World Hepatitis Summit

What we learnt

Ten years of the World Hepatitis Alliance
Charles Gore shares his stand-out moments

What’s next for WHA?
As this will be the last edition of hepVoice during my time as WHA President, I thought it might be appropriate for me to share some final thoughts in this month’s foreword. As the organisation embarks on a new era, it also celebrates ten years of existence. And in those years together we have achieved so much. In this edition I share some of my most memorable moments from the past decade. One of these is, of course, the World Hepatitis Summit. The event has truly set the stage for what needs to happen next in our fight to eliminate hepatitis. Personally, it was also an opportunity to say goodbye to many of you personally and to thank you for all your work that has got us where we are today. While I may be stepping down from the global stage, I will continue the be fighting for our cause at a national level with The Hepatitis C Trust in the UK so on that note I wish us all every success in driving our efforts forward and making the elimination of viral hepatitis the reality we are all striving for.

Charles Gore
WHA Founder and President (2007-2017)

Want to contribute?
We welcome your contributions so please get in touch at contact@worldhepatitisalliance.org to have your news included in future issues and feel free to share the magazine with your network

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Where in the world

**World Hepatitis Summit 2017**

**SÃO PAULO, BRAZIL 1-3 NOVEMBER**

The World Hepatitis Summit 2017 was undeniably a huge success. Over 750 delegates from more than 100 countries came together in São Paulo, Brazil with one aim in mind: setting the stage for the elimination of viral hepatitis. Over three days, policy makers, patient advocates, global health experts and civil society actors discussed, debated and formulated solutions to reach this goal by 2030. To all that attended, thank you for joining us for this ground-breaking event. We hope you found the Summit informative and inspiring. If you were unable to attend, here are some of the key messages from the event as well as links to resources so you don’t miss out.

**Champion countries are leading the way**

Showing strong commitment from governments across the globe, 11 ministerial representatives took to the stage to share their successes in implementing initiatives to reach elimination. These included ministers and representatives from Brazil, China, Egypt, Georgia, Lesotho, Malta, Mongolia, Pakistan, Sudan, Syria, Uganda plus a video from Australia. Adding to the prestige, Bollywood star and WHO SEARO Goodwill Ambassador Amitabh Bachchan delivered a video message, in which he reiterated his support and commitment to lead the fight to eliminate viral hepatitis. Six governments (Brazil, Bangladesh, Egypt, Georgia, Mongolia and the Gambia) also pledged their support to spearhead the NOhep Visionaries Programme in their respective regions. Governments that have shown commitment to the cause and are already making headway towards elimination are beacons of best practice for countries that still have much catching up to do.
Putting people living with viral hepatitis at the heart of the response pays off

WHA President Charles Gore closed the event by saying: “Seven years ago, I dreamt of a forum where patients and policy makers could come together. Thank you for making my dream a reality.” The fact that the World Hepatitis Summit is the only event that brings together both decision makers and people with lived experience makes it truly unique. The importance of this was reiterated in almost every aspect of the event. Initial findings from WHO’s Country Profiles revealed that there is strong correlation between the countries who involve civil society in their hepatitis response and those with a national plan and dedicated funding. Supporting this, our new Holding Government Accountable Civil Society Global Report, launched at the Summit, showed significant levels of dissatisfaction with governments’ hepatitis response in countries where civil society have little or no involvement. During the event itself, civil society and WHA members featured heavily on the programme (turn to page 17 to find out more) while the Pre-Summit Member Conference that took place directly ahead of the Summit was an opportunity for patient advocates to share learnings, network and build capacity in order to strengthen the global patient voice. Finally, as the event concluded with the announcement of the São Paulo Declaration from high level government representatives, civil society and patient advocates responded by launching the São Paulo Community Declaration on Viral Hepatitis, demanding involvement of people living with the disease in the national response.

Efforts must reach the furthest behind first

From Indigenous populations to children and people who use drugs to prisoners, often overlooked groups featured heavily in discussions at the Summit. Speakers throughout the event stressed the need for harm reduction policies while presentations and side meetings looked at issues including service delivery for priority populations, hepatitis in children and the burden of hepatitis D. A unique interactive workshop on delivering equitable services encouraged delegates to work together and think differently by applying an equity framework to imagined country scenarios. Fifteen civil society organisations including the Médecins du Monde, International Drug Policy Consortium, Treatment Action Group, Coalition Plus and World Hepatitis Alliance launched a declaration calling political leaders to remove barriers that prevent people using drugs from accessing services, including criminalisation of drug offences and to adopt a public health approach. Evidently, one of the resounding messages of WHS2017 was not only to leave no-one behind but ensure that efforts reach the furthest behind first.
FINANCING DOESN’T HAVE TO BE A BARRIER

With the question of how we pay for the hepatitis response never far from anyone’s lips, the sessions on financing were some of the most anticipated. While only 35% of national plans currently have funding strategies attached to them, the resounding message was that financing needn’t be a barrier to elimination. WHO estimates that financing the hepatitis response will cost approximately $6 billion per year for all low-and middle-income countries; a figure that was starkly contrasted with the $3 billion spent on the 2010 South Africa World Cup and the $4 billion India spent on the Commonwealth Games. Coinciding with the event was the publication of this article in the Lancet stressing the need for donors to enter the space while an evening event acted as the soft launch of ENDhep2030, a dedicated fund to eliminating hepatitis. To support discussions around financing, we launched our National Viral Hepatitis Programme Financing Strategy Template that aims to guide governments on how to adopt a strategic approach to costing and financing programmes. Across the sessions, presenters reiterated that integration into wider health systems will be key to achieving elimination and crucially, as Homie Razavi, CDA Foundation, reminded us, “countries will spend less eliminating hepatitis C than doing nothing at all”.

Rediscover the World Hepatitis Summit 2017 with all our resources

• Presentations
• Abstract posters
• Videos

This month we celebrate ten years of the World Hepatitis Alliance (WHA) and in those ten years previously unimaginable progress has been made. From a little-known illness almost completely ignored by policymakers to a global commitment to eliminate viral hepatitis from every country in the world, the past decade has proven that a strong patient voice really can change the world.

This month also marks the end of Charles Gore’s term as WHA President. In this role he has driven efforts across the globe to put hepatitis on the agenda and his leadership has helped the hepatitis community realise great achievements.

To commemorate this momentous occasion, Charles reflects on some of his stand-out moments as WHA President.

**WHA ESTABLISHED IN 2007**

“It all started with awareness. Exasperated by the fact that viral hepatitis was such a little-known disease, we assembled patient advocates from across the globe and together agreed to establish a World Hepatitis Day. We then had to create the World Hepatitis Alliance to run it. That was all we initially set out to do.”

“Very quickly we learnt that there was much more that needed to happen. Without an official mandate, governments weren’t interested in supporting World Hepatitis Day. So WHA was forced to move into advocacy. We mobilised patient groups from around the world and started working with governments to develop the first resolution on viral hepatitis.”
WHO Global Hepatitis Programme established

“As a result of the first World Health Assembly resolution, WHO set up the Global Hepatitis Programme in 2011. When I learnt that this would form part of the Department of HIV, I initially had concerns. Viral hepatitis had been overshadowed by HIV/AIDS for so long. But I was proved wrong. In fact, by being part of this department, hepatitis got more resources than it otherwise would have received and helped us develop an extraordinarily productive relationship with WHO.”

194 Governments committing to elimination

“28 May 2016 was truly a landmark moment for me and for the community. When WHO Member States adopted the elimination strategy, I couldn’t help thinking back to 2010 when I first saw, just as it was getting ready for its unveiling, the statue outside WHO HQ that commemorates 30 years since the eradication of smallpox. At the time, it felt like we were so far from even considering elimination, let alone eradication, for viral hepatitis. It just shows that with a strong and united patient voice and sheer, gutsy determination, we can achieve miracles.”

World Hepatitis Summit 2017

“By concluding my time as WHA President with the second World Hepatitis Summit in São Paulo, Brazil, I really am going out on a high note. Its success proved that it is a truly unique and important event and it has set the stage for what we need to do now: to turn elimination from a concept into tangible action on the ground.”

Charles has also written a farewell statement that can be read on the WHA website and recorded a special video message for all WHA members.
We have come a long way but as we celebrate our ten year anniversary, we cannot allow ourselves to become complacent. A global strategy and targets alone are not enough to turn an aspiration into reality. As an organisation that represents the 325 million people living with viral hepatitis, we know that elimination will not be achieved without putting the people affected by viral hepatitis at the heart of the solution.

We therefore embark on 2018 with a renewed mission. A mission to “harness the power of people living with viral hepatitis to achieve its elimination”. With 325 million people affected by viral hepatitis, we have potential to build a powerful army of advocates but of those, 290 million people are completely unaware of their illness. Without finding these “Missing Millions” that are yet to be diagnosed and linking them to care, all other efforts will only have marginal success. Our first step is therefore to find them.

Find out how to plan to do this in our newly launched 2018-2020 Strategic Plan.

To coincide with the launch of our 2018-2020 Strategic Plan, we have developed a special video that celebrates WHA’s trailblazing journey so far and sets out our vision for the future.

Watch the video here. (Français ici) (Español aquí)

We are inviting all WHA members the unique opportunity to learn more about the newly launched strategic plan and find out how you can be part of our plans and programmes for 2018. This is an important opportunity to hear directly from WHA and get involved in our activities. Register here.
Together our stories can change the way the world sees viral hepatitis. The stories of those living with or impacted by viral hepatitis can help educate and raise awareness, provide support and inspiration, tackle stigma and discrimination, and highlight the true impact of this global disease. Share your story here.

With people with real life experiences of viral hepatitis making up a large part of the delegation at the World Hepatitis Summit, we took the opportunity to film some of their stories.

**Lisa, Australia**

“It was a long two years of worrying to wait for the test to see if she was hep C positive.”

Hear Lisa’s story here.

**Members at the heart of the event**

True to our aim of putting the people living with viral hepatitis at the centre of discussions, many WHA members presented in sessions at the Summit: Carlos Varaldo of Grupo Otimismo shared his experiences of living with hepatitis C in the opening session; Dr. Mohammad Ali, National Liver Foundation of Bangladesh, provided insights into running successful awareness campaigns in Bangladesh; Rajkumar Nalinikanta, CoNE Manipur, highlighted the role of civil society in accessing generics; Emalie Huriaux of Project Inform presented on the innovative way End Hep C SF have reached marginalised populations; Hepatitis Victoria’s Lien Tran showed how the Little HepB Hero project used child ambassadors to reach new audiences.
And finally, the feedback from WHA members speaks for itself. We have been overwhelmed by the number of blogs, articles and even podcasts authored by WHA members. The response highlights what a truly ground-breaking event the Summit is and the huge benefit it has to our community. Here is just a selection of views on WHS2017:

- Teresa Casanovas, ASSCAT, Spain
- Melisa Dickie, CATIE, Canada
- Melanie Eagle, Hepatitis Victoria, Australia
- Fundación HCV Sin Fronteras, Argentina
- Tove Frisch, Riksforeningen Hepatit C (RHC), Sweden
- Carlos Varaldo, Grupo Otimismo, Brazil

Exasperated by Russia’s lack of national strategy, Aleksey Lakhov of United Against Hepatitis used the Summit as an opportunity to record video messages from activists from around the world. Directing their pleas at Russian Prime Minister Dmitry Medvedev, delegates called for Russia to develop and implement a national hepatitis strategy immediately.

We love to highlight the great work of our members, so get in touch with updates on your national activities.