



CHIPO: Coalition Against Hepatitis for People of African Origin

Conference Call Minutes

Monday January 23, 2023, 2:00-3:00 pm EST

Zoom:

<https://us02web.zoom.us/j/85699532256?pwd=ZWczclpFYjdVUDRK>

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

Beatrice Zovich (Hepatitis B Foundation), Chari Cohen (Hepatitis B Foundation), Maureen Kamischke (Hepatitis B Foundation), Dr. Wendy Spearman (University of Cape Town), Dr. Robert Gish (Hepatitis B Foundation), Mary Grace Sharpe (Asian Health Coalition), Elizabeth Koch (Columbus, Ohio Dept. of Public Health), Mwape Chisonde (Hep Initiative, Zambia), Dolapo King (Outbreak Response, Columbus DOPH), Alma Chavez (NYC Department of Public Health), Kosh Agarwal (Kings College Hospital, London and UK NHS), Amadou Diagne (Gilead Sciences), Daphine Mundondo (Gilead Sciences), Laurie Williams (Gilead Sciences), Agatha Adigwe (Multicultural AIDS Coalition, Boston), Kenya Mack (Philadelphia Department of Public Health), Sunyasemeni Almond (Jeneso Development Initiative, Nigeria), Nonso Maduka (Bensther Development Foundation, Nigeria), Seun Aluko (Outbreak Response Coordinator Columbus DOPH), Chimwemwe Phiri (Hep Initiative, Zambia), Luul Ahmed, Fiona Borondy-Jenkins (Hepatitis B Foundation), Essi Havor, Bilal Hussein (Columbus DOPH), Amadou Goita (ONG Adilo, Mali) (let me know if I misspelled or missed part of your name!)

**2:00pm: Welcome and Introductions**

**2:05pm: Announcements**

- Open letter to GAVI:
  - Calling for increased access to hep B birth dose vaccination and broadening vaccination efforts after the pandemic. Open letter published in the *Lancet* by multiple organizations including the Hepatitis B Foundation and the World Hepatitis Alliance. [Read the full letter here.](#) We will keep you posted if there is any forward movement by Gavi.
- Advocacy Year in Review
  - People living with HBV in the US are now able to serve in the Public Health Service Corps
  - There is now a universal hepatitis B vaccination recommendation for all adults living in the United States
  - A letter has been signed by various U.S. House Representatives to HHS that advocates for federal designation of National African Immigrant and Refugee HIV/AIDS and Hepatitis Awareness (NAIRHAA) day as a national health observance.
  - You can read more about 2022's Advocacy Wins [in this blog post.](#)
  - Universal hepatitis B screening recommendations will hopefully be introduced later this spring and we will have a call focused on their implementation in African communities.
- Upcoming Hep B United Webinar about staying healthy while living with HBV, including diet tips and lifestyle changes, presented by nutritionist Dr. Jennifer Lai, and happening on February 6<sup>th</sup> at 5pm Eastern. [Register here!](#)
- New translated resources with information for people who are recently diagnosed with HBV. The resources are available in [English](#), [Swahili](#) and other languages – [the full list can be found here, under Fact Sheets.](#)
- There is a new #justB storyteller, FK, from Burkina Faso, who talks about the fight against stigma surrounding HBV. #justB storyteller videos normalize conversations centered around HBV and feature people who experience stigma firsthand, yet talk about their diagnosis to increase awareness and

acceptance of this chronic disease. [You can watch the video here](#). Please feel free to use it in community work and advocacy efforts going forward! FK's story is available in English and French.

- Valentine's Day social media campaign "I love someone with hepatitis B"
  - This campaign aims to lower the stigma surrounding people living with hepatitis B, and emphasizes the message that everyone is worthy of love, despite one's HBV status.
  - To be a part of this campaign, you can email photos or quotes to Abby Showalter ([abby.showalter@hepb.org](mailto:abby.showalter@hepb.org)).

## **2:23pm: Presentation: Treatment of Hepatocellular Carcinoma in Sub-Saharan Africa: Challenges and Solutions**

Presenter: Dr. Wendy Spearman, Head of the Division of Hepatology, Department of Medicine, Faculty of Health Sciences at the University of Cape Town

- Management of HCC in Africa
  - Barriers to testing and treatment include people having to pay out of pocket for screening and antiviral therapies, and when we look at the geopolitical context in African countries, we notice that this increases the burden of disease, and it is worse in some areas due to the lack of doctors and nurses.
    - The study revealed that the burden of disease is worse in rural areas than in urban areas.
    - While antiviral therapy is an effective, evidence-based option for HBV treatment, only a minimal number of people who are diagnosed with HBV are receiving treatment (out-of-pocket costs further impact this already small % of people's access to treatment)
- Hepatocellular Carcinoma (HCC) in Africa
  - HCC is the second leading type of cancer in men and the third leading type of cancer in women
  - The prevalence is underestimated, but it does vary between different African regions
    - The mortality rate of HCC is that of the incidence rate (meaning that those who have HCC are dying from it).
  - Risk factors include undiagnosed HBV, obesity (and diabetes), alcohol consumption and smoking, but viral hepatitis is the most common risk factor among all African regions (Western sub-Saharan African, Central sub-Saharan Africa, Eastern sub-Saharan Africa, Southern sub-Saharan Africa)
    - The Africa Liver Cancer Consortium data reveals that in sub-Saharan African countries, the median overall survival of HCC is 2.5 months, which is very poor (Egypt's median overall survival rate is 10.9 months)
    - HBV-related HCC mortality rates are attributed to late diagnostics (90% of people lack liver disease diagnosis, 59% of people lack symptoms so do not seek HCC screening), and HBV-related HCC in sub-Saharan African countries appears to be rapid and aggressive, so early diagnosis of HBV can improve mortality rates and reduce rapid progression to HCC. Approximately 40% of HCC occurs in younger, non-cirrhotic HBV patients in sub-Saharan Africa, emphasizing that screening is essential despite feeling healthy, as people who seek medical help when having symptoms have lower survival rates, as the HCC has become too severe.
  - Barriers to HCC Surveillance
    - Access to appropriate imaging methods
    - Need to train health workers to read imaging more accurately, need for experienced radiologists and specialists to educate and train local healthcare workers on imaging to expand knowledge across communities.
  - Palliative Treatment in Africa
    - TACE (trans arterial chemoembolization) is the best supportive care option, however, it is limited
      - Need to improve overall HBV/HCC preventive strategies

- Many countries are planning liver transplantation programs
  - The lack of healthcare training impedes palliative treatment for people living with HBV/HCC, and fear of opioid treatment options further reduces people's access to palliative treatment
- Calls to Action: Active Screening Programs and Access to Therapy
  - Appropriate guidelines tailored to various African communities
    - Regulations need to expand access to the birth dose vaccine to reduce risk of HCC
  - Screening and Surveillance
    - Active Liver Cancer Registries (use imaging rather than histology)
      - Fibroscan, US, CT scan, MRI (interventional radiology)
    - Improve point-of-care testing and treatment (establish guidelines)
    - It is necessary to build up existing expertise centers, which can then train new health centers to become active referral sites.
      - Academic training centers
      - Sites for clinical trials
  - Population-based HBV screening in sub-Saharan Africa is a critical strategy for identifying people who need to be screened for HCC
    - Create targeted screening and vaccination guidelines based on available resources
  - The burden of HCC and HBV is high in all African regions, but there are limited clinical trials held in Africa, reducing one's access to treatment – it is necessary to expand the number of clinical trials held in African countries
    - Fewer than 1% of currently ongoing clinical HCC trials are conducted on the African continent
    - Improve service cascade to ensure that people are able to access treatment and maintain their treatment regimen.
  - Decrease aflatoxin exposure – this can reduce HCC prevalence by 20%
    - Replace affected crops, improve storage facilities

## 2:51pm: Q&A

**Question: Kosh Agarwal:** Do you think the diagnostic field has changed for people with HCV/HBV?

- **Answer: Dr. Spearman:** It has not improved - every week, there is a first-time patient presenting with HBV, HCV or HCC, and since their disease is so severe when they seek out care, they usually die within the first three months after seeking medical attention. The lack of knowledge of the diseases are the driving factor behind this - we need better community education efforts. Additionally, pediatricians do not believe that HBV is an issue, so they do not screen pregnant people or administer the birth dose. Mothers need to advocate for prenatal screening, increased access to the birth dose, and antiviral medication.

**Question: Kosh Agarwal:** What is the most beneficial way to decrease HCC (awareness raising, vaccination efforts, point of care testing)?

- **Answer: Dr. Spearman:** Screening people when they are pregnant and immediately linking them to antiviral treatment and administering the birth dose is the best way to decrease one's risk of HCC. Screening pregnant people would likely increase the number of people screened, as partners, friends and family would learn about the benefits.

**Question: Chari Cohen:** Would creating initiatives targeting pregnant people be too fragmented? Creating a demand letter made up of demands from people with lived experience and specific calls to action feels like the best way to leverage support for achievable tasks.

- **Answer: Dr. Spearman:** Making actionable demands based on community input would be a good method.

## 2:58pm: Member Updates

- If there are any programs or events that your organization is starting / hosting or you need advice, please share in CHIPO listserv or email Beatrice directly.

## 3:00pm Closing Remarks

- Look out for a follow-up survey towards the end of this week about ways in which CHIPO can better support your organization and what you would like to see from the coalition moving forward.

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: March 20<sup>th</sup>, 2023, 3pm Eastern Time