The Unsung Heroes of Hepatitis C
In the early days of the hepatitis C (HCV) movement, there was very little accurate information about HCV available to patients. Additionally, there was an incredible amount of stigma attached to a diagnosis of HCV and almost no support services for people with HCV. There were a few web-based organizations, but some of the information was dubious.

To fill this gap in services, HCV support groups formed to provide support, information and advocacy. Over the years hundreds of support groups were established across the country to help support and educate people with HCV. I was privileged to witness various groups and the power they had to transform the lives of people with HCV.

That power of being in a group setting, sharing personal stories and supporting people “in-person” was so incredibly important.

I can only imagine how many lives the support group leaders saved.

Now, there are web-based support groups such as Facebook that have mostly replaced the in-person support groups. They are not as effective as an in-person support group, but they do provide much-needed support, education and encouragement for people with HCV.

In think it’s important that when we look back on how the advocacy movement has grown that we remember and honor the leaders who contributed so much to the community and movement.

Alan

— CONTINUED ON PAGE 2

IN THIS ISSUE
Celebrating 20 Years .......................................................... 2
HealthWise Honoring Twenty Years of Hepatitis C Advocacy ........................................ 4
Top Ten Stories .................................................................. 7
A Year in the Life of a Trainer ........................................... 10
What’s Up ........................................................................... 12
That’s how long we have been publishing the HCV Advocate newsletter. I know it’s a cliche but these 20 years have gone by in a flash. What isn’t a cliche is that we have had amazing advances in hepatitis C (HCV) in the past 20 years.

When the HCV Advocate newsletter was launched in 1998, there was only interferon monotherapy. Interferon monotherapy could cure less than 10% of people who took it and the side effects were horrible. Cure? That word wasn’t even in use at that time. Now, we have drugs that can cure practically everyone, and the side effects are minimal.

Hepatitis C awareness in 1998 was nonexistent except among some patients and HCV medical providers. That was one of the reasons we started the newsletter. Pretty much everyone I spoke with, including medical providers, had never heard about hepatitis C. Patients wanted to understand more about hepatitis C so that they could educate themselves, inform their medical providers and make the best possible medical decisions. Now, many have at least heard of HCV, even if it is just about the high price tag of treatment. Additionally, we now have a robust advocacy movement, knowledgeable HCV medical providers, awareness programs to test people at-risk for HCV and educate the public about HCV. There is an HCV cell culture and it is now common knowledge that HCV is not just a liver disease—that is, it can affect many parts of the body. One instance is that HCV can cause type 2 diabetes in some people infected with HCV.

Beginnings

In 1996, shortly after a diagnosis of HCV, I started the Hepatitis C Support Project (HCSP). The HCV Advocate newsletter, our website and our national training program came later. Our humble beginnings started with support groups (HCV and HIV/HCV coinfected) and a local helpline. I also had one-on-one counseling in my home (I had no boundaries!). Additionally, I started to develop educational materials—the first one was our HCV Information Packet.

We raised money for these services with sidewalk sales in my front yard in the Haight Ashbury district of San Francisco, right next to the Haight Ashbury Free Medical Center—that was ALWAYS entertaining. We also received donations from friends, family, my personal savings account, and other members of our start-up non-profit. A friend gave me a very large personal contribution that kept us from going under at a critical time. Subsequently, we eventually received donations from our readership and pharmaceuticals that kept us in business for the long haul.
Celebrating 20 Years — CONTINUED FROM PAGE 2

The success of an organization is never because of one person. The people behind the scenes of HCSP and HCV Advocate are a talented group who brought their passion to make the organization a success. Without these devoted people, HCSP and HCV Advocate would not have been able to grow and persevere over these 20-plus years.

The Team

Shortly after an article about me appeared in the San Francisco Chronicle, I was contacted by many people from all over the country, San Francisco and the Bay Area. It was during this time that I met one of the people who would be instrumental in the success of HCSP — Rosanne Christensen. Rose started as a volunteer and shortly afterwards we hired her. Through the years, Rose’s role in the organization grew and she wore many hats—office manager, supervisor, part-time trainer, training coordinator, editor, training manager, and a good friend.

Shortly afterwards I met Lucinda Porter, RN at an ill-fated stint at another organization. Lucinda started as a volunteer. She has also become a good friend, and mentor. Lucinda has written articles, fact sheets, guides, and is an editor of our newsletter. Lucinda also heads up our Board of Directors. Lucinda, along with another medical provider wrote our first published and distributed educational material—A Guide to Making Sense of Research and Medical Literature.

Another person who started out as a volunteer was David Mazoff, Ph.D. who later was hired on as webmaster. David was also an editor, formatted many of our fact sheets, guides and occasionally wrote articles. David contributed to our success through the many years he worked with us before retiring in 2016 from HCSP.

Leslie Hoex—Owner of Blue Kangaroo Design, has been our design and production person almost from the beginning. Leslie has designed and formatted our fact sheets, guides, publications of distributed materials, mastheads; pretty much any design that you see is the work of Leslie. As you can tell from the materials, Leslie is a very talented designer.

Judy Barlow joined us in 2016 as our webmaster. Judy makes sure that our websites are running in tip-top shape and keeps the nasty bugs from infiltrating our various websites.

The people who work at HCSP/HCV Advocate all share a common trait—we are all hard-working, dedicated people that strive to provide highest quality accessible information to educate and advocate for our readership—the hepatitis C community.

Most of us who started with HCSP/HCV Advocate are still plugging away all these years later. HCSP/HCV Advocate has been fortunate to have such talented and dedicated people to sustain HCSP, HCV Advocate and our newsletter throughout the years.

We all keep moving along. I was hoping to ride into the sunset when we eliminate HCV. I don’t know if that is a pipedream, but hey it just might happen—dreams do come true…now if I can only remember who said that, I would hold them to it!

Check out HCSP Fact Sheet: A Brief History of HCV to learn more about how far we have come: http://hcvadvocate.org/hepatitis/factsheets_pdf/Brief_History_HCV.pdf

Alan Franciscus is the Executive Director of the Hepatitis C Support Project and the Editor-in-Chief of the HCV Advocate Website.
Honoring Twenty Years of Hepatitis C Advocacy

—By Lucinda K. Porter, RN

January 1998, Alan Franciscus launched the HCV Advocate. It was a paper edition consisting of six black and white pages. One of those pages was the cover page; so technically, there were only five pages of content. There was no website or digital newsletter. I didn’t write an article until March, and it wasn’t named Healthwise until September.

The HCV Advocate was the first regular hepatitis C newsletter. Although its beginnings were humble, its mere existence filled a huge need. My boss and mentor, Emmet Keeffe, MD believed in it so much that he was a paid subscriber. Dr. Keeffe’s money was well spent, and here we are, 20 years later. I am celebrating the event by looking back in order to look ahead. Here’s some brief history.

In 1996, Alan Franciscus was diagnosed with chronic hepatitis C virus infection (HCV). He looked for a hepatitis C support group in San Francisco. Finding none, Alan started his own. The rest, as they say, is history. After some brainstorming, the Hepatitis C Support Project (HCSP) was born.

In 1997, Alan’s first publication was the HCSP Information Packet. Now titled, “A Guide to Understanding Hepatitis C,” it keeps company with hundreds of fact sheets and other guides relating to HCV. The newsletter and literature are translated in multiple languages.

When the first HCV Advocate was published, hep C treatment was long, tough, and the response rates were low. The only treatment was interferon. It was not pegylated and injections were three times weekly. Ribavirin was not yet in the picture. Now HCV medications can cure just about everyone with a short, tolerable treatment.

I met Alan in 1997. I was a volunteer at a local underground syringe exchange site started by Joey Tranchini. Joey invited me to a meeting of people who were trying to increase hepatitis C awareness in the San Francisco Bay area. I met Alan there and like many people who meet him, I was smitten. Alan is fun, smart, driven, and humble. So, when he asked me to write for the HCV Advocate, it was easy to say yes.

One of Alan’s gifts is attracting others who are eager to make a difference. The list of contributors to the HCV Advocate is endless. Rather than forget to mention someone, please know that I honor you too in this anniversary issue. However, I must name one person, and that is Rose Christensen. She has worn many
Hats during her years with HCSP, including business manager, trainer and board member. Rose has been with the Project practically from day one and HCSP owes its life to Rose.

Of course, there are the many more who contributed. You know who you are. Thank you, thank you.

Those who know Alan, can probably guess that he is squirming over these accolades. Alan doesn’t like attention or praise; he likes action and results. So although I want to salute Alan, I know that the best way to honor him is to continue this work until hepatitis C is gone.

Which brings me to ask, “What do we need to do in order to eliminate hepatitis C?” Quite simply, we need you. 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?

You may be wondering what you can do to make a difference. It starts by saying, “Yes.” That is how Alan and I began. We and countless other hepatitis advocates didn’t turn our backs on this need. We didn’t let our own illness and incapacity hold us back. Alan was racked with hepatitis C symptoms, yet he focused on what he could do rather than on what he couldn’t do. It started with one thing, and one thing led to another. You may be saying, “I have no special skills.” That doesn’t matter either. When Alan began, he had no medical background and no known writing skills. He was terrified of speaking in public, and didn’t like to travel. However, one thing led to another, and Alan wrote thousands of articles, accumulated many miles on cross-country trips, and is a powerful public speaker. That is only a little of what he has done. (Stop squirming, Alan. This article really isn’t about you; it is about showing others how they can make a difference.)

Let’s get down to the nitty-gritty and discuss the opportunities to which you can say yes. To see where we are, you can read the 42-page progress report, “Progress Toward Viral Hepatitis Elimination: National Progress Report with Data through 2015.” (cdc.gov/hepatitis/DVH2017NationalProgressReport.htm) It’s interesting reading, but if you are new to advocacy, that’s not where I’d start. Here are my suggestions:

- Tell your story and put a face on hep C. This is a powerful way to defy stigma. (hepmag.com/hep_stories.shtml)
- Ask every baby boomer you meet to get tested.
- Join an online or in-person support group. When we care for our wounded, we help them fight for their lives. (forums.hepmag.com)
- Sign up for action alerts so you know what is going on. Make the occasional call, send a fax or email to
your elected officials—local, state or federal. Silence is apathy. Let them know you care about hepatitis C, and you expect them to care too. An office visit or speaking at public hearings has an even bigger impact. You can sign up for action alerts from NVHR (nvhr.org) and Caring Ambassadors (hepcchallenge.org).

• Use your email signature line to send a message, such as, “One in 30 Americans born between 1945 and 1965 is living with hepatitis C. Get tested, get treated, get cured!” I use a graphic from the CDC’s website. (cdc.gov/knowmorehepatitis/media/supportingimages.htm)

• Post messages to social media reminding the world about hepatitis C.

• Write a letter to the editor of your local paper about the need to reduce the risk of liver cancer by screening people for hepatitis C.

• Send money to your favorite viral hepatitis organization. No amount is too small. If everyone with HCV donated ten dollars, it would amount to nearly $30 million dollars.

• Ask organizations that have community calendars to promote local testing or awareness events. Check the NVHR member list to see what groups are active in your state. (nvhr.org/content/nvhr-members-map)

• For more ideas, check out this link to the CDC’s Know More Hepatitis campaign. (cdc.gov/knowmorehepatitis/spreadtheword.htm)

• Fight for health care for all. There is more to hepatitis C than this virus, such as liver cancer and all the medical conditions that people with hep C are at risk for. And then there is the simple fact that everyone should have access to health care.

And of course, please continue to read and support the HCV Advocate (hcvadvocate.org). Thank you Advocate readers. Your stories and support provide the inspiration that makes this worthwhile. Ten years ago, I ended our anniversary issue with the words of Margaret Mead, “Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.” These words are still true today. We have come a long way, but we still have more to do. Please say yes to the invitation to make a difference.

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 and HepMag.com
Every year there is always a lot of noteworthy news and information about hepatitis C (HCV), and the trend continues in 2017. What was surprising was the amount of news about hepatitis A in 2017. In this article, I will provide a brief overview of some of these newsworthy items about HCV and the outbreaks of hepatitis A around the country. For more information about these news items, you can check out our HCV Advocate News & Pipeline Blog [http://hepatitisc.hcvadvocate.org/](http://hepatitisc.hcvadvocate.org/).

All of the stories listed below are important. I will let you decide which story is the most important. The news story that stood out for me is the convergence of the opioid crisis and the second epidemic of HCV.

**Opioid Crisis & Second HCV Epidemic**

The on-going opioid crisis and the second HCV epidemic go hand-in-hand. The current opioid epidemic is the largest in U.S. history. In 2016, it killed approximately 64,000 Americans. It touches every socio-economic level of Americans—rich/poor, educated/uneducated, employed/unemployed, privileged/underprivileged, urban/rural, etc. It has occurred all across the United States. It is affecting adults, children, teenagers (males and females equally) and unfortunately, babies.

The opioid crisis is also fueling the second epidemic of HCV. New infections of hepatitis C in the U.S. have reached a 15-year high. The CDC estimates that there were 34,000 new infections in 2015. This reported number of new infections is likely low since national surveillance system is underfunded understaffed; as a result, acute infections are likely underreported.

**Needle Exchange**

Needle exchange services are an important way to slow down and stop the spread of hepatitis C, HIV and other communicable diseases. There are some counties and states that have embraced needle exchange. More needs to be done to stop the spread of diseases. We must also include more funding to support needle exchange and provide rehabilitative services.
Top Ten Stories of 2017 — CONTINUED FROM PAGE 7

Medicaid Restrictions

Many state Medicaid systems have removed restrictions on access to HCV medications based on liver disease severity. Hopefully, in 2018 all the restrictions on disease severity will be removed. The next battle will be to drop the ridiculous restrictions about alcohol and drug sobriety.

Visit the National Viral Hepatitis State of Medicaid Access, https://stateofhepc.org/ to view a comprehensive report by state.

HCV-Positive Organs to HCV-Negative People

There are on-going successful organ transplants of HCV-positive kidney transplants into people who are HCV-negative. There are similar types of transplants with livers and hearts; recipients are treated for HCV post-transplant. The people who received HCV+ organs would have had to wait years or possibly die waiting for a transplant without the HCV+ organs.

DAAs & Liver Cancer

There has been a lot of controversy regarding treatment with direct-acting antiviral (DAA) medications causing liver cancer. So far, most of the evidence points to the same types of HCV progression to liver cancer after treatment as seen with interferon-based therapies:

1. People with severe fibrosis or cirrhosis treated with DAAs and cured had a lower risk of developing liver cancer. Importantly: follow-up monitoring is required.

2. People with no or minimal disease (no fibrosis or minimal fibrosis) treated with DAAs and cured had no further disease progression. Importantly: no further follow-up is required.

Two reports that we wrote about from the Liver Conference are in the December 2017 HCV Advocate newsletter. (http://hcvadvocate.org/publications/newsletter/2017-2)

New HCV Drugs Approved

Children: There were two drugs approved by the FDA to treat children ages 12 to 17 – Harvoni and Sovaldi. The cure rates were up to and over 90%.

Adults: Vosevi and Mavyret: Two new medications were approved by the Food and Drug Administration (FDA) in 2017 to treat HCV in adults. Both drugs have cure rates approaching 100% for all genotypes. Vosevi and Mavyet are the last HCV drugs to be approved. There were two other HCV drugs in development, but the pharmaceutical companies have discontinued their development. We now have all the medications needed to cure everyone with hepatitis C.

To view the Food and Drug Administration (FDA) direct-acting drugs approved to treat hepatitis C, go to http://hepatitiscmedications.hcvadvocate.org/
Medication Costs
The costs of HCV medications are coming down. Mavyret was approved this year and came in at the lowest price of any DAA yet, and the other DAAs have been negotiated to lower price points. Still, we need even lower costs to make the medications available to everyone with HCV.

Clinical Trials: Drugs to Use in Pregnancy
Finally, studies are being conducted to find out if the current direct-acting antiviral medications can be safely given to pregnant women to prevent motherto-child transmission of hepatitis C. To view clinical trial information, go to our Clinical Trial Reference Blog http://hcvclinical.hcvadvocate.org/ and www.clinicaltrials.gov.

Eliminating HCV
The goal to eliminate HCV is falling short in the United States and worldwide except for the Veterans Administration, which is on track to eliminate HCV. Hurrah for the VA and our veterans!

Another bold project is the plan to screen all tribal citizens of the Cherokee Nation health centers. Those Cherokee citizens who test positive for HCV will be treated for hepatitis C.

Some cities and states (examples are San Francisco and New York City) set goals to eliminate HCV. They have very effective strategies in place.

Hepatitis A
Although not HCV-related, an important story this year were the outbreaks of hepatitis A. There were outbreaks all over the country, but one of the major outbreaks occurred in San Diego County. As of the beginning of December, there were 567 reported cases, 20 deaths and 382 hospitalizations. Hepatitis A is usually not this deadly, but this outbreak predominately affected the homeless population. The homeless are a very vulnerable people who are at-risk the most severe consequence of hepatitis A. The reasons are many—compromised immune systems, limited access to healthcare and sanitary services, and living on the streets—just to name a few.

How could the HAV outbreak in San Diego County and elsewhere be prevented? The easy answer is prevention—hepatitis A vaccination. The other preventive strategy that should have been put into place as soon as the outbreak started was massive hepatitis A vaccination of the homeless population. One reason the outbreak occurred was due to lack of plastic bags because of the new California law banning the plastic bags. The law was good for the environment, but the homeless population used the bags to clean up their waste (poop). There are biodegradable bags available but were not handed out to the homeless. Something so simple was one of the reasons for the outbreak.

While I’m on my soapbox and none of this is a blame game—there are also many outbreaks of hepatitis A transmitted from food service workers. These outbreaks occur all over the country. Why don’t we require hepatitis A vaccination of food service workers? They do this in Las Vegas, and we should be vaccinating every population that has the potential to transmit to the public.
This will be my final article for the HCV Advocate. Having an opportunity to work in this field over the last year has been an enjoyable experience. It’s been challenging but also fun. I’ve had the chance to talk with many different people in this field and to learn from them much more than they learned from me. Teaching and collaborating with others is a true joy of mine. I have no hard feelings or disappointments about the work and journey I’ve taken over the last year. The one thing I know for certain is that above all else, you should be willing to bet on yourself and take a shot on your dreams no matter what the odds of success are. I’ll be defending my master’s thesis on Jan. 4th, 2018 and I’m looking forward to finishing that chapter of my life and looking ahead.

In the field of HCV, to reach the path to zero means not only compromise but courage. Not only return on investment but risk. We must be willing to try what hasn’t been done to regain what we seem to continually lose. Our success or failure in eradicating HCV will hinge on more than one person, idea, initiative or entity. METAVIR score and sobriety restrictions alone are not what hinder our success. Rather, it is the presence of stigma. And the duality by which we view the epidemic of HCV. The association we place on it with people who inject drugs, how we view them within our society, and their chances of recovery, have a profound impact. Much like the HIV/AIDS epidemic, for us to make meaningful headway we must realize that our barriers to success are less concrete and more abstract.

...above all else we cannot be afraid to fail, or to take a risk on something that may make us uneasy.
There currently exist few services for mono-infected HCV individuals when compared to HIV mono-infected individuals. This must change. The burden falls on us to innovatively and painstakingly continue to create these service pathways through any means possible. To fix the deficiencies in surveillance, we must also look to the strengths to the points of information that current data shows us such as growing trends among vertical transmission and where new risk groups may be. We must always look forward while being aware of the moment we live in and the circumstances that not only our neighbors exist in, but we as a collective community exist in.

We cannot fail to fuel the eradication of this epidemic with heart and inspiration as much as logic and science. We must look back to understand what we missed so that we can see what is in front of us. We can prevent future Scott counties. We don’t need new tools, or new fancy processes. Everything we need exists now. All the resources are laid out before us. I’ve seen it all over this country in the people I’ve talked to in HCV workshops. Those who’ve taught me so much and shown me that the path to zero will be reached not in solitary but in solidarity. We, of course, need to continue to improve our systems, but we only need to look to HIV for examples of how to build a system that works.

If there is no one to help navigate the health insurance marketplace, to explain medications, to help keep doctors’ appointments and navigate medical care, then it isn’t a surprise that people left to do this on their own fail. And when we add into the equation the stigma and difficulties surrounding addiction, it becomes obvious why the path to zero cannot be reached in our current state. We must not only transform but we must take from other successful initiatives. We must replicate those processes which we know to work. And above all else we cannot be afraid to fail, or to take a risk on something that may make us uneasy.

I took a shot a year ago on Umbrella Way and myself, not because I knew it would succeed, but because I believe that we all owe it to ourselves to fail at what we love rather than succeed at what we feel will make others happy. Simply because we fail doesn’t mean there isn’t value in what we did. Find happiness in failure and your life will never cease to have meaning and joy. Look to those around you when tackling life’s biggest problems and the answers will come easier and be clearer than you could have imagined. We are a family. All of us will fail or succeed together. Whether we want to fully accept that as truth in our current moment of divisiveness doesn’t change the reality of such a statement. We have never, and will never, succeed alone. John Donne famously wrote, “No man is an island unto himself.” I know that to be truer now more than ever.

Thank you again to Alan, Rose, Lucinda, all the HCSP staff, those who attended and hosted the training workshops and to all the readers of this newsletter. I’m a guy from Southern Indiana who was given a chance to enact change, but most importantly, be changed by all of you. For that I will be forever grateful.

Matthew Zielske is the Training Manager for the Hepatitis C Support Project’s Train-the-Trainer workshop. He has a Master’s in Communication with a focus on health communication and health literacy.
The prevalence of FM in people with hepatitis C has been found to exhibit symptoms such as inflammation around joints, bursa (sac containing plaque-like shiny flat-topped itchy bumps. Lichen planus, other extrahepatic manifestations, and the many disease consequences of hepatitis C. There have been studies that have found the prevalence of HCV in people of the joints and/or soft tissues and causes chronic pain. It is, however, considered a rheumatic condition that impairs life-long condition for most people, but it is not a progressive disease and is a chronic condition – that is, it is a condition (rather than a disease) which causes widespread cognition issues, muscle and joint pain. The exact association has not been discovered, but many experts believe that HCV may act as a trigger to the body. The pain is felt all over the body and it been described as aching medications, and can be triggered by emotional stress.

CAUSES

The primary one, but it is considered a more severe condition that is caused medical condition. The secondary form of Raynaud's is less common than the primary form. Raynaud's phenomenon is a painful condition that affects the blood vessels in the fingers, mostly in people who are in their 50's and 60's. It also happens somewhat between 15 and 40 years old. Between 5 to 10% of all cases are diagnosed in women who are between 15 and 40 years old. Between 5 to 10% of all cases are diagnosed in women who are between 15 and 40 years old.

DIAGNOSIS

Raynaud's affects more women than men – about 75% of all cases are Raynaud's phenomenon in the hepatitis C population is unknown, but it is believed to be an autoimmune disease that can be caused by genetic factors. The most common symptoms include white patches of skin that itch. It can be triggered by emotional stress.

SYMPTOMS

Vitiligo is diagnosed with various tests–physical examination, blood tests thyroid dysfunction, skin injury, severe sunburns, chemicals, and medicines that are not approved for the drugs to treat hepatitis C, you may qualify for your symptoms or conditions recorded in your medical records. If you are interested in learning more about these conditions, please visit the following websites:


© 2017 Hepatitis C Support Project