"My mom was afraid that she had given it to me"
NOTE FROM OUR CEO

The end of the year gives us the opportunity to pause and reflect on all of our achievements over the past 12 months. For WHA, this includes hosting the first NOhep village at the Global Hepatitis Summit where we launched the NOhep Guide for Medical Professionals, co-ordinating World Hepatitis Day under the Find the Missing Millions theme and supporting countries to build the financial case for the elimination of viral hepatitis.

This time of year is also a reminder of the progress that still needs to be made to make elimination a reality. In 2018 1.4 million people died of viral hepatitis, despite there being a vaccine and treatment for hepatitis B and a cure for hepatitis C. 2019 is the last year countries have to reach the 2020 interim targets set out by the World Health Organization in the Global Health Sector Strategy on Viral Hepatitis. We know that the majority of countries are likely to miss these targets unless there is a concerted effort to change the current outlook. WHA members will be playing a leading role in advocating for governments to ensure action is taken and that no one is left behind in the fight for elimination.

Further, 2019 will be a year of change for the World Hepatitis Alliance. We will have new members on the board, a new president elect and, as many of you know, I will be stepping down as CEO after being with the organisation since its inception in 2007. These are big changes but with change comes the opportunity to explore new ways of working with our members and partners to translate the global commitment to hepatitis elimination to regional and national action.

I am looking forward to this next chapter and to seeing WHA prosper in its elimination vision.

Raquel Peck
Chief Executive Officer

CONTENTS

REGULARS

4  Hep headlines
5  For the diary

FEATURES

6  The Investment Case for Hepatitis C Elimination in Nigeria
8  WHA Board Elections
10  WHA Welcomes New Members
12  Highlights from AASLD and WISH
14  Wall of Stories: Sylvester’s Story
15  Find the Missing Millions in Action

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

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.

Stay connected

www.worldhepatitisalliance.org
contact@worldhepatitisalliance.org
www.facebook.com/worldhepalliance
@Hep_Alliance
@worldhepatitisalliance
Hepatitis is regularly making the news thanks to the efforts of WHA members. Here are a few highlights.

**Gavi Prioritises Hepatitis B Birth Dose**

Gavi, the Vaccine Alliance, has approved an investment in the hepatitis B birth dose vaccination as part of its Vaccine Investment Strategy. One of six new and expanded vaccine programmes, the hepatitis B birth dose will prevent chronic cases of hepatitis B infection, which develops in up to 90% of infants infected with HBV at birth or in the first year of life.

Gavi’s Board made the decision to prioritise the hepatitis B birth dose during a two-day meeting to shape the organisation’s strategic approach for the period 2021-2025.


**AASLD Strengthens its Relationship with Patient Groups**

The Liver Meeting 2018, held in San Francisco in November, saw the leadership of the American Association for the Study of Liver Diseases (AASLD) host a patient advocacy meeting to explore ways in which AASLD can work closer with patient organisations.

WHC President, Michael Ninhburg, and Executive Board Member, Dr. Su Wang, spoke at the meeting about how WHA has coordinated patient and medical professional interaction through advocacy work.

Read more about the issues raised by patient advocates at the meeting and the agreed next steps: [www.aasldnews.org/aasl-deepens-its-relationship-with-patient-groups/](http://www.aasldnews.org/aasl-deepens-its-relationship-with-patient-groups/)

**Hepatitis C Re-infection Rate Low in People with High-risk Behavior**

The results of a large population-based study in Canada have shown that the overall number of people re-infected with hepatitis C after effective treatment with direct-acting agents (DAAs) was low.

The study therefore provides further evidence in support of offering high-risk populations widespread treatment.

Naveed Janjua, PhD, a senior scientist with the British Columbia Centre for Disease Control said that delivering treatment quickly to people with hepatitis C who display high-risk behaviour was essential to reducing the passing on of hepatitis C to others and to eliminating the disease. Janjua also commented that unlike with interferon, side effects are rare with DAAs and compliance with long-term treatment programmes is not an issue.

Read more at [www.medpagetoday.com/reading-room/aga/lower-gi/76361?fbclid=IwAR2ayQod41Jbg8M0WSAq0pVmpCnNahyF-](http://www.medpagetoday.com/reading-room/aga/lower-gi/76361?fbclid=IwAR2ayQod41Jbg8M0WSAq0pVmpCnNahyF-)

**Hepatitis B Prevalence Rate drops in Uganda**

Uganda’s State minister for Primary Health Care, Dr Joyce Moriku Kaducu, has announced that there has been almost a 6 per cent drop in hepatitis B prevalence in the country, where more than four million Ugandans are living with the disease.

The decline from 10.3 per cent to 4.5 per cent prevalence is attributed to a large-scale vaccination and treatment programme against the disease.

Read more at [www.monitor.co.ug/News/National/Hepatitis-B-prevalence-rate-drops/688334-4836884-f0au5/index.html](http://www.monitor.co.ug/News/National/Hepatitis-B-prevalence-rate-drops/688334-4836884-f0au5/index.html)

**Hepatitis C Cure, Sofosbuvir, Turns 5 Years Old**

People living with hepatitis C, access to medicines activists, and the medical community around the world are “marking” the fifth birthday of the first all-oral, one dose per day cure sofosbuvir (Sovaldi®), launched by Gilead Sciences in 2013.

A global hepatitis C coalition has released a fact sheet revealing treatment barriers that have resulted in only 1.85 million of the 71 million people worldwide who need treatment, receiving the sofosbuvir-based drugs, largely due to pricing, patents and registration delays.


**HepHIV Conference, Bucharest**

The HepHIV aims to provide an overview of innovative initiatives and best practices on optimal testing and earlier care for HIV and viral hepatitis from different settings across Europe, including progress and challenges in the integration of service, sustain and fuel the political discussion of testing policies, increase political commitment and public awareness by discussing how to translate global and regional goals, objectives and targets into local implementation plans, and provide opportunities for multi-stakeholder dialogue to develop creative solutions to unresolved challenges in research and implementation of HIV and viral hepatitis, TB and STI policies and programmes to improve early diagnosis and care.

**4 FEBRUARY 2019**

**World Cancer Day**

Each year on 4 February, World Cancer Day empowers all of us across the world to show support, raise our collective voice, take personal action and pressure our governments to do more. World Cancer Day is the only day on the global health calendar where we can all unite and rally under one banner in a positive and inspiring way.

**DATES FOR THE DIARY**

**Upcoming events and activities taking place in the coming months.**

**28-30 JANUARY 2019**

**HepHIV Conference, Bucharest**

The HepHIV aims to provide an overview of innovative initiatives and best practices on optimal testing and earlier care for HIV and viral hepatitis from different settings across Europe, including progress and challenges in the integration of service, sustain and fuel the political discussion of testing policies, increase political commitment and public awareness by discussing how to translate global and regional goals, objectives and targets into local implementation plans, and provide opportunities for multi-stakeholder dialogue to develop creative solutions to unresolved challenges in research and implementation of HIV and viral hepatitis, TB and STI policies and programmes to improve early diagnosis and care.

Email us or contact us on social media.
Making the Financial Case for Hepatitis C Elimination in Nigeria

By Jessica Hicks
Head of Programmes, WHA

Nigeria is faced with one of the largest burdens of hepatitis C in the world, with an estimated 2.5 million people affected across the country. Despite launching a national hepatitis programme in 2015, Nigeria’s Federal and State Governments have yet to secure sufficient financial resources to reach the targets set out in the national programme. The World Hepatitis Alliance (WHA), together with partners and WHA members, has been working with Nigeria’s Federal Ministry of Health to create the investment case for hepatitis C elimination and, crucially, to explore financing options for this elimination plan.

Previous investment cases for hepatitis C elimination in other countries have shown that elimination is cost-effective, with savings achieved within a decade. In Nigeria’s case, WHA and partners modelled multiple scenarios, comparing the cost forecast for maintaining the current situation to cost models of a conservative scale-up (achieving elimination by 2030), a moderate scale-up (achieving elimination by 2028), and an aggressive scale-up (achieving elimination by 2026).

All scenarios found projected cost savings to the healthcare system compared to taking no action. The modelling also showed that despite the need for more investments at the start, mainly due to the significant number of new infections prevented, the more aggressive elimination efforts would achieve the most rapid and highest cost benefit in later years.

Much of the work to date has focused solely on the investment case, leaving countries still facing the challenge of how to finance their viral hepatitis programmes. In addressing this question, Nigeria has shown global leadership and demonstrated that financing does not need to be a barrier to elimination. Through the project, a total of four financing recommendations were made that were deemed to have strong short and/or long-term impact.

“All scenarios found projected cost savings to the healthcare system compared to taking no action.”

The results were recently presented at the first ever Nigeria Hepatitis Summit on 3rd and 4th December 2018, which brought together civil society, policy makers, and medical professionals to discuss the challenges that Nigeria faces in eliminating viral hepatitis and how these could be overcome. The Summit facilitated the discussion of financing work with key stakeholders within Nigeria’s Federal and State Governments, with Ministers and officials attending alongside more than 60 members of Nigeria’s civil society.

There were a number of other positive outcomes from the Summit, including a meeting held by WHA for civil society to discuss the future of our advocacy for financing projects in Nigeria. Through consultation with WHA members and other civil society organisations, we established the need to change our focus to advocacy at the State level, rather than the Federal level, and representatives from 11 states expressed their interest in driving this work forward.

In 2019, WHA and partners will be expanding this work and partnering with more countries to create the investment case for hepatitis elimination. WHA will also be encouraging policymakers to use the WHA National Viral Hepatitis Financing Strategy Template tool launched in 2017.

“the more aggressive elimination efforts would achieve the most rapid and highest cost benefit in later years.”
### 2019 WHA Board Elections

2019 is an election year for the World Hepatitis Alliance Board. Three regional positions are up for election, the European Region (EURO) with two candidates standing, the South East Asia Region (SEARO) with three candidates standing and the America’s Region (PAHO) with one candidate standing. The elections will be held in early January when eligible voting members of WHA will receive the voting information by email. Full candidate profiles can be seen at [www.worldhepatitisalliance.org/2019-elections](http://www.worldhepatitisalliance.org/2019-elections).

#### EURO Candidates

**George Kalamitsis — Greece**

“I am a founding member and Chair of Hellenic Liver Patient Association “Prometheus”, since 2012. I am engaged in Health Policy, specialized in the public health sector. My work is related to providing support to people living with viral hepatitis, advocating for their rights and providing evidence-based policy actions. Recently, I was assigned as President of the Committee Protecting the Rights of Recipients of Health Services (Greek Ministry of Health 2017). I have been working extensively with multiple stakeholders, focusing on patients’ rights as well as building communication channels with organizations and stakeholders, on a National, European and International level.”

**Rachel Halford — United Kingdom**

“I have worked for over 20 years with people at high-risk of viral hepatitis – the homeless, prisoners, substance misuse and migrants. Before joining The Hepatitis C Trust (HCT) as deputy CEO 3 years ago, I was CEO of Women in Prison, a national UK NGO supporting women affected by the criminal justice system. In July 2018 I became CEO of HCT. I have extensive experience in all areas of running a NGO. I have sat on a number of national boards and represented HCT on a European level as a member of ELPA. I cleared hepatitis C in 2007.”

#### SEARO Candidates

**Dr. Md. Humayun Kabir — Bangladesh**

“I am a medical graduate with a post-graduate degree in Primary Health Care from Mahidol University Thailand in 1994. I worked in various government health facilities from 1982 to 2009. I spent most of my service at the national level in the Directorate General of Health Services. My primary duties were national health program formulation, monitoring and overseeing their implementation. I have experience in coordination of WHO country programs as well as global programs implemented in Bangladesh. I was elected Regional Board Member of WHA in 2011-12 and 2013-14 and participated in the WHO guidelines preparation workshops in Geneva.”

**R.P. Shanmugam — India**

“I was the first qualified Surgical Gastroenterologist in India; with a special interest in Liver disease, I founded the famous Dept of Gastroenterology, Stanley Medical College, Chennai. I also performed the country’s first liver transplant way back in 1996. With over 50 years of medical practice and my passion for serving the needy, I have just opened our own hospital, so that linkage to care will never be a problem. We are also in the process of collaborating with the government to push for elimination of viral hepatitis by 2030.”

#### PAHO Candidates

**Patricia Vélez-Möller — Guatemala**

“I was diagnosed with hepatitis C at 37 years old. I have used my knowledge and experience as a physician and patient to fight against unawareness and stigma surrounding hepatitis. I am the Co-Founder and President of the Guatemalan Liver Association, the Regional Advisor for the Americas of World Hepatitis Alliance, a member of the PAHO/WHO Technical Advisory Committee on Viral Hepatitis and a Representative of Civil Society and Academy for the National Viral Hepatitis Task Force. I aim to find the undiagnosed millions and help them get treatment.”

**Edo Agustian — Indonesia**

“I come from a drug-user community and had worked in the field of HIV and access to medicines since 2003. Since then I co-founded several organizations at the regional and national level to do advocacy work for harm reduction and human rights. I was elected as the National Coordinator for Indonesian Drug User Network (PKNI) in 2011. Under my leadership, the Network had received several recognitions such as Red Ribbon Award and I was also felicitated with the rolleston Award. PKNI became members of the World Hepatitis Alliance in 2015 during my time serve as National Coordinator of PKNI.”
The Family Health Association is a full member of the International Planned Parenthood Federation and also benefits from special consultative status in the UN-ECOSOC. For the past two years they have held hepatitis screenings that are mostly aimed at high risk women in the poorest neighbourhood of Tehran. With the help of donors and medical facilities, they also assist in getting people access to treatment. They undertake advocacy programs to educate local communities and engage authorities and other NGOs to tackle the problem.

**Malady Chase Foundation – Nigeria**

Malady Chase Foundation works in the area of health and child education with a focus on the fight against viral hepatitis and HIV/AIDS. Awareness-raising in the state and in local communities, advocacy work and free screenings for hepatitis B and C feature prominently in their programmes. They also work with patients and health services to provide referrals and treatment plans.

**Hope For Healthy Life Foundation - Nigeria**

The main objective of Hope for Healthy Life Foundation is to create a healthy society free from hepatitis and related deaths. The organisation aims to help individuals to access hepatitis services in an easy and affordable manner. The organisation is a registered body with the Federal government of Nigeria’s Corporate Affairs commission, and the State registration body, Ministry of Youths and Social development.

**WHA’s first member in Tanzania, the People’s Development Forum**

WHAs first member in Tanzania, the People’s Development Forum work to promote improved health services in Tanzania. The organisations primary work focuses on HIV counselling and testing but they encounter hepatitis in their day-to-day activities as a result. They are in the process of spearheading movements to fight hepatitis at the national level and aim to reduce stigmatisation. The process of this includes the formation of a National Level Task Force. Their activities have evolved to include access to care and treatment in accordance with universal health coverage. They also advocate for budget allocation to be directed towards viral hepatitis services.

**PPAN was one of the NGOs that were invited to a round-table discussion with the Ministry of Health to discuss the first National Hepatitis prevention and treatment plan/guidelines in Armenia.**

PPAN was one of the NGOs that were invited to a round-table discussion with the Ministry of Health to discuss the first National Hepatitis prevention and treatment plan/guidelines in Armenia.

**Positive People Armenian Network - Armenia**

WHAs first member from Armenia. Whilst hepatitis is not Positive People Armenian Network’s (PPAN) main focus, it features prominently in their mission and vision. The organisation’s goals are to improve the quality of life of people living with hepatitis, combatting stigma and discrimination and preventing the spread of the disease. PPAN participated in World Hepatitis Day and promoted NOhep on the streets. They implemented the first Armenian testing week for hepatitis in 2017, where free and anonymous testing took place in several major cities. PPAN also carries out advocacy and policy activities, raising the importance of ensuring hepatitis C treatment is accessible and affordable to all. PPAN was one of the NGOs that were invited to a round-table discussion with the Ministry of Health to discuss the first National Hepatitis prevention and treatment plan/guidelines in Armenia.

**Drive For Health Foundation - Ghana**

Although hepatitis is not the primary focus of the organisation, Drive for Health Foundation are involved in counselling, advocacy, screenings and vaccinations for hepatitis. In the last couple of years they have celebrated World Hepatitis Day by conducting educational campaigns and screenings. They currently provide the hepatitis B birth dose free of charge to all babies born at the Tamale Teaching Hospital. They actively engage with the Ministry Of Health and other bodies for the inclusion of hepatitis B screenings and vaccinations to be included in the National Health Insurance Scheme.

**WHA has recently welcomed seven new members to the organisation which now represents 266 members across 89 countries.**
Recently WHA attended AASLD, The Liver Conference, in San Francisco and the World Innovation Summit for Health (WISH) in Doha. These events bring together key stakeholders to push forward global hepatitis elimination efforts. Here are a few highlights.
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 Sylvester from Malawi who shares his story.

"In April 2010, my close friend’s dad needed a blood transfusion and I, as usual, offered to donate blood. I have always had the desire to help others when the need arises. Whilst undergoing the screening, I was told that I have hepatitis B, I knew nothing about it.

Unfortunately, the doctor who screened me at the Government Hospital seemed to be rushing to the next appointment, frankly he offered me very little information about my diagnosis. I started trying to find the right information on my own, only then did I realize how big hepatitis B is and what my diagnosis truly meant.

I visited a specialist who explained to me more about the disease and my diagnosis and what I had to do now I was diagnosed. I reluctantly had to give up my favourite wine and had to make some adjustments to my life.

Today I can claim to know more about hepatitis B because of the information that I found out from WHA member the Hepatitis B Foundation. I want to say a big thank you to them because without their information, I would have died. Before I got more information I was suffering with anxiety, there was no emphasis in my local hospital on informing patients about hepatitis B or C. HIV is at the centre of all efforts and emphasis. Nobody talks about hepatitis.

I want to change things and raise more awareness of viral hepatitis in Malawi. I will be taking part in World Hepatitis Day and trying to encourage journalists to cover stories about the disease so we can spread the word and encourage more people to get screened and know their status.

I feel like I am living my life like a king now as I know what to avoid and more importantly what to feed my liver. I would like to encourage others to get screened and look after your liver."

"On World Hepatitis Day 2018, together with partners, the Liver Foundation of West Bengal launched the “Reaching the Unreachable” project with the aim of finding people unaware of their hepatitis diagnosis in West Bengal.

Of the 325 million people living with viral hepatitis globally, upward of 290 million (that’s 9 in 10) are living with hepatitis B or hepatitis C without knowing. 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.

In India, 68% of the population live in rural areas, for many people health services can be hard to reach. The rural population of India is greatly impacted by viral hepatitis and to ensure we find all of the estimated 52 million people living with hepatitis B or hepatitis C in India it is crucial that no one is left behind, even those that are hardest to reach.

In Sitarampur, a very remote village 7-8 km away from Ajodhya hill top of Purulia district, we implemented the “Reaching the Unreachable” programme. We screened 459 people for hepatitis B and hepatitis C over three days, including 44 primary health care practitioners who work with the community. The village has a total population of 500, so we managed to see the majority of the population.

Alongside the vaccination and testing drive we also ensured the residents of the village were made aware of viral hepatitis so that they could pass on their knowledge to more people. We also achieved some media coverage from the event, further raising awareness of hepatitis."

"It is crucial that no one is left behind, even those that are hardest to reach.”