5 WAYS TO MAKE AN IMPACT IN 2018

Liver cancer deaths increase drastically

New year, new look
Note from our CEO

2018 marks a dawn of new beginnings for us here at the World Hepatitis Alliance. With the new year, we welcome Michael Ninburg as our new President and look forward to working together with him to achieve our vision for hepatitis. We have launched a new strategy to focus our activities for 2018-2020 – turn to page 6 to find out how you can make an impact with us. We’re also introducing a new look for hepVoice. This month we’ve got some great new features – do get involved and share your contributions to help make the magazine work for you. We look forward to embarking on this new era for WHA with you.

We hope you enjoy reading!

Raquel Peck
Chief Executive Officer

Content

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

1000 courses of hepatitis C treatment donated to the Ministry of Health of Argentina by the Messi Foundation.

4 new member organisations welcomed to the World Hepatitis Alliance in December 2017.

16 (46%) of the 35 European countries and jurisdictions require patients to have fibrosis at stage F2 or higher for reimbursement of interferon-free DAAs, according to findings from the Lancet.

6 funded exhibition spaces available in the NOhep Village at the Global Hepatitis Summit.

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.

Regulars

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Focus: Deaths from liver cancer on the rise

New data reveals deaths from liver cancer nearly doubled

Wall of Stories snapshots: Life after cure

Aleksey Lakhov shares his experiences

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Features
Viral hepatitis is making the headlines. Here’s the latest news from the field of viral hepatitis this month.

**WHA welcomes a New President**

Michael Ninburg begins his term as WHA President and will serve for the period 2018-2019. Michael brings a wealth of knowledge, experience and passion to the role, having served as Executive Director of the Hepatitis Education Project (HEP) since 2001 and worked as a consultant to a variety of governmental agencies and multilateral organisations, including the World Health Organization and the U.S. Department of Health and Human Services. Michael has also served on WHA’s Board in both an Executive and Non-Executive capacity.

**NHS England hopes England will be the first country to eliminate hepatitis C**

The National Health Service (NHS) sets its sights on the title of the first country in the world to eliminate hepatitis C. Health leaders in England have called on the pharmaceutical industry to provide the treatment at the best value for money so they can commit to elimination by 2025, five years sooner than the WHO’s global target.

**Civil society urge Trump to fund the US hepatitis response**

Over 60 organisations in the United States wrote an open letter to the President of the United States, calling on the government to take action to achieve the 2030 elimination target and to fund the national hepatitis action plan. While the impact is yet to be seen, this initiative serves as an important reminder that as advocates, our voices are stronger together.

**France makes hepatitis B vaccination compulsory for all children**

As of 1 January, the Government of France made it mandatory for all children to be vaccinated against hepatitis B. Infants in France will now receive all three doses of the vaccine within the first two years of life. Vaccination coverage is a key pillar to the WHO’s elimination strategy, which calls on governments to vaccinate all newborns within the first 24 hours of birth. 48% of countries – including France – are still failing to implement the birth dose.

**USA hit by hepatitis A outbreaks**

From Michigan to Missouri and California to Utah, news of hepatitis A outbreaks has been grabbing headlines across the States this month. The vast majority of cases are being reported at food establishments and stresses the importance of employers implementing hand-washing hygiene practices. If you think you’ve been exposed to hepatitis A, don’t panic. While there is an increased risk for groups with underlying conditions, often including homeless people or people who use drugs, life-threatening complications from hepatitis A are rare in development countries. If you haven’t been exposed to the virus, the hepatitis A vaccine can prevent infection. More here.

**Kazakhstan steps up efforts to tackle hepatitis**

The Ministry of Health of Kazakhstan has announced that in 2018 it will prioritise treatment of hepatitis B and C. Access to hepatitis B and C treatment will increase more than 3.6 times compared to previous years and DAAs Sofosbuvir and Daclatasvir will be included in its list for free drug provision for the first time. The Ministry are also taking steps to prevent hepatitis B transmission, purchasing almost half a million doses of the hepatitis B vaccine.

**World Cancer Day**

World Cancer Day is an international day to raise awareness of cancer and to encourage its prevention, detection, and treatment. Turn to page 12 to learn more about the link between liver cancer and viral hepatitis.

**World Day of Social Justice**

World Day of Social Justice recognises the need to promote efforts to tackle issues such as poverty, exclusion and unemployment. Stigma and discrimination continue 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 and stigma and discrimination perpetuate the epidemic. This World Day of Social Justice, we’re launching our #StigmaStops campaign. Turn to page 8 to find out how to get involved.

**Zero Discrimination Day**

Zero Discrimination Day understands 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 and stigma and discrimination perpetuate the epidemic. This World Day of Social Justice, we’re launching our #StigmaStops campaign. Turn to page 8 to find out how to get involved.

**Submissions close for NOhep Village**

Looking for an opportunity to showcase your work to the world? This year we’re bringing the NOhep Village to the Global Hepatitis Summit (14 – 17 June 2018, Toronto, Canada) and as a civil society organisation, you can join us there. Don’t miss out on the opportunity to sign up or apply for one of 6 funded exhibition spaces. Applications close 2 March. More details on page 9.

**Striving towards the elimination of HCV infection: EASL monothematic conference**

Eminent medical professionals will meet in Berlin, Germany to discuss strategies to reach WHO targets for hepatitis C elimination. Follow the conversation on Twitter with #EASLmono.

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**For the Diary**

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

- **2-3 Feb**
  - Striving towards the elimination of HCV infection: EASL monothematic conference
  - Eminent medical professionals will meet in Berlin, Germany to discuss strategies to reach WHO targets for hepatitis C elimination. Follow the conversation on Twitter with #EASLmono.

- **4 Feb**
  - World Cancer Day
  - World Cancer Day is an international day to raise awareness of cancer and to encourage its prevention, detection, and treatment. Turn to page 12 to learn more about the link between liver cancer and viral hepatitis.

- **20 Feb**
  - World Day of Social Justice
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**Participating in a hepatitis related activity or have an event planned?**

Email us or contact us on social media.
In action

FIVE WAYS TO MAKE AN IMPACT WITH THE WORLD HEPATITIS ALLIANCE IN 2018

We have 13 years to hit our ultimate goal of elimination by 2030, 13 years to make viral hepatitis a thing of the past. So now more than ever, the time to act is now. This month we hosted a special webinar on how our member organisations can join us in delivering our 2018 – 2020 strategy. Here’s a snapshot of the top five things you can do too.
1 #StigmaStops

From social exclusion and inferior healthcare to denial of employment opportunities and verbal assaults, stigma stops the majority of people living with viral hepatitis enjoying the quality of life they deserve. Our new report “Holding Governments Accountable: World Hepatitis Alliance Civil Society Survey Global Findings Report” found that more than 90% of countries surveyed reported stigma and discrimination to some degree.

On Zero Discrimination Day (1 March 2018), we will launch our year-long global awareness-raising campaign called #StigmaStops, in an effort to highlight the true impact of stigma, dispel myths and encourage people living with the disease to speak out.

Don’t let stigma stop you – get involved:

- Visit the WHA website for more information on the campaign
- Share the #StigmaStops graphics on social media
- Learn more about the issue with our Holding Governments Accountable: World Hepatitis Alliance Civil Society Survey Global Findings Report
- Participate in our social media campaign to help highlight how widespread stigma really is: Write the hashtag #StigmaStops along with form of discrimination you have faced on the palm of your hand and post a picture or video on social media (example here). Don’t forget to use the hashtag #StigmaStops. Your submissions will be used in a special video that we will launch on Zero Discrimination Day to call for an end to stigma.

2 NOhep Village at the Global Hepatitis Summit

This year we’re bring a NOhep Village to the Global Hepatitis Summit (14 – 17 June 2018, Toronto, Canada). The NOhep Village will be an innovative and interactive space and a unique opportunity to bridge the gap between civil society and the scientific community to better advocate for the elimination of viral hepatitis. The Village will showcase the work of civil society and patients through civil society exhibition stands, short talks and panel discussions, videos and networking areas.

We are looking to partner with organisations who wish to exhibit their work in the NOhep Village and we have a number of exhibition spaces available, 6 of which will be funded. This is an excellent opportunity to network with key influencers, to gain exposure to sponsors and to harness the learning opportunities available at a large global event. In addition to the opportunity to exhibit, selected NGOs will also get a chance to present as part of the NOhep Village programme of talks and panel discussions.

Applications to take part in this exciting new opportunity are now open. For further information and to apply, visit our website.
3 Finding the Missing Millions

Of the 325 million people living with viral hepatitis, up to 300 million are unaware they are living with the disease. Without finding the “missing millions” that are yet diagnosed and linking them to care, we will not eliminate hepatitis. In response, this year we’re launching the “Finding the Missing Millions” programme that aims to help countries reach the WHO diagnosis target they committed to. As a first step, we are working with experts, partners and members from across the globe to highlight the challenges to diagnosis, the context in which they are experienced and the role people living with viral hepatitis can have in overcoming the barriers.

This month we’ll be sharing a global survey to learn the barriers in your country. Keep an eye on your inbox and our social media channels to ensure your voice is heard.

4 Wall of Stories

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.

Has viral hepatitis impacted your life? We welcome stories from every corner of the globe and from all those impacted by viral hepatitis; from patients to family members, medical professionals and policy makers - everyone has a story to tell!

You can share your story in a number of ways – you can write a short story, create a poem, or a pen letter to hepatitis, or you can send us a short video or photo essay highlighting your experiences. We accept entries in all languages. Share your story to our Wall of Stories here and help to change the way the world sees viral hepatitis.

5 Share your successes

People living with viral hepatitis have a unique and critical role in the elimination of viral hepatitis and we must ensure their efforts do not go unnoticed.

We utilise every opportunity to promote the activities of our 255 member organisations across 87 countries. From profiling on-the-ground projects to highlighting member case studies, we strive to give our members international visibility and provide opportunities through our website, social media channels and monthly magazine as well as reports, media outreach and webinars.

Get in touch to let us know if you have something you’d like to promote via WHA channels.

For more information on all these activities, read the WHA Strategic Plan 2018-2020 here and re-watch the webinar here.
Deaths from liver cancer nearly double since 1990s

New data reveals that deaths caused by liver cancer have increased by 80% over the past two decades, making it one of the fastest-growing causes of cancer deaths worldwide.

On World Cancer Day (4 February), we’re highlighting the deadly link between viral hepatitis and liver cancer.

According to the Global Burden of Disease Study, the most comprehensive worldwide observational epidemiological study to date, 830,000 people died as a result of the disease in 2016 compared to 464,000 people in 1990. This makes liver cancer the second leading cause of cancer deaths worldwide, after lung cancer.

Globally, two out of three liver cancer deaths are caused by hepatitis B or C. The Western Pacific and South East Asia regions record the largest numbers of people living with the viruses and also some of the highest cases of liver cancer deaths globally. In China alone, over 260,000 liver cancer deaths caused by hepatitis B and C were recorded in 2016, accounting for a third of the global liver cancer death toll.

According to the findings, the hepatitis C virus was responsible for 160,000 liver deaths in 2016. The USA was amongst the top three countries with the highest numbers, alongside Japan and China. The American Cancer Society suggests this is because of the high rate of hepatitis C infection among baby boomers (born between 1945 through 1965), of which prevalence is approximately 2.6%, a rate 6-fold greater than that of other adults in the USA. Highly-effective cures for hepatitis C do exist which can halt progression to liver cancer, however only 3 of the 71 million people living with the virus globally, have accessed these life-saving treatments in the last two years.

The study also found that 350,000 liver cancer deaths were caused by the hepatitis B virus, of which China and India accounted for 80% of these. The high majority of these deaths could have been prevented if people received the hepatitis B vaccination after birth. Today, only 52% of countries provide the hepatitis B birth dose vaccine to newborns.

“Globally, two out of three liver cancer deaths are caused by hepatitis B or C.”
Each month we share the story of someone whose life has been affected by viral hepatitis. This month, Russian activist Aleksey Lakhov shares his experiences of undergoing hepatitis C treatment and the new beginnings he’s embarked on after being cured.

“I found out that I have hepatitis C in 1999. I was 19 years old. Back then I’d been using drugs so this news didn’t surprise me that much. For me it was like a right of initiation that I had successfully passed. At that time, hepatitis C was basically an incurable disease, so both doctors and drug users believed that this is the end. My beautiful friend, as Jim Morrison said. To tell you the truth, I didn’t feel much about this disease. For me, it was like permission to continue using drugs. Of course, it was just bravado and I understood it that only after I quit using drugs and got clean.

To tell you the truth, I didn’t feel much about this disease. For me, it was like permission to continue using drugs. Of course, it was just bravado and I understood it that only after I quit using drugs and got clean.

Approximately ten years after I became infected with the hepatitis C virus, I began to experience symptoms. I lost my appetite and even my favourite food tasted like junk. I felt nauseous, but most of all, I felt this overwhelming sense of fatigue when I couldn’t even get up from my bed in the morning and go to work. It was like I had a clinical depression.

The doctors decided that I needed treatment and so they prescribed me standard interferon plus ribavirin. My therapy continued for one year and during this time I had a lot of different side effects. For example, dermatitis, allergies on my legs, when I scratched them until they bled. Bouts of rage when I shouted at my wife and baby daughter. Of course, I felt bad about this behaviour but it seemed like I couldn’t do anything about it.

I hope it was worth it in the end because I was cured. When I tested negative for hepatitis C, it felt as though a huge burden fell off my mind and body. I felt really re-energised and ready to take on the whole world. Maybe this is why I quit my job in a real estate agency and decided to engage in activism. I wanted to help other patients because I had been there and I wanted to share my stories with them. I truly believe that little steps go a long way and I will keep going.”

Watch Aleksey’s full video story here.