

# Eliminating Hepatitis B in Asian American, Native Hawaiian, and Pacific Islander Communities

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# Learning Objectives

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1. Recognize the health disparities associated with hepatitis B and liver cancer and describe the impact on Asian American, Native Hawaiian, and Pacific Islander communities.
2. Understand the challenges and barriers to hepatitis B screening and care among highly affected, underserved communities in the U.S.
3. Design and replicate innovative, multi-level strategies to eliminate hepatitis B-related health disparities among Asian American, Native Hawaiian, and Pacific Islander communities.



# Eliminating Hepatitis B in AAPI Communities

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- Hepatitis B Virus
- Hepatitis B-Related Health Disparities
- Hepatitis B and Liver Cancer
- Barriers to Screening & Treatment
- HBV-Related Stigma & Discrimination
- Strategies to Eliminate Disparities
- Resources



## What is Hepatitis B?

Hepatitis B is caused by the hepatitis B virus (HBV) that attacks and injures the liver.

Known as a "silent epidemic"

Most people **do not** show symptoms even when chronically infected.



## Who is most at-risk?



People of Asian or African descent



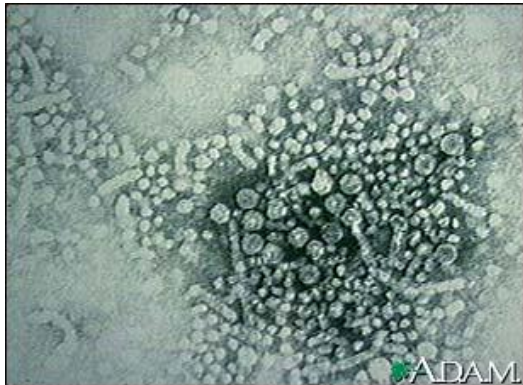
Health care providers



Injection drug users



Infants born to infected mothers



## How common is it?

most are unaware of their status



2.2 million people in the US

[3,000 people die annually]

292 million people worldwide

[600,000 people die annually]

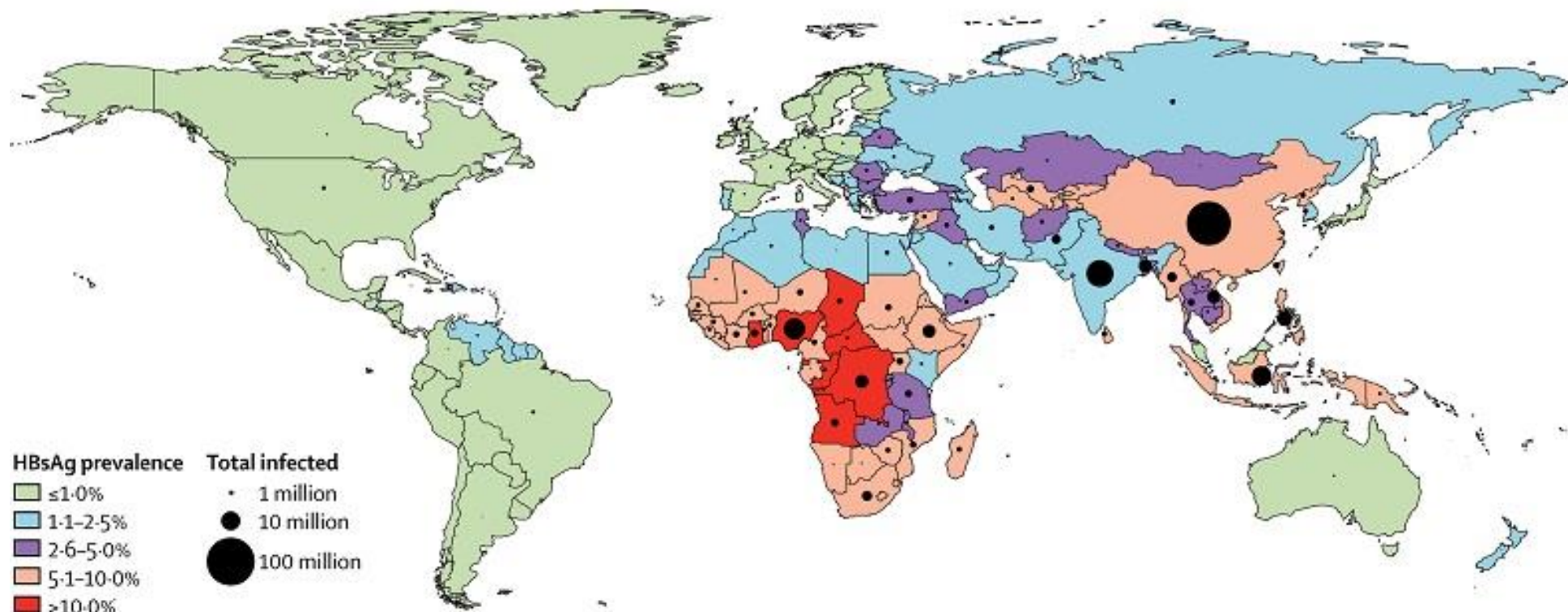


# The Hepatitis B Virus

- Hepatitis B is the world's most common, serious liver infection in the world
- **Transmission:** direct blood contact; sexual transmission; from mother to child (most common route worldwide)
- Chronic HBV can lead to premature death from cirrhosis, liver failure and liver cancer
- **The Good News:** we have safe and effective vaccines (2 or 3 doses) that offers life-long protection!



# Hepatitis B Global Epidemiology



Almost 300 people worldwide are chronically infected  
884,000 people die each year from HBV-related liver disease



# Hepatitis B Related Health Disparities

- Chronic hepatitis B and liver cancer represent the #1 health disparities for Asian Americans and Pacific Islanders (AAPI)
- 50% of the U.S. hepatitis B burden occurs among AAPIs
- AAPI and African immigrant communities have hepatitis B infection rates of between 5% and 15%
- **NEW (2017) CDC Surveillance Report:** AAPIs experience the highest hepatitis B-related mortality rates (5.3x higher); this rate increased from 2015-2017



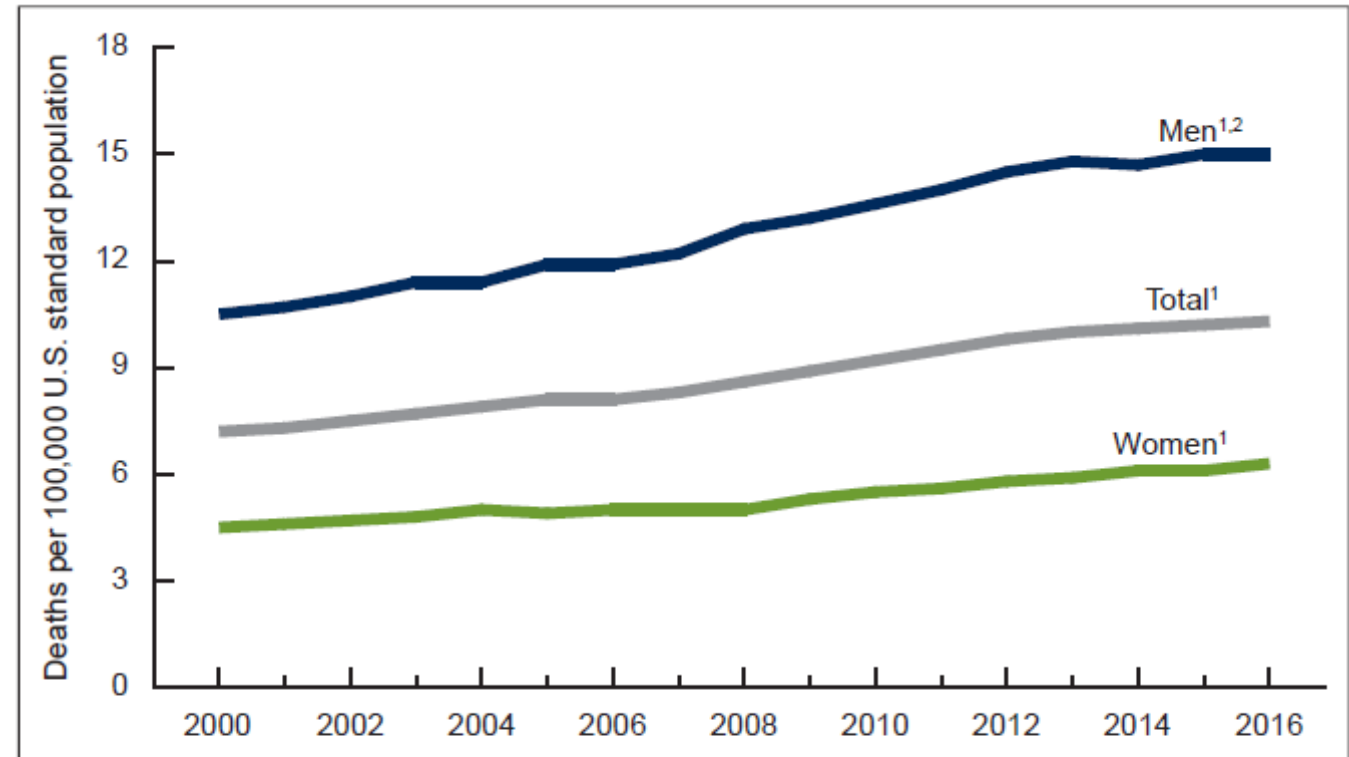
Did you know that  
**1 in 12 Asian  
Americans have  
Hepatitis B?**

# Liver Cancer in the U.S.

- Only **17.6%** of people survive 5-years
- 5<sup>th</sup> leading cause of cancer death among men in the U.S.
- In 2017, there were **40,170** new cases and **28,920** deaths

Age-adjusted liver cancer death rates increased steadily from 2000 through 2016 for both men and women aged 25 and over.

Figure 1. Age-adjusted death rates for liver cancer among adults aged 25 and over, by sex: United States, 2000–2016



<sup>1</sup>Significant increasing trend from 2000 to 2016 ( $p < 0.05$ ).

<sup>2</sup>Significantly higher than women throughout the period ( $p < 0.05$ ).

NOTES: Liver cancer deaths are identified with *International Classification of Diseases, 10th Revision*, using underlying cause-of-death code C22. Access data table for Figure 1 at: [https://www.cdc.gov/nchs/data/databriefs/db314\\_table.pdf#1](https://www.cdc.gov/nchs/data/databriefs/db314_table.pdf#1).

SOURCE: NCHS, National Vital Statistics System, Mortality.



# HBV-Related Liver Cancer Disparities

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## Rates among AAPI men are 6-13 times higher than Caucasian men

- 13x higher in Vietnamese men
- 8x higher in Korean men
- 6x higher in Chinese men

## Other related risk factors – smoking + hepatitis B

- Vietnamese men had the highest lifestyle pattern prevalence (current smoker or alcohol user) and Vietnamese men most likely to have lifestyle + viral (hepatitis B or hepatitis C)<sup>1</sup>
- Cigarette smoking in male patients with chronic hepatitis B worsens liver disease and delays improvement with hepatitis B treatment<sup>2</sup>
- Risk of HCC highest among HBV-positive smokers followed by HBV-positive non-smokers and lowest in HBV-negative smokers<sup>3</sup>

<sup>1</sup>Stewart SL, Dang JH, Török NJ, Chen MS Jr. Patterns and co-occurrence of risk factors for hepatocellular carcinoma in four Asian American communities: a cross-sectional study. *BMJ Open*. 2019;9(6):e026409. Published 2019 Jun 28. doi:10.1136/bmjopen-2018-026409

<sup>2</sup>Xiong M., Li J., Yang S., et al. Impacts of cigarette smoking on liver fibrosis and its regression under therapy in male patients with chronic hepatitis B. *Liver International*. 2019;39(8) doi: 10.1111/liv.1410

<sup>3</sup>Chuang SC, Lee YC, Hashibe M, Dai M, Zheng T, Boffetta P. Interaction between cigarette smoking and hepatitis B and C virus infection on the risk of liver cancer: a meta-analysis. *Cancer Epidemiol Biomarkers Prev*. 2010;19(5):1261–1268. doi:10.1158/1055-9965.EPI-09-1297





## There are around 2 million Americans living with chronic Hepatitis B



**Only 25% are aware of their infection**



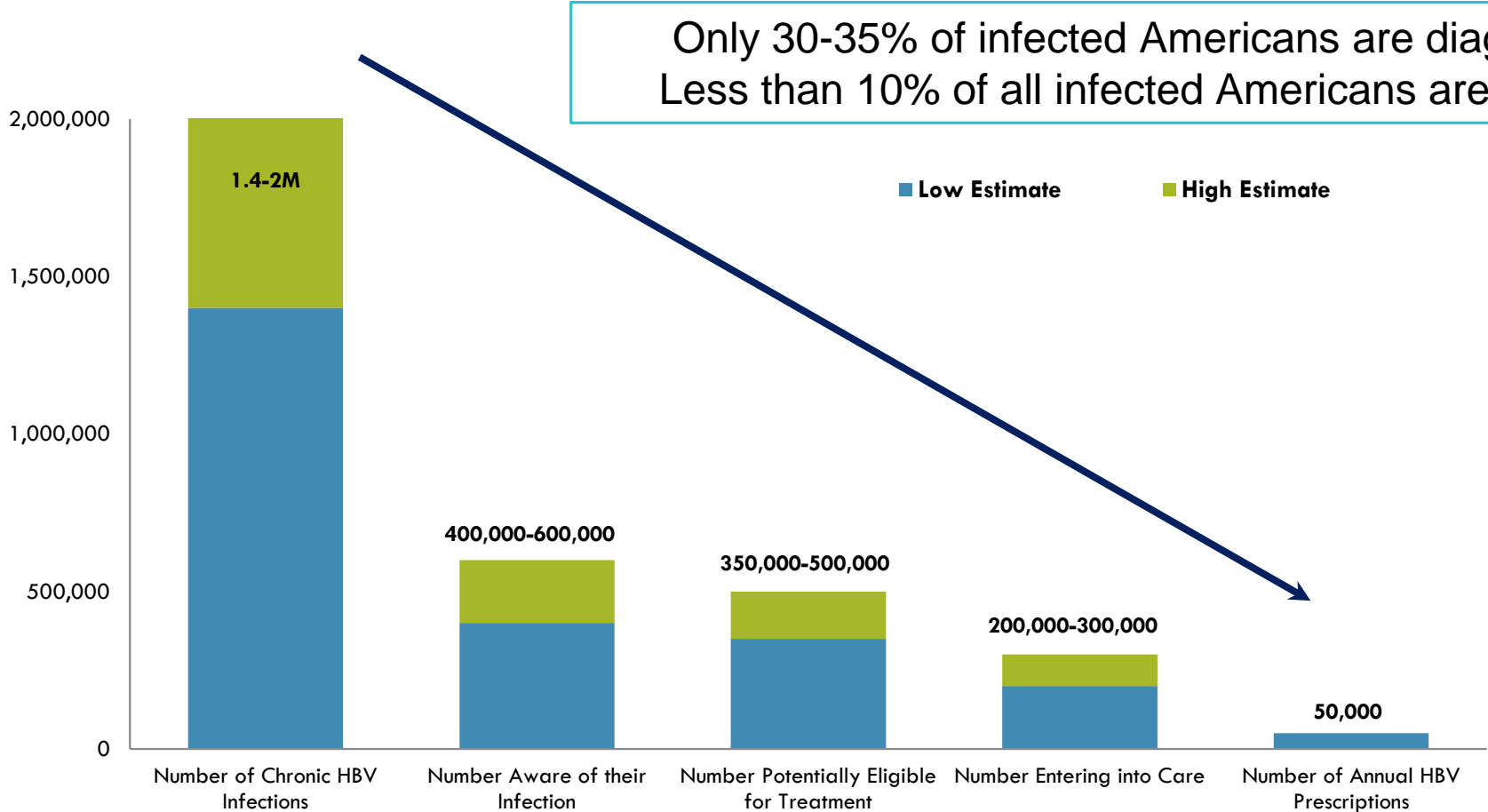
**Only 10% can access care or treatment**

## Hepatitis B in the U.S.

- Very few people are screened and most don't know they are infected
- Among those diagnosed, less than 50% access sustainable care and 20% receive prescription medication
- Hepatitis B screening is NOT routinely conducted among most health care systems in the U.S.
- Only 25% of adults in the U.S. are vaccinated, and there are challenges to hepatitis B vaccine access



# HBV Care Cascade



# Patient-Related Barriers to Hepatitis B Screening & Care

## Society

- Discrimination laws (in China and U.S.)
- Shared experiences of stigma/discrimination
- Immigration policies (health insurance)
- Poverty

## Community

- Proximity to doctor
- Access to appropriate and accessible health care systems (community clinic with language capacity)
- Transportation options

## Organizational

- Worksite employee policies (hepatitis B-related, time off)
- Clinical policies of physicians/hospital (HBV screening)

## Interpersonal (Doctor/Patient)

- Lack of shared language between doctor/patient
- Limited communication
- Lack of trust between doctor patient

## Individual

- ✧ Limited English proficiency
- ✧ Lack of health insurance or under-insurance
- ✧ Fear of stigma/discrimination
- ✧ Inability to navigate the health system
- ✧ Fear of severity of HBV outcomes
- ✧ Time (shift-work, lack of benefit)
- ✧ Low health literacy
- ✧ Belief that HBV is fatal
- ✧ Perception of feeling well
- ✧ Low HBV-related knowledge
- ✧ Lack of belief in preventive care
- ✧ Fear of change in immigration status
- ✧ Low income
- ✧ Low education level
- ✧ Fear of burdening family
- ✧ Trust in physician



# Physician-Related Barriers to HBV Screening

## Organizational Factors

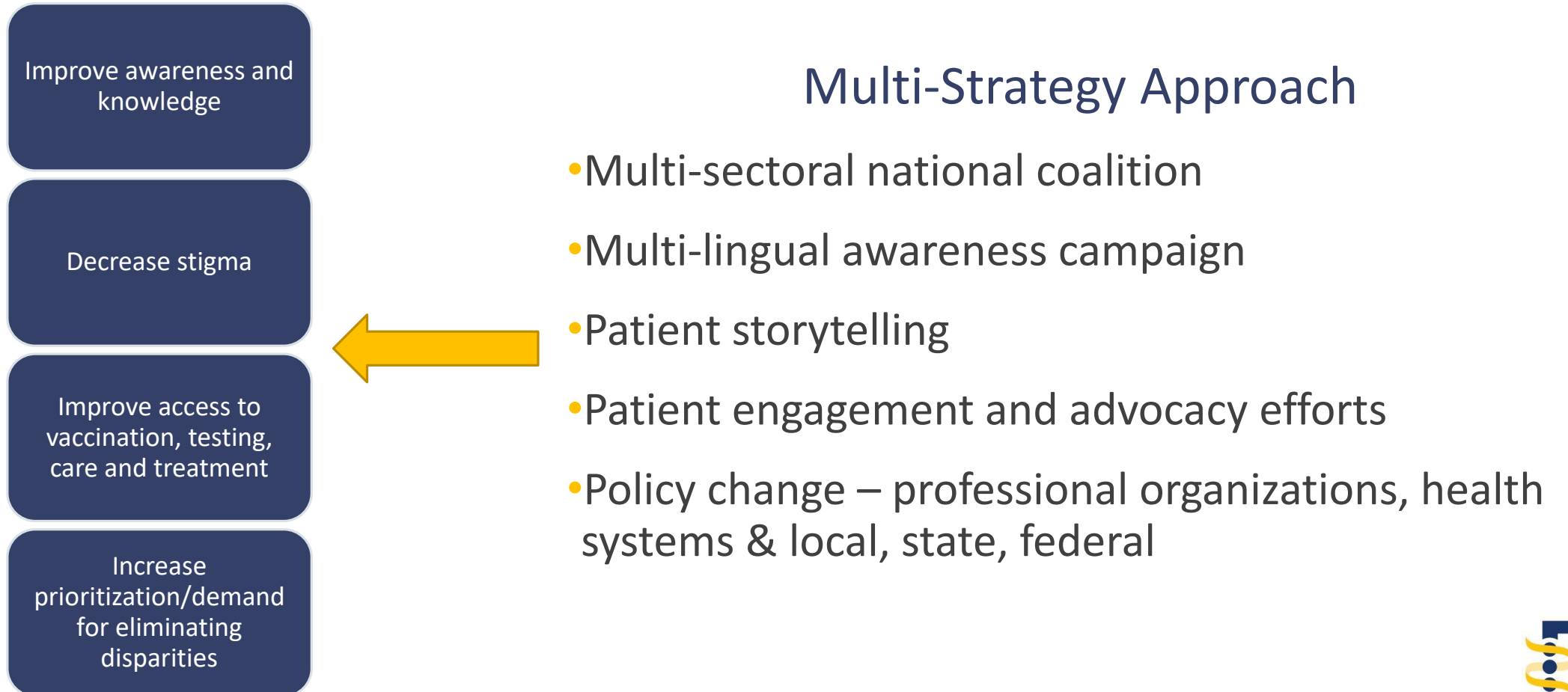
- Physical practice environment (private practice vs. university hospital)
- Dissemination of major screening recommendations by CDC & USPSTF
- Policy endorsements from professional organizations
- Inclusion of HBV screening in professional clinical outcomes assessment
- Organizational culture/climate/attitude re: HBV testing (among physicians' practice setting)

## Social Factors

- Perceived severity of the problem
- HBV-related knowledge (prevalence, risk groups)
- HBV-testing knowledge (test ordering; test interpretation)
- Physician-patient communication
- Perception of patients' ability to understand test results
- Perception of patients' ability to afford treatment
- Access to/knowledge of HBV screening guidelines
- Ethnicity
- shared language with patient
- Vaccination behaviors
- perceptions re: reimbursement for testing
- Social learning/role modeling of colleagues
- Access to educational sessions/conferences/seminars/CMEs



# Strategies for Overcoming Barriers to Improve Screening and Care and Reduce Disparities





[hepbunited.org](http://hepbunited.org)



# Multi-sectoral Community Coalition: Hep B United

40+ local coalitions & national organizations in 20 states

**Mission** - Hep B United is a national coalition dedicated to reducing the health disparities associated with hepatitis B by increasing awareness, screening, vaccination, and linkage to care for high-risk communities across the United States.





# Goals of Hep B United

## Awareness

Raise the profile of hepatitis B and liver cancer as an urgent public health priority.

## Prevention

Increase hepatitis B testing and vaccination, particularly among AAPIs and other communities at higher risk.

## Intervention

Improve access to care and treatment for individuals living with hepatitis B to prevent end-stage liver disease and liver cancer.







# Asian American and Pacific Islander Populations Served\*

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Chinese

Korean

Vietnamese

Cambodian

Thai

Laotian

Burmese

Hmong

Karen

Chuukese

Marshallese

Tongan

Mongolian

Nepalese

*\*2017 HBU Coalition Survey*





# Local Hepatitis B Coalitions

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Arizona

California

Colorado

District of Columbia

Delaware

Georgia

Hawaii

Illinois

Maryland

Minnesota

Michigan

Mississippi

Nevada

New Jersey

New York

Ohio

Pennsylvania

Texas

Virginia

Washington



# Capacity Building, Training, Support

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Mini-grants



Training, capacity building, technical assistance



Peer Mentorship



Monthly webinars



Monthly coalition calls



National HBU Summit



Collaborative opportunities



# Hep B United Impact



HBV Education: >72,000 hepatitis B education sessions



HBV Screening: >20,000 screened each year



Mini-Grants: \$361,000 awarded to 24 coalitions in 18 states



Peer Mentoring: 15 organizations matched -- 6 new hepatitis B coalitions formed



Training Webinars: reached nearly 4,000 live and >25,000 online views

Annual Summit: agenda led by local  
community partners

2012 summit – 15 founding partners  
2019 summit - >100 attendees



Know Hepatitis B Campaign

>5,000 resources disseminated to HBU partners  
PSAs and materials - >461 million impressions



#justB Storytelling Campaign  
Partnership

15 HBU community awareness events --> 500  
educated

# Multi-lingual Awareness Campaign: Know Hepatitis B



[CDC.GOV/KNOWHEPATITISB](https://www.cdc.gov/knowhepatitisb)

- Launched in 2013: Increase awareness and promote testing primarily among non-English speaking AAPIs, primarily age 40-55
- Primarily Korean, Vietnamese, Chinese – but additional languages have been added
- Print, digital and audio-visual components
- Launched in 4 phases, with message testing for all materials in key cities
- Dissemination strategy through Hep B United – HBU partners assist with tailoring materials based on need, and use of materials in online messaging and at community events, distribute direct to community
- Paid and donated space on time on ethnic news websites, TV and radio spots in key cities – millions of impressions and thousands of viewings
- Direct distribution of thousands of materials



# Know Hepatitis B Resources

Posters, Infographics, Flyers, Quizzes



**What is the Hepatitis B vaccine?**  
For most people, the vaccine is usually given as three shots over six months. People should get all three shots to keep them from getting Hepatitis B.

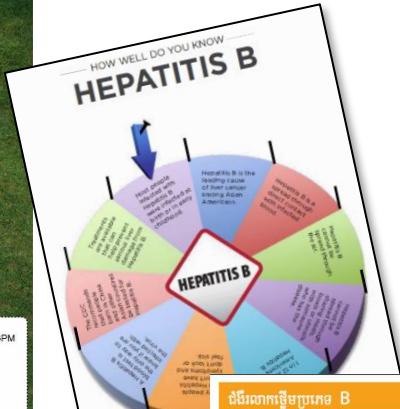
Keep track of your vaccine series:

<input type="checkbox"/> Dose 1	<input type="checkbox"/> Dose 2	<input type="checkbox"/> Dose 3
Date: _____	Date: _____	Date: _____
Next shot is in _____ months	Next shot is in _____ months	

**A health screening for you puts your family first.**

Health checkup information.

Sunday, May 03, 2014 | 10AM-3PM  
Sponsoring Organization Name  
100 Main Street, | City, State  
Call (123) 456-7899 for more info.



**Hepatitis B** is the leading cause of liver cancer for Asian Americans. Come get tested for Hepatitis B. It could save your life.

**NO HEPATITIS B**  
HepB United

Sunday, May 19, 2014 | 10AM – 3PM  
Sponsoring Organization Name  
100 Main Street, | City, State  
Call (000) 999-9999 for more information

Resources include: "1 in 12 Asian Americans have Hepatitis B?", "VIÊM GAN SIÊU VI B", "乙型肝炎", "接受乙型肝炎检查", "A Lesson on Hepatitis B That Could Save Your Life", "HEPATITIS B BLOOD TEST", "Testing Asian Americans and Pacific Islanders for Hepatitis B".

**KAB MOB SIAB B**  
Thaum Lee Twg haux yv Tsev Neeg maj Kab mob siab B

**乙肝**  
如果家人得了乙肝

乙肝有什么症状?  
乙肝如何传播?  
乙肝疫苗为什么重要?

**B형 간염에 걸릴 위험이 있습니까?**  
병을 완쾌할 것인 것일 수 있습니까?

**အသုံးပြုဆောင်ရွက်သည့် အားကိုး ဝါး။**  
သန့်ရှင်းစေရန် ချိတ်သည့်အားကိုး

**ພະຍາດຕັບອັກເສບ ປີ**  
ເປັນໄປສະນະທີ່ໂກດລາຍດີເພີ່ມຂຶ້ນຂອງ ສາຍເສັ້ນ ປີ

**VIÊM GAN SIÊU VI B**  
có nguy cơ mắc bệnh không?

**接受乙型肝炎检查**  
能够救您一命

什么是乙型肝炎?  
您知道吗?

接受乙型肝炎检查 能够救您一命

什么是乙型肝炎?  
您知道吗?





# Raising Awareness, Combating Stigma, and Empowering Patients: #justB

#justB is national, multi-lingual, digital storytelling campaign that aims to:



- Increase **awareness** and **advocacy** around hepatitis B
- Decrease **stigma** and **discrimination** associated with the disease
- Promote **testing**, **vaccination**, **linkage to care**, and **treatment**
- **Empower** people living with hepatitis B to share their stories to help educate the public and inspire action

STORY  
CENTER





# #justB Campaign Progress and Activities



- Coordinated **5 workshops** in 2017-2019 for **40 participants** and produced **40 digital stories**
  - **18 translated** – Mandarin, Cantonese, Vietnamese, Korean, Arabic, Twi, Yoruba, Tagalog, Khmer, Mongolian, and Chuukese
- Launched website for #justB stories and accompanying resources: [www.hepb.org/justb](http://www.hepb.org/justb)
- 2.4 million views, drove 24,000 people directly to [www.hepb.org](http://www.hepb.org)
- Continued engagement: storytelling/public speaking opportunities and ongoing training/support
- Program evaluation: impact on storytellers and audience





# Patient Advocacy

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## Grassroots Advocacy

- Constituent letter-writing campaigns
- Fly-In's - bring patients to Congressional visits, briefings, provide testimony (i.e. ACIP); Annual Hep B United Advocacy Day

## Legislative Advocacy

- Congressional Hepatitis Caucus
- Hepatitis Funding/Appropriations
- Hepatitis and Liver Cancer Legislation

## Administrative Advocacy

- Proposed regulations
- USPSTF Hepatitis B Recommendations
- National Viral Hepatitis Action Plan

Dear Kate,

Although Members of Congress are very focused right now on addressing the COVID-19 crisis in the U.S. and around the world, their regular appropriations bills are still moving through the process as required each year. Allocating federal resources to respond to the COVID-19 outbreak is critical at this time and of top priority, but at the same time, it remains important for advocates to continue pushing for longer-term program funding to address the ongoing viral hepatitis epidemic in our country.

## Help Stop Insurers from Over-Charging Patients for Hepatitis B Drugs on the Healthcare Marketplace

March 30, 2016 | hepbtalk



**By Christine Kukka**

For years, people with pre-existing conditions like chronic hepatitis B struggled to get health insurance. News stories and Michael Moore's documentary *Sicko* highlighted insurance companies' refusal to cover pre-existing conditions and their practice of inflating premium prices if consumers had chronic health problems.

## Policy Change

- **Addressing Adverse Drug Tiering** of Hepatitis B Treatments
- **Increasing HBV Screening and Improving Guidelines** – integrating into health systems, weighing in on USPSTF recommendations, changing chronic HBV definition
- **Increasing Adult Hepatitis B Vaccination Coverage**
- **Combatting HBV-Related Discrimination** and Legal Advocacy

# Combating HBV-Related Discrimination

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- Medical, Dental, and Other Healthcare-Related School Policies
  - Student living with hepatitis B applies to medical school and comes across admissions policy asking for proof of hepatitis B immunity for enrollment and/or stating admission could be revoked if a persons tests positive for hepatitis B infection.

- U.S. Armed Services / Department of Defense Policies

- Service member living with hepatitis B faces a medical evaluation board, limited deployment status

**Title VI of the Civil Rights Act** “No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”<sup>26</sup> Title VI of the Civil Right Act is relevant given the disparate effect of hepatitis B infection on some US populations, including Asian American, Pacific Islander, and African immigrant communities.

**Hepatitis  
and Sect**





# Patient Engagement

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Goal: Document the lived experience from patients and caregivers

Strategies: Focus groups, in-depth interviews, online survey, externally led PFDD meeting

What is the impact of living with hepatitis B on the lives of this chronically infected; how can we improve clinical trial participation; what do patients prioritize in terms of treatment; how can we include patient reported outcomes into future HBV treatment regimens and clinical trials?

- Physical, emotional, professional and social impact
- Experiences with stigma and discrimination
- Treatment experiences and thoughts on future/ideal treatment
- Beliefs on clinical trial participation and thoughts on how to improve participation





The [Hepatitis B Foundation](https://www.hepb.org) is a national nonprofit organization dedicated to finding a cure and improving the quality of life for those affected by hepatitis B worldwide.

- **Hepatitis B Foundation**
  - Outreach and Education
  - Patient and Provider consultation
  - Multi-lingual resources and website [www.hepb.org](https://www.hepb.org)
  - Public Health Research
  - National Advocacy
  - PA Biotechnology Center and Biotech Incubator
- **Baruch S Blumberg Research Institute**
  - Biomedical Research – drug discovery and early detection methods for cirrhosis and HCC





*“We were left to connect the dots because the medical profession is failing to address an epidemic that kills more than 700,000 people a year. It’s also ignored by Asian cultures that consider talk about deadly diseases a taboo. Sometimes I wonder if hepatitis B is being ignored here in the U.S. just because it impacts so many Asians, especially given the country’s history of discrimination toward immigrants.”*

- Alan





Thank You!



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