We are pleased to present the quarter one report from the World Hepatitis Alliance (WHA) covering the period 1st January to 31st March 2019.

This has been a period of change for WHA as our long-term CEO, Raquel Peck, stepped down from the role at the end of the last quarter to take up ventures new, although she is still working with the Alliance as a Senior Advisor. The Alliance is delighted to welcome our new CEO, Cary James, who started with the organisation early in April and has begun working with the global board and the staff team to deliver the ambitious strategy that we have for 2019.

The WHA board met in March, in London to discuss the progress each region is making towards elimination. At this meeting, the board selected Dr Su Wang as President-elect to shadow me in my final year as President. Su has a long history of championing hepatitis B care in underserved populations and has been a strong advocate of expanding hepatitis B and C services to frontline providers. She is a well-respected leader in the field and has also been an integral part of developing our NOhep Medical Visionaries programme.

This period also saw us welcome ten new members to the Alliance, which now represents 276 organisations in 91 countries. Our collective voice has never been louder and we will use it to ensure that the elimination of hepatitis is made a reality. We hope you enjoy reading what we have been working on and look forward to continuing to communicate the impact we have.

Michael Ninburg, President

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

Launched a NOhep Google Doodle sub-campaign to feature Dr Barry Blumberg on WHD 2019.

Welcomed two new regional board members for EURO and PAHO, and two skills-based board members.

10 new member organisations, taking our total to 276 across 91 countries.

Delivered presentations on our Find the Missing Millions work in Romania, Georgia and Philippines.

Announced the appointment of Dr Su Wang as WHA President-Elect for 2019.

Launched our In-country advocacy programme.
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 a national and global level. 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

**PROJECTS**

**FIND THE MISSING MILLIONS**

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**

• After a delay in receiving the testing equipment, United Against Hepatitis in Russia unfortunately discovered that the tests had been damaged in transportation and could therefore not be used. However, the new equipment was received in March and they have begun their testing campaign.
• Spark of Hope in Ukraine began their testing in December. They conducted 938 rapid tests and plan to complete their testing campaign as part of World Hepatitis Day in July.

**CHALLENGES**

• The delays in the tests being delivered mean that we have had to extend project deadlines.

**IN-COUNTRY ADVOCACY PROGRAMME**

We were pleased to launch our In-country advocacy programme in February. Through this new programme, WHA will support five members from across the globe to take action to break the barriers to diagnosis.

Over 18 months, successful applicants will be supported to develop advocacy action plans that aim to increase diagnosis rates. In addition to receiving a small amount of seed funding to help initiate their activities, members will be invited to pool expertise and learn from leading experts working within the field. This will include a number of face to face meetings alongside regular chances to feedback and receive support from fellow members and other stakeholders.

**HIGHLIGHTS**

• We received an unprecedented number of applications for the programme, all of which were of a very high standard.
• Planning has begun for the kick-off meeting which will be a face to face meeting in London in July. It will bring together the successful applicants for the first time alongside relevant global stakeholders that will help enhance their strategies. In addition to peer to peer support, members will benefit from hearing from experts in the areas in which their advocacy action plans focus.

**CHALLENGES**

• Due to the high number of applications that we received for the programme, the assessment stage has taken longer than originally anticipated. We are currently undertaking a rigorous review process against the selection criteria and the programme’s objectives and we hope to announce the successful applicants in quarter two.
World Hepatitis Alliance Quarterly Progress Report: January-March 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 momentum of WHD 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, and support linkage to care.

HIGHLIGHTS

- New WHD materials have been generated, reflecting key target populations. A film has been produced which can be used by members to highlight the need for people to get tested. The film outlines what hepatitis is and the dangers of living with hepatitis unaware.

World Hepatitis Day 2019

WORLD Hepatitis Day 2019

Visit www.worldhepatitisday.org to see how you can get involved in World Hepatitis Day 2019

NOhep

NOhep is a global movement aimed at uniting all stakeholders to eliminate viral hepatitis by 2030.

HIGHLIGHTS

- NOhep launched its first sub-campaign encouraging people to sign a letter asking Google to celebrate WHD 2019 with a Google Doodle of Dr Barry Blumberg, the founder of the hepatitis B vaccine. 100 people signed the campaign within the first 24 hours.
- CEVHAP hosted the first NOhep Twitter takeover, using the platform to live tweet from the Public Health Forum at APASL.
- We organised a small NOhep Medical Visionaries breakfast reception at EASL. This was designed as an opportunity to reengage with our current NOhep Medical Visionaries ahead of the launch of the face-to-face element of the NOhep Medical Visionaries programme at AASLD later this year. Dr Norah Terrault, Dr Anna Lok and Dr Jordan Feld have all been invited to give a short presentation on some of their work towards elimination and the reception will be chaired by Dr Su Wang.

Join the NOhep Google Doodle campaign at nohep.org

This man prevented more cancer-related deaths than anyone else in history.

Let’s make him famous!
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), and 2017 data suggests that only 58% reported dedicated funding for these plans. A lack of financing strategic planning is clearly preventing the implementation of these plans. A lack of financing strategic 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.

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

**HIGHLIGHTS**

- Following the discussions with our members and wider civil society organisations at the Nigeria Hepatitis Summit, this quarter we confirmed a core group of 27 civil society organisations that wanted to partner with us to explore how to best advocate for financing at a State level.
- Of the 27 civil society organisations, 16 were not WHA members and so had not previously been made aware of the financing for viral hepatitis report in Nigeria. All have now received a copy of this to help build the evidence base for their advocacy. Furthermore they have also received information on how to apply for membership, with one new member already being accepted.
- At a State level this quarter has seen a number of exciting developments which have been driven by our members.
  - Grassroots Economic Empowerment Initiative (GREEIN) reported that the Akwa Ibom State government created a standalone desk officer for hepatitis.
  - Community Development Awareness and Health Empowerment Foundation (CDAHEF) and Movement Against TB, HIV/AIDS and Malaria in Nigeria (MATHAMAN) have had meetings with Oyo State Ministry of Health on viral hepatitis with further conversations to resume after the elections.
  - Hope Life Support and Empowerment Initiative helped to convene a stakeholders meeting on viral hepatitis in Plateau State. It was well attended with the commissioner on special duties to the government there, who will take the outcomes of the meeting to the governor.
  - CFID/CCT Taraba have secured funding from industry for healthcare worker training and testing in three states with the hope that the data from the testing will help to strengthen the advocacy in those states for government funded programmes.

**Challenges**

- Given the limited funding available for advocacy activities and the broad spread of our members, discussions are ongoing about the best way to move forward with this.

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

**HIGHLIGHTS**

- The Ministry of Health in Colombia is drafting 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 next quarter.

**India Punjab State and Cambodia:** The work in India Punjab State and Cambodia is being conducted in partnership with the Clinton Health Access Initiative (CHAI).

**HIGHLIGHTS**

- Building on the success of the work in Nigeria with CHAI we signed a contract with them to replicate this work in India Punjab State and Cambodia. These are two countries/states that are at very different stages in their response and so will provide two different and important case studies.
- Kick off meeting for India has taken place with the protocol for the costing work being agreed now.
- Initial discussions were had with CHAI regarding how to best integrate our members in India into the programme.
- Discussions in Cambodia regarding the work are ongoing since it is aligning with work being carried out to develop a national strategic plan, and work will begin shortly.

**Challenges**

- Due to competing priorities within the respective Ministries there has been some delay to the initial work plans but at this stage work is expected to finish on target at the end of July 2019.
PARTNERSHIPS

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

FOUNDATION FOR INNOVATIVE NEW DIAGNOSTICS (FIND)

We continued to refine discussions with FIND regarding partnership opportunities, leading to a memorandum of understanding which is under final review. WHA will be involved in an active advisory group looking at advocacy activities in the area of diagnosis. Alongside WHA and FIND, Coalition Plus, Treatment Action Group (TAG) and Delhi Network of Positive People (DNP+) form part of this group and the first call was held in March. This was an opportunity to share updates from each organisations activities and to explore potential areas of synergy.

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 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 main highlight for this quarter was the commencement of in-country hepatitis surveillance in Uganda (March 11 to 15), Tanzania and Zanzibar (March 29 to April 3). Each mission was associated with:

- Public health and clinical collaboration projects for quick assessment of hepatitis related liver disease and liver cancer evaluation at national tertiary centres to assess the burden of hepatitis sequelae (a condition which is the consequence of a previous disease or injury). These projects were commissioned four weeks prior to each mission and were presented during the national strategic information and surveillance capacity-building workshops below.
- Organising a national capacity-building workshop. Each workshop brought together about 30 stakeholders committed to hepatitis prevention and treatment from public and private sectors and included partners, NGOs and civil society.
- Reporting hepatitis surveillance onto the WHO Global Hepatitis Reporting System (GHRS).

The other main activity related to civil society collaboration is the ongoing planning of the upcoming African Hepatitis Summit (Uganda, June 18-20, 2019) in collaboration with Government of Uganda and African WHA members.

EURO (DR ANTONS MOZALEVSKIS)

- Supporting implementation of the regional action plan on viral hepatitis: provision of technical assistance at the Uzbekistan hepatitis elimination policy project advisory board; improving hepatitis surveillance and strategic information in Georgia; organising the hepatitis response assessment mission in Kosovo.
- Co-organising a regional workshop on HIV and viral hepatitis testing, and the first regional consultation on viral hepatitis.
- Mobilising political commitment and raising public awareness for the response to viral hepatitis, promoting an integrated and people-centred approach to the hepatitis response in Europe at the HepHIV 2019 conference in Bucharest.
- Promoting regional partnership and collaboration in viral hepatitis responses at the first Global Partners’ Meeting on Hepatitis, aimed at taking stock of the progress towards elimination and identifying new opportunities for collaboration.
EVENTS AND MEETINGS

LANCET COMMISSION MEETING

WHA President Michael Ninburg represents the patient voice at the Lancet European commission on viral hepatitis, focusing on stigma and discrimination.

GPRO INNOVATIVE FINANCING MECHANISM LAUNCH – UZBEKISTAN, JANUARY

This pilot will provide HCV and HBV testing and treatment which will be paid for by out of pocket patient payments at a reduced price, but with a small mark-up to provide free testing and treatment for those who can’t afford it.

WHA sits on the Program Advisory Board, and as the sole patient representative and civil society organisation at this meeting, raised ethical concerns about the patient payment model, leading to changes being made to the protocol.

HEPHIV 2019 BUCHAREST CONFERENCE – ROMANIA, JANUARY

WHA presented at a panel discussion on “How does the integration agenda support the elimination agenda?” stating our support for integrated programmes whilst emphasising that they must be designed for and in partnership with patients in order to be properly effective.

WHA’s Lancet comment piece on the involvement of civil society in the response to viral hepatitis elimination was quoted by Correlation European Harm Reduction Network in their presentation.

The conference highlighted that while the data on viral hepatitis is poor, it does show that the EU is not currently on track to reach elimination targets. The European Centre for Disease Prevention and Control will be reporting at ILC 2019 in Vienna on the preliminary results from their Hepatitis B and C monitoring system focussing on prevention, testing and treatment, with the full report to be launched in June.

Stigma and discrimination, and lack of harm reduction services were consistently raised as key barriers to diagnosis in Europe. The conference itself made little mention of Hepatitis B.

WHO EURO TECHNICAL MEETING – GEORGIA, FEBRUARY

WHA delivered a presentation on Find the Missing Millions, tracking and reporting of progress. A key part of the meeting was a stock-take of progress towards implementation of action plans within the region.

We input to discussions on countries’ progress towards the elimination targets, pushing for patient and service user involvement to be formalised in questionnaires and checklists issued by WHO. A draft report from responses provided to the EMCDDA monitoring system will be produced in June 2019 – information to date suggests that 27 countries have action plans, with a further 15 in development.

This meeting gave our regional board member the opportunity to engage with our new member from Georgia, and to discuss peer-to-peer work, engaging the hardest to reach people. It was also an opportunity for her to engage with ministers of health and their representatives from across the region.

APASL – MANILA, FEBRUARY

WHA presented on the FMM programme at the Public Health Forum. The presentation included the patient perspective on the current cascade of care in the Asia-Pacific region, including a video on the patient perspective from Dee Lee, our WPRO regional board member. We also participated in the planning for the Hep Free Asia Summit 2019.

Stigma and discrimination remains a significant problem in the region, with no clear approach to address this. A greater need to focus on hepatitis B was identified to respond to high burden levels in the region.

CLICK HERE TO WATCH DEE LEE’S VIDEO ADDRESS
WHO PARTNERS MEETING – GENEVA, FEBRUARY

This was the first meeting to be convened in five years, but subject to confirmation should become an annual meeting. It focused on how Viral Hepatitis fits into the context of Universal Health Coverage (UHC). As part of the Civil Society Engagement Mechanism (CSEM), civil society organisations will need to promote UHC as a unified approach, addressing the difficulties and challenges it presents.

Once endorsement for the approach is gained, more specific angles and asks can be presented. It will be important to demonstrate the potential for high impact of policies such as including viral hepatitis into existing screening programmes.

The need to put forward a civil society manifesto was discussed, to include data on the scale of the epidemic, how much it will cost to reach the targets, and negotiating prices on behalf of multiple countries.

COALITION PLUS MEETING ON VIRAL HEPATITIS CIVIL SOCIETY STRATEGY – GENEVA, MARCH

We attended this meeting with partners working in hepatitis to discuss synergies between civil society organisations and how we can best work together. As the only stakeholder present which has worked on both hepatitis B and C globally, we presented on the progress made on hepatitis B and C elimination over the past decade, as well as the challenges we still face.

Discussions were held on developing collaborative work focussed on micro-actions, taking a broader approach than micro-elimination.

The group decided to look at global pressure points for trying to develop political will and exploring the development of a country-level blueprint to develop national political will.
ORGANISATIONAL UPDATE

MEMBERSHIP

In March, the Board approved ten new organisations for membership. All ten are non-voting members and two were from countries where WHA previously had no member presence (Zimbabwe and Jamaica). The remaining members came from Iran, Nigeria and Ghana. This means we now have 276 members spanning across 91 countries (123 voting members and 153 non-voting members).

- Charitable Fund ‘Humanitarian Action’ (Russia) - testing for hepatitis is a regular occurrence for them and they are committed to primary prevention by disseminating information on HBV and HCV through lectures, leaflets and other media.
- Community Development Awareness and Health Empowerment Foundation (CDAHEF – Nigeria) - the organisation focuses on community self-help projects with a particular emphasis on hepatitis.
- Hepatitis Alliance of Ghana (Ghana) - their mission is to decrease incidents of new infection of viral hepatitis and to generally improve the life of those individuals affected by the disease in Ghana through education and follow-up care.
- United Way Mumbai (India) - their hepatitis-related work is channelled through various projects, namely their Yuvroshni, Pahal and SEHAT projects.
- Seed The Change (New Zealand) – the organisation includes ‘Hep C Action Aotearoa’, a patient advocacy group, formed specifically to provide a patient voice to the elimination campaign of hep C in Aotearoa by 2025 - five years ahead of the WHO target.
- Siddiqui Foundation (Pakistan) - their main activities include setting up free hepatitis screening camps. They have discovered that for every 100 individuals screened, 16 to 20 are found to have been infected.
- Hepatitis Zimbabwe Trust (Zimbabwe) – working to raise the profile of hepatitis on the health agenda of Zimbabwe as the only hepatitis-focused NGO in the country.
- Roots Community Health Centre (USA) – a comprehensive healthcare organisation which both tests and treats hepatitis.
- Caribbean Hepatitis C Alliance (Jamaica) - they aim to be the leading patient-oriented hepatitis organisation in the Caribbean, eliminating the incidence of acute hepatitis and reducing the disease burden from chronic HCV infection.
- Yayasan Koalisi Satu Hati (Indonesia) - their mission statement is to establish a fair and equitable approach to the prevention and treatment of viral hepatitis and HIV in Indonesia. Their activities include advocacy, community-based studies and partnerships.

GOVERNANCE

The WHA Board welcomed new regional representatives who were voted in by WHA membership: Rachel Halford from Hepatitis C Trust for the EURO region, and Patricia Velez-Moller from Asociacion Guatemalteca del Higado for the PAHO region. Additionally, two skills-based Board members were appointed: Helen Tyrrell from Hepatitis Australia, and Edo Agustian from Indonesia.

The Board also elected Su Wang as WHA’s President Elect for 2019. Su has been WHA’s regional board member for PAHO since 2015. She will be working closely with WHA’s President Michael Ninburg this year, before becoming President in 2020.

STAFFING

In January WHA appointed a new Chief Executive Officer, Cary James. Cary will take up his new role with us in April.

We welcomed three new members of staff this quarter. Danielle Roe is our project co-ordinator, helping to deliver WHA’s programmes of work. Lucy Ferrier is our new communications manager. Both Dani and Lucy bring experience, ideas and enthusiasm from their work in other NGOs to WHA. And finally, we welcomed back Isabel Bull, formerly our communications intern, who has returned to WHA as our new Member engagement and communications officer. All three are already valued and established members of the team.

In March WHA said goodbye to Jack McDonald, our communications intern. Jack worked hard to analyse and improve our NOhep communications channels, and brought lots of great ideas into WHA. We wish him all the best in his new role at the RSA.