In 2015, for the first time, we brought our members from around the world together in Scotland to meet, learn from one another and build the advocacy voice. Building on the incredible momentum of that event, we were delighted to welcome not only our members but also expert speakers, World Health Organisation staff and industry representatives, to Brazil in October 2017 for the second Pre-Summit Member Conference.

The event was designed to highlight the role that civil society have to play in reaching elimination and the importance of harnessing the patient voice to achieve that. It aims to connect and strengthen the community of hepatitis advocates and give delegates the tools to have a meaningful engagement in their countries.

The objectives of the Pre-Summit Member Conference were:

- To increase members’ engagement with the NOhep elimination movement and to highlight how the NOhep brand can be incorporated into their current activities;
- To educate members about new developments in diagnostics and treatments;
- To educate members around barriers to access for medicines and diagnostics, exploring areas beyond the issue of pricing and how to overcome them;
- To empower members to advocate at a national level for access to diagnostics and medicines;
- To initiate a working relationship between members and their WHO focal points;
- To facilitate networking and collaborative learning between delegates.
PARTICIPATION

The Pre-Summit Member Conference brought together 215 individuals from 71 countries. 157 of the attendees were members of the World Hepatitis Alliance (WHA) representing 138 different viral hepatitis patient groups.

The conference was made possible with the support of the below sponsors.

PROGRAMME

The programme for the Pre-Summit Member Conference was developed using feedback from the first Pre-Summit Member Conference in Glasgow and our own needs assessment. It was designed to be a mix of expert led and peer to peer learning opportunities.

Monday 30 October

9:00 – 9:15  Welcome
9:15 – 10:20  Access 101
10:20 – 10:50  Refreshments and networking
10:50 – 13:15  Access 101 continued
13:15 – 14:15  NOhep: building a global movement
15:50 – 16:15  Refreshments and networking
16:15 – 17:30  EGM
19:00 – 22:00  Pre-Summit Member Conference Dinner

Tuesday 31 October

9:00 – 9:20  Welcome
9:20 – 10:25  WHO and WHA Regional Advocacy
10:25 – 11:00  Refreshments and networking
11:00 – 12:30  Open Space
12:30 – 12:45  Pre-Summit Member Conference close

Abbott  abbvie  Alere

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GILEAD  INNOVAX  janssen

MSD  PHARCO PHARMACEUTICALS  Roche

SANOFI PASTEUR  ICM The John C. Martin FOUNDATION
**Sessions**

**Access 101**

**Purpose**
The purpose of this session was to look at the barriers to access beyond pricing and give members the tools to more effectively advocate for access within their countries. Presentations were given by experts in their fields, with the final presentation given by not only an expert but also a patient representative and WHA member. This brought the patient voice back to the centre of the conference and was an important message to conclude the presentations.

**Overview**
The presentations given were:

- Introduction and setting the scene – Homie Razavi, Center for Disease Analysis Foundation
- What is in the pipeline for HBV and HCV? – Sebastian Marciano, Hospital Italiano de Buenos Aires
- Registration of medicines: when does it facilitate and when does it hamper – Ellen ’t Hoen, University Medical Centre Groningen
- Testing algorithms, simplicity and affordability – Francesco Marinucci, FIND
- Pre-qualification – Philippa Easterbrook, World Health Organization
- Personal import and buyers clubs – Giten Khwairakpam, TREAT Asia
- Public health orientated licensing through the Medicines Patent Pool: how does it contribute to access to treatment in low and middle income countries? – Esteban Burrone, Medicines Patent Pool
- Rationing: public health approach, equity and stigma – Rachel Halford, Hepatitis C Trust

We did not allow time for questions after each presentation and instead had a question and answer session with all presenters at the end of the session. Prior to the Q&A members broke into pre-determined groups for 30 minutes to decide which three questions they would like to pose to the panel. The reason for structuring the session in this way was to allow for members to discuss what they had just heard and give them the opportunity to voice their opinions, before agreeing on what questions were most important to them. Each group had the opportunity to ask one question to a member of the panel with other members of the panel adding to their answer if time allowed.

**Conclusion**
The narrative around access is often on pricing and so to explore the other barriers, which are often technical, and to have this information tailored for civil society organisations is a unique capacity building opportunity. It gave delegates the knowledge to better understand the barriers that may exist in their country and so leave them better able to advocate for their removal. The questions asked during the panel discussion reflected the breadth of the topics presented and the different interests of the delegates in attendance. Despite the variety in the questions the key message that came out of the session was that civil society has a key role to play in overcoming the barriers to access and more advocacy is needed, especially in relation to hepatitis B and diagnostics, if we are to reach elimination.

“Invaluable information essential as an advocate lobbying governments and funders.”

United Kingdom

“This provided me with information that I had found hard to find/hard to understand previously.”

Australia
NOhep: Building a Global Movement

Purpose
NOhep is a global movement of people working to eliminate viral hepatitis by 2030. Pioneered by the World Hepatitis Alliance in 2016, NOhep brings governments, medical professionals, patients and the hepatitis community together to accelerate action to achieve the World Health Organization’s (WHO) elimination targets. The NOhep session was designed to re-introduce NOhep to our members, highlight how it has been used across the world and update them on the plans for the movement in 2018.

Overview
NOhep is for everyone and in keeping with this ethos presentations were given by advocates from across the world. Members from China, Bangladesh, Uganda and Slovenia presented on how they have incorporated NOhep into their activities with presentations highlighting the different approaches that groups have taken. These presentations were complemented by a number of informative presentations by members of the NOhep Secretariat, who amongst other things, spoke about the future of NOhep. Following the presentations a lively panel discussion was had, with delegates given the opportunity to pose questions to any of the presenters.

Conclusion
The NOhep: Building a global movement session was a great opportunity for delegates to learn from one another and gain inspiration from what their peers have done. The patient voice was central and it showed how powerful grass roots advocacy and awareness campaigns are in helping to build a global movement. The session encouraged delegates to make NOhep part of their activities and was a clear call to action and something tangible that they could take away and implement.

WHO and WHA Regional Advocacy

Purpose
The objective of the WHO and WHA Regional Advocacy session was to link our members with the WHO hepatitis focal point for their region and start a dialogue between WHO and civil society organisations in their region.

Overview
The members were split into each of the six WHO regions with the Pan-American region further split into English and Spanish speaking. By breaking the groups into the WHO regions it ensured that discussions could be tailored to that region. For each of the regions the WHO focal point gave a brief presentation at the start of the session. Topics covered included WHO structure in the region and regional meetings, regional updates including action plans, targets and key issues and priority issues at a regional advocacy level. Time was then allowed for questions and discussion, with the outcomes captured by the WHA board member for that region. The outcomes from each of the sessions can be found in Appendix 1.

Conclusion
This session was rated as the most beneficial to delegates with feedback highlighting that they gained a greater knowledge and understanding of the work that WHO does within their region. It was the first time that we had brought the members together with their WHO regional focal point and it acted to strengthen connections. The outcomes of the discussions for each of the regions was different and the programme was designed to ensure that each region had the flexibility to discuss what was most relevant to them. Splitting the members into their regions also enabled people to better understand the progress of their country in relation to their region. A key theme which came out of the discussions was the need to better integrate the work that WHO and civil society are doing, whether that be through attendance at meetings or aligning on messages. The need to use WHO reports as a tool was also discussed by a number of groups.

It help me how to organise awareness campaign in my country for eliminating hepatitis.

Pakistan

... the NOhep one was probably more inspiring and appropriately urged more people to participate.

Australia

Because I learn process (step by step) how to start collaboration with WHO.

Serbia
OPEN SPACE

Purpose
The Open Space session gave participants the opportunity to define the topics they were most interested in and to join discussions most relevant to their interests. In this way they were able to shape the programme, learn from each other and to make connections with others working on similar issues.

Overview
At the start of the Pre-Summit Member Conference the opening speaker introduced the concept of Open Space to the audience. Throughout the first day of the event, people were encouraged to suggest topics they wanted to talk about by writing TOPIC IDEAS on post-it notes and sticking them to a noticeboard in the foyer area. They were also encouraged to volunteer to be a session convenor by adding SESSION PROPOSALS to another noticeboard (TOPIC IDEA + CONVENOR = SESSION PROPOSAL).

Ahead of the Open Space session the organisers collated the proposals and the session chairs chose the below topics, which covered a variety of issues that may not have previously been covered.

- Partnership between government and civil society
- Perinatal HBV & HCV
- Drug policy / harm reduction & accessing to diagnosis and for people using drugs
- Patient stories
- General population – how do we include them in screening and treatment?
- Diagnosis
- Access to treatment in rural areas
- Stigma and discrimination (in workplace)

At the start of the session delegates were advised of the topics selected and told that they could join any discussion and change group at any point. To report back on their discussions, participants were brought back into the main room before the end of the session and some of the groups were asked to present what they had discussed. In addition, each group was asked to hand in a written summary of their discussion. The summaries can be found in Appendix 2.

Conclusion
The session received overwhelmingly positive feedback, much of which focused on the advantages of cross-country learning, sharing experiences and interacting with organisations from around the world. The topics put forward also offer an important insight into the issues civil society organisations and patients are facing. While a mix of topics were put forward six of them were either specifically focussed on diagnosis or included diagnosis as part of their discussions. This reinforces one of the key messages that came out of the panel discussion in the access session; diagnosis is a significant issue that is affecting people around the world.

OPEN SPACE
Open space was great, we should have 1 each day. It brought together people addressing the same issues across the globe.
USA

GENERAL FEEDBACK

Delegates were asked to rate the Pre-Summit in terms of the below, where 1 equals poor and 5 equals very good.

<table>
<thead>
<tr>
<th>Score</th>
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<tbody>
<tr>
<td>Benefit to your role/organisation</td>
</tr>
<tr>
<td>Programme content</td>
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<tr>
<td>The mix of plenary sessions and workshops</td>
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<tr>
<td>Venue facilities</td>
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<td>Event organisation</td>
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<td>Invitation process</td>
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<td>Registration process</td>
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<td>Networking opportunities</td>
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<td>Overall rating</td>
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All sessions were well received with the most beneficial session, as ranked by delegates, below.

- NOhep: Building a Global Movement (19%)
- Access 101 (25%)
- Open Space (26%)
- WHO and WHA Regional Advocacy (30%)
IMPACT

The objective of the Pre-Summit Member Conference is to bring members together to build their capacity and strengthen the patient voice so that they are better able to advocate for the elimination of viral hepatitis within their country.

In assessing the immediate impact of the Pre-Summit Members Conference we considered three areas which together achieve the objectives of the conference.

- How did it contribute to convening and networking?
- Was participation inclusive?
- Did it increase knowledge?

CONVENING AND NETWORKING

- The Pre-Summit Member Conference brought together 158 civil society representatives from 66 countries. It is the only event of its kind which brings together hepatitis charities from across the globe and in doing this it fosters a sense of community which is important as communities allow people to connect faster and on a deeper level, making stronger networks.

  “Best place to share experiences and to learn from each other.”
  Germany

  “It allowed me to interact with other activists from across the globe.”
  Russia

  “Utilize relationships gained to enhance activities.”
  USA

  “Networking! I am new to advocacy and this has been instrumental in getting me started.”
  USA

- Importantly the Pre-Summit connected not only civil society organisations with each other but also facilitated meetings with key strategic stakeholders, such as their WHO focal points, that they otherwise may not have the opportunity to meet with. Alongside civil society organisations also in attendance were representatives from the World Health Organisation, experts in the field of access, programme managers and supporters.

INCLUSIVE PARTICIPATION

- 124 WHA member organisations were fully funded to attend.
- 43 presenters and group leads of which 25 were civil society representatives.
- Presenters and group leads represented 25 different countries.

  “Provision and opportunity to convey to WHO how we can strengthen our partnership interaction and amplify the voice of civil society in engagement with government.”
  Malawi

  “Offered the opportunity for different communities to come together and share ideas, learn from each other towards elimination of viral hepatitis.”
  Ghana

  “Feeling of ownership and motivation”
  Australia

  “Thank you for the opportunity to join the convention. I feel important and one who might be able to make a difference in my country.”
  Denmark

- Plenary sessions were translated into French, Spanish and Portuguese while workshops were either translated or conducted in French and Spanish.
- All sessions encouraged questions and discussions to remove any barriers to participation.
- The design of the open space session was collaborative and empowered delegates to shape the programme and discuss the topics that they think would most benefit them.
**INCREASING KNOWLEDGE**

- 1.5 days of programming designed to increase delegate’s knowledge on a variety of topics and inspire them to take action.
- A mix of presentations and workshops to enhance capability building.

- Opportunities for cross-country and cross-regional learning from peers.
- Delegates feedback on how they will apply what was learnt to their everyday activities. The key themes that came out of this were:
  - Share the learnings with colleagues
  - Follow up with those they have met at the Pre-Summit and explore possible collaborations
  - Re-evaluate their organisational strategies
  - Increase engagement with governments
  - Include NOhep in future activities

- Encourage screening amongst my colleagues for our patient population and encourage it via my professional medical organizations (AAFP, PAMED, etc.).
  - USA

- Communicate with new network opportunities. Work on raising the profile of hep elimination by using WHO and WHA resources.
  - New Zealand

- Using data to increase awareness & advocacy. Inclusion of this in our strategy and planning.
  - Uganda

- Know the broader context - plan better programmes.
  - Australia

- I will feel more informed and have more confidence in lobby and developing programmes of support.
  - UK

- Inspired to push for hepatitis elimination at state level in California.
  - USA

- Information sharing in the communities I serve. Also to continue the networking process I’ve engaged in while here.
  - Canada

- Deepen interaction and engagement with other civil society organisations in Africa & in country.
  - Malawi

- I will customise all the discussion to my local area to use it for effective delivery.
  - USA

- I sure intend to adopt the Bangladesh model to promote NOhep movement in my country and region.
  - Uganda

- I will endeavour to advocate for other countries to receive support from our country.
  - UK
APPENDIX 1

OUTCOMES OF WHO AND WHA REGIONAL DISCUSSIONS

African Region
- Still need to raise awareness on viral hepatitis to interest policy makers.
- Both WHO AFRO, governments and patient organisations all have an important role to play in ensuring:
  - Information for focused action
  - Interventions for impact
  - Delivering for equity
  - Financing for sustainability
  - Innovation for acceleration
- Need to advocate for national plans in countries without plans
- Need to talk to governments to wave taxes on hepatitis medicines
- Reinforcing private partnerships in mobilising the communities in addressing viral hepatitis

Eastern Mediterranean Region
- To include civil society organisations in WHO meetings, technical meetings and by focal points. It is important to listen to their voices as they are part of the problem and should be involved in planning and implementation.
- Integration with international and local organisations to provide DAAAs for reduced prices.
- Help with prioritisation e.g. for screening either for HBV and/or HCV “the need”
- Support the establishment of health centres for refugees in Pakistan and Afghanistan.
- Database for civil societies and NGOs which enables them to share documents and help hearing different voices.
- Open channel with WHO through engagement of WHO focal points with civil societies as well as acting as an intermediate channel between the Ministry of Health and the NGOs.
- Support for harm reduction.

European region
- Questioned how much WHO can push the government on a topic.
- WHO and patient groups need to coordinate the advocacy activities, to align messages, even if using different mechanisms
- WHA members need to approach the WHO country offices copying the WHO regional focal point
- WHA members need to refer to WHO committal documents, global strategies and regional plans in their advocacy work
- Involve patient groups in the monitoring process

Pan American Region – English
- Americas report (PAHO 2016)
- Many gaps in care, treatment and screening

- We did introductions, outcomes and discussed gaps and priority areas
- Will send slides
- Nick was great to have there

Pan-American region - Spanish
Learnings
- The countries’ responses and advances for the elimination of hepatitis are different in Latin American countries.
- Not all the countries celebrate World Hepatitis Day.
- In countries that have hepatitis plans/programmes, not all civil society groups have participated.
- Not all countries have access to medicines from the Strategic Fund.
- Not all civil society groups have met the person in charge of the hepatitis program at PAHO’s National Office.
- Not all of the civil society groups of the WHA in Latin America have been invited to PAHO sub-regional meetings South America.
- There are many countries which have not created patients groups.

Suggestions
- In order to accelerate the hepatitis response in Latin American countries, civil society groups belonging to WHA need to establish links with the Minister of Health (MoH) and medical societies for advocacy. Maybe PAHO national offices could support these links and facilitate meetings among these groups so that they could work together (in countries where they don’t work together).
- With PAHO support we can promote the World Hepatitis Day celebration, not only by civil society groups but also by MoH and medical societies.
- It is necessary the formation of patients groups in the countries that do not have them. PAHO must support this process. Maria Eugenia de Feo from Argentina has offered to be the focal point for South America. Patricia Velez from Guatemala has also offered to be the focal point for Central America and the Caribbean. They could also work together in the whole region (Latin America).
- This meeting is the first we had all together with PAHO. It was very interesting and informative to know all the resources, advances and gaps in the region.
- We believe that it could be of great value to have another working meeting with PAHO in 2018, so that we could update what we have been doing in our countries, be aware of the needs and difficulties we maybe be facing, find solutions, provide support and be better prepared, and present this new information in the next hepatitis summit.
- In the next Pre-Summit, it will be very enriching to have a session with the English speaking countries and the Spanish speaking countries to meet each other and share experiences.
- It is imperative to continue having the Latin American session.
South-East Asia Region
- Regional meeting to be planned at least once a year
- All agree that local targets to be fixed
- Interaction with government and make them accountable
- Government initiative missing
- Chennai Liver Foundation can offer free medical advice
- Formation of registry

Western Pacific Region
- Everyone wants to learn from each other, knowing each other and working together. Through ice breaking we managed, for the very first time, to know about 15 others.
- WHO showed a very optimistic and open mind set to engage with the patient groups. WHA’s significance is in everybody’s perception. The role of groups is yet to be defined.
- A WhatsApp group will be set up to have everybody there, sharing and learning.
- The regional alliance is united at least face to face to end hepatitis.
- The priority slide enlightened everyone in the group.

Feedback From the Group Discussions at the Open Space Session

Partnership between government and civil society
- Serious problem.
- Rwanda – demonstrations made the government look up. Insurance companies started funding. Now reasonably streamlined & all join hands to provide access.
- WHO needs to change strategy, they need to engage civil society.
- California – started at the local level to identify stakeholders & to engage the entire community. Took very specific tasks, vaccinations, testing etc., and do one at a time.
- National public dialogue, government needs to take the initiative.
- Sufficient data needs to be generated to consume government.
- Government has to work with civil societies in partnership to reach to the public.
- It has to be a win-win situation.

Perinatal HBV & HCV
- Enormous varieties of practice between & within countries:
  - Screening pregnant women
  - Care of HBV +
  - HBV DNA & TDF antecel
  - HBV vax – birth dose
  - HBIG access
- Healthcare access disparity dictates quality of care:
  - Government funding
  - Insurance
  - Self-pay
  - Affordability
- Pockets of government practice in countries
  - Birth-dose (pentavalent at levels d.n. client)
  - Policy vs real life practice
  - Find the missing millions – pregnant

Drug policy / harm reduction & accessing to diagnosis and for people using drugs
- As part of the missing millions campaign prioritise people who use drugs including people in prison, youth, trans, indigenous and any other ‘hidden’ population.
- We recommend WHA reach out to drug policy, harm reduction, drug user groups, youth-led organisations to invite them to become voting members
- WHA, in collaboration with WHO, should promote HCV diagnosis & tx with no restrictions.
- Government take a strong stand on syringe access & OAT access, HR in prison.
- Peer led interventions/outreach
- Syndemic approaches > no more sylos
• And strong stand/statement against criminalisation/punishment/stigma.

Patient stories
• Hep B Foundation’s (U.S.) success with #justB stories – great model! www.hepb.org
• Getting patients to share is a challenge
  • Stigma
  • Consequences from disclosure (example - firing HBV+ employee – Uganda)
  • Can’t because they are involved in litigation (HCV example – U.S.A.)
• Need to share existing stories and spread the word in an organised way

General population – how do we include them in screening and treatment?
• Lack of empathy, support & resources for hepatitis patients compared to other diseases. There is also stigma & self-shame among viral hepatitis patients, as well as a lack of general awareness among the general public. What is the next step?
  • General awareness & education with help from media engagement
  • Engagement with healthcare provider, patient, civil society & community leader
  • Get government buy in (guideline, mandatory testing, capacity building, infrastructure for testing & enforce message)
  • Partnership (e.g. with Ministry of Education)
• Age consort vs. risk based testing

Diagnosis
• NGOs have to fight for screening in parallel to access to treatment.
• People with fatty liver or those that intake alcohol can save their liver with AB test, stopping intact of alcohol or taking care of their fatty liver. Reducing one factor that can lead to cirrhosis.
• Every national plan should start with prevention (screening).

Access to treatment in rural areas
• Harm reduction at start of treatment for HBV in Africa. Sustainability – big number of non-compliance due to cost.
• Training for GPs in treating + management / peer testing. Move away from specialist centres.
• Outreach – fibroscan. Peer support.
• Mobile screening.
• Screening access – in Mongolia. PCR testing problematic, only in city not in rural areas. Treatment outcomes cannot be monitored.

Stigma and discrimination (in workplace)
• Senegal, Gambia: practically no stigma or discrimination because no HepC diagnosis and very low prevalence. HepB: Everyone is infected or affected. Hep is such a huge problem that there is not much stigma.
• Congo (Kinshasa), Benin, Burkina Faso, Serbia: very high stigma! In Serbia & Congo confusion between HIV & hepatitis & groups at risk (SW, IDU…). In Benin attempts from health workers to protect chronic carriers and status disclosure. In Burkina Faso, Serbia & Congo: stigma within health system!!
• China & Philippines: Millions of workers stigmatised in factories. Horrible situation with often compulsory screening and although published in China since 2020. Situation still very bad for state workers, education workers etc.
• Australia, New Zealand: public policies enacted to fight stigma but still lots of discrimination in particular for:
  • Hep C: association between drug use & hep C
  • Hep B: misconception brought from everywhere, in particular from Asian immigration
• USA: public policies also enacted and situation used to be worse but still discrimination. In particular for health workers & medical students.