Many more countries with comprehensive hepatitis strategies in place or at least in development

Exploring how we can fund hepatitis

Discussions around hepatitis are dominated by the pioneering new treatments rapidly transforming the landscape and the ensuing heated discussions over the cost of a cure. But with such noise on the topic and few viable solutions being presented, the World Hepatitis Alliance was compelled to address this gap and hosted the first World Hepatitis Advisory Committee meeting (WHAC). A three day meeting held from 11th-13th February, it focused on two key questions: what is the future for hepatitis treatment? And how can we find ways to fund hepatitis programmes? To gain an insight into the new treatments on the horizon, the first half of the WHAC meeting focused on pharmaceutical companies’ pipeline of new drugs and the access programmes they plan to roll out. The second half of the WHAC meeting then featured presentations from experts in healthcare financing from all over the world including the World Bank, the Center for Global Development and the Microinsurance Network. Read the WHAC report here.

Supporting WHO’s efforts to provide guidance to countries on how to treat hepatitis

In March, WHO released the first-ever guidelines on the treatment of chronic hepatitis B. The vast majority of the 240 million people with hepatitis B do not have access to the medicines that can prevent cirrhosis and liver cancer. The new guidelines provide clear information on diagnosis, treatment and care but in particular on who to treat and how to identify them in resource limited settings. As well as being part of the guidelines development group, during the press launch of the guidelines the World Hepatitis Alliance presented the patient and community perspective on hepatitis B and joined WHO on the panel to answer questions on the global burden of hepatitis and how guidelines will help prevent deaths worldwide. In February, WHO also launched a new Injection Safety Programme to raise awareness and provide guidance in best injection practice with a goal of transitioning to reuse-prevention and needlestick-prevention syringes for all therapeutic injections by 2020. At the launch WHA chaired the session on the other essential part of the programme – how to reduce unnecessary injections. Read the WHO Hepatitis B guidelines here and the WHO Injection Safety guidelines here.

Stressing the importance of patient advocacy and the need for clinicians to help establish new patient groups

Patient led advocacy is vital in generating change within the hepatitis community and persuading governments to adopt national strategies. In March we used the 24th Conference of the Asian Pacific Association for the Study of the Liver as an opportunity to highlight the global importance of this. Co-hosting a symposium with CEVHAP and ELPA entitled “Reduce the Burden of Viral Hepatitis from East to West”, we delivered a presentation on the fundamental role patients play in advocacy efforts and how clinicians, because they are in touch with patients, could be instrumental in helping to get them together to form new patient groups. In order to help clinicians with this process, we have been developing an online learning tool that explains the benefits setting up patient advocacy groups and how these can be established and supported.
Renewed official relations status with WHO

Fundamental to our ability to influence global hepatitis policy and bring about real change is our relationship with the World Health Organization, so we are delighted to announce our official relations status with WHO has been renewed for another three years. We hold this relationship in great esteem and truly value our ability to represent the voice of hepatitis patients around the world at the highest level of global public health. Following the World Health Assembly 2014 resolution on viral hepatitis, in which governments called on civil society actors to become more involved with WHO and its work, WHA’s relationship with WHO has invaluable benefits to our members. Through our official relations with WHO, all WHA member organisations are consequently in official relations with their WHO regional offices. We will strive to support our members in understanding how to make best use of this opportunity, and provide tools and advice on how to engage with their local WHO representatives.

Promoting screening among high risk communities with new multi-lingual tool

In Europe, migrant populations are disproportionally affected by hepatitis B and C so in January 2015 we developed a multi-lingual leaflet tool as part of the HepScreen initiative to raise awareness and promote screening among these communities. The online tool allows healthcare professionals to download leaflets that provide information in simple language to accompany testing initiatives. From the 42 languages currently available in the tool, the leaflets can be downloaded in any two languages – the language of the country where the testing is taking place and the language of the migrant group being offered the test. This allows the healthcare workers to know exactly what information those being tested are getting. We have already received positive feedback from groups across Europe and beyond who are using the tool to improve knowledge and awareness of hepatitis, to prepare people for test results, and to reduce feelings of stigma, fear and shame. View the leaflet tool here.

Joining expert committees to promote harm reduction

The World Hepatitis Alliance believes a global commitment to the harm reduction approach is fundamental in reducing hepatitis infection. Harm reduction policies are crucial to tackling viral hepatitis among people who inject drugs (PWIDs). Adoption of such policies can reduce hepatitis C acquisition risk among PWIDs by 75-80%. Ensuring policies that address hepatitis are being implemented is vital to reducing infection among this group so by becoming part of expert committees including the New York NGO Committee on Drugs (NYNGOC), Vienna NGO Committee on Drugs (VNGOC) and the International Drug Policy Consortium (IDPC), WHA is using its status as the voice of hepatitis patients worldwide to reinforce the need for practical harm reduction policies. Through joining these formal civil society mechanisms, we will be able to engage in UNGASS 2016 (Special Session of the United Nations General Assembly on the World Drug Problem), raise awareness about the transmission risks of hepatitis and stand up for the needs of a population that is often overlooked and at particularly high risk. In March we attended the 58th Session of the Commission on Narcotic Drugs (CND) to emphasise this. During the plenary sessions and side events we attended, we stressed the importance of including viral hepatitis in harm reduction strategies, worked with civil society actors to ensure hepatitis was included in the civil society statement, urging organisations to promote viral hepatitis harm reduction, and made an intervention to remind member states of their commitment to the WHA67.6 resolution. The event was an opportunity for us to raise the profile of WHA within this field and develop our relationship with harm reduction partners.

Raising the profile of WHA members’ successes

Patient advocacy organisations have a pivotal role to play in stimulating political interest in hepatitis. As a global alliance of patient groups, we know that together our voices are much stronger. We are keen to showcase the work of WHA members in order to provide them with the global profile and influence that their actions deserve. In the past quarter, we’ve highlighted some of the many
exemplary activities our member organisations are doing all over the world. This has included advocacy work in Ghana, an initiative in Bangladesh providing free treatment, and a member group in Mongolia launching a national programme with the government. We were also delighted to be able to bring together WHA members to support a successful social media campaign in Brazil. By encouraging WHA members to join the #selfieHepatiteC campaign from member group C Tem Que Saber – C Tem Que Curar, we helped to bring the campaign to people all over the world with members from countries including USA, Bangladesh, and Serbia joining the movement.

Representing the voice of hepatitis patients

The World Hepatitis Alliance prides itself as the true voice of hepatitis patients living all over the world. All our work is overseen by an executive board of patient representatives, each elected by WHA member organisations to represent their region. The new regional board was elected in November 2014 and met in London in February for the first time to attend the Annual Executive Board Meeting. From reviewing internal processes of the organisation to advising on the Alliance’s strategic objectives, the board members spent two days examining the key elements of how the Alliance functions. The strategic direction provided by our board members is essential to our work and the productive meeting has triggered many further actions and even new directions for WHA to explore.

Attending high profile meetings

From 28th February to 2nd March, WHA attended a meeting on HIV co-infection with viral hepatitis in Singapore, which was an opportunity for key figures in the hepatitis community to discuss approaches to overcoming barriers to access and to consider ways to inspire further international and local action. WHA opened the meeting and asked delegates to consider the issue of co-infection as potential ‘pathfinder’ for the issue of mono-infection.

Greatly increased profile of viral hepatitis

Advising WHO on hepatitis strategy and targets

As part of an expert advisory committee, WHA is currently assisting WHO in developing its Global Hepatitis Strategy and defining global elimination targets. Following the first target discussion meeting in December, the WHO Strategic and Technical Advisory Committee for hepatitis (STAC-HEP) met in March to discuss the 2016-2020 Global Hepatitis Strategy and a meeting of the hepatitis Civil Society Reference Group was held in May. WHA attended all these meetings and is supporting the proposed ambitious targets. These are: by 2030, 90% of chronic hepatitis diagnosed, 90% of eligible patients treated and 90% of those treated are viral-suppressed (HBV) or cured (HCV).

Supporting WHO regional offices

WHO regional offices are central to addressing the burden of viral hepatitis throughout the world so, as part of the development of the Global Hepatitis Strategy, WHO are holding regional consultations this year. Working with regional offices is also vital to our efforts so in March WHA CEO Raquel Peck met the viral hepatitis team at WHO EURO to discuss our respective strategies and to ensure they are aligned with one another.

Progress of the World Hepatitis Summit

In February, we were delighted to welcome a new member to the WHA team. Alex joined the team as World Hepatitis Summit Project Manager and is managing all logistics and communications surrounding the event. Alex brings great enthusiasm and experience in event management and communications to the team and his support in organising the Summit will be crucial to its success.