

Community Perspectives on HBV Road to Cure

HBV Forum

April 12, 2018

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Medical Director, Center for Asian Health

Livingston, NJ

Board Member, World Hepatitis Alliance

Physician (caring for Hep B patients)

HBV Patient

Mother of 4 HBV-free children*



*Yet, ~1.8 million five-year old children in the world currently with HBV (Polaris, 2018)

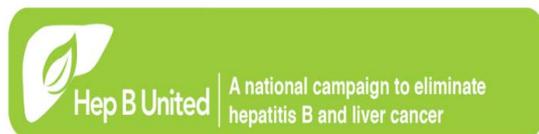
Patient engagement on “The Road to Cure” is vital

“Nothing about us or for us, without us.”

- **Patient community is important partner to HBV cure**
 - Can elevate HBV as a priority area for policymakers, funders & providers
 - Current HBV advocacy groups:
 - US- Hep B Foundation, Hep B United, NVHR
 - Global- World Hepatitis Alliance
- **Current challenges which will impact HBV elimination**
 - Low awareness in general public and physician community
 - Disjointed medical care
 - Guidelines not followed, patients not getting ALT or HBV DNA or meds as recommended
 - No HBV screening or care quality measures for any federal quality program (Medicare, Meaningful Use, NQF)
 - Healthcare access: Coverage issues of Rx, radiology, bloodwork

Successes in Community Partnership

- 2010 1st IOM report on **Hepatitis & Liver Cancer**
- 2012 **Hepatitis B United** national coalition formed
- Discrimination of HBV+ students & healthcare workers
 - 2012-**CDC Recommendations for Infected Students/HCW**
 - 2013- **DOJ Settlement**, HBV protected status under ADA
- 2014 **USPSTF Hepatitis B Screening** recommendations, grade B
- 2016 CMS **Medicare coverage of Hepatitis B Screening**
- Community input to **National Viral Hepatitis Action Plan 2017-20**
- 2016 National Academy of Sciences: **National Strategy for the Elimination of HBV/HCV**
- 2017 **Hepatitis B Cure Campaign** to increase NIH funding



Michael Ninburg

Executive Director, Hepatitis Education Project

Seattle, WA

President, World Hepatitis Alliance

Cured Hep C Patient

Wife from China with Hep B



- WHO goal of Hepatitis Elimination by 2030
 - Only 11% of those with HBV/HCV are aware of diagnosis
 - Need massive scale up of screening & linkage-to-care

World Hepatitis Alliance

Find The **Missing** Millions.

World Hepatitis Day 2018

300 million people are living with viral hepatitis and don't know it. Join us on World Hepatitis Day 2018 in the quest to find the missing millions.



NOhep = Making Hepatitis Elimination a movement.



The race to elimination by 2030



Commentary and Analysis

What is required to get us across the finish line:



Improving data

Closing gaps in prevention

Public health approach

Accelerating innovation

Scaling-up testing and treatment



Maureen Kamischke

Social Media Manager, Hepatitis B Foundation

Daughter adopted from China with HBV

Hepatitis B Voices



20 and Hep B free



I have 4 daughters and 3 sons. Imran and his elder brother test positive and my other 3 daughters, son and myself test negative. Imran is terribly stressed and depressed. His fiancée left him, which made him more depressed. He said to me, 'I am living dead'.



My doctor where I'm doing my antenatal from tells me to wait for six months to vaccinate my child. Which is risking like you advised me. It's my prayer that my new born is safe from the virus.



I live in the Philippines and I am afraid to apply for work and do the things I want to do to improve my life, because I have hepatitis B. I am afraid someone might blame me if they get this disease too, and I am afraid for the sake of my kids. I was really trying my best to go on living normally but my fears have taken over...

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Joan Block, RN

Cofounder, Hepatitis B Foundation

Doylestown, PA

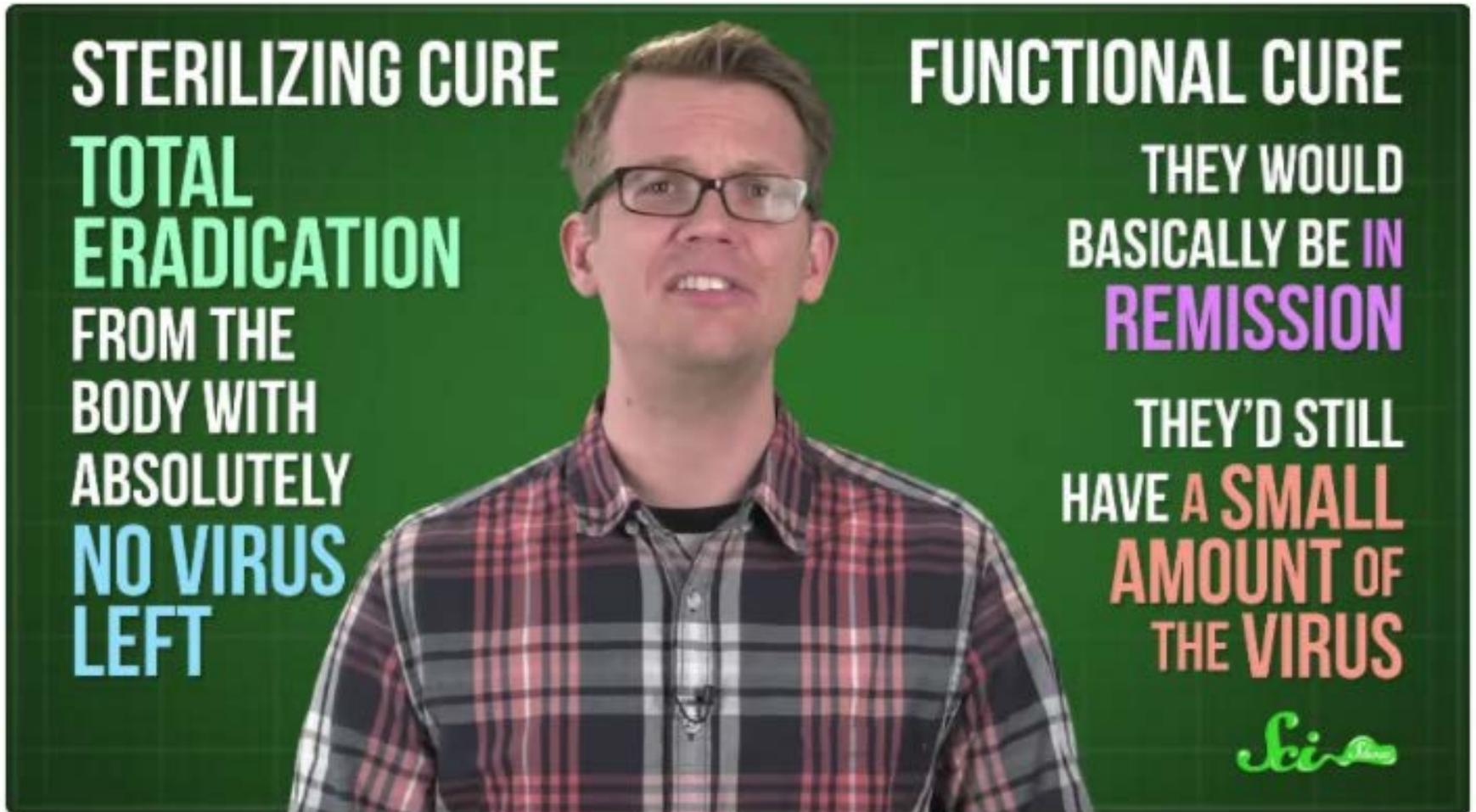
HBV Patient

“Retired” but still an advocate



- **Importance of HBV Cure Terminology**
- **Definition of Cure & Ramifications**

HIV Cure Language?



Credit: Hank Green of [@SciShow](https://twitter.com/SciShow)

Proposal:

HBV Forum Community Workgroup

- How do we want to partner with the community on the road to HBV cure ?
- What roles can the community play for HBV elimination- in awareness, policies, prevention, care/treatment and cure research?
- What are the best practices & proposals to get community involvement in the road to HBV cure? What will facilitate the process?
- How do we disseminate relevant information from HBV Forum to the community?
- What research is needed to collect community perspectives on HBV cure?