

hep VOICE

Your monthly magazine from the World Hepatitis Alliance



**FIND THE MISSING
MILLIONS IN PRISON**

**CIVIL SOCIETY AND
TECHNOLOGY**

WALL OF STORIES

**“Because I don’t look sick, my
family think I’m Ok”**



NOTE FROM OUR CEO

This month has seen hepatitis in the news: at the UN we saw the launch of the first-ever United Nations Common Position on Ending HIV, TB and Viral Hepatitis through Intersectoral Collaboration in the WHO European Region; Egypt launched a large scale testing and treatment drive to eliminate hepatitis amongst its 52 million citizens and in England we saw the launch of the blood inquiry, an investigation into how thousands of people were given infected blood leaving many with hepatitis C. All of these actions were made possible by the hard work of WHA members.

Indeed, WHA members are leading the way in the battle against hepatitis and I remain inspired by their determination and commitment that leads to these results. Yet, as we celebrate these successes, we know that more needs to be done to ensure that we find the missing millions and eliminate this global killer. WHA has recently updated its [2018-2020 Strategy](#) which sets out what we will be doing to find the missing millions. Enjoy the reading!

Raquel Peck
Chief Executive Officer

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hep HEADLINES

Hepatitis is making the news regularly thanks to the work of WHA members, here are a few highlights.

Groundbreaking pledge of United Nations agencies to end HIV, TB and viral hepatitis epidemics in Europe at high-level meeting on ending TB.

For the first time, 14 United Nations agencies have joined forces to end the epidemics of HIV, tuberculosis (TB) and viral hepatitis – Europe’s deadliest communicable diseases. The commitment was demonstrated with the launch of the first-ever United Nations Common Position on Ending HIV, TB and Viral Hepatitis through Intersectoral Collaboration in the WHO European Region.

This took place on 27 September 2018 in New York, United States of America, at a dedicated side event during the United Nations General Assembly high-level meeting on ending TB. The meeting’s theme was “United to end tuberculosis: an urgent global response to a global epidemic”.

[Read more at www.euro.who.int](http://www.euro.who.int)

Egypt launches historic hepatitis drive.

Egyptian authorities launched a historic hepatitis testing drive that will put the country on track to eliminate hepatitis by 2030.

Minister of Health and Population Hala Zayed said at a press conference “The state, the government and civil society organisations give great importance to this historic initiative that will be a turning point in the whole region and a model for the world”

[Read more at www.gulfnews.com](http://www.gulfnews.com)

The Hepatitis C Trust granted ‘Core Participant’ status as Infected Blood Inquiry begins.

WHA member The Hepatitis C Trust has been designated a ‘Core Participant’ in the UK Infected Blood Inquiry in recognition of their significant role in supporting people affected. Samantha May, Head of Support Services at The Hepatitis C Trust, provided a contribution to the Inquiry at the preliminary hearings, speaking on behalf of those infected with hepatitis C after receiving infected blood.

[Read more at www.hepctrust.org.uk](http://www.hepctrust.org.uk)

Little progress towards ‘test all baby boomers for hepatitis C’ since 2013, US study shows.

The proportion of baby boomers who have been tested for hepatitis C in the United States since 2013 has increased only marginally despite a US Centers for Disease Control and Prevention (CDC) recommendation that everyone born between 1945 and 1965 should be tested for hepatitis C at least once, researchers from Johns Hopkins University report in Clinical Infectious Diseases.

The CDC made its recommendation to screen everyone in the ‘baby boomer’ generation because studies showed that three out of four people with hepatitis C virus in the United States fell into the baby boomer age group.

[Read more at www.infohep.org](http://www.infohep.org)

Overwhelming evidence demonstrates hepatitis C treatment effective for people who inject drugs.

Researchers are calling on an end to discriminatory health and illicit drugs policies, based on overwhelming evidence that new hepatitis C therapies are effective

at curing the virus in people who inject drugs.

The Kirby Institute research, which was presented at the 7th International Symposium on Hepatitis Care in Substance Users in Cascais, Portugal and published in The Lancet Gastroenterology and Hepatology, provides the strongest evidence-base to date to support the removal of restrictions to accessing hepatitis C therapy based on recent drug use.

[Read more at www.kirby.unsw.edu.au](http://www.kirby.unsw.edu.au)

Australia launch provides a vital missing link to eliminating hepatitis C.

“Eliminating Hepatitis C Australia” was launched in August at Parliament House by the federal health minister, the Hon Greg Hunt MP, in partnership with the Paul Ramsay Foundation. The project is a multi-million dollar targeted, national response to the serious decline in the uptake by Australians of highly effective drugs to cure hepatitis C.

Since new, highly effective hep C treatments were listed on the PBS in March 2016, tens of thousands people living with the disease across Australia have been treated. However, the number of people commencing treatment is falling, putting the country at risk of missing its elimination targets. Over 170,000 Australians are yet to start this life saving treatment.

[Read more at www.hep.org.au](http://www.hep.org.au)

FOR THE DIARY

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

14TH- 16TH OCTOBER

The World Health Summit, Berlin

Bringing together stakeholders and decision-makers from every field in the healthcare spectrum, this high level event provides the perfect forum for exchange with experts from academia, industry, politics and civil society. WHA CEO, Raquel Peck, will represent our community in the meeting.

15TH OCTOBER

Global Handwashing Day

A global advocacy day dedicated to increasing awareness and understanding about the importance of handwashing with soap as an effective and affordable way to prevent diseases and save lives.

9TH-13TH NOVEMBER

The Liver Meeting® 2018, San Francisco

The Liver Meeting, hosted by AASLD, brings together 9,500 attendees from around the world to exchange the latest research, discuss new developments in treatment outcomes, and network with other experts in the field. WHA will be co-hosting The Hepatitis Elimination Symposium and Workshop with the Chronic Liver Disease Foundation at 6:30pm on Monday 12th November.

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

Email us or contact us on social media.

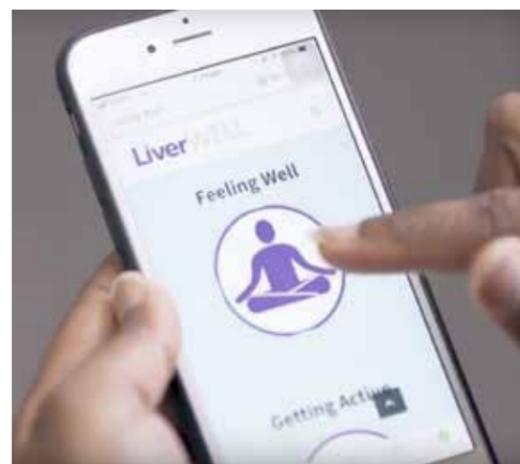
CIVIL SOCIETY ORGANISATIONS HAVE AN IMPORTANT ROLE IN THE DEVELOPMENT OF HEALTH TECHNOLOGY TO ELIMINATE VIRAL HEPATITIS.

Currently, out of 71 million people living with hepatitis C, only 20% know they are ill. That's 57 million men, women and children at risk of developing cirrhosis and liver cancer. Given there's a cure for this condition, it is imperative we "find the missing millions". World Hepatitis Alliance (WHA) is calling for a scale-up of diagnosis to find those affected by viral hepatitis and link them to care. Technology can be an effective weapon to increase access to testing and treatment.

When technology is tailored to the end user it has a greater impact. Nowhere is this more apparent than in health technology. Key to the success of any health innovation is patient involvement in its development to establish the needs of the patient group. WHA members across the world are leading the way by collaborating with private sector partners to develop innovative solutions to eliminate hepatitis.

Recently, WHA members in Pakistan 'The Health Foundation' and the 'Gujranwala Liver Foundation' have been working with Mastercard on a pilot scheme to treat hepatitis C patients. The project tailors the 'Mastercard Aid' technology to the local environment, delivering impact in this field.

Technology and innovation allow us to connect and bring communities together, and that's crucial when you are looking to enhance the patient journey. Telemedicine, such as 'Project Echo', is now being widely used globally to train health care professionals and raise awareness of hepatitis. Aside from democratising knowledge, software is currently being rolled out in a number of countries for use in different settings, including prisons, hospitals and primary care centres to remind doctors to test for hepatitis C should other results indicate they are at risk.



“Technology and innovation allow us to connect and bring communities together, and that’s crucial when you are looking to enhance the patient journey.”

In Pakistan, the Medical Research Council is using SMS text message to increase awareness and link people to testing facilities. Through their system, a text message is sent about the risk factors and recipients are asked to reply with '1' if they have experienced any of these or '2' for they haven't. If the message reply is 'yes' the mobile company will send them another message with details of a nearby health centre for testing. This message will include the name, address and phone number of the facility. On receiving the message a reasonable amount of money will be transferred to the user's mobile account to ensure they are able to attend their testing.

In India, WHA member 'Chennai Liver Foundation' is developing an app to educate doctors on viral hepatitis. In Australia, WHA member, 'Hepatitis Victoria' has launched an app that helps patients manage their illness by enabling them to record their results, manage medications and appointments and find out the latest health information, and in the US, St Joseph's Medical Centre now uses multi-lingual touch-screen kiosks, separate from the patient waiting-area to screen patients. These kiosks help overcome people's embarrassment and reluctance to discuss drug use and sexual history with a medical professional.

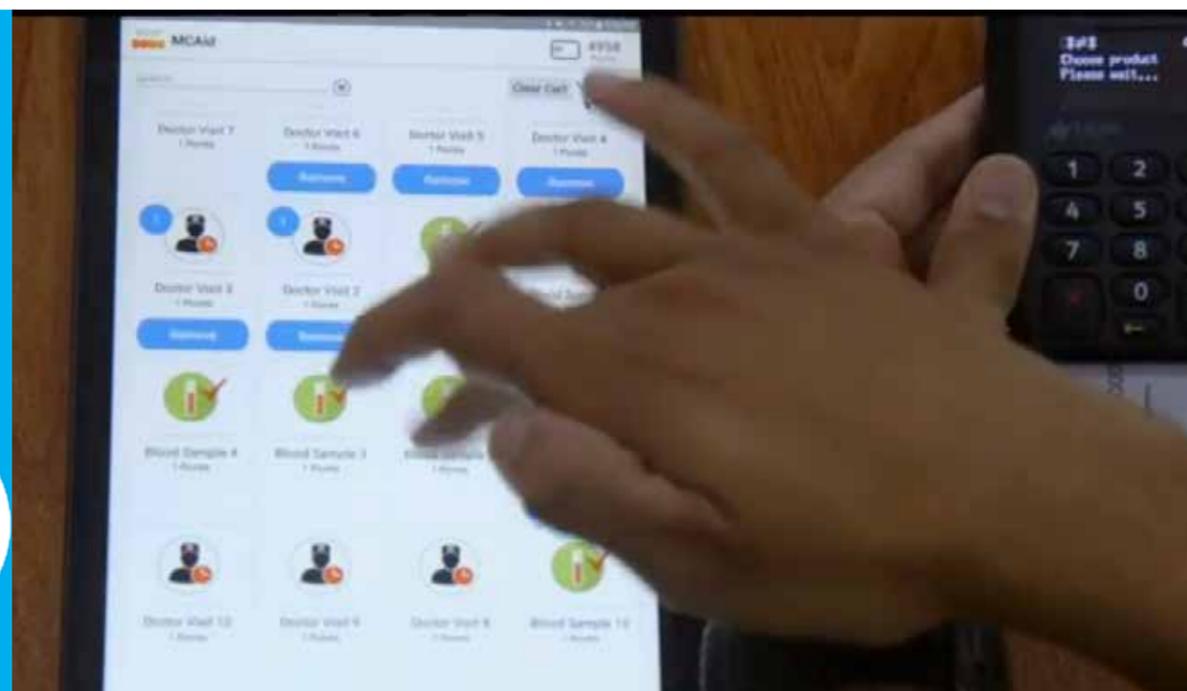
There are many more examples of technology being used around the world and as more innovative solutions get developed, the needs of the end user have to be at the centre of the technology. Developers need to utilise the knowledge and experience of civil society to work with affected communities to develop technology that has impact and help us eliminate hepatitis C.

See the Mastercard project in action at www.worldhepatitisalliance.org



“The patients who used the technology have been excited and feel that they are being provided with some very high-level hi-tech healthcare It was a great learning experience to work with this technology and we hope that the learnings can be used to create more holistic healthcare delivery.”

Dr Laila Rizvi,
Executive Director
The Health Foundation (Pakistan)



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 a prison in France who have prioritised hepatitis elimination.

ELIMINATING HEPATITIS C IN PRISON.

In France the prevalence of Hepatitis C amongst the prison population can be as high as 30%. However hepatitis C (HCV) treatment in prison remains low. A strategy implemented in Villeneuve les Maguelone, a French remand prison is looking to tackle this. Since 2003, all detainees have been offered HCV, hepatitis B and HIV screening upon arrival. If a prisoner tests positive for HCV they are offered an 8-12 week course of direct-acting antivirals (DAA).

Since the DAA's were made available, nearly 90% of the prisoners who tested positive for hepatitis C have completed the treatment course while in custody. By 2016, 98% of prisoners who tested positive for hepatitis C were cured.

Prisoners are some of the most marginalised and hardest to reach people in society but for hepatitis elimination to become a reality no one can be left behind. The example set in Villeneuve Les Maguelone is a rare example of prisons prioritising hepatitis in their health care responses yet HCV treatment for incarcerated people especially those who inject drugs, could reduce HCV transmission in prison and the community.



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.

“Prisoners are some of the most marginalised and hardest to reach people in society.”

WHA PRESIDENT ADDRESSES HEP-C COMMUNITY SUMMIT HELD BEFORE INHSU 2018.

“Every country in the world has committed to the elimination of viral hepatitis by 2030. But this is not going to happen without a comprehensive, holistic approach that involves the active engagement of the patient community. This must include people who use drugs” Michael Ninburg, President of the WHA said in a video address at the start of Hep- C Community Summit held on the 18th September before INHSU 2018 (The International Symposium of Hepatitis Care in Substance Users).

“Let’s be very clear, when it comes to people who use drugs, this is about more than hepatitis, this is about human rights, self-determination and the health and wellbeing of a historically underserved and marginalised group of people.”

The World Health Organization (WHO) 2017 Global Hepatitis Report, highlighted the need for a significant increase in the

availability of sterile needles and harm reduction services.

People who inject drugs (PWID) are some of the most marginalised people in society, but to make the elimination of hepatitis a reality we need to work to eliminate hepatitis amongst the hardest to reach.

“We have great examples of sound drug and health policy around the world. Some of the best in Portugal. Sadly however, there are far more failed policy efforts that have resulted in criminalisation, stigma and the dehumanisation of people who inject drugs. More now than ever it is our duty to mobilise our communities and advocate for what is right.”

Z, a Hep Community Peer Outreach Worker for the Hepatitis Education Project in Seattle, USA, himself cured of hepatitis C, engages with PWIDs in the community.

“I’ve met people who tell me they get sores from reusing needles. For no reason whatsoever should you have to use someone else’s needle, we make enough needles!”

Kenny, another volunteer with the Hepatitis Education project cured of hepatitis C, feels that more

needs to be done to engage the community.

“A lot of people in the drug-using community are becoming aware of treatments that don’t make you sick, but the biggest thing is to really engage with them, they just need to be shown that the treatment is safe and effective. And on the side of clinicians it’s about removing the stigma, to stigmatise drug users is to throw away a whole class of people and it’s not right.”

Michael closed his address by reiterating the importance of community engagement “Nothing about us without us, nobody knows what the community needs better than the community itself. We need to ensure that PWIDs are part of the solution.”

[Watch the full video on the WHA website.](#)



		baseline		
4	Harm reduction	Syringes & needles distributed/PWID/year	27	200 300

*Global Hepatitis Report, 2017

THE NOHEP MEDICAL VISIONARIES PROGRAMME IS LAUNCHED IN AFRICA.

In September the NOhep Visionaries Programme for Medical Professionals in Africa was launched at the Conference on Liver Disease in Africa (COLDA) in Kenya, 13 – 15 September. The first conference of its kind, COLDA saw local liver experts come together to discuss how to prevent, treat and achieve a cure for liver disease in Africa.

Medical professionals are the gatekeepers to elimination and have a powerful role in achieving the public health approach needed to eliminate viral hepatitis by 2030.

NOhep Medical Visionaries are passionate and committed to combating hepatitis in their role as a medical professional, helping to bridge the gap between medicine and public health. To date, hundreds of medical professionals have signed up to the NOhep Visionaries Programme, committing their time and expertise to drive action to meet the 2030 targets.

The NOhep guide for medical professionals sets out the five principles of a NOhep medical visionary.



ATTENDING THE WHO REGIONAL WORKSHOP ON HEPATITIS STRATEGIC PLANNING, MONITORING AND EVALUATION.

By Kenneth Kabagambe
WHA Board member for the Africa Region.



Finding the missing millions of hepatitis patients in Africa was at the heart of the WHO regional workshop on hepatitis strategic planning meeting. It was recognised that diagnosis would need to be a key priority if elimination in the region was to be possible. I attended the workshop to emphasise the importance of the patient voice in the planning of hepatitis strategies, I was the only representative from the community but I was able to give a presentation on the role of civil society in the elimination of viral hepatitis.

The participants recognised the need to work with and involve members of civil society, highlighting the unique skills that civil society brings to complement the work of medical practitioners to access communities.

WHO AFRO made a commitment to continue engaging with the community organisations so that they can have meaningful engagement at the region.

“The participants recognised the need to work with and involve members of civil society”

This was the first WHO workshop in Africa to build regional capacity and to provide a clear direction to the African elimination strategy of viral hepatitis. A localised response is needed to address the issues that are unique to Africa, particularly the issue of the prevention of mother to child transmission being key to elimination efforts.

A birth dose of hepatitis B (HBV) vaccine was highly accepted by delegates as the only way to reduce the prevalence of HBV in Africa and a long term and cost-effective measure towards elimination.

5 PRINCIPLES OF A NOhep MEDICAL VISIONARY



1. EDUCATE PEERS

You educate peers that elimination of viral hepatitis is achievable



2. RAISE AWARENESS

You raise awareness amongst key audiences of viral hepatitis as a human and economic issue, and the urgent need to act



3. ENABLE OTHERS

You enable other medical professionals to play their role in eliminating viral hepatitis



4. FACILITATE COLLABORATION

You facilitate collaboration between key stakeholders, teaming up with NGOs and the hepatitis community to advance viral hepatitis elimination efforts



5. VOCAL AMBASSADOR

You are an ambassador for all efforts to eliminate viral hepatitis, promoting action and driving change that will help achieve ambitious goals

Download the guide at www.NOhep.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 Elaine from Canada who shares her story.

“Because I don’t look sick, my family think I am ok.”

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

Elaine

In 1982, I had surgery to help me conceive a child. Ironically, all I conceived was a case of hepatitis C that was in one of the bags of blood involved in a transfusion. I did not learn about my infection until an insurance medical in 2003 revealed high liver enzymes. Further investigation confirmed I had hepatitis C. My family doctor was less than sympathetic when giving me the news, saying not to use needles and then walking out wishing me a nice day! I was too shocked to respond since I neither drink nor smoke and I have never used drugs. My doctor’s assumption was still disturbing and I later complained to the specialist that I now see once a year.

Treatment was prescribed in 2005, but I was unable to complete the treatment. I was convinced my death was imminent due to the wicked side effects.

I had little support during the treatment (being a single mother didn’t help).

Because I don’t look sick, my family assumes I am OK. When I get tired, they say I am using the hep C as an excuse to rest. It makes me very angry and there have been arguments that are not helpful.

I have a home-based business so I am able to rest when required. That said, I am still very busy and have several clients. The work has enabled me to maintain my own home and pay the bills, but I worry how long this can continue. I have told three colleagues about my condition and afterwards, it was never mentioned, only in passing.

I am selective about telling people because I know some have unfounded fears. Once, I was told not to use someone’s keyboard! I am trying to live a healthy lifestyle, lose a bit of weight and exercise regularly. After my diagnosis, I decided to take a vacation every year and I usually go hiking in the Rockies for the fresh mountain air, as well as the solitude and spectacular scenery, which I find calms the soul. I do quite well and am able to hike up to 10 km on a round trip. Not bad, considering I am over 60 with distinctly creaky knees!

Hep C is no one’s fault and we all share the same trials - and the same trail.



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