



World Hepatitis Alliance



Finding the Missing Millions

The World Hepatitis Alliance's 2018 – 2020 Strategic Plan

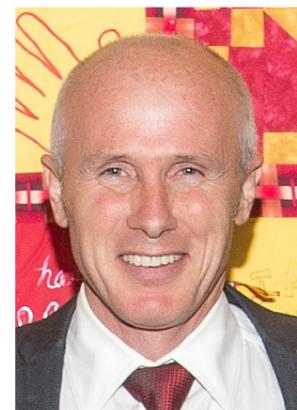


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FIGHTING FOR A WORLD FREE FROM VIRAL HEPATITIS

FOREWORD



Rarely in history has there been such disparity between the burden of disease and the global response as with viral hepatitis. As the world celebrates decreasing mortality from HIV/AIDS, tuberculosis and malaria, our community rebukes the rising number of deaths from viral hepatitis

– a staggering 1.3 million each year that has increased by 22% since 2000. More worrisome yet is just how many more deaths we could be talking about. Across the globe as many as 325 million people are living with hepatitis B and C but only every 1 in 10 people are aware of their illness and just 1% access treatment.

Viral hepatitis is a global problem that demands immediate action. It is not found in one location nor amongst one group of people. In fact, those most affected are those already disadvantaged, marginalised and often silenced, such as people who use drugs, indigenous peoples, prisoners, men who have sex with men and migrants. Elimination is not conceivable without significant efforts to ensure that not only is 'no-one left behind' but that the furthest behind are reached first. Furthermore, success will require a comprehensive approach. From harm reduction and access to medicines and diagnostics, to blood and injection safety, to sanitation and access to clean water, these are all issues that must be addressed in order to tackle this global epidemic.

Yet, progress is finally in sight. Following advocacy by the World Hepatitis Alliance and its members, 194 governments adopted WHO's Elimination Strategy in 2016, with many countries now enhancing their efforts to tackle this disease. Still, we have much to do to make up for decades of neglect and WHA has developed an ambitious workplan to accelerate the response to viral hepatitis. Unequivocally, the time for action is now.

Michael Ninburg
WHA President, 2018-2019



We have an opportunity to eliminate a global killer. With effective vaccines and treatment for hepatitis B and a cure for hepatitis C as well as global commitment to the cause, elimination is achievable. So few devastating diseases can boast this. And yet, while all the tools needed exist, a crucial

piece of the puzzle is missing to make this goal a reality. What's missing is the people: 290 million people who are suffering from hepatitis B and C but are completely unaware of their illness. These people can transmit the disease to others and are at risk of developing fatal end-stage liver disease. Without finding the missing millions, elimination will remain nothing but a pipe dream.

Furthermore, we know that the voice of people affected by viral hepatitis is paramount to achieving elimination. The efforts made over the past decade is testament to this. The progress already made would be inconceivable without strong patient advocacy that has tirelessly demanded attention. With drastically scaled-up awareness and diagnosis efforts to find and educate the millions currently in the dark, there is potential to shout so much louder. Once the missing millions become aware, we have a powerful army of 325 million advocates who can drive prevention, demand access, encourage innovation and save lives.

The road ahead may be long but this is exactly why we must speed ahead. Unlocking the potential of the missing millions and harnessing the power of the people living with viral hepatitis means acceleration, momentum and determination towards our elimination goal.

Raquel Peck
WHA CEO

OUR STORY SO FAR: A TRAILBLAZING JOURNEY

In just 10 years of existence, we have not just changed the course of history for viral hepatitis, we have put it on the map. We pioneered the fight through our awareness raising, advocacy and capacity building activities and from uniting the community on the first World Hepatitis Day in 2008 to a decade of strong patient advocacy, a decade of tenacious effort and unwavering commitment has resulted in 194 governments pledging to the elimination of viral hepatitis by 2030.

We are at a turning point. We have vaccines and a treatment for hepatitis B and a cure for hepatitis C. Very ambitious targets were set when the WHO Elimination Strategy was ratified in 2016, including 90% reduction in new cases of chronic viral hepatitis B and C infections, 65% reduction in viral hepatitis B and C deaths and 80% of eligible persons with chronic hepatitis B or C virus infection treated by 2030.

Although we have come a long way and great progress is being made, a global strategy and targets alone are not enough to turn an aspiration into reality. Today, only 9 out of the 194 countries that committed to eliminating this epidemic are on track to reach the 2030 goal. They cannot do it alone. Collaboration will be key and we know that elimination will not be achieved without putting the people affected by viral hepatitis at the heart of the solution.

May 2016 First global elimination strategy

March 2017 first WHO STAC HIV-HEP meeting on elimination strategy

September 2015 Viral hepatitis mentioned in the Sustainable Development Goals

September 2015 – September 2016 Regional action plans adopted

January 2015 – present WHA seconds a technical officer to WHO EURO to be the hepatitis focal point for the region

May 2014 Adoption of the second resolution on viral hepatitis (WHA67.6)

August 2013 WHA granted Special Consultative Status by the United Nations Economic and Social Council

July 2012 WHO launches its Prevention and Control of Viral Hepatitis Infection Framework for Global Action

December 2011 Global Hepatitis Programme established

May 2010 Adoption of the first resolution on viral hepatitis (WHA63.18)

2008 Advocating for support for the first World Hepatitis Day

2007 WHA established

2009 Development of the first World Health Assembly resolution on viral hepatitis

19 May 2008 First community-led World Hepatitis Day

July 2011 First official World Hepatitis Day

January 2012 WHA establishes Official Relations status with WHO

May 2013 WHA organises a side meeting on viral hepatitis at the World Health Assembly

September 2012 WHA seconds a member of staff to the WHO Global Hepatitis Programme

2014 WHA joins WHO Director-General's STAC-HEP on hepatitis

December 2014 – February 2015 WHA participates in WHO consultations on viral hepatitis elimination targets

May 2015 WHA makes intervention at WHO technical briefing on elimination strategy

January 2016 WHA advocates for global elimination strategy at WHO Executive Board meeting

July 2016 NOhep launched

April 2016 Need to address hepatitis in drug policy recognised by United Nations General Assembly

April 2017 first global hepatitis report with WHO-validated estimates

November 2017 Second World Hepatitis Summit

September 2015 WHA launches the World Hepatitis Summit

MAKING AN IMPACT

A snapshot of how our work benefits our members:

“Since 2010, we have joined forces with the World Hepatitis Alliance to celebrate World Hepatitis Day. The resources and guidance they provide us each year connects us with a global community of organisations, patients and governments, helping us to build awareness and deliver national impact.”

Deutsche Leberhilfe e.V., Germany

“We are delighted to be working with WHA in-country here in Nigeria. Working collaboratively, we hope the financing project will produce tools that encourage governments to consider the right of their citizens to quality health care, to allocate more funds and further the viral hepatitis cause.”

Chagro-Care Trust (CCT) Taraba, Nigeria

“More than 15 million people are living with Hepatitis in Pakistan. We used the platform of NOhep to engage multi stakeholders including young people, homeless people, pregnant women, transgenders, people who inject drugs, media, health care workers, academia and religious groups in Hepatitis awareness and screening programs to achieve the common aim of leave no one behind.”

Bridging Health Foundation, Pakistan

“Working with the World Hepatitis Alliance has helped us build our awareness and knowledge of the global policy landscape and through their regular capability building webinars, have helped us translate global policies into national actions.”

Liver Foundation, West Bengal, India

“The highly successful 2017 World Hepatitis Summit in Brazil was testament to WHA’s role as a global convener. More than 900 policymakers, people living with viral hepatitis, community advocates and professionals came together to debate, discuss and formulate plans to eliminate viral hepatitis. The interactions at the Summit were both inclusive and powerful and serve as an excellent platform to create global change. The health and welfare of people living with viral hepatitis can only be advanced as a result.”

Hepatitis Australia, Australia

“Being a member of the WHA means to belong to a global community where people with different languages and cultures, they put aside their differences and cooperate together to help stop the spread of viral hepatitis, to benefit the health of patients.”

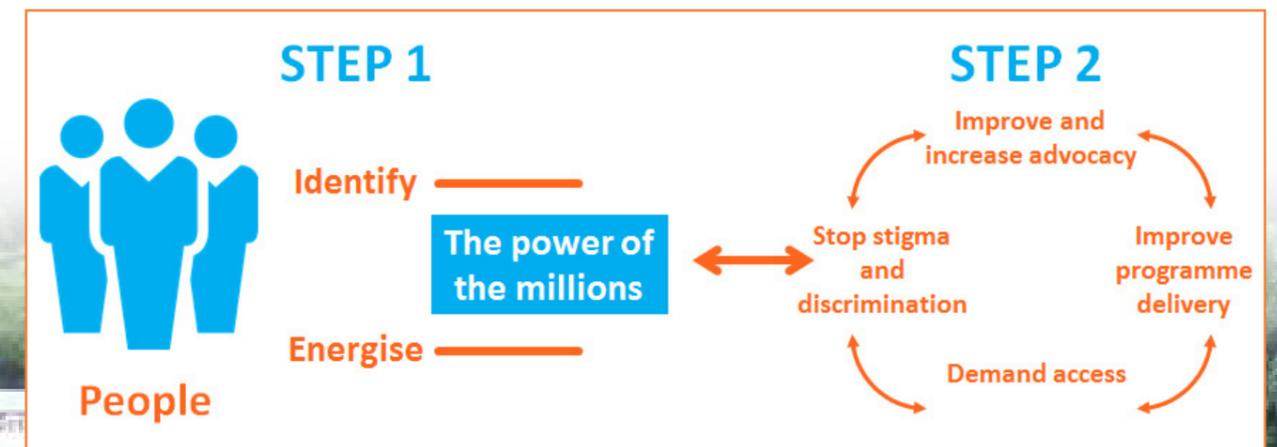
Fundación Hepatos Aión, Mexico

WHAT’S NEXT

We have 13 years to hit our ultimate goal. 13 years to make viral hepatitis a thing of the past. So where do we start? With 252 members working on the ground in 86 countries, we start by uniting on a renewed mission to:

“Harness the power of people living with viral hepatitis to achieve its elimination”

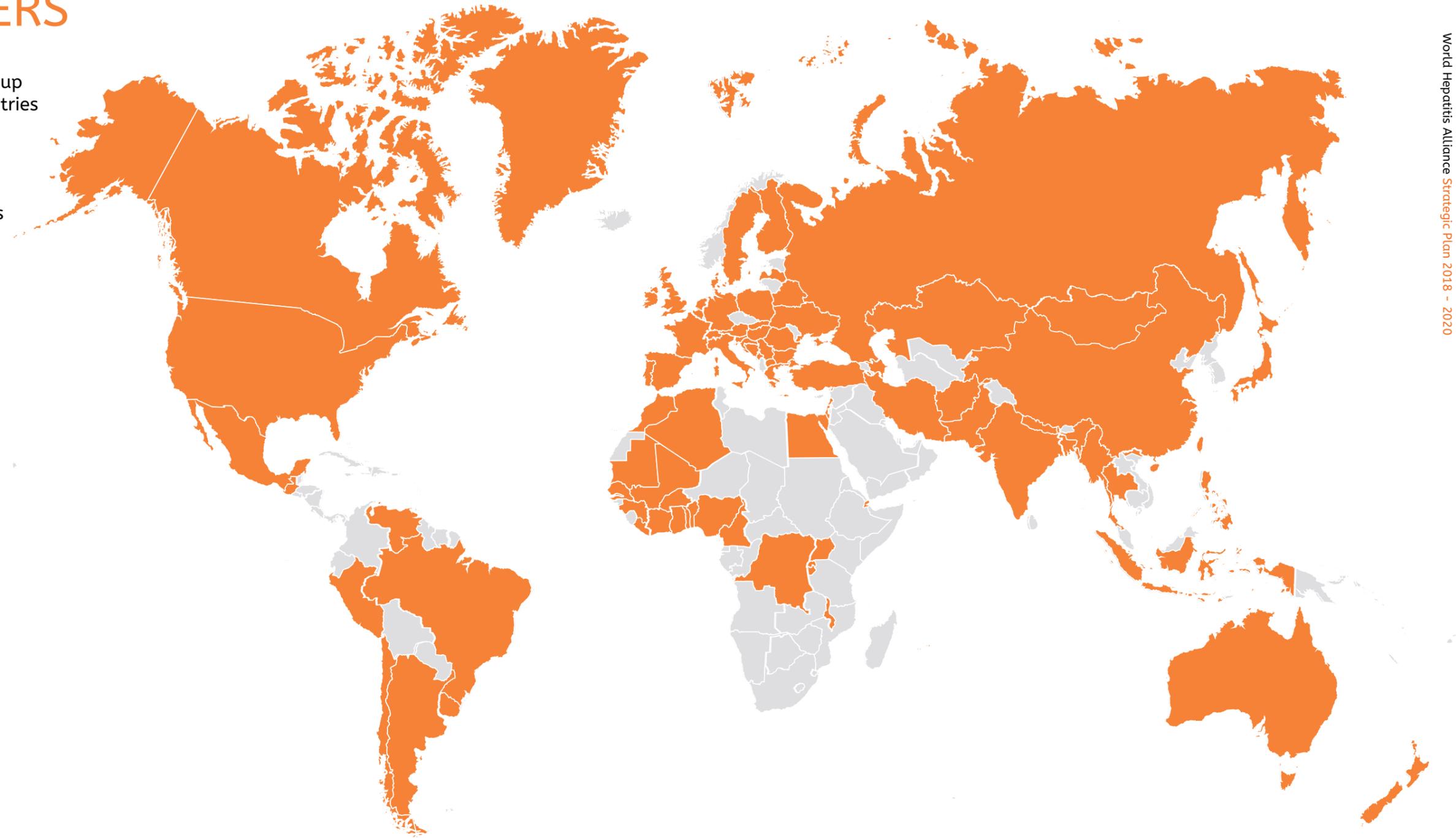
From prevention and diagnosis through to treatment and care, people living with viral hepatitis need to be recognised for the unique contribution they can make and their power should be harnessed to bring about the changes we need to make elimination a reality. Of the 325 million people currently living with either viral hepatitis B or C, upwards of 290 million are unaware they have the disease. Without finding those “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 to find them.



OUR MEMBERS

Our global membership is made up of 250+ organisations in 86 countries worldwide.

Our members are the core of our organisation. Predominantly made up of patient organisations fighting on behalf of people living with viral hepatitis, they advocate, raise awareness, lobby governments and deliver life-saving interventions and initiatives.



Afghanistan	Benin	Chile	Djibouti	Guinea	Kazakhstan	Mexico	Pakistan	Serbia	Turkey
Algeria	Bosnia and Herzegovina	China	Egypt	Hungary	Lebanon	Mongolia	Peru	Singapore	Uganda
Argentina	Brazil	Chinese Taipei	Finland	India	Liberia	Montenegro	Philippines	Slovakia	Ukraine
Australia	Bulgaria	Congo, the Democratic Republic of the	France	Indonesia	Lithuania	Morocco	Poland	Slovenia	United Kingdom
Austria	Burkina Faso	Côte d'Ivoire	Gambia	Iran	Macedonia	Myanmar	Portugal	Spain	United States
Azerbaijan	Burundi	Croatia	Germany	Ireland	Malawi	Nepal	Romania	Sweden	Uruguay
Bangladesh	Cameroon	Denmark	Ghana	Israel	Mali	Netherlands	Russian Federation	Switzerland	Venezuela
Belarus	Canada		Greece	Italy	Mauritania	New Zealand	Rwanda	Thailand	Viet Nam
Belgium			Guatemala	Japan	Mauritius	Nigeria	Senegal	Togo	

How we'll do it:

2018 – 2020 IN ACTION

WHA will make the challenge of finding the *Missing Millions* its focus from 2018-2020. As such, we have developed our programmes to fulfil this aim.



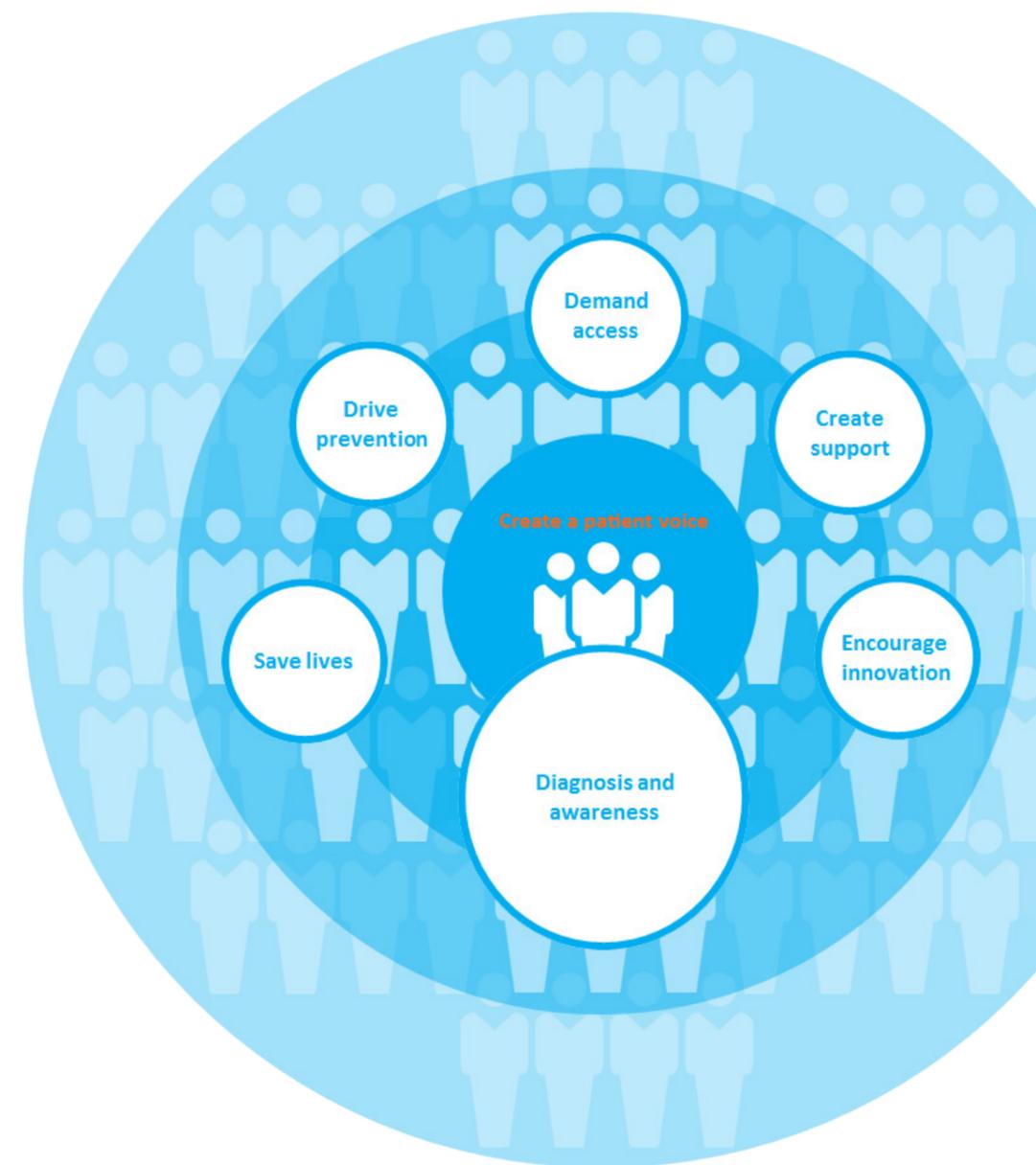
FINDING THE MISSING MILLIONS: BREAKING DOWN THE BARRIERS TO DIAGNOSIS

The WHO Elimination Strategy calls for a major increase in diagnosis of chronic viral B and C infection, with 30% of people infected knowing their status by 2020 and 90% by 2030. Currently, only 11% of those living with viral hepatitis are aware of their diagnosis. Without a massive scale-up in diagnosis, treatment rates will fall and infection rates will rise. We know significant barriers to diagnosis exist, at a global and national level, and as such we are undertaking a multi-year project with the aim of helping countries reach the diagnosis targets they committed to.

Finally, we will work in close partnership with our members in different countries through to 2020 to design and implement on the ground projects and campaigns that will focus on finding the undiagnosed and addressing country-specific issues identified in the first phase of this project. Alongside this, we will also develop and disseminate advocacy tools and support advocacy efforts globally.

The first phase of this project will focus on better understanding the barriers within countries to inform our future programmes. We will do this by carrying out a global consultation with key stakeholders. The outcome will be captured in a summary report highlighting the challenges to diagnosis and the context in which they are experienced.

We will then convene a round table of experts and key partners to discuss the findings and explore the role people living with viral hepatitis can have in overcoming the barriers. A white paper providing a series of recommendations will be produced and launched on World Hepatitis Day 2018.



WORLD HEPATITIS DAY: A GLOBAL DAY FOR LOCAL IMPACT

With so many 'world days' populating our calendars, many people remain sceptical about the impact of global awareness dates. However, World Hepatitis Day (WHD) proves the sceptics wrong. In ten short years, WHD has evolved and exceeded all expectations: from the first community-led World Hepatitis Day in 2008, supported by patient groups from around 47 countries, to today where millions of supporters in almost every country in the world celebrate the day with awareness activities, testing drives and countless other events. WHD has become a global day of action which unites policymakers, medical professionals and patients to raise awareness of the huge burden of viral hepatitis and to influence real change in disease prevention and access to testing, treatment and care.

In the next three years we will use this momentum to accelerate progress toward achieving the 2020 diagnosis target and develop an integrated campaign that will bring the world together in finding the Missing Millions. By working on the ground in local communities, our members are uniquely placed to raise awareness and drive action to *ELIMINATE HEPATITIS*.



FINANCING FOR HEPATITIS

Without fully-funded national plans, countries will not have the resources to scale-up the services needed to find the missing millions. Nor will they have the ability to provide treatment and adequate preventative measures.

NATIONAL PROGRAMMES

Nigeria and Colombia: the focus of the first phase of this project was to assist these two countries with the process of costing a hepatitis C response, making an investment case, budgeting and examining financing strategies with the aim of achieving the agreed WHO 2020 and 2030 regional and global elimination targets.

In embarking on the project, both governments have shown considerable political will to taking a strategic approach to financing and actively exploring their options in regards to sources of funding for their hepatitis C programmes. Building on the first phase of this work, the second phase will build the advocacy in those two countries to ensure that momentum continues once external stakeholders have left the country.

We will work in close partnership with our members in those countries to increase their knowledge and expertise in this area thus building their capacity to advocate for political commitment that will translate into effective government action. This work will include capacity building activities, support in designing and implementing country-specific advocacy campaigns and projects, and facilitating relationship building with a range of key stakeholders including WHO regional and local offices and the relevant departments within the government.

This second phase of the project will run throughout 2018 with progress assessed at the end of the year. Once completed, we will explore opportunities to replicate this project in other countries.

NATIONAL VIRAL HEPATITIS PROGRAMME FINANCING STRATEGY TEMPLATE

The National Viral Hepatitis Programme Financing Strategy Template is a tool for countries facing challenges in fully funding their hepatitis response. It provides guidance on how to adopt a strategic approach to costing, creating the investment case, budgeting, and financing a viral hepatitis programme. The website was launched at the World Hepatitis Summit in São Paulo, Brazil and in 2018 we will further promote this tool, with both policy makers and our members being key audiences.

The website will also be used to disseminate the learnings from our programmes in Colombia and Nigeria and will continue to be updated as these projects develop.

STRENGTHENING THE VOICE OF PEOPLE LIVING WITH VIRAL HEPATITIS

People living with viral hepatitis have a unique and critical role in the elimination of viral hepatitis. Those diagnosed have insider knowledge about the illness and its impact on day-to-day life. This is why patients are instrumental in eliminating viral hepatitis. At WHA we work to mobilise people living with viral hepatitis and support, build on and utilise their expertise to accelerate the hepatitis response and find the missing millions.

EDUCATIONAL WEBINARS

We continue to educate patients and patient representatives about relevant topics in the area of viral hepatitis. So far, we have up-skilled viewers on various aspects of advocacy and the tools needed to effectively lobby for change as well as addressing key topics in the areas of access to diagnostics, medicines and generics. Topics for future webinars will be

carefully selected based on feedback from our Pre-Summit Member Conference (São Paulo, 2017) and wider consultation with our members as well as strategic priorities. Webinars will also be used as a medium to further engage our membership in our current projects.

MEMBERSHIP EVALUATION

Our membership has doubled in the last 6 years but engagement levels vary greatly across regions. Working together with our members will be key to making the elimination of viral hepatitis a reality and as such we need to build a greater understanding of the excellent work they do on the ground and harness their local expertise. We also need to know who the most engaged members are to identify potential partnerships and champions moving forward.

To do so, we intend to conduct an in-depth assessment of our membership and we will, in the first instance, collate all the information we have available, carrying out internet research if necessary. This will include type of membership, social media presence, influence and authority in the field of viral hepatitis, reach and network and finally engagement with WHA in key projects and campaigns. We will then reach out – via survey and phone interviews – to all our members for the second part as we seek to

hear more about their work and build on the first stage of our research. The final stage of this work will be for us to categorise all of our members according to their level of engagement, expertise and participation in the community.

The knowledge acquired will be used to inform the development and delivery of future programmes including, but not limited to, educational campaigns, on-the-ground projects and participation in existing WHA activities. Every effort will also be made to share best practices and connect members with similar interests.

This work will be carried out in 2018.

WALL OF STORIES

To successfully harness the power of people living with viral hepatitis, they must have a platform through which their voices are heard. Telling the ‘real’ stories and lived experiences of viral hepatitis is not only crucial to highlighting the true impact of the disease, but an essential part of tackling the stigma, fear and discrimination that prevents people from understanding the illness and coming forward for testing. In 2017, we re-developed the Wall of Stories section of our website and launched a series of new video stories as a call for others to share their experiences. As we move to put a greater focus on people living

with viral hepatitis, we will continue to build a bank of stories, with a particular focus on experiences of barriers to testing and receiving and dealing with a diagnosis. We will use this as a powerful tool to provide support and inspiration, to empower others to come forward and to strengthen the voice of those living with viral hepatitis. Crucially, the Wall of Stories will equip us with the lived experiences required to ensure that the needs of people living with viral hepatitis remain at the heart of every conversation.



In 2016 we launched NOhep, the first ever global movement to eliminate viral hepatitis by 2030. Since then #NOhep has reached more than 90 million people online and over 67,400 NOhep actions have been taken. We secured commitment from over 200 medical professionals and 6 governments as part of the NOhep Visionaries Programme. To date, 20 national NOhep groups have been established.

Building on this success, 2018 will mainly focus on building the NOhep Visionaries Programme, which is a programme to engage medical professionals, governments and civil society as advocates. We will launch the medical professionals' stream in the Asia and Africa regions. Alongside this, we will host a NOhep Global Village at the Global Hepatitis Summit in June 2018, where we will produce a NOhep guide for medical professionals. One of the key learnings is that NOhep has been more successful in developing countries, which is fantastic and that needs to be built on. As such, we will identify key civil society organisations to spearhead and replicate the programme in their regions.

We will also leverage WHO's two year GHSS progress report, which is likely to be presented at the World Health Assembly in May 2018. We will use this as an advocacy opportunity to encourage supporters to drive action to meet the global targets.

Alongside these actions, we will continue to implement social media campaigns and build partnerships.



STRATEGIC PARTNERSHIPS: COLLABORATING TO REACH ELIMINATION

WHA firmly believes that collaboration will be key if we are to achieve the ambitious elimination targets for viral hepatitis in the next 13 years. As such, we will seek to form new partnerships, where relevant, and will continue to build on the work we undertake with a variety of stakeholders. Currently, our work partners include the Clinton Health Access Initiative, the Medicines Patent Pool, the US Centers for Disease Prevention and Control, the European Liver Patients Association, the Coalition for the Eradication of Viral Hepatitis in Asia Pacific, the American Association for the Study of the Liver, the European Association for the Study of the Liver, Coalition Plus, International Drug Policy Consortium, amongst others.

Furthermore, we are working with a select group of experts from all over the world to produce a report on viral hepatitis for the **WORLD INNOVATION SUMMIT FOR HEALTH (WISH)**. The theme will be one of the focus areas for this important event where we will be highlighting innovative practices around the economics of elimination, testing and treating the disease, addressing stigma and discrimination, etc. The objective is to provide policy makers with actionable recommendations to help reach ambitious disease elimination targets. This will also be an opportunity to profile viral hepatitis in the health world stage, creating awareness and supporting our objective to find the missing millions.



WORLD HEALTH ORGANIZATION

WHA has always worked closely with WHO and was awarded “Official Relations” status in 2012. In 2011, despite our limited resources, we seconded someone part-time to their then newly-formed Global Hepatitis Programme and we have since been their key civil society partner, ensuring the voice of the affected community is always reflected in their actions and outputs, be it in technical guidelines and reports or through the input we provide to their Strategic Technical Advisory Committee on hepatitis and Civil Society Reference Group, of which we are part.

Furthermore, for the past two years we have seconded a full-time focal point to the WHO Regional Office for Europe after hearing that hepatitis was going to be dropped out of their work plan due to lack of funds. This secondment proved to be critical in advancing the hepatitis response in the region and led to the development and adoption of the regional Action Plan based on WHO’s Elimination Strategy.

WHA will continue to partner with WHO and work together to help countries achieve the elimination of viral hepatitis by 2030.

SECONDMENT OF VIRAL HEPATITIS FOCAL POINTS TO WHO (REGIONAL OFFICE FOR EUROPE AND AFRICA)

WHA will continue to second a focal point to the European Region to ensure their Action Plan can be effectively implemented. We have agreed a workplan with them that focuses on their continued support to Member States. This involves the provision of technical assistance to countries in strengthening viral hepatitis strategic information, looking at ways to improve hepatitis prevention, testing, treatment and care of people living with the disease, and working with relevant civil society partners to advance the hepatitis response.

Similarly, WHA will second a full-time focal point to WHO’s Regional Office for Africa, where there is a great burden and so many barriers to be addressed in the path to elimination. The region has never had a dedicated person working in the field to support countries with their viral hepatitis strategies so we believe this opportunity could be catalytic and ultimately of immense benefit to the millions of people living with the disease in the continent.

WORLD HEPATITIS SUMMIT 2019

In 2015, we pioneered the World Hepatitis Summit (WHS), a unique, biennial global policy event to advance the viral hepatitis agenda, organised with WHO and in collaboration with a different host country for each Summit. We successfully held the first two Summits in Glasgow, Scotland in 2015 and Sao Paulo, Brazil in 2017. Negotiations with potential host countries for 2019 are still ongoing at the time of writing.

The purpose of WHS is to bring together all relevant stakeholders for an improved dialogue that results in concerted global action against viral hepatitis. It is the only global forum that offers governments the opportunity to focus on viral hepatitis. In 2017, the Summit focused on

implementing the GHSS and translating it into effective national strategies. The programme for 2019 will be inspired by both the outcome of 2017 and the progress – or lack of – made towards the 2020 targets.

WHS19 will add a new dimension as it will feature a Global Village as opposed to a Pre-Summit Member Conference. An integral part of the Summit, the Global Village will be a diverse and vibrant space that will promote networking between communities from across the globe and provides our members a place for displays, discussions and debates. Through these rich and varied activities, civil society will have a unique opportunity to demonstrate the crucial role they can play in the elimination of viral hepatitis.

WHY WHA?

We are ten years into this journey; we bring the expertise, experience and passion that will be required to make the 2030 goal of elimination a viable reality. We've built a community of 252 patient organisations in over 80 countries who know how to make significant local impact, alongside our role in championing global

initiatives. We have a unique opportunity to represent the millions of people living with viral hepatitis from across the world, harnessing their energy and expertise to overcome barriers and drive action to elimination.

DELIVERING IMPACT

Progress will be measured against WHO's global hepatitis targets, specifically the target to increase diagnosis of chronic viral B and C infection to 30% in 2020 and 90% in 2030.

undertake a series of activities and work with relevant stakeholders to make advances to this important target.

We are aware that as an organisation, we cannot solely contribute nor be responsible for achieving this goal. However, we will work to

FUNDING

Almost all of the World Hepatitis Alliance funding comes from foundations and from industry, specifically pharmaceutical and, to a lesser extent, diagnostic companies. Even though the pharmaceutical industry has no say in how the organisation is run, we are aware that having them as funders creates a negative perception (our Code of Ethics and Business Conduct can be found [here](#)). We are very transparent about this.

The funding environment is very challenging for us. Awareness of viral hepatitis remains low, perhaps especially amongst funders. For example, many funding bodies have drop-down menus with their areas of interest. Viral hepatitis is very rarely even on the menus. It is also important that we do not take what scarce national funding there is away from our

members, who suffer from the same challenges we do.

In spite of those challenges we are committed to diversifying our sources of income and as we do so raise much needed awareness in the corporate world. We are putting a lot of efforts into this but it will take some time for our strategy to bear fruits.

Nevertheless we are confident that, as the elimination of viral hepatitis gains traction as both a health and a social cause, we will be able to access a whole new funding landscape that will allow us not just to continue our crucial work but to significantly expand it until viral hepatitis ceases to be a public health threat.



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