

2024

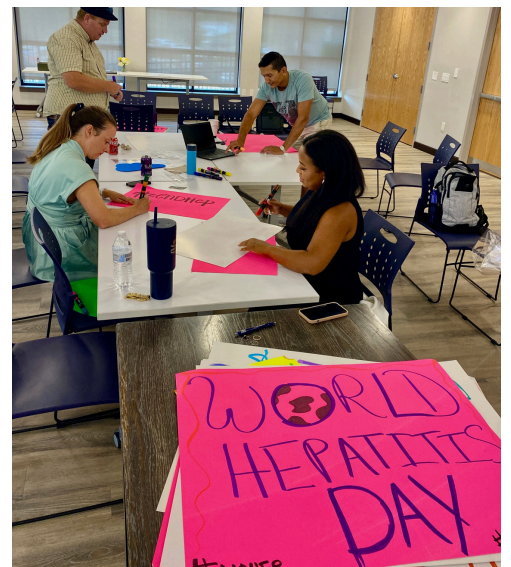


**Informed**  
**Patient Conference**

# Happy World Hepatitis Day!



The **Hepatitis B Foundation** and the **Sidney Kimmel Cancer Center** hosted the **B Informed Patient Conference on World Hepatitis Day in Philadelphia** to provide a platform for people with lived experience, health care providers, and researchers to engage in meaningful conversation about hepatitis B and liver cancer. Over 70 people attended the conference with representation from the scientific and medical communities, community health organizations, storytellers from across the East Coast, and public health professionals with a dedicated interest in addressing hepatitis B. The day featured presentations and panel discussions focused on patient advocacy and empowering people living with hepatitis B to overcome stigma and find meaning beyond their diagnosis. Medical providers shared crucial insights about monitoring liver health, testing for hepatitis delta (a co-infection that can occur with hepatitis B), and adopting healthy lifestyle changes. Scientists shared updates on drug development and clinical trials for hepatitis B.



# Hepatitis B & Delta Overview

*Su Wang, MD*



**Dr. Su Wang is the Medical Director for the Center for Asian Health at Cooperman Barnabas Medical Center, as well as the Global Health Advisor for the Hepatitis B Foundation.**

## Lived Experience & Advocacy

Dr. Wang works as a primary care provider while living with hepatitis B and has firsthand experiences associated with diagnosis and management. This has greatly been shaped by her own experiences as a provider and patient and directly impacts her commitment to enhancing the health and well-being of communities impacted by hepatitis B.

## Hepatitis B and Delta

### Hepatitis B (HBV)

- Hepatitis B is a virus that damages the liver. Without proper treatment and monitoring, it can cause liver cancer.
- Vaccination effectively prevent new hepatitis B infections for those who have not been exposed.
- Western Pacific, African, and South East Asian regions have the highest burden of hepatitis B globally.
- In the United States, hepatitis B disproportionately impacts Asian and African populations.



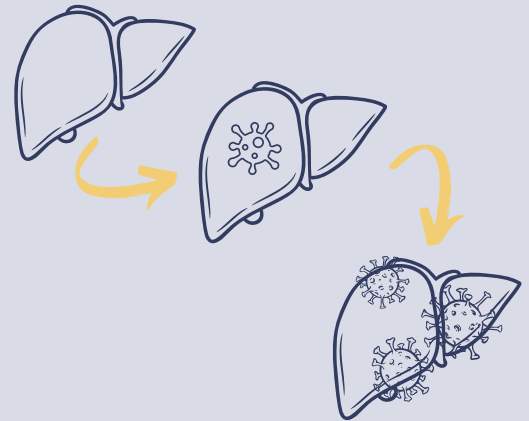
Global prevalence of HBV is estimated at 296 million.

### Hepatitis Delta (HDV)

- Hepatitis Delta is a co-infection of HBV, and while not as common, it can cause serious damage to the liver such as cirrhosis or cancer without proper intervention.
- Only those who have hepatitis B can get hepatitis Delta.
- Globally, 5% to 10% of people around the world are coinfecting with hepatitis Delta.

# Hepatitis B and Cancer Development

The hepatitis B virus produces new virus within liver cells. Symptoms are not always visible but eventually, the liver can become inflamed over time, especially when there is a lot of viral reproduction occurring. This can damage the liver over time. When the damage is too severe, the liver gets scarred, and cannot work as well, or liver cancer can develop.



## HBV Care and Treatment

- Without proper treatment, the chances of liver damage or cirrhosis can be higher. Hepatitis B treatments are available as antiviral medications and immune modulator drugs to prevent serious liver damage and liver cancer.
- The treatments for hepatitis B work to reduce HBV DNA and boost the immune system to fight the infection by preventing replication of HBV DNA.
- Aside from treatment, it is important to maintain a healthy lifestyle. This includes avoiding alcohol, quitting smoking, eating healthy foods, exercising, and maintaining a healthy weight.
- Make sure to get HBV blood tests every six months, follow up with providers, and get screened for liver cancer.

## Patient Voice

The conversation about starting or stopping treatment for hepatitis B is one that includes shared decision making from patients and providers. Providers should take into account the cultural considerations, preferences and values of their patients. It is important to share knowledge about treatment options, side effects, and the role of treatment in preventing cancer before prescribing medication to patients. It's important for patients to ask questions and learn more about their health.



# Storyteller Session

Wendy Lo

DeWayne Walters

Ravshan Yakubov

## Wendy Lo, Patient Advocate and #justB Storyteller

Wendy was diagnosed with hepatitis B at 21 years old and lived in silence with it for 28 years. It wasn't until 2020, when she saw a #justB video, that she decided to share her story. In 2022, Wendy became a storyteller for the Hepatitis B Foundation's #justB storytelling campaign.



[Watch Wendy's Story Here!](#)

## Wendy's Priorities



Debunking myths and misconceptions about hepatitis B



Breaking the silence and normalizing conversations about living with hepatitis B



Providing support and a sense of community to those with lived experience

## Rav, Patient Advocate and #justB Storyteller

Rav was diagnosed with hepatitis B when he was a young child in Uzbekistan. Navigating life with hepatitis B impacted his ability to play with other children. As an adult, Rav discovered he was coinfecting with hepatitis Delta.



[Watch Rav's Story Here!](#)

### Rav's Priorities



Spread awareness about hepatitis delta and get more people to share their stories



Engage in awareness and advocacy events to end the stigma around hepatitis B

## DeWayne, Patient Advocate and #justB Storyteller

DeWayne was diagnosed with hepatitis B as a child during a blood transfusion procedure. This happened before blood was screened for hepatitis B virus. He remembers feeling isolated and banned from playing sports due to his status.



[Watch DeWayne's Story Here!](#)

### DeWayne's Priorities



Promote awareness about hepatitis B transmission, vaccination, and treatment among providers



Monitor liver health and continue treatment to be able to see his son grow up

# Storyteller Discussion

Below are helpful recommendations and strategies for advocating for your health shared by storytellers

## ◆ Advocating for Your Health

- Find a knowledgeable provider and build a trusting relationship with them. Prioritize three topics to share with your doctor at each visit.
- Learn more about hepatitis B so that you can ask better questions and engage in meaningful discussions about liver health, cancer risk, and treatments with your providers.
- Make modifications to your lifestyle by quitting smoking, and reducing alcohol use.
- Consider starting a medical journal to keep track of your health and record questions and concerns to share with providers.
- Remember that in the U.S., all adult are recommended to get tested. Anyone can have hepatitis B. This message helps prevent the stigmatization of screening and encourages more people to get tested.

## ◆ Recommendations

- Encourage people to get tested and vaccinated for hepatitis B.
- Offer the #justB and #BetheVoice storytelling programs in different languages to make it more accessible for people around the globe and non-English speaking communities.
- Share more videos and stories of other storytellers and those with lived experience to end the silence and stigma related to hepatitis B.

# Provider Panel

*Jessie Torgersen, MD, Tatyana Kushner, MD  
Kenneth Rothstein, MD, Su Wang, MD*



**Jessie Torgersen, MD, MHS, MSCE, Director, Center for Viral Hepatitis, Penn Presbyterian Medical Center, Director, Hepatitis Linkage Team, Penn Medicine, Assistant Professor of Medicine at the Hospital of the University of Pennsylvania.**



**Tatyana Kushner MD, MSCE, Associate Professor of Medicine in the Division of Liver Diseases at the Icahn School of Medicine at Mount Sinai.**



**Ken Rothstein, MD, Director of Regional Outreach and Regional Hepatology, Professor of Clinical Medicine (Gastroenterology) at Penn Medicine.**



**Su Wang, MD, Medical Director for the Chinese Medical Program at Cooperman Barnabas Medical Center, Past President, World Hepatitis Alliance, Board Member and Advisor to Hepatitis B Foundation.**



## FAQ: "I feel fine. What do I do?"

- Hepatitis B does not always have symptoms. The damage may still be happening but patients usually don't know about it until it gets worse. This is why considering treatment options and monitoring for signs of liver damage and liver cancer is crucial.
- Implement a healthy lifestyle and focus on behavioral changes in addition to regular follow up appointments with providers.



## FAQ: "What does hepatitis Delta monitoring look like?"

- This panel agreed that all patients who test positive for hepatitis B should be screened for hepatitis Delta. This is currently not the recommendation in the U.S., but panelists felt that risk-based screening may miss many people with hepatitis Delta.
- Hepatitis Delta testing is evolving and better treatments will be available soon.
- Hepatitis Delta can be an additional risk factor for liver cancer so it is crucial to get tested and follow up with providers in a consistent manner.

## FAQ: "Should I be concerned with taking medication long term?"

- Hepatitis B medications are crucial to lowering HBV DNA levels and preventing liver damage. It is never a good idea to stop treatment without consulting a provider. Even if the viral load is undetectable, stopping treatment can cause a flare up and elevate the viral load.
- It is important to reassure patients about the benefits and reasons for taking medication. The disease is typically more harmful than the medication.
- Better and more treatments are needed for hepatitis B management so that patients have more liberty and autonomy to make their own health decisions.
- For patients that may struggle with getting affordable medications or if insurance changes impact their cost of treatment, it is better to consult with providers. Providers can help find other resources to help patients with finding medications. The Hepatitis B Foundation can help you find accessible resources, too.

## Perspectives from Providers on Updated Guidelines

- Providers generally have to follow medical society guidelines but they also need to make sure that patients are comfortable with treatment decisions. Medical guidelines can be effective in getting more people into care.
- Providers and patients need to be able to make the decision on starting treatment together, taking into account guidelines, patient choice and preferences, and other factors.
- Side effects of medications can outweigh the benefits of taking the medication for some people.

# What is the accuracy of ultrasound & AFP Testing for liver cancer?

- AFP testing alone is not considered the best practice as its accuracy is limited.
- Standard care should be imaging (MRI or ultrasound) and an AFP test every six months. However, this can be costly and not always covered by insurance.
- The best approach is early screening as recommended by clinical societies to ensure early detection and prevention of liver cancer.

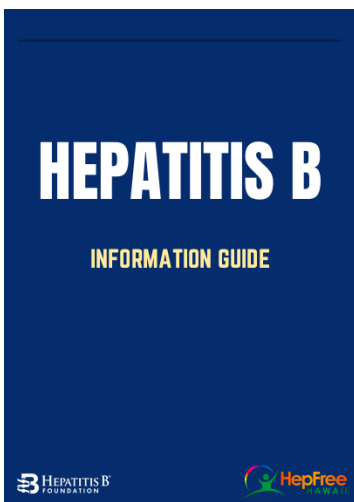
## Resources for Patients

Cost or changes in health insurance plans can prevent access to affordable hepatitis B medications. The following resources can provide hepatitis B treatments at a low cost for many patients. GoodRx, CostPlus and Amazon Pharmacy are good options for affordable treatments (listed below). We have also included helpful information guides from the Hepatitis B Foundation that you might be interested in.

① [GoodRx](#)

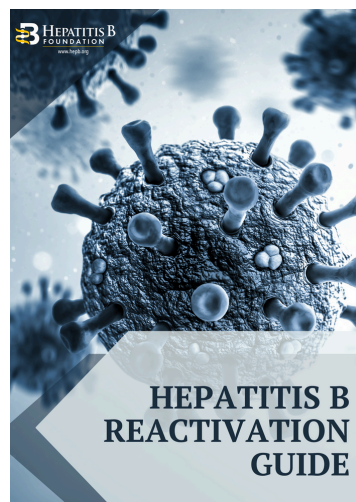
② [CostPlus](#)

③ [Amazon Pharmacy](#)



Click Here!

This is an information guide for patients to learn more about understanding their hepatitis B diagnosis.



Click Here!

This is an important tool for people living with hepatitis B to learn more about hepatitis B reactivation.

# Updates on Hepatitis B & Delta Treatment

Timothy M. Block, PhD, Co-Founder and Board Chair, Hepatitis B Foundation



## Absolute Cure

**Definition:** Resolved infection so that the viremia is completely eradicated and the individual returns to the same level of liver disease risk as the person who has never been infected.

## Functional Cure

**Definition:** Sustained off drug undetectable viral DNA, loss of surface antigen, and normalization of liver enzymes in the blood.

## Current Drugs in Development

## Drug Watch

Combination therapy is considered to be the best way forward to achieving a functional cure for people living with hepatitis B by inhibiting virus replication, removing surface antigen in the blood, and stimulating the immune system to better respond to the infection. While antiviral drugs are effective at reducing viral load, they are not curative. A new approach is to pair antiviral drugs with immune modulation to maximize the chances to obtain a functional cure. Current drugs in the pipeline are in preclinical, phase I, II, and III trials. View the Hepatitis B Foundation's Drug Watch to see all of the drugs in development.

<b>GSK Bepirovirsen (antisense RNA)</b>	<b>Suppresses and destroys the viral messenger RNA, which is crucial in making proteins and replicating HBV DNA. Clinical trials have shown an effective reduction in HBV DNA levels and viral proteins.</b>
<b>ALG-000184 - Capsid Assembly Modifiers (CAMS)</b>	<b>Capsids provide a protective space for the genetic material of the virus to make sure it is able to transfer to the host cell without any complications. By disrupting the formation of the capsids, the virus is unable to replicate itself as the genetic material gets destroyed during the process.</b>
<b>Therapeutic Vaccines</b>	<b>Stimulate HBV specific B and T cells to boost immune system response.</b>

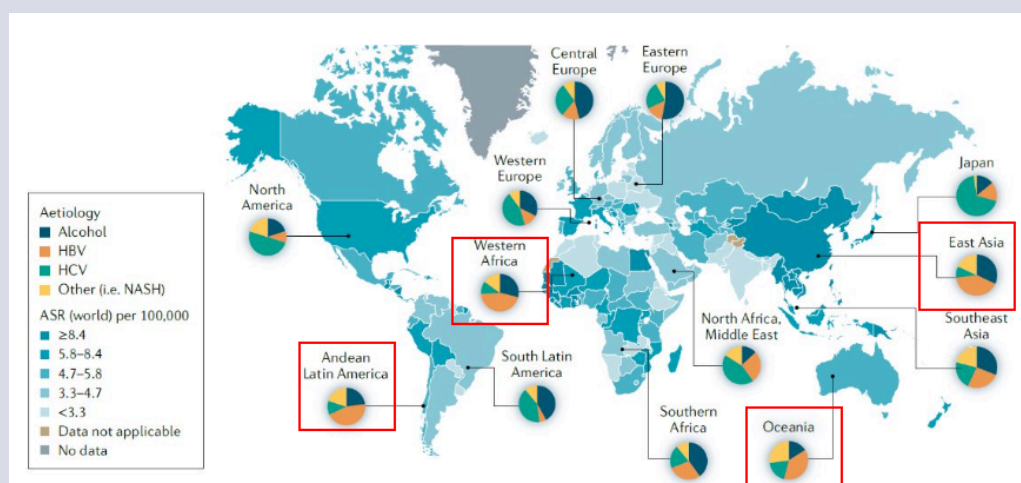
# Healthy Liver & Cancer Screening

Hien T. Dang, PhD



## Global Etiology of Liver Cancer (HCC)

There are multiple causes for HCC. Chronic hepatitis B infection remains one of the most prominent causes of HCC, especially in East Asia and Africa.



## Screening and Early Detection

Screening tools consist of AFP testing and ultrasounds which can detect cirrhosis and inflammation of the liver. CT and MRI testing are considered to be the more effective diagnostic tools but more costly as well.

## Treatment Strategies

Early detection and treatment with curative resection/transplant is gold standard but, unfortunately, uncommon. 18% have a 5-year survival and median survival of 6–20 months from time of diagnosis. Ablation, resection or transplantation is recommended in the early stage. Chemotherapy is recommended in the intermediate stage and systemic therapy is recommended in the advanced stage. Supportive care is recommended at the advanced stage of HCC.

### HCC Risk Factors

- Aflatoxin
- Alcohol use
- Diabetes
- HBV and HCV
- Fatty liver
- Fibrosis
- Cirrhosis

# Conference Key Takeaways

## **1) Empower the Patient Voice**

- It is imperative that the patient community is involved in conversations about hepatitis B prevention, education, and treatment. People living with hepatitis B provide a firsthand perspective on best practices and overcoming stigma and other impacts of hepatitis B.

## **2) Monitor Liver Health**

- Chronic hepatitis B remains a strong risk factor for liver cancer and serious liver disease. It is crucial to monitor liver health, follow up with appropriate tests and get screened for liver cancer in accordance with guidelines and provider recommendations.

## **3) Stay Updated & Informed**

- The drug development landscape for hepatitis B is always changing with new and improved therapeutics and ongoing clinical trials with promising outcomes.