

hep VOICE

Your monthly magazine from the World Hepatitis Alliance

Find The **Missing** Millions.

**WHA launches in-country
programme**

**Raising awareness with a
cup of coffee in Australia**

WALL OF STORIES

"I no longer feel shame"



NOTE FROM OUR PRESIDENT

Happy Lunar New Year!

WHA is excited to launch an new initiative which will support 5 WHA members from different countries to develop and implement action plans to increase testing and diagnosis rates in their countries. I encourage all members to consider applying; you can read more about this program on [page 8](#).

WHA has also had a busy few months attending high-level meetings across the globe. On February 21st in Manila, we participated in a Public Health Day symposium at the annual meeting for APASL, the Asian Pacific Association for the Liver. WHA Board member for the WPRO region, Dee Lee, gave [powerful examples of the impact of discrimination and stigma](#) which are particularly prevalent issues within the region. Zero Discrimination Day takes place on March 1st and provides another opportunity for our community to highlight the impact that discrimination has on those living with viral hepatitis.

Unfortunately, a new study has shown that we are likely to miss the 2030 hepatitis elimination targets. I see this report as yet another Call to Action. As a community, we need to hold our governments and policymakers to account. We need to ensure that hepatitis remains a global health priority and that our voices are heard as we advocate for the elimination of this global killer.

We hope you enjoy this issue of hepVoice and please remember to share your contributions to help make the magazine work for you.

Michael Ninburg

Don't miss out - receive hepVoice straight to your inbox!

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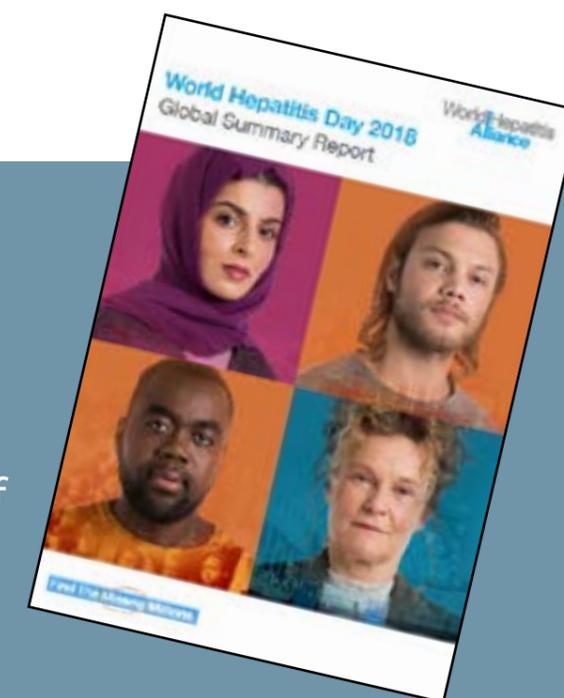
Want to contribute?

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

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



hep HEADLINES

Hepatitis is regularly making the news thanks to the efforts of WHA members. Here are a few highlights.

Pharmac to fund new Hep C treatment in New Zealand

New Zealanders will now receive access to hepatitis C treatment no matter what type of the virus they have. The announcement, which was made by Pharmac, the government drug agency, in December 2018, kicked in at the start of February.

Previously, only two types of treatment were available: Viekira Pak for those with type one and Harvoni for end stage liver disease involving all types. Pharmac stated that about 3000 people received these two drugs since they were funded in 2016, but that an estimated 24,000 others have been living without a funded treatment.

Now, Pharmac have stated that the funding of the drug Maviret means that most people with hepatitis C will now have the opportunity to access a funded treatment that had the potential to cure hepatitis C. While the move is a major step forward

in terms of funding, there is still a large challenge in terms of reaching the roughly 50% of people living with hepatitis C who are unaware of their diagnosis. Now that the treatment infrastructure is in place, the challenge is to expand awareness and testing campaigns.

Read more at www.radionz.co.nz/news/national/378443/pharmac-to-fund-new-hep-c-treatment

Ugandans not completing Hepatitis B vaccine injections

Sarah Opendi, State Minister for Health in Uganda, has told Ugandan Parliament that many Ugandans take the first dose for hepatitis B, but that few are returning for the second and third doses that are required for the vaccine to be effective.

Opendi stated: "The challenges faced in implementing the hepatitis B programme are the high rates of loss to follow up after the first and second doses of vaccination".

She also stated that there was a challenge posed by the untimely provision of data from districts to the ministry on the implementation progress.

Uganda is highly endemic for hepatitis B with a prevalence of 4.5% among adults 15-64

years old. According to Opendi, the health ministry has been implementing hepatitis B control activities including screening and vaccination of adolescents since 2015. So far 69 of 127 (54.3%) districts have been covered.

Read more at www.newvision.co.ug/new_vision/news/1494036/ugandans-completing-doses-hepatitis-b-vaccine

CEVHAP host first NOhep Twitter Takeover

On 21st February the NOhep Twitter platform was taken over by CEVHAP (The Coalition for the Eradication of Viral Hepatitis in Asia Pacific).

The takeover came live from Manila at the APASL Public Health Forum highlighting key issues in the fight against hepatitis in the region.

At the event, representatives from Taiwan presented on how they intended to reach elimination by 2025. Stigma and discrimination were key issues highlighted at the event with Senator the Hon Nancy Binay from the Philippines delivering a keynote presentation about how they are tackling discrimination in the workplace.

Read more at www.nohep.org
Follow CEVHAP on [Twitter](#) and [Facebook](#).

DATES FOR THE DIARY

Upcoming events and activities taking place in the coming months.

1 MARCH

Zero Discrimination Day

Zero Discrimination Day is an annual day celebrated by the UN and other international organisations. The day aims to promote equality before the law and in practice throughout all of the member countries of the UN. With stigma and discrimination being leading barriers to diagnosis for viral hepatitis, this day provides an important platform to address these issues. Join in the conversation on social media using **#ZeroDiscrimination**.

22 MARCH

World Water Day

Sustainable Development Goal 6 is crystal clear: water for all by 2030. By definition, this means leaving no one behind. But today, billions of people are still living without safe water – their households, schools, workplaces, farms and factories struggling to survive and thrive. Join in the conversation on social media using **#WorldWaterDay**.

24 MARCH

World TB Day

World TB Day, falling on 24th March each year, is designed to build public awareness that tuberculosis today remains an epidemic in much of the world, causing the deaths of nearly one-and-a-half million people each year, mostly in developing countries. Join in the conversation on social media using **#ItsTimetoEndTB** and **#WorldTBDay2019**, and by tagging **@StopTB**.

10-14 APRIL

International Liver Conference

The International Liver Congress™ (ILC) is the most influential congress of its kind worldwide, with participants attending from across the globe. ILC serves as the leading platform to exhibit best practice and science, introduce the latest trends in hepatology, present scientific advances, offer education and nurture networking at an international level. Join in the conversation on social media using **#ILC2019**.

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

Email us or contact us on social media.

Raising awareness in Perth, Australia with a cup of coffee



By HepatitisWA



HepatitisWA wants to grow awareness in our local community about the new lifesaving hepatitis C treatment.

After discovering an organisation called the Paper Cup Project that partners with local not-for-profits, artists and cafes, we believed that placing our message on a coffee cup would be a unique way to share the message.

We worked with a local artist called Bertie Louise who helped design our cup.

The cafes receive the cups for free, helping us to distribute our message and the artist receives free exposure. It's a win, win for everyone. All we needed to do was pay for the printing of the cups.

People may not be aware the current treatments exist, even though it has been available to Australians on the Pharmaceutical Benefits

Scheme (PBS) since March 2016.

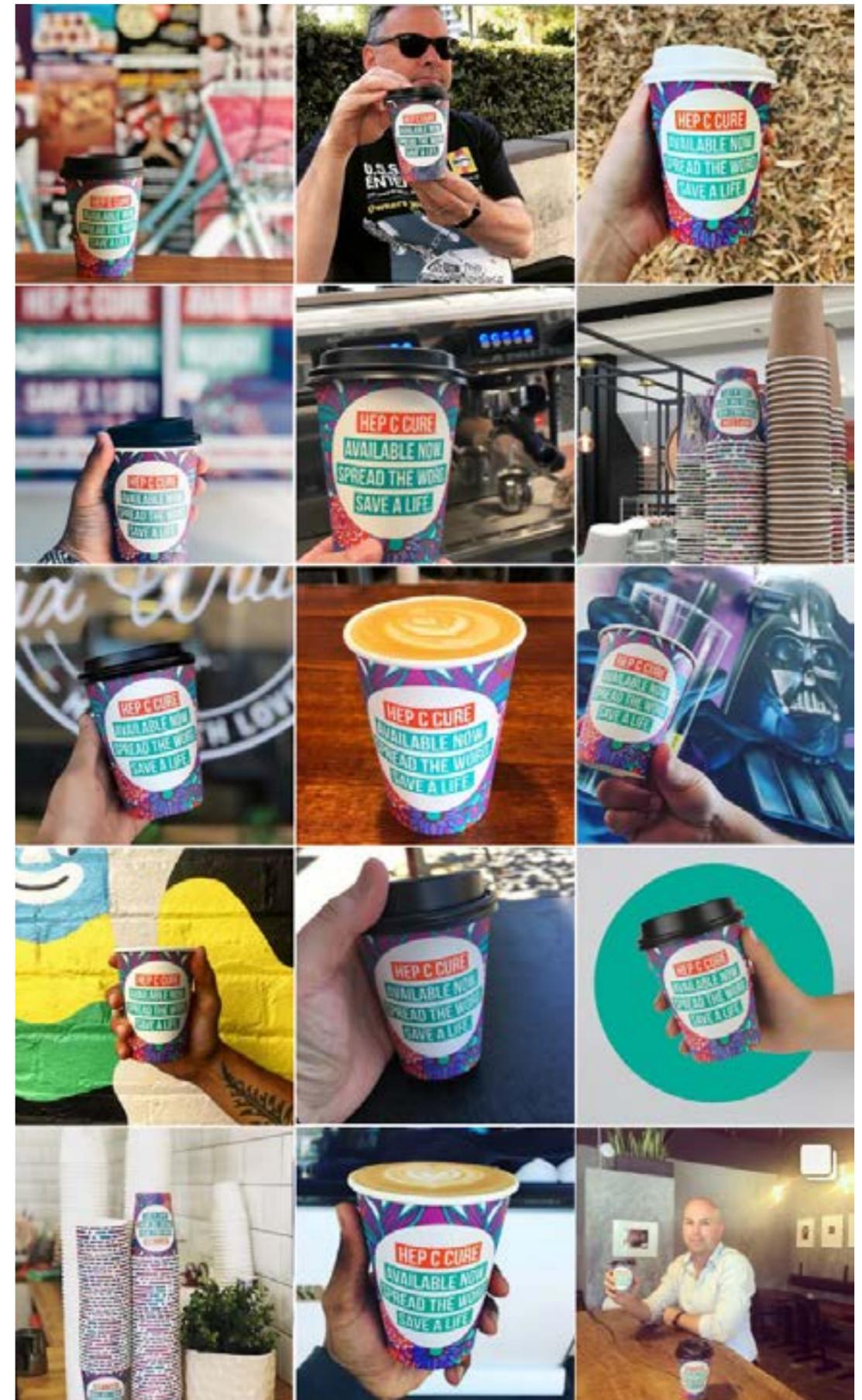
We believe there are many people in the Perth suburbs who are living with hepatitis C but are not aware there is something they can do about it.

The treatments have virtually no side effects and can be completed in 8 – 12 weeks, with a 97% cure rate.

Therefore, we wanted to promote the hepatitis C cure in an artistic way, on coffee cups, to encourage conversations about the cure.

We have had 15,000 cups created and they have been distributed to 16 different cafes. People have been contacting us about the impact of the cups; one person told us that their father has had hepatitis C for 30 years and had no idea about the cure until they were shown the cup.

“We wanted to promote the hepatitis C cure in an artistic way, on coffee cups, to encourage conversations about the cure”



WHA Launches the Find the Missing Millions In-country Programme

In 2016, 194 governments committed to eliminating viral hepatitis by 2030. However three years later, only 11% of men, women and children living with this silent killer are aware of their condition worldwide. Sadly, diagnosis remains one of the biggest challenges to elimination.

In the face of this, last year we launched our Find the Missing Millions campaign, a three-year global awareness-raising and advocacy campaign aimed at addressing the main barriers to diagnosis. We are now pleased to welcome applications from World Hepatitis Alliance (WHA) members for our Find the Missing Millions In-country advocacy programme.

The World Health Organisation's strategy for eliminating viral hepatitis calls for a major scaling-up in diagnosis of both hepatitis B and C, aiming for 90% of infected peoples to know their status by 2030. At WHA, we have long

championed the unique and critical role that civil society organisations and the affected community have to play in achieving this. The In-country advocacy programme is part of this commitment, putting five WHA members from across the world at the forefront by enabling them to take action to break the barriers to diagnosis.

Over a period of 18 months, the programme will bring together five successful applicants to implement effective action plans that advocate for policy makers within their countries to drive action for increased diagnosis rates. A small amount of seed funding will also be given to help initiate advocacy activities.

Only by working together will we increase diagnosis. So as part of this programme, WHA aims to facilitate partnerships and up-skill our members in the areas of diagnosis and diagnostics.

Successful applicants will be invited to join an international working group made up of key stakeholders, from whom they can learn best practice through a series of face-to-face meetings and monthly catch-up calls.

The objectives of the programme are varied, including to stimulate action towards increasing diagnosis rates at a national level, up-skill members, and strengthen the patient voice. On top of this, each participating member will have their own objectives to ensure meaningful action relevant to their own country or state.

How to apply

Applications close Friday 15th March 2019 at 17.00 GMT. To apply please send a completed application form to projects.team@worldhepatitisalliance.org Please also send any queries to this address. Visit our website for more information

www.worldhepatitisalliance.org/find-missing-millions-advocacy



hepinion



Are we surprised that the 2030 targets are set to be missed?

By Prof. Dr. Ammal Mokhtar Metwally

A recent study published in [the Lancet](#) has shown that even with an upscaling of diagnosis, treatment and prevention, we are set to narrowly miss the 2030 elimination target for the reduction in mortality set out in 2016 by WHO.

The study, [‘Scaling up prevention and treatment towards the elimination of hepatitis C: a global mathematical model’](#) estimated the worldwide impact of scaling up interventions that reduce risk of transmission, improve access to treatment, and increase screening for HCV infection. The mathematical modelling in the study predicts that the 65% target for the reduction in the mortality rate can be achieved by 2032 if a comprehensive package of prevention and treatment interventions and an upscaling of screening and testing is conducted.

That’s a big *if*. The majority of countries are not putting in place any form of package of

interventions, let alone a comprehensive one.

Currently only 12 countries are on track to eliminate hepatitis C. Globally, governments have been slow to create national strategies for the elimination of viral hepatitis, the commitment to elimination set out in 2016 has yet to be filtered down to the national and regional level. Yet, we know what needs to be done to achieve elimination and we have the tools to do it. We have a cure available for hepatitis C, we have the global commitment, and [we have a growing evidence base which demonstrates that elimination is cost-effective.](#)

The Lancet study also showed the importance of comprehensive blood safety and infection control measures, with the implementation of these estimated to reduce the number of new hepatitis C infections by 58% in 2030, compared to

if things continue as they are. In addition, extending harm reduction services to 40% of people who inject drugs could reduce the number of new infections by a further 7 percentage points.

The mortality target is the first target that has become mathematically impossible to hit, but many more targets are not on track either.

Work needs to be done to ensure that hepatitis remains on the health agenda and that more countries are put on track to achieve elimination. Successful, scalable and replicable programmes exist around the world which can lead the way, including many examples of micro-elimination programmes targeting at-risk groups such as refugees and asylum seekers.

We are seeing some progress. In Europe, 27 countries now have national plans compared to just 13 five years ago. Generic versions of the lifesaving cure will start becoming available in some countries thanks to the work of the [Medicines Patent Pool \(MPP\) and the deal with AbbVie](#), and more countries are utilising the skills and experience of civil society to ensure that no one is left behind as we try to make elimination a reality.

Never before have we been so close to the elimination of viral hepatitis, but a lack of action endangers our ability to see the elimination of this disease in our lifetime and future generations will have to bear the burden of this disease.



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 in hepVoice. This month, we are highlighting the efforts of WHA member Beacon Youth Initiative (BYI) in Nigeria.

Engaging with the community in Nigeria

Over the past six years, BYI has conducted a number of hepatitis programmes, engaging with policy makers, private companies and other civil society organisations to raise awareness of viral hepatitis, scale up screening and vaccinations, and to offer training to healthcare workers. In recent months they've turned their attention to finding the missing millions, seeking to increase diagnosis through community engagement.

Nigeria has one of the highest hepatitis B burdens in the world. An estimated 25 million people live with the disease, equalling 11% of the country's population. Sadly a large proportion of those living with this silent killer are unaware, due to low awareness and the high costs of diagnosis and treatment.

In early February, BYI partnered with Doctors on the Move Africa, ZK Medical Konsults LTD and Federal Medical Centre Abuja to host a hepatitis programme in Zuba, on the outskirts of Abuja.

A previous needs assessment conducted in the community found that over 96% of Zuba residents lacked basic knowledge on viral hepatitis. As a result, many of those living with the disease in the area remain undiagnosed

and turn to ineffective alternative treatments to help alleviate symptoms. According to BYI, the region's vaccination programme is also ineffective because of low availability and the poor storage of vaccines.

BYI and their partners started organising the programme by contacting community leaders in Zuba through an advocacy and sensitization visit, mobilising the local

community ahead of the programme to ensure high attendance.

On the day of the programme itself, BYI and their partners offered hepatitis B vaccines, hepatitis B and C screening and testing, and distributed condoms to encourage safe sexual practices. Throughout the day they also educated the local population on

viral hepatitis. Overall, they engaged with over 300 beneficiaries mostly between the ages of 7 and 87.

One of the more interesting outcomes of the day was increased willingness from community leaders to take action for increased diagnoses in their community. At the same time, BYI also identified an increased demand for

services on viral hepatitis from the local population pushing for action from the other side. True to BYI's goal to find the missing millions, the day resulted in 98% of beneficiaries knowing their hepatitis B and C status for the first time ever.

“96% of Zuba residents lacked basic knowledge on viral hepatitis. As a result, many of those living with the disease in the area remain undiagnosed”



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.

Each month we share the story of someone whose life has been affected by viral hepatitis. This month, we hear from Colleen Price from Canada who shares her story.

“ My name is Colleen Price. I am 45, a survivor of trauma, addiction, hepatitis C and HIV who resides in Ottawa, Canada.

At the time of my hepatitis C diagnosis in 1997, it didn't overly impact me. I saw hepatitis C as a chronic, manageable disease that would probably take many years before it became an issue. My GP didn't encourage treatment as it was very difficult at that time and my liver was not problematic.

I lived in silence and denial. Then, in 2000, I was diagnosed with HIV. I associated both diseases with a death sentence at first and for a long time after. With the combined diagnosis, I reverted into a helpless and hopeless mode, relapsing to cocaine use and increased drinking, which culminated in a DUI. For me, this was a final wake-up call and I subsequently entered a drug treatment centre.

I thank my illnesses because my paths to my own destruction were ingrained and my denial and negativity were absolute. Mental re-framing, harm-reduction and support have all helped me to break the chains of addiction and self-destructiveness. I am in recovery from addiction and always will be.

I am not ashamed of hepatitis C or HIV or my past. I am who I choose to be now. The hardest part emotionally was disclosing my diagnosis to my partner, parents, friends and employer.

Treatment was an emotional, physical and spiritual roller-coaster but in the end, I persevered and

“The hardest part emotionally was disclosing my diagnosis to my partner, parents, friends and employer.”

completed treatment. The journey changed me from victim to survivor via strong emotional releases while on hepatitis C treatment. I have run into many barriers individually, clinically and systemically.

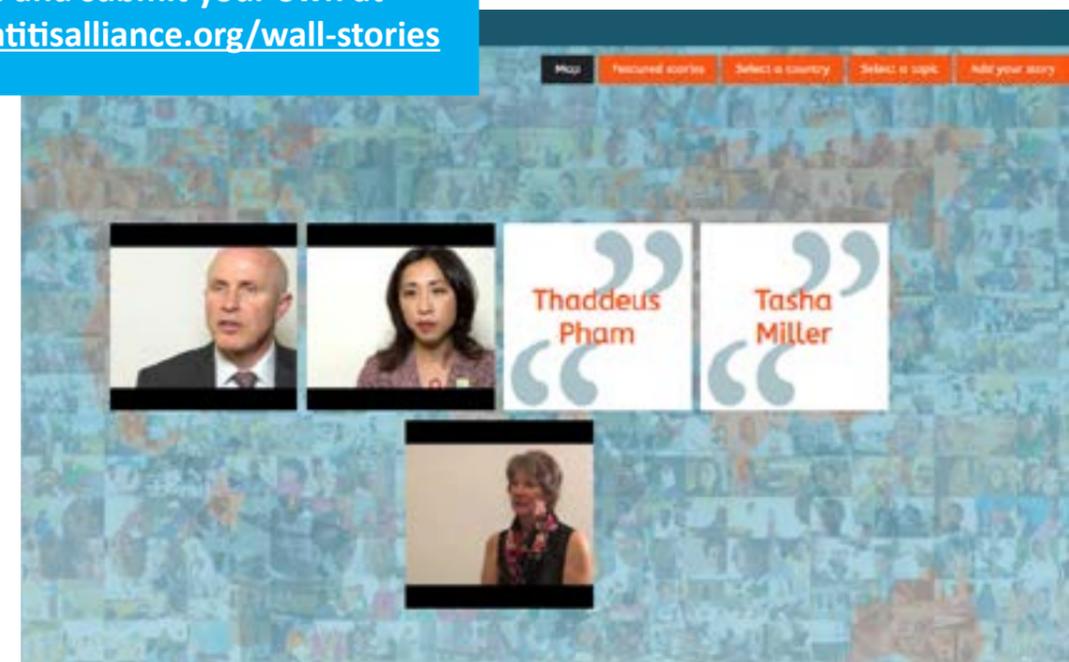
Co-infection was 'double-trouble' mentally, physically and spiritually, yet I have evolved.

It is a continual period of both challenges and growth for me. I no longer feel shame, guilt or fear. I have found a way out of depression and despair. I have found acceptance, empowerment and hope. I am still very much a work in progress, as I re-define my identity, my values, my goals, my dreams and as I face chronic illnesses.

I have been working as an advocate for access to care, treatment and support services including mental health, addictions and peer support. I encourage testing and treatment if possible. Treatment can and does work; it is difficult, but there is hope. ”

“I no longer feel shame, guilt or fear. I have found a way out of depression and despair. I have found acceptance, empowerment and hope.”

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



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