

Addressing barriers to hepatitis C care faced by individuals who use drugs

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National Viral Hepatitis Roundtable (NVHR)

- National coalition of about 500 members
 - Mission: working together to eliminate hepatitis B and C in the U.S.
- NVHR advocates at the federal and state levels for increased access to hepatitis B and C prevention, testing, treatment, and care.
 - Expand access to syringe service programs, to link people who use drugs with HBV/HCV screening/testing and treatment.
 - NVHR partnered with the Center for Health Law and Policy Innovation of Harvard Law School (CHLPI) to create the first-ever comprehensive assessment of state Medicaid restrictions on hepatitis C cures.
- NVHR provides hepatitis C education, technical assistance, coalition building, & capacity building
 - Webinars, Fact Sheets & Online Resources
 - Working Groups for HCV Treeters & Pharmacists
 - Programs: Hepatitis C – it's about More than Liver Disease; More than Tested, Empowered Project
 - Community Stakeholder Engagement in PCORI Studies
 - Mini-Grants - Technical assistance & \$10K of financial support
- www.nvhr.org

Background – Hepatitis C: State of Medicaid Access

The **National Viral Hepatitis Roundtable (NVHR)** and the **Center for Health Law and Policy Innovation at Harvard Law School (CHLPI)** launched “**Hepatitis C: State of Medicaid Access**” – a report and interactive project grading all 50 state Medicaid programs, as well as the District of Columbia and Puerto Rico, according to restrictions preventing access to treatments for hepatitis C, *including:*

- **Sobriety / History of Alcohol or Substance Use Restrictions**
 - **Liver Damage (Fibrosis) Restrictions**
 - **Prescriber Restrictions**
- The interactive report is available at www.stateofhepC.org featuring all 52 state-by-state report cards, advocacy resources and materials, and a petition urging widespread access to a cure.



- Since we launched the report, **16 states** have announced less restrictive HCV treatment policies.

Alaska



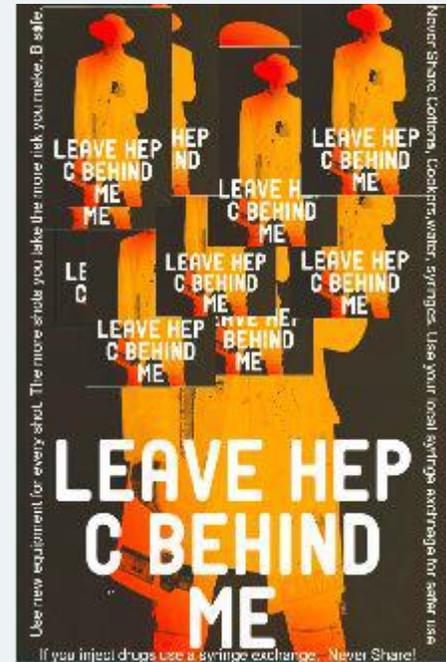
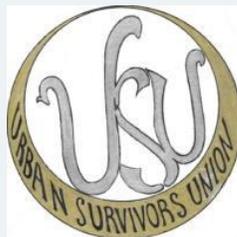
Grade: A-

- Alaska has significantly improved access to hepatitis C medications and removed most barriers to treatment in all three categories of restrictions.
- **Currently, Alaska Medicaid requires screening and a referral to treatment for active alcohol and illicit substance use.**
- Alaska Medicaid does not have any liver damage (fibrosis) requirements or prescriber restrictions.
- **By removing its sobriety restriction, Alaska could have open access.** In recognition of Alaska's sobriety restriction, a "minus" has been added to the state's A grade.

More than Tested, Empowered

A Novel Project to Meaningfully Engage Drug Users in hepatitis C (HCV) Work

- collaboration between NVHR & three harm reduction organizations with local focus
- overcoming barriers requires input of directly impacted individuals
- unique model of a partnership
 - Shared grant writing and project management responsibilities
 - Disseminated findings locally and nationally
- www.nvhr.org/programs/more_than_tested_cured



Overview of Year One Accomplishments

I. Engaging Individuals who use Drugs in Defining the Solution

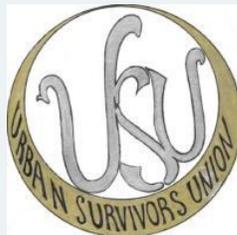
II. Developing and Disseminating Culturally Appropriate HCV Education Materials

III. Expanding Access to HCV Services for Individuals Who Use Drugs:

a. Expanding Services available at Syringe Exchange Sites

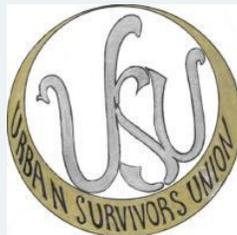
b. Reducing Stigma and Barriers for Specialists to Treat Active Users

IV. Strengthening the National Network



Year 1 Evaluation Findings

- “Make sure that what you are doing is drug user led and that you are incorporating perspectives from drug users in every level of your project. It will greatly improve how responsive you are to the problems that people who use drugs are facing.” --project staff member
- “Involving the people who...have the disease in the conversations and hearing why people aren’t getting access to care is the only thing that will tell us what people’s actual barriers are.” --project staff member



Stigma on patient and provider level

- **Patients:**

- ❖ Stigma associated with drug use and rejection for treatment
- ❖ Lack of knowledge and stigma associated with HCV treatment
- ❖ Lack of trust among health care providers
- ❖ Difficulty navigating through healthcare system

- **Providers:**

- ❖ Not keeping up with appointments
- ❖ Dropping out of Care
- ❖ Fear of re-infection
- ❖ Drug Resistance



People's Harm Reduction Alliance (PHRA)

- Peer-run organization promoting harm reduction and safer drug use
- Need-based needle distribution and safer smoking supplies
- Active drug users at all levels
- Fixed and delivery sites
 - Seattle, Everett, Olympia, and Bremerton, WA
 - Portland, OR



HCV Program: Year 1 (Seattle)

- Needs assessment
 - 20 client interviews
- Provider engagement and client education
- Increased testing
 - 66% increase
- Offered case management

| Testing/Treatment | Number (%) |
|--------------------------------|------------|
| Number screened | 166 |
| HCV + | 41 (25%) |
| Returned for confirmatory test | 30 (73%) |
| Confirmed positive | 23 (77%) |
| Linked to treatment | 3 (13%) |

HCV Program: Year 2

- Case management
 - 4 clients since March
- Expanding testing and linkage to care
 - Kitsap, Olympia, Portland
- Survey of WA providers
 - Opinions & barriers to treating drug users
 - Information needs & education

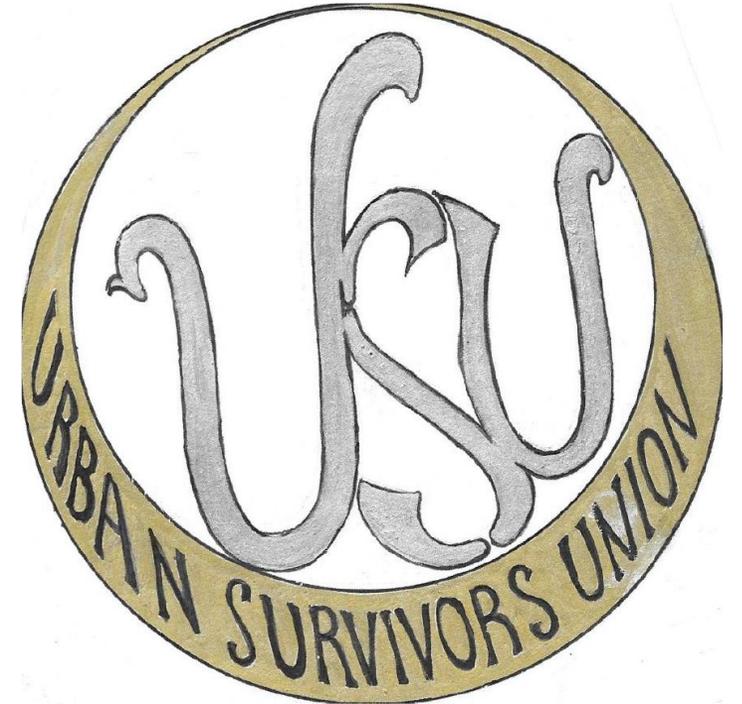


Urban Survivors Union (USU)

Urban Survivor's Union is a grassroots coalition of drug users (former and active) dedicated to ensuring the respect, dignity, and social justice for people with substance use experiences.

We contest the dominant culture's misguided attitudes and biases about drug use and users.

USU stands for a new direction in drug policy. Our programs are centered on improving conditions for people that use drugs, their families, and communities.



Meaningful Engagement

- Growing Grassroots Groups led by Impacted People
- Working as a Team with Similar Groups
- “Grant Parents” - having an organization really take us and train us
- Planning, implementing, evaluating - good public health
- Sharing our story



General Focus Group Findings

- Syringe exchange is vital for the health and well being of PWUD.
- Confusion over how HCV infection is spread and new all-oral HCV treatments
- Frustration over not being able to care for self even when they want to.
- Frustration regarding the lack of information received over the years; even after exposure to treatment, jail, prison, and other mandatory programs.
- No trust in medical system; no desire to go to doctor even when it's needed.
- Unemployment affects ability to go to doctor; long-term lack of insurance
- Medicaid impossible to get; Medicare and Disability also impossible to access.
- Most diagnosed with mental health issues, yet have no access to medication.

Findings: Women Who Inject Drugs

- Veins – struggle to inject self
- Not having control of injection supplies and drugs
- Need to letting others inject them
- Not wanting track marks to show
- Fear of going to doctor or treatment due to children
- Not able to talk to anyone about drug use- social services involvement
- Isolation; feeling stuck
- Doing what you have to do to take care of family; kids have to be taken care of
- Self-hatred
- No way to stop using drugs without making things worse

Findings: Stimulant Users

- No real understanding on how increasing injecting increases HCV risk.
- No real understanding why staying up for days increases health risks.
- Adderall prescriptions helped control cocaine use but most doctors will not prescribe amphetamines to patients they know use illicit stimulants
- Stimulants increase sex drive and this increases risk. (Reports of having sex for extended periods of time due to uppers)

Atlanta Harm Reduction Coalition, Inc (AHRC)

AHRC is a community based wellness organization committed to promoting health and dignity by reducing the impact of HIV/AIDS, Hepatitis C, STI, and Substance Use within vulnerable communities.

Linkage to Care Model

- Harm Reduction Therapy
- Specialty Education
- Syringe Exchange Program
- Existence of Specialty Pharmacy (340B)



Removing Barriers

Step 1: Education

- Patients:
 - Education on the virus, course of disease, complications, and treatment options
- Providers:
 - Education on Harm Reduction, Linkage to Care, and Syringe Exchange Services

Step 2: Case Management/Linkage

- Patients:
 - Removing underlying barriers: Housing/Food/Transportation
 - Active Linkage to Medical Care
 - Linkage to Syringe Service Programs
- Providers:
 - Linkage to Harm Reduction Agencies
 - Linkage to Syringe Service Programs

Step 3: Peer Navigation

- Patients:
 - Education on receiving care and linkage to care through stories from peers who have completed treatment



Achievements at AHRC

2014: Creation of HCV program at AHRC via educational groups

2015: Offering preliminary HCV testing through collaboration with GDPH and Orasure Technologies, and Linkage to Grady Liver Clinic

2016: Guest Speaker at Harm Reduction Conference

2017: Offering confirmatory HCV testing, providing education to HCV providers, and becoming 340B participant

2017 Data:

- Conducted needs assessment: Out of 25 respondents, 68% said they currently would not provide HCV treatment for active drug users and 96% said they did not offer sliding scale fees for services.
- AHRC worked with 16 specialists to increase their willingness to treat HCV among PWID
- AHRC staff built relationships with charity organizations who fund HCV treatment. 25 clients were connected directly to financial resources available to pay for their HCV treatment
- Number of completed confirmatory tests increased from 0 to 6
- Specialists treating HCV-positive drug users increased from 2 to 9
- HCV-positive injectors with referrals to treatment increased from 1 to 9

2018: Linkage to Piedmont Hospital

Learner Evaluation

- Please use the link below to complete the learner evaluation. This link will also be emailed to you within a few days. Please check your junk and spam email folders if you don't receive it.

<http://sgiz.mobi/s3/July-NW-ECHO>