

Hepatitis B Free Annual Report

2017-2018



Hepatitis B Free

B Free B Aware B Well



**WORKING TOGETHER
TOWARDS A WORLD
FREE OF HEPATITIS B**

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Contents

Who we are.....	3
Year in Review.....	6
Highlights	7
Australia.....	8
Democratic Peoples’ Republic of Korea	8
Kiribati	10
Myanmar	12
Papua New Guinea	13
What is hepatitis B?.....	15

This Annual Report is for the period of July 2017 – June 2018.

Authorised by the Directors of Hepatitis B Free

Financial Report available separately.

Who we are

Our History

Hepatitis B Free is an Australian registered tax-concession, not-for-profit charity. We are run by a group of passionate volunteers mostly based in Sydney, Australia who want to give back and make a difference. Our volunteers come from diverse backgrounds and professions, including doctors, nurses, allied health, lawyers, and students.

Hepatitis B Free was founded in 2013 by five Australian doctors and nurses. The team was led by Associate Professor Alice Lee, a gastroenterologist and hepatologist with expertise in viral hepatitis and Sue Huntley, a clinical researcher with a background in nursing and project management. Galvanised by their experience in remote Papua New Guinea, where they travelled on foot to vaccinate and provide basic health clinics for tribal villages, they decided to continue taking action towards addressing the huge unaddressed need of hepatitis B in resource-poor areas.



VISION, MISSION & VALUES

VISION

A world free of hepatitis

MISSION

To educate, improve access to care, provide hope, and advocate for people and communities affected by hepatitis

VALUES

- **Equity:** we believe that healthcare is a human right.
- **Respect:** we pledge to have the utmost regard for the feelings, wishes, rights and traditions of all people we serve. We strive to provide compassionate care through culturally sensitive programs.
- **Partnership:** we work cooperatively with our supporters, local health workers, patients, families, communities, and governmental and non-governmental organisations.

- **Education:** we empower health workers with knowledge and skills, promote health awareness within communities, and identify local champions who can advocate for hepatitis education, prevention and treatment.
- **Evidence:** we follow current international and local guidelines when delivering hepatitis services such as vaccination, testing and treatment.
- **Sustainability:** we design programs to be economically viable and plan to hand them over to local health workers, so our projects have long-lasting impact. We work hard to stretch every dollar as far as possible by minimizing costs and using 100% of public donations towards our programs.
- **Transparency:** we strive to openly disseminate information about each of our activities to our volunteers, donors and the general public.

Year in Review

The end of 2018 marks five years since we started Hepatitis B Free. The scope of work has grown substantially from hepatitis B vaccination in rural Papua New Guinea, to treatment projects for hepatitis B, and in the last 12 months, hepatitis C. Preventing hepatitis infection will always remain a core part of our mission but treatment is essential to helping the vast majority of people who are at risk of serious liver disease and death due to chronic hepatitis. Locally in Australia we are continuing to engage with migrant communities, attending community fairs and providing education and free point-of-care testing for hepatitis B.

The HOPE program, first piloted in North Korea, has become a model used in other countries to make treatment accessible for those without it. Collaboration is a fundamental part of this program. On World Hepatitis Day in 2017, we signed a Memorandum of Understanding with our long-standing partners in Papua New Guinea to start developing a program to treat hepatitis B patients in the Oro Province. This is a public-private partnership between Hepatitis B Free, New Britain Palm Oil, Popondetta General Hospital, and Oro Provincial Health. Public-private partnerships as a model of healthcare delivery have been emerging worldwide as we are faced with the challenge of making healthcare accessible in difficult or resource-limited settings. Each party has a role to play, including medical and logistical issues.

In 2017 we began hepatitis C treatment in Myanmar, in partnership with two local NGOs Medical Action Myanmar and Myanmar Liver Foundation. In countries where there are a limited number of liver specialists to treat hepatitis, an important part of the program is linking general physicians to specialists both in-country and internationally who they can contact for training and advice about complex cases.

Throughout 2017 and early 2018, we have been travelling to Kiribati, a beautiful Pacific Island nation, to build relationships and lay down the steps for hepatitis B treatment. This is a unique country with very high rates of hepatitis B, and another virus hepatitis D that occurs concurrently, as well as other significant challenges such as geographic remoteness across the many islands and high rates of metabolic disease such as obesity and diabetes. Over this past 12 months, we have started preparing patients for treatment, including performing FibroScans (non-invasive assessments of liver scarring), and in early 2018 commenced the first group of patients on antiviral therapy.

The Asia Pacific Region has one of the highest rates of hepatitis B and C in the world. Many countries with high rates of viral hepatitis are low to middle income countries with limited development and infrastructure. Addressing this challenge in our local region will take continued effort, advocacy with health officials and policymakers, education in the general community and with health professionals, and expanded access to diagnostic and treatment services. We are excited to continue working in this space and to share this progress with our community of volunteers, donors, and partners and are extremely grateful for all of the support that allows this to happen.

Alice Lee & Sue Huntley
Co-Founders, Hepatitis B Free

Highlights



DPRK

Over 1200 patients on hepatitis B treatment

KIRIBATI

New hepatitis B program
70 patients started on treatment

MYANMAR

New hepatitis C program
100 patients started on treatment
20 already cured

PAPUA NEW GUINEA

Preparation underway to start hepatitis B treatment

DPRK: Democratic Peoples' Republic of Korea

Australia

Whilst the overall rate of hepatitis B in Australia is low compared to other countries globally, hepatitis B prevalence is much higher in certain populations. These include migrants from countries with endemic hepatitis B, and Aboriginal and Torres Strait Islanders. People from these communities often face other challenges in accessing health care such as lack of awareness, and language and cultural barriers.

To address this issue, Hepatitis B Free partners with Concord Repatriation General Hospital and Culturally and Linguistically Diverse (CALD) communities around Sydney to provide free education and hepatitis B testing. Our aim is to improve awareness about hepatitis B amongst this higher risk population and to encourage people who test positive to see their local general practitioner for further testing. Our volunteers attend community events throughout the year and set up stalls where they talk to people, hand out educational materials, and provide free testing. The test is a simple finger prick test which takes about 20 minutes for the result.

The Burmese community in Sydney is one community we have been working with for many years. We typically set up stalls at health fairs, temple and other events where people come together, listen to educational talks, and share cultural meals. In November 2017 we also attended a special educational and fundraising event which starred famous Myanmar singer Saung Oo Hlaing.

Other events attended in 2017-2018 included testing days for the Chinese and Korean communities along with an educational stall at a Harmony Day event hosted by the Great Lakes Agency for Peace and Development International and Bayside Council Multicultural Fair.

Democratic Peoples' Republic of Korea



DPRK

Population 25.5 million

Dr Alice Lee (Director) training local physicians in Raesong

It has been almost three years since we started our first cohort of patients on therapy for hepatitis B. Now there are over 1200 patients on treatment and volunteer teams have been returning four times each year.

About the HOPE Program

The hepatitis program is called HOPE - Hepatitis B Overview and Program to trEat. It is a structured program that aims to provide antiviral therapy for chronic hepatitis B patients in the DPRK in partnership with international NGOs, the Ministry of Public Health, and local physicians. The first treatment sites were in Pyongyang #2 (Hepatitis) prevention Hospital and Kaesong #2 (Hepatitis) Prevention Hospital, a rural town a few hours drive from the capital Pyongyang.

Treatment

Patients are reviewed in each of the clinics and assessed for suitability for treatment. There is a great deal of trust for us and our program with relationships strengthened on each visit. We continue to be supported by generous donations of medicines that find their way into country despite the significant challenges and increasing needs. We continue to identify other significant needs, such as nutrition and cancer diagnosis and treatment, and are working towards addressing these gaps.

The hepatitis clinics in Pyongyang and Kaesong are now well-established. For the first time we saw patients in a third clinic in Haeju. Electricity supply for the clinic was provided by a portable generator, and the water for the hospital was sourced from a single pump previously donated by CFK. The hospital laboratory contains only basic equipment such as test tubes and pipettes. Plans are currently underway to construct a new building for the hospital, including a well-equipped laboratory.

Challenges

The progress of the program over a relatively short time has been very encouraging. However there are many ongoing challenges, both logistical, such as limited infrastructure, and political, with the travel ban on American citizens and delays in visa approvals creating uncertainty around trips until even a few days before departure.

The hepatitis C virus (HCV), like hepatitis B, is transmitted through blood and body fluids, and is another major cause of chronic liver disease. All patients on the DPRK HOPE program are tested for HCV, and around 50 patients have so far been found to be positive for HCV, or co-infected with both HBV and HCV. Many of these patients are very unwell due to liver failure.

In most cases, chronic hepatitis C can be cured with 12-24 weeks of treatment. However, these medications are expensive and current international treatment guidelines recommend a diagnostic test that is not currently available in the DPRK. We are working to make treatment for HCV available in DPRK and to source medications to treat these patients.

Despite this, HOPE DPRK remains a great source of joy for many, bringing healing and a real sense of change for those who are afflicted by these diseases as well as their families. We remain ambitious in our plans to expand, not only in numbers of patients seen and treated, adding clinics in extra sites, but also in adding complex services including diagnostics. Ongoing efforts to find creative solutions for otherwise impossible situations have not stopped us before and we will continue to work hard.

Kiribati



KIRIBATI

Population 116,000

Capital Tarawa

Hepatitis B rates 15-20%

In November 2017, an exciting new project began in Kiribati, a beautiful island nation in the Pacific Ocean. Its capital, Tarawa, lies roughly halfway between Australia and Hawaii. Due to its very remote location and limited development, Kiribati mostly relies on foreign aid as well as revenue from tourism and fishing. Rising sea levels are also presenting a serious threat to this island nation. Its geographic remoteness - with 33 islands that span 3000 kilometres across the Pacific Ocean - makes access to medical care extremely difficult. Although healthcare is free for people in Kiribati, there is a shortage of healthcare workers: one doctor may be caring for up to 100 people each day. The hospital infrastructure is limited and few tests are available.

Hepatitis B is endemic in Kiribati, with an estimated 15-20% of adults suffering from chronic hepatitis B infection. (According to the World Health Organisation, rates above 8% are considered high.) Most infections are caused by transmission from mother to child during birth or during early childhood. There

is a vaccination program for hepatitis B, however problems such as a lack of refrigerators to store vaccines limit its effectiveness. Prior to 2017, there has been no access to life-saving antiviral therapy in Kiribati. Many people infected with hepatitis B are treated for their symptoms but not the underlying disease, and often resort to herbal remedies which do not help treat the disease.

Hepatitis B treatment in Kiribati

Hepatitis B Free, together with the Victorian Infectious Diseases Reference Laboratory and the World Health Organisation (Western Pacific Region), and Kiribati's local doctors and healthcare workers, began a program to provide chronic hepatitis B patients with antiviral treatment.

The first batches of antiviral therapy arrived in Kiribati in March 2018, and the first patients were started on treatment. Two months later, volunteers from Hepatitis B Free travelled to Kiribati to perform FibroScans (a non-invasive test of liver scarring) for 215 patients. As of June 2018, 70 patients were receiving antiviral therapy, and this number has continued to grow.

A key part of the program is ongoing training and education of local health workers. Since 2017 the team has been travelling to Kiribati four times per year. Each month, Dr Alice Lee and Dr David Hilmers provide online training via Zoom teleconferences for the physicians in Kiribati. This is an opportunity to talk about how to manage hepatitis B as well as to troubleshoot complex patient cases seen by the local doctors. In between these training sessions, they remain in regular contact via Whatsapp and email.

Challenges

In addition to the challenges of geographic remoteness and limited infrastructure, other issues faced in this program include medical record systems, staffing and medication dispensing.

Myanmar

**MYANMAR
(BURMA)**

POPULATION 53 MILLION
HEPATITIS C RATES 2.65%



Myanmar is a South-east Asian nation bordered by China, India, Bangladesh, Laos and Thailand. Hepatitis B and C are significant public health issues in Myanmar and the prevalence of hepatitis C virus (HCV) is estimated to be 2.65%. Many people living with HCV are undiagnosed and untreated. Additionally, HCV infection often goes hand in hand with hepatitis B and/or HIV infection. In the past, HCV treatment was long, caused many side effects and had limited cure rates. However, new direct acting antiviral (DAA) drugs offer cure rates as high as 95%, and can be taken orally with very few side effects. HCV treatment is provided free of charge through the National Hepatitis Control Program, however access remains limited due to quotas on the number of people who can be treated at present.

In 2017, Hepatitis B Free commenced a new project to treat 100 people with HCV infection and 100 people with HCV/HIV coinfection with DAA medications (sofosbuvir and daclatasvir). This project is in partnership with two leading health NGOs in Myanmar: Medical Action Myanmar (MAM), and Myanmar Liver Foundation. The program treats patients according to National Myanmar Hepatitis C treatment guidelines with medications that have been donated for the program.

A team of local and international specialists provide support for the physicians treating patients on the ground in Myanmar. Hepatitis B Free volunteers travelled to Myanmar clinics to deliver in-person training on hepatitis treatment and FibroScan assessments at the start of the program. Training is provided on a monthly basis by Dr Alice Lee via Zoom teleconference, and until the end of 2018, Dr Ed Wilkins (HIV specialist based in the UK) was in-country to assist with reviewing challenging cases. This expert specialist team is in regular contact with local doctors via Whatsapp and email.

As of June 2018, over 100 patients were receiving HCV treatment and 20 patients have already successfully been cured.

Papua New Guinea



PAPUA NEW GUINEA

Population 8.3 million
Hepatitis B rates 15%

Sue Huntley (Director) with WHO Officers meeting the First Lady of Papua New Guinea

Papua New Guinea is one of the most culturally, biologically and linguistically diverse nations in the world, with over 800 languages spoken. With over 80% of the population living in remote areas, there are immense challenges to accessing healthcare, including geographic remoteness, limited infrastructure and few health professionals. Hepatitis B is a huge issue in PNG, like other Pacific Islands. Due to limited testing and virtually no available treatment, it is common for medical wards in the hospitals to be full of people suffering from severe liver disease. One of these complications, known as ascites, is so common that it is locally referred to as “big belly”. Unfortunately, once liver disease reaches this stage it is often very difficult to manage and can lead to significant suffering and death.

PNG is our oldest-running project to date. We have been working in the Oro Province since 2013 in both remote villages as well as the provincial capital of Popondetta. In this time, we have expanded from running immunisation and medical outreach clinics in villages around Itokama, to supporting the health services operated by the company NBPOL which provides healthcare for its 20,000 employees and their families. Collaborating with NBPOL has allowed us to provide training for their community health workers, send regular shipments of medical supplies, and promote hepatitis B testing and immunisation. Our volunteers travel to PNG annually to meet with local doctors, health workers, government officials, to run training sessions, and to assist with general medical clinics.

Treatment

Whilst our work has focussed primarily on prevention to date, providing treatment for hepatitis B has been a goal for a number of years. On World Hepatitis Day (July 28) in 2017, Hepatitis B Free signed a landmark memorandum of understanding (MOU) with NBPOL, Popondetta General Hospital, and Oro Provincial Health. This MOU was to start a program to treat hepatitis B in Oro Province at two initial sites - Siroga, the largest clinic of NBPOL, and at Popondetta General Hospital. The model of care is very similar to the hepatitis B projects we run in other countries such as DPRK and Kiribati, with a structured protocol of testing, counselling, training for health workers, and monitoring. Working within the challenges of PNG, Dr Alice Lee and Dr David Hilmers provide monthly online training to the community health workers and doctors involved in the hepatitis B program.

Advocacy

With a complex health system and many competing public health priorities, raising awareness about hepatitis B has been a huge component of our work in PNG. Sue Huntley has travelled frequently to meet with health professionals and government officials in Port Moresby as well as in the Oro Province. There has been much support expressed for our proposals by the PNG government and other partners we have collaborated with for several years. One highlight in 2018 was when Sue met with the First Lady of Papua New Guinea, who has graciously agreed to be a spokeswoman for World Hepatitis Day!

Anecdotally, the community health workers at NBPOL have gained knowledge and are much more aware about hepatitis B testing and vaccinations. This is particularly noteworthy as they are the frontline of healthcare in PNG. Empowering local health workers to deliver better care for their community is the cornerstone of our mission.

What is hepatitis B?

Somewhere in the world, one person dies every minute from hepatitis B-related complications.

What is hepatitis B?

The hepatitis B virus (HBV) is the most common cause of liver infection in the world. It is spread via blood and certain body fluids, including through unprotected sex, sharing needles, and from mother to child at birth.

One in three people in the world have been exposed to HBV. There are 240 million people worldwide living with chronic hepatitis B. Every year around 700,000 people die from complications of hepatitis B. The highest rates are found in sub-Saharan Africa, East Asia, the Pacific Islands, and the Amazon basin of South America.

Hepatitis B infection can be acute or chronic. When the infection lasts for longer than 6 months, it becomes chronic hepatitis B. The virus can remain in the body for many years, often without any symptoms. Without treatment, chronic hepatitis B can increase the risk of liver cancer or scarring (cirrhosis).

Vaccination

Vaccination is one of the most cost-effective ways to prevent disease. The hepatitis B vaccine is safe and highly effective in providing immunity against infection.

Newborns are particularly vulnerable to hepatitis B – if they are exposed to the virus, they have >90% chance of developing lifelong infection, chronic hepatitis B. Therefore, the World Health Organization (WHO) recommends all infants should be vaccinated for hepatitis B at birth (within 24-48 hours of birth) followed by the two remaining doses in infancy. These three doses are 95% effective in preventing infection. However, birth dose vaccination is a major challenge in countries with limited access to healthcare, particularly when women give birth at home without a health care worker..

Other priority groups for vaccination include:

- Health care workers
- Household and sexual contacts of people with known hepatitis B
- Young adolescents
- Migrants from countries with high hepatitis B rates

- People who inject drugs
- Men who have sex with men
- Persons with multiple sexual partners

Testing

Testing is important because many people with hepatitis B infection do not experience noticeable symptoms. A blood sample tested in a laboratory is the gold standard to determine whether a person has been infected with the hepatitis B virus.

There are a range of tests that are used and these can be ordered as individual tests or a series of tests. These include:

- Hepatitis B Surface Antigen – the protein on the surface of the hepatitis B virus. A positive result means a person has hepatitis B virus in the blood.
- Hepatitis B Surface Antibody – the body normally produces antibodies (proteins that are part of the immune system) in response to infection. A positive test means that either: a person has been successfully vaccinated against hepatitis B; or they have recovered from an acute infection from hepatitis B and the body has produced an antibody.
- Hepatitis B DNA – can be used to quantify the amount of hepatitis B virus in the blood. This can assist doctors to assess if a person is at increased risk of liver damage.

In resource-limited settings, rapid point of care test kits, typically conducted via a simple finger prick, can provide results within minutes and can be beneficial in the absence of laboratory infrastructure.

Treatment

Hepatitis B is not curable, but it can be treated. Not all people with chronic hepatitis B need treatment, however all people should be monitored by a health professional who can monitor their liver function and virus levels.

Treatment with antiviral therapy medicines such as tenofovir and entecavir reduces risk of death after five years from nearly 30% to about 5% in the sickest patients. Not only is this treatment life-saving, it brings health and a future for patients and those around them. Treatment can turn a death sentence into a treatable condition.