RWANDA LAUNCHES HEPATITIS C ELIMINATION PLAN

NEW ZEALAND TO GET FULLY FUNDED TREATMENT FOR ALL

WALL OF STORIES
“"I WALKED A LONELY ROAD ALL BY MYSELF"

MEET THE WHA BOARD
Happy New Year! 2019 marks another pivotal year for the World Hepatitis Alliance. Our long-time CEO, Raquel Peck, has moved into an advisory role at WHA; and we will be hiring her replacement in the first quarter of the year. While it is impossible to truly replace Raquel, we are conducting interviews this month and hope to have the new CEO on board soon.

Our Executive Board will also see changes as we will welcome two new board members: Rachel Halford from the EURO region and Patricia Vélez-Möller from the PAHO region. Our SEARO board member, RP Shanmugam was re-elected for a second term.

One of our most exciting new initiatives will launch in the coming weeks- our ‘Find the Missing Millions’ in-country advocacy program. This program will support 5 WHA members from different countries to develop and implement effective action plans to increase testing and diagnosis rates in their countries. Applications for this program will come out within the next few weeks and we expect a high level of interest.

Finally, as always, this month we’ve got some great features in hepVoice. We hope you enjoy it and please remember to share your contributions to help make the magazine work for you. We wish you all the best for a happy and healthy year and great progress toward the elimination of viral hepatitis.

Michael Ninburg
President

The World Hepatitis Day 2018 Global Summary report is out now.

The report features details of the activities undertaken across the world which can be used as a source of inspiration when planning your WHD2019 activities.

See the report at www.worldhepatitisalliance.org/whd-2018-global-summary
Hepatitis is regularly making the news thanks to the efforts of WHA members. Here are a few highlights.

Peru Launches New Health Guidelines for Hepatitis C
Peru’s Minister of Health, Silvia Ester Pessah Eljay, has approved the ‘Health Guidelines for the Prevention, Diagnosis and Treatment of Viral Hepatitis C in Peru’. The objective of the guidelines is to regulate procedures for the prevention, diagnosis and treatment of the hepatitis C virus in Peru, in order to reduce morbidity and mortality in the general population, especially in at-risk groups with greater vulnerability.

Peru’s unique geography presents a challenge for the health system, with 25 regional health departments overseeing services for wildly different regions ranging from the sprawling capital of Lima to remote villages in the pockets of the Amazon rainforest accessible only by boat. Peru’s new guidelines look to ensure that no one is left behind as they make hepatitis elimination a reality.

Louisiana adopts ‘Netflix model’ to pay for hepatitis C treatments
Louisiana officials announced that their state would become the first to move forward with a new way to pay for hepatitis C treatments that could dramatically increase the number of people cured and provide a model for other places struggling to afford the medications.

Instead of paying for each prescription individually, Louisiana Governor John Bel Edwards said that the state would in effect pay a subscription fee to a drug company, an alternative payment arrangement that has become known as the “Netflix model.” The state would then get unlimited access to the drug, similar to how consumers pay a monthly fee to stream unlimited television shows and films.

The state’s goal is to treat 10,000 people with hepatitis C by 2020 instead of about 1,000 people treated last year, at the cost of $35 million.

Read more at: https://busquedas.elperuano.pe/normanormalesaprubean-lanorma-tecnica-de-salud-para-la-prevencion-diag-resolucion-ministerial-n-1317-2018minsas-1724730-5/?fbclid=IwAR026FVx_wfk8Dv6lrq_jJuVFb_o9O1jF-XcsPRKnVvu35VNB25aYUfM

Belgium on the right track towards the elimination of hepatitis C virus
Belgium’s Minister of Health Maggie De Block has announced that from 1 January 2019 funds will be available to make innovative medicines for the treatment of hepatitis C accessible to all patients, regardless of how far they have progressed in their illness.

Katrien Lammens, Chair of WHA member Vlaams Hepatitis Contactpunt (VHC), said: “This is a great relief for infected patients who did not have a route to treatment. They were burdened with a huge emotional and psychological weight. Now they will be able to continue their lives safely.”

Read more at: https://www.hepatitis-c-virus#

The Lancet releases new viral hepatitis commission
A global panel of experts have published their key recommendations to advance the fight against viral hepatitis.

The Commission, published in The Lancet Gastroenterology & Hepatology, assesses the global landscape of the disease and identifies priorities at a global, regional and national level that are key to its elimination.

Despite presenting a major public health challenge, viral hepatitis has been historically marginalised as a health and development priority. However, in 2015, the UN adopted a resolutioncalling for specific action to combat viral hepatitis as part of its 2030 Agenda for Sustainable Development, which was followed by the publication of the World Health Organization’s (WHO) first global health sector strategy on viral hepatitis in 2016. This newfound, coordinated focus on viral hepatitis means that eliminating the disease is now a realistic goal.

Read more at: https://www.thelancet.com/commissions/elimination-of-viral-hepatitis-test-today/

HepHIV Conference, Bucharest

HepHIV aims to provide an overview of innovative initiatives and best practices on optimal testing and earlier care for HIV and viral hepatitis from different settings across Europe, including progress and challenges in the integration of service, sustain and fuel the political discussion of testing policies, increase political commitment and public awareness by discussing how to translate global and regional goals, objectives and targets into local implementation plans, and provide opportunities for multi-stakeholder dialogue to develop creative solutions to unresolved challenges in research and implementation of HIV and viral hepatitis, TB and STI policies and programmes to improve early diagnosis and care.

World Cancer Day

Each year on 4 February, World Cancer Day empowers all of us across the world to show support, raise our collective voice, take personal action and pressure our governments to do more. World Cancer Day is the only day on the global health calendar where we can all unite and rally under one banner in a positive and inspiring way.
New Zealand to get fully funded hepatitis C treatment for all, putting it on track for elimination.

Our team, Hep C Action, is jubilant that treatment for all genotypes will be available in New Zealand from 1 February. Simplifying access to medicines means that we can now concentrate on raising awareness, reducing stigma, and encouraging people to get tested.

This has been a long road and for me a personal battle. I was diagnosed with hepatitis C in 1992, nearly as soon as the test became available. My experience of the disease has followed the timeline of the development of treatment options for the virus, which I now expect to see eliminated from the world in my lifetime. I initially had interferon plus ribavirin treatment (both sorts) whilst bringing up three young children, but in 2003, aged 39 I was diagnosed with cirrhosis by biopsy.

Then came DAA’s. In 2015, with a scan showing a kPa of 40, climbing Liver Function Tests (LFT’s), I was told I needed treatment ‘yesterday’. I sourced 24-weeks’ sofosbuvir and daclatasvir and was cured. My most recent scan showed no cirrhosis, and a normal liver.

With the dramatic increase in energy resulting from my cure, I have completed a law degree and started Hep C Action, an NGO aimed at eliminating hepatitis C worldwide and in New Zealand by 2025. We have been advocating for the government drug-buying agency, PHARMAC, to make treatment available to all, previously 43% of patients were unable to receive the treatment. I want to thank PHARMAC for listening to submitters like me, and our experts, in negotiating a price we can afford to treat everyone.

On February 1 our group will be meeting up to celebrate the decision by PHARMAC, we will be speaking to the media to raise awareness about why this decision is so important and to encourage people to come forward for testing.

We are now in an era where hepatitis elimination is possible; such exciting times. In my country, at least 250 lives per year will be saved, and there will be a big increase in wellness and productivity for many more people as a result. Hep C Action will be playing our part, we have created a butterfly symbol to help erode the stigma of hepatitis C and we have an action-packed year planned of campaigns, media and public speaking.

We are focussed on the campaign to “find the missing millions” – those who don’t know they are infected. We estimate that 30,000 people in New Zealand are unaware that they are living with hepatitis C. We will be bringing our unique, grassroots advocacy to EASL (European Association for the Study of the Liver) in April. If you’re there come look out for our colourful stand. Our brand new website has posters to download, useful anywhere, and more information.

By Hazel Heal
Advocate Hep C Action Aotearoa

“With the dramatic increase in energy resulting from my cure, I have completed a law degree, and started Hep C Action, an NGO aimed at eliminating hepatitis C worldwide and in New Zealand by 2025”
Following the recent elections for the World Hepatitis Alliance Executive Board, we are delighted to introduce the Alliance Board. The Board will be supported by a number of skills-based board members. Full details of the Alliance team can be seen at [www.worldhepatitisalliance.org/our-organisation](http://www.worldhepatitisalliance.org/our-organisation).
Rwanda Launches hepatitis elimination strategy.

In December 2018, I was in Rwanda with WHA members attending the launch of an ambitious new strategy that looks to eliminate hepatitis C in Rwanda within the next five years. Incredibly, at the event Rwanda Biomedical Centre Director General, Dr. Jeanine Condo, declared that although it’s a five year plan, they believe that hepatitis C elimination can be achieved in just two years.

The Rwandan government has prioritised hepatitis C elimination for some time. In 2011 the government was the first country in sub-Saharan Africa to establish a hepatitis control unit, which sits within the Division of HIV/AIDS, STIs and Other Blood Borne Infections at the Rwanda Biomedical Centre. The unit utilised the infrastructure built to combat other epidemics including HIV to combat hepatitis. In 2013, the viral hepatitis technical working group was set up, comprising health ministry specialists, clinicians, academic researchers, laboratory experts, implementing partner organizations, United Nations agencies, and civil society organisations. Since then they have tested 300,000 individuals.

The new plan sees a massive upscaling of testing and screening, with 4 million people aged 15 and above due to be tested within the next three years. Those who are found to have hepatitis will be given access to treatment and care. Rwanda has a population of 12 million people with 4% of the population expected to have hepatitis C.

The launch of this plan has been made possible with support from the Clinton Health Access Initiative, who have provided technical assistance to the country.

The Alliance has been undertaking similar work in Nigeria, where we have been working with partners, civil society and the government to put together the investment case for hepatitis C elimination there. You can read more about that work on our hepatitis financing site www.hepatitisfinance.org

It’s encouraging to see African countries prioritising hepatitis elimination and to see African governments willing to work with civil society in creating elimination plans. There is much work to be done in Africa to make the elimination of hepatitis a reality, but we are seeing steps in the right direction.

“although it’s a five year plan, they believe that hepatitis C elimination can be achieved in just two years”
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 in hepVoice. This month, we are highlighting the efforts of the Canadian Society for International Health and Correctional Service Canada.

Raising Awareness in Canadian Prisons

As is the case across much of the world, the prisoner population in Canada suffers disproportionately from viral hepatitis. In 2005, around 29% of federal prisoners in the Canadian prison system were known to be infected with hepatitis C. The prevalence of the virus amongst prisoners can be attributed to many incarcerated people having a history of injecting drug use.

However, the lack of awareness about viral hepatitis presents a barrier when trying to address the hepatitis epidemic in prison populations. Each year, World Hepatitis Day (WHD) provides an opportunity to raise awareness of the prevalence of viral hepatitis, reiterate the crucial importance of testing and treatment and break down the barriers to elimination. Since 2012, the Canadian Society for International Health (CSIH) has organized a World Hepatitis Day Art Contest for federal inmates across Canada, doing so in partnership with Correctional Service Canada (CSC) and with support from Gilead Sciences Canada.

With both male and female categories, the objectives of the contest in 2018 were to increase awareness about hepatitis and encourage inmates to learn their hepatitis status by getting tested. These objectives were in keeping with WHD 2018’s theme: “Finding the Missing Millions: Breaking barriers to diagnosis”.

“The objectives of the contest in 2018 were to increase awareness about hepatitis and encourage inmates to learn their status”

The high concentration of high-risk groups in the prison system provides a golden opportunity to address one of the main barriers to elimination: the lack of easily accessible testing. Correctional facilities have the ability to ensure that each prisoner receives hepatitis B vaccination or completes a full course of hepatitis C treatment (which takes around 8-12 weeks) without falling off the radar of health professionals. In Canada, inmates of federal correctional institutions can access hepatitis treatment. CSIH were pleased to report that in 2018, the Art Contest contributed to an increase in diagnoses and a subsequent increase in the number of people receiving the treatment that they need. Securing this relatively early diagnosis and treatment in the prison system is cost effective, having the potential to prevent more expensive and drawn out treatment costs once the prisoners are released.

When treating viral hepatitis in prisoner populations, the main barrier to diagnosis and treatment reflects the main barrier amongst non-prisoner populations: a lack of public knowledge about the disease. Initiatives such as the CSIH Art Contest are a refreshing and original way to address this key barrier and should be applauded; the most sincere appreciation of these grassroots initiatives would come, however, in the form of robust financing plans and an aggressive, committed approach to early diagnosis all year round.
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 Evelyn McKnight from the USA who shares her story.

In the autumn of 2000, I was diagnosed with breast cancer. I was assured that it was just a little bump in the road of life, but this diagnosis changed my life in a profound and permanent way in a way that I could never have foreseen.

I was shocked when test results came back positive for hepatitis C because I had no risk factors and no explanation for how I had contracted this disease. As the doctor questioned me about sexual practices and substance use, anxiety welled up inside me. The questions embarrassed me so much that I couldn’t meet their eyes. I quickly left the building. I walked the labyrinth of hallways, my confusion increasing with each and every step.

I didn’t know how I could move forward with courage in my life with hepatitis C. If I were to survive the breast cancer, I didn’t know how I could go forward from there as a wife, a mother or a healthcare provider myself.

I felt so stigmatized by my diagnosis that I told nobody about it, not even my family. I walked along a lonely road all by myself. I didn’t want anyone to know that I had a disease that was associated with risky behaviour. I was afraid that I would be judged.

Public health authorities investigated and found out that 99 of my fellow cancer patients had become infected through unsterile injections.

Hepatitis C diagnosis has huge repercussions for patients, their families, the medical community and the general public. People suffer physically, emotionally, socially and financially. At least six people died, not from the cancer, but from hepatitis C.

89 lawsuits followed, dividing the community between supporters of the medical system and supporters of the patients. I would venture to say that many in the community are still struggling to get past what happened - I know that I am.

I grieve for the families who have lost loved ones to the disease and I feel betrayed by a healthcare system that transmitted a life-threatening disease to me and to innocent victims through negligence.

In their honour, I am working to prevent what happened to me from happening to anyone else. I used the settlement money from my lawsuit as seed money to establish the Hepatitis Outbreaks National Organisation for Reform, or HONOR, which is dedicated to the prevention of hepatitis through injection safety.

I have vowed never again to let stigma control my life and I speak out against it at every opportunity. It’s rewarding to share my experience with others and to pass on hope for life with hepatitis C.

“I felt so stigmatized by my diagnosis that I told nobody about it, not even my family. I walked along a lonely road all by myself.”

WATCH EVELYN TELL HER STORY ON THE TEDX STAGE AT bit.ly/evelynWHA

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

Wall of Stories