



Advocating for Hepatitis C in New York State and City

Coordinating the Roles of State and City
Viral Hepatitis Coordinators

Outline

- Viral Hepatitis Coordinator's Role as an Advocate in NY
- Role of Advocates in NY
- Limitations on Advocacy
- Overview of Advocacy Efforts
- Accomplishments
- Challenges
- Next Steps

Role of the Viral Hepatitis Prevention Coordinator

- New York State
 - Limited role, fine line
 - Provide a venue for advocates to meet
 - Provide feedback when necessary
 - Develop educational packets for Legislative awareness day
 - Hill Visits
 - Educational information only
 - Approval from Governmental Affairs
 - NYSDOH AIDS Institute long history of working with advocates

Role of the Viral Hepatitis Prevention Coordinator (2)

- New York City
 - Organize advocates:
 - Hepatitis C Task Forces
 - Disseminate information on public health policies that impact hepatitis service provision
 - Develop Legislative Agenda (Federal, State and City)
 - Track and assess impact of legislative action on hepatitis-related public health issues
 - Collaborate with Bureau of Intergovernmental Affairs to produce comprehensive analyses and policy positions and to coordinate response to pending or planned legislation

Limitations on Advocacy

- New York State
 - Required to work with our Governmental Affairs who serves as the liaison to elected officials.
 - Coordinates all communications with elected and appointed government officials
 - Coordinates comments on various hepatitis related Bills
 - Hill visits, Lobby days, Legislative awareness events

Limitations on Advocacy (2)

- New York City
 - All legislative contact must be made through Bureau of Intergovernmental Affairs:
 - Coordinate all communications with elected and appointed government officials
 - Hill visits, Lobby days, Legislative awareness events
 - Coordinate with Mayors Office and other City agencies to assure unified City policy
 - Cannot support policy initiatives if targeted to City or State agencies
 - NO grant or tax money can be used to support legislative action

Advocates Role

- Meet separately from State and City Programs
- Letter writing, phone calls
- Meetings with representatives
- Organize Legislative Awareness Day
- Develop Community Budget
- Meetings with:
 - NYS Division of Budget
 - NY City Council
- Host Other Events
 - Test days, marches/walks, Hepatitis Awareness Month Activities

Advocacy Efforts

- New York State
 - Legislative Awareness Day
 - Every March
 - DOH provides packets with educational information
 - Statewide HCV Conference
 - Advocacy Workshop
 - Advocacy Presentations
 - Exhibitor Booth

Advocacy Efforts (2)

- New York City
 - Annual Legislative Agenda
 - Proposed New Needs funding package
 - Task Force activities
 - HCV Policy group
 - HIV policy expert meeting
 - CDUHR Policy Forum
 - Managing City Council contracts

Advocacy Efforts (3)

- Northeast Hepatitis Coordinators Alliance
 - 11 CDC-funded AVHPC in the NE Region of the U.S
 - The purpose is to provide a coordinated, collaborative, and creative approach for improving strategies, integration efforts and public health interventions to meet the challenges of viral hepatitis disease.
 - Host an annual meeting
 - 2009 Washington, DC
 - Hill Visits

Advocacy Efforts (4)

- Hepatitis C Community Workgroup
 - Initiated back in 2005
 - Grew out of a request to have regular communication with community members and DOH
 - Currently 25 members
 - State DOH, NYCDOH, consumers, providers, CBOs, ALF, provider groups
 - Facilitates community input to achieve consensus on priorities for hepatitis C planning and policy development

Advocacy Efforts (5)

- Hepatitis C Community Workgroup - Objectives
 - Provide a venue where the HCV community can develop the knowledge, skills, abilities and strategies to raise awareness of the issues associated with hepatitis C.
 - Foster communication and information sharing among partners.
 - Develop a better understanding of the accessibility and availability of services in NYS.
 - Examine specific issues such as HIV/HCV coinfection in relation to hepatitis C needs, resources, program and policies.

Advocacy Efforts (6)

- Hepatitis C Community Workgroup – Objectives (continued)
 - Develop strategies to educate community partners and increase awareness of best practice models for providing hepatitis C prevention, care and treatment.
 - Explore the resources necessary for the development of model HCV care and prevention programs.
- Washington, DC Hill Visits
 - State and City together

State/City Coordination



- Limited resources at City or State level
 - Sharing resources and coordinating efforts most effective strategy
- Must adopt a unified voice for entire state

State/City Coordination (2)

Work closely on numerous projects:

- Statewide HCV conference
- HCV Continuity Program (released prisoners)
- HCV Advisory Council
- HCV Community Workgroup
- HCV Policy Group
- Northeast Hepatitis Coordinators' Alliance
- Hill visits
- Policy analysis and response to legislative action

Accomplishments



Accomplishments - NYS

- Resolutions
- NYS Executive Budget Funding
 - First time ever!
 - \$1.58 million for Comprehensive HCV Program
 - Screening
 - Education and social marketing
 - Access to care and treatment
 - Advocates did a lot of letter writing, meetings with Div of Budget and DOH executives

Accomplishments -NYS (2)

- Hepatitis C Advisory Council
 - Vetoed Bill
 - 13 member council, plus DOH and OASAS commissioners
 - Commissioner appointed
 - The members reflect a broad range of expertise and experience in dealing with hepatitis C
 - Council is responsible for advising the NYS Department of Health on the development and implementation of a comprehensive hepatitis C program.

Accomplishments - NYC

- Annual Hepatitis Awareness Month resolutions
- Hepatitis C Policy Forum – 4/25/08
- City Council funding for Hep C and B *
 - Hepatitis C “Public Education Campaign” - \$750K annually
 - “B Free New York City” Hepatitis Program - ~\$3 million
- Ensuring agencies who receive scarce hepatitis funding are held accountable
- Hepatitis B resolution – 6/12/08*
 - Established the goal of screening and vaccination of all NYC residents at risk for HBV infection

* Not a result of direct DOHMH action

Challenges

- Lack of large pool of advocates
- Lack of funding to support events
- Difficult to unify various CBOs' or institutions' agendas
- Little awareness or knowledge of viral hepatitis among general public and legislators
- Little hepatitis policy being considered at any level

Challenges (2)

- Difficult to coordinate responses between Govt. agencies on policy initiatives
- Inability to act on own at program level
 - Have to work within limits of DOH bureaucracy
- Hepatitis policy not top priority at City, State or Federal levels (unlike obesity, HIV, smoking, hypertension, etc.)
- Limited awareness of hepatitis policy by City or State agencies

Next Steps

- Outreach to more advocates
- Viral Hepatitis Strategic Plan – Update
- Hepatitis C Advisory Council
- Research Consortium
- HCV Policy Group
- HBV Advisory Group

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