

Tuberculosis:

The cruel scourge for children
in Papua New Guinea

A report by Jo Chandler for ChildFund Australia

August 2016





About the Author

Jo Chandler

Jo Chandler is an award-winning Australian journalist, author and editor, as well as an Honorary Fellow at Deakin University's Contemporary Histories Research Group. She has filed news and features from assignments across sub-Saharan Africa, Papua New Guinea, rural and remote Australia, Antarctica and Afghanistan. Jo has earned distinctions as an essayist, profile writer and narrative journalist, and is recognised for work across a range of specialty areas: science; environment; health; human rights; women's and children's issues; aid and development. In addition to a Walkley Award, Australia's most prestigious journalism prize, Jo has received a range of other accolades for her work as an investigative journalist, including the Melbourne Press Club Quill for Best Feature, the George Munster Prize for Independent Journalism, the University of New South Wales Bragg Prize for Science Journalism, the Australian Council for International Development Media Prize, and the United Nations Association of Australia Media Peace Award.

About ChildFund Australia

ChildFund Australia is an independent and non-religious international development organisation that works to reduce poverty for children in the developing world. The organisation is a member of the ChildFund Alliance – a global network of 11 organisations which assists more than 14 million children and families in 63 countries.

ChildFund works in partnership with children and their communities to create lasting change by supporting long-term community development, responding to humanitarian emergencies and promoting children's rights.

Established in 1994, ChildFund Papua New Guinea is the representative office of ChildFund Australia and undertakes child-focused community development programs in the Central Province and National Capital District. Key projects are implemented in the areas of maternal and child health, education, water and sanitation, livelihoods and child protection. In 2015, ChildFund PNG also established the country's first Family and Sexual Violence Counselling Hotline which operates in Port Moresby and provides national coverage.

ChildFund Australia is a registered charity, a member of the Australian Council for International Development, and fully accredited by the Department of Foreign Affairs and Trade, which manages the Australian Government's overseas aid program.

Contents

Foreword.....	01
Executive Summary	02
Preface: a reporter's notebook.....	04
Tuberculosis: a beginner's guide.....	07
Tuberculosis in Papua New Guinea	10
TB's youngest victims.....	11
Calculating the casualties and the cost	13
Battling TB: a view from the frontline	15
The last word: solutions and recommendations	18
A strategy to end TB	18
The Global Fund	20
Medical research and development	21
References	23

Foreword



Nigel Spence

Nigel Spence
CEO, ChildFund Australia

“**Tuberculosis is the child of poverty, and also its parent and provider.**”

*Archbishop Desmond Tutu,
childhood tuberculosis survivor*

There can be few more challenging and imperative goals in the field of child health than to beat the cruel scourge of tuberculosis (TB).

It is shocking and shameful that globally more than 140,000 children die each year, and that one million become sick, from an entirely curable and largely preventable disease.

Many children do survive, but with their bodies and minds profoundly damaged after the bacteria infiltrates their bones or brains. The luckiest recover at substantial cost to their education, their prospects and their families, whose fragile livelihoods are eroded by the effort to provide care, medication and nutrition to sick children over months and even years of treatment. This feeds into a diabolical generational cycle of more disadvantage, brewing more disease.

As childhood TB survivor Archbishop Desmond Tutu has observed: “Tuberculosis is the child of poverty, and also its parent and provider.”

Fifty years ago, we witnessed the vanishing of tuberculosis from the wealthy world. With the arrival of antibiotics to treat it, many experts predicted it was only a matter of time before this ancient killer was wiped out entirely, like smallpox. But they underestimated the tenacity of *Mycobacterium tuberculosis*, and they overestimated humanity’s resolve.

Today the Asia-Pacific region carries the heaviest burden of disease. Over the past three years in Papua New Guinea (PNG), Australia’s nearest neighbour and former colony, the death toll from TB was 9,000. A sobering point of comparison is that the Ebola virus, which galvanised such international fear and concern, killed 11,300 people globally in the same period.

PNG is also recording outbreaks of deadlier drug-resistant strains of TB. Often referred to as “Ebola with wings”, Jennifer Furin, writing for *The Lancet Respiratory Medicine*, describes this modern-day mutation as having “health, population and economic consequences that will almost certainly eclipse those of both the Ebola and the recent Zika virus outbreaks”.

Many failures have contributed to the problem unfolding today: in medicine, in the markets, in politics and diplomacy. But there are also heroic stories of individuals and communities doing their best to utilise the tools and understanding we now have to beat the disease, and it is these people whom ChildFund is supporting.

While we continue to urge that leaders find the will, resources and strategies to win the war, ChildFund is equipping communities at the frontline with the means to win their battles, to save lives and livelihoods, and protect children’s futures.

Executive Summary

Tuberculosis is a contagious, airborne and – for the past 60 years – curable disease caused by one of the most infectious bacteria in human history. Today it ranks alongside the human immunodeficiency virus (HIV) as a leading cause of death worldwide.

In 2014, TB killed 1.5 million people, including 140,000 children, according to the World Health Organisation.¹ Of the 9.6 million people estimated to have fallen ill with the disease in 2014, one million were children.

While TB has largely vanished – even from memory – in the wealthy world, it continues to thrive in conditions of poverty. Today, more than half the TB disease burden falls in the Southeast Asia and Western Pacific regions; the biggest tolls in India, Indonesia and China.

PNG has only a fraction of the population of these nations, but is suffering a “rampant” tuberculosis emergency.² It has one of the highest prevalence rates globally: 529 cases per 100,000 population.³ It is also a country which has some of the worst human development indicators in the world.

Children account for 26 per cent of detected TB cases in PNG⁴ but this is likely to be just a fraction of the real story. In PNG, as in other TB-endemic nations, there are formidable challenges to the diagnosis and treatment of paediatric cases⁵, with the disease frequently misdiagnosed or overlooked.⁶

Although TB characteristically occurs in the lungs, it can affect any part of the body. Infants and small children are particularly vulnerable to infection in the brain or bones or other organs, and the consequences if they survive can be profound lifelong disability. In a nation in which there is little, if any, disability support, this is shattering for the prospects of the child and their family.

In recent decades, the TB bacteria has evolved to resist the antibiotics that have been the main weapon against it since the 1950s. New strains of multidrug-resistant TB (MDR-TB) and extensively drug-resistant (XDR-TB) are deadlier and much more difficult and expensive to treat. Regular TB requires a standard six months of treatment; MDR-TB presently requires a regime of daily, intensive drug treatment over two years, with a success rate of only 50 per cent.⁷

Outbreaks in PNG have been described by international experts as “unprecedented”.⁸ A joint statement on the TB emergency in PNG signed by representatives of the PNG, Australian and US Governments, the World Health Organisation, non-government organisations (NGOs) and medical research partners in November 2015 declared: “The cost of inaction will be catastrophic in terms of



“

While TB has largely vanished – even from memory – in the wealthy world, it continues to thrive in conditions of poverty.

lives lost, and astronomical in terms of financial cost ... ultimately, TB and drug-resistant TB pose a great threat to Papua New Guinea's development".⁹

The PNG National Department of Health has developed plans to tackle the national TB situation and the drug-resistant outbreaks. They rely on strengthening the health system. However, to date, progress on these plans has been stymied by a lack of funding and political will.

Finding effective solutions to address the TB epidemic in PNG is not impossible, but will require far greater levels of cooperation and determination, internationally, across agencies, and at all levels of society.

In addition to the key principles outlined in WHO's End TB Strategy, experts note that moving from a passive to active case finding model is critical in the context of PNG. This requires improved detection methods, increased community awareness of the disease and its symptoms,

and better healthcare support for patients – to not only reduce infection rates and improve health outcomes, but to avoid further increases in MDR-TB. This will require significant investment in PNG's healthcare systems and infrastructure.

Innovative solutions in the area of medical research and development will also play an important role in reducing caseloads, both in PNG and other TB-endemic nations. Already, new TB vaccines are being trialed, improved pharmacological treatment products are available, and the roll-out of GeneXpert diagnostic machines is improving healthcare efficiencies in terms of TB testing and treatment.

More broadly, it is absolutely crucial to address the social and economic conditions which perpetuate the spread of the disease in PNG. The combination of poor nutrition, inadequate housing, and limited access to basic services, which is the reality for much of PNG's largely rural population, provides the ideal conditions in which TB continues to thrive.

Preface: a reporter's notebook

In June 2011, ABC Radio carried a story about a man from Western Province in PNG who had put his sick 14-year-old daughter in a dinghy and paddled her the short distance between one of the worst health systems in the world and one of the best.¹⁰

After arriving on an Australian island in Torres Strait, the girl was airlifted to Cairns Base Hospital where she died of TB. The father was diagnosed with the same disease and treated. He was then told that he would have to take his daughter's body back to PNG in his dinghy. A public appeal by Queensland MP Warren Entsch raised enough money to fly them both home with some dignity.

The report was sparse, but its desperate undercurrent stuck with me.

I was then a reporter for *The Age* in Melbourne. An occasional foreign correspondent, I had a reasonable understanding of TB and its powerful resurgence as a consequence of the HIV and AIDS epidemic in Africa. I had visited TB wards and HIV clinics in Mozambique, Democratic Republic of Congo and Malawi. People living with HIV are around 30 times as likely as others to develop tuberculosis.

What was the story in PNG? Research soon revealed that specialists in PNG and Australia were deeply concerned about what they feared had the makings of an epidemic. Curiously, it appeared to be largely unhooked from the HIV epidemic. Co-infection rates were – certainly compared to sub-Saharan Africa – comparatively low.¹¹

Daru, just off the PNG coast and close to Australian waters, was by all accounts the epicentre of this outbreak. So I added Daru to my itinerary for a forthcoming field research trip for *The Age*.

What we found in Daru Hospital in August 2011 were conditions beyond the worst I had seen in hospitals in Kinshasa, hitherto my baseline for as-bad-as-it-gets. The broken-down hospital was overflowing with patients. They spilled from the beds onto the floors, into corridors, outside on the wide verandahs, under the mango trees.

Vital equipment was broken, drug supplies had run out, infection control was non-existent. There were no doctors on the wards and nurses were stretched beyond their limits. It later emerged that several contracted TB during this period.

"Each morning, the sick are turned too quickly out of 90 beds to accommodate the next wave," I reported in *The Age*. Many came from the town settlements where thousands pour in from villages along the Fly River delta to get access to health, education and other services, or because drought, seawater inundations or the tailings from the Ok Tedi mine upstream have wiped out their crops.

The patients included two little girls with TB meningitis, the infection having damaged their brains. Felina was seven months old, and her young parents kept vigil with a Bible and prayers. Next to her was Christina, six years old but weighing just eight kilograms. Her mother washed her in a shallow plastic dish on the floor. Christina's eyes were wide and vacant. The infection had profoundly damaged her brain. Christina did not survive.

In the settlements, where it is not unusual to find shanty houses with more than 30 residents, I saw what happens when children disabled by TB survive. I met Soba, a mother cradling her four-year-old son, Sawai (see p6). He had a beautiful smile but withered legs he couldn't use. He was too big to carry, but Soba had no choice but to haul him over the mudflats as she went about her business of getting food, water and firewood for her family.

In November 2012 I passed through Daru again and found that while conditions in the hospital had improved, thanks to investment by the Australian Government, the dimensions of the TB situation were growing.

GeneXpert machines, a relatively new tool which can quickly diagnose strains of TB, had revealed that instances of drug-resistant TB were, in the words of the head of WHO's PNG chief at the time, "off the charts" in Western Province and neighbouring Gulf Province. By November 2015, an international meeting convened by the PNG Government and WHO officials in Port Moresby appealed for an urgent response, describing the cost of inaction as "catastrophic". Still, not much happened.

In April 2016 I returned to Daru, reporting for ABC Radio National. There were still nowhere near enough beds, healthcare staff or outreach programs to meet the needs of diagnosed patients, let alone discover those people incubating and unwittingly spreading disease. Doctors told of cases where children were living in households with parents diagnosed with TB, including drug-resistant strains, but those children had not been tested or treated because of a lack of resources. It was almost inevitable that they would contract the disease.

“

What we found in Daru Hospital were conditions beyond the worst I had seen in hospitals in Kinshasa, hitherto my baseline for as-bad-as-it-gets.

The failures were many and complex: a weak, overburdened and poorly resourced health system; a free-falling national economy; complex local and regional politics; lumbering international health bureaucracies. And at the bottom of it all, growing communities of closely packed, poorly nourished people – the very conditions in which *Mycobacterium tuberculosis* thrives.

I've reflected on the story of Daru over the years because it highlights the casualties of TB, and testifies to the complexities of the disease. This is not merely a health issue. It is a combination of social, political, economic, commercial and diplomatic factors, all of them conspiring to give this wily bacteria its enduring, diabolical power.

Finally, I must declare a personal interest. At some point during that first visit to Daru in 2011, maybe in the hospital, maybe visiting the close communities of the settlements, I breathed in a drug-resistant strain of *Mycobacterium tuberculosis*.

I had the luck to be born into one of the world's best health systems and received treatment over an 18-month period, worth more than \$200,000. This report is dedicated to the millions of people who share my diagnosis every year, but not my privilege.



Jo Chandler discovered that instances of drug-resistant TB in Western Province were "off the charts"



Soba and four-year-old son Sawai, who is suffering from wasting as a result of TB infection (image by Jason South/Fairfax Syndication)

Tuberculosis: a beginner's guide

“Tuberculosis and HIV are now competing to be the number one cause of death from infectious disease,” according to the latest global figures.¹² Caused by bacteria, it is easily transmitted through the spread of airborne germs, most commonly when an infected person coughs, talks or sneezes. It is, however, both curable and preventable.

Key to the bacteria's devastating success is the ease with which it travels. In a contained space the bug might linger for several hours; in fresh air and sunlight it won't last long. In the wrong place at the wrong time – a close room, a store, an aircraft cabin – you can catch it simply by breathing.

Not everyone with TB is infectious. If their disease is extra-pulmonary – outside their lungs – they won't spread it. If they have commenced effective treatment, they also don't pose a contagious risk.

Breathing in the bug may not always lead to infection, and not all infected people become sick. An individual's proximity to the diseased person, the length of exposure and their own health status are all variables that determine if they will contract active disease.

If disease progresses – which may take months or years – it will typically affect the lungs, and is characterised by fever, fatigue, a hacking cough and physical wasting. But having entered the body, *Mycobacterium tuberculosis* can travel through the blood or lymph system to strike anywhere, causing swelling and distortion in organs and bones – often showing up in the spine, the belly, the brain.

These latter forms are referred to as disseminated TB, and children are particularly susceptible. Among infants and young children, TB can often manifest in deadly or profoundly disabling forms such as TB meningitis, which affects the brain.¹³ Because the disease can hide in a young body in so many ways, paediatric cases are often overlooked or misdiagnosed.

Although statistics from WHO show that TB incidence and deaths have gradually declined over the past decade, the staggering numbers starkly testify to the bacteria's formidable endurance. The evolution and spread of drug-resistant strains have prompted urgent warnings that TB again looms large as a critical global health threat.¹⁴



Among infants and young children, TB can often manifest in deadly or profoundly disabling forms such as TB meningitis.

The ABCs of TB

LATENT TB:

This is where an individual is infected but the disease lies dormant, so they are not contagious and have no symptoms. The disease can become active later. WHO estimates that about one-third of the world's population has latent TB.

DRUG-SUSCEPTIBLE OR DRUG-SENSITIVE TB (DS-TB):

This is a standard form of TB which responds to a combination of antibiotic drugs, such as Isoniazid, Rifampicin, Pyrazinamide, Ethambutol and Streptomycin. Treatment typically requires six months of daily doses.

MULTIDRUG-RESISTANT TUBERCULOSIS (MDR-TB):

This strain is immune to the two most deployed antibiotics: Isoniazid and Rifampicin. Treatment typically requires two years of first and second-line drugs.

EXTENSIVELY DRUG-RESISTANT TUBERCULOSIS (XDR-TB):

This strain is immune to the four most powerful drugs used to treat the disease and until recently was a terminal diagnosis. New, but highly toxic, drug regimens are increasing life expectancy, and clinical trials of the drug Bedaquiline¹⁵ are also showing positive results.



Key to the bacteria's devastating success is the ease with which it travels.

A DOCTOR'S STORY

Dr Henry Welch



Dr Henry Welch is paediatrician and senior medical officer at the Port Moresby General Hospital. An American specialist, he worked with children suffering tuberculosis in Botswana and Ethiopia before coming to PNG in 2013 on secondment from Baylor College of Medicine-Texas Children's Hospital, Texas.

In PNG, Welch says the infrastructure and public health campaigns are strong, but still developing. However, the terrain is much more difficult. "The TB is out there in the community, but we are waiting for it to come to us," he says. "It's passive case finding, not active case finding where we would say 'you have TB, we are going to your house with a healthcare worker, we are going to see who lives in the house and screen them for TB'. And some live with 18,20 people in the house."

Welch says proactive programs are needed to ensure children and family members are tested, diagnosed and treated earlier. Conditions like TB meningitis can quickly leave small children damaged for life. "With TB meningitis, some will recover to the point where they can open their eyes, and that is it. Those kids are the toughest to deal with.

"Some kids just don't recover at all. Around 10 to 13 per cent of children admitted with TB die – that is countrywide."

For children who do survive, there are other issues to consider. Two children Welch recently admitted to his MDR-TB ward are now doing well, however, they couldn't be sent home straightaway due to multiple MDR-TB cases in their household and other issues in terms of crowding, living standards, access to transport and healthy food. He couldn't be sure their treatment would continue.

Despite working in the nation's premier public hospital, Welch is not immune from the notorious dropouts in critical systems and services that blight the PNG health network. One of the biggest challenges is lack of human resources: "It not only affects the health system, but is a cross-cutting issue". For instance, Welch notes that cultures need to be sent to the Mycobacterium Reference Laboratory in Queensland to be grown in order to make a diagnosis, "but they don't have the capacity to accept all the cultures we need".

Despite these challenges, Welch believes PNG will tackle this problem. He mentions that the National Department of Health has made some amazing achievements. This includes expanded programs to find TB in the community and the recent construction of a new TB laboratory in which to grow their own cultures. Additionally, they have imported the newest child-friendly TB drugs into the country. "These drugs will really simplify treatment in children, and they have had them in the country less than a year after they first become available. PNG is of the earliest countries to do this, and it's quite remarkable".

According to Welch, the best resources PNG has are its own people. "They know what they're doing and they're working with partners to meet this challenge head on. They just need the political will and support of partners to keep the momentum going."

“
Conditions like TB meningitis can quickly leave small children damaged for life.”

Tuberculosis in Papua New Guinea

Why has tuberculosis found such fertile ground in PNG? The seeds of the epidemic are in the social, economic and geographical landscape.

PNG is wildly beautiful, culturally incomparable and blessed with some of the richest natural and biological treasures on the planet. It is also economically impoverished. Collapsing commodity prices plus volatile political conditions create a deeply challenging landscape for improving the capacity, reach and infrastructure required by overburdened health and education programs.

Health indicators here are poor. PNG ranks 158th out of 188 nations on the UN Human Development Index. The average life expectancy is 53 years, infant mortality is 49 per 1,000 live births, and the maternal mortality rate is one of the highest in the world at 733 deaths per 100,000 live births.¹⁶

Many people live long distances from the nearest functional health facilities which, as a consequence of years of neglect and mismanagement, are often "struggling against the odds and unable to fulfil basic functions".¹⁷ Doctors are extremely scarce, particularly in rural areas¹⁸, and the health workforce overall is only a fraction of the firepower required to maintain even basic programs.

In ChildFund's experience, working in Central Province, health clinics are often of such sub-standard quality that families can be forced to seek treatment in Port Moresby, if they are able to afford the costs of travelling. If not, which is most often the case, they remain undiagnosed, at risk of infecting other members of their community, and potentially dying of a treatable disease.

A study by the Burnet Institute¹⁹ in Western Province found almost every hospital bed taken up by TB; the disease sucking up scarce resources, marginalising other urgent health concerns.

In Daru, much of the overcrowding that is today feeding the TB outbreak is due to the influx of people from drought-affected communities.²⁰ Climate change is expected to have a profound effect on food security and poverty in PNG and other vulnerable Pacific nations.²¹

With an exploding, and young, population living largely in scattered villages, often not accessible by road, people are increasingly flocking to the cities looking for services or income, and end up in densely packed settlements without water, sanitation or power. Not only is this spurring an increase in levels of family and sexual violence, but disease continues as an ever-present threat.

Meanwhile, PNG is experiencing economic stress, intensifying domestic political tensions and civil unrest. There has been international anxiety about the fallout of these issues on containing the TB situation. A flashpoint came in March when *The Lancet Respiratory Medicine* published a paper describing the national and international response to the Daru outbreak in particular as "woefully inadequate".²²

The Western Pacific Regional Green Light Committee, a group of international TB experts supporting the public health response to drug-resistant TB across the Western Pacific, made a series of recommendations after it visited PNG in May 2015, and is due to send its next mission to evaluate progress in August 2016.

“
PNG ranks 158th out of 188 nations on the UN Human Development Index.”

TB's youngest victims

Tuberculosis remains a major, but often unrecognised, cause of disease and death among children in countries where the disease is endemic, like Papua New Guinea.²³ Getting treatment to children in these contexts is stymied by the lack of strategies and tools to guide diagnosis and treatment.

The World Health Organisation²⁴ lists the major reasons for this:

#1

TB in children is rarely bacteriologically confirmed. As Dr Henry Welch, paediatrician and senior medical officer at Port Moresby General Hospital explains, diagnosis relies on patients coughing up sputum samples – which can be difficult to obtain from a young child. Even if a sample is obtained, it may not show a lot of TB “bugs” even if the disease is present.

#2

Even when diagnosed, cases are not always reported to public health authorities. There are discrepancies between the data methodologies. These factors skew statistics and the imperatives for future programs.

#3

In high-burden countries, children get lost under the weight of adult casualties. Welch explains that childhood TB, not just in PNG but worldwide, is often put on the backburner because from a public health perspective the focus is on controlling TB in adults, because it is they who typically spread TB. This is despite, as Welch believes, that children are most affected by the disease.



Children account for 26 per cent of detected TB cases in PNG, although that is likely to be just a fraction of the real story.

Children account for 26 per cent of detected TB cases in PNG²⁵, although this is likely just a fraction of the real story. Welch is convinced that malnutrition “absolutely” plays a substantial part in the disease profile. “In PNG, 43 per cent of children are too short, they are stunted, because they don’t have proper nutrition. That’s almost half of the population of children.” This is supported by UNICEF, which states that malnutrition is the underlying cause for the majority of deaths of children under the age of five in PNG.²⁶

“
In PNG, 43 per cent of children are too short, they are stunted, because they don’t have proper nutrition.”

Welch adds: “TB is one of those social diseases. The medicines for TB really aren’t that difficult – we’ve got that figured out. But it is really about treating the social problems behind the disease ... it’s a disease of poverty.”

ChildFund’s health project coordinator Olive Oa has both professional and personal experience of the potentially lethal obstacles facing children with TB in PNG. This includes growing evidence of diagnosed and undiagnosed TB in children in the communities she visits in Central Province as part of her work.

“Because adults are not getting treatment, you will then see children with large lymph nodes. The parents think it is normal until the child starts to lose weight and becomes tired, then they get diagnosed as having TB.”

Oa was convinced that a 10-year-old family member had tuberculosis. She told health workers her suspicions, but he was misdiagnosed at two clinics in Port Moresby, and again at a hospital. When a chest X-ray came back clear, she pushed hard for a referral for more tests. Her determination meant the boy eventually had a CT scan, and was diagnosed immediately. The TB was in his stomach.

By this time, the boy was gravely ill. But within a week of treatment his health had improved dramatically. “He ate a lot of food. He gained back weight. He took the medicine for nine months,” Oa reports. Today he is in his second year at university.

Calculating the casualties and the cost

Almost 6.2 million cases – two-thirds of the global TB burden – are estimated to occur in the Asia-Pacific region. But even against the bleak backdrop of the regional TB story, PNG distinguishes itself for all the wrong reasons.

Tuberculosis is “rampant” throughout PNG.²⁷ The young nation has amongst the highest prevalence rates of tuberculosis in the world: 529 cases per 100,000 population.²⁸ This figure is regarded as an underestimate, due to the high number of cases that are never detected.

By August 2014, there were about 1,000 new cases of MDR-TB being diagnosed in PNG per annum, which on top of the existing burden equates to around 2,000 cases in treatment each month.²⁹

The overall prevalence of drug-resistant forms of TB in PNG is high, but unclear. A recent survey indicated that the proportion of MDR-TB among new cases was perhaps slightly lower than the regional average.³⁰ However, the latest observation from WHO is that major diagnostic gaps on drug-resistant TB persist in many parts of the world, and are reportedly the worst in the Western Pacific Region, where detected cases represent just 19 per cent of estimated cases.³¹

The PNG National Department of Health (NDoH) has drafted both a National TB Strategic Plan 2015-2020 and an Accelerated Response Plan for drug-resistant TB hotspots. These blueprints have strong endorsement from international health agencies and program partners.

In November 2015 an emergency meeting in Port Moresby on the MDR-TB outbreak in Daru produced a joint statement imploring the PNG Government to release promised funding to allow the crisis to be tackled with “utmost urgency ... the cost of inaction will be catastrophic in terms of lives lost, and astronomical in terms of financial cost”.³² The 57 signatories included senior PNG health officials, the Australian Government, WHO, Global Fund, World Bank, Burnet Institute, USAID, NGOs and resource companies.

To date, only PKG8m (AUD\$3.3m) of the emergency response funding has been released – a fraction of what is required. Meanwhile, the PNG NDoH has been hit with heavy budget cuts as a consequence of economic pressures. It is understood that the PNG Government has made a loan request to the World Bank to assist.

Costing a cure

AUD\$62 (PGK150):

To treat a person with standard TB. Treatment lasts up to six months, mostly at home, but requiring close medical supervision. WHO recommends healthcare professionals adopt the DOTS strategy: directly observed treatment, short-course.³³

AUD \$12,420 (PGK30,000):

To treat a person with MDR-TB. Treatment takes place over two years, including up to six months of hospitalisation.

AUD \$20,700 (PGK50,000):

To treat a person with XDR-TB. They may be hospitalised for their entire treatment, which takes place over two years or more, if they survive.³⁴

THESE ARE PHARMACEUTICAL COSTS ONLY:

They do not include remuneration for healthcare staff, TB diagnostics, hospital fees and additional health services, which form part of a TB treatment program.



The cost of inaction will be catastrophic in terms of lives lost, and astronomical in terms of financial cost.



Battling TB: a view from the frontline

Several international organisations, including ChildFund, have focused their efforts on grassroots initiatives to help health workers better identify, diagnose, treat and support TB patients.

With over 20 years of experience working in PNG's rural communities, ChildFund launched the Stop TB in My LifeTime project in 2013. Working closely with the PNG NDoH, the project aims to increase the capacity of community health workers, improve clinic facilities in rural areas, and raise community awareness and knowledge of the disease.

The ChildFund project capitalises on existing relationships and networks, explains Olive Oa. By integrating TB education and awareness into maternal child health and nutrition programs, ChildFund can tackle a range of issues that help identify and prevent TB in children: vaccinations, weight checks, dietary information, strategies for avoiding infection, danger signs and disease symptoms, and building general household awareness about what to look for and when to seek treatment.

Oa and her colleagues instruct health staff on dispensing the latest treatment regimes, new diagnostic techniques and how to identify and seek out potential cases, particularly notoriously under-recognised paediatric cases.

The program also trains village health volunteers who can then identify symptoms within their communities, and refer potential patients for treatment – an inroad into the kind of active case finding that many experts say is critical to gaining control of TB.

Education and awareness at the wider community level is also part of the ChildFund agenda. This recognises that a lack of understanding of disease and how it spreads is often a powerful impediment to treatment. In many PNG cultures, traditional beliefs blaming illness and death on witchcraft and sorcery still endure.

Oa explains: "People have cultural beliefs that delay a lot of presentation to the health facilities." When they eventually do seek treatment, "the disease is very advanced and they are much weaker". If they are parents, they may have also infected their children.

Stigma is another obstacle. Sometimes people who show symptoms or are diagnosed are ostracised from their families, who are unaware that the disease won't spread via eating utensils or body contact, or that once in treatment, they are no longer contagious.



Village health volunteers can play an important role in identifying TB symptoms, and referring potential patients for treatment

A key message to communities, says Oa, is that people should not be afraid of those who are diagnosed with TB. The real danger is from those who are undiagnosed and untreated.

Oa adds: "Lack of manpower is one of the biggest issues. In some health centres there are one or two staff and they are doing everything." Patients may have to wait hours if not days to be seen, and this may be after travelling days to access treatment.

A stronger health network is central to the National TB Strategy and accelerated response plans³⁵ supported by WHO, the Australian Department of Foreign Affairs and Trade, Burnet Institute, Médecins Sans Frontières, World Vision and other expert partners. These plans turn on increasing its expertise and capacity to diagnose, treat and, ultimately, actively find cases.³⁶

Recently these efforts gained additional support from USAID, which announced a new program of technical assistance, Bedaquiline for 85 patients and rollout of more GeneXpert machines for improved diagnosis.³⁷

“

Sometimes people who show symptoms or are diagnosed are ostracised from their families.

A MOTHER'S STORY

Ruth



In 2013, mother-of-three Ruth developed a chronic cough, fever and aches. She would sit in the sun to try and ease her chills. She tried Panadol and antibiotics, but the sickness grew worse.

"I thought maybe someone was poisoning me, or that someone had put a curse on me," recalls Ruth. Known as the 'wasting disease' in PNG, traditional beliefs mean many people with tuberculosis blame sorcery.

Unable to care for her children, aged one to five years, their father took over as sole carer and provider. But their eldest boy, Ravu, was so concerned that he stopped attending school, missing his first year of education, to stay at his mother's side. "When she wanted water, I would get it for her. I would make tea for her and wash my clothes, and my sister would wash her clothes."

Ruth's village is 40 kilometres from the closest health centre in Agevairu. It's a rough dirt track and it takes the local PMV (bus) two hours to make the journey navigating around the potholes. An adult fare costs twice what many people earn. So mostly, unless they are just too sick to stay on their feet, they walk to the clinic, or don't go at all.

It wasn't until a family member visiting from Port Moresby suggested TB could be the cause of Ruth's failing health, that she travelled to the clinic for testing. The diagnosis was confirmed. She started feeling better after just a week of treatment.

But her problems were not over. "I was always worried that one of my smaller children would catch it, as they were with me so much," she recalls. "But I didn't think it would be my eldest, Ravu, as he is bigger."

Ravu began to lose a lot of weight in 2014. He was always tired and very pale and suffered from pains in his chest. "I think he caught TB from either me or my brother, who he sleeps under the same mosquito net with," says Ruth. She sent a message to the clinic asking for help. A TB officer came to her home, along with a project officer from ChildFund. Ravu was diagnosed with TB and started on treatment.

The five-year-old boy is physically recovered now, but his education has a long way to go to catch up lost time.

Note: Name of mother and child changed to protect their identity.

“

I thought maybe someone was poisoning me, or that someone had put a curse on me.

The last word: solutions and recommendations

To end the scourge of TB in PNG will require cooperation, determination and the rollout of resources across nations, across agencies, and at all levels of society.

Dr Justin Denholm, infectious diseases specialist and founding chair of the Australian Tuberculosis Forum³⁸, says: "What sort of response is necessary? I think all of us want to see PNG and its health care system strengthened and empowered to be able to effectively manage the terrible situation it finds itself in.

"I think we also have to be realistic about the scale of the problem in PNG and to accept that resources and infrastructure there are simply not sufficient to do that."

He adds: "TB is an international disease, and it needs an international solution."

A strategy to end TB

The experts interviewed for this report, consistent with my previous reporting and the international literature, confirm the strategies reflected in the ambitions of WHO's End TB Strategy.³⁹ This aims to reduce TB deaths globally by 95 per cent, to cut new cases by 90 per cent between 2015 and 2035, and to ensure that no family is burdened with catastrophic expenses due to TB.

The strategy is designed around four principles (see p19), supported by three key pillars:

- Integrated, patient-centred care and prevention: Early diagnosis through active case-finding; systematic screening of contacts and high-risk groups; treatment of all TB patients; prophylactic treatment and vaccination. This is an area where NGOs and other community actors can facilitate increased access to services and treatment.
- Bold policies and supportive systems. This is where political commitment and resources are imperative - providing universal health coverage, social support and tackling the poverty which drives disease. This can be assisted by NGO development programs in partnership with communities, churches, other civil society groups and health care providers.
- Intensified research and innovation. Supporting the discovery, development and rapid uptake of new tools and strategies.

In the context of Papua New Guinea, additional priority areas were identified by those experts interviewed for this report:

- Strengthening the capacity, infrastructure and resources of health systems to detect and treat TB patients. This includes regular health patrols into remote areas.
- Training and supporting healthcare workers at all levels – village health workers, nurses, doctors, health administrators.
- The priority rollout of GeneXpert machines for rapid testing and diagnosis, and easy access to second-line drugs for treatment of MDR-TB.
- Moving from passive case finding – waiting for sick people to come through the clinic door – to active case finding. This includes screening the family and contacts of newly diagnosed patients, and where appropriate providing prophylactic treatment.
- Building awareness among communities on disease sources, symptoms to watch for and supporting patients to complete their treatment. This includes tackling stigma and sorcery beliefs.
- Alleviating the social and economic conditions perpetuating disease spread – poor housing, broken infrastructure, poor nutrition, lack of access to basic services.

At the village level, the urgent and fundamental requirement is for better management and support of individuals affected by TB – patients and their families. Serving vulnerable populations at the community level is also a critical plank of WHO’s End TB Strategy.

The Key Principles of the End TB Strategy

1. Government stewardship and accountability, with monitoring and evaluation.
2. Strong coalition with civil society organisations and communities.
3. Protection and promotion of human rights, ethics and equity.
4. Adaptation of the strategy and targets at country level, with global collaboration.

Source: www.who.int

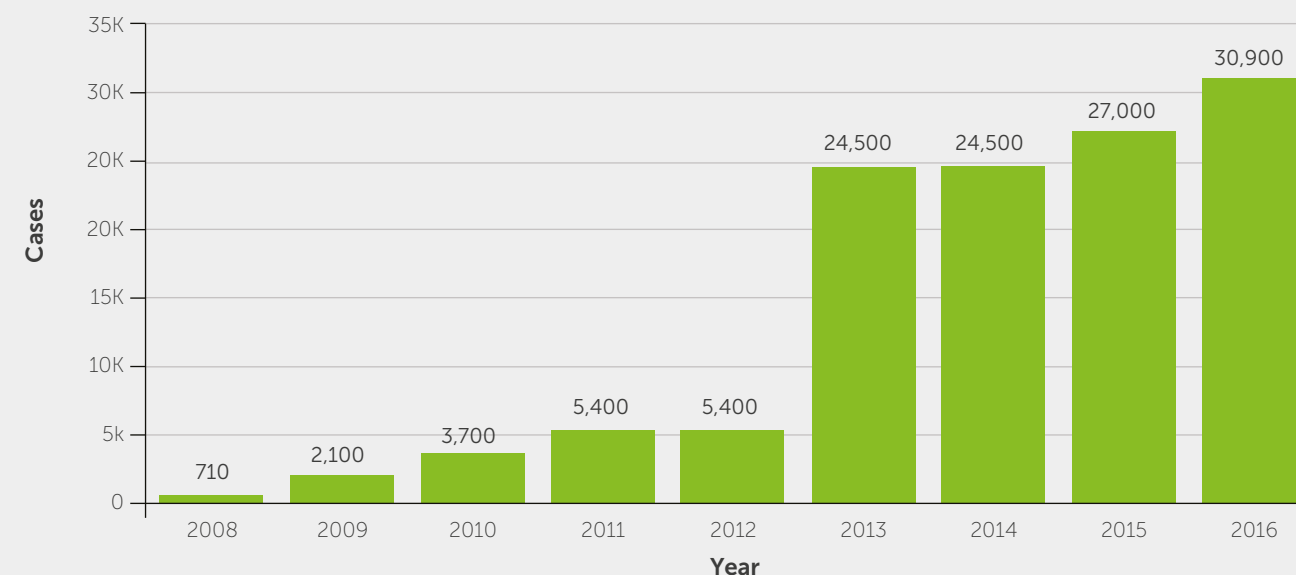
The Global Fund

The Global Fund has been the major international source of funding for TB since it was founded in 2002, investing more than \$US4.8 billion in programs in more than 100 countries, including PNG.⁴⁰

While finance for TB programs has more than doubled since 2006, “this is still well short of the global need”.⁴¹ To date, the Global Fund has signed off on more than US\$45m of TB programs in PNG partnering with the PNG NDoH and NGOs. These programs, some of which are still underway, have been part of a ramping up of efforts which has seen the number of smear-positive TB cases leap from 5,000 in 2012 to almost 25,000 in 2015, and reaching more than 30,000 so far in 2016.⁴²

However, Global Fund activity in PNG has been hampered by problems with the PNG NDoH’s capacity to account for and manage the grants. This has seen the department step down as principal recipient in TB and malaria programs. Oil Search stepped up as principal recipient to keep the malaria program running⁴³, and World Vision became the principal recipient for the TB effort.

New smear-positive TB cases detected and treated in PNG



Source: The Global Fund PNG Results 2008-2016.



There are currently three TB vaccines in advanced trials, and more appearing.

Medical research and development

Australia could potentially play a powerful role in regard to the third pillar of the End TB Strategy – stoking the machinery of medical and pharmacological research to come up with better instruments to tackle this modern plague.

“**TB is an international disease, and it needs an international solution.**”

“Australia has significant research and industry capability that could be brought to bear on finding new tools like vaccines and new drugs that could help countries like PNG with TB control and ultimately eliminate TB as a public health risk,” says Denholm.

Internationally there is mounting pressure to find a modern, more effective successor to the 95-year-old BCG (Bacillus Calmette–Guérin) vaccine for TB. While it is effective in children who receive it (88 per cent coverage in PNG⁴⁴) it does not provide effective protection for adults, and they are the ones who spread the disease.

There are currently three TB vaccines in advanced trials, and there are more appearing in the early stages of the pipeline. The Bill and Melinda Gates Foundation’s deputy director for TB Willem Hanekom said at the AIDS 2016 conference that there were now seven novel ideas being tested in the TB vaccine field.⁴⁵

There are also new developments in the pipeline specifically geared to improving TB prevention, diagnosis and treatment in children. Studies underway, or due to start soon, include evaluating preventative therapy for children exposed to MDR-TB, and for shortening the treatment regime for children with less severe forms of drug-sensitive TB.⁴⁶

A PATIENT'S STORY

Grace



Grace is 10 years old, but battling tuberculosis for the second time in her life.

She arrived at a small rural clinic in Central Province so weak and wasted she couldn’t walk. “I thought I was going to die,” she says. “It was painful and hurt the most in my neck.”

She had first come to the clinic in the village of Agevairu two years earlier. It’s a basic shack, typical of many across PNG; one room with four beds for patients, one treatment room, a delivery room for labouring mothers and a small office. Termites had eaten through some of the walls, which ChildFund arranged to repair.

There are just six staff to provide support for around 15,000 people at Agevairu, some of them travelling six hours by boat for medical attention. As it happened, ChildFund had just been in the area implementing the Stop TB in My Lifetime project. Celestine l’Ova, the Agevairu health officer, diagnosed Grace and started her on the treatment of tablets she would need to take every day for the next six months.

She was sent back home, but the written instructions about which tablets and doses to take were lost. “I was worried about overdosing her by giving her too much medicine,” her mother, Lani, explains. “And Grace seemed better.” She stopped taking her treatment.

“**I was worried about overdosing her by giving her too much medicine.**”

This is a common story. TB drugs can have a miraculous effect on how people feel, but unless they are taken for the full duration, they won’t provide a cure. Worse, they give the TB bug the chance to fight back and progress into a drug-resistant form of the disease.

A few months later, Grace was sicker than ever. “First we went to another health centre. The staff there said she didn’t have TB,” Lani says. “They referred us to the hospital in Port Moresby where they did a biopsy of her gland in her neck.

“We waited and waited for the results, but eventually ran out of money, so we had to return home without them. We have no relatives in Port Moresby and it was very expensive.”

This, too, is an all-too-common tale. The vast majority of the population live in rural areas and survive on what they grow in their gardens. If they have to leave their land to access health services, they don’t have the means to support themselves, and must rely on wantoks (relatives) for food and accommodation.

Fortunately when Lani took Grace back to the Agevairu clinic, l’Ova was able to track down the missing results in Port Moresby. They were positive for TB, so treatment began again, but this time a much stronger course of medicine was required.

ChildFund has recently supplied the clinic with a microscope to analyse sputum samples. This simple piece of equipment is saving lives, says l’Ova, because people who don’t have the time or means to get to Port Moresby for testing are coming to her clinic. “I always give priority to TB patients,” she says. “They are never turned away, even if we need to have people sleeping on the porch outside.”

Note: Name of mother and child changed to protect their identity.

References

¹ World Health Organisation (WHO) Global Tuberculosis Report 2015. www.who.int/tb/publications/global_report/en/

² WHO Joint External Review of the National Tuberculosis Programme of Papua New Guinea 7-21 February 2014. www.wpro.who.int/papuanewguinea/mediacentre/who_review_tb_program/en/

³ WHO Papua New Guinea Tuberculosis Profile. https://extranet.who.int/sree/Reports?op=Replet&name=/WHO_HQ_Reports/G2/PROD/EXT/TBCountryProfile&ISO2=pg&outtype=pdf

⁴ MDR/XDR Emergency Response Team Annual Report (September 2014-August 2015), PNG National Department of Health.

⁵ TBfacts.org: TB & Children – Getting, diagnosing & preventing TB. www.tbfacts.org/tb-children/

⁶ WHO Global Tuberculosis Report 2015. www.who.int/tb/publications/global_report/en/

⁷ WHO Multidrug-resistant tuberculosis (MDR-TB) 2015 Update. www.who.int/tb/challenges/mdr/mdr_tb_factsheet.pdf

⁸ Outbreak of multidrug-resistant tuberculosis on Daru Island, The Lancet Respiratory Medicine. [www.thelancet.com/journals/lanres/article/PIIS2213-2600\(16\)00101-6/abstract](http://www.thelancet.com/journals/lanres/article/PIIS2213-2600(16)00101-6/abstract)

⁹ Joint statement from the Meeting on the Multi Drug-Resistant-TB Outbreak in Daru. www.burnet.edu.au/system/asset/file/2033/Joint_Statement_TB-Mtg_25Nov2015_1_.pdf

¹⁰ ABC News: www.abc.net.au/news/2011-06-17/png-dad-spared-dinghy-ride-with-daughters-body/2762336

¹¹ International Journal of Infectious Diseases: Tuberculosis and HIV co-infection-focus on the Asia-Pacific region. [www.ijidonline.com/article/S1201-9712\(14\)01712-3/abstract](http://www.ijidonline.com/article/S1201-9712(14)01712-3/abstract)

¹² World Health Organisation (WHO) Global Tuberculosis Report 2015. www.who.int/tb/publications/global_report/en/

¹³ Centers for Disease Control and Prevention. www.cdc.gov/tb/topic/populations/tbinchildren/

¹⁴ Reuters news article: Drug-resistant tuberculosis at crisis levels, warns WHO. www.reuters.com/article/us-health-tuberculosis-idUSKCN01B1V20141022

¹⁵ International Journal of Basic & Clinical Pharmacology: Bedaquiline - a new weapon against MDR and XDR-TB www.scopemed.org/?mno=31883

¹⁶ WHO PNG country profile. www.wpro.who.int/countries/png/en/

¹⁷ Development Policy Centre: A lost decade? Service delivery and reforms in Papua New Guinea 2002-2012. http://devpolicy.org/publications/reports/PEPE/PEPE_A_lost_decade_FULL_REPORT.pdf

¹⁸ Health Service Delivery Profile: Papua New Guinea 2012. www.wpro.who.int/health_services/service_delivery_profile_papua_new_guinea.pdf

¹⁹ Evaluation of Risks of Tuberculosis in Western Province Papua New Guinea. www.burnet.edu.au/system/publication/file/3606/2012_Evaluation_of_Risks_of_Tuberculosis_in_Western_Province_PNG.pdf

²⁰ ABC Radio National: Ebola with wings: the TB crisis on our doorstep. www.abc.net.au/radionational/programs/backgroundbriefing/2016-04-17/7326118

²¹ <http://www.adb.org/publications/climate-change-food-security-socioeconomic-livelihood-pacific>

²² Outbreak of multidrug-resistant tuberculosis on Daru Island, The Lancet Respiratory Medicine. [www.thelancet.com/journals/lanres/article/PIIS2213-2600\(16\)00101-6/abstract](http://www.thelancet.com/journals/lanres/article/PIIS2213-2600(16)00101-6/abstract)

²³ The New England Journal of Medicine: Tuberculosis in children. <http://www.nejm.org/doi/full/10.1056/NEJMra1008049>

²⁴ WHO Global Tuberculosis Report 2015. www.who.int/tb/publications/global_report/en/

²⁵ MDR/XDR Emergency Response Team Annual Report (September 2014-August 2015), National Department of Health, PNG.

²⁶ UNICEF: Malnutrition - a silent emergency in Papua New Guinea. www.unicef.org/png/media_22749.html

²⁷ WHO Joint External Review of the National Tuberculosis Programme of Papua New Guinea 7-21 February 2014. www.wpro.who.int/papuanewguinea/mediacentre/who_review_tb_program/en/

²⁸ WHO Papua New Guinea Tuberculosis Profile. https://extranet.who.int/sree/Reports?op=Replet&name=/WHO_HQ_Reports/G2/PROD/EXT/TBCountryProfile&ISO2=pg&outtype=pdf

²⁹ MDR/XDR-TB Emergency Response Team Annual Report August 2014-August 2015, National Department of Health, PNG.

³⁰ WHO Papua New Guinea Tuberculosis Profile. https://extranet.who.int/sree/Reports?op=Replet&name=/WHO_HQ_Reports/G2/PROD/EXT/TBCountryProfile&ISO2=pg&outtype=pdf

³¹ World Health Organisation (WHO) Global Tuberculosis Report 2015. www.who.int/tb/publications/global_report/en/

³² Joint statement from the Meeting on the Multi Drug-Resistant-TB Outbreak in Daru. www.burnet.edu.au/system/asset/file/2033/Joint_Statement_TB-Mtg_25Nov2015_1_.pdf

³³ WHO: The five elements of DOTS. www.who.int/tb/dots/whatisdots/en/

³⁴ Annual Report of the PNG National Department of Health DR-TB Emergency Response Team (August 2014-August 2015).

³⁵ Stop TB Partnership. www.stoptb.org/wg/mdrtb/

³⁶ ABC Radio National: Ebola with wings: the TB crisis on our doorstep. www.abc.net.au/radionational/programs/backgroundbriefing/2016-04-17/7326118

³⁷ USAID to Provide Technical Assistance to Detect and Treat Multidrug-Resistant TB in PNG. www.onepng.com/2016/06/usaidth-to-provide-technical-assistance.html

³⁸ The Tuberculosis Centre of Reseach Excellence. <http://tbcre.org.au/australian-tb-forum/>

³⁹ WHO End TB Strategy. www.who.int/tb/post2015_strategy/en/

⁴⁰ The Global Fund: PNG country overview. www.theglobalfund.org/en/portfolio/country/?loc=PNG

⁴¹ The Global Fund: TB factsheets. www.theglobalfund.org/en/newsroom/factsheets/

⁴² The Global Fund: PNG country overview. www.theglobalfund.org/en/portfolio/country/?loc=PNG

⁴³ Aidsfan: Principal Recipient for Papua New Guinea Grants Resigns. www.aidsfan.org/gfo_article/principal-recipient-papua-new-guinea-grants-resigns

⁴⁴ UNICEF State of the World's Children 2015. www.data.unicef.org/resources/the-state-of-the-world-s-children-report-2015-statistical-tables.html

⁴⁵ Bioworld: TB is getting attention; will new vaccines, drugs follow? www.bioworld.com/content/tb-getting-attention-will-new-vaccines-drugs-follow

⁴⁶ Treatment Action Group Pipeline Report. www.treatmentactiongroup.org/pipeline-report

Author: Jo Chandler

Editor: Larissa Tuohy

Designer: Spade & Arrow

Photography: Vlad Sokhin, Jason South/Fairfax Syndication (page 6), Cam Suttie, ChildFund staff

© ChildFund Australia, August 2016

ChildFund
Australia

ChildFund Australia

Address: 162 Goulburn Street, Surry Hills NSW 2010

Phone: 1800 023 600

Email: info@childfund.org.au

ABN: 79 002 885 761

ChildFund
Papua New Guinea

ChildFund Papua New Guinea

Address: PO Box 671, Gordons NCD, Papua New Guinea

Phone: (675) 323 2544

Email: admin@childfund.org.pg

**BECAUSE
EVERY CHILD
NEEDS A
CHILDHOOD**

childfund.org.au