



CHIPO: Coalition Against Hepatitis for People of African Origin

Conference Call Minutes

Monday November 14, 2022, 3:00-4:00 pm EST

Zoom:

<https://us02web.zoom.us/j/83476670868?pwd=YjY0UzY3dXVRM2dmclVwM0QvN1VrZz09>

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

Beatrice Zovich (Hepatitis B Foundation), Yasmin Ibrahim (Hepatitis B Foundation), Chari Cohen (Hepatitis B Foundation), Chimwemwe Phiri (Hep Initiative, Zambia), Shaibu Issa (Organization for Medical Outreach to Communities, Tanzania), Charles Ampong Adjei (Hepatitis Alliance of Ghana), Ganiat Sarumi (African Health Coalition, Chicago), Mwape Chisonde (Hep Initiative, Zambia), Stacie Ko (Center for Asian Health Equity, Chicago), Sunyasemini Almond Ezra (Jeneso Development Initiative, Nigeria), Nonso Maduka (Bensther Development Foundation, Nigeria), Oludolapo King, Fiona Borondy-Jenkins (Hepatitis B Foundation) (let me know if I misspelled or missed part of your name!)

3:11pm: Welcome and Introductions to New CHIPO Members

Welcome to our new U.S.-based coalition members:

- African Cultural Alliance of North America (ACANA)
- African Health Coalition
- American Liver Foundation
- Association of Nigerian Physicians in the Americas
- National Alliance of State and Territorial AIDS Directors (NASTAD)
- National Viral Hepatitis Roundtable (NVHR)
- United States Coalition on African Immigrant Health (USCAIH)

Welcome to our new Africa-based coalition members:

- Bensther Development Foundation in Nigeria
 - Promotes evidence-based interventions and programs to reduce the burden of viral hepatitis.
 - Trains community members and hosts monthly discussions to promote community members seeking hepatitis B screening.
 - Before the COVID-19 pandemic, Bensther received subsidized vaccines and HBV tests from the pharmaceutical company XYZ
 - Bensther also advocates for policies to include free HBV screening services and HBV vaccines at a reduced cost.
- Hep Initiative of Zambia
 - Nonprofit organization that is recognized by the World Health Organization and the Ministry of Health.
 - Hep Initiative raises community awareness of viral hepatitis by reaching out to local medical schools and recruiting medical school students in Lusaka City to link people to hepatitis B treatment and join advocacy efforts to prioritize hepatitis in health policy.
- Organization for Medical Outreach to Communities, Tanzania
 - OMOC is recognized by the Ministry of Health, as it links people living in rural areas to hospital-based hepatitis care.
 - Educates, screens, and vaccinates community members.
 - OMOC advocates for measures to reduce the burden of hepatitis in Tanzania by calling for a national hepatitis elimination plan and an increase in funding.
- Hepatitis Alliance of Ghana
- Jeneso Development Initiative, Nigeria

- ONG-Adilo, Mali
- Community Vision Group (CVG) in Cameroon and Malawi
- Falcons Health Foundation, Ghana
- Rise Against Hepatitis Global Initiative, Nigeria

3:22 pm: Topics for Discussion

- NAIRHHA Day Updates
 - On September 09, 2022, the Hepatitis B Foundation, Multicultural AIDS Coalition, and CHIPO coalition members pushed for federal designation of [NAIRHHA Day](#) (National African Immigrant and Refugee HIV/AIDS and Hepatitis Awareness Day) as a national health observance, to raise awareness of viral hepatitis on a grander scale.
 - There was a successful Twitter chat, and members of the U.S. Congress wrote a letter supporting this push and sent it to the Department of Health and Human Services. We are still waiting to hear about their decision.
 - There is a [link to the petition](#) for individuals to sign, calling for NAIRHHA Day to be federally observed, and an [organizational sign on letter](#) for organizations to sign in support of this initiative.
- The American Association for the Study of Liver Disease hosted the annual Liver Meeting during November 4-8, 2022. Below are some highlights:
 - A National Hepatitis Elimination Plan has recently been introduced in the United States, and there is an advocacy letter pushing to include hepatitis B more prominently in this plan, which will be sent to Dr. Francis Collins, head of the National Institutes of Health. There is a lot of momentum to get hepatitis B screening, vaccination, and linkage to care included.
 - Presentations included the “U = U” framework (Undetectable = Untransmissible), based on the HIV framework.
 - Using this framework and educating people can reduce stigma and discrimination
 - There was lots of discussion about the benefits and drawbacks of treatment vs. non-treatment for everyone living with hepatitis B (and comparisons between different racial and ethnic groups). Researchers are leaning toward changing treatment guidelines to recommend treatment for everyone living with hepatitis B, addressing a significant equity issue.
 - A hep B cure continues to be 5-10 years away
 - Focus on minimizing the risk of progression to liver cancer (non-invasive tests (such as fibroscans), rather than biopsies) and earlier linkage-to-care practices
 - There were many patient advocates and people with lived experience in attendance – a great improvement from previous years!
- Check out a recent podcast “[Spotlight on Stigma](#)” with Dr. Thomas Tu and several HBF researchers
- Recent Witte lecture by Dr. Robert Gish on hepatitis B treatment guidelines and recent AASLD presentations – recording and slides will be shared when they are available!

3:28 pm: Topics for Discussion

- Thoughts on bringing more students/young people into the coalition
 - Direct outreach to medical schools and recruitment of medical students (Hep Initiative Zambia)
 - Use of incentives (“join the fight against hepatitis”)
 - Important to onboard early to educate and inform younger generation on HBV so that they can bring this information with them throughout their professional careers
 - Please share any additional ideas about this with Beatrice! (beatrice.zovich@hepb.org)
- Creating a registry for African providers (or those who are familiar with African communities and have cultural sensitivity)
 - How to increase outreach to providers of African origin, or who can perform culturally sensitive care
 - We ran out of time to discuss this more fully, but will ask again at the next meeting. We will

work on starting to build this registry – please reach out to Beatrice with any ideas or suggestions around this.

3:34pm: Presentation: Attitudes Toward Clinical Trial Participation Among People Living with Chronic Hepatitis B

Presenter: Dr. Yasmin Ibrahim, Senior Public Health Program Manager at the Hepatitis B Foundation

- Overview of Patient Engagement Program
- Understanding willingness to participate in clinical trials:
 - “What do people who participate in clinical trials look like (demographic factors, are they representative of the target population)?”
 - “Why do people not want to participate in clinical trials?”
- Conducted 24 telephone interviews and online surveys (1,700 respondents) to understand the patient’s experience of hepatitis.
 - Survey items included factors related to the social impact of hepatitis B, treatment experiences and the perceived value of current treatments, challenges related to treatment and perspectives on future treatment options, and clinical trial participation.
- First ever virtual Patient-Focused Drug Development Meeting (PFDD) held in 2020, where people living with hepatitis B contributed to and participated in the drug development process.
- In terms of future treatment,
 - International participants want future treatments to target the HBV surface antigen to eliminate the disease
 - U.S.-based participants want future HBV treatments to reduce their risk of hepatocellular carcinoma (HCC)
- The willingness to participate in clinical trials varies by age, gender, and geographic location
 - Males are more willing than females to participate in clinical trials
 - Females may be less willing to participate due to competing societal roles such as being caregivers and having family obligations
 - Age: U.S. adults between the ages 31-45 years are least likely to participate in clinical trials,
 - There is less variation between international participants’ willingness to participate (in terms of age)
 - Geographic Location: International participants are more willing to participate in clinical trials. U.S.-based participants are more likely to be undecided on whether they will participate in clinical trials
 - Black Respondents (International): 85% willing
 - Influential factors could include the prevalence of HBV in one’s country, one’s perception of clinical trials (believe it is a way to access care)
 - Black Respondents (U.S.): 50% willing
 - Influential factors could include one’s hesitancy to accept treatment or medicine (due to history of abuse/neglect in U.S. medicine/research against Black Americans), the design of clinical trials (direct and indirect costs of participation, barriers preventing people from participating)
- This study calls for the need for culturally tailored efforts and approaches to recruit more diverse populations in clinical trials
- The study emphasizes the need to work with local authorities to create a legal framework to bring clinical trials to other countries, and establish a strong research infrastructure to conduct clinical trials
- Questions going forward:
 - How do the barriers interplay in the HBV space?
 - HBV is unique and has many complex layers - how can we incorporate treatment at the different levels of HBV diagnosis? How do we combat HBV-related stigma?
 - How can we accommodate immigration changes and the value of culture when dealing with HBV?
 - How can we reach those willing to but not participating in clinical trials?

- Why are people undecided on participating in clinical trials?
- [Here is the link to the PFDD recording and report.](#)
- [Here is the link to patient-facing documents that were used during the study.](#)

3:52 pm: Q&A

- **Question:** (from Phiri) How can we raise awareness to get people to seek care earlier, to reduce the number of people getting tested because they are dealing with HBV symptoms (which leads to poor health outcomes due to late diagnosis)? How can we advocate for an increase of public interventions to educate people on HBV, HBV symptoms and getting people to screen without symptoms, and also recruiting health clinics to do walk-in screenings?
 - **Answer:** Advocate for more education to increase awareness of the benefits of HBV screening and early diagnosis/vaccination. Education is important to reduce stigma - we need to coordinate our efforts to incorporate stigma into education efforts, otherwise we won't be addressing the whole picture.
- **Question:** (from Chisonde) Are there incentives for people who participate in clinical trials? What measures are being put in place to overcome barriers?
 - **Answer:** The online survey was translated, and the one-on-one interviews were conducted in participant's preferred language to overcome language barriers. The hope is that the current study being conducted, based on this study, will propose strategies to overcome barriers identified in this study.
 - Need for collaboration with partners / regulatory authorities and people in the drug development field, and incorporating the patient voice to improve diversity in clinical trials

4:00 pm: Closing Remarks

There will be a follow-up email with these questions to consider for the next meeting:

- What resources or actions would you like to see or hear more of from CHIPO?
- What topics would you like to see addressed at upcoming meetings?
- How could CHIPO better support you as a member?
 - Some previous ideas that have been suggested that we are exploring include:
 - Training in resource mobilization (public health infrastructure and capacity building - how to build partnerships and coalitions and provide training, and technical assistance)
 - Extending hepatitis services to vulnerable groups during COVID
 - Partnering with various levels of government to promote hepatitis awareness (including WHO)

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!

Next Coalition Call: January 23rd, 2023, 2pm Eastern Time