New viral hepatitis elimination progress data

hepinion: The African Union must provide leadership for hepatitis elimination

Annual NOhep cricket match held

WALL OF STORIES
“I decided to spend my last atom of energy educating people about viral hepatitis.”
Note from our CEO

Welcome to the first hepVoice of 2020. I hope that you have had a good start to the year. I have had a busy few weeks attending the Prince Mahidol Awards Conference (PMAC) and the World Health Organization (WHO)’s Executive Board Meeting, both of which had a heavy focus on Universal Health Coverage (UHC). I was there in my dual capacity as CEO of the World Hepatitis Alliance and Advisory Group Member for the Civil Society Engagement Mechanism for UHC2030, not only to learn from my peers but also to ensure that viral hepatitis is included in conversations and decisions about UHC.

It was heartening to see hepatitis C cure research pioneer Dr Ralf Bartenschlager accept this year’s Prince Mahidol Award in Bangkok. He used his keynote speech to champion hepatitis C elimination as a central part of UHC. Viral hepatitis is too often overlooked at global health events, and we must do everything we can to bring it to the centre of global policy generation and implementation planning. You can read more about Dr Bartenschlager and his speech on page 16.

New data from the Center for Disease Analysis Foundation’s Polaris Observatory makes for sobering reading. It indicates that only five countries are on track to meet WHO’s 2030 hepatitis C elimination targets. I hope that this will serve as a wakeup call for countries, and that governments will redouble their efforts to ensure that we do not let the opportunity to eliminate hepatitis slip from our grasp. Read more on page 10.

I am confident that 2020 will bring us many new opportunities. I hope you enjoy the other updates and stories in this edition of hepVoice, and look forward to seeing more of your amazing work in the coming year.

Cary James
Hepatitis is regularly making the news thanks to the efforts of WHA members. Here are a few highlights.

One third of people living with hepatitis C in Georgia identified and treated

Since the launch of Georgia’s hepatitis C elimination programme in 2015, one third of the estimated 150,000 people living with the virus in the country have been identified and received treatment.

As of December 2018, more than 1.1 million adults (39.6 per cent of the adult population of Georgia) had been screened with rapid antibody tests under the programme, and approximately 67,000 people who were diagnosed with hepatitis C started treatment.

The programme evolved to overcome barriers including the cost of diagnostic tests, as well as access to treatment. Their programme provides best practices which can be adapted to other country’s national elimination plans, specifically to reduce the barriers to hepatitis C diagnosis and linkage to curative treatment.

The study’s authors wrote: “Georgia will encounter new, unforeseen challenges, and must continue to identify and develop innovative approaches to overcoming barriers as the country strives to meet elimination goals. This country’s robust hepatitis C elimination efforts can serve as a model for countries developing programs not only to eliminate viral hepatitis, but other public health threats as they emerge.”

Read more

Hearts donated by people with hepatitis C may be safe for transplant

A new study conducted in the USA has revealed that it may be safe to transplant hearts from donors with hepatitis C.

Researchers found that the one-year survival rate of transplant patients who receive a heart from a donor with hepatitis C are similar to those of patients who receive hearts from someone without the virus.

Just over four per cent of the 7,900 heart transplant patients studied received hearts from donors with hepatitis C. A year after their transplant, 90 per cent of patients whose donors had hepatitis C and 91 per cent of patients whose donors did not have the virus were still alive.

Dr. Arman Kilic, co-director of the Center for Cardiovascular Outcomes and Innovation at the University of Pittsburgh Medical Center and lead author of the study, said: “We are encouraged by these results and believe this is a landmark change in our ability to better meet the demand for heart transplantation by increasing the donor supply.”

Read more

Ministry of health rolls out free hepatitis B vaccination in central Uganda

Uganda’s Ministry of Health has announced a free hepatitis B screening and vaccination programme in central Uganda, an area of the country with an estimated two per cent prevalence of hepatitis B.

This announcement follows sustained petitioning from local leaders and members of parliament to provide free vaccination, in response to the prohibitive cost of vaccination if paid by individuals and the prevalence of fake vaccines administered by private healthcare workers.

Free screening will be rolled out in several districts in central Uganda, and anyone who tests positive for hepatitis B will be treated for free at regional hospitals. The Ministry of Health has indicated that it has plans to scale this up to include national hospitals.

Read more
Dates for the Diary

Upcoming events and activities taking place in the coming months.

1 MARCH
Zero Discrimination Day
Zero Discrimination Day aims to promote equality before the law and in practice throughout all of the member countries of the UN. With stigma and discrimination identified as leading barriers to diagnosis for viral hepatitis, this day provides an important platform to address these issues and to call for an end to discrimination. Join in the conversation on social media using #ZeroDiscrimination.

22 MARCH
World Water Day
Sustainable Development Goal 6 is crystal clear: clean, safe water for all by 2030. But today, billions of people are still living without safe water – their households, schools, workplaces, farms and factories struggling to survive and thrive. A lack of access to safe water and sanitation facilities fuels the spread of hepatitis A and E, often among some of the most marginalised communities. Join in the conversation on social media and call for safe water for all by using #WorldWaterDay.

24 MARCH
World TB Day
World TB Day is designed to build public awareness that tuberculosis (TB) today remains an epidemic in much of the world. It is the only infectious disease that claims more lives each year than viral hepatitis. Together, these diseases kill almost three million people each year. By better integrating our efforts and tackling the epidemics of TB and viral hepatitis together, we will achieve a more efficient, sustainable, and impactful response to both diseases, as well as substantial gains for public health and the health of communities impacted by the diseases. Join in the conversation on social media and call for better integration of testing and treatment services using #WorldTBDay.

Participating in a hepatitis related activity or have an event planned? Email us on contact@worldhepatitisalliance.org or contact us on social media.

PRIME has developed a downloadable, multilingual toolkit to assist healthcare professionals (HCPs) in Europe to engage patients in hepatitis B screening and patient-centered care.

In addition to providing helpful information on hepatitis B management, the tools will assist HCPs in removing barriers to care by supplying them with communication strategies to engage and counsel patients at risk for or living with hepatitis B. The toolkit is designed for use in general or specialised health care settings, including hospitals, general practices, and community-based testing and outreach centers that serve diverse patient populations, such as immigrants, incarcerated individuals, people who inject drugs, and men who have sex with other men.

The tools are available for both HCPs and patients, thereby ensuring access to important resources that facilitate point-of-care hepatitis B testing and counseling and patient-centered care.

DOWNLOAD THE TOOLKITS
Dear Colleagues,

It is my honour to take up the role of President of the World Hepatitis Alliance (WHA) this year. It is a privilege to represent patients and the affected community on the global stage, and I’m looking forward to working with our members, the WHA global board and staff team over the next two years.

The start of my term has coincided with an unexpected health diagnosis. I was found to have early stage breast cancer and underwent surgery in January. I am doing well, and because I had bilateral mastectomies, the cancer was completely removed and I will not need chemotherapy or radiation. I have been working closely with Michael Ninburg and the WHA team since serving as president-elect last year, and we have been speaking regularly throughout my diagnosis and treatment. As I recover, past-president Michael Ninburg and the executive board will be fulfilling some of the duties of president. I’ve seen the strength of our team exemplified during this time, and I am grateful to Michael and the WHA team for their dedication, support and friendship.

While I have received excellent medical care, it is the breast cancer patient community that has blown me away. I have benefited so much from the women whose lived experience has given me an incredible wealth of experience to navigate the day-to-day of this journey and provided the emotional support to keep me going. This wisdom has come in many forms—from speaking to them in person or on the phone, to conversations in online patient forums, and even through personal memoirs in books and movies. There is an awareness of breast cancer that makes support accessible, and patients can easily find advice that is relevant to them from time of diagnosis through their treatment and recovery.

I’m even more convinced now that we need a stronger and more visible patient community in the hepatitis world. We need the same kind of awareness and accessible networks of people with lived experience telling their stories and providing support for each other. I have a vision that when we do “find the missing millions,” they will not be overwhelmed or feel alone.

They will find the viral hepatitis community supporting them with powerful stories of lived experience, empowering them with the knowledge and voice to get the care they need, and giving them the tangible hope that they can live healthy and fulfilled lives. This experience has given me a renewed sense of determination to ensure that patient voices are heard at the highest levels and that #NOhep becomes a reality.

“This experience has given me a renewed sense of determination to ensure that patient voices are heard at the highest levels.”

The start of my term as president begins in a landmark year for the hepatitis elimination movement. Countries now have just a decade to fulfil the promise they made in 2016 to eliminate viral hepatitis. We know the majority of countries are not on track to reach elimination. Huge gaps remain in funding and access to diagnosis and treatment. Over the next decade, we need to accelerate action to elimination. Patients and civil society need to be involved at every level of decision making.

We have the tools we need to eliminate viral hepatitis. With prioritization of resources and political will, elimination is possible. We must dismantle the barriers to elimination and ensure that prevention, testing and treatment are available to everyone, everywhere.

In 2020 WHA will be working closely with our partners to ensure that hepatitis is firmly on the global health agenda and countries are held to account for the promise they made in 2016. We will be empowering civil society with the knowledge and tools to effectively engage with policymakers, especially on the Universal Health Coverage (UHC) and integration agendas. WHA will be using our platforms to give a voice to the affected community and civil society, championing their role in the development of health systems. We will highlight good practices, innovative models, and we will lead global advocacy efforts and campaigns including growing the NOhep movement and World Hepatitis Day.

WHA has ambitious plans, I look forward to working with you to accelerate action so that we can reach elimination.

Su Wang, MD, MPH, FACP
New viral hepatitis data available

The Center for Disease Analysis Foundation (CDAF)'s Polaris Observatory, the authoritative source of epidemiological data, modelling tools, training, and decision analytics to support global elimination of hepatitis B and C, is back online after receiving new funding.

The relaunched Polaris Observatory now includes hepatitis B and hepatitis C “progress to elimination” dashboards displaying key metrics for more than 100 countries.

New data from the Polaris Observatory indicates that progress towards eliminating hepatitis C could be stalling. In 2019, 12 countries were deemed on track to meet the World Health Organization’s 2030 hepatitis C elimination targets. In January 2020, CDAF announced that seven of these 12 countries had slipped behind, leaving just Egypt, France, Iceland, Spain and Switzerland on the list.

CDAF have cited insufficient screening as the main reason for Australia, Georgia, Italy, Japan, Mongolia, Netherlands and the United Kingdom’s removal from the list.

WHA Board meet in London

The World Hepatitis Alliance (WHA)'s Executive Board convened in London between 12 - 14 February, bringing a wealth of professional, advocate and patient experience together for a lively and constructive board meeting.

Each board member gave an update on the hepatitis situation and the challenges and progress to elimination in their region, and WHA staff presented on the organisation’s progress to date and plans for 2020. It was a great opportunity for board members to network, share their experience, and put their heads together to shape WHA’s future strategy, while ensuring that the patient voice and perspective stays at the heart of all activities.

2020 World Indigenous Peoples’ Conference on Viral Hepatitis

September 23-26, 2020
Sheraton Cavalier Hotel
Saskatoon, Canada

Find out more at wipcvh2020.org
The African Union must provide leadership for hepatitis elimination.

By Dr Alioune Coulibaly

In February the African Union met and the Presidency of the Union handed over from Egypt to South Africa. During Egypt’s presidency there has been a concerted effort to ensure hepatitis elimination is on the Union’s agenda, including the creation of the African Union Declaration on Hepatitis which committed African Union members to creating and financing hepatitis elimination programmes as part of the Universal Health Coverage framework.

Egypt has been a leading example of countries that are making vigorous efforts to eliminate hepatitis. Through their mass screening and treatment programme, the country has committed to finding and treating over one million people living with hepatitis C. This created momentum in the African Union. Countries including Chad, Eritrea and South Sudan are receiving support from Egypt and other agencies to catalyse their hepatitis elimination work.

However, now the Presidency moves to South Africa, a country which is less focused on hepatitis elimination, we need to ensure that momentum is not lost and that the promise to eliminate hepatitis by 2030 is met.

“If we do not eliminate viral hepatitis in Africa, it will have consequences that reach far beyond health.”

If we do not eliminate viral hepatitis in Africa, it will have consequences that reach far beyond health. I myself have seen the impact of viral hepatitis on the productivity and development of my country, Mali, and others. If people are sick, they may not be able to work, to complete their education, or to live the fulfilling life that every person deserves. If people do not know they are sick – which is very common with viral hepatitis – they cannot seek treatment, and they cannot adequately protect their loved ones from infection.

Despite challenges of climate and conflict in some countries, Africa is booming in so many ways – but if viral hepatitis is not addressed, it will continue to prevent many African nations from achieving their potential.

WHA attended the African Union meeting in February where WHA Past President Michael Ninburg moderated a session on viral hepatitis and met some members of the Organisation of African First Ladies for Development, a group with considerable influence on policy in Africa. We must continue to seize these opportunities to meet with and advocate to individuals of influence. Hepatitis advocates have a vital role to play to ensure that people living with viral hepatitis are heard and their voices are included on the health agenda, and hepatitis elimination will not happen in Africa if we do not speak up.

“Key to any elimination strategy in Africa will be the elimination of mother-to-child transmission of hepatitis B.”

Key to any elimination strategy in Africa will be the elimination of mother-to-child transmission of hepatitis B through screening all pregnant women, linking them to care and ensuring that babies receive the hepatitis B birth dose vaccine. We must ensure that this tool is used to prevent mother-to-child transmission of this deadly disease. The vaccine can be administered easily and countries can obtain it at low cost. With it we can at least ensure that the next generation does not have the same burden of hepatitis B. We also need to raise so much awareness about this disease. It needs to be spoken about and the stigmas and myths, which are prevalent in some communities in Africa, dispelled.

We have been presented with a once in a lifetime opportunity to eliminate viral hepatitis in Africa. We have the tools. Civil society must play a key role in the journey. We need buy-in of and influence from our leaders and decision makers, including – and perhaps especially – the government of South Africa, as they take on the presidency of the African Union.

While there are many challenges to overcome, including financing, an upscale of diagnosis and testing, and political will, we must fight to ensure that we seize the opportunity and eliminate the disease to help every country in the African Union prosper.
Through the Find the Missing Millions campaign, we are highlighting best practice and innovations in screening and testing so that other organisations can learn and develop their national activities. This month, we are highlighting the efforts of CAPAHC in Canada.

By Marjolaine Pruvost, Project Coordinator at CAPAHC

In Canada, 44 per cent of people who are living with hepatitis C do not know their status, and 35 per cent of hepatitis C infections occur in immigrants.

There are approximately 13,000 Pakistani immigrants living in Québec. People who have emigrated from Pakistan are considerably more likely to be living with viral hepatitis than those born in Canada; the prevalence of hepatitis C among the broader population of the province of Québec is 0.71%, whereas the prevalence in Pakistan is much higher at 5.6%. To increase hepatitis C awareness, screening and linkage to care among the Pakistani community in Montréal, we developed the Aagahi micro elimination project.

The main aims of the project were to:

- Raise awareness of viral hepatitis among the Pakistani community of Montréal
- Offer rapid screening for hepatitis C
- Enhance linkage to care for those who need it.

To develop the project we hired a community consultant. Two out of the three nurses and one of the volunteers working on the project were also members of the Pakistani community, which helped us to ensure our approach was culturally sensitive and allowed us to provide services in Urdu, Punjabi, English and French to increase accessibility.

We created partnerships with key representatives of the community and reached community members through cultural activities and events including the Pakistan Independence Day festival, and in mosques. During these six events, we provided information about hepatitis C in a culturally sensitive manner, identified and addressed knowledge gaps and misconceptions, provided awareness-raising materials and tools developed in English and Urdu, and organised screening sessions. During the screening sessions, we tested 164 people for hepatitis C. People who tested positive for hepatitis C antibodies were linked to care.

Our partner, Dr Christina Greenaway, conducted a scientific study alongside the project to address key public health problems surrounding immigrant health and to assess knowledge and seroprevalence of hepatitis C. The study design included a questionnaire (demographics, risk factors, hepatitis knowledge and awareness) and point-of-care hepatitis C screening.

The key to the success of the event was our culturally sensitive approach. By adapting our approach and offering information in different languages, we were able to create a bond of trust with the community and reduce any barriers to engagement. We found that people really appreciated the opportunity to be screened, especially with services provided in Urdu and by people from the Pakistani community.

Key findings

- We need to develop adapted cultural and linguistic services for immigrants and newcomers, which also support people to navigate the healthcare system.
- We have to raise awareness about hepatitis C among doctors, and encourage screening.
- Migrants with precarious status need to have access to screening and treatment for hepatitis.

Top tips for success

- Identify the right people to speak to (e.g. community leaders) to access the community you want to reach.
- Take a culturally sensitive approach: speak to people in their own language and aim to include members of the community you are working with within your staff/volunteer team and offer services to people in their own language.
- Take your events to where the community already are, e.g. at cultural activities and centres.
Leading hepatitis researcher receives top award

Professor Dr Ralf Bartenschlager was presented with the Prince Mahidol Award in the field of medicine at the Prince Mahidol Award Conference in Bangkok, Thailand. Dr Bartenschlager’s research into the life cycle of the hepatitis C virus provided the basis for the development of the direct-acting antivirals which changed the face of hepatitis C treatment and cure.

Dr Bartenschlager used his keynote speech to advocate for universal access to curative treatment for hepatitis C, as well as the development of a hepatitis C vaccine to accelerate elimination efforts. He also highlighted the opportunities that Universal Health Coverage would bring to the elimination of hepatitis C, saying: “Diagnosis and treatment [of hepatitis C] must be provided very early, which requires an adequate medical infrastructure, but also the financial resources to establish and sustain such programmes. In that respect, the implementation of a universal healthcare system is a very important step towards this goal with the antiviral therapy of chronic hepatitis C providing a great opportunity to demonstrate the benefit of this system.” Watch Dr Bartenschlager’s full speech here.

Hitting a six: National Liver Foundation of Bangladesh host annual NOhep cricket tournament

NOhep supporters around the world are very creative in the ways they raise awareness of viral hepatitis, and the National Liver Foundation of Bangladesh (NLFB) are no exception.

At the end of December 2019, NLFB organised their annual NOhep six-a-side cricket tournament, donning NOhep-branded cricket shirts and playing a day of exhilarating cricket. NLFB’s Secretary General, Professor Mohammad Ali, opened the event, urging all who took part to take the NOhep message back to their respective communities. The event was shared widely on social media, including on the Bangladesh Cricket Supporters’ Association Facebook page which is liked by over 120,000 people.

You can watch some highlights from the day here.
I was motivated to join the fight against viral hepatitis through a horrifying personal experience.

My uncle was diagnosed with liver cancer caused by hepatitis B. While he was in hospital, a rumour started in the family that my uncle's wife had poisoned and bewitched him.

As a result of this rumour, my uncle's wife was prevented from visiting him in the hospital. Sadly he died two days later. The family also prevented her from attending my uncle's funeral, and then demolished her house because they claimed she had caused his death. Some family members also sexually assaulted my uncle's wife and subjected her to gender-based violence.

All of this happened despite me and my colleagues at the hospital telling the family that my uncle had died from liver cancer as a result of hepatitis B.

This unbearable and uncalled for situation occurred due to inadequate knowledge and information about viral hepatitis infection in the community. I am certain that more families are going through the same thing, so I decided to spend my last atom of energy informing, educating and communicating about viral hepatitis to help tackle this dangerous lack of knowledge.

As well as helping close relatives and friends living with viral hepatitis with psychosocial support and counselling, I have helped set up a number of initiatives to raise awareness of viral hepatitis in the community and to support patients and their families.

I am a focal person in charge of hepatitis B at Bwera General Hospital, where we raise awareness about hepatitis and have a group which works to prescribe solutions to hepatitis-related challenges.

I also work as a capacity-building and mentorship officer at Great Lakes Peace Center, where we work to prevent viral hepatitis and other infectious diseases in rural communities. We do this through raising awareness and through networking and partnerships with local, regional, national and even international bodies who are also committed to eliminating viral hepatitis.

"I decided to spend my last atom of energy informing, educating and communicating about viral hepatitis."

"Many people are still ignorant about hepatitis and think it’s caused by witchcraft."

Many people are still ignorant about hepatitis and think it’s caused by witchcraft or a rudimentary African monster. We therefore work hard to raise awareness, break down stigma, reduce barriers to diagnosis to find the missing millions, and encourage people to get tested. We make sure to involve and support people who are living with hepatitis B, providing psychosocial support and counselling and supporting them when they face discrimination and stigma.

See more stories and submit your own at www.worldhepatitisalliance.org/wall-stories