Dear Partners,

We have reached the end of the first quarter of 2018 and what a busy few months it has been. As more countries join the race to eliminate viral hepatitis by 2030, we’ve been charging ahead raising awareness, influencing policy and building the capacity of our 258 member organisations.

One of my stand-out moments of this quarter has to be the launch of the World Hepatitis Day 2018 campaign. The Find the Missing Millions campaign, which supports our organisation’s focus to increase diagnosis and linkage to care, calls on all individuals and organisations to take action to find the 300 million people unaware that they are living with viral hepatitis.

Recognising that there are many reasons why so many people live with viral hepatitis without knowing, we also launched a global survey to understand the main barriers to diagnosing hepatitis B and hepatitis C. The feedback was incredible with responses from over 100 countries. This data will be the basis of our global stakeholder consultation, which will further explore the role people living with viral hepatitis can play in overcoming the barriers to diagnosis. Key recommendations will be captured in a white paper due to launch on World Hepatitis Day, 28 July.

Harnessing the power of people living with viral hepatitis always remains at the heart of our work and as such, this quarter we gave the patient voice a platform through our #StigmaStops campaign. Launched on Zero Discrimination Day, this awareness-raising campaign highlighted the impact of stigma on the lives of people living with viral hepatitis and provided a space for people to speak out and share their stories of stigma and discrimination. We are delighted to see so many of our members using the campaign in their own countries.

Supporting our members at a national level is pivotal to our strategy. This quarter, we travelled to Nigeria and held a workshop on financing with our member organisations and the Ministry of Health. Similarly, we supported our members in Germany in engaging the Ministry of Health ahead of World Hepatitis Day and coordinated our annual capacity building member webinar.

We also strengthened and forged new partnerships this quarter. We participated at the WHO-led civil society meeting on Universal Health Coverage, co-sponsored a side event on hepatitis C and drug use at the Commission on Narcotic Drugs, and supported MasterCard roll out their treatment plan in Pakistan. Underpinning all of our activities this quarter is our focus on building momentum towards the elimination of viral hepatitis. This is especially critical given only a handful of countries are on track to reach the 2030 goals. In that vein, we continue to support and grow the NOhep movement. Over the last three months, we brought our NOhep Visionaries Programme for Medical Professionals to the Asia-Pacific region, mobilised our supporters through online activities and started work on organising the NOhep Village at the Global Hepatitis Summit in Toronto, Canada.

2018 is set to be a busy year, which is exactly why we must work together, forge new partnerships and collaborate in order to maximise on resources, reduce inefficiencies and make real progress towards finding the missing millions.

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

Karine Belondrade,
COO/Acting CEO

Stay up-to-date with our activities, sign up to hepVoice here.
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.

**Highlights**

- Global survey launched to understand barriers to diagnosis and the populations most affected. With over 500 responses from over 100 countries, this was the first survey that addressed the topic on a truly global scale and which asked such a broad range of stakeholders for their opinions.
- Invites sent for a two-day global stakeholder consultation meeting in London. This will use the survey findings as a base to explore the role that people living with viral hepatitis have in overcoming the barriers to diagnosis.
- Find the Missing Millions named as the WHD2018 campaign.

**Challenges**

- Obtaining a good response rate to the online survey was always going to be a challenge as these are often quite low. To overcome this we implemented a robust marketing and communications plan that was designed to both encourage people to respond and also share the survey with their networks to increase the number of people we were reaching. To further increase the response rate we also extended the deadline for the survey.

Find the Missing Millions named as the WHD2018 campaign.
World Hepatitis Day (WHD) takes place every year on 28 July to raise awareness of the global burden of viral hepatitis and to influence real change. Under the theme of Eliminate Hepatitis, we launched this year’s WHD campaign called Find the Missing Millions. Find the Missing Millions aims to raise awareness of viral hepatitis, increase testing both at individual and policy level and support linkage to care.

**Highlights**

- Launched the WHD2018 campaign called Find the Missing Millions. The launch included a new WHD microsite within the World Hepatitis Alliance (WHA) website and over 400 campaign materials including posters, social media graphics, merchandise designs and a campaign toolkit. This is the largest number of resources we have ever produced for WHD.

- Worked to ensure that the campaign was as globally representative as possible, running a global consultation with our memberships, sourcing models from a wide range of ethnicities and using more regional data in our key message development. We hope that this will encourage uptake of the campaign and make it suitable for audiences across the globe. A customisable poster tool is also available to allow groups to adapt the campaign to their local priorities.

- The campaign strapline Find the missing millions is idiomatic in English which resulted in some difficulties in translation. To overcome this, we worked closely with our translation agency, as well as native speakers from our board and membership, to ensure the agreed translations were as accurate and effective as possible.

- Initially we had hoped to profile specific at-risk groups with the campaign and include diagnosis data for these groups in our key messages. Due to limited data available, we were unable to provide such specific messaging but for the first time, we have included regional data in key messages. Country data on diagnosis will be available from the Find the Missing Millions webpage from 14 June and we encourage participants to include national and regional data in their campaigns.

**Challenges**

- Implementation of our NOhep community page was delayed due to a technical fault. It is now available on the website.

- Uncertainty around the programming for APASL meant that we were unable to organise a NOhep booth.

- Mitigating algorithm changes on Facebook has been a challenge for us. We have initiated a strategy to combat this which in turn has improved our Facebook engagement rates.

**NOhep**

NOhep is a global movement aimed at uniting all stakeholders to eliminate viral hepatitis by 2030. The main objectives for Q1 were to expand the NOhep Visionaries Programme for Medical Professionals, build awareness online and support in-country awareness raising activities.

**Highlights**

- Increased sign-ups by 10%.

- Increased engagement on Facebook by 55%.

- Secured endorsement from eight leading healthcare professionals in the Asia Pacific region.

- Partnered with CEVHAP to launch the NOhep Visionaries Programme for Medical Professionals at APASL. This led to a 12% increase in sign-ups to the programme.

- Initiated the development of a NOhep Guide for Medical professionals, which included interviews with 20 NOhep Visionary Medical professionals i.e. The NOhep Medical Professionals Steering Group. The Guide will support healthcare professionals in advocacy activities. It will be launched at the Global Hepatitis Summit in June.

- Initiated the development of the NOhep Advocacy Toolkit. A framework was shared with members of the NOhep Working Group and a global taskforce of advocacy specialists. The Toolkit will be launched in May to coincide with the World Health Assembly.

- Launched the community page on the NOhep website.

**Challenges**

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Examples of the World Hepatitis Day 2018 posters for the Find the Missing Millions campaign
NOhep Village at Global Hepatitis Summit

The NOhep Village is an interactive civil society space which we are organising at the 16th ISVHLD Global Hepatitis Summit (GHS), taking place in Toronto on 14 – 17 June 2018. It will include 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**

- Publicly announced the NOhep Village and our role in convening civil society groups at the GHS.
- Received a large number of high-quality applications to exhibit in the Village from civil society organisations across all six WHO regions.
- Confirmed six funded and a number of self-funded exhibitors for the Village, with at least one exhibitor from each WHO region.
- Secured speaking slots for civil society in the opening plenary and parallel sessions.
- Secured a reduced registration fee for WHA members and civil society.

**Challenges**

- Agreement on the design of the Village was delayed due to budget limitations, this is now close to being confirmed.

NOhep Village is an interactive civil society space which we are organising at the Global Hepatitis Summit

Strengthening the Patient Voice

#StigmaStops is a social media campaign aimed at highlighting the true impact of stigma, dispel myths that perpetuate stigma and encourage people living with viral hepatitis to share their experiences. It was developed using results from our Holding Governments Accountable report and was launched on Zero Discrimination Day (1 March 2018).

**Highlights**

- Full suite of materials created including posters and social media graphics. Since the campaign launch, the materials have been downloaded 257 times.
- Encouraged participants to share a photo of their hand with the hashtag #StigmaStops and the type of stigma they have experienced. Nearly a hundred photos were received and WHA compiled a video call to action with the submissions. Since the video launched on 1 March, it has been viewed 9,210 times.
- Directed people to the Holding Governments Accountable report to learn more. Since the campaign’s launch, the report has had a 50% increase in downloads.
- Produced an article encouraging participation in the campaign that featured on HepMag’s site and a blog exploring the issues around stigma and discrimination that was published by the Hepatology, Medicine and Policy (HMAP) Journal. The article on HMAP received 350 views.
- Sparked additional campaigns amongst our memberships. Hepatitis Victoria ran a media campaign, published infographics, videos and a podcast series. We also received strong support from the Hep B Foundation, Hepatitis Queensland and APAHE.
- Over a month period, the hashtag #StigmaStops was used 433 times across Twitter, Facebook and Instagram. The hashtag was also picked up by eminent organisations including the British Embassy to Belarus and the Ministry of Foreign Affairs of Denmark.
- Encourage people to share their experiences of stigma on our Wall of Stories. Three stories were added to the platform.

**Challenges**

- It can be very difficult to get people to share their personal experiences, as the limited number of submissions to the Wall of Stories proves.
- Some people who submitted photos requested that they remain anonymous, which impacted how much their submissions could be included in the video or in social media posts.

WHA Members’ Webinar

The first in our 2018 webinar series designed around capacity building for our members was delivered this quarter. The WHA team discussed the organisation’s vision for 2018 and highlighted key activities to promote better engagement, collaboration with members and a greater impact on the ground.
FINANCING FOR HEPATITIS

Many countries now have or are developing national hepatitis strategies. However, they are rarely accompanied by a well-developed plan for financing the strategies. 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).

• Investment case completed.
• Interviews with key stakeholders from both the public and private sectors held to discuss financing options for the hepatitis C programme.
• Consensus meeting held with WHA members and the hepatitis desk officer at the Nigerian Federal Ministry of Health to discuss the financing recommendations.
• The outcomes of the consensus meeting were:
  • A multi-disciplinary stakeholder committee was created with CHAI, WHA members and the hepatitis desk officer at the Federal Ministry of Health to discuss next steps in regards to taking the financing recommendations forward.
  • WHA members and WHA London office team will work together to build an advocacy strategy around key recommendations.

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

• Following the completion of the investment case at the end of 2017 and the presentation of key findings of the World Hepatitis Summit by the Colombian Ministry of Health, the final report was sent to the Colombian Ministry of Health for their approval.

CHILE:

• Following the investment case work in Colombia, we were asked by the Pan American Health Organization and the Chilean Ministry of Health to act as an observer for the investment case on hepatitis C they are conducting in Chile. Two initial phone calls have been had to date to discuss the investment case and what is needed to start work on this. There will be a face to face meeting to further develop this work in the next quarter.

WHA members met for the consensus meeting in Abuja, Nigeria
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 Center 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. If you’d like to find out more, you can access our World Hepatitis Day Campaign Toolkit here.

**INTERNATIONAL DRUG POLICY CONSORTIUM**

WHA President, Michael Ninburg, was elected to serve on the Members’ Advisory Council (MAC) for the International Drug Policy Consortium (IDPC). In this role, he is able to emphasise the important connection between drug policy, harm reduction and viral hepatitis. In addition, WHA co-signed a letter to the WHO Director-General about questionable normative guidance related to the treatment of drug use disorders. We also co-sponsored a hepatitis C side event on 16 March at the 61st Session of the Coalition on Narcotic Drugs. Please see further details below.

**FÉDÉRATION ADDICTION, INTERNATIONAL DOCTORS FOR HEALTHIER DRUG POLICIES (IDHDP), INTERNATIONAL NETWORK FOR PEOPLE WHO USE DRUGS (INPUD) AND MÉDECINS DU MONDE (MdM)**

People who inject drugs are disproportionally affected by hepatitis B and C, and so without access to harm reduction services we cannot hope to eliminate viral hepatitis. To address this issue, we co-sponsored a side event on 16 March at the 61st Session of the Coalition on Narcotic Drugs with Fédération Addiction, International Doctors for Healthier Drug Policies (IDHDP), International Network for People who Use Drugs (INPUD) and Médecins du Monde (MdM). The side event discussed the global state of hepatitis C among people who use drugs and made recommendations to curb the epidemic. The side event received a high level of interest from government contacts but as it took place after the main programme had finished, many delegates had already left the conference, which hindered attendance. A blog summarising the event discussions is available here and you can watch a video recording from the event here.
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. This platform is a non-financial digital solution that helps facilitate the distribution and tracking of aid funds and is the first time the points-based network has been used in a healthcare context. The advantage of the MasterCard technology is that it enables donor funds to be used transparently while also tracking project outcomes, in this case the number of patients achieving SVR. In addressing these donor concerns it is intended that the outcome of the project will be a global shift in terms of donor interest. The pilot will conclude later in 2018.

Over the last couple of months 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.

As a member of the ACHIEVE (Associations Collaborating on Hepatitis to Immunize and Eliminate the Viruses in Europe), we co-signed a letter to the Romanian Minister of Health requesting that the government make viral hepatitis monitoring a priority during the Romanian Presidency of the Council of the European Union in the first half of 2019 and forge a political commitment from EU Member States to eliminate the disease. Efforts are being made to strengthen policies in Europe to coincide with a European Commission Staff Working Document which is being developed on hepatitis, HIV/AIDS, STDs and Tuberculosis to take stock and identify existing good practice. This will be published in July 2018.
ECDC Testing Guidance for HBV, HCV and HIV: Stockholm, Sweden: 5-7 February

We were invited to attend a meeting which reviewed European Centre for Disease Prevention and Control (ECDC)'s first-ever guidance on hepatitis testing. The two-day meeting was used to review the current draft and discuss the viability and impact of the recommendations. The main consensus from the meeting was that the current draft needs to be strengthened especially in regards to hepatitis B screening amongst pregnant women. WHA will be listed as an expert advisor in the final guidance.

ELPA University: Nicosia, Cyprus: 12 February

We were invited to lead a seminar at European Liver Patients’ Association (ELPA) University on the subject of stigma and successful campaigning. The interactive session helped build capacity among ELPA members (many of which are also WHA members), and in particular, emphasised the importance of collaboration, a cornerstone of WHA’s mission. We also used this opportunity to profile the Stigma Stops campaign and encouraged groups to think more strategically about their national campaigning activities. All attendees were asked to write their #StigmaStops message on their hands and photos were taken of each participant, which were used in the #StigmaStops video message on Zero Discrimination Day.
We participated at an event hosted by Wilton Park on the subject of injection drug use. The two-day event explored ways to diagnose, treat and engage people who inject drugs, in an effort to increase the number of people accessing hepatitis C treatment. Several examples of successful HCV-related initiatives were presented and discussed, including efforts in Ukraine, Georgia and India. HIV-related initiatives were also discussed. We emphasised the importance of integrating these services, especially in the absence of hepatitis-specific funding.

On 22 – 23 March, we joined civil society groups at WHO for a two day meeting on Universal Health Coverage (UHC). Entitled “Promote health, keep the world safe, serve the vulnerable: HIV, Viral Hepatitis, Tuberculosis, STIs and Universal Health Coverage”, the meeting encouraged different organisations to share their experiences of serving vulnerable populations and their views of the overall topic of UHC within their context. Along with a number of our members, we spoke on the subject of viral hepatitis and the fact that so many people living with the disease are often left behind in healthcare settings. Recognising that UHC cannot be achieved without the key contributions of civil society, the meeting explored ways to better engage and highlighted that siloes need to be broken down and that infectious diseases must be addressed at a horizontal level. A statement by Dr Tedros Adhanom Ghebreyesus was delivered stressing the importance of incorporating UHC in advocacy. It was also confirmed during the meeting that a viral hepatitis civil society working group is being created.

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Ministry of Health Germany: Berlin, Germany: 15 February

Our German member organisation, Deutsche Leberhilfe invited us to present at a high-level ministerial meeting on the subject of World Hepatitis Day 2018. The meeting convened a wide range of stakeholders involved in the hepatitis response to discuss the various ways they could work together to celebrate World Hepatitis Day. Stakeholders included ministerial representatives from the Department of Health and the Department of Justice, dentistry and pharmacy representatives along with members of harm reduction and HIV/AIDS organisations. The meeting concluded with the Ministry offering their support for World Hepatitis Day and an acknowledgment that collaboration is key to accelerate the response.

WHA President Michael Ninburg and NOhep Visionaries Prof Rosmawati (left) and Dr Khin (right).
Organisational updates

In March 2018 the Board approved four new organisations for non-voting membership. These members come from the AFRO and EMRO regions of Nigeria, Cameroon, Uganda and Pakistan. Sadly, we also lost Canadian organisation Let’s Find a Way and the Danish organisation Dansk Hepatitis Forening who have both ceased operating. As we no longer have a member presence in Denmark this means we now have 258 members spanning across 86 countries (121 voting members and 137 non-voting members).

• Back To The Life (Pakistan) - their primary objective is to eliminate hepatitis in the Balochistan area of Pakistan through awareness and blood screenings across schools, colleges, universities and remote areas.
• Global Forum for the Defence of the Less Privileged, GFDLP (Cameroon) – are actively working in the field of viral hepatitis conducting screenings across orphanages and marginalised border areas and ports of entry.
• Trinity Healthcare (Nigeria) – they aim to raise public awareness about viral hepatitis and to provide ‘humanitarian services’ to those living with hepatitis B and C.
• Save Your Liver Foundation (Uganda) – Board Member Kenneth Kabagambe also sits on the board of this organisation who are proactive in their awareness raising activities.

New members

• This quarter we say goodbye to Paul Taylor, WHA Event Director. Paul has been instrumental in making our second World Hepatitis Summit in Sao Paulo such a huge success. Paul was an integral part of our team and he will be missed.
• Our Communications and Campaign Intern Henry Arnold successfully completed his 6-month internship with us in March. We thank him for all his hard work and wish him the very best for the future.
• This quarter we welcomed Isabel Bull who will take over from Henry as Communications & Campaigns Intern for the next six months. Isabel is studying for a Master’s in Political Communications at Goldsmith’s University.
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