Quarterly Progress Report
April - June 2019
Welcome to our quarter two progress report. This was my first quarter as CEO of the World Hepatitis Alliance and this report is a reflection of how enjoyable a time it has been so far. I joined the organisation just before the International Liver Conference (EASL) in April. In Vienna I had the opportunity to meet with partners, NOhep Visionaries and WHA members and get my first taste of the organisation. Over the past few months, it has struck me how highly WHA is regarded by our partners, stakeholders and members and I look forward to building on the amazing work of the organisation.

Quarter two saw us launch our World Hepatitis Day campaign, with a new film made to highlight the importance of finding the missing millions. We also released new materials to raise awareness. These tools have been made available in multiple languages so that we can reach as many people as possible with our campaign. We look forward to reporting on the success of that in the next quarterly report.

This quarter the Alliance launched the Find the Missing Millions online advocacy resource. This unique new online tool empowers civil society with the knowledge and skills to advocate for an upscaling of diagnosis and testing. The resource features case studies from WHA members who are successfully implementing programmes that address the barriers to diagnosis.

In May we announced the five members working with WHA on the in-country advocacy programme. We will now start to work with them on plans to address the barriers to diagnosis in their countries and look forward to reporting on their progress over the coming months.

I hope you enjoy reading this report about what we have been working on. Please feel free to get in touch if you have any comments or questions about our work.

Cary James, 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 have only marginal success.

Find the Missing Millions is a multi-year programme aimed at raising awareness, driving policy change and increasing testing at national and global levels. Recognising that barriers to diagnosis must be understood and overcome to reach our objectives, the programme takes a multifaceted approach to the issue. It is building the evidence base, engaging with a range of stakeholders and helping 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.

The five programme participants were confirmed, they are:
- Charles Among Adjei, Hepatitis Alliance of Ghana.
- Zunaid Paiker, National Liver Foundation of Bangladesh.
- Anahit Harutyunyan, Positive People Armenian Network Social NGO, Armenia.
- Caroline Thomas, Yayasan Koalisi Satu Hati, Indonesia.
- Shelly-Ann Myrie, Caribbean Hepatitis C Alliance, Jamaica.

Planning continues for the kick-off meeting which will be a face to face meeting in London on the 10 and 11 July. It will bring together the successful applicants for the first time alongside global experts, Dr Naranbaatar Dashdorj, Co-Founder and Chairman of the Board - Onom Foundation, Mongolia; Rachel Halford, Chief Executive Officer of the Hepatitis C Trust, UK; Giten Khwairakpam, Community and Policy Program Manager at amfAR’s TREAT Asia programme, Thailand; Dr John Ward, Director, Coalition for Global Hepatitis Elimination, The Task Force for Global Health, USA; and Michael Ninburg, Executive Director of the Hepatitis Education Project and President of the World Hepatitis Alliance, USA.

The purpose of the meeting is to help the programme participants determine the barrier/s to diagnosis that they can have the greatest impact on and start to develop advocacy strategies which address that barrier.

The advocacy resource builds on the findings of our White Paper and gives practical tips on how civil society and the affected community can implement the recommendations set out in the White Paper.

The FMM advocacy resource was launched at the African Hepatitis Summit on the 20 June.
- The resource was launched as part of a workshop developed and led by WHA which featured a panel discussion with representatives from FIND, CHAI and MPP. The purpose of this was to upskill members and other participants on issues around diagnostics, access to medicines and service delivery. This was received very well with an audience of over 120 people, and a large number of comments and questions from the audience stimulating great discussions.
- The resource was launched with 11 case studies across 9 different countries, and included a mix of text and videos. We will continue to identify and publish further case studies.
- The advocacy resource was launched with a press release and social media support from key partners and influencers in viral hepatitis.

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- Some participants have experienced difficulty in obtaining a visa to join the meeting in London. Alternative arrangements are being made to ensure that they are still able to participate in the meeting.
HCV TESTING INITIATIVE

As part of the Find the Missing Millions programme we have partnered with InTec Products, an infectious disease diagnostics manufacturer, to distribute 25,000 point-of-care rapid tests for viral hepatitis C (HCV) to five World Hepatitis Alliance member organisations around the world. In providing these tests to WHA members we are increasing the scope of their screening campaigns and so helping to “Find the Missing Millions”.

HIGHLIGHTS

- Fundación Mexicana Para La Salud Hepática in Mexico, Spark of Hope in Ukraine and the Hepatitis C Trust in the UK are continuing their screening activities in a variety of settings.
- After the delay in receiving testing equipment and the inability to use them, United Against Hepatitis in Russia started to use their new equipment in April. Testing is being carried out at two mobile harm reduction units with people who inject drugs, people who use drugs and street sex workers. 291 tests have been carried out, 172 have been positive. All the HCV+ persons have been directed to the AIDS Center or the S.P.Botkin Clinical Infectious Diseases Hospital.

CHALLENGES

- In Mexico, there were plans to use 3,500 tests to conduct a screening campaign in a large public university but due to the delay in the tests arriving they were no longer able to do this as scheduled. They are now exploring other options and will use the tests on WHD.
- Testing is still ongoing and so we do not expect to report on this project until the fourth quarter of this year.

WORLD HEPATITIS DAY 2019

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 Find the Missing Millions campaign as the theme under the overarching theme of “Eliminate Hepatitis”. The campaign aims to raise awareness of viral hepatitis, increase testing and support linkage to care.

HIGHLIGHTS

- We launched the Find the Missing Millions film in three languages, open sourcing the film to allow campaign supporters to translate it into more languages.
- We launched posters and social media graphics for the global campaign and revamped the World Hepatitis Day website to include a global map of events.
- We launched a series of online masterclasses, lessons from WHA members who successfully undertook WHD activities in 2018, to enable the replication of activities.

CHALLENGES

- In previous years the WHD campaign has benefited from a social media tool called Thunderclap, this shut down last year and a suitable replacement has not emerged. Whilst we have found a new solution this is likely to have a significant impact on the social media numbers.
NOhep is the global movement aimed at uniting all stakeholders to eliminate viral hepatitis by 2030.

HIGHLIGHTS

• WHA hosted a NOhep Medical Visionaries breakfast reception at EASL to re-engage with those visionaries that have already signed up, especially members of the steering committee for the Medical Visionaries guide. The reception brought together 20 visionaries from more than 6 countries and featured presentations from Dr Norah Terrault and Dr Anna Lok on some of the actions they have taken to help drive elimination. This opened into a lively group discussion and highlighted that there is a need for these elimination stories to be shared. It also gave WHA the opportunity to talk about the future of the programme and start to engage with key stakeholders on this.
• NOhep held a stand at EASL, where we signed up over 100 new NOhep Medical Visionaries.
• The NOhep Google Doodle campaign continued, with 633 people signing up by end of June, with George Blumberg, son of Dr Baruch Blumberg, joining the campaign.

CHALLENGES

• Despite a lack of engagement from Google, the campaign has provided a positive focus for the NOhep community to unite behind a cause.

FINANCING FOR HEPATITIS

According to the preliminary review of the Global Health Sector Strategy on Viral Hepatitis, only 124 countries reported in 2019 that they had viral hepatitis plans in place (of which 44 were in draft). 2017 data suggests that only 58% of countries reported dedicated funding for these plans. A lack of strategic financing planning is clearly preventing the implementation of these 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 four countries, 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.

HIGHLIGHTS

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NIGERIA AND COLOMBIA:
The work in Nigeria is being conducted in partnership with the Clinton Health Access Initiative (CHAI). The work in Colombia is being conducted in partnership with the Center for Disease Analysis Foundation and the Pan American Health Organization.

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CHALLENGES

• Given the limited funding available in Nigeria for advocacy activities and the broad spread of our members, discussions are ongoing about the best way to use the investment case as an advocacy tool in Nigeria.

HIGHLIGHTS

• The African Hepatitis Summit in June gave us the opportunity to meet with a number of stakeholders from Nigeria, including our members, CHAI’s local team in Nigeria and representatives from Nigeria’s Federal Ministry of Health.
• The Ministry of Health in Colombia has prepared an article based on the investment case work and once published WHA will support the dissemination of this. In light of this article WHA will focus on producing an interim lessons learnt report to be shared with stakeholders shortly.

CHALLENGES

• Due to ministerial priorities the completion date for this project has been pushed to later this year.

HIGHLIGHTS

• The costing work in India Punjab State is ongoing and should finish early next quarter with the final pieces of work being undertaken to better understand the HR costs and private sector data. WHA members have inputted into this process.
• The investment case and discussions about the financing work in India Punjab State will take place early next quarter and as such the date for the report deliverable has been pushed back to August.
• The costing work in Cambodia has commenced and the model has been designed to ensure it aligns with the newly-developed National Strategic Plan.
• The investment case in Cambodia had already been completed by CDA in collaboration with WHO and so this work has been deprioritised but the new costing data can be made available to CDA so that the investment case can be updated.

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PARTNERSHIPS

This quarter we continued to work actively with important partners, sharing our commitment to advance the hepatitis response.

FOUNDATION FOR INNOVATIVE NEW DIAGNOSTICS (FIND)

Our partnership with FIND was formalised this quarter as we signed a Memorandum of Understanding at the International Liver Conference in April. The second teleconference for the active advisory group, which specifically looks at advocacy activities in the area of diagnosis, took place in May. Alongside WHA and FIND, Coalition Plus, Treatment Action Group (TAG) and Delhi Network of Positive People (DNP+) are members of this group and all updated on their activities. This opportunity to share updates is very useful and resulted in a further call with FIND where they fed into the diagnostic literacy section of the FMM advocacy resource.

WORLD HEALTH ORGANIZATION

WHA seconds hepatitis focal points (technical officers) to the European and African Regions to ensure their action plans can be effectively implemented. We have agreed a workplan with them that focuses on their continued support to Member States. This involves the provision of technical assistance to countries on strengthening viral hepatitis strategic information, on looking at ways to improve hepatitis prevention, testing, treatment and the care of people living with the disease, and on working with relevant civil society partners to advance the hepatitis response.

AFRO (DR OLOFUNMILAYO LESI)

The four main highlights for this quarter:
1. The organization and planning of the African Hepatitis Summit (Uganda, June 18-20, 2019) in collaboration with Government of Uganda and African Chapter of WHA.
2. Development of hepatitis status report in the region and the hepatitis score card.
3. In-Country hepatitis surveillance in Cameroon (Uganda, Tanzania were completed in first quarter).
4. Technical support to various other countries and workshops.

Key outputs:
• Technical support and Capacity building for hepatitis co-ordination and national surveillance in Uganda, Tanzania & Cameroon.
• Regional Hepatitis score card and progress report for the WHO Africa Region developed.
• Coordination, collaboration and participation at the African Hepatitis Summit (AHS).
• Technical assistance for the development of evidence-based policies and comprehensive guidelines and/or capacity building or information sharing.

Plans for Quarters three and four:
• Planning for high level regional advocacy event in collaboration with African Union (AU) and Africa CDC.
• Planning ongoing to collaborate with the Government of Egypt to support the hepatitis programme in 18 countries for the “Egypt presidential initiative for HCV treatment”.
• Surveillance mission to South Sudan, South Africa, Nigeria and Ethiopia.

EURO (DR ANTONS MOZALEVSKIS)

Quarter two highlights:
1. Supporting implementation of regional action plans on viral hepatitis:
   • Providing technical assistance to Croatia at the national conference and roundtable to finalize the national elimination strategy in May 2019, and to Ukraine on improving hepatitis strategic information through surveillance and monitoring and revision of the draft hepatitis surveillance guidelines.
   • Mobilizing political commitment and raising public awareness:
2. Participated in the launch of the Romanian Hepatitis Framework Action Plan, which was developed with the support of the WHO Regional Office in alignment with the Action Plan;
   • Coordinated development and preparation for the implementation of the WHO/Europe Member States Regional World Hepatitis Day 2019 campaign.
   • Coordinated the launch of the collation of good practice in the viral hepatitis response – to be published in a WHO/Europe report in October-November 2019.
3. Promoting regional partnership and collaboration in viral hepatitis response:
   • Ongoing close collaboration with ECDC through the inputs provided to the first EU hepatitis B and C monitoring report (to be published in October 2019).
   • Initiated designation of two new WHO Collaborating Centres on viral hepatitis (Georgia NCDC and Robert Koch Institute, Germany). This will increase and formalize collaboration with these institutions and support implementation of the WHO/Europe work plan on viral hepatitis.

Joint technical assistance to EU/EEA Member States are planned for quarters three and four of 2019.
EVENTS AND MEETINGS

INTERNATIONAL LIVER CONFERENCE (EASL, VIENNA, AUSTRIA)

WHA made our presence felt as we presented at the opening session, at the HBV forum and ICE-HBV press conference, and at the HCV in prisons session, with presentations from our President, President-Elect and European board member. We held a reception for 20 WHA members, which provided a great opportunity for new CEO Cary James and European board member Rachel to meet and talk with members. We recruited 130 new NOhep medical visionaries, and held a networking breakfast for existing visionaries to meet and exchange experience.

WORLD HEALTH ASSEMBLY (GENEVA, SWITZERLAND)

We attended the World Health Assembly and several side meetings on Universal Health Coverage and the role of civil society organisations. We met with WHO colleagues to discuss forthcoming collaborations and upcoming events. We also discussed collaborating with UNITE to provide opportunities for our members to engage with their parliamentarians, and for UNITE to expand their membership.

AFRICAN HEPATITIS SUMMIT (KAMPALA, UGANDA)

WHA co-ordinated two sessions at the first African Hepatitis Summit, and presented at the opening ceremony and a number of other sessions. We launched our Global Advocacy Resource at an interactive workshop for civil society.

RAK MICRO-ELIMINATION WORKSHOP (RAS AL KHAIMAH, UAE)

WHA presented on the importance of involving patients in elimination programmes, presenting best-practice examples and promoting our medical visionaries programme. We will also be participating in a further meeting in the region in September. We used the opportunity to explore the potential for a regional meeting of patient organisations to help kick-start elimination efforts.

HEPATITIS B PATIENT SUMMIT (WASHINGTON D.C, USA)

WHA presented at the hepatitis B patient summit held in Congress in Washington D.C. The community event was live-streamed on Facebook by the Hepatitis B Foundation. There were sessions on the hepatitis B pipeline for cure therapies, access to medication, patient involvement with clinical trials and stories from those living with hepatitis B.

MULTI-STAKEHOLDER HEARING IN PREPARATION FOR THE UNITED NATIONS GENERAL ASSEMBLY HIGH-LEVEL MEETING ON UHC (NEW YORK, USA)

WHA participated in the interactive multi-stakeholder hearing on Universal Health Coverage (UHC). The hearing is part of the preparatory process for the UN General Assembly high-level meeting on universal health coverage, which will take place on 23 September 2019 in New York.

WHERE WE ARE WORKING

ORGANISATIONAL UPDATE

Staffing

In April, WHA welcomed a new Chief Executive Officer, Cary James, who began his civil society career in the grassroots HIV movement in London. He went on to become Head of Health Improvement Programmes at the Terrence Higgins Trust (THT), one of Europe’s largest HIV and sexual health organisations. There he led HIV Prevention England – the official government funded national HIV prevention programme. He contributed to the establishment of the world’s first national HIV self-sampling programme as well developing a free online HIV self-test service.

He is the former chair of European [Hepatitis/HIV] Testing Week and is currently an advisory board member of INTEGRATE - a programme to integrate early diagnosis and linkage to prevention and care of viral hepatitis, HIV, TB and STIs in Europe; as well as other expert groups and strategic partnerships. He is also a faculty member of the European AIDS Clinical Society’s online HIV Clinical Management course, presenting the module on key populations.