RAISING AWARENESS ON
World hepatits day

THE INVESTMENT CASE FOR
HEPATITIS ELIMINATION

FIND THE MISSING MILLIONS
IN-COUNTRY PROGRAMME PARTICIPANTS
NOTE FROM OUR CEO

Welcome to the May edition of hepVoice.

It’s been a busy month with lots of new reports and data being released on the global progress to hepatitis elimination. Earlier this month I attended the 72nd World Health Assembly in Geneva, as the global health agenda sets its sights on Universal Health Coverage (UHC) it is crucial that the elimination of viral hepatitis is represented and included in countries’ UHC plans. Our financing work has proven how hepatitis elimination programmes can be integrated with UHC and we are pleased to be working in two more countries to establish the investment case for viral hepatitis elimination – read more about that on page six.

This month we also selected the five WHA members that will work with us on the Find the Missing Millions in-country advocacy programme, you can read more about this on page eight. We had an unprecedented number of applications for the programme and the selection process was difficult, but we are delighted to be working with a diverse global group of members and we will continue to keep you updated about their work.

This month we also released materials for World Hepatitis Day 2019. The suite of videos, social media graphics and posters can be downloaded for free from the World Hepatitis Day website. We have also created a global map where you can upload your events to let the world know what amazing work you’ll be doing.

As ever, if you have any stories that you would like to be included in hepVoice then please email them in, this magazine is here for you.

Cary James

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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.
Hepatitis is regularly making the news thanks to the efforts of WHA members. Here are a few highlights.

World Health Organization (WHO) Launches the Progress Report on HIV, Viral Hepatitis and Sexually Transmitted Infections 2019

WHO launched the first ever report on the progress to implementing the Global Health Sector Strategies on HIV, Viral Hepatitis and Sexually Transmitted Infections based on data received from countries. The progress report highlights the need to strengthen data, in particular, to update sexually transmitted infection and hepatitis data more regularly and strengthen the disaggregation of data to improve implementation.

Read more at: https://bit.ly/2WXaLWi

Liberia Launches a New Hepatitis B Vaccination Project

On May 10th, the Government of Liberia launched the Hepatitis B Vaccination Project through the National Public Health Institute.

The Director General of the National Public Health Institute of Liberia, Talbert Nysenswah, said that the project seeks to protect health workers, including medical and paramedical students, against the hepatitis B virus. Through a safe and easy vaccine, the project wants to ensure that 16,000 health workers in Liberia are protected from hepatitis B. Nysenswah is encouraging health workers to take advantage of this opportunity.

This step forward in the fight against hepatitis B is being credited to two international organisations, the Probitas Foundation and Grifols. Both organisations donated 54,000 doses of the hepatitis B vaccines on behalf of the National Public Health Institute of Liberia through UNICEF.

Read more at: frontpageafricaonline.com

The Hepatitis Foundation of New Zealand Launches New Website

The Hepatitis Foundation of New Zealand website – www.hepatitisfoundation.org.nz – has been rebuilt over the past several months. It now features improved functionality, a more modern appearance, and up-to-date information about the various types of hepatitis. It is also mobile-compatible and will be easier for patients and health professionals to navigate.

Foundation staff continuously strive to raise awareness of hepatitis and the importance of getting tested, and chief executive Susan Hay says the new website will play a key part in this work. “Our website is the first port of call for anyone wanting information about hepatitis. There are 50,000 people living with hepatitis in New Zealand, and many of them are undiagnosed, so getting detailed information to New Zealanders and encouraging people to get tested is vital in the fight against hepatitis.”

See more at: hepatitisfoundation.org.nz

Participating in a hepatitis-related activity or have an event planned? Email us or contact us on social media.

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Dates for the Diary

Upcoming events and activities taking place

18-20 JUNE

African Hepatitis Summit

The first ever African Hepatitis Summit will take place in June in Kampala, Uganda. The summit will bring together patient representatives, ministers of health, policy makers, civil society, international organisations, global funders and public health specialists under one roof to provide regional advice on how to accelerate viral hepatitis elimination. This summit will support hepatitis elimination efforts by providing a platform that allows World Health Organization (WHO) African Member States to learn from other countries, gain access to technical advice from WHO’s global and regional hepatitis programme as well as discuss the implementation of an intensified national response to the disease with key stakeholders in the field.

Find out more at: www.africanhepatitissummit.com

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Find out more at: www.africanhepatitissummit.com
Together, we can find the missing millions who are unaware they are living with viral hepatitis.

More than 325 million people worldwide are living with viral hepatitis – but 9 in 10 of them (290 million) have no idea they are living with a deadly disease in their blood.

On World Hepatitis Day, 28 July, join us to find the missing millions.

Campaign materials – including an exciting new video – are available now to help you raise awareness of this silent killer.

Already planning a World Hepatitis Day event? Add it to our interactive map to let the world know what you are doing at www.worldhepatitisday.org

The World Hepatitis Alliance (WHA) has announced that it is expanding its hepatitis C financing work to India (Punjab State) and Cambodia.

WHA will work with partners, civil society, WHA members and governments to create the investment case for hepatitis C elimination. It will then explore the financing options available to the government to fund and implement an elimination strategy. WHA has already completed similar work in Colombia and Nigeria.

Jessica Hicks, WHA Head of Programmes said “By collaborating with the government in the creation of the investment case we are able to get early commitment, ensuring that the work can have a real impact. We are already seeing the results of our work in Colombia and Nigeria and we are excited to use the lessons we learnt from those projects in our work in Cambodia and India, Punjab State.”

With little financial support available, it is important that countries are given the evidence to prove that hepatitis elimination is cost-effective. WHA’s finance work demonstrates how taking action now will save both lives and money in the future. Civil society can then use this evidence as an important advocacy tool to ensure action is taken. The programme also identifies financing options for the elimination plan, including exploring integrating the hepatitis elimination strategy into Universal Health Coverage (UHC) plans.

WHA and partners have also created the national viral hepatitis programme financing strategy website www.hepatitisfinance.org. The site offers a guide for national governments on how to adopt a strategic approach to the costing and financing of a viral hepatitis programme and provides an interactive costing tool to help countries that want to start looking at financing themselves. Importantly, the website also highlights the critical role that advocating for financing plays in achieving a fully funded viral hepatitis programme.

On World Hepatitis Day, 28 July, let’s find the missing millions.
The World Hepatitis Alliance (WHA) is delighted to announce the five WHA members selected to take part in the Find the Missing Millions, in-country advocacy programme.

The members, from Ghana, Jamaica, Bangladesh, Armenia and Indonesia, will work with WHA to create and implement advocacy strategies that overcome the barriers to diagnosis identified in WHA’s 2018 White Paper, ‘Overcoming the Barriers to Diagnosis of Viral Hepatitis: The Role of Civil Society and the Affected Community in Finding the Missing Millions.’

Cary James, WHA CEO, said “We had an extraordinary number of applications for this programme and we are thrilled to be working with a diverse group of organisations from around the world. We are looking forward to exploring ways that we can find the missing millions with each of the participants and support efforts to eliminate hepatitis at the country level.”

In addition to receiving a small amount of seed funding to help initiate their activities, the five participants will participate in a capacity building workshop where they will be able to pool their expertise and benefit from the opportunity to learn from leading experts working within the field. Throughout the 18 month programme, WHA will report on the member’s activities and outcomes in hepVoice and on social media, ensuring that best practice and lessons learned are shared.

The Caribbean Hepatitis C Alliance is a non-profit, non-governmental organisation that focuses on education, screening, advocacy and support for the hepatitis community in the Caribbean.

“THE LACK OF KNOWLEDGE ABOUT HEPATITIS C AMONG THE PUBLIC AND HEALTH CARE PROFESSIONALS HAS A GREAT IMPACT ON THE TESTING LANDSCAPE HERE IN JAMAICA. EVEN IF PEOPLE WANT TO UNDERGO TESTING, IT CANNOT BE DONE WITHOUT THE RECOMMENDATION OF A DOCTOR AND IN MANY CASES, DOCTORS HAVE DISMISSED THE PATIENTS’ REQUESTS.”

The Hepatitis Alliance of Ghana is a non-governmental organisation operating in five out of ten regions in Ghana. Their vision is to create a viral hepatitis-free society in Ghana.

“We believe that in the Ghanaian context the uptake of hepatitis testing will increase significantly when we implement this programme and the missing hepatitis patients will be identified and linked to care.”

The National Liver Foundation of Bangladesh (NLFB) is a not-for-profit organisation dedicated to the prevention, treatment, education and research of liver diseases in Bangladesh.

“BANGLADESH IS A Densely-Populated COUNTRY, ABOUT 65% OF THE TOTAL POPULATION LIVE IN RURAL AREAS, WHERE THERE IS A LACK OF AWARENESS OF VIREAL HEPATITIS AND THE COMMUNITIES ARE OFTEN UNSERVED BY HEALTH CARE SYSTEMS.”

The Positive People Armenian Network’s mission is to protect the rights of people living with HIV, tuberculosis and hepatitis through the implementation of advocacy activities.

“ONE OF THE MAJOR BARRIERS FOR DIAGNOSIS IS THE COST. IT’S IMPORTANT TO HAVE AN EFFECTIVE ADVOCACY STRATEGY TO MAKE ACCESSING DIAGNOSIS AFFORDABLE, IF NOT FREE, FOR THOSE WHO ARE AT HIGH RISK OF ACQUIRING THE DISEASE. THERE IS A NEED FOR A NATIONAL HEPATITIS PREVENTION AND TREATMENT PROGRAM WHICH IN TURN REQUIRES OFFICIAL STATISTICS OF THE NUMBER OF PATIENTS IN THE COUNTRY, ARMENIA IS CURRENTLY LACKING BOTH.”

Yayasan koalisi satu hati is a non-profit organisation for people living with, and affected by, hepatitis and HIV. The organisation was formed to increase awareness of viral hepatitis and HIV in Indonesia and to educate the general public about the diseases and the treatment options available in Indonesia.

“In recent years, promotion and prevention efforts have been carried out for high-risk groups in Indonesia but there is a need to increase these efforts and to continue education and awareness-raising among key at-risk groups. This expansion must not only include drug users but other key groups, such as prisoners and people in the general population.”

The Hepatitis Alliance of Ghana is a non-governmental organisation operating in five out of ten regions in Ghana. Their vision is to create a viral hepatitis-free society in Ghana.

“The lack of knowledge about hepatitis C among the public and health care professionals has a great impact on the testing landscape here in Jamaica. Even if people want to undergo testing, it cannot be done without the recommendation of a doctor and in many cases, doctors have dismissed the patients’ requests.”

In recent years, promotion and prevention efforts have been carried out for high-risk groups in Indonesia but there is a need to increase these efforts and to continue education and awareness-raising among key at-risk groups. This expansion must not only include drug users but other key groups, such as prisoners and people in the general population.”
The World Health Organization (WHO) has called for greater commitments to scale up hepatitis C virus testing and treatment services to people who inject drugs and people in prisons.

WHO reports that people who inject drugs are still overlooked in more than a third of national hepatitis plans, and the needs of people in prisons are overlooked in two-thirds of national plans.

Furthermore, even when services are available, they may still impose restrictions such as abstinence from drug use to be eligible for treatment, or may require health insurance coverage to obtain treatment.

WHO says that approximately 400,000 people who inject drugs acquire hepatitis C each year, out of an estimated global total of 1.75 million new infections. This represents nearly a quarter of all new infections.

Scale-up of harm reduction services, proven to reduce the risk of acquiring hepatitis C, including needle and syringe programmes and opioid substitution therapy services, must form a major part of hepatitis C prevention among people who inject drugs.

The WHO policy brief stresses the importance of addressing structural barriers (such as criminalisation of drug use) to improve access to treatment.

Countries should also look at how testing and treatment services can be provided to people who inject drugs through community-based harm reduction services such as drop-in centres, needle and syringe programmes, drug dependence services and opioid substitution therapy sites.

Improvement of prison health services and availability of voluntary testing and treatment for hepatitis C for all people entering prisons are also priorities for hepatitis C elimination, as the prevalence of hepatitis C in prisoners is much higher than in the general population. People in prison are also at high risk of acquiring hepatitis C through sharing of injecting equipment and other exposures to blood.

WHO also stresses that expanding treatment coverage for people who inject drugs and other key populations will require further reductions in the cost of direct-acting antivirals.

Read the full report at [who.int](http://who.int)

WHO also highlights several examples of national plans that have prioritised testing and treatment for people who inject drugs.

### Australia

Australia recently published its fifth national strategy (2018-2022) on the path to hepatitis elimination by 2030. The country used a simplified approach to service delivery, integrating hepatitis testing, treatment and harm reduction for people who inject drugs at decentralised sites, and engaging peer workers and general doctors. Concerted implementation of HCV testing and treatment in several prisons shows elimination in these settings is possible.

### India

India launched a national action plan to combat viral hepatitis in February 2019, targeting people who inject drugs as a priority population, aiming to provide 100,000 direct-acting antiviral treatment courses annually over the next three years.

### Iran

The Islamic Republic of Iran has a three-year national hepatitis plan that proposes interventions for people who inject drugs and people in prisons. Direct-acting antivirals can be obtained for as little as US $81, but only for people with health insurance. Many people who inject drugs and people in prisons without insurance face a higher cost of US $2,200.

### Ukraine

Ukraine is developing a national strategy to contain tuberculosis, HIV and viral hepatitis. Generic direct-acting antivirals are now available for less than US $100. Effective collaboration with the Ministry of Justice enabled HCV testing for 1,000 people in prisons living with HIV in 2018. Of these people, 50 were treated with direct-acting antivirals achieving a 98% completion rate.
For a long time WHA has strongly advocated for governments to view civil society as valuable partners in the creation and implementation of hepatitis elimination strategies. Civil society brings the knowledge and expertise that can help hepatitis elimination strategies access hard to reach communities, reduce stigma and discrimination, and ensure that patients’ needs are represented and met. Yet many governments have been slow to see civil society as a valuable partner.

Data presented in the Journal of Hepatology provides clear evidence of the advantages of engaging with civil society. The data was generated by a World Health Organization (WHO) survey of Ministries of Health (in all 194 WHO Member States) which asked them to complete a country profile on their viral hepatitis policy. The data showed that the proportion of Member States reporting engagement with civil society ranged from 47% in the Western Pacific region to 63% in the Americas and South-east Asia. Engagement ranged from 38% in upper-middle income settings to 54% in high income settings. Crucially the data found the Member States which engaged with civil society were more likely to have national viral hepatitis plans (84% vs 44%); were more likely to have dedicated funding (52% vs 23%) and were more likely to have officially observed World Hepatitis Day (85% vs 47%). The data also showed that Member States which engaged with civil society were slightly more likely to have laws or policies to combat stigma and discrimination (79% vs 71%)

This is important data for us. It proves the importance of civil society engagement, and it shows our impact. The hard work of civil society has changed the course of viral hepatitis elimination. Through over a decade of passionate advocacy, we have successfully put hepatitis on the global health agenda culminating in the creation of the Global Health Sector Strategy on Viral Hepatitis. It has committed all 194 WHO Member States to eliminate viral hepatitis by 2030. As hepatitis elimination strategies are cascaded down to the regional and national level, it is vital that civil society and the affected community are kept at the heart of hepatitis elimination.

We are essential to accelerate hepatitis elimination. The governments that do work with civil society are seeing the value; just this month the Minister of Health of Romania recognised the role of civil society at the launch of their hepatitis elimination strategy saying, “We would especially like to thank Marinela Debu (President of WHA member APAH-RO) for great collaboration.”

The value of civil society must be recognised at the highest levels. We now have the evidence to demonstrate what many of us have always known. The work of civil society organisations makes a huge positive impact and should not be seen as a desirable extra to programmes, but a central element of every elimination plan around the world.

“Civil society changed the course of viral hepatitis elimination, through over a decade of advocacy work”
In the lead up to World Hepatitis Day we will be sharing the experiences of the people and organisations that use the day to help Find the Missing Millions.

This month we focus on raising awareness through the experiences of Katen Usick from Hepatitis C Care Clinic, Niagara Health System, Canada, who raises awareness through events.

We held our first WHD event in 2014. Last year was our fourth annual event. We were delighted to work with over 50 agencies and organisations and to have over 500 people attending. This year we hope to reach even more.

Each year, our event starts with messages of support from local dignitaries from the 12 different municipalities throughout the Niagara Region. Our 2019 programme includes free food and refreshments (we have volunteers from a community partner coming to barbecue for us), music and entertainment, private health teaching, viral hepatitis and HIV testing, a community health and social service fair. We also have the Mobile Cancer Screening Coach and Niagara Region’s mobile dental services, both of which are offering free cancer education and screening and free preventive dental services. Our clinic team will be offering free Naloxone kits and providing training too. Each year, we also partner with GIANT FM, a Canadian radio station, who attend with their ‘community cruiser’ and promo team.

This broad mix of activities helps spread the word and attract passers-by.

The main event, is our “Glow-It-In Green” campaign, which seeks to get different landmarks throughout Ontario to light up green on the 28th July. This year, the Niagara Falls, Peace Bridge and Welland Historic Lift Bridge will all be illuminated.

Advice

Our “Glow-It-In Green” campaign takes a lot of planning, but for the most part each year it passes with few glitches. Many landmarks already have illumination facilities and may have online applications to use their services. Nonetheless, be prepared for some obstacles. Over previous years, the Skylon Tower had participated in our campaign, but due to changes in their lighting equipment they are no longer able to do so.

When organising the activities, it is important to create a planning guide. This can be as simple as an Excel worksheet. It will help you keep track of what needs to be done and timelines. We also start planning very early — the day after the previous WHD - and book our venue early on. Sometimes you find you may have to book up to a year in advance.

We work with many different partners to put on our events to ensure a varied and engaging programme. We have on-boarded many of them by simply approaching and asking. Never be afraid to ask, you may be surprised with the answer you receive. Some of the most valuable partnerships that we have secured have come from stepping outside the box. We have also found that our client users can make some of the best volunteers for the day’s activities thanks to their passion and willingness to muck in.

Why not tap into the resources of peer-support groups local to you?

Above all else, don’t forget to thank all those involved in making the event possible. They will be great contacts for organising your activities next year.

TOP TIPS FOR SUCCESS

• BE CREATIVE, THINK BIG, CREATE YOUR VISION AND GO FOR IT.
• THINK ABOUT CREATING AN EVENT THAT HAS A HEPATITIS MESSAGE, RATHER THAN AN EVENT ABOUT HEPATITIS, YOU MIGHT ATTRACT MORE PEOPLE.
• NEVER BE AFRAID TO ASK. YOU MAY BE SURPRISED WITH THE ANSWER YOU RECEIVE.
• NEVER GIVE UP!

Want more inspiration? Visit www.worldhepatitisday.org for more masterclasses.
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 Riane Nesper, from the USA.

“I was diagnosed with hepatitis C 11 years ago. I contracted it through drug use. I continued to use regardless of my diagnosis. Throughout my drug use, I had short stints of sobriety. I would see a doctor, get my liver checked out and maybe get some blood tests if I could follow through. I saw multiple doctors over the course of the years. Each time I was told I could live my life completely normally and symptom free. Hepatitis C is a “slow progressive disease.” Which is the case for some, I guess. Not once was I warned of the actual damage that could happen in the meantime or how hepatitis C could affect my hormones, my emotional state and my physical body. I knew it could possibly kill me in the long run but that was more or less brushed under the rug. “You’ll be fine”, they said. “Most people live 20-30 years symptom free”, they said. Wrong.

Fast forward to the best years of my life. I found the man of my dreams, got sober and had a beautiful daughter. I was living a life that I never thought I’d be alive to live.

Then, a year and a half to two years into my sobriety I began to have sudden, life-changing symptoms. Drenching night sweats (changing my clothes 4-6 times a night), inability to eat or properly digest foods which I’d been eating my whole life, flu-like symptoms, extreme physical pain, depression, anxiety, an inability to control my emotions.

I also began to look forward to my period because it was the only time I felt normal and had energy – which was super weird. I was unable to be a wife, mother or friend. I lost myself in my sickness.

I began going to doctor after doctor, I had test after test but no results and no answers. No one could figure out what the cause was. Not one person. Heartbroken, all I wanted was my life back.

After over a year of sadness and hopelessness, I was referred to a liver specialist and I finally felt a sense of hope. My issues were a result of me losing the ability to digest protein, because of my liver. I felt normal on my periods because my liver lost the ability to filter my hormones. The night sweats and fevers happened because my body was trying to fight for me. Everything I’ve been experiencing was a result of a virus that was killing me. I never once thought that I would experience any of this because of hepatitis C, not this early on.

The difference for me was my genotype. I was part of 10% of the world with the most rare and aggressive strain of the hepatitis C virus.

I am now 100% cured and free of hepatitis C. I was lucky enough to be able to take Epclusa. It was not fun, I felt terrible. But I now have a future to look forward to. I am regaining my health and am able to function to the fullest for my family. My symptoms have slowly faded away since being cured and I am feeling better than I have in many years.

I am not sharing this for any other reason than to raise awareness. My hope is that my story can be a comfort or helping hand to others. My wish is to break the stereotype and stigma. My advice is to ask questions, do your homework and fight for your health because no one else will.”

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

“I was part of 10% of the world with the most rare and aggressive strain of the hepatitis C virus.”
"I no longer feel shame, guilt or fear. I have found a way out of depression and despair. I have found acceptance, empowerment and hope."

www.worldhepatitisalliance.org