

Introduction

2011 saw considerable progress in the world of hepatitis. For the first time ever a viral hepatitis unit has been established at World Health Organization headquarters in Geneva; a global hepatitis strategy has been developed; and the first official WHO World Hepatitis Day was held, achieving one of the World Hepatitis Alliance's first objectives. The Alliance has been closely involved with all of these, advocating for the establishment of the unit, providing input to WHO as experts on the creation of the strategy and, of course, partnering with WHO in the organisation of World Hepatitis Day.

Following the formal adoption of membership criteria towards the end of last year, the Alliance has been adding new members continuously and now has 134 members in 58 countries. As a result of elections held last December the Alliance now has a Board with six regional members, one from each WHO world region and each someone who has or has had chronic viral hepatitis. Apparently by chance, four of the six are hepatitis B patients and two hepatitis C patients, exactly matching the relative global prevalence of the two diseases. The Alliance has a staff of three full-time employees.

Presence at international conferences

Every year the World Hepatitis Alliance attends the main liver congresses worldwide in order to keep informed of the most recent advances in the field of hepatitis and to network with prominent members of the medical community as well as with sponsors and civil society.

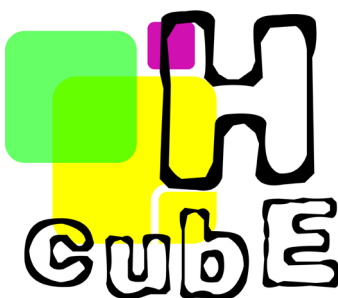
This year we participated in the Asian Pacific Association for the Study of the Liver (APASL) meeting in Bangkok in February where the president of the Alliance Charles Gore spoke on behalf of patients at two press conferences.



At the European Association for the Study of the Liver (EASL) meeting in Berlin in April Charles again gave the patient view at the official press conference to launch the event and we also liaised with the major players about the first wave of protease inhibitors to treat HCV and presented in one of the symposiums on the global subject: Viral Hepatitis, a Call for Action.



At the American Association for the Study of Liver Diseases (AASLD) meeting in San Francisco in November we had a booth to present the work of the Alliance and its members and we showed the 2011 World Hepatitis Day wrap-up report on a continuous loop. Hundreds of participants came to visit our stand and new relationships emerged, which will benefit not only the Alliance but its members as well.



The Alliance presented on our work at the H-Cube 3rd project seminar which took place at the Ministry of Health in Warsaw, Poland. We attended the meeting as an external expert. H-Cube is an EU-funded multinational HIV and hepatitis B&C prevention project. For many of the groups there hepatitis had not been their primary area of work so this was a useful opportunity to engage with them and persuade them to use the focus that World Hepatitis Day provides in their hepatitis prevention work.

We were also invited to present at the Sitges IV meeting taking place in Barcelona under the theme: 'Optimizing treatment access and outcomes among difficult-to-treat groups with hepatitis C and HIV/HCV coinfection'. Following this meeting, we got involved with the HCV Community Advisory Board (H-Cab), which is an international group working with the pharmaceutical industry, academia, clinicians and regulatory agencies on efficient and ethical development of more effective, less toxic treatment for hepatitis C virus. We have been working closely with H-Cab since.

Capacity Building

The World Hepatitis Alliance works to increase the capacity of existing patient groups and to establish new ones in countries that lack them; this year we facilitated the creation of a patient group in Moscow and have been working to get a patient group off the ground in Georgia. We also helped our members with their policy/awareness projects; for instance, the staff went to Peru in June to support the Comité Ciudadano de Lucha contra la Hepatitis. Meetings with local and national governments as well as with representatives of the indigenous peoples, among whom hepatitis B is a major problem, have been arranged and the trip was very successful resulting in the launch of a national hepatitis B plan.



Furthermore, we were made aware by our members in Poland, Foundation Gwiazda Nadziei, that the national guidelines for the treatment of hepatitis B which were put in motion in April 1 2011 were outdated and didn't benefit all patients. Hence, we contacted the European Association for the Study of the Liver and together, we supported their efforts by endorsing a letter that Gwiazda Nadziei addressed to the Minister of Health.

The Alliance also got involved with the establishment of a hepatitis francophone network. This idea originated at the 'Appel de Dakar' International Conference, which brought together key players in the field of hepatitis from all over francophone Africa. Together with our members, we contributed to the creation of a statement addressed to all African Heads of State calling on them to tackle viral hepatitis in their countries. We will continue to work with our francophone members and will update everyone on the development of the network via our monthly newsletters next year.



We were invited to present at the hepatitis patient group policy workshop in Hong Kong, which took place last month and brought different hepatitis NGOs together (mostly from Western Pacific and Europe). We gave the participants an update on the global hepatitis policy landscape and assisted them during break-out sessions on how to use this information to support their advocacy work nationally.

Finally, we have been in contact with many of our members, responding to their queries and working to identify opportunities for them.



New Members

Thirty eight organisations joined the Alliance as members this year. Our new members come from: Afghanistan, Australia, Belgium, Brazil, Burkina Faso, Cameroon, Canada, China, Croatia, D.R. Congo, Gambia, Guatemala, India, Japan, Kazakhstan, Malawi, Mali, Mongolia, New Zealand, Nigeria, Pakistan, Philippines, Serbia, Slovakia, Togo, Ukraine, United Kingdom and the United States.

Partnerships

The Alliance has established/renewed partnerships with the following organisations: American Association of the Study of Liver Disease (AASLD), Asian Liver Center, Asian Pacific Association for the Study of the Liver (APASL), Latin American Association for the Study of the Liver (ALEH), the European Association for the Study of the Liver (EASL), the European Liver Patients Association (ELPA), the Coalition to Eradicate Viral Hepatitis in Asia-Pacific (CEVHAP), GAVI Alliance, Hepatitis B and C Public Policy Association, the International Alliance of Patients' Organizations (IAPO), International Harm Reduction Association, Pan American Health Organization (PAHO), Viral Hepatitis Prevention Board (VHPB), the Global Hepatitis C Network and the World Health Organisation (WHO)

Website and online resources

Throughout the year, the Alliance has been revamping its website, creating a more interactive and dynamic platform to support our members and the hepatitis community at large. As part of this project, a new blog page and a wall of stories were created to facilitate the exchange of experiences amongst the hepatitis community. The architecture of the website as well as layout were changed to accommodate new content and to increase the accessibility of information. Moreover, several core documents and materials were translated into the official languages of the Alliance (Arabic, Chinese, French, Portuguese, Russian and Spanish), including our newsletters. We plan to continue with this trend and have as much information as possible available in other languages.



As in previous years, the Alliance developed campaign materials to be used on World Hepatitis Day with an overarching theme to link activities around the globe. In order to better accommodate local campaign messages and enhance the use of the materials in different countries we created an online tool that allows anyone to customise the materials and write messages into any language. Another novelty was the creation of an official webpage for WHD 2011, featuring a large clock counting down the days and hours until July 28. In order to promote the first official World Hepatitis Day, the World Health Organization (WHO) produced a campaign video with the financial support of the World Hepatitis Alliance. The video called attention to the huge problem viral hepatitis poses, affecting everyone, everywhere, and was very well received by many of our members. Also, WHO's Director General, Dr. Margaret Chan, recorded a statement to mark WHD in which she acknowledged the importance of partnerships with civil society and the fact that civil society and the Alliance had been the instigators of World Hepatitis Day.

Following the feedback we received from our needs assessment exercise at the end of last year, we have produced two sets of toolkits, one covering awareness-raising including WHD itself, working with the media, ideas for events, the use of online social and media resources, and the other covering policy topics, including an updated version of the '12 asks' to reflect a number of developments including the passing of the WHO resolution, suggestions on how to work with governments to develop national strategies and template letters to guide members through this process. Also, a new WHD factsheet was produced incorporating the evolution of the hepatitis movement and the involvement of WHO.

Furthermore, we have been involved in the creation of an interactive, educational tool called PATH B ("Patients and Professionals Acting Together for Hepatitis B"). This programme was designed to improve the lives of people living with chronic hepatitis B by providing information and tools to guide them through the different stages of chronic hepatitis B from diagnosis to long-term disease management. Although developed primarily for patients it can also be a helpful resource for healthcare professionals and assist in discussions with their patients on disease progression, treatment and the importance of adherence. A link to the tool can be found on our website.



On a final note, in 2011 the Alliance has been promoting awareness and news, feeding the community through our social media channels, Facebook and Twitter.

Governance

The Executive Board of the Alliance was elected in December of 2010 and their first meeting was held in London on February 2011 to discuss the Alliance's direction and next steps. Amongst many of the decisions which were taken during the meeting, we would like to highlight that the board agreed to continue to focus on three main areas of work: advocacy, awareness-raising and capacity building. We have been working with the board since to make sure the needs of all regions are taken into account in every step we take.

Policy and public affairs

In January this year the Alliance attended a meeting of experts at WHO in Geneva to discuss the global hepatitis strategy that is required by the resolution. As well as giving our input on the strategy we also discussed at length with Dr Fukuda, the WHO Assistant Director General with overall responsibility for hepatitis, the nature and size of the viral hepatitis unit needed at WHO to oversee the strategy. The unit is now in place, currently with five members of staff, and the strategy will be launched before the end of the year.



During the AASLD Liver Meeting in November we had several meetings with WHO to discuss joint working next year, including planned trips with WHO headquarters staff to the WHO regional offices and ways to evaluate the strategy.

In conjunction with the Hepatitis B and C Public Policy Association we are organising a meeting in December to look at the practicalities of having viral hepatitis included in the Millennium Development Goals when they are reassessed in 2015. If we could achieve this, it would help raise the priority of hepatitis and make it much easier to attract international funding. Amongst others, the Global Fund and WHO will be attending the meeting.

Awareness raising

On 28 July 2011, the Alliance coordinated the fourth global World Hepatitis Day and the first working in partnership with the World Health Organization! The aim for 2011 was to continue to raise awareness of chronic hepatitis B and C around the globe and to drive policy change for improvements in health outcomes for patients. What in the previous three years had been a strong community initiative is now a permanent official fixture (WHD is one of the only four disease specific official WHO days). This year we received reports from 81 countries about their WHD activities, which were featured on our summary report.

We are already preparing for WHD 12 and, because after WHD 11 the contract we had with our communications agency expired, we invited some 15 agencies to propose their ideas for WHD 12 and WHD 13. After a thorough selection process with WHO, we felt Red Door Communications had the best concept. Hence, we are proud to introduce you to next year's communication platform:

IT'S CLOSER THAN YOU THINK.

More details about the rationale behind the theme of the WHD 12 campaign as well as information about materials, timings, etc will be sent to you by the beginning of next year.



World Hepatitis Day

As you know, World Hepatitis Day was moved to July 28 in recognition of the birthday of Professor Baruch Blumberg, who won the Nobel Prize for discovering the hepatitis B virus. Sadly Professor Blumberg died in April 2011, adding further poignancy to the date this year.

Elections 2012

We would like to remind all our voting members that 2012 is an election year for the Regional Board Members of the Alliance. More details about the nominations and election process will come next year!