

# Patients Driving Change: Storytelling and Advocacy

B Informed Patient Conference | June 8, 2019





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

Our commitment includes funding focused research, promoting disease awareness, supporting immunization and treatment initiatives, and serving as the primary source of information for patients and their families, the medical and scientific community, and the general public.



[Hep B United](#) is a national coalition established and co-chaired by the Hepatitis B Foundation and the Association of Asian Pacific Community Health Organizations (AAPCHO). It is comprised of more than 40 organizations in 19 states.

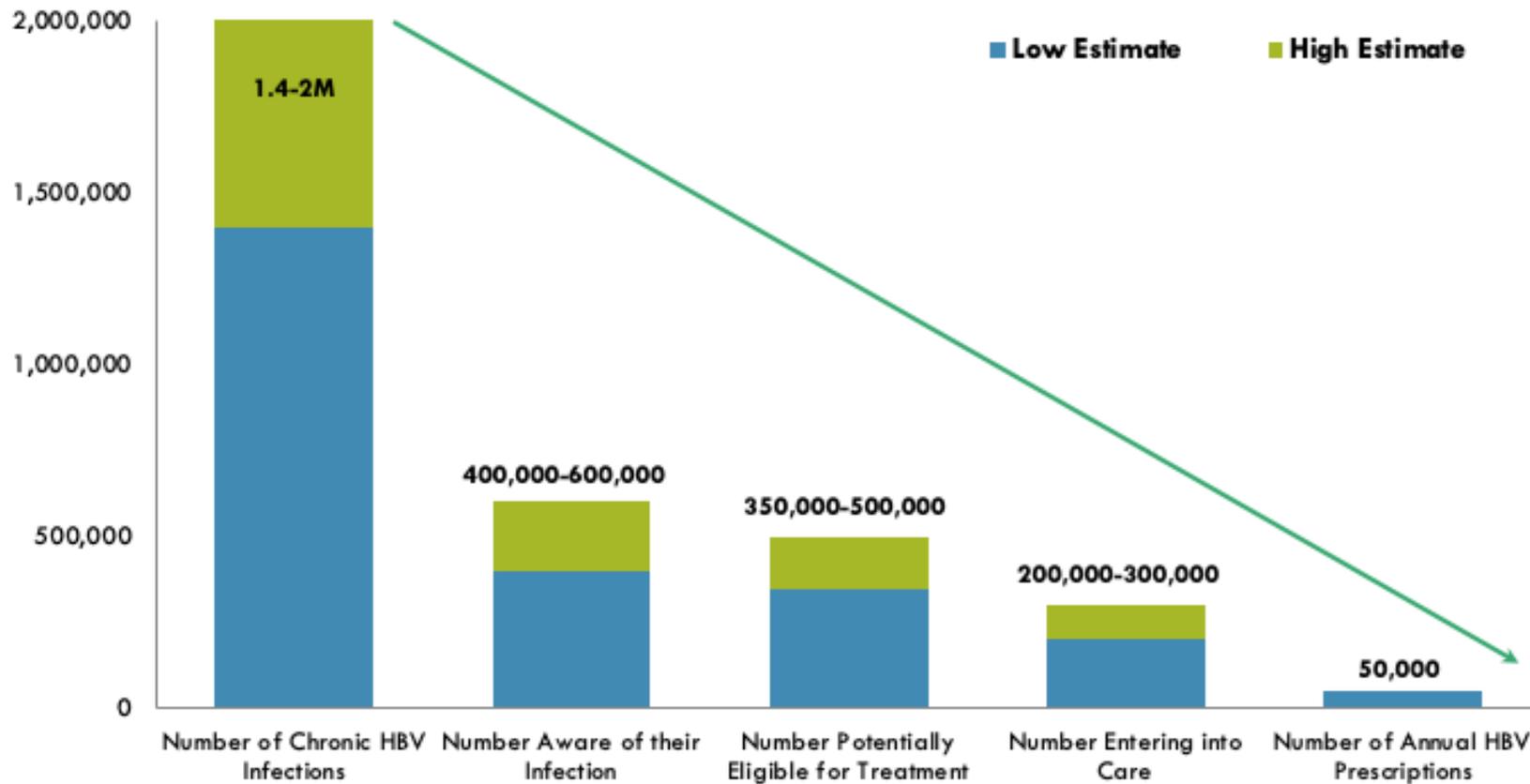
The coalition is dedicated to reducing the health disparities associated with hepatitis B by increasing awareness, screening, vaccination, and linkage to care for high-risk communities across the United States.

# The Landscape of Hepatitis B in the U.S.

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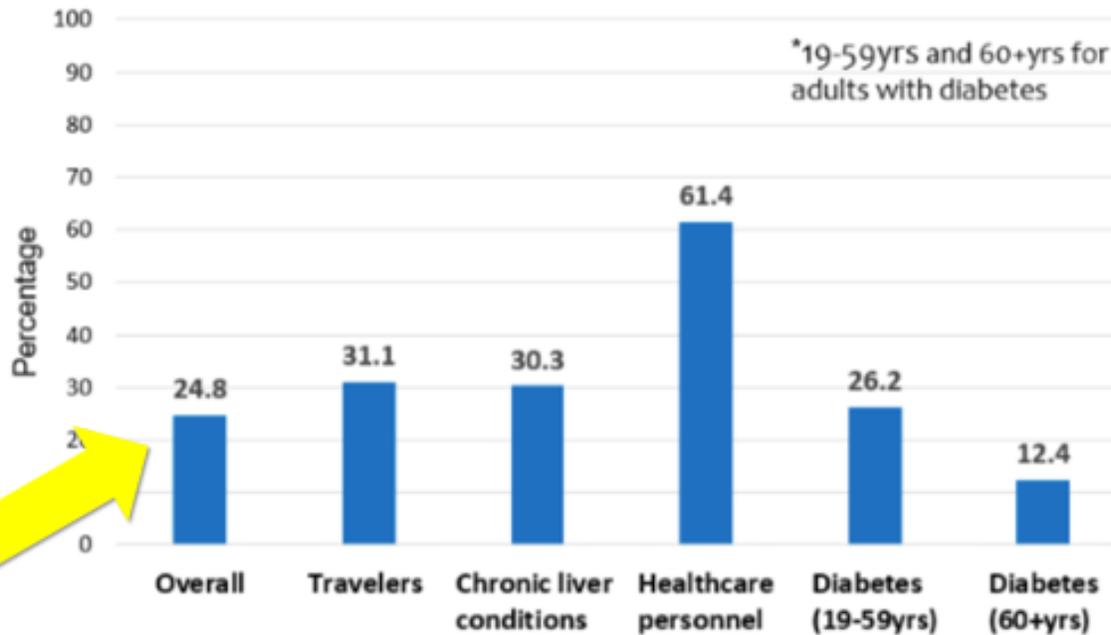
# The State of Hepatitis B in the U.S.

Only 30-35% of infected Americans are diagnosed  
Less than 10% of all infected Americans are treated



# Most Adults Are Not Vaccinated!

**Hepatitis B Vaccine Coverage (≥3 doses)  
Among Adults Aged ≥19 years\* in the U.S. - NHIS 2016**



National Foundation for Infectious Diseases

- Universal infant vaccination program in 1991
- Requirements for healthcare workers
- Most of U.S. population is unvaccinated (75.2%)
- Opportunities for transmission and spread of disease
- Complications with coinfections; HCV and HIV

# NEW Cases of Hepatitis B are Rising

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**20%**

**Rise in Acute HBV  
Cases in the U.S.  
in 2015**



# Key Challenges/Barriers to Hepatitis B Elimination

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No cure, **BUT** we have highly effective vaccines and treatments

- **Lack of awareness** and education about hepatitis B among the general public, health care providers, and **policy makers**
- Hepatitis B prevention and research is **under-prioritized and under-funded**
- People living with hepatitis B face **stigma and discrimination**

# Hep B Advocacy



# What “Advocacy” Means to Us

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*“Advocacy begins when someone says ‘No’.”*



- ❑ *Championing our cause*
- ❑ *Giving people a voice*
- ❑ *Building relationships*

*(Borrowed from Caring Ambassadors Grassroots Advocacy Toolkit)*

# Hep B Advocacy Priorities

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Increase funding for hepatitis B surveillance and prevention programs



Increase funding for hepatitis B and liver cancer research to find a cure



Improve adult hepatitis B vaccination coverage



Improve access to treatment for people living with hepatitis B

Hepatitis B prevention and research is **under-prioritized and under-funded**

**Hep B Advocacy Priority:**



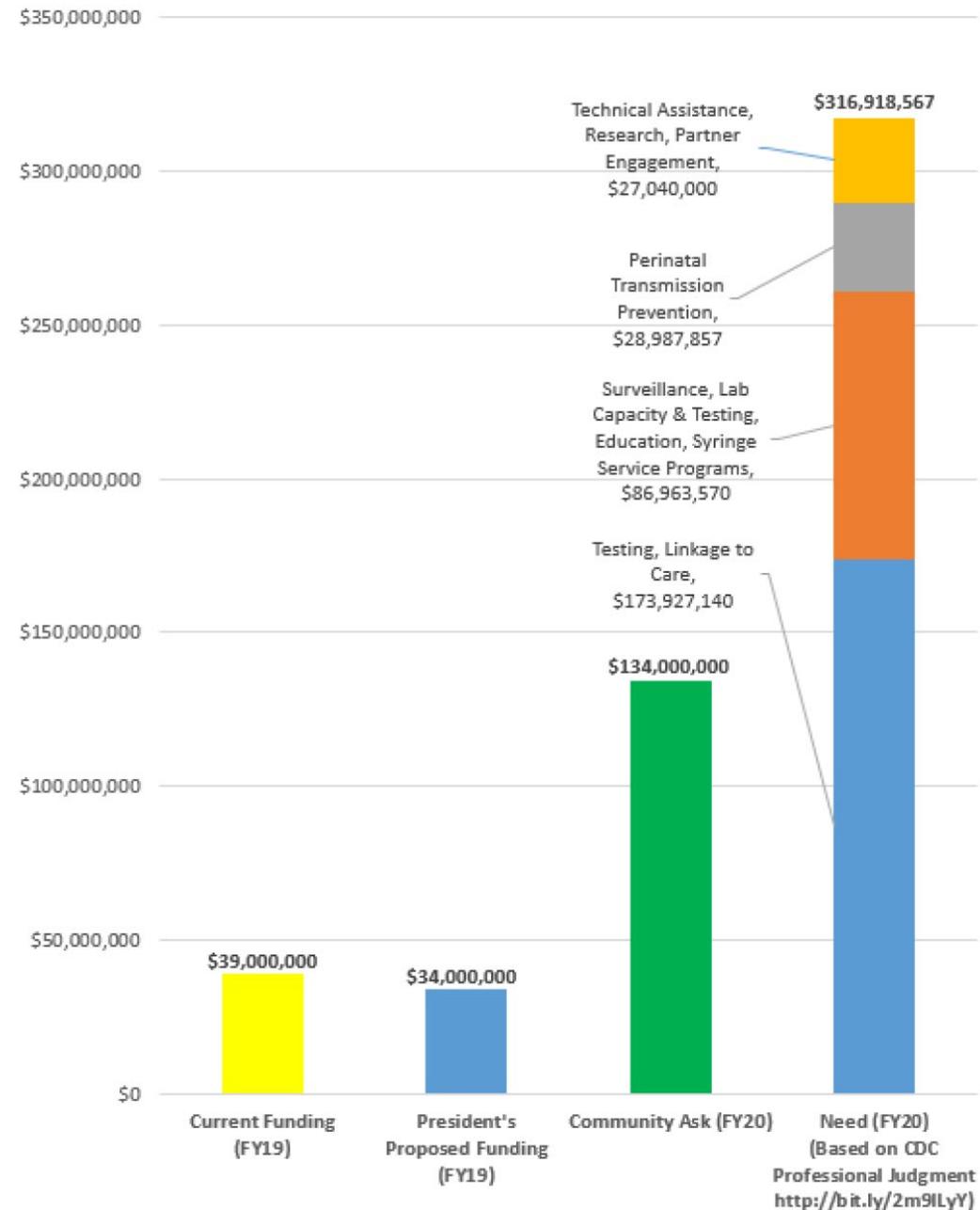
Increase funding for hepatitis B surveillance and prevention programs

# Centers for Disease Control and Prevention (CDC)

- Current Funding Level: **\$39 million**
- FY20 asks:
  - **\$134 million** (+\$95 million increase)
  - **\$40 million** to fully fund a recently passed program to eliminate opioid-related infectious diseases

## CDC - Division of Viral Hepatitis

Current Funding vs. Need



Hepatitis B prevention and research is **under-prioritized and under-funded**

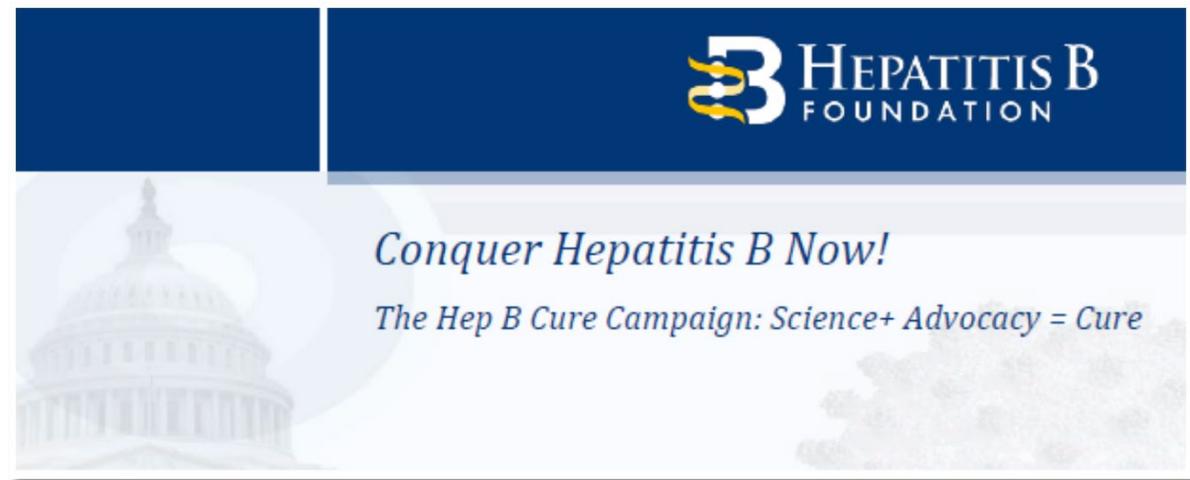
**Hep B Advocacy Priority:**



Increase funding for hepatitis B and liver cancer research to find a cure

# National Institutes of Health (NIH)

- Current Funding Level: **\$39.1 billion**
- FY20 asks:
  - Increase overall, and for the National Cancer Institute (NCI)
  - Increase HBV research funding by **\$38.7 million** (per year for 6 years)
  - **Report language:** prioritization of HBV and liver cancer; targeted calls for research proposals



<http://www.hepb.org/research-and-programs/roadmap-to-a-cure/>



# H.R. 3016

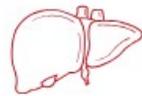
A bill introduced on May 23, 2019 by  
Congresswoman Nydia Velazquez (NY-7)

- 9 co-sponsors - **we need more Members of Congress to support!**

**What does this bill do? \$\$\$ for....**

- **CDC** – create new programs for liver cancer awareness and prevention activities, such as screenings, vaccination, and treatment for liver cancer, hepatitis B and hepatitis C
- **NIH** – increase research on liver cancer and hepatitis B

Ask your Congress member  
to be a co-sponsor today!



## **LIVER ACT OF 2019**

TO PRIORITIZE LIVER CANCER AND LIVER  
DISEASE RESEARCH



**Lack of awareness** and education about hepatitis B among the general public, health care providers, and **policy makers**

**Hep B Advocacy Priority:**



Improve adult hepatitis B vaccination coverage



# National Adult Hepatitis B Vaccination Awareness Day



## H.Res. 331 / S. Res. 177

Resolutions introduced on April 30, 2019  
by Congresswoman Grace Meng,  
Congressman Hank Johnson, Senator  
Mazie Hirono (HI), and Senator Angus King  
(ME)

- 10 co-sponsors - [we need more Members of Congress to support!](#)

**What do these resolutions do?**

**Increase awareness about  
hepatitis B prevention!**

People living with hepatitis B face **stigma and discrimination**

### **Hep B Advocacy Priority:**



Improve access to treatment for people living with hepatitis B

# Combating HBV-Related Discrimination

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- Medical, Dental, and Other Healthcare-Related School Policies
- U.S. Armed Services / Department of Defense Policies
  - “Deploy or Discharge”
- **Adverse Drug Tiering**

**Hepatitis B is a protected condition under the Americans with Disabilities Act and Section 1557, the non-discrimination provision of the Affordable Care Act.**

Under the ACA, qualified health plans sold through federally-facilitated health insurance marketplaces must not employ market practices or benefit designs that will have the effect of discouraging the enrollment of individuals with significant health needs.

**RECOGNIZE THE INTERSECTION OF**

- **HEPATITIS B HEALTH DISPARITY**
- **DISABILITY DISCRIMINATION**
- **OUTDATED, UNSCIENTIFIC HBV POLICIES THAT HAVE A DISPROPORTIONATE AND UNJUSTIFIED EFFECT ON PERSONS OF A PARTICULAR RACE, COLOR, OR NATIONAL ORIGIN, I.E., DISCRIMINATION UNDER TITLE VI**

**TAKE ACTION TO END SYSTEMIC DENIAL OF SCHOLARSHIP AND CAREER OPPORTUNITIES**



**for accomplished graduates, healthcare and public health students, and aspiring military college appointees living with chronic hepatitis B**

**End HBV Discrimination by the U.S. Uniformed Services**

**ARMY \* AIR FORCE \* NAVY \* MARINES**

**(includes the NATIONAL GUARD AND RESERVES)**

**PUBLIC HEALTH SVC \* COAST GUARD**

**NATL OCEANIC & ATMOSPHERIC ADMIN**

Nadine Shiroma, Hepatitis B Foundation Policy Advisor



Hepatitis B Advocacy, Hepatitis B Treatment, Living with Hepatitis B

## 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.

<http://www.hepb.org/blog/>

Advocacy  
Strategies and  
Opportunities to  
Get Involved!

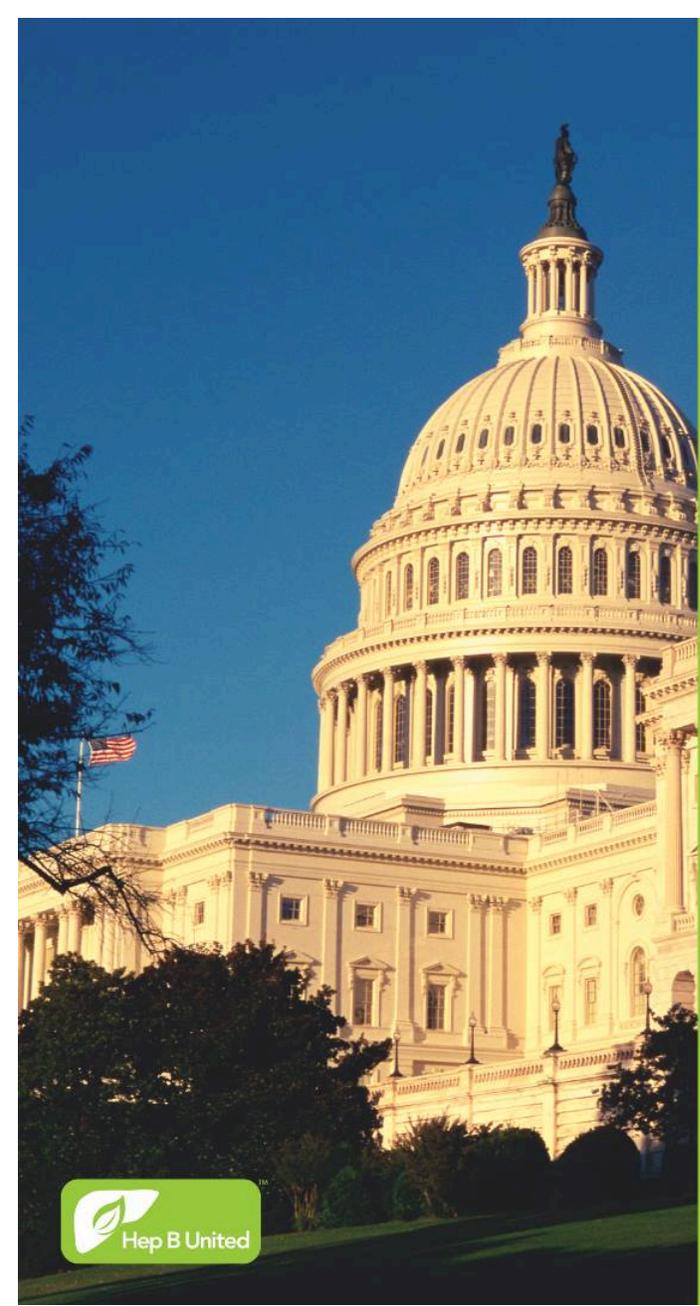


# Examples of Advocacy Strategies

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- Hill Visits / Advocacy Days (meet with Members of Congress and/or staff)
- Agency / Admin Meetings (meet with government agency leadership and/or staff)
- Congressional Briefings
- Congressional Sign-on Letters (“Dear Colleague” Letters)
- Organizational Sign-on Letters
- Coalitions
- **Grassroots and Digital Advocacy**



JOIN OUR ACTION  
ALERTS TO HELP US  
TAKE ACTION!

**ADVOCACY  
IS  
THE KEY  
TO CHANGE !**



[www.hepbunited.org/  
advocacy/action-center](http://www.hepbunited.org/advocacy/action-center)



# Grassroots and Digital Advocacy

- Help with education/outreach to new Members of Congress in 2019 – send emails/messages, set up meetings, build relationships with staff
- Share personal stories, local data, and helpful resources with your representatives
- Invite policymakers (federal, state, local) to see your organization in action – site visits, screenings, community events, receptions
- Attend town hall meetings
- Write a letter to the editor or op-ed
- Utilize social media
- **Sign up for the Hep B Action Center!**

# Hep B Action Center

<http://www.hepbunited.org/advocacy/action-center/>



**Become a Hep B Advocate!** Sign up below to receive the latest news and updates about hep 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 hep B policy issues
- Recruit and organize other hep B advocates and champions in your community
- Promote and participate in ongoing national, state, and local advocacy efforts

First Name\*  Last Name\*

Email Address\*

Country\*

City\*  State\*  Zip Code\*

Organization/Affiliation  Title/Occupation

How did you hear about the Hep B United Action Center?

Sign me up to receive policy and advocacy news/updates from Hep B United!

[Sign Up](#)

# Sample Action Alert

<http://www.hepbunited.org/advocacy/action-center/alerts/>

## Ask your Representative to support the LIVER Act

Help raise awareness about liver cancer and increase support for the LIVER Act by sending a message to your U.S. House Representative and asking them to become a co-sponsor of the bill. **Fill out the brief form below and use the template provided to email your Representative today!** Feel free to customize your message by including details about the impact of hepatitis B and liver cancer in your community or including a brief personal story about why this bill is important to you. *Note: If your Member of Congress is already a sponsor/co-sponsor, you will see a different template message thanking them for their support.*

## Email Your Representative Today!

First Name\*

Last Name\*

Email Address\*

Address, line 1\*

City\*

State\*

Choose one...

Zip Code\*

I'd like to continue receiving policy and advocacy updates from Hep B United.

Take Action

This email will be delivered to 1 recipient:



**Rep. Kay N. Mullendore  
Granger**  
R - US Representative  
(202) 225-5071

**Subject:** Please Support the LIVER Act of 2018 (H.R. 7063)

**Message:**

I am writing to express my support for H.R. 7063, the Liver Illness, Visibility, Education, and Research (LIVER) Act of 2018, and ask you to sign on as a co-sponsor of this bill. Introduced by Congresswoman Nydia Velazquez, the bill calls for increased prioritization and investments in research, prevention, and awareness activities to address liver cancer and its major risk factors, including hepatitis B.

Liver cancer is the second deadliest cancer in the United States and worldwide. In 2018, approximately 42,220 people in the United States will be diagnosed with primary liver cancer, and approximately 30,200 will die from the disease. While the overall cancer death rate has decreased recently, the liver cancer death rate is on the rise. With increased research and improved methods of early detection, prevention, and treatment, we can reverse this trend. In fact, vaccinations and improved treatments for hepatitis could prevent about half of liver cancer cases worldwide.

Raising awareness about prevention and treatment of hepatitis B (HBV) and hepatitis C (HCV) and their link to liver cancer is also critical. Despite the availability of a safe and

Remaining: 780

The targets for this email are asking for a couple more pieces of information:

Title\*

Please Select

Would you like a response?\*

Yes

# #JustB Storytelling Campaign

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# Wendy's Story: #justB Hopeful

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# Alan's Story: #justB Proactive

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# Kat's Story: #justB Knowledgeable

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# 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



# Campaign Progress and Activities

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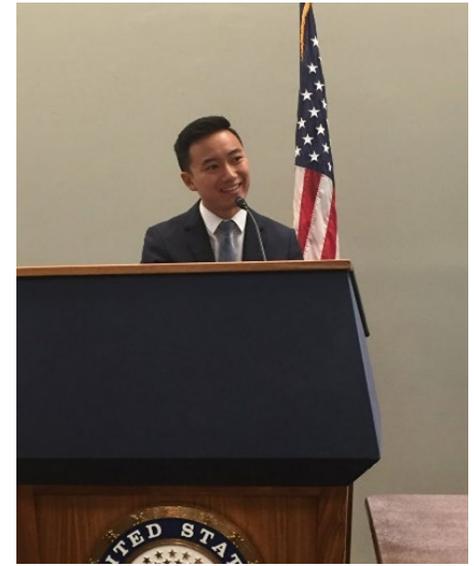


- Coordinated **5 workshops** in 2017-2019 for **36 participants**
- Produced **36 digital stories**
  - **18 translated stories** – languages include Mandarin, Cantonese, Vietnamese, Korean, Arabic, Twi, Yoruba, Tagalog, Khmer, Mongolian, and Chuukese
- Launched website for #justB stories and accompanying resources: [www.hepb.org/justb](http://www.hepb.org/justb)
- Continued engagement: storytelling/public speaking opportunities and ongoing training/support
- Program evaluation: impact on storytellers and audience

# Story Distribution

- Monthly featured story: websites, newsletters, social media, ads
- Media outreach: press releases, interviews, blogs, local news, ethnic media
- Printed materials: postcards, posters
- Advocacy events: issue briefings, Congressional meetings, Hill days
- HBV testing and awareness/outreach events
- Conference presentations/exhibits
- Local story screening events
- Film festivals





# Jason's Story: #justB Aware

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Thank You!



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