Voice
Your monthly magazine from the World Hepatitis Alliance

September 2018: Vol.28

hep VOICE

Find the missing millions in Bangladesh

Focus on the solution

Wall of Stories

“I was determined to fight”
Note from our CEO

World Hepatitis Day created an incredible amount of momentum in the fight to eliminate hepatitis. We have seen this momentum used to deliver actions all over the world, with WHA members playing leading roles in their countries elimination goals through on the ground activities, advocacy and awareness campaigns. It is important that the momentum is kept up if we are to reach the 2030 goal of elimination.

Our “Find the Missing Millions” campaign is being used by our members to increase diagnosis through projects and advocacy to ensure testing and diagnosis is available to the 290 million people unaware of their illness. You can read about how WHA member the National Liver Foundation of Bangladesh are running their Find the Missing Millions campaign on page 8.

At WHA we are working on our strategy for next year already and have exciting plans to expand our work, continuing to empower our members to make the elimination of viral hepatitis a reality. We look forward to sharing these plans with you soon.

Raquel Peck
Chief Executive Officer

Want to contribute?

We welcome your contributions so please get in touch at contact@worldhepatitisalliance.org to have your news and stories included in future issues and feel free to share this magazine with your network.

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This month in numbers

A round-up of some of this month’s stand-out facts and figures:

- 20% Fall in deaths from liver failure or liver cancer caused by hepatitis C in the UK and Australia.
- 39.2% of recent injection drug users are living with HCV.
- 500,000 social media impressions for the #Findthemissingmillions campaign

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Don’t miss out - receive hepVoice straight to your inbox!
Hepatitis is making the news regularly thanks to the work of WHA members, here are a few highlights

First ever conference on eHealth and the elimination of viral hepatitis

WHA member, the Chennai Liver Foundation, hosted the first ever Summit on ‘eHealth & the Elimination of Viral Hepatitis’ on 11th August 2018 in India. The conference was opened by WHA CEO Raquel Peck who emphasised the important role of Civil Society giving examples of how patient groups are using innovation to enhance the elimination response. Read more at chennailiverfoundation.org/news-and-events.html

Rwanda offers regular tests and vaccines to eliminate hepatitis

Rwanda’s Minister of health, Diane Gashumba says the country regards viral hepatitis as a serious public health concern in the country but the Government has increased the commitment to maintain momentum to scale up screening and treatment. Read more at www.irwanda24.com/?p=19781

FIND and DNDi team up to support Malaysian MOH efforts to simplify and decentralize hepatitis C screening & treatment

The Foundation for Innovative New Diagnostics (FIND) and the Drugs for Neglected Diseases initiative (DNDi) will partner to generate evidence that will support policy change and scale up of hepatitis C (HCV) diagnosis and treatment in collaboration with the Ministry of Health in Malaysia. It forms part of a larger FIND project known as Hepatitis C Elimination through Access to Diagnostics (HEAD-Start), supported by Unitaid. Read more at www.dndi.org

Research shows that nearly 40% of recent injection drug users are living with HCV

An international research study designed to estimate the global, regional, and national prevalence of hepatitis C virus (HCV) infection among people who inject drugs (PWID) has determined that nearly 40% (39.2%) of recent injection drug users are living with HCV. According to the study authors, the data on HCV infection burden produced by the study could assist World Health Organization (WHO) efforts to eliminate HCV as a “global public health threat by 2030,” allowing for more accurate monitoring and targeting of prevention/treatment strategies. Read more at www.mdmag.com

End-stage liver disease deaths due to hepatitis C fall in the United Kingdom and Australia

Deaths from liver failure or liver cancer caused by hepatitis C fell by 20% between 2016 and 2018 in Australia, the Kirby Institute at the University of New South Wales reported in August. A similar trend was evident in the United Kingdom, Public Health England (PHE) reported. Read more at kirby.unsw.edu.au/news/affordable-treatment-leads-feWER-deaths-hepatitis-c.

For the Diary

Here are some upcoming events and activities taking place this month.

13-15TH September

The Conference on Liver Disease in Africa (COLDA) 2018, will be held from 13th-15th September in Nairobi, Kenya. Organized by Virology Education in close collaboration with local societies, COLDA 2018, aims at empowering local liver experts to prevent, treat and achieve cure for liver diseases for the benefit of patients in Africa. Many NOhep medical visionaries will be speaking at the event.

22-29TH September

Global Goals week

The third annual week of action where the United Nations and partners from around the world come together to drive action, raise awareness and hold leaders to account in order to accelerate progress to the Sustainable Development Goals (SDGs), also known as the Global Goals. Follow on social media using #GlobalGoals

Participating in a hepatitis related activity or have an event planned?

Email us or contact us on social media.
World Hepatitis Alliance President, Michael Ninburg speaks at Australasian viral hepatitis conference.

WHA President Michael Ninburg addressed the 11th Australasian Viral Hepatitis Conference in August. The conference held at the Adelaide Convention Centre, focussed on the theme “No One Left Behind”

Michael used his speech to highlight the low diagnosis rates globally and to speak about the Find the Missing Millions campaign.

“Viral hepatitis elimination will not be achieved without involving the people and communities who are affected by the epidemics.

Even if we treated everyone who was diagnosed with viral hepatitis, we would still only be at the tip of the iceberg of the global hepatitis burden because only 1 in 10 people are aware of their illness. Without an increase in diagnosis we won’t be able to progress to the next step of elimination. We have parts of the world that are struggling more than others to test and diagnose people, Australia is a notable exception in this.

‘Find the Missing Millions’ is a campaign to put patients and the community at the centre of the issue to address the barriers to diagnosis. The first phase of the campaign, launched in 2018, looked to work with partners and civil society to identify the barriers to diagnosis, Phase two will be looking to work with some of our member states to set up replicable projects that will support countries find the undiagnosed whilst keeping the patient and civil society front and centre of the elimination strategy.

Many Alliance members are working hard to find the missing millions, over the next few years we will be working with them to help grow those projects and gain government backing.

Australia is one of the countries leading the way, in part due to the recognition of the need for access to harm reduction for people who inject drugs. This has been a huge step in the right direction.

‘Find the Missing Millions’

9 out of 10 people living with viral hepatitis are unaware

I have been greatly impressed by this Australasian delegation which brings together, patients, civil society and public health clinicians, to really have a vibrant discussion between critically important groups in getting to the root causes of the epidemics of hep B and hep C and most importantly the solution on how we are going to get to the target of elimination of these viruses by 2030.

I think the focus on the patient has been absolutely critical, I think the organisers of the conference have done a great job at having the patient voice front and centre throughout the conference, and that is one of the things that I have appreciated more than anything.”
Find the missing millions: examples from around the world

No one should have to live with viral hepatitis without knowing. Yet more than 290 million men, women and children do. Unless there is a massive scale-up in screening, diagnosis and linkage to care, more people will become infected and lives will continue to be lost.

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. Each month we profile a successful diagnosis initiative. This month, we’re highlighting the efforts of WHA member The National Liver Foundation of Bangladesh to find the missing millions with their screening drive.

Hepatitis screening, diagnosis and treatment in Bangladesh

By Prof. Mohammad Ali
Founder, National Liver Foundation of Bangladesh

“The National Liver Foundation of Bangladesh used the ‘Find the Missing Millions’ campaign on the eve of World Hepatitis Day to promote testing and diagnosis among the indigenous people (Chakma tribe) of the Chittagong Hill Tracts, Bangladesh.

The Chakmas are the largest indigenous tribe consisting of 444,748 people. They mostly live in Rangamati, Chittagong Hill Tracks. They have their own language, culture, tradition and history.

We needed to raise awareness of hepatitis amongst the community as we discovered most of the people had never heard of viral hepatitis. Local NOhep activists from our “NOhep Network Bangladesh” worked to encourage people to get tested. Although we were offering free screenings, many people didn’t see the need to be tested for a disease they had no awareness of.

We conducted hepatitis B and C screenings for 810 people of at Rangamati Government College and in the community, diagnosing 42 people (40 with hepatitis B and 2 with hepatitis C).

The success of the programme was, in part, due to collaboration with the local Government health authority, local doctors and civil society.

The programme would not have been possible without the NOhep activists working with people to inform them about hepatitis, the safety of the test itself and the importance of encouraging others to come forward for testing. Crucially they reassured participants that their information was confidential, as many in the local community felt that a positive diagnosis would lead to discrimination.

Have you implemented an innovative screening or diagnosis project? We want to hear from you! Complete the Find the Missing Millions case study submission form here and email us at contact@worldhepatitisalliance.org.
Together, our stories can change the way the world sees viral hepatitis. The stories of those living with or impacted by viral hepatitis can help educate and raise awareness, provide support and inspiration, tackle stigma and discrimination, and highlight the true impact of this global disease.

Each month we share the story of someone whose life has been affected by viral hepatitis. This month, we hear from Baltazar from the Philippines who shares his family's story.

Baltazar

Between 2008-2013, I lost all 3 of my brothers to hepatitis B and liver cancer, and now at the age of 32 I have been diagnosed with liver cancer from hepatitis B. As the last of my brothers remaining, it can be easy to lose hope, but I am also a son, a husband and a father, and I cling to the hope that I will not leave my remaining family prematurely.

It all started when my youngest brother, Marc Anthony, fell ill in January 2008. He was diagnosed with TB but responded poorly to treatment. After medical exams he was found to have hepatitis B. We tried everything we could, including alternative therapies but despite our best efforts, Marc deteriorated and died of liver failure before the year ended, shortly before he was to turn 20.

We all decided to have ourselves checked and we found out that we all had hepatitis B except for my father. I gathered from the internet that if you have it since birth, it’s “chronic” and there is no known cure for it up to this time. I vowed to myself to practice clean and healthy living, avoiding drinking and smoking to increase my chances of surviving the disease.

For a while, life went on for us. The computer shop business was good for my brother Aris, the second sibling. My third brother Joey was a Videographer for the City of Malolos. I got married and had a son. Little by little we were building our dreams.

But, in April 2013 my brother Aris began to feel bloating and “gas pains”. He lost his appetite, got thinner and weaker as the days passed. Initial medication and consultations did not improve his condition and we decided to bring him to Manila for evaluation. Aris was diagnosed with late stage liver cancer. We lost Aris in September of that year. Shortly after Aris passed away, Joey began to feel ill. I had Joey checked and the results were not good. Joey also had liver cancer and by that time it had spread to other parts of his body. I already knew what this meant and what will happen. Joey died November 2013, a month after Aris. He battled the cancer to the very end.

“I tell my story in the hope that others may learn about how common hepatitis B is, how deadly it can be, but also how early detection can help.”

Given our family history, I had myself frequently tested. But in December 2013, I was surprised to find out that I too already had liver cancer despite all precautions. A 10 cm mass in the right side of my liver can cause my early death. I was heartbroken but I refused to think that this was to be the end for me. I was determined to fight!

I consulted with my doctor and had my tumour removed as soon as possible. The operation was a success. I followed all my doctors without question. I became hopeful again and very thankful to God, the doctors and all those who supported me.

“I am sure that somewhere my brothers are rooting for me to pull through.”

In January 2014, I was able to go back to work but was on close follow-up. In May 2014, tests showed that the cancer had come back. I decided to undergo TACE (Transarterial Chemoembolization) to stop the growths while they were small. At present, I still am not cancer-free. I have been advised that a Liver Transplant will be the next step in this fight against this brutal disease. My hepatitis B infection is now controlled with medication. I continue to work as a computer programmer as long as my physical condition allows me, to continue to support my family and my medical needs.

I am sure that somewhere my brothers are rooting for me to pull through. I am all that’s left of my brothers and I am all that my parents, wife and son have.”

Photo: WHO/Y. Shimizu