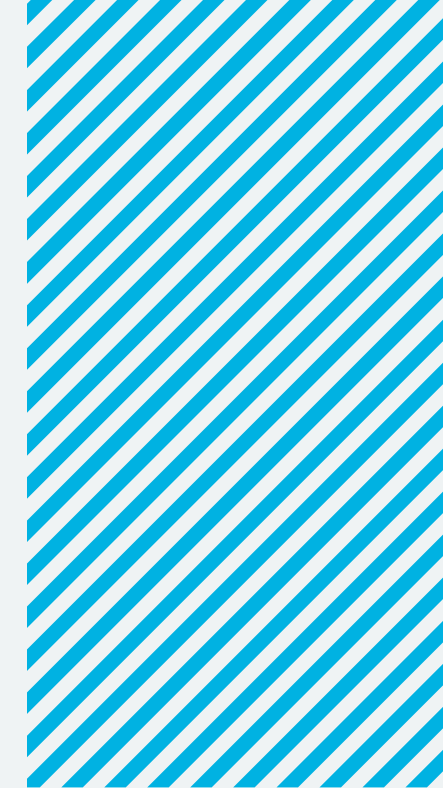




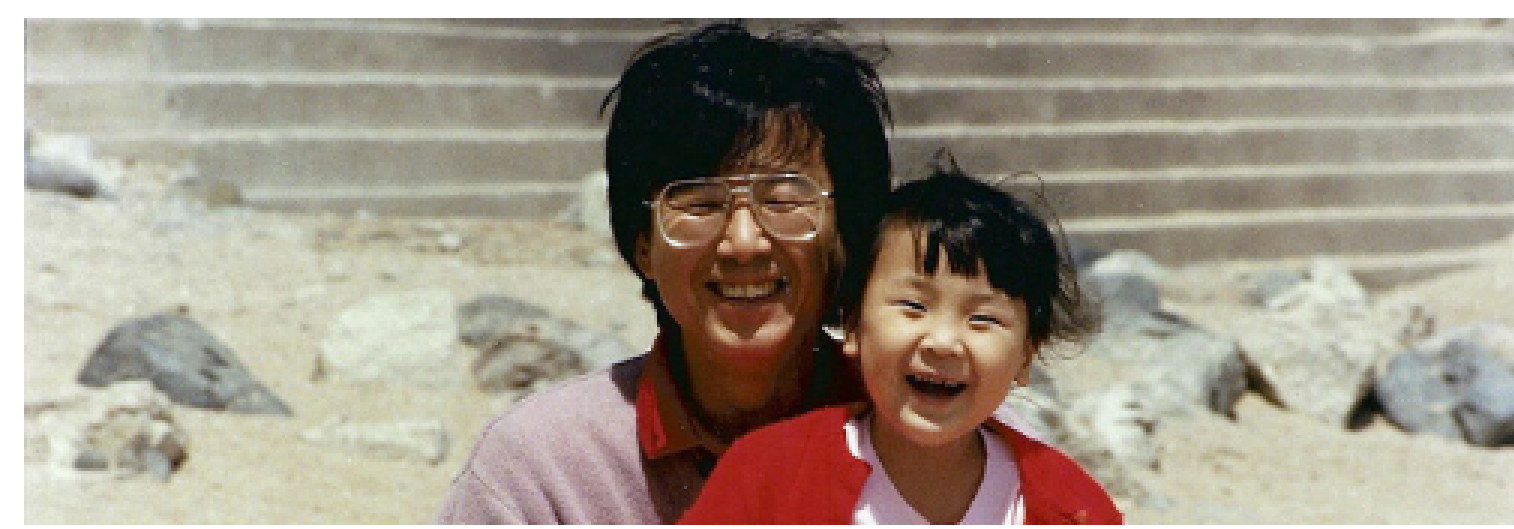
# Patient Storytelling Opportunities

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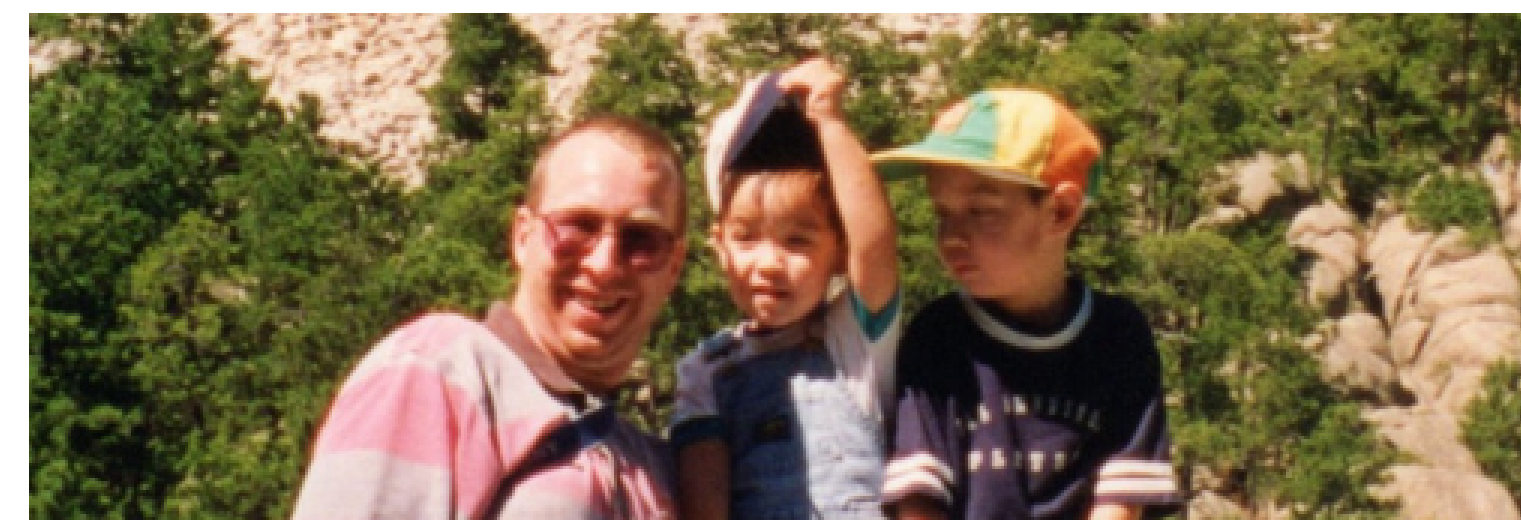
#JUSTB &  
B THE VOICE







**#justB**  
*Everyone has a story.*



# About the Campaign

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- #justB is a national, multi-lingual storytelling campaign that shares true, personal stories of people directly affected by hepatitis B & D
  - Digital stories (videos)
  - Printed materials
  - In-person storytelling
- Launched in 2017 in partnership with StoryCenter and AAPCHO

# Goals of the Campaign

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## ■ AWARENESS & ADVOCACY

Increase awareness and advocacy around hepatitis B

## ■ COMBATTING STIGMA & DISCRIMINATION

Decrease HBV-related stigma and discrimination

## ■ HEALTH EDUCATION & PROMOTION

Promote hepatitis B testing, vaccination, linkage to care, and treatment

## ■ EMPOWERING & ENGAGING PATIENTS

Empower people living with chronic HBV to share their stories to help educate the public and inspire action



# What is Digital Storytelling?

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## METHODOLOGY DEVELOPED BY STORYCENTER

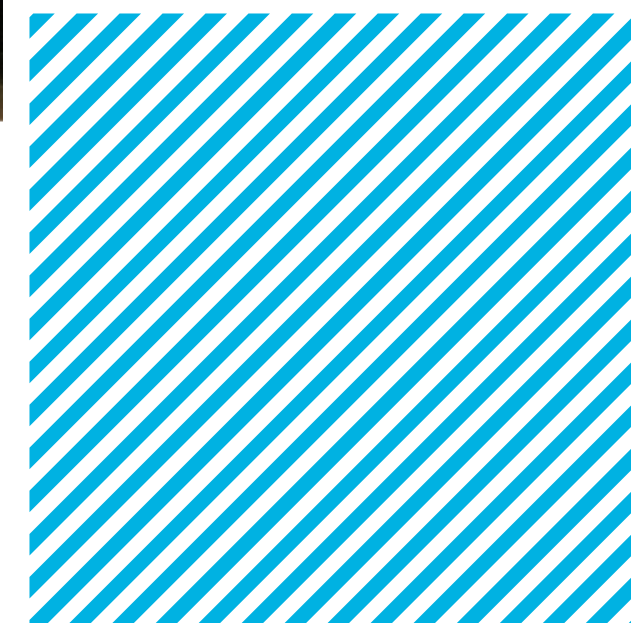
- Blend of oral history, popular education, and participatory media approaches
- Used for community-based public health practice and research
- Stories can be shared widely as tools for individual behavior, community, and policy change
- Centered around first-person stories (“I” voice)
- Small group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

# Storytelling Workshops

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## 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





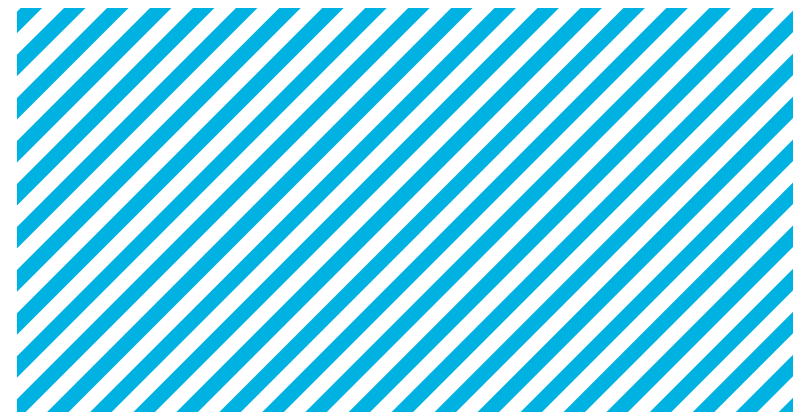
# Joe's Story: #justB Persistent



## #justB Persistent

“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.”

[WWW.HEPB.ORG/JUSTB/JOE](http://WWW.HEPB.ORG/JUSTB/JOE)









# Campaign Progress & Activities

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2016–2019

## 5 WORKSHOPS

40 storytellers from 20 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

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- 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



“

## Surveys & Phone Interviews with Storytellers

“It was an awesome, life-changing experience and I look forward to doing more work with the Hepatitis B Foundation and various other organizations to raise Hepatitis B awareness and prevention.”

“I remember feeling very lonely when I first got diagnosed. I was, I don't know, a leper or something but then to hear other people having gone through that same fear and that same sort of feeling of isolation, just super impactful. It made you recognize that this doesn't have to be a lonely or solitary thing. There are other people who have the same struggles and experience the same fear, I guess, that you did. That was incredibly powerful, and definitely something that I didn't know I was missing that.”

“

## Surveys & Phone Interviews with Storytellers

**#justB**

EVERYONE HAS A STORY.

“ This storytelling workshop was a true blessing for me personally. Before, I felt isolated and disconnected. After the workshop and getting to know how hep B has affected others, I feel a great sense of family and inclusion. My true hope is that our stories can change how others not affected view those who are and that more emphasis would be placed on the treatment and cure for this condition.

”



“

## Audience Surveys/Event Feedback Forms

“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 VOICE:

*Share Your Hepatitis B Story!*





# About the Campaign

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- The B the Voice story bank provides an online platform for people living with hepatitis B & D, their families, and community health workers and health care providers to share their first-hand knowledge and experiences with a global audience
- Launched in 2020 to expand our storytelling efforts internationally, building on the success of #justB



**Almost 300 million people worldwide live with chronic hepatitis B, but so many of their stories remain untold.**

“This new program provides many more people with the chance to tell their stories about living with hepatitis B around the world, and the Foundation and our partners will continue sharing this compelling content through our social media and other means.” – Chari Cohen, DrPH, MPH, Senior Vice President, Hepatitis B Foundation

“Speaking out relieves one from self-stigma and denial, but more importantly creates room for one to advocate towards changing something for the better. When you keep silent, the people in power will assume everything is okay until one comes out to challenge the status quo... I also want people to know that while Hepatitis B is a silent killer, one can live a positive and productive life as long as one knows early and follows the doctors’ advice.” – Kenneth Kabagambe, Director, Africa Hepatitis Initiative (Kampala, Uganda)



# How to Share Your Story

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## ■ B THE VOICE STORY BANK SUBMISSION FORM

<https://www.surveymonkey.com/r/bthevoice>

Learn more: <https://www.hepb.org/blog/voice-story-bank-launch>

## ■ #JUSTB WORKSHOP APPLICATION FORM

<https://storycenter.wufoo.com/forms/zyu5qsb02lscca>

Learn more: <https://www.hepb.org/justb>

# Thank you!

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