

# MOTHERS AND BABIES

## CAN'T WAIT

A CALL FOR  
ACTION TO END  
MOTHER-TO-CHILD  
TRANSMISSION OF  
HEPATITIS B



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## ABBREVIATIONS:

**DNA** - Deoxyribose nucleic acid

**EPI** - Expanded program on immunization

**HBV** - Hepatitis B virus

**HBeAg** - Hepatitis B e antigen

**HBIG** - Hepatitis B immunoglobulin

**HBsAg** - Hepatitis B surface antigen

**MTCT** - Mother-to-child transmission

**PMTCT** - Prevention of mother-to-child  
transmission

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# GLOSSARY:

## **Chronic hepatitis B infection -**

Persistence of the hepatitis B surface antigen in serum for more than six months following an acute infection.

## **Hepatitis B surface antigen (HBsAg) -**

Hepatitis B envelope protein produced in abundance and detected in the blood in acute and chronic hepatitis B infection

## **Hepatitis B e antigen (HBeAg) -**

Hepatitis B protein detectable in the high replicative phase of the virus. It correlates with high levels of viral replication and is used as a proxy to assess the infectivity of a hepatitis B-positive individual.

## **Hepatitis B viral load -**

Hepatitis B viral DNA produced as a result of viral replication. It can be quantified in serum using nucleic acid diagnostic techniques.

## **Mother-to-child transmission -**

A disease transmitted from a mother to her infant either in utero or during delivery, also referred to as vertical or perinatal transmission.

## **Hepatitis B birth dose vaccine -**

The first dose of the hepatitis B vaccine administered post-delivery within a maximum of 24-hours. This is followed by two or three doses of the hepatitis B vaccine at least four weeks apart.

## **Maternal antiviral prophylaxis -**

Initiation of antiviral therapy against hepatitis B, currently advised from 28 weeks of pregnancy to prevent mother-to-child transmission of hepatitis B.



# FOREWORD

**Hepatitis B has been called a silent killer.**

**It is a silent killer because those who are affected by it most, often have no voice.**

**It is a silent killer because those who are affected may not know until it is too late.**

**It is a silent killer because it is often passed from mother-to-child without any outward sign**

**It is a silent killer because a safe and effective vaccine has been available for more than four decades, but many countries do not provide it.**

**It is a silent killer because despite the evidence, most global funding organisations do not support efforts to eliminate it.**

**We can be silent no longer ...  
HEPATITIS CAN'T WAIT.**

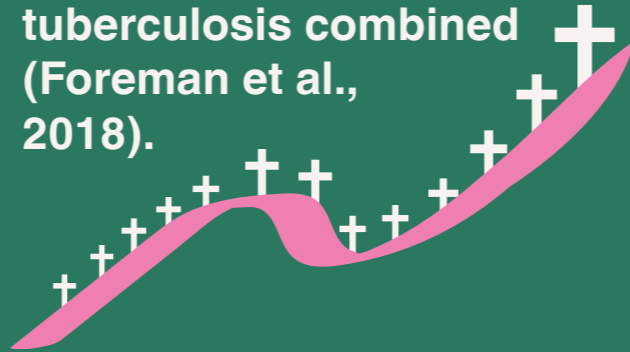


In 2019,  
**1.5 million**

(1.1 million-2.6 million) people newly acquired hepatitis B (WHO, 2021a). Most of these were as a result of mother-to-child transmission.



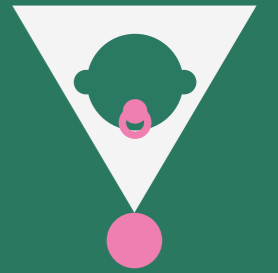
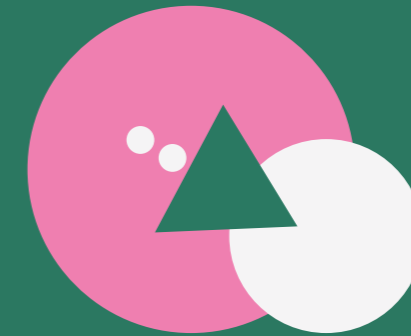
By 2040, deaths from viral hepatitis are expected to exceed mortality from HIV, malaria, and tuberculosis combined (Foreman et al., 2018).



**296 million**

people live with hepatitis B worldwide

Hepatitis B is most often transmitted from mother to child at birth



The birth dose vaccine can prevent transmission and is available for USD 0.20

## WHY IS IT IMPORTANT?

Out of  
**296 million**

people living with hepatitis B around the world (WHO, 2022),

**197 million,**

live in low- and middle-income countries (LMICs) in the African and Western Pacific regions (WHO, 2017a).



Approximately  
**9 in 10**

infants who are exposed hepatitis B (GOV.UK., 2021) develop chronic infection hepatitis, and around

**25%**

of them will die of liver-related complications later in life (Nelson et al., 2014).

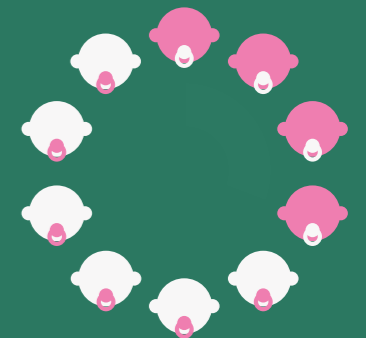


Hepatitis B is a leading cause of liver cancer



Only  
**43%**

of babies had access to the birth dose vaccine



**820 thousand**

people die each year because of hepatitis B





# INTRODUCTION

**As the World Health Organization (WHO) works toward its goal to eliminate hepatitis B by 2030, the quest to halt hepatitis B mother-to-child transmission has never been more urgent.**

WHO estimated that in 2019, 296 million people were living with chronic hepatitis B (WHO, 2022a). Hepatitis B can cause liver scarring, liver failure and liver cancer. The burden of the disease disproportionately affects the economically disadvantaged, with an estimated 197 million of hepatitis B-positive people (~79%) living in LMICs in the African and Western Pacific regions (WHO, 2017a). The majority of chronic hepatitis B cases result from infections acquired through mother-to-child transmission, with a smaller proportion being acquired through horizontal transmission (child-to-child or household transmission) during early childhood. The virus is also passed on through contact with blood or other body fluids during sex with a person living with hepatitis B, unsafe injections, contaminated blood transfusion, or exposure to sharp instruments which have not been sterilised

Among people living with chronic hepatitis B, 10-25% will develop primary liver cancer (Nguyen et al., 2009; Edmunds et al., 1993; Chang, 2008). Those whose infection was acquired through mother-to-child transmission have the greatest risk of progressing to liver cancer and liver failure (Shimakawa et al., 2013).



Wendy, from Canada, found out she was living with hepatitis after her mother was diagnosed. She didn't take her hepatitis status seriously until her mother was diagnosed with liver cancer.

I guess this was 10 years or so after I found out [I was living with hepatitis B]. I needed to seriously consider how I live my life and how I wanted to treat myself. It was a wakeup call for me to realise the seriousness of hepatitis B and how it can lead to further complications such as fibrosis and liver cancer.

In May 2022, the World Health Assembly issued a new Global Health Sector Strategy (GHSS) on viral hepatitis, setting targets for 2025 and 2030. These targets include reducing new cases of hepatitis B by 90% and reducing mortality by 65% by 2030. In order to reach this target, the mother-to-child transmission of hepatitis B must be urgently addressed.

There has been some progress in hepatitis B vaccine coverage. From 2015 to 2020, worldwide coverage of the third dose of the hepatitis B vaccine increased marginally from 82% to 85% and administration of the





If we are to reach the 2030 hepatitis B elimination goals, we must address the systemic barriers to PMTCT around the world. Caring for women means providing antenatal care, sexual and reproductive health promotion, and access to essential and lifesaving care. Providing this to mothers, their newborns and their children is vital for ensuring that hepatitis B is adequately addressed.

The triple elimination of mother-to-child transmission of HIV, syphilis and hepatitis B is an effort by WHO to encourage integrated care, and a commitment from countries to address all three diseases. As a global community, it is an opportunity for us to work together, strategically and cooperatively, to alter the lives of poor and underserved women and children within our global society

birth dose vaccine rose from 38% to 43% (WHO, 2021a). In addition, the sustainable development goal (SDG) target to reduce hepatitis B surface antigen prevalence to less than 1% among children under five has been met. However, with our current rate of progress, it is clear that we will not reach the viral hepatitis GHSS targets (CDA Foundation, 2022). More than half of infants worldwide still do not have access to the hepatitis B birth dose vaccine. In Africa, for example, only about 6% of infants receive timely birth dose vaccine (WHO, 2022b).

Many of the key issues brought into focus over recent years combine to impede progress of the prevention of mother-to-child transmission (PMTCT) of hepatitis B. Such issues include racial inequality, discrimination against women, and gross inequalities of healthcare access across the globe.

**In Africa, only about 6% of infants receive timely birth dose vaccine.**

# BACKGROUND

Hepatitis B is caused by a virus which attacks the liver. Depending on the age at which it is acquired, it can cause a mild, short-lived, acute disease of not more than six months, or a serious, life-long, chronic disease (WHO, 2022a). Chronic lifelong infection leading to complications is primarily seen among those infected as infants and young children (WHO, 2022a). About 95% of cases acquired during infancy and 30% to 50% of childhood cases acquired between the ages of one and six will progress to chronic hepatitis (Hyams, 1995). This is particularly alarming because these children are at high risk of developing severe liver complications such as liver cirrhosis, liver decompensation, and liver cancer later in life.

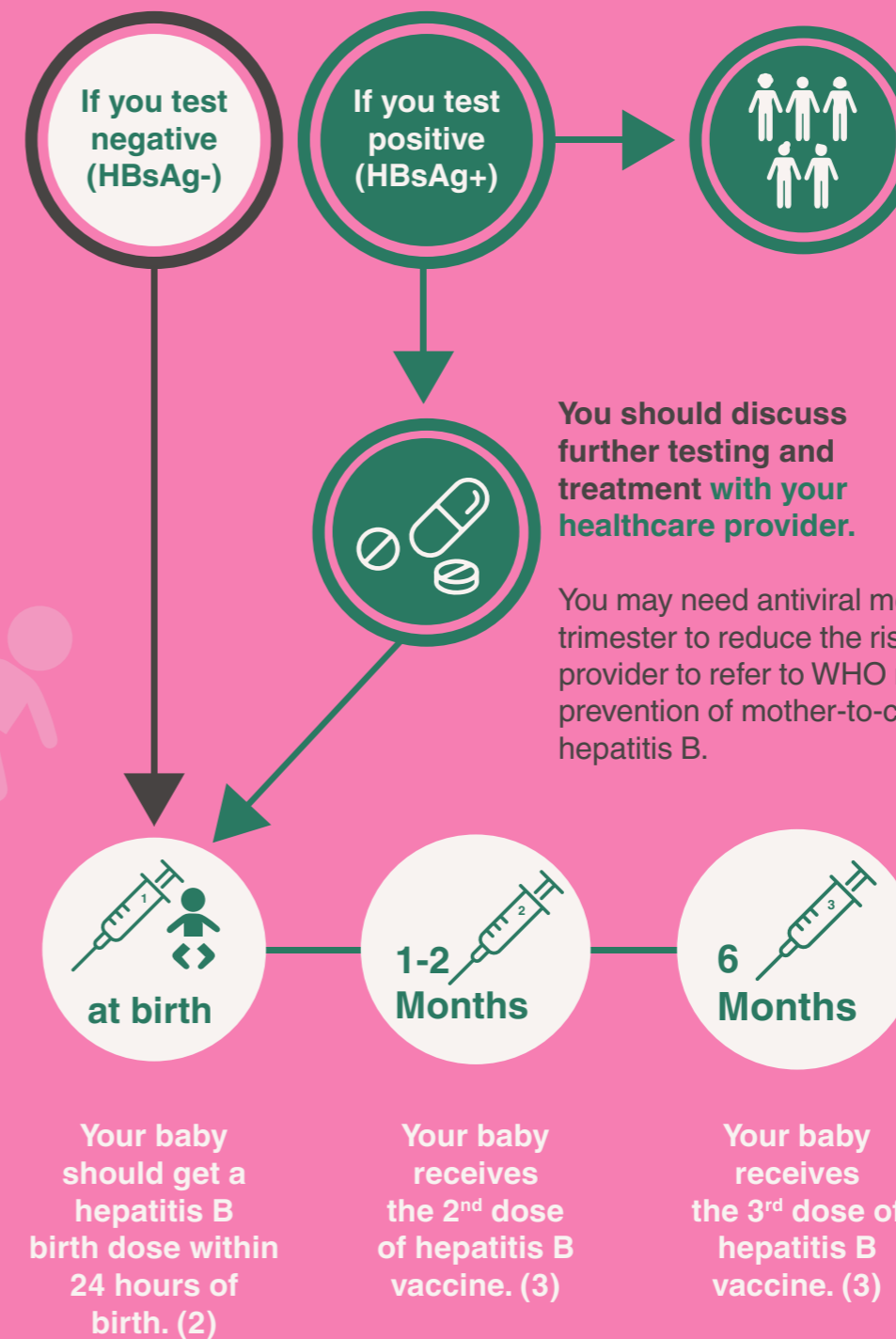
Vaccination remains the cornerstone of preventing transmission, and the hepatitis B vaccine has been available since 1982. It is safe, inexpensive, and was the very first vaccine to prevent cancer. The wide implementation of this three-dose vaccine (given at six, 10, and 14 weeks of age) as part of the Expanded Program on Immunization (EPI)<sup>1</sup> has been tremendously successful in preventing the transmission of hepatitis B through child-to-child interactions and household contacts in early childhood (WHO, 2022a). However, it does not prevent infections acquired in infancy either in utero or during delivery from hepatitis B-positive mothers.

An estimated 4.5 million women living with chronic hepatitis B give birth annually – most of them live in Africa and the Western Pacific (Keane et al., 2016). Women with a very high hepatitis B viral load in their blood during pregnancy and at the time of delivery — have the highest risk of transmitting the virus to their babies. This risk is estimated as being somewhere between 40% and 100% in the absence of preventive measures (Thio et al., 2015; Keane et al., 2016; Mavilia et al., 2017).

<sup>1</sup> The Expanded Program on Immunization (EPI) was established in 1976 to ensure that infants/children and mothers have access to routinely recommended infant/childhood vaccines. Six vaccine-preventable diseases were initially included in the EPI: tuberculosis, poliomyelitis, diphtheria, tetanus, pertussis and measles.

In early pregnancy, you should be tested for **HEPATITIS B!**

## A mother's guide to preventing the transmission of hepatitis B



Your immediate family and sexual partners should be tested.

If they are not immune, they can get the vaccine series to be protected. If they have hepatitis B, they too should get care.

You should discuss further testing and treatment with your healthcare provider.

You may need antiviral medication in the 3rd trimester to reduce the risk. Ask your medical provider to refer to WHO recommendation on prevention of mother-to-child transmission of hepatitis B.

When your baby is 9-12 months old your medical provider may advise a blood test to check if they are protected against hepatitis B. (4)

# POLICY

## RECOMMENDATIONS

This report outlines the context and human impact of mother-to-child transmission. These recommendations, when carried out in addition to established guidelines, will ensure that PMTCT services are equitable, accessible, and available to all who need them.



- Hepatitis B education must be provided to pregnant women as a prenatal standard of care, allowing women to be empowered and informed.

- Health care professionals must be provided with mandatory training to increase access to services and reduce hepatitis-related stigma in antenatal care.



- Educational programmes providing accurate information and sharing people's experiences of living with hepatitis B must be accessible to all to combat stigma and misinformation.



- Community-based organisations should be resourced and empowered to inform and support communities and play a recognised role in health care systems and hepatitis B elimination

- Funding and resources must be provided to support the implementation of known, cost-effective PMTCT of HIV, viral hepatitis and syphilis interventions.





# KNOWLEDGE AND EDUCATION

Lack of knowledge and awareness of hepatitis is common around the world.

I used to hear about hepatitis but I didn't know how serious it was until I was pregnant...I found out I had hepatitis B. I was eight months pregnant.

Remembers Funmi, from Nigeria, who was 23 years old when she found out she had hepatitis B.

I used to hear hepatitis B was a deadly disease. I was really scared, and I thought I was going to die after I Googled it.



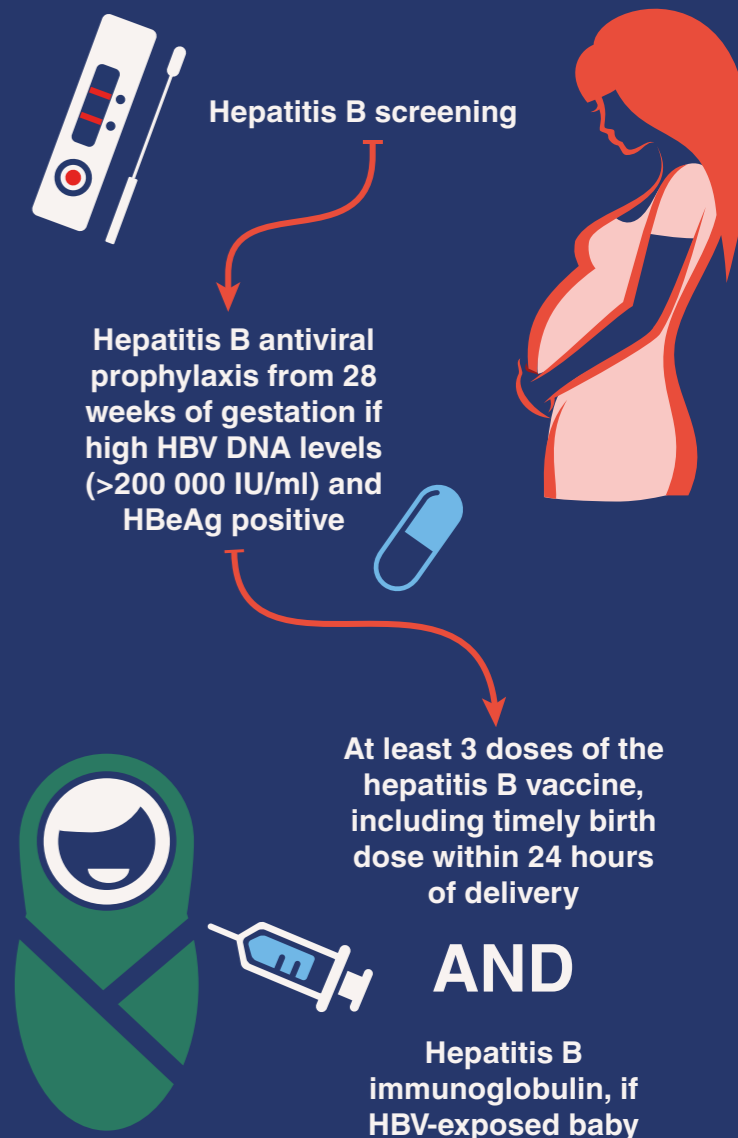
Marinela, from Romania, was diagnosed with hepatitis B in 2006. Nine months later, she found out she was expecting her first child:

I was hospitalized because of my hepatitis symptoms when I found out I was pregnant. I knew little about hepatitis B at the time and I lived in constant fear of passing a potentially deadly virus to my child. It took a great toll on my mental health.

Research conducted across different countries in Asia, Europe, the Americas and Africa indicates that often pregnant women do not have the information necessary for them to make informed decisions about their healthcare. Studies from the United States and Canada show that one in ten women lacks knowledge of hepatitis B testing related to their children (Lisker-Melman et al., 2020). Only 10.8% of Vietnamese women correctly answered questions about hepatitis B (Hang Pham et al., 2019). In Kenya and Mozambique, fewer than half of women asked had even heard of hepatitis B (Chaquisse et al., 2018; Malungu Ngaira et al., 2016), and fewer than 20% of Ethiopian and Ugandan women know that hepatitis B could be transmitted to their baby (GebrecherKos et al., 2020; Nankya-Mutyoba et al., 2018).

## WHO GUIDELINES FOR THE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HEPATITIS B EXPLAINED

While this paper provides additional policy recommendations on how to make PMTCT of hepatitis B a reality, here we explore the recommendations contained in the recent WHO guidelines, which should inform the design of all PMTCT programmes (WHO, 2021b).





In almost all of these studies, better knowledge was associated with better education (Chaquisse et al., 2018; Malungu Ngaira et al., 2016; Noreen et al., 2015; Kwadzokpui et al., 2020; Han et al., 2017). Across the world, major gender discrepancies still exist in access to education, and these discrepancies become more apparent in poorer and marginalised communities. In Africa, the 2019 data from UNESCO shows that 52 million girls are not in school (UNESCO, 2019). This impacts women's ability to access healthcare, both for themselves and their children.

One recent study showed that in areas where knowledge of hepatitis B was good, acceptability of PMTCT of hepatitis B was also high (Al-Essa et al., 2020). Indeed, knowledge enables women to seek protection for their babies and close contacts as well as caring for themselves. This often also empowers women to help others.



**I want to reach out and educate the Chinese community and women of childbearing age**



Says Alice (pictured left) who lives in the USA.



**At Chinese New Year I set up a booth for hepatitis B. I could see a lady out there was hesitant to come to the booth. She was watching from faraway. Then she gradually stepped closer and talked to me in Chinese when no one was around. It was like a secret, as there is stigma to have an open discussion with someone you don't know. She asked about how hepatitis B is transmitted. I was able to give her the information available to me. I could see she was expecting a baby and had no partner next to her, but she was talking to me.**



## 1. Hepatitis B antenatal screening

Systematic antenatal screening for hepatitis B is recommended (WHO 2017c) in populations with hepatitis B rates of at least 2% to prevent the cycle of transmission within communities. This forms part of the triple elimination of MTCT of HIV, syphilis and hepatitis B strategy (WHO, 2022c).

Screening for hepatitis B should be performed in the first trimester of pregnancy. Diagnosis also provides the opportunity to treat women living with hepatitis B, to vaccinate those who test negative, and to identify household members and sexual contacts of cases to offer them testing, vaccination or hepatitis B care and treatment (Boucheron et al., 2021; Chen et al., 2012; Wen et al., 2013)<sup>2</sup>.

<sup>2</sup> Pregnant women who test positive for HBsAg should be further tested for hepatitis B viral load, to assess their infectiousness and risk of MTCT. Where hepatitis B viral load infrastructures are limited, the WHO recommends testing for hepatitis B e antigen (HBeAg), another marker of infectivity. HBeAg can accurately identify pregnant women carrying hepatitis B viral load above 200 000 IU/ml; thus, it can be used as an alternative to determine infectiousness of the infected pregnant women and her eligibility for peripartum antiviral prophylaxis (Boucheron et al., 2021).







When examining how to educate a community about a healthcare issue, access to information is not the only consideration. The quality of this information is also important. Of those who have access to information about hepatitis B, many cite the media as their source. However, information from this source may not always be accurate. Since this is where alternative health care practitioners advertise their products, information may be biased (Adjei et al., 2016). Poor knowledge and misinformation fuel the stigma surrounding the disease, impeding access to care.

Funmi remembers:

**I lived in a village when I gave birth to my first child, but we no longer live there. Even where I live now, there is so much discrimination. I am married and my partner has been vaccinated against hepatitis B. He has been very supportive, but we have not told family members due to discrimination.**

In many of the most affected areas, local languages do not even have words to describe the condition. Since hepatitis B-positive women usually feel well, it is difficult for them to convey the necessary level of concern about their condition. The key features of programmes addressing this problem suggest that strategies for engaging and empowering women should consider using understandable language; that they be tailored to the local health literacy level; that they provide only pertinent information; that they are repeated over the antenatal period; and that they attempt to ensure patient privacy (Bierhoff et al., 2021; Johnson et al., 2021).

Anita, Ghana, uses her experience to support pregnant women living with hepatitis:

**There isn't any specific education when they let you know you are hepatitis positive. You are just left on your own to do your own research and left on your own to sort treatment.**

**Most people don't talk about it because they are afraid to be stigmatised. I decided that I would try and help other mothers... to create awareness and help stop mother-to-child transmission. Now I try to advise mothers and talk to a lot of people.**



Alice describes how pivotal screening was for her:

**I have been living with chronic hepatitis B for many decades. I didn't know until my first pregnancy and the blood test showed I was a chronic hepatitis B carrier despite being asymptomatic. I was really shocked.**

**There weren't government screening guidelines at that time, but my gynaecologist decided to do the hepatitis B screening. I was glad he was able to test me.**

Despite such stories, hepatitis B screening does not form part of national policy in many countries. Survey data<sup>3</sup> from World Hepatitis Alliance shows the absence of this intervention, with 27% of African respondents reporting clear evidence of limited access to antenatal hepatitis B screening. "NOT all women are offered screening," was the answer given by 54% of respondents. Reasons for limited access to hepatitis B screening are diverse, and include:

<sup>3</sup> World Hepatitis Alliance. 2022. Online survey.



Wendy, Canada, had very little knowledge about hepatitis and relied on the internet for information after being diagnosed with hepatitis B.



**I knew nothing whatsoever about hepatitis before. I had done some medical classes, being in healthcare, but I knew nothing about it and how complex the damage can be. I'm still learning. It's such a complex disease.**



In Shenyang, China only 21% knew about antiviral treatment to prevent hepatitis B mother-to-child transmission (Sheng et al., 2018). A study from Guangdong, China showed whilst 89.8% would allow their child to receive vaccination and 85% hepatitis B immunoglobulin, only 16.5% agreed to take antivirals during pregnancy (Han et al., 2017). Yet, a small African study showed high acceptance of antiviral therapy (Thompson et al., 2021).

## **POLICY RECOMMENDATION**

Hepatitis B education must be provided to pregnant women as a prenatal standard of care, allowing women to be empowered and informed.

- A lack of capacity and resources such as the unavailability of testing kits and poor staffing;
- Testing being available in only some parts of the country;
- Testing being performed at tertiary facilities;
- Low attendance at antenatal care services;
- Cost implications. 57% of African respondents reported that screening is not offered to all women, irrespective of ability to pay.



**Screening of HBV among pregnant women is not routinely done in the country. They are captured only in chance events or during blood donations and blood transfusions**



A physician from Tanzania responded.

Patient uptake must be taken in consideration to achieve maximum health benefits. The data exploring attitudes to the use of antiviral therapy for hepatitis B prophylaxis in pregnancy is sparse. Studies published suggest that women asked about the use of antivirals during pregnancy can be suspicious and concerned about risk of teratogenicity (WHO, 2020), though many studies have shown good safety profile of the antivirals during pregnancy (Funk et al., 2021; Gerlich, 2021; Pan et al., 2016; Jourdain et al., 2018; Salvadori et al., 2019; Kourtis et al., 2018).







# HEALTHCARE WORKERS

Although healthcare workers can be a trusted source of knowledge, they can also often have gaps in their knowledge of hepatitis B. Data suggests that more than half of health staff surveyed about their hepatitis B knowledge and preventive measures against the disease are poorly informed (Hu et al., 2012; Mhata et al., 2017; Van Ommen et al., 2017; Djaogol et al., 2019; Hang Pham et al., 2019). Whilst national policies need to be implemented to improve access to the vaccine for healthcare workers, for those who can access the vaccine, increased knowledge and education can support the uptake of the vaccine, especially amongst newly recruited healthcare workers (Aaron et al., 2017).

Wendy, Canada, recalls misconceptions in her workplace as a healthcare worker:

**My co-workers would be hyper-vigilant, and if someone was coming in with HIV or any other clinical diseases they wondered if we needed to gown up, even for hepatitis B. I told them, no you don't need to gown up for hepatitis B.**

Pregnant women rely on their healthcare providers both to ensure they have access to the right therapy and also for education. Programmes must ensure that healthcare workers can provide women with the hepatitis B literacy they need in order to make informed choices and seek further support if needed.

Marinela, Romania, describes how she gained information about hepatitis B and PMTCT:

**During the second trimester of my pregnancy I managed to get in touch with a gynaecologist and a gastroenterologist who had experience with hepatitis B-positive mothers. They guided me through my pregnancy and shared information about prevention of mother-to-child transmission of hepatitis B.**

We need to be able to normalize the discussion about hepatitis B without hesitancy or fear," advises Alice. "When we keep talking about hepatitis B transmission, prevention and vaccination, eventually people will feel this is a health topic that...everyone needs to know about.



**Not all are offered [screening] for HBV and syphilis because the test kits are not always available. With HIV though, efforts are made to get the test done in government facilities during pregnancy**

Said a physician from Sierra Leone.

A community healthcare worker from the Republic of Congo wrote it was:

**Because the costs are chargeable, and the health services do not have medical products or equipment to offer for free.**





Anita, Ghana, describes the misinformation she experienced from her midwife:

**A midwife told me I should take a herbal medicine to help me cure the hepatitis B. I told her it doesn't work like that, but she kept insisting that I should do it. Health professionals need more education, especially the midwives and nurses. I get sad by the way they talk about hepatitis and the way they treat patients with hepatitis B. Most of them would advise that you use herbal medication, which is not the best option.**



These reasons were emphasised in answers related to barriers to access to hepatitis B screening. Other reasons given included a lack of education in both pregnant women and health care workers, and a lack of national policies and guidance. In contrast, systematic antenatal screening for HIV is well established, with high coverage rates in many parts of the region.

Commercial rapid point-of-care tests for hepatitis B have demonstrated they perform well in field settings and are accepted by communities (Njai et al., 2015; Lemoine et al., 2016; Chotun et al., 2017; Chisenga et al., 2018) Evidence from Africa shows that adding hepatitis B screening using rapid tests to current HIV screening programmes is a feasible and low-cost solution (Tamandjou Tchuem et al., 2021; Thompson et al., 2021). Rapid point of care tests should be implemented to screen for hepatitis B, HIV and syphilis. Identifying women at risk of transmitting infection is the first key step to eliminating these infections.

## **POLICY RECOMMENDATION:**

**Health care professionals must be provided with mandatory training to increase access to services and reduce hepatitis-related stigma in antenatal care.**





# STIGMA AND MISINFORMATION

Individuals living with hepatitis B often face challenges due to the stigma associated to the disease. This may hinder both health-seeking behaviours and public health efforts aimed at promoting hepatitis B testing and linkage to care.

Surender, India, describes how his brother learnt that he was hepatitis B-positive when he tried to donate blood. He then encouraged Surender and his mother to get tested. Their tests both came back positive:

**There is a lot of stigma surrounding hepatitis B in India because of the misconceptions surrounding transmission methods. Hepatitis B is seen solely as a sexually transmitted disease. However, there are many people who don't know what it is and whether they have it.**

In some areas it is commonly believed that hepatitis B is transmitted through handshakes and sweat (Adjei et al., 2018). Many believe the disease has spiritual connotations, linking it to witches and wizards. These beliefs, coupled with stigma in communities, can adversely affect health-seeking behaviours. It has been previously reported that many women would attend a traditional healer if they experienced symptoms of hepatitis B (GebrecherKos et al., 2020). Such real-life observations emphasise the need to consider the likely sources of misinformation and stigma, and to attempt to redress their impact.

Funmi, Nigeria, worked with UNICEF as a water, sanitation and hygiene (WASH) facilitator, helping raise awareness in the community. She describes her experience of disclosing her hepatitis B status:

**When I was working I was looking for a babysitter. Before you take on anyone you have to say if you have hepatitis B. There's a feeling I have sometimes that I should disclose my identity and let people know I have hepatitis B. It's really sad. I don't mind coming out. I want to share my experience. But am I ready for that now? I don't think I am because of the discrimination. Sometimes I don't mind that I'm positive, I want to help raise awareness. I would come out about my hepatitis B but in Africa it's impossible.**



## 2. Timely birth dose vaccination

Since 2009, WHO has recommended that all infants should receive the hepatitis B birth dose vaccine, preferably within 24-hours of delivery. The implementation of this recommendation has been slow and inconsistent in many parts of the world. In the WHO Western Pacific and African regions, where the burden of hepatitis B is the highest, a significant contrast exists. While most countries in the Western Pacific region have successfully implemented timely hepatitis B birth dose vaccine (Woodring et al., 2019), only 13 of 48 African countries offer the birth dose vaccine (Njuguna, 2021). As a result, Africa has not met the WHO AFRO Regional Committee target of at least 25 countries implementing timely hepatitis B birth dose vaccine by 2020 (WHO, 2017d).

Timely administration of the birth dose vaccine reduces the risk of mother-to-child transmission of hepatitis B to between 10% and 30% in highly infectious pregnant women, and to under 0.5% in women with a lower hepatitis B viral load (Lee et al., 2007; Machaira et al., 2015).



Wendy, Canada, has a simple message:



**People should not be afraid of us. My family and close friends all know I have hepatitis B. They don't treat me differently and I do appreciate that.**



Storytelling has recently become a powerful tool in addressing the stigma and increasing awareness around hepatitis B. This health communication method uses personal stories told by those affected by the disease to educate others. The storytellers might be those living with hepatitis B, the child of a person with hepatitis B-related cancer, or the spouse of a person with hepatitis B. Personal stories are often perceived as being more relatable than general health messaging heard on the radio or seen on adverts. More importantly, storytelling provides a space for people living with hepatitis B and helps them to relate to others with similar conditions (Alber et al., 2020).

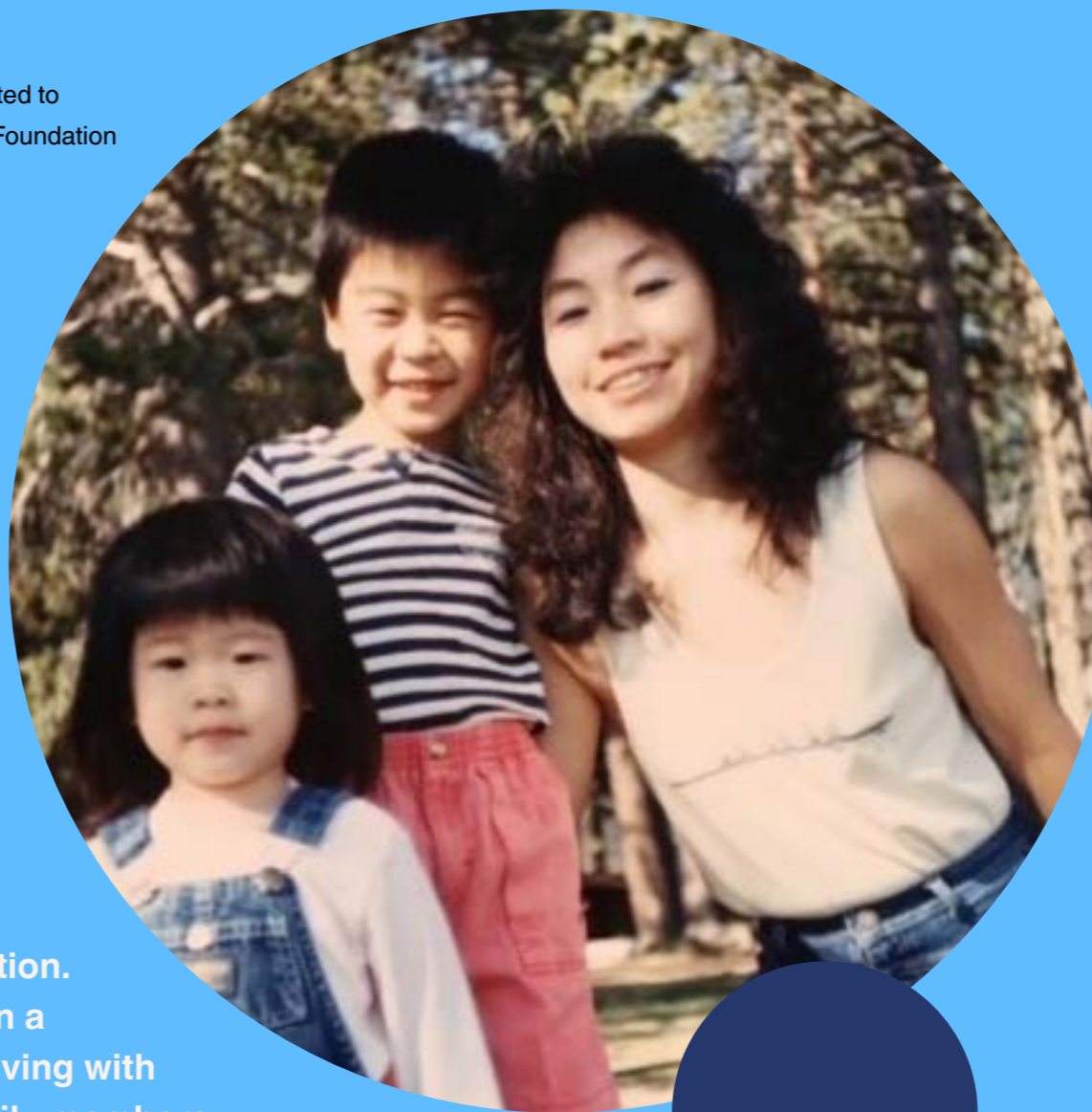
Previous studies have found storytelling to be a successful tool in tackling the stigma and knowledge gaps around specific diseases such as HIV and TB (Zeelen et al., 2010; Dike et al., 2021). The Hepatitis B Foundation have ongoing storytelling projects (Hepatitis B Foundation, 2022), in which people living with hepatitis B are invited to tell their personal living experiences on videos or in written form, these stories are accessible to all. May of those involved use these stories as a means of sharing their status and experiences with their families and close contacts.

Alice, (pictured right) was invited to participate in the Hepatitis B Foundation storytelling program:



**I still feel a profound stigma because of how I was raised. I was ashamed to share my health status until 2018, when I was invited to participate in the storytelling campaign of the Hepatitis B Foundation. It was storytelling in a circle with people living with hepatitis B and family members, the circle time enabled me to open up.**

**I could hear people sharing their story around me and I felt comfortable. Once I started talking and sharing my experience, I felt the trust and comfort in this circle of people. I thought, yes, I'm fine, I can share my information with everyone. It's also a rewarding experience, encouraging me to continue the outreach to promote hepatitis B prevention and vaccination.**



## **POLICY RECOMMENDATION**

**Educational programmes providing accurate information and sharing people's experiences of living with hepatitis B must be accessible to all to combat stigma and misinformation.**

Anita describes how her brother, a lab technician, ensured her first baby received the birth dose vaccine.



**In 2014, I got pregnant and gave birth to my first child. I told my brother about it and he gave him an injection at the hospital. I don't really remember the name of that type of injection, but I was told it was for hepatitis B. So, they gave him the injection, before I breastfed him for the first time. After I wasn't told anything, they didn't educate me on anything.**

**After three months we ran a test and he was negative, it was the same for my second child. So, I decided that I would try and help other mothers who are just like me just to create awareness so that we would help stop mother to child transmission.**





# THE VITAL ROLE OF COMMUNITY ORGANISATIONS

Community-based organisations are uniquely placed to support their communities and health care systems in PMTCT of hepatitis B.

Marinela, Romania, used her experience as the basis for her advocacy work to empower women:

**I started APAH-RO, a patient organisation to support other people living with viral hepatitis and advocate for policy change. Now I work together with other women to decrease the stigma surrounding hepatitis B in pregnancy and help inform them how to protect their children.**

Surender, through his non-profit organisation, the Rann Bhoomi Foundation, uses his own experience of living with hepatitis B to spread positive messages in India:

**If we approach the community with a positive attitude about screening and a positive attitude about whatever the results may be, [people] are more likely to come forward. I always give the example of how I am hepatitis B-positive, and I am living a healthy life and I am able to do anything I want to. We should spread this positive message in India and globally.**

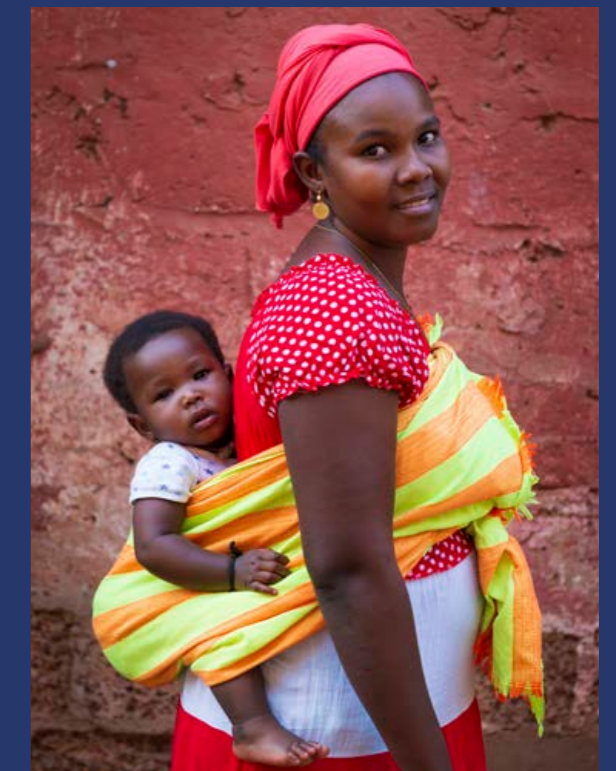


The key roadblocks to implementing the hepatitis B birth dose vaccine in Africa include a lack of country-specific evidence of the rates of hepatitis B, high financial costs of vaccine distribution and delivery, insufficient cold-chain storage, a lack of trained community health workers (CHWs), and a high proportion of at-home births.

Funmi, Nigeria, is now a mother of three. She shares her experience of being pregnant with her first child:

**[The birth dose vaccine] wasn't available in my district. The pharmacist told me it was available elsewhere, but it was quite far away. They told me it would lose potency if I waited. We had to get a car, and the vaccine was administered to my baby after 24 hours but under 48 hours. I found out my baby was supposed to have the vaccine in 24 hours, so I was worried.**

Other non-profit and civil society organisations have tapped into local resources and the media to spread hepatitis B information. Arafat Bwambale is devoted in abolishing harmful misconceptions around hepatitis B in Uganda. Along with his colleagues, they have put together strategies adapted to their local context. They have designed outreach activities and implemented them through the Great Lakes Peace Center, a charity centre that disseminates health messages translated into local languages and organises traditional meetings, allowing communities to share the challenges they are facing. Further education is provided through radio jingles (Sightsavers, 2022) to reach a wider audience in the country (Ainsworth, 2022).







Arafat (pictured above) describes the work they do in Uganda and what elimination of hepatitis means to him.

**We engage local leaders and village health team members of parliament to influence policy to shift stigma and discrimination. Challenges exist such as a lack of funding to our activities, language barriers to translate and develop precise and accurate materials to from English to local languages. The role of community organizations is so important in client counselling, raising awareness of viral hepatitis through advocacy, and holding policy leaders accountable. Indeed, I am ready to spend my last atom of energy to eliminate hepatitis by 2030.**

In Nigeria, the Women in Hepatitis Africa WIHA – a subsidiary of the public health NGO LiveWell Initiative LWI – is an inspiring example of health empowerment around hepatitis B. Women of all ages and all backgrounds receive training and train other women around hepatitis B (World Hepatitis Alliance, 2020). Bisi Bright, Vice Chairman and CEO of LiveWell Initiative LWI, explains their work further.

**Having trained over 5,000 African women from 18 countries including Ghana, Mauritius, Egypt and Namibia, WIHA uses a powerful approach to empower women from all backgrounds**

**including ‘never schooled women’ to seek care for themselves and others, and to become hepatitis champions in their communities. In addition, LWI was**

**the first organisation to adopt PMTCT in hepatitis as a policy on World Hepatitis Day 2019, and has since then consistently screened pregnant women for viral hepatitis, with linkages to care, and promotion of birth dose vaccination and**



Cost is cited as a persistent barrier to implementation. Yet, many economic evaluations comparing the costs and health outcomes of healthcare interventions have demonstrated favourable value for money compared to the three-dose schedule starting at six weeks that is currently in place in almost all African countries. In Sao Tome and Principe, the birth dose vaccine is only administered to babies born to mothers known to be living with hepatitis B. Research shows that overall cost savings of approximately 44% (95% CI, 42-46%) may be achieved by generalising the birth dose vaccine to all babies, irrespective of their mother’s status, and that this would prevent the same number of chronic hepatitis B infections each year (Hagan et al., 2019).







**education of the women. At its recent 4th Liver Health Confab, LWI brought together several Hepatologists, Gastroenterologists and hundreds of Physicians, Healthcare Workers, Carers, and the general public from several countries around the world to further discuss PMTCT in hepatitis. The key outcomes included a call for women to start demanding for screening for hepatitis B, and a call to end the high prevalence of hepatitis B in Africa. With no funding now nor in the past since its inception, the WIHA runs the Women's Wellness Center for Hepatitis WWC-H, the first of its kind in Africa. However, the project cannot be scaled or expanded for greater impact due to lack of funding. WWC-H shall make an even greater impact in the effort towards eliminating viral hepatitis by 2030 if the necessary funding is provided, for scale; and for enhanced PMTCT activities, including access to infrastructure, consumables, and to the low-cost multi-disease anti-HIV/syphilis/ HBsAg rapid diagnostic tests.**

By engaging spouses, partners and family members, community organisations can encourage hepatitis education, testing and vaccination. This is an important way of creating a supportive network for women and addressing stigma and discrimination. Such participation and leadership among community members and people living with hepatitis B not only improves education and service uptake, but is also critical in the move

toward hepatitis elimination. WHO's guidance for country validation of viral hepatitis B and C elimination lays out this civil society involvement in its checklist for countries applying for validation (Easterbrook et al., 2021). Community organisations should be funded and represented as they play an active role in national hepatitis elimination, planning, and implementation.



Anita, Ghana, describes how communities need hepatitis education:

**[In] the village I come from they really lack education. It has been one of my top priorities to help people get to know more about hepatitis. It's really killing a lot of people and there's a lot of mother-to-child transmission. Community organisations [should] educate the community about hepatitis and against stigmatisation. A lot of people hardly talk about it.**

## **POLICY RECOMMENDATION**

**Community-based organisations should be resourced and empowered to inform and support communities and play a recognised role in health care systems and hepatitis B elimination**



If nothing is done to scale up distribution of birth dose vaccine, achieving the WHO target of fewer than 0.1% hepatitis B infections in ≤ five-year-olds will not be a reality before the year 2100 in Africa, 70 years after the target date of 2030. However, scaling up the hepatitis B birth dose vaccine strategy to at least 90% by 2030 would prevent about 41 million chronic cases between 2020 and 2100 across the globe. It would also result in 710,000 fewer deaths among those born between 2020 and 2030 globally. Most of those saved would be African due to the continent's high rates of hepatitis B and low birth dose vaccine coverage (de Villiers et al., 2021).





# HUMAN RIGHTS

It seems the most fundamental basis for needing to act is because health is a fundamental human right and we all deserve to live lives of dignity.

In 1946, the right to the highest attainable standard of health was first articulated in the WHO constitution, which stated (WHO, 2017b):

...the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being...

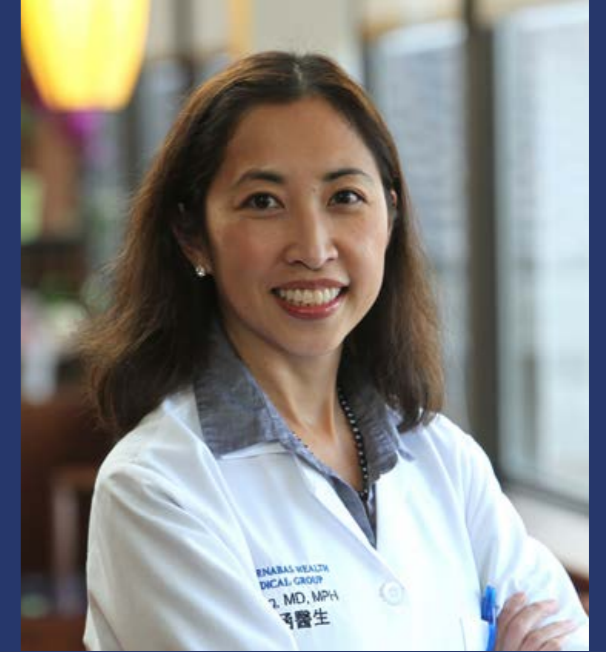


Article 25 of the Universal Declaration of Human Rights clearly articulates (United Nations, 1948):

Everyone has the right to a standard of living adequate for the health and wellbeing of himself and of his family, including food, clothing, housing and medical care...

Nearly every state in the world has ratified at least one international human right agreement imposing specific obligations on governments regarding the right to health, such as article 12 of the 1966 International Covenant on Economic, Social and Cultural Rights (OHCHR, 1966) which advocates: "the prevention, treatment and control of epidemic, endemic, occupational and other diseases." In this same agreement is enshrined the right to enjoy the benefits of scientific progress and its application (article 15).

It is these basic rights, protected by statute books across the world, that form the framework for highlighting and addressing the inequalities which characterise the global response to hepatitis B elimination. They should be integrated in our efforts towards PMTCT of hepatitis B.



Dr Su Wang (pictured above), is a mother living with hepatitis B. She is also the medical director at the Center for Asian Health & Viral Hepatitis Programs at Cooperman Barnabas Medical Center in the USA. She says:

As a mother living with hepatitis B and a doctor treating patients with hepatitis B, I see this as an urgent crisis. My four children received the birth dose and are hepatitis B-free and I am eternally grateful. But I am gravely concerned that this is not accessible to everyone. Mothers everywhere are struggling to get services, and they worry about passing on the virus.

Dr Wang is calling for urgent action:

It is time for parents and family members to speak up. Mothers and babies deserve these simple tools to combat hepatitis B. The prevention of mother-to-child transmission of hepatitis B is critical and is within our reach, but we must not wait to act any longer.





# TRIPLE ELIMINATION

WHO has combined the strategies for the elimination of mother-to-child transmission of hepatitis B, HIV and syphilis, within the context of the Triple Elimination Initiative (WHO, 2022c). This strategy will address some of the discrepancies that currently exist between resourcing for hepatitis B, syphilis and HIV, as well as promoting integration (WHO, 2021b).

In his area of Nigeria, Danjuma Adda (pictured left), President, World Hepatitis Alliance; and Executive Director, Center for Initiative and Development (CFID) and Chagro-Care Trust (CCT), sees these discrepancies first-hand:

**We do not have universal hepatitis testing and screening of pregnant women. HIV testing is provided free of charge as a part of antenatal care, and hepatitis is not. That is not fair.**

There has been successful implementation of systematic HIV screening compared to little, and sometimes no testing for hepatitis B and syphilis. Up to 95% of pregnant women are tested against HIV, while fewer than 50% are tested for syphilis (Storey et al., 2019), with even fewer being tested for hepatitis B.

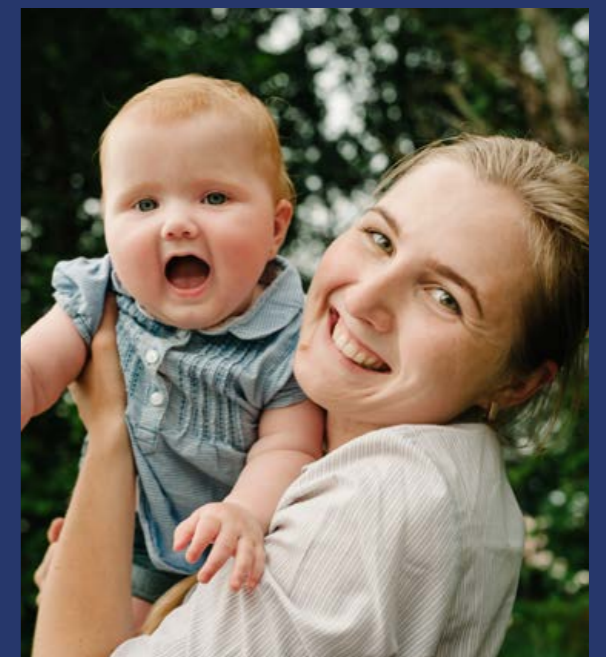
There are differences in political support and integration between the three conditions, with nation-led HIV PMTCT programmes available in many countries compared to non-governmental and research-funded hepatitis B PMTCT programmes. Fewer than 40% of African countries have a strategic and technical advisory group on viral hepatitis, and only 20% have published strategic plans and have dedicated funding for viral hepatitis (Smith et al., 2019).

Treatment for HIV PMTCT is free-of-charge in many places, but this is not always true for either hepatitis B or syphilis. In many low- and middle-income countries, and even in some high-income countries such as USA, women may have to pay for their treatment against syphilis and hepatitis B (Ishizaki et al., 2017).



## 3. Hepatitis B immunoglobulin

Timely birth dose vaccine is not always enough to prevent transmission in some hepatitis B-exposed babies. However, other strategies can increase vaccine effectiveness. Hepatitis B immunoglobulin (HBIG) provides short-term immediate protection to exposed babies. This intervention is particularly recommended for infants born to highly infectious mothers, however, administering HBIG is considered standard care for all infants born to mothers with hepatitis B, regardless of HBV DNA level (Terrault et al., 2018). Infants should receive HBIG as soon as possible within seven days of birth (Indolfi et al., 2019).





Dr Solomon Obekpa from Nigeria recounts the challenges this inequity causes:



**About one in every four pregnant women is not able to complete the required investigations due largely to financial constraint. Some women even disappear from the clinic when they realize the entire cost of the investigation, and sometimes will become lost to follow up.**

HIV PMTCT services and platforms are widely available across many parts of the world and have been remarkably successful in many regions. These services include testing with rapid point-of-care tests, using antivirals for therapy, and integrating women into care pathways. Integrated antenatal services using the platforms established for HIV, hepatitis B and syphilis, offer the opportunity to reach out to all pregnant women.



Today, low-cost multi-disease anti-HIV/syphilis/HBsAg rapid diagnostic tests are commercially available. These devices offer the unique opportunity to test woman for many pathogens at once, improving patient flow at clinics, and assisting in the provision of adequate follow-up care. This critical step is helping to protect the next generation from all three diseases.

## **POLICY RECOMMENDATION**

**Funding and resources must be provided to support the implementation of known, cost-effective PMTCT of HIV, viral hepatitis and syphilis interventions.**



Alice (pictured above), found out she was living with hepatitis B when she was pregnant with her first child:



**My gynaecologist informed me of the measures to take to avoid perinatal transmission. My newborn had the hepatitis B immunoglobulin shot at birth and the first shot of the hepatitis B vaccine. At the age of one, my baby tested negative for hepatitis B. At two years he had further testing and still tested negative. I felt so relieved.**



The timely use of birth dose vaccine and HBIG increases the prevention of mother-to-child transmission of hepatitis B from 70-75% to 90% (Beasley et al., 1983; Lee et al., 2007). While there are challenges associated with implementing HBIG in low resource settings, evidence suggests that HBIG may be cost-effective in these settings too (Tamandjou Tchuem et al., 2021). However, strict cold-chain requirements and costs remain as limitations during implementation. For this reason, further data on efficacy and cost benefit are needed in LMICs.





# CONCLUSION

The issue of PMTCT should put the focus and attention on the needs of women. Because of gender and socioeconomic disparities, the women who are most likely to be affected by hepatitis B are often the ones least likely to have access to the healthcare needed to prevent passing it to their newborns. Hepatitis B infection during pregnancy and childbirth is associated with the highest likelihood of transmission leading

to chronic infection. This perpetuates the incidence of infection in communities. In Africa in particular, progress toward gender parity is often slow in many regions. It is well accepted that the status of women in a society impacts the health of that community.

PMTCT services reduce deaths from liver cancer and cirrhosis in mothers and prevent hepatitis B from being passed to the next

generation. Funding PMTCT can help kick-start a rolling cycle of health improvement and increased quality of life. In this way, not only is the health of individual women improved, but that of whole communities. The care of women living with hepatitis B is an important catalytic investment in families, communities, and future generations, and it should be prioritised.

## 4. Providing antiviral therapy to pregnant women living with hepatitis B who are at high risk of mother-to-child transmission (antenatal antiviral prophylaxis)

Hepatitis B birth dose vaccine, even when administered in a timely manner, does not eliminate mother-to-child transmission. Those most at risk of passing hepatitis B on to their babies are pregnant women with very high viral loads<sup>4</sup> (Pan et al., 2016). Decreasing high viral load during pregnancy through antiviral therapies is key to further reducing the risk. (Ayoub et al., 2016). Current guidance recommends prophylaxis from Week 28 of pregnancy (WHO, 2021b). Given the high efficacy of antiviral prophylaxis in preventing vertical transmission of hepatitis B, scale-up of this intervention is needed to reach WHO targets.

Antivirals are recommended by hepatology societies too (Lampertico et al., 2017; Terrault et al., 2015). Antiviral therapy to prevent HIV has been implemented in antenatal clinics with significant impact, the same is required for hepatitis B. Tenofovir is available in many countries, often in combination with lamivudine, another hepatitis B active drug, but has not been licensed and/or is not made available for hepatitis B therapy. Governments and public health officials need to ensure that tenofovir is made available to women living with hepatitis B to prevent onward transmission during birth.



<sup>4</sup> of over 200,000 IU/ml



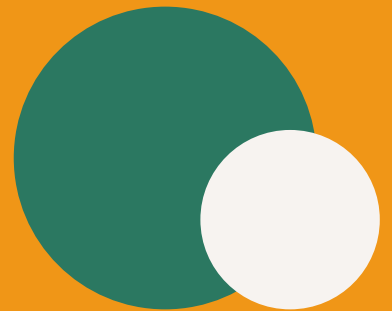
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