



# Hepatitis B Policy & Advocacy Overview

April 2023

## HEPATITIS B POLICY PRIORITIES



## FEDERAL FUNDING FOR HEPATITIS B AND LIVER CANCER

- Appropriations Advocacy (CDC, NIH)
- The LIVER Act



## PREVENTION: HEPATITIS B SCREENING AND VACCINATION

- Expanding Hepatitis B Screening Guidelines
- Increasing Adult Hepatitis B Vaccination



#### TREATMENT ACCESS

 Ensuring affordability and access to hepatitis B treatments



## ENDING HEPATITIS B-RELATED DISCRIMINATION

- Health Care Students and Professionals
- U.S. Military

#### **HEALTH EQUITY**

Health Equity and Accountability Act (HEAA)

## Federal Funding for Hepatitis B and Liver Cancer

## CDC (DVH)

## CDC's viral hepatitis prevention and surveillance programs are underfunded and under-prioritized.

- Estimated cost to implement a comprehensive, national program to eliminate viral hepatitis:
  - \$3.9 billion over 10 years
- Current funding level for CDC's Division of Viral Hepatitis:
  - \$43 million for FY23

We urge Congress to allocate no less than \$150 million in funding for viral hepatitis programs at the CDC.

## NIH (NIAID, NIDDK, NCI)

Hepatitis B is preventable and treatable, but there is still no cure for this disease.

The lack of a cure for hepatitis B costs the U.S. an estimated \$4 billion per year in medical costs and has a devastating effect on patients and their families. The hepatitis B research community developed a comprehensive Roadmap for a Cure, along with a professional judgment budget, which recommends increasing NIH funding for hepatitis B research by \$232.3 million over 6 years.

We urge Congress to increase NIH funding for hepatitis B research by \$38.7 million per year.

## WHITE HOUSE ELIMINATION PLAN

The Biden-Harris Administration recently announced a National Plan to Eliminate Hepatitis C. While we applaud this effort, there is a clear missed opportunity in not including any activities or funding towards hepatitis B. Many of the proposed activities are overlapping and could work towards elimination of both hepatitis B and C.

We recommend that strategies to eliminate hepatitis B are integrated into the new National Plan, including around diagnostics, linkage to care and vaccination, treatment access, and expanding screening and prevention efforts, particularly among highrisk populations.

Appropriations Report Language Community Project Funding (Congressional Earmarks)



## Prevention: Increase Hepatitis B Screening

In the U.S., ~2.4 million people live with hepatitis B and the majority (~65%) are undiagnosed.

The CDC now recommends a one-time universal screening for hepatitis B among adults 18 and older. The previous, risk-based screening guidelines were stigmatizing and ineffective in improving diagnosis rates.

### **Policy Priorities:**

- Ensuring implementation of universal screening guidelines
- Advocate for an update to the U.S Preventive Services Task Force (USPSTF) Recommendation

<u>Call to Action: Eliminating Hepatitis B Virus Through Universal</u>
<u>Screening and Vaccination for Adults Ages 19-59</u>



## Prevention: Improve Adult Hepatitis B Vaccination Coverage

Only 30% of adults are fully protected against hepatitis B.

The hepatitis B vaccine is universally recommended for all adults aged 19-59, and for those 60 and older who have risk factors.

- Policy Priorities:
  - Increase access to hepatitis B vaccines
  - Eliminate systemic barriers to vaccination

#### Advocacy Strategies:

- Sign-on letters, petitions, surveys (needs of state/local health departments - Section 317 Funding)
- Public Comment Submissions: federal immunization objectives, considerations, and proposals
- National Adult Hepatitis B Vaccination Awareness Day (April 30th)
  - Toolkit (2023)

## **Treatment Access**

With no cure for hepatitis B, access to affordable medication is extremely important to preventing significant liver damage or cancer and improving the quality of life of people impacted by hepatitis B.

## **Policy Priorities:**

- Adverse drug tiering
- Cost of hepatitis B medication
- Co-pay accumulators

Report: <u>Health Insurance Costs Impacting People</u> <u>Living with Hepatitis B</u> (2020)



## Ending Hepatitis B-Related Discrimination





Hepatitis B is a protected condition under the Americans with Disabilities Act (2013 DOJ Settlement)

- Health Care Schools Admission Policies Hepatitis B-infected health care providers and students face discrimination, impacting training and/or practice.
- Department of Defense and U.S. Public Health Service
   Accession Policies People living with hepatitis B who are
   pursuing careers/serving in the U.S. military and the
   Commissioned Corps of the USPHS face discriminatory hepatitis B accession policies.

## Addressing HBV-Related Health Disparities

Hepatitis B is associated with significant health disparities. Asian Americans and Pacific Islanders represent 6% of the U.S. population but make up 50%+ of the burden of chronic HBV infection. Among African immigrant Communities in the U.S., infection rates are as high as 15%.



## **HEALTH EQUITY AND ACCOUNTABILITY ACT (HEAA)**

The **Health Equity and Accountability Act** (**HEAA**) = a comprehensive bill to eliminate racial and ethnic health disparities.

HEAA seeks to address the wide spectrum of inequities in health care access, quality, and outcomes including:

- Age
- Disability
- Sex
- Gender
- Immigration status
- Sexual orientation

- Gender identity and expression
- Language
- Socio-economic status
- Historical injustices
- Contemporary injustices
- Introduced by the Congressional Tri-Caucus, comprised of CAPAC, CBC and CHC
- Title VII, "Addressing High Impact Minority Diseases," includes a subtitle on viral hepatitis and liver cancer control and prevention
- Also includes titles on culturally and linguistically appropriate health care, health workforce diversity, and social determinants of health

## Learn More

## **2022 Advocacy Year in Review**





**B THE CHANGE 2022 YEAR IN REVIEW** 

#### 2022 Advocacy Wins

**Comment Letters** 





156



354



138 Written public



384



#### Get Involved!

Join B the Change for advocacy updates and action alerts.

Contact us at

#### Updated U.S. Public Health Service Corps Medical Standards

In December 2022, the U.S. Public Health Service (USPHS) Commissioned Corps announced it is updating its medical standards to accept future applicants living with chronic hepatitis B and HIV. Previously, HIV and hepatitis B infection were both considered disqualifying medical conditions. Working alongside partners, we successfully advocated for a change in this policy by meeting with senior administration official and Congressional champions, and getting language included in the FY 2022 House Labor-HHS Appropriations report urging the USPHS to allow officers with hepatitis B to serve in the Commissioned Corps.

#### Community Project Funding: PA Center of Public Health Excellence

With the passage of the Fiscal Year (FY) 2022 Omnibus Appropriations Act in March, the Hepatitis B Foundation received \$475,000 to create a Center of Public Health Excellence focused on hepatitis B elimination by providing expert resources, advice, training, capacity building and technical assistance for state and local partners on how to best prevent, treat and control hepatitis B and to increase the rate of adult vaccination and testing for hepatitis B. The Center of Public Health Excellence was one of nine community projects that Congressman Brian Fitzpatrick secured funding for in the FY 2022 Omnibus.

#### FY23 Omnibus Sees an Increase for CDC, NIH

The FY 2023 Omnibus also included a small increase of \$2 million for CDC's Division of Viral Hepatitis (\$43 million total) and an increase of \$5 million for CDC's Eliminating Opioid Related Infectious Diseases Program (\$23 million total). The bill also appropriated \$1.5 billion for the Advanced Research Projects Agency for Health (ARPA-H). Additionally, NIH funding was increased to \$47.5 billion, including \$150 million to help address the low rate of success of grant applications to the National Cancer Institute and \$88 million to address health disparities.

#### Implementing Universal Hepatitis B Recommendations

In April 2022, universal hepatitis B vaccination for adults aged 19-59 became official policy. HBF immediately embarked on a dissemination campaign to raise awareness of the new recommendation amongst various stakeholder groups. HBF also launched the Hepatitis B Vaccination and Screening Advisory Council, which is comprised of key stakeholders from the provider and patient advocate communities and hepatitis B experts. The Council held a 2-day meeting in June to develop implementation strategies for universal hepatitis B vaccination and screening (expected in 2023), and will publish their findings in a white paper.

State Advocacy Meetings - This year, we began hosting monthly meetings for Hep B United partners, patients, providers, and other community advocates interested in/working on hepatitis B advocacy at the state level to share updates, highlight successful campaigns, exchange resources, get feedback on ideas, discuss challenges/barriers, connect with other advocates, and help identify opportunities for hepatitis B state advocacy across the U.S.

State Advocacy



Spotlight on HBF

Regional Advocacy Trainings - We collaborated with Hep B United partners in the Mid-Atlantic, South, West, and Northeast to co-host three regional advocacy trainings focused on Getting Started in State Advocacy, These virtual workshops aimed to provide a foundation for organizations and advocates interested in getting more involved in advocacy efforts at the state level.

Viral Hepatitis Elimination Planning - We worked to increase hepatitis B community involvement in state viral hepatitis elimination planning workgroups.

## Global Advocacy

Hepatitis B and Hepatitis Delta Global Community Advisory Boards

As pre-clinical and clinical research efforts lead to progress towards development of a functional cure for hepatitis B and effective treatments for hepatitis delta, it is critical to include community perspectives and experiences in this process. This year, the Hepatitis B Foundation created two global Community Advisory Boards (CABs), comprised of 23 CAB members who applied and were selected from 19 countries. The CAB membership reflects the demographics of chronic hepatitis B and D globally, and emphasizes the inclusion of traditionally under-represented communities. Since July, the CABs have been preparing to start meeting with drug and clinical trial developers in 2023, with the goals of integrating community voices, inputs, and recommendations; ensuring patient-centered

decision making; and promoting awareness and engagement on drug and clinical trials.

#### Urging Gavi to Support Hepatitis B Birth Dose

Gavi, the Vaccine Alliance, is an international partnership created to improve access to new and underused vaccines for children living in the world's poorest countries. Previously, Gavi committed to providing support for countries to introduce hepatitis B birth dose, particularly in areas where mother-to-child transmission of hepatitis B is high; however, they have not yet followed through on this. Over the past few months, the Hepatitis B Foundation sent a letter to the Gavi, met virtually with Gavi's Policy Team and Vaccine Programmes Team, and signed on to an open letter published in The Lancet urging Gavi to start their hepatitis B birth dose campaign. We will continue to pressure Gavi through advocacy.

## ANNUAL HEP B UNITED ADVOCACY DAY





## + Remote Opportunities

- Virtual Advocacy Day and Hill Meetings
- Virtual Congressional Briefings

## ADVOCACY ACTION CENTER



**About Us** 

**Local Partners** 

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### **Advocacy**

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**Events and Trainings** 

Congressional Hepatitis Caucus

State Advocacy

## **Action Center**



Become a Hep B Advocate! Sign up below to receive the latest news and updates about hepatitis B policy issues, learn about upcoming advocacy events, and be notified of opportunities to take action and show your support for our policy initiatives.

We'll provide resources, information, and tools to help you:

- · Communicate effectively with your elected officials
- · Educate and engage your community on hepatitis B policy issues
- · Recruit and organize other hepatitis B advocates and champions in your community
- · Promote and participate in ongoing national, state, and local advocacy efforts

Sign up at: <a href="https://www.hepbunited.org/action">www.hepbunited.org/action</a>





## Contact Us

#### **Frank Hood**

Associate Director, Policy and Partnerships frank.hood.hepb.org

#### Michaela Jackson

Program Director, Prevention Policy michaela.jackson@hepb.org

#### **Rhea Racho**

Program Director, Advocacy and Engagement rhea.racho@hepb.org

