HEP VOICE

The Magazine

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We can build a future and world free of stigma, discrimination, and hepatitis.

Joshua Pacayra

World Hepatitis Alliance

Your online magazine from the World Hepatitis Alliance

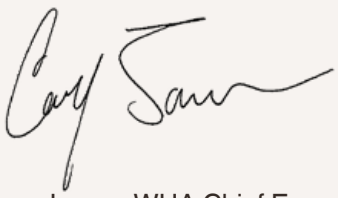
WELCOME TO HEP VOICE!

In this issue, we speak to two remarkable hepatitis advocates driving change in their communities– Rachel, the new president of WHA, who has been a passionate advocate since joining the Hepatitis C Trust, and Adesuwa, who explains the role of school clubs in combatting viral hepatitis.

We also celebrate the women living with hepatitis who are leading the fight against the virus and highlight the launch of our hepatitis e-learning course, designed to strengthen community voices in your advocacy efforts. Page 7 has the details on how you can sign up to the course.

And our Hep Voice feature this issue spotlights Joshua Pacayra, who shares her journey of living with hepatitis B in the Philippines and her efforts to combat stigma and discrimination associated with it.

I hope you enjoy this issue and as always please get in touch to share your story with us!



Cary James, WHA Chief Executive

CONTENTS

04
Dates for your diary

06
Hep Headlines

08
Meet WHA's
new president

11
Championing women
living with hepatitis

12
Empowering Youth:
The Role of Anti-Hepatitis
Clubs in Secondary Schools
for Policy Change

15
Shabana
Can't Wait!

16
Hep Voices
Joshy'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 Hepatitis Summit 2024

April 9-11

Secure your spot to attend the World Hepatitis Summit in-person or virtually!

WHS 2024 is the only global hepatitis conference focussed on a multi-stakeholder, multi-sector public health approach. It will bring together diverse participants, from civil society to policy makers, private sector to academics, to make the dream of hepatitis elimination a reality.

The Summit is brought to you by the World Hepatitis Alliance, co-sponsored by the World Health Organization (WHO), with the support of the Ministry of Health in Portugal.

Register here and see you in Lisbon!

SOLDA

19 April

The Society on Liver Disease in Africa (SOLDA) was founded in 2022, and is dedicated to pursuing excellence in liver research, improving clinical care for liver disorders, and providing education in hepatology across Africa. Their upcoming webinar on **World Liver Day, 19 April 2024** will feature five speakers discussing prevalent and emerging liver diseases in their respective regions across the continent. Register for the event.

World Immunization Week

24-30 April

World Immunization Week highlights the collective action needed to protect people from vaccine-preventable diseases.

WHO recommends all infants receive the hepatitis B vaccine as soon as possible after birth. The birth dose vaccine is highly effective at preventing liver cancer, also contributing to Sustainable Development Goal target 3.4 to reduce premature mortality from non-communicable diseases by a third by 2030. Find out more.

European Testing Week

20-27 May

European Testing Week encourages community, healthcare and policy institutions in Europe to unite, increase testing efforts, and promote the benefits of earlier hepatitis and HIV testing.

Many people living with hepatitis are unaware of their diagnosis, so this is an important week to increase awareness of testing to save more lives. Sign up for the Spring 2024 European Testing Week.

77th World Health Assembly

27 May-1 June

The World Health Assembly is the decision-making body of WHO. It is held annually in Geneva, Switzerland, and is attended by delegations from all WHO Member States. Together, they make decisions on health goals and strategies that will guide countries' public health programmes towards better health and wellbeing for all.

In May 2022, the Health Assembly updated its global strategy for viral hepatitis between 2022 and 2030 – find out more.

EASL Congress

5-8 June

Registrations are open for the hybrid European Association for the Study of the Liver (EASL) Congress, hosted in Milan, Italy this June.

The congress fosters interactivity and expands opportunities to share research and network with the global liver community, both onsite and online. Early-bird registrations close April 2, 2024. Secure your place here.

World Food Safety Day

7 June

World Food Safety Day inspires action to prevent, detect and manage foodborne risks, contributing to food security.

Hepatitis A and E are mostly transmitted through consumption of contaminated food and water, so this day is a crucial time to raise awareness about food safety and proper sanitation. Both are necessary to reduce the risk of exposure to diseases. Learn more about Food Safety Day here.

HEP HEADLINES

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

Gavi, the Vaccine Alliance appoints new CEO

Gavi announced the appointment of Dr Sania Nishtar as its new Chief Executive Officer in January. Dr Nishtar is currently serving as a senator in her home country of Pakistan and will resume the role in March 2024.

The hepatitis B birth dose vaccine is highly effective at preventing liver cancer and contributes to the Sustainable Development Goals to reduce premature mortality from non-communicable diseases by a third by 2030.

The hepatitis community looks forward to the roll out of Gavi's hepatitis B birth dose programme, which will not only protect against liver disease, but strengthen countries' ability to deliver other routine vaccinations.

Global hepatitis community commemorate World Cancer Day

This World Cancer Day, 4 February, global hepatitis organisations collaborated to raise awareness of liver cancer's connection to viral hepatitis.

Viral hepatitis is the leading cause of liver cancer, the third cause of cancer deaths globally. Using the hashtags #WorldCancerDay and #CloseTheCareGap, hepatitis advocacy organisations expressed their commitment to drive equitable access to hepatitis treatment, screening, and vaccines among communities and people living with viral hepatitis. Increased access to cancer preventing services will save the hundreds of thousands of lives lost each year to the disease.

WHA also developed an advocacy briefing outlining the connection between viral hepatitis and liver cancer and calls for greater action. Read more here.

Strengthening community voices for hepatitis elimination

To strengthen our community voice, and support our mission to harness the power of people living with viral hepatitis to achieve its elimination, WHA has introduced the Community Impact Programme (CIP).

CIP aims to improve your ability to advocate at a local, state and national, state and national level for viral hepatitis services and funding through an **e-learning course**, and a taught **accelerator programme**.

Together, these will help you become a more powerful force for change by giving you the knowledge needed to form your message, and the tools to deliver it – bringing both the head and the heart to your advocacy. Learn more about the programme and sign up.

Community Impact Programme

MEET WHA'S NEW PRESIDENT

Rachel Halford, CEO, Hepatitis C Trust has been elected as the new president of the World Hepatitis Alliance. Hep Voice speaks to Rachel to get her reaction about her appointment and discuss her hopes for hepatitis elimination by 2030.

What first motivated you to become a hepatitis advocate?

Throughout my life, I have been an advocate for justice and those underserved by health and social systems. But it was not until I started working for the Hepatitis C Trust in 2015 that I was motivated to become an advocate for hepatitis, even though I was diagnosed with hepatitis C in 1998.

My diagnosis was a consequence of a lifestyle I had been living, so there was stigma attached not only to my hepatitis C, but to the transmission route, too. At first, rather than shout and advocate for change about hepatitis C, I focused my attention on people affected by homelessness and women affected by the criminal justice system. I hid my diagnosis – something I think is common for many people affected by viral hepatitis.

My motivation today comes from the journey I have been on since then, and what I see and hear from around the world: the stigma, which due to lack of education and understanding is still so widely spread, and the global inequities of access to healthcare, including diagnostics and viral hepatitis treatment.

Like many people, I have lost loved ones to hepatitis. What drives my motivation most is that we have a cure for hepatitis C and a vaccine for hepatitis B. No one, wherever they are in the world, needs to die.

How important is it for people living with hepatitis to speak out?

Before I joined the Hepatitis C Trust, I had not spoken out about my hepatitis C, but I learnt very quickly that there is immense power in speaking out, particularly when we use our voices together.

“Like many people, I have lost loved ones to hepatitis. What drives my motivation most is that we have a cure for hepatitis C and a vaccine for hepatitis B.

We know that the only people who can truly say how living with, or having had hepatitis affects them is the person affected; we are the experts through our experiences. There is a great power in the lived experience we all bring.

Speaking out creates change not only for the individual, but for all those affected. We saw this in the collaboration between patients and the World Health Organization in developing and implementing the global goal to eliminate viral hepatitis by 2030.

With only six years left, people living with hepatitis need to speak out. We need our voices to be loud and clear to ensure we not only reach that global goal, but that no one is left behind either.

Speaking out creates change not only for the individual, but for all those affected.

What motivated you to apply to become president?

When I joined the Hepatitis C Trust, I attended the first World Hepatitis Summit in Glasgow in 2015. It was an incredible event. The patient's voice was loud and clear in what was discussed, and there was such a great atmosphere of hope and excitement, as the World Health Assembly had unanimously adopted the resolution that viral hepatitis should be eliminated by 2030. I was inspired by the World Hepatitis Alliance bringing together so many patient organisations, professionals and health ministers from across the world for it.

In 2018, I became the European Regional Board member for the World Hepatitis Alliance, and began to truly understand the impact of viral hepatitis on a global level. The inequitable reality of hepatitis healthcare around the world was, and remains stark. I believe the Alliance plays a central role in keeping the patient voice at the centre of all decision-making, but it is not easy and there is still much to do.

My motivation to apply to become president was that no one needs to die from viral hepatitis. I wanted to keep the patient voice central, be a part of the fight for equal access to viral hepatitis healthcare across the world, and remind people about the hope we had and the commitments made by our governments in 2016.

What do you hope to achieve as president?

Globally, we tend to work within our own country contexts, which are already determined by so many factors, particularly economic. While platforms like social media gives us a glimpse of what others are doing, we rarely get an opportunity to share and help.

> **I want to increase the volume of our collective voices to bring about change, including reducing stigma.**

I want to increase the volume of our collective voices to bring about change, including reducing stigma. I hope to encourage and support patients to reach out to their governments and lobby for renewed commitment and investment to eliminate viral hepatitis. I would love them to share what they are doing, and join World Hepatitis Alliance campaigns like the amazing World Hepatitis Day Relay.

It is a privilege to be president, to represent patient voices and ensure they are heard. I take lessons from the remarkable presidents that have come before me, and hope that I can represent and bring as much as they have.

How do you believe we can eliminate hepatitis by 2030?

I believe we have to work together as a global community to achieve elimination, with the patient at the centre. Patients have a vital role to play in elimination through their collective voices when lobbying for access to funding, diagnostics and treatment.

During the COVID-19 pandemic, people of the world supported each other globally, learning how to do so along the way. By reaching across the boundaries of income and partnering with other countries, we can do this again and achieve the elimination of viral hepatitis.

CHAMPIONING WOMEN LIVING WITH HEPATITIS

Women living with viral hepatitis face unique challenges. While hepatitis affects women from all ages and backgrounds, there is limited data on the number of women living with hepatitis. Research primarily focuses on the burden of hepatitis B among pregnant women. Although a very important group, this focus limits overall knowledge of hepatitis in different stages of women's lives. It is important to understand the experiences of all women living with or affected by hepatitis to ensure they have proper access to care and support.

To celebrate International Women's Day, WHA organised a panel discussion on 7 March to explore the unique perspectives of women living with hepatitis. The event also celebrated the women that are driving the hepatitis response and supporting other women living with hepatitis.

WHA also developed an advocacy briefing to support advocates in empowering women living with hepatitis. The briefing highlights the different challenges that different groups of women with hepatitis face and calls for greater action.

Watch the replay of the panel discussion and read the briefing here.

EMPOWERING YOUTH: THE ROLE OF ANTI-HEPATITIS CLUBS IN SECONDARY SCHOOLS FOR POLICY CHANGE

Adesuwa Oni, CEO, Rise Against Hepatitis Nigeria, discusses how empowering teenagers can contribute to viral hepatitis elimination efforts.

Can you tell us more about anti-hepatitis secondary school clubs initiatives?

Anti-hepatitis Clubs in Secondary Schools is an initiative born from finding little or no knowledge of hepatitis during a sensitisation campaign in secondary schools in 2023. We thought of a longer-term measure through which young people and students would get to understand the disease, instead of just a one-off sensitisation campaign.

Since then, we have built quite a detailed line up of activities for the clubs. Here are a few:

- **Awareness campaigns** using posters and morning announcements.
- **Guest talks** from health professionals and **Survivor Stories** from individuals with lived experience of hepatitis.
- **Interactive activities and competitions** like games, quizzes and debates around hepatitis, with small rewards for winners.
- **Artistic initiatives**, like drawing or painting contests and drama performances about hepatitis.

Why should we be looking to young people to become hepatitis advocates?

From the surveillance report on viral hepatitis by the Centre for Disease Control (below), it's clear that the rate of infection in people aged 0–19 is relatively low, but as they advance into adulthood the rate of infection increases.

The basic reason is that teenagers do not have enough knowledge of hepatitis before they reach a stage of active sex, tattoos, piercings, drugs and more. As a result, the infection rate increases. For example, in 2005, if teenagers between the ages of 15 and 19 had been well equipped with knowledge of hepatitis, the rate wouldn't have advanced from 0.2 to 3.7 in adulthood in the same year. We are empowering youth to reduce the rate of infection in adulthood.

Policymakers are also more likely to pay attention when young voices demand change. Youth involvement in advocacy can pressure policymakers to allocate resources, support research, and implement policies that address hepatitis prevention and treatment. By educating

young people about hepatitis, we are investing in a generation that understands the importance of prevention. They can carry this knowledge into their adult lives, ensuring a sustained effort against the disease.

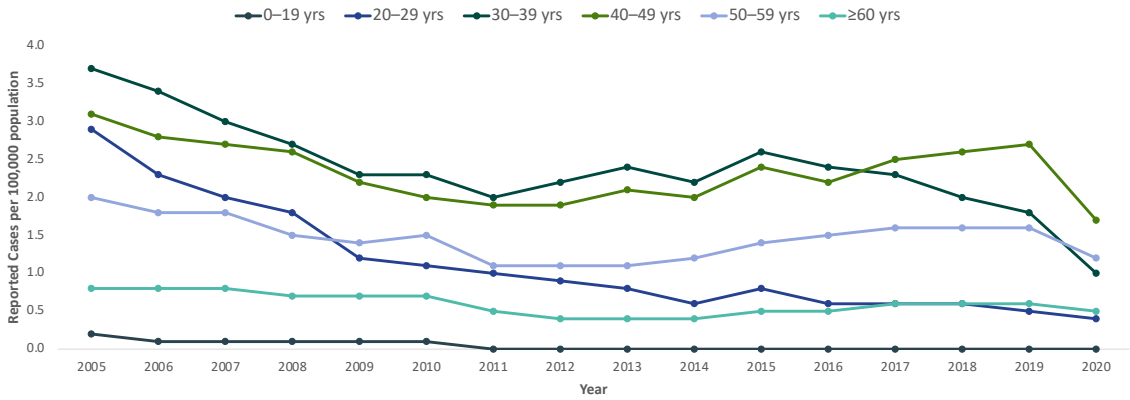
Are there any particular benefits to working through schools?

Yes, several:

1. **Access to target audience**: Schools provide access to a large number of students, allowing an NGO to reach its target audience effectively.
2. **Behaviour change**: Working with students allows for early intervention and the opportunity to instil healthy behaviours and habits related to hepatitis prevention, such as vaccination, hygiene practices, and avoiding risky behaviours.

Figure 2.4 – Part 1 of 2

Rates* of reported cases† of acute hepatitis B virus infection, by age group United States, 2005–2020



* Rates per 100,000 population.

† Reported confirmed cases. For the case definition, see https://ndc.services.cdc.gov/conditions/hepatitis-b-acute/.

Source: CDC, National Notifiable Diseases Surveillance System.

Centers for Disease Control and Prevention. Viral Hepatitis Surveillance Report – United States, 2020. https://www.cdc.gov/hepatitis/statistics/2020surveillance/index.htm. Published September 2022.

3. **Community engagement**: Schools are often at the heart of communities, so engaging with them can lead to broader engagement and support for an NGO's initiatives.
4. **Partnership opportunities**: Collaborating with schools can open doors to partnerships with educational institutions, government agencies, healthcare providers, and other NGOs working in similar areas, enhancing the reach and impact of the anti-hepatitis initiative

How do anti-hepatitis secondary school clubs fit into the wider hepatitis advocacy landscape?

The clubs play a crucial role raising awareness, promoting prevention measures, and destigmatising the disease. They engage young people early on, empowering them with the knowledge and skills to protect themselves and others from hepatitis.

They also contribute to breaking down barriers to testing and treatment by fostering a supportive environment. Students feel comfortable discussing hepatitis-related issues, and can be more easily be encouraged to seek testing, treatment, and support without fear of judgement.

By mobilising youth at the grassroot level, these clubs amplify the impact of larger advocacy efforts and drive positive change in communities.

What would you recommend to readers who want to set up a school club?

Setting up an anti-hepatitis club in secondary schools is a great initiative that can be an effective way to create viral hepatitis awareness. Here are some tips:

- **Celebrate successes**: Recognise and celebrate students' achievements and contributions, whether big or small. This will motivate members and reinforce their dedication to the cause, leading to brainstorming new ideas for engaging activities.
- **Make connections**: Expand the club's reach by networking with other anti-hepatitis organisations regionally, nationally, and internationally. This can lead to valuable partnerships and collaboration opportunities.
- **Evaluate**: Regularly assess the effectiveness of club activities through surveys, feedback sessions, and observation. Use this information to refine strategies and tailor future efforts to better meet the needs of students.

SHABANA CAN'T WAIT!

The next video in WHA's "I Can't Wait" series is out! The series aims to change the way people think about people living with hepatitis – to build empathy, understanding and to 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.

Shabana, a hepatitis advocate from Yorkshire, United Kingdom, is the latest person to be featured. In her film, she shares how since treating the virus, found purpose in raising awareness about hepatitis in the British South-Asian community.

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

Why did you choose to be part of this film?

I felt it was important to share my personal experience dealing with stigma in South Asian communities and how I overcame it.

How has sharing your story made you feel?

I felt privileged to be able share my story so that we can educate people and save lives.

How did living with hepatitis C impact your daily life?

I was always ill and unable to function normally. I was short tempered, unable to look after my children, and my marriage and family suffered. I was fed up and suicidal.

What has kept you motivated since you were diagnosed with hepatitis C and treated it?

The promise I made to God that, now I was blessed with a new lease of life, I would raise awareness with every breathe I take. I have experienced the devastation of losing several loved ones in my immediate family, and I wanted to save lives by educating people. My work gives me the satisfaction that I have made a difference. I continue to uphold my promise.

Are you attending the World Hepatitis Summit in April? As a hepatitis C advocate, what are you looking forward to at the Summit?

Yes, I am attending. I look forward to networking with other attendees, sharing ideas, and possibly learning different strategies to approach hard-to-reach communities.

What's your advice to young people living with hepatitis C?

If they are being treated, to complete their treatment, be health conscious, and to talk to people like family and friends. Educate them and find support within them, or access support groups. There is nothing to be ashamed of, or to fear. Become a champion and help others by sharing your experiences and saving lives. It will make you feel empowered.

Watch Shabana's film here.

Hep-voices

JOSHY'S STORY

Joshua Pacayra, or Joshy, is a hepatitis advocate from the Philippines. As this issue's Hep Voice, she shares her struggle with stigma due to living with hepatitis B, and how she found a sense of purpose after joining a support group in her community.

Can you share your experience with hepatitis B, including how you became aware of your diagnosis?

When I was younger, my dream was to be a nurse. I wanted to work in a hospital like my aunties, taking care of patients, receiving good pay, and helping my family.

I was able to take nursing as my undergraduate degree. It was 2005, during my third year of studies, when we were required to take a series of tests and screening for a hospital internship the following year.

At the time, I was not bothered. I didn't know a lot about hepatitis B, or any case of it in my family. I only knew we had to be vaccinated against hepatitis B after screening as a course requirement.

The result came out and I was asked to go to the doctor. I was 17 years old at the time. The doctor told me that I had hepatitis B, and that after 20 years of living with hepatitis, it would develop into liver cancer. Confused and panicked, I did not know what to do – the doctor gave no explanations, no prescriptions, and no additional laboratory requests.

I hid my diagnosis from other people for 13 years. I did not tell anyone except my family and one friend. I felt overwhelmed with sadness and anxiety for a long time.

"I hid my diagnosis from other people for 13 years. I felt overwhelmed with sadness and anxiety for a long time.

How did your family and friends react when you shared the news with them?

I informed my family on the same day I discovered I am reactive with hepatitis B. My parents found it hard to believe, because I looked perfectly normal and healthy. Their initial reaction was to separate me from them. They thought I was contagious.

My friend and I did some research on our own to know about hepatitis B. We found out that one transmission route is through mother and child. I shared this information to my family and, after some time, they understood and agreed to undergo screening. Two of my sisters and one brother were found to be reactive with hepatitis B; our parents were not.

The results of my family's screening further confused not only me, but my entire family. They decided to ignore it after knowing that hepatitis B is incurable. We never talk about it, nor our results, to extended family and friends for fear of stigma and discrimination.

What kind of medical support did you receive after being diagnosed with hepatitis B?

I never sought medical support after I was diagnosed in 2005. I was resigned to what my doctor told me about hepatitis B – that it is incurable – and that there was also no publicly available information on hepatitis B.

In 2018, I learned about research for the early detection of liver cancer. The information that stuck with me was that the end-stage of hepatitis B is liver cancer. I participated in the research, which was a partnership between private sector hospitals and a group of hepatologists, which also made it my first monitoring and check-up in 13 years.

Have you noticed any changes in the available medical support since your initial diagnosis?

My initial diagnosis in 2005 was prohibitively expensive. At the time the screening alone was costly, as was the confirmatory test. There was a very limited number of diagnostic facilities with available hepatitis B DNA, aside from the few medical practitioners who could fully support people living with hepatitis.

Since then, more initiatives have arrived, such as preventing hepatitis B at birth. Selected cities and municipalities provide free screening. Confirmatory tests are not entirely free, but are now more widely available at government hospitals. Selected HIV treatment facilities integrate hepatitis care and treatment.

There is still no nationwide hepatitis programme, but interest among and partnerships between government and civil society organisations are slowly increasing.

Have you faced any stigma or discrimination living with hepatitis B?

Living with hepatitis B in the Philippines is very stigmatising. It is like having a very contagious disease. People often compare it to hepatitis A.

My personal experience with discrimination was from my own family. After I told them about my status, they gradually drew a line between us. They separated my utensils and personal belongings. A separate dish drawer was bought for me. I was allowed to eat only by myself, and only after they had finished. It was very depressing. It hurt me. I thought that a family cares for and protects each other, but my experience was the opposite. It lasted for a while, until my friend and I informed them more about hepatitis B.

As a result, I never disclosed my status to anyone outside of my immediate family for fear of discrimination. When I was studying, I refrained from mingling with my classmates and friends. I had to let go of my dream of being a nurse. I had to select jobs that did not require hepatitis B screening. I've struggled to decide if and when to disclose my status, and have thought about it a million times.

What do you do now and what is the nature of your work?

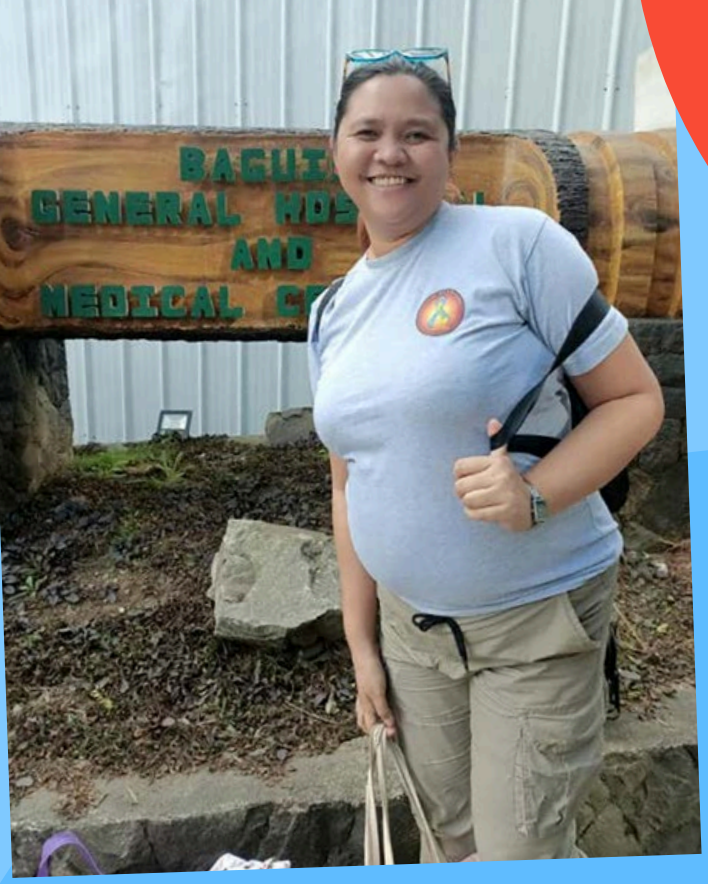
I am happy that I have found a way to realise my dream of working in healthcare. I help lead and develop community-designed health programs as Community Organiser of a university and a part-time Communications Officer of a non-profit. My volunteer work as an Officer/Board Member of Yellow Warriors Society of The Philippines allows me to interact, support, and empower fellow people living with hepatitis.

Has living with hepatitis B affected your lifestyle?

Having hepatitis B caused a tremendous change in my lifestyle. I enjoyed Filipino karaoke parties. I loved adventures. Night was my daytime. As an extrovert, I was very friendly and loved to talk to everyone. But after my diagnosis, I refrained myself from drinking alcohol and attending parties. I became self-conscious and distanced myself from my friends. I became very careful and chose to isolate myself. That continued for 13 years, until I discovered a support community that renewed my sense of purpose and helped me rediscover myself and the world.

What has helped you deal with the emotional challenges associated with hepatitis B?

My initial coping mechanism was to act as if nothing happened, but I soon found it difficult. I did not find anyone to talk to about my condition,



> **Unlike HIV or other conditions, there is no anti-discrimination law that protects people living with hepatitis.**

emotions, and future. We didn't talk about it at home. Nobody asked me if I was okay. I simply focused on finding a job that did not require hepatitis B screening so I could take care of my son.

After 13 years, I decided to find another group of friends or a community with the same condition as me. I searched through many social media sites, and found the Yellow Warriors Society of The Philippines on Facebook. There, I was able to connect with new people and gained a new set of friends.

I attended seminars, workshops, and other team-building activities that allowed us to learn, connect, and make a change for people living with hepatitis. We shared different stories and challenges that finally resonated with how I felt. I found myself engaging more with it to become an advocate to end discrimination in my country.

How would you describe social attitudes towards hepatitis B in the Philippines?

The majority of people living with hepatitis are still afraid to disclose their status because of stigma and discrimination.

Many local companies and international employment agencies still refuse to employ persons living with hepatitis B. Some food industries outright refuse applicants that show a reactive result during employment screening of hepatitis. And the government itself refuses to employ them in the military or in public hospitals. Unlike HIV or other conditions, there is no anti-discrimination law that protects people living with hepatitis – despite years of multisectoral work with other groups in the country.

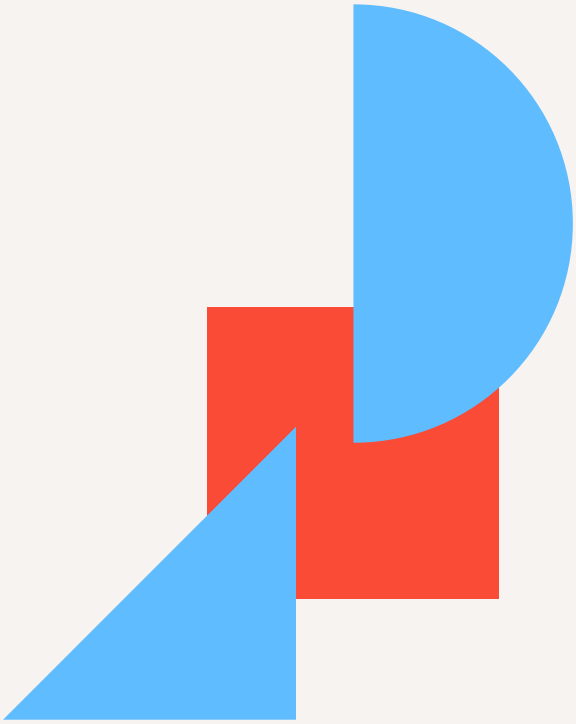
Among the population, people still have a hard time differentiating the different types of hepatitis. They often lump them together incorrectly, like hepatitis A with hepatitis B. And the insufficiency of information dissemination leads to stigma and discrimination.

What advice do you have for others living with viral hepatitis?

For other people living with hepatitis, please know that all is not lost. My story of dealing with my condition, stigma, and discrimination has been very challenging, but I found a supportive group that empowers me to live my best life.

Wherever you may be, there is a supportive community that is ready to help and support you. Knowing about your status and seeking care is already a huge step forward. Your bravery is amazing, and when we combine our efforts, we can build a future and world free of stigma, discrimination, and hepatitis.

It is still a long way to go, but we have already come a long way – and we need to continue to effect change and raise our voices by taking action together.



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World Hepatitis Alliance

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