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# **Protecting the Hepatitis B vaccine**

In recent months, the new members of the Advisory Committee on Immunization Practices (ACIP) have taken several actions that directly threaten access to the hepatitis B birth dose in the U.S. and undermine public trust in vaccines. The ACIP reviewed the longstanding universal hepatitis B birth dose vaccine recommendation during their meeting on Sept. 18 but decided to delay voting to remove this recommendation after their two-day meeting was overshadowed by confusion and ambiguity.

The Committee, however, made it clear on Sept. 19 that they will continue to deliberate changing the longstanding, successful recommendation from universal to risk-based, which is a strategy that has previously failed to protect those most vulnerable. They are also expected to vote on removing funding for the hepatitis B vaccine through the Vaccines for Children (VFC) Program-a federal program that provides childhood vaccines at no cost to millions of families across the U.S.—at some point in the near future.

In response to the meeting, the **Hepatitis B Foundation** partnered with several national organizations, including the American Academy of Pediatrics, the American Association for the Study of Liver Diseases, Immunize.org and the Association of Asian Pacific Community Health **Organizations**, on a joint statement (posted here) expressing concern around the lack of evidence to remove universal birth dose, and calling for ACIP to utilize their previous scientific framework for evaluating changes to vaccine recommendations. The Foundation prepared and responded to the September ACIP meeting by organizing hundreds of public comments, given numerous national media interviews, and playing a key role in dispelling misinformation about the vaccine. In the past months, we have conducted dozens of Congressional office visits, hosted webinars reaching thousands of people, and created a new media toolkit to help improve knowledge about the hepatitis B vaccine.

The Foundation has played a key role in raising awareness about the benefits of the hepatitis B birth dose through Hill visits, webinars, public comments and a new media toolkit. Dr. Chari Cohen (president), Dr. Su Wang (public health advisor), and Michaela **Jackson** (director of prevention policy) also gave numerous national media interviews, including a live appearance on ABC News, highlighting the significant impacts of removing the universal recommendation.











To celebrate the 100th birthday of the brilliant scientist and Nobel Prize Laureate who discovered the hepatitis B virus, Baruch S. Blumberg, MB, DPhil, more than 100 of his admirers, friends, family members and former colleagues gathered on July 29 for an event in Philadelphia. Sponsored by the Hepatitis B Foundation, Baruch S. Blumberg Institute and American Philosophical Society (APS), the event was held at the APS in Benjamin Franklin Hall.

The event included a panel discussion with **Dr. Jane Blumberg**, who is Dr. Blumberg's daughter; **Dr. Timothy Block**, co-founder of the Hepatitis B Foundation and Blumberg Institute; Dr. Chari Cohen, president of the Foundation; and **Dr. Walter Tsou**, president of the Philadelphia County Medical Society; and moderated by Dr. Michelle McDonald, director of the APS Library and Museum. A recording is posted on our YouTube channel.

Dr. Blumberg and colleagues discovered the hepatitis B virus in 1967. Two years later he co-invented the first hepatitis B vaccine, the world's first anti-cancer vaccine. Sir Mark Thompson,

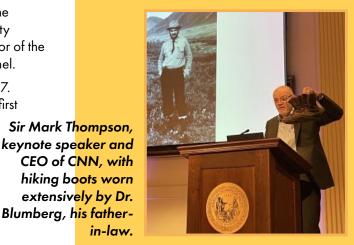
After helping launch the Foundation and what today is the Baruch S. Blumberg Institute, Dr. Blumberg worked continuously with our team and maintained an office on our Doylestown campus until his passing in 2011.

Dr. Blumberg was born on July 28, 1925, and on that date every year people around the globe celebrate World Hepatitis Day in his honor.

Use the QR code to watch the event video to learn how Dr. Blumberg and his team made groundbreaking scientific discoveries, and the auspicious role Philadelphia has played in hepatitis B research and public health.



Dr. Block (left) and Dr. Blumberg in 2005.





# **Storytellers in Action: Amplifying Voices, Inspiring Change**

**Storytellers in Action** is a unique program designed to empower individuals living with hepatitis B, hepatitis D and liver cancer to share their personal journeys with confidence and impact. Since January 2025, our pilot cohort of storytellers has gathered monthly, featuring engaging guest speakers, interactive workshops and open discussions. Over six months, participants had an opportunity to strengthen their storytelling skills, gain confidence and become powerful advocates for change.

At the April workshop, we warmly welcomed our newest #justB storytellers— MW, Lynette, Bruno, Tay and Trieu—who are bravely sharing their journeys with hepatitis B. Their stories reflect resilience, advocacy and the process of healing, reminding us of the power of lived experiences to educate and inspire. You can explore their moving stories at www.hepbstories.org.

Each participant brings a unique perspective:

- # Bruno reflects on the strength of family.
- # Lynette shares the importance of early diagnosis and care.
- # MW speaks to the challenges of stigma.
- # Tay highlights the role of community support.
- # Trieu reflects on navigating treatment and recovery.

We are proud to spotlight these individuals and celebrate their courage in transforming personal challenges into awareness and action. Their voices are helping to break stigma, influence policy and inspire hope for the 300 million affected by hepatitis B worldwide.

Together, we are making a difference—one story at a time.





Meet our newest #justB storytellers—MW, Lynette, Bruno, Tay and Trieu—who bravely shared their hepatitis B journeys at our April workshop. Their stories reflect resilience, identity, advocacy and healing. Explore their experiences at www.hepbstories.org







## **Hepatitis B Foundation** hosts Inaugural **Liver Cancer Patient** Conference



The Hepatitis B Foundation hosted the first liver cancer-focused B Informed! patient conference, Working Together to Tell a New Story, in June of 2025.

The purpose was to explore hepatocellular carcinoma (HCC), or primary liver cancer, from a variety of perspectives that are most relevant to those with lived experience or at high risk, and to hear from experts about the most effective strategies for improving early detection and HCC outcomes in the U.S.

The online event included presentations from experts in the field discussing the current epidemiology of HCC and some of the biggest obstacles to routine HCC surveillance for people living with risk factors, from both clinical and socio-ecological perspectives. A panel discussion with individuals who themselves had been treated for, or were at high risk for HCC, discussing their experiences across the full cascade of care and the impacts of the disease on their lives, was one of the event's highlights.

Research updates and an overview of the current HCC drug pipeline, as well as strategies for effective community outreach and social support, were also discussed.

The conference had over 80 real-time attendees at its peak and the recording has had 159 views over subsequent



weeks. The success of this endeavor will hopefully lay the groundwork for similar events going forward. The key findings from the conference can be found in this infographic to the right. >

You can view the conference recording at: www.youtube.com/watch?v=8Ceaa4SUbw0



### **Working Together to Tell a New Story Key Takeaways**



### Importance of early detection

The HCC journey can have physical, emotional and professional impacts, and support from various sources is critical throughout the process.



It is important that there is a multisectoral team supporting people with HCC through the journey (healthcare providers, social workers, case navigators, family/friends, support groups, advocacy orgs), all of whom are seen as equal partners along the way.



Sharing personal HCC stories and serving as a community educator and advocate can be a rewarding experience for people who have been impacted by HCC.



Cultural competence & community awareness.

There are new medical innovations in the research pipeline for HCC that can potentially lead to better health outcomes and offer hope for the future

All those who are at increased risk for HCC should have access to surveillance for early detection, though many challenges remain and most liver cancers are still found at a later stage.

02. The impacts of HCC are multifaceted.



These can be social, environmental, cultural, and/or economic in nature.

04. Different types of support are critical.



Individuals need to be empowered to advocate for themselves and their care. Collectively, we need to advocate to improve care, treatment and services for people with HCC.

06. The power of storytelling & community education

It is imperative that we improve community awareness in culturally competent ways, to promote both screening for HCC risk factors and HCC surveillance.

08. Promising new research.



Do you have thoughts on how to move the needle on improving HCC outcomes in the United States? We would love to hear from you! Click this link or scan the QR code to share your opinions!











## **Global Hepatitis B & D Community Advisory Board (CAB) Update**

The mission of the Global Hepatitis B & D Community Advisory Board (CAB), established in 2022, is to integrate community perspectives and lived experience into hepatitis B and D drug development and clinical research. By ensuring that people living with, and affected by, these conditions are meaningfully represented, the CAB works toward advancing equitable and effective cures.



THE CAB HAS 24 MEMBERS FROM 16 COUNTRIES IN AFRICA, EUROPE, ASIA, AND NORTH AMERICA. EACH CAB MEMBER BRINGS A UNIQUE PERSPECTIVE AND REPRESENTS THE **COMMUNITIES MOST IMPACTED BY** HEPATITIS B, ENSURING THAT THE GROUP'S WORK REMAINS INCLUSIVE, RELEVANT, AND COMMUNITY-DRIVEN.

Members launched several key initiatives this year. Three members wrote a two-part blog on the lived experiences of, and best practices for, disclosing hepatitis B or D status to partners and family. This resource, now in its final drafting phase, will be translated into Bulgarian and other languages for distribution on members' organizational websites. Two members collaborated on a statement examining how current U.S. politicals are affecting people worldwide living with hepatitis B and D. One led the CAB's submission of comments on the American Association for the Study of Liver Diseases' draft hepatitis B treatment guidelines, gathering input from across the membership before submitting. The CAB also participated in two meetings with pharmaceutical companies this year.

Recent and forthcoming publications highlight both lived experiences and

practical guidance for improving care. These include Lived experiences of clinical trials and how patient insights can improve equity in process and outcomes (blog), Global Hepatitis B and D community advisory board: expectations, challenges, and lessons learned, Best practices for engaging with affected communities: chronic hepatitis B as a case study, and two blogs on disclosure: Disclosure: How to tell your partner, family, or friends about your hepatitis B or D status – Tips and tricks and Importance of disclosing your hepatitis B and hepatitis D status.

## **Improving Capacity for Patient-Centered** Research to Address Hepatitis B

The Hepatitis B Foundation has been approved for funding through the Eugene Washington PCORI Engagement Award Program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI). This project aims to amplify the voices of people living with hepatitis B by integrating their perspectives into the development of new therapeutics and clinical research.

Through comparative effectiveness research (CER), the project will build and train a diverse consortium of patients, caregivers, advocatses, health care providers, researchers and policy stakeholders. Together, they will identify patient-prioritized research questions, develop strategies to educate and empower the broader community, and establish a comprehensive patient-centered CER agenda. This framework will guide future research on hepatitis B diagnosis, prevention and management, ensuring that patient needs and lived experiences are at the center of progress. Ultimately, the initiative seeks to improve quality of life and treatment outcomes for people with hepatitis B in the U.S. and worldwide.

## **Community Health Center Learning Collaborative**

The annual Community Health **Center Learning Collaborative fosters** a cohort of four to eight communitybased health centers across the U.S. serving Asian American, Native Hawaiian / Pacific Islander and African communities, and/or people who use drugs. Hosted in collaboration with the Association of Asian Pacific Community Health Organizations (AAPCHO), cohort members learn to integrate and improve their capacity to implement hepatitis B education, screening, vaccination and linkage to care programs and promote cross-sector partnerships with community-based organizations. The cohort meets weekly for a month, and members complete homework in between sessions.



The project brings together staff with selected community health centers from across the U.S. to model hepatitis B community engagement, prevention and control programs. They share best practices, skills, strategies and tested resources in a virtual group learning series. This intensive training allows cohort members to begin to implement changes to their organization with minimal delay and real-time technical assistance. Hepatitis B Foundation staff provide one-on-one support to each organization over the following year to ensure cohort members are able to implement their projects. Since its launch in 2023, the Learning Collaborative has graduated 20 participants from its three cohorts, fostering improved capacity and helping 13 community clinics to improve the hepatitis B care cascade.



## New therapies in development

The Foundation maintains a comprehensive list of drugs currently in pre-clinical and clinical development for chronic hepatitis B. We update this list monthly and you can find it on our website.

www.hepb.org > Treatment & Management > Drug Watch





https://www.hepb.org/blog High-value insights on many topics



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The Hepatitis B Foundation is a global nonprofit organization dedicated to finding a cure and improving the quality of life for those affected by hepatitis B worldwide through research, education and patient advocacy.

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## Fighting to save birth-dose vaccination in the U.S.

The current Advisory for Committee on Immunization Practices (ACIP), which the new federal administration re-created this year, is seriously considering removing current universal recommendations for hepatitis B birth dose vaccine in the U.S. It seems clear that ACIP is inclined to remove or greatly weaken the birth dose recommendation, which we believe would be a grave mistake.

#### What does this mean?

We will undoubtedly see completely preventable hepatitis B infections among babies and children in the U.S.

Before universal birth dose was introduced in the U.S., 18,000 babies and young children were infected with hepatitis B each year. With universal birth dose, those infections decreased dramatically – in 2019, only 16 babies tested positive for hepatitis B at birth. The hepatitis B vaccine saves lives. Almost all babies and children exposed to the virus develop chronic infection, and up to 25% will develop liver failure or liver cancer without medical care and treatment.

### What can be done now?

Help us continue to fight to save lives. Your gift to the Foundation will support our advocacy, education and public health programs that prevent new infections and save lives.

Your gift fuels our ability to perform this work.

#### Help us save lives.

Your support today is needed now more than ever.

Donate online at hepb.org/donate

### For More Information About **Hepatitis B Foundation Programs**

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