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

World Hepatitis Summit: Glasgow, Scotland, 2-4 September

In May 2014 the adoption of the World Health Assembly resolution 67.6 signalled a significant leap forward in the fight against hepatitis, calling on governments to develop and implement comprehensive national strategies and asking the World Health Organization (WHO) to assist them in doing so. It also asks WHO to examine the feasibility of eliminating hepatitis B and C with a view to setting targets. Responding directly to the resolution and to build momentum towards national plans and the elimination of viral hepatitis, the World Hepatitis Alliance (WHA) and WHO convened the inaugural World Hepatitis Summit 2-4 September. The event was hosted by the Scottish Government and supported by Glasgow Caledonian University and Health Protection Scotland and offered an unprecedented opportunity to forge relationships between civil society and governments. To directly assist governments with their efforts to tackle hepatitis in their countries, the central theme of the meeting was ‘developing and implementing national plans’.

More than 500 delegates from 84 countries attended the event and took part in a great variety of sessions and exercises. Presentations from renowned experts and government officials summarised current best practice and examples from countries leading the fight against hepatitis. Specialised parallel sessions provided delegates with the most up-to-date knowledge and practical help to support the development of national plans. A highly interactive simulation exercise gave participants the real-life experience of responding to a national viral hepatitis crisis and gain an understanding of the different components necessary to respond effectively. WHA organised side events, such as a ‘speed dating session’ and a session hosted by the Medicines Patent Pool (MPP) provided delegates with the opportunity to explore ways access to treatment can be improved. The speed dating session enabled government policy-makers and pharmaceutical and diagnostic companies to discuss drug pipelines and future plans for registration and generic licensing and, as in real speed-dating, decide whether they wished to take the ‘relationship’ further and meet again. During the MPP session, delegates had the opportunity to learn more about the organisation and ask questions on how they propose to speed up and expand access to hepatitis C treatments through voluntary licensing agreements. To conclude the Summit and cement delegates’ commitment to eliminating viral hepatitis, the Glasgow Declaration on Viral Hepatitis was endorsed which demands governments develop national plans and programmes in order to realise the goal of elimination of by 2030.

To access presentations, photos and videos from the event, visit the Summit website. A full content report will be available by the end of October.

1st European Roundtable on Hepatitis Cure & Eradication: Frankfurt, Germany, 9-10 September

As global momentum to eliminate viral hepatitis builds, responses to tackling the epidemic must be adapted to regional needs and challenges. In order to identify the particular issues Europe faces in scaling up its response to hepatitis, experts from the medical profession, government representatives and civil society came together at the 1st European Roundtable on Hepatitis Cure & Eradication in
Frankfurt, Germany on 9-10 September. Discussions at the meeting included an analysis of the current situation in Europe, addressing the issue of under-diagnosis and approaches to elimination among key risk groups. Representatives from Spain, Scotland, France, Germany, Georgia and Poland also presented on the steps their countries are taking in developing a national plan. WHA ensured the patient voice remains central in the region’s approach to defining and implementing and elimination by participating as a panel member in a roundtable discussion.

**World Health Organization Regional Committee for Europe: Vilnius, Lithuania, 14-17 September**

Taking place from 14 to 17 September in Vilnius, Lithuania, the 65th Session of the WHO Regional Committee for Europe provided a platform for Dr Gottfried Hirnschall, Director of the WHO HIV/AIDS Department and Global Hepatitis Programme, to present the draft Global Health Sector Strategy on Viral Hepatitis and the proposed global targets to European Member States. Following the presentation WHA President Charles Gore led an intervention in which he commended WHO for developing the strategy, but noted that the proposed global targets are not sufficiently ambitious. WHA also used the opportunity to stress the need for Europe to develop and implement a regional Action Plan of its own. With the burden of viral hepatitis in Europe disproportionally affecting marginalised and vulnerable populations, such as migrants and people who inject drugs, it is crucial that Europe identifies its own targets and interventions, following the lead of regions like the Western Pacific, which already has such an Action Plan. “Europe must not lag behind simply because many of its affected populations are marginalised,” emphasised Charles Gore, “On the contrary, this should be a spur to rapid action, since the Global Health Sector Strategy has a strong focus on addressing health inequities in viral hepatitis.” Following the Committee meeting, we have received news that the WHO European Office has drafted a concept note for a regional Action Plan.

**Sustainable Development Goals**

Following the expiry of the Millennium Development Goals, the United Nations General Assembly’s adoption of the Sustainable Development Goals (SDGs) heralds the most significant commitment to global development to date. Goal 3 of the SDGs focuses on health and well-being and specifically Target 3.3 strives to “end the epidemics of AIDS, tuberculosis, malaria, and neglected tropical diseases and combat hepatitis, water-borne diseases, and other communicable diseases” by 2030. Given that viral hepatitis was left out entirely from the Millennium Development Goals, it is a great leap forward to see mention of hepatitis in these new targets. However, to simply endeavour to ‘combat’ the global hepatitis epidemic does not accurately reflect the scale of the issue nor encourage the commitment needed to significantly reduce the death toll. Ahead of the approval of the SDGs we sought to strengthen the language of Target 3.3, including an intervention at the World Health Assembly in May 2015. Consequently we will continue to call on the global health community to push viral hepatitis to the forefront of global health discussions and strive to bring efforts in line with the proposed WHO target of eliminating the disease as a public health threat by 2030.

**World Health Organization Regional Committee for Americas adopt regional plan**

Despite viral hepatitis impacting almost every country in the world, the burden differs significantly from region to region. Thus in order to achieve the global elimination of hepatitis it is crucial that efforts are adapted to suit regional needs. In the Americas region, 20 million people live with hepatitis B or C and approximately 3% of all deaths in Latin America and the Caribbean are caused by viral hepatitis and its complications. Responding to the increasing need to tackle this epidemic in the region, viral hepatitis was a key topic on the agenda at the 67th Session of the WHO Regional Committee for the Americas. At the Regional Committee meeting the 54th Directing Council of the Pan American Health Organization (PAHO) agreed to a comprehensive regional action plan to prevent and control viral hepatitis in the region. The Plan for Action for the Prevention and Control of Viral Hepatitis 2016-2019, to which we actively contributed to at the regional consultation in April
2015, asks governments to develop and implement national plans which include the integration of prevention, surveillance, treatment and control into health systems, expand coverage of hepatitis B vaccination, and ensure governments run awareness campaigns including acknowledging World Hepatitis Day. The adoption of a regional strategy for the Americas region signifies an important step forward in the prevention and control of hepatitis and follows a heightened level of interest and commitment, which pioneering events such as the World Hepatitis Summit is undoubtedly encouraging.

Increased influence of the Alliance and its members

Pre-Summit Members’ Conference: Glasgow, Scotland 31 August-1 September

Ahead of the World Hepatitis Summit, we invited all member organisations of the World Hepatitis Alliance to attend an exclusive, members-only event aimed at uniting patient organisations and building members’ capacity in key areas in order to strengthen the community voice in viral hepatitis. 155 individuals from 136 member groups joined us from 62 countries across the world for a 2-day conference in which members took part in workshops on advocacy, media and public relations and fundraising with fellow organisations from their region. To promote the exchange of experiences between patient advocates, a session was organised in which members each presented a poster on their World Hepatitis Day activities while our first physical Annual General Meeting enabled members to input into WHA governance and activities in the pipeline. The event and its unprecedented opportunities for networking spurred many groups to independently organise and conduct regional meetings and undoubtedly fostered a real sense of solidarity that continued to build throughout the World Hepatitis Summit that followed.

A detailed report of the Pre-Summit Members’ Conference will be available on the WHA website from the end of October.

World Hepatitis Summit: Glasgow, Scotland, 2-4 September

With such broad attendance at the Summit from WHO, government officials, global funders, civil society and pharmaceutical representatives, our member groups had a unique opportunity to showcase our work as well as network and build valuable partnerships. The WHA booth and poster terminals enabled us to promote the activities of the WHA members while we also seized the opportunity to regularly remind delegates of the real reason the Summit was taking place by including patient testimonials where patients shared heart-felt stories, vox-pop style video links underlining important issues that patients need governments to address, and a film emphasising the true impact of living with hepatitis comprised of members clips. WHA members demonstrated the importance of civil society playing an integral role in the fight against hepatitis by leading on much of the question asking throughout the event and ensuring their voices were heard at every opportunity.

WHA Executive Board Member presents on patient advocacy: Glasgow, Scotland, 3 September

The World Hepatitis Summit sparked a heightened global interest in the viral hepatitis epidemic and provided numerous opportunities to highlight the importance of patient advocacy in tackling the disease. Inspired by the international event taking place on their home turf, NGO Hepatitis Scotland hosted a hepatitis C education and awareness evening on 3 September during the week of the Summit. The World Hepatitis Alliance was invited to speak to attendees from the North West Glasgow Recovery Community and provide an insight into patient activism around the world. WHA Executive Board Member for Europe George Kalamitsis attended the event where he introduced his organisation the Hellenic Liver Patient Association and presented on what is taking place across the globe with hepatitis C and the corresponding advocacy movement.
Expanding our membership base

In this quarter the membership base of the World Hepatitis Alliance once again grew as we welcomed another five organisations: Bonnie Morgan Foundation for HCV, USA; SHECA Foundation, Nigeria; Gujranwala Liver Foundation, Pakistan; Dutch Liver Patients Association, the Netherlands; Evidence Based Medicine Foundation, Russia. Our membership is now composed of over 220 members in 80 countries across the world. We are always actively looking for new members as further expanding this network helps to create greater unity and cooperation among the global hepatitis community, which is, of course, fundamental to efforts in tackling the global hepatitis epidemic.

View all our member organisations here and find out how you can be part of the World Hepatitis Alliance on our website.

Greatly increased profile of viral hepatitis

World Hepatitis Day

A unique opportunity to unify the global response to hepatitis, every year World Hepatitis Day vastly improves public awareness and enables us to demand better prevention programmes, access to treatment and government action by showing policy-makers that communities in different countries and regions are confronting many of the same key issues. Once again this year on 28 July we celebrated another extremely successful day and saw the global hepatitis community, governments across the world, WHO and the general public come together to highlight the urgent need to tackle viral hepatitis.

In order to support efforts throughout the world, we created a global campaign to assist individuals to raise mass public awareness. The theme of World Hepatitis Day 2015 was Prevent hepatitis: it’s up to you, emphasising the fact that the majority of the deaths caused by viral hepatitis can be prevented and everyone from policy-makers to the general public must play their part to prevent new transmissions. The campaign key messages were split into four key pillars (Know the Risks, Vaccination and Treatment, Blood and Injection Safety, and Harm Reduction) and were brought to life with posters and infographics.

To encourage individuals across the globe to help raise awareness, we created the 4000 voices social media campaign, asking people to tweet #4000voices and provide a voice for the 4,000 lives lost every day due to hepatitis. All tweets were collated in an online mosaic, producing a powerful visual representation. The campaign was supported by an online quiz and Thunderclap and saw well-known celebrities and international organisations get involved, including Sir Richard Branson, singer Natalie Cole, British comedian Stephen Fry, TV Doctor Dr Christian Jessen, Fightstar, the United Nations, WHO and the UN Office on Drugs and Crime.

The day was celebrated throughout the world with every region organising education events, vaccination drives, fundraisers and public health seminars. The World Hepatitis Day 2015 Summary Report, detailing the day’s successes and highlighting WHO, government and WHA members’ WHD events and activities, will soon be available to download from our website.

WHO’s World Hepatitis Day observation in Cairo, Egypt

To commemorate World Hepatitis Day 2015 and inspire action across the globe, the World Health Organization held an event in Egypt, a country with one of the world’s highest burdens of hepatitis C and a commendable level of commitment to tackle this. WHA attended the event to represent
civil society and was joined by WHO Regional Director for the Eastern Mediterranean Dr Ala Alwan, Minister of Health of Egypt H.E. Dr Adel Adawi and Dr Gottfried Hirnschall, Director of the HIV Department, WHO headquarters. In line with this year’s overarching theme for World Hepatitis Day, the event was an opportunity to highlight the importance of hepatitis prevention as well as showcase the efforts being made in Egypt to combat the epidemic. The event focussed on two of the key planks of Egypt’s national plan – its new injection safety programme as one of WHO’s pilot countries and the treatment programme for which more than 1 million people have registered online.

HCV Quest Global Patient Survey country reports

In April this year we launched the HCV Quest Global Patient Survey Report, summarising the survey responses from almost 4,000 people across 73 countries and revealing the hard-hitting reality of living with hepatitis C. It is evident that far more must be done to ensure that people with hepatitis C are given the support and care they deserve, so we wanted to assist patient groups in using the findings as a powerful tool for advocacy. Analysing the responses in greater depth, we produced country specific reports that reveal insights into the experiences shared by patients in each country and highlight pertinent findings in comparison with regional results. Reports are currently available in the native language of the following countries from which the most survey responses were received: Australia, Belgium, Bulgaria, China, Egypt, Greece, Hungary, Malaysia, Mexico, Romania, Russia, UK and USA. In order to intensify the impact of the HCV Quest Global Patient Survey findings and ensure government and health service responses to hepatitis C are vastly improved, further country reports will be released alongside accompanying user guides and resources to assist patient advocates in best putting the results to use. All WHA members attending the Summit were given USB sticks with copies of the reports to complement their newly consolidated advocacy skills.

HCV Quest Global Patient Survey Report and country reports can be viewed online here.

ELPA University: Split, Croatia, 24 August

The overwhelming stigma attached to viral hepatitis remains one of the most significant barriers to raising mass public awareness and as patient advocates we must find innovative ways to overcome the discrimination and shame that surrounds the disease. The ELPA University is a year-long module based training programme combining theoretical learning and skills based training run by the European Liver Patients Association (ELPA). In response to requests from the 20 patient organisations attending the programme, WHA delivered a workshop addressing both the causes and effects of stigma and discrimination and highlighting examples of campaigns that have addressed stigma and discrimination of viral hepatitis. By tapping into emotion, such as by using personal stories to humanise the disease, by ridiculing those fearful of the disease or by normalising the disease, such campaigns can significantly alter people’s misconceptions and encourage far greater public awareness of hepatitis.

World Hepatitis Summit: Glasgow, Scotland, 2-4 September

The World Hepatitis Summit undoubtedly catapulted the issue of viral hepatitis to centre stage with significant media interest both in the run-up to and during the event. With over 75 pieces of news coverage across the globe and an audience reach of over 5 million, the Summit succeeded as a platform to elevate the global profile of hepatitis. Across social media, delegates and followers alike joined the conversation and more than 5,500 tweets were sent using the Summit hashtag #Hepatitis2015. We will now strive to maintain this momentum and ensure viral hepatitis continues to receive the visibility and priority needed to tackle the global epidemic.