



Testimony for Joint Legislative Budget Hearing On Health January 30, 2013

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Hello, my name is Diane Nunez. I am living with the hepatitis C virus and am a community leader with VOCAL-NY. VOCAL-NY is a grassroots organization building power among people affected by hepatitis C, HIV/AIDS, drug use and incarceration in order to create healthy and just communities in New York.

Here's the good news – we have the tools to end the hepatitis C epidemic in New York. Although there is no vaccine, we know how to effectively prevent new infections and ensure access to care and treatment for those already living with hepatitis C. In fact, current treatments can actually cure most people living with the virus, and there are even better medications in the pipeline that we will be available in the next couple years. Make no mistake – ending the hepatitis C epidemic in New York is fully attainable if we are willing to make the investment.

Let me thank Assembly Member Gottfried in particular for his leadership in raising awareness of hepatitis C, including through Governor Cuomo's Medicaid Redesign Team. We always appreciate the New York State Department of Health's willingness to partner with VOCAL-NY to regional community forums on gaps in hepatitis C services throughout the state. The recommendations we present today are based in part on gaps in hepatitis C services we heard about during those forums.

But first, here are the facts about hepatitis C.

Hepatitis C is the most common blood-borne infection in the United States, with an estimated 3 to 4 million people living with the virus.

In New York, it is estimated more than 300,000 people have chronic hepatitis C, including more than 130,000 in New York City.

Baby boomers, or people born between the years of 1945–1965, account for approximately three-fourths of all chronic hepatitis C infections. That is why the Centers for Disease Control and Prevention (CDC) now recommends one-time screening of all baby boomers.

Populations with the highest prevalence of hepatitis C include people with a history of injection drug use, people who are living with HIV/AIDS and immigrants from countries

with high hepatitis prevalence, including Egypt, Pakistan and the former Soviet Union. Veterans in the VA system have a high prevalence of hepatitis C too, with data suggesting at least 1 in 20 veterans enrolled in the VA have hepatitis C.

Although effective treatments exist, most people living with hepatitis C do not know they are infected or receive needed care.

More than 15,000 people in the US, most of them baby boomers, die each year from hepatitis C-related illness, such as cirrhosis and liver cancer. Since 2007, more Americans die from hepatitis C-related causes than HIV/AIDS. While not everyone who is infected with hepatitis will develop liver failure, the number of deaths due to hepatitis C continues to grow.

During the past decade, the annual rate of new hepatitis C infections has plateaued. There are an estimated 17,000 people newly infected with hepatitis C each year nationally, a majority of who are people who inject drugs.

The following recommendations are well aligned with goals and objectives in the New York State Viral Hepatitis Strategic Plan released in 2010. As I stated earlier, they also reflect the needs we heard during regional hepatitis C forums around the state.

VOCAL-NY recommends that the Assembly and Senate:

→ Renew the current investment of \$1.9 million in grant-based hepatitis C education, prevention, and medical care coordination through the NYS Department of Health.

→ Renew \$2.1 million in new grant funding first recommended through the Medicaid Redesign Team.

→ Prevent new hepatitis C infections by expanding access to drug treatment and improving syringe access programs for people who inject drugs.

- End the waiting lists and close gaps in geographic coverage for methadone maintenance and buprenorphine treatment, especially in upstate New York and Long Island.
- Fully deregulate syringe possession to reduce law enforcement harassment of people who participate in syringe access public health programs.
- Integrate syringe access into opioid treatment programs and drug treatment programs. Or, all OASAS licensed programs.

→ Fund community-based organizations that currently provide hepatitis C antibody testing to also provide viral load tests and care coordination. This model is successfully being utilized by the "Check Hep C" project currently being piloted in New York City.

→ Evaluate and support peer-delivered hepatitis C services in community-based organizations, where peers already assist with recruitment for testing, prevention and support groups and offer treatment adherence support. Support hepatitis C care and peer

work by increasing New York's Medicaid reimbursement for peer-delivered services to the national average of \$41 per unit, currently set at \$31 per unit.

→ Require both OASAS-licensed drug treatment programs and DOCC's correctional institutions to provide basic reporting on hepatitis C prevalence, availability of services, linkage to care and number of persons receiving HCV treatment.



October 2012

Recommendations for Improving Hepatitis C Services in Opioid Treatment Programs (OTPs)

VOCAL-NY recommends that OASAS issue the following requirements for OTPs in order to promote greater access to HCV prevention, care and treatment in these high prevalence settings. We also endorse more detailed recommendations for improving HCV services in OTPs drafted by Dr. Alain Litwin of Albert Einstein College of Medicine.

Screening & Counseling

- All patients should be tested for HCV antibodies and receive their test results on a timely basis, with documentation they received their test results in their patient record. Patients who test negative but have ongoing risk (e.g. positive toxicology results) should be tested during annual health exams.
- All patients who test positive for HCV antibodies should be offered an *onsite* HCV viral load test in order to determine whether they have chronic infection. Patients who do not have adequate health insurance coverage should be referred to an appropriate provider where they can obtain a viral load test.
- Brief post-test HCV counseling should be made available to all patients. Those who test positive for HCV antibodies should be counseled about the need for further evaluation, basic health information and the availability of effective HCV treatment.

Linkage to Care

- Issue best practices for HCV prevention, testing, care and treatment in OTPs.
- All medical staff and counselors receive updated HCV trainings that reflect the current standard of care.
- Provide onsite HCV care and treatment where possible. Programs that are unable to offer HCV diagnostic tests (e.g. liver biopsy) or treatment onsite should establish a concrete referral system and establish linkage agreements with medical providers for follow-up care for OTP patients with chronic HCV. Referrals should be documented in the patient case record.
- Substance use counselors and medical providers should review the status of HCV care for patients with chronic infection as part of their treatment/recovery plan, and help facilitate access to care when only available offsite.

Peer Services

- Encourage programs to support peer-based HCV counseling and support groups that provide social support and promote access to care.
- Increase the reimbursement rate for peer services to at least \$40 to enable more OTPs to utilize peers for HCV support services.

Prevention

- End the waiting lists and close gaps in geographic coverage for methadone maintenance and buprenorphine treatment, especially in upstate New York and Long Island.
- Provide referrals to syringe exchange programs (SEPs) for all patients during intake and whenever a patient has a positive toxicology test for drugs that are injection related.
- Register with the NYS Department of Health (DOH) for the Expanded Syringe Access Program (ESAP) in order to make syringes available to patients without a prescription.
- Encourage physicians to prescribe syringes to patients who inject drugs, clarifying existing billing options.
- Register with the NYS DOH Safe Sharps Collection Program, which would allow patients to safely dispose of used syringes.

Reporting & Transparency

- Track HCV prevalence, availability of HCV services, and how well OTPs link patients with chronic HCV to care and treatment by monitoring the following indicators on an aggregate basis at each program:
 - Causes of mortality among patients;
 - Prevalence of HCV, including the number of patients who test positive for HCV antibodies and the number of those with chronic HCV infection;
 - Availability of diagnostic tests, onsite treatment, support groups and peer-based services;
 - Number of patients receiving treatment onsite;
 - Number of patients enrolled in HCV treatment offsite;
 - Number of referrals for HCV services offsite.
- Ensure proper documentation of HCV health history and receipt of HCV services in patient case records.

Resources

- Consult with OTPs about any needed adjustments to APGs or financing mechanisms to implement expanded access to HCV services.
- Expand grant funding available to high prevalence settings, including opioid treatment programs, to provide enhanced hepatitis C services, especially care coordination and onsite treatment.