Patients Driving Change

#JUSTB STORYTELLING CAMPAIGN
About the Campaign

#justB

- #justB is a national, multi-lingual storytelling campaign that shares true, personal stories of people directly affected by hepatitis B
  - Digital stories (videos)
  - Printed materials
  - In-person storytelling

- Launched in 2017 in partnership with StoryCenter and AAPCHO

- Funded by individual donors and educational grants from Arbutus Biopharma, Dynavax Technologies, and Gilead Sciences
Goals of the Campaign

■ AWARENESS
  Increase awareness and advocacy around hepatitis B

■ DESTIGMATIZATION
  Decrease stigma and discrimination associated with the disease

■ HEALTH EDUCATION
  Promote testing, vaccination, linkage to care, and treatment

■ EMPOWERMENT
  Empower people living with hepatitis B to share their stories to help educate the public and inspire action
What is Digital Storytelling?

**METHODOLOGY DEVELOPED BY STORYCENTER**

- Blend of oral history, popular education, and participatory media approaches
- Used for community-based public health practice and research
- Stories can be shared widely as tools for individual behavior, community, and policy change
- Centered around first-person stories ("I" voice)
- Small group process, not individual production
- Participatory and hands-on: Storytellers create their videos!
Storytelling Workshops

FACILITATED BY STORYCENTER & HBF

- Agenda includes: "Story Circle" script writing and voice recording, image gathering and story boarding, hands-on video editing, group story screening
- Process of creating stories is as important as the final media product: it provides healing, builds community, and develops public speaking and leadership skills
Campaign Progress & Activities

2016–2019

5 WORKSHOPS
36 participants from 19 states

40* DIGITAL STORIES
+18 translated videos – Mandarin, Cantonese, Vietnamese, Korean, Arabic, Twi, Yoruba, Tagalog, Khmer, Mongolian, and Chuukese

ONGOING ENGAGEMENT
National and local storytelling/public speaking opportunities and ongoing training/support

PROGRAM EVALUATION
Analyzing the impact on storytellers and audiences
Story Promotion

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

- **Campaign Reach & Video Views**
  - By video
  - By language
  - Via different platforms
  - Media coverage
  - Partnerships

- **Impact on Storytellers**
  - Post-workshop surveys (18 completed)
  - Follow-up interviews (23 completed)

- **Impact on Viewers**
  - Feedback from online viewers and in-person attendees of story screening events

- **Impact on Partners**
  - Usefulness of videos and materials in their work
  - Connections with storytellers
FACEBOOK REACH: 2 MILLION
1.4 MILLION VIDEO VIEWS

YOUTUBE VIEWS: 22,000+

Campaign Reach

Randy's Story

"I tell my son, Don’t let this event define you; you can be whoever you want to be. Just keep dreaming."
Story Screening Events

- 8 local story screening events in 6 cities for a total of 188 attendees
- 74% of survey respondents reported an increase in their HBV knowledge after attending an event
- 86% on average agreed that the stories increased their understanding of HBV transmission, risk factors, prevention, treatment, and/or populations impacted
“I really enjoyed the personal stories. Hearing first person experiences re: HBV has such a significant impact and realism that is not accessible when approaching the topic from a clinical or third person perspective. It’s very sad but powerful to hear the experiences re: stigma, isolation, perseverance, and how they are fighting for their families, friends, and others.”

“It was very informative. I came in not understanding what it really was. Now I understand how important vaccinations are. It is an important topic to discuss, and I want to let my friends and family know how serious the problem is.”

“The stories were extremely powerful. That paired with data and key messages [was] a very effective presentation.”
“The stories were so impactful and truly inspired me to want to educate others. Great presentation.”

“JustB storytelling was very moving! The diversity in storytellers was great.”

“Very powerful + moving + essential!”

“Very touching, impactful and inspirational! Thank you to all the storytellers for your bravery!”

“Amazing job. The stories were inspirational.”

“The storytelling was wonderful. I will definitely be using the stories in our education and awareness outreach.”
Kim’s story is a loving tribute to her father, who died of liver cancer caused by hepatitis B. She wonders whether the stigma about hepatitis B in the Vietnamese community prevented him from telling the family and seeking medical care earlier and suggests that access to culturally and linguistically appropriate resources could have prevented his death from liver cancer.

He knew he was dying. But he chose to live - until the very end.

#justB

www.hepb.org/justB/kim

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2019

• Increase Capacity for Hepatitis B and C Testing and Linkage to Care (ICHTL) Grant Reviewer

• API Heritage Month “Be About It” and justB Storytellers Screening

Happy API Heritage Month! Thanks to all Minnesota Department of Health staff who participated in our events this month! Special thanks to all of our storytellers and community leaders for sharing your experiences!
2018

• HBI Accomplishments Luncheon and justB Storytellers Screening

• Hepatitis Awareness Month and justB Storytellers Screening at Hmong Health Care Professional Coalition
• HepB Taskforce – Training Providers and Community Leaders event

HBI-Minnesota/HBI-MN is with O'Liver B
Hepatitis and Hepb Taskforce at Minneapolis Airport Marriott.
April 25, 2018 - Bloomington, MN - 📞

Thanks to Dr. Richard Andrews and Dr. Amy Trang from the Hepb Taskforce for training our providers and community leaders on hepatitis B and hepatitis C! Special thanks to Gilead Sciences for supporting our event and to Minneapolis Airport Marriott for hosting!

• Health Fair at the Midtown Global Market

• Asian Health Equity Conference

HBI-Minnesota/HBI-MN is at The University of Chicago.
May 30, 2017 - Chicago, IL - 📞

Rounding out Hepatitis Awareness Month with some takeaways from Asian Health Coalition’s and The University of Chicago Center for Asian Health Equity’s Conference! Great visual notes by Ink Factory Studio #healthequity17 #HepatitisAwarenessMonth #NoHep
2017 - 2018

• St. Anne – St. Joseph Hien Church Festival

HBI-Minnesota/HBI-MN is at Saint Anne - Saint Joseph Hien.
June 23, 2017 • Minneapolis, MN • 🏛️

Thanks to Saint Anne - Saint Joseph Hien for joining our efforts to eliminate viral hepatitis! Special thanks to our volunteers and phlebotomist!
“After my liver transplant, my hepatologist said, “You should never have been taken off the hepatitis B medication in the first place.””

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 now 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.

www.hepb.org/justB/peterv

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A year after my diagnosis, my brother came to visit me. 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."

Growing up in a small town in Ghana, Bright faced many obstacles early in life, including the loss of his mother. After a hepatitis B diagnosis and period of hopelessness, he found strength and resiliency to not only cope, but thrive.

www.hepb.org/justB/bright

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“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.”

Growing up interpreting for her dad at his doctor’s appointments wasn’t easy. With time, education, and understanding doctors, he was able to get the care and attention he deserved in their new lives in the U.S. Being the daughter of Vietnamese refugees and now working as a hepatitis B caseworker, Xuan understands the struggles and barriers many immigrant families face in advocating for their health.

www.hepb.org/justB/xuan

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