



million
ONE JAIL AT A TIME.
story

E7S3 Where Hep C Remains Untreated For Those in Custody

Sean Wesley knew he had Hepatitis C when he started serving his prison sentence in Louisiana, and spent years trying to get treatment. Despite an innovative arrangement between a drug manufacturer and the state's Department of Corrections, he was transferred from facility to facility, and even finished his sentence, without ever receiving proper care. Reporter Alexander Charles Adams looks into why.

A PODCAST BY

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The Story

In the U.S., Hep C claims more lives than malaria, HIV and tuberculosis combined. There's a cure, but getting it to the incarcerated and uninsured is no easy feat.



Dr. Alex Billioux was Assistant Secretary of Health for the Louisiana Department of Health's Office of Public Health. He is pictured here in front of the Governor's Office of Homeland Security and Emergency Preparedness. Photo: Zelena Williams

“It’s a significant public health threat, but most other folks are not aware that this is the deadliest infection in the United States, that it kills more people than every other reportable infection combined. And that it does that slowly...So it’s a really big problem.”

-Dr. Alex Billioux, former Assistant Secretary of Health for the Louisiana Department of Health

Hepatitis C, an infectious disease that can spread through blood to blood contact, claims more lives in the United States than malaria, HIV and tuberculosis combined. But there's good news: a course of treatment can completely cure Hep C in just a few months. Advocates for the incarcerated have argued for years that Hep C is a public health risk, and that treatment must be made available to more people. But because of the cost of treatment, the slow-moving nature of the disease, and a lack of motivation on the part of state officials, most prisons and jails have failed to provide that treatment.

In Louisiana, a deal was brokered in 2019 with a drug manufacturer to provide treatment to people on Medicaid and people in control of the Department of Corrections who have Hep C. But the roll-out of that treatment is happening at a glacial pace and in the meantime, the sick are getting sicker.

But Hep C is hardly confined to inmates. It affects a broad swath of Americans, including baby boomers who may have been exposed through blood infusions before testing requirements were instituted for donated blood. The opioid epidemic has also intensified the need for testing and treatment. And while advocates say that there isn't as much funding to treat Hep C as there ought to be, resources are available, as are programs for reduced-cost treatment.

The Mission

Create public awareness about Hep C so more people can be tested and treated before the disease takes lives unnecessarily.



Jamila Johnson is the Managing Attorney for the Promise of Justice Initiative where she leads the Jim Crow Juries Project. She is pictured here at Clay Square in New Orleans.

“There’s a lot of misinformation within the prison system as to what causes Hepatitis C. So you would have individuals who believe that they were getting Hepatitis C because they were in prison and thought maybe it was in the water or thought maybe it was coming to them through a medication that was being provided to them by the prison.”

-Jamila Johnson, Promise of Justice Initiative

Advocates like Jamila Johnson, the Managing Attorney for the Promise of Justice Project, say that beyond the agreement between Louisiana and drug manufacturer Asegua Therapeutics, there is a lack of concrete information about how that treatment will be rolled out. Unfortunately, around the country, there is a lack of advocacy around Hep C, fueled by a stigma around the causes of the disease that leads to a lack of donor support.

As of 2016, the CDC estimated that about 3.5 million people were living with Hep C in the United States, and, of those, about half were unaware of their condition. Hep C causes liver inflammation and damage, but because the progression of the disease is slow and testing for Hep C is not a routine part of a doctor’s visit, it can be years or decades before a diagnosis is made. Sometimes, it’s too late. While some people may naturally clear the disease on their own, the majority of those infected will need treatment to recover.

The mission is clear: create more awareness about Hep C to get people tested and treated before the disease takes their lives, a process that can happen silently and slowly over many years. Recently infected people usually have no symptoms, and Hep C can be spread to others regardless of whether symptoms are present.

The Strategy

Connect individuals who are incarcerated with the information they need to get tested and treated.



“For the people who I have talked to who’ve wanted treatment for their Hepatitis C in Louisiana Department of Corrections, they haven’t received it yet. That doesn’t mean that they won’t receive treatment, but it does mean that they still exist with very limited information about the stage and the state of their Hepatitis C and whether the state intends to provide them treatment. And when that treatment might come.”

-Jamila Johnson, Promise of Justice Initiative

Jail and prison reform advocates have argued for years that mass-scale incarceration is a public health risk. Warehousing people in overcrowded and unhygienic living conditions with limited access to medical care facilitates the spread of disease. Not surprisingly, Hep C infection rates in prison are higher than in the general population. As a result, the risk of reinfection is high, not only because of the number of people with Hep C, but because access to proper management and treatment is more difficult.

Keep a Paper Trail:

Because of the associated costs, it’s still a struggle for incarcerated people to get treatment, even when they have a positive diagnosis of Hep C. In those cases, one strategy is to create and maintain a paper trail—showing that the prison is aware of your condition and attempts to get treated. Continue to update this information on a regular basis, to demonstrate a pattern of treatment denial. This can be used for litigation, as in Sean Wesley’s case.

Peer-to-Peer Mentoring:

Resources vary by state, but in Washington State, the Self Help in Eliminating Life-threatening Diseases (SHIELD) peer mentoring project trains incarcerated people as educators about the dangers of, and treatment options for, blood-borne infections, including Hep C and HIV. These educators have more credibility inside of their communities, allowing evidence-based information to reach more people.

Know Your Rights:

The ACLU has put together [this](#) informational booklet to inform incarcerated people of their medical, dental and mental health rights. It defines terms like “deliberate indifference,” and “serious medical need” that can help those seeking care to advocate for their rights.

The Promise of Justice Initiative, based in New Orleans, is a non-profit law-firm focused on civil rights protection and advocacy for incarcerated people in Louisiana. Photo: Zelena Williams

The Strategy

Connect the public with the information they need to get tested and treated.



The Louisiana Department of Health (LDH), located in downtown Baton Rouge, manages public health services such as public and behavioral health, Medicaid, and services for residents who are seniors or have developmental disabilities. Photo: Zelena Williams

“If I told someone they had the flu, but they feel fine, they probably won’t go to doctor. With Hep C, a lot of people feel fine, but they need to go to the doctor. You don’t want to run the risk of having living scarring and extrahepatic manifestations.”

-Christine Sewell, Executive Director, Hep C Alliance

To prevent unnecessarily illness and death from Hep C, more people need to get tested and treated. That will require education and awareness, access to testing, and, finally, treatment. The strategy is to urge clinicians to universally test for Hep C among adults and spread the word through educational programs, especially among communities at risk..

How can I contract Hep C?

Hep C is spread through blood to blood contact. Baby Boomers may have been exposed through injections or blood transfusions before testing protocols were in place to check donated blood for Hep C. It can also be spread through some forms of sexual contact, needle sharing, informal tattoos and piercings, or communal use of intimate products like razors, or passed from a mother to her baby during birth or breastfeeding. The CDC had previously called for one-time testing of all Baby Boomers, but now recommends that all adults be tested. As with the prevention of other STI’s, condoms are recommended.

How can I get tested and what is treatment like?

A simple blood test can check for the presence of Hep C. Ask your healthcare provider, or, if you’re unable to cover the cost of the test, check the resource guide on the following page for assistance programs. Several companies now manufacture medications to treat Hep C, completely curing the disease in more than 90 percent of cases. Usually, patients must take between one and three pills a day. Those treatments cost between \$20,000 and \$30,000. For those who cannot afford treatment, many companies offer assistance programs. Find out more about these on the resource page. Advocates say that treatment tends to have few major side effects, and takes between eight and 24 weeks.

Educational Programs:

Though the CDC’s national campaign aims to educate the public about Hep C, some states have created their own inventive methods. Washington State, the Hepatitis Education Project holds classes for youth at high schools, shelters, group care treatment centers and more to create evidence-based awareness. In New Mexico, Project ECHO educates community clinicians about Hep C to promote testing and treatment in underserved communities.

Resources

The Hep C Alliance, based in Columbia, Missouri, has a number of resources through its websites for those looking for testing, information or reduced-cost treatment. <https://hepcalliance.org/what-is-hep-c/resources/> You can also search for free, local testing at <https://gettested.cdc.gov/>

Help 4 Hep features a call line staffed by peer-to-peer counselors personally affected by Hep C: <http://www.help4hep.org/lets-talk> You can reach them at 877-HELP-4HEP, 9 am to 9pm ET Monday through Friday. They also offer an app which can be used by patients to track their illness and treatment: <http://www.help4hep.org/app>

Drug manufacturers offer cost-assistance programs for people who can't afford Hep C treatment. These include <https://www.mysupportpath.com/>, <https://www.mavyret.com/patient-support> and <https://www.merckhelps.com/>

SHIELD's peer mentoring program helps incarcerated people to become informed educators in their communities: <http://www.hepeducation.org/what-we-do/correctional-health-program>

One of the entrances of the Orleans Parish Prison is pictured here. The prison itself has been bombarded with accusations of misconduct over the years including issues of health and sanitation, prevention of violence among inmates, and other jail conditions. Photo: Zelena Williams



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