National Viral Hepatitis Roundtable (NVHR)

Deborah L. Wexler, MD, Executive Director
Immunization Action Coalition / Hepatitis B Coalition
St. Paul, MN, USA
deborah@immunize.org

Viral Hepatitis Prevention Board
Lucca, Italy
March 13, 2008
A coalition of more than 100 organizations working to eliminate viral hepatitis in the United States. NVHR is the only national coalition focused on all aspects of viral hepatitis.
The National Viral Hepatitis Roundtable is dedicated to developing, implementing and maintaining a national strategy to eliminate viral hepatitis in the United States.
Current NVHR Members

• Professional Groups
• Hepatitis B Groups
• Hepatitis C Groups
• Harm reduction organizations
• AIDS / Hepatitis Co-Infection Groups
• General hepatitis organizations
• Federal government
• Local government
• General health organizations
• Manufacturers
Professional groups

- American Medical Association
- National Medical Association
- American Academy of Physician Assistants
- Health Care for the Homeless Clinician’s Network
- Council of State & Territorial Epidemiologists
Professional groups cont...

- American Association for the Study of Liver Disease
- National Association of County and City Health Officials
- American Association of Occupational Health Nurses
- National Coalition of STD Directors
Hepatitis B

- Hepatitis B Foundation
- Hepatitis B Information & Support List
- HBV Adoption Support Group
- Hepatitis B Initiative
- Asian Liver Center
- National Task Force on Hepatitis B
Hepatitis C

- Center for Study of Hepatitis C, Cornell University
- HCV Advocate
- Latino Organization for Liver Awareness
- H.E.A.L.S. of the South
- Hepatitis C Association
- LiverHope
- Hepatitis C Multicultural Outreach
- Hep-Can
- Hep C Connection
Hepatitis C cont…

- Caring Ambassadors
  Hepatitis C Program
- Education for Healthy Choices
- National Hepatitis C
  Advocacy Council
- Hepatitis Education Project
- California Hepatitis Alliance
- Michigan Hepatitis C Foundation
- Hep C Alert
Harm reduction

- Harm Reduction Coalition
- National Alliance of Methadone Advocates
- Harm Reduction Project
- Positive Health Project
- Therapeutic Communities of America
AIDS / hepatitis co-infection

- The AIDS Institute
- National Alliance of State and Territorial AIDS Directors
- National AIDS Treatment Advocacy Project
- Treatment Action Group
General hepatitis

- American Liver Foundation
- Hepatitis Foundation International
- Immunization Action Coalition
- Liver Health Today
General health including hepatitis

- Association of State and Territorial Health Officials
- Kaiser Permanente
- Institute for Criminal Justice Healthcare
- Center for the Study of Asian American Health
- Health Partners, Liver Research Institute
- National Health Care for the Homeless Council
- American Social Health Assn.
General health cont...

- PKIDS
- National Association of Community Health Centers
- Task Force for Child Survival and Development
- Foundation for Healthy Living
- American Cancer Society
- Asian & Pacific Islander American Health Forum
- Association of Asian Pacific Community Health Organizations
- Sabin Vaccine Institute
Federal government

- Indian Health Service
- CDC’s National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention
- Substance Abuse & Mental Health Services Administration
- Department of Veterans Affairs
- Federal Bureau of Prisons
- Nat’l Institute of Diabetes and Digestive and Kidney Diseases
Local government

- Anne Arundel County Health Department
- Arizona, California, Colorado, Connecticut, Indiana, Michigan, North Dakota, Utah, and Washington state departments of health
- University of New Mexico
Manufacturers

• Bayer
• Bristol-Myers Squibb
• Chiron
• Gen-Probe
• Gilead Sciences
• GlaxoSmithKline
• Merck Vaccine Division

• Roche
• Schering Plough
• Valeant Pharmaceuticals International
• Vertex Pharmaceuticals
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<th>NVHR Members and Sponsors</th>
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<td>Assn of Asian Pacific Community Health Organizations</td>
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<td>Albert B. Sabin Vaccine Institute</td>
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<td>American Correctional Association</td>
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<td>American Liver Foundation</td>
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<td>American Medical Association</td>
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<td>American Social Health Association</td>
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<td>Anne Arundel County Department of Health</td>
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<td>Asian Liver Center at Stanford University</td>
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<td>Association of State &amp; Territorial Health Officials</td>
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<td>Bristol Myers Squibb</td>
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<td>California Dept of Health Services</td>
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<td>Center for Disease Control and Prevention</td>
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<td>Center for Health Improvement</td>
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<td>Center for the Study of Asian American Health</td>
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<td>Colorado Dept of Public Health &amp; Environment</td>
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<td>Connecticut Department of Health</td>
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<td>Council of State &amp; Territorial Epidemiologists</td>
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<td>Education for Healthy Choices</td>
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<td>FAIR Foundation</td>
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<td>Federal Bureau of Prisons</td>
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<td>Frontline Health Worker Safety</td>
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<td>Gen-Probe, Inc.</td>
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<td>Gilead Sciences</td>
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<td>GlaxoSmithKline</td>
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<td>H.E.A.L.S of North Georgia</td>
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<td>Harm Reduction Coalition</td>
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NVHR Members and Sponsors

Harm Reduction Project
HBV Information and Support
HBV-Adoption
Hep C Advocate Network (HepCAN)
Hep C Connection
Hepatitis B Foundation
Hepatitis B Initiative
Hepatitis C Association
Hepatitis C Caring Ambassadors Program
Hepatitis C Multicultural Outreach
Hepatitis Education Project
Hepatitis Foundation International
Hepatitis Magazine
Hep Prevention, Educ, Treatment & Support, Hawaii
Hep-C ALERT
HepCAN
Hoffmann-La Roche, Inc.

Hope for Hepatitis C Foundation
Immunization Action Coalition
Indian Health Service Division of Epidemiology
Indiana State Department of Health
Institute for Criminal Justice HealthCare
Iowa Department of Public Health
Julia Spears Foundation
Kaiser Permanante - Georgia Region
Latino Org for Liver Awareness (LOLA)
Liver Research Institute
LiverHope Inc.
Maryland Hepatitis C Action
Merck & Company, Inc.
Michael F. White & Associates
Michigan Department of Community Health
Missouri Hepatitis C Alliance
National Alliance of Methadone Advocates (NAMA)
NVHR Members and Sponsors

NAMA MA HCV Coalition
National AIDS Treatment Advocacy Project
Natl Alliance of State and Territorial AIDS Directors
Natl Association of Community Health Centers, Inc.
Natl Association of County & City Health Officials
Natl Association of Hepatitis Task Forces
National Coalition of STD Directors
National Health Care for the Homeless Council
National Hepatitis C Advocacy Council
Natl Institute of Diabetes/ Digestive/ Kidney Diseases
Natl Task Force on Hep B: Focus on APIAs
National Medical Association
New Mexico Department of Health
Nor-Cal Hepatitis C Task Force
North Dakota Department of Health
Positive Health Project, Inc.
Regions/Health Partners
Roche
Substance Abuse Mental Health Administration
Schering Plough
Stanford University Medical Center
Strategic Health Policy International, Inc
Task Force for Child Survival and Development
The AIDS Institute
The Brucker Group
Therapeutic Communities of America
Treatment Action Group
US Indian Health Service
Utah Department of Health
VA NAMA (Natl Assn of Methadone Advocates)
Valeant Pharmaceuticals International
Veterans Health Administration
Washington State Department of Health
<table>
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<tr>
<th>Board of Directors</th>
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<tr>
<td><strong>Bruce Burkett</strong></td>
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<td>Missouri Hepatitis C Alliance</td>
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<tr>
<td><strong>Jeff Caballero</strong></td>
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<tr>
<td>Association of Asian and Pacific Community Health Organizations</td>
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<tr>
<td><strong>Deborah Wexler, MD</strong></td>
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<tr>
<td>Immunization Action Coalition</td>
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<tr>
<td><strong>Steven Graham</strong></td>
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<tr>
<td>Hepatitis Education Project --Treasurer***</td>
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<tr>
<td><strong>Henry Pollack, MD</strong></td>
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<tr>
<td>Center for Study of Asian American Health</td>
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<td><strong>Chris Taylor</strong></td>
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<tr>
<td>National Alliance of State &amp; Territorial AIDS Directors-- Chair***</td>
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<tr>
<td><strong>L.J. Tan, PhD</strong></td>
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<tr>
<td>American Medical Association</td>
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<tr>
<td><strong>Dennis Simon</strong></td>
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<td>Hepatitis C Association</td>
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<tr>
<td><strong>Lorren Sandt</strong></td>
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<tr>
<td>Hepatitis C Caring Ambassadors</td>
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<td><strong>Daniel Raymond</strong></td>
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<td>Harm Reduction Project</td>
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# Advisors

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<tr>
<th>John Ward, MD</th>
<th>Dan Riedford</th>
<th>Bob Lubran</th>
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<tr>
<td>CDC - Division of Viral Hepatitis</td>
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<td>Substance Abuse and Mental Health Services Administration</td>
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NVHR Administrator

- Nov 2007, Board hired Martha Saly as acting administrator for 3-6 month
- 50% time paid staff member
- Communicating with members
- Communicating with funders
- Arranging board calls and working with Chair to establish agenda
- Carry out day-to-day activities of NVHR
History 2002

• Hepatitis Foundation International, the Centers for Disease Control and Prevention, and the National Alliance of State and Territorial AIDS Directors were the founding partner organizations.

• HFI obtained generous startup money from Roche to develop NVHR, and HFI hired an administrator, Dick Conlon, to coordinate NVHR.
History 2003

• Organizing Committee invited to meet face-to-face January 2003 – 23 people
• Purpose: to unite organizations around viral hepatitis – many challenges
• Hired facilitator, Dr. Glenna Crooks, to keep us moving forward as we went through classic coalition stages: “forming, storming, and norming”
• Developed mission statement . . .
• Committees developed bylaws, goals
• Launched website
Welcome to the Roundtable

The National Viral Hepatitis Roundtable is a coalition of public, private, and voluntary organizations dedicated to reducing the incidence of infection, morbidity, and mortality from viral hepatitis in the United States through strategic planning, leadership, coordination, advocacy, and research.

Click here for the latest National Viral Hepatitis Roundtable (NVHR) Update - December 2007

The NVHR Strategic Plan to Eliminate Viral Hepatitis is ready for release!

ELIMINATING HEPATITIS: A Call to Action
Launching of NVHR! The Inaugural Meeting

- Held in Washington DC, Dec. 7-9, 2003
- 170 people representing more than 100 organizations attended
- The beginning of a national partnership to create a national strategy to eliminate viral hepatitis
- Discussion group topics relative to HAV, HBV, HCV
  - Policy and Legislation
  - Prevention and Screening
  - Education of Public and Providers
  - Care and Treatment
  - Research
History 2004 – Writing of the plan

• In 2004, streamlined work of NVHR
  – Exec Committee (6 people) met every 2wk by phone
  – Board met every 3 months by phone
• Identified Alexandra Levitt, PhD at CDC to draft document – invited content resources from all members
• Later contracted with Dr. Crooks to edit the plan
History 2005

- Nat’l meeting April 2005 to review draft plan and provide input in each section
More History 2005

- Followed by phone calls every two weeks to discuss plan content topic-by-topic
- Countless in-kind hours of board members, consultants, administrator, and NVHR members
NVHR Plan Is Done!

• April 2006: NVHR published
  “Eliminating Hepatitis: A Call To Action
  NHVR Plan to Eliminate Viral Hepatitis”
  – 48 pages in length

• Also published Exec. Summary, 7 pages
Eliminating Hepatitis: A Call To Action
National Viral Hepatitis Roundtable
Plan to Eliminate Viral Hepatitis

Eliminating Hepatitis: A Call to Action
National Viral Hepatitis Roundtable
Plan to Eliminate Viral Hepatitis

April, 2006

Eliminating Hepatitis: A Call to Action
National Viral Hepatitis Roundtable
Plan to Eliminate Viral Hepatitis

Sometimes it takes only a thoughtful moment to act quickly and save a life. Sometimes, preventing a tragedy requires a long-term commitment bolstered by skill, passion, dedicated help and substantial resources. Viral hepatitis demands both.

In the high impact areas of hepatitis, there is a human cost. We have seen it personally in our families. We have seen it in our patients. We have seen it in our communities. We have seen it in the people we treat and in the people we try to prevent. We can become involved in larger, more dedicated actions as well. Preventive methods and medical treatment now don’t mean all those who are infected can benefit from them and their cure is still in the planning.

You can help. And together we can make history by eliminating a disease that has already devastated too many people. We can offer hope to those who already suffer from viral hepatitis. We can protect those who are at risk. We can let those who have already lived through the disease know that healing is possible.

Our comprehensive reach and the involvement of patients, doctors and nurses will make a difference. The National Viral Hepatitis Roundtable has been more than two years developing and releasing the best way to prevent the unnecessary suffering and death caused by viral hepatitis. Now, with our action plan in place, we need your help. Our plan is our future, and the growth and success of the campaign is the nation’s health system.”

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Who We Are: A Coalition to Eliminate Viral Hepatitis

The National Viral Hepatitis Roundtable is a coalition of more than 100 organizations working to end viral hepatitis in the United States. The only national coalition focused on all aspects of viral hepatitis, its mission includes advocacy, private, public, and non-profit organizations, public health agencies, drug treatment programs, for-profit and non-profit organizations, and government health agencies. The campaign is helping to increase awareness and prevention of viral hepatitis and end the devastating impact of viral hepatitis.

Our plan is for patients, doctors and nurses to make a difference. The National Viral Hepatitis Roundtable has been more than two years developing and releasing the best way to prevent the unnecessary suffering and death caused by viral hepatitis. Now, with our action plan in place, we need your help. Our plan is our future, and the growth and success of the campaign is the nation’s health system.”

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Executive Summary: A Call to Action

Eliminating Hepatitis: A Call to Action
National Viral Hepatitis Roundtable
Executive Summary
April 2006

American no longer suffer from polio, measles, and mumps; we have learned to ensure that no American suffers from viral hepatitis.

Sometimes it takes only a thoughtful moment to act quickly and effectively to ensure a long-term commitment bolstered by will, passion, dedication, and dollars.

In the fight against viral hepatitis, quick action is possible. We know how to finish this paragraph. You can take action by deciding to learn, spread the word, and get your story out there.

You can help and you can make history by eliminating a disease that was once widespread. You can offer hope to those who already suffer from viral hepatitis.

The National Viral Hepatitis Roundtable has spent more than two years developing an action plan that will prevent the unnecessary suffering and death caused by viral hepatitis. We need your help. Our proposal for action builds on the strengths and successes of the public health sector. We have developed the plan and will spearhead the partnership.

Our comprehensive study and discussions with national experts have led to the following recommendations:

- Build the capacity to address the challenges of viral hepatitis
- Vaccinate America to eliminate vaccine-preventable viral hepatitis
- Ensure a coordinated national action plan for viral hepatitis
- Conduct research to prevent and control viral hepatitis
- Ensure a dedicated and coordinated system for viral hepatitis

The burden of illness:

The healthcare expenditures associated with hepatitis A, B, and C and to a lesser degree hepatitis D and E, can exceed the billions of dollars.

<table>
<thead>
<tr>
<th>Disease</th>
<th>Hepatitis A</th>
<th>Hepatitis B</th>
<th>Hepatitis C</th>
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<tr>
<td>Estimated Infections, 2006</td>
<td>61,000</td>
<td>73,000</td>
<td>20,000</td>
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<tr>
<td>Chronicly Infected (n/a)</td>
<td>1.25 million</td>
<td>2.7 million</td>
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<td>Annual Deaths due to Chronic Liver Disease</td>
<td>n/a</td>
<td>5,000</td>
<td>0,000-10,000</td>
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<td>Direct Healthcare Costs</td>
<td>$13.3 million</td>
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<td>$700 million</td>
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<td>Indirect Costs</td>
<td>$207 million</td>
<td>$700 million</td>
<td>$700 million</td>
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The cost of vaccination, education, and treatment to prevent and control viral hepatitis is an upfront investment with substantial payback in reducing future medical and social costs.

Hepatitis A and B are vaccine-preventable.

Hepatitis A and hepatitis B continue to be among the most prevalent vaccine-preventable diseases in the United States. The human toll is great and there is tremendous financial burden as well. Hepatitis A and B cost Americans $2 billion each year in direct and indirect costs.

We each year, more than 250,000 Americans are infected with hepatitis A, between 1% and 2% of those infected are hospitalized, and nearly 100 of those infected die.

Furthermore, 75,000 Americans are infected with hepatitis B every year. Nearly 1.25 million currently have chronic hepatitis B infections, and an estimated 5,000 will die from liver-related diseases. What's more, it is estimated that 35% of those infected at birth or in early childhood with HBV may develop end-stage liver disease or liver cancer.
NVHR Goals to Eliminate Viral Hepatitis

• Goal 1: Build the capacity to eliminate viral hepatitis
• Goal 2: Vaccinate America
• Goal 3: Counsel, test, and refer persons at risk for chronic disease
• Goal 4: Care for persons with chronic hepatitis
Goal 1: Build capacity – fund infrastructure, information, and manpower in the public and private sectors

- Congress should fund hepatitis programs in every state
- Congress should fund a national surveillance system
- Congress should fund vaccination including a Vaccines for Adults Program
- Gov’t and private sector fund counseling, screening, testing
- Congress should fund comprehensive care for the uninsured
- Gov’t improves community health center services
- Gov’t funds prevention and care for incarcerated persons
- Gov’t funds improved prevention for drug users
- Eliminate health disparities
- Gov’t and private sector improve laboratory tests
- Fed agencies and industry accelerate new treatments for hep B and C
- Congress fund health systems research
- Gov’t support national CDC for patient outreach and education
- Create an information network
Goal 2: Vaccinate America – vaccination is the most humane and cost effective intervention. We need a HCV vaccine.

- Vaccinate at-risk populations
- Protect Americans through global outreach
- Achieve universal hepatitis A/B immunization
- Protect hepatitis C patients
- Protect newborns
- Require vaccination for school entry
- Accelerate hepatitis C vaccine development
Goal 3: Counsel, test, and refer persons at risk for viral hepatitis

- Gov’t should launch nat’l campaign to develop awareness and understanding
- Gov’t launch a nat’l counseling, testing, and referral program
- Health care providers increase education to patients and increase access to testing
- Gov’t, industry, and clinicians use most up-to-date testing and assure lab quality
Goal 4: Care for persons with chronic hepatitis. Quality care is imperative and possible.

- Promote and disseminate guidelines-based care for patients with chronic disease (AASLD and gov’t promote).
- Expand access to expert care.
- Update gov’t disability criteria so they can accurately reflect level of disability for chronic hepatitis patients.
How much money was spent to write the NVHR plan?

• Cost to write the national plan
  – Actual dollars spent: $955,498
  – In-kind time / services donated: $1,550,000
  – Total cost: $2.5 million

• Was it worth the investment?
  – Plan is thorough, specific, inclusive, directive
  – It’s now complete and can be used by others and built upon.
Special recognition for these individuals for their contributions to the Plan

- Dick Conlon, past administrator
- Glenna Crooks, PhD, Strategic Health Policy
- Alexandra Levitt, PhD, NCID, CDC
- Dan Riedford, DVH, CDC
- Hal Margolis, MD, DVH, CDC
- John Ward, MD, DVH, CDC
Special recognition for NVHR Chairs, past and present

- Deborah L. Wexler, MD – Immunization Action Coalition (2003-05)
- Laurie Schowalter – National Association of State and Territorial AIDS Directors (NASTAD) (2005-06)
- Molli Conti – Hepatitis B Foundation (2006-07)
- Chris Taylor – NASTAD (2007-08)
Current NVHR Activities

- NVHR works with CDC to help raise funds to support an Institute of Medicine report on viral hepatitis
- NVHR disseminates information to member organization on hepatitis policy issues
- NVHR is lead U.S. organization on World Hepatitis Day activities
- NVHR chair is North America representative on World Hepatitis Day planning committee
NVHR Accomplishments

- Wrote and published a national plan advocating for the elimination of viral hepatitis in the U.S.—completed April 2006
- Delivered the plan to Congress, May 2006
- Built a national coalition of organizations that care about and will work together on viral hepatitis issues
- NVHR leads on or disseminates information on policy issues as needs arise
- Agreed to work with CDC to help raise funds to support an Institute of Medicine report on viral hepatitis
- NVHR is lead U.S. organization on Word Hepatitis Day
Obstacles

- Competing interests hepatitis B vs hepatitis C
- Some of the organizations didn’t have harmonious relationships between each other at the outset
- Some partners felt their funding would be jeopardized by having a new hepatitis organization
- Initially too many board members, making it hard to advance the project
- Identifying the ideal organizational structure is an ongoing challenge ---should we be independently operated, a program of a bigger entity, who should be the fiscal agent?
- U.S. government administration not supportive of funding new health initiatives
Summary about NVHR

• NVHR is a national organization whose mission is to eliminate all types of viral hepatitis in the U.S.
• NVHR is the first coalition in the U.S. that hepatitis B and C groups have united
• NVHR has written a national plan for elimination of viral hepatitis in the U.S. – and it was very expensive
• NVHR is glad to share its work in any way possible, adapt it for other country needs, or partner internationally
• In the Congress, we have tremendous shortfalls in funding public health programs
• Our next steps are:
  – NVHR is lead U.S. organization on World Hepatitis Alliance
  – NNVHR works on hepatitis policy issues that are actionable
  – NVHR will advocate for implementing contentes of NVHR plan when Congress is more receptive.
More information about National Viral Hepatitis Roundtable

• Go to the website:  www.nvhr.org

• Email administrator Martha Saly:  mbsaly@chipolicy.org

• Email Chair Chris Taylor:  ctaylor@nastad.org

• Email board member Deborah Wexler:  deborah@immunize.org