Sidney Vo tells her story to fight hepatitis B stigma

Welcome to the last Hep Voice of the year
WELCOME TO THE LAST HEP VOICE OF 2021

As we come to the end of 2021 we can start to look back on the past year and look across all of the achievements that we have seen towards the elimination of viral hepatitis.

Don’t miss out - recieve Hep Voice straight to your inbox!

Categories
1. Innovations – in technologies and/or service delivery, including integration, decentralisation, task-shifting, simplification and community led initiatives
2. Advocacy, awareness and education campaigns
3. Combating stigma and discrimination
4. The power and impact of lived experience
5. Prevention of mother to child transmission of viral hepatitis and hepatitis in children
6. Developing and implementing elimination plans (national, state or local level)
7. The role of good data, surveillance, monitoring and evaluation in elimination
8. Hepatitis and Covid-19 – impact and opportunities
9. Partnerships (Private/Public, Cross-sectional)
10. Financing for viral hepatitis (including investment cases and financing models)
11. Universal Health Coverage and person-centred approaches
12. Health disparities, health equity & key populations (e.g. PWID, MSM, refugees, indigenous populations)

We must also recognise that 2021 was impacted by COVID-19 and health services, including hepatitis elimination services, have been impacted. This impact was minimised by the determined efforts of our members across the world who continue to work with their communities to fight hepatitis.

In this edition of Hep Voice we have many exciting announcements, including the launch of our hepatitis B stigma report, which highlights the challenges that many people living with hepatitis B face everyday. We also highlight the stories from our NOhep stories contest which gave a platform to the people and communities impacted by hepatitis.

As ever, I hope you enjoy this issue. As we look into 2022 we welcome you to share your news with us for future editions of Hep Voice.

See you in 2022.
Cary James
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HEP HEADLINES

Let’s look at some of the latest hepatitis news from around the world.

Global guidance on criteria and processes for validation for elimination of mother-to-child transmission of HIV, syphilis and hepatitis B

The World Health Organization (WHO) has updated its global guidance on criteria and processes for validation for elimination of mother-to-child transmission of HIV, syphilis and hepatitis B virus. This updated guidance brings the elimination of mother-to-child transmission of hepatitis B to the previous guidance document to deliver a package of interventions and metrics to support management and monitoring of mother-to-child transmission of these major communicable diseases.

The EASL–Lancet Liver Commission


This commission set out to provide a snapshot of the European landscape on liver diseases and to propose a framework for the actions required to improve liver health in Europe.

Read more here.

KEY ADVOCACY DATES

20 December

International Human Solidarity Day

International Human Solidarity Day serves to raise awareness of solidarity as a crucial element in the fight against poverty. Viral hepatitis affects some of the most impoverished communities in the world and partnership between civil society and the affected community is key to overcome barriers to hepatitis diagnosis and treatment.

Find out more here.

28 February

Rare Disease Day

Each year on 28 February the rare disease community comes together to raise awareness among the general public and decision-makers about rare diseases and their impact on patients’ lives. Hepatitis B/Hepatitis D co-infection is the rarest, yet the most serious form of chronic viral hepatitis due to more rapid progress towards liver cancer and liver-related death. More must be done to improve awareness of viral hepatitis in all its forms.

Find out more here.

4 February

World Cancer Day

Each year more than 800,000 people die from liver cancer, the second deadliest cancer. Hepatitis B and C are responsible for 80% of these deaths. Thanks to the hepatitis B vaccine and the curative treatments are available for hepatitis C, these deaths are fully preventable.

World Cancer Day is an excellent opportunity to demonstrate the impact of a joined-up approach to reduce the annual cancer death toll of more than 8 million people worldwide.

Find out more here.
On 28 July 2021, individuals, organisations and governments around the world celebrated the tenth official World Hepatitis Day (WHD), which is one of the WHO’s seven officially-mandated global public health days. United under the ‘Hepatitis Can’t Wait’ theme, the WHO, governments, civil society, people with lived experience and others came together and made an incredible impact both online and in their communities.

The 2021 World Hepatitis Day Summary Report highlights WHA members’ activities in all six WHO regions. Read it to learn how they implemented ‘Hepatitis Can’t Wait’ campaign to highlight the need to accelerate hepatitis elimination efforts, especially during the COVID-19 pandemic.

Read the 2021 global summary report here.
NOhep and the London School for Hygiene and Tropical Medicine open call for stories finalists

NOhep, in collaboration with WHA and the London School for Hygiene and Tropical Medicine (LSHTM) announced the finalists of their open call for stories contest.

The submissions come from submission to the NOhep and LSHTM open call, which encouraged individuals and organisations to submit real stories of how hepatitis affects individuals, families and communities where they are. Submissions were welcomed in the form of text, audio, visual art, video or infographics. The submissions were reviewed by a group of independent judges. The stories are a powerful reminder to decision makers about the need for action on viral hepatitis.

The submission covered personal experiences, care-seeking encounters, local actions from advocacy groups, civil society organisations, family and community impacts. Twenty-nine best submissions are available to read now on nohep.org. Prizes will be awarded to the top submissions.

NOhep stories winners are:

1. “Family diary beating hepatitis B” – an infographic from China
2. “Let’s not whisper, let’s speak loudly and openly about who we are, how we feel, and lend a hand to the others like us” – Silvana Lesidrenska, Bulgaria
3. “Tackling hepatitis and COVID-19” – a video from Yiyou Charity Liver Center and Yiyou Aigan Public Welfare Development Center, Yuexiu District, Guangzhou, China
4. “My hepatitis C journey” – Dr Evelyn McKnight, USA
5. “Faces of hepatitis C” – Asociación Civil Buena Vida, Argentina
6. “The story of Muslima Kader Mill” – a video from the National Liver Foundation of Bangladesh, Bangladesh
7. “How to prevent hepatitis B in newborns” – an infographic from Wu Nan from the Institute of Liver Diseases, First Affiliated Hospital of Peking University
9. “A call to action from Bralise, a young advocate” – Democratic Republic of Congo
10. “The personal story of Aleksey Lakhov” – Russia

We children say, stop hepatitis in children.
Bralise, NOhep stories winner
New report calls for the end of stigma and discrimination impacting people living with hepatitis B

The report released by WHA brings together the latest research on stigma and discrimination and the stories of the people and communities affected by hepatitis B. The report highlights the need to address hepatitis B stigma and discrimination so that no one has to suffer the additional consequences of living with hepatitis B.

Across the world, stigma and discrimination impact people living with hepatitis B, with careers and personal relationships affected. Stigma and discrimination also affect families and communities and negatively influence testing strategies.

Two hundred ninety-six million people live with hepatitis B worldwide, and for many, their lives are made infinitely more challenging by stigma and discrimination. In a 2017 survey of WHA members, 93% of respondents indicated that hepatitis-related stigma and discrimination impacted people in their countries, yet little is being done globally to tackle the issue.

Stigma and discrimination can have a huge impact on the lives of people living with hepatitis B. It impacts our rights to work, to travel and to live our lives. The Stigma Report shows that it is time to tackle this issue to protect the rights of the millions of people living with hepatitis B. We can no longer suffer in silence; the time for action is now.

Danjuma Adda, president-elect of WHA

VIEW THE STIGMA REPORT
The new report gives clear policy suggestions to assist decision-makers in addressing hepatitis B stigma and discrimination. Key to the success of these is the engagement of the people and communities impacted by hepatitis B.

Cary James, WHA Chief Executive

Policy and decision-makers play an essential role in ensuring that anti-discrimination laws, public health policy, education and health systems work together with civil society and the affected communities to tackle the crisis of stigma and discrimination.

To address these challenges, the report recommends health systems adopt the following policies:

- Provide accurate and accessible information regarding hepatitis B for those newly diagnosed including transmission, health promotion information, rights and responsibilities, and long-term health plan.
- Ensure all newly diagnosed individuals are linked to appropriate and supportive health care services for ongoing monitoring and management.
- Ensure equitable and affordable access to prevention of mother-to-child transmission (PMTCT) programs for all women.
- Ensure that mental and emotional support is provided to people diagnosed with hepatitis B and their families.
- Require that all healthcare professionals receive ongoing hepatitis education and are aware of stigma and how to address it.
- Ensure testing for hepatitis B is conducted in the context of health care services, that the results are confidential, that the testing is of direct benefit to the person being tested, and that it is not required as a condition of employment or education.
- Ensure anti-discrimination laws and policies are correctly implemented and that adequate recourse is given to enable people experiencing discrimination to pursue justice through the legal system.
- Ensure there are legal protections in place for people with hepatitis B, including protection from government sanctioned discrimination.
- Ensure that immigration and visa policies do not limit the freedoms of people living with hepatitis B because of their diagnosis.

This report was made possible with funding from the Janssen Pharmaceutical Companies of Johnson & Johnson.

The new report gives clear policy suggestions to assist decision-makers in addressing hepatitis B stigma and discrimination. Key to the success of these is the engagement of the people and communities impacted by hepatitis B.

Download the report at worldhepatitisalliance.org/stigma

A webinar in December will bring together experts and people impacted by stigma and discrimination to discuss the issue and the actions needed to tackle stigma and discrimination. Sign up for the webinar at worldhepatitisalliance.org/registration

VIEW THE STIGMA REPORT
In partnership with the World Hepatitis Alliance, Kautz5, a non-profit project and consulting company in the health sector, launched a pilot project “Hepatitis Delta: Educate - Understand - Test”. This project brings together various stakeholders from the fields of medicine, health policy and culture to use their expertise to raise awareness of hepatitis D among the Mongolian community living in Germany and call on people potentially affected to get tested.

According to the WHO, 5% of people living with hepatitis B are suffering from hepatitis D co-infection. This dangerous co-infection can lead to severe chronic conditions in 70-90% of all cases. Although Germany is a low-prevalence country, there are high-risk groups in Germany, such as population groups with a migration background from countries with significant prevalence. It is expected that a large proportion of these vulnerable groups have little or no knowledge of how hepatitis D is transmitted and its connection to hepatitis B, leading to low demand for testing.

The aim of the pilot project is to inform particularly vulnerable groups about hepatitis D and to engage them in education activities and encourage them to come forward for testing. In order to build up and communicate the information and messages in a culturally sensitive way Kautz5 worked with various Mongolian cultural associations. At a joint round table meeting the project was presented, Kautz5 used the meeting to understand existing experiences the community had with the topic of hepatitis and possible communication channels for the hepatitis D campaign were discussed. The associations showed great interest in the topic of hepatitis D and indicated their willingness to support the project. In constant communication with the community Kautz5 determined which messages and what information should be used for dissemination via social media. Together they agreed on World Hepatitis Day as a particularly suitable date for the kick-off of the awareness campaign.

Based on the WHA materials, posters, social media posts as well as headlines, fact sheets and explanatory videos were provided and published on the Facebook pages of the various Mongolian associations. In addition, family doctors and specialist clinics were informed about hepatitis D in four major cities, where more people of Mongolian descent live. The materials were also made available to the community as the first point of contact.

A second part of the campaign was kicked off in November 2021 with a roundtable organized with the Support of the Mongolian Embassy in Berlin and the German Federal Ministry of Health. During the meeting the speakers emphasized the importance of bilateral collaboration among stakeholders to increase awareness of hepatitis D, increase the number of at-risk people tested, and reduce the spread of this viral disease.

This project was made possible thanks to the funding from Gilead Sciences. To learn more about the project please visit kautzhoch5.de.
“Creating a Healthier Asia” video series shines a light on living with hepatitis B

World Hepatitis Alliance (WHA), in collaboration with the Coalition to Eradicate Viral Hepatitis in Asia Pacific (CEVHAP) and Gilead Sciences, has launched the Creating a Healthier Asia video series. Produced on behalf of this partnership by BBC StoryWorks commercial productions, the video series provides insight into the real-world challenges of living with hepatitis B in Asia from the point of view of the people managing it. Topics covered include misinformation, inaction, delayed diagnosis, and other barriers to receiving care.

Hepatitis B remains an invisible chronic disease, especially for those born before national immunization programs. More than 50 percent of the estimated 257 million people living with chronic hepatitis B infection lived in Asia Pacific. A study by the WHO suggests only 10 percent of individuals infected with hepatitis B are aware that they have it. Furthermore, most people with asymptomatic hepatitis B are often diagnosed only when it has developed into more severe conditions.

Four individuals are featured in this campaign: Min Kyung Yoon (South Korea), Lai Wang Yu (Hong Kong), Chua Cher Joo (Singapore) and Ho Qing Quang (Taiwan). They cover a variety of experiences – ranging from bereavement of family members, surviving liver transplant to multiple cancer diagnoses – shedding light on unique — yet relatable — journeys. They are just some examples of how regular screening, in-depth discussion with clinicians, and persistent medication may detect and deter complications early.

Five videos, as part of the ‘Creating a Healthier Asia’ video series, will be released on the hub from November to December 2021. Visit the hub [here](#) (not available in the UK).

Early diagnosis can be crucial for people living with hepatitis B to live long and happy lives. Raising awareness of hepatitis is an essential driver for people to come forward for testing and diagnosis. Medical advancements have made hepatitis B a treatable condition. The stories shared in the video series are testament that people living with hepatitis B can lead a long and fulfilling life. Our collaboration with CEVHAP and Gilead Sciences on this video series cannot come at a better time. I hope that this series will bring the message home to people living with hepatitis B that they are not alone – there is a strong support system for you out there.

Cary James, CEO, World Hepatitis Alliance

CEVHAP is delighted to work with like-minded organizations to provide a platform for people living with hepatitis B to share their personal stories. It is our hope that this series can inspire and empower community leaders to help drive hepatitis B elimination in every country. It goes beyond awareness to prevention, community action, and collaboration with healthcare professionals in Asia, to make real strides towards disease elimination and ultimately, eradication.

Professor Rosmawati Mohamed, Co-Chair, CEVHAP

By focusing on the experience of people living with hepatitis B from Hong Kong, Korea, Taiwan and Singapore, the video series brings to light the possibilities of improving the management of chronic hepatitis B. Storytelling can bring discussions of hepatitis to the forefront and empower those living with, or vulnerable to hepatitis B, to step up their own care.

Caroline Choi, Senior Director, Medical Affairs Asia 5 of Gilead Sciences
Through the Find the Missing Millions campaign, we are highlighting inspiring work from around the world. This month we hear from Care for Social Welfare International on their work to implement maternal and child health programmes and viral and non-viral hepatitis projects across rural and urban communities in Nigeria.

Care for Social Welfare International (CASWI) is a non-profit, non-governmental organisation founded on the interests of vulnerable and indigent populations. They carry out a number of activities such as advocacy, raising awareness, implementing maternal and child health programmes and viral and non-viral hepatitis projects across rural and urban communities.

The goal of the organisation is to help reduce the spread of hepatitis and enhance the lives and health status of persons living with and/or affected by hepatitis. In April 2020, CASWI started with an advocacy visit to the Ministry of Health. The Ministry gave CASWI the permission to start the awareness-raising project, and they soon discovered that people in their community did not know what hepatitis was. CASWI decided to use existing establishments such as churches and mosques to conduct hepatitis awareness raising seminars.

Currently, in Cross River State, CASWI is the main organisation that supports the Ministry of Health and carries out hepatitis activities in the state. Previously there weren’t any organisations carrying out these activities and the Ministry did not have any members on the ground working to raise awareness about hepatitis.

One of the organisation’s main achievements was from World Hepatitis Day 2020. They held a weeklong campaign, the first of its kind in the state, where they screened over 400 people. Also, in early 2021, after the NOhep Moms campaign launch, CASWI was the first organisation to carry out the campaign in Cross River State. This led them to discover that the general hospital hadn’t had any birth dose vaccines for babies for a long period of time. They informed the Ministry of Health and this pushed them to source birth dose vaccines for their facilities. They were also able to recruit mothers to become advocates for NOhep Moms. They were responsible for telling other mothers and women in their communities about the procedure to follow after giving birth. This allowed the advocates to educate those who had no knowledge about hepatitis, knowledge they wouldn’t have received from regular maternity clinic visits.

CASWI also launched “Hepatitis at your Doorstep” a project providing a 24/7 phoneline where individuals could call and enquire about hepatitis services. They had a medical team taking the calls and who could visit them at their home or office for screening or vaccinations. The phoneline allowed individuals who were not comfortable asking about hepatitis in person due to stigma to receive potentially lifesaving information.

TOP TIPS FOR SUCCESS

1. Make use of existing establishments such as churches, banks, mosques and associations. This allows access to a large group of people in once place.

2. Associate yourselves with state HIV/AIDS and STI control units to help gain public trust.

3. Use posters and stickers to make your campaign visible to those afraid of discrimination.

KEY MESSAGES

1. Don’t assume people are knowledgeable about hepatitis. Always explain what hepatitis is and how to prevent it.

2. Constant communication with people who are being vaccinated increases the chances of them coming back for a second dose.
When I was at college, I secured a scholarship to study at a university in Europe. I felt fortunate and proud, as I was the first person from my small village in Northern Vietnam to get the opportunity to study abroad. As a part of the paperwork for my scholarship, I had to do a health check and hepatitis B test was on the list. When I came to get the results, the doctor at the health check department told me I had hepatitis B and that I would therefore not be able to go overseas. I did not know about hepatitis B, so I did not question his advice. I blindly trusted him and rejected the scholarship. It was only when I was older that I found out that that doctor was wrong. I could have taken up the scholarship.

Losing my scholarship was not the worst part of my diagnosis. The only thing I knew about hepatitis at the time was that it was a liver disease, as hepatitis in Vietnamese translates to “liver inflammation”. My grandmother passed away due to liver cancer when I was a child and I thought I would die too. I was given no further information about the reality of living with hepatitis B.

Oddly enough, since I had no symptoms, I nearly forgot about my diagnosis. A few years later, I started researching hepatitis B on the internet. At the time, using the internet was a luxury, with one-hour access at an internet cafe costing me as much as one meal. It took me many meals to discover I can live with hepatitis B.

When I told my husband, then boyfriend, about my status, I was met with empathy and acceptance. Even though he did not know much about the disease and was afraid of contracting it, he chose to love and not stigmatise. Unfortunately, most people do not react with such acceptance. Therefore, I chose not to tell my friends, colleagues, in-laws, or anyone who was not at risk of contracting the disease.

Worries about my condition crept up again during my pregnancy. Luckily, I had access to a private hospital that specialised in delivery for mothers living with viral hepatitis and my children received hepatitis B vaccinations at birth. Unfortunately, a lot of women in Vietnam do not have the same privilege.

I lost my opportunity to study abroad because of my status. A friend of mine lost the chance to have a life partner because she was rejected upon disclosing her diagnosis. Other people I know lost their jobs. The elimination of hepatitis for me means opportunity. A hepatitis B cure is something everyone living with hepatitis B longs for; it would also be a cure for the social illness of hepatitis B stigma.