Viral Hepatitis: not just a silent killer but also a silencer

#StigmaStops me speaking out!

Help us find the missing millions
Note from our CEO

We’re kicking off this month by marking Zero Discrimination Day with the launch of our new campaign, #StigmaStops. As our new report confirms, stigma is experienced by almost everyone affected by viral hepatitis. On page 10 we share different experiences of stigma and discrimination and highlight how talking about the issues helps to tackle stigma. Turn to page 8 to find out how you can join our efforts.

From denial of work opportunities to producing barriers to healthcare, #StigmaStops the majority of people living with viral hepatitis enjoying the quality of life they deserve. There is hope though. Efforts are being made in the Philippines to overcome discrimination in the workplace (more on page 4) while our Find the Missing Millions survey allows you to share the biggest barriers to diagnosis in your country and suggest ways to overcome them (turn to page 6 to have your say).

By coming together as community to challenge misconceptions and act on violations, we can stop stigma.

We hope you enjoy reading!

Raquel Peck
Chief Executive Officer

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

CONTENTS

3 This month in numbers
Hepatitis C treatment, new initiatives, Summit

4 Hep headlines
Commitments to elimination, stigma policies, generics

5 For the diary
Zero Discrimination Day, Commission on Narcotic Drugs, APASL

FEATURES

6 In action: Find the Missing Millions
Barriers to diagnosis in your country

12 Focus: Viral hepatitis: not just a silent killer but also a silencer
Stigma experienced by people living with viral hepatitis

14 Wall of Stories snapshots: #StigmaStops me speaking out
Su Wang shares her experiences

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This month in numbers
A round-up of some of this month’s stand-out facts and figures:

At least 11,000 patients in Moldova will receive hepatitis C treatment in 2018.

18 members of the US House of Representatives call for compulsory license on patents for hepatitis C treatments.

New 7 point solution to end hepatitis C endorsed by WHA member Action Hepatitis Canada (AHC).

Initiative launched in 10 villages across Egypt by WHA member Association of Liver Patients Care (ALPC) to treat anaemia induced by hepatitis C treatment.

215 individuals from 71 countries attended our Pre-Summit Member Conference as confirmed in the new report (available here from 7 March)

8,060 tweets were sent to the World Hepatitis Summit event hashtag #HepSummit2017. (Official Summit report available here from 7 March)
Spain commits to finding the undiagnosed
The Alliance for the Elimination of Viral Hepatitis in Spain (Alianza para la Eliminación de las Hepatitis Virícas en España (AEHVE)) met with the Ministry of Health of Spain to discuss a strategy to find people living with hepatitis C unaware. The strategy will be proposed as soon as data is available from the seroprevalence study that is currently being carried out at a national level.

Belarus starts manufacturing generic DAAs
In an effort to scale up the national treatment programme, Belarus has started locally manufacturing generic interferon free medicine.

Steps to tackle stigma in the workplace in the Philippines
In Davao City, a councillor has proposed an amendment to the city’s anti-discrimination laws that would prevent anyone rejecting job applicants due to health status. The councillor specifically called out companies that make hepatitis B testing mandatory in a way to deny people living with hepatitis B work.

Stage set for next steps in hepatitis C elimination in Scotland
WHa member the Hepatitis C Trust marked the launch of their new report Eliminating Hepatitis C in Scotland with an event hosted in the Scottish Parliament. The report sets out a series of recommendations to move closer to the elimination of hepatitis C in Scotland.

Malta steps up elimination efforts following World Hepatitis Summit
This month the Government of Malta announced that they plan to eliminate hepatitis C by 2025 and have launched an open consultation on their proposed strategy. This follows their promise to meet the WHO elimination targets when Malta steps up efforts following World Hepatitis Summit 2017. The open consultation runs until 15 March.

Scotland: MSP hosts launch of Hepatitis C elimination report
Here are some upcoming events and activities taking place this month.

1 MAR Zero Discrimination Day
Discrimination continues to undermine efforts to achieve a more just and equitable world and causes pain and suffering for many. This couldn’t be a truer statement for viral hepatitis: an epidemic that is undeniably perpetuated by stigma and discrimination. This Zero Discrimination Day, we’re launching our #StigmaStops campaign. Turn to page 8 to find out how to get involved.

2 MAR Submissions close for NOhep Village
Last chance to apply for an exhibition space at the NOhep Village! If you are a civil society organisation looking for an opportunity to showcase your work to the world, join us at the Global Hepatitis Summit (14 – 17 June 2018, Toronto, Canada). Applications close 2 March. More details here.

13 MAR ALF Annual Day on the Hill
WHA Member American Liver Foundation will hold their annual advocacy day on 13 March. The event is an opportunity for patient advocates to come together, share their stories and provide insight about how decisions made on Capitol Hill will personally affect the lives of people living with viral hepatitis. Join the conversation by following them on Twitter or watching the live stream on the American Liver Foundation’s Facebook page.

14-18 MAR Asian Pacific Association for the Study of the Liver (APASL)
At this year’s APASL Annual Meeting, the Coalition for the Eradication of Viral Hepatitis in Asia Pacific (CEVHAP) will host a symposium to bring together civil society, WHO representatives and eminent medical professionals from the region to share thoughts and experiences on working towards elimination. WHa President Michael Ninburg will provide an update on the Find the Missing Millions campaign and the NOhep Visionaries Programme for Medical Professionals. If you’re attending APASL, join us at the meeting on 15 March 17:00 – 18:15.

For the Diary

 Participation in a hepatitis related activity or have an event planned?
 Email us or contact us on social media.

For the diary

09:00 – 09:50 with Fédération Addiction, International Doctors for Healthier Drug Policies (IDHDP), International Network for People who Use Drugs (INPUD) and Médecins du Monde at the 61st Session of the Commission on Narcotic Drugs. The side event will discuss the global state of hepatitis C among people who use drugs and make recommendations to curb the epidemic. Follow the hashtags #CND2018 or #CND61 for updates from the event. Ahead of the CND, the International Drug Policy Consortium will host a webinar explaining the Commission’s functioning, key issues for 2018 and guidance to facilitate NGO engagement. More info here.

13 MAR ALF Annual Day on the Hill

12-16 MAR 61st Session of the Commission on Narcotic Drugs (CND)

People who inject drugs are disproportionally affected by hepatitis B and C and without access to harm reduction services, we cannot hope to eliminate viral hepatitis. To address this issue, we are co-sponsoring a side event on 16 March 09:00 – 09:50 with Fédération Addiction, International Doctors for Healthier Drug Policies (IDHDP), International Network for People who Use Drugs (INPUD) and Médecins du Monde at the 61st Session of the Commission on Narcotic Drugs. The side event will discuss the global state of hepatitis C among people who use drugs and make recommendations to curb the epidemic. Follow the hashtags #CND2018 or #CND61 for updates from the event. Ahead of the CND, the International Drug Policy Consortium will host a webinar explaining the Commission’s functioning, key issues for 2018 and guidance to facilitate NGO engagement. More info here.

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Help us find the missing millions!

With 300 million people living with viral hepatitis unaware of their status, diagnosis will be key to reaching elimination and so, for the next three years the World Hepatitis Alliance will be focusing on finding and diagnosing these people - the ‘missing millions’.

As a first step, we are undertaking a global survey to understand the nature of barriers to diagnosis within countries. The information generated by this piece of research will form the basis of future programmes. We understand that time is precious but your views are of great value so we would be grateful if you could complete the short survey at the following link by 22 March: bit.ly/WHASurvey

It is important that we capture as many viewpoints as possible, from different stakeholders around the world, to ensure that we get a truly representative response. We would therefore like to encourage you to share the survey link with your colleagues and wider networks.

Please do not hesitate to contact projects.team@worldhepatitisalliance.org if you have any questions.
Focus

Viral hepatitis:

NOT JUST A SILENT KILLER BUT ALSO A SILENCER

Stigma and discrimination around viral hepatitis has long prevented people from speaking openly about their illness. For those brave enough to disclose their status, their reward, more often than not, may be social exclusion, diminished employment opportunities or unjust barriers to receiving healthcare. This harsh reality can have a devastating impact on an individual’s personal life and psychological well-being and prevent people from accessing much-needed diagnostics and treatment. There is no doubt that stigma and discrimination further perpetuate the epidemic of viral hepatitis.

We recently launched our Holding Governments Accountable: World Hepatitis Alliance Civil Society Survey Global Findings Report, which surveyed civil society organisations from 72 countries to better understand experiences of stigma and discrimination across the world. The findings confirmed and quantified what we had long suspected: stigma is felt in almost every corner of the globe (people from 93% of countries surveyed reported stigma and discrimination to some degree) and its impact is far-reaching (respondents reported on average 6 different types of stigma and discrimination).

However, it isn't until we hear the personal experiences behind the statistics that we can grasp the true impact of stigma and discrimination. One story from China stressed the drastic measures stigma can drive people to take. Dee Lee, Director of Inno Community Development Organisation and hepatitis B carrier was subjected to mandatory testing when applying for a job but desperate for the role, he asked a friend to provide a blood sample. After securing the position, he witnessed stigma and discrimination in the workplace first hand: his colleagues living with the disease were forced to sit at the “hepatitis table” specifically designated for them with a flag revealing their status. Dee Lee turned his experiences into a positive and was inspired to set up an organisation to tackle the issue. But for so many others stigma prevents people from fulfilling their potential.

“The person who discriminated against me first was myself” reveals George Kalamitsis, Chairman of Hellenic Liver Patient Association, Greece. Self-stigmatisation can include feelings of blame, worthlessness, internalised shame or a sense that viral hepatitis is a punishment for certain behaviours. It is truly heart-breaking to learn that 72% of people living with the virus experience these feelings. Self-stigma has both emotional and long-term physical consequences, often preventing people from speaking out and breaking down the confidence needed to seek help and access medical care.

Despite stigma having a devastating impact on so many aspects of an individual’s life and being a hindrance to our elimination efforts, very few respondents felt that their government was effectively addressing it at a national level. In response to this, on Zero Discrimination Day (1 March), we launch our #StigmaStops campaign that aims to highlight the true impact of stigma, dispel myths and encourage people living with the disease to speak out. Find out how to take part and watch our video message here.

This is an excerpt from a blog by WHA CEO Raquel Peck that first appeared in Hepatology, Medicine and Policy. Read the full blog here.
Voice

Su

“I found out I had hepatitis B when I donated blood in college. It was a total surprise. I immediately called my sister and I said “I’ve just found out I have hepatitis B. I don’t know how I got it but don’t tell Mom!” My sister responded “Mom has hepatitis B, didn’t you know?” That’s how I found out that it was something that may have been passed from my mother. If it hadn’t been for donating blood, I would not have gotten care and probably would have lived somewhat in oblivion. I might have been afraid as well. Afraid of not knowing if this disease was something really awful that could ruin my life.

This is what I see in my role as a physician. When newly diagnosed people come to me, they often feel like it is the end of the world. They feel like their life has ended and that they are going to die soon. They fear that they can’t get married or have children. They worry that they can’t be around their family or they can’t eat at the same table. When I see people in that scenario, when they are really worried and afraid, it is an opportunity for me to share my own experiences. I tell them “I am just like you. I have hepatitis B and I live with this disease. It’s not the end of the world. You can live a very productive, happy, healthy life.”

I don’t always share my personal diagnosis with people but it definitely helps when I discuss my experiences with patients. Out of 3 people who have viral hepatitis don’t share it with anybody. They don’t tell their family, friends or loved ones. They live with the secret. But there’s nothing to be embarrassed about. The more you open up about it, the less there is to be afraid about. I believe that the more we talk about it, the more it destigmatises it for the whole community.”

Watch Su’s full video story here.

Lucinda

Lucinda was open about having hepatitis C but when her babysitter’s parents called her and said that their daughter would no longer be coming to her house, she was stunned. She admits that her brush with stigma was a sting rather than the full blown bite that many marginalised groups experience but it still angered and upset her. Read more about Lucinda’s experiences here.

Allan

In 2016, Allan went to get a tooth extracted at a dentist in Melbourne. After disclosing his positive hepatitis C status, his dentist began asking personal and intrusive questions and declined to perform a straightforward procedure. While Allan eventually had the tooth removed by another dentist and has since been cured of his hepatitis C, the pain inflicted by this experience still lingers. Listen to Allan’s story here in a podcast from WHA member Hepatitis Victoria.

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.

Each month we share the story of someone whose life has been affected by viral hepatitis. This month, Medical Director for the Center for Asian Health at St. Barnabas Medical Center and WHA Board Member for the Americas region, Su Wang tells us how she has used her unique position as both a medical professional and a patient to help others overcome stigma. As speaking out is so crucial to tackling stigma, this month we are sharing not one but three stories!