



# Annual Report

Hepatitis B Free

*January 2016 – June 2017*



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

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## Year in Review



*Sue Huntley, Co-Director, Hepatitis B Free*

2017 was one of Hepatitis B Free's busiest years and encapsulates the spirit of what a handful of people are able to do. We celebrated milestones for a number of our local and international projects.

Our local project to raise awareness about hepatitis B and conduct screening in high-risk Australian communities has grown, thanks to invitations from new community groups. These events occurred throughout 2016 and 2017. Wonderfully, word is spreading and we have been privileged to receive invitations from communities where we have not previously had a presence, including Aboriginal, Assyrian, Iranian and Lebanese communities. We have also continued to work with events organised by the Korean, Chinese and Burmese communities. These events have been supported by volunteers from Hepatitis B Free who give up their time during the weekend and sometimes week days, and we are very grateful to all of our volunteers.

In 2017 we celebrated five years since the beginning of our project in Papua New Guinea, our closest international neighbour. We have grown our ties with communities in Popondetta and remote areas in the Oro Province. In July 2017, we formalised an agreement with local partners of New Britain Palm Oil and the Oro Provincial Health in Popondetta, allowing us to start planning a pilot hepatitis B treatment program in the region. This is a huge dream we have been working towards since starting the program in 2013.

Myanmar, also in our Asia Pacific region, has been a growing hepatitis C treatment project organised by Dr Alice Lee in collaboration with partners, Medical Action Myanmar and Myanmar Liver foundation. In 2017 we provided education for doctors, nurses and pharmacist at the participating facilities. This included sharing computer-based medical record tools developed by Hepatitis B Free; essential for ongoing management of the program. In October 2017, we celebrated the first patient to start hepatitis C treatment.

The Democratic Peoples' Republic of Korea (DPRK) is never far from our thoughts. Despite the challenges of working in country, we are as dedicated as ever to keep up our

efforts to treat patients for hepatitis B, together with our partners including Christian Friends of Korea. As of November 2017, 750 patients had started treatment. We plan to expand the program to new sites across the country.

One of my personal highlights was attending the World Hepatitis Summit in November 2017, held in San Paulo Brazil. The theme was “Eradicating Hepatitis B by 2030” and the energy and enthusiasm of all the participants was inspiring and motivating. The trip allowed me to raise the profile of Hepatitis B Free, meet likeminded people from across the world, share lessons from our projects, and form ties to work towards addressing the huge needs in our Asia Pacific region. We were invited to speak at The Burnet Institute in Melbourne to share our experiences about implementing hepatitis programs with international representatives from Myanmar, China, Egypt and the Philippines.

In November 2017, Hepatitis NSW recognised Dr Alice Lee for her contribution to raising awareness about hepatitis B in the Asia Pacific and amongst high risk migrant populations in Sydney. She was presented the Cheryl Burman Award, named in honour of the late advocate and former board member and President of Hepatitis NSW. Alice is never one to seek out the spotlight and it was wonderful to celebrate this special acknowledgement.

*Left: Alice Lee (Co-Director) receiving the Cheryl Burman Award, Hepatitis NSW*



Nothing can be achieved without the tireless efforts of our volunteer members who come and support this cause. We were thrilled to welcome new volunteers throughout 2016 and 2017 and aim to continue keeping up our presence and raise awareness in 2018.

At the end of 2017, we introduced our first paid position of an Assistant Project Manager. This is a wonderful step that allows us to oversee some of the day to day activities needed to keep our NGO going.

At times the huge needs are daunting, but we are fortunate to have the opportunity to contribute and make an impact, little by little. I am honoured, humbled and grateful to be part of this group.

## Our Impact: Highlights



### Growing our impact:

- Commenced (2016) and expanded (2017) the HOPE hepatitis B treatment program in the DPRK
- New hepatitis C treatment project developed in Myanmar during 2017

### Continuing our commitment:

- Annual medical trips to the Oro Province, Papua New Guinea
- Water tanks installed in Itokama villages, Oro Province, Papua New Guinea
- Local community testing and education events in Sydney, Australia with Korean, Chinese, Burmese, Assyrian, Iraqi and Aboriginal communities

### Project challenges:

- Need for diagnostics suitable for resource-limited settings (price, laboratory infrastructure), including hepatitis B and C tests and other blood tests
- Geopolitical climate in DPRK making travel difficult for volunteers
- Limited volunteer capacity as projects expand, with need for future growth in volunteer and staff positions

## Current Projects

### Australia

Over 200 000 people in Australia are living with chronic hepatitis B. Nearly half of these people do not know they are infected. This places them at risk of developing cirrhosis (liver scarring), liver cancer or liver failure. Many who don't know they have hepatitis B may be missing out on treatment. Furthermore, there is still a lot of stigma surrounding hepatitis B.

Whilst the overall rate of hepatitis B in Australia is low compared to other countries globally, hepatitis B rates are much higher in certain at-risk populations, including migrants from countries with high rates of hepatitis B in the Asia Pacific, the Middle East, and Africa. Aboriginal and Torres Strait Islanders also have higher rates of hepatitis B. These at-risk populations often face other challenges in accessing health care due to cultural, social and language barriers.

### **Our Impact: Community education and testing events**

Hepatitis B Free is working to raise awareness and educate the general public, particularly at-risk communities, about hepatitis B and the importance of prevention and testing. Our focus is on working together with the most affected populations in Australia, including Culturally and Linguistically Diverse (CALD) and Aboriginal communities.

We run hepatitis B testing and education events at local community and health forums with the help of our volunteers. The test is a simple finger-prick giving us a result in 20 minutes. If anyone is found to have a positive test, we refer them to health professionals for further care. We hope that getting people talking about hepatitis B will help to reduce stigma.

This is an Ethics-approved project run by Concord Repatriation General Hospital, Sydney.

### Highlights

- Hepatitis B testing events with Korean, Chinese, Burmese, Lebanese, Assyrian, Iraqi, and Aboriginal communities
- 436 people tested for hepatitis B from January 2016- June 2017 (319 in 2016, 117 in 2017)



### Democratic Peoples' Republic of Korea

Hepatitis B is a major public health problem for the 25 million people in the DPRK. Whilst antiviral therapy can effectively treat chronic hepatitis B, most people living in the DPRK do not have access to these life-saving medications. There are healthcare facilities specifically dedicated to the care of these patients known as “hepatitis hospitals”, but these can only provide Korean traditional remedies, food and rest.

### Our Impact: The HOPE Program



*“The first woman we started on treatment in Kaesong has a young toddler at home. She was diagnosed with very advanced liver disease. She and her family had been waiting for the expected sad ending...”*

*“After receiving medicine, she could not stop smiling – it was contagious... Now she has a real chance to see her daughter grow up, a chance to take her to her first day of school.”*

*Dr Alice Lee, Co-Director of Hepatitis B Free*

HOPE provides treatment to the sickest patients with chronic hepatitis B in the DPRK. This is the first time people in the DPRK have been able to receive antiviral therapy. More than a life-saving pill, we are providing hope to people with chronic hepatitis B in the DPRK - a message that we care and are committed.

Patients are screened for hepatitis B, then undergo tests to assess their liver function. Eligible patients<sup>1</sup> are then commenced on treatment (tenofovir or entecavir). Every six months, they come to clinic for a monitoring consultation and tests. At these clinics, local and international physicians see patients together, side-by-side.

Trust and commitment are essential for our work. We have been building relationships with local physicians and officials over many visits to the DPRK starting in 2015. There are immense logistical and geopolitical challenges involved in working in the DPRK, making collaboration ever more important.

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<sup>1</sup> Patients who meet the HOPE protocol criteria, based on World Health Organization (WHO) treatment and care guidelines



*Patients receiving their hepatitis B medicines*

After two years of preparation, the first patients were screened in March and May 2016, and the first 73 patients started receiving antiviral therapy in September 2016. The first six-month follow-up was held in March 2017. As of June 2017:

- 1430 patients screened for treatment
- 540 eligible patients receiving HBV antiviral therapy

**Over 800 patients currently receiving antiviral therapy\***

\*As of January 2018

### **Key facts about HOPE:**

- HOPE stands for Hepatitis B Overview and Program to trEat
- HOPE is a partnership between the DPRK Ministry of Public Health, and Christian Friends of Korea<sup>2</sup> (CFK) and Global Care Partners, and Hepatitis B Free.
- HOPE operates at two sites, as of June 2017, with plans to expand to new sites: Pyongyang (the capital) and Kaesong (a rural town 175km from Pyongyang)
- HOPE is highly structured: our protocol determines who can be treated and aligns with World Health Organization (WHO) guidelines

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<sup>2</sup> Christian Friends of Korea (CFK) is a United States 501c3 charity that has been delivering humanitarian aid to DPRK since 1995. CFK's work is mostly in the healthcare sector, including building infrastructure to supply clean water, sustainable power, and food; training local staff; and supplying advanced TB and clinical diagnostics.



- HOPE is all-encompassing: we supply medications and laboratory consumables, renovate local laboratory renovations, maintain and improve other hospital infrastructure, assess patients, and train local physicians
- HOPE is funded by external donors



*Local physicians with members of Hepatitis B Free, Christian Friends of Korea, and Global Care Partners*

## **Future Impact**

The needs of the hepatitis patients in DPRK are enormous. We will continue to make four annual visits to the DPRK to monitor and assess patients, and expand the program. The program partners have begun planning for new treatment sites in remote areas to treat more people. We are also planning to expand treatment for pregnant women, to prevent mothers from passing hepatitis B infection to their babies. In time, we plan to introduce treatment for other forms of viral hepatitis, such as hepatitis C.

The program will require increasingly complex diagnostics, and we are working with several experts and organisations to make this happen. Liver cancer and liver failure still remains virtually untreatable.

Our efforts so far only reach a fraction of the people in the DPRK with hepatitis B. However, for those whom we reach, we make a life-changing difference.

## Papua New Guinea

Papua New Guinea (PNG) is one of the most ecologically, culturally and linguistically diverse countries in the world. Over 85% of the population reside in rural areas, including remote communities with scarce infrastructure and access to health services.

Hepatitis B is endemic in PNG. Like other neighbouring Pacific Island nations, there is little published data about the prevalence of hepatitis B in PNG. It is estimated to be higher than 8%. Hepatitis B tests since 2013 in the Oro Province estimate a prevalence of 12% in this region.

### Our Impact

Since the start of this project in 2013, we have worked in the Oro Province in Ilokama and surrounding villages, Popondetta (the provincial capital) and surrounding villages, and Kokoda. We prioritise helping people in isolated regions as few in these communities can access timely health care.



Working together with local community leaders, health workers, private organisations and health authorities has been essential for the growth of this project. In particular, close partnership and logistical support from the health staff of New Britain Palm Oil Ltd has greatly facilitated our work in Popondetta and the surrounding network of health posts.

Our main project is to provide immunisations and to support health workers operating from local health posts and clinics. During our annual medical outreach trips, our clinics are attended by adults and children alike, and we see conditions ranging from skin infections, HIV and tuberculosis; to asthma, chest infections, cataracts and eye conditions, fractures and injuries.



Our volunteer doctors consult patients together with local health workers to allow skills transfer, and we also prepare training presentation for community health workers (CHWs) on their nominated topics. During 2015 and 2016, a volunteer optometrist from Hepatitis B free worked with an eye nurse at the Siroga clinic in Popondetta and in 2016 donated equipment that she has been using regularly at the clinic.

**Over 8000 patient consultations since 2013**

### *Immunisation*

As well as hepatitis B, we facilitate delivery of tetanus, measles mumps and rubella (MMR) vaccines, and a combined vaccine for diphtheria, tetanus, pertussis, hepatitis B and haemophilus influenzae type B (pentavalent). All immunisations have been in accordance with the national immunisation policy, in partnership with the local health care sector.

### **Over 7000 vaccinations provided since 2013**

### *Water tanks*

In 2016, Hepatitis B Free organised the provision of four rainwater tanks for the remote Barai villages. Before this, local residents had to walk down a steep hill to the river, and carry the water for substantial distances to their dwellings.

The tanks were installed in July 2016, when a Hepatitis B Free medical team returned to the Oro Province. Arrangements were made with a builder who was visiting the area to show the locals how to construct the tanks. Local men volunteered to install the tanks and were shown how to assemble the materials.

The water tanks are located in the villages of Itokama, Tahama and Naokanane Elementary School, each tank sits beside a local community building. These villages and sites were nominated by the leaders and elders of the Barai tribe as ideal sites for the entire village to access.

We gratefully acknowledge Rotary International who assisted with fundraising for the costs of equipment and transport.



*Photos by the Redeemer Baptist Church team*

## Myanmar

Access to affordable healthcare is difficult for most of the 50 million people living in Myanmar. High costs make hepatitis B vaccinations and treatment unaffordable for most people in the private sector, particularly for people in remote areas and those from lower socioeconomic backgrounds.

There are approximately 3.3 million people living with hepatitis B, a national prevalence of 6.5% according to a 2015 nationwide survey by the Ministry of Health. A national HBV vaccination program has covered 75% of Myanmar. Prevention of mother to child transmission of HBV is challenging, especially given the limited antenatal care available in most areas.



*Hepatitis B Free volunteers helping to vaccinate people at the Mingalar Parahita Monastery & Orphanage (January 2016)*

## Our Impact

We are working to address gaps in vaccination, treatment and care services for hepatitis B with local health authorities and non-government organisations Myanmar Liver Foundation (MLF)<sup>3</sup> and Medical Action Myanmar (MAM)<sup>4</sup>.

Our project in Myanmar began by working with MLF to immunise children at the Mingalar Parahita Monastery & Orphanage in January 2016. It has since expanded to a comprehensive hepatitis C treatment program run by Hepatitis B Free, MLF and MAM. Like the HOPE project in the DPRK, this treatment program is based on a structured protocol developed by all the partners, in line with

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<sup>3</sup> Myanmar Liver Foundation (MLF) is the largest organisation in Myanmar working with the Ministry of Health to promote education about hepatitis B and C and prevent transmission. They also offer point of care testing of hepatitis B surface antigen and provide vaccinations around the country.

<sup>4</sup> Medical Action Myanmar (MAM) is a medical aid organization, whose mission it is to improve access to quality health care for the poorest of Myanmar people. They focus on the most vulnerable people in very remote areas and in urban slums, where most people cannot afford to pay for adequate health care services.

national guidelines and with local ethics approval. Training for local health professionals is provided by volunteers from Hepatitis B Free and MLF.

2016

- Volunteer medical trip in January 2016
- 881 children vaccinated and 922 tested for hepatitis B (41 positive) at the Mingalar Parahita Monastery & Orphanage

2017

- 231 workers vaccinated and 243 tested for hepatitis B (12 positive) at the Diamond Dragon Factory, Yangon in February 2017
- In February 2017, Hepatitis B Free conducted site visits at MLF and MAM. A FibroScan was donated to the MLF Than Sitt Charity clinic to assess patients for the hepatitis C treatment program. Training was provided for health professionals at MLF and MAM by Dr Alice Lee and Dr David Hilmers, Hepatitis B Free.
- In October 2017, the first patients started receiving hepatitis C treatment
- In January 2018, 80 patients were receiving hepatitis C treatment



*Members of Myanmar Liver Foundation (MLF), Medical Action Myanmar and Hepatitis B Free attending a training session at the Than Sitt Charity Clinic, named in memory after the late Professor Than Sitt, founder of MLF (February 2017)*

## Financial Report

The reporting period for this Annual Report (January 2016 – June 2017) bridges two financial years. Future annual reports will describe activities during the course of a financial year in order to align activities with financial reporting periods.

A full financial report is available separate to this annual report.

### Summary

As shown in Table 1, close to all expenses are invested in international projects (including equipment, infrastructural support and healthcare worker training). Most income is sourced from donations, with the exception of fundraising events held every two years (\*2016 Charity Ball) and a grant received in 2017.

*Table 1: Financial summary for 2016-2017 (by financial year)*

	<b>2017 FY</b>	<b>2016 FY</b>
<b>INCOME</b>		
Donations	73 578	67 505
Fundraising	0	20 922*
Grants	20 000	0
Interest	427	1327
<b>Total income</b>	<b>94 005</b>	<b>89 753</b>
<b>EXPENSES</b>		
International projects	30 768	71 567
Program administration costs	2026	1918
Fundraising	0	4915*
Bank charges	15	19
<b>Total expenses</b>	<b>32 809</b>	<b>78 419</b>
<b>Profit for year</b>	<b>61 196</b>	<b>11 334</b>
<b>Balance at EOFY</b>	<b>123 152</b>	<b>61 956</b>

\*Values refer to HBF Charity Ball, generating net fundraising income of \$16,007

## Thank you

### **Board (2016)**

Associate Professor Alice Lee, *Co-Director*  
Sue Huntley, *Co-Director*  
Dr Liz Walsh, *Chief Medical Officer*

### **Committee**

Magdalena Budzinska, *Medical records*  
Jessica Cheng, *Youth & Publicity Officer*  
Dr Joseph Chung, *Medical Officer*  
Fiona Doukas, *Pharmacist*  
Professor David Hilmers, *Medical Officer*  
Melissa Kermeen, *Secretary*  
Dr Robyn Laube, *Medical/Education Officer*  
Carrie Lee, *Youth & Publicity Officer*  
Peter McGhee, *Legal Counsel*  
David Ng, *Student Volunteer*  
Dr Calvin Park, *Medical/Education Officer*  
Sai Sankare Siritharan, *Student Volunteer*  
Dr Moe Moe Thinn, *Medical Officer*  
Lechuan (David) Wen, *Student Volunteer*

### **Partners & Organisations**

Australian & New Zealand Gastroenterology International Training Association (ANZGITA)  
Burmese Doctors Association  
Christian Friends of Korea  
Concord Repatriation General Hospital  
Department of Hepatology, Yangon  
Global Care Partners  
Hepatitis NSW  
Korean Australian Medical Society (KAMS)  
Korean Health Committee  
Lebanese Muslim Association (LMA)  
Medical Action Myanmar  
Ministry of Public Health DPRK  
Myanmar Liver Foundation  
New Britain Palm Oil Ltd  
Higaturu  
Popondetta General Hospital  
Provincial Government  
Oro Province  
Provincial Health Oro Province  
Sogeri Enterprises Ltd

### **Funders & Donors**

Canterbury Hospital  
DAK Foundation

Rotary Club Macquarie Park  
Medical Technologies Australia (Bruce Waldron)  
Sydney Champions Inner West Lions Club

### **Individuals**

Salwa Barmaky  
Michael Cheung  
Hae Chung  
Isaac Chan  
Manjekah Dunn  
Ting Fan  
Damindri Fernando  
Savisha Fernando  
Emma Glascott  
John Granata  
David Kai Ho  
Abeer Khan  
Vivien Hsu  
Abidev Kuhasri  
Su Htun  
Lily Iqbal  
Iram Khan  
Manuela Kim  
Michael Kozok  
Abidev Kuhasri  
Thao Lam  
Marcus Lau  
David Lee  
Nathan Lee  
Lisha Lobo  
Nikita Malhotra  
Chit Lay Naing  
Agnish Nayak  
Debbie Ouyang  
Rengen Parlange  
Lucy Zhang

## 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.

### **Our Vision**

To work together towards a world free of hepatitis B

### **Our Mission**

To facilitate improved awareness, vaccination, testing, and life-saving treatment and care services for hepatitis B aimed at those most in need.

### **Our goals are globally aligned**

Our ultimate goal is the elimination of hepatitis B. The World Health Organization has called for the elimination of hepatitis B by 2030. Sustainable Development Goal 3.3 states that “by 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases”.<sup>5</sup>

### **Our values**

#### *Partnership*

We identify and collaborate with key stakeholders in each community, including health care workers, community members, Local Health Authorities and government departments.

#### *Education*

We raise awareness about hepatitis B among key high-risk groups, including in countries with high prevalence rates of hepatitis B, people with limited access to health services, and culturally and linguistically diverse communities.

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<sup>5</sup> United Nations, Sustainable Development Goal 3. <https://sustainabledevelopment.un.org/sdg3>





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We train and upskill local healthcare workers, who we believe are instrumental in providing ongoing health care to their communities. Through consultation, we provide skills and resources in areas they identify as most important.

### *Sustainability*

We work towards making our impact long-term and sustainable, through combined efforts of education in the general community and for healthcare workers, collaboration with local partners and government, regular evaluation of our projects, and advocacy at a policy level.

## 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 as soon as possible (within 24-48 hours) followed by at least two other 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 skilled attendant.

Other priority groups for vaccination include:

- Health care workers
- Household and sexual contacts of people with 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 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.