Dear Partners,

As we reach the halfway point of 2018, it’s clear that the elimination of viral hepatitis is in jeopardy. According to a mid-way review of the Global Health Sector Strategy on viral hepatitis, presented at the World Health Assembly in May, only 82 countries reported that they had viral hepatitis plans in place and of these, only 35% reported dedicated funding for such plans.

Similarly, only 1.76 million patients received hepatitis C treatment in 2016, a small increase from 1.1 million in 2015. This is exacerbated by the fact that most countries are facing the critical issue of finding the millions of people who are undiagnosed. Whilst some countries like Egypt are deploying innovative ways to scale-up diagnosis and treatment, they are pockets of success. The fact remains that without unrelenting advocacy, a massive increase in awareness and political will, we will not eliminate viral hepatitis by 2030.

To combat this, we’ve been charging ahead raising awareness, influencing policy and building the capacity of our 258 member organisations to find the missing millions.

One of my most memorable moments this quarter has to be the Find the Missing Millions stakeholder consultation which we hosted in May. The two-day event brought together 30 experts and patient representatives from across the world to discuss and create recommendations on how civil society and the affected community can help overcome barriers to diagnosing hepatitis B and hepatitis C. The discussions and recommendations will be captured in a white paper, which will be released to coincide with World Hepatitis Day, 28 July 2018.

Harnessing the power of people living with viral hepatitis always remains at the heart of our work. As such, this quarter we also hosted the NOhep Village at the Global Hepatitis Summit (GHS) in Toronto and facilitated the exhibiting of over 20 civil society groups. With a three-day packed programme of presentations, lightening talks and panel discussions, the event fostered networking and collaborative learning between civil society organisations, patient groups and the scientific community.

Creating advocates amongst civil society and healthcare professionals was a key focus for the NOhep movement this quarter. At the GHS, we hosted a panel-discussion with our NOhep Visionaries to explore and highlight various ways healthcare professionals can advocate within and outside healthcare settings. This dynamic event was also used to officially launch a new guide for healthcare professionals entitled “The NOhep Guide for Medical Professionals: 5 principles for taking action to eliminate viral hepatitis.”

NOhep also launched a complementary resource for civil society organisations. Recognising that only a handful of countries are on track to eliminate hepatitis C and 72 countries on track to eliminate hepatitis B in under-5s by 2030, NOhep launched “Race to 2030: Accelerating action at a national level” advocacy toolkit for our members, patient groups and other civil society groups.

Ensuring the patient voice is always front and centre is pivotal to our strategy and our mission. In that vein, we travelled to Trinidad to represent civil society at the first-ever Caribbean sub-regional meeting on hepatitis. We spoke at the opening ceremony of the International Liver Congress about the critical importance of patient-centred health and made an intervention at the World Health Assembly on why hepatitis needs to be included in the Universal Health Coverage package.

The elimination of viral hepatitis is in jeopardy but there is hope. This quarter, we witnessed the strength of collaboration, the passion in partnerships and the common goal which binds us all together. I am hopeful that if we continue to work together, share experiences and challenge inefficiencies, we can eliminate viral hepatitis by 2030.

We hope you enjoy reading our progress report. Don’t hesitate to contact me if you have any questions.

Karine Belondrade,
COO/Acting CEO
Worldwide, only 11% of those living with viral hepatitis are aware of their diagnosis. Unless we find the 290 million people - the “missing millions” - that have yet to be diagnosed and link them to care, all other efforts to eliminate viral hepatitis will only have marginal success.

Find the Missing Millions is a multi-year programme aimed at raising awareness, driving policy change and increasing testing at a national and global level. Recognising that barriers to diagnosis must be understood and overcome to reach our objectives, the programme will take a multifaceted approach to the issue. It will build the evidence base, engage with a range of stakeholders and help drive advocacy at a global level and on the ground. We will do this by putting the people affected by viral hepatitis at the heart of the solution.

- WHA President Michael Ninburg officially launched the Find the Missing Millions campaign to over 10,000 hepatologists, nurses and public health experts at the International Liver Congress in Paris, France. “I’m calling on everyone in this room to take responsibility,” urged Michael in his speech at the Opening Ceremony, “Those who are diagnosed must speak up and speak out, policymakers must take action and implement, and medical professionals, you have the biggest responsibility of all. You have the responsibility to diagnose.”
- Launched global report on the barriers to diagnosis. A report of the global survey findings was prepared giving a picture of the key barriers to diagnosis of hepatitis B and C globally. This report was the basis for discussion at the two-day global stakeholder meeting in London. It was released online with the launch of the Find the Missing Millions microsite on the 14 June. You can find it here.
- Convened a two-day expert stakeholder consultation. WHA convened a two-day consultation in London on the 17 and 18 May which brought together people living with viral hepatitis, civil society organisations and experts in the field. The purpose of the meeting was to validate the global survey findings and then discuss the role that civil society and the affected community have to play in overcoming the barriers to diagnosis. The meeting resulted in a set of recommendations which will be further refined and put forward in the white paper ‘Overcoming the barriers to diagnosis of viral hepatitis: The role of civil society and the affected community in finding the missing millions’. The white paper will be launched on 27 July to coincide with World Hepatitis Day. Professor Jeffrey Lazarus, Associate Researcher at ISGlobal, Hospital Clinic, University of Barcelona, has been commissioned to write the white paper.
- Launched the Find the Missing Millions self-assessment tool. Online risk-assessments are useful ways to engage the wider audience and share vital information about hepatitis risk factors. We have launched a bespoke tool which allows users to check if they are at risk. Click here to access it.

PROJECTS

Acting CEO Karine Belondrade presents the Find the Missing Millions programme at the expert stakeholder consultation
**World Hepatitis Day 2018**

World Hepatitis Day (WHD) takes place every year on 28 July to raise awareness of the global burden of viral hepatitis and influence real change. This year we are using the momentum of World Hepatitis Day to launch the Find the Missing Millions campaign. Under the overarching theme of Eliminate Hepatitis, the campaign aims to raise awareness of viral hepatitis, increase testing both at individual and policy level and support linkage to care.

**Highlights**

- **Hosted our annual WHD webinar on 25 April.** The webinar provided an overview of the Find the Missing Millions campaign, tips and tricks on making an impact on WHD and inspiration for events and activities. We were inundated with great questions from WHA members and the recording has received over 670 views. If you were unable to attend, catch up on the discussions with the video recording and slide deck.

- **Launched the Quest to Find the Missing Millions on 14 June.** The event was an opportune time for the World Hepatitis Alliance to promote the Find the Missing Millions campaign, to launch the Global Quest to Find the Missing Millions and to encourage participation in WHD among healthcare professionals. The Quest is an interactive space for stakeholders to access up to date information about diagnosis, take a self-assessment tool and learn about testing and screening initiatives from across the world.

- **Hosted a Find the Missing Millions launch event.** Attendees heard successful screening case studies and patient testimonials to inspire action. Within one week of the launch, the campaign site had been visited over 300 times. For more details on how we used the GHS to promote the Find the Missing Millions campaign, turn to the GHS section.

- **Hosted a Find the Missing Millions launch event.** Attendees heard successful screening case studies and patient testimonials to inspire action. Within one week of the launch, the campaign site had been visited over 300 times. For more details on how we used the GHS to promote the Find the Missing Millions campaign, turn to the GHS section.

- **Promoted the Quest through the WHA booth in the Village.** Delegates were able to find out more about the Find the Missing Millions campaign and how they can participate in WHD as well as sign up to the Quest to Find the Missing Millions. During the event, 45 individuals and organisations joined the Quest to Find the Missing Millions.

- **Celebrated the efforts of civil society and patient groups across the globe who are taking the lead in increasing efforts to find the undiagnosed.** From the pilot Spring Testing Week in Europe to the National Hepatitis Testing Day as part of the Hepatitis Awareness Month in the United States, testing activities have been taking place across the globe. We have profiled these activities in our monthly magazine, hepVoice, and across our social media channels to create buzz ahead of World Hepatitis Day.

- **Set up a Thunderclap to help our WHD message reach more people.** By joining the Thunderclap, a message is automatically shared from participants’ social media accounts at a specific time. Sign the Thunderclap to add your voice to our global call to find the missing millions on 28 July.

**CHALLENGES**

- **Footfall through the NOhep Village was lower than expected, which impacted the number of sign-ups to the Quest to Find the Missing Millions, however those who visited the booth fully engaged with the Quest and were keen to stay updated about the campaign.** We also used other methods like social media and email marketing to encourage sign-ups.

Speakers share their experiences at the launch event of the Global Quest to Find the Missing Millions at the Global Hepatitis Summit
NOhep is a global movement aimed at uniting all stakeholders to eliminate viral hepatitis by 2030. The main objectives for Q2 were to increase advocacy efforts amongst healthcare professionals and civil society organisations, alongside raising awareness of NOhep and increasing sign-ups to the NOhep movement.

### Highlights

- **Launched the “Race to 2030” campaign and supporting toolkit.** Race to 2030 is a global advocacy campaign calling on civil society organisations to take action to get their countries on track to meet WHO’s elimination targets. To coincide with the World Health Assembly in May 2018, we launched the campaign alongside the Race to 2030: Accelerating action at a national level Toolkit, which guides activists through the process of developing an advocacy strategy. To date, the toolkit has been downloaded 1,459 times and is proving to be a popular resource with civil society organisations.

- **Created the NOhep Supporter Spotlight series.** To showcase the pioneering work of NOhep activists around the world, we developed spotlight pieces on advocates in the community with an aim to highlight the work they are doing on a global platform and share best practices with the NOhep community. So far we have featured Yasir Waheed from Bridging Health Foundation in Pakistan and Jennifer Slepin from HepCareStream in the United States of America. This resulted in 25% increase in website views.

- **Hosted a booth at the first-ever NOhep Village at the GHS.** Over three days, we hosted an interactive booth which led to over 100 new sign-ups to NOhep and a 20% increase in sign-ups to the NOhep Visionaries Programme. It also provided an opportunity to inform delegates about NOhep and our key programmes. More than 160 delegates took part in the NOhep photo-booth.

- **Launched the NOhep Guide for Medical Professionals.** Medical Professionals are a core component of the NOhep Visionaries Programme and are critical in helping to bridge the gap between medicine and public health. To help expand medical professionals’ knowledge and provide the tools and resources needed to become a NOhep Medical Visionary, we developed a practical resource with the NOhep Visionaries Steering Group, a group of world-leading medical professionals. This NOhep Guide for Medical Professionals and complementary resources aims to equip and empower medical professionals to strengthen efforts that support the NOhep campaign and undertake activities that progress towards elimination. To date, 1,379 people have downloaded the resource.

- **Hosted a NOhep Visionaries panel-discussion at the GHS.** To support the launch of the NOhep Guide for Medical Visionaries, we convened a panel-discussion with members of our steering Committee. Moderated by Dr Su Wang and Dr Jordan Feld, this event centred on demonstrating the key principles of being a NOhep Medical Visionary. Dr Manel El-Sayed, Dr Heiner Wedemeyer and Dr Norah Terrault also provided real-life examples of the NOhep Principles and how they are moving beyond traditional approaches to meet the 2030 targets; from working with the media, to collaborating with patient groups and setting up peer to peer education amongst medical professionals. The event was a great success, attracting more than 50 people.

- **Increased NOhep engagement.** As a result of the NOhep Village and resource launches, this quarter has seen a big increase in audience numbers and online engagement. Over the last quarter, we increased sign ups by 9% and increased website views by 87%. Online, we increased engagement on Twitter by 24%.

### Challenges

- Footfall through the NOhep Village was lower than expected, which impacted the number of sign-ups to the Quest to Find the Missing Millions, however those who visited the booth fully engaged with the Quest and were keen to stay updated about the campaign. We also used other methods like social media and email marketing to encourage sign-ups.
NOhep Village at Global Hepatitis Summit

The NOhep Village was an interactive civil society space organised by WHA at the 16th ISVHLD Global Hepatitis Summit (GHS), which took place in Toronto on 14 – 17 June 2018. It included civil society exhibition stands, networking spaces and an area for presentations, videos and panel discussions. The objective of the NOhep Village is to foster networking and collaborative learning between patient groups and the scientific community, to create a greater and better connected community of advocates.

Highlights

- The Village bought together 21 civil society organisations from 10 different countries, including 10 WHA members, to share their experiences with each other and the Summit delegates. Our “NOhep Villagers”, who hailed from countries including Canada, India, New Zealand, Pakistan, Uganda, United States and more, were able to profile their activities and share their experiences through vibrant and informative exhibition stands and a packed three-day programme of presentations, lightening talks and panel discussions. Importantly the event was also a forum for patient stories to be shared, ensuring that the people living with viral hepatitis were at the heart of the Village. On Saturday 16 June, we hosted the NOhep Advocacy Day which was open to the general public to attend for free, further expanding the reach of the Village. A report on the NOhep Village will be released in early August.
- Excellent opportunity for networking and collaborative learning. Feedback on the NOhep Village highlights that the event provided WHA member organisations and civil society groups with excellent opportunities for networking and partnerships, with both the scientific community and other civil society organisations. The majority of civil society representatives in attendance (74%) said this aspect of the event was ‘good’ or ‘very good’. Additionally, collaborative learning was consistently identified as a highlight of the event and, as a result, the programmatic content at the Village was rated most positively with an average score of 4.5 (where 1 is poor and 5 is very good). Overall, 78% of exhibitors rated the NOhep Village either ‘good’ or ‘very good’ and comments indicate that many organisations found the event useful and a positive experience that will have a direct impact on their work.
- Delivered speech at GHS opening ceremony. WHA Board Member for the Americas Region Su Wang highlighted the role of patients and the community in the global hepatitis response in the GHS opening ceremony. Su delivered an inspiring talk, sharing her own personal experiences living with hepatitis B while emphasising the global burden of viral hepatitis. In her speech, Su also introduced the NOhep Village and encouraged delegates to attend the Village in order to learn more about the work of the civil society groups exhibiting and to participate in the Launch of the Quest to Find the Missing Millions. Through the launch event, the NOhep Village programme and through video screenings. These efforts ensured that the NOhep Village and encouraged delegates to attend the Village in order to learn more about the work of the civil society groups exhibiting and to participate in the Launch of the Quest to Find the Missing Millions. Through the launch event, the NOhep Village programme and through video screenings. Additional patient testimonials were also shared throughout the NOhep Village programme and through video screenings.
- Broadcasted the event. Civil society organisations also took the initiative to enlist technology to extend the reach of their voices, and many of the NOhep Villagers filmed their sessions to bring learnings to a wider audience. This proved very successful and live streams and videos of NOhep Village sessions had amassed over 100 views just days after the conference.
- The role of WHA members in the hepatitis response was further promoted in activities to launch the Quest to Find the Missing Millions. Through the launch event, the online hub and collateral handed out at the event, 5 innovative screening activities were profiled as case studies and four patient testimonials were shared. Additional patient testimonials were also shared throughout the NOhep Village programme and through video screenings.
- This visibility cemented the importance of advocacy in a new audience and these comments were echoed by visitors to the booths, who opened recognised the vital role of advocates and the affected community in the hepatitis response.

The NOhep Villagers gather at the NOhep Village at the Global Hepatitis Summit

WHA and NOhep booths at the Global Hepatitis Summit

Social media analytics show that WHA, NOhep and the NOhep Villagers dominated online conversations. These efforts ensured that the voice of civil society and people living with viral hepatitis was heard among a traditionally medical professional delegation. NOhep was visible in almost every #GHS2018 post on Instagram and #NOhep was included in 65% of tweets to #GHS2018. During the event, WHA gained 59 new Twitter followers and received over 1,700 profile visits.
Financing for Hepatitis

According to the mid-way review of the Global Health Sector Strategy on viral hepatitis, presented at the World Health Assembly in May, only 82 countries reported that they had viral hepatitis plans in place and of these, only 35% reported dedicated funding for such plans. A lack of financing strategic planning is clearly preventing the implementation of those plans. In the absence of large external donor funding, there is consequently a high risk that the strategies will not be effectively implemented, jeopardising the global goal of elimination of hepatitis B and C by 2030. We are working with the governments of two pilot countries, Nigeria and Colombia, to cost their entire hepatitis C programme in budgetary terms, develop a business case to support the required investment and then produce a range of options for financing the investment.

Nigeria: The work in Nigeria is being conducted in partnership with the Clinton Health Access Initiative (CHAI).

• The final report setting out the process undertaken in Nigeria and the outcomes was drafted by CHAI and is undergoing minor edits.
• WHA have held initial discussions around an advocacy strategy with its national members with work ongoing to build a comprehensive implementation plan for the remainder of 2018.

Colombia: The work in Colombia is being conducted in partnership with the Center for Disease Analysis Foundation and the Pan American Health Organization.

• The Colombian Ministry of Health is still reviewing the final report. Once finalised the report will be published on the National Viral Hepatitis Programme Financing Strategy Template website and disseminated through our communication channels.

Challenges

• Four exhibitors that had been invited to attend on a funded basis were refused visas to visit Canada. This has been an obstacle to having global representation at the NOhep Village.
• As a feature of the exhibition space the delegates who came into the hall did engage with the Village, often speaking with multiple Villagers. However, footfall into the exhibition hall, and subsequently the NOhep Village was lower than expected. This was caused by wider factors, including the location of the hall. To address this we worked with the GHS organisers to devise a strategy to encourage delegates to visit the exhibition hall with results seen on the day.

Due to issues with internet connectivity in Nigeria, it has not always been possible to have group calls with the members there. We are overcoming this challenge by carrying out much of the discussion and consultation process via email or one-to-one phone call.

Highlights

Nigeria: The work in Nigeria is being conducted in partnership with the Clinton Health Access Initiative (CHAI).

• The final report setting out the process undertaken in Nigeria and the outcomes was drafted by CHAI and is undergoing minor edits.
• WHA have held initial discussions around an advocacy strategy with its national members with work ongoing to build a comprehensive implementation plan for the remainder of 2018.

Colombia: The work in Colombia is being conducted in partnership with the Center for Disease Analysis Foundation and the Pan American Health Organization.

• The Colombian Ministry of Health is still reviewing the final report. Once finalised the report will be published on the National Viral Hepatitis Programme Financing Strategy Template website and disseminated through our communication channels.

Challenges

• Due to issues with internet connectivity in Nigeria, it has not always been possible to have group calls with the members there. We are overcoming this challenge by carrying out much of the discussion and consultation process via email or one-to-one phone call.

The NOhep Village at the Global Hepatitis Summit featured exhibition booths from 20 organisations and presentations from civil society organisations.
This quarter we continued to actively work together with important partners sharing our commitment to advance the hepatitis response.

**CENTER FOR DISEASE ANALYSIS**

We partnered with the Centre for Disease Analysis on the World Hepatitis Day campaign. The CDA provided us with global and national diagnosis estimates which we have used to develop messages for the campaign and on our microsite. If you'd like to find out more, you can access our World Hepatitis Day Campaign Toolkit [here](#).

**MASTERCARD**

In conjunction with MasterCard, Gilead and Ferozsons Laboratories Limited, the World Hepatitis Alliance is implementing a pilot project in Pakistan which gives low-income patients access to hepatitis C treatment through the use of the MasterCard Aid Network. WHA member, the Gujranwala Liver Foundation, was the first local Pakistani NGO to implement the pilot project and currently have over 100 patients enrolled. This quarter The Health Foundation, another WHA member in Pakistan, also started enrolling patients further widening the reach of the pilot. WHA continues to liaise with all stakeholders involved in the project.

**WORLD HEALTH ORGANIZATION**

This quarter we have continued to work closely with WHO, both with the Global Hepatitis Programme in Geneva and regional focal points. To that end, we continue to financially support two key posts at WHO EURO and WHO AFRO.
Over the three days, we attended a number of events and meetings including Coalition Plus’ side meeting on screening for HCV, where we presented on the Find the Missing Millions programme. We also attended ELPA’s side meeting on advocacy and presented about World Hepatitis Day 2018 at their annual general meeting. We also participated in a number of other events including the EASL Foundation meeting and the ICE-HBV Stakeholders’ forum. We also had the opportunity to speak at the ILC opening ceremony and address an audience of over 10,000 delegates on the importance of diagnosis.

We participated in the first meeting of the Lancet Commission on Liver Disease in Europe. Organised by EASL, the Commission will be chaired by Professors Michael Manns and Patrizia Burra and will have a wide ranging remit with a particular focus on areas related to liver disease. The Commission is set to be released late 2018 – early 2019. WHA has been assigned to three workgroups: Burden and Prevention Policy; Stigma, Human Rights and Patients’ Voice; and Educational Framework to Support Standards.
**71st World Health Assembly: Geneva, Switzerland: 21 – 23 May**

We had the opportunity to make an intervention on the importance of including viral hepatitis within the Universal Health Coverage package. Member States discussed the WHO thirteenth general programme of work 2019–2023, which includes viral hepatitis although at a minor level. As such, WHA President Michael Ninburg used this opportunity to underscore the voice of people living with hepatitis and highlight how tackling hepatitis would have wider benefits on healthcare systems.

**Health is indeed a human right. And access to healthcare should be universal. […] Including viral hepatitis services in UHC means reducing deaths related to liver cancer and cirrhosis. It means addressing health disparities and promoting health equity. It means directly contributing to the vision of ensuring healthy lives and promoting well-being for all.**

Michael Ninburg
President of the World Hepatitis Alliance

#WHA71

WHA President Michael Ninburg made an intervention on the need to include viral hepatitis services in Universal Health Coverage.

**National Action Towards the Elimination of STIs and Viral Hepatitis in the Caribbean: A Sub-regional Meeting: Port of Spain, Trinidad: 23 May**

We were invited to attend the first-ever Caribbean sub-regional meeting on hepatitis in Trinidad. The two-day meeting was attended by representatives from the Ministries of Health from Antigua and Barbuda, Bahamas, Belize, Dominica, Dominican Republic, Grenada, Guyana, Haiti, Jamaica, Monserrat, St Kitts & Nevis, St Lucia, St Vincent’s and the Grenadines, Suriname and Trinidad & Tobago. To date little has been done in the region to address hepatitis, there is widespread routine vaccination with some countries also implementing the birth dose vaccination, but beyond this there is little to no testing and treatment of viral hepatitis. Furthermore, in nearly every country there is no access to DNA/RNA tests and there is limited civil society presence in the region. As such, WHA attended as the only civil society representative with the objective of stressing the important role that advocacy and civil society has to play if we are to reach elimination. The meeting concluded with all countries presenting ambitious plans for what they would like to achieve in the next 1-2 years. PAHO will play a role in supporting them in that.

**The Science of HBV Cure: Singapore, Malaysia: 8 – 9 June**

Running as a parallel programme to the Singapore Hepatology Conference, the Science of HBV Cure event brought together clinicians, civil society and public health experts to discuss strategies and mechanisms that may lead to a cure and how current and future therapies are likely to achieve this. WHA Board Member for the Western Pacific Region Dee Lee attended the two-day meeting to highlight the role of the patient in the search for a cure.

WHA Board Member Dee Lee presents at the Science of HBV Cure meeting.
Organisational updates

In June 2018 the Board approved one new organisation for membership of WHA. The new member organisation is based in Nigeria. With this new addition, WHA has 259 members in 86 countries.

- **Women in Hepatitis Africa (WIHA) (Nigeria)** – WIHA focuses on helping women living with viral hepatitis to access care through government designated treatment centres in Lagos and Nassarawa State. WIHA also trains and empowers women to become advocates. By instilling knowledge and confidence, they become “Women Leaders in Hepatitis”, carrying out advocacy and awareness-raising activities and working towards WIHA’s elimination agenda.

New members

WHA takes your personal data very seriously. That’s why anything you share with us, from contact details to more sensitive information, is treated with the utmost care and robustly protected. In keeping with recent GDPR legislation changes, we’ve updated our privacy notice to better communicate how we handle your personal data. Click [here](#) to read our new privacy policy in full.

Data protection

WHA Head of Communications steps down

After nearly three very exciting years, this quarter we sadly say goodbye to Tara Farrell, Head of Communications. During her time at WHA, Tara has brilliantly led our communication strategies and has been instrumental in creating and launching NOhep. Tara has been a very valuable and respected member of the team. We will miss her professionalism, enthusiasm, optimism and great sense of humour.
UK and mailing address:
1, Baden Place
London
SE1 1YW
UK

Swiss address:
86bis, route de Frontenex
Case Postale 6364
1211 Genève 6
Switzerland

Telephone: +41 (0) 22 518 06 16
Email: Contact@worldhepatitisalliance.org

www.worldhepatitisalliance.org