Packet now titled A Guide to Understanding HCV. Since this is the last newsletter, we thought it would be a good idea to end it with an updated version of the ‘Guide.’ The ‘Guide’ provides comprehensive basic information about hepatitis C.