Quarterly Report
July - September 2017

Our strategic plan clearly states what we will do in order to make the biggest impact and make a major contribution towards improving the lives of millions of people living with viral hepatitis. This quarterly report covers our progress towards the ambitious objectives we have set for ourselves for the months of July, August and September 2017.

Our Core Areas of Work

1. Raising awareness of viral hepatitis
2. Advocating for viral hepatitis
3. Ending the social injustice of viral hepatitis
Actions

World Hepatitis Day – celebrating our global awareness day

Ahead of World Hepatitis Day (WHD), we continued to promote the #ShowYourFace campaign and work closely with partner and member organisations to support the planning of their activities.

On 28 July the world once again came together to mark WHD:

- Over 1,200 events took place in 162 countries across the world
- 106 governments acknowledged the day
- 172 WHA members took part

At WHA we participated in a number of activities:

- WHA President Charles Gore participated in a press conference in Russia
- WHA President Charles Gore attended a WHD event organised by the Ministry of Health of Georgia and WHO Regional Office for Europe
- WHA CEO Raquel Peck appeared on the Sky News breakfast show
- WHA staff attended and participated in the Hep C Trust’s patient conference
- WHA Board Member for the African region Kenneth Kabagambe, and his organisation the National Organisation for People Living with Hepatitis B (NOPLHB), held a symposium with the Ministry of Health and WHO Country Office, organised an awareness walk with free testing and vaccination and appeared on national TV
- WHA Board Member for the Americas region Su Wang, and her organisation Saint Barnabas Medical Center, conducted free testing and encouraged hospital visitors to take part in the #ShowYourFace campaign. Su Wang also featured in the U.S. Department of Health & Human Services Viral Hepatitis blog
- WHA Board Member for the Eastern Mediterranean region Ammal Metwally, and her organisation Association of Liver Patients Care (APLC) organised a number of activities including a concert, competitions, a children’s fun day with prize giveaways, a magic show and a cartoon film raising awareness of hepatitis transmission as well as free hepatitis B and C screening and liver function tests
- WHA Board Member for the European region Ivana Dragojevic, and her organisation HRONOS, took a mobile information centre, equipped with a fibroscan across Serbia. They also held a panel
As well as events taking place all over the world, organisations and individuals worldwide used social media to raise awareness:

- Thousands of people took part in the #ShowYourFace campaign with over 3,500 selfies added to the gallery
- #WorldHepatitisDay trended globally and in many countries and cities throughout the world
- There was a tweet to #WorldHepatitisDay every 6 seconds on 28 July
- The #ShowYourFace Thunderclap was signed by 357 organisations and individuals, helping the elimination message reach 15.6 million people

The World Hepatitis Day 2017 Global Summary Report was released in September and provides full details of events and activities taking place on the day. Read the full report here.

**NOhep - expanding awareness-raising activities beyond a single day, increasing the support for viral hepatitis and the impact on the ground**

Significant progress continues to be made towards the implementation of this strategy in this quarter:

**NOhep Visionaries Programme**

Medical Professionals: This quarter we secured commitment from 14 leading medical professionals in the Americas Region to spearhead the launch of the programme at The Liver Meeting in October.

Governments: Six countries were identified, based on their commitment and efforts to eliminate viral hepatitis, to launch the NOhep Visionaries Programme for Governments. They are Bangladesh, Brazil, Egypt, the Gambia, Georgia, and Mongolia. So far, Bangladesh, Brazil, Egypt, the Gambia and Georgia have accepted and we are currently in discussions with Mongolia to secure their commitment. The programme will be officially launched at the World Hepatitis Summit in November, where Ministers of Health from each of the countries will speak at the plenary session.

**Increasing the level of NOhep Supporters**

NOhep actions have increased from 52,232 to 66,557 by the end of this quarter and #NOhep reached 72.3 million people on Twitter. This increase is largely as a result of our strong social media presence during World Hepatitis Day and the World Indigenous Peoples Conference (WIPC) along with our social media engagement, monthly newsletters and partner activations. In addition NOhep supported WIPC by calling on delegates to pledge their support for Indigenous Peoples rights. Over the 2 day conference, more than 4,000 people visited the pledge page.

**NOhep Campaign Resources and Materials**

This quarter saw the launch of the “We Are NOhep: Global Documentary” on World Hepatitis Day. This short video showcased the different methods people, governments, and communities are taking to reach the elimination of viral hepatitis by 2030. It was viewed by over 50,000 people in 125 countries. The video can be accessed here.
**LIVER CANCER AND VIRAL HEPATITIS** - raising awareness of the strong link between the two and promoting the positive impact that the elimination of viral hepatitis will have on liver cancer deaths and the advancement of the Non-Communicable Disease goals

No updates this quarter.

**THE REALITY OF VIRAL HEPATITIS** - illustrating the lives of the 325 million people worldwide living with viral hepatitis to bring home the reality of the disease beyond the statistics

**WORLD HEPATITIS DAY**

The #ShowYourFace campaign for World Hepatitis Day (WHD) focused on humanising and individualising elimination. The WHD website received over 3,500 selfies, successfully showing the many faces behind elimination. We also used patient case studies as part of our media outreach for WHD and successfully secured a slot on Sky News breakfast show with UK patient Michelle Tolley.

**WALL OF STORIES**

This quarter we have continued to promote the new Wall of Stories on our website. Every month we have profiled a different story of someone living with viral hepatitis through the ‘Wall of Stories Snapshots’ section of hepVoice.

**WORLD HEPATITIS SUMMIT**

As well as continuing to gather patient experiences for the Wall of Stories, in August we put out a call for patient testimonials among our membership. A wide variety of testimonials were received and six have been selected to be filmed and shown at the World Hepatitis Summit with the idea these testimonials will highlight the devastating impact viral hepatitis has on peoples’ lives and remind delegates why immediate action must be taken.

**DATA** - advocating for consistent and reliable data on the diseases and develop and promote our own data

**AGREE ON CONSISTENT GLOBAL DATA WITH THE GBD DATA AND WHO**

The Institute for Health Metrics and Evaluation (IHME) released the new Global Burden of Disease study for 2016 which showed that viral hepatitis accounts for 1.34 million deaths globally, exceeding tuberculosis (1.2 million), HIV/AIDS (1 million) and malaria (719,000). The World Hepatitis Alliance presented this new data to media which resulted in 157 articles in 30 countries, reaching 214.5 million people. The data has not been verified by WHO.

**WHA CIVIL SOCIETY SURVEY**

A report summarising the global findings of the civil society survey is being drafted and will be disseminated at the World Hepatitis Summit next quarter. It was agreed that this report will focus on stigma and discrimination and members’ involvement in their country’s response to viral hepatitis only. The landscape for access to diagnostics and treatment has been rapidly changing meaning that the findings from this section of the survey were unlikely to still be an accurate representation of what is happening within countries.
Advocating for Viral Hepatitis

Political Will - building the case for eliminating viral hepatitis and supporting governments fulfill their commitment

HCV and HBV - Developing Global Business Cases

The economic and development case for viral hepatitis was piloted with three potential donors and their feedback incorporated into the final presentation. Following this the project deliverables from Dalberg Global Development Advisors were signed off.

The focus of the project now moves towards dissemination of the white paper which was developed as part of this project. The findings of the white paper have been used to create an editorial for the Lancet that is intended to complement an economic analyses of HCV elimination that the Centre for Disease Analysis in the United States of America, have submitted.

Financial Barriers to Elimination of Hepatitis C in Low and Middle Income Countries - Assisting countries with costing, financing and investment case development

The Clinton Health Access Initiative (CHAI) and the Centre for Diseases Analysis (CDA) were selected to carry out this project - CHAI in Nigeria and CDA in Colombia - based on both their experience in the area of financing and their relationship with Ministries of Health.

Nigeria

This project is now underway with a meeting in Nigeria being scheduled for October to discuss project approach, methodology, unit costs and target setting.

Colombia

CDA is working on this project in collaboration with the Pan American Health Organization (PAHO). A meeting was held in Colombia in September to discuss the epidemiological inputs, costs and look at the different treatment scenarios that Colombia could implement. A follow up meeting will be held in October to sign off on these inputs following which further conversations can begin around budgeting and financing.

A Viral Hepatitis Financing Strategy Blueprint for Countries

Work on drafting the blueprint by WHA is ongoing with CHAI providing input as appropriate. Discussions with both CHAI and CDA are underway to determine how to best incorporate the learnings from the projects we are conducting with them in Colombia and Nigeria into the template as case studies.

It was agreed that creating a website for the blueprint would be the best way to present it. This will allow for it to be more interactive and will also enable the blueprint to be dynamic as we will be...
Following conversations with WHO last quarter CHAI, WHO and ourselves have been further discussing methodologies regarding the costing and investment case with a meeting held in Geneva in September to ensure that we are aligned on approaches. These discussions will be reflected in updates that CHAI is making to their costing tool. This tool will then be integrated into the financing blueprint website, to be launched at the World Hepatitis Summit.

World Hepatitis Summit (1–3 November 2017)

Strong progress has been made this quarter. 85 global speaker experts have been confirmed to the organisation’s flagship event and over 950 delegates have registered their attendance across 108 countries. The Programme Secretariat finalised their primary programme content and 7 side meetings have been developed with partner organisations to cover additional areas of content not covered within the main agenda.

It is worth noting that the Summit is significantly over capacity and a waiting list is in place for most ticket types. Similarly, the number and sizes of workshops have been increased to allow for these increased numbers. The Programme Manager ticket remains open as the event has been specifically designed as a platform for civil society and government to come together for the benefit of hepatitis patients. A significant amount of progress has been made in identifying national hepatitis Programme Managers of which there are now 68 registered (up from 28 in Q1 and 50 in Q2).

In order to maintain the ambition and momentum generated from this year’s, work started this quarter to secure a suitable government to host a possible event in 2019.

The Why of Viral Hepatitis - sharing reasons why viral hepatitis should be championed by everyone

No updates this quarter.
Ending the Social Injustice of Viral Hepatitis

3

Actions

Stop the Stigma and Discrimination - giving people with viral hepatitis a voice and exposing prejudices suffered

Painful case studies identified and profiled across our communication channels

See 'The reality of viral hepatitis'.

Topic given prominence at the World Hepatitis Summit 2017

A series of patient testimonials are being produced and will be included across the 3 days of the World Hepatitis Summit to highlight the impact hepatitis has on individuals’ lives and in particular to focus on the stigma and discrimination experienced. This will include a testimonial from prominent Bollywood actor Amitabh Bachchan who is currently living with hepatitis B.

Equity - making the lack of access to lifesaving interventions a priority

WHA awareness-raising activities – ensuring a special focus on access

On 8 – 9 August the World Hepatitis Alliance supported the WIPC conference by raising awareness of Indigenous Peoples’ rights to health, through WHA and NOhep social media platforms. We also implemented a traditional media campaign to promote the link between human rights and health. In total, the conference was covered in 15 international media outlets including Voice of America. The WIPC hashtag reached nearly one million and more than 100 people participated online.

World Indigenous Peoples’ Conference on Viral Hepatitis

On 8 – 9 August the World Hepatitis Alliance and the Alaska Native Tribal Health Consortium hosted the second World Indigenous Peoples Conference on Viral Hepatitis in Anchorage, Alaska. Coinciding with the International Day of the World’s Indigenous Peoples, the event brought together over 150 delegates from 14 countries and provided a platform to profile and further the conversation on viral hepatitis in Indigenous communities. A total of 31 scholarships were awarded which helped to ensure greater representation of Indigenous Peoples. A key outcome of this meeting was the Anchorage consensus statement which built on the consensus statement drafted at the inaugural meeting in Alice Springs in 2014. The updated consensus statement addresses the need to maintain the momentum the conference created and calls for the formation of a working group to drive international action for the elimination of viral hepatitis in Indigenous People.
WHAS Civil Society Survey - Identifying Levels of Access in Countries

The civil society survey, which was disseminated in the fourth quarter of 2016 and first quarter of 2017, included a section aimed at assessing the level of access to diagnostics and treatments in countries from a civil society’s perspective. Since then we have found that the landscape for access has moved so rapidly that the findings are no longer an accurate representation of what is happening within countries. In light of this it has been decided not to disseminate this information.

Topic Given Prominence at the World Hepatitis Summit 2017

A simulation exercise has been developed by the Programme Secretariat on the subject of “Delivering for Equitable Services”. This interactive session explores how to undertake a health equity impact assessment for viral hepatitis and is anticipated to be one of the event highlights for this year’s Summit.
With the emergence of new organisations working in the field of viral hepatitis we conducted a mapping of all key actors delivering interventions and programmes. This enables us to get a better understanding of existing coverage to avoid duplicating activities and funding competition, and identify core partners to widen the scope and impact of our ambitious work.

Key partners identified and actions taken this quarter:

**RAISING AWARENESS**

**WORLD HEALTH ORGANISATION/ CEVHAP / CENTERS FOR DISEASE PREVENTION AND CONTROL (US) / ELPA**

This quarter we continued to work closely with WHO in many fronts; delivering a very successful World Hepatitis Day and continuing to lead efforts around raising awareness of NOhep. Through NOhep we were also in contact with ELPA, CEVHAP and CDC to continue to push the NOhep brand and identify opportunities for growing the movement.

**ADVOCATING FOR VIRAL HEPATITIS**

**WHO/ UNITAID/ COALITION PLUS/ LIVER SOCIETIES/ CLINTION HEALTH ACCESS INITIATIVE (CHAI)/ CENTER FOR DISEASE ANALYSIS (CDA)**

**WORLD HEALTH ORGANIZATION (WHO)**

In September we had the opportunity to input on WHO’s HCV Treatment Guidelines – see full update below.

We also held a meeting with the Global Hepatitis Programme in Geneva in September to finalise arrangements for our World Hepatitis Summit, discussing last minute programme changes, programme managers’ attendance and the next host country for the 2019 Summit, amongst other topics. Furthermore, we have been working with WHO and the Ministry of Health of Brazil (as well as their permanent mission in Geneva) on a political declaration, to be hopefully ratified by other Member States and officially launched at the end of our Summit.

**UNITAID**

In September we met with UNITAID to discuss their plans for 2018 and identify areas of collaboration. UNITAID is currently the only global donor for HCV but their focus is limited to co-infection. Hence, much of the discussion revolved around an expansion of their work area to HCV monoinfection as well as HBV, the barriers involved and how to possibly overcome them.

**COALITION PLUS**

In July, we attended a partners meeting organised by Coalition Plus to input in their hepatitis C and HIV advocacy project which has a focus on creating demand for treatment. More on this meeting can be found below.
This quarter we held many discussions with the four liver societies (The American Association for the Study of the Liver (AASLD), The European Association for the Study of the Liver (EASL), The Asia-Pacific Association for the Study of the Liver (APASL) and the Latin American Association for the Study of the Liver (ALEH)) around their side meeting taking place at the World Hepatitis Summit where they will present on how each medical society can contribute towards elimination in their own region (e.g.: their roles in improving access to treatment, to ensuring linkage to care, to improving diagnosis, etc).

Furthermore, we worked closely with AASLD on our upcoming launch of the NOhep Visionary Programme for Medical Professionals at their International Liver Meeting (ILM) in October. WHA will also deliver presentations in key meetings taking place at the ILM.

As reported earlier, we have contracted these two organisations to deliver financing work for us in Nigeria and Colombia respectively. Hence, we have been in frequent contact with them as they input into the process.

Discussions with MPP took place this quarter around their new priorities in licensing and how we could help with HCV access strategies. Furthermore, we finalised arrangements for MPP to participate in our Pre-Summit Members Conference where they will update civil society on their current plans around HCV and a possible expansion to HBV. MPP will also host a plenary talk on Voluntary Licensing at the main World Hepatitis Summit, taking place in the days that follow the Members Conference.
Coalition Plus Partners Meeting: Paris, 25 July 2017 (goal 2)

Coalition Plus brought together the organisations they are currently working with on advocating for hepatitis C treatment (with a focus on co-infection). The meeting focused on reviewing achievements to date and driving the project forward. We were invited to give some highlights from our project on financing for hepatitis C, to introduce NOhep, and to give updates about our World Hepatitis Summit.


When in Paris, we took the opportunity to meet with TAG and MdM and share updates on ongoing projects in the pipeline with one another as well as explore potential collaborations. Possible areas of collaboration identified were predominantly within the policy area and included working together to get a resolution on hepatitis and drug use adopted by the CND next year and expanding civil society representation at our World Hepatitis Summit 2019.

Gates Foundation: Seattle, 11 August 2017 (goal 2)

We secured a meeting with Duncan Steele, deputy director of enteric diseases at the Gates Foundation. While his interest in hepatitis to date has been confined to the hepatitis E vaccine, he was nevertheless very receptive to our plea for the foundation to take a more active role in tackling viral hepatitis. Indeed since Gates funds the Institute for Health Metrics and Evaluation (IHME) to produce Global Burden Disease data precisely to determine where the burden is and hence where to intervene. It is this very data that shows hepatitis is amongst the top 10 causes of mortality, yet it is completely neglected. He agreed to speak to Susan Desmond-Hellmann, CEO. We will follow up.

PATH: Seattle, 11 August 2017 (goal 2)

PATH works in global health with approximately 1600 staff in 70 countries, 15 of them in sub-Saharan Africa. We met David Fleming from their global health team and Tony Marfin from their vaccines department. While they are not involved in hepatitis, they were interested in the idea of providing technical assistance for the hepatitis B birth dose in Africa. Unfortunately they would require funding to do anything.

70th Session of the WHO Regional Committee for the South East Asia Region: Maldives, 6–10 September 2017 (goal 2)

Hepatitis took centre stage at the WHO SEARO Regional Committee. What had been planned as a side meeting became a plenary session on viral hepatitis. It was introduced by a short film on the subject made by SEARO, followed by each of the 11 ministers speaking. Speeches were then made by Amitabh Bachchan via Skype, the WHO Director-General, Director of the WHO Global Hepatitis Programme, Gottfried Hirnschall, and Charles Gore, WHA President. The focus of our intervention was to praise the development of the Regional Action Plan and urge Member States to adopt it. We are pleased to report that Member States adopted the Action Plan in a motion following our intervention.
Hope for Cure Vernissage: Budapest, 14–15 September 2017
(goal 2)

Our objective of attending this meeting was to encourage doctors in Central Europe to get behind the concept of elimination and introduce them to NOhep. Our intervention aimed at putting the treatment of individual patients into the context of global and regional elimination. This again gave us the opportunity to explain WHA’s central role in the elimination agenda.


We attended the HCV treatment update guidelines development group meeting to discuss which of the new drugs should be recommended (Glecaprevir/Pibrentasvir, Sofosbuvir/Velpatasvir, Sofosbuvir/Velpatasvir/Voxilaprevir) either alongside or in place of current recommendations. In addition, the GDG considered whether there is enough evidence to recommend treating everyone rather than prioritising certain groups. The GDG came to some tentative conclusions but there is still much to be finalised before it goes to the Guidelines Review Committee, which will make sure that any recommendations have followed the strict GRADE process and are therefore justified.
This year WHA celebrates its 10-year anniversary, which presents us with a great opportunity to acknowledge the tremendous advances we have made so far and look forward to our next phase (2018-2030). To help us navigate through and prepare for the next challenges ahead, we have been working with a communications and branding agency to guide and support us in taking a fresh look at our mission and in developing a robust communications strategy including a World Hepatitis Day campaign for 2018. Parallel to this we are also finalising our programmes for 2018-2020. Interviews have been conducted with various stakeholders and a final draft will be unveiled to our membership at the Pre-Summit Member Conference.

**ANNUAL GENERAL MEETING**

The World Hepatitis Alliance's 2017 Annual General Meeting was conducted virtually in accordance with the by-laws. Annual accounts were approved, SFER will be re-appointed as the auditor for the next reporting period and responding members were unanimous in their satisfaction with WHA’s report of activities for 2016.

**TREASURER**

Last quarter we announced the appointment of an Honorary Treasurer for an initial probation period of six months. As we are coming up to the end of this period it has been unanimously agreed that the appointment should not be confirmed due to differing views relating to management practices. Steps are being taken to fill this role.

**WELCOMING NEW MEMBERS**

While a few applications are in the pipeline there are no new members to welcome this quarter. We are sorry to lose the Hepatitis Foundation International – a voting member based in the US – who have now closed their doors after operating for 27 years.

**WHA TEAM**

We are delighted to welcome Elaine Nelson, Communications & Campaigns Officer as a new addition to our Communications team. Elaine joins us from the BBC where she worked for world newsgathering on news and current affairs programmes, as well as doing a short stint at Children in Need working under the infamous Pudsey Bear! Elaine will be leading on the NOhep campaign and will be presenting the 2018 strategy to the working group at the World Hepatitis Summit in November.

Our Communications and Campaign Intern Ben Laycock-Bordman successfully completed his 6-month internship with us in September and we welcome Henry Arnold in his place for the next 6 months. Henry joins WHA having graduated from Leeds Beckett University with a Journalism degree. He has demonstrable experience within a PR and Communications setting, where he has helped develop content plans to assist both large and small organisations in achieving high engagement levels and increasing follower numbers. Henry will be working across both NOhep and WHA communications.
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