



THE HEPATITIS FOUNDATION OF NEW ZEALAND

PERFORMANCE HIGHLIGHTS - A YEAR IN REVIEW

JULY 1, 2019 - JUNE 30, 2020



The Hepatitis
Foundation
of New Zealand

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*“Many people with hepatitis B
are unaware they have it.
It’s important to raise awareness
of the risk factors so people can get
tested and receive the monitoring
and follow-up they need.”*

Susan Hay, CEO

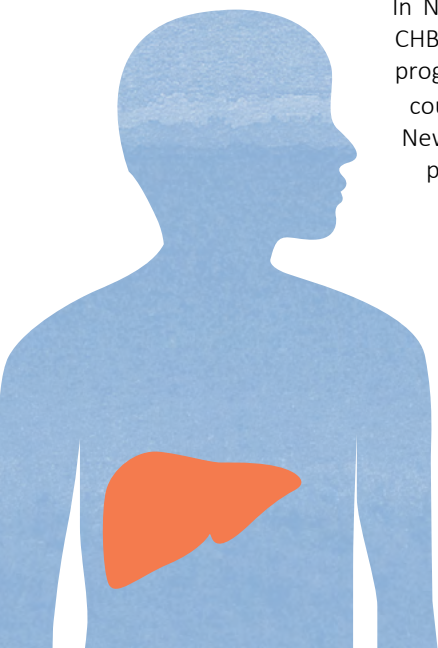


INTRODUCTION

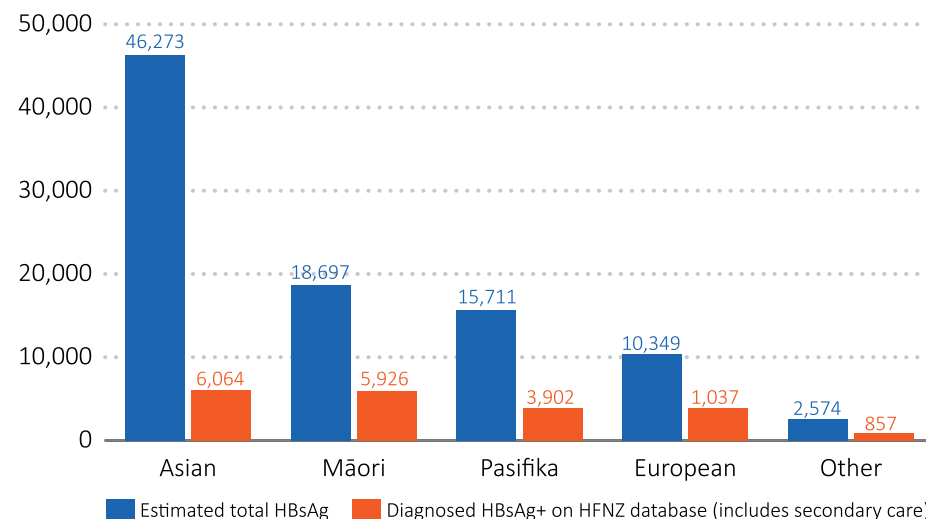
An estimated 240 million people worldwide have chronic hepatitis B. More than one million people die from it every year.

The disease is a global health burden with significant morbidity and mortality. Up to 40 percent of people with the virus will develop chronic hepatitis B (CHB) and face possible liver-related complications such as cirrhosis, liver failure and hepatocellular carcinoma (HCC).

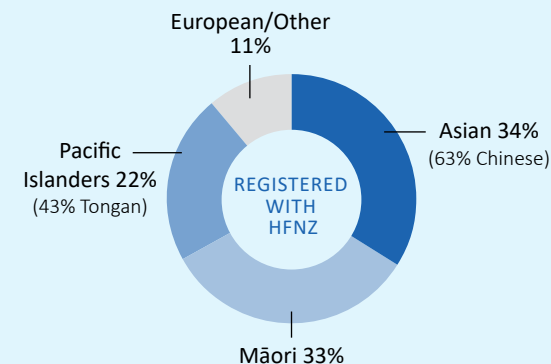
In 2018, an estimated 93,604 New Zealanders were living with CHB - nearly two percent of the population. In November 2019, 17,784 New Zealanders with CHB were registered on the national monitoring programme, representing just 19 percent of the country's estimated total hepatitis B population. New Zealand data has shown nearly 40 percent of patients who presented with advanced hepatitis B-related HCC were not aware of their condition at the time. This suggests there are a lot of people living with undiagnosed hepatitis B (HBV) in NZ.



ESTIMATED NUMBERS OF NEW ZEALANDERS WITH HEPATITIS B AND REGISTERED WITH HFNZ (BY ETHNICITY)



Minority ethnic groups comprise 89 percent of patients registered with us



ABOUT US

We are a not-for-profit organisation that supports people living with hepatitis B.

We run a free monitoring programme that was established in the early 2000s and provides initial assessments and long-term monitoring to all New Zealanders living with CHB. It gives patients access to blood tests, fibroscans and education and support via a phone helpline and a team of community nurses.

Our clinical staff members monitor registered patients every six months for evidence of active CHB or HCC and link patients to specialist care for treatment when needed.

We also provide advocacy and support for people with hepatitis C.

We have completed many major screening, vaccination and research programmes in New Zealand, the Pacific Islands and Vietnam during our history, which began with a 1984 Kawerau Seroprevalance Study run by a team including one of our clinicians, Dr Chris Moyes. The study saw 93 percent of Kawerau's population tested for hepatitis B and led to NZ launching the world's first national universal vaccination programme for children nine years later. This programme has saved thousands of lives through prevention of new CHB cases and is the most cost-effective intervention NZ's health system has ever introduced.

We continue to promote the need for screening in the high-risk adult Māori, Pacific and Asian communities and have monitored more than 30,000 people, making our programme the largest of its kind in the world.

We have a team of experienced community nurses who ensure patients receive high-quality information about living with viral hepatitis. We also deliver community-based fibroscan services and offer free support through clinical trials, research and awareness-raising initiatives such as World Hepatitis Day.

We promote positive health outcomes to New Zealanders through education and research into viral hepatitis and early detection and long-term monitoring of chronic hepatitis B.



150,000 people in New Zealand are living with hepatitis B and C.

All New Zealanders living with chronic hepatitis B will benefit from participating in our community-based programme.

CHAIRPERSON'S REPORT

DR WILLIAM RAINGER



I stepped into the role of chairperson of the Hepatitis Foundation of New Zealand in March 2020. The organisation works closely with medical professionals and other health organisations to reduce the incidence of hepatitis B and help the thousands of New Zealanders with the virus manage their condition.

An estimated 240 million people worldwide have HBV, with high rates in the Asia-Pacific and sub-Saharan regions. Hepatitis B is an important global health burden with significant morbidity and mortality. Up to 40 percent of people living with the virus will develop CHB with a lifelong risk of liver-related complications of cirrhosis, liver failure and HCC.

Chronic hepatitis causes more than one million deaths each year. It remains the leading indication for liver transplantation in most countries within the Asia-Pacific, including NZ. This accounts for more than 50 percent of HCC cases globally and up to 80 percent in regions with high rates.

Chronic hepatitis B is a recognised global health priority. In 2016 the World Health Organisation (WHO) adopted the first global hepatitis strategy to eliminate viral hepatitis as a public health threat by 2030. New Zealand is one of the 196 member countries to adopt the WHO strategy. The Hepatitis Foundation has developed a draft hepatitis B plan to support a national strategic approach and help determine the number of people with the virus in NZ, and to characterise the patients recruited into our programme to inform on unmet needs in New Zealanders living with hepatitis B.

As well as delivering services and supporting those with hepatitis B, we work closely with research organisations and clinical trial units. Hepatitis B treatments are going through clinical trials and we hope a cure will be available within five years.

In 2018, an estimated 93,604 New Zealanders had CHB, representing nearly two percent of the population. The numbers of patients estimated to be living with CHB varies across NZ, with more than half (51 percent living in or around Auckland).

Viral hepatitis is highly represented in Māori and Pacific Islanders, making indigenous hepatitis B important for NZ. Social determinants of health play an important role in the health outcomes of individuals and groups, particularly for Māori and Pacific Island people, who are more likely to live in deprived areas and have higher mortality rates across all age groups. Reducing social inequalities in the health of New Zealanders remains an important challenge.

A big thanks to HFNZ trustees and staff for their continued commitment to supporting New Zealanders living with viral hepatitis.

William Rainger
CHAIR

Liver health research shows 27 percent of our patients live in NZ's most deprived areas. More than half (51 percent) live in the Auckland region.

CEO'S REPORT

SUSAN HAY



COVID-19 hit countless organisations across the world hard in 2020. The Hepatitis Foundation was no exception.

Our office was closed from late March to mid-May, 2020, and our services were reduced, but we continued to keep our patients top of mind and deliver as much care and support for New Zealanders with hepatitis B as possible. Our helpline and Hepatitis Foundation email address were still manned, and our nurses and clinicians were fully available to offer advice.

We are internationally recognised as a leading provider of healthcare for people living with CHB. All our work aims to help our patients enjoy improved quality of life. We are committed to further reducing the devastating consequences of CHB and improving the lives of people with the virus. We are continuously refining how we engage with our patients and with NZ healthcare professionals, and we strive to keep up with best-practice digital technology so we can offer the most efficient service and support possible.

During the past year we focused on encouraging patients to receive blood test forms and results by email, saving postage and making the process more secure for them. Our nurses began offering virtual consultations as a result of COVID-19 and we encouraged our patients to take up opportunities to attend these, as well as making use of e-laboratory requests.

EDUCATION AND TRAINING

We believe in continuing to invest in hepatitis education. Training is one of the most strategic steps we can take to stop people suffering from advanced liver disease and dying from liver cancer. As part of our work in this area we launched a series of online education videos aimed at helping healthcare professionals stay informed and keep up with best practice. The videos are on our website and social media channels and have been well received.

WORKING TOWARDS A CURE

We partner with international research organisations in ground-breaking research to identify early predictors of liver cancer and other complications, including cirrhosis and liver failure. Through this research we hope to help reduce the devastating health burden associated with hepatitis B. We also support clinical trial units around NZ to help develop a cure for hepatitis B.

STRATEGY

Chronic hepatitis B is a recognised global health priority. We have developed a draft hepatitis B plan to support a national strategic approach toward meeting WHO elimination targets. Higher levels of deprivation are associated with increased rates of many diseases and higher mortality rates. Reducing social inequalities in the health of New Zealanders remains an important ongoing challenge.

CLINICIANS' REPORT

DR CHRIS MOYES AND DR ALEX LAMPEN-SMITH



This has proved to be a unique year for all New Zealanders, especially those working in healthcare. The COVID-19 pandemic has affected the delivery of our community monitoring programme in several ways. Firstly, our community nurses couldn't conduct home visits for delivery of patient education or assistance with phlebotomy. Secondly, patients were encouraged not to participate in unnecessary activities during lockdown. Visits to pathology labs for routine monitoring of long-term medical conditions fell into this category.

Thirdly, when we did need blood tests, the National Microbiology Forum placed a restriction on hepatitis B viral load tests as these use the same machine and/or reagents as the COVID-19 test. Hepatitis B educational sessions for primary care had been planned for various venues around the North Island and these unfortunately had to be cancelled.

Health and safety of our nursing and administrative staff took priority, with our CEO and nurse manager taking the lead on rapid development of policies to ensure the continued safe work of our team. Our community nurses are already familiar with working remotely and working from home, but our administrative team in Whakatāne also had to adapt to the new work environment. Thankfully these restrictions have eased at this time.

Many of our nursing staff took the opportunity to make phone contact with patients overdue for follow-up. We have seen increased numbers of patients come forward for blood testing since lockdown ended. From June 1 to August 31, 2020 we received 4222 blood test results. This compares to 1217 for the same period in 2019.

Promotion of hepatitis B to primary care professionals continues to be a focus. The release of the recent paper by Prof Ed Gane and others, including our clinical staff, about the unmet need of hepatitis B in NZ highlights a huge concern for us. We have been proud to be a part of that research. The full article can be viewed [here](#). Its publication coincided with World Hepatitis Day and we actively promoted both events through print, digital and social media.

With the removal of Pharmac Special Authority requirements for entecavir and tenofovir in 2018, non-specialist doctors have been able to initiate anti-viral therapy in the community. However many hepatology specialists around the country have not promoted this, to avoid confusing the messaging around hepatitis C testing and treatment in the community. Maviret has been available and widely advertised for the community treatment of non-cirrhotic hepatitis C for more than a year. If approached by primary care representatives about hepatitis C, we continue to refer patients to GPs for treatment, or to other agencies as needed. However we now need to step up our education for GPs regarding the management of CHB.

Given this virus' more complex nature, it requires a more nuanced approach. We are proud that our clinicians have been accepted to present about the management of CHB at the 2021 Rotorua GP Continuing Medical Education Conference.

Some statistics on care provided by our specialists over the past 12 months:

- 430** HFNZ clinician to reviews
- 549** HFNZ nurse triage queries
- 66** patients seen face to face for annual review
- 197** referrals to specialists
- 577** referrals to ultrasounds

We would like to acknowledge and appreciate the untiring efforts of administration and field nursing staff. They are the essential cogs in the organisation and their willingness to go the extra mile ensures a smooth monitoring process that is in the best interests of our patients.

NURSING ACTIVITY

KELLY HAYES, OPERATIONS MANAGER



Our nursing team plays a key role in ensuring clinical care and support is delivered at the highest level possible.

Our seven nurses work in the community, caring for people with hepatitis B patients around NZ. They help monitor and support patients by ensuring patients know why it's so important to have their six-monthly blood tests and fibroscans (liver ultrasounds) if required. The nurses link patients with our clinicians if needed, and provide education, blood testing and fibroscan services.

To ensure people understand information given to them about their condition and the importance of regular blood tests, they need adequate time during initial consultations with nurses. Our nurses strive to provide all this information in a language and manner people can understand. We produce a range of hepatitis resources to help with this. These resources have been found to work well. Our nurses encourage patients' family members to attend these initial consultations to help patients feel more comfortable and supported when receiving new information.

Unfortunately, patients still face stigma and discrimination because of their hepatitis B. Over the past year, one of our nurses has helped someone who faced discrimination by their employer and threats of dismissal. The nurse advocated for and supported this person and, thanks to her input and determination, the patient is now working again within their organisation with no further discrimination issues.

Our nurses work hard to help improve quality of life for people with hepatitis B and those who may be at risk of the virus without knowing it. Over the past year we have increasingly focused on reaching at-risk population groups such as Māori, Pacific and Asian people. Our nurses have worked closely with GP practices and Māori healthcare providers to find patients with a high risk of contracting hepatitis B or who need to re-engage with our services because they're overdue for blood tests

and they've attended cultural networking group events, festivals and community health days set up by the various DHBs.

Over the past year the nursing team has also focused on building awareness with other healthcare groups, to let them know about our organisation and the services we provide. They have strengthened relationships with various stakeholders to encourage working together to benefit patients. In the year from July 1, 2019 - June 30, 2020, our nurses engaged with 200 organisations and healthcare providers, such as Salvation Army Drug and Alcohol Centres, the Police College, sexual health and prison clinical teams, probation teams in the lower North Island, midwives, public health organisations, marae clinics, youth services and mental health services.

Educating community groups and healthcare professionals has helped us form relationships, increase knowledge and link patients to our organisation for more help, care and support.

Our nurses were actively involved in many national and international conferences in 2019. They managed stands at the Rotorua GP, NZ Gastroenterology Society and Sexual Health conferences and attended the Australasian Hepatology Association nurses conference. They also presented at our viral hepatitis conference in October 2019, sharing their knowledge with other nurses from various health services.

There have been 30,657 people enrolled in our hepatitis B programme.

LIVER HEALTH NURSING: A DAY IN THE LIFE

BECKY LEONG, AUCKLAND COMMUNITY NURSE



I believe everyone desires good health, and that everyone has their own perspective of what it means to them. However sometimes good health isn't a priority due to people's busy lives, commitments and responsibilities.

Literacy is crucial in decision-making; our choices are the key to good health, and what we base our decisions on determines the outcome. Every decision people make involves weighing up pros and cons.

I make it my mission to engage with my patients and discuss choices that will help them enjoy good health. Making fundamental lifestyle changes can be difficult, but it's easier with motivation, commitment and an understanding of the reasons for them. Hepatitis B can be a daunting diagnosis for many people and this patient-nurse engagement can help them realise control is still in their hands.

A typical day for me involves meeting with my patients, through home visits, online or over the phone, to provide support and encouragement to empower them to manage their own health. Home visits are sometimes more suitable, some people need visual aids and a face-to-face discussion to fully understand their condition. Hepatitis community nurse consultations focus on education; they are a chance to increase people's health literacy, breaking down the barriers to accessing healthcare.

Throughout my career I have seen many people make better choices about managing their hepatitis B after they've gained good health literacy

In Auckland, we understand a lot of people are busy, so providing effective nursing care means we need to be flexible with our patients to help them enjoy improved lifestyles. In some cases, involving families in developing a health management plan brings additional understanding and support, which increases the chances of the patient keeping up with their good choices.

My work also involves engaging with specialists, family doctors and other healthcare services to promote understanding of hepatitis B. We work collaboratively to attend to patients' needs and analyse abnormal blood test results to provide the right monitoring services. Every day I have a list of abnormal blood test results to triage. I take this opportunity to engage with my patients to explain what the results mean, and work with them to come up with a plan for lifestyle changes.

There are still thousands of New Zealanders with hepatitis B who can benefit from our service. Our organisation works hard to raise awareness in our communities and start conversations about hepatitis B. I'd like to see the virus receive the increased attention it deserves.

People with hepatitis B can and do live normal lives, and I'd also like to see this recognised. There is plenty of work to do and I believe enhancing patient health literacy is the first step towards improved lifestyles.



COMMUNICATIONS ACTIVITY

JUSTINE MCLEARY, COMMUNICATIONS MANAGER



DIGITAL STRATEGY AND SOCIAL MEDIA

Digital communications are increasingly important and we continue to grow our online engagement initiatives to educate people about hepatitis. In 2019 we launched a new-look website that is more user-friendly for our patients and offers better functionality and resources for health professionals and communities.

REPUTATION MANAGEMENT

We were the focus of some negative media coverage from late 2019 to early 2020 but this has not impacted our patients or distracted us from our purpose; we continue to focus on supporting New Zealanders living with hepatitis B and on working with healthcare professionals to provide a wrap-around service.

EVENTS AND PROMOTIONS

- National viral hepatitis conference. We held a successful conference in Whakatāne in October 2019, which brought primary care nurses from around New Zealand together to upskill and learn about the recent developments in the management and cure of viral hepatitis.
- Chinese New Year Festival. Three of our nurses attended this annual Auckland event in January 2020 to engage with Chinese populations and raise awareness about liver health.
- July 28 saw us celebrate World Hepatitis Day with increased awareness of the virus and the need to get tested for it.

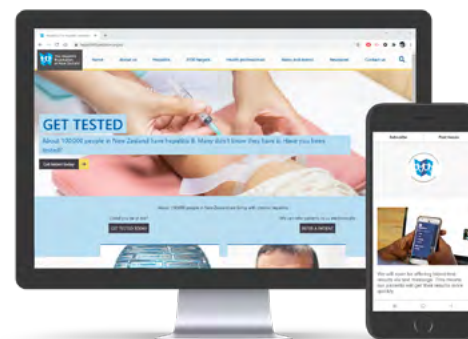
We also planned to participate in many other community-based events that were unfortunately postponed due to COVID-19.

COMMUNICATIONS AND ENGAGEMENT

- Regular e-newsletters
- Flyers
- Support for health partner events
- Patient education and incentives

PUBLIC RELATIONS

We have worked hard to increase awareness of hepatitis B, with features appearing in NZ Doctor and Pharmacy Guild magazines, the Asian Network Incorporated newsletters, the GP Pulse website and various other print, digital and broadcast outlets throughout the year.



HIGHLIGHTS



WHAT ELSE HAVE WE BEEN DOING?

From July 1, 2019 to June 30, 2020:



WE'VE SENT
12,639
BLOOD TEST FORMS



707
PEOPLE HAVE BEEN
REFERRED TO US

23,223
LETTERS
HAVE
BEEN SENT



10,828

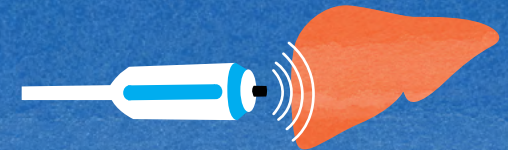
ADMINISTRATION
ENQUIRIES AND CHANGES
HAVE BEEN MADE TO
PATIENT RECORDS



OUR CLINICIANS
HAVE REVIEWED
336
PATIENT CASES



ABOUT
6900
CALLS HAVE COME
THROUGH OUR
HELPLINE



OUR NURSES
HAVE CONDUCTED
332
FIBROSCANS

LIVED EXPERIENCE

A HEPATITIS B PATIENT

Life has been a struggle for Thomas* over the past year.

In March 2020 the 41-year-old fencing contractor caught COVID-19, thanks to contact with someone from one of New Zealand's main clusters. He first noticed symptoms about March 19, but put them down to an existing ear infection. Within two days he was bedridden. "I lost my sense of taste, my sense of smell."

Trips to the toilet, Thomas says, tired him out so much he could do nothing but sleep afterwards. There were headaches too, making him feel as though someone was stabbing him in the head, and a weird smell that reminded him of a hospital. He lost 14kg in 14 days and antibiotics made no difference. "I needed to lose a bit of weight but that wasn't a healthy way to do it."

By the time he was eventually tested on March 28 and diagnosed, he was on the road to recovery, but it was a scary time. To the people who have suggested COVID-19 is simply a bad case of flu, Thomas has this to say: it's not. "This thing hit me pretty hard."

Luckily, he says, no one in his household – including his young grandson- became infected.

The effects haven't been just physical: COVID-19 has also affected Thomas's attitude to his work. "I know I'm better but I'm hesitant to go back. I have a couple of elderly clients and I'm anxious about it. There may be symptoms, I don't know."

Thomas was born with hepatitis B and diagnosed in 2010. Could this have aggravated the symptoms? "Possibly," he admits. "Everyone I've spoken to (who's

had COVID-19) sailed through it more easily than I did. I've noticed in the past few years I get sick more easily than everyone else and I put that down to hepatitis."

Thomas's liver condition was picked up during a regular check-up. It was, understandably, a shock. "I didn't know much about it," he says. He's since learned to manage it by having regular blood tests and eating properly. "I don't really drink, don't smoke. I only eat meat every few days."

He also makes a lot of vegetable juices to boost his immune system. "I've always liked veges." He stays fit, exercising at home on a treadmill, and his physical work helps. It's a far cry from his pre-hepatitis days. "I was pretty bad back then, eating pies before work," he chuckles down the phone.

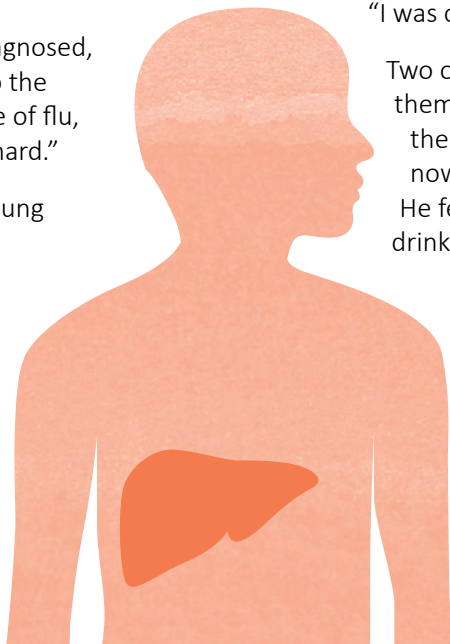
"I was over-indulging."

Two of Thomas's three brothers also have hepatitis B and it's them, he says, who keep him motivated to stay healthy. "One of them is a talented musician but he can't do any of that work now. He can't sign his name, can't eat with a knife and fork. He feels like an animal, and he's a solo dad with six kids, so he drinks to cope."

"He's the reason I look after myself. I take extra precautions."

It's not an easy life. Thomas is open about that. But he tries to look on the bright side. "You've got to carry on. As long as you're looking after yourself that's all you can do. There's not much else you can do except stay positive."

** Name has been changed for confidentiality reasons.*



The Hepatitis Foundation of New Zealand will continue to look to the future on how to improve the lives of people living with hepatitis B. We are committed to further reducing the devastating consequences of chronic hepatitis B.

Help, care and support for all

www.hepatitisfoundation.org.nz

Find us on Facebook and YouTube.



Hepatitis helpline
0800 33 20 10

Give us a call, we're
here to help.

Our helpline is a free, confidential service that provides general advice, information and guidance about hepatitis B, diagnosis, treatment and ongoing care. It is linked with a number of other agencies, and staff can point you in the right direction if you need support or advice regarding issues unrelated to hepatitis B.



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