

# LIFE

FULL OF



THE STORIES OF PEOPLE  
AFFECTED BY HEPATITIS C



## **ABOUT THIS REPORT**

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This issue brief was developed by the Hepatitis Policy Project. The views expressed here are those of the authors and interviewees alone.

The profiles were developed following interviews with the subjects, who reviewed them for accuracy and provided consent to publish both the images and profiles. We thank the profile subjects for their willingness to share their stories and for their leadership in responding to the Hepatitis C virus (HCV) epidemic.

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## WHEN YOU HEAR THE WORDS HEPATITIS C, WHAT DO YOU THINK?

Do you think of drug abuse and sexually transmitted infections (STIs)? Is your reaction based on sadness or fear? Or, do you realize that treatments are now available that are highly effective at curing hepatitis C virus (HCV) infection? Do you respond with optimism and hope?

Real people make up the HCV epidemic, and their experiences and the full lives they lead offer motivation and resolve to work to eliminate HCV as a public health threat. But, as this report will show, the reality of what is happening to respond to HCV in the United States (US) falls short of the possibility of what we could make happen to save lives and strengthen communities.

The epidemic of HCV has rarely received significant public attention. The facts about HCV are often overshadowed by misinformation and stigma that detract from understanding the harm caused by untreated HCV and the opportunities to improve lives and move us closer to eliminating the HCV epidemic in the US and around the world.

## NUMBER OF HCV CASES IN THE US AND WORLDWIDE



HCV affects 3.5 million people in the United States and 71 million people around the world.<sup>1,2</sup> In 2016, 18,153 people died of HCV-related illnesses in the US.<sup>3</sup> New cases are on the rise, with approximately 41,200 new cases occurring in 2016,<sup>4</sup> and a 290 percent increase in annual cases of new HCV infections between 2010 and 2015.<sup>5</sup>

## HCV CAN BE CURED

**IMPROVING OUR COLLECTIVE UNDERSTANDING** of the facts about HCV is essential to dispelling misconceptions and mobilizing efforts to eliminate the disease both in the US and worldwide.



### CURE

Recovery or relief from disease or condition; a complete or permanent solution or remedy.

Modern medicine has produced marvels. In the lifetime of anyone living today, we have observed great leaps in human health. And yet, much of our progress has been to alleviate or minimize illness. The ability to cure is often an elusive goal that seems just out of reach.

Prior HCV treatments required a very lengthy medication regimen using ribavirin and interferon to boost the immune system and suppress viral multiplication. These drugs produced serious and sometimes debilitating side effects, and were not always effective. Newer treatments that emerged on the market in 2013 are a marked improvement. Called direct acting antivirals (DAAs), these new medications have cure rates that approach 100%.<sup>6,7</sup> Typically taken for 8 to 12 weeks, most people experience mild side effects that are tolerable enough to complete a course of therapy.<sup>8</sup>

## THE US HCV EPIDEMIC IS BETTER UNDERSTOOD AS TWO EPIDEMICS

**IN THE US, THERE ARE TWO DISTINCT COHORTS OF THE EPIDEMIC.** One group is the “Baby Boomer” population of Americans born between 1945 and 1965. The hepatitis C virus was not discovered until 1989, but it had been spreading undetected within the population for decades beforehand. Members of this cohort may have acquired the infection through blood transfusions or other medical procedures before effective blood screening or present-day safety precautions were implemented, or through long ago injection drug use.<sup>9</sup> HCV can remain asymptomatic for many years. Thus, many people who are infected may have no idea that they were ever at risk and may not understand the need to be screened for the virus. Testing for HCV in blood and tissue did not become a common practice until 1992.<sup>10</sup> Many of these infected Baby Boomers are now dealing with the adverse health consequences of undetected chronic HCV infection, such as liver damage and liver cancer.

Newer cases of HCV can be largely attributed to injection drug use. This is an increasing and urgent concern with the exploding opioid crisis in the US. The sharing of needles and supplies that are contaminated with infected blood has caused an exponential increase of new cases of HCV infections, mostly among younger adults under 40.<sup>11</sup> The asymptomatic nature of the disease, coupled with the decreased likelihood that persons engaging in injection drug use will seek regular health care means that most of these infections are not identified in a timely manner. Therefore, the behaviors that put others at risk are proceeding with little to no intervention to curtail the spread.

HCV is a bloodborne virus, which means in order to become infected one must come into contact with infected blood. This is why the disease is so prevalent among those who engage in activities such as injection drug use or tattooing under non-sterile conditions

that are deemed to be high-risk. HCV is more easily transmitted than HIV because the hepatitis C virus is 10 times more concentrated in an infected person's blood relative to the concentration of human immunodeficiency virus (HIV) in the blood of someone with that illness.<sup>12</sup> Thus, anything contaminated by HCV-infected blood is more likely to have a significant amount of the virus present, raising the probability that it will transmit the infection to others. In the case of HIV, providing sterile syringes to people who inject drugs has led to declines of about 80% in HIV transmission in this population.<sup>13</sup> By contrast, sterile syringes alone are not sufficient to prevent HCV transmission, as unsterile works (the spoons and other equipment used to prepare drugs before injection) that have been in contact with infected blood also can transmit the virus.<sup>14</sup> HCV is sometimes, albeit not commonly, spread through sexual contact.<sup>15</sup> It is not spread through casual contact, such as handshakes and kissing.<sup>16</sup>

There was a recent outbreak of HIV infection in rural Scott County, Indiana. This generated significant attention and a strong public health response because a county that typically saw about 5 HIV diagnoses in a year experienced an outbreak of 181 HIV diagnoses in one 12-month period.<sup>17</sup> Follow-up testing confirmed that virtually all of these cases could be traced back to one individual living with HIV who had been introduced into the drug-using network in that county. A startling facet of this outbreak that received very little public attention is that more than 92% of those infected with HIV were co-infected with HCV, indicating that this might be a larger public health problem than previously thought.<sup>18</sup>

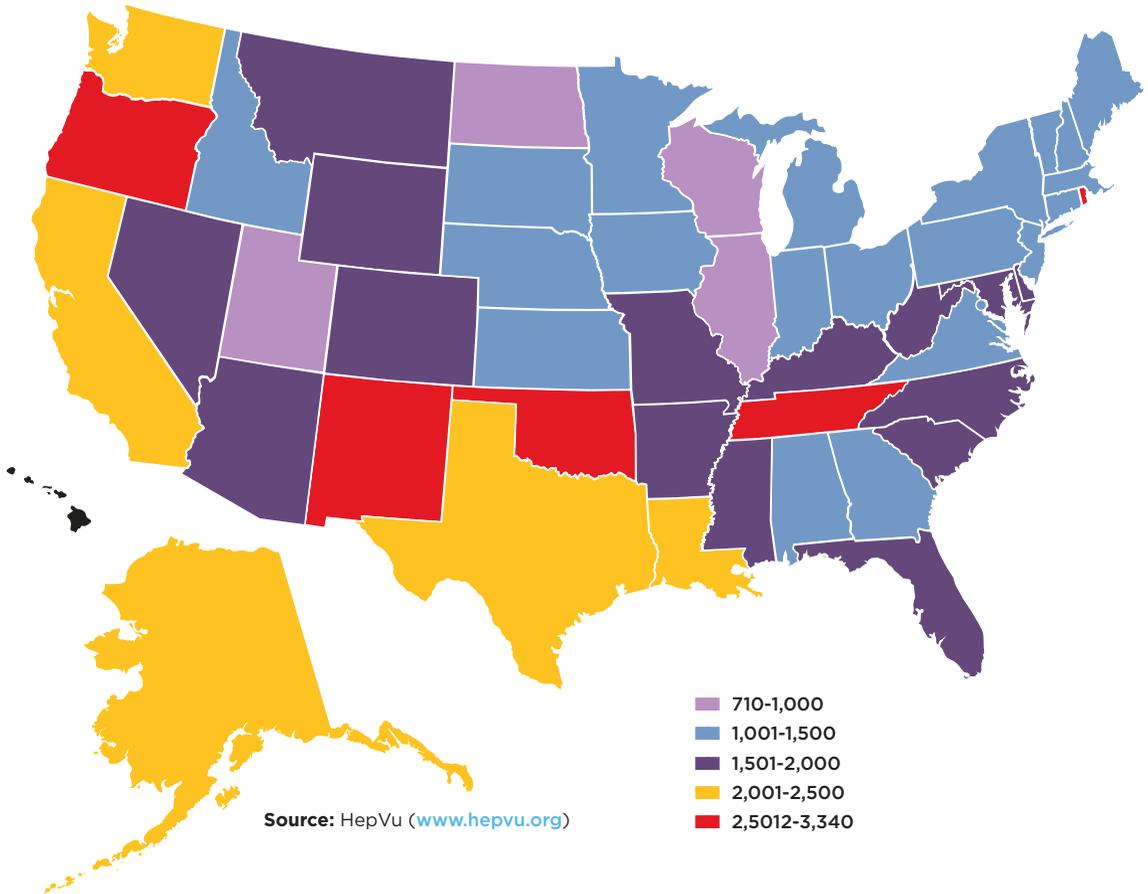
**HEPATITIS C CAN BE TRANSMITTED FROM MOTHER TO CHILD**, otherwise known as 'vertical transmission'. In the US, 1 – 2.5% of pregnant women are infected with hepatitis C, and this carries an approximately 5% risk of transmission from mother to newborn.<sup>19</sup> The risk of maternal transfer of the virus from mothers with HCV to their newborns is an issue for both cohorts. For the Baby Boomers, their exposed children are now adults who may not even be aware of their status.

The latest research estimates the number of women in the US with a diagnosed HCV infection at the time of giving birth increased 89% between 2009 and 2014.<sup>20</sup> The increase in maternal HCV infections is also correlated with the increase in heroin and opioid drug misuse in the country. Although the risk of vertical transmission is low, as the number of pregnant women who are infected with HCV rises, so does the potential for more babies to be born infected with HCV.

As the number of pregnant women who are infected rises, so does the potential for more babies to be born with hepatitis C.

## ESTIMATED HEPATITIS C ANTIBODY RATE

PER 100,000 PERSONS | UNITED STATES, 2010



The nature of hepatitis C infection leaves it asymptomatic in people for years, and testing for the virus is not typically part of regular medical screenings.

## ELIMINATION OF HCV IS POSSIBLE, IF PEOPLE MAKE IT HAPPEN

**IN 2016 AND 2017**, The National Academies of Science, Engineering and Medicine collaborated with the CDC to investigate the feasibility and strategic interventions needed to curtail the epidemic rate of HCV infections in the US, cure existing cases, and ultimately eliminate the disease as a public health threat.<sup>21</sup> For this to happen, there needs to be a collective push from the public, political leadership, and the medical community to mobilize the various resources needed.

In their reports, the Academies identified key priorities to be addressed for elimination to occur.<sup>22, 23</sup> High on this list is the need to turn HCV into a public interest priority by increasing awareness of the disease and the human toll it takes.



### ELIMINATE

To put an end to or get rid of.

Public pressure is a principal driving force in getting government officials and policy makers to act on an issue. As people become more informed of a health issue and how it can affect them, they will take steps to have their concerns addressed. An example in recent history is the mobilization starting in the 1980s and 1990s to raise awareness and to combat HIV/AIDS.

The beauty of the opportunity we now face with HCV is that people can be diagnosed and cured, so that living with the virus does not need to become part of a person's identity in the same way that it is for people living with HIV and many other disabilities. The challenge is that this means that HCV does not have the same level of publicly identified people to champion the cause. More work is needed to highlight and share the experiences of individuals and families impacted by HCV.



### LIVING

Full of life and vigor.

**These are the stories of Americans who have been or are living with HCV. Their stories are of hope and the desire to improve their quality of life being threatened by the virus. A virus that can now be eliminated. Their stories are familiar. They are our sisters, brothers, fathers, mothers, friends and neighbors.**

# JESSICA



**JESSICA IS 30 YEARS OLD, AND LIVES IN OAKLAND, CALIFORNIA.** She is a mother of a 2-year-old daughter and recently had a baby boy. She is also living with HCV and has been repeatedly denied treatment for her infection. Jessica knows all too well the repercussions of an untreated HCV infection, as she cared for her mother while she suffered from the illness and watched how the infection ultimately claimed her life.



Jessica is the youngest of 3 children. As the “surprise” child, she grew up closer to her parents than to her much older siblings. She was particularly close to her mother, Jay. In 2011, Jay began feeling quite ill and one day suddenly passed out at a gas station. After testing, the doctor informed her that she was suffering from health complications caused by a chronic HCV infection she never knew she had. Following the diagnosis, the entire family was tested for HCV. Jessica was the only one to test positive for the virus.

Though mindful of the need to treat her own diagnosis, Jessica’s priority at the time was to care for her mother, who was in rapidly failing health. Jay was experiencing kidney and liver failure resulting from the

infection. Her liver biopsy in January 2012 showed that she was at stage F4 liver damage (Liver damage is scored on severity. F0 shows no liver scarring and F4 is the most advanced stage of liver damage.) This meant that she would need to have a liver transplant in order to have any chance for survival. Doctors concluded, however, that Jay’s condition no longer made a transplant a viable option. She died in May 2012 from complications caused by advanced cirrhosis of the liver, less than a year after her diagnosis. Jay and her doctors concluded that she had contracted the virus from a blood transfusion she received in her twenties, and she unwittingly passed it on to her youngest child.

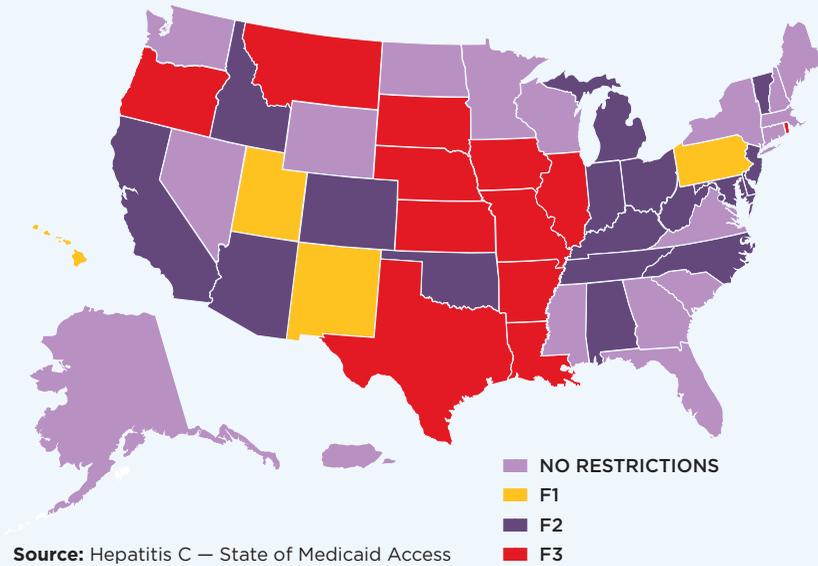
After her mother’s death, Jessica shifted her focus to treating her own infection. It was then that she learned how hard getting the treatment she needs would be. As a Medi-Cal beneficiary (i.e. Medicaid in California), she is subject to a restriction that normally limits HCV drug treatment to those with liver scarring ratings of F2 or higher. Jessica is at F0. Medi-Cal guidelines, however, theoretically establish an exception to this scoring restriction for women of childbearing age. Jessica pleaded with her doctor for the treatment, but was denied. **“The doctor told me ‘oh, you’re young, there’s pills you can take in a few years, we will get back to you. Go ahead and have a couple of babies.’”** Jessica was horrified that failing to treat her own infection could lead her to pass it on to her own children.

**“If this was cancer, would you tell me to pop out some babies then come back for chemo?!”**

Witnessing her mother’s death due to HCV has given Jessica the impetus to keep fighting for her own treatment.

## HEPATITIS C: STATE OF MEDICAL ACCESS: LIVER DAMAGE RESTRICTION

2017 MEDICAID FFS LIVER DAMAGE RESTRICTIONS FOR HCV TREATMENT

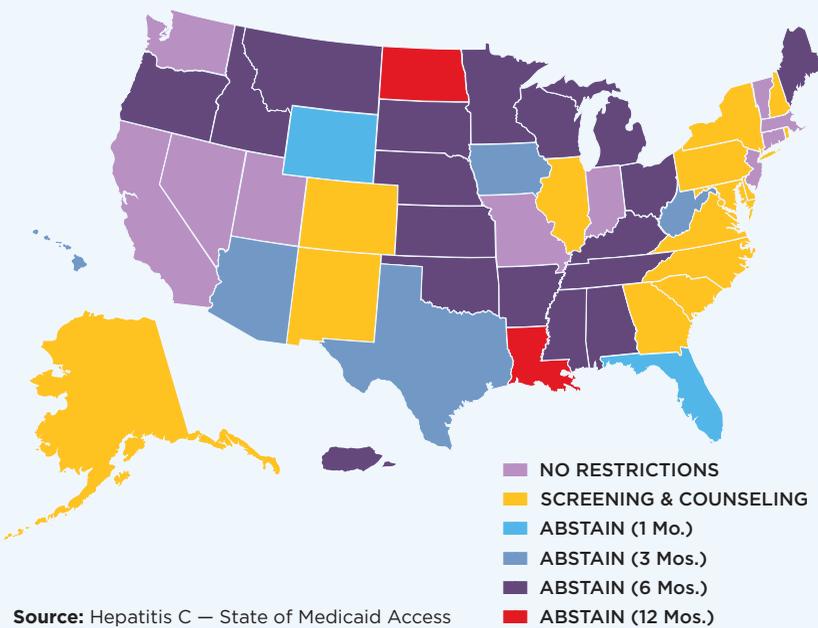


Source: Hepatitis C — State of Medicaid Access  
([www.stateofhepC.org](http://www.stateofhepC.org))

An analysis of 2017 Free-For-Service Medicaid data demonstrates that several Medicaid programs have eliminated liver damage requirements for patients seeking to access hepatitis C (HCV) cures, while others highly restrict access.

## HEPATITIS C: STATE OF MEDICAL ACCESS: SOBRIETY RESTRICTION

2017 MEDICAID FFS SOBRIETY RESTRICTIONS FOR HCV TREATMENT



Source: Hepatitis C — State of Medicaid Access  
([www.stateofhepC.org](http://www.stateofhepC.org))

An analysis of 2017 Free-For-Service Medicaid data demonstrates that several Medicaid programs have eliminated sobriety requirements for patients seeking to access hepatitis C (HCV) cures, while others highly restrict access.

Jessica has a daughter who, fortunately, was born free of the virus. Yet, despite the exception for women of childbearing age, she has continually been told that she is “not sick enough” for treatment.

She is still waiting for the baby to be old enough to be tested, and hopes to start treatment herself very soon, if her insurer makes good on covering the cost of the medication.

Following this interview, Jessica was put in touch with a hepatitis advocacy group in California that will assist her to get the HCV treatment drugs she is entitled to but has been wrongfully denied.

Jessica’s experience is far too common. States often are not even abiding by their own rules in providing care to patients, thereby breaking the law and endangering the health of their citizens. Jessica is tenacious and refused to take NO for an answer. She reached out to advocacy groups, talked to other patients, and educated herself on her right to treatment. However, not all patients have the capacity to fight for their healthcare in this way. Many would just give up, or yield to the directives they receive from doctors and insurers. Many wouldn’t even think to question whether they were receiving incorrect information.<sup>24</sup>

The American Association for the Study of Liver Disease (AASLD) and the Infectious Diseases Society of America (IDSA) have collaborated to develop testing and treatment guidelines for HCV.<sup>25</sup> They recommend widespread screening for HCV, particularly for those born between 1945 and 1965, and those who exhibit risk factors, such as intravenous drug use, prior incarceration, or healthcare workplace exposure.<sup>26</sup>

The guidelines also recommend that ALL persons with a confirmed diagnosis of HCV and who do not have an end-stage life threatening illness or a contraindication for treatment be treated for HCV and cured of their infection. It seems perfectly intuitive to provide an available cure to those who need it, yet, as seen in Jessica’s story, patients with HCV often face barriers to accessing treatment that are rooted far less in science and more in economics and bias.

Despite the recommendations for treatment from the doctors and scientists who specialize in the study of HCV, most public and private insurers in the U.S. have established guidelines that limit access to the treatment for HCV based on the severity of the infection or the patient’s history of substance abuse.

In 2015, the Centers for Medicare and Medicare Services (CMS) issued a letter to all states advising them to provide HCV treatment without imposing unreasonable restrictions on the Medicaid patients they cover.<sup>27</sup> Since each state manages its own Medicaid program, CMS cannot mandate the removal of restrictions, however all states are required to provide needed care to Medicaid recipients without undue limitations on access to care. A 2017 study revealed that despite the guidance from health care and government experts, many states continue to limit coverage of hepatitis treatment to those who have moderate to severe liver scarring, as defined by a F2 or higher fibrosis score. Many states also require that a patient with a history of substance or alcohol abuse have a documented period of sobriety prior to treatment authorization, often 6 months to a year.<sup>28</sup>

INTRAVENOUS DRUG USE IS CURRENTLY THE LEADING CAUSE of new hepatitis C infections in the US. People who inject drugs face public ridicule for their behavior on top of the health and personal

burdens they deal with because of their addiction. However, addiction is not what defines them. It is not where their story begins, nor where it should end. Many have made strides to overcome their drug use

and improve their lives, yet they still face the negative consequences of public disapproval that often causes others to only see their problem, and not the person.

## JESSE



**JESSE, 39, IS AN OUTREACH WORKER WITH THE NORTH CAROLINA HARM REDUCTION COALITION**, and runs their syringe access programs in Wake and Johnston counties.

Married with two children, Jesse is a recent graduate from North Carolina State University with a Bachelor of Social Work degree. His life has not always been this good.

Jesse is in recovery from injection drug use and he also has been incarcerated. Like many people in recovery, his path to

recovery took a while. He sold drugs and had used them since high school. He was first arrested in 1997, in Georgia, for drug use and this started a cycle of being in and out of prison and on and off of drug use. At one point he was in a 16-month residential treatment program, but the cycle continued. He attests to the benefits of overdose reversal using naloxone, as he believes it saved him from dying a few times. During one of his hospital stays following an overdose, he was diagnosed with HCV. He is not sure if it was the drug use or the prison tattoos that exposed him to the virus, but he acknowledges many potential exposures that could have caused his infection. This was approximately in 2006-2007, and given where he was regarding drug use at the time, he didn't really care when he learned of his status. "Chaotic drug use" is the term he uses to describe not being able to maintain normal day-to-day functioning. **"Everything revolved around the next use, and not paying attention to my health or well-being."**

By 2015, Jesse was back in recovery and he was able to get insurance coverage through the Affordable Care Act (ACA). This enabled him to seek HCV treatment when his insurance coverage was supplemented by support from a patient assistance program. He had heard about the new treatments that were much more easily tolerated than the interferon treatments he had seen people endure in the past. Luckily, he learned that he didn't have any significant liver scarring. He is now HCV free.

By sharing the story of his successful treatment for HCV, Jesse hopes to encourage people who are incarcerated and those who inject drugs to seek treatment.



**“In the drug-using community, we don’t think of HCV being as bad as HIV. For inmates, this perception means they will get treatment for most other illnesses while in prison, but not for HCV.”**

Jesse graduated in December 2017 and he plans to become a social worker like the ones who helped him without judgment during his “chaotic” drug use times, when no one else wanted anything to do with him.

**“When life is really out of control, it is nice to have someone who is level-headed who is not attached to everything you do to help direct and guide you.”**

He really understands the mindset of someone who is going through chaotic drug use and approaches his work from that perspective. He views his role as to empower people. **“If someone wants to do something, what does that look like for that individual? What does decreasing drug use look like to you?”** No one ever asked him that. **“People told me what I should be doing, but nobody asked me what I wanted to do.”**

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## JUDITH



**LIKE JESSICA, JUDITH FACED A MYRIAD OF CHALLENGES TO GETTING TREATMENT** and had to become her own advocate and change agent to get the care that she needed.

When her doctor first suggested that she be tested for HCV, Judith declined. She was aware of the effects of the illness, because she had a friend living with it and another who had recently passed away. Still, she did not think she had any of the risk factors to make her susceptible to infection, so she felt testing was unnecessary. At an appointment in

January 2016, her doctor brought it up again and informed her that the CDC recommends that all persons born between 1945 and 1965 be tested regardless of risk, so she finally relented. She assumed the result would be negative. It wasn't. A subsequent RNA test confirmed she had an active HCV infection. Judith didn't engage in the behaviors she commonly associated with high risk for HCV infection such as tattooing or injection drug use. She'd had various medical procedures in her childhood, but based on the information her parents gave her about them, she never received a blood transfusion, so she had few other ideas of how she became infected.

**"I was totally floored and freaked out. I reached out to all of my sexual partners, past and present, assuming that must be the way that I got it. It is pretty rare for it to transmit heterosexually, but that was my assumption."**

However, she combed through medical records dating back to her childhood, and discovered that she did, in fact, receive a blood transfusion during a surgery in 1970.

**"When AIDS came out in the early 80s I asked my parents if I had a transfusion with the surgery, and THEY said no. [But] when I went back to the records, [the doctor] never used the word "transfusion." It said "600cc blood lost and 500cc blood given."**

Now that she had the answer to how she got infected, Judith threw her energy into getting treated. Fortunately, her fibroscan showed no liver damage (F0), but her doctor told her that would also mean her health insurance company would not deem her to be "sick enough" to authorize treatment. Sure enough, her claim was rejected.

Using her experience as a writer and a journalist, she swung into action. She drafted a comprehensive appeal to her insurance company. She researched medical journal articles, wrote letters to her members of Congress, and even wrote a letter directly to the CEO of her health insurance company.

**"I tracked down the email address of the CEO [of my insurance company] and sent him an email saying I am a 59 year old mother of two who deserves to be treated, and I will go to the media if you don't do something."**

Judith's appeal was approved shortly thereafter, and she completed a 12-week course of treatment in December 2016. She has maintained an undetectable viral load ever since. She was both frustrated and enlightened by her experience and it has motivated her to be a vocal advocate for HCV patients' rights.

Judith is emblematic of one of the two main cohorts of people with HCV in the US — baby boomers. She was infected as a child through a medical procedure and completely unaware that she ever had an exposure to the virus.

Judith was forever changed by this experience, and has written an e-book chronicling her journey through diagnosis and treatment as a source of empowerment and inspiration for others.

**“I have a lot of privilege, and I am well aware of it. I have educational privilege, and intellectual privilege, and I’m articulate enough and I’ve dealt with the medical system enough that I do not piss off doctors when I talk to them. Plus, [I have] economic and racial privilege. It shouldn’t be this hard, because if it was hard for ME, what is it like for most people?”**

## CARLEEN



**CARLEEN MCGUFFEY, A MARRIED MOM OF SIX** is not who most people would picture when they think of HCV, and neither did she, even when there were signs pointing to this diagnosis. **“The thing with HCV,”** she says, **“is that its symptoms can be attributed to so many other illnesses; that’s the problem, it doesn’t have any unique symptoms.”**

**“I was having issues with my spleen. I just happened to have a doctor who was notorious for checking every box on the lab slip. The girls in the lab would make fun of her because it meant tube after tube of blood. But I am so grateful to her because she happened to check that box for an HCV test even though I never indicated that I had any liver issues.”** She guesses that her diagnosis came 25 to 30 years after she contracted it. And, by this

time she was at a fibroscan score of 2 to 3, indicating significant liver damage.

Carleen had warnings that could’ve alerted her to her infection status earlier, but she was unaware of the threat and was not given enough information to properly follow up. Years before her diagnosis, she participated in a blood drive at her church and was told by the screeners that she showed the presence of HCV antibodies in her blood, but never was it suggested that she get tested for the virus. **“I thought antibodies just meant you were exposed enough to build up an antibody to resist [an illness], but not that I could have it.”**

Carleen injected drugs as a teen and believes that is when she became infected. She also received a blood transfusion following a miscarriage, so her infection may have come from either source. She admits that because of the stigma and the shame attributed to HCV, when she first learned of her infection, she would blame the transfusion for her infection, although she believes that drug use was the most likely culprit.

## HCV stigma and shame over long ago drug use was a barrier to Carleen seeking treatment



Carleen is a devout Christian and her church is a big part of her life. When she was first diagnosed, she told nobody except for her husband. He has been 100% supportive from the very beginning. She admits that she was ashamed of having HCV primarily because of how she contracted the virus and her knowledge of the negative perceptions held by her friends and family. She was afraid of how they would react to the news. She was especially worried that knowledge of her HCV status could negatively impact her husband and children. She was so secretive that she did not want to risk going to the doctor and being found out. Plus, she didn't have very good health insurance at the time, so she did not feel empowered to seek out treatment. She had to go to the county hospital, where she found the physicians to be overwhelmed, under-resourced, and rude. Her overall circumstances did not motivate her to want to pursue treatment.

A health emergency finally forced Carleen to reveal her infection status to the rest of her family. About 6 years ago, she had a liver biopsy as part of monitoring her liver scarring from HCV. She was not getting treated for HCV both because she did not want people to know her status, and at that time the only treatment available was the ribavirin and interferon therapy, which she heard had low cure rates and was very hard to tolerate. However, during the biopsy, the doctor cut an artery in her liver, which nearly killed her. She was in the hospital for a month, and spent a year recovering from a large hematoma (swelling of clotted blood) on her liver. Members of her church rallied around her and her family to help during her health crisis, bringing meals and lending support. Finally, Carleen decided to tell her parents and one of these Good Samaritans from church that she had HCV. The news spread through her church community very quickly, earning a mostly cold reaction. Her parents did not shun her, but they also seemed unsure how to respond. Carleen says that they never brought up HCV or asked about her health. She thinks their reaction was shaped by embarrassment.

**“The disease doesn’t hurt as much as people’s crappy reaction to it. Nobody responded well at all.”**

These negative reactions were incredibly hurtful to her. She recalls only one person from her church asking about her HCV infection and her health. She was grateful for his inquiry because the silence from others was so hurtful. She longed for people to ask her about her condition, so she could share her story and educate them about the disease. Ultimately, this stigmatization caused her to disconnect from that church community.

**One of the final straws was when her children were forced to use a separate bathroom for fear they could spread the virus.**



During her year-long recovery, Carleen's entire family had to take on new responsibilities. The silver lining of this experience for their family is that they are now able to serve as advocates and improve the lives of many others affected by HCV. Carleen's husband even established the "Climbing for Carleen" Foundation. He dons a liver costume while he and two of their sons climb mountains as fundraisers to support awareness and fund programs Carleen has started in her community, like free HCV testing for low-income people without health insurance. They bought a bus with their own money that her husband is converting into a mobile testing site and resource unit. Climbing for Carleen relies on grants and donations to sustain its outreach efforts. She says that, "God can make something so hard and tragic and turn it into something fruitful." Last year, they tested about 1,000 people with about 100 (10%) testing HCV positive.

**"I did lock myself the basement and pulled the covers over my head for a while. Thankfully, it didn't last long."**

She still struggles with bitterness and resentment, but she is also able to focus on the important work being done by her husband and family.

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## SHAUN



**SHAUN'S LIFE IS FILLED WITH MANY INCREDIBLE STORIES**, and he has no qualms sharing his experiences. He is openly gay and participated in the "gay play scene" for many years, which he describes as engaging in casual sex and using drugs to enhance and prolong the sexual experience. His drug of choice was crystal methamphetamine.

He makes no excuses for his actions and the consequences his choices have had on his health, but he knows his diagnosis of bipolar disorder does affect his behavior and decision-making. He also credits his bipolar

## Having been multiply diagnosed with HCV, HIV and mental illness, being cured of HCV is an important component of his healthier and better life.

disorder with suddenly filling him with the unshakeable urge to get tested for HCV in 2008. The interferon and ribavirin treatment that was available in 2008 was contraindicated with his bipolar medication, so the infection persisted in his body, leading to F4 fibrosis scarring.

**“So many people I socialize with have a connection to HCV. I didn’t run from the stigma it has....How I got it is irrelevant to the fact that you have to take care of yourself.”**

Shaun was diagnosed with HIV in 2010 and began HIV treatment soon after. Once new HCV drugs became available that worked better with his medications for bipolar disorder, he completed a 24-week course of treatment for his HCV infection in 2015 and no longer has HCV.

One of the biggest challenges he is currently facing is returning to the workforce and addressing the misperceptions, discrimination and stigma he may face from potential employers or co-workers. He has faced rejection from his closest family members because of his lifestyle, and it has had a profound effect on his emotional state. He faced depression, and even quit his job upon hearing of his diagnoses, but he has worked hard to rebuild his resilience and take better care of his overall health. **“I take responsibility for whatever situation I put myself in. However, now I am much more cautious”**

Shaun credits having a supportive team of physicians as key to giving him the strength to overcome his health and challenges despite rejection and hurt from his family and friends.

**THE DIRECT ACTING ANTIVIRAL TREATMENTS** currently available to treat HCV are potential game-changers for removing the life-threatening effects this illness can have. However, treatment for HCV was not always as simple as taking a few pills a day. The original treatment for HCV involved patients receiving almost a year of medication therapy with injections of interferon to boost the body’s immune response, and ribavirin as an antiviral drug to kill the virus and curb its spread. These drugs came with serious side effects similar to chemotherapy, and only yielded a 40-50% efficacy rate.<sup>29</sup> Many patients stopped this treatment due to the side effects, but for some the original treatment was not even an option because of other health issues they faced. That left these patients having to make the choice to live with their HCV infection and hope it would not further adversely affect their health.

# SHARON



## **SHARON IS ONE OF THOSE PEOPLE WHO HAD TO FORGO TREATING HER HCV INFECTION.**

Sharon is in her 60s, lives in Maryland, and was diagnosed with HCV in 1996. She was likely infected from a transfusion she received as part of her treatment for leukemia. She was offered interferon treatment at the time, but the physical toll the chemotherapy had already taken on her body made her feel too weak to put herself through interferon treatment. She also kept her diagnosis to herself for many years, due to fear of stigma. Over time, Sharon did not think about her HCV diagnosis, focused instead on the other health challenges she faced that posed a present threat to her life.

**“I always worried about those blood transfusions. I got as many as 2-3 a week.”**

In 2014, a heart condition led doctors to inform Sharon that she needed a heart transplant, but her HCV infection needed to be treated before she could be put on the transplant list. The new drug therapies were much more tolerable for her to take, and she completed a 90-day course of treatment in 2016.

Sharon feels blessed that the virus did not do the damage to her body it could have. She has now made it her duty to share her story so it will help someone else, because she did not have the opportunity to get insight from others living with HCV. One of her favorite success stories is when she approached a gentleman who had revealed he had HCV, told him her experience and about the new treatments, and encouraged him to seek treatment. He did, and now he is cured!

Sharon also credits having a great doctor who advocates for her and knows how to provide care for her as a patient in a way that makes her feel exceptionally important. Her physician has supported both her healthcare needs and her outreach and advocacy efforts to improve the lives of those with HCV.

Sharon knows that many in her age group are not going to look online for research and information, so it is important to do face-to-face education and outreach to inform this demographic. That is part of what motivates her to be an advocate. She also discusses the importance of organ and tissue donation, as she is still on the donor list awaiting a new heart.

# GUNTER



**WHEN YOU HEAR THE PHRASE “THEY DON’T MAKE GUYS LIKE THAT ANYMORE” YOU MAY THINK OF GUNTER.**

Gunter is a Vietnam veteran and a retired military civilian employee in his 60s. He read a veterans article in 1991 discussing HCV, decided to get tested, and was told he had it. He is not sure how he got the virus, but has spoken to other veterans who have also heard of untraceable HCV infections. He says he may have gotten it from exposure to fellow servicemembers’ blood during the war, or perhaps from vaccination needles that may have been used multiple times. He never did IV drugs, got an unsterile tattoo, or engaged in sexual contact with anyone while in Vietnam.

Gunter did not pursue getting treatment when he was first diagnosed, because he was younger and thought it was not an immediate threat to his health. He understood what he needed to do to protect his health, but admits that he was not ready to address the diagnosis at the time. But as he got older, his wife encouraged him to follow up with treatment so he would not suffer long-

term health consequences. In 2004, he went to the VA hospital and started ribavirin and interferon treatment. Despite the strong side effects that many compare to those endured by chemotherapy patients, and which made him very ill, he completed the treatment. However, as was often the case with the original treatment for the infection, it came back and once again the virus began to multiply rapidly in his body.

Gunter was undeterred. He repeated the 10-month course of treatment and endured the side effects of nausea, severe gastrointestinal irritation (which he gave the nickname “*Fire-rhea*”), and debilitating fatigue - but it came back again! When he returned in 2009 to get treated for the 4th time, he decided to retire, knowing all too well the toll treatment would take on his health. Plus, he wanted to do whatever possible to ensure this would be the LAST time he had to endure this treatment.

**“I felt awful all of the time. I wasn’t going to be able to work or do anything while getting treated. I need to be home 24/7 until I get this [illness] squared away.”**

Gunter would not have made it through any of his rounds of treatment without the support of his wife and adult children, who cared for him when he could not do things for himself.

**THE VETERANS ADMINISTRATION (VA) IS A SUCCESS STORY** of combating the HCV epidemic. The VA provides healthcare for a large number of Americans who fall within the 1945-1965 birth year cohort for high risk of HCV infection. A report issued by the agency in 2017 states that the VA has tested 79.5% of its patients in this cohort, and has treated over 96,000 veterans for HCV, averaging 1,500 people a month.<sup>30</sup>

The VA employs an extensive system of education and outreach to inform patients of their risk and encourage them to get tested. HCV screenings are including in regular physical exams for all veterans, and the VA has no liver damage or sobriety restrictions that limit a patient's access to treatment.<sup>31</sup>

He wishes that he could have taken the DAA treatments, which are much easier to tolerate and have far less intense side effects, but he is grateful to be rid of the infection and looks forward to enjoying life with his family.

**“The new stuff out there [DAA drug treatments] ...I would've done anything to go through that, as opposed to what I went through.”**

Gunter wants to share his story because of the positive impact his doctor and nurse had on him during his recovery, and to help others. He also knows that many of his fellow veterans were dissuaded from getting treated because of the side effects of the old treatment, so he helps to spread the word about the new, well-tolerated drugs now available. He is a member of several veterans groups and uses that as opportunities to promote testing and treatment.

**“I wouldn't discourage anyone from doing this. Get it done, get it fixed. We are not getting any younger!”**

**WHEN A STIGMA IS ATTACHED TO SOMETHING**, it often becomes all people think of, becoming one in the same with the thing or person being stigmatized. For many with HCV, the disease is that glaring mark that stops others from seeing the person behind the virus.



## STIGMA

A mark of disgrace associated with a particular circumstance, quality, or person.

For those with HCV, the perceptions held by others can silence their true voice and drown out what they need the public to know and understand about the disease and how to best help those it affects. This collection of profiles is intended to give that voice back to the millions of Americans affected by HCV to try to correct misperceptions and improve efforts to eliminate this disease in this country. The first step toward elimination is understanding. Elimination can only happen if the public transcends stereotypes and negative connotations of the infection by listening to and learning from the people it affects. An honest and compassionate understanding of this disease and the toll it takes on those infected is essential to bolstering support for initiatives to stop the spread and get people cured.

WE HAVE A CURE FOR  
HEPATITIS C, BUT WE FIRST  
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OF THEIR STATUS BY  
EXPANDING TESTING  
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CURATIVE DRUGS THAT LEAVE  
PEOPLE FULL OF LIFE MORE  
WIDELY AVAILABLE.

THIS IS HOW WE WILL  
ELIMINATE THIS HEALTH  
THREAT AND MAKE  
THE HEPATITIS C EPIDEMIC  
HISTORY.

## ENDNOTES

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