How did you mark the day?

“Hepatitis C test changed my life”

Find the Missing Millions

Examples from around the world

Overcoming the barriers to diagnosis

Wall of Stories

“Hepatitis C test changed my life”
Once again the world joined forces on 28 July to mark World Hepatitis Day (WHD). We are overwhelmed by the sheer number of individuals and organisations who participated in the day and have shown their commitment to helping to find the missing millions. It is particularly encouraging to see civil society making a stand and demanding action on diagnosis. Governments must recognise that civil society and the affected community are strong partners in their response to hepatitis. This message is reflected in our white paper that we launched at the WHO official WHD event in Mongolia. Turn to page 12 to find out more about the white paper and its recommendations.

Elsewhere hundreds of events took place all over the world – photos are already pouring in! Don’t forget to send us information and pictures of your activities to be included in the WHD 2018 Global Impact Report.

We would like to thank you for supporting WHD and hope you enjoy reading this special WHD edition of hepVoice!

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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Note from our CEO
This month in numbers
A round-up of some of this month’s stand-out facts and figures:

1 tweet to #WorldHepatitisDay every 6 seconds on 28 July.

5,026 mentions of World Hepatitis Day in the media.

12,278 Find the Missing Millions campaign material downloads.

43,141 social media posts about World Hepatitis Day across Twitter, Facebook, Instagram and Youtube.
Thanks to World Hepatitis Day, viral hepatitis made the news more than ever this month. Here’s just a snapshot of some of the announcements made on WHD this year.

**WHO calls for urgent increase in testing and treatment**
The World Health Organization (WHO) is calling on countries to urgently increase hepatitis testing and treatment to reach elimination. On WHD WHO Director-General Dr Tedros Adhanom Ghebreyesus shared a video statement, saying “We have a clear vision for elimination, and we have the tools to do it. But we must accelerate progress to achieve our goal of eliminating hepatitis by 2030.” We joined WHO and the Mongolian Ministry of Health for several events in Mongolia, a country heavily burdened by hepatitis but also a champion in the fight. Watch a video of the WHD press conference here. To mark WHD, WHO also released its updated global guidelines on hepatitis C treatment, which include a crucial new recommendation that all adults living with hepatitis C should receive treatment with DAAs. Read more here.

**WHA partners with InTec to find the missing millions**
On 28 July we launched a new pilot project with InTec Products to increase diagnosis of hepatitis C. As part of our Find the Missing Millions programme, InTec donated 25,000 point-of-care rapid tests for hepatitis C. WHA members in the UK, Mexico, Russia and Ukraine received free tests in an effort to increase the scope of their screening campaigns. Find out more here.

**ICE-HBV call for the integration of hepatitis B cure in elimination efforts**
The International Coalition to Eliminate HBV (ICE-HBV), a global group of researchers, patient representatives and health organisations released a commentary calling for the integration of a hepatitis B cure in global plans to eliminate viral hepatitis. The commentary published on 27 July argues that there is a need for appropriate cure research and preparedness to complement the WHO’s global elimination strategy, the hepatitis B vaccine and the well-tolerated but poorly accessed therapy. Read the release here.

**IHME launch new site highlighting hepatitis trends by country**
The Institute for Health Metrics and Evaluation have launched a new website with simple tools that dive into the burden of viral hepatitis. The data visualisations include hepatitis prevalence and country trends and hope to improve understanding of the epidemic and its global impact. Explore the website here.

**Highest-risk groups left behind in pursuit of hepatitis C elimination in Europe**
On WHD the European Liver Patients’ Association (ELPA) released their annual update on the state of hepatitis C policy in Europe. The latest results from their Hep-CORE 2018 survey on hepatitis C micro-elimination show that many European
New report highlights impact of first NOhep Village at the Global Hepatitis Summit

In June we hosted the first ever NOhep Village as part of the 16th ISVHL Global Hepatitis Summit in Toronto, Canada. The NOhep Village was unique opportunity to foster networking and collaborative learning between civil society organisations, patient groups and the scientific community to create a greater and better-connected community of advocates. It was a vibrant area where regional and global communities gathered to meet, share and learn from one another. Just launched, the NOhep Village Event Impact Report summaries the event and assess its impact. Download the report here.

For the diary

9 August

International Day of the World’s Indigenous Peoples
Viral hepatitis disproportionately affects Indigenous Peoples and rates can be up to 10 times higher than in the general population. International Day of the World’s Indigenous Peoples is our opportunity to highlight the impact of hepatitis among Indigenous Peoples. Learn more about the issue by reading testimonials from Soma Shekar of the Jenu Kurba tribes of state of Karnataka, India and Sandy-Leo Laframboise of the First Nations Matts People, Canada. Raise awareness online using the hashtags #WeAreIndigenous, #IndigenousDay and #IndigenousPeoplesDay.

13-15 August

11th Australasian Viral Hepatitis Conference 2018
This year the 11th Australasian Viral Hepatitis Conference takes places in Adelaide, Australia on 13-15 August. Inspired by the 2030 Agenda for Sustainable Development and its focus on inclusion and health for all, the conference theme is ‘No one left behind’. The programme will showcase and critically examine ways to effectively reach everyone living with viral hepatitis. WHA President Michael Ninburg will be delivering a keynote speech. If you can’t attend, stay up-to-date with the conversation by following #VH18 on social media.

31 August

International Overdose Awareness Day (IOAD) 2018
International Overdose Awareness Day aims to raise awareness of overdose and reduce the stigma of drug-related deaths. In many countries, substance misuse is treated as a matter for the criminal justice system and is heavily stigmatised. Globally 52% of people who inject drugs are living with hepatitis C and 9% with hepatitis B, a health-centred approach to drug policy is fundamental to reaching elimination. IOAD is an opportunity to stimulate debate about the policies and practices that can save lives and tackle viral hepatitis. You can find out how to get involved here.

Participating in a hepatitis related activity or have an event planned?
Email us or contact us on social media.
On 28 July 2018 the world once again came together to mark World Hepatitis Day (WHD). Thank you for all your efforts to ensure this was a momentous occasion where we joined forces with governments, medical professionals and the general public to raise awareness and demand action to find the missing millions. The efforts of each and every organisation and individual mean that steps have been taken to eliminate hepatitis and transform the lives of the 325 million people living with the illness.
GLOBAL DAY FOR LOCAL IMPACT

Events took place all over the world to raise awareness and demand change. Here’s just a snapshot of activities that marked WHD 2018:

Su Wang, St. Barnabas

USA
To raise awareness of the importance of testing, the Hepatitis B Foundation asked people around the world to create short videos of themselves stating why people should get tested for hepatitis B. You can watch the video here.

Nigeria
LiveWell Initiative organised a host of activities to mark WHD in Lagos, Nigeria. The organisation provided free testing and hepatitis B vaccination and held an advocacy walk around the city with awareness raising placards.

Bangladesh
The National Liver Foundation of Bangladesh organised various awareness raising activities. They kicked off their activities on 15 July by launching the Find the Missing Millions campaign among indigenous people of Rangamati, Chittagong Hill Tracts, providing free hepatitis B and C screening. On 28 July, they provided free screening to another at-risk group, thalassaemia patients. To raise awareness of viral hepatitis among the public, they held an awareness rally with roller skates, horse-drawn carts and motorbikes and an educational seminar.

Egypt
The Association of Liver Patients Care (ALPC – Egypt) distributed promotional materials such as T-shirts, flyers and posters. They provided 100 nurses with free hepatitis B and C rapid tests and organised a fun day for kids with a puppet show and magicians.

Macedonia
Hepar Centar Bitola organised a press conference with the Minister of Health to discuss future steps for hepatitis elimination in Macedonia. They also took to the streets to raise awareness and hosted an evening of activities for the public with DJs and entertainment.

Chinese Taipei
The Kaohsiung Research Association for the Control of Liver Disease marked WHD with a series of public health educational seminars and community screening where 3,600 people were tested.

We want to hear from you!
Share information and photos from your event and we will profile your activities in our World Hepatitis Day 2018 Global Impact Report, launching October 2018. Please complete our survey and share any photos and videos from your activities by 31 August: http://bit.ly/WHDsurvey
Focus

**Overcoming the barriers to diagnosis of hepatitis B and C**

Nine out of 10 people living with viral hepatitis are unaware – that’s more than 290 million people across the globe. Only 20% of people living with hepatitis C are aware of their condition and less than 10% of people living with hepatitis B.

In every region, diagnosis remains one of the biggest challenges for the elimination of viral hepatitis. Without timely diagnosis, infection rates will continue to escalate and people won’t be able to access life-saving treatments. The African and South East Asia regions have the lowest diagnosis rates, with 93% and 91% of the population living with viral hepatitis being unaware. This is compared to 83% in Eastern Mediterranean, 79% in Western Pacific, 68% in European and 64% in the Americas region.

**Barriers to diagnosis**

People across the globe are being denied their right to know their health status. In an effort to increase diagnosis rates across the globe, this year we commissioned a multi-country survey to identify the key barriers to the diagnosis. Based on our research, we found the main barriers to diagnosis globally are:

1. Lack of public knowledge of the disease
2. Lack of knowledge of the disease amongst healthcare professionals
3. Lack of easily accessible testing
4. Stigma and discrimination
5. The out-of-pocket costs to the patients

Find out more about the barriers to diagnosis and regional findings in this report here.

**Overcoming the barriers to diagnosis**

Overcoming the barriers to diagnosis will be critical if we are to reach elimination so once we had identified the barriers, we convened a two-day stakeholder consultation meeting. Throughout the meeting, global experts discussed ways in which the barriers can be overcome and decided on a number of recommendations to tackle the diagnosis gap. The resounding message from the meeting was clear: governments must act immediately in each of the areas and must adopt a multi-stakeholder response. Outcomes of the meeting are captured in a White Paper that was launched on World Hepatitis Day.

The white paper acts as a roadmap, highlighting actions to be prioritised such as integrating targeted hepatitis testing strategies into existing services, making testing affordable and combating stigma and discrimination.

Actions in overcoming the barriers require all stakeholders to engage in three main activities:

1. Raising awareness
2. Making testing more accessible
3. Removing cost barriers to viral hepatitis testing

**The role of civil society and the affected community**

Civil society and the affected community have a unique and important role to play in addressing the barriers to diagnosing viral hepatitis. Civil society organisations bring fundamentally important perspectives and experiences, which greatly enhance the effectiveness of strategies and programmes. Meaningful partnership with the affected community can contribute to stronger awareness campaigns, strengthen innovative approaches to finding the undiagnosed through peer support services, help identify gaps within actions plans and offer a platform to address stigma and discrimination. Policymakers should harness the voices of those affected by viral hepatitis, recognising them as vital partners in the elimination effort.

Find out more about the role of civil society and the affected community and the key recommendations for overcoming the barriers to diagnosis in the white paper here.
Find The Missing Millions.

**EXAMPLES FROM AROUND THE WORLD**

**Hepatitis C screening, diagnosis and treatment in Manipur, India**

Hepatitis C is a serious concern in Manipur state, India, particularly among key populations such as people who use drugs and people living with HIV. Recent studies indicate that prevalence among people who use drugs is alarmingly high in Manipur, with some districts reporting prevalence of 45% and even 98% in the hardest hit regions. Just 25% of people living with hepatitis C are diagnosed. The disease is not currently addressed in government public health programmes so the Community Network for Empowerment (CoNE), a state level network of community based organisations of people who use drugs, works to improve access to hepatitis C testing, diagnosis and treatment across the state.

Their activities towards eliminating hepatitis C in Manipur follow a robust cascade of care:

1. **Community outreach and mobilisation:** In the first instance, CoNE encourage people to attend awareness and screening camps by building rapport, raising awareness and conducting one-to-one and group meetings with key stakeholders including people living with HIV, local community based organisations and government officials. This helps the organisation reach out to at-risk individuals and identify hidden high risk populations.

2. **Awareness and confidence building camps:** With support from local NGOs, diagnostic centres, people living with HIV and people who use drugs organisations and government departments, they regularly carry out awareness raising and confidence building camps. Since 2014, they have conducted 76 camps in all 9 districts of Manipur, reaching 3815 people. Each interactive camp includes sessions on basic information on hepatitis C, mode of transmission, preventative measures, importance of early testing, diagnosis and treatment options. The informative sessions are immediately followed with the option of getting tested on site.

3. **Hepatitis C antibody testing:** Thanks to their awareness and confidence building camps, demand for testing has increased. Their screening camps follow a private-public partnership model with shared responsibilities: the state Department of Health provides space and trained professionals, generic pharmaceutical companies provide rapid testing kits and CoNE’s staff mobilise individuals to get tested. They have carried out 76 screening camps since November 2014, testing a total of 3251 people.

4. **Counselling:** Individuals who attend the screening camp are provided with counselling services so they understand the importance of prevention and repeat testing. Those who are reactive to the antibody test are informed of the need of an RNA test as well as the importance of early diagnosis and treatment and how they can access the additional test and treatment.

5. **Completing diagnosis:** During the counselling process, CoNE assess the individual’s ability to pay for the RNA test and treatment. CoNE then provide the test and treatment at a preferential price. It has proven challenging to motivate people to start treatment due to financial constraints or the fact that the patient does not consider the illness a priority since they have not experienced symptoms. CoNE’s staff overcome this by maintaining regular contact with the patient as well as involving family members to provide further support. They have initiated treatment with 405 people, 67 of which received free treatment.

6. **Treatment:** 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.

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**Find the missing millions: examples from around the world**

**Hepatitis C is not currently addressed**

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 Community Network for Empowerment (CoNE) to find the missing millions with their cascade of care model.
“HEPATITIS C TEST CHANGED MY LIFE”

Jawaid

“My name is Jawaid and I’m a security guard at a university hospital in Karachi, Pakistan. One hot and humid day, I noticed they were screening people for hepatitis C with finger prick rapid tests. One of the members of the hepatitis C project research team approached me and suggested I get tested. At first, I hesitated. I didn’t want the test. But when the team member pointed out that my eyes were relatively yellowish, I started thinking a bit more. It’s true that I had been feeling generally quite weak over the past few weeks. So gradually a knowing feeling in my gut developed. I should at least take the test, regardless of the outcome.

I was shocked when the results came back positive. I was told that I now needed to take a full diagnostic test to confirm if the virus was in my blood. But resources are limited at the hospital where I work and with my meagre salary, I couldn’t afford the diagnosis and treatment packages they provide. So they directed me to the public sector tertiary care hospital. At the public hospital I had the PCR qualitative test and again it came back positive. I started treatment at the same hospital and took the medicine every day for three months.

I was lucky that I didn’t suffer any side effects and was able to complete the treatment without any problems. Finally, when I stopped taking the drugs, I had another PCR qualitative test. I was so happy when they told me the result was negative.

I feel very proud that I am hepatitis C free now and am happy that my life has gone back to normal. I have been able to go back to work and am feeling much more energetic and motivated. It’s changed my life.”

Read Jawaid’s full video story here.

We welcome stories from every corner of the globe and from all those impacted by viral hepatitis: from patients to family members, medical professionals and policy makers - viral hepatitis has a unique experience of each of our lives. Share your story to our Wall of Stories here and help to change the way the world sees viral hepatitis.