

hep VOICE

Your monthly magazine from the World Hepatitis Alliance



**FIND THE MISSING
MILLIONS IN EGYPT**

**THE MEDICINES PATENT POOL
SIGNS LICENCE WITH ABBVIE**

WALL OF STORIES

**"My mom was afraid that she
had given it to me"**



NOTE FROM OUR CEO

As the end of the year fast approaches the WHA team have been busy working on our 2019 plans. More details of these plans will be released in the New Year, but I can say that we have exciting new ways for members to get involved in our work. Crucially, 2019 is an election year for the WHA Board and I would urge members to get nominating. You can read more about this process on page 7

The WHA team have also been busy meeting members and key stakeholders at conferences and events. I was at the World Health Summit in Berlin earlier this month looking to include civil society's voice in the Universal Health Coverage agenda. You can read more about this on page 7. WHA and NOhep also attended AASLD's The Liver Meeting in San Francisco and I was at the World Innovation Summit for Health (WISH) in Doha, reports from those meetings will be in the next issue of hepVoice.

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 this magazine with your network

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CONTENTS

REGULARS

- 4 Hep headlines
- 5 For the diary

FEATURES

- 6 The Medicines Patent Pool signs licence with AbbVie to expand access to key hepatitis C treatment
- 7 2019 Elections
- 8 Find the Missing Millions: Hepatitis C elimination in Egypt
- 10 Wall of Stories: Camilla's story

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hep HEADLINES

Hepatitis is making the news regularly thanks to the work of WHA members, here are a few highlights.

Iceland could eliminate hepatitis C by 2020

In Iceland, a nationwide program has been launched offering treatment for the entire population living with hepatitis C virus (HCV). A mathematical model was used to estimate the additional health system requirements to achieve the HCV elimination targets of the World Health Organization (WHO), as well as the year that this could occur. With some additional screening of people who inject drugs, Iceland could reach the WHO targets by 2020, becoming one of the first countries to achieve HCV elimination. The model estimated that once elimination targets were reached, maintaining current monitoring and harm reduction services while providing ongoing access to DAA therapy for people diagnosed with HCV would ensure that future HCV outbreaks are unlikely to occur.

[Read more at www.journal-of-hepatology.eu](http://www.journal-of-hepatology.eu)

Australia releases annual HIV, viral hepatitis and sexually transmissible infections report

The Kirby Institute have released their annual surveillance report. According to the report, an estimated 199,230 people were living with chronic hepatitis C infection at the beginning of 2017 decreasing to 182,144 by the end of 2017, with over 20,454 cured of hepatitis C since the end 2016 thanks to increased access to new treatments subsidised by the Pharmaceutical Benefits Scheme.

[Read more at www.kirby.unsw.edu.au](http://www.kirby.unsw.edu.au)

The Hepatitis C Trust responds to select committee report on prison health

Rachel Halford, Chief Executive of The Hepatitis C Trust, said: "We welcome calls for a 'whole system' approach to prisoner healthcare, and are pleased that the Health and Social Care Committee has acknowledged that prisons are in a vital position to address health inequality. However, there was a disappointing absence of specific recommendations on the better implementation of opt-out testing for blood borne viruses and on

increasing hepatitis C treatment availability in prisons. We would also have liked to have seen a recommendation for prisons to provide sterilised needles and syringes to prevent transmission of BBVs through the sharing of equipment for injecting drugs."

[Read more at hepctrust.org.uk](http://hepctrust.org.uk)

FOR THE DIARY

Here are some upcoming events and activities taking place this month.

23-30 NOVEMBER

European Testing Week

European Testing Week provides the unique opportunity for organisations – in community, health care and policy institutions to unite across Europe to increase testing efforts and create more awareness on the benefits of earlier testing for hepatitis and HIV.

1 DECEMBER

World Aids Day

World AIDS Day takes place on the 1st December each year. It's an opportunity for people worldwide to unite in the fight against HIV, to show support for people living with HIV, and to commemorate those who have died from an AIDS-related illness

12 DECEMBER

Universal Health Coverage Day

International Universal Health Coverage Day (UHC Day) on 12 December aims to mobilize diverse stakeholders to call for stronger, more equitable health systems to achieve universal health coverage, leaving no one behind.

Participating in a hepatitis related activity or have an event planned?

Email us or contact us on social media.

The Medicines Patent Pool signs licence with AbbVie to expand access to key hepatitis C treatment

The Medicines Patent Pool (MPP) has announced a new, royalty-free licence agreement with AbbVie for glecaprevir/pibrentasvir (G/P) – a World Health Organization (WHO) recommended treatment for people living with chronic hepatitis C (HCV). The licence will enable quality-assured manufacturers to develop and sell generic medicines containing G/P in 95 low- and middle-income countries (LMICs) and territories at affordable prices, enabling access to and treatment scale-up with the most effective pan-genotypic regimens. The agreement was launched at the American Association for the Study of Liver Diseases (AASLD) The Liver Meeting 2018 in San Francisco.

“G/P is a priority therapy for licensing for the MPP, so this agreement with AbbVie is very good news for public health,” said Dr Marie-Paule Kieny, Chair of the MPP Governance Board. “It is a really important new option for a significant proportion of HCV patients throughout the world. As with previous MPP licences, we look forward to facilitating access to generic versions of this product

as quickly as possible in as many territories as possible.”

Globally, 71 million people are currently living with chronic HCV, many of them in LMICs. By the end of 2015, only 20 percent had been diagnosed and a mere seven percent of them had received treatment. In February 2017, the MPP issued its annual report on priority medicines for in-licensing. Given its favourable clinical profile and high potential in LMICs, G/P was listed as a key priority treatment.

G/P is an all-oral, once-daily, pan-genotypic combination regimen and was originally approved in 2017. It has achieved high cure (SVR12) rates of 98 per cent in treatment-naïve non-cirrhotic patients across all six genotypes of the virus. It is recommended by the WHO as a first-line treatment for eight weeks in treatment-naïve non-cirrhotic patients. Treatment-naïve patients with compensated liver cirrhosis require a 12-week treatment course.

Further, the regimen is also indicated for use in HCV patients with any degree of renal impairment, including patients on dialysis. Globally between five and ten percent of all people living with chronic HCV infection are estimated to be living with kidney disease and this treatment will be

very helpful for them.

There are 95 countries and four territories included in the MPP/AbbVie licence for G/P at this point. The countries are Afghanistan, Angola, Antigua and Barbuda, Bangladesh, Belize, Benin, Bhutan, Bolivia, Botswana, Burkina Faso, Burundi, Cambodia, Cameroon, Cape Verde, Central African Republic, Chad, Comoros, Congo, Cook Island, Côte d'Ivoire, Democratic Republic of the Congo, Djibouti, Dominica, Egypt, Equatorial Guinea, Eritrea, Ethiopia, Fiji, Gabon, Gambia, Georgia, Ghana, Grenada, Guadeloupe, Guinea, Guinea-Bissau, Guyana, Haiti, Indonesia, Jordan, Kenya, Kiribati, Laos, Lesotho, Liberia, Libya, Madagascar, Malawi, Maldives, Mali, Marshall Islands, Mauritania, Mauritius, Micronesia, Morocco, Mozambique, Myanmar, Namibia, Nauru, Nepal, Niger, Nigeria, Niue, Pakistan, Palau, Papua New Guinea, Philippines, Rep., Reunion Islands, Rwanda, Saba, Saint Eustatius, Saint Kitts and Nevis, Saint Lucia, Saint Vincent & the Grenadines, Samoa, Sao Tome and Principe, Senegal, Seychelles, Sierra Leone, Solomon Islands, Somalia, South Africa, South Sudan, Sri Lanka, Suriname, Swaziland, Tanzania, Timor-Leste, Togo, Tunisia, Turkmenistan, Tuvalu, Uganda, Vanuatu, Vietnam, West Bank & Gaza, Yemen, Zambia, Zimbabwe.

World Hepatitis Alliance 2019 Elections

2019 is an election year for the World Hepatitis Alliance Board.

The time has come for members to have a say about who is representing them at both a regional and global level.

Nominations are now open for new Board members for the EURO, SEARO and PAHO regions. Members from those regions are able to

nominate candidates from their countries for the board elections to be held in January 2019.

All members are also able to nominate candidates for the position of President-Elect who will be selected by the newly elected Board from the candidates' members put forward. The President-Elect selection will take place at the WHA board meeting in March 2019. The selected candidate will be learning the role of WHA President for a year before being endorsed as President

by the Board at the end of their term as President-Elect.

WHA members have been sent details of the nomination process. If you are a member and have not received the relevant documents to make your nomination then please email us on admin@worldhepatitisalliance.org. The deadline for nominations is Friday 30th November.

WHA at the World Health Summit

In October, WHA CEO, Raquel Peck attended the World Health Summit in Berlin, an annual event bringing together global leaders including heads of state, development agencies, researchers, physicians as well as representatives from industry and NGO. At the event the World Health Organization released the [Global Action Plan for healthy lives and well-being for all](#). A report to leverage the experience and expertise of the global health community to accelerate progress towards SDG3



“Claiming over one million lives each year, viral hepatitis is one of the world’s major public health challenges and disproportionately affects people living in LMICs. Therefore access to safe, quality-assured treatments, affordable for all, has to be the fundamental aim of the public health community. This is a big step in that direction. The next step is to see more territories included in the agreement. Each step makes the dream of hepatitis C elimination more real.”

Raquel Peck, CEO, World Hepatitis Alliance

Find The Missing Millions. EXAMPLES FROM AROUND THE WORLD

Through the Find the Missing Millions campaign, we are highlighting best practice and innovations in screening and testing so that other organisations can learn and develop their national activities. Each month we profile a successful diagnosis initiative. This month, we're highlighting the efforts of Egypt, one of just 12 countries on track to eliminate hepatitis C by 2030.

estimated 150,000 people being newly infected annually, the majority of new infections were among people under 25. Egypt was facing a growing HCV crisis. The prevalence of the disease in Egypt has been attributed largely to persistent unsafe injection and health care practices. At the National Level, the Egyptian government launched an ambitious national HCV treatment program with the goal of achieving HCV elimination by 2030.

The results of this plan have seen 5 million people screened for HCV and all positive cases have received treatment. Key to Egypt's success has been the involvement of civil society to ensure everyone is reached and the missing millions are found.

My involvement in supporting Egypt's hepatitis response was the planning and implementation of an innovative project called "Towards a village free from viral hepatitis." This project aimed to find the missing millions in rural settings, treating the affected population

and educating people through community-based outreach interventions targeting the poorest villagers.

Being part of the Association of Liver Patients Care, a WHA member, and heading up the Epidemiology unit of the Egyptian Liver Research Institute and Hospital in Dakhlya Governorate-Egypt, we promoted HCV testing through awareness campaigns that built a community coalition to reach the whole population. We worked with donors to raise money to ensure we could remove the financial barriers for the poorest to access testing.

"Key to Egypt's success has been the involvement of civil society to ensure everyone is reached and the missing millions are found."

Through this approach, free screening was offered to 39,388 residents and free treatment and care for 3,418 people. I'm proud to say that in May 2017 we were able to declare 30 villages as free from hepatitis and we are now working to have 33 more villages boast this status by the end of the year.

Our approach of creating a community model to support the elimination of HCV in Egypt was intended to complement the existing national treatment program. This community-based

program achieved high uptake of HCV testing, linkage to care and treatment.

The Egyptian government has now launched the world's largest HCV testing and treatment campaign, covering 45 million people with a \$561 million dedicated fund to find the estimated 3.5-4.2 million people living with HCV unaware.

Community based approaches could be an important strategy for other nations to adopt as they look to reach communities

in rural, and other hard to reach settings. We are keen to share our findings and learnings to help other countries with a similarly high HCV prevalence and burden in the general population. If you would like to learn more, our model of elimination in one village in northern Egypt, was published in Lancet gastroenterology journal. Our program is currently being extended to 63 other villages in Egypt from which additional lessons will be learned to inform further scale-up.

ELIMINATING HEPATITIS C IN EGYPT



By Prof. Dr. Ammal Mokhtar Metwally

In 2015, the figures for chronic hepatitis C (HCV) in Egypt were shocking. Approximately seven million people had HCV with an

"We are working now to declare 63 villages free from hepatitis by the end of 2018."



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, we hear from Camilla from Denmark who shares her story.

“My world crashed. All I’d ever wanted to do was to donate my blood for people who need it.”

CAMILLA

One Wednesday afternoon after school I went to the local blood bank to become a donor. My mom came with me.

I filled out the forms with my name, birth date, address, etc and answering “no” to pretty much every question there was. “No, I haven’t shared needles with other individuals,” “no, I haven’t had unprotected sex,” and so on. I went home - with a brochure about bone marrow donation in my hand - smiling, feeling good about myself and I couldn’t wait to get a call from the blood bank.

5 days later I got the devastating call. *“Not everything in your tests came out good. You have hepatitis B.”* I couldn’t be a blood- or bone marrow donor. My world crashed! All I’d ever wanted to do was to donate my blood for people who need it.

We were told that I’ve had it for most of my life and that’s when my aunt remembered that there had been a sign up at the kindergarten I went to,

when I was 3-6 years old, about hepatitis B going around. I guess I was “lucky” to only have it as a chronic, inactive disease.

As it is chronic and inactive, it doesn’t do much to my body. Yes, I’m extraordinarily tired, I get nauseous and I sometimes get pains in my liver, but other than that – I am not sick from the disease, I’m healthy, except for this horrible virus lurking underneath my skin.

I’m also not allowed to drink too much or even too often. Sure, that’s not the end of the world, but it’s tough to explain to my friends that I don’t feel like going out, because of the fact that I can’t drink like they can. Yes, I know I can still have fun without drinking, but that doesn’t change the fact that I get jealous about them drinking in front of me and I have to stick to sodas and Red Bull. Not fun.

“I remember when we were first told and my mom was so afraid that she was the one who’d given it to me”

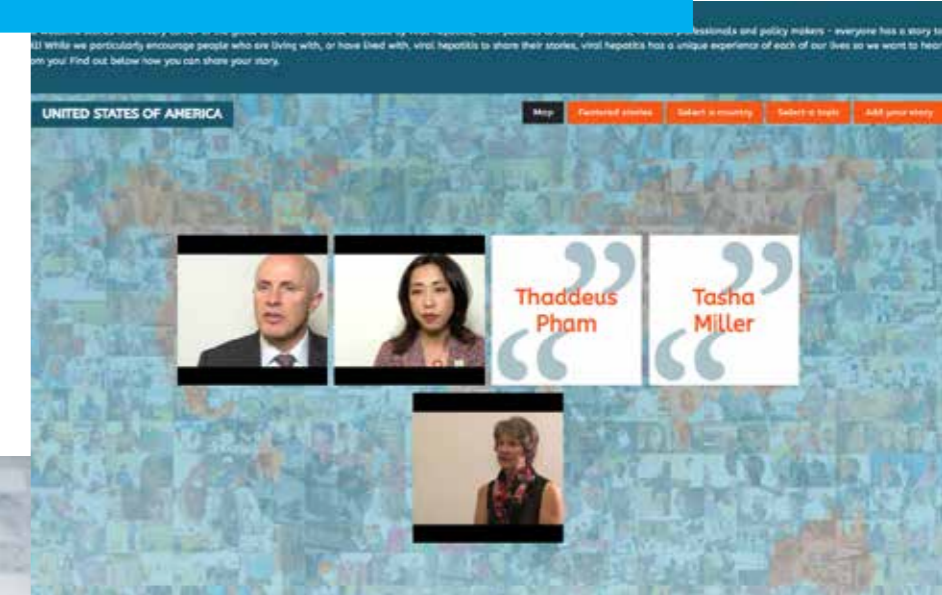
Back when I was diagnosed, we were told that we didn’t have to take any kind of precautions in the home, but now my baby sister is 5 years old and she has a tendency to bite. So far, she hasn’t bitten me yet, but she’s trying hard and I’m afraid she’ll succeed one day. I don’t intend to explain to her why she particularly isn’t allowed to bite me more than she’s not allowed to bite other people.

I remember when we were first told and my mom was so afraid that she was the one who’d given it to me, since she got blood transfusions, after she’d given birth to my big brother back when they didn’t screen the blood. She was terrified that she was the cause. Fortunately, she wasn’t. Now I have that same feeling she did for 10 days after we were informed of my “condition”. I don’t want my

sister to get inhibited by this disease. I want her to live her life and be able to give blood, if she wants to. I don’t even care about having this disease anymore – I’m only worried about her getting it. I hope to bring more awareness about this disease and not have it be a taboo subject. People should get vaccinated, even if they aren’t travelling abroad. It should be a necessity. Hepatitis is a horrible disease and it MUST BE STOPPED!

“I hope to bring more awareness about this disease and not have it be a taboo subject.”

See more stories and submit your own at www.worldhepatitisalliance.org/wall-stories



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