With education we can reduce stigma and increase awareness of hepatitis B globally

Bright Ansah
It was terrific connecting with hepatitis stakeholders from nearly 100 countries at the World Hepatitis Summit in Lisbon this April. The summit served as a vital call to strengthen and integrate our advocacy efforts within our communities – particularly as, according to new data, hepatitis is now the world’s second deadliest virus, alongside TB, and behind only COVID-19.

In this edition, we share highlights of the summit, our statement, and insight from partner site visits. We also provide updates on advocacy activities and events hosted this quarter towards hepatitis elimination, including those by WHA members.

As we approach World Hepatitis Day, 28 July, we prepare for another significant opportunity for global action and awareness. This year’s theme is ‘It’s Time for Action’, emphasising the urgency of our goal to eliminate hepatitis by 2030. We look forward to bringing the world together to raise awareness about the global burden of viral hepatitis and to drive meaningful change. More details can be found on pages 14-15.

And our Hep Voice this issue is Bright Ansah, who shares his story and experience living with hepatitis B in Africa and Maryland. I hope you find this issue of Hep Voice insightful and thought-provoking. As always, if you have any stories you would like to share with us, please get in touch. We would love to hear from you!

Cary James, WHA Chief Executive

Want to share a feature for Hep Voice?
Share your news or story by emailing contact@worldhepatitisalliance.org
DATES FOR YOUR DIARY

AIDS 2024
July 22-26
2.7 million people living with hepatitis B also live with HIV, and 2.3 million people live with both hepatitis C and HIV. AIDS 2024 will bring together thousands of individuals living with HIV, those affected by it, and professionals working in the field. The hybrid event will facilitate the exchange of knowledge, best practices, and lessons learned from the past 40 years of HIV response, as well as the responses to COVID-19, mpox, and other public health threats. WHA will be at the global village. Be sure to stop by and say hello if you are attending. Register for the conference here.

World Hepatitis Day
July 28
World Hepatitis Day takes place every year on 28 July bringing the world together under a single theme to raise awareness of the global burden of viral hepatitis and to influence real change. Hepatitis is now the world’s deadliest virus, after COVID-19, and more than 300 million people are living with it. We have the tools we need to eliminate hepatitis by 2030, but progress is still too slow. This World Hepatitis Day, it’s time for action. Learn more about WHD this year on pages 14-15.

World Breastfeeding Week
August 1-7
World Breastfeeding Week is a platform to raise awareness about the significance of breastfeeding, one of the most effective ways to ensure a child’s health and survival. It is an opportunity to encourage communities and policymakers to provide safe and effective antenatal care to prevent the transmission of hepatitis B to unborn children, and birth-dose vaccines to babies as soon as they are born. Find out more about World Breastfeeding Week here.

International Youth Day
August 12
International Youth Day is celebrated annually on 12 August to bring youth issues to the attention of the international community and celebrate the potential of young people as partners in today’s global society. As one of the key populations most at-risk and affected by hepatitis, hepatitis elimination can only be achieved if young people are part of the response as equal partners.

World Humanitarian Day
August 19
World Humanitarian Day provides an opportunity to raise awareness about hepatitis and drive prevention, testing and treatment. As partners across the humanitarian system come together, the hepatitis community can create activities to inspire action, mobilise resources and advocate for policy changes towards viral hepatitis elimination efforts. Learn more about World Humanitarian Day here.

World Cancer Congress
September 19
Viral hepatitis is the leading cause of liver cancer, the third most common cause of cancer deaths worldwide, and their connection needs to be better known. The World Cancer Congress provides an excellent chance to make connections, as a leading multidisciplinary event featuring the latest successful cancer prevention, diagnosis, treatment and care interventions. Organised by the Union for International Cancer Control, the event will be hosted in their hometown of Geneva, Switzerland, at the International Conference Centre. Register here.

COLDA
September 19-21
Co-organised by the Society on Liver Disease in Africa and Academic Medical Education, in close collaboration with regional societies, the Conference on Liver Disease in Africa (COLDA) aims to empower healthcare professionals to diagnose, prevent, treat, and achieve a cure for liver diseases in Africa. This year, the hybrid event is hosted in Cairo, Egypt. Register here.
Let’s look at some of the latest hepatitis news from around the world.

**Namibia achieves milestone in eliminating mother-to-child transmission of HIV and hepatitis B**

Namibia has become the first country in Africa – and the first high-burden country in the world – to reach a significant milestone on the path towards eliminating vertical mother-to-child transmission of both HIV and viral hepatitis B.

Based on specified criteria, WHO awarded Namibia ‘silver tier’ status for progress on reducing hepatitis B and ‘bronze tier’ for progress on HIV. Namibia’s achievement follows a concerted strategy to curb the transmission of hepatitis B, HIV and syphilis. WHO’s Triple Elimination Initiative aims to safeguard the health of mothers and children and affirm the rights of every child to be born free from the burden of these viruses.

**Hundreds of people in the UK living with undiagnosed hepatitis C**

According to BBC analysis, about 1,750 people in the UK are living with an undiagnosed hepatitis C infection after being given a transfusion with contaminated blood.

Up to 27,000 people caught it when they were given transfusions with infected blood from the 1970s until 1991. Since BBC’s reveal, there has been a surge in demand for hepatitis C tests across the UK. If left untreated, viral hepatitis can cause chronic liver disease and can be fatal.

**New report highlights significant rise in STIs amid ongoing HIV and hepatitis challenges**

A recent WHO report reveals that global epidemics of HIV, viral hepatitis, and sexually transmitted infections (STIs) continue to present major public health challenges, resulting in 2.5 million deaths annually.

New data indicates that STIs are on the rise in many regions. In 2022, WHO Member States established an ambitious goal to reduce the annual number of adult syphilis infections ten-fold by 2030, from 7.1 million to 0.71 million. However, syphilis cases among adults aged 15-49 years rose by more than 1 million in 2022, reaching 8 million. The highest increases occurred in the Americas and the African Region.
NOhep Medical Visionaries Forum at EASL 2024

Milan, Friday 7 June, 2024

What was discussed?

Stigma and discrimination faced by people living with viral hepatitis continues to be a significant barrier to hepatitis elimination. The NOhep Medical Visionaries met in Milan at EASL 2024 to reflect on new hepatitis stigma data from a recent European pilot survey conducted by WHA and the European Centre for Disease Prevention and Control (ECDC).

What were the key take-aways?

1. Intrinsic biases in the healthcare system put blame and responsibility on the patient.
2. Healthcare professionals must be educated on the impact of stigma and discrimination and treat patients with empathy.
3. It is important to have adequately resourced peer support within clinical teams.
4. Testing for hepatitis, like HIV, should be routine.
5. The hepatitis stigma survey data can fill gaps, drive advocacy, and is an important tool for discussions with policy makers.

From Experience to Action: Youth Voices on Hepatitis and HIV

Webinar – Tuesday 21 May, 2024

What was discussed?

WHA and Y+ Global held a joint webinar to foster meaningful conversations and gather insights from young people living with hepatitis and/or HIV. The event explored gaps, challenges and solutions, and shared stories from young people leading change in their communities. Co-chaired by Tung Doan (Y+ Global) and Adesuwa Oni (Rise Against Hepatitis Global Initiative and WHA member), speakers included Zipporah Achieng (Kenya), Priscilla Ama Addo (Ghana), and Edgar Mudoogo, Young Medical Doctor, Mbarara University (Uganda).

What were the key take-aways?

Many young people lack access to educational materials about hepatitis and HIV.

1. Young people living with hepatitis and HIV often encounter stigma and discrimination and experience isolation.
2. New digital tools and educational materials are needed for young advocates living with hepatitis and/or HIV.

Watch the recording and learn more here.
The World Hepatitis Summit 2024 took place 9-11 April in Lisbon, Portugal, organised by WHA, co-sponsored by WHO, and supported by the Ministry of Health, Portugal. The event welcomed close to 700 delegates from 95 countries.

Speaking at the opening session, Dr Tedros Adhanom Ghebreyesus, Director General of WHO, said, “WHO remains committed to supporting all countries to scale up the use of vaccines, tests and treatments for hepatitis as part of their journey towards universal health coverage.”

Rachel Halford, WHA President said, “We have the tools, we have the guidelines to eliminate viral hepatitis, yet we’re not on track. More than 1.3 million people are dying from an entirely preventable disease. We need to do better for people living with viral hepatitis.”

At the event, WHO launched the ‘Global Hepatitis Report 2024: action for access in low- and middle-income countries’. It reports that viral hepatitis is a major public health challenge of this decade, and the world is still far from achieving its elimination by 2030. Combined, hepatitis B and C cause 3500 deaths per day, and mortality is increasing.

In total, the summit featured more than 30 sessions, side meetings, plenaries, and workshops. Policy makers, civil society members, representatives from the private sector, academics and other stakeholders convened to deliberate and share updates on innovative approaches to increase access to testing, vaccination, and treatment services, and eliminate viral hepatitis by 2030.
World Hepatitis Summit 2024 Statement

Following engaging and inspiring sessions, the organisers issued a statement with input from summit delegates:

To improve the lives of the more than 300 million people living with hepatitis, the attendees of the fourth World Hepatitis Summit call for a reset and reinvigoration of the response.

The elimination of viral hepatitis by 2030 is within our reach, but only if we act now to dramatically scale up responses that are person-centred and culturally appropriate.

The tools to eliminate viral hepatitis by 2030 already exist, we have a vaccine and effective treatments for hepatitis B and hepatitis C. However, despite this, new data from WHO has shown that mortality is increasing, with hepatitis now the second most deadly infectious disease, in line with TB, and behind only COVID-19.

While incidence is decreasing, mortality from hepatitis related liver cancer is rising. There are still 2.2 million new infections a year and diagnosis and treatment rates remain far below where we need to be, with only 13% of people with hepatitis B diagnosed and 2% treated, and 36% of people with hepatitis C diagnosed and 20% treated. Furthermore, acute hepatitis A and E continue to impact people’s health all over the world.

This is not acceptable.

We call for simplified and decentralised hepatitis responses, which are integrated within health systems, designed for the people they serve, and developed in partnership with the affected community.

We call for an acceleration of access to testing, treatment, peer support and care which is affordable and accessible to those that need it. This will require innovative case finding strategies, service delivery in a wide range of settings, including prisons and harm reduction services, commitment and improved collaboration to procure commodities at the lowest possible prices, and investment in community-led services to ensure people living with hepatitis are supported and linked to care responsive to their needs.

Critically, improved access requires all stakeholders to address the underlying health and human rights inequity, lack of awareness and education, and stigma and discrimination. These not only stop people coming forward for testing, but also have a lasting, devastating impact on people’s lives, wellbeing, health and livelihoods.

To achieve this, we call for immediate increased prioritisation of hepatitis elimination by governments. Responses must be nationally led, have the meaningful involvement of affected communities, and domestic financing must be committed.

We cannot continue on the current trajectory. People living with and affected by viral hepatitis deserve better and we call on all stakeholders to stand with us to make the elimination of viral hepatitis by 2030 a reality.

Hepatitis Can’t Wait!

Thank you to all of the partners, supporters and friends that made WHS possible.

The World Hepatitis Summit 2026 will take place in Bangkok, Thailand.

The World Hepatitis Summit 2026 will take place in Bangkok, Thailand.
Every year, 1.3 million people lose their lives to hepatitis – because they weren’t tested, or didn’t have access to treatment, or were never vaccinated. And new data from WHO shows the number of deaths is rising. With only six years left to meet the global goal of eliminating hepatitis by 2030, we are moving backwards.

For World Hepatitis Day 2024, WHA, our partners, allies, and our 337 members in 102 countries are calling for action to end this entirely preventable disease.

We have the tools we need to eliminate hepatitis by 2030 – but progress is still too slow. Resources are not being mobilised; stigma and discrimination are not being addressed; and despite commitments made by governments and institutions, millions are being left behind.

World Hepatitis Day 2024 will provide a platform for this message, and make sure it is heard by those with the power to make real change happen. It will amplify the voices of people living with hepatitis demanding testing, treatment, vaccinations and the end of stigma. It will make it clear there is no time to waste, and that leaders, politicians, doctors and communities must act now.

People living with hepatitis are still not being heard or getting the resources they need, despite the global scale of the problem. This World Hepatitis Day, it’s time for action.

Take action. Visit worldhepatitisday.org

- Pledge your support and an action you will take to end hepatitis
- Keep an eye on our social media channels and use our assets to raise awareness in your community.
- Use #WorldHepatitisDay and #TimeforAction and tag us on social media
- Join our webinar series – more details to come
- Let us know your plans for the day this year
- Join our #WHDRelay on social media

World Hepatitis Day is supported by Hep Voice by World Hepatitis Alliance
HEPATITIS ADVOCATES
CHAMPIONING CHANGE
IN THEIR COMMUNITIES

WHA members across the world engage in campaigns and activities to increase awareness of viral hepatitis and contribute towards the elimination of the disease.

The Budi Lukmanto Foundation, Indonesia, organised a hepatitis B screening at orphanages in their community. 45 children were screened and 40 of them will need to receive complete immunisation.

Women and Children Health Empowerment Foundation, in collaboration with ActionAid Nigeria, the Association of Public Health Physicians of Nigeria, and through the Local Right Programme, organised a viral hepatitis awareness campaign for women and children in the Nyaladi Shombung community, Taraba State, northeast Nigeria. More than 200 adults and 250 children were sensitised on viral hepatitis, and community members also pledged to be tested and vaccinated.
Hepatitis B treatments cost so much in Ghana that only a few people can afford it.

Initially, it was hard because I did not have health insurance at the time. There was a period where for over a year I did not seek any medical care.

But things are different now. I have access to healthcare at one of the best hospitals in the US, and I have a hepatologist who is one of the best in the world. I therefore count myself lucky. I have access to the treatment and services that I need to manage this disease, compared to Ghana, where access to providers, treatments, hospitals, and other hepatitis B services are lacking or unavailable. Hepatitis B treatments cost so much in Ghana that only a few people can afford it on a monthly basis. At times these antivirals can be hard to find, besides their high cost.

What do you do and what is the nature of your work?

Due to my continuous battle with chronic fatigue and muscular pains, I have been unable to work for some years now, so I decided to devote my time to school. I am currently enrolled in a graduate programme, and I volunteer with the Hepatitis B Foundation and other local health organisations whenever I am able to.

I currently co-host the Foundation’s B Heppy podcast, discussing all things related to hepatitis B, and I help out moderating the hepbcommunity.org platform, an online community for hepatitis B patients around the world to connect, support and share experiences.

In what ways, if any, has living with hepatitis B affected your lifestyle?

I battle with severe chronic fatigue and muscular pains (fibromyalgia), and this has affected my lifestyle physically. How, or if this is connected to hepatitis B, I do not know. But I was very active before all this started, and now I live a more sedentary lifestyle. I am unable to do stuff that keeps me active, like exercising. I will grade my overall health and lifestyle as fair at this moment.

Can you share a bit about your background and where you are originally from in Africa? What motivated your move to Maryland in the US?

I was born and raised in Ghana for most of my life, but in 2007 I had an opportunity to move to the US, where I have been living since. Emigrating to the US was not planned, but a great opportunity became available and I could not refuse. So here I am.

Can you share your experience with hepatitis B, including how you became aware of your diagnosis?

My experience with hepatitis has been all my life, but I was diagnosed in 2014. In 2013, I started experiencing some issues with fatigue that I could not explain, and multiple medical tests found nothing. After exhausting all opportunities trying to understand why I felt fatigued all the time, my doctor suggested I get further tests with the Maryland Health Department, which has a clinic that performs detailed STI tests. Through that, I became aware of my status as a chronic hepatitis B patient, and my journey with this disease became official. I have been managing it with antivirals since 2015.

How did your family and friends react when you shared the news with them?

I did not tell my family initially, because I had lost my mother suddenly in 2012 and my family was still reeling from it. I did not want to burden or worry them, thinking that I was also going to die. But later on, when I thought it was the right time, I was able to share it with them and got most of them tested and vaccinated. I now know I have siblings who also have this virus. I got my friends to test and get vaccinated as well. It was odd sharing [my status], as many in my culture view topics like this as taboo.

What has been your experience with accessing healthcare and managing hepatitis B in Maryland compared to your home country?

Bright Ansah, shares his journey of living with hepatitis B and as an advocate. He contributes to the Hepatitis B Foundation and actively engages in community support efforts in Maryland.
It is hard to get through each day, and emotionally and psychologically it is tough and challenging. The impact of living with this disease is very real; I have had my fair share of depression. This disease has affected my lifestyle immensely, but I always try to do my best giving the circumstances.

Have you experienced any stigma or discrimination related to your condition in either place?

Not personally, but I have heard stories of other patients that have faced some of these issues. These issues do exist, and that is bad.

Can you share any strategies or activities that helped you deal with the emotional challenges associated with hepatitis B?

Sure, I did psychotherapy for a while, but I did not find it that helpful. Medications were just horrible. I changed my mindset and decided to appreciate every opportunity I have and enjoy each day as if it was my last. I practice positive affirmations and a lot of positive thinking. I have developed the intentional habit of always seeing the glass as being half full rather than half empty. I keep being optimistic and hopeful, no matter the challenge or difficulty. Being resilient and stubborn even when things get really tough have been nice values for me. Practicing self-care in whatever ways I think is positive, such as listening to music, taking walks whenever I am able to, and so on. I try to manage my stress and worry less about the future, which is not even here yet. I find engagement in hepatitis B advocacy work whenever I can helpful. Reading about the disease further has also helped improve my emotional life as the years have passed. I do not see hepatitis B as a death sentence anymore, but rather as a manageable disease. This change in perception helps a lot.

Is there any advice you would give to others who are living with hepatitis B and considering relocating to a new country?

First, I would like to acknowledge the difficulties associated with this disease and say to all patients and their families that I hear you, and you are not alone. As for my advice, try not to overwhelm and stress yourself. Smile and take deep breaths whenever you can, even in those darkest moments. Try to find a support system or create one if needed and use it. Build a healthy working relationship with your medical staff and others, ask questions and ask for help if needed. Take some time to educate yourself a bit about this disease, it will help ease some of the emotional and psychological issues. And finally, be grateful and thankful for your life. Live your life to the fullest of your ability and continue to dream. Don’t give up or let this diagnosis or disease control you and your life. Rather, it is what you do from this point forward that is vital.

What do you think are the most important steps to increase awareness and reduce stigma around hepatitis B in Africa and the US?

The answer is simple: education, education, education. As they say, knowledge is power, and when people know more, they do better. I believe stigma happens due to ignorance, misconception and lack of knowledge about hepatitis B. With education we can reduce stigma and increase awareness of hepatitis B globally. This is the most important step in my view.

Is there anything else you would like to share about your journey and experiences with hepatitis B?

A small commentary: Life is difficult and challenging as it is without living with any disease, so expect challenges. But do not let these challenges rob you of your life. Remember to live your life. We tend to focus on a future which is not here and forget to live our life and enjoy today. This is not helpful or positive. I am hopeful that together we can create a better world where hepatitis B will be in the rear-view mirror, a world where there is a cure to treat all chronic patients no matter where they live, and everyone is able to live their life as predetermined by their creator. Be resilient and remain hopeful. Do not give up. We are many, strong and mighty. We shall win. We shall overcome all these challenges one day soon.

I changed my mindset and decided to appreciate every opportunity I have and enjoy each day as if it was my last. I practice positive affirmations and a lot of positive thinking.