



CHIPO: Coalition Against Hepatitis  
for People of African Origin  
Conference Call Minutes

January 22<sup>nd</sup>, 2024

3:00-4:00 pm EST

Zoom:

[https://us02web.zoom.us/j/8546166290?  
pwd=TTVtajl1QjQraHhVcU9nR1lvdFhsQT  
09](https://us02web.zoom.us/j/8546166290?pwd=TTVtajl1QjQraHhVcU9nR1lvdFhsQT09)

Phone: +1 646 558 8656

**Attendees: Please let me know if I missed you, misspelled your name, or got only your partial information!**

Holly Moore (Hep B Foundation), Beatrice Zovich (Hep B Foundation), Chari Cohen (Hep B Foundation) Alma Chavez (NYC Department of Health and Mental Hygiene), Peyton Thompson (University of North Carolina, Chapel Hill), Bilan Hussein (Columbus Department of Health), Tishonie Sam (NYC Department of Health and Mental Hygiene), Adrienne Simmons (National Viral Hepatitis Roundtable), Oludolapo King (Columbus Department of Health), Nonso Maduka (Bensther Development Foundation, Nigeria), Kenneth Kabagambe (National Organization for People Living with Hepatitis B), Zainabu Sesay-Harrell (Sierra Leone Nurses Association), Amadou Diagne (Gilead Sciences, Inc.), Lewis Roberts (Mayo Clinic)

**3:00pm: Welcome and Updates:**

- **Learn the Link: Educational Materials about the Link between Hepatitis B and Liver Cancer**

Educational materials have been created based on community member focus groups specifically for 12 different communities heavily impacted by hepatitis B and liver cancer. Nine community materials are available now and the rest will be published by February along with a survey to request printed materials to be mailed. View materials here: <https://www.hepb.org/research-and-programs/liver/hbv-liver-cancer-connection/>

- **New CHIPO Blog Post**

The most recent Hepatitis B Foundation blog highlights the work of CHIPO partner, Community Vision Group, that does a lot of grassroots work in reducing the burden of hepatitis in Cameroon and Malawi. Read the full blog here: <https://www.hepb.org/blog/chipo-partner-highlight-community-vision-group/>

- **Featured Storyteller: Kenneth**

The #BtheVoice featured storyteller for the month of January is Kenneth! He speaks about his personal experience living with hepatitis B and how he turned his diagnosis into advocacy by creating the National Organization for People Living with Hepatitis B in Uganda. View Kenneth's story here:

<https://www.hepbstories.org/b-the-voice/kenneth>

- We are working on finding ways to expand peer mentorship opportunities in the US and Africa – we are working to formalize this for African partners, but if you are in the United States and are interested in providing or receiving mentorship or support from your peers in a particular area of hepatitis B elimination (education, advocacy, screening, vaccination, linkage to care, etc.), please reach out to Beatrice!

**3:15pm: Presentations on Building Effective Partnerships and Coalitions**

**Adrienne Simmons (National Viral Hepatitis Roundtable – U.S.)**

Overview of National Viral Hepatitis Roundtable Achievements

- 2003: The roundtable began in Washington DC with 100 organizations with a focus on dismantling policy barriers for hepatitis elimination
- 2006: Created a call-to-action elimination plan that was shared with Congress
- 2010: NVHR partnered with the Institute of Medicine and published a report on hepatitis and liver cancer to develop the first action plan around viral hepatitis
- 2011: Hosted *Tune in to Hep C* with American Liver Foundation as a benefit to raise funds for mini-grant program for hepatitis C treatment
- 2017: Teamed up with Harvard Center for Health Law and Policy Innovation to improve access to hep C treatment and create a national strategy for elimination of hep B and C
- 2019: Hosted hep C patient summit with 100 attendees and became part of the Hepatitis Education Project
- Established Working Groups of NVHR
  - o Grassroots Advocacy Working Group
    - Monthly Grassroots Advocacy Call for updates on what is happening in the world of hepatitis and invites different speakers to inform member organizations.
      - Sign up for the next Grassroots Advocacy Call here: <https://zoom.us/meeting/register/tctdO6rqDkrHd0zrfV1lwH7JoUDLJkfzXik?emci=a57586e2-dd57-ee11-9937-00224832eb73&emdi=8eac8205-e257-ee11-9937-00224832eb73&ceid=8834010#/registration>
  - o Diagnostics working group works on bringing point of care test approval to the US.
  - o Advocacy groups working on increasing funding for viral hepatitis through CDC and other advocacy initiatives.

What has made them successful in addressing policy barriers for hepatitis care?

- Continuing focus on centering people with lived experience to tell a story about hepatitis.
  - o Those attending the patient summit felt it was their introduction to advocacy work.
- Engagement was mostly focused on social media a few years ago and now there is some virtual fatigue among the public, so they focus on monthly newsletters now as a consistent way to keep people informed.
  - o Providing resources, articles, raising awareness, centering those with lived experience, and providing something for people to do (ex. How to call to legislators as a form of advocacy)
    - Sign up for newsletter on their website: <https://nvhr.org/>
- Direct Advocacy Outreach: Once people sign up for the newsletters, the NVHR team looks into the contact to see what they have to offer and let them know there is someone on the other end they can reach out to within the organization.
- As a small team with large network across the nation it is difficult to keep tabs on what is going on and trying to be everything for everyone
  - o Have an advisory committee separate from board of directors, including those with personal or professional interest in hepatitis, and diversify accordingly (geographic, community interaction, skillset) to help make new connections and set strategic priorities.
    - Will soon publish their strategic plan for the next three years.

Questions

- How did you identify the initial organizations for coalition development based on commonality?
  - o Think about what organizations and systems you need to interact with and how you reach them.

Additional Questions reach out to: [adrienne@nvhr.org](mailto:adrienne@nvhr.org)

**Kenneth Kabagambe (National Organization for People Living with Hepatitis B - Uganda)**

Overview of National Organization for People Living with Hepatitis B

- Program areas: Health and well-being, human rights, economic empowerment (including liver cancer as of 2024 as new program)

- Achievements include building capacity of 1120 frontline health workers in management and response, including treatment of hepatitis B, in 10 districts of Uganda.
- The Hepatitis Technical Working committee was established at the Ministry of Health in 2014 and NOPLHB is an active member.
- Advocated for domestic funding equal to 3 million USD every year to respond to hepatitis interventions in Uganda.
- Convened the first African Hepatitis Summit in 2019 in Uganda with over 600 delegates across the region and world.
- Advocated for birth dose and improved testing for pregnant women which has currently been rolled across Uganda countrywide.

#### Experience Building Effective Partnerships

- Identify the right partners that align with programs (and which department of the Ministry is responsible for hepatitis to communicate with them)
- Use patient stories to drive advocacy toward the government's commitment to elimination.
  - o It may be difficult getting patients to come out because of stigma that comes along with disclosure.
- Identify areas of mutual benefit within existing health structures and programs that can propel partnerships.
- Integrate delivery of care for hepatitis B into existing HIV structures and programs
  - o Some managers see hep B as burden that does not come with funding, but can discuss the public health approach and cost effectiveness data for integration to gain buy-in with existing programs.
- World Hepatitis Day has provided a platform to engage with larger organizations and partners such as Gilead, Roche, Abbott etc.

#### Questions

- When you started your organization did you find that you had a lot of challenges with the Ministry of Health in terms of politics and who is in power? There is significant difficulty identifying support in services since there is political bias and hardship finding funding.
  - o Identify the right department who is supposed to oversee the program. Work with the media and religious leaders and kings that are prominent outside of the government and they themselves become hepatitis ambassadors to speak with the president during election period which will eventually be discussed with Ministry of Health.

Additional Questions reach out to: [kkabagambe@noplhb.org](mailto:kkabagambe@noplhb.org)

#### **3:50pm: Member Updates**

Feel free to send member news and updates you might have to the listserv!

#### **4:00pm: Conclusion**

Our next regularly scheduled meeting will be on **Monday March 18<sup>th</sup> 10am Eastern Time.**

Thanks so much for joining! Please keep us updated about research and programmatic news and let us know if you'd like to present at the next meeting!