



Bridging Science, Policy and Public Health

# **Viral Hepatitis Policy: Challenges and Opportunities**

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# NASTAD

- NASTAD is a non-profit national association representing state HIV/AIDS health department programs
- Due to the overlap in populations affected, health department HIV/AIDS programs have become increasingly responsible for addressing hepatitis A, B & C
- The majority of CDC-funded hepatitis C coordinators are located within the health department HIV/AIDS program; all work closely with the HIV/AIDS program
- NASTAD's viral hepatitis program has two major components: Technical Assistance and Public Policy

# Overview

- Current federal response
- Challenges to being heard
- Current advocacy efforts
- Your role in advancing viral hepatitis policy

# Few Federal Dollars are Available to Support Hepatitis Prevention Services

- Congress appropriated \$17.5 million to CDC's Division of Viral Hepatitis (DVH) in FY2005 to mount a **public health response** to viral hepatitis
- CDC, Division of HIV/AIDS Prevention:
  - Health Departments are allowed to use HIV prevention dollars, with the endorsement of their HIV CPG, to purchase hepatitis C testing services
- 317 dollars for vaccine are used mostly for kids
  - There is no dedicated funding stream for adult vaccine
- Hepatitis B coordinators are funded through CDC NIP

# Few Federal Dollars are Available to Support Hepatitis Prevention Services

- Substance Abuse and Mental Health Services Administration
  - One program was recently awarded which gives grantees the flexibility to purchase hep C testing
  - Implementing an adult hepatitis vaccine demonstration project (*fyi—there will be a presentation on this program on Thursday at 1:30 if people are interested*)

# Federal Hepatitis Care & Treatment Programs

- There is no dedicated funding stream for care for HCV or HBV mono-infected
  - Community health centers and others need increased resources to help meet the needs of these complex patients
  - Provider training is critically needed
- Persons co-infected with HIV and HCV are dependent on the already stretched too thin Ryan White HIV care system
  - CARE Act grantees are struggling to provide comprehensive services to their HIV infected clients
  - ADAPs must be fully funded to address the needs of the HIV-infected and the co-infected
    - 20 states provide HCV drugs on their formulary, 22 provide vaccine

# Federal Hepatitis Care & Treatment Programs

- Veterans Health Administration
  - National model for providing care and treatment to veterans with hepatitis

# Challenges to Being Heard

- Focus and funding on war and homeland security
- Focus now is on paying down the deficit
  - Medicaid is expected to take deep cuts
  - Discretionary health programs continue to take cuts
- Health care concerns such as implementation of the Medicare prescription drug benefit is taking center stage
- A single political party holds the White House and both chambers of Congress
- Crisis du jour – Katrina and Avian Flu

# Challenges to Being Heard

- For HCV: Natural history of the disease—“silent epidemic”—slow progressing virus
- For HCV and HBV: Lack of chronic disease surveillance makes it difficult to demonstrate the burden of disease
- For HCV and HBV: Lack of credible spokesperson to bring a “face” to the disease and help personalize it, e.g, Ryan White, Katie Couric
- For HCV: Impacts largely underserved, medically needy populations with a whole host of issues
- For HBV: Largely impacts API communities who may not be comfortable challenging health care providers or advocating

# Challenges to Being Heard

- HHS has yet to demonstrate leadership on the disease
- Lack of leadership from CDC, HRSA, medical providers, national HIV organizations...still in the position of persuading our allies
  - HRSA tells me they get virtually no requests from their grantees about co-infection
  - DVH is low priority at CDC
  - HIV community is faced with dwindling resources and wants to protect its resources
- Grassroots and national advocacy needs to be developed

# Hepatitis C Appropriations Partnership

- Partnership of public health and provider associations, patient advocacy organizations, national HIV and HCV organizations, and the pharmaceutical and diagnostics industry
- Dedicated to increasing public funding and support for HCV
- Meet monthly with an annual meeting
- Created series of fact sheets
- Meetings with Congress and the Administration
  - Seeking leadership

## Hepatitis C Epidemic Control and Prevention Act (S 521/HR 1290)

- Sponsored by Senators Kay Bailey Hutchison (R-TX) & Ted Kennedy (D-MA)
- Sponsored by Reps. Heather Wilson (R-NM) & Ed Towns (D-NY)
- Legislation supports:
  - State and local HCV testing, counseling and referrals for medical management
  - HCV surveillance
  - HAV and HBV vaccine for those at high-risk for HCV
  - HCV coordinators to integrate HCV services into existing public health programs

# Co-Infection and Reauthorization

- NASTAD and other AIDS organizations are working on more visible inclusion of co-infection with HBV and HCV into Reauthorization of the Ryan White CARE Act
- Congressional Staff have indicated that hepatitis will be addressed

# Potential Opportunities

- Hepatitis community is coalescing and working well together; many HIV organizations are contributing their expertise
- Growing grassroots: good response to the first Viral Hepatitis Grassroots Training and Hill Education Day, this experience will help engage affected persons
- NVHR has completed it's recommendations: the recommendations can be used by all to articulate the case for hepatitis
- The continued improvement of treatments and cure will help justify financing care

# But We Can't Do this Without You!

- Grassroots is critical
  - Community engagement = change
- If MOC's do not hear from their constituents on hepatitis, it's hard for us to move above all of the other noise
  - Politics is personal and your story is important
- As public health professionals, health care providers, community advocates and persons affected or infected by hepatitis C, this disease is **our responsibility**

# For More Information

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