WHA announces new CEO and President-Elect

WHA welcomes seven new members

hepinion: Why are we not making progress on stigma and discrimination?

WALL OF STORIES
“I want to show those fighting viral hepatitis that they are not alone.”
NOTE FROM OUR PRESIDENT

The World Hepatitis Alliance has exciting news as we announce a new CEO, Cary James, and a new President-Elect, Dr. Su Wang. These are two important additions to the WHA leadership team and will help us drive the Alliance into the next phase of its development.

Earlier this month I spent some time with Cary and Su in London at the WHA Board meeting, where we met with regional board members to discuss progress each region is making to eliminate hepatitis. Globally there is a mixed picture; and while it is concerning to see that some regions are falling behind in their hepatitis response, it is always inspiring to hear about the tireless work WHA members are doing to accelerate hepatitis elimination.

This month we also strengthened the Alliance by adding seven new members. WHA now represents 273 members in 90 countries. The power of our collective voices has never been greater as we work to ensure that the elimination of viral hepatitis becomes a reality.

Finally, as always, this month we’ve got some great features in hepVoice. We hope you enjoy it!

Michael Ninburg

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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.

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The World Hepatitis Day 2018 Global Summary report is out now.

The report features details of the activities undertaken across the world which can be used as a source of inspiration when planning your WHD2019 activities.

See the report at www.worldhepatitisalliance.org/whd-2018-global-summary
Hepatitis is regularly making the news thanks to the efforts of WHA members. Here are a few highlights.

Civil Society Collaboration with Policymakers Advances the Viral Hepatitis Response: An Interview with Professor Sharon Hutchinson

In the latest instalment of his ongoing interview series, Professor Jeffrey Lazarus sat down with Professor Sharon Hutchinson to discuss her work, the role for hepatitis patient groups in research and advocacy, and her vision of the future of hepatitis treatment.

Prof. Hutchinson is a Professor of Epidemiology and Population Health at Glasgow Caledonian University. She holds an honorary appointment at Health Protection Scotland and has over 20 years’ experience in conducting epidemiological research. She is using this research to inform the design and impact of public health interventions.

Prof. Hutchinson also leads a broad translational research programme on the prevention, diagnosis, and treatment of hepatitis C and other blood-borne viruses, and is also one of the newest members of the Hep-CORE Advisory Group.

Commenting on her work, Prof. Hutchinson said:

“My research provided the key evidence to guide a public health response to hepatitis C in Scotland, which culminated in the Scottish Government investing significantly in their Action Plan. The evidence-based National Plan – cited as an example of best practice by the United Nations Drug Policy Unit and the Global Commission on Drugs – was the stimulus for the World Health Organization and the World Hepatitis Alliance to stage the inaugural World Hepatitis Summit (involving governments and civil society representatives from over 80 countries) in Glasgow in 2015.”

Read more here.

India begins National Viral Hepatitis Control Program (NVHCP)

New Delhi’s Minister of State for Health, Ashwini Kumar Choubey, launched a national programme to eliminate viral hepatitis in Mumbai on 24 February.

The minister launched the National Action Plan, which provides a strategy and framework to bolster elimination efforts, in the presence of Amitabh Bachchan, a Bollywood superstar and hepatitis B patient.

The national programme has its origins in a consultation that began on World Hepatitis Day 2018 and is now part of a sustained commitment towards achieving SDG 3.3.

Speaking at the launch, Bachchan commented on the adverse effects that hepatitis has particularly on women, and the barriers to accessing healthcare they face:

“Discrimination against women has been most disturbing for me. This shouldn’t happen. Women are half the power of the country, they are the strength of the country. They must be given the respect and dignity that all deserve... to be discriminated [against] ... just because they are carrying hepatitis B virus is not acceptable. I will fight for this as long as I am alive.”

Read more here.

New Hepatitis C cases down by almost 70% in HIV-positive men in London

Researchers behind a new study from Imperial College London have suggested that regular screening and improved access to new treatments have contributed to greatly reducing new cases of hepatitis C amongst HIV positive men in London.

The researchers analysed data of 6,000 HIV-positive men at risk of acute hepatitis C at St Mary’s Hospital in London, subsequently presenting their findings at The Conference on Retroviruses and Opportunistic Infections in Seattle on 6 March.

Professor Graham Cooke, NIHR Professor of Infectious Diseases at Imperial College London and co-author of the paper, stated:

“The results from our study should give us great encouragement as we try to eliminate Hepatitis C. There is a risk that these gains might be reversed if we can’t re-treat patients and we hope that soon this might be possible through NHS services.”

The researchers also suggested that if this progress can be maintained and replicated, London will be on track to achieve the targets set out by the British HIV Association to eliminate Hepatitis C in HIV patients by 2021.

Read more here.

Dates for the diary

Upcoming events and activities taking place in the coming months.

7 APRIL

World Health Day

Universal health coverage is the key theme for this year’s World Health Day on 7 April. Universal health coverage is integral to achieving the elimination of viral hepatitis by 2030; this year, the main purpose of World Health Day is to help people better understand what universal health coverage means and how people who have adequate healthcare can better advocate for equal access to healthcare for all. The World Health Organization has created a range of communications materials to use and you can get involved on social media by using #HealthForAll.

10-14 APRIL

International Liver Conference (EASL 2019)

The International Liver Congress™ (ILC) brings together leading doctors and specialists from across the world. It serves as the leading platform to exhibit best practice and science, introduce the latest trends in hepatology, present scientific advances, offer education, and nurture networking at an international level. Staff and representatives from WHA and NOhep will be attending, so please do come along to say hello. You can join in the conversation on social media using #ILC2019.

Participating in a hepatitis-related activity or have an event planned? Email us or contact us on social media.
Cary James has been selected as WHA’s new CEO and will begin in April. Dr. Su Wang, who previously served as Executive Board Member for the PAHO region, has been appointed President-Elect.

Cary brings decades of experience in public health programmes and health policy at the national and international levels. He is a recognised leader in putting patients and communities at the centre of policy and programmes.

“I am excited for this opportunity to use my skills and experience to champion our members and people affected by viral hepatitis to make viral hepatitis elimination a reality,” Cary said.

Cary has worked extensively in hepatitis and HIV response, having developed innovative and successful campaigns and collaborated with numerous civil society organisations during his time as a member of the leadership team at the UK’s Terrence Higgins Trust. He has been a member of international advisory panels and expert groups on diagnostics, digital communications, health equality, HIV, hepatitis, tuberculosis and sexual health.

“Cary has a proven record of working closely with governmental and non-governmental organisations to tailor programmes to unique populations as well as high-level engagement with the WHO and UN, which are important skills in the work of the Alliance,” said Michael Ninburg, president of WHA.

“I am delighted to be passing on the torch to Cary who will be a great fit to the organisation and an exciting appointment to drive the Alliance forward,” added Raquel Peck, senior advisor and former CEO of World Hepatitis Alliance.

Dr. Su Wang has been appointed WHA President-Elect, having served on the executive board of the WHA since 2014 as a regional representative for the PAHO region. Su is an internal medicine physician who discovered she had hepatitis B after donating blood in college and has used her own personal experience to advocate for the elimination of hepatitis. She worked for many years in New York City leading outreach and care programmes for hepatitis B patients, and now directs a number of hepatitis B and C programmes in her current role as Medical Director for the Center for Asian Health at Saint Barnabas Medical Center in New Jersey.

“Su has a long history of championing hepatitis B care in underserved populations and has been a strong advocate of expanding hepatitis B and C services to frontline providers. She is a well-respected leader in the field and has also been an integral part of developing our NOhep Medical Visionaries programme. She is also a good friend,” said Michael Ninburg.

Dr. Wang added, “I am honoured to have this opportunity to serve as President and continue the great work of the Alliance in moving us towards elimination by 2030.” As President-Elect, she will shadow current President Michael Ninburg until January 2020, when she will take up the role of President.

“T am thrilled with this next generation of leadership at the Alliance. We are well positioned for the next chapter in the race to eliminate viral hepatitis” said WHA President Michael Ninburg.

Click here to find out more about WHA’s new CEO and President-Elect, and to watch Michael, Cary and Su discuss the new appointments.
CIVIL SOCIETY’S IMPORTANT ROLE IN ADDRESSING FINANCIAL BARRIERS TO ELIMINATION

Globally 325 million people are living with hepatitis B and hepatitis C yet, despite the fact that the solutions to eliminate these infectious diseases exist, efforts to implement them at scale are only just beginning. As of May 2018, only 82 countries reported having national viral hepatitis plans in place. Of these only 35% reported dedicated funding for these plans, highlighting that financing is proving to be a significant barrier to elimination.

WHA and partners have been working with countries to provide the investment case for hepatitis C elimination, showing that elimination is not only cost-effective; it is cost saving in the long run. Crucially, WHA is also working collaboratively with governments to assess how they can finance an elimination programme. This will likely involve a combination of different financing sources for different elements of the care cascade, and should consider including hepatitis elimination in the framework of Universal Health Coverage alongside catalytic financing sources where required.

These investment cases are an important advocacy tool that can be used by civil society and the affected community to call for action on hepatitis elimination. In Nigeria, where WHA has done the investment case and financing work alongside the Federal Ministry of Health and other stakeholders, civil society has been using this to call for action at the national and state level. Following the ongoing advocacy efforts of WHA member Grassroot Economic Empowerment Initiative (GREEINProject) in Akwa Ibom State, the State Government has recently created a standalone desk officer for hepatitis. This important development demonstrates Akwa Ibom State’s commitment to viral hepatitis. It will ensure that hepatitis is kept on the state’s health agenda and that the needs of patients are listened to at the highest levels.

It is important that civil society is able to understand and utilise the investment cases for hepatitis elimination so that they are equipped with the advocacy tools to ensure that hepatitis elimination strategies are financed and translated into real action. To help support this, WHA launched the National Viral Hepatitis Programme Financing Strategy Template website in 2017. The website sets out the investment case and financing process, and contains case studies highlighting the work done to date.

Support NOhep’s Google Doodle Campaign!

We need your help! Join us in requesting that Google mark World Hepatitis Day, 28 July, with a Google Doodle sketch to commemorate Barry Blumberg, the man who discovered the hepatitis B virus and developed the hepatitis B vaccine.

A Google Doodle is a temporary change to the Google logo on its homepages commemorating holidays, events, achievements and people. Since 2010, Google Doodles have also hyperlinked to search results for the subject of the Doodle, making them a great way to reach new audiences and raise awareness.

Dr Blumberg – whose hepatitis B vaccine is thought to have prevented more cancer-related deaths than any other intervention in history – is the perfect ambassador for the NOhep movement on World Hepatitis Day (which is also his birthday!). A Google Doodle in his memory could save lives by raising awareness of viral hepatitis.

It’s really easy to get involved

Simply add your name to the letter on the NOhep website, share it on social media, and encourage your friends, families, colleagues and networks to get involved!

This man prevented more cancer-related deaths than anyone else in history
Charitable Fund “Humanitarian Action” - Russian Federation

Charitable Fund “Humanitarian Action” works to prevent infection of HIV and viral hepatitis in Russia. Although HIV is their primary focus, Charitable Fund “Humanitarian Action” offer testing for hepatitis C, targeting PWIDs and sex workers with the help of their hepatitis-branded van. Their referral system with St. Petersburg Hospital ensures hepatitis C patients are linked to the care they need. On top of this, they also offer primary prevention education on hepatitis B and hepatitis C, and monitor State procurement of hepatitis C drugs. Follow them on Facebook.

Hepatitis Alliance of Ghana - Ghana

Hepatitis features predominantly in the Hepatitis Alliance of Ghana’s constitution. Their mission is to decrease incidents of new infection of viral hepatitis and to improve the lives of those individuals affected by the disease in Ghana through education and follow up care. Their main objectives are: to raise public awareness about hepatitis (particularly amongst women and children); capacity build for healthcare providers in the area of hepatitis prevention; provide psychosocial support for those living with viral hepatitis; to conduct research; to influence public health policy; and to collaborate with other organisations who share a similar vision. Follow them on Facebook and Twitter.

Seed The Change – New Zealand

A NOhep supporter and one of the NOhep Villagers at the Global Hepatitis Summit in Toronto last June, Seed the Change is a New Zealand-based initiative which exists to help manifest an environmentally sustainable, equitable and joyous world. Their hepatitis activities are channelled through their ‘Hep C Action Aotearoa’ project. This, at essence, is a patient advocacy group which hopes to propel elimination in Aotearoa by 2025 – five years ahead of the WHO target. A key part of their work is to combat stigma around the virus through the national and global promotion of their butterfly symbol. Their work ranges from representing the patient voice on the Ministry of Health national steering committee for hep C elimination, to supporting patients who have been diagnosed. Follow them on Twitter and Instagram.

United Way Mumbai – India

As part of the 130-year-old international movement “United Way”, United Way Mumbai has a broad remit of work covering numerous social issues. They partake in substantial viral hepatitis-related work channelled through their Yuvroshni, Pahal and SEHAT projects. They are practitioners of the Information-Education-Communication (IEC) model and work to build community participation and targeted immunisation. To celebrate World Hepatitis Day over the past few years, they have held week-long celebrations. Last year, they also adopted the Find the Missing Millions campaign. Follow them on Facebook, Twitter and Instagram.

Community Development Awareness and Health Empowerment Foundation (CDAHEF) – Nigeria

CDAHEF’s vision is to contribute meaningfully towards the elimination of viral hepatitis in Oyo State, Nigeria. Recently, they have attended the 1st Nigerian Hepatitis Summit in 2018, conducted trainings for organisations who could not attend the Summit, and enabled other organisations to join the Hepatitis Network. They also offer outreach and education on viral hepatitis, drug adherence counselling, testing and screening, and advocate relevant stakeholders in Nigeria.

Siddiqui Foundation – Pakistan

Siddiqui Foundation works under the banner of ‘prevention is better than cure’, having set up a project of the same name in 2012 to raise awareness of hepatitis B, hepatitis C, AIDS and Polio. As part of this project, Siddiqui Foundation have set up free hepatitis screening camps and have found that for every 100 individuals screened in Pakistan, 16 to 20 are living with viral hepatitis. The organisation also raises awareness through printed brochures and public announcements, as well as seminars and workshops across different institutional platforms. Follow them on Twitter and Facebook.

Hepatitis Zimbabwe Trust – Zimbabwe

WHA’s first member in Zimbabwe, Hepatitis Zimbabwe Trust, delivers awareness activities and support for people living with viral hepatitis through education, anti-stigma and community development activities following the Ottawa Charter principles. They also lobby their government to provide services for referral pathways for screening and treatment. Their goal is to equip Zimbabwean people with knowledge so they can have control over their own health.

WHA has recently welcomed seven new members to the organisation which now represents 273 members across 90 countries.
“We need more people to come forward to share their stories and to educate others on hepatitis.”

Stigma and discrimination are some of the biggest issues facing people living with viral hepatitis. Despite the massive developments we are making globally to eliminate the disease, we are making very little progress in reducing stigma and discrimination.

The hepatitis field needs to take inspiration from how the stigma around mental health has been addressed. People speaking out about mental health have been a significant catalyst for the reduction in the stigma surrounding it. Some of those speaking out have a high profile, which helps to spread the message widely, but many more are people who want to share their own experiences of living with mental ill health.

We need more people with hepatitis to come forward to share their stories and to educate others on hepatitis. It’s not an easy thing to do, but it is important. Recently WHO Goodwill Ambassador for Hepatitis in South-East Asia Region, Amitabh Bachchan, shared his experience of living with hepatitis B at the launch of India’s National Action Plan on Viral Hepatitis. His profile in the region will encourage others to come forward to tell their stories which will reduce stigma, meaning more people will come forward for testing.

The impact of the stigma around hepatitis cannot be over-exaggerated; in China we see people living with hepatitis being driven to suicide as their whole life becomes engulfed in discrimination. It’s not uncommon in China to have special ‘hepatitis tables’ in workplaces where people living with hepatitis have to sit, excluded from others. It’s this isolation that causes serious long-term effects.

In 2017 WHA found that 93% of civil society organisations reported stigma and discrimination being issues in their country, and whilst many hepatitis elimination strategies mention addressing stigma and discrimination as a goal, few have the associated work needed to address the issue.

Civil society has an important role to play to ensure that awareness raising and education is at the centre of the discussion. There is still so much misinformation about hepatitis feeding the stigma and discrimination. By educating the public and raising awareness we will be able to ensure that people understand viral hepatitis, and that stigma is reduced. The rights of hepatitis patients are basic human rights and we need to ensure that they are upheld.

“Why are we not making progress on stigma and discrimination?”

By Dee Lee, WHA board member for the WPRO region

“hepinion”

“The rights of hepatitis patients are basic human rights”

#StigmaStops
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 in hepVoice. This month, we are highlighting the crucial role of civil society in raising awareness of viral hepatitis to scale-up diagnosis and find the missing millions.

Raising awareness: the key to finding the missing millions

Worldwide, 290 million people live with viral hepatitis unaware. Despite 196 countries making the commitment three years ago to eliminate viral hepatitis by 2030, without increasing efforts to find these missing millions we will fail to eliminate this global killer.

Last year as part of our Find the Missing Millions programme, we released a white paper looking into the main barriers to diagnosis and put forward key recommendations to overcoming them. The white paper stressed the unique and important role civil society and the affected community have to play in this. Civil society and those living with viral hepatitis bring fundamentally important perspectives and experiences to the table, which help the dissemination of accurate and reliable information and greatly enhance strategies and programmes.

One of the recommendations identified is to raise awareness of viral hepatitis. Raising awareness combats three of the barriers to diagnosis – the lack of public knowledge of the diseases, the lack of knowledge among healthcare professionals and wide-spread stigma and discrimination. Through raising awareness we can break down these barriers collectively, facilitating increased diagnosis.

Whilst different strategies are required for different populations and country contexts, in all cases civil society involvement is crucial.

With the view to raising awareness, civil society and affected community involvement can contribute to the delivery of stronger awareness campaigns and offer platforms from which stigma and discrimination can be effectively addressed. What’s more, as more people living with viral hepatitis become aware of their diagnosis, they and their friends and family can raise awareness amongst their personal networks too. Only through bottom-up awareness-raising efforts will we find the missing millions.

Civil society can actively engage in many different activities to raise awareness of viral hepatitis to increase diagnosis. They can partner with other stakeholders – be they medical professionals or policy-makers – to advocate for continuous medical and professional education on viral hepatitis, the enforcement of anti-discrimination laws, and for national governments to uphold their 2016 commitments.

Civil society can also partner with other stakeholders to take action to highlight the life-threatening complications of viral hepatitis.

Another approach they can take is to find influencers like celebrities and political leaders who can raise even greater awareness and contribute to communication and awareness-raising campaigns by helping to formulate culturally-specific messaging to debunk myths, convey a sense of urgency and reduce stigma.

For more tips and activities on how civil society can help scale-up diagnosis through raising awareness, read our white paper.

Examples from around the world

Get in touch

Email us at contact@worldhepatitisalliance.org to tell us how you are raising awareness of viral hepatitis to scale-up diagnosis.
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 Mariam from Pakistan.

Three years ago, I was diagnosed with hepatitis B during a regular pre-employment screening. I did not know anything about the disease.

Being confronted with a chronic illness generally is crushing. Being diagnosed with an infectious chronic illness like hepatitis B can be beyond overwhelming. The fact that it is an infectious disease not only contributes towards stigma surrounding its diagnosis, but can also lead to an extreme sense of paranoia for the patient. Having an infection that I cannot get rid of makes me feel dirty, like I have to be cautious and aware that my blood is hazardous for others. There is a fine line between being cautious and being engulfed by a paralyzing sense of paranoia threatening to push you into isolation.

I have learnt that the strongest weapon I can use in my defense against this paranoia is my sense of rationality and knowledge about the disease that shares my body. To fight it holistically, it is imperative that first you understand the nature of this disease in order to win the battle in your mind—only then will you be able to fight the battle within your body.

Nearly 15 million people live with hepatitis B in my country Pakistan. There are many reasons why this disease, which is preventable and treatable, is prevalent in a developing country like mine. Pakistan lacks a proper healthcare system that can implement effective preventive methods. There are no pregnancy screenings or effective mechanisms to ensure babies are vaccinated against hepatitis B either.

For three years, I hid away from my illness. I wanted to disassociate myself completely and so I tucked it away, in the farthest corner of my mind. I stopped going to follow-ups and did not share my story with friends or family. I did not know many people with whom I felt safe talking about it, whom I trusted to not see me through the lens of stigma.

That was until one day when I was at a fundraising event for a charity cancer hospital and got the chance to sit with a doctor. He was a stranger and a doctor so I felt safe telling him why I’m so interested in trying to understand where my country stands in the fight against hepatitis B—I told him I was diagnosed with it. He made me realise that I need to go to my follow-ups before I can make a difference in combating hepatitis B.

The elimination of viral hepatitis by 2030 is one of the World Health Organization’s Sustainable Development Goals, but we cannot achieve this without dedicated efforts by all stakeholders including health-care professionals, patients, media, and policymakers.

Today, I want to share my story with others in the hope of showing those who are fighting viral hepatitis that they are not alone.

Today, I am determined to play my role in defeating this disease.”

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

“For three years, I hid away from my illness.”
"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