

Viral Hepatitis Advocacy Toolkit



The National Alliance of State & Territorial AIDS Directors (NASTAD) represents the nation's chief state health agency staff who have programmatic responsibility for administering HIV/AIDS and viral hepatitis health care, prevention, education and supportive service programs funded by state and federal governments. NASTAD represents the Adult Viral Hepatitis Prevention Coordinators as a part of our membership.

NASTAD strengthens state and territory-based leadership, expertise, and advocacy and brings them to bear in reducing the incidence of HIV and viral hepatitis infections and on providing care and support to all who live with HIV/AIDS and viral hepatitis. NASTAD's vision is a world free of HIV/AIDS and viral hepatitis.

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For more information on NASTAD's work on viral hepatitis policy and programs and a listing of Adult Viral Hepatitis Prevention Coordinators, go to www.NASTAD.org.

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List of Key Terms

AASLD	American Association for the Study of Liver Diseases	IDU	Injection Drug User
ACIP	Advisory Committee on Immunization Practices	IOM	Institute of Medicine
AHRQ	Agency for Healthcare Research and Quality	NASTAD	National Alliance of State & Territorial AIDS Directors
AIDS	Acquired Immunodeficiency Syndrome	NCHHSTP	National Center for HIV/AIDS, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis Prevention
ALT	Alanine Aminotransferase	NEDSS	National Electronic Disease Surveillance System
anti-HBc	Hepatitis B core antibody	NETSS	National Electronic Telecommunications System for Surveillance
anti-HBs	Hepatitis B surface antibody	NGO	Nongovernmental Organization
anti-HCV	Hepatitis C antibody	NHANES	National Health and Nutrition Examination Survey
API	Asian and Pacific Islander	NVAC	National Vaccine Advisory Committee
AVHPC	Adult Viral Hepatitis Prevention Coordinators	NVHR	National Viral Hepatitis Roundtable
CDC	Centers for Disease Control and Prevention	OMH	Office of Minority Health
CHIP	Children’s Health Insurance Program	QALY	Quality Adjusted Life Year
CMS	Centers for Medicare and Medicaid Services	RIBA	Recombinant Immunoblot Assay
DIS	Disease Intervention Specialist	RNA	Ribonucleic Acid
DVH	Division of Viral Hepatitis	SAMHSA	Substance Abuse and Mental Health Services Administration
EIA	Enzyme Immunoassay	SEP	Syringe Exchange Program
EIP	Emerging Infections Program	STD	Sexually Transmitted Disease
FDA	Food and Drug Administration	TB	Tuberculosis
FQHC	Federally Qualified Health Center	USPHS	US Public Health Service
HAP	Hepatitis Appropriations Partnership	USPSTF	US Preventive Services Task Force
HAV	Hepatitis A virus	VA	Department of Veterans Affairs
HBIG	Hepatitis B immunoglobulin	VFC	Vaccines for Children
HBsAg	Hepatitis B surface antigen	WHO	World Health Organization
HBV	Hepatitis B virus		
HCC	Hepatocellular Carcinoma		
HCV	Hepatitis C virus		
HIV	Human Immunodeficiency Virus		
HRSA	Health Resources and Services Administration		

Introduction

This toolkit is intended to be used by anyone involved in hepatitis policy and program work to assist in advocacy efforts. It can be used by advocates and interested persons at all levels of policy experience to assist both in developing an individual advocate's skills as well as enhancing the capacity of grassroots networks. State and local government employees using this toolkit may be restricted in which advocacy activities they can actively participate but are encouraged to disseminate this document to advocacy partners.

An effective advocacy effort must include many partners and this advocacy can take many forms. This toolkit will assist you in improving and forming a cohesive advocacy strategy and coalition in your jurisdiction and will lay out the many advocacy efforts that can be utilized at the local, state and national level. We hope that this toolkit is useful. It is intended to be a “living” document. As such, we would love to hear from you about your successful advocacy efforts. Please feel free to send materials or stories from your efforts to NASTAD@NASTAD.org.

In addition to the toolkit, NASTAD's *Viral Hepatitis Primer* is another important document designed to increase your advocacy skills by helping you understand the various funding mechanisms and policies that influence viral hepatitis programs. The *Primer* is available at www.NASTAD.org.

Role of Public Health

Public health is the backbone to controlling, monitoring and eliminating viral hepatitis. Public health agencies are entrusted through U.S. law as the central authorities of the nation's public health system; as such, they bear the primary public sector responsibility for health and serve an essential role in the prevention and management of viral hepatitis. Unlike other infectious diseases, there is no dedicated amount of funding for the provision of viral hepatitis services, including testing, surveillance and care programs. Because of the lack of federal guidance, leadership, and support for state and local hepatitis programming, public health agencies are severely challenged in carrying out their important role as protectors of their constituents' health.

State health departments often have only two public health professionals dedicated to viral hepatitis. They are the adult viral hepatitis prevention coordinator (AVHPC) and the perinatal hepatitis B coordinator. The Division of Viral Hepatitis (DVH), which is located within the Centers for Disease Control and Prevention (CDC), currently funds the salary and some travel for the AVHPC in 49 states, the District of Columbia and 5 city health departments with a total funding level of about \$5 million per year or an average award of \$90,000.¹ CDC's Immunization Services Division in the National Center for Immunization and Respiratory Diseases funds the perinatal hepatitis B coordinators in 67 jurisdictions.² Funding for this position is included in a larger immunization cooperative agreement to state health departments.

1 The directly funded health departments under the Adult Viral Hepatitis Prevention Coordinator program: 49 states, the District of Columbia; Chicago, IL; Houston, TX; Los Angeles, CA; New York City, NY; Philadelphia, PA

2 Includes 50 states; the District of Columbia; eight directly-funded cities: Chicago, Detroit, Houston, Los Angeles County, New York City, Philadelphia, San Antonio and Washoe County, NV; and eight territories including American Samoa, Federated States of Micronesia, Guam, Marshall Islands, Commonwealth of the Northern Marianas Islands, Puerto Rico, Palau and the U.S. Virgin Islands.

AVHPC responsibilities include:

- Public and provider education in addition to training for professionals;
- Oversight of counseling, testing, and referral services, partner services, community planning and capacity building;
- Developing a viral hepatitis prevention plan;
- Integrating core viral hepatitis prevention services into existing programs;
- Epidemiology and surveillance;
- Immunization of hepatitis A (HAV) and hepatitis B (HBV) of at-risk adults (immunization of infants is covered by the perinatal HBV program);
- Working with infection control programs for hepatitis exposure in medical settings;
- Working with substance abuse treatment programs for persons who use injection- or non-injection illicit drugs;
- Working with populations in high-risk settings such as jails and prisons, STD and HIV clinics, and homeless shelters;
- Services for HIV-infected persons, including HAV/HBV vaccination of all susceptible persons and testing to identify HIV-infected persons with chronic HBV/HCV infection;
- Assisting with primary health care services for the uninsured and underinsured;
- Administrative and fiscal management of hepatitis services.

Perinatal Hepatitis B responsibilities include:

- Identifying all hepatitis B surface antigen positive (HBsAg-positive) women of child bearing age;
- Conducting case management of all identified infants at risk of acquiring perinatal HBV infection;
- Reporting of HBsAg-positive infants and providing appropriate care to infants born to mothers of unknown HBsAg status;
- Developing a state plan to put into practice a universal reporting mechanism with documentation of maternal HBsAg test results for all births; and
- Working with hospitals to achieve universal birth-dose coverage and documentation of the birth dose in an immunization information system.

We encourage advocates to work with the AVHPC and perinatal hepatitis B coordinator in their jurisdiction. In some jurisdictions this is the same person and there may be one for your city and one for your state. They are your state's public health expert who can aid both programmatically in providing education and hepatitis trainings as well as a resource to increase your grassroots network to build your jurisdiction's advocacy capacity. For more information, please go to <http://cdc.gov/hepatitis/Partners/index.htm> or see **Resources** at the end of this toolkit.

Background on Advocacy

What is Advocacy?

Advocacy is targeted support directed at changing the policies, positions or programs at any type of institution and encompasses a broad range of activities. Advocacy is one of many strategies aimed at drawing attention to and influencing decision-makers on an important issue.

Effective advocacy can:

- Educate leaders, policy makers or those who implement policies;
- Alter existing policies, laws and budgets;
- Develop new programs; and
- Create more open dialogue with decision-makers.

Advocacy vs. Lobbying

While advocacy is the promotion of an idea, lobbying is the act of asking an elected official to take a particular position on a specific piece of legislation or issue. Lobbying can often be thought of as educating a legislator on an issue with a specific ask for something such as to support a bill or increase funding to a particular program. While some may consider lobbying a negative term, it is important to note that all issues require lobbying. Government employees and other health officials are often prohibited from *lobbying*, but are not prohibited from doing *advocacy* such as educating their policymakers on the burden of viral hepatitis and their jurisdiction's needs.

If you are a government employee, your advocacy efforts play an integral role at every level of policy development and implementation. Without your data, analysis, information of jurisdictional needs and expert opinion, lawmakers would not be able to develop effective solutions. To be clear, basic educational information you provide to a decision maker is not *lobbying* because you are not asking for specific legislative action. Outside your role as a government employee, any private citizen can and should *lobby* their elected official to ensure their concerns are being represented.

If you are part of a non-profit organization, be sure to determine any federal and state lobby restrictions as part of your non-profit designation such as 501(c)(3) or 501(c)(4) and if any legal registration and/or compliance is required. More information can be found at www.irs.gov, at lobby disclosure sites at www.house.gov and www.senate.gov, and at your state and local government websites.

Elected Officials and Government Policy Makers

While much emphasis is placed on advocating for additional funding and policy change with elected officials, there are other areas in government that are important in funding allocations and policy development. Health department staff and advisory committees have some discretion in setting priorities at the state and local level. In addition to advocacy efforts focusing on elected officials, it is important to identify opportunities within state and local government agencies to educate and impact viral hepatitis prioritization.

State and local advocates should be meeting with state and local health officials, HIV/AIDS directors, immunization program managers, communicable disease program managers, behavioral health program staff and chronic disease directors to discuss how viral hepatitis may fit into their priorities and programs. Similarly, all health departments have advisory committees that provide input and guidance to health department programming and policies. State and local advocates should seek to become involved in their jurisdiction's hepatitis task force, HIV/AIDS community planning group, adult immunization coalition and other relevant advisory bodies.

Get the facts

In order to affect change, you first need to be able to clearly articulate the issue or problem at hand. Take the time to collect information about the problem. Gather relevant facts about the current challenges and needs of addressing viral hepatitis in your jurisdiction. Once you have all of the pertinent information in hand, create simple, easy to follow fact sheets and informational pieces about your program and your program's needs. Often times there are materials already created that can be tweaked to suit your needs. This will be discussed in greater detail in the **Advocacy Materials Module**.

Some things you can advocate for:

- Increased federal, state and local funding for viral hepatitis;
- Development of a federal or state comprehensive hepatitis prevention program;
- Congressional, State and City Resolutions to commemorate World Hepatitis Day and National Hepatitis Awareness Month;
- Proclamation to commemorate World Hepatitis Day and National Hepatitis Awareness Month from the President, your Governor your Mayor, your City Council or your County Supervisors; and
- Formal creation of a state and/or city task force on hepatitis by your elected officials.

Resources

Use the resources around you to get your information and message to the public and to legislators. Health department staff working on hepatitis such as the AVHPC, grassroots organizations, community members, clients and other interested individuals can all advocate and be a unified constituency voice to your policymakers. In some instances, the media may be interested in your story. Use the media to get the problem and the solution heard more widely. This will be discussed in greater detail in the **Media Tools Module**.

Important Timelines

The following is a general timeline of the federal funding process for you to incorporate in your advocacy activities and planning. Your state and local funding processes will have different timelines that you will need to research. It is important to target advocacy activities not only at the federal level, but at the state and local levels as well.

Federal Funding Process		
Date	Process	What You Can Do
January-March	Congressional Appropriators begin considering funding issues for next fiscal year. Individual offices have deadlines for weighing in on funding levels.	Weigh in with your Members of Congress, especially if they are Appropriators
First Monday in February or later if incoming Administration	President submits next fiscal year's budget to Congress	Weigh in with the White House
March-April	Members of Congress submit their priority funding request letters to the Appropriations Committees	Weigh in with your Members of Congress
March-Mid-April	House and Senate Budget Committees release a budget resolution laying out a spending and tax plan for the year. The budget resolution is supposed to be passed by April 15, but it often takes longer if at all.	Weigh in with Budget Committee members for highest possible health funding.
Mid-April	Office of Management and Budget (OMB) begins developing President's next budget	Weigh in with OMB for next fiscal year's spending
March-July	House and Senate Appropriations Committees hold hearings and mark-ups on the spending bills	Weigh in with Members on these Committees, submit testimony for the record and requests to testify
May-Oct 1	House and Senate pass their spending bills. If they are different they go to a Conference Committee where they are combined and resent to the floor for a vote.	Weigh in with the Conferees
By Oct 1	Next fiscal year begins and is supposed to have spending bills passed and signed by President. Otherwise Congress passes a continuing resolution (CR) to fund things at their current level.	Weigh in with Congress to finish spending bills

Authorization Process

Process	What You Can Do
Bill is drafted	Weigh in with your Member(s) of Congress to get them to support the bill as original cosponsors before introduction
Bill is introduced and referred to Committee of jurisdiction(s)	Weigh in with your Member(s) of Congress to cosponsor if not already done
Bill stays in Committee, typically subcommittee	Weigh in with Committee Members, particularly on subcommittee to cosponsor, bill
Bill is marked up in Committee and voted on to move to the floor	Weigh in with Committee Members and leadership
Bill is voted on the floor	Weigh in with all Members of Congress
If approved by Congress, bill sent to President	Weigh in with White House

Key opportunities to speak to your Members of Congress

Date	Process	What You Can Do
January - December	District work periods occur almost monthly. To determine when a Member is in the district consult the House and Senate calendars.	Meet with your Member of Congress at the district office
August-September	Summer Recess for House and Senate. Every even numbered year all Members of the House are up for re-election and one-third of the Senate. Your Members of Congress will be back in your district heavily campaigning.	Meet with your Member(s) of Congress at a campaign event, fundraiser, community event or at the district office
October	House typically adjourns, especially in election years.	Meet with your House representative in-district.
The Tuesday after the first Monday of November	Election Day	Vote!

Action Plan Worksheet

INSTRUCTIONS

This worksheet is designed to help you develop an action plan to identify specific steps toward affecting policy change on hepatitis at the local, state and national level.

1. Issue

Write a clear, brief statement articulating one issue or problem.

2. Solution

Identify the solution(s) to the issue. What is the end result you are looking to achieve?

3. Decision-Makers

Identify the decision-makers that will make your solution a reality. Typically your decision-makers are national, state and locally elected officials however there may be other decision-makers involved such as health officials and heads of various federal, state and local agencies. Be sure to identify all the decision-makers.

4. Key Stakeholders

Identify stakeholders that will help convince decision-makers to achieve the solution you want. Key stakeholders are people who have political influence on decision-makers. If your decision-maker is an elected official, these stakeholders typically represent an important constituency in your district and have clout with the official. Key stakeholders are often leaders in your community and/or field such as health and medical professionals, directors of organizations and businesses, administrators of public health programs, community faith leaders and even celebrities.

To help you answer this question, think of your decision-maker(s) in a room deliberating over your proposed solution. Now answer these two questions:

- (a) Who should my decision-makers have heard from already; and
- (b) Who should be in the room when the solution is decided?

5. Action Steps

Identify achievable and measurable activities that will help you achieve your solution with as many necessary steps identified along the way.

6. By Whom?

Once action steps are identified, who is going to be the lead on each of the action steps?

7. By When?

Once action steps are identified, when is the action step supposed to be carried out?

8. Resources

Identify the cost to and financial resources needed to support each action step, especially available resources.

9. Progress

Always keep a tab on your progress.

Action Plan Worksheet Grid

Issue	Solution(s)	Decision-Makers	Key Stakeholders	
Action Steps	By Whom?	By When?	Resources	Progress
1.				
2.				
3.				
4.				
5.				

Action Plan Worksheet Grid – Sample

Issue	Solution(s)	Decision-Makers	Key Stakeholders	
Minimal federal funding for hepatitis prevention	Increase federal funding for hepatitis prevention	US Senators and Representatives	Members of my organization, American Liver Foundation chapter, liver and infectious disease doctors, city health clinic, local patient group	
Action Steps	By Whom?	By When?	Resources	Progress
1. Call/e-mail Members of Congress from action alert (more information on action alerts at Mobilizing and Organizing Tools Module)	Everyone	This month	None	
2. Do in-district visit with Member, go to Member's town hall, community breakfast and fundraiser	Director X of City Health Clinic, patient Y from patient group, Hepatologist Z	This month, fundraiser in August for re-election	None	
3. Do community-sign on letter to Members	Policy Director of local organization	This month	None	
4. Organization submits testimony to Congress for hepatitis funding	Me and members X, Y, and Z of my organization	Testimony appropriations deadline	None	
5. Host a Hill Day and rally on funding	I will form planning and budget committee	First meeting next month	\$500-5,000	



Advocacy Tools Module

GUIDE TO DOING HILL VISITS

HOW TO SCHEDULE A HILL VISIT

Call the national office of the Member of Congress. The phone number can easily be found on the House and Senate web sites www.house.gov and www.senate.gov or you can call the U.S. Capitol Switchboard at (202) 224-3121 and ask for the office of your Senators and/or Representative. When you call the office, staff will answer the phone.

If you are a constituent or are scheduling a visit on behalf of constituents, you can try to schedule a meeting with the Member of Congress. You will be directed to the scheduler in the office who sets the Member's calendar.

For the most part you will be scheduling a meeting with the health staffer in the office responsible for issues such as hepatitis. Tell the staff person that you would like to speak to the person that handles health issues and schedule a meeting with this person. If this person is unavailable, leave a message.

Often times it will be easier to send an e-mail meeting request rather than a phone request. The health staffer may give you his or her e-mail over the phone however congressional staff are not permitted to give out e-mail addresses of other staff. You can ask for the health staffer's name and correct spelling. Typically in the House, e-mail addresses are firstname.lastname@mail.house.gov and in the Senate are firstname_lastname@senatorlastname.senate.gov.

Be sure to highlight if there is going to be a constituent at the meeting whether you are scheduling the meeting over the phone or in an e-mail.

This process is the same for in-district meetings with your Member of Congress and fairly universal when contacting state and locally elected officials. Be sure to find the appropriate contact information for each office. State and local officials rely on their staff just as Congressional Members do and you will most likely be meeting with the health staffer in their office.

BEFORE THE HILL VISIT

Identify the Issues

When you are going on a visit take time to identify the issues you would like to discuss prior to walking in the door. It is always important to educate Members and staff about the viral hepatitis epidemic within their state or district. If you are meeting with an authorizer, be sure to talk with them about legislation they have jurisdiction over, i.e. a hepatitis bill or resolution. If you are meeting with an appropriator, be sure to talk with them about funding needs for hepatitis.

Identify Roles for the Meeting

For group visits or visits with more than one person, be sure to plan who will speak on each issue. This will ensure that all speakers are prepared and that no issues are lost in the shuffle. You should identify a “facilitator” who frames the issues, hands out materials, makes sure that all the issues are covered, keeps track of time and introduces each presenter.

Know What You Want From Your Meeting

When you discuss issues with a Member or staff, you should always have an “ask,” i.e. support increased funding, co-sponsor a bill, sign onto a letter. This should be the first thing that you do after introducing yourself or the group. Staffers will tend to have writing materials on hand and will typically first write down who you are and then your ask.

Know Your Target

Be sure to know party affiliation, committee or subcommittee membership of the member and past record on the issue. These facts will help guide your discussion and convey that you have done your homework. It is also important to target your meeting request depending on whether the Member of Congress is an authorizer or appropriator. The chart below details the differences between the two types.

Type of Committees	Committee Names	Purposes
Appropriation Committees	<ul style="list-style-type: none">• House Appropriations Committee• Senate Appropriations Committee	<ul style="list-style-type: none">• Write 12 spending bills that fund government programs• 12 Subcommittees
Authorization Committees	<ul style="list-style-type: none">• House:<ul style="list-style-type: none">○ Energy & Commerce Committee○ Ways & Means Committee• Senate:<ul style="list-style-type: none">○ Health, Education, Labor & Pensions○ Finance Committee	<ul style="list-style-type: none">• Write authorization legislation to establish, continue or modify an agency or program• Do not provide funding

Bring Written Materials

Make sure you have materials as a leave-behind packet that contains pertinent information on the topics you are going to address. Brief jurisdiction-specific information on the hepatitis epidemics is always preferred. While introducing yourself, you can briefly go over what the leave-behind packet contains or point to which sheet is relevant while discussing the issues with the staffer. Do not assume that staffers will not use the materials.

Be Prepared

Be sure you have all your facts and arguments lined up prior to the meeting. If you cannot answer a question, tell them you will get back to them with the information and be sure to do so or ask a colleague who can get the information to follow-up. Anticipate questions or arguments against your position on an issue.

DURING THE HILL VISIT

Getting There

It is very important to arrive on time. If you are late, you are likely to miss your appointment entirely. As a courtesy, call the office if you are running late. Make sure to give yourself plenty of time to travel to the office to account for security lines into the building.

Meeting with the Member of Congress or Staffer?

Your Member of Congress will most likely not be available to meet with you and you will meet with the staff person responsible for health issues. This staffer is typically the health legislative assistant or aide who is responsible for and reports directly to the Member on health issues. It is not a negative thing to meet with the staffer. Legislators are very busy and rely a great deal on their staff and do receive detailed reports on visits with constituents. It is not unusual for the staffer to be young.

You may be able to meet directly with your Member, especially if the Member is from a smaller state or district. These are called Member-level visits and your Member will always be accompanied by his or her staff. Keep in mind that occasionally something unforeseen comes up and even if you were expecting to meet with your Member, you may see the staffer instead. Remember that staff members are just as important as meeting with the Member and can be very important in shaping legislation and policy. When building a relationship with your Member, it is also important to build a relationship with this staff person.

Introduce Yourself

Open the meeting with an introduction. Handing out your business card at the beginning of the meeting provides ease in name recognition and may be used by the staff for future reference. It can also be useful to tell your personal story if you are directly impacted by hepatitis in your introduction.

Some sample introductions are below:

“Thank you for taking this meeting. My name is X and I am a lifelong resident of state Y. I am living with chronic hepatitis B or C and am the founder of Z organization. I very much appreciate this opportunity to speak with you about some important issues for our community.”

“Hello, Congresswoman X. My name is Y and work at Z where I see constituents such as myself living with hepatitis. I am here to talk with you about hepatitis and its impact in your district, and some things that the advocacy community would like you to do to champion several issues for us such as A, B and C.”

The Ask

The ask is the most important part of the meeting. The staffer is expecting concise and clear information from you on your issue as well as a specific ask. Your conversation should revolve around the ask and address any concerns the staffer may have. To be sure that the staffer will take your ask to your Member of Congress, you can verbally ask for a commitment such as “can I count on Member X to support this?” or “how can I ensure that Member X will support this?”

The Meeting Location and Duration

Given the limited space in Congressional offices, meetings happen in all sorts of places, from the Member's office to the hallway. You should not take it personally if you need to meet in the hallway. Just block out the distractions and go on with your meeting. Most meetings will last at most 20 minutes.

Thank the Member or Staff

Always start off a meeting by thanking a Member for their support or ask the staff to thank their boss for you. Letting an office know that you recognize the important role they play is always appreciated.

Assume No Knowledge

Members and staff are less familiar with your issues than you. Be sure to explain all acronyms, programs, funding sources, which agencies administer the funds, etc., especially for the AVHPC program. Be comfortable with having to dedicate more time in the meeting to going over the basics of a program or even the disease itself. Any chance you have to further a staffer's knowledge will help establish a working relationship with the office and you as a trusted resource.

Keep it Local

If possible, explain your position in terms that relate to the Member's district or state. Provide information on the status of the epidemics in their state. This helps them identify with the problem and understand why they need to be of assistance.

Ask Questions

Meetings should be seen as a two-way street, with information flowing both ways. Take the opportunity to find out where the Member stands on the issues you are presenting if not already known to you.

Ask questions such as: "Where do you see your boss being on this issue...?" "I know your office has/has not cosponsored X before, do you foresee any issues coming up in cosponsoring Y?" "What do you think is the best way for us to work with your office on doing X, Y and Z?"

Stay on Course

Resist any side conversations or tangential issues. Making social conversation is important, but time is limited. Do not hesitate bringing the conversation back by saying, "I know that in terms of our issue..." or "That's a good point but when it comes to our issue..."

Use Your Expertise

In general, you will be much more knowledgeable of the issues than the person you are meeting with. Expound on this knowledge when explaining positions or making requests. In addition, you can offer yourself as an expert for them to call upon.

Hill Visit Etiquette	
DO	DON'T
Wear business attire	Wear jeans, t-shirts or flip-flops
If multiple people in visit, assign someone in your group a facilitator role	Talk over one another or leave someone without a speaking role
Make it personal. Talk about who you are and what expertise you bring as a person living with hepatitis, someone working in the field or a concerned community member	Provide no human or personal element to your conversation
Offer solutions about what is working in addition to what can be done better	Complain or point fingers
When telling your story or delivering your ask be succinct and to the point	Talk about 10 different things
Read the staffer's body language to assess attentiveness	Continue talking despite cues that the meeting is over or that it is clear the staffer is not receptive
Assess the staffer's knowledge on hepatitis	Use hepatitis jargon unless staffer is well versed
Go with the flow	Be surprised or offended if: <ul style="list-style-type: none"> • The staffer does not know about your community or issues; • You do not get to say everything you want to; • Meet in the hallway or lobby area of the office; • Meet with a staff person rather than Member of Congress
Follow-up	Not follow-up, even if no follow-up is needed be sure to thank them

AFTER THE HILL VISIT

Evaluation of the Meeting

Be sure to write down any information that was disclosed in the meeting that would be helpful following up. The most important information is a definitive answer to your “ask(s)” such as: “Yes/no I will cosponsor X.” Other useful information can be any personal connections that relate to the issues you discussed and jurisdiction-specific information that influence the Member’s understanding and support for the issues.

Follow Up

Be sure to send a thank you email to people with whom you have met reiterating your points, providing them with any information you promised and thanking them for their time. The goal is to maintain relationships with offices so that they turn to you for information when legislative decisions are made.

SAMPLE E-MAIL REQUEST LETTER

[Date]

The Honorable _____

[Address]

[City, State, Zip Code]

TO: [Full name of health staffer]

RE: [Constituent] Meeting on [legislation / policy issue / funding decision]

Dear [Name of health staffer]:

I am writing on behalf of [name of organization/constituency], which is [describe your organization/constituency, including where it is based and where it operates, who you represent, etc.]. I am requesting a brief meeting with you on [policy/legislation/funding decision/etc] for [date and window of time available] however can work with you on scheduling a convenient time. This [issue] is critical to addressing the viral hepatitis epidemics in this country. I look forward to hearing from you soon.

Sincerely,

[Name]

[Title]

[Address]

[Contact information]

SAMPLE FOLLOW-UP OR THANK YOU LETTER

Please tailor to include points made in your meeting and follow up information requested, state specific information, and/or to invite them to visit you the next time they are back in the state or district.

[Date]

The Honorable _____

[Address]

[City, State, Zip Code]

TO: [Full name of health staffer]

RE: [Constituent] Meeting on [legislation / policy issue / funding decision]

Dear [Name of health staffer]:

I would like to thank you for taking time out of your busy schedule to meet with me on [date]. As we discussed in the meeting, [issues discussed] is/are necessary to ensure an effective response to these infectious diseases. [You or your organization] is/are committed to finding solutions to reduce the morbidity and mortality associated with these infections and hope [Member of Congress] can join me in obtaining this goal.

I look forward to working with you to ensure [restate issues discussed]. [If you would like, add state-specific issues you would like to discuss, other policy issues and be sure to include any follow-up requested of you].

Please feel free to contact me for more information. I can be reached at (###) ###-#### or myemail@email.com.

Sincerely,

[Name]

[Title]

[Address]



Media Tools Module

PRESS RELEASES

Press releases are a great part of an organization's overall strategy to increase public attention to an issue, and promote one's organization and its cause using the media. Please note that press releases are for organizations and not individuals.

How to Write a Press Release

A press release is an important tool for getting your message out to the media and public. Reporters often get story ideas, quotations and background information from press releases. In addition, it provides a way for members of the media and public to contact you or your organization.

Keep It Brief

The press release should be brief and read like a news story. It should be limited to one page and maximum of two pages.

Write Like a Reporter

The title should be an attention grabbing headline that suggests your point-of-view. Below the headline, write the name of the city and state where the event took place (or the city where your group or coalition is located), your group's name and provide a designated contact.

The first paragraph should contain 1-2 sentences that answer the questions "who," "what," "when," "where," and "why". This should encompass the most important details and that readers of all backgrounds and hepatitis knowledge could understand. Be sure to write in the active voice to set the tone of the press release.

Be Quotable

Highlight your viewpoint and include positive, succinct quotes from a member of your organization or coalition. Your goal is to get reporters to insert these quotes, verbatim, into their stories. Identify the person (and organization) from whom the quote originates. You also want to include supporting facts on your organization's position as these may also be put into a story verbatim.

Make the Press Release Professional

To make your press release look as professional as possible, be sure to include a date, contact name, and phone number at the top of the release. End the release with "-###-"; this journalistic convention indicates that this is the end of the release.

Not all Press Releases are Free

The development and dissemination of a press release to your networks and media contacts is typically free and can be done in-house relatively quickly. However, if you plan on issuing a press release in a widely-syndicated publication or using a newswire or service to get your press release picked up or covered by major news sites, this can cost your organization a significant amount of money. Budgeting and analyzing the cost-benefit to such an investment is necessary.

SAMPLE PRESS RELEASE



January 11, 2010

FOR IMMEDIATE RELEASE
Contact: Chris Taylor
202.434.8041

NASTAD Calls for Increased Federal Funding and Leadership in Response to Institute of Medicine Report on Hepatitis and Liver Cancer

Washington, DC – The National Alliance of State and Territorial AIDS Directors (NASTAD) applauds the Institute of Medicine (IOM) report *“Hepatitis and Liver Cancer – A National Strategy for Prevention and Control of Hepatitis B and C”* for its decisive assessment of the viral hepatitis crisis in the United States (U.S.). The report highlights a troubling lack of knowledge among health-care and social-service providers, at-risk populations, the general public and policy makers about the devastating impact of viral hepatitis. The report concludes that inadequate public funding for viral hepatitis prevention, control and surveillance programs is an apparent cause.

“It is imperative that the U.S. address the viral hepatitis epidemics that impact over five million Americans,” said NASTAD Executive Director Julie Scofield. “Hepatitis B and C have never been given adequate attention by policy makers and the health system overall; this indifference has resulted in millions of dollars in unnecessary medical expenses and avoidable morbidity and mortality.”

The IOM report estimates that in the next 10 years, about 150,000 Americans will die from liver cancer and related complications caused by these preventable diseases. The Centers for Disease Control and Prevention (CDC) estimates that 5.3 million Americans are chronically infected with hepatitis B and C and roughly three-fourths are unaware of their infection. Because the U.S. lacks an adequate surveillance system to collect viral hepatitis data, these estimates are believed to be a significant underestimate of the true impact of these epidemics. “Surveillance forms the foundation for public health action by measuring and describing the extent of the problem. The IOM report calls for the support of a national system to conduct core hepatitis surveillance. This system does not currently exist,” said Randy Mayer, Chief, Bureau of HIV, STD, and Hepatitis, Iowa Department of Public Health and member of the IOM committee.

Without adequate funding and a meaningful commitment by the U.S. government, expert estimates indicate that the domestic viral hepatitis epidemics will increase costs to private and public insurers, including Medicare and Medicaid, by billions of dollars and account for additional billions lost due to decreased productivity from the millions of American workers who suffer from chronic hepatitis B and C.

Dan Church, Adult Viral Hepatitis Prevention Coordinator for the Commonwealth of Massachusetts and an IOM committee member notes, “Health departments struggle to provide education and services to address these epidemics due to a lack of resources. The IOM report calls for CDC and other federal partners to work with stakeholders to develop such programs, which are greatly needed throughout the U.S.” The CDC’s Division of Viral Hepatitis (DVH) currently receives only \$19.3 million each year to fight viral hepatitis in the U.S.; roughly \$5 million of its small budget is used to fund one person in each state to oversee the prevention of viral hepatitis.

The report outlines 22 recommendations to better prevent and control hepatitis B and C. Many are directed at the CDC and state and local health departments. “Unfortunately, due to lack of federal leadership, inadequate funding, and restrictive policies, the expertise of public health programs in responding to the viral hepatitis epidemics has not been fully utilized,” said Scofield. “We call upon Congress and the Administration to put into action the recommendations in this report and increase public resources allocated to viral hepatitis prevention, control and surveillance programs.” Scofield noted.

Founded in 1992, NASTAD is a nonprofit national association of state and territorial health department HIV/AIDS program directors who have programmatic responsibility for administering HIV/AIDS and viral hepatitis health care, prevention, education, and supportive services programs funded by state and federal governments. For more information, visit www.NASTAD.org.



FOR IMMEDIATE RELEASE

February 2, 2010

NVHR: Administration's 2011 Budget Proposal Shortchanges Five Million Americans Afflicted with Chronic Viral Hepatitis

*Administration Continues Pattern of Underfunding CDC's Division of Viral Hepatitis
NVHR Urges Action on Bipartisan Honda-Dent Legislation to Fund State-based Viral Hepatitis Education, Detection, & Surveillance Programs*

Washington, DC—Just weeks after the Institute of Medicine (IOM) blasted the federal government for its failure to respond to the nation's viral hepatitis epidemic, the Administration has continued a pattern of neglect with its 2011 budget proposal. In calling for an inadequate funding increase of \$1.8 million for the Centers for Disease Control and Prevention's (CDC) Division of Viral Hepatitis, the Administration has shortchanged five million Americans afflicted with chronic viral hepatitis and has failed to translate the IOM's recommendations into decisive action, the **National Viral Hepatitis Roundtable (NVHR)** said today.

NVHR is a coalition of more than 150 public, private, and voluntary organizations dedicated to reducing the incidence of infection, morbidity, and mortality from chronic viral hepatitis that afflicts more than 5 million Americans. www.nvht.org

"While the Administration's proposed \$1.8 million increase for the Division of Viral Hepatitis is better than we have seen in years, its budget proposal ultimately shortchanges more than five million Americans afflicted with chronic viral hepatitis," said **Ms. Lorren Sandt, Chair of the National Viral Hepatitis Roundtable (NVHR) and Executive Director of Caring Ambassadors Program, based in Portland, OR.** "Members of Congress from both sides of the aisle have mobilized to address the chronic viral hepatitis crisis and we need a commensurate response from the Administration. We are hopeful that the bipartisan Honda-Dent legislation (HR 3974) will provide a rational starting point for how best to fund the needs of five million Americans afflicted with chronic viral hepatitis."

The CDC's National Center for HIV/AIDS, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Prevention (NCHHSTP) is the umbrella federal agency overseeing the Division of Viral Hepatitis (DVH). While still inadequate, the Administration's FY 2011 budget proposal released yesterday is a marked improvement from last year's meager \$51,000 increase the Administration proposed for the DVH's viral hepatitis, prevention, treatment, and surveillance programs. Perhaps most tellingly, the Administration's total 2011 budget proposal for DVH of \$21 million is still less than the \$25 million in annual funding that was allocated ten years ago. Meanwhile, the depth and breadth of this crisis has only worsened.

With roughly 1 in 50 Americans afflicted with chronic viral hepatitis B or C – and an overwhelming majority unaware they are infected – millions of Americans are at risk, especially African Americans and Asian Americans. Without detection and treatment, chronic viral hepatitis leads to liver cancer, cirrhosis, or liver failure. In the absence of federal leadership, the research firm Milliman estimates that public and private payers' cost of treating chronic viral hepatitis C alone will more than triple by 2024 to \$85 billion. Medicare and Medicaid would absorb a disproportionate share of these added costs.

Last month, the Institute of Medicine (IOM) issued a landmark report finding that the federal government has failed to provide adequate resources for national and local prevention, control, and surveillance programs for chronic viral hepatitis. As a result, the IoM made nearly two-dozen recommendations for improving our nation's public health infrastructure. Regrettably, the Administration's budget all but ignores these expert recommendations.

In contrast to the Administration's indifference, bipartisan legislation, "The Viral Hepatitis and Liver Cancer Control and Prevention Act," sponsored by Representatives Mike Honda (D-Calif.), Charles Dent (R-Pa.) and 21 other House Members would provide \$90 million in funding in 2011 and beyond. The Honda-Dent legislation would increase the ability of the CDC to support state health departments in their prevention, immunization and surveillance, and referral to care efforts. Much of the Honda-Dent legislation tracks with the IoM's recommendations.

"The Administration's budget proposal is only the first step in a long process," added **Ms. Sandt.** "We urge Congress to close the funding gap through the appropriations process. Until the Administration and Congress come together to take decisive, bipartisan action to address the chronic viral hepatitis crisis, NVHR and the entire viral hepatitis community will continue to sound the alarm from coast to coast. We are not going away and we will not be ignored."

Contact: Phil Blando, pblando@abmpartnersllc.com, 202-534-1772

LETTER TO THE EDITOR

Letters to the Editor are an effective way for your voice to be heard by a publication and its readers in addition to being covered in mainstream press. A letter to the Editor allows you to offer a short rebuttal to an article or provide additional commentary such as to add a crucial missing perspective in the publication's coverage of an issue. First and foremost, you must understand the specific guidelines for the local publication that you would like to write a letter to by visiting its website or contacting their editorial department. The following are tips to crafting a letter to the Editor.

1. Be relevant. Tie your piece to something that recently ran in the publication or happened in your community.
2. Keep it short. Respond quickly to the article you have read (note the headline and date it ran). Make your points short and specific. It is better that you edit your words than allow the publication to cut what you consider to be your key point. As always, be sure to keep to word count restrictions.
3. Be factual and accurate. State important facts that back up your point, but only use documented statistics and information.
4. Be civil. If responding to the publication or to the opposition, make sure to address their view in a respectful manner. Characterizing others in a negative derogatory manner will reflect poorly on your viewpoint.

The following tips are activities you can do in addition to your letter or if your letter is not published.

1. Use alternative forums to respond. Many media outlets have online reader forums and interactive online discussions with reporters. Some newsmagazine shows encourage viewers to respond while a show is on air, and then read selected e-mails in real time. These e-mails should be short, clear and punchy — only a few sentences will be used.
2. Blog. Blogs provide an excellent opportunity for public education and outreach. Monitor blogs addressing these types of issues and be sure to comment on relevant threads. Also consider finding opportunities to guest blog on the topic and the work you're doing in your community.

SAMPLE LETTER TO THE EDITOR

Author	Subject	Primary Targeted Outlet
Martha Saly and Ryan Clary of CAL-HEP	Federal Leadership	1. San Jose Mercury-News 2. Sacramento Bee 3. San Francisco Chronicle

California Political Leaders Help Point the Way on HCV Crisis Response. Is Washington Listening?

By
Martha Saly and Ryan Clary

While the viral hepatitis crisis looms ever larger as a major public health threat, hepatitis B and hepatitis C receive little federal attention and even less federal funding.

There are some hopeful signs, however. Political leaders are beginning to sound the alarm about viral hepatitis – and four of them happen to reside right here in California.

At the federal level, U. S. Rep. Mike Honda from San Jose recently introduced a resolution in the House of Representatives supported by 30 other members of Congress calling for a robust governmental and public health response to stem the tide of viral hepatitis. Sen. Dianne Feinstein (D-CA) also has authored a resolution in the Senate urging greater action on the viral hepatitis epidemic. Longer term, Congressman Honda the National Hepatitis B Act in the last two Congresses and he is currently working on a bill that would create a national strategy to deal with both hepatitis B and C.

Meanwhile, at the state level, Assemblywoman Fiona Ma has taken a leadership role in the fight against hepatitis B and C through legislation and public awareness. And in San Francisco, Mayor Gavin Newsom is establishing a San Francisco Hepatitis C Task Force. This promises to provide much needed leadership to deal with a major medical and economic threat to the city, state and country. And,

That is the beginning of wisdom in responding to this crisis.

The urgency of the situation is underscored by a new study by Milliman, one of the world's leading actuarial firms. Without changes in how these patients are diagnosed and treated, the cost of advanced liver disease in HCV-infected patients will jump to \$85 billion in the next two decades. The study forecasts that Medicare costs associated with Hepatitis C (HCV) will soar six-fold from \$5 billion to \$30 billion.

What explains these skyrocketing projected costs? Largely, it is a matter of demographics. According to the Milliman study, baby boomers account for two-thirds of the cases of chronic HCV infection in the United States. As this population reaches Medicare eligibility, they will bring with them the disproportionate economic burden of their generation's epidemic.

Meanwhile, the Federal response to this looming epidemic has been sadly lacking. Currently, there is no federal funding to provide core public health services for viral hepatitis. States receive on average only \$90,000, on average, annually for adult prevention, barely enough to hire one staff position. Moreover, there is no federally funded chronic hepatitis C surveillance system, the first step to monitoring disease incidence, prevalence and trends.

Shockingly, the Division of Viral Hepatitis of the Centers for Disease Control and Prevention (CDC) is funded at only \$18.3 million for FY2009, which represents approximately 2% of the budget of the CDC's National Center for HIV/AIDS, Viral Hepatitis, sexually transmitted diseases, and TB prevention. Because of lack of funding, the CDC is forced to address HCV outbreaks on an individual, rather than a systematic, basis because of a lack of funding. Addressing an epidemic outbreak by outbreak is a dismal and ultimately costly substitute for screening, diagnosis and early treatment.

While the situation is serious, Congress and the Administration can take concrete steps to avert a worst-case scenario. But action is needed urgently. There are two things the federal government can do immediately to address the shortfalls in viral hepatitis prevention and care.

First, substantially increase funds for the Centers for Disease Control and Prevention -- from its current level of \$18.3 million to a bare minimum of \$50 million. CDC's Division of Viral Hepatitis is funded at \$18,316,000 for FY 2009, and states receive an average of \$90,000 to support adult viral hepatitis prevention. This provides for little more than one staff position for an entire state.

Second, appoint a senior member of the staff of the Secretary of Health and Human Services to focus on proper screening and care for hepatitis patients and to ensure that insurance for chronic viral is included in the details of the Administration's health care reform package. Currently, there is no federally funded hepatitis awareness campaign, hepatitis B or C counseling and testing program, chronic hepatitis surveillance system, adult hepatitis A and B vaccination program, linkage to care system for persons infected with hepatitis B or C, or treatment program for un/underinsured Americans.

The good news is that increased funding through the CDC can ease the economic and health-related burdens of HCV. Those diagnosed through early screening can be treated well before the onset of the most severe complications of the disease. Currently, diagnosis lags until the symptoms are full-blown. Consequently, patients with HCV may live only a few years after diagnosis. The costs associated with the most severe HCV cases are obviously much higher than those associated with early detection and treatment.

Our state may be nearing fiscal bankruptcy but we are hardly bereft of the political foresight that so often over the years has gotten Washington to sit up, take notice and act on issues of major import. HCV is one of those issues where we can once again help point the way.

#

[EDITOR'S NOTE: Martha Saly is the Director of the National Viral Hepatitis Roundtable and a founder of the Sacramento-based California Hepatitis Alliance (CalHEP) and Ryan Clary is a CalHEP steering committee member and policy director of Project Inform in San Francisco.]

Word Count: 790

HOW TO DO A MEDIA INTERVIEW

General Tips:

- Never wing it. Practice, practice, practice!
- Never believe that a camera or a microphone is off
- Never say anything you do not want recorded
- Nothing is ever “off the record”
- Do not think that because print reporters have more space they may use longer quotes
- Create a one-page summary sheet of your main points and leave it with reporters, along with contact information where they can reach you with follow-up questions

Body Language Tips:

- Do not slouch
- Do not chew gum or have anything in your mouth
- Minimize gesturing and movement. If you talk with your hands, try to constrain them by holding them in your lap.

Appearance Tips:

- Make sure your face is clearly visible with nothing obstructing you
- Do not wear anything that will distract the audience from your message
- At demonstrations, try to wear or be around a clearly noticeable sign with your logo or a message that you want to convey to the public
- Dress appropriately for formal interviews

Delivery Tips:

- Speak slowly, use short sentences and repeat yourself
 - Always have your top three messages in your mind before speaking or answering a question
 - Stay on track
 - Do not personally disparage or denounce anyone, including the reporter
 - Support your messages with anecdotes, statistics and sound bites. Keep your answers to between 10 and 20 seconds.
 - Use “off-message” questions to bridge back to your message. Use phrases such as “That’s a good question however before I address it, I’d like to go back to my earlier point...”
 - If reporters interrupt you or barrage you with rapid-fire questions, remain calm; finish your sentences and then pick one question to answer with your message.
 - If an interviewer misstates something or has a fact wrong, do not be polite and keep quiet. Speak up in order to correct the record.
 - Use transition and flag words to get and keep the audience’s attention:
 - “If I could only say one thing about this it would be...”
 - “First...Second...Third...Finally . . .”
 - “The most important thing to remember . . .”
 - “What you need to know...”
 - Repeat your message over and over. This may come off as foolish or ineffective to you. However the media will only take sound bites and this ensures both that your message is included and reproduced accurately.
-

Example media interviews

Thelma King Thiel HFI CEO Interview on News Channel 8

<http://www.youtube.com/watch?v=gNBXFC5mk4k>

Hepatitis B Campaign Targets Asians In San Francisco

<http://www.npr.org/templates/story/story.php?storyId=127409718>

Example press conferences

Listing of press conferences and media coverage

<http://www.nvhr.org/calltoaction.htm>

UTILIZATION OF NEW MEDIA

New media is defined as the interactive forms of communication that use the Internet. New media makes it possible for anyone to create, modify and share content and share it with others, using relatively simple tools that are often free or inexpensive. New media requires a computer or mobile device with Internet access. New media can help you connect and collaborate with people from all over the world and from different sectors, and create content that can be delivered instantaneously and freely. While new media continues to evolve at a rapid pace, the following are considered examples of new media:

- Blogs
- eCards
- Mashups
- Photo Sharing Sites
- Podcasts
- RSS Feeds
- Social Bookmarking
- Social Network Sites
- Text Messaging
- Texting Reminders
- Twitter
- Video Games
- Video Sharing Sites
- Virtual Worlds
- Webcasts/Webinars
- Wikis
- Widgets

For more support and resources with step-by-step instructions to create and/or improve your new media skills, please go to AIDS.gov's new media website: <http://www.aids.gov/using-new-media/>.

New Media Resources

Blogs

National Viral Hepatitis Roundtable blog

<http://nvhrblog.org/>

Twitter

<http://twitter.com/hbvadvocate>

<http://twitter.com/sfhpbfree>

<http://twitter.com/BAdvoCate>

<http://twitter.com/hcvadvocate>

<http://twitter.com/nastad>

<http://twitter.com/cdchep>

To identify additional hepatitis tweets, simply go to <http://twitter.com> and search "hepatitis."



Mobilizing and Organizing Tools Module

COALITION BUILDING

Establishing new or improving existing coalitions in your jurisdiction is key to influencing your federal, state and local officials. Presenting a group of diverse individuals and organizations who are constituents in a collective body will shore up greater force behind your messages. Further, a coalition can create a structure to organize and increase the efficiency of your advocacy work.

Why is Coalition Work Important?

Coalitions have been the cornerstone of all successful advocacy movements, and viral hepatitis is no exception. The current political and economic challenges, combined with decreasing resources for advocacy efforts, require new and creative strategies for legislative victories. Forming coalitions allows organizations and individuals to share the workload and pool their expertise and resources. A diverse coalition can tap into the strengths, resources and skills of the many communities affected by viral hepatitis. In addition, elected representatives pay attention when they know they are being held accountable by several organizations and individuals.

Should I Start a Coalition?

Many advocates begin coalitions that do not succeed because they are grounded on unrealistic and ill-conceived expectations. Before deciding whether to create a new coalition from scratch, ask yourself the following questions:

1. Is there already an existing advocacy group in my jurisdiction that is doing the work I want to accomplish AND could I work with them?
2. Are there existing advocacy groups that I can integrate with and/or leverage their support in lieu of creating a separate coalition AND could I work with them?
3. Is there anyone else trying to create a similar coalition?
4. Do I have a core group of advocates who want to create this coalition with me AND that I can rely on to get the work done for free?
5. Can I dedicate most if not all of my free time to this coalition, especially in the beginning of the coalition's development (6 to 12 months at least)?
6. Will my coalition make a difference in a new AND positive way?

If you answered YES to any of questions 1-3, you most likely do not need to create a coalition from scratch and can work with the existing advocacy groups in your jurisdiction to build the coalition.

If you answered NO to any of questions 4-6, your coalition will most likely not be successful until you are able to answer YES to all three.

Purpose

A coalition must have a clear purpose that can be understood as the same thing to everyone. The purpose can be synonymous with the definition of the coalition. In addition to a statement of purpose, it must have a vision or mission that need not be realistically achievable in the short-term but is specific and consists of realizing your coalition's purpose such as "Our mission is to increase

federal resources to viral hepatitis.” Your purpose and mission or vision statement should only be one or two sentences. To maximize the success of the coalition, limit your mission or vision to one or two ideas; your coalition cannot be the be-all-end-all.

Leadership

Every successful coalition has an individual leader and leadership body. One person must be the dedicated organizer or leader of the coalition such as the chair, director, facilitator or coordinator. Further, depending on the size of the coalition, other advocates who rise as leaders within the coalition must be given the opportunity to influence the coalition’s growth and its leadership through some kind of Steering Committee, Board or other leadership body mechanism. To encourage participation and to ensure coalition accountability, you may want to make a leadership position an elected position and only allow members of the coalition the ability to vote. Typically the membership of the coalition will want a leader and a leadership body who will reflect them such as an individual personally impacted by viral hepatitis or who has great expertise in viral hepatitis advocacy.

Composition

Some coalitions are composed only of established policy advocates, while others broaden to include service providers, medical professionals and/or public health officials. Many advocacy coalitions, especially at the state level, include representation from one or more pharmaceutical companies. Ensure your coalition includes a great range of diversity for stakeholder input. Your hepatitis coalition should include patients, providers, public health professionals, researchers and academics, policy experts and private sector representatives in addition to ensuring that the diversity present in your community such as age, race, socioeconomic status, disability, gender, faith and geography is reflected in the composition of the coalition. Most importantly, most if not all members of the coalition must be constituents of your jurisdiction.

Structure

Depending on the size of the coalition, a coalition can have a list of ground rules, by-laws and constitution. An accountable and effective coalition dictates a code of ethics with repercussions for how business must be conducted, expectations of professionalism, a way of voting or election procedures, a way of decision-making whether it is built on consensus or not, the descriptions of leadership positions and so on.

Everyone Has a Job

Everyone in the coalition must be assigned a task to complete. A good way of dividing up labor is to create standing and/or ad hoc working groups or committees to delegate responsibility to a select group of members. If someone does not have a job or opportunity to engage, they may not continue to participate.

Communications

A coalition must have a way for regular and confidential communication such as through a list-serv, e-mail group or other online mechanism. Use of new media tools is another way to further communicate with the coalition.

Meetings

A coalition must have regularly scheduled meetings with a standard agenda and minutes.

Fundraising

While most coalitions are unfunded, the best way to ensure a dedicated position maintains the coalition or that the coalition is able to grow is through fundraising. Any successful coalition will need some resources for its work, ranging from hosting conference calls to hiring administrative staff or a contract lobbyist, if needed. Coalitions are funded a variety of ways, including membership dues, sharing organizational staff and resources, providing in-kind support, and raising donations from foundations and private donors. Some coalitions receive all or part of their funds from pharmaceutical companies. The only feasible way to receive significant individual or organization donations is through a fiduciary agent that can accept donations such as a non-profit 401(c)(3). Either the coalition can be registered as a non-profit or some other entity will have to sponsor the coalition. Further, if your advocacy is ever to get federal, state or local funding directed to the coalition, it must be a registered financial entity in order to receive such funds.

Community Partnerships

Hold regular meetings and communications with other key stakeholders in your jurisdiction who can bring expertise and clout to your coalition.

Building Advocacy Networks

Effective advocacy of your coalition requires a network of activists willing to take action at critical times. It is important that you collect contact information of activists in your area who are willing to respond to your coalition's e-mails such as action alerts or contact their elected officials during critical times. Depending on your coalition's structure, they may or may not be members of the coalition. Be sure to identify local events to get your coalition out in the community for recruiting and promotional purposes. Produce palm cards with contact information and a brief description of your work. Produce posters and flyers with bright colors and eye-catching designs that briefly explain the issue with tear-away contact information. Distribute flyers, posters and palm cards to popular venues in as many different communities as possible (you can vary the look of your posters and flyers to appeal to different audiences). Meet with other advocacy groups to have them include information about your coalition in their newsletter. You may also want to leverage personal networks to enlist the help of your friends, family and colleagues to expand your advocacy networks. Lastly, do not forget to use social networking sites and other new media strategies to expand the reach of your coalition.

Please find below some examples of mobilizing and organizing letters.

SAMPLE LETTER TO ELECTED OFFICIAL

The Honorable Barbara Mikulski
United States Senate
Washington, DC 20510

Dear Senator Mikulski:

The undersigned individuals and organizations in Maryland respectfully ask you to be a lead sponsor of the Viral Hepatitis and Liver Cancer Control and Prevention Act. We Marylanders greatly appreciate your leadership in the areas of healthcare reform, HIV/AIDS and Breast Cancer. We very much hope you will also take a leadership role in championing vital legislation in the area of viral hepatitis and liver cancer.

According to a recent Institutes of Medicine (IOM) report, an estimated 5 million Americans are infected with hepatitis B and/or C. The overwhelming majority are unaware of their status. Left untreated, chronic hepatitis B and C can lead to liver disease, cirrhosis, and liver cancer, the only type of cancer still on the rise. 15,000 people in the United States die per year of these preventable diseases.

Despite these alarming statistics, the U.S. government has not taken significant leadership to fight the hepatitis epidemics. Only \$19 million per year is spent on hepatitis prevention programs which funds one staff person in each state and falls far short of supporting comprehensive prevention activities. The IOM has recommended a much stronger response from Congress.

We are urging you to help by being a lead sponsor of the Viral Hepatitis and Liver Cancer Prevention and Control Act of 2009. The House version, H.R. 3974, has already been introduced and has bipartisan support. This bill would establish, promote, and support a comprehensive prevention, research, and medical management referral program for chronic hepatitis B and chronic hepatitis C.

Maryland has been hit particularly hard by both hepatitis B and C. Baltimore has one of the highest rates of hepatitis C in the country. Hepatitis B disproportionately affects Asian Americans and immigrants from endemic areas such as Africa and Asia and hepatitis C disproportionately impacts African American, Latinos, homeless, veterans, and people with HIV/AIDS. Many cities, including your hometown of Baltimore, have responded by building coalitions and task forces to address both hepatitis B and C. Governor O'Malley also realizes the importance of this legislation and will be writing to the Maryland Delegation about how this bill will help Maryland.

We believe you could play a major role in establishing a comprehensive effort at the national level to fight the hepatitis B and C epidemics by sponsoring this important legislation. We urge you to work with hepatitis advocates at the national level, particularly the National Viral Hepatitis Roundtable, to ensure that the bill becomes law. Many lives are at risk. We could also save billions of dollars by dealing with this issue now instead of at a time when many people with hepatitis will need expensive liver transplants.

We again thank you for your many efforts on behalf of Marylanders, especially in the field of health. We appreciate your work and advocacy on our behalf in these tough partisan times. We are glad you are in the Senate to help us in these endeavors.

Respectfully yours,

(list in progress)

SAMPLE TESTIMONY FOR CONGRESSIONAL RECORD



Testimony Submitted by

Mr. Daniel Church
Epidemiologist/Viral Hepatitis Coordinator
Massachusetts Department of Public Health
Jamaica Plain, MA

Representing the Hepatitis Appropriations Partnership

Presented to the House Appropriations Subcommittee on Labor, Health
and Human Services, and Education

On the Fiscal Year 2011 budget including:
Centers for Disease Control and Prevention's Viral Hepatitis Prevention
Program and 317 Vaccine Program;
Health Resources and Services Administration's Community Health
Centers and Ryan White Program; and
Substance Abuse and Mental Health Services Administration

Wednesday, May 12, 2:00PM

As the Adult Viral Hepatitis Prevention Coordinator and epidemiologist in the Department of Public Health for the Commonwealth of Massachusetts, member of the Hepatitis Appropriations Partnership (HAP), and member of the National Alliance of State and Territorial AIDS Directors (NASTAD), I respectfully submit testimony for the record on behalf of HAP and NASTAD regarding federal funding for viral hepatitis in the FY2011 Labor, HHS and Education Appropriations legislation.

Viral hepatitis refers to a group of contagious liver viruses such as hepatitis B and C that are the leading causes of liver disease, liver cancer, liver transplantation and premature death in about 15,000 Americans annually. It is also the most common cause of death in Americans co-infected with hepatitis and HIV where as many as 25% of HIV-positive Americans are living with hepatitis C and 10% with hepatitis B. These diseases impose a chronic disease burden on Americans where over 5 million people are living with lifelong hepatitis B or C infection and 65-75% do not know it. Chronic hepatitis B and C infections cost the United States approximately \$16 billion each year. If left unchecked, the projected direct and indirect cost in the next decade of just the current hepatitis C epidemic, not including the hepatitis B epidemic, is \$85 billion. Especially given that baby boomers account for two out of every three cases of chronic hepatitis C, we know millions of Americans will be progressing in their liver disease and aging into Medicare within the decade. In addition, chronic viral hepatitis disproportionately affects racial and ethnic communities. African Americans have the highest rate of acute hepatitis B infections in the United States. African Americans and Hispanics have higher rates of hepatitis C infection than Caucasians. Finally, chronic hepatitis B is a leading cause in death in Asian Americans, with as many as 1 in 10 living with chronic hepatitis B.

Despite these burgeoning diseases and the ramifications of mortality and cost, viral hepatitis is one of the most underfunded and neglected diseases compared to other chronic diseases. States receive on average only \$90,000 annually for hepatitis prevention in adults. This provides for little more than one staff position I am that staff person in the Massachusetts Department of Public Health. In the states, there is typically no funding for actual core public health services such as hepatitis outreach and education, screening and testing, or management and care. There is almost no funding for a surveillance system to capture the prevalence and incidence of these diseases. Because of this, there is no funding for community-based organizations to provide these and other services.

In Massachusetts, it is estimated that over 100,000 people are living with hepatitis C virus alone, most of whom have not been diagnosed and may not be aware of their infection. Since 2002, we have received reports of 8,000-10,000 newly diagnosed cases of chronic hepatitis C and 2,000 newly diagnosed cases of chronic hepatitis B each year. Since 2005, there has been a striking increase in the numbers of people under the age of 25 being reported with chronic hepatitis C infection, indicating

a new epidemic of disease, largely due to heroin use among youth. Despite this remarkably high volume of morbidity and mortality, the public health response has been greatly constrained by limited awareness and subsequent low funding to support prevention, screening and medical management programs. The Massachusetts Department of Public Health has had a Viral Hepatitis Program in place since 1999. Currently, there is no state funding available directly for the program and we rely on federal funding—especially under the current economic climate of state budget cuts, state furloughs, and a diminishing and aging public health workforce. In addition, due to the limited funds for viral hepatitis, many hepatitis programs rely on other funding streams such as HIV prevention funding and we have seen in the past year a significant decrease in funding to these programs as well. Given these funding challenges, states can do little to effectively prevent, control and manage the hepatitis epidemics in their jurisdictions.

The Institute of Medicine recently issued a report *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C*. I was a member of the panel that authored the report and the report has attributed the lack of knowledge and awareness among the American public and health providers, the large health disparities, and the high mortality rates, to the lack of dedicated resources. Without concerted efforts to respond, Americans will continue to be infected and fail to be identified, diminishing their quality of life and life expectancy, as well as increasing labor and health costs, especially to Medicaid and Medicare.

As you craft the FY2011 Labor-HHS-Education Appropriations legislation, HAP and NASTAD urge you to consider the following critical funding needs of viral hepatitis programs:

Specific funding needs:

- We are requesting an increase of \$30.7 million for a total of \$50 million for the Centers for Disease Control and Prevention (CDC) Division of Viral Hepatitis (DVH);
- At least \$20 million for an adult hepatitis B vaccination initiative through the CDC Section 317 Vaccine Program;
- \$10 million for the Substance Abuse and Mental Health Services Administration (SAMHSA) to fund a project within the Programs of Regional and National Significance (PRNS) to reach persons who use drugs with viral hepatitis prevention services;

General funding needs:

- Increase funding for Community Health Centers to increase their capacity to serve people with chronic viral hepatitis and provide coordinated care;
- Increase funding for the Ryan White Program to adequately cover persons co-infected with HIV and viral hepatitis through additional case management, provider education and coverage of viral hepatitis drug therapies;

- Increase funding for the National Institutes of Health to support their *Action Plan for Liver Disease Research*

Specific funding needs

Division of Viral Hepatitis

FY2011 Request: \$30.7 million

The recently released Institute of Medicine (IOM) report, *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C* found that the public health response needs to be significantly ramped up. The IOM report attributes low public and provider awareness to the lack of public resources. Seventeen of the 22 recommendations in the report are specific to CDC DVH and state health departments. In order to implement these recommendations to improve the federal response, resources must be increased to health departments which are the backbone of the nation's public health system and coordinate the response to these epidemics.

President Obama's budget proposal includes a \$1.8 million increase for a total of \$21.1 million for the Division of Viral Hepatitis (DVH) at CDC, which is woefully insufficient to address infectious diseases of this magnitude. States and cities receive \$5 million total that averages to \$90,000 per jurisdiction. This is only enough for a single staff position and is not sufficient for the provision of core surveillance and direct care services. These services are essential to preventing new infections, increasing the number of people who know they are infected, and following up to help those identified to remain healthy and productive. We believe at a minimum funding to health departments should double to \$10 million. This increase is an important first step to making hepatitis prevention services more widely available. The expanded services should include hepatitis B and C education, counseling, testing, and referral in addition to delivering hepatitis A and B vaccine, and establishing a surveillance system of chronic hepatitis B and C.

Section 317 Vaccine Program

FY2011 Request: \$20 million

CDC identified funds through program cost savings in the Section 317 Vaccine Program, allocating \$20 million in FY2008 and \$16 million in FY2009 for purchase of the hepatitis B vaccine for high-risk adults. We commend CDC for prioritizing high-risk adults with this initiative, but relying on the availability of these cost savings is not enough. Additionally, this initiative does not support any supplies, infrastructure or personnel and health departments need additional funding to support the delivery of this vaccine. We request a continuation of \$20 million in FY2011 for an adult hepatitis B vaccination initiative through the CDC's Section 317 Vaccine Program.

Substance Abuse and Mental Health Services Administration

FY2011 Request: \$10 million

Persons who use drugs are disproportionately impacted by hepatitis B and C. The Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Substance Abuse Prevention (CSAP) and Center for Substance Abuse Treatment (CSAT) are uniquely positioned to reach populations at risk for hepatitis B and C. The existing infrastructure of substance abuse prevention and treatment programs in the United States provides an important opportunity to reach Americans at risk or living with viral hepatitis. We urge you to provide \$10 million to SAMHSA to fund a project within the Programs of Regional and National Significance (PRNS) to reach persons who use drugs with viral hepatitis prevention services.

General funding needs

Medical Management and Treatment

Access to medical care, available treatments and support services are critical to combat viral hepatitis mortality. While we are supportive of the President's efforts to modernize and expand access to health care, we also support increased funding for existing safety net programs. Low-income patients who are uninsured or underinsured can and do seek services at Community Health Centers (CHCs). Even for those with health insurance, treatment of viral hepatitis is complex and requires care coordination among many different providers and services. With the growing importance of CHCs as a safety net in providing frontline support for these individuals, we support increasing resources for CHCs to increase their capacity to serve people with chronic viral hepatitis.

Many low-income individuals co-infected with viral hepatitis and HIV can obtain services through the Ryan White Program, however only half of the state AIDS Drug Assistance Programs (ADAPs) are able to provide viral hepatitis treatments to co-infected clients. We urge you to increase Ryan White funding so states can provide adequate coverage for co-infected clients. Increased resources are also needed to improve provider education on viral hepatitis medical management and treatment, to cover additional case management for patients undergoing treatment and to allow more states to add viral hepatitis therapies and viral load tests to their ADAP formularies. While Ryan White providers offer lifesaving care to co-infected clients, they also have the expertise and infrastructure to provide limited services to viral hepatitis mono-infected clients.

Research

Finally, research is needed to increase understanding of the pathogenesis of hepatitis B and C. Further research to improve hepatitis B and C treatments that are currently difficult to tolerate and have low "cure" rates are also needed. The development of clinical strategies to slow the progression of liver disease among persons living with chronic infection, especially to those who may not respond to current treatment must be addressed. With effective vaccines against hepatitis A and B, it is important to continue to work towards the development of a vaccine against hepatitis C infection.. The Liver Disease Branch, located within the National Institute of Diabetes and

Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), has developed an *Action Plan for Liver Disease Research*. We request full funding for NIH to support the recommendations and action steps outlined in this *Action Plan for Liver Disease Research*. Until a vaccine for hepatitis C is available, enhanced prevention services for people at-risk are needed. These need to be evaluated and expanded to ensure that effective prevention programs are available nationally.

It is absolutely essential and urgent that we act aggressively to address the threat of viral hepatitis in the United States. In 2007 alone, the CDC estimated that 43,000 Americans were newly infected with hepatitis B and 17,000 with hepatitis C. Unfortunately, it is believed that these estimates of hepatitis B and C infections are just the tip of the iceberg. Most people living with hepatitis B and over three-fourths of people living with hepatitis C do not know that they are infected. It is estimated that the baby boomer population currently accounts for two out of every three cases of chronic hepatitis C. It is also estimated that this epidemic will increase costs by billions of dollars to our private insurers and public systems of health such as Medicare and Medicaid, and account for billions lost due to decreased productivity from the millions of American workers suffering from chronic hepatitis B and C.

As you continue to draft the FY2011 Labor-HHS Appropriations bill, we ask that you consider an increased federal response to viral hepatitis to diminish the costly impact of these diseases on our health care system and individual's health. A strong public health response is needed to meet the challenges of these costly infectious diseases. The viral hepatitis community welcomes the opportunity to work with you and your staff on this important issue.

SAMPLE ACTION ALERT



The House of Representatives is about to decide the funding amount for viral hepatitis prevention

**Do not miss this opportunity to tell your Representative to support an increase
of up to \$50 million for viral hepatitis prevention in FY2011.**

YOU MUST CONTACT YOUR REPRESENTATIVE NOW

The House Appropriations Subcommittee on Labor, HHS, Education and Related Agencies is about to decide the funding amount for viral hepatitis prevention for the Division of Viral Hepatitis (DVH) at the Centers for Disease Control and Prevention for Fiscal Year 2011.

On July 14th, the House of Representatives will begin to mark up the FY2011 Labor-HHS-Education bill which includes funding for viral hepatitis prevention. Given a highly partisan Congress, the economy and the President's discretionary funding freeze, we are hearing that Appropriators have been told to cut funding across the HHS agencies. The President's FY2011 Budget proposed the slightest funding increase of \$1.8 million to DVH as part of a broader \$26 million initiative at the National Center for HIV, Viral Hepatitis, STD, and TB Prevention directed towards gay men, men who have sex with men (MSM) and transgender Americans at risk for HIV. While we support this increased funding and appreciate the need for these prevention programs, it does not support core prevention funding such as hepatitis B and C counseling, testing, and referral, in addition to delivering hepatitis A and B vaccine, and establishing a national surveillance system of chronic hepatitis B and C. HAP and coalition partners will continue to work with Appropriators to include broader prevention priorities in report language.

The greatest opportunity we have to fund hepatitis prevention services is in newly authorized money within health reform's Prevention and Public Health Fund. We believe it will be an enormous missed opportunity to overlook one of the most underfunded chronic, infectious diseases that continues to take a heavy toll on the

individuals infected and contribute to greater health system costs. Hepatitis services have historically been and continue to be critically underfunded and despite the new evidence-based Institute of Medicine recommendations, hepatitis received none of the \$650 million in prevention and wellness funding authorized under the American Recovery and Reinvestment Act nor any of the FY2010 \$500 million authorized under the Prevention and Public Health Fund.

Congressional staff have told us that any increase hinges upon Members of Congress hearing now directly from state and local constituents on why increased funding is needed. **Please continue to help us fight for increased viral hepatitis prevention funding by contacting your Representative about the tremendous need in your area of the country.** Please take a few minutes to make these important phone calls!

HOW YOU CAN HELP

It is urgent that your calls be made immediately. Please call your Representative's Washington, DC office. Ask to speak to the staff person who handles healthcare issues. Whether you speak to this person directly or leave a message, tell them:

"My name is _____ and I'm a constituent of Representative _____. I am calling to urge your office to weigh in with Chairman Obey of the Subcommittee on Labor- HHS-Education to support increased funding for CDC's Division of Viral Hepatitis for a total of \$50 million. **I urge you to invest in hepatitis prevention by leveraging funds from health reform.** Hepatitis B and C affects over 5 million Americans. Chronic viral hepatitis is the leading cause of liver cancer, one of the top 10 killers of Americans every year, and the leading cause of liver transplants each year. Congress has historically cut or flat funded the Division of Viral Hepatitis. Money for prevention of hepatitis B and C is critical to increase counseling, testing and referral in order to begin to get a handle on this potentially life-threatening and expensive, chronic disease."

You can call your Representative at 202.225.3121. You will get the Capitol switchboard. Ask to be connected to your Representative's office.

Thanks for taking the time to make these important phone calls!

Background

The Division of Viral Hepatitis received \$19.3 million in FY2010. With this level of funding, DVH can only support states and cities with **an average federal funding award of \$90,000.** This is only enough for a staff position of the Adult Viral Hepatitis Prevention Coordinator (AVHPC) and not for the provision of core prevention services. An estimated 65-75% of infected Americans do not know their status, compared with 20-30% who do not know their HIV status. Compared to

prevention funding for HIV at \$728 million, STD at \$154 million and TB at \$144 million, viral hepatitis is the most underfunded and defunded disease, representing less than 2 percent of the budget of CDC's National Center for HIV/AIDS, Viral Hepatitis, STD and Tuberculosis Prevention.

Policymakers must be made aware of the consequences of continued inaction. The costs to the healthcare system generated by advanced liver disease associated with chronic hepatitis C infection will increase from \$30 billion to \$85 billion per year. Medicare will be especially hard hit because two-thirds of Americans with chronic hepatitis C infection are baby boomers and the vast majority (75 percent) is unaware; these patients will soon age into Medicare and are likely to progress to advanced liver disease unless they are identified, evaluated and treated soon. In addition to causing 15,000 deaths each year, hepatitis will continue to be the most common cause of non-AIDS-related death in co-infected Americans with HIV with as many as 25 percent co-infected with hepatitis C and 10 percent with hepatitis B. Acute hepatitis B will continue to disproportionately impact African Americans, particularly in the southern states, and chronic hepatitis B among Asian Americans where it is the leading cause of death and 10 percent remain infected. Even with a safe and effective vaccine against hepatitis B, 3,000 Americans will continue to die and roughly 1,000 babies will still be infected at birth.

The following Representatives are of great importance at this juncture since they are all Appropriators. If you live in any of these jurisdictions, it is of the utmost importance that you contact your Representative as his or her constituent to weigh in on increased funds for viral hepatitis prevention:

Alabama

Jo Bonner (R)
Robert Aderholt (R)

Arkansas

Marion Berry (D)

Arizona

Ed Pastor (D)

California

Lucille Roybal-Allard (D)
Barbara Lee (D)
Michael Honda (D)
Sam Farr (D)
Adam Schiff (D)
Ken Calvert (R)
Jerry Lewis (R) (Ranking Member on full Appropriations committee)

Colorado

John Salazar (D)

Connecticut

Rosa Delauro (D)

Florida

Allen Boyd (D)
Debbie Wasserman Schultz (D)
Bill Young (R)
Ander Crenshaw (R)

Georgia

Sanford Bishop (D)
Jack Kingston (R)

Idaho

Michael Simpson (R)

Illinois

Jesse Jackson Jr. (D)
Mark Kirk (R)

Indiana

Pete Visclosky (D)

Iowa

Tom Latham (R)

Kansas

Todd Tiahrt (R) (Ranking Member on
Labor-HHS Subcommittee)

Kentucky

Ben Chandler (D)
Harold Rogers (R)

Louisiana

Rodney Alexander (R)

Maryland

Dutch Ruppersberger (D)

Massachusetts

John Olver (D)

Michigan

Carolyn Kilpatrick (D)

Minnesota

Betty McCollum (D)

Missouri

Jo Ann Emerson (R)

Montana

Dennis Rehberg (R)

North Carolina

David Price (D)

New Jersey

Steve Rothman (D)
Rodney Frelinghuysen (R)

New York

Nita Lowey (D)
José Serrano (D)
Maurice Hinchey (D)
Steve Israel (D)

Ohio

Tim Ryan (D)
Marcy Kaptur (D)
Steve LaTourette (R)

Oklahoma

Tom Cole (R)

Pennsylvania

Chaka Fattah (D)
Patrick Murphy (D)

Rhode Island

Patrick Kennedy (D)

Tennessee

Lincoln Davis (D)

Texas

Chet Edwards (D)
Ciro Rodriguez (D)
Kay Granger (R)
John Culberson (R)
John Carter (R)

Virginia

Frank Wolf (R)

Washington

Norman Dicks (D)

West Virginia

Alan Mollohan (D)

Wisconsin

David Obey (D) (Chair of full
Appropriations committee and Labor-HHS
subcommittee)

The Hepatitis Appropriations Partnership (HAP) is a national coalition based in Washington, DC and includes community-based organizations, public health and provider associations, national hepatitis and HIV organizations, and diagnostic, pharmaceutical and biotechnology companies from all over the country. HAP works with policy makers and public health officials to increase federal support for hepatitis prevention, testing, education, research and treatment. Please contact Colin Schwartz at 202.434.8005 or cschwartz@NASTAD.org if you have any questions or need additional information.

SAMPLE POSTCARD

Postcards that advocates can easily sign at an event are an easy way to get constituents to send your messages to targeted elected officials. Ideally, the postcards you make and print should already include postage depending on your budget. In addition to action alerts that include phone calls and having constituents send their own letters to offices, postcards can ensure that advocates will actually deliver the message because you can mail the postcard immediately after they sign it.

POST CARD

Place
Stamp
Here

Dear Lawmaker,

Passing the Viral Hepatitis and Liver Cancer Prevention and Control Act (H.R. 3974, S.3711) is the fair thing to do for people living with viral hepatitis. Viral hepatitis is the leading cause of liver cancer in this country. It affects nearly six million people and leads to fatal and expensive liver disease. Many do not know they are infected. I urge you to show leadership in the fight against hepatitis and liver cancer by supporting this bill.

Sincerely,

ORGANIZING COMMUNITY AND PUBLIC EVENTS

Holding House Parties

House parties are a convenient and cost-effective way to raise funds for your organization, galvanize community advocacy, raise awareness around a certain issue and invite key stakeholders or speakers to increase their involvement.

- Step 1: Choose a date
- Step 2: Choose an accessible space, consider disability access and access to public transportation
- Step 3: Collect the names, phone numbers, e-mail addresses and mailing addresses of everybody you want to invite. Ensure that the list is representative of all parts of the hepatitis community
- Step 4: Write your invitation — see sample and be aware of required language about whether or not donations are tax-deductible
- Step 5: Mail/e-mail invitations
- Step 6: Call invitees two weeks before the event to remind them about the party, thank them, ask for a donation and thank them again
- Step 7: Based on the number of anticipated guests (typically about half the number of people invited) plan light snacks and beverages or catering if needed
- Step 8: Plan to have two or three helpers, sign-in sheets, envelopes to collect checks and/or a lockbox, nametags, markers, any extra chairs or tables you need and any printed materials
- Step 9: Prepare a short speech based on the talking points and your relationships with guests. Create an agenda of speakers and presentations if needed.
- Step 10: Thank all who attend in person, follow up with thank you notes.

And do not forget to have fun!

Organizing a March or Rally

Holding marches or rallies or similar public events can raise community awareness about hepatitis, bring together supporters and send a powerful message to observers.

Location

These events can take place in a community area such as a park, plaza or city hall or be organized as a march. Be strategic about a start and end point if it is a march; consider the route that would show your message to the most people or important stakeholders. Consider accessibility and traffic throughout the route and if you will require a police escort. Check with your local government and law enforcement about necessary permits and regulations. Find out if you can fundraise at the event. There may be noise, trash, food, size of group, restroom accessibility and first aid restrictions. Some places will require a good amount of time in advance for registering for the public space and a nominal fee.

Date

Research a date and select one with the least possible conflicts for media attention and participant turnout

Agenda

Select speakers from various stakeholder groups such as politicians, grassroots activists, civic employees if they can speak, celebrities, faith leaders and others to ensure there is diverse representation in your speakers. Assign someone the role of facilitator or moderator. Have a printed agenda at the event. If your event is being sponsored or you are fundraising, you may need to print a notice on the agenda or pamphlet.

Advertisement

Create flyers and post in public spaces two to three weeks in advance. Create routes for organizers to solicit patrons and pedestrians about the upcoming event and to post flyers. Advertise online through new media platforms and in printed publications. Issue a press release or statement to notify the media and your contacts. Depending on the event, issue press releases in other languages to engage different communities and media. Hold a press conference to raise the issue to members of the general public and engage media for interviews.

Suggested Supplies

Podium, stage, amplification such as microphone or bullhorn
Posters, signs, candles (if vigil),
Chairs, tables
Water, food
First aid

Suggest Mementos

Clothing: T-shirts, hats
Buttons, Pins
Stickers

NATIONAL HEPATITIS RALLY, MAY 19, 2010



SAMPLE RALLY FLYER

Sponsored by:

NVHR

National Viral Hepatitis Roundtable


Supported by:

*AIDS Action Baltimore
Association of Asian Pacific
Community Health Organizations
Caring Ambassadors Program
Greater Washington Viral
Hepatitis Support Group
Harlem United Community
AIDS Coalition
Hepatitis B Foundation
Hepatitis C Support Group
Hepatitis Education Project
HCV Advocate
Immunization Action Coalition
Missouri Hepatitis C Alliance
National Alliance of State and
Territorial AIDS Directors
Project Inform
Treatment Action Group*

Endorsed by:

*The AIDS Institute
American Liver Foundation
Asian & Pacific Islander
Wellness Center
Bexar Area Harm Reduction Coalition
California Hepatitis Alliance
Center for Health Improvement
Downtown Manhattan
HCV Support Group
Education for Healthy Choices
Georgia AIDS Coalition
HealthHIV
H.E.A.L.S. of the South
Hepatitis C Association
HepCCanada
Hep C Connection
Hepatitis - HIV/AIDS Awareness Project
LASHgroup.org
Maryland Hepatitis Coalition
National Minority AIDS Council
New York Harm Reduction Educators
New York University Medical Center
Hepatitis C Support Group
North Carolina Hepatitis
Community Voice
North Shore Health Project
O'Connor Hospital
HCV & HBV Support Group
PYODs
Positive East Tennesseans
Recovery 2000, Inc.
San Francisco Mayor's
Hepatitis C Task Force
Stelus C Unknown
STOPHepC
Sun Coast Hep C Friends Org
Upstate New York
HCV Awareness Project
Women Organized to Respond to Life
Threatening Diseases*

As of 5/12/2010
To endorse this event, please contact
info@nvhr.org



This is hepatitis...

Rally

May 19, 2010—Noon
United States Capitol
Upper Senate Park
(See Map Below—Rally Area #2)
Washington, DC

Millions of Americans are infected with a “silent killer” that
can be prevented and treated.

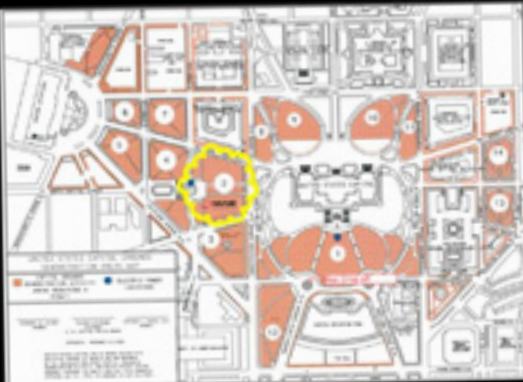
15,000 Americans die needlessly each year.

We will be silent no more!

Join us as we rally to demand that Congress fully fund
hepatitis programs in the United States!

To sign up to attend or endorse this event,
please visit www.NVHR.org

For more information, contact info@nvhr.org



SAMPLE RALLY AGENDA

Sponsored by:

NVHR

National Viral Hepatitis Roundtable

Supported by:

AIDS Action Baltimore
Association of Asian Pacific
Community Health Organizations
Caring Ambassadors Program
Greater Washington Viral
Hepatitis Support Group
Harlem United Community
AIDS Coalition
Hepatitis B Foundation
Hepatitis C Support Group
Hepatitis Education Project
HCV Advocate
Immunization Action Coalition
Missouri Hepatitis C Alliance
National Alliance of State and
Territorial AIDS Directors
Project Inform
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The AIDS Institute
American Liver Foundation
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Wellness Center
Bexar Area Harm Reduction Coalition
California Hepatitis Alliance
Center for Health Improvement
Downtown Manhattan
HCV Support Group
Education for Healthy Choices
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HealthHIV
H.E.A.L.S. of the South
Hepatitis C Association
HepCCanada
Hep C Connection
Hepatitis - HIV/AIDS Awareness Project
LASHgroup.org
Maryland Hepatitis Coalition
National Minority AIDS Council
New York Harm Reduction Educators
New York University Medical Center
Hepatitis C Support Group
North Carolina Hepatitis
Community Voice
North Shore Health Project
O'Connor Hospital
HCV & HBV Support Group
PKIDs
Positive East Tennesseans
Recovery 2000, Inc.
San Francisco Mayor's
Hepatitis C Task Force
Status C Unknown
STOPHepC
Sun Coast Hep C Friends Org
Upstate New York
HCV Awareness Project
Women Organized to Respond to
Life Threatening Diseases

As of 5/14/2010

This is hepatitis...

May 19, 2010 Noon—2 PM
United States Capitol—Washington, DC

Scheduled Speakers

Lorren Sandt, Chair, National Viral Hepatitis Roundtable
Caring Ambassadors Program

Chris Taylor, North American Delegate, World Hepatitis Alliance
National Alliance of State & Territorial AIDS Directors

Martha Saly, Director, NVHR

Reverend Joyce Turner, Louisiana Hepatitis C Task Force

Congressman Mike Honda (CA)

Congressman Charles Dent (PA)

Congressman Bill Cassidy (LA)

Congressman Hank Johnson (GA)

Congressman Anh "Joseph" Cao (LA)

Silent Vigil: Tribute to those lost to hepatitis B or hepatitis C

Group Photo

Jeffrey Caballero, Vice Chair, NVHR
Association of Asian Pacific Community Health Organizations

Gary Rose, Community AIDS National Network

Dr. Timothy and Joan Block, Hepatitis B Foundation

Tim Halloran, Maryland Hepatitis Coalition

Daniel Raymond, Harm Reduction Coalition

Gloria Searson, North General Hospital

Michael Ninburg, Hepatitis Education Program

Dr. Mark Li, President, Chinese American Medical Society

Jane Pan, Hepatitis B Initiative-DC

Jules Levin, National AIDS Treatment Advocacy Project (NATAP)

Dr. Shannon Hader, District of Columbia Department of Health

Alan Franciscus, Hepatitis C Support Project

Kelly O'Dell, Hep C Canada

Closing Remarks: Lorren Sandt and Martha Saly, NVHR



Hill Day Module

ORGANIZING A HILL DAY

A “Hill Day” is a day of doing educational and advocacy visits with offices of elected officials. In tandem with the Advocacy Tools Module, this module is for organizing a Hill day that can be applied to federal, state and local advocacy. While organizing a Hill day can be a lot of work, it is one of the most effective ways of delivering your messages to your officials and can easily be tagged on to meetings that bring in many people who would not otherwise be able to do visits. Further, a well-organized Hill day will be a positive experience for many who will come out of it feeling more confident and empowered to do more visits. Here are some tips to help you organize your own Hill day.

Determine the best time for a Hill day

Ideally a Hill day should be during a legislative session and should not conflict with capitol-wide activities that would limit the meeting availability of staff and elected officials. Since most staff will not know their schedule far in advance, scheduling visits 4-8 weeks before the Hill day is a good amount of time. You cannot plan an effective Hill day if you do not have at least two months in advance.

Determine who can do a Hill day

A Hill day will typically be a half or whole day in a capitol building with constituents doing numerous visits. Advocates must dress appropriately for the capitol building but also for standing and walking at length. Further, not all people in their professional capacity may be able to do a visit without prior authorization.

HILL VISIT PREPARATION

While some participants may be veteran advocates, many will need preparation. Send out and incorporate materials in the Advocacy Tools Module prior to the Hill day and set aside at least one hour to go over the materials and respond to questions and concerns, especially for people who have never done a visit. If the majority of the group are novices, the evening before the Hill day is the best time for preparation. This will give participants time to review background materials and become more comfortable with doing the visits. As part of the preparation, you may want to role play a typical visit starting with someone who is seasoned and then eliciting participation from the audience to role play another meeting with a novice. Then allow time for discussion at the end. If the majority of the group is experienced with Hill visits, a refresher can be done the morning of the Hill day. Keep in mind the location of the facility where the preparation meeting is taking place to account for traveling to the Hill visits. The meeting can also provide time to go over logistics and provide additional materials.

Hill Visit Debrief Meeting

At the end of the Hill day, reserve time for a debrief to share intelligence and experiences while it is

still fresh in everyone's mind. Collect evaluation forms from participants to incorporate suggestions for improving future Hill days and determine whether any offices need follow-up.

Hill Visit Coordinator

Depending on the size of the group, scheduling visits can be an incredibly time- and work-intensive process. If you are not able to dedicate the time it will take to schedule visits, let alone be present at the last minute when some visits will always need to be rescheduled or canceled, someone must be designated as the scheduler and keeper of a master schedule. Participants must be able to contact the coordinator. It is best if only one person is responsible for all scheduling and maintaining a master schedule of visits. If some participants end up scheduling their own visits, this person must be notified of these visits to incorporate them. Visits always must take into consideration distance of getting from one office to the other and duration of the visit. After visits are scheduled, other advocates may be added to the visit to make group visits.

The Hill visit coordinator should also make individual schedules for those doing Hill visits. The schedule should include the time and location of the visit, as well as the name of the staffer and Member office. A helpful resource to add to a schedule is some background information on the Member being met with including relevant committee membership, co-sponsorship of bills, and signatories to letters.

On the Hill day, someone must have a copy of the master schedule with contact information of all participants and offices, with additional leave-behind packets on site in case someone gets lost or needs more materials.

Group Hill Visits

The best way to organize a Hill day with numerous participants is to team people up for each visit. Ideally each visit must have at least one actual constituent from the district present. Other non-constituents are usually welcome to attend however some offices will only allow the constituent to be present. A group visit should consist of no more than 3-5 people. Groups do not have to stay the same in each visit. Depending on the visit, the group can be assigned by home geographic area, diversity of perspective, diversity of Hill experience and availability. Group visits will give the staff person or elected official a greater sense of the importance of the issue and a more diverse perspective. Participants on the other hand are able to take turns or have different roles in the visit and will have the support of their peers. It is important that novice advocates are paired up with experienced advocates. Depending on the comfort level of the novice advocate, the first visit should be lead by the experienced advocate. The novice advocate should never be alone in a visit or without a more experienced advocate.

Security

For advocates who may have their luggage or other travel bags, a space must be reserved at the meeting or lodging site to hold luggage for the duration of the Hill day. Bringing luggage to a capitol building will increase time at the security checkpoints and become a major inconvenience in doing multiple visits. Check your capitol building's security rules in advance of the Hill day.

SAMPLE HILL VISIT SCHEDULE

Contact Information: John Doe (Hill Visit Coordinator) – (555) 555-5555

Jane Doe – Alaska

Member	Staff/ Phone Number (202)	Time	Location
Sen. Mark Begich (D)	Bruce Scandling 224-3004	2:00p	144 Russell Senate Office Building
Sen. Lisa Murkowski (R)	Member 224-6665	2:30p	709 Hart Senate Office Building
Rep. Don Young (R)	Holly Croft 225-5765	3:30p	2111 Rayburn House Office Building

Senator Mark Begich (AK-D)

Committees of Interest	
Cosponsor of the Viral Hepatitis and Liver Cancer Control and Prevention Act (S. 3711)	No
Other important notes	Signed Lautenberg comprehensive sexual education FY11 sign-on letter

Senator Lisa Murkowski (AK-D)

Committees of Interest	Appropriations; Health, Education, Labor & Pensions
Cosponsor of the Viral Hepatitis and Liver Cancer Control and Prevention Act (S. 3711)	No
Other important notes	

Rep. Don Young (AK-R)


Committees of Interest	
Cosponsor of the Viral Hepatitis and Liver Cancer Control and Prevention Act (HR 3974)	No
Other important notes	

SAMPLE MASTER HILL VISIT SCHEDULE

Time	Member	Last Name	First Name	State	Party	Intel	Phone (202)	Staffer	Location	Attendees
10:30	House	Bishop	Sanford	GA	D	HCV bill (108)	225.3631	Jonathan Halperin	2429 Rayburn	John Doe, Jane Doe
10:30	House	Hinchey	Maurice	NY	D	HCV bill (109), HCV for vets (108), Liver Act	225.6335	Erika Conway	2431 Rayburn	Jane Doe
11:00	Sponsors Briefing									
12:00	House	Royball-Allard	Lucille	CA	D	Nat'l Immunization Awareness Month	225.1766	Debbie Jessup	2330 Rayburn	Jane Doe, John Smith, John Doe
12:00	Lunch									
1:30	Senate	Cochran	Thad	MS	R	HCV bill, HCV bill (109), Appropriations/Labor-HHS Ranking Member	224.5054	Will Crump	113 Dirksen	John Doe

SAMPLE HILL DAY FLYERS

save the date!



Join us as we educate policy makers on the need for improving New York State's response to the hepatitis C epidemic.

*New York State
Hepatitis C Legislative Awareness Day*

March 9, 2011
Albany, N.Y.

www.hcna.org
for online or phone registration.

Hepatitis Awareness Day



**Thursday, March 17, 2011
9:00 AM – Noon
3rd Floor Rotunda
Florida Capitol
Tallahassee**




**Exhibits and
FREE
Educational Materials**



**Free hepatitis A and B vaccines by the
Leon County Health Department**

**Community HIV/Hepatitis
Advocates of Iowa Network**

**CHAIN
DAY ON THE HILL**



Thursday, February 22, 2007

Advocacy Training
9:00 to 11:00 AM
Holiday Inn Downtown
Des Moines East Room
1050 6th Avenue

Legislative Luncheon
11:30 AM to 1:30 PM
Iowa State Capitol
Room 116

Don't miss this opportunity to educate your legislators about health issues that are important to you! Please RSVP by Feb 15 to Scott Clair: 515-294-0682 or seclair@mchsi.com

SAMPLE EVALUATION

Name:

Date(s):

Senator/ Representative Staffer Name	Knowledgeable? Receptive?	Topics Discussed	Response	Follow Up Needed	Items of Note
	Knowledgeable: Y N Receptive: Y N				
	Knowledgeable: Y N Receptive: Y N				
	Knowledgeable: Y N Receptive: Y N				
	Knowledgeable: Y N Receptive: Y N				
	Knowledgeable: Y N Receptive: Y N				
	Knowledgeable: Y N Receptive: Y N				

LEAVE-BEHIND MATERIALS

The following is a list of suggested materials to include in a packet that participants leave with the staff or elected official in their meeting:

- Fact sheets (in **Advocacy Materials Module**)
- Publications
- Flyers
- List of resources

Logistical Materials

The following is a list of suggested materials to include in a packet for the participants to keep for themselves for preparation before and resources during the Hill visits.

- Guide to Doing Hill Visits (in **Advocacy Tools Module**)
- Sample Follow-Up or Thank You Letter (in **Advocacy Tools Module**)
- Evaluation form (in **Hill Day Module**)
- Hill map and transportation directions
- Talking Points (in **Advocacy Materials Module**)
- Cheat sheet: background information and record of championship of elected officials (in **Advocacy Materials Module**)




Advocacy Materials Module

DEVELOPING MATERIALS

Included in this *Toolkit* are examples that can be used as a model for crafting your own documents (samples).

SAMPLE STATE/CITY FACT SHEET



The State of Viral Hepatitis in California

The Centers for Disease Control and Prevention (CDC) funds one Adult Viral Hepatitis Prevention Coordinator (AVHPC) in 49 states, the District of Columbia and five cities as the sole dedicated health department professional responsible for adult hepatitis prevention efforts. AVHPCs across the country receive an average award of \$90,000 that only supports salary and does not provide for core prevention services. In addition, CDC funds one Perinatal Hepatitis B Coordinator in 67 jurisdictions to support elimination of hepatitis B among mothers and their infants. The current level of federal funding does not adequately support core public health services.

FUNDING FOR VIRAL HEPATITIS	
California AVHPC Award:	\$115,084
State Funding:	\$0
Private Funding:	\$0

FY 2012 Federal Funding Recommendation
Currently the CDC budget for the AVHPC program is \$5.2M. NASTAD proposes at least a doubling of \$10M for the AVHPC awards to support core prevention services in 55 jurisdictions.

FUNDING FOR CORE PREVENTION SERVICES MUST BE INCREASED

- **There is no federal funding for hepatitis B and C testing.** California leveraged federal HIV prevention dollars to fund 1,550 hepatitis C tests in 10 local health departments and to identify 246 new unconfirmed cases in 2009. Local health departments must develop a hepatitis C services referral guide to receive testing funds. Clients must have risk factors to receive a hepatitis C test, such as ever having injected drugs or engaging in high risk sexual behaviors. California penal code requires hepatitis C screening for persons incarcerated in state prisons at-risk or who request it at no cost. California does not fund hepatitis B virus (HBV) testing or confirmatory hepatitis C virus (HCV) testing. By partnering with birth hospitals and other providers, California reaches its goal of screening all pregnant mothers for HBV with a success rate of 97%. California strives to meet its goal for universal access to HCV testing for at-risk adults through testing at HIV testing sites but is challenged by the lack of adequate funding.
- **There is no federal funding to provide linkages to care.** Of the persons identified through its funded projects, California was only able to link 26-50% of those testing positive for HCV to care in 2009 and did not have the resources to verify linkages to care. With no funding, this leaves between 123 and 182 individuals newly diagnosed with HCV unlinked to care, further increasing both transmission rates and negative health outcomes that are costly and can be fatal.

BARRIERS AND CHALLENGES DUE TO NO FEDERAL FUNDING

- Lack of adequate or sustained funding overall;
- Lack of provider capacity to treat and manage hepatitis;
- Lack of provider understanding of hepatitis and lack of specialists;
- Lack of culturally competent/appropriate educational literature and lack of providers who speak a language other than English.

This fact sheet neither endorses nor reflects the opinion of the health department and is a product of NASTAD and of its members. NASTAD strengthens state and territory-based leadership, expertise, and advocacy and brings them to bear in reducing the incidence of HIV and viral hepatitis infections and on providing care and support to all who live with HIV/AIDS and viral hepatitis. NASTAD's vision is a world free of HIV/AIDS and viral hepatitis.



The State of Viral Hepatitis in California

THE IMPORTANT UNFUNDED WORK OF THE ADULT VIRAL HEPATITIS PREVENTION COORDINATOR (AVHPC)

The work of the AVHPC is crucial to the federal government's viral hepatitis prevention and control efforts and AVHPCs have made great strides with nominal support. However, their impact is limited by the continued federal under-investment in viral hepatitis prevention. AVHPC responsibilities include:

- Public and provider education in addition to training for health professionals;
- Oversight of counseling, testing, and referral services, partner services, community planning and capacity building;
- Developing a viral hepatitis prevention plan;
- Integration of core viral hepatitis prevention services into existing programs;
- Immunization of at-risk adults against hepatitis A (HAV) and hepatitis B (HBV) (immunization of infants is covered by the perinatal HBV program);
- Work with infection control to prevent viral hepatitis exposure in medical settings;
- Work with substance abuse treatment programs for persons who use injection- or non-injection illicit drugs;
- Work with high-risk populations in settings such as prisons, STD and HIV clinics, and homeless shelters;
- Services for HIV-infected persons, including HAV/HBV vaccination of all susceptible persons and testing to identify HIV-infected persons with chronic HBV/HCV infection;
- Assistance with primary health care services for the uninsured and underinsured;
- Administrative and fiscal management of viral hepatitis services;
- Implementation of core functions of public health such as assessment, assurance, community mobilization and policy development.

THE IMPORTANT ROLE OF THE AVHPC IN HEALTH REFORM

AVHPCs are poised to leverage health reform to increase access to viral hepatitis prevention, screening, vaccination and care.

- Preparing federally qualified health centers (FQHCs) and other Community Health Centers (CHCs) for an influx of new hepatitis B and hepatitis C patients when health reform is fully implemented in 2014;
- Ensuring access to viral hepatitis screening, vaccination, and care for people not covered by health reform and for marginalized populations who do not seek care in traditional health care settings;
- Ensuring provider capacity and public awareness of viral hepatitis to take advantage of health services under the reforming system.

CALIFORNIA'S VIRAL HEPATITIS PLAN MUST BE FUNDED

California released its first-ever statewide adult viral hepatitis prevention strategic plan in 2010. The plan outlines a coordinated approach to preventing viral hepatitis transmission and reducing the costs and consequences of hepatitis B and hepatitis C-related liver disease and complications in California over the next five years. The plan was developed in collaboration with 80 representatives from a broad range of State agencies, local health departments, community-based organizations, membership organizations, and individuals living with or affected by hepatitis B and C. The plan calls for three major strategic directions for adult viral hepatitis prevention:

- Improving surveillance and data use;
- Educating the public, providers, and policymakers; and
- Targeting and integrating services and building infrastructure.

For more information, please go to www.cdc.gov/hepatitis/partners/avhpc.htm or www.NASTAD.org

4-5 MILLION AMERICANS INFECTED¹ AND 180 MILLION PEOPLE WORLDWIDE²

NEW YORK STATE³

- 300,000 + New Yorkers have been infected with Hepatitis C, (over 230,000 are chronically infected).
- 2/3 of those living with chronic Hepatitis C are unaware they are infected.
- There are often no symptoms until advanced liver damage occurs.
- Hepatitis C is highly infectious and is transmitted 10 times more easily than HIV.
- There is **NO** vaccine.

BURDEN OF DISEASE⁴

- 165,900 deaths from chronic liver disease
- 27,200 deaths from hepatitis-related cancer
- \$10.7 billion in medical expenditures for Hepatitis C
- 720,700 years of decompensated cirrhosis and hepatitis-related cancer
- 1.83 million years of life lost for those younger than age 65, a societal cost of \$21.3 billion

HEALTH DISPARITIES IN NYS^{5,6}

- 3.2% of African Americans are infected compared to 1.5% of whites with higher percentages in inner city communities.
- African Americans have a significantly lower response rate to treatment for chronic Hepatitis C than non-Hispanic Whites
- 2.8% of Latinos/Hispanics not only have higher rates of infection but are at higher risk to develop cirrhosis than any other ethnic group or race.
- Language, cultural differences and socioeconomic factors, including lack of medical insurance, are significant obstacles to diagnosis and treatment in New York's communities of color.

Interventions and strategies are urgently needed to combat the severity of liver disease in these populations.

ACTION NEEDED

Establish Integrated Models of Care

- Community health centers are in the best position to provide comprehensive services to those at risk for Hepatitis C.
- Funding will establish outreach, staff training and support to increase access

to care and treatment in one convenient location.

- HIV/AIDS service organizations and Substance Treatment providers need resources to integrate Hepatitis C services that include training and capacity-building to increase staff to address high rates of Hepatitis C among their patients.

Expand Screening Programs

- Community-Based Organizations need resources to raise awareness and provide screening in their communities. These services will augment the expanded efforts by community health centers to provide an access point for Hepatitis C services.

We Urge the New York State Legislature to Approve the Governor's Recommendation for \$1,190,000 in the Budget...

for the development of a Comprehensive Hepatitis C Plan

\$54 Budget / A154 / Budget Article VII Internal #6-2009 Health & Mental Hygiene

Who is at Risk for Hepatitis C?⁸

- ✓ Anyone who received a blood transfusion, blood clotting factor, tissue or an organ transplant before 1992
- ✓ Anyone who has been on hemodialysis
- ✓ Anyone who injected drugs, (even once a long time ago)
- ✓ Anyone who shared drug use equipment, (needles, cookers, cotton, straws, pipes).
- ✓ Anyone who has had sex when blood passed from one partner to another
- ✓ Anyone who has been stuck with a needle or exposed to another person's blood on the job
- ✓ Anyone whose mother had Hepatitis C
- ✓ Anyone who has gotten a tattoo or piercing from a non-licensed business

References

1. http://www.who.int/csr/resources/public/world_health_report
2. http://www.who.int/csr/resources/public/world_health_report
3. Centers for Disease Control and Prevention (CDC)
4. American Journal of Public Health, March 2000, 90(3), 40-46
5. http://www.who.int/csr/resources/public/world_health_report
6. http://www.who.int/csr/resources/public/world_health_report
7. http://www.who.int/csr/resources/public/world_health_report
8. http://www.who.int/csr/resources/public/world_health_report

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Status C Unknown is a 501(c)(3) not profit organization

Content approved by:

AIDS Treatment Data Network

811 Broadway, Suite 813
New York, NY 10012

Columbia Harm Reduction

206 East 144 St
New York, NY 10041

Drug Policy Network

79 West 36th Street
New York, NY 10018

FRONT D

Foundation for Research on Sexually Transmitted Diseases

224 West 30th Street, Suite 901
New York, NY 10001

Harm Reduction Coalition

22 West 27th Street
New York, NY 10001

New York City AIDS Housing Network

80-A Fourth Avenue
Brooklyn, NY 11217

New York Harm Reduction Educators

353 Southern Boulevard, Suite 302
Bronx, NY 10455

NYU Medical Center

Hepatitis C Support Group
Registration Desk
550 First Ave
New York, NY 10016

Treatment Action Group

811 Broadway Suite 308
New York, NY 10012

Status C Unknown Rochester

251 Parkfield Rd
Rochester, New York 14625

VOICAC

Voice of Community Advocates & Leaders
80-A Fourth Avenue
Brooklyn, NY 11217

NACAC

National Hepatitis C Advisory Council
Together by need. United by choice.
www.hepatitisnetwork.org

MORE THAN

300,000

NEW YORKERS

have been infected with the

HEPATITIS



VIRUS

**IT'S TIME TO FOCUS
ON A GROSSLY IGNORED
& UNDER FUNDED PUBLIC
HEALTH ISSUE IN NYS**

FY2012 Viral Hepatitis Funding Recommendations



Funding Recommendations

An increase of at least \$40 million for CDC's Division of Viral Hepatitis for a national testing, education and surveillance initiative

- Testing to identify persons with viral hepatitis early and refer them into care is the highest priority for reducing illness and death related to viral hepatitis in the professional judgment budget submitted to Congress by CDC.
- Testing must accompany education efforts to reach those already infected and at high risk of death and of spreading the disease.
- Developing a national surveillance system is the Division's second highest priority. Surveillance is needed to monitor disease trends and evaluate evidence-based interventions. Unlike other infectious diseases, viral hepatitis lacks a national surveillance system.
- This funding would enhance the role of Adult Viral Hepatitis Prevention Coordinators based in state health departments to implement and integrate testing, education and surveillance into the existing public health infrastructure.

Funding must support HHS in strengthening the federal response to viral hepatitis

- Implementation of recommendations from the [IOM viral hepatitis report](#).
- Implementation of the *HHS Viral Hepatitis Action Plan*
- Coordination and increased capacity of viral hepatitis activity across HHS agencies.
- Establishment of a multi-disciplinary HHS treatment guidelines panel.

The Prevention and Public Health Fund must support viral hepatitis

Chronic hepatitis B and C are the primary causes of liver cancer, one of the fastest growing, most expensive and lethal cancers in America. In addition, viral hepatitis must be integrated into other health reform initiatives and made eligible for other funding mechanisms for activities not currently being funded by CDC.

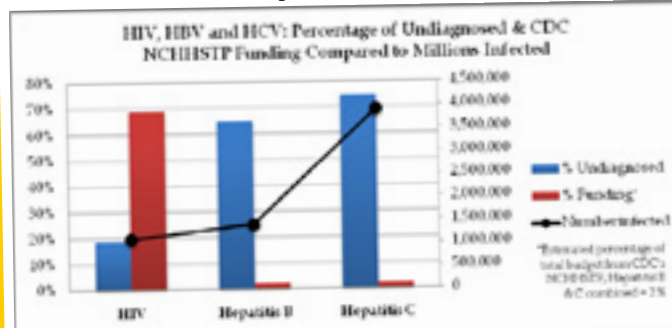
- Preventable and curable diseases like viral hepatitis must be eligible for the \$1 billion in mandatory funding already authorized for the Prevention and Public Health Fund for FY2012.

At least a \$20 million increase for adult hepatitis A and B vaccination

- From 2007-2010, CDC provided free hepatitis A and B vaccine for settings serving at-risk adults. This initiative enabled health departments to deliver cost-effective and life-saving immunizations. However this program was eliminated in September, 2010.
- The IOM report attributes low immunization coverage among high-risk adults to the lack of funding for dedicated vaccine programs. The report cites the need for an adequate, accessible, and sustainable hepatitis B vaccine supply, and recommends expanding immunization-information systems to include adolescents and adults.
- Vaccines are one of the most successful and cost-effective public health tools for preventing disease and death. Every \$1.00 spent on perinatal hepatitis B vaccination saves, for example, \$14.70 in health costs.

Leverage Health Resources and Services Administration funds to provide services to low-income persons at risk or living with chronic hepatitis B or C

- The IOM report calls upon community health centers (CHCs) to increase their capacity to serve people with chronic viral hepatitis and integrate comprehensive viral hepatitis services into settings that serve high-risk populations such as STD clinics, sites for HIV services and care, homeless shelters, and mobile health units.
- Ryan White-funded clinics must adequately cover persons co-infected with viral hepatitis through additional case management, hepatitis A and B vaccinations, provider education and coverage of viral hepatitis treatment.
- In order to achieve a community-level impact on HIV incidence, the White House's National HIV/AIDS Strategy (NHAS) promotes a more integrated approach to health that addresses viral hepatitis and other co-morbidities.



The Economic Benefits and Consequences

If We Act: The Benefits of Action

What We Could Achieve¹

- Increase hepatitis B and C diagnosis rates from 30-40 percent to 75-80 percent.
- Avert 227,000 cases of end-stage liver disease and 11,000 liver transplants.
- Obtain complete and accurate demographic and risk information on 75 percent of new infections to target future prevention activities.
- Increase state and local capacity to respond to outbreaks.
- Eliminate transmission of hepatitis B.
- Provide prevention services to 25,000 families affected by hepatitis B.
- Increase hepatitis B vaccination of high-risk adults to 75 percent by 2020.
- Reduce new hepatitis C infections by 50 percent by 2020.

Cost Savings of Screening

Cost savings of hepatitis B and C screening are comparable to health screenings currently established as routine public health interventions.

- A recent analysis of Centers for Medicare & Medicaid Services (CMS) data found that early Medicaid coverage and treatment of individuals with chronic hepatitis B may reduce mortality by up to 20 percent and decrease liver transplants by 60 percent, resulting in savings to Medicaid in as early as ten years.²

Cost Savings of Treatment

Antiviral treatment for chronic hepatitis B and C produce cost savings in averting more expensive outcomes such as liver cancer and end-stage liver disease similar to other well-accepted medical interventions such as hemodialysis, screening for colon cancer, treating hypertension or treating HIV infection.³

- Published analyses of 18 studies of chronic hepatitis C therapy found incremental cost-effectiveness ratios ranging from cost-saving to \$90,000 per QALY[†] gained.
- Published analyses of seven studies of chronic hepatitis B therapy found incremental cost-effectiveness ratios ranging from cost-saving to \$22,500 per QALY gained.
- Providing appropriate early care for chronic hepatitis B can be highly cost-effective compared to providing treatment only for serious hepatitis B-related illnesses, as money spent on early-stage treatment helps prevent expensive complications.⁴

[†]The Quality-Adjusted Life Year (QALY) is a measure of the quality and the quantity of life lived and is used in assessing the value of a medical intervention.

If We Wait: The Costs of Inaction

Costs overall due to liver disease

- Liver cancer treatment can be more than \$62,000 for the first year.⁵
- The first-year cost of a liver transplant can be more than \$523,400.⁶
- End stage liver disease: \$30,980 - \$110,576 per hospital admission.⁷

Costs due to hepatitis C

- The medical costs of hepatitis C are expected to increase from \$30 billion to over \$85 billion by 2024. The major driver of cost will be from Americans aging into Medicare, resulting in a sixfold increase in Medicare costs from \$5 billion to \$30 billion.⁸
- Hepatitis C infection already represents a substantial health care burden with approximately 27,000 hospitalizations and \$500 million in hospital charges.⁹
- The number of patients with advanced liver disease will more than quadruple in 20 years.
- Over the next decade, the number of patients with livers that can no longer function due to cirrhosis or scarring will more than quadruple.

Costs due to hepatitis B

- The 2008 NIH consensus development conference on the management of hepatitis B estimated that more than \$1 billion is spent each year for hepatitis B-related hospitalizations.

REFERENCES

- ¹ Division of Viral Hepatitis. *Professional Judgment Budget for Comprehensive Viral Hepatitis Prevention and Control in the U.S.* 2010
- ² Conway T, et al. *Early Medicaid Coverage of Chronic Hepatitis B may Reduce Medicaid Spending and is Associated with Positive Health Outcomes.* Health Management Associates. May 2009
- ³ A Rajendra, JB Wong. *Economics of chronic hepatitis B and hepatitis C.* Journal of Hepatology, 2007 Oct; 47 (4):608-17. Epub 2007 Jul 30
- ⁴ Post, Sarah et al., *A Simulation Shows That Early Treatment Of Chronic Hepatitis B Infection Can Cut Deaths and Be Cost-Effective.* Health Affairs, 30, no.2 (2011):340-348.
- ⁵ Trust for America's Health. *HBV & HCV: America's Hidden Epidemics.* September, 2010.
<http://healthyamericans.org/assets/files/TFAH2010HepBCBrief09.pdf>
- ⁶ Hauboldt, Richard., et al. *2008 U.S. organ and tissue transplant cost estimates and discussion.* Milliman, Inc., April 2008
- ⁷ Wong, L.L., P. McFall, and L.M. Wong. *The cost of dying of end-stage liver disease.* Arch Intern Med, 1997. 157(13): p. 1429-32.
- ⁸ Pyenson, B., et al., *Consequences of Hepatitis C Virus (HCV): Costs of a Baby Boomer Epidemic of Liver Disease.* Milliman, Inc., 2009
- ⁹ Grant, C., et al., *Trends in Health Care Resource Use for Hepatitis C Virus Infection in the United States.* Hepatology, Vol. 42, No. 6, 2005

The Hepatitis Appropriations Partnership (HAP) is a national coalition based in Washington, DC and includes community-based organizations, public health and provider associations, national hepatitis and HIV organizations, and diagnostic, pharmaceutical and biotechnology companies from all over the country. HAP works with policy makers and public health officials to increase federal support for hepatitis prevention, testing, education, research and treatment. Please contact Colin Schwartz at 202.434.8005 or cschwartz@NASTAD.org if you have any questions or need additional information.

CHAMPIONSHIP RECORD

The following document modified from the [Association of Asian Pacific Community Health Organizations](#) can be used as a model for developing your own resource on cultivating championship among elected officials and easily substituted for your target populations.

Level:	-1 Opponent	0 Neutral/Uninformed	1 Supporter
<p>Determining Their Level –</p> <p>They Might Say:</p>	<p>--"I can't meet with your group."</p> <p>--"I won't/can't support this."</p> <p>--"It's not a problem"</p> <p>--"Your solution will not fix this."</p> <p>--"My constituents will not support this."</p> <p>--"We don't have money for that, it's not a priority."</p>	<p>--"Why should I support this?"</p> <p>--"Tell me more about this."</p> <p>--"Which other MoCs of Congress are supporting this?"</p> <p>--"Do you have more information?"</p> <p>--"What are you asking me to do?"</p>	<p>--"If it gets to the floor I will vote for it. You should talk to the MoCs who don't support this."</p> <p>--"I might co-sign and op-ed."</p> <p>--"Who else are you talking to?"</p> <p>--"I believe in this. We are on the same page."</p> <p>--"I will co-sponsor the legislation."</p>
<p>Description of Level</p>	<p>--Not receptive to information and requests.</p> <p>--Will not cosponsor, sign letters.</p> <p>--Will not meet with group.</p> <p>--States opposing viewpoints.</p> <p>--Aides do not pass requests or information to MoC.</p>	<p>--Never know whether they will take a requested action.</p> <p>--Ignores requests to speak to leadership.</p> <p>--May occasionally cosponsor or sign with media and constituent letters.</p> <p>--Appears generally uninformed on the issues.</p> <p>--Meets rarely with group.</p>	<p>--Takes basic actions i.e. cosponsors legislation, signs letters with persistence.</p> <p>--Aides may attend briefings and hearings if asked.</p> <p>--Meets with group once per year or less.</p> <p>--Responds to media and multiple constituent letters.</p> <p>--MoC may attend MoC-only hearing.</p>
<p>Objectives at This Level</p> <p>Note: objective is to move him/her to the next level</p>	<p>--Weaken their opposition toward neutral.</p> <p>--Find common ground between your point of view and theirs.</p> <p>--Educate them on our issues as they relate to where the MoC is.</p>	<p>--Educate on issue or cause.</p> <p>--Determine and start to build areas of support.</p> <p>--Reach aides and decision-maker at the "gut" or emotional level via stories, video.</p> <p>--Get them to take some action on our issues.</p>	<p>--Move MoC beyond taking basic action toward being vocal (in media, public, and hearings) and enrolling colleagues.</p>

Level:	-1 Opponent	0 Neutral/Uninformed	1 Supporter
<p>Moving MoCs to Next Level</p> <p>In General:</p> <p>--Research MoC's background and voting history on our issues</p> <p>--Use stories that personalize & move MOCs</p> <p>--Always make requests beyond current level to encourage them to move up.</p>	<p>--Get the ear of the key aide first</p> <p>--Share stories (DVD, spoken word) with MoCs and aides that leave them moved on the issues.</p> <p>--Research MoC's interests and background to find ways to show how AAPCHO aligns w/their interests. Use his/her website and other sources.</p> <p>--Find foothold with one issue, or one aspect of one issue.</p> <p>--Be persistent about getting in front of MoC in meetings and public gatherings.</p>	<p>--Ask for action on their hot button topics.</p> <p>--Tell them stories that leave them moved by our issues.</p> <p>--Research MoC's interests and background to find ways to show how AAPCHO aligns w/their interests.</p> <p>--Be persistent about getting in front of MoC in meetings and public gatherings.</p>	<p>--Request regular meetings with key DC aide(s).</p> <p>--Be persistent about getting in front of MoC in meetings and public gatherings.</p> <p>--Provide regular positive feedback on MoC's action via letters and media.</p> <p>--Look for opportunities to put MoC in contact with people affected by the issues.</p> <p>--Always ask that MoC do more than take the basic action (sign the letter <u>and</u> get committee colleagues to sign).</p> <p>--Demonstrate community support for his/her actions.</p>
<p>Skills & Knowledge Needed by Advocate</p>	<p>--Multi-faceted knowledge of issues and/or ability to get additional information.</p> <p>--Ability to develop relationships and partnerships.</p> <p>--Ability and courage to tell moving stories.</p>	<p>All preceding skills plus:</p> <p>--Ability to be polite, yet firm with aides about what you expect of them.</p>	<p>All preceding skills plus:</p> <p>--Ability to mobilize community leaders</p> <p>--Ability to generate media</p>

Glossary: MoC – Member of Congress

SAMPLE HILL VISIT BACKGROUND

When providing background information for Hill visit schedules, be sure to develop a key for interpreting them by visit participants.

Legislation	
CAHP Act	The Community AIDS and Hepatitis Prevention Act would permit the use of Federal funds for syringe exchange programs for purposes of reducing the transmission of blood-borne pathogens, including HIV and viral hepatitis
Cosponsor HBV bill (###)	Designates cosponsored the HBV bill in a past congressional session
Cosponsor HCV bill (###)	Designates cosponsored the HCV bill in a past congressional session
Cosponsor Hepatitis bill (HR3974)	Designates cosponsored the Viral Hepatitis and Liver Cancer Control and Prevention Act of 2009 bill
HCV vets (108)	H.R.73 (108) would establish a comprehensive program for testing and treatment of veterans for the HCV
Liver Act (108)	H.R.1108 (108) would establish a National Center on Liver Disease Research at NIH
National Immunization Awareness Month	H.RES.709 (111) is a resolution to recognize the month of July as National Immunization Awareness Month to raise awareness of the benefits of immunization
STD Awareness Month	H.CON.RES.107 (111) is a resolution to recognize the month of April as National STD Awareness Month
World Hepatitis Awareness Month	H.RES.466 (111) is a resolution to recognize the month of May as World Hepatitis Awareness Month and World Hepatitis Day as May 19

Membership for House of Representatives	
CAPAC	Either a member or associate of the Congressional Asian Pacific American Caucus (CAPAC)
E&C	Member of the Energy and Commerce Committee, the authorizing committee that has jurisdiction over the Viral Hepatitis and Liver Cancer Control and Prevention Act of 2009
Appropriator	Member of the Appropriations Committee, the committee that has jurisdiction over funding viral hepatitis programs

SAMPLE TALKING POINTS



Hill Visit Talking Points

Meeting Intro

- Thank the staff for meeting with you.
- In introducing yourself, describe your program and the role and importance of state governmental public health.
- Describe impact of state budget situation and cuts real or potential to your programs.
- Ask staff if they are familiar with hepatitis. Be prepared to provide a brief hepatitis 101 as many staff know very little.

Hepatitis Prevention Funding

- **ASK: \$31 million increase for CDC viral hepatitis prevention programs for a total of \$50 million.**
- DVH currently receives \$19.3 million.
- Seek to double Adult Viral Hepatitis Coordinator budget from \$5 to \$10 million (Avg. award \$90,000).
- Currently no funding for public health services.
- Don't know impact of epidemic due to lack of national surveillance.
- Not building new silo, integrate into existing programs.
- To reduce costs to the health system, it is critical that people know they're infected so they can take action to protect their health.

Viral Hepatitis and Liver Cancer Prevention and Control Act of 2009 (HR 3974)

- Sponsored by Rep. Mike Honda (D-CA) in House. If not a sponsor in the House, ask to co-sponsor.
- No Senate bill yet (likely Senator Kerry (D-MA). Ask to be an original co-sponsor.
- Directs HHS to implement a comprehensive public health program to address viral hepatitis focused on prevention, research, and referral into care across the HHS agencies with focus on CDC, HRSA and SAMHSA.

World Hepatitis Day Resolution

- Sponsored by Rep. Hank Johnson (D-GA) and Rep. Joseph Cao (R-LA) in House. Ask to contact Rep. Johnson's office to sign Dear Colleague in support of resolution.
- Senator Diane Feinstein (D-CA) in Senate. Ask to contact Feinstein's office to sign Dear Colleague in support of resolution.

Resources

HEALTH DEPARTMENT VIRAL HEPATITIS COORDINATORS

For more information, please go to <http://www.cdc.gov/hepatitis/partners/avhpc.htm> and <http://www.cdc.gov/hepatitis/Partners/PeriHepBCoord.htm>. The following list is current as of June 2011.

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COMMUNITY RESOURCES

AIDS Action

www.aidsaction.org

Alert Health

www.hep-c-alert.org

American Association for the Study of Liver Diseases

www.aasld.org

Asian Liver Center

<http://liver.stanford.edu>

American College of Gastroenterology

www.acg.gi.org

American Gastroenterological Association

www.gastro.org

American Liver Foundation

www.liverfoundation.org

American Social Health Association

www.ashastd.org

Association of Asian Pacific Community Health Organizations (AAPCHO)

www.aapcho.org

Association of Immunization Managers

www.immunizationmanagers.org

Caring Ambassadors Program

www.hepcchallenge.org

Center for the Study of Hepatitis C at Weill Medical College of Cornell University

www.hepccenter.org

Community AIDS National Network

www.tiicann.org

Harm Reduction Coalition

www.harmreduction.org

Hepatitis B Foundation

www.hepb.org

Hepatitis B Support Project

www.hbvadvocate.org

Hepatitis C Association

www.hepcassoc.org

Hepatitis C Caring Ambassadors Program

www.hepcchallenge.org

Hepatitis C Support Project

www.hcvadvocate.org

Hepatitis Education Project

www.hepeducation.org

Hepatitis Foundation International

www.hepfi.org

HONOReform

www.honoreform.org

Immunization Action Coalition

www.immunize.org

Julia Spears Foundation

www.helpwithhepc.org

Missouri Hepatitis C Alliance

www.mo-hepc-alliance.org

National AIDS Treatment Advocacy Project

www.natap.org

National Alliance of State & Territorial AIDS Directors

www.NASTAD.org

National Association of Community Health Centers

www.nachc.org

National Association of State Alcohol/Drug Abuse Directors

www.nasadad.org

National Coalition of STD Directors

www.ncsddc.org

National Viral Hepatitis Roundtable

www.nvhr.org

O.A.S.I.S. Clinic

www.oasisclinic.org

Parents of Kids with Infectious Diseases (PKIDS)

www.pkids.org

Project Inform

www.projectinform.org

Status C Unknown

www.statuscunknown.com

The AIDS Institute

www.theaidsinstitute.org

Treatment Action Group

www.treatmentactiongroup.org

World Hepatitis Alliance

www.worldhepatitisalliance.com

On June 17, 2010, the House Committee on Oversight and Government Reform held a bipartisan hearing with national stakeholders entitled “Viral Hepatitis: The Secret Epidemic.” These are some of their stories.

“The overarching challenge is that many of those infected with both hepatitis B and C are asymptomatic...That is why we need to bring greater attention to these diseases – to improve prevention for those not yet infected, and to make sure those who are infected have access to early and consistent treatment that can stop their progression.”

– Chairman Ed Towns (D-NY)

“I am testifying today because I know from firsthand experience just how devastating these hepatitis viruses can be on Americans. I am one of the lucky ones who found out I was infected, had insurance, and has received treatment.”

– Representative Hank Johnson (D-GA), Patient

“I trust that just as I testify today ... someone else in 10 or 20 years will be able to testify that she or he used a bill that we passed to diagnose, prevent and treat viral hepatitis. And this person will be able to say as I can, that because of this, there are those who are alive today and there are those who are healthier because of the wisdom of this Congress.”

– Representative Bill Cassidy (R-LA), Hepatologist

“Given the substantial and increasing disease and economic burden from viral hepatitis, HHS is taking immediate and coordinated steps to reverse these trends, which represent a health priority for our nation.”

– Assistant Secretary for Health, U.S. Department of Health and Human Services (HHS),
Dr. Howard Koh

“...the [IOM] committee believes that implementation of its recommendations would lead to reductions in new HBV and HCV infections, in medical complications and deaths that result from these viral infections of the liver, and in total health costs in our nation.”

– Randy Mayer, Chief of the Bureau of HIV, STD, and Hepatitis, Iowa Department of Public Health and Member, Institute of Medicine’s (IOM) Committee on the Prevention and Control of Viral Hepatitis Infections

“We have an opportunity and we have a responsibility to use this momentum and act now... If we wait, hundreds of thousands of Americans will die unnecessarily premature deaths. If we act now, we can save many of those lives.”

– Michael Ninburg, Patient and Executive Director, Hepatitis Education Project