Meet the NOhep Villagers
Global Hepatitis Summit 2018

Find the Missing Millions launched to 10,000 healthcare professionals

Wall of Stories
“Timely diagnosis saved my life”
Following the community launch of the Find the Missing Millions campaign at the end of March, we are continuing to spread the word and highlight the need for greater efforts to diagnose. This month, WHA President Michael Ninburg officially launched Find the Missing Millions to the wider community at the International Liver Congress while our communications team answered your questions on the campaign in our annual World Hepatitis Day webinar.

With just three months until World Hepatitis Day, we are seeking more and more opportunities to get the message out there – Spring European Testing Week and Hepatitis Testing Day in the USA are just two activities coming up this month! As well as promoting the campaign, we will also bring together a group of experts to examine the results of our global survey on barriers to diagnosis and make recommendations on how we can overcome them.

The importance of our efforts is highlighted in this edition’s Wall of Stories snapshot: Antonio from Mexico would probably have lost his life if he hadn’t received his hepatitis C diagnosis when he did.

This month we are also really pleased to announce our NOhep Villagers! Turn to page 6 to find out who will be exhibiting at the NOhep Village at the Global Hepatitis Summit and find out what they’re most looking forward to about the event.

We hope you enjoy reading!

Raquel Peck
Chief Executive Officer

NOTE FROM OUR CEO

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THIS MONTH IN NUMBERS

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

298 people have been cured of hepatitis C in the past year through simplified, decentralised models of care at an MSF clinic in Meerut, India.

Over 10,000 healthcare professionals attend EASL’s International Liver Congress and hear the official launch of the Find the Missing Millions campaign.

100,000th veteran began treatment for hepatitis C under the Veteran Health programme.

Just 6 European countries are on track to eliminate hepatitis C by 2030, according to new research from the Center for Disease Analysis Foundation.

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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 the magazine with your network.
Viral hepatitis is making the headlines. Here’s the latest news from the field of viral hepatitis this month.

**Founder of the World Hepatitis Alliance appointed as Executive Director of the Medicines Patent Pool**

This month the Medicines Patent Pool (MPP) announced the appointment of Charles Gore as the new MPP Executive Director. Charles takes up the role after two decades of advocating on behalf of people living with viral hepatitis on both the national and global stage. WHA COO/Acting CEO, Karine Belondrade, congratulated Charles’ on the appointment, stating “We cannot think of a better person to lead the Medicines Patent Pool. People affected by viral hepatitis have always been the driving force behind Charles’ tireless efforts to rid the world of one of the greatest global health threats. With him steering the ship, we hope that millions of others will benefit and secure access to life-saving treatments.”

**World Health Organization announces new hepatitis C recommendations**

According to new evidence gathered for WHO’s upcoming hepatitis C treatment guidelines, access to a cure for hepatitis C is increasing, with simplified and more affordable treatments becoming more readily available. Major simplification and its delivery means global scale-up is now possible. WHO announced the new direction at the International Liver Congress where they also highlighted findings from their recent Progress report on access to hepatitis C treatment.

**Innovative new approach to explaining hepatitis B to children**

WHA member Hepatitis Victoria has launched a unique children’s book and animation Little Hep B Hero that aims to help families raise awareness about viral hepatitis, increase health literacy and break the silence. The book is written primarily for 6 to 12 year-olds and includes a glossary and discussion section for families. The concept was first presented at the World Hepatitis Summit 2017 as part of the Innovation for Acceleration session. The book is available in English, Simplified Chinese and Vietnamese and can be ordered from Hepatitis Victoria’s website here.

**Turkey launches viral hepatitis plan**

The Government of Turkey committed to hepatitis elimination at the viral hepatitis elimination conference in Ankara, Turkey on 3 April. The Ministry of Health hosted an event that brought together global experts to discuss the importance of developing and implementing a strategy for elimination. WHA Member HepYasam were also invited to present the patient perspective on hepatitis C.

**Interactive webinar provides tips and tricks for marking World Hepatitis Day 2018**

On 25 April we hosted our annual World Hepatitis Day webinar. The webinar provided an overview of the Find the Missing Millions campaign, tips and tricks on making an impact on World Hepatitis Day and inspiration for event and activities. We were inundated with great questions from WHA members. If you were unable to attend, catch up on the discussions with the video recording and slide deck.

**May**

**Hepatitis Awareness Month USA**

Every year in May, the Centers for Disease Control and Prevention, public health partners and civil society organisations mark Hepatitis Awareness Month in the United States and Hepatitis Testing Day on 19 May. Find out how you can support activities here.

**17-18 May**

Find the Missing Millions two-day stakeholder consultation

This month we will bring together around 30 experts to review the findings of our global survey on the barriers to hepatitis B and C diagnosis, identify recommendations to overcome these and further explore the role people living with viral hepatitis can play in this. Outcomes from the meeting will form a white paper that will be launched on World Hepatitis Day. Keep an eye on our Twitter feed for live updates from the meeting.

**18-25 May**

Spring European Testing Week

In an effort to promote testing and address barriers to implementation, the European Liver Patients Association (ELPA) and partner organisations in Europe will pilot the Spring European Testing Week this month. Find out more here.
Meet the NOhep Villagers

Next month we will host the very first NOhep Village at the Global Hepatitis Summit. This will be an interactive space for patient groups and civil society organisations to engage with medical professionals and share the exceptional work they are doing around the world.

We have had an overwhelming responses to the NOhep Village, with so many organisations interested in showcasing their activities on the global stage. We are delighted to now announce the NOhep Villagers - the organisations that will be exhibiting at the event in Toronto, Canada. And as you’ll see from their profiles on the next few pages, it’s set to be a great event.

For the full NOhep Villager profiles, visit the NOhep website.
Meet the NOhep Villagers

**Action Hepatitis Canada, Canada**

What do you plan to do at your booth in the NOhep Village?

“We will be promoting the CanHepC Elimination Blueprint and will have a map of Canada highlighting remaining barriers to equitable access to hepatitis C treatment and care. We also plan to run a digital campaign where visitors can send a one-click letter to their provincial or territorial health ministers urging them to adopt an implementation strategy for the elimination of hepatitis C.”

What will make your booth stand out?

“Through visual and written content, discussions and traditional ceremonies, we will articulate how CAAN engages in research with Indigenous Peoples and the scientific community through the “Two-eyed Seeing” approach. This creates safe and ethical spaces where both communities are able to share different Ways of Knowing and has been, and continues to be, an effective way for two world views to respectfully engage together where everyone is valued and heard, and power is equally distributed. All our activities will be housed in a tipi that we hope to bring to the event!”

**Bridging Health Foundation, Pakistan**

Please describe your organisation in 2-3 sentences.

“Bridging Health Foundation was founded in 2010 by a group of researchers doing MPhil and PhD thesis research on viral hepatitis. Bridging Health Foundation works on hepatitis awareness, screening, and drug treatment response in Pakistan by conducting hepatitis awareness surveys and doing research on issues related to hepatitis.”

**Canadian Aboriginal AIDS Network (CAAN), Canada**

What do you plan to do at your booth in the NOhep Village?

“Through visual and written content, discussions and traditional ceremonies, we will articulate how CAAN engages in research with Indigenous Peoples and the scientific community through the “Two-eyed Seeing” approach. This creates safe and ethical spaces where both communities are able to share different Ways of Knowing and has been, and continues to be, an effective way for two world views to respectfully engage together where everyone is valued and heard, and power is equally distributed. All our activities will be housed in a tipi that we hope to bring to the event!”

**Canadian Treatment Action Council (CTAC), Canada**

What will make your booth stand out?

“We will be encouraging delegates to get involved with our work and stay in touch with CTAC. One of the ways we plan to do this is by asking delegates to add their voice to our campaign to Eliminate hepatitis C in Canada. Their voices will create a jigsaw puzzle of personal hopes for elimination of hepatitis C. We hope to have a local artist who has lived experience do live painting and talk to delegates about his work.”

What do you hope delegates will learn from your booth?

“We hope to show that a multi-sector, collective impact approach to elimination is an effective and inspiring model. We will share outcomes of our initiative, including significant increases in community-based testing and treatment numbers to support this point.”

**CATIE, Canada**

Please describe your organisation in 2-3 sentences.

“CATIE is Canada’s source for up-to-date, unbiased information about HIV and hepatitis C. We connect people living with HIV or hepatitis C, at-risk communities, healthcare providers and community organizations with the knowledge, resources and expertise to reduce transmission and improve quality of life.”

**End Hep C SF, USA**

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Meet the NOhep Villagers

Hepatitis B Foundation, USA

What will make your booth stand out?

“Our booth will feature 25 unique personal stories from individuals and families affected by hepatitis B and liver cancer. The stories are told in 7 different languages, and our storytellers represent diverse cultures and different aspects of living with hepatitis B (including stigma, co-infection, discrimination, treatment, disclosure, caregivers, adoption, transplantation, and liver cancer). The stories help humanise the global hepatitis B epidemic, bringing to life the alarming statistics and consequences of this silent killer.”

What do you plan to do at your booth in the NOhep Village?

“We’ll be engaging delegates in conversations about injection safety. We will draw them in with attractive signage and a selfie station, photos from which may be uploaded to social media. Educational handouts in each of the injection safety areas (medical injections, drug diversion, needlestick injuries and harm reduction) will be available. We’ll also be giving away a flashdrive in the shape of a syringe with lots of injection safety resources pre-loaded on the drive.”

Hepatitis Outbreaks’ National Organization for Reform (HONOReform), USA

What will make your booth stand out?

“Our booth is a unique collaboration between people living with hepatitis B, advocates and researchers. It will bring much needed attention on hepatitis B, a disease which was close to neglected until recently. Community and scientists joining forces can make a huge difference in this context. HBV research has been largely underfunded compared to other diseases; enhanced investments could make a big difference and create important resource-savings from treatment scale-up by 2030. While our focus is on HBV research and the Asia-Pacific region, our collaboration will raise the overall visibility of hepatitis B in the global viral hepatitis elimination agenda.”

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International Coalition to Eliminate HBV (ICE-HBV), Coalition to Eradicate Viral Hepatitis in Asia Pacific (CEVHAP) and Yellow Warriors Society

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What do you plan to do at your booth in the NOhep Village?

“We will be using the booth to actively promote and encourage sign ups to the NOhep Visionaries Programme for Medical Professionals and the newly launched ‘NOhep Guide to becoming a NOhep Medical Visionary’. This guide has been produced in collaboration with eminent health care professionals with the aim of creating resource that helps others become advocates for the elimination of viral hepatitis. Alongside this, we’ll also a NOhep photo booth where medical professionals can get a photo taken proving their commitment to elimination while receiving a copy of the guide direct to their inbox!”

NOhep
Meet the NOhep Villagers

Seed the Change | Hākano Hāpai, New Zealand

What are you most looking forward to about the Global Hepatitis Summit?

"Meeting other patient advocates, as I have worked mostly alone or online. I am really looking forward to hearing and sharing ideas for news stories and in particular, talking to doctors about generics, research, putting a face to the buyers’ club story and answering questions about New Zealand."

The National Organisation for People Living with Hepatitis B, Uganda

How have you worked with the scientific community in the past?

"We have been mobilising frontline health workers and through our programmes we have been able to facilitate them during training. We also develop materials together with the scientific community and link our members to them." 

United Against Hepatitis, Russian Federation

What are you most looking forward to about the Global Hepatitis Summit?

"We’re planning on meeting with medical professionals from all around the world to discuss the latest trends in prevention and treatment of viral hepatitis and then take this information back home to Russia. We’re looking forward to learning best practices in advocacy and access to treatment from patients’ groups from other countries, especially the ones that are “stuck in the middle” - i.e., neither rich nor too poor."

World Hepatitis Alliance

What are you most looking forward to about the Global Hepatitis Summit?

"We can’t wait to bring some many engaged patient advocates together under one roof. We’ll be launching our global quest to find the missing millions at the event and encouraging advocates and medical professionals alike to join the quest. We’ll also be keeping our supporters across the world in the loop with live updates from the event."

What do you hope delegates will learn from your booth?

"We hope delegates will learn about VIDC’s mission and initiatives towards using the medical model as a tool for social engagement for marginalised populations, which can not only be applied in Vancouver, but also internationally. Our aim is also to introduce the idea that at VIDC, the meaning of ‘care’ means to provide the optimal medical, social, psychological and addiction-based needs of all individuals and that is the ‘4-legged chair model’ in which we follow for socially engaging the vulnerable population."

Viral Hepatitis Care Network (VIRCAN), Canada

Please describe your organisation in 2-3 sentences.

"VIRCAN is a structured academic-community partnership that will address issues throughout the care of viral hepatitis, from diagnosis to treatment to cure. Based out of the Toronto Centre for Liver Disease (TCLD), one of the largest liver units in North America, the VIRCAN team looks forward to demonstrating how viral hepatitis screening and treatment should be optimized in other urban settings across Canada, and around the world."

Vancouver Infectious Diseases Centre, Canada

What do you hope delegates will learn from your booth?

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Our highlights from the International Liver Congress 2018

The International Liver Congress remains one of the biggest international conferences for viral hepatitis and this year it brought over 10,000 hepatologists, nurses, public health experts and patients together to share the latest research and new initiatives. With so much information coming out of the event, here are some of our highlights:

Official launch of the Find the Missing Millions campaign
WHA President Michael Ninburg officially launched the Find the Missing Millions campaign in his speech in the Opening Ceremony. “I’m calling on everyone in this room to take responsibility,” urged Michael, “Those who are diagnosed must speak up and speak out, policymakers must take action and implement, and medical professionals, you have the biggest responsibility of all. You have the responsibility to diagnose.”

Community initiatives awarded at poster session
Civil society organisations highlighted how they are working to engage hard-to-reach populations in a poster session. WHA sat on the judging panel and was impressed by the initiatives being carried out by groups across the world.

Controversial review challenged by experts
We were delighted to see the Cochrane review debated in the critical reflection on landmark papers session. The Cochrane review was released last year and denied benefits of DAAs. We submitted an open letter to The Lancet Gastroenterology & Hepatology and were glad to see eminent medical professionals challenge the findings.

Patient voice at the heart of discussions
From speeches from patients in the opening ceremony to discussion of a patient ribbon on future delegate badges, the patient voice is starting to become more and more present at these meetings. We congratulate EASL on making efforts to include our voice and believe that the meeting vastly benefits from ensuring that the experiences of people living with viral hepatitis are heard.
“TIMELY DIAGNOSIS SAVED MY LIFE”

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 Antonio Oñante from Mexico whose personal experiences highlight the importance of timely diagnosis.

Antonio

“For me, the key to eliminating viral hepatitis is education, prevention and timely diagnosis. I am proof of that. In 2002, a routine medical examination found that I had hepatitis C and severe liver damage. It seems that I was infected during surgery in 1984, where I almost died, and I received a blood transfusion.

The doctor gave me the news in a really bad way. He told me that I had almost no chance of a cure with the treatment available at the time. My chances of eliminating the virus with interferon and ribavirin was very low and perhaps the only way to save my life would be through a liver transplant.

I remember this moment so clearly. The news shocked me. I cried for a long, long time. But thanks to the diagnosis, I was able to change my lifestyle. I improved my diet, I started to work out more, I tried to handle stress better and I improved my sleeping habits.

Later, in 2006, I started treatment, taking peg-interferon and ribavirin for 48 weeks. But the side effects were so unpleasant. For weeks and weeks, I felt as if my bones could break. My hair started falling out and I lost lots of weight.

Without a proper diagnosis, it is very likely that my liver would have become cirrhotic and I would probably be dead by now. So thanks to my diagnosis, my life was saved. The treatment worked and I got rid of the virus. Thankfully now, my liver is healthy with a minimum fibrosis.

Since then, I have been involved in patient support groups. I have seen through my foundation, Fundación Hepatos Aión, how hundreds, literally hundreds, of people die because they don’t receive a proper diagnosis in time.

In my country, Mexico, the impact of late diagnosis translates into more than 13,000 deaths per year. My experience has taught me how important it is that people receive a proper diagnosis because that is the opportunity to save their life. But people also need to access proper education and proper information about the disease. So I encourage governments to try and find people that still don’t know they are living with viral hepatitis. If we don’t, more and more people will die every year.”

Watch Antonio’s full video story here.