



**Stories by People Living With and Affected by Hepatitis B,
to Challenge Stigma, Support Education, and Advocate for Care**

Discussion Guide

*Produced by:
The Hepatitis B Storytelling Project,
a collaboration of the Hepatitis B Foundation and StoryCenter*

April 2017
Updated January 2020



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Acknowledgements

The *#justB* digital stories were created through a partnership of the Hepatitis B Foundation (HBF), Association of Asian Pacific Community Health Organizations (AAPCHO), and StoryCenter.

Thank you to individual donors, Arbutus Biopharma, Dynavax Technologies, Gilead Sciences, and Janssen Pharmaceuticals for providing unrestricted educational grants that made this project possible.

Our special thanks go to the storytellers whose work is featured online and in this guide. Their openness to documenting their lives puts them at the forefront of global public health promotion. In order to respect their privacy online, they are noted in the digital stories and in this guide by first names only.

Thanks as well to the fantastic digital storytelling workshop co-facilitators Orchid Pusey, Anand Kalra, and Jacqueline Sofia, and to Joe Kye, who composed original scores for many of the stories.

Finally, thank you to Amy Hill at StoryCenter, who led the digital storytelling workshops and co-authored this guide; Radhika Agarwal, who contributed to the guide; Chari Cohen, Rhea Racho, Catherine Freeland, Kate Moraras, Sierra Pellechio, and Joan Block with HBF, who coordinated the workshops and provided important content to the guide; and Ashley M. Biggers, who provided editorial support and design services.

About the Project

For many years, the HBF has been advocating for people living with hepatitis B, but because of stigma, the patient voice has largely been missing. In 2016, the board and staff made it a priority to find ways to showcase the voices of those impacted by hepatitis B. After attending an informational webinar on digital storytelling facilitated by StoryCenter, HBF, and AAPCHO, staff were struck by the genuine honesty and impact of the digital storytelling process. They developed an outreach, education, and advocacy project focused on the personal stories of people living with and affected by hepatitis B. In collaboration with StoryCenter, HBF conducted outreach through its partner networks across the United States and identified people interested in sharing their stories. The partner organizations have organized digital storytelling workshops in Berkeley, California; Doylestown, Pennsylvania; and Washington, D.C., to support these courageous women and men in sharing their stories and producing them as short videos.

The stories are now being shown online to a national and international audience and at events around the country, to raise awareness about hepatitis B, educate audiences about screening and prevention, and advocate for increased attention to the virus within the health professions and broader medical community. The storytellers shared their experiences with hepatitis B in the hopes that they would inspire others to do the same. The stories that are a part of this project mobilize individuals and communities to reduce stigma and eliminate common misconceptions associated with hepatitis B. Visit the project online at www.hepb.org/justB, and join the conversation through social media using the hashtag #justB.

Hepatitis B Foundation

The Hepatitis B Foundation (based in Doylestown, Pennsylvania) is a national nonprofit organization dedicated to finding a cure and improving the lives of those affected by hepatitis B worldwide. HBF's 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. Today, the Hepatitis B Foundation has become a leading authority in the areas of outreach, public health, and patient advocacy. More information: www.hepb.org

StoryCenter

StoryCenter (based in Berkeley, California) uses innovative storytelling and story listening methods to create healthier individuals and communities and a more just world. Since 1993, StoryCenter has enabled thousands of people from all walks of life to share their experiences and craft short, first-person videos. StoryCenter's digital storytelling methodology combines oral history, group process, and participatory media methods in a workshop format. Stories and videos produced through our partnerships amplify voices often ignored by mainstream and online media outlets, engage audiences in learning and making a difference, and lend honesty and dignity to civic dialogues and advocacy efforts at local, national, and international levels. More information: www.storycenter.org

AAPCHO

The Association of Asian Pacific Community Health Organizations (AAPCHO) was formed in 1987 to create a national voice to advocate for the unique and diverse health needs of Asian American, Native Hawaiian and Pacific Islander (AA&NHPI) communities and the health providers that served their needs. AAPCHO is dedicated to promoting advocacy, collaboration, and leadership that improves the health status and access of AA&NHPIs. More information: www.aapcho.org

Terms of Use

These stories were created by and for people living with and affected by hepatitis B. HBF, AAPCHO and StoryCenter are sharing them to provide information and raise awareness about hepatitis B issues in the United States and globally. We invite you to share the stories, as long as you follow the instructions presented in this guide. Please refrain from screening or selling stories for commercial gain. Please also be sure to acknowledge the [Hepatitis B Foundation](#) and [StoryCenter](#) as the producers of these materials.

Guidelines for Presenters

People often underestimate the degree of the emotional response viewers may have to digital stories, which at their best are honest expressions of real peoples' experiences. Please review these guidelines before sharing the #justB stories, so that you are adequately prepared to lead discussions that do not inadvertently trigger viewers or cause them to shut down. Prepared presenters will be able to give viewers the opportunity to be heard, to learn, and to identify actions they can take to promote hepatitis B awareness.

Before Your Screening Event ...

Know when and where NOT to show stories

The sensitive nature of the stories demands that they be shared in closed, structured settings where an audience's attention can be captured fully and where healthy discussions can emerge. They should not be shown at large, unstructured community events, where follow up conversations are not possible, and they are not intended for viewing by people under age 12.

Make sure you are well versed on the issues

Before sharing the stories, know about current views and issues related to hepatitis B (see the Appendices to this guide, for links to relevant fact sheets). The more prepared you are to address challenging situations and questions, the more successful your screening will be.

Know your purpose

Think about and identify your goals and create an agenda that can meet them. Key questions to ask when planning your event: What is the call to action for your audience? How many people do you expect to attend? What are your goals for this event? For example: Are you striving for understanding and analysis, or hoping to promote behavior change or local action? Are you interested in encouraging individuals to seek health screening and hepatitis B testing services, or do you want to mobilize a larger community to get involved in advocacy?

Create an agenda

1. Introduce the stories (4–5 minutes)
2. Show the stories you've selected (we recommend sharing no more than five at one time)
3. Conclude with discussion/question and answer (20–30 minutes)
4. Encourage action (share experiences on social media, share stories online using #justB)

Plan well in advance

Be clear with people about what day your screening will take place, where to go, when to arrive, and how much time the event will take. Give advance notice about these details, and remind people about the details several times beforehand. If you plan to invite a storyteller, patient, or healthcare expert on hepatitis B, be sure to invite them well in advance, and maintain communication with them regularly until the screening has concluded.

Know your audience

The #justB stories are intended for a broad audience, including members of the general public; public health and medical workers and professionals; and local, state, and national policymakers and analysts. Try to find out as much as possible about your expected audience –whether they are attending voluntarily and what their knowledge of hepatitis B might be. The more you know, the better prepared you can be to address questions and issues that might arise.

Be aware of support services

Identify available support and advocacy services where you can refer audience members afterwards, if necessary. These might include health organizations where people can get tested for hepatitis B or find out more about treatment, counselling services, etc. Be sure to prepare a list of what's available in your area.

Know your equipment

ALWAYS test the audio/visual set-up before your event. If you're using a laptop and an LCD projector, make sure you have the right power sources, adapters, cables, and speakers, as well as a white wall or screen on which to project the stories. Make sure your sound is audible throughout the space.

When You Present Stories ...

Introduce the stories appropriately

Please be sure to explain the following points prior to showing any of the *#justB* digital stories:

- These stories were created in participatory media workshops led by StoryCenter and coordinated by the Hepatitis B Foundation.
- The workshops focused on providing a meaningful process as much as it did on producing well-crafted videos — the storytellers bonded together as groups, learned skills for photography and digital media production, and found a sense of relief and pride in speaking out about their lives.
- Every effort has been made to honor and protect the dignity of the storytellers and their loved ones in these videos. Please refrain from making judgmental or negative comments about the storytellers and their life experiences, which they have so generously shared.

Inform viewers about the subjects of the stories you're going to show

Some viewers may react strongly to the contents of particular stories, depending on their personal experiences. Offer a brief introduction prior to any screening, regarding the nature of the stories you're planning to show.

Establish an open space for discussion

- If your audience is small and/or if your space allows, make the room comfortable and relaxed by arranging chairs in a circle, taking tables out of the room, and starting with games or icebreaking activities.
- It may be helpful to involve an expert such as a healthcare professional or individual with a personal connection to hepatitis B. If you don't fill one or both of these categories, think about inviting people who do, to share and discuss their experiences. This can help bring the stories to life, address audience questions, and facilitate discussion about shifting the stigma of hepatitis B in communities nationwide.
- Provide refreshments when possible!

Set ground rules

Ask your audience for their ideas about rules that everyone can agree to, and share your own favourites, such as active listening, respect, openness, and confidentiality. This will help to set the tone of the discussions.

Try to involve everyone

Watch out for who is dominating the discussion and who is not contributing and be respectful of different reasons people may have for being quiet. Gently suggest that more talkative people allow others to participate, and invite quieter people to join in.

Vary your presentation and discussion methods

Be sure to offer a variety of ways for people to connect with one another — using a combination of paired, small group, and whole group discussions will help encourage everyone to join in.

Practice empathy

Think about how you will respond with empathy to someone in the audience who shares a difficult personal story about his/her own experience. Appropriate responses might be, “Thank you for telling us your own story ... how can we support you right now?” or “That’s a very powerful story; thank you for bringing it up because it relates to what we’ve seen.” Remember to validate people’s experiences and relate them back to the discussion.

Discourage judgemental attitudes

If viewers suggest that what a storyteller went through is “their own fault,” take care to talk about the role played by the structures (social, economic, and political factors) influencing the storyteller’s life. Ask audience members to reflect on an experience in their own lives when they feared judgement or felt self-conscious about something that happened to them. Remind people that the stories capture particular moments in time and should not be viewed as “ultimate truths” about storytellers’ lives and identities. The storytellers, like all people, are complex individuals who are growing and evolving over time; they cannot be defined solely by the stories they shared in the videos.

Deal appropriately with conflict or difficult people

Disagreement is healthy and should be welcomed, not discouraged. Heated conflict, on the other hand, is not healthy. Managing conflict is an important task for facilitators. If you’re not comfortable with this role, be sure to find someone to work with who is.

Evaluate what worked and what might be improved

Allow time at your event to assess people’s reactions — brainstorm what worked and didn’t, administer a short survey to collect information, or have people submit anonymous feedback to a suggestions box. You’ll learn a lot about how the stories affect viewers and how you can improve future screenings. (For a simple approach to evaluation, see Appendix A.)

Above all, adapt. Story screenings rarely go exactly as planned. These suggestions are offered as general guidance; use your own common sense and judgment as needed. If an exercise is raising tensions or sensitive issues that make you uncomfortable, do not be afraid to adapt to those circumstances.

Story Discussion Tools

This section of the guide provides tools for facilitators to use in leading discussions about the #justB stories. Included is a set of general discussion questions that can be applied to all of the digital stories. For each individual story, a short content summary, a list of key take-away points, a complete story transcript, and a set of specific questions that aim to bring out details and encourage more thoughtful discussion about what viewers have seen and heard are included.

General Discussion Questions For All Stories

1. What are your initial reactions to the story? Describe the parts of the story (audio and visual) that especially moved you and talk about why. Take time to relate the feelings that came up for you in watching the story to your own experiences – for example, if the story reminded you of painful, frustrating, or joyful events in your life.

2. From watching the story, what did you learn about:

- The people in it?
- The place where it happened?
- The health issues it raised?
- Your own life?

3. Identify some of the life challenges the storyteller raises. What are some of the ways that she/he handled, or might have handled, these challenges? What similar challenges exist in your own community? How have you handled, or would you handle, such challenges in your own life?

4. What actions can be taken to confront the storyteller's challenges by:

- Individual people?
- Community groups, such as a support group or group of peer educators?
- Health, education, or development organisations?
- Government agencies (local, provincial, and/or national)?

5. How would you take action if any of the events in the story had happened to you? How would you take action in relation to a similar situation in your own life?

Story Topic Index

	Living with HBV	Caregiving, Supporting Family Members with HBV	Awareness, Education	Testing, Diagnosis	Prevention, Vaccination	Treatment, Monitoring	Barriers to Care	Stigma, Discrimination	Perinatal (Mother to Child) Transmission	Liver Transplant	Liver Cancer	Fulminant Hepatitis	Co-Infection	Adoption
Alan	X		X	X		X	X	X			X			
Alice	X		X		X	X		X	X					
Binh	X		X	X		X	X	X						
Bright	X			X		X								
Bunmi		X	X		X		X	X			X			
Carolyn		X									X			
Chenda	X				X	X	X	X	X					
Cinder		X	X				X	X			X			
Dai		X	X				X	X			X			
David	X			X		X	X	X						X
DeWayne	X			X		X	X							
Edwin	X		X	X		X			X					
Espi	X		X	X		X	X							
Heng		X		X							X			
Jacki	X	X	X	X	X	X			X		X			
Jason	X		X	X		X	X						X (HIV)	
Jin	X		X	X	X			X						X
Joe	X					X	X						X (HDV)	
John	X		X	X										
Kat		X	X				X	X						
Kenson	X		X				X	X		X				
Kim		X	X				X	X			X			

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M.D.	X		X					X						
Maureen		X												X
Michelle		X								X				
Nancy		X				X	X	X			X			
Peter A	X			X	X		X	X						
Peter V	X				X	X	X			X				
Randy		X						X	X					
Rensely		X	X				X			X				
Roger	X			X	X	X								
Sura			X		X		X					X		
Tuya			X	X			X							
Wendy	X		X			X			X		X			
William	X			X		X		X						
Xuan		X	X			X	X							

Content Summaries, Key Take-Away Points, Story Transcripts, and Discussion Questions and Answers for Individual Stories

Alan – #justB Proactive

Content Summary:

Many of Alan's immediate family members passed away due to liver cancer, but it wasn't until Alan himself became ill that the family realized the role hepatitis B played in these deaths. Alan talks about how stigma prevents open discussion about the virus and raises questions about the medical community's failure to adequately address hepatitis B. He worries that continued silence will prevent others from knowing the same joy he experiences in his life.



Key Take-Away Points:

- When it comes to assessing your risk for hepatitis B, knowing your family history is crucial.
- If someone in your family tests positive for the virus, everyone in the family should seek testing.
- Those who test negative should be vaccinated, if they haven't already been.
- Those who test positive need to seek medical care (and possibly treatment) right away, as doing so can be lifesaving.

Discussion Questions and Answers:

1. In his story, Alan talks about how long it took for his family to find out that the deaths of his uncles were caused by hepatitis B. What reasons does he give for this? (There's a lack of attention to hepatitis B in the medical community, stigma about the virus, discrimination against Asian Americans in the U.S.)
2. After he was diagnosed with the chronic form of hepatitis B, Alan mentions health providers encouraged him to talk to his family. Why is open conversation so important? (Family members need to get tested, and, if they test negative, they may need to be vaccinated. If silence is maintained, they can't know their own hepatitis B status.)
3. As a result of Alan's experience, some of his family members also learned they have hepatitis B. What should they be encouraged to do? (Seek early treatment; it can prevent the development of liver cancer.)

Story Transcript:

When I listen to my son sing, I just wrap myself around that moment. Somehow it takes me back to all the memories, the beautiful experiences my uncles and so many others never had... simply because they didn't know. Uncle Peter passed away in his mid-50s. Then Uncle Luther a few years later... and it eventually caught up with my Uncle Henry in his 60s.

My family only knew my uncles died from liver cancer, because the doctors never say a person dies from hepatitis B. So we didn't know what was killing us until around the time I met Jill who became my wife. My liver became so badly inflamed that a doctor finally diagnosed me with the chronic form of the virus.

It was only because I was an anchor and news reporter with a medical reporter friend who connected me to a leading hepatologist that I got the attention I needed. Only then was I asked about my family history and encouraged to talk to my family and begin treatment. Later, we found out my older brother and sister had been rejected at the blood bank because they had hep B. Then my mother and younger sister decided to get a blood test. They had it, too.

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 bad enough that hepatitis B is a silent killer with few symptoms until it's too late. It's also ignored by Asian cultures that consider talk about deadly diseases to be 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. I think about this a lot. I also think about the millions of other people who could lose the same joy I have, because they simply don't know they have the virus. And about how lucky I am that my early treatment gave my liver a chance to regenerate itself.

We're not just trying to cure cancer, we're trying to prevent it before it happens. The biggest battle is against ignorance, among patients and doctors. We can do this.

Alice – #justB Grateful

Content Summary:

Alice comes from a Chinese family where talking about illness is taboo. It was only when she became pregnant with her first child that she discovered she has hepatitis B. She learned then that her mother also has the virus and that it was probably transmitted to her at birth. Fortunately, Alice's two children were vaccinated at birth and are currently living hepatitis B free. Today, they are all committed advocates for prevention and care.

Key Take-Away Points:

- Because talking about illness is taboo in some cultures, people with the virus often do not openly speak about hepatitis B with anyone, including their family members.
- Many people infected with hepatitis B do not learn of their status until adulthood, partly because there is no open communication about it in their families.
- Vaccination at birth can prevent infection and transmission of the virus from mother to child.
- Getting tested is vitally important, because hepatitis B is a "silent killer" that often presents with few or no symptoms. The first step to living a long, healthy life with



hepatitis B is getting tested!

Discussion Questions and Answers:

1. In her story, Alice mentions that she found out she was infected with hepatitis B when she was pregnant with her first child. What reasons does she give for this? (There was a lack of communication about hepatitis B in the family and speaking about illness is viewed as taboo in her culture.)
2. Why are education and outreach about hepatitis B so important for the prevention of the virus? (Education and outreach can encourage discussion of how important it is to get tested, vaccinated, and/or treated. People need to know that hepatitis B often goes undiagnosed, because there can be few or no symptoms.)
3. Alice talks about how her mother likely transmitted the virus to her at birth. Did this guarantee that Alice would also transmit the virus to her children at birth? (No, vaccination at birth can prevent the transmission of hepatitis B from an infected mother to her newborn. All children born to mothers living with hepatitis B must be tested after receiving the full three-dose vaccination series to ensure the vaccination was successful.)

Story Transcript:

I remember my mom always telling me, “Don’t ask, don’t tell,” in regards to illness. For my Chinese family, being sick is a taboo. So, we never talked about it.

When I became pregnant with my first child, I found out I have hepatitis B. I was very shocked. Only then did I learn from my mom that she also has chronic hepatitis B virus, and that I probably got it from her. I know the transmission wasn’t her fault, and yet I wish she had told me sooner. I decided I wanted to do motherhood differently.

I was blessed because my OB/GYN knew what to screen for and took precautions to prevent transmission from mother-to-child. My two children got vaccines at birth, and then completed the three shots afterward. When they were re-tested at age one and again at age two, the tests came back negative.

But my doctor told me that because I have chronic hepatitis B, I have a 25% chance of getting liver cancer. Would I be able to see my children grow up to adulthood? Would I have to leave them too early?

I chose to be very open with my children about the virus, and I started reaching out to Asian communities too. When my children attended Chinese language school, I set up a hepatitis B education booth for parents. My children manned the booth with me and talked to their friends about vaccination. Later, when they left home for university, they continued doing hepatitis B outreach on their own! I did, too!

I remember my son coming home during a school break and saying, “Hepatitis B is a silent killer... testing is so important, and vaccination can prevent the infection.”

I told him “You got it! I am so proud of you.”

I used to think my passion for preventing hepatitis B would live in me until I die. Now I think it will live longer than that.

Binh – #justB an Advocate

Content Summary:

When the time came for him to get checked for STDs, Binh chose to go to a clinic rather than to his family doctor; this allowed him to remain anonymous. He learned he has hepatitis B, but his youth and good health led him to put off treatment. Fortunately, several years later he began taking medication for the virus and avoided liver damage. He feels that the openness surrounding testing and prevention for STDs and HIV/AIDS should be extended to conversations about hepatitis B.

Key Take-Away Points:

- Clinic visits focused on primary care or sexual and reproductive health also present opportunities for people to get screened for hepatitis B.
- Age and perceived good health are not reliable indicators of hepatitis B viral load; it's important for those who test positive to go in for follow-up, to assess whether medication might be necessary.
- The same degree of attention that has been devoted to promoting STD screening and HIV testing and encouraging frank discussions of safe sex should be given to hepatitis B.



Discussion Questions and Answers:

1. Why did Binh decide to go to the community clinic rather than to his family doctor? (Like Binh, the doctor is Vietnamese; because Binh is gay, he didn't feel comfortable visiting this gentleman. Binh may have worried that the doctor would respond with a homophobic attitude or "out" him in the community.)
2. What led Binh to initially put off seeking follow-up care, after he tested positive for hepatitis B? What eventually led him to go back to a doctor? (He believed that because he was young and healthy, he didn't have to worry about the virus. He went back again due to concerns about STDs, only to find that his hepatitis B viral load was high.)
3. How does Binh see his family history as informing his attitude about what it means to live with hepatitis B? (Binh's parents were refugees; he feels that having hepatitis B pales in comparison to what they endured and is grateful to them for the life he leads today.)
4. What does Binh think needs to happen, before discussions about hepatitis B can become routine in relationships? (He feels that the openness and advocacy about HIV/AIDS needs to be mirrored in public health, to help people understand hepatitis B and know how to talk about it.)

Story Transcript:

Sitting in the waiting room, I was still sweaty. I had almost missed the walk-in hours at the community clinic. With all we knew about being safe, about HIV, about STDs, it felt normal to get checked. I liked going to the community clinic – it was just a mile off campus, and I liked the sense of being anonymous. I

had a family doctor, actually. He's an older gentleman, Vietnamese as well, and a family friend. But being gay, I just ... wasn't comfortable seeing him.

That afternoon, I went in to get tested for STDs and came out knowing I have hepatitis B. But I wasn't surprised. I knew my three older brothers had it. They'd been encouraging me for a while to look into my status, but I'd thought, "I feel fine, I'm young, I feel healthy." Now knowing I had the virus, I still felt healthy, so I put off any follow-up.

It took several years. It just so happened my roommate was a nurse. One day we were talking, and he suggested I go get PrEP as an extra precaution. It's a pill you take that prevents HIV infection even if you're exposed. My roommate set-up the appointment, so I wouldn't put it off. I went in to get evaluated for safe sex meds, and I left knowing my hepatitis B viral load was very high. I started treatment. "Not a moment too soon," my doctor said.

Sometimes people ask me, "Was it hard finding out you have the virus?" Being the son of refugees is a big part of who I am. I feel like any adversity I might face in my life pales in comparison to what my parents have experienced to get me here.

Other people ask, "Why is it important to talk about hepatitis B?" I went to get tested in the first place, and I knew the value of communicating with sexual partners because of all the advocacy around HIV and STDs. But I would pause before I tell them I live with hepatitis B. And they always pause before asking, "What is that?" And then I begin to explain ...

Bright – #justB Resilient

Content Summary:

Born in a small town in Ghana, Bright immigrated to the U.S. after finishing teacher training college. Several years later, he learned that his mother, who he adored, had passed away back home. Devastated, he began to receive counseling. After seeking healthcare for feelings of fatigue, Bright also learned he is living with chronic hepatitis B. In time, Bright found strength to start facing the unknown, and found himself feeling more resilient than ever before.

Key Take-Away Points:

- Knowing one's hepatitis B status is very important, so that treatment and monitoring can begin, to help prevent liver damage.
- Researching and understanding healthy lifestyle and treatment options can help those living with the virus to overcome feelings of hopelessness and depression.
- Resilience can be a powerful protective factor for coping with chronic conditions like hepatitis B.



Discussion Questions and Answers:

1. What caused Bright to seek medical care? (His symptoms of fatigue, but it is important to remember that not everyone shows symptoms of chronic hepatitis B.)
2. What helped Bright begin to reclaim his earlier sense of resilience? (Over time, Bright began to accept his condition and take control by researching treatment options and understanding how to live healthfully with chronic hepatitis B.)

Story Transcript:

I was born in a small town in Ghana. My family was not wealthy or powerful, but my mom cared for me and my four brothers. We loved her special pancakes made with nutmeg and fried in coconut oil.

Somehow, I managed to finish Teacher Training College, won the American visa lottery, and immigrated to the U.S. I was shy and quiet, but I thought of myself as pretty strong and resilient. Life had not been easy!

Five years later, I learned that my mom had passed away back home. All of my earlier strength and resilience fell away. I couldn't concentrate, I wanted to hide from the world, and sometimes I didn't want to live anymore. My friends helped me so much. They said, "You loved your mom. She would not be happy seeing you give up on your life." So, I got some counseling, and I got a little stronger again.

But then, I started feeling tired all the time. Four or five days a week, I had absolutely no energy. My doctor helped me, and eventually I learned that I was living with chronic hepatitis B.

I started treatment, but the fatigue and back pain got worse. Were they connected? Every morning, I woke worrying about my future and what would happen next with my hepatitis. I might be okay today, but what about tomorrow? Or next year? Or five years from now?

Slowly I started to have days when I wasn't hopeless, when I could face the unknown. I talked to my doctors, did my own research, and made my own decisions.

A year later, my brother came from Ghana, and I picked him up from the bus station. After a moment, he said, "You have changed." I couldn't imagine what he saw so quickly in me. But now I realize, I have changed – I am more resilient than ever before.

Bunmi – #justB Open

Content Summary:

After her father passed away, Bunmi had to request his death certificate to learn the cause of death: liver cancer. She felt stifled by the lack of willingness within her family to talk about hepatitis B, and she wonders if old superstitions about illness in Nigeria are contributing to the stigma surrounding the virus both there and in African immigrant communities in the U.S. She is determined to help end the silence.

Key Take-Away Points:

- Many people in communities in the U.S. and globally are not aware that liver cancer can be caused by the hepatitis B virus.
- The stigma surrounding hepatitis B can be linked in some instances to inaccurate traditional beliefs about health and illness.
- Stigma surrounding hepatitis B is not the only thing that causes people to avoid testing; when healthcare is simply not available, they may not see the point of knowing their status.
- Testing and treatment for hepatitis B need to be integrated into health systems and made accessible to all communities, regardless of socio-economic status.



Discussion Questions and Answers:

1. Why did Bunmi have to request her father's death certificate to learn how he died? (Her family was reluctant to talk openly about hepatitis B, due to stigma and a desire to "save face." Her father's doctor in Nigeria was also reluctant to discuss the topic.)
2. What reasons does Bunmi suggest for why some Nigerians living in Nigeria may resist knowing their hepatitis B status? (They may have friends or family members who tested positive and who are living full, healthy lives. They may not be able to afford follow-up care, should they learn they are positive.)
3. How can the value of tradition be preserved, at the same time that traditional beliefs rooted in misinformation are challenged? (Community members can be encouraged to identify the positive elements of tradition and can educate themselves and their peers about when ideas about "tradition" are damaging to people's health.)
4. What does Bunmi think needs to happen, regarding the issue of hepatitis B, within communities of African descent in the U.S.? (She believes that efforts must be made to reach out to Nigerian and other African immigrants, to let them know that resources for testing, vaccination, and treatment are available, regardless of people's ability to pay.)

Story Transcript:

Nobody wanted to talk about it. His friend, who is a well-respected doctor, knew, but it wasn't something to be shared. It was viewed as taboo.

A few years after our dad passed, when I was back home in Nigeria, I requested his death certificate. That's when I found out for sure he had liver cancer. Before he died, my mom complained, "Your dad's not eating." By the time he decided to actually go for a checkup, he never came out of the hospital. He was gone, just like that.

We were supposed to be a perfect family that never had health problems, never had to take medicines. How could this happen? No one wanted me to say anything about it. I felt like I was a bomb about to explode, and I was capping it in a bottle. I felt helpless. I also started thinking, "I wonder who's next?"

I came to the United States when I was 18. I know that some people in Nigeria, especially in the villages, believe there is an evil force that people can use against each other, leading to illness. In my family, we were not exposed to this kind of thinking. Still, sometimes I wonder if it's true. Maybe this is why people don't believe my father's cancer was caused by a virus: hepatitis B. Stigma is everywhere, rooted in this old belief. People don't think about the facts of how the virus is transmitted– they are afraid to even touch someone who has it.

Some people in my community know they were infected with hepatitis B, but blood tests show their immune system fought it off, and they are fine. Others find out they have chronic hepatitis B infection, but do not understand the need for follow up.

In Nigeria, many people don't even want to get tested, because treatment is either not available or costs too much money. They say, "What's the point?" In the U.S., the services are here, and I want to make sure that people of African origin know there are resources.

I want to end this silence.

Carolyn – #justB Family

Content Summary:

When Carolyn's mother told her, "He's just tired. He needs to work less," Carolyn suspected that something more was going on. She flew to visit her parents in Hawaii and learned that he was dying of liver cancer, the result of chronic hepatitis B. Carolyn regrets how quickly her father's health deteriorated, and yet she cherishes the time they spent together in the hospital. She recognizes that the experience helped her find compassion for her patients, in her own work as a nurse.



Key Take-Away Points:

- The impulse of cancer patients to "protect" their family members from the truth is rooted in love and should not be confused with shame or stigma.
- Chronic hepatitis B means that someone is infected with the hepatitis B virus, and since their immune system cannot fight the virus, they will be infected for life; this condition can lead to liver damage, or even liver cancer over time.
- Chronic hepatitis B often has no symptoms; anyone who tests positive for the virus should not wait to seek medical care.

Discussion Questions and Answers:

1. What caused Carolyn to worry about her father's health? (The fact that her mother had been saying for months that her father was tired, didn't feel well, and had a chronic cough.)

2. Carolyn states that she understands why her father was reluctant to share his hepatitis B status with her and her sister; what reasons does she give for his decision? (Her father's desire to see his daughters live their own lives rather than having to worry about his health.)

3. How might things have been different, if Carolyn's father had disclosed his status earlier? (They could have spent more time together. Carolyn and her sister could have advocated for him to seek treatment earlier, which may have prevented the cancer from developing.)

Story Transcript:

I was driving my car when I got the text from our neighbor Megan, asking if you were okay. I immediately phoned mom right away, hoping for a clear story. But all she said was, "Oh, dad's just not feeling well."

It was what she had been saying for months: He's tired. He's not feeling well. He can't get rid of his cough. He needs to work less.

I jumped on the next plane and went straight to the hospital, dragging my large suitcase through the corridors to your room. You looked different sitting in that hospital bed. Like you aged 10 years in less than one.

You said, "Hi bebe, I love you," like you always do. And it immediately made me feel better, like it always did. But you weren't just not feeling well. Your physicians told us you'd had chronic hepatitis B for years, and you hadn't wanted me and Kathy to know. So both you and mom kept it from us. And now it was taking over your body and mind.

Those three months we all spent in and out of the ICU took over my world. And I wanted it to last so much longer. I understand why you thought it was right to protect us, Dad. You wanted us to live our own lives instead of worrying about you. And yes I also wish you'd shared more of your situation and your suffering. So we could have spent more time — better time — together.

But I want you to know that I'm okay. You gave me such a good life. I completed nursing school on time, and because of our experience together, I'm better at caring for other people's parents, and other people's daughters.

My whole body aches when I think of how much I miss you. Take care, Dad. I love you, too.

Chenda – #justB Inspired

Content Summary:

Recently engaged and waiting to join her fiancé in America, Chenda got a blood test, only to find out that she has hepatitis B. Upon seeing a doctor in Cambodia, she was inspired to learn how to protect her family and partner from the disease. Hepatitis B no longer haunts Chenda; she transformed herself from survivor to helper and is ready to make sure her soon-to-arrive first child is vaccinated against the virus.

Key Take-Away Points:

- If someone tests positive for the hepatitis B virus, they should inform their partner immediately, so that the partner can get tested and either get vaccinated (if found to be susceptible) or see a doctor for follow-up care (if found to be infected).
- ALL pregnant women should be tested for hepatitis B, and if infected, should ensure that their newborn receives the hepatitis B birth dose and Hepatitis B Immunoglobulin (HBIG) within 12 hours of birth followed by the three-dose hepatitis B vaccination series to help prevent mother to child transmission of the virus. Infected pregnant women should also talk to their doctor about monitoring their hepatitis B throughout their pregnancy and starting treatment if needed.
- Monitoring the virus is very important and can help prevent cirrhosis and liver cancer.



Discussion Questions and Answers:

1. Why might Chenda have assumed she needed to know her hepatitis B status in order to obtain a U.S. visa? (Even though testing for hepatitis B is not required as part of the U.S. visa process, some countries do require hepatitis B testing as part of the immigration process.)
2. When Chenda initially found out that she tested positive for the hepatitis B virus, she believed her life would end. What helped her change this view? (Chenda's mother and husband reassured her and urged her to consult a doctor, who explained that with careful monitoring of the virus, she can live a normal life.)
3. How does Chenda plan to handle her own pregnancy and birth, now that she knows she is living with the virus? (She has found a well-informed doctor who will make sure her baby is vaccinated, to offer a solid chance of prevention. When a mother has hepatitis B, if the first dose of the hepatitis B vaccine and one dose of Hepatitis B Immune Globulin (HBIG) is given to a newborn at birth, followed by the completion of the hepatitis B vaccine series, the baby will have greater than a 95 percent chance of being protected against infection.)

Story Transcript:

In 2012, when I was living Phnom Penh, I got engaged to a Cambodian-American man. The atmosphere was full of blessings and congratulations.

Three months later, everything collapsed. I took a blood test – I thought I needed it to get a U.S. visa. I learned I have hepatitis B. I was sure this meant I could not join my husband. I barely remember riding home on my motorbike. My eyes blurred, and my soul went out. Other drivers yelled at me, but I didn't hear them

When I gave my mom the test result, she could not read it, but she knew from the look on my face that something was wrong. She put her hand on my shoulder and said, "Honey, it's okay. We never know when we will die ... you might live longer than people without this virus."

I didn't believe her at first. One night, there was a funeral nearby, and there was a black out. I was afraid of

the darkness, so I lit a candle. I listened to the sad music and felt like I was the flame: the wax would melt ... and my life would end due to hepatitis B.

When my fiancé called, I was scared to answer. But I told him the truth. He said, “I love you,” and encouraged me to see a doctor. The first one told me I needed treatment costing a thousand U.S. dollars a month. Too expensive! But a second doctor said, “You just need to monitor the virus carefully.”

So, I threw away all negative thoughts. I wrote “CHANGE” in big letters and put it on the wall. I researched how to protect my family and my lover from hepatitis B. And a year later, I got my visa!

Now, I am pregnant. I’m talking with my doctor about how to make sure my beloved baby won’t get the virus. I have transformed myself from survivor to helper. Hepatitis B does not haunt me anymore.

Cinder - #justB Educated

Content Summary:

Cinder and her husband grew up on a small island in Micronesia, where there is great stigma against seeing doctors. Even after they moved to Hawaii and her husband became an advocate for their community, he didn’t want to receive treatment for his hepatitis B. When he became seriously ill, Cinder cared for him every day for two years at the medical center. After he passed away, Cinder took up his mantle in their community by interpreting, volunteering at the church, and, now, educating others about hepatitis B.

Key Take-Away Points:

- There is a stigma around receiving medical treatment in many Asian and Pacific Islander communities.
- Men face additional stigma when it comes to seeking health care, which is viewed as “unmanly” in some cultural contexts.
- In addition to health insurance, culturally sensitive, in-language education and outreach are key aspects of addressing hepatitis B in vulnerable and marginalized communities.

Discussion Questions and Answers:

1. Why did Cinder’s husband avoid going to the doctor? (In the Micronesian community, it is a common belief “real” men bear pain and should not seek medical help.)
2. How did her husband’s death inspire Cinder’s work in her community? (She took over his duties interpreting. She also educates the community about hepatitis B and helps people enroll in health insurance.)
3. How has singing helped Cinder’s healing? (She first started singing to her husband while he was in the hospital and now sees it as a release that helps her cope with her grief and fears.)



Story Transcript:

My husband and I had our children on Chuuk, a small island in Micronesia. Life was simple, and health services were limited. People say, "If you're a real man, you bear the pain." So when my husband was sick, he said, "No need to see the doctor."

After we moved to Hawaii, he became a huge advocate for our Micronesian community. He liked to serve. He did interpretation and was a pastor in our language. I liked working in the background as an accountant. Everyone called me "Manny's wife."

In 2010, we learned he had cirrhosis and liver cancer. Still, he said, "No need to see the doctor." One day, he was so sick, I had to call 911. At the hospital, the nurses asked: "Does he understand English?" I said, "Yeah, are you kidding? He's one of the best-known interpreters for our Chuukese people." But at that moment, he just couldn't take it all in.

It was a moment I had always feared. I had to interpret for him, and he was dependent on me. During the two years I cared for him at the Medical Center, he asked me to sing to him, early every morning. I hadn't wanted to sing out loud before, but I did it.

The month our son graduated from elementary school, I lost my husband. Everything changed.

I started serving the church and interpreting for the community. I saw how desperately my children, grandchildren, and community need education about hepatitis B and how to prevent liver disease. And I started doing health insurance enrollment for our people.

Singing has become my way of coping with my grief and my fears. Now I can't wait to go up to the podium every week, to sing my lungs out. I am not known as Manny's wife anymore. I'm known as Cinder.

Dai – #justB There

Content Summary:

For three years, Dai dedicated her life to caring for her severely ill father. She made sure he took his meds, went with him to doctor's appointments, and sought support for him in the Vietnamese community. While Dai regrets that so little information about hepatitis B and liver cancer were available in her area, even within her own profession in public health, she feels lucky to have been able to spend time with her father before his death.



Key Take-Away Points:

- While chronic hepatitis B often has no symptoms, some people may experience weight loss, fatigue, and tremors.
- For reasons that are not fully understood, the prevalence of hepatitis B in Asian and Pacific Islander communities is high.
- Because the mainstream public health community is not always well informed about hepatitis B, it's important to advocate for greater attention to the virus.

Discussion Questions and Answers:

1. Dai spent a great deal of time as a caregiver, for her father. What resources could have been helpful to her in this role? (Information and support tailored to the Vietnamese community, to help her navigate the health care maze and better understand the treatment of hepatitis B and liver cancer)
2. Why do you think Dai, as a public health worker, knew so little about hepatitis B before her father was diagnosed with liver cancer? (While materials in Vietnamese may exist, they don't always make their way to places in local communities where people can easily access them. Stigma also prevents open discussion of the virus.)
3. What remedy does Dai give, to the problem of lack of open discussion about hepatitis B, in the Vietnamese community? (Information and open discussion, which require challenging stigma)

Story Transcript:

For three years, my alarm goes off every day at eight a.m. I don't bother to change my clothes. I throw my grandma coat over my PJs and walk the block and a half to my dad's, to give him his insulin and make sure he takes his meds, and is OK. At noon, my alarm goes off again — the same routine. Then again at six, and again at nine.

For these three years, I take him to all his appointments and stay with him when he's hospitalized every few months. He's always tired and gets thinner and thinner. My brother has school, and my sister has work, so caretaking falls to me and Mom.

Before the diagnosis, he had been silent about his pain. How could I have missed the weight loss, the fatigue, the tremors? How could the mainstream public health community have been so silent about this disease that I knew almost nothing about it, as a public health worker?

He's treated with radiation but decides against surgery. He never complains. I learn how prevalent hep B and liver cancer are, in our Asian communities. I look online for resources in Vietnamese and support groups for people who don't speak English. I find nothing.

The cancer spreads to his bones in 2015. More alarms, medications, radiation, chemo that doesn't work, and then three months in the hospital, surrounded by us.

We celebrated his 100-day memorial mass this past weekend. For us, three years is lucky. If we had talked sooner, if people knew more about this, he could have lived for so many more years. But for us, three years is lucky. I don't regret a single day.

David - #justB Honest

Content Summary:

David learned as a teenager that he has hepatitis B, and at first, he was confused and depressed. He tried to commit suicide his freshman year of high school. David started therapy after that, but the sessions focused solely on his suicide attempt and not on the questions and challenges he was dealing with related to his hepatitis B diagnosis. He began taking opioids, which led to his family finally having conversations about hepatitis B. David is now living healthfully with the virus.



Key Take-Away Points:

- In addition to medical care, people living with hepatitis B need emotional support and access to educational resources about living with chronic hepatitis B, particularly when they are newly diagnosed.
- Physician-patient conversations need to include discussions of if/how living with the virus will impact patients' social lives and career ambitions.

Discussion Questions and Answers:

1. What did David want to know from his doctor that wasn't explained? (David wanted information about how the virus would affect his dating life, if he could have a family, if he could remain active and achieve his goals.)
2. How can family members help people manage their emotional needs around living with hepatitis B? (It is important to have open communication and talk about the diagnosis and what it means to live with the virus.)
3. How did David cope with his concerns? (He attempted suicide and turned to opioids. Eventually, he found support within his network of friends and family members.)

Story Transcript:

I was adopted out of South Korea when I was 5 months old. I remember my parents taking me to the clinic when I was 13 and hearing about this thing called "hepatitis B." I was in middle school, thinking about dating, doing sports, not about having a chronic illness.

The doctor said, "You can live a long, healthy life." But nobody helped me talk about the things that mattered to me.

It built up, and during freshman year in high school, I tried to stop all the questions by swallowing a bunch of Tylenol pills. After that, I started therapy, but it focused on my suicide attempt and not on hepatitis B.

In my early 20s, I found opioids. They were an escape from feeling. The silver lining was that my loved ones noticed, and we started talking about it, which led to me talking about hep B for the first time... And

things started to change.

I still alternated between not caring, being worried, and wanting to ignore it. I didn't go to the doctor as often as I should have. Then in November of last year, I found out my liver wasn't doing so hot. The doctor suggested a liver biopsy.

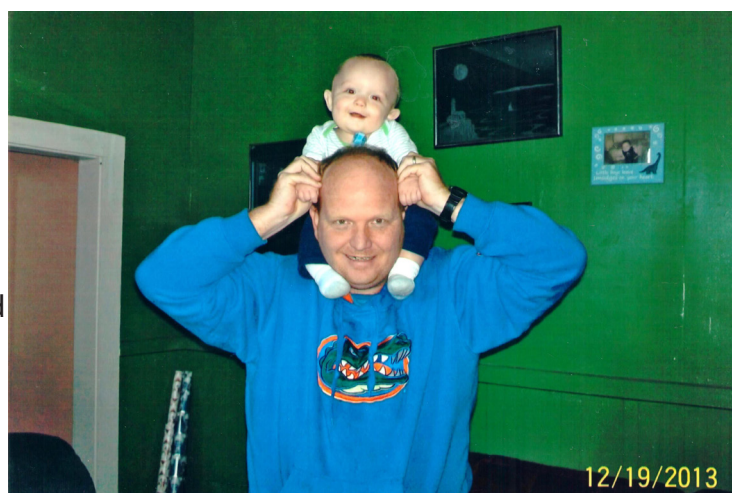
I went home afterwards to have dinner with my parents. The spinach from their garden was crisp, the smell of garlic filled the house, we laughed and enjoyed each other's company. I thought, "I like this moment, I want more of them." So I scheduled the biopsy.

It's been a wild ride. I'm on medication now. Most days are still tough, but my liver is healthy! The struggles and successes, they're all linked together. I feel more comfortable in my own skin, I'm learning from my past, and I'm living with Hepatitis B.

DeWayne - #justB Extraordinary

Content Summary:

DeWayne contracted hepatitis B when he had a blood transfusion as a child. His guardian and doctor didn't teach him more about what that meant; all he got was a devastating pronouncement that he wouldn't live past 30 years old. DeWayne survived a liver failure at age 12, but was left feeling confused as to his future. Being uninsured and told that nothing could be done about this hepatitis B, DeWayne ignored the virus for years. But after getting married, becoming a dad, and experiencing a decline in his health, DeWayne was motivated to see a doctor, start taking hepatitis B medication, and live healthier with his family's future in mind.



Key Take-Away Points:

- Lack of information and barriers to accessible, affordable health care affects how patients make decisions regarding their overall health and futures.
- Physicians play large roles in how people receive their hepatitis B diagnoses and perceive their futures living with the virus.
- Families can play vital roles in convincing people to seek medical care and treatment.

Discussion Questions and Answers:

1. Why did DeWayne at first choose not to pursue treatment? (Because of his doctor's pronouncement, he didn't believe help was possible. He also felt he couldn't afford the care.)
2. How did DeWayne's lack of information affect his feelings about the virus and his life? (He grew up con-

fused about his future and as a result participated in risky activities.)

3. How did DeWayne's insurance status contribute to the mismanagement of his virus? (Because he didn't have insurance, he didn't seek medical treatment. He was eventually able to get insurance through his disability and receive medical care.)

Story Transcript:

I was 7 years old, at the clinic for a follow-up visit. It was 1985, and I'd been in an accident a few months before, where I had a blood transfusion. The blood supply wasn't being tested for hepatitis B until 1992. I overheard the doctor tell my guardian, "He probably won't live past 30."

When I was 12, my liver started failing. My body wasn't able to fight the infections I had. Luckily, I didn't need a transplant. After that, I felt like I was immortal, but I was also confused.

As I grew up, the confusion led me into all kinds of risky things, and I pretty much ignored the hepatitis B. For so long, doctors said there wasn't much that could be done.

I'd grown up in foster care, didn't have insurance, so I wasn't going to spend money on my health. I also didn't feel comfortable with the idea of putting medicines in my body.

I got married, and our son was born in 2013. Then my health went downhill. One night, I was hurting so badly, I literally collapsed. I called for my wife to help me up. As I lay on the floor, the thought flashed through my brain, "What if I'm not here, for my son?"

My wife convinced me to go to the doctor, and I was able to get insurance through my disability. I was told I had to get it under control, stop doing certain things, start taking medication for the rest of my life.

After a few months, my viral load dropped dramatically. I'm moving forward and trying to be at peace. I can't wait to see my son graduate from high school.

Edwin - #justB Enduring

Content Summary:

Edwin contracted hepatitis B through exposure to blood from his mother during childbirth. Even though she shared her status with him, he grew up not understanding the serious effects the virus could have on his health. In 2017, during a routine check-up, his doctor informed him he needed to lose weight, eat healthier, and exercise regularly to prevent cirrhosis. Resolved, Edwin changed his diet, started running, and lost 35 pounds over the following year. Now he trains for and competes in Ironman triathlons to raise awareness and funds to find a cure.

Key Take-Away Points:

- It is important for people living with hepatitis B to manage their overall



health. This includes maintaining a healthy weight, eating well, avoiding alcohol and exercising regularly. - Those with the virus don't necessarily need to avoid strenuous physical activity.

Discussion Questions and Answers:

1. How did his doctor's concern about cirrhosis change Edwin's life? (It made him understand how serious the consequences of hepatitis B can be, inspiring him to lose 35 pounds and train for a triathlon.)
2. How did Edwin's experience growing up affect how he looks at hepatitis B? (Because hepatitis B is usually asymptomatic, Edwin and his mother were not aware of how serious the disease can be. Because he was active, strong, and healthy overall, Edwin felt he was unstoppable.)
3. What is Edwin's future goal, and why does he want to achieve it? (He wants to complete an Ironman triathlon to raise awareness of hepatitis B and prove what he can achieve while living with the virus.)

Story Transcript:

So you're probably wondering what triathlon training has to do with hepatitis B. Let's rewind a bit... This is the spring of 2016. I'm in a lot of pain and can't do much of anything. I'm on muscle relaxers and a high dose of naproxen to treat the herniated disk in my back.

Fast forward a year... I go to a routine checkup for my hepatitis B. The doctor tells me I have a fatty liver and super elevated levels of liver enzyme. She warns me, "This could lead to cirrhosis." She says, "You need to lose weight, eat healthier, and get regular exercise."

For the first time in my life, I feel completely vulnerable. Is hepatitis B this big of a deal? I got the virus from my mother at birth. She knew she had it but didn't realize it was important to tell me. We didn't know how serious it was.

Growing up, I thought I was unstoppable. I'd gotten up from every fall and healed from every scrape. So I do it – I change my diet and start working out. Over the course of a year, I lose 35 pounds. And I don't want to stop there. I want to kick it up a notch. Now I'm getting ready to do an Ironman triathlon in a few months, to raise awareness and funds for a cure. That's 2.4 miles of swimming and 112 miles of biking, topped off with a marathon.

I am going to prove what I can achieve even while living with hepatitis B.

Espi – #justB Empowered

Content Summary:

Espi found out that she has hepatitis B when she was 64. For some time, she was monitored every six months, but eventually a doctor told her she could die if she didn't begin treatment. Instead of automatically taking his advice, she researched her options. She also kept active, ate well, and tried not to worry. Finding a support group helped her to decide on her own terms to take medication, when she had all the information she needed.

Key Take-Away Points:

- With proper monitoring and healthcare, many people living with hepatitis B can avoid taking medication.
- Maintaining a healthy diet and lifestyle are important aspects of self-care, for those with the virus.
- Connecting with others is an important way for people living with hepatitis B to find support and information.

Discussion Questions and Answers:

1. Espi had a good experience with her first doctor. What was it that he told her, and what did she decide to do? (He told her that hepatitis B doesn't have to be a "big deal" and explained her options: medication or monitoring. She decided to be monitored every six months.)
2. Espi's next experience with a provider was not positive; what happened, and what was the result? (He told her, "you'll die from this" and insisted she take medication. She did not go back and instead continued her healthy lifestyle and researched the possible side effects of treatment)
3. How did Espi eventually make the decision to go on medication? Why is support so important, for those living with hepatitis B? (She researched side effects and discussed the situation with her support group. Support is important as part of the process of understanding information, weighing options, and making decisions that feel right.)

Story Transcript:

At 64, I was diagnosed with hepatitis B. The doctor told me, "It's no big deal, you were likely infected at birth." He explained my options, and I decided for myself to monitor it by coming in every six months for tests.

When I retired to Florida a few years later, my new gastroenterologist told me something very different. He said, "You'll die from this. I'm going to prescribe medication." He thought he should decide for me.

I said I wanted to continue monitoring, since my blood tests were only slightly elevated. I'll never forget his response: "Oh, so you want to be your own doctor?" I was confused and didn't know what to do. I felt like he had one hand on his prescription pad and the other on the door. I did not go back to him.

Instead, I made sure to eat healthy, keep active, and stay positive. I also researched my options — I even called the pharmaceutical company to find out what they could tell me about side effects ... just about nothing.

So, I worried. A lot. For two years, I had insomnia. I lay awake night after night, terrified that hepatitis B was my death sentence.

I got a lot of comfort and educated myself, when I connected with a support group. When I finally decided to go on medication, it was the stories I heard from members of the group that gave me confidence and strength. I was able to speak to my doctor and ask for a lower dose than usual, since I only weigh just over 100 pounds.



The way I see it is that doctors have their training, their body of knowledge they bring. But they are not God. As patients, we need to know when to listen, when to seek more information, and when we feel ready to make the choices that feel right for ourselves.

Heng – #justB Loving

Content Summary:

Heng met Wendy when both were in college and fell in love with her right away. When Wendy told him she has hepatitis B, he got tested and found out he was already protected from the virus. They later married and had children. When Wendy's mom passed away from liver cancer, Heng and Wendy realized the virus can have serious consequences and began learning about the importance of monitoring and medical care for people living with chronic hepatitis B. Today, Heng continues to love Wendy unconditionally and support her in living a healthy life.



Key Take-Away Points:

- Even when someone living with hepatitis B appears to be very healthy, it's important for them and their loved ones to learn all they can about the virus.
- Partners of people living with hepatitis B should always be tested (and then vaccinated if they are not infected).
- Learning someone you love has hepatitis B should not impact your relationship with them.
- People with hepatitis B can live long and healthy lives as long as they take care of their health and are properly monitored by a doctor for their hepatitis B.

Discussion Questions and Answers:

1. Heng mentions in his story that "his body was already protected" from hepatitis B. What does he mean by this? (Through a blood test, Heng confirmed that he was already immune, or protected from, the hepatitis B virus. A person can be protected from the virus if they completed the hepatitis B vaccination series, or if they recovered from a past hepatitis B infection.)
2. When Wendy's mother dies of liver cancer, what changes for Heng and Wendy? (They realize the importance of educating themselves about hepatitis B, because if not managed correctly, hepatitis B can lead to liver cancer or other serious complications. Wendy and Heng live active lifestyles and a knowledgeable doctor monitors Wendy regularly for her hepatitis B.)
3. What are Heng's views about the importance of hepatitis B, in his and Wendy's life? (He understands

that while awareness is important, their relationship is defined by love, not by Wendy's hepatitis B status.)

Story Transcript:

I first saw Wendy when she started coming to the church I was attending. She was so elegant. I thought, "She's way above my caliber," and I admired her from a distance. I fell for her even before she knew I existed. One of the first times she paid attention to me was when I sprained my ankle playing volleyball. As a physiotherapy student, she came to attend to my injury, and I fell even further for her.

We finally did get together, and once our relationship became more serious, she told me she had hepatitis B. She said, "You should get tested." I found out my body was already protected from hep B. Back then we didn't really think much about it. She was very athletic, and it just didn't seem like an issue.

Every year, we learned more about hep B, especially after her mom died of liver cancer. We make lifestyle choices because of her illness, but we don't allow it to define our lives. We've been married now for 29 years, raised two wonderful children, and have built more than our fair share of meaningful memories. We don't know how much time God will give us, so we live life to its fullest, making the most of every opportunity.

We don't know the end of our story. I do know that whatever comes, I have already been blessed by having Wendy in my life. I do know that we will be active in writing the future chapters of our lives together, and it will be defined by our love and not by hepatitis B.

Jacki - #justB Treated

Content Summary:

While studying in the U.S., Jacki received a call from his family in Taiwan informing him that his brother had liver cancer caused by hepatitis B. Concerned for his health, Jacki got tested and learned he also had hepatitis B—as did his wife. Together, they created a Taiwanese hepatitis patient group to provide information and support for people living with hepatitis, and to advocate for prevention and treatment. With his brother now in remission from liver cancer, Jacki is grateful for the experience because it allowed him and his wife to get diagnosed and treated, and to prevent transmitting the virus to their children.



Key Take-Away Points:

- With the help of antiviral treatment, vaccination, and immunoglobulin, people living with hepatitis B are able to have children without passing along the virus.
- A diagnosis from one family member often leads to others learning that they have hepatitis B as well. If a

family member tests positive, everyone in the family should get tested.

- Support groups are available for those living with hepatitis B to receive information and connect with other patients and caregivers.

Discussion Questions and Answers:

- How did Jacki's brother's transparency with his diagnosis enable other family members to receive treatment or prevent the virus from spreading? (Jacki and his wife got tested for hepatitis B after Jacki's brother was diagnosed. This led them to being able to appropriately manage and treat their hepatitis B. They were also able to take proactive measures to prevent spreading the virus to their children.)

- How do support groups help those living with hepatitis B? Why is it important to have such groups among people that share common backgrounds? (Through advocacy and support groups, people can learn about prevention, testing, and treatment options, and receive emotional support.)

- Why is it important to have such groups among people that share common backgrounds? (It is important that people feel comfortable in support groups. Because there is significant stigma surrounding hepatitis B in Asian communities, having culturally and linguistically appropriate support groups may help increase awareness, promote open dialogue, and reduce stigma.)

Story Transcript:

In 1989, I came to the U.S. from Taiwan for my PhD studies. After I finished my degree in 1992, I got a call from my sister. She said, "Our brother is in the hospital. You need to come back." So, I went home to see him and our family. That's when I found out he had liver cancer, caused by hepatitis B. He was infected when he was born.

I worried about my siblings, my aunties and uncles... And I worried about myself. I wondered, "Am I also hepatitis B positive?" I got tested and learned I do have the virus.

My brother started treatment for liver cancer and hepatitis B. Later, I got treatment for hepatitis B, too, to prevent liver cancer, because I also had liver inflammation and severe fibrosis.

Later, we found out my wife also has hepatitis B. When she got pregnant, I thought, "How can we protect our next generation?" We researched and got her treatment with antivirals during her last trimester. This, together with the hepatitis B vaccine and immunoglobulin, successfully protected our son.

As the years passed, we wanted to help other families as well, so we set up a Taiwanese hepatitis patient group. We help answer patients' questions and make sure people get the treatment and support they need. We gather regularly to talk about living with hepatitis and about prevention and treatment.

Today, my brother has been cured for ten years. This is rare, for liver cancer. I feel so grateful to him, because if he hadn't gone through what he did, I would never have known I have the virus.

My wife and I are living healthy and taking antiviral medications. And all of our kids are free from hepatitis B.

Jason – #justB Aware

Content Summary:

Jason was at a difficult time in his life when he found out that he has hepatitis B. The news pushed him into recovery from addiction, but when he moved home to seek treatment, he could only find specialists in hepatitis C. After a disastrous experience with one provider, Jason fell into depression and attempted suicide. Finally, he located a caring and knowledgeable doctor who gave him hope. Jason now teaches young people about HIV and hepatitis B prevention.

Key Take-Away Points:

- Although everyone may be at risk for a hepatitis B infection during his/her lifetime, there are groups of people who are at higher risk because of where they were born, their occupation, or sometimes, risky behaviors. People who think they might be in a high-risk group should seek testing for hepatitis B. This can include people born in areas of the world where hepatitis B is common (or their children), health care providers, men who have sex with men, and people who inject drugs.
- HIV/hepatitis B co-infection is common; anyone who tests positive for one virus should be tested for the other.
- Hepatitis B is different from hepatitis C, for which a cure has been found. Hepatitis B requires unique monitoring and treatment approaches.
- People living with hepatitis B need support in advocating for appropriate medical care.



Discussion Questions and Answers:

1. What are some of the ways that hepatitis B is transmitted, and what aspects of Jason's life may have put him at risk for the virus? (mother-to-child transmission, blood-to-blood contact; Jason may have contracted hepatitis B through sharing needles.)
2. How can this kind of hepatitis B transmission be prevented? (by making needle exchange programs and harm reduction education widely available)
3. What measures can people like Jason take to make sure their sexual partners don't contract hepatitis B or HIV? (safe-sex practices, including condom use)

Story Transcript:

I remember all the questions swimming around in my head — why me? Why now? In 2011, I was living in New York City. One day, from a routine medical examination, I discovered the devastating news: I have hepatitis B. At the time my life was unbalanced due to misgivings with addiction, leaving me lost, spiritually bankrupt, confused. All the while living with AIDS.

I relocated back to my native Kansas after the untimely passing of my mother, which catapulted my life into recovery. Nearby Kansas City, which is flooded with hepatologists who only specialize in hep C. That's not what I have.

The doctor who was treating me had very little experience with hepatitis B/HIV co-infections. She put me on a higher dose of medication, which led to me developing kidney disease. She told me there was nothing she could do for me. When I lived in New York City, I learned to be proactive. So I started signing up with every research study I could find, as far away as Oklahoma and Texas.

I fell into a deep depression and attempted suicide, because I thought there was no hope. My husband stood by my side. Without him, I doubt I would have made it through those tough times.

Finally I found a hepatologist 290 miles away in Saint Louis. He was flabbergasted at the measures used to treat my hep B. He let me know right there everything was going to be all right; new medicines are coming down the pipeline in a few years. He enrolled me into his cohort study to monitor what makes hep b better or worse. He made me feel like I mattered.

So today I educate high school students about hepatitis B as well as HIV. Let me tell you something hep B: I have you; you don't have me.

Jin – #justB You

Content Summary:

When she was very young, Jin's mother told her she had a germ and that she shouldn't touch anyone if she was bleeding. Later, Jin disclosed to her entire class that she has hepatitis B. Her mother visited Jin's school to make sure everyone was aware of what it meant, for a student to live with the virus. Today, Jin feels that it's her responsibility to disclose to new potential romantic partners that she is hepatitis B positive, and each time she does this, she gains new confidence and strength.



Key Take-Away Points:

- Healthcare delivery challenges mean that in some parts of the world, hepatitis B tests might be unreliable.
- Children living with the virus should be given age-appropriate information about what it means and how to protect others.
- Even though most people born in the U.S. after 1991 were immunized at birth and do not have to worry about contracting the virus, children who did not receive the vaccine when they were born (or who were born outside of the U.S.) should be tested for hepatitis B and, if negative, they should be vaccinated.
- With practice and support, those living with hepatitis B can feel confident about how to have conversations with potential partners about protection.

Discussion Questions and Answers:

1. How did Jin's classmates react, after Jin decided to tell them she had hepatitis B? (They reacted poorly,

due to a lack of information and understanding.)

2. How did Jin's mother react, after Jin decided to tell the class about her status? (She came in and did education sessions for students and teachers, to put them at ease about the situation.)

2. If most people have been vaccinated, why is it still important for people with hepatitis B to disclose their status to new partners? (In the U.S., only 25 percent of adults have been vaccinated against hepatitis B. For people born before 1991, it's important that they get tested and, if necessary, practice safe sex with their hepatitis B positive partners.)

Story Transcript:

When I was really little, my mother often told me, "Jin, you have a germ. It means that if you get a booboo, you shouldn't touch anyone." It made no sense to me. I just always felt that I was different.

Then, when I was in fourth grade, she officially told me that the germ is called hepatitis B. She said, "You don't have to tell anyone, though ... It's up to you." The very next day, I told my best friend and pretty much everyone in my class. I didn't get the best response.

My mother adopted me when I was four months old. According to my medical record, I didn't have hepatitis B. Two years later, she read an article that said children from China should be re-tested, because the tests over there weren't always accurate.

After she found out about my status, my mother made sure to learn everything she could. She became a real advocate for families and communities dealing with the virus. So after I shared my news with my classmates, my mother came in and did a seminar. She explained how viruses spread and how to be careful with blood. No one pointed fingers and said, "You have hepatitis, and that's why we're all talking about this," but they all knew. I felt singled out, embarrassed ... of course.

I got over it, and pretty soon regular doctors visits just became my normal life. I haven't been on meds at all; my viral load has always been low.

Every time I have a new partner or meet someone special and want to welcome them into my life, it's still up to me, but I have to disclose my status to them. Despite the fear, it gets a little easier each time. I take a deep breath and just say it: "I have hepatitis B."

Joe – #justB Persistent

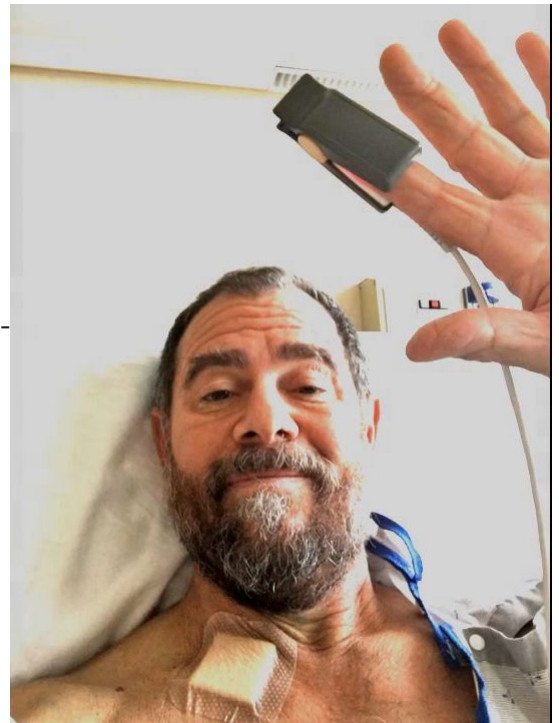
Content Summary:

After being diagnosed with hepatitis B, Joe didn't seek regular monitoring because his doctor didn't provide information about what his diagnosis meant. Years later, he learned that his liver was inflamed, and that he was also infected with hepatitis delta – a serious coinfection of hepatitis B. Joe began to learn as much as he could about his coinfection, and after discovering that treatments were limited for hepatitis delta, he joined the only clinical trial available at the time. Although Joe had to discontinue the trial early, his health is now stable, and he is glad he has been able to contribute to important research. Even after

his difficult journey, he is still hopeful that better treatments, and even a cure, are on the way.

Key Take-Away Points:

- Hepatitis delta is a severe form of viral hepatitis that can infect people living with hepatitis B. All people with chronic hepatitis B should be tested for hepatitis delta!
- Seeking social support is very important when living with hepatitis, so you don't have to go through the journey alone!
- By advocating for his health, and joining a clinical trial, Joe's health advocacy was key in helping him get the monitoring and treatment he needed.
- While current treatments to control hepatitis delta are limited, there are promising new drugs in clinical trials.
- Because hepatitis delta requires someone to also have hepatitis B, the best way to prevent a coinfection is by getting the hepatitis B vaccine series (if you are not already infected with hepatitis B).



Discussion Questions and Answers:

1. What led Joe to initially put off seeking follow-up care, after he tested positive for hepatitis B? (His doctor did not educate him about hepatitis B, or let him know that he should be monitored by a doctor.)
2. How did Joe become his own healthcare advocate? (He did his own research after receiving very little information from his doctors, talked to his loved ones and community about his hepatitis, and found a clinical trial to join so that he could be monitored and treated by doctors who were more knowledgeable about hepatitis delta.)
3. What does Joe wish was available in the 1970s, before he contracted hepatitis B? How would this have changed his story? (The hepatitis B vaccine. It could have prevented both hepatitis B and delta.)
4. After watching Joe's video, what might you tell someone who is living with hepatitis B? (Get tested for hepatitis delta, and be your own healthcare advocate.)

Story Transcript:

As a kid who loved nature, I was always smelling the flowers, digging in the garden.

In the mid 70's, as a young, gay flower child, I faced my fears and came out to myself, my mom, and friends.

One day a friend said, "Hey Joe, your skin's a little yellow, you should see a doctor."

I found out I have hepatitis B, but was told nothing about what that meant, and I just forgot about it.

The AIDS crisis hit. Everybody was worried. I got tested and was relieved – I'm negative, but I did still have hepatitis B.

I learned how to be safe. I did lots of research at hospital libraries. I faced my fears again, and I came out to

my gay men's community about having hepatitis.

I still didn't feel ill when, in 2013, my liver became inflamed. It turned out I'm also infected with a rare, serious virus: hepatitis delta. In a follow-up email, the specialist typed, "There's no good treatment. Good luck."

I wasn't about to leave it up to luck. I got online and found out more about hepatitis delta, and that it only affects people who also have hepatitis B. I wish they'd had the hepatitis B vaccine back in the 70's – it could have prevented both viruses.

At the time, the only drug trial for hepatitis delta in the U.S. was at the National Institutes of Health. I hoped this trial could save my life. I joined and flew across the country some 60 times in 6 years to get the treatments I needed.

Last December, the delta virus in my body was near zero. The treatment was really working!

Then, with just two months of the trial left, I fell ill. *Really* ill. I lost 25 pounds in three weeks, and my abdomen filled with fluid.

In drug trials, the patient's well-being is always the first priority. My doctors took me off the drugs and I've recovered.

Sure, I'm disappointed I didn't finish the trial, but I feel so good about my part in the research. I'm still being tested, still monitoring myself, and I'm *still* hopeful we'll find a cure.

John – #justB Positive

Content Summary:

When he was 16, John learned during a routine medical checkup that he had hepatitis B. After his mother reacted with tears and concern, he decided that he needed to demonstrate to himself and others that people living with the virus can live full, adventurous lives. John decided to organize a charity bike ride to raise money for hepatitis B research. The support he received from people following his journey from Florida to Pennsylvania gave him the strength necessary to endure a multi-state bike trip.



Key Take-Away Points:

- Young people can still be infected with hepatitis B, even though vaccination has become routine.
- Sometimes people who have hepatitis B do not know how they were infected, and don't fit into any identified risk group.
- Living with hepatitis B doesn't always mean managing multiple symptoms; most people with the virus pursue the same activities they enjoyed before learning their status.

- Raising awareness about an often-ignored health issue like hepatitis B can inspire hope in families affected by the virus.

Discussion Questions and Answers:

1. If all newborns in the U.S. are immunized, how might John have become infected with hepatitis B? (He could have been born just before routine vaccination began in the U.S.; he could have contracted the virus through contact with blood in preschool or elementary school; he could have been a non-responder to the vaccine — about three percent of people do not respond to the vaccine.)
2. How is it that some people experience extreme fatigue and other symptoms, when they have hepatitis B, and others, like John, can live highly active lives? (Viral loads can vary dramatically — for those with a high viral load, symptoms may be present. For those like John, with low or dormant concentrations of hepatitis B in their blood, symptoms can be absent altogether.)
3. What motivated John to continue his bike ride, even when he was sweating and exhausted? (The support and phone calls of people affected by hepatitis B motivated him to continue bringing visibility to the issue.)

Story Transcript:

I'm cycling in the middle of the afternoon. It's June in rural Georgia. Waves of heat rise from the terry asphalt of the highway as semi's roar past, my bike and I blowing like a leaf in the wind. The air is so thick you almost have to chew it before taking a breath. Salt from sweat stings my eyes, and I'm trying to distract myself from the hundreds of miles left to ride. I'm thinking about my 18th birthday, only a couple weeks away, and how so much can change in a short amount of time ...

Like when my mom took me to see the doctor a couple of years earlier. I was 16 and having stomach pains, so we waited what felt like an eternity in the small exam room, the high hum of the fluorescent lights buzzing overhead. Finally, the door swung open, and the physician assistant entered. "We've done some blood work, Mr. Ellis. There may be some mistake, but you tested positive for hepatitis B."

I didn't even know what that meant, but my mom's reaction said it all. When I went back for more tests, my mom stayed in the waiting room, so I wouldn't see her cry.

Just like that my life changed. I knew I had to prove to myself that I could be bigger than my diagnosis. I wrote to the Hepatitis B Foundation about organizing a charity bike ride to raise awareness and funding for research.

The summer after my senior year, my best friend and I left from our high school with my mother and grandmother in a van driving along with us. Averaging 60 miles a day, it took us three weeks to travel the 1,200 miles from Pensacola, Florida, to Philadelphia, Pennsylvania.

What we were doing was so much bigger than us. People I didn't even know called me. An elderly woman who was living with the disease, a father with a teenage daughter who was recently diagnosed. They told me how good it felt to know I was doing this, to know that there was hope for those living with hepatitis B.

So I kept on pedaling.

Kat – #justB Knowledgeable

Content Summary:

Kat's father has hepatitis B, but nobody in the family is willing to talk about it. For years, they weren't allowed to share the same chopsticks or eat dinner with him, for fear of transmission. As Kat grew older, she learned how hepatitis B is actually spread and shared this information with her family. Kat later became a hepatitis B outreach and education worker, drawing on her personal experience to teach other families about hepatitis B transmission, screening, prevention, and care.

Key Take-Away Points:

- Hepatitis B is not spread by casual physical contact, including: sharing utensils, eating food out of the same bowls, or eating food prepared by someone who is infected.
- It is important for family members of those who are living with the virus to educate themselves, so that they are knowledgeable about how it is transmitted.
- Stigma within some communities keeps people from talking and learning about hepatitis B.
- It is important that we break the myths about hepatitis B, so that we do not stigmatize or discriminate against people who live with the virus.

Discussion Questions and Answers:

1. Why was Kat's father not allowed to have dinner at the table with his family? (They believed that they could contract the hepatitis B virus by eating with the same utensils or being in close physical proximity with one another.)
2. If hepatitis B is not transmitted through casual contact, how does it spread? (The hepatitis B virus is transmitted through direct contact with infected blood, unprotected sex, contaminated or improperly sterilized needles, injection drug use, or mostly commonly from an infected mother to her newborn during pregnancy or childbirth.)
3. What reasons did Kat's immigrant and refugee patients give for keeping silent about hepatitis B? (Kat's patients were afraid of losing their jobs, even though the Americans with Disabilities Act prohibits employment discrimination based on someone's hepatitis B status. They were also afraid of losing family relationships and friendships.)

Story Transcript:

We were all sitting at the dinner table. Everyone except dad. I asked, "What is Hepatitis B, anyway? Why can't dad eat with us anymore?" My mother answered. "Because you might catch it from him."

I was confused when I found out about my father's diagnosis. No one in the family was willing to talk about it, so, I thought that it must be something like flu that would go away on its own. But we weren't allowed to have dinner together anymore. My mom wouldn't let us use the same utensils. When I tried to hug my



dad, he backed away from me.

As I grew older, I looked online, and I read community resources to learn about how hepatitis B is actually spread. It's not spread by sharing dinner or using the same chopsticks or spoon. It's not spread by being close or by hugging family members and loved ones. But so many people believe that it is because the people around them tell them so.

Later, when I started working as a hep B advocate, I supported other immigrant and refugee patients. Their stories of families and communities reminded me of my own. I heard their fears of losing their jobs and their friends and family if they talked about it. But we need to talk about it.

Looking back, I realize how much my father missed, and how much he suffered. I missed out, too.

Kenson – #justB There for Others

Content Summary:

Kenson was living at home in the Marshall Islands when he learned he has hepatitis B. After being told that treatment was unavailable there, he and his wife moved to Hawaii, where he had a successful liver transplant. His recovery was challenging, and he thought a great deal about why he had to go through the surgery. Now, Kenson and his wife educate the Pacific Islander community in Hawaii about hepatitis B risks, challenge myths held about the virus, and do all they can to promote testing and care.

Key Take-Away Points:

- Inadequate healthcare resources prevent many people from accessing appropriate care for chronic conditions like hepatitis B.
- Liver cancer caused by hepatitis B is preventable. Efforts must be made to advocate for access to treatment — regardless of geographic location or ability to pay.
- Cirrhosis of the liver does not have to be a death sentence; many people have had successful liver transplants.
- For those with hepatitis B, doing community education can be a way of helping to make sure others do not have to face cancer or other severe outcomes of the virus.

Discussion Questions and Answers:

1. Why did it take so long for Kenson to discover that he has hepatitis B? (Inadequate healthcare resources in the Pacific Islands mean that many people at risk do not have access to testing and treatment.)
2. What does Kenson's story show, about the value of community education about hepatitis B? (If people have accurate information, they can seek testing; if they test positive for the virus, they can pursue appropriate follow-up and treatment.)



3. How does Kenson decide to help address hepatitis B in the Pacific Islander community in Hawaii? (He and his wife get involved in outreach and education, by going to the places where their community members gather and providing information and resources.)

Story Transcript:

I didn't know I had hepatitis B until I got really sick. I knew I needed treatment. But when I went to see the doctor back home, the doctor said, "I'm sorry — nothing we can do for you." This was in the Marshall Islands, where I grew up. The resources for healthcare just aren't there.

I was lucky: my wife and I were able to move to Hawaii so I could get treated. A year later, I had a successful liver transplant. As I lay in my hospital bed, struggling in pain, I felt so angry about my situation. I didn't know for so many years that I even had hepatitis B, and I never had access to healthcare and treatment.

That's when the thought came: Maybe this is the time for me to do something about this. I decided to teach my community about the disease to save lives. I wanted my community to break the taboo, so we can freely talk about it, especially because there are resources out there to help you live a long, healthy life.

My wife and I now talk to our communities about hepatitis B. We go out family to family, church to church, student to sports groups, to fishermen and women's weaving groups. We've been welcomed by so many people who are hungry for information. We talk about risks, explain how the virus is spread, urge everyone to get tested, and advocate for improvements for our health facilities.

We are a great team, and I am so lucky to have her as a partner. Together, we are working to save the younger generation.

Kim – #justB Courageous

Content Summary:

Kim's father was forced to escape to the United States from Vietnam, in the wake of the war. He located his family and brought them to Minnesota. Kim shares her love for her father and wonders whether the stigma about hepatitis B in the Vietnamese community prevented him from telling the family and seeking medical care earlier. She celebrates his gentle spirit, and suggests that access to culturally and linguistically appropriate resources could have prevented his death from liver cancer.



Key Take-Away Points:

- The stigma surrounding hepatitis B prevents people from speaking up about their status; stigma must be challenged.
- Hepatitis B is not transmitted through casual contact, it is transmitted through direct contact with in-

fectured blood, unprotected sex, contaminated needles, or from an infected woman to her newborn during pregnancy and childbirth.

- Culturally appropriate and language specific resources about hepatitis B must be made available, so that those who test positive for the virus can be encouraged to seek treatment and support.

Discussion Questions and Answers:

1. Why does Kim talk in her story about her family's history of immigration to the United States? (Health disparities often prevent immigrant communities from being able to access services; this can be a factor in hepatitis B education and treatment.)

2. Kim gives several reasons for why her father may have failed to reveal his hepatitis B status or seek treatment. What are they? (Fear that people would avoid him, gossip about him, or refuse to hug him or use utensils that he has recently used)

3. Kim celebrates her father's courage in living until the end. What does she say about how the stigma in her community might be addressed, and where might resources be made available? (Vietnamese-language health-education resources and information about testing and treatment can be made available not only at health centers serving the community, but also at gathering places like churches, markets, and restaurants.)

Story Transcript:

I was always daddy's little girl. In this picture, he's holding me when I first came to America. He had been a soldier in the Vietnam War and had to escape to America in 1981. A year later, my mom, sister, and I escaped by boat to a refugee camp in Indonesia. He was able to find us and sponsor us to bring us to Minnesota, and worked for years to help others find safety like we did.

He and I are so much alike. Except he was always stoic and upright, and I was always throwing my arms around him whether he liked it or not. Even though my siblings may disagree – I was his favorite.

He knew he had hepatitis B for many years before he was diagnosed with liver cancer. It's pretty common in the Asian communities, but no one talks about it. He was the same way. He never told us he had it ... maybe because he thought people would gossip and treat us differently. They would be afraid to shake his hand, share our food, or even be in the same room with him.

I can understand why he was afraid to say or do anything about it. Maybe if we had resources in our language, people could be educated, and more of us would know better. And I might have been able to help my dad sooner.

When the doctors told him he had six months to a year to live, he didn't let that stop him from doing what he loved. This picture was taken on our last trip to Hawaii, his favorite place. He said they had the sweetest tasting longan (a fruit that grows throughout Southeast Asia and the Pacific islands) here.

He was in and out of the hospital a lot, being poked and prodded. But he never complained. He always just smiled and sweet-talked the nurses into giving him apple juice. He knew he was dying, but he chose to live until the very end. Always with a gentle smile.

M.D. – #justB Vocal

Content Summary:

M.D. grew up in Vietnam and learned at age 12 that she has chronic hepatitis B. She kept this information to herself until she came to the United States to attend college. After attending a student conference, she wondered why people with various health conditions keep them secret. She decided eventually to tell her roommates and is gradually coming forward to speak about living with the virus.



Key Take-Away Points:

- Deciding to disclose one's hepatitis B status can be a process that unfolds over time.
- Hepatitis B is not the only health condition that is stigmatized; many people keep their health status to themselves, for fear of discrimination.
- Disclosing to friends and colleagues can open a space for seeking support with the challenges of living with hepatitis B.
- Talking about hepatitis B can be normalized, so that those who live with it don't have to keep secrets.

Discussion Questions and Answers:

1. How does M.D.'s chronic hepatitis B affect her life? (Physically, she is often tired and needs to be careful of taking on too many activities. Emotionally, she struggles with feeling safe enough to disclose her status.)
2. What are some of the reasons why people living with hepatitis B might decide not to share this information? (They are concerned about discrimination, even though hepatitis B is a protected condition under the Americans with Disabilities Act. They are afraid of being judged by others, due to the stigma attached to the virus.)
3. How can disclosing one's hepatitis B status offer benefits that might outweigh perceived risks? (Like M.D., they can then ask for the help and support they need; additionally, they are contributing to stigma reduction and setting an example for others living with the virus to follow.)

Story Transcript:

Back in Vietnam, my friends usually hung out late in the city center or stayed up to watch movies. As much as I wanted to enjoy the companionship until the end, I held back. I always politely declined by saying, "I'm tired. I need to recharge." The true reason was that I have known I have chronic hepatitis B since I was 12 years old.

When I was 17, I hopped on a plane to the United States to study. A new horizon, a hopeful chapter of my life, but still, I kept my secret. I just wanted to successfully complete four years of study while not making my liver condition any worse.

A year later, I was at a student-leadership conference. An activist talked about ableism, which is discrimination because of disability or disease. She gripped my heart with her words. In a room full of 100 students,

I felt like she was talking directly to me. I wondered, “How many other people in this room are keeping secrets about their health conditions? Why can’t we talk about it?”

When I was younger, I didn’t know how serious it is. Now, I understand it’s a life-long disease. Even though sometimes I’m afraid I’ll be discriminated against, I told my roommates. I was tired of keeping the secret, and I wanted to be able to ask them for help, if I needed it.

I have a burning desire to say openly that I have chronic hepatitis B — just like I would say I have the flu, even though hep B is way less contagious than a flu is. We hide our conditions inside.

So many people keep their secrets bottled up. They think, “I’m the only one,” because they’re afraid to speak out, they’re worried they’ll be judged.

But if we all speak out, no one will feel like “the only one.”

Maureen – #justB Brave

Content Summary:

Maureen did not learn that her soon-to-be adoptive daughter, Libby, has hepatitis B until she went to China to pick her up. She and her husband made the decision to go through with the adoption. Libby and her adopted sister, also hepatitis B positive, have led happy, healthy lives. Maureen has always been open with the girls about risks of transmission, but now that her daughters are entering adolescence, Maureen struggles with how best to talk to them about what living with hepatitis B means for any intimate relationships they may form.



Key Take-Away Points:

- A positive hepatitis B test does not mean that children should not be considered for adoption.
- Many parents are safely raising families with children who have hepatitis B; once other family members are vaccinated, there is no risk of transmission.
- Resources exist to support parents in learning how to talk openly with their children about hepatitis B.
- Although the risk of transmission is small, given routine vaccination at birth in the U.S., those living with the virus still need to know how to protect partners.

Discussion Questions and Answers:

1. Why do you think the doctors in China looked so serious, as they were informing Maureen of her adoptive daughter’s hepatitis B status? (They were aware of the possibility that Maureen might decide not to go through with the adoption; they understood the challenges of living with hepatitis B.)
2. What considerations may have gone through Maureen’s and her husband’s minds, as they made their decision about adopting their two daughters? (They may have worried about bringing hepatitis B positive children into the family. They ultimately decided the risks didn’t outweigh the importance of creating their family. They

didn't want Libby to feel isolated, as the only Chinese sibling AND the only one with hepatitis B.)

3. How can parents facing challenges like Maureen's access accurate information about talking to their hepatitis B positive children about risks? (They can seek resources at their local health center or online, through the Hepatitis B Foundation. They can reach out to other parents in similar situations.)

Story Transcript:

When I heard the knock on the door, I was glad. It was the day before I was supposed to meet my daughter, and I was alone in my hotel room in China. I was the only one in our group of adoptive parents who had traveled without a partner or a friend, and I felt alienated from everybody. I thought, "A little company would be nice" and said, "Come in."

The doctors with our group entered, and they looked very serious. One of them said, "Maybe you should sit down."

I remember thinking, "Wow, people really say that."

The other said, "We did some blood work. I'm so sorry, but your baby is hepatitis B positive."

No one had wanted me to go through with this. My husband and I already had two kids. But I had always wanted to adopt. I earned the money to finance the adoption myself by taking on a paper route, on top of my regular job. So, when the doctors told me they could find another child for me, I had already seen her picture. I said, "No, I'm not leaving her here." When I emailed my husband, to my relief, he agreed.

I met her the next day, and she was beautiful, healthy, and happy, and I knew I had made the right decision. Because I didn't want Libby to be both the only Chinese child in our family and the only hepatitis B positive child, a year later, we adopted Leilei.

I've always been really open with the girls about their status. I've said, "Most people have been immunized, now, so it's not that a big deal." And I've reminded them to be careful about blood, just in case.

But now they're 14 and 16, getting ready to start dating. And they sure don't want to talk to me about what that means — for relationships, for potential partners. About what the risks, however small, might be. They don't really want to talk to their pediatrician either.

Sometimes I worry that I'm not qualified to parent them through this tough time of life. Day by day, I'm just trying to learn what I can and find ways to be open with them. Together we'll find our way.

Michelle – #justB Faithful

Content Summary:

Michelle focuses her story on the experience of caring for her husband Peter, who went from feeling relatively healthy to being in a medically-induced coma due to liver failure. She speaks of the anxiety she felt as their family waited to find out whether an appropriate donor could be found, and the relief they expe-

rienced once Peter was approved for a liver transplant. Michelle acknowledges that while the medical team was top notch, what made the difference through the process was the ongoing support of their extended family.

Key Take-Away Points:

- Hepatitis B is known as “the silent killer,” because people can be asymptomatic until they are very ill. Some people who have hepatitis B will ultimately need a liver transplant.
- Liver transplants, while life saving, can be a long and difficult process for all those involved.
- Family involvement/support can play a key role in the successful recovery of liver transplant patients.



Discussion Questions and Answers:

1. What did Michelle learn about the process of obtaining a liver transplant, through her husband’s experience? (Michelle and her husband Peter found out that the criteria for transplants are quite extensive.)
2. Why did it take so long, for the doctors to identify an appropriate liver donor for Peter? (Donors need to be well enough to withstand lengthy surgery and recovery processes, and livers need to be matched in size to recipients.)
3. What challenges did Michelle face after her husband’s liver transplant? (She had to calm him when Peter experienced post-surgery delusions, and she and their extended family needed to be there to offer him ongoing support.)

Story Transcript:

We had no idea it involved so much to even get listed as needing a liver transplant. You need a high score on the criteria for liver damage, but you also need to be stable enough to go through the surgery. In ten days, my husband had gone from feeling tired and looking jaundiced, to being in a medically-induced coma because of liver failure. He was now first in line for a transplant in Arizona.

We were told there were two liver donors for him. I felt so hopeful. Then the first available liver was turned down because it was physically damaged. The second one looked good, but it wasn’t compatible based on my husband’s body size and weight. We didn’t hear anything for several days.

Finally, one afternoon, the doctor told me that there was a “possible” third. They scheduled the surgery for midnight. At 11 p.m., we still had not gotten a for-sure confirmation. I finally called the nurse and said, “Please tell us what’s happening.” I held my breath, and she told me, “Yes, they’re going to do it.”

I was really nervous when they rolled my husband’s bed to the operating room. The transplant took about five hours. Afterwards, he was delirious. He didn’t know where he was, he was seeing and imagining things, he thought someone was trying to kill him. I tried to calm him down, and I told him, “You’re okay, you need to rest.” Even though I understood why he was in that state, because I work in the medical field, I was still very worried.

The medical team was great, but what made the difference was our family. We stayed together, we prayed together, and everyone was so supportive. Now, six months later, my husband is almost recovered.

Nancy – #justB Tested

Content Summary:

Nancy recounts the story of her father's death. She and her family tried to get him into treatment, but it was too late; liver cancer had spread throughout his body. Nancy did not know how long her father had been living with hepatitis B. She wonders what could have been done, if only the family had known of the importance of screening and found out earlier about her father's status.

Key Take-Away Points:

- Hepatitis B infection can become chronic and lead to severe complications including liver scarring (cirrhosis), liver failure, or liver cancer if not detected and managed early.
- Being educated about hepatitis B is critically important for ALL, regardless of one's educational status and/or socioeconomic, cultural, or religious background.
- It is important for people who are at high risk for hepatitis B to be tested, so that they can enter medical care and prevent serious liver damage and liver cancer. This includes people who were born in Asia or Africa (where hepatitis B is common), as well as their children.



Discussion Questions and Answers:

1. What might some of the reasons be, for why Nancy's father failed to learn he had hepatitis B until it was too late? (He may have been in denial, felt ashamed due to the stigma and misinformation surrounding the virus, or afraid to question his doctor, who prescribed medication for indigestion. He might not have known that he was at risk for hepatitis B infection.)
2. Nancy wonders in her story how things might have turned out, if her family had found out early about her father's hepatitis B status. What actions could have been taken? (If Nancy's father had been tested years prior to his death, he could have begun monitoring and possibly treatment for the virus, which may have prevented his liver cancer.)
3. How is Nancy helping to ensure that other families don't have to go through what hers did? (By educating others about hepatitis B and helping people to understand the importance of getting tested.)

Story Transcript:

Good morning, Dad. The other day, mom and I looked through some pictures of you... You immigrating

here to the U.S. in the mid 1970's, getting your degree, buying your first car. Then mom looked down suddenly and sighed. She said, "It was too early for him."

My daughter, your granddaughter, was helping to interpret for mom and me. She interrupted and said to me in English, "I don't think grandma wants to talk about grandpa. Why do people have to die?" We cried together.

I remember that day so clearly. I had just graduated, and I'd done what you'd wanted—gotten a job in D.C., working for the government. You called me and said, "Come home!" What could be so wrong that you wanted me to come home permanently?

The first time we heard the words "terminal illness" from the doctor, we didn't understand what they meant. We tried to find a hospital that could treat you, but it was too late. The liver cancer had spread all over your body, and there was nothing else we could do. You lost your appetite, and we had to take you to the doctor to drain your stomach of fluid buildup.

Your sister was so upset. She said to you, "If you are so educated, why were you not smart enough to ask for a blood test? How could you not confirm what was going on with your health?"

To this day, we are not sure how long you had been living with hepatitis B. After you passed, we found boxes of medication prescribed to you for stomach indigestion. I am sure that was not treatment for hepatitis.

Sometimes I think about what could have been, if we had found out early. We could have gotten treatment to save your life.

I miss you, Dad.

Peter A – #justB Real

Content Summary:

Peter worked for years as a teacher in his native Nigeria, living in fear that his colleagues would discover that he has hepatitis B. He contracted it from a blood transfusion when he was just six years old. Later, Peter realized that the superstitions surrounding hepatitis B must be challenged, and that there are real ways to deal with the virus.

Key Take-Away Points:

- It is important to know that hepatitis B is a real medical condition, not just a superstition.
- Open communication among family members is key, so that relatives and loved ones of those infected can get tested, and vaccinated if needed.
- Life with hepatitis B does not have to mean fear or hopelessness; most people with hepatitis B live long lives, and there are treatment options, and support, available.



Discussion Questions and Answers:

1. Why didn't Peter attend the workshop on hepatitis B at the school where he was a teacher? (Peter already knew he has hepatitis B, and he feared he would lose his job if his colleagues found out.)
2. How does Peter believe he contracted the hepatitis B virus? (He thinks he got the virus through a blood transfusion he received when he was a child, before blood donations were routinely screened for hepatitis B in Nigeria.)
3. What keeps many people in Nigeria from learning their status early? (Because the importance of preventive healthcare is not widely accepted, people often do not seek medical attention until they are already sick. With hepatitis B, this is especially dangerous, since people can live without symptoms for years before suddenly succumbing to liver failure or liver cancer.)

Story Transcript:

In 2013, I was a teacher in a private secondary school in the southwestern part of Nigeria. One day, there was a workshop on hepatitis B transmission, prevention, and management. The trainers were testing everyone's blood. I already knew I was positive for the virus, and I was scared of losing my job.

Without saying anything, I quickly snuck out of the room. I was just trying to live my life, but really, I was living with a fear of liver transplant, cirrhosis, or sudden death. Sometimes, thinking about my situation made me feel hopeless.

I had discovered that I have hepatitis B thanks to my wife. She is a medical laboratory technician, and she had screened my blood for several diseases. I knew I had her support, but outside my home, I didn't have anybody to talk to about my health.

In Nigeria, people don't go to the doctor unless they are already sick. So, they don't find out about things like hepatitis B, and they don't know how it's transmitted.

I found documents showing that I had a blood transfusion back in 1989, when I was 6 years old. That was before they started screening blood donations. That was how I contracted the virus.

After I discovered my status, my wife and two kids got vaccinated, so they would not contract the virus from me.

Some people in Nigeria are superstitious and believe you can get Hepatitis B from witchcraft, if someone casts a spell on you. But I know Hepatitis B is real, and there are real ways to deal with it. Medicines can reduce the viral load and keep the liver healthy. There's no reason to live in fear and hopelessness.

Peter V – #justB Optimistic

Content Summary:

After being on medication for hepatitis B for more than a decade, Peter's GI doctor told him that his reduced viral load meant he could stop taking his medication. Just a year and a half later, Peter was in the hospital awaiting a liver transplant. Fortunately, a donor was found, and Peter is recovering well. He realizes that his GI doctor may not have understood the dangers of taking him off his hepatitis B medicine, and he has now found a trusted hepatologist to monitor his condition moving forward.



Key Take-Away Points:

- Most people on hepatitis B medication should expect to be on medication long term.
- Stopping medication for hepatitis B is a serious decision that can result in life changing complications.
- Liver transplants are no small matter and can result in a variety of related health problems.
- Those living with hepatitis B should always ask questions, do their own research, and seek the guidance of experts before following the recommendations of doctors who do not specialize in liver disease and may be less-informed about hepatitis B treatment.

Discussion Questions and Answers:

1. Why did Peter decide to stop taking his hepatitis B medication? (When tests found that his viral load was undetectable, his GI doctor felt he no longer needed to be medicated.)
2. How could Peter have gone from feeling alert and healthy, to being in a medically-induced coma, so quickly? (A damaged liver can still work, until there is too much damage for the liver to do its job. So, most people who have liver damage don't have symptoms until the liver stops functioning (liver failure), and then they can become symptomatic very quickly")
3. After his liver transplant, what new health challenges did Peter have to face? (He lost weight and mobility, and he became diabetic, due to the medicine he needed to take to make sure his body didn't reject the new liver.)

Story Transcript:

I have hepatitis B and was on medication for 12 years. The medicine reduced my viral load to an undetectable level, and my GI doctor said I didn't need to take it anymore. He said he would just review my blood-work results about every six months, so I stopped.

About a year and a half later, I spent Christmas with family, like we do every year. We even went to the park, and I did cartwheels. But shortly after New Year, I was feeling very fatigued. My wife told me my skin and eyes looked very yellow. I told her my pee was very dark and my poop was very light in color. She immediately took me to the emergency room.

I don't remember much after this, because they placed me in a coma to keep me alive. After 10 days, I woke up, and my wife told me the virus had completely destroyed my liver, and that I'd had a liver transplant. I remained in the hospital for another two weeks for follow-ups and therapies to regain my strength and speech.

It has been six months since my surgery. I'm on medications to make sure my body doesn't reject the new liver. My kidneys and immune system have been affected, I've lost 30 pounds, and I'm diabetic now, too, due to the medicine. Even though my life feels more fragile now, I'm very blessed to have my wife and family supporting me, so that I can continue to live longer.

After the transplant, my hepatologist said, "You should never have been taken off the hepatitis B medication in the first place." Maybe my GI doctor did not have enough knowledge of hepatitis B treatment. Back then, it never occurred to me to ask questions or research further. Now I know better.

Randy – #justB Determined

Content Summary:

The excitement in Randy's family over his son Cody's acceptance to the U.S. Naval Academy turned to disappointment when they learned that Cody has a hepatitis B infection. Even though monitoring and treatment have advanced considerably, the U.S. military does not admit people living with the virus. Randy hopes this policy can be changed, and he continues to support Cody in moving on and embracing a hopeful future.

Key Take-Away Points:

- While discrimination against people living with hepatitis B is illegal under the Americans with Disabilities Act (ADA), the U.S. military is not obligated to follow the ADA, and nonetheless bars those who are infected from being admitted.
- Treatment and care of hepatitis B have advanced considerably; this policy of the Department of Defense is unjust, outdated, and should be changed.
- Through patient advocacy, and people like Randy sharing their story, we can successfully advocate to change discriminatory policies. To learn how to join these efforts, contact us at info@hepb.org.

Discussion Questions and Answers:

1. What makes the military policy barring people with hepatitis B so unfair? (The Department of Defense is not using the most up to date clinical guidelines – the current policy violates the ADA, and it's also outdated, given the advances in treatment and care for hepatitis B, which can considerably lower a patient's viral load. Additionally, hepatitis B is vaccine-preventable, and the vaccine is required for all incoming military personnel.)
2. How does Randy respond to learning that his son cannot attend the Naval Academy in Annapolis after all? (At first, Randy and the entire family are very disappointed, but now they are trying to move on and encourage Cody to envision a different future rather than letting his hepatitis B status define him. Randy also hopes his family's story can help bring about change in the military's outdated policy regarding hepatitis B.)



Story Transcript:

Our whole family was expecting the phone call. That day, I was mowing the lawn, and I had our cordless phone in my pocket. I felt it vibrate, and I was so excited to see that the number was from Annapolis. I yelled to my son, “Cody, it’s them!” He had always wanted to serve his country, and he had made it into the Naval Academy.

We saw him swear in, and it was one of the proudest moments of my life. Then, while he was doing his basic training, we received a call. Cody said, “Dad, I tested positive for hepatitis B.” I said “What? That’s not possible...”

I married my wife in 1993, in Korea, when I was there in the Air Force. She and I knew she was positive for the virus, so we had both of our kids vaccinated at birth. Then they were re-tested when they were in grade school, and we learned our oldest son Daniel had hepatitis B. Now, it turned out Cody was actually infected. The news crushed us. We still struggle with it now, even three years later.

Right now, the Department of Defense says you can’t be in any branch of the military if you have hepatitis B. I’m hoping my story will help change this, so that others don’t have to face this type of stigma and discrimination. Having the virus is not as big a deal as they’re making it out to be. Things have come so far in the medical aspect, to keep it under control and prevent transmission.

I also hope that for Cody’s sake, he doesn’t take the disappointment as meaning he can’t throw himself into something else. He’s figuring out what’s next, and I tell him, “Don’t let this event define you; you can be whoever you want to be. Just keep dreaming.”

Rensely – #justB Strong

Content Summary:

When Rensely’s husband Kenson was diagnosed with liver cirrhosis, the doctor complimented her on her strength. She continued to be strong as she cared for him in his journey through a liver transplant. Eventually, as their resources depleted, Rensely had to go back to work to support the family. While their day-to-day survival is still tenuous, Rensely and her husband have decided to educate Pacific Islander communities in Hawaii, so that other families don’t have to face what they endured.

Key Take-Away Points:

- Adults with warning signs of chronic hepatitis B, such as fatigue, flu-like symptoms, and/or jaundice (yellowing of the skin and eyes), should get tested right away and begin appropriate care if they test positive.
- With medical care and treatment, serious liver disease and liver cancer caused by hepatitis B can often be prevented; this is why community education is so important.



- Caring for a family member with liver disease can be all consuming. Resources must be made available to support those facing this reality.
- A proper safety net and system of insurance is essential, if cirrhosis and liver cancer deaths are to be prevented.

Discussion Questions and Answers:

1. How do you think Rensely managed to stay strong while supporting her husband through his diagnosis and liver-transplant surgery? (She had no choice, as the family's sole caregiver. Like many people who are especially resilient, she knew that moving forward required her to remain hopeful.)
2. Why did Rensely eventually have to return to work, while caring for Kenson, and what devastating result did this have? (They ran out of money to pay their bills and were about to be evicted. She was forced to juggle the responsibilities of work and caregiving, but her income put the family over the Medicaid limit and almost eliminated their healthcare.)
3. What does Rensely's story suggest about the importance of universal access to healthcare? (Low income families, like Kenson's and Rensely's, often struggle to make ends meet and pay for medical care, which is why universal access must be maintained. With accessible and affordable preventive care, Kenson could have learned earlier about his hepatitis B status, started treatment, and avoided getting cancer in the first place.)

Story Transcript:

My husband was so frustrated, he just stormed out of the clinic. The doctor had just told us that there was nothing they could do for his hepatitis B, there in the Marshall Islands. I looked up at the doctor, when he complimented me for being strong. I said, "If I'm not, how can we move on?"

I stayed strong when we moved to Hawaii, and Kenson had his liver transplant. He was so sick. I wasn't able to work for a year, because I had to take care of him. Our children were in school, but they had to drop out, so they could help support the family. We wondered how we would survive, when we used up all our resources. We were about to be evicted from our apartment. We had nothing, we couldn't keep up with our needs. So, I decided to find a job, even though Ken was still very sick from his liver transplant.

Every day was the same. At eight a.m., I went to work; at noon, I came home to care for him; at one p.m., I went back to work; and in the evening, more care. On top of all this there were the insurance appeals. When I started my job, Ken lost his access to Medicaid, because my income put us over the income limit by two dollars and thirteen cents. We were living paycheck to paycheck ... we're still paying hospital bills now, still barely making it.

Every time I think of what we went through, I shed tears. But I also find that strength to keep moving on. I tell people, "Get tested for hepatitis B, and make sure you see a doctor to keep your liver healthy, if you are infected. You can prevent your family from going through what my family did."

Roger - #justB Focused

Content Summary:

Roger felt he was in good health because he was active, worked out regularly, and had regular medical checkups. After a physical, Roger was surprised to learn he has hepatitis B. He set about researching the disease, and he discovered he had been infected as a child. His education also led to his family members getting tested and vaccinated to prevent infection. Roger began taking medication and is living healthier now than ever.

Key Take-Away Points:

- Because chronic hepatitis B may not show symptoms, it's important for everyone to get tested for the virus.
- Education, as well as knowing your family health history, is key to identifying who may be at risk of infection and how the virus can be prevented and treated.
- vaccination is essential to preventing transmission of hepatitis B, and testing is important to know if you are infected.



Discussion Questions and Answers:

1. How did Roger's perception of himself as a healthy individual inform his reaction to his diagnosis? (Because he believed he was in good health, Roger was surprised to discover he was living with chronic hepatitis B—and had since he was a child.)
2. What was Roger's reaction to his hepatitis B diagnosis? (He began educating himself about the virus, investigating possible sources of infection, and seeking ways to protect his family members. He sought information about current hepatitis B research and clinical trials, is optimistic about a cure being discovered, and does not let hepatitis B prevent him from living life to the fullest.)
3. How does Roger's outlook contribute to his ability to manage his symptoms? (Roger has adopted a positive outlook, which he shares with others, and he speaks openly about his hepatitis B status. He considers the virus to be a blessing, as it led him to living an even healthier lifestyle than before.)
4. What is Roger's advice to others in his situation? (He feels that hepatitis B shouldn't keep them from doing things they want to do and doesn't preclude living healthfully.)

Story Transcript:

I had a pretty healthy childhood. I was very active, always the star athlete in school. I've been going to the gym since I was 18. Sure, like any young person, sometimes I went out on the weekend and had a few drinks. But I always got my regular physical checkups.

About six years ago, after one of those checkups, my doctor called me and said, "Hey, Roger, something doesn't look quite right from your blood tests. I want you to come in and get more testing." So I did. And afterwards, she called me into her office and said, "You've got hepatitis B." I just looked at her and said,

“What’s that?”

I really didn’t know what it was. So I went home that day and started to research it. That education was so key for me. I realized I had been infected as a kid. My family got tested, and when we found out my brother had it, too, I made sure my wife got vaccinated and our kids, too.

When I got diagnosed, my viral load was pretty high. My doctor decided to put me on medication. I take it once a day now, and I’ll have to for life. That medicine is a lifesaver. At my last check-up, I was completely healthy. I don’t feel any side effects. I’ve also been volunteering in trials for years now. It’s just a matter of time until a cure is found – it’s coming.

I tell others in my situation, “Don’t let it keep you from doing what you want to do.” It could be a curse, but it’s a blessing, too. Since I found out my status, I’ve started to live even healthier than I did before. Even though I think about it a lot, I live every day to the fullest!

Sura - #justB Vaccinated

Content Summary:

Sura and her brother were in medical school in Syria when her brother was punctured with a needle and infected with hepatitis B. Sadly, her brother passed away shortly after, due to fulminant hepatitis, a rare condition that can result from acute hepatitis B infection. Back in 1995, when her brother died, awareness of hepatitis B vaccination was low, and there was no opportunity for her brother to get a liver transplant. Sura is now training to practice medicine in the U.S. and is telling everyone to get vaccinated so they can avoid what her family went through.



Key Take-Away Points:

- Vaccinating health care workers and taking precautions in medical settings to prevent needle punctures can protect providers from becoming infected with hepatitis B.
- Knowledge about hepatitis B and available treatment options are increasing, although a divide between what is available from country to country continues to exist.
- Fulminant hepatitis, a rare, life-threatening condition that may cause sudden liver failure, can occur after someone has been infected with certain hepatitis viruses.

Discussion Questions and Answers:

1. How did the time period and location of his diagnosis affect Sura’s brother’s treatment? (Medical trainees like Sura misunderstood the severity of the virus, believing it could be treated with rest and a healthy diet. In 1995, in Syria, liver transplants were not available to save Sura’s brother’s life.)
2. How can medical professionals manage the risks of hepatitis B? (Because the CDC observes, “Health care

and public-safety personnel have a reasonably anticipated risk for exposure to blood or blood-contaminated body fluids,” all providers should be vaccinated.)

3. How is her brother’s death influencing Sura’s medical training in the U.S.? (She is learning more about hepatitis B, how to prevent and treat it, and encouraging everyone to get vaccinated.)

Story Transcript:

My family is from Iraq but we were living in Syria when it happened. My brother and I were in medical school. One day a friend called me. He said, “Come see your brother. He has hepatitis.”

In school I had learned, “Hepatitis just requires rest and for the patient to eat a healthy diet with honey.” So I thought there was no need for me to go. Then my friend called again and said, “Come home now.”

When I arrived, I saw my father and neighbors waiting in the street outside our home. From their faces, I knew he had passed. It was just one week after the symptoms started.

When I read the medical records, I learned it was fulminant hepatitis B. This is when the liver fails very quickly. At that time, it was not common to get vaccinated; no one was aware of the need. Even medical professionals did not know.

Three months before my brother had passed away, he told me, “Sura, I was suturing, and the needle broke. I pierced my finger.” Soon after, he got hives and fatigue. I told him “It’s probably nothing serious.” But it was.

He was just 21 years old. For my family, it was the hardest moment in our lives. My brother was so strong, so smart. But in the end, we are human beings, and we are not always strong.

I have since learned that fulminant hepatitis is very rare. In 1995, when it happened, there was no opportunity for a liver transplant to save his life.

Today many people still aren’t aware about hepatitis B. I am studying medicine again, this time to practice in the U.S. I am learning everything I can about hepatitis B, and I tell everyone, “Get vaccinated!” – so they don’t have to go through what my family has gone through.

Tuya – #justB Screened

Content Summary:

After her own family’s experience of immigrating to the United States from Mongolia and their relief at moving to a community where friends could point them to resources, Tuya saw the struggles of other newcomers and decided she wanted to help. She found work with a program that does hepatitis B and C outreach, testing, and treatment referral for immigrants in the greater Washington, D.C., area and has been gratified to see the community’s growing trust in her, her organization, and the medical system in the U.S.

Key Take-Away Points:

- Immigrant communities are often more vulnerable to the impacts of hepatitis B, as they often face cultural, linguistic, financial, and other challenges to accessing health care.
- If approached with understanding and sensitivity, newcomers can become trusting of health services offered in the U.S.
- Testing and treatment for immigrant communities disproportionately impacted by hepatitis B is crucial to improving the lives of those with hepatitis B, and preventing the further spread of the virus.

Discussion Questions and Answers:

1. Why did Tuya decide that she wanted to help her Mongolian community and other immigrant communities? (She saw their struggles to find jobs, arrange schooling for the children, and access quality, affordable healthcare.)
2. What issues do the Mongolian community face, when it comes to hepatitis B? (While hepatitis B and C are prevalent in the community, testing is not common. Many people are unaware of their status until they develop cirrhosis or liver cancer.)
3. What opportunity allows Tuya to give back to her community and support hepatitis B and C care and prevention? (Tuya finds a job at a local organization doing outreach to vulnerable immigrant communities, including the Mongolian community, and is connecting people who are infected with these viruses to specialists and ongoing care.)

Story Transcript:

My family, we came to the U.S. from Mongolia in 2014. Our first impression was, “Wow, what a wonderful place to live, especially for our kids...” But after some time, the reality of needing to survive in a very different culture sank in.

We moved to Arlington, Virginia, where there is a small Mongolian community. We wanted to live near our friends, so they could help us to adapt. Most newcomers settle in the area for the same reason – to get support from the community with finding jobs, enrolling their kids in schools, and getting used to the new environment. I saw frustration among people here, because of the language barrier and not knowing where to go when they get sick. Healthcare is much more expensive here. I wanted to help them, but I didn’t know how.

Then I got a chance to join a nonprofit organization doing outreach to minority groups, including Mongolians, to test for hepatitis B and C and link people to healthcare. I was so excited. Hepatitis B and C are big issues in Mongolia. Some of my friends have parents or relatives who suddenly got diagnosed with liver cirrhosis or cancer. It usually comes as a surprise, because they don’t show any symptoms. Most people with hepatitis B or C do not know they have it, because they look and feel healthy. The only way to know their status is to get tested. When people know they have hepatitis B or C, they can be monitored and treated, and we can prevent liver cancer and save lives.

When I call people to share their test results, I always explain that we can connect them to a specialist. People are starting to be confident that we can actually help them. They are appreciative, and it’s a noble feeling to realize you’re doing something important.



Wendy – #justB Hopeful

Content Summary:

Growing up in Canada, Wendy lived a typical upbringing, considered herself to be athletic, and was involved in many sports. When Wendy was in college, she found out she had hepatitis B and learned she got it from her mother at birth. Years later, when her mom was diagnosed with liver cancer, it was a wake-up call for Wendy – she realized the importance of educating herself about hepatitis B and committed to living a healthier lifestyle, getting regular checkups, and having her doctor actively monitor her hepatitis B.



Key Take-Away Points:

- It is very important for people living with chronic hepatitis B to be monitored regularly, since they are at increased risk of cirrhosis, liver failure, or liver cancer. If Wendy's mother been monitored and treated for hepatitis B, her liver cancer could have been prevented.
- If someone finds out they are infected with hepatitis B, they should seek care from a provider experienced in managing and treating the virus, even if they seem very healthy and have no symptoms.
- Lack of awareness about hepatitis B is still high, even in the medical field; patients living with the virus need to take initiative in monitoring their status, having regular abdominal ultrasounds, and living a healthy lifestyle.

Discussion Questions and Answers:

1. Why did Wendy not learn her hepatitis B status until she was in college? (Her mother may not have known her own status, or, if she did know she was infected, may not have understood the importance of having Wendy tested as a child.)
2. How did Wendy react to learning that she is infected with hepatitis B? (Because she was athletic and healthy, she assumes that she need not take action; her provider at the time may not have recommended follow up out of a lack of information about how to manage and treat hepatitis B.)
3. What advice does Wendy give, later in her story, about how people living with hepatitis B should take care of themselves? (She suggests the importance of learning all one can about the virus, being monitored regularly, and being aware that providers are sometimes not up to date about patient care for people with hepatitis B.)

Story Transcript:

My parents were immigrants from China, and I was born in Canada. I lived a pretty typical North American upbringing – celebrating Christmas, going on car trips. I was also athletic when I was younger, excelled in sports. I thought I was invincible.

It wasn't until university that I found out I have hepatitis B. All I knew was that I got it from my mom at birth and that it could be transmitted to others. My soon to be husband was tested, too. We were relieved to find out he was not. At that time, I didn't think I had to change my lifestyle.

Then about 15 years later, in the fall, my family found out my mom had liver cancer. We were devastated. She had never been treated for hepatitis B, nor had an abdominal ultrasound.

That Christmas, while the family sat together in the living room, my mom held our three-year-old daughter in her lap and sang a Chinese song to her, hoping she would remember it. She knew she would never get to see her grandchildren grow up. She died a few months later.

It was a wake-up call for me. I realized, "Wow, this is serious." I learned about a quarter of the people who have the virus eventually develop liver cancer. We need to be monitored and educate ourselves. Some doctors don't always know as much about hepatitis B as those of us who have it, so it is important to find a doctor who is knowledgeable about the treatment of this condition.

Now I monitor myself more regularly, get abdominal ultrasounds, live healthier. I want to be there for my family, for the grandkids I hope to have one day.

William – #justB Dad

Content Summary:

Excited by the impending birth of his first child, William decided to plan for his family's financial future. He was shocked to learn through a required health insurance blood test that he has hepatitis B and spent sleepless nights wondering how he contracted the virus and whether it was a death sentence. After wading through dense layers of information online, he went in for further tests and was reassured by a caring provider that with monitoring, dietary changes, and an active lifestyle, he can live a long life. He realized that knowing where hepatitis B came from isn't as important as focusing on staying healthy.



Key Take-Away Points:

- While it's normal to wonder "where the virus came from," excessive preoccupation with how one contracted hepatitis B can make it difficult for those living with the virus to move forward, accept their diagnosis, and seek appropriate medical care.
- Many adults with hepatitis B may have contracted the infection through mother-to-child transmission, or through unsafe practices in health settings (e.g., re-use of needles).
- Researching the potential impacts of a new hepatitis B diagnosis should be balanced with face-to-face conversations and follow-up testing to assess viral load and determine an appropriate response.

Discussion Questions and Answers:

1. How did William react to the news that he has hepatitis B? (He was shocked, as he had never heard of the

virus. He became very fearful about what the news might mean and sought information online.)

2. Although seeking information about hepatitis B online can be immensely helpful, what other actions should those who are recently diagnosed take? (Follow-up testing to assess viral load and determine an appropriate approach to care)

3. Why does William decide that knowing how he contracted the virus is less important than embracing a healthy lifestyle? (He is reassured after talking to his doctor that he will likely live for many years. He is able to re-direct his energy towards what is happening now: his relationship with his family.)

Story Transcript:

I was 35, newly married, and looking forward to the birth of our first child. I was excited and ready to be the world's number one dad. As a finance person, I wanted to get some planning in gear — a will, a rainy day fund, life insurance I was going to check these off by the time baby came. The insurance application included a blood test.

One afternoon I got a call from the insurance company. The test results were in. The man asked, "Do you know when you contracted hepatitis B?" I was floored. I had no idea what he was really talking about. All I knew about hepatitis was that it was supposed to be something bad. That night, I told my wife. She was as surprised as I was.

The next day, I locked myself in my office and spent hours online. Roaming through the search engines was like walking through a thick forest. Some articles roared at me like monsters, telling me I was doomed and would be six feet under by age 45. Others told me I'd be OK and could have a normal and full life.

As I read on and on, I could not help wondering, "What did I do, to get this? Did it happen when I came here to the U.S., or was it way back home in Ghana, where I lived for a couple years, or in Tanzania, where I grew up?"

The next several months were a journey through fear, understanding, and reassurance. After visits to a gastroenterologist, and a battery of tests, it was clear that I was going to survive. The doctor said that the virus was not replicating and was not currently causing any harm. He told me, "It's good that you found out, because with minor lifestyle changes, you will be ok." Stop drinking? Check. More veggies? Check. More cardio classes? Check. Bring it on!

I understand now that like all of us with this virus, I didn't do anything, to get hepatitis B. Knowing exactly where it came from isn't so important. What matters is what I can do to take care of myself ... so that I can still be the world's number one dad.

Xuan – #justB Supportive

Content Summary:

Sitting in the doctor's office and acting as an interpreter for her Vietnamese-speaking father, 12-year-old Xuan found out that he has hepatitis B. With the support of family members, doctors, and healthcare

workers, Xuan's father started to learn about the virus and take control of his health and his life. Xuan is now an advocate for multilingual resources to address hepatitis B, particularly in her local Vietnamese community.

Key Take-Away Points:

- Understanding the cultural and linguistic context of patients and providing appropriate language support is the responsibility of healthcare organizations; family members should not be expected to act as medical interpreters.
- Hepatitis B doesn't have to be a terminal illness – if diagnosed early, management and treatment options are available.
- Healthcare workers, community organizations, and family all play a pivotal role in providing ongoing education and support to those living with hepatitis B.



Discussion Questions and Answers:

1. What was it like for 12-year-old Xuan to act as an interpreter during her father's doctor appointment? (Xuan was shocked by the graphic images of internal organs in the room as she tried to interpret, and she was confused by the unfamiliar medical terminology.)
2. What factors contributed to Xuan being in the position of language interpreter, and to her father not already knowing his hepatitis B status? (Many healthcare facilities do not have trained medical interpreters and/or the resources to provide culturally and linguistically appropriate services, and Xuan's father's social and economic situation as a Vietnamese refugee likely made it difficult for him to access adequate preventive healthcare services.)
3. What helped Xuan's father and the whole family learn about hepatitis B and come to a place of understanding and gratitude? (With the support of Xuan, culturally-educated health workers, and knowledgeable doctors, Xuan's father learned what he needs to stay strong, while Xuan's current work as a hepatitis B caseworker and interpreter has brought the family together and benefitted the Vietnamese community in her area.)

Story Transcript:

The room was glaring white, with pictures of the insides of people's stomachs and livers. The doctor stared at me, and my dad sat there silently, waiting. I was just 12 years old, and there I was, trying to figure out how to interpret words like 'virus' and 'enzymes' from English into Vietnamese.

Both of my parents are from Vietnam, from a time of poverty, poor healthcare, and political restriction. They fled the country on separate boats. Some of my siblings died on the way, and it took a long time for my parents to find each other again in the U.S.

That day in the doctor's office, things got even more difficult: that's when we all found out my dad has hepatitis B. We had little knowledge of the disease. I didn't know how to use google yet. We thought

things could only get worse.

My dad deserved a professional interpreter, but I did my best. With me, kind health workers, and understanding doctors, he started to learn about hepatitis B and take control over his life. He told me, "There is nothing to worry about now. I know what is going on."

Today, my dad's mom has passed from liver disease, but my dad is strong. He has seen each of us graduate from school, and if we get married one day, he will be there to see it.

And me? I am a hepatitis B caseworker and interpreter. Every day, I meet people who are either newly diagnosed or going through treatment. I see faces of confusion and fear turn into faces of understanding and bravery.

Our family's story could have been different, but with support and knowledge, we were able to transform something that seemed devastating into something beautiful. Hepatitis B doesn't have to be an end. It can be a new beginning.

Appendices

Appendix A: Evaluating Your #justB Story Screening

Objectives

To give participants an opportunity to reflect on what they learned and experienced

To support participants in sharing what was useful and what might be done differently in future screenings

Time

15 minutes

Materials Needed

Chart paper, markers

Steps

1. On a piece of chart paper posted to the wall, draw two vertical lines to create three equally wide vertical columns. At the top of the first column, draw a "+" sign; at the top of the next column, draw a delta sign (Δ , the Greek sign for change); and at the top of the third column, write "ACTION".

2. Ask participants to respond to the following questions:

- What did you like about the session? (Note responses in the "+" column.)
- What did you learn or gain in this session? (Note responses in the "+" column.)
- Have your opinions changed as a result of participating? (Note responses in the " Δ " column.)
- Do you intend to do anything differently as a result of the session? (Note responses in the " Δ " column.)
- What would you change in future sessions? (Note responses in the " Δ " column.)
- What actions do you plan on taking as a result of attending? (Note responses in the "ACTION" column.)

Give participants the option of sharing comments verbally or in writing. If they speak, document their comments in the appropriate columns. If they prefer writing, ask them to write their comments on sticky notes or pieces of scrap paper, and post the comments on the flip chart.

3. Draw the discussion to a close by offering a brief summary of the key points mentioned during the activity and making any other closing points you feel are important but were not mentioned. Thank participants for their time.

Appendix B: #justB Story Screening Event Questionnaire

We would love to hear about your digital story screening event! Following your event, please complete the following questionnaire and send to rhea.racho@hepb.org, or you may complete the electronic version of this form at: <https://goo.gl/forms/WtIHjOSCgwOZbLz63>.

Date of Screening Event:	Time of Event (Start-End):
Location of Event (City, State):	Total # of Attendees:
Who planned and coordinated this event (name of person and/or organization)?	
Where did you hold the event (health fair, community organization, school, etc.)?	
Please describe the composition of your audience. For example: youth group, women's group, men's group, students (primary, high school, university, etc.), church group, teachers, politicians, policy/decision makers, healthcare providers, parent group, NGO, community group, co-workers, etc.	
Please describe the demographic characteristics of your audience. For example: urban and/or rural; ethnicities; number of men and number of women, audience age ranges, etc.	
What was the purpose of the screening? For example: part of a training; to mobilize community support; to move/educate policymakers; etc.	

Whose story or stories did you show? How did you determine which story/stories and how many to show at this event?

If applicable, what language did you show the video(s) in? What language did the group discussion/Q&A take place in?

How did the audience react to the story/stories)? To the best of your recollection, please provide quotes or examples of the reactions/comments that audience members made.

Did the screening inspire discussion among attendees? If so, what key issues and/or areas of interest came up during the group discussion?

What were the top questions that audience members asked during the Q&A discussion?

In what specific ways do you think audience members were inspired to act as a result of watching the story/stories? For example: get tested for hepatitis B, encourage others to get tested, or share stories with friends and family members, etc.

What worked well during the screening?

What did not work well during the screening? Were there any issues or problems?

What would you recommend/change for future screening events?

How was your event advertised/promoted (social media, flyers, mailouts, listservs, etc.)? Was the event open to the general public or invite-only?

What media outlets attended, if any? Were any participants interviewed? If so, who?

How useful was the [#justB Discussion Guide](#), in your efforts to plan and lead a story screening? Please comment on what resources were most useful, and what else might be added.

Please share any additional comments, observations, feedback, etc. that would be helpful for us to note for future screening events.

Appendix C: #justB Social Media Guide

Social media can help us spread the word about hepatitis B and share the stories you saw today with a larger audience. Please help us continue to break the silence surrounding hepatitis B by sharing the #justB stories on social media. For a sure retweet, like, share, or tag us @HepBFoundation — we would love to hear from you or other viewers on social media.

Sample Tweets and Posts:

Join us (DATE) at (VENUE) to learn more about #hepatitisB through #storytelling #justB (insert link to RSVP, or video example)

Chronic #hepB is the most common cause of liver cancer— learn more about it at our #justB story screening: (DATE and VENUE) (insert link to RSVP, or video example)

Help us break the silence around #hepB by attending our screening of #justB stories on (DATE) at (VENUE) (insert link to RSVP, or video example)

Excited about the stories from @hepbfoundation from real people impacted by #hepB #justB (insert link to RSVP, or www.hepb.org/justb)

#HepB is the world's most common liver disease, yet people aren't talking about it — help #endthesilence #justB (insert link to RSVP, or www.hepb.org/justb)

Up to 2.2 million people in the US are infected with #hepB — help raise awareness about this deadly disease #justB (insert link to RSVP, or www.hepb.org/justb)

Social Media Best Practices:

- Images go a long way — include photos and videos when possible in your social media items!
- In Twitter and Facebook, upload the digital stories directly to the page so that, as people are scrolling through, they can immediately see the video. This helps grab attention much more than having to click to an outside link.
- Be sure to re-tweet other posts using #justB to reach a larger audience and support others working on this initiative.
- Know your audience; personalize messages to them when possible.
- Share disease-awareness posts and encourage attendance at your story screening event.

Appendix D: Links to Online Fact Sheets About Hepatitis B

Note: If you're working with a print version of the guide, you can find these fact sheets here: www.hepb.org/justb and www.hepb.org/resources-and-support/fact-sheets/.

1. How Well Do You Know Hepatitis B?
2. Getting Tested for Hepatitis B
3. Understanding Risks of Hepatitis B
4. Understanding Acute vs. Chronic Hepatitis B
5. Preventing Hepatitis B
6. Living with Chronic Hepatitis B
7. Hepatitis B Treatment Information
8. Hepatitis B and Your Liver
9. Hepatitis B Fast Facts

Appendix E: Resources for Getting Involved in Hepatitis B Education and Advocacy

Hep B United Policy and Advocacy Resources

Hepatitis B is an illness that greatly affects many groups, particularly Asian American, Native Hawaiian, Pacific Islander and African immigrant populations. Hep B United – 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 – leads advocacy efforts to raise the profile of hepatitis B and liver cancer as urgent public health priorities and to amplify the voices of people and communities most impacted. [Hep B United](#) was co-founded and is co-chaired by the Hepatitis B Foundation and the Association of Asian Pacific Community Health Organizations (AAPCHO).

It is important that advocates, including community organizations, academic institutions, health professionals, and individuals, know about current issues in hepatitis B policy and advocacy. For more information, including how you can add your voice to the discussion, visit www.hepbunited.org/advocacy. If you have any questions, please email us at connect@hepbunited.org.

AAPCHO's B Activated Resource Guide

This three-part series (www.aapcho.org/resources_db/b-activated-resource-guide) is designed to give individuals and organizations the skills and knowledge necessary to develop programs and conduct hepatitis B-related policy and media activities.

Part One: [B Activated Compendium Highlighting Innovative Hepatitis B Community Models](#)

The compendium consists of case studies highlighting the standard practice of care of six community health centers/organizations across the country working to address hepatitis B in Asian American, Native Hawaiian, and Pacific Islander communities. The goal is to capture the innovative strategies used by these organizations, as well as the challenges each experienced. These case studies are not a prescription for success but tools to generate ideas to develop your own hepatitis B services and activities.

Part Two: [B Activated Hepatitis B Needs Assessment Report](#)

The needs assessment report explores hepatitis B prevention and care activities that exist in community health centers serving Asian American, Native Hawaiian, and Pacific Islander communities. The report also surveys medical providers for their perceptions and expressed need for resources to enhance their efforts in the prevention and management of hepatitis B.

Part Three: [B Activated Hepatitis B Policy Advocacy & Media Outreach Toolkit](#)

The toolkit is a useful resource to help individuals and organizations in their advocacy and outreach efforts at local, regional, and national levels of policy and media. A wide-range of information and resources are found throughout the toolkit.

AAPCHO's Understanding and Combating Stigma Toolkit

This toolkit (bit.ly/HBVStigmaToolkit) is written for health care providers and community health advocates who want to improve care and support for people affected by hepatitis B. The aim of this toolkit is to support you and anyone you are working with to confront and reduce the stigma associated with hepatitis B, and to promote increased prevention, care, and treatment of the disease.