

justB!

**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



Hepatitis B Foundation

Baruch S. Blumberg Institute

Contents

Acknowledgements	p. 3
About the Project	p. 4
Terms of Use	p. 5
Guidelines for Presenters	p. 6
Story Discussion Tools	p. 9
- General Discussion Questions for All Stories	
- Story Topic Index	p. 10
- Content Summaries, Key Take-Away Points, Story Transcripts, and Discussion Questions and Answers for Individual Stories	p. 11
Appendices:	
A. Evaluating Your Screening	p. 32
B. Screening Event Questionnaire	p. 33
C. Social Media Guide	p. 34
D. Links to Online Fact Sheets:	p. 35
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. Treatment of Hepatitis B	
E. Resources for Getting Involved in Hepatitis B Education and Advocacy	p. 36

Acknowledgements

The *justB* digital stories were created through a partnership of the Hepatitis B Foundation and StoryCenter.

Our gratitude goes to Arbutus Biopharma and Dynavax Technologies, for providing the funding that made this project possible. Thanks as well to the Association of Asian Pacific Community Health Organizations (AAPCHO) for allowing us to integrate the stories into the existing *justB* campaign.

Our special thanks go to the digital storytellers whose work is featured online 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 with StoryCenter, who led the digital storytelling workshops and co-authored this guide; Chari Cohen, Rhea Racho, Catherine Freeland, Kate Moraras, and Joan Block with the Hepatitis B Foundation, 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

In 2016, after attending an informational webinar on digital storytelling facilitated by StoryCenter, the Hepatitis B Foundation (HBF) decided to develop 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 15 people interested in sharing their stories. The two partner organizations arranged digital storytelling workshops in Berkeley, California, and Doylestown, Pennsylvania, to support these courageous women and men in sharing their stories and producing them as short videos.

The stories are now being shown online and 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. Join the conversation through social media, using #justB. The stories that are a part of this project aim to mobilize individuals and communities to reduce stigma and eliminate common misconceptions associated with hepatitis B. Visit the project online at www.hepb.org/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, HBF 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: storycenter.org

Terms of Use

These stories were created by and for people living with and affected by hepatitis B. The Hepatitis B Foundation 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 the #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 a 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 held in Berkeley, California, and Doylestown, Pennsylvania, 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. 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?

3. 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?

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

	Stigma	Disclosure	Living with Hepatitis B	Caregiving, Supporting Family Members with Hepatitis B	Barriers to Care	Treatment	Prevention, Vaccination
Alan	X		X		X	X	
Binh	X	X	X		X		X
Bunmi	X				X	X	X
Carolyn				X		X	
Kim	X			X	X	X	
Dai	X			X	X	X	
Espi			X		X	X	
Jason			X		X	X	
Jinqiu	X	X	X				X
John			X			X	
Kenson	X		X		X		X
MD	X	X	X				
Maureen		X		X			X
Rensely	X			X	X		X
William	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 life saving.

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.

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 ...

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 traditional beliefs about health and sickness.
- Stigma is not the only thing that causes people to avoid getting tested: when healthcare is simply not available, they may not see the point of knowing their statuses.
- 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 ability to pay.

Story Transcript:

Nobody wanted to talk about it. His friend who's 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 were 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.

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 infected 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.

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.

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 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.

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.

Jinqiu – justB You

Content Summary:

When she was very young, Jinqiu's mother told her she had a germ and that she shouldn't touch anyone if she was bleeding. Later, Jinqiu disclosed to her entire class that she has hepatitis B. Her mother visited Jinqiu's school to make sure everyone was aware of what it meant, for a student to live with the virus. Today, Jinqiu 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 Jinqiu's classmates react, after Jinqiu decided to tell them she had hepatitis B?
They reacted poorly, due to a lack of information and understanding.

2. How did Jinqiu's mother react, after Jinqiu 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."

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 hepatitis B positive, 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.
- Some parents of children living with the virus struggle to come to terms with their children's status/
- Living with hepatitis B doesn't always mean managing multiple symptoms; many 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 tarry 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.

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 shuts many people out of 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 symptoms 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 young generation.

MD – justB Vocal

Content Summary:

MD 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.
- The hepatitis B virus is much less contagious than the flu; talking about it can be normalized, so that those who live with it don’t have to keep secrets.

Discussion Questions and Answers:

1. How does MD’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 MD, 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:

1. A positive hepatitis B test does not mean that children should not be considered for adoption.
2. Many parents are safely raising families where hepatitis B is present among children; once other family members are vaccinated, there is no risk of transmission.
3. Resources exist to support parents in learning how to talk openly with their children about hepatitis B.
4. 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.

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; 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."

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 hepatitis B positive adults may have contracted hepatitis B through mother-to-child transmission in the years before the vaccine was available, 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.

Appendices

Appendix A: Evaluating Your 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: 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.

1. Approximately how many people attended your event?
2. Where did you hold your event (health fair, community event, school, etc.)?
3. In your opinion, was your audience engaged/attentive throughout the event? Please describe as best you can their reactions to the stories.
4. Did you have a speaker/expert/patient lead a discussion after you showed stories? If so, who was this person, and what topics did they focus on?
5. To the best of your recollection, please provide examples of the types of questions that audience members asked.
6. In your opinion, did the screening inspire discussion among attendees? If so, what were key areas of interest among attendees?
7. In what specific ways do you think audience members were inspired to act, as a result of seeing the stories you showed?
8. Please describe your use of social media in helping to promote your event.
9. How useful was this 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.

Appendix C: 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 story screening (DATE and VENUE) #justB

Excited about the stories from @hepbfoundation from real people impacted by #hepB #justB www.hepb.org/justb

Help us break the silence around #hepB by attending our screening of stories on (DATE, VENUE) #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 the campaign website <http://ow.ly/c09x30awZnf>)

Up to 2 million people in the US are infected with #hepB — help raise awareness about this deadly disease #justB (insert link to RSVP, or the campaign website <http://ow.ly/c09x30awZnf>)

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

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

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. Treatment of Hepatitis B

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

Hep B United Policy Resources

Hepatitis B is an illness that greatly affects many groups, particularly in Asian American, Native Hawaiian, and Pacific Islander populations. It is important that advocates, including community organizations, academic institutions, health professionals, and individuals, know about current issues in hepatitis B policy. Current policy and advocacy issues on hepatitis B are listed here, including Hep B United's responses and ways in which you can add your voice to the discussion. If you have any questions, please email us at connect@hepbunited.org.

Association of Asian Pacific Community Health Organization's B Activated Resource Guide

This three-part series 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.