Finding the Missing Millions

The World Hepatitis Alliance’s 2018 – 2020 Strategic Plan (2019 Update)
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 1 in 10 people are aware of their illness and just 1% of people 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.

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 a 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.

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 the 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. 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 a 90% reduction in new cases of chronic viral hepatitis B and C infections, a 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. Because viral hepatitis was neglected for so long, there’s a lot of catching up to do. Countries won’t be able to reach the 2030 goal alone. Collaboration will be the key, we know that elimination will not be achieved without putting the people affected by viral hepatitis at the heart of the solution.

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. Because viral hepatitis was neglected for so long, there’s a lot of catching up to do. Countries won’t be able to reach the 2030 goal alone. Collaboration will be the key, we know that elimination will not be achieved without putting the people affected by viral hepatitis at the heart of the solution.
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 connect 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 served 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 over 260 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 global membership is made up of 260+ 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.
HOW WE’LL DO IT:

2018 – 2020 IN ACTION

WHA has made the challenge of finding the missing millions its focus from 2018 – 2020. As such, we have developed our programmes to fulfil this aim.

Find the Missing Millions: Breaking Down the Barriers to Diagnosis

The WHO Elimination Strategy calls for a major increase in the diagnosis of chronic viral hepatitis 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 – that’s 250 million men, women and children at risk of developing cirrhosis and liver cancer. 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 programme with the aim of helping countries reach the diagnosis targets they committed to.

The first phase of this programme (2018) will focus on better understanding these barriers and defining the role civil society has to play in overcoming them. As such, WHA will conduct global surveys and consultations with members and key partners publishing the findings and recommendations in a White Paper.

Alongside this, we will launch the “Find the Missing Millions” (FMM) global campaign with the objective to raise awareness, influence national testing policies and encourage people to get screened and/or become advocates in the journey to find the undiagnosed.

The second phase (2019-2020) will focus on implementation. WHA will examine the findings from the White Paper and build advocacy resources to support them. We will also enhance the diagnostic literacy of our membership, strengthen partnerships and expand our global campaign in an effort to tackle the current diagnosis challenges.

Finally, the FMM programme will feature an 18 month pilot project aimed at a select number of countries to develop/build on the national advocacy voice. Working with our members in those countries we will develop and implement advocacy strategies designed to catalyse action at a national level.
WORLD Hepatitis day: A Global day for local impact

World Hepatitis Alliance

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 continue to use this momentum to accelerate progress toward achieving the 2020 diagnosis target by developing an integrated campaign that will bring the world together to Find the Missing Millions.

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. To address this, WHA has been helping national governments to cost, create the investment case and explore financing options for their hepatitis C programmes. We have also launched a financing template to support countries to look at how they can overcome funding challenges in their hepatitis response.

National programmes

WHA will assist the governments of a select number of 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, these governments have shown considerable political will to taking a strategic approach to financing, actively exploring their options in regards to sources of funding for their hepatitis C programmes.

Once the financing work is complete, WHA will strengthen the national advocacy voices to ensure that momentum continues once external stakeholders have left the countries. As such, 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 will 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.

Opportunities to replicate this project in other countries will also be looked at during 2018-2020.

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 the next three years 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 in-country programmes and will continue to be updated as these projects develop.
UNLOCKING THE POWER OF THE COMMUNITY

People living with viral hepatitis and the affected community should be at the heart of every effort to eliminate viral hepatitis. Aside from fulfilling the need for trusted entities that consistently disseminate reliable information, civil society organisations bring fundamentally important perspectives and experiences which greatly enhance the effectiveness of strategies and programmes. In the context of addressing the barriers to diagnosis and finding the missing millions, a meaningful partnership with the affected community and civil society organisations can, amongst other things, contribute to the delivery of stronger awareness campaigns; strengthen innovative approaches to finding the undiagnosed through peer support services; help identify gaps within action plans which would otherwise be missed; and offer a platform to address stigma and discrimination, ensuring an equitable response so that the most vulnerable and marginalised are not left behind in the effort to eliminate viral hepatitis. As such, policy-makers should harness the voices of those affected by the disease, recognising them as vital partners in the elimination effort.

As more people living with viral hepatitis are aware of their diagnosis, they and those in their social environment can be part of the drive to prevent the disease by ensuring access to services, from prevention to testing to treatment and follow-up care, and by encouraging innovation, such as health systems reforms that facilitate new, more people-centred health services. As such, WHA will continue to represent, convene and provide a platform for the community to accelerate the hepatitis response.

REPRESENTATION

Throughout 2018–2020 WHA will speak on behalf of its membership and the millions of people living with viral hepatitis at key hearings, meetings and conferences to highlight the unique patient perspective and to influence high-level discussions pertinent to our cause, such as those around the Sustainable Development Goal 3 and Universal Health Coverage.

CONVENING POWER:

WHA will also bring members, partners and other key stakeholders together to strengthen the call for increased diagnosis rates.

Furthermore, WHA currently holds a seat at Médecines Patent Pool, the Lancet Commission on hepatitis, WHO Civil Society Reference Group, amongst others.

Finally, we will support the delivery of the third World Indigenous Peoples Conference (WIPC) on Viral Hepatitis (2019). WIPC is an initiative which we established in 2014 together with experts in the field when the need for a platform that calls for equality of care in this population became apparent.

PLATFORMS FOR ENGAGEMENT:

- **Webinars:** WHA will produce more webinars to educate patients and patient representatives on various aspects of advocacy and the tools needed to effectively lobby for change, with a special focus on the drive to find the millions of people living with viral hepatitis who are currently undiagnosed.

- **Wall of Stories:** This tool showcases the real stories and lived experiences of viral hepatitis, highlighting the true impact of the disease and tackling the stigma, fear and discrimination that prevents people from understanding the illness and coming forward for testing. WHA will continue to amplify and disseminate the tool to provide support and inspiration, empower others to come forward and strengthen the voice of people living with viral hepatitis.

- **NOhep:** Despite being in its infancy (NOhep was launched in 2016), our global movement to eliminate viral hepatitis by 2030 has already established itself as the brand for the hepatitis cause and a platform through which one can implement social media campaigns and build partnerships. In 2018–2020 WHA will continue to grow the NOhep voice, driving the online conversations, engaging new partners and audiences and expanding existing programmes, such as the Visionaries Programme for Medical Professionals. See more in the next section.

---

Led by Indigenous Peoples and designed for the Indigenous communities, clinicians, those working in Indigenous health, civil society organisations and policy makers, WIPC aims to ensure that national viral hepatitis plans include specific strategies to facilitate access to prevention, care and treatment for indigenous populations and minorities.
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.

Finally, we will publish an advocacy toolkit to encourage supporters to drive action to meet the global targets. In 2019-2020 we will continue to strengthen the visionaries programme, looking at delivering advocacy workshops to the medical community. We will also start the process of democratising the NOhep movement, using the platform as the voice of people on the ground demanding change and engaging key influencers to grow the supporter base.
**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 American Association for the Study of the Liver, Clinton Health Access Initiative, the Coalition for the Eradication of Viral Hepatitis in Asia Pacific, Coalition Plus, the European Association for the Study of the Liver, the European Liver Patients Association, FIND, International AIDS Society, International Drug Policy Consortium, the Lancet, Medicines Patent Pool, the US Centers for Disease Prevention and Control, World Health Organization, amongst others.

**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, we have been seconding a full-time focal point to the WHO Regional Office for Europe since 2016 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 Members 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.
**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 dropdown 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.

---

**Delivering Impact**

Why WHA?

Not only has WHA changed the course of viral hepatitis history, it has put it on the map.

We can make bold statements like this because we have the results to back it up. Since our inception in 2007, we’ve spearheaded global awareness days, convened high level meetings and global summits, propelled the rise of advocacy in the field, launched an international movement and built capacity.

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 over 260 patient organisations across 86 countries who know how to make significant local impact.

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

Find out more about our impact in our quarterly and annual reports.