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

Executive Board Member for the African Region, Danjuma Adda, visit to Bamako, Mali

From 31st May – 4th June Executive Board Member for the African Region, Danjuma Adda travelled to Bamako, Mali to meet with a number of key stakeholders in order to strengthen efforts to tackle viral hepatitis in the country. Accompanied by Dr Coulibaly Aliuone who was recently appointed as the Regional Advisor for the African Region by the World Hepatitis Alliance, Danjuma Adda attended a number of important meetings to boost the government of Mali’s national response to hepatitis. Meeting with the Ministry of Health, Danjuma Adda commended the government’s current efforts including their HBV infant immunisation programme, the national blood screening centre and its support of treatment for those living with chronic hepatitis B while urging the government to increase its engagement with WHA members and hepatitis patients and their involvement in the hepatitis response programmes as well as offering technical assistance and support from WHA to further develop a sustainable viral hepatitis response and strategy. There was also the opportunity to meet with the Prof. Sounkalo Dao, head of the Centre for Infectious Diseases Service Mali and the Inspector of Foreign Office, Moussa Coulibaly who both committed to enhanced engagement with WHA and expressed willingness to increase action to tackle viral hepatitis in Mali. Danjuma Adda also had the opportunity to meet with WHA member groups to seek ways to strengthen the patient voice in Mali. Danjuma Adda and Dr Coulibaly Aliuone examined the current standing of WHA members throughout Africa and discussed ways to address communications gaps between members and WHA and strengthen capacity and capability among African members. It was agreed that a survey will be conducted to identify the level of members’ engagement and ways to enhance participation. The WHA representatives also organised a meeting with members SOS Hepatites Mali and APSAD Mali to seek ways to strengthen collaboration between member organisations and consider ways to establish a national network of viral hepatitis patient groups in Mali.

Meeting members and ministers in Mongolia

From 17th-24th June World Hepatitis Alliance President, Charles Gore visited Mongolia to support, and learn more about, the country’s efforts in tackling viral hepatitis. A country with by far the highest liver cancer mortality rate in the world, viral hepatitis in undeniably a significant problem in Mongolia yet its actions to combat the disease are commendable. Speaking on the global hepatitis situation at the National Viral Hepatitis Meeting, Charles Gore highlighted the opportunity Mongolia has to be an example to the world of how to scale up efforts, as the country is aiming to test the entire adult population of the country for hepatitis B and C. Charles Gore also had the opportunity to meet ministers from the Health Standing Committee at the launch of the country’s ‘Healthy Liver’ initiative where discussions centred around the national hepatitis plan currently in development. Most importantly of all, Charles Gore spent time with member organisation Onom Foundation whose impressive work has been critical in pushing the government to develop a national strategy.
EASL International Liver Congress 2015

Promoting the World Hepatitis Alliance, our members and our work to a range of audiences is crucial if we hope to eliminate a disease that affects people from all corners of the globe and all walks of life. Therefore a conference with over 11,000 attendees from 105 countries provides us with a unique opportunity to reach many. Taking place from 22nd-26th April in Vienna, Austria, the EASL International Liver Congress 2015 brought together thousands of clinicians to discuss the latest innovations in the prevention, diagnosis, screening and treatment of viral hepatitis. With a number of new projects to launch, the WHA team filled a large booth in the centre of the exhibition hall with information, videos, demonstrations, and even free coffee in order to engage as many doctors and healthcare workers as possible. Throughout the event delegates were keen to hear more about the World Hepatitis Alliance and learn how they could do more to support their hepatitis patients. Our attendance at such events is one of the most important ways we spread the word about the work of WHA and its members.

Patient Advocacy Creation Tool: An online learning platform

Patients are an integral part of successful advocacy and we know the advocacy voice provided by patient groups can help to deliver a vastly increased priority on the need to tackle viral hepatitis. Yet patient group numbers throughout the world are extremely small. To address this and thus lead to greater advocacy, we developed the Patient Advocacy Creation Tool (PACT). Launched at EASL ILC in April, PACT is an online tool to support those setting up patient advocacy and support groups and help them to develop. Although primarily aimed at physicians and healthcare workers, as these are the people most likely to be in regular contact with patients, the tool is appropriate for anyone interested in establishing a patient group for hepatitis. Supported and enhanced by videos and infographics, the text explains the reasons for setting up patient groups and provides guidance on how to do this and includes interviews with physicians, academic and patient group representatives from around the world. Easy to use, engaging and completely free, the online learning tool can be worked through at your own pace and will also be available in Chinese. Visit the Patient Advocacy Creation Tool here.

New website

As an international NGO with wide reach across the globe, the World Hepatitis Alliance’s website is an important representation of our organisation and is undoubtedly the first point of call for those interested in finding out about WHA, our members and viral hepatitis. Therefore it is crucial that the website adequately reflects the organisation and our members and provides accurate, current information. We thus decided to develop a brand new website, adopting a slicker design and updated identity and producing new, more engaging content. Providing our members with an opportunity to promote their work and enhance their profile is one of the key benefits we offer so each and every member has an individual page dedicated to providing a platform for them to champion their organisation and boost their online presence. Visit the new World Hepatitis Alliance website here and let us know your thoughts by emailing contact@worldhepatitisalliance.org.

New members

The World Hepatitis Alliance has welcomed a surge of new members over the past 3 months and is proud to now have 216 member groups in 80 countries across the globe. Extending our reach and enhancing our membership base, the new member groups span all six of our regions and join us from Australia, Brazil, Canada, Chile, Denmark, Ireland, India, Indonesia, Mauritius, the Netherlands, Pakistan, Rwanda, Serbia, Slovenia, Spain and USA. With activities ranging from advocacy and awareness-raising to screening and improving access, our member organisations are central to the work of the World Hepatitis Alliance and collaboration among patient groups is fundamental to tackling viral hepatitis throughout the world. As our membership base goes from strength to strength, we are particularly looking forward to meeting all our members, both old and new, at the inaugural World Hepatitis Summit in September.
Greatly increased profile of viral hepatitis

World Hepatitis Day

Despite a harrowing death toll, viral hepatitis continues to be remarkably neglected, so in order to drastically boost the global profile of hepatitis, World Hepatitis Day aims to raise awareness and demand better prevention programmes, access to treatment, and government action. This year’s campaign was launched in April and focuses on prevention as better understanding of how to reduce transmission is fundamental to preventing future deaths. We have created a multitude of materials and resources for those wishing to mark the day. Key messages on testing, vaccination, treatment, blood and injection safety, and harm reduction are accompanied by attention grabbing visuals and are designed to enhance individuals’ and organisations’ events and activities as well as helping to raise public awareness, and also to provide advocacy tools for patient groups to engage their governments in providing better access to services and treatment. Posters, logos, toolkits and infographics are available and free to use and we have created a unique custom poster tool, which allows organisations to adapt the official posters to a local audience or specific campaign while retaining the overall look and feel that unites the global campaign. This year we are also using a number of innovative social media platforms to generate public awareness including the ‘4000 voices’ online mosaic and the Thunderclap. The Thunderclap will help us to send a unified message to millions of people on World Hepatitis Day and this year we already have received support from Sir Richard Branson along with British comedian/actor Stephen Fry. Last year we were delighted to see events and activities taking place all over the world with more than 150 countries taking part and this year we hope to see even more engagement. For more information about World Hepatitis Day, visit the website. For assistance in or advice on organising an event for World Hepatitis Day, email contact@worldhepatitisalliance.org.

HCV Quest Global Patient Survey results

Inexplicably, so little of the information available about hepatitis C comes from those living with the disease. In order to address this imbalance and ensure the patient voice is truly heard throughout the world we created HCV Quest and surveyed almost 4,000 people from 73 countries on how living with hepatitis C impacts all aspects of their lifestyle, how much they knew before they were diagnosed and their experience of diagnosis, care and treatment. In April we revealed the findings in a Global Report that confirms not nearly enough is being done by governments to raise awareness, that physicians persistently miss opportunities to diagnose people, that living with hepatitis C and undergoing interferon-based treatment has a greater than appreciated impact on a person’s physical, psychological and emotional health, that the impact is too often unappreciated by healthcare professionals in particular and that in general not enough is being done to inform and support patients throughout the world. The findings of the survey send very clear messages that more action is needed across the globe and that far more must be done to ensure that people with hepatitis C are given the support and care they deserve. Read the full HCV Quest Global Patient Survey Key Findings report here.

WHO technical consultations on the Global Health Sector Strategy on viral hepatitis

Throughout the past few months, the World Health Organization Regional Offices have been holding technical consultations on the Global Health Sector Strategy on viral hepatitis currently being developed. The strategy will be finalised for submission to the 69th World Health Assembly in 2016 and proposes ambitious targets of 90% diagnosed, 90% of those eligible treated and 90% of those treated either virally suppressed (hepatitis B) or cured (hepatitis C) by 2030. Representing the patient voice, the World Hepatitis Alliance attended the PAHO regional consultation 14th-16th April in Brazil, the WPRO regional consultation 27th-30th April in the Philippines, the EMRO regional consultation 8th-10th June in Egypt and the EURO regional consultation 23rd-26th June in Denmark. Throughout the consultations, clear support for the strategy was voiced and a number of debates around the
targets took place. Reinforcing the need for ambitious targets to propel action, we used the regional consultations as an opportunity to advocate government buy-in to the targets and urged countries to adopt the strategy. Ahead of the consultations, we contacted member groups and encouraged them to share their comments and concerns about the strategy so that each organisation had the opportunity for their views to be heard as it is fundamentally important that patients are able to input into a strategy that aims to improve their lives. We continue to be closely involved with the World Health Organization’s development of the Global Strategy and greatly value this role as an opportunity to ensure the patient’s voice is heard and has a visibly present in the strategy’s development.

**Intervention at the 68th session of the World Health Assembly**

The 68th session of the World Health Assembly (WHA68) took place in Geneva from 18th-26th May and the World Hepatitis Alliance was invited to attend a technical briefing entitled “Changing the trajectory of three epidemics: HIV, viral hepatitis and sexually transmitted infections through the development of global health sector strategies” where discussions focused on the global strategies being launched next year. The briefing was an opportunity for us to ensure the voice of people living with hepatitis is heard in the strategy’s development. World Hepatitis Alliance CEO, Raquel Peck led an intervention to highlight the need for governments to address hepatitis and commit to the targets set out in the global strategy. The briefing also allowed us to draw attention to the wording used to address viral hepatitis in the proposed Sustainable Development Goals. The language around hepatitis under Goal 3.3 is weak, merely calling on governments to “combat hepatitis”. Therefore, at the briefing we urged governments to strengthen the wording and strive to “end the epidemic of” viral hepatitis. We stressed that only if the language mirrors that used for HIV/AIDS, TB and malaria will hepatitis achieve the priority it needs.

**World Hepatitis Summit**

Planning and organisation of the World Hepatitis Summit is progressing well. Hundreds of patients, health ministers, policy makers, civil society actors, public health specialists and pharmaceutical companies have confirmed their attendance at the unique event taking place in September while the programme is shaping up with sessions on the latest innovations in prevention, diagnosis, screening and treatment, an unprecedented experiential learning exercise and parallel sessions on different aspects of national action plan development. An exclusive, invite-only event, the World Hepatitis Summit will be an unparalleled opportunity for key stakeholders in the field of viral hepatitis to unite to advance the global hepatitis agenda. For more information on the World Hepatitis Summit, visit the website [here](#).