Efforts ramp up to Find the Missing Millions

Countdown on to World Hepatitis Day

How to procure affordable medicines and diagnostics

Wall of Stories

“A journey through fear, understanding, and reassurance”
Note from our CEO

The countdown is now well and truly on to World Hepatitis Day! It’s less than two months until the world unites to raise awareness and influence real change. 28 July will be a particularly momentous occasion for us this year as we launch our Find the Missing Millions campaign. Civil society and patient groups across the globe are taking the lead in increasing efforts to find the undiagnosed and screening initiatives have taken place in almost every region of the world.

The launch of Find the Missing Millions will be supported with the publication of our white paper on overcoming the barriers to diagnosis and this month we held a global stakeholder consultation to discuss civil society and the affected community’s role in this. One of the biggest barriers remains the lack of affordable diagnostics so we’re pleased to share information on the Global Procurement Fund. Turn to page 12 to see if your organisation is eligible.

Finally, we’re especially excited to be bringing the first-ever NOhep Village to the Global Hepatitis Summit and we’ll be using the opportunity to launch the next phase of the Quest to Find the Missing Millions. Be one of the first to join the quest, more info on page 8.

We hope you enjoy reading!

Raquel Peck
Chief Executive Officer

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This month in numbers

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

Less than 2 months until World Hepatitis Day! Download posters, social media graphics, toolkits, merchandise designs and all you need to support your activities here.

More than 13,000 people have been vaccinated against hepatitis B in Venezuela over the past 2 months.

Over 1,700 tweets were sent in support of Spring Testing Week, which took place 18-25 May across Europe.

35 global experts joined us for a two-day stakeholder meeting on 17-18 May to discuss overcoming the barriers to diagnosis of hepatitis B and C.

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 the magazine with your network.

Don’t miss out - receive hepVoice straight to your inbox!
Viral hepatitis is making the headlines. Here’s the latest news from the field of viral hepatitis this month.

**WHO reports progress on global hepatitis strategy**

Discussions at the 71st Session of the World Health Assembly focused around the WHO’s 13th General Program of Work, that sets out ambitious agenda for the next five years and includes three targets: to ensure that by 2023, 1 billion more people have access to universal health coverage, 1 billion people are better protected from health emergencies and 1 billion people enjoy better health. Strong partnerships will be key to achieving these goals and we welcomed the opportunity to deliver an intervention supporting the GPW framework and asking for Member States to ensure viral hepatitis services are adequately included in Universal Health Coverage programmes. You can read the full intervention from WHA President Michael Ninburg here. WHO also reported on mid-way progress of the global health sector strategy on viral hepatitis. Since the adoption of the elimination strategy in 2016, regional action plans have been developed and new standards have been developed for improving health for people living with viral hepatitis. The progress report can be found here.

**Spring Testing Week pilot receives support across Europe**

In an effort to promote testing and address barriers to implementation, the European Liver Patients Association (ELPA) and the INTEGRATE Joint Action this month launched a pilot campaign, Spring European Hepatitis-HIV Testing Week 2018. The Spring Testing Week took place 18-25 May 2018 and had significant support both online and offline. For a snapshot on the testing activities that took place across Europe, turn to page 8.

**WHO announces first-ever list of essential diagnostics tests**

Today, many people are unable to get tested for diseases because they cannot access diagnostic services. Many are incorrectly diagnosed. As a result, they do not receive the treatment they need and, in some cases, may actually receive the wrong treatment. To address this gap, the World Health Organization has published its first Essential Diagnostics List, a catalogue of the tests needed to diagnose the most common conditions as well as number of global priority diseases. We are pleased that tests for hepatitis B and C have been included and hope the next step will increase testing across the globe.

**Leading hepatitis C experts rebuke claims against DAAs efficacy**

The medical community is in dismay after editors of the British Medical Journal (BMJ) published an article questioning the efficacy of DAAs. The article claims insufficient evidence to judge whether the treatments reduce mortality or further liver complication from chronic hepatitis C. The conclusion is based upon finding from last year’s Cochrane Review on the new DAA hepatitis C drugs. Last year we issued an open letter warning against the unwarranted and dangerous conclusion. As the discussion around DAAs efficacy ignites once more, we are encouraged to see the medical community fight back to ensure a cure is available for people living with hepatitis C.

**New NOhep resource to support national advocacy activities**

Marking two years since governments adopted the global elimination strategy, this month NOhep launched a new campaign ‘Race to 2030’. The campaign calls on civil society organisations to take action to get their countries on track to meet WHO’s elimination targets. To support campaign activities, NOhep has produced an in-depth advocacy toolkit that provides lots of information, resources and templates to support civil society organisations through each step of developing an advocacy strategy. Download the toolkit here.
Here are some upcoming events and activities taking place this month.

14 June

World Blood Donor Day
Every year on 14 June, countries around the world celebrate World Blood Donor Day. The day serves to thank voluntary, unpaid blood donors for their life-saving gifts of blood and to raise awareness of the importance of safe and accessible blood and blood products for people across the globe. For those of us working in the field of viral hepatitis, the day serves as an opportunity to highlight the importance of blood screening. This year’s theme is “Be there for someone else. Give blood. Share life.” Find out more here.

14-17 June

Global Hepatitis Summit
This month we are excited to bring together the first ever NOhep Village! This will be an interactive space at the Global Hepatitis Summit in Toronto which aims to foster networking and collaborative learning between patient groups and the scientific community. At the Village there will be exhibition stands from over 20 civil society organisations and an exciting programme of talks, panel discussions and more! If you will be attending the event, please visit us in Exhibition Hall F. If not follow the conversation on Twitter at #NOhep #GHS2018 @Hep_Alliance @NO_hep.

14 June

Quest to Find the Missing Millions – Global launch
On 14 June, we will launch the first phase of the Quest to Find the Missing Millions. The Quest is an interactive space for stakeholders to access up to date information about diagnosis, take a self-assessment tool and learn about testing and screening initiatives from across the world. The Quest will be officially unveiled at the Global Hepatitis Summit. If you’re attending, join us for the launch event on Thursday 14 June at 18:00 in the NOhep Village where you’ll hear from organisations running successful screening initiatives and people living with viral hepatitis stressing the importance of finding the missing millions. If you’re unable to attend in person, follow us on Twitter for live updates.

15 June

Launch of the NOhep Guide for Medical Professionals: 5 principles for taking action to eliminate viral hepatitis
On 15 June, NOhep will launch the NOhep Guide for Medical Professionals: 5 principles for taking action to eliminate viral hepatitis. Developed by medical professionals for medical professionals, the guide offers insight on steps medical professionals can take to advance action towards the 2030 elimination targets. The guide will be launched during a panel-discussion at the Global Hepatitis Summit in the NOhep Village on Friday 15 June at 13:15. Make sure you’ve signed up to NOhep to receive the guide straight to your inbox.

26 June

Support. Don’t Punish Global Day of Action
26 June is the United Nations’ International Day Against Drug Abuse and Illicit Trafficking – a day on which many governments celebrate their contributions to the global ‘war on drugs’. In the past, some governments have even commemorated this day by holding public executions or beatings of drug offenders. By taking part in the Global Day of Action, you can help to “reclaim” the message on this important day. The International Drug Policy Consortium spearheads the day and you can find out more about how to get involved here.

Participating in a hepatitis related activity or have an event planned?
Email us or contact us on social media.
With less than two months to go, World Hepatitis Day 2018 and the official launch of the Find the Missing Millions campaign are fast approaching.

Ahead of this, civil society organisations and WHA members are leading the way in efforts to find the millions people living with viral hepatitis unaware. From the pilot Spring Testing Week in Europe to the National Hepatitis Testing Day as part of the Hepatitis Awareness Month in the United States, testing activities have taken place across the globe throughout May.

Last month, we also brought together 35 global experts for our Find the Missing Millions two-day stakeholder consultation. Participants reviewed the findings of our survey on the barriers to hepatitis B and C diagnosis and agreed a set of recommendations on how civil society and the affected community can overcome the barriers to find the missing millions. These recommendations will form a white paper that will be launched on World Hepatitis Day. Watch this space for more details on the white paper as well as the launch of the first phase of the Quest to Find the Missing Millions, coming 14 June!
In action

Here’s how organisations across the world are already ramping up efforts to find the missing millions:

**In Ghana**, the Hepatitis Foundation of Ghana provided free hepatitis B and C screening at Sekondi Takoradi, testing more than 1,000 people.

**In Mexico**, FundHepa beat their screening goal and tested 10,029 people for hepatitis C in one day.

**In Austria**, Hepatitis Hilfe Österreich offered free rapid tests and provided information about hepatitis C and liver disease.

**In Germany**, the Hepatitis Foundation of Germany provided free hepatitis B and C screening in Berlin.

**In the United States**, the UCSF Hepatitis C ECHO Program parked their deLiver Care testing van outside San Francisco City Hall and provided free hepatitis C testing.

**In Romania**, four organisations participated in Spring Testing Week. APAH-RO ran a testing initiative in Bucharest while Baylor Black Sea Foundation tested 600 doctors and nurses for HIV, hepatitis B and hepatitis C at a local hospital in Constanta.

**In Pakistan**, Bridging Health Foundation held a hepatitis screening drive at Kamsar refugee camp to help find the missing millions.

**In Nigeria**, the Advocacy for the Prevention of Hepatitis in Nigeria (APHIN) organised a programme titled ‘War Against Hepatitis’, which included a hepatitis education workshop with over 1,000 students at the University of Jos. 500 students were screened for hepatitis B and C and 200 students were vaccinated against hepatitis B.

**In Cameroon**, military men and women and civilian servants participated in a walk and the Global Forum for the Defence of the Less Privileged (GFDLP) used the opportunity to screen and vaccinate against hepatitis B.

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HOW TO PROCUREMENT AFFORDABLE MEDICINES AND DIAGNOSTICS FOR

Are you an organisation running screening initiatives or providing treatment for hepatitis B and C? By working with the Global Procurement Fund (GPRO), you may be able to access more affordable diagnostics tests and medicines.

What is the Global Procurement Fund?

GPRO is a non-profit organisation whose mission is to help organisations (CSOs, NGOs, public & private health systems, national governments, etc.) procure affordable hepatitis medicines and diagnostics. GPRO is a major initiative of the Center for Disease Analysis Foundation (CDAF) and focuses on low and middle-income countries. GPRO was established in 2017 in order to expand access to quality tests and treatments for Hepatitis B and C at pre-negotiated, discounted prices.

What are the benefits of working with GPRO?

**Competitive Pricing:** Using pooled procurement mechanisms, GPRO is able to pool orders across member organisations. Higher order volumes allow GPRO to negotiate lower prices for medicines and diagnostics than most organisations can negotiate on their own.

**Assured quality:** All medicines available through GPRO are authorised for use by:
- WHO pre-qualification or FDA tentative approval
- Stringent Regulatory Authority (SRA)
- Independent Expert Review Panel (ERP) when pre-qualification, FDA tentative approval, or SRA is not available

What products are available through GPRO?

GPRO offers the following quality-assured products:
- Screening: CE-marked Rapid diagnostic tests (RDTs) for HBV and HCV
- Diagnostics: Cepheid GeneXpert Diagnostic System for viral load (NAT)
- HBV/HCV Medicines: Sofosbuvir, Daclatasvir, Tenofovir, Entecavir

GPRO only works with manufacturers that have freedom to operate – either with a license from the originator-companies or those with a license from the Medicines Patent Pool.

What products are available in your country?

This map highlights which countries can procure medicines and diagnostics for hepatitis B and C from GPRO.

For more details on what products are available in your country, click [here](#).

How do organisations order through GPRO?

You can learn more about GPRO, including how GPRO works and how to order through GPRO [here](#), or via...
“A JOURNEY THROUGH FEAR, UNDERSTANDING, AND REASSURANCE”

William

“I was 35, newly married, and looking forward to the birth of our first child. I was excited and ready to be the world’s number one dad. As a finance person, I wanted to get some planning in gear – a will, a rainy-day fund, life insurance. I was going to check these off by the time baby came. The insurance application included a blood test.

One afternoon I got a call from the insurance company. The test results were in. The man asked, “Do you know when you contracted hepatitis B?” I was floored. I had no idea what he was really talking about. All I knew about hepatitis was that it was supposed to be something bad. That night, I told my wife. She was as surprised as I was.

The next day, I locked myself in my office and spent hours online. Roaming through the search engines was like walking through a thick forest. Some articles roared at me like monsters, telling me I was doomed and would be six feet under by age 45. Others told me I’d be okay and could have a normal and full life.

As I read on and on, I could not help wondering, “What did I do to get this? Did it happen when I came here to the U.S., or was it way back in Ghana, where I lived for a couple years, or in Tanzania, where I grew up?”

The next several months were a journey through fear, understanding, and reassurance. After visits to a gastroenterologist and a battery of tests, it was clear that I was going to survive. The doctor said that the virus was not replicating and was not currently causing any harm. He told me, “It’s good that you found out, because with minor lifestyle changes, you will be okay.”


I understand now that like all of us with this virus, I didn’t do anything to get hepatitis B. Knowing exactly where it came from isn’t so important. What matters is what I can do to take care of myself, so that I can still be the world’s number one dad.”

Watch William’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.

A journey through fear, understanding, and reassurance

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