HEP VOICE

The Magazine

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Supporting Indigenous people in Australia's Northern Territory

World Hepatitis Alliance

Your online magazine from the World Hepatitis Alliance

WELCOME TO THE LAST HEP VOICE OF 2023!

It has been a busy and inspiring year as the hepatitis community works towards achieving the Global Health Sector Strategy 2025 targets and hepatitis elimination by 2030.

In this issue of Hep Voice, we provide highlights from hepatitis elimination conferences in Africa and efforts to integrate hepatitis elimination as one of the United Nations' Universal Health Coverage pillars.

We congratulate Egypt on its incredible progress achieving gold-tier status for hepatitis C elimination, and provide a summary of new WHO guidelines on countries' paths to eliminating hepatitis B and C.

Two stories give valuable insight into developing hepatitis community programmes. We speak to the UK's first NHS hepatitis B peer support worker, and learn about work being done towards eliminating hepatitis B from Indigenous communities in Australia's Northern Territory.

Our Hep Voice this issue is Carlos from Guatemala, who shares his 25 years of experience with hepatitis, and his tireless advocacy to see a world free from it.

And finally, we are fast approaching the fourth World Hepatitis Summit, taking place in Lisbon 9-11 April. Early-bird spaces close 31 January, so register now at **www.worldhepatitissummit.org**

I hope you enjoy this issue and as always, please do not hesitate to share your stories with us for future editions of Hep Voice.

Enjoy the holidays and see you in 2024!

Cary James
World Hepatitis Alliance Chief Executive

CONTENTS

04 Dates for your Diary

06 Hep Headlines

08 Keeping watch on hepatitis stigma

10 Putting community first

12 Shaibu Can't Wait!

14-17 Event reports

18 Making inroads in the Outback

20 The path to elimination

22 Hep-voices Carlos's Story

Want to share a feature for Hep Voice?

Share your news or story by emailing contact@worldhepatitisalliance.org

DATES FOR YOUR DIARY

World Cancer Day

4 February, 2024

World Cancer Day 2024's theme is a call to "challenge those in power" to create innovative strategies that confront inequity, and invest resources to achieve a just and cancer-free world. With viral hepatitis being the leading cause of liver cancer – the third most common cause of cancer deaths globally – this is a chance for the hepatitis community to demand greater action to include hepatitis in global cancer prevention programmes. **Take action here**.

EASL Liver Cancer Summit

22-24 February, 2024

The European Association for the Study of the Liver (EASL)'s Liver Cancer Summit is a hybrid meeting to be held in Rotterdam, The Netherlands, bringing together stakeholders in liver cancer care. Attendees will discuss the latest in diagnostic and treatment strategies and address challenges in practice.
Find out more about the summit here.

Zero Discrimination Day

1 March, 2024

Zero Discrimination Day is a global movement of solidarity to end all forms of discrimination. People living with viral hepatitis experience stigma and discrimination, with careers and personal relationships affected. **Read the World Hepatitis Alliance (WHA)'s stigma report** to discover the latest research on social discrimination and stories of people and communities affected by hepatitis B.

International Women's Day

8 March, 2024

International Women's Day is dedicated to accelerating women's equality across the world. Its theme for 2024 – "Inspire Inclusion" – is important for hepatitis, as discrimination against women has contributed to delayed progress of prevention of mother-to-child transmission (PMTCT) of hepatitis B. **Read WHA's PMTCT report** for recommendations on making services equitable, accessible, and available to all who need them.

APASL 2024 – Kyoto, Japan

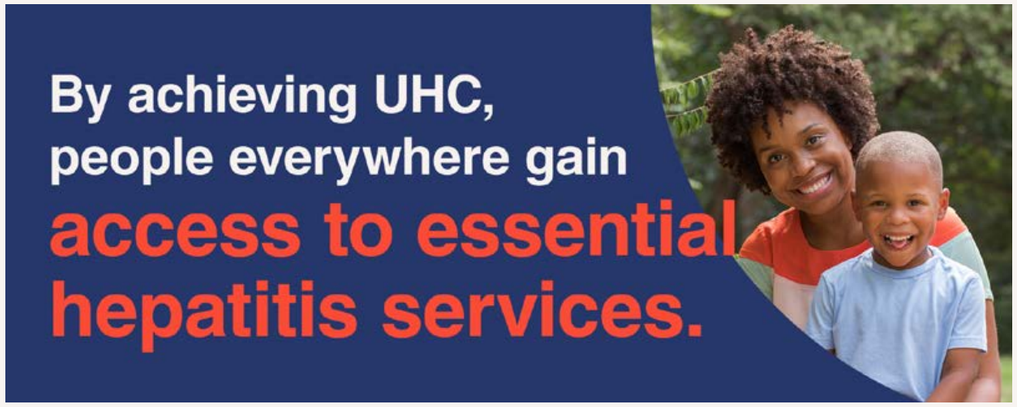
27-31 March, 2024

The Asian Pacific Association for the Study of the Liver (APASL)'s 33rd annual meeting will provide a forum for the exchange of cutting-edge knowledge and experience in all aspects of the liver, including hepatitis. **Find out more about the event here**.

HEP HEADLINES

Let’s look at some of the latest hepatitis news from around the world.

Recognition at the highest level



The United Nations High-Level Meeting for Universal Health Coverage took place on 21 September, providing member states with an opportunity to reinvigorate progress towards delivering health for all.

Evidence shows that viral hepatitis elimination ultimately strengthens health systems – being cost effective, reducing mortality, and engaging underserved populations. However, it remains one of the leading causes of death worldwide, claiming more than 1.1 million lives every year.

Hepatitis must therefore remain a top priority for countries in their UHC response. Hepatitis programmes can be efficiently and effectively integrated into HIV/AIDS, tuberculosis, noncommunicable disease and primary care programmes, and be used as a tool to engage vulnerable people.

Viral hepatitis disproportionately affects some of the most underserved communities, but by making it a pillar of UHC, countries can ensure no one is left behind. The hepatitis community must encourage UN Member States to engage with civil society to develop and implement these vital services.

Taking action for Liver Cancer Awareness Month

October was Liver Cancer Awareness Month, and global hepatitis organisations collaborated to raise awareness of its connection to viral hepatitis.

A 2023 study conducted by WHA found that 42% of people worldwide were unaware that viral hepatitis is one of the leading causes of liver cancer. Chronic viral hepatitis can lead to hepatocellular carcinoma, which accounts for 80% of all liver cancer cases and is the third most common cause of cancer deaths worldwide.

Using the hashtag #LiverCancerAwarenessMonth, the hepatitis community emphasised the need for hepatitis vaccination, testing, treatment and care to be integrated into national cancer prevention and control strategies and programmes.

See more of the resources and activities used during Liver Cancer Awareness Month here**.**

Going for gold

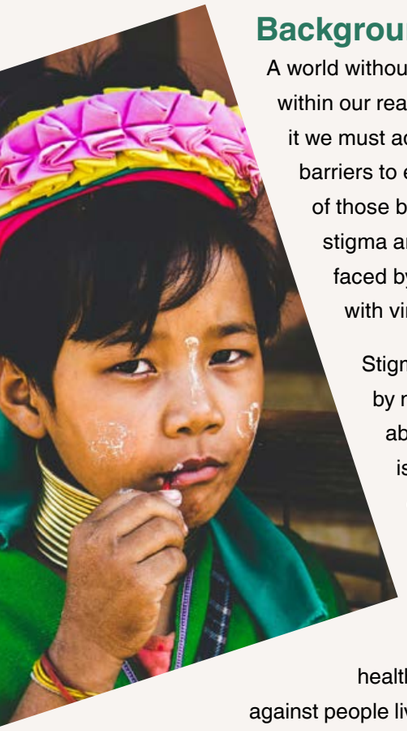
The Arab Republic of Egypt has achieved a historic milestone, becoming the world’s first country to attain World Health Organization (WHO) gold tier certification on the path to eliminating hepatitis C.

Egypt has diagnosed 87% of people living with hepatitis C, and provided 93% of those diagnosed with curative treatment – exceeding the WHO Gold Tier targets of 80% diagnosed and 70% treated.

Egypt has successfully transitioned from having one of the highest rates of hepatitis C in the world to one of the lowest by reducing prevalence from 10% to 0.38% in just over a decade.

According to 2023 WHO Guidance, countries can apply for full validation of gold, silver or bronze tiers on the path to elimination based on achieving relevant targets. **Read more about this guidance on page 20.**

KEEPING WATCH ON HEPATITIS STIGMA



Background

A world without hepatitis is within our reach, but to achieve it we must address the barriers to elimination. One of those barriers is the stigma and discrimination faced by people living with viral hepatitis.

Stigma, often caused by misunderstandings about how hepatitis is transmitted, can drastically affect people's personal and professional lives and mental health. Discrimination against people living with hepatitis frequently impacts their right to work, study and travel.

While global tools are available to measure stigma and discrimination related to tuberculosis and HIV, similar instruments are lacking for viral hepatitis. An equivalent would be powerful.

The Hepatitis Stigma Watch

The European Centre for Disease Prevention and Control (ECDC) and WHA have partnered to make such a tool. "European Region Survey to Explore the Experiences of Living with Hepatitis B and/or Hepatitis C" aims to standardise measuring stigma and discrimination experienced by people living with viral hepatitis B and C, and the subsequent impact on their quality of life.

The pilot's objectives are to:

- Develop a globally recognised and standardised hepatitis stigma survey.
- Implement the survey to measure stigma among people living with hepatitis B and hepatitis C in the European and Central Asian region (WHO Europe).
- Establish a benchmark of perceived and experienced hepatitis-related stigma and discrimination among people living with hepatitis in the WHO Europe region.

Following the pilot in the WHO Europe region, the Hepatitis Stigma Watch will be implemented in wider global regions in the second half of 2024.

Can you help?

ECDC and WHA are currently looking for organisations and people within Europe to assist the pilot by distributing it across networks. This could be as simple as emailing the survey to mailing lists, sharing on social media channels, or advertising it within relevant support groups.

To take part please get in touch with us - **click here**, and tell us your name and the country you are working in.

Once the survey is closed, all its data will be shared with you, and you will be mentioned as a partner in the pilot report presented at the World Hepatitis Summit 2024.

World Hepatitis Summit 2024

LISBON, PORTUGAL 9-11 APRIL

INTEGRATE ACCELERATE ELIMINATE

Early-bird registration closes 31 January

For both virtual and in-person attendance – register here.

It is an honour for Portugal to host the World Hepatitis Summit 2024. Now is the moment to scale up interventions, to all contexts, in all countries.

Portuguese Minister of Health, Manuel Pizarro

www.worldhepatitissummit.org

For information, email: summit@worldhepatitisalliance.org

PUTTING COMMUNITY FIRST

In July 2023, the hepatitis clinic team at Mortimer Market Centre, Central North West London NHS Trust, appointed the UK's first peer support worker for hepatitis B. We caught up with them to learn more about their community-focused approach.

How did the hepatitis B peer support service start?

Peer support has been shown to be a valuable tool for improving health outcomes for people living with long-term infections including tuberculosis, HIV and hepatitis C. Hepatitis B affects 200,000 people in the UK, and we could see how one-to-one support from someone with lived experience could improve the services we offer.

How do the peer support worker and clinical team work together?

The peer support worker has become an integral member of our clinical service. We meet every week as a team to review patients with specific needs, and reflect on the way we offer services for a broad community of people across North Central London. Activities include providing education about hepatitis B, supporting interventions for prevention like family screening and vaccination, helping people consider and take long-term treatment if needed, and offering advice to reduce hepatitis B's social impacts.

What has helped foster a supportive environment for users of the service?

Some of the initiatives currently available include translation and interpretation, text message reminders, funding and Find and Treat support to help people attend the clinic, and telephone follow-ups for those who can't. All patients are also notified that a peer support worker can provide further advice and share her own journey of living with hepatitis B.

Can you share some of the hepatitis B voices you have heard so far?

We have heard many experiences of stigma, concerns about treatment, and fear of disease progression. People have shared their frustrations about lack of services, and stories about difficult times. Others suffer anxiety from misleading information. Such narratives can limit bonding and cause strain in families, but can be avoided if knowledge and support are offered to individuals and the wider community.

What are the next steps for this initiative?

We are keen to develop a hepatitis B support group for people to create their own network, and will continue campaigning for investment in peer support and better government services. We are also promoting the voices of people with lived experience of hepatitis B by working with agencies like the World Hepatitis Alliance, the British Liver Trust and the UK Health Security Agency. We hope our foundations can be used to establish similar programmes, and look forward to sharing more of our resources and experiences in the future!

MEET JOY KO, PEER SUPPORT WORKER

18 years ago, I was diagnosed with hepatitis B after my regular blood donation. However, because of stigma, I didn't get support from my family and was rejected by my boyfriend. Because of this, I just wanted to avoid hepatitis B. I didn't attend appointments or monitor my blood tests for years.

But when I was pregnant with my first child, my doctor told me that my viral load was very high and that I needed to start medication. That consultation was extremely distressing for me, and I cried outside the consultation room. There were many worries on my mind. Am I going to die of liver cancer? Will there be side effects for my baby? Can I breastfeed? Although all these concerns were addressed by my doctor, I still struggled.

I was then helped by a volunteer, a lady who came to me and shared her lived experience of hepatitis B, receiving treatment, and having a healthy family life and children. I was so relieved! I felt very hopeful that I could just live like her.

My peers helped me understand the complexity of our shared diagnosis, and they also built my confidence and reassured me that I can live well with it. I am keen to give this wonderful gift back to people living with hepatitis B.

I have been enjoying my time with patients to share our experiences and stories. We have often experienced things like stigma and fear, but can also share by recognising that we can have a family, and a happy life. We see hope as the most beautiful thing to motivate us.

SHAIBU CAN'T WAIT!

The next video in WHA's "I Can't Wait" series is out! The series aims to change the way people and decisionmakers think about people living with hepatitis – to build empathy, understanding, and drive action for change. The videos amplify the voices of people affected by viral hepatitis, calling for immediate action and the end of stigma and discrimination.

Shaibu Issa, a hepatitis advocate from Tanzania, is the latest person to be featured. In his film, Shaibu discusses his brother's his brother's death from hepatitis B, his own diagnosis while in high school, and how he now works tirelessly for hepatitis elimination in Africa.

We caught up with him to discuss his motivations for taking part:

Why did you choose to take part in "I Can't Wait"?

Since I began advocacy about hepatitis B, I became inspired to participate in projects related to hepatitis elimination. I chose to take part in this project to amplify my voice as a person with lived experience, and advocate for change in the current situation of hepatitis globally. I feel a real need to [achieve a] free hepatitis generation.

How has sharing your story made you feel?

I feel like I took on a responsibility that many people don't. I feel heroic inside. I feel happy to be part of a global community that fights for a better tomorrow in hard times.

What keeps you motivated since you were diagnosed with hepatitis?

I have been motivated by accurate information. I became motivated to be an advocate because much information [about it] is false. I never knew it before. I'm motivated to tell the truth about hepatitis.

How has living with hepatitis B impacted your daily life?

People still keep their distance from me because they believe that I'm a dangerous person to them. I lose a lot of opportunities, and this reduces the quality.

This year's World Hepatitis Day theme is "We're Not Waiting". As a hepatitis B advocate, what are you not waiting for?

I can't wait to serve more people with knowledge and vaccines for hepatitis B. It's not enough to only show evidence of the number of people affected, who die and suffer with hepatitis complications. We need to eliminate hepatitis now, or hepatitis will eliminate us.

What advice do you have for other young people like yourself living with hepatitis in Africa?

Hepatitis can be managed and risk of liver cancer can be prevented, but reduce or abstain from alcohol, cigarettes and food that can damage your liver further.

Young people should be advocates, too. Being sick should be a motivation to tell the world about it and demand elimination.

Watch Shaibu's film here.

AFRICAN HEPATITIS SUMMIT

Abuja, Nigeria, 24-26 October

The African Hepatitis Summit was organised by the African members of the World Hepatitis Alliance (WHA), in collaboration with WHO AFRO, WHA, Africa Centres for Disease Control (Africa CDC), CDA Foundation, Coalition for Global Hepatitis Elimination (CGHE), Clinton Health Access Initiative (CHAI), Hepatitis B Foundation, and SOGHIN. It was hosted by the Federal Government of Nigeria.

The Summit brought together more than 500 people from 15 countries.

What was discussed?

This year's summit theme was 'Putting Africa on track towards viral hepatitis elimination'. Guests were invited to share their insights and expertise, discuss common barriers and explore regionally relevant solutions.

WHA also organised a pre-meeting for members, civil society representatives and more than 50 advocates. A series of lightning talks by WHA members covered topics including hepatitis D, team building and partnerships, the importance of engaging young people as advocates, advocating for financing, and hepatitis B birth dose vaccinations.

What were the key take-aways?

"One of the key takeaways from the summit was the emphasis on collaborative efforts and global solidarity. In the fight against hepatitis, participants and speakers emphasised the significance of partnerships between governments, non-governmental organisations, and the private sector. By exchanging best practices and success stories from various African nations, we gained invaluable insight into overcoming obstacles and implementing effective, long-lasting hepatitis programmes.

My participation in the African Hepatitis Summit was both a professional and deeply personal endeavour. It strengthened my belief in the effectiveness of collaboration, education, and compassion to overcome healthcare obstacles. As I return home, I carry with me the Summit's spirit of unity and resolve. Every person in Africa should have the opportunity to live a healthy and hepatitis-free life, which motivates me to contribute actively to this cause."

Kolawole Oreoluwa, Executive Director, Youth Development and Health Initiative

The outcome of the summit was a declaration, including a number of calls to action for African governments. These were:

- Scale hepatitis B and hepatitis C testing, adopting strategies that are co-designed by people with lived experience, and delivered by public, private and community-based services. These should use innovative point-of-care screening and diagnostic tools which are well-integrated with existing one-stop testing services.
- Improve linkage to care and provide access to life saving treatments for people living with viral hepatitis.
- Provide an enabling environment for collaboration with partners, including the affected community, who should be at the heart of the response.
- Integrate viral hepatitis into health systems, especially in antenatal care as part of a triple elimination strategy.
- Include newborn and infant hepatitis B vaccination in routine immunisation programmes to avert 500,000 deaths among children born this decade in Africa.
- Adopt and enforce laws, policies and practices to protect the equal rights of people living with viral hepatitis, to enable them to live their lives and pursue goals free from discrimination or disadvantage.
- Significantly increase domestic financing for hepatitis programmes so that all Africans are able to access vaccination, testing, care and treatment.

EVENT REPORTS

CONFERENCE ON LIVER DISEASE IN AFRICA (COLDA)

Dar Es Salaam, Tanzania, 7-9 September

What was discussed?

WHA, in partnership with the Hepatitis B Foundation, organised a session at COLDA titled "The Path to Person-Centred Care for People Living with Viral Hepatitis".

The panellists shared their thoughts on what person-centred care meant to them and the role of medical professionals and community groups in achieving this.

What were the key take-aways?

1. The need for active partnerships to ensure person-centred care was agreed and explored.
2. Language and communication were also highlighted for their importance. Many attendees noted that the session made them think about how they speak with their patients to help them make informed decisions about their own health.

AORTIC INTERNATIONAL CONFERENCE ON CANCER IN AFRICA

Dakar, Senegal, 2-6 November

What was discussed?

In partnership with the Union for International Cancer Control (UICC), WHA held a session at the AORTIC conference to highlight the epidemics of both hepatitis and liver cancer in Africa.

The session was titled "Liver Cancer Can't Wait: Bridging the Gaps for Prevention and Treatment of Hepatitis and liver cancer in Africa". This was the first time WHA has participated in the AORTIC conference and it was an important opportunity to emphasise the link between hepatitis and liver cancer with more partners in the cancer community.

What were the key take-aways?

1. Discussion highlighted the heavy burden of liver cancer in Africa, with many attendees sharing how they have been personally impacted.
2. There is an urgent need for a more comprehensive and coordinated response to prevention, early detection, and treatment of liver cancer in Africa.
3. Effective and low-cost hepatitis interventions can ensure that no one else dies from what is a preventable cancer.

NOHEP MEDICAL VISIONARIES FORUM

Boston, USA, 11 November

What was discussed?

The session was facilitated and led by WHA and the Hepatitis B Foundation. It presented an important opportunity to bring the hepatitis community and medical professionals together to explore the new hepatitis B guidelines by AASLD, and the role of treatment in hepatitis B elimination.

What were the key take-aways?

1. Increasing access to testing and treatment for people living with hepatitis B will drive elimination efforts.
2. Medical professionals are important advocates to help improve this.
3. Multiple guidelines often result in confusion, so simplification is essential.

WE'RE NOT WAITING – UHC WEBINAR

Virtual, 30 November

What was discussed?

Universal health coverage (UHC) is the principle that all people, everywhere, can access affordable quality essential health services. In September 2023, the UN High-level Meeting on UHC adopted a new political declaration, stating that member states must sustain and strengthen their commitments to hepatitis elimination as part of UHC.

To mark UHC Day, this webinar – facilitated and led by WHA – explore UHC as a social movement, government policy, and advocacy opportunity.

What were the key take-aways?

1. Hepatitis elimination is key to UHC. It strengthens health systems, engages underserved communities, enhances vaccination programmes, reduces cancer mortalities, and supports HIV responses.
2. The UN High-Level Meeting was a major opportunity for UHC, and hepatitis advocates must continue to push governments to uphold the commitments they made.
3. Partnerships and joint advocacy are critical to advancing UHC and hepatitis elimination. Civil society is uniquely placed to support communities and health systems as part of this.

MAKING INROADS IN THE OUTBACK

Australia's Northern Territory has the highest prevalence of chronic hepatitis B in the country, with Aboriginal and Torres Strait Islander peoples disproportionally affected. The Hep B PAST project is working hard to change this through inclusive approaches to healthcare. We spoke with Kelly Hosking of Menzies School of Health Research to learn more.

What is Hep B PAST?

Hep B PAST is a partnership between government and community-controlled health organisations, Menzies School of Health Research, peak organisations, and the community. It started in 2018, but our hepatitis B team has been working in communities and building strong and trusted relationships for more than ten years.

Together, we aim to eliminate chronic hepatitis B from Aboriginal and Torres Strait Islander peoples in the Northern Territory.

Has the project been successful in meeting its aims?

Yes! We have demonstrated outcomes, and by implementing the comprehensive chronic hepatitis B model of care, we have enabled equitable access and an improved cascade of care. We are exceeding chronic hepatitis B elimination targets, with 99.9% of people living with it diagnosed, 86.3% engaged in care, and 24.1% on treatment.

What has the Aboriginal community's response been so far?

We've had an amazing response from our communities, and overwhelmingly positive feedback and engagement from our wonderful Aboriginal health workforce.

What challenges have you encountered during the project?

Distance, time, and many languages. The Northern Territory is enormous! It's bigger than Texas, but very sparsely populated, with only 233,000 people. The 66 communities we work in range from 20 to 2,700 people and span the tropics and remote islands, to arid desert. Many are inaccessible by land during the monsoonal wet season.

We are fortunate to work with diverse Aboriginal and Torres Strait Islander cultures, with over 100 different languages! However, this can pose challenges. Sarah, a senior Aboriginal Health Practitioner, identified the need to create hepatitis B educational resources in Aboriginal languages, as most clients of her clinic did not primarily speak English.

We have overcome this by developing the 'Hep B Story' app and by having a trained Aboriginal health workforce to support the community and other clinicians. The app is a collaboration between local healthcare staff, community members and Menzies. It can be downloaded from the Google Play or Apple App stores, or viewed at **hepbstory.menzies.edu.au**

What three tips would you give to anyone hoping to get a community project off the ground?

1. Co-design and meaningful engagement, involving people with lived experience, is essential at all stages: design, implementation, and evaluation.
2. Be flexible and responsive to change. This requires adequate time and ethical space to ensure cultural safety and empowerment.
3. A trained and supported First Nations health workforce is invaluable as part of a care team.

Hep B PAST also uses a hub and spoke support model, systematic data organisation, and the use of in-language health resources. We think its model could be used in other regions and countries to improve chronic hepatitis B care in primary healthcare, enhance the cascade of care, and work towards eliminating hepatitis B as a public health threat.

What are your long-term ambitions for Hep B PAST?

To eliminate chronic hepatitis B from all our communities!

HEP B PAST SUCCESSES TO DATE

- **Systematically established the hepatitis B status of more than 33,000 people and linked each person to care.**
- **Established a 'Hep B Hub', a facilitation tool for clinical care teams to access complete, up-to-date records.**
- **Strengthened the health workforce by training more than 150 doctors and nurses and more than 150 Aboriginal Health Workers in the Northern Territory.**
- **Developed the 'Hep B Story' app in nine Aboriginal languages and English, enabling people to access hep B information in their first language.**

NEW WHO GUIDANCE

THE PATH TO ELIMINATION

WHO published an updated 'Guidance for country validation of viral hepatitis elimination and path to elimination' in October 2023. The new guidance builds on the 2021 interim guidance, and includes the development of a global criteria for a path to elimination of hepatitis B and C as public health problems.

The update includes measurement approaches recognising major progress milestones for countries on their paths to elimination. They are presented as a framework with three tiers of achievement: bronze, silver and gold.

Egypt is the first country to achieve WHO validation on the path to elimination of hepatitis C. It received gold tier status in October, after fulfilling the criteria necessary to reduce new hepatitis C infections and deaths to levels that position the country to end its hepatitis C epidemic.

Going forwards, advocates can now urge their governments and ministries of health to meet the targets set by the UN's guidance and reach each tier to complete the path to elimination.

Path to Elimination (PTE) tier	Hepatitis B programme targets (Prevention (except EMTCT), testing, treatment)	Hepatitis B programme targets for EMTCT	Hepatitis C programme targets
GOLD TIER	**100%** blood safety **100%** injection safety **≥80%** of people living with chronic hepatitis B are diagnosed **≥70%** of people diagnosed and eligible are treated for hepatitis B Establishment of sentinel surveillance programme for sequelae of hepatitis	**≥90%** coverage of hepatitis B third dose infant vaccination **≥90%** coverage of universal timely birth dose Antenatal HBsAg testing coverage **≥30%**	**100%** blood safety **100%** injection safety **≥150** needles/syringes/year in PWID (or OAT coverage for PWID **>20%** in countries with defined opioid epidemics) **≥80%** of people living with chronic hepatitis C are diagnosed **≥70%** of people diagnosed with hepatitis C are treated Establishment of sentinel surveillance programme for hepatitis sequelae
SILVER TIER	**100%** blood safety **100%** injection safety **≥70%** of people living with chronic hepatitis B are diagnosed ≥60% of people diagnosed and eligible are treated for hepatitis B	**≥90%** coverage of hepatitis b 3rd dose infant vaccination **≥50%** coverage of universal timely hepatitis b birth dose Antenatal HBsAg testing (available in public sector)	**100%** blood safety **100%** injection safety NSP and OAT present in country **≥70%** of people living with chronic hepatitis C are diagnosed ≥60% of people diagnosed with hepatitis C are treated
BRONZE TIER	**≥95%** blood safety **≥95%** injection safety **≥60%** of people living with chronic hepatitis B are diagnosed **≥50%** of people diagnosed and eligible are treated for hepatitis B	**≥90%** coverage of hepatitis b 3rd dose infant vaccination National implementation of universal timely hepatitis B birth dose policy	**≥95%** blood safety **≥95%** injection safety NSP is present in the country **≥60%** of people living with chronic hepatitis C are diagnosed **≥50%** of people diagnosed with hepatitis C are treated

Hep-voices

CARLOS'S STORY

Carlos Zabala is a certified electrician in Guetamala, working in industrial, commercial and home installations. He contracted hepatitis C nearly 25 years ago, and has dedicated much of his life to raising awareness about hepatitis and supporting others living with it. We spoke with him to learn more about his experiences.

Hi Carlos, thank you for being our Hep Voice this issue. Can you tell us when you were first diagnosed with hepatitis?

I was diagnosed in 1999, when I donated blood for a friend´s child who had heart disease. One day, I came home from work and my wife told me to return to the lab. "They want to talk to you about your blood," she said. "It looks like you're not well."

At the lab, I received the news: "You have hepatitis C. You were infected because you are promiscuous, and you should not donate blood again!" I rejected this. My emotions went from fear to anger, anger to astonishment, then back to anger, anger, anger. That promiscuous man was not me. I was really angry for a long, long time.

What kind of treatment options were available to you?

I told my wife and we asked for a second opinion. We were scared because we had heard that hepatitis is a 'silent killer'.

The second doctor explained the different ways hepatitis C is transmitted, and the need of a viral load and liver biopsy before treatment. I was terrified of injections. The liver biopsy was with a large needle on my right side, not by endoscopy. It was painful!

I had to spend a lot of money on lab tests, hospital visits and medicine. At the beginning my only option was Interferon injections, which were expensive and stressful. I had to buy my own before I was admitted to the subsidised social security system, IGSS. Interferon's side effects were chills and fever, loss of appetite, and apathy. I was tired and scared.

Have you encountered any stigma or discrimination living with hepatitis C?

When workers at the ultrasound and the endoscopy clinics became aware that I had hepatitis C, they moved me to the bottom of the waiting list. People thought I contracted hepatitis C because I was promiscuous. I was not.

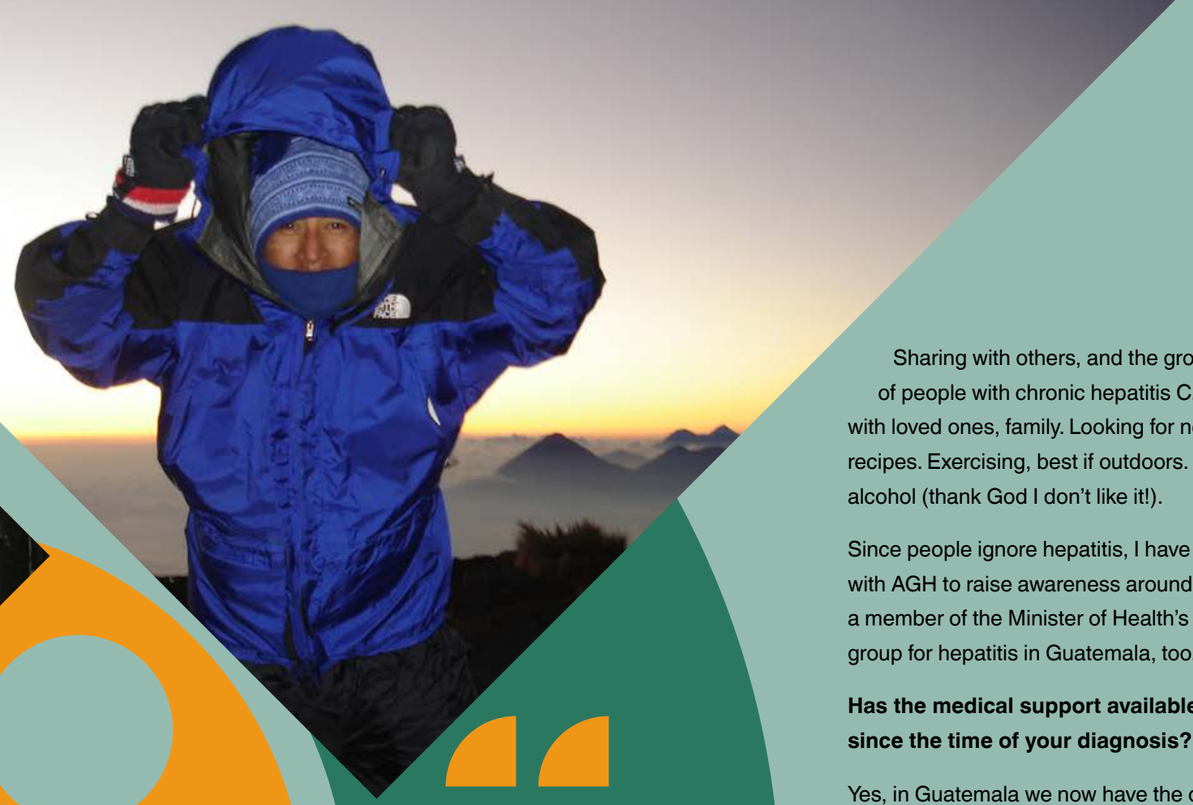
How did you manage your hepatitis C?

My doctor recommended a normal life, so I decided to do something to overcome the depression. I climbed the Pacaya volcano twice, the Agua volcano around six times, and the Acatenango volcano four times. I ran the Max Tott Half Marathon, Ultra Marathon of Guatemala City, the Cobán Half Marathon, the Las Rosas Half Marathon, and The New Beginning Half Marathon. In some races I used the Logo of the Guatemalan Liver Association, which I felt very proud to do.

I also found friends in the world of viral hepatitis C. My support group – Asociación Guatemateca del Hígado (AGH) – boy, they understand what it means to have the virus! As a carrier, you bear the secret, yet feel the active stigma everywhere. But from the moment I met them, I didn't feel alone. My life was renewed. I learned to organise my ideas about the disease and take better care of my preventive and curative actions, physically, morally and emotionally.

My family has been a great support for me during this. When the tears flowed, they were shared, as was the laughter, the good surprises and the not so good.

Could you tell us any strategies or activities that helped you cope with the emotional challenges of living with hepatitis C?



My doctor recommended a normal life, so I decided to do something to overcome the depression. I climbed the Pacaya volcano twice, the Agua volcano around six times, and the Acatenango volcano four times.

Now there is a cure for hepatitis C, get tested and get treatment as soon as possible!

Sharing with others, and the group support of people with chronic hepatitis C. Sharing with loved ones, family. Looking for new healthy recipes. Exercising, best if outdoors. And no alcohol (thank God I don't like it!).

Since people ignore hepatitis, I have volunteered with AGH to raise awareness around it, and was a member of the Minister of Health's technical group for hepatitis in Guatemala, too.

Has the medical support available changed since the time of your diagnosis?

Yes, in Guatemala we now have the option to cure hepatitis C with DAA, which is available universally at no cost. You can also take a FibroScan test instead of a liver biopsy.

Is there a message you would like to share with others living with viral hepatitis?

I am one of the few people cured by Interferon, but I had esophageal varices bleeding that needed an intervention, and have cirrhosis due to my chronic hepatitis C. Because of this, I have to be treated with medication for life and monitored for liver cancer.

Now there is a cure for hepatitis C, get tested and get treatment as soon as possible! Prevent living with it for years without knowing, and prevent cirrhosis and liver cancer. Don´t be afraid of sharing your diagnosis with your family, either. Your loved ones could be of great support to you.

Lastly, if you see me running around, listen closely and you will hear the little song I like to sing: "I have a happy liver, a happy liver full of joy." That's me, Carlos.

HEP VOICE

The Magazine

World Hepatitis Alliance

www.worldhepatitisalliance.org | contact@worldhepatitisalliance.org