

PATIENT SUPPORT NEWSLETTER

Volume 6, January, 2021

lable of Content	
Welcome	1
Treatment Update	2
Risk Factors	3
Terminology	4
The Hero Study	6
Wounds and Hep C	7
Patient Assistance Programs	8
The Circle Model	10

In this new year, we have a new opportunity to confront the challenges facing our communities.

HCMSG remains committed to providing the resources needed to enable you to be as strong and healthy as possible. We are dedicated to eliminating Hepatitis C and addressing healthcare inequities through partnerships with community based organizations, syringe exchange programs, clinics, and hospitals.

Hepatitis C Mentor and Support Group's mission is to empower individuals and communities to manage their own health. We provide education and supportive services for anyone affected by Hepatitis C and/or co-infected with HIV.

In this newsletter you will find resources for education and support that will arm you with the tools to prepare you for wherever you are in the process of dealing with Hepatitis C and its impact on your life. As always, we are here for you. All our services and support are available in-person and virtually.

Stay Safe and Hopeful,



HEPATITIS C TREATMENT UPDATE:

Matthew Akiyama, MD, MSc

Asst Professor of Medicine, Montefiore Medical Center, Medical Advisor to HCMSG

Much progress has been made since the emergence of Direct Acting Antivirals (DAAs) for the treatment of HCV. DAAs were developed to improve the effectiveness and minimize the side effects of HCV treatment regimens by targeting viral proteins including the NS3/4A protease, NS5A, and NS5B polymerase. Inhibiting these proteins prevents the virus from reproducing and leads to eradication of the virus from the body, leading to HCV cure.

The first single-tablet combination DAA regimen, **Harvoni (ledipasvir/sofosbuvir)**, was approved for use in October 2014. Many other single- and multi-tablet regimens have been approved since that time.

Most recently, two regimens have been approved that can treat all genotypes of HCV: **Mavyret (glecaprevir/pibrentasvir)**, which is three tablets once per day taken with food and **Epclusa (sofosbuvir/velpatasvir)**, which is 1 tablet once per day taken with or without food. The regimens are 8 to 12 weeks in length for most individuals and very easy to take.

The keys to successful HCV treatment is taking your medication consistently missing as few doses as possible. If you take your DAA therapy daily without missing any days, the chances of being cured are at least 95%.

Don't forget that maintaining good liver health beyond HCV treatment involves consuming alcohol only in moderation or avoiding it altogether and eating a healthy diet.

Looking for assistance? See page 8

Risk Factors

ALL ADULTS AGES 18+ are recommended to be screened for Hepatitis C

Sharing syringes to inject drugs, hormones or steroids

Tattoos & body piercings in unregulated settings

HIV-infection

History of incarceration

Children born to mothers infected with Hepatitis C

Non-injection drug use is a risk factor for HCV (and many other infectious diseases)

Sharing drug use equipment (pipes, cotton, cookers, water, etc.)

Sharing straws for snorting drugs

Occupational needlestick

Received blood transfusions or blood components before 1992

Sharing personal care items such as razors, clippers or toothbrushes

Sexual transmission (not common, however, some sexual practices may involve blood)

HOW LONG DOES HEPATITIS C LIVE ON SURFACES

Cotton Filters 24-48 Hours

Cookers 14 Days

Syringes 63 Days

Water 21 Days

Surfaces 16 Day

References:

http://jid.oxfordjournals.org/content/202/7/984.full.pdf

http://www.projectinform.org/pdf/pwidtoolkit whatkillsHepatitis C.pdf

http://harmreduction.org/issues/hepatitis-c/overview/hepatitis-c-transmission/

WHY IS TERMINOLOGY SO IMPORTANT?

Published in 2020 by INPUD - The International Network of People who Use Drugs www.inpud.net

Term to Use	Description	
Clients	People who use drugs should be referred to as 'clients' accessing services, not patients (see below).	
Non-stigmatising language	Objective terms such as 'people who use drugs'	
People who Inject Drugs	One of our networks' key constituency, since these communities are often the most discriminated against and stigmatised.	
People who Use Drugs	Collective, descriptive, objective term for all people whose interests we, as drug user networks and rights organisations, represent.	
Stigmatizing Terms	Description	
Abuse ('Drug abuse')	Emphasises a moral judgement, that the drug is being used for an incorrect purpose	
Addicts	Obviously derogatory. Reduces people who use drugs to a particular moralised and compromised state and status.	
Clean	The implication is that people who use drugs are dirty, unclean, unsanitary.	
Druggies	An abusive term for people who use drugs.	
Junkies	Derogatory term used to dehumanise people who use drugs.	
Patients	Referring to people who use drugs as 'patients' is disempowering and pathologizing (see 'Clients').	
Recover	Relies on the stigmatising acceptance of addiction as disease; implies drug use is necessarily tumultuous and traumatic.	
Treatment	We reject the idea that people's drug use and drug dependency can be subject to treatment as a disease can; various services catering to people's nuanced and variable realities, must be provided on their own terms.	

See the full article including list of terms at www.inpud.net

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Language can be stigmatising and discriminatory: It can be used to denigrate, bully, and otherwise; it can be used to pathologize and demonise; and it can disempower. And if disempowering and denigrating language is used by various healthcare, social and legal service providers, then this disincentivizes people from visiting these services: the wrong language presents very real barriers to people who use drugs accessing services.

Language can incite violence and abuse, it can dehumanise, it can incite genocide. Such language, language that attacks a human being or group on the basis of certain stigmatised attributes is often referred to as hate speech. Hate speech is so powerful – not only in inciting violence, but in the very real violence which it does to those to whom it pertains – that in many jurisdictions it is, correctly, illegal.

Language can also uplift: it can empower, include, and accurately and helpfully describe. It can subvert and question. It can make the difference between inclusive and holistic services and organisations, and services and organisations that fail. Language, both in verbal and non-verbal forms, when used respectfully and thoughtfully, has the power to transform attitudes and perceptions towards the issue, group, and/or a person to which (or to whom) it refers.

In short: language is not a distraction; language is important. Though of course we recognise that language cannot (and should not) be curtailed, forbidden, or regulated, it is very important to set out why some terms are offensive and hateful, and why others are preferred by our communities.

Published in 2020 by INPUD - The International Network of People who Use Drugs See the full article including list of terms at www.inpud.net

THE HERO STUDY



"The HERO Study" funded by PCORI, and supported by a large group of national and international stakeholders.

Patient-Centered Models of HCV Care for People Who Inject Drugs

HERO was a national study involving 25 sites in 8 different states. The study enrolled active people who inject drugs who injected drugs within 12 weeks of study entry and were treated for HCV either in community-based clinics or methodone clinics. Participants were either treated through modified directly observed therapy or patient navigation.

Over 80% of PWID enrolled initiated treatment, and of those greater than 70% were cured. The majority found to NOT be cured were lost to follow-up and just did not obtain bloodwork to see if they were cured. Among those who received bloodwork to see if they were cured, 90% were cured.

There was no difference in cure rates for those receiving modified directly observed therapy or patient navigation, but those who received care in methadone programs had improved adherence if they received modified directly observed therapy compared to patient navigation.

People who inject drugs in multiple settings (8 different states, urban or rural, and in methadone programs or in community-based clinics) can be successfully treated for HCV

Directly observed therapy is not necessary but if you are in a methadone program and you have the opportunity to take advantage of receiving HCV pills with methadone-- go for it-- it might improve your chance of adherence.

Most people who were deemed "not cured" were lost to follow up-- remember to get your last blood work 3 months after you complete treatment to make sure you are actually cured!

All people who inject drugs should be offered HCV treatment. However, several factors were associated with decreased cure rates – people who were marginally housed, those who were enrolled in buprenorphine versus methadone; those who injected drugs within one month of enrollment versus between one and three months; and those who injected three or more times daily versus less than three times daily.

EVERYTHING IS RELATED: WOUNDS AND HEP C

By Thaddeus Pham,

Viral Hepatitis Prevention Coordinator
Hawaii Department of Health
Hep Free Hawai`i



Honolulu Star Advertiser

Hep C is not everyone's priority

When we talk about hep C in Hawai`i, we have to talk about so many other things. Currently, more than 6 out of 10 people who use our syringe service programs (SSPs) in Hawaii are infected with HCV. For most of them, hep C is not a priority because they are dealing with more visible or urgent things like homelessness, mental health diagnoses, and legal troubles. With that in mind, we at Hep Free Hawai`i joined with our SSP and health department partners, as well as medical champion Dr. Christina Wang, to ask people at SSPs what THEIR main health concerns were.

People were more concerned about wounds

People at SSPs told us that their main health concerns were ongoing wounds. They could not get quality care from medical providers and the emergency department due to stigma around their drug use, but they were willing to seek care at the SSPs. We realized that providing wound care at the SSPs would be an effective way to engage clients who might have hep C. In 2015, Dr. Wang started a street-based wound care clinic that eventually expanded to include hep C testing, linkage, and care coordination. Since the program started, more than 800 visits for over 150 unique clients have been provided. Due to the low-threshold, high-quality care that they receive, clients are more likely to address their hep C and many other concerns.

Give the people what they want

Through this program we learned the importance of practicing the philosophy of harm reduction in everything we do. By asking people at SSPs what they want and providing it to them, we built stronger communities and relationships that allowed us to address hep C and many other related harms.



Christina Wang, DNP, MPH, APRN, AGPCNP-C (right) providing wound care to an SSP participant



Learn more about hepatitis in Hawai`i

Go to www.hepfreehawaii.org, or @hepfreehawaii on social media

Adapted from a longer article at

https://www.hhs.gov/hepatitis/blog/2018/05/11/opening-doors-for-hcv-services-at-syringe-services-programs.html.

PHARMACEUTICAL PATIENT ASSISTANCE PROGRAMS

Most pharmaceutical companies offer help to patients who cannot afford the medications needed to treat Hepatitis C. You should work with your medical provider to select and contact programs for assistance.

Gilead
Harvoni (ledipasvir/sofosbuvir)
Epculsa - (sofosbuvir/velpatasvir)

AbbVie MAVYRET (glecaprevir/pibrentasvir) 877-628-9738 www.mavyret.com/patient-support

Gilead Support Path
1-855-769-7284
https://www.mysupportpath.com/

PATIENT COPAY ASSISTANCE PROGRAMS

Patient Access Network (PAN) Foundation:

An independent non-profit organization that provides assistance to underinsured patients for their out of pocket medical expenses. PAN assistance covers multiple Hepatitis C medications and a patient's choice of medication does not influence the amount of assistance a patient is able to receive.



To learn more or to apply, visit www.panfoundation.org or call 1866-316-7263



Patient Advocate Foundation

To provide Hepatitis C patients with hands-on case management support Hepatitis C Co-Pay Relief fund award HIV, AIDS and Prevention Co-Pay Relief fundHepatitis C CareLine-1800-532-5274

For additional information, go to www.hepatitiscmsg.org/patient-assistance-programs

HCM56 ENT EDUCATION

PATIENT EDUCATIONAL TRAINING

You may be eligible for a \$15 food gift card for participating**

Visit us: https://www.hepatitiscmsg.org/hepctraining

**Exclusions apply. See full details on our website.

Training Addresses

- ABC's of Viral Hepatitis
- The Basics of Hepatitis C and its differences from Hepatitis A and Hepatitis B
- Co-infection with HIV
- People with Hep C and co infected with HIV are at increased risk of developing chronic liver disease.
- Safe Sexual Practices
 Unlikely but possible. Learn about how to reduce risk of transmission during sex.
- Harm Reduction Strategies
 The Circle Model meets people where they are at with forcing anyone down a specific path

And more...

The Circle Model



HCMSG's "The Circle Model" address the basic needs of all people affected by Hepatitis C and/or co infected with HIV. In response to what is clearly a connection between substance use and Hepatitis C, we educate each person in regards to transmission and the benefits of being tested for Hepatitis C. This may be through a group or one on one. In order to effectively accomplish this, trust must be first established. The participants who test positive are then navigated through the process with the goal of receiving treatment for Hepatitis C and to endeavor to reduce the harm of substance use. The participants are identified through programs, such as syringe exchanges.

"The Circle Model" provides a non-hostile environment where participants are treated with respect encouraging them to reduce the harm of infection and encourage changes for a healthier lifestyle. With many having had bad experiences with the healthcare system, we offer support without forcing one down a specific path. There is no judgment of lifestyle and participants are given hygiene kits to provide options in an effort to reduce the harm. In addition to addressing the medical concerns, we provide guidance for participants who face non-medical challenges. We provide insight and direction into providing options and developing effective ways to engage participants in their own care and treatment. Our goal is to empower them to be able to be active in developing a long term plan and take control of their overall health.

HCMSG's Current Circle Sites



- -ekiM for Change Syringe Exchange Greenville, NC
- -Hawaii Department of Health Honolulu, HI
- -Hep Free Hawaii Honolulu, HI
- -Hawaii Health and Harm Reduction Center Honolulu, HI
- -Choice Health Network/ Positively Living Knoxville, TN
- -Harm Reduction Clinic Knoxville, TN
- -Washington Corner Project Washington Heights, NY
- -Sun River Health Bronx. NY





If you are interested in starting a Circle Model, go to www.hepatitiscmsg.org/circleregistration



We welcome your suggestions and any stories you want to share.

To contact us: Email hepatitisCmsg@gmail.com Website: www.hepatitisCmsg.org