THE PULSE

BRINGING MEDICAL HUMANITARIAN ACTION TO YOU

MEDECINS SANS FRONTIERES
DOCTORS WITHOUT BORDERS

SEPTEMBER 2022

THE ROHINGYA FIVE YEARS ON

CAUGHT IN A LEGAL AND POLITICAL LIMBO, THEY DESERVE AN ENDURING SOLUTION

KIRIBATI

HOW THE CLIMATE CRISIS IS IMPACTING A NATION'S HEALTH

THE PULSE

SEPTEMBER 2022
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Rohingya refugees fleeing a violent crackdown by the Myanmar military in August 2017, braved monsoon rains and arduous conditions to make the 12-14-day crossing into Bangladesh where they sought refuge in the camps of Cox's Bazar. © Moises Saman, MAGNUM

ABOUT MÉDECINS SANS FRONTIÈRES

Médecins Sans Frontières is an international, independent, medical humanitarian organisation that was founded in France in 1971. The organisation delivers emergency medical aid to people affected by armed conflict, epidemics, exclusion from healthcare and natural disasters. Assistance is provided based on need and irrespective of race, religion, gender or political affiliation.

When Médecins Sans Frontières witnesses serious acts of violence, neglected crises, or obstructions to its activities, the organisation may speak out about this.

Today, Médecins Sans Frontières is a worldwide movement of 24 associations, including one in Australia. In 2021, 113 field positions were filled by Australians and New Zealanders.

Front cover:
25-year-old Latifa Begum, with her two-year-old baby Nurujan, came to Bangladesh from Myanmar 11 years ago. Over the past year, she has been receiving treatment from the Médecins Sans Frontières mental health team. "I've had problems in my head since I had the baby," she says. "When someone talks around me it makes me unhappy."
© Robin Hammond/MSF

The Pulse is the quarterly magazine of Médecins Sans Frontières New Zealand.

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EDITORIAL

Alive but in limbo

Five years after many fled Myanmar, nearly a million Rohingya people are still living in the crowded chaotic quagmire that is Cox's Bazar, without any real prospect of safe repatriation or resettlement. Caught in a legal and political limbo, they deserve an enduring solution.

In August 2017, the Myanmar authorities launched a violent crackdown on the Rohingya, a largely Muslim minority in the southern state of Rakhine, driving close to 700,000 people to flee their homes and villages in a mass exodus to neighbouring Bangladesh.

Médecins Sans Frontières immediately launched an emergency response, as tales of unimaginable violence and cruelty began to surface from Rakhine. This was not the first campaign targeting the Rohingya, but it was by far the largest and most brutal. Accounts of homes razed to the ground, crops and cattle destroyed, sexual violence and the brutal killing of men, women and children in front of their families - all with seeming impunity - were recounted by one refugee after another, many adding that they couldn't sleep for weeks after witnessing such events.

This was matched only by the stories of the most extraordinary endurance demonstrated by each of the Rohingya that managed to survive the gruelling 12-14-day border-crossing. Walking with little rest, across heavily flooded rivers and swamps, with virtually no food and certainly no shelter against the driving monsoon rains, they were, as so many told us later, determined, despite having all but given up hope, to keep going for the sake of their children.

Alive but living in limbo, stripped of land, possessions and livelihoods, a new life of sorts began for them in the makeshift camps of Cox's Bazar. The international humanitarian response initially stretched in its efforts to provide food, water, shelter and adequate sanitation for so many so quickly, but eventually succeeding in reducing massively high mortality rates and countering deadly waves of diseases such as diphtheria and measles.

To treat this newly arrived and highly vulnerable community, Médecins Sans Frontières's response eventually included setting up two hospitals, three healthcare centres and the launch of multiple lifesaving healthcare services including mental health services for a population that was universally and severely traumatised before being crowded into what is now the largest refugee camp on the planet.

For half a decade, ours and other international humanitarian organisations have been able to provide short-term relief to the Rohingya people, including during the COVID-19 pandemic, but we can't keep pretending it is anything more than that.

> "The Rohingya remain hostage to the international community's lack of interest in finding an enduring solution."

Five years on Bangladesh continues to bear the burden of hosting nearly a million refugees, yet regionally, there is no meaningful political dialogue on what to do next to assist this population. And the truth is there are no easy answers. As new crises like Ukraine stretch limited humanitarian budgets, intensifying geopolitical contests direct the attention of world leaders elsewhere.

Across the Indo-Pacific region, the stateless Rohingya are persecuted, exploited and denied protection.

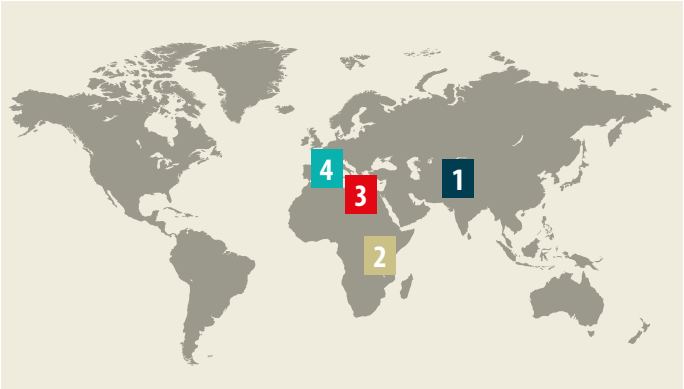
Meanwhile the conditions in Cox's Bazar are increasing fragile. Fires, flooding and outbreaks of disease the norm. People continue to struggle with physical and mental health conditions, while there is no solution to the root cause of their situation in sight.

Many of Médecins Sans Frontières' Rohingya patients tell our teams that they have given up on a future for themselves, but they can't bear to accept this fate for their children. At the end of a psychosocial session, they return to an existence with little hope or prospects, in overcrowded camps that are becoming increasingly unsafe. And yet somehow, for the sake of their kids, muster the will to live.

On the outskirts of Cox's Bazar, in an area known as Goyalmara, there is a Médecins San Frontières hospital. In the neonatal intensive care unit of this hospital there is a wall that stands out from the rest of the hospital walls. Covered with hundreds of tiny brightly coloured baby footprints, it's known as the babies' wall. Each imprint celebrating a newborn child that has survived a difficult welcome into the world. One for every child that gets to meet their family.

I know that our staff don't manage to save all the children that enter that neonatal ward. I also know that they work to provide care and dignity to every child that does, in a place where these are sometimes denied. I also know that those footprints represent much more than the success and skill of our paediatric staff, each one proof of a life waiting to be lived. We owe it to the children of Cox's Bazar, to find a way to make this happen in joy and freedom before their lives too are cloaked in hopelessness and despair.

Jennifer Tierney
Executive Director
Médecins Sans Frontières, Australia




MSF doctor Solveig Köbe with Nyayesh, eight months old, who was severely malnourished and had pneumonia when she was admitted to the intensive care unit of the MSF- supported paediatrics department of Herat Regional Hospital, Afghanistan © MSF

1 AFGHANISTAN

Afghanistan one year on…

A year since the fall of Kabul, the people of Afghanistan continue to experience many consequences from the withdrawal of foreign forces in August last year. Despite this MSF has been able to continue operating without interruption or hindrance. We remain in contact with the government in Kabul and in the provinces where we have medical projects and are assured our work is valued. We continue to be able to employ both Afghan and international female staff in our projects.

However, the country's health system which has been reliant on foreign funding for decades, has been greatly affected. While some international funding has resumed, it is at significantly lower levels and tertiary and specialised healthcare facilities no longer receive any funding from international donors. There is a lack of skilled staff, training, medicine and equipment in local health facilities, and many people are choosing to travel long distances to reach one of our facilities as those closer to home, are unable to meet their needs.

In recent months there has been an upsurge in the number of patients presenting with severe malnutrition which is being exacerbated by the country's economic crisis and the impact of the drought on harvests.

2 MOZAMBIQUE

Peer educators drawn from at risk groups

Stigmatised groups are taking ownership of their health and wellbeing in Beira, Mozambique where Médecins Sans Frontières has implemented a peer-led strategy, working closely with people who face sexual and other stigmas, to create an environment where they feel safe and confident to access medical care. The strategy uses peer educators who are sex workers, men who have sex with men, and at-risk youth, to ensure more people are receiving sexual and reproductive healthcare as well as information, services and tools to prevent, diagnose and treat sexually transmitted infections, including HIV. This programme has mobilised many people to improve their own health and support people at risk in their communities.

One of the peer-educators, Domingas who is living with HIV, was previously a sex worker and originally accessed our services herself. "But it was a bit late for me," she says. "I wish I'd had the chance to know everything I know today, then. Now I go to the community, I identify the girls who are at risk, I talk to them, and then I take them to the clinic."

Domingas says that from her experience, a lot of children are having sex for money. "Men exploit them because they know they are desperate to get little things, like a phone or a dress. They charge very little and don't use protection. Most of the girls have issues with sexually transmitted infections. We keep telling them to use a condom. It's complicated, but I help a lot of people. Sometimes I can't believe I'm that person!"


Peer educator for sex workers in Beira, Domingas says working with Médecins Sans Frontières as a peer educator is very rewarding. © Mariana Abdalla/MSF

3 LIBYA

Médecins Sans Frontières provides shelter and continuity of care to 27 people evacuated from Libya, here some of them sit in the internal courtyard of the building where they are currently being hosted while receiving care. © Yarin Trotta del Vecchio/MSF

Evacuation of 27 at risk of torture and violence

Médecins Sans Frontières used a humanitarian corridor from Libya to Italy, to evacuate 27 people identified as being particularly vulnerable cases, either as victims of torture or at high risk of abuse and violence. Fourteen of the evacuees are now patients at our project in Italy, where they are able to live while undergoing care at our interdisciplinary clinic for the rehabilitation of survivors of intentional violence and torture which Médecins Sans Frontières runs in collaboration with local health authorities. For the remaining 13 evacuees, Médecins Sans Frontières has facilitated follow up medical consultations to allow appropriate continuity of care through the public health system.

4 MEDITERRANEAN

More than 1,000 rescued from Central Mediterranean

An unprecedented 1,045 children, women and men have been rescued from the central Mediterranean in just over a month, by Médecins Sans Frontières search and rescue vessel, the Geo Barents now in its second year of operation. More than 3,100 people were rescued by the Geo Barents in its first year. A rescue in July ended tragically with the loss of 29 missing at sea and the death of one pregnant woman who was rescued but could not be resuscitated once on deck. Two subsequent missions were very intense, with six rescues in 12 hours and 11 rescues in 72 hours. The third mission resulted in an unprecedented 659 survivors. The normalisation of policies of deterrence and non-assistance at sea, as well as forced returns, continues to generate immense human suffering and loss of life on the Southern European border.

A Médecins Sans Frontières search and rescue (SAR) team use a RHIB inflatable life raft to rescue refugees in distress on the central Mediterranean seas. More than 1,045 children, women and men been taken onboard the Geo Barents, Médecins Sans Frontières SAR vessel since it commenced its second year of operation in early July. © MSF

ROHINGYA

POPULATION: 2.2M (APPROX)

25 AUGUST 2022 marks the **FIVE-YEAR ANNIVERSARY** of the 2017 violent crackdown against the Rohingya people

ROHINGYA PEOPLE are a mostly **MUSLIM MINORITY** from northern Rakhine State, Myanmar

Firoza, a 41-year-old Rohingya woman lives with her five children and husband in the camps of Cox's Bazar, Bangladesh. © Yusuf Sayman

"We should not be forgotten"

Five years after the Myanmar military's 2017 campaign of targeted violence against them, the Rohingya people are asking to be able to live as humans.

Mohib* still recalls the violent days and nights of August 2017, as he watched streams of fellow Rohingya fleeing their homes in Myanmar's Rakhine State, risking the crossing of the Naf River to reach the relative safety of Bangladesh.

"At night I heard gunshots from all directions. I saw houses burning with my own eyes I saw the smoke billowing from the embers of Rohingya communities in downtown Maungdaw."

Mohib – a Médecins Sans Frontières staff member – and his family had packed their bags, preparing to leave, but due to the recent monsoons, the river levels were precariously high. "I did not want to drown with my family, so we decided to stay," he says. "Over 100 members of my family, including my parents and sisters, did leave. They now live in camps in Cox's Bazar, Bangladesh. I have not seen my mother since April 2017."

Everyone was a target

The Rohingya were running from extreme violence perpetrated by the Myanmar military, which in the early hours of 25 August 2017, had launched 'clearance operations' targeting the Rohingya community.

Almost 700,000 Rohingya people crossed into Cox's Bazar. They were not the first: around 200,000 Rohingya were already living in camps there, having fled previous campaigns of violence. But this time, the displacement was unprecedented in size and speed.

It was a critical humanitarian emergency, as families sought safety in makeshift shelters, water and food, and medical care for gunshot wounds, burns and broken bones, and for sexual violence.

HOW WE SUPPORT THE ROHINGYA PEOPLE

Médecins Sans Frontières is working with the Rohingya in Bangladesh, Myanmar and Malaysia. We run activities across eight facilities in Cox's Bazar, including emergency and intensive care, paediatrics, obstetrics, sexual and reproductive healthcare and treatment for conditions such as hepatitis C, diabetes and hypertension.

In Myanmar's Rakhine State, Médecins Sans Frontières runs mobile clinics offering basic healthcare, hospital referrals, treatment for sexual and gender-based violence and psychosocial support to Rohingya, ethnic Rakhine and other groups, and operate in a fixed clinic in Sin Tet Maw camp for internally displaced Rohingya and Rakhine people.

Our services for Rohingya people in Malaysia include primary healthcare and mental health support.

The **UNHCR** estimates that at least **ONE MILLION ROHINGYA REFUGEES AND ASYLUM SEEKERS** from Myanmar are living in neighbouring countries

MEDECINS SANS FRONTIERES has been working with the Rohingya people for **30 YEARS – SINCE 1992 IN BANGLADESH**

According to surveys conducted by Médecins Sans Frontières in Cox's Bazar that year, at least 9,400 Rohingya lost their lives in Myanmar between 25 August and 24 September 2017. More than 6,700 of these were killed by violent means, including an estimated 730 children under five years of age. These figures are considered conservative.

Split between places

The violence of 2017 came after decades of persecution and entrenched discrimination of the Rohingya which has affected all aspects of their lives.

In some areas of Rakhine State which the Rohingya consider their ancestral lands, their presence has been erased. "I feel sad when I drive past where the villages used to be, where [Médecins Sans Frontières] used to provide health services. It is unbelievable to see this land, which used to be so full of life and activity, now desolate," says Mohib. "There is nothing left of the Rohingya villages that were burned down. All traces of the people who lived there have been scrubbed from existence."

An estimated 600,000 Rohingya remain in Myanmar, but thousands are confined to camps, where daily they struggle to afford food, always fearing for their safety while limited freedom of movement effectively denies them access to paid work, as well as education and healthcare.

Faced with such parlous conditions, many have attempted dangerous land and sea journeys to Bangladesh and Malaysia in the hope of a better life.

As refugees in Bangladesh, Malaysia, India, Thailand and other countries, the Rohingya live with complete uncertainty about their future, often dependent on humanitarian aid and vulnerable to further abuse. In Australia, several Rohingya asylum seekers remain in indefinite detention.

What sort of future?

The humanitarian response in Cox's Bazar has been successful in preventing many deaths and assisting the community to access care for major health issues such as infectious diseases and mental health conditions, as well as the basics of food, water and sanitation. But it is a band aid only.

Firoza, a 41-year-old mother living in the camps says the food they receive is not enough for the seven members sharing their makeshift home. "We don't have any source of income… on top of that, my husband isn't well. The insects and dirt give my children skin diseases and we can't find a solution."

"We are in a dire situation," says 25-year-old Nabi, a father of three also living in Cox's Bazar. "I worry about my children and building a future for them. I want education for them. There is no bigger wealth than education.

"We all miss our home terribly… [but] we can only return if the government accepts us as citizens and returns our houses, lands and documents. We want to go to the place where our rights will be ensured."

> "Today, I fear for the future of my community and country under Myanmar's dehumanising, segregated system."

There is international recognition of the need for a durable, regional solution for the Rohingya but five years on there has been no progress towards this.

"Today, I fear for the future of my community and country under Myanmar's dehumanising, segregated system," says Mohib, who believes there is some grounds for hope, after detecting a more sympathetic attitude in some of his fellow country people, following last year's military coup in Myanmar.

"I see a chance for change as people's perspectives on the Rohingya slowly begin to shift."

*Name has been changed.

WHAT DOES IT MEAN TO BE STATELESS?

The Rohingya became the largest stateless population in the world, after Myanmar rescinded their citizenship in 1982.

A stateless person is someone who is not recognised as a citizen by any country, and is unable to claim legal protection or any of the normal entitlements afforded citizens, including the right to education, healthcare, employment, housing, marriage, freedom of movement (for example, to enter other countries) and voting.

Most Rohingya contest that they are stateless, insisting that Myanmar remains their homeland but without the legal status and protections of citizenship, they are exceptionally vulnerable to exploitation and abuse. According to humanitarian affairs coordinator with Médecins Sans Frontières, Gina Bark, this includes trafficking, violence, forced labour and arbitrary detention. "The Rohingya suffer all of these," she says.

"There's a 65-year-old Rohingya man," says Bark, "he said, I'm saying to the world, we are just as human as you. We are requesting the world to help us live as humans.'"

Almost a million refugees, the majority of them Rohingya, have taken shelter in the sprawling camps of Cox's Bazar Bangladesh, where Médecins Sans Frontières work to support their physical and mental health. © Sara Creta, MSF

Doctors on rails

The train's medical team project coordinator, Yasser Kamaledin, prepares for the onboarding and transportation of war-wounded and sick patients at Pokrovsk station. © Andrii Ovod

Médecins Sans Frontières' Dr Guadalupe Garcia Noria, from Mexico, inside the train on its return journey to Pokrovsk, where the team pick up war-wounded patients and transport them to hospitals in the west. © Andrii Ovod

Médecins Sans Frontières staff and members of the Ukrainian Red Cross work together to transfer a critically ill patient onto the specially equipped train. © Kate Geraghty

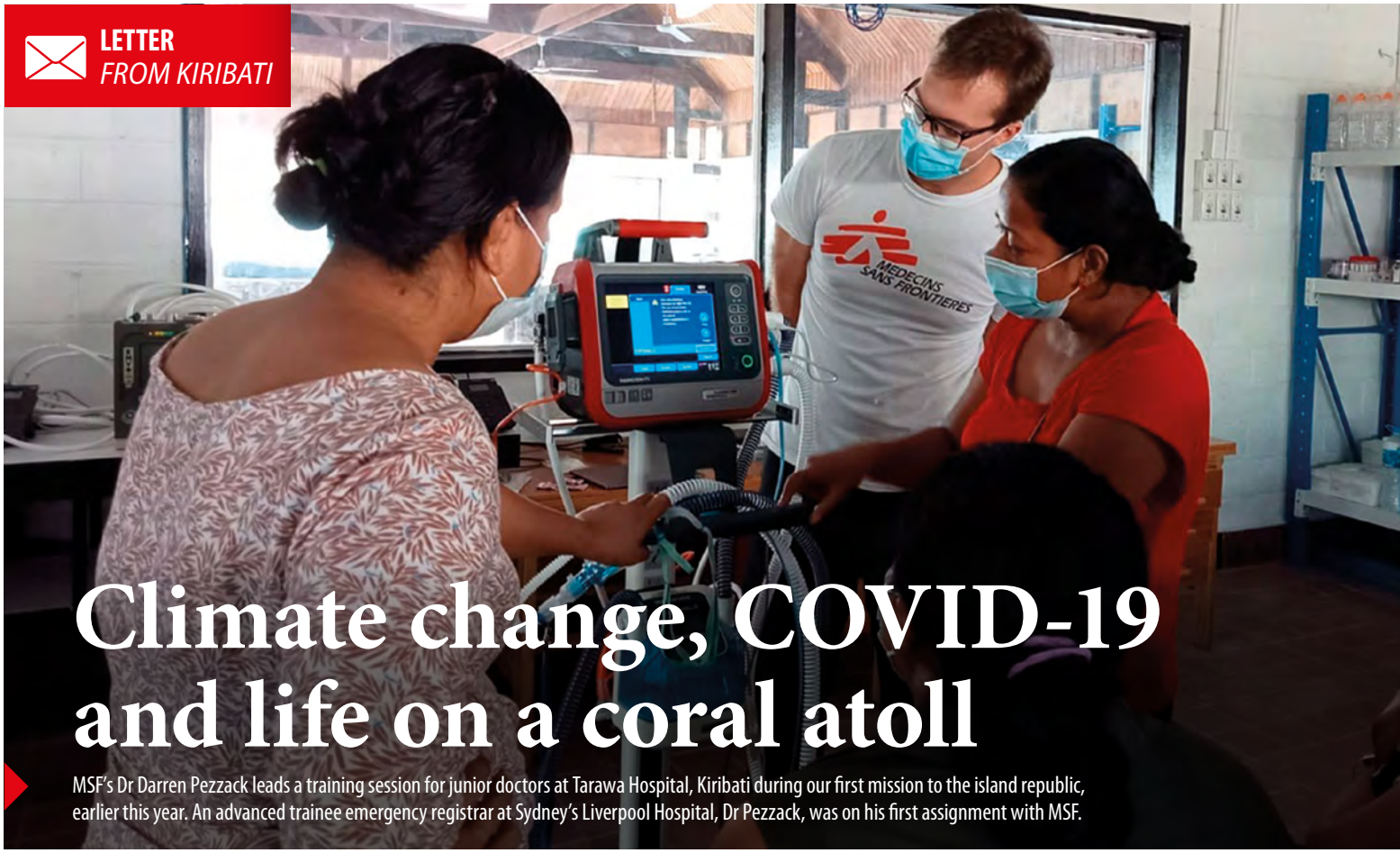
Since March this year Médecins Sans Frontières has used a specially equipped and staffed medical train to transfer over 1,000 critically ill and wounded patients from hospitals under attack in eastern Ukraine to the relative safety of the western region. Developed and operated in collaboration with the Ukrainian Railways and the Ministry of Health, the train has eight carriages including an intensive care unit, enabling our doctors and nurses to monitor patients and keep them stable during the 20-to-30-hour journey. Over 40 per cent of the war-wounded on the train have been elderly people and children with blast wounds, traumatic amputations, shrapnel, and gunshot wounds.

Our doctors and nurses monitor and stabilise a seriously war-wounded patient inside the intensive care unit (ICU) of the train. © Andrii Ovod

Pokrovsk station master, Iryna Serdyuk is comforted by Médecins Sans Frontières staff member (right) after watching ill and wounded patients being transferred onto the medical train for another evacuation from eastern Ukraine. © Kate Geraghty.

Viktor Telsenko 57, who had lost his left arm five days earlier when an artillery shell exploded next to his house in the village of Mykolaivka, waits with his wife Svetlana to board the medical train. © Kate Geraghty

LETTER
FROM KIRIBATI



Climate change, COVID-19 and life on a coral atoll

MSF's Dr Darren Pezzack leads a training session for junior doctors at Tarawa Hospital, Kiribati during our first mission to the island republic, earlier this year. An advanced trainee emergency registrar at Sydney's Liverpool Hospital, Dr Pezzack, was on his first assignment with MSF.

In March Dr Darren Pezzack, an advanced trainee emergency registrar at Sydney's Liverpool Hospital, joined Médecins Sans Frontières' very first team to work in the Pacific Islands nation of Kiribati

There are the three things that stand out for me from my time in Kiribati. The lack of very basic resources available for healthcare; the amazing and positive attitude of the i-Kiribati doctors and nurses; and the reality that is climate change and the very real impact it is already having on people's lives.

This was my first assignment with Médecins Sans Frontières, so I wasn't sure what to expect but we were also breaking new ground in the Pacific, so initially we spent quite a bit of time just explaining who we were and how we worked, what we were there to do, and how we were different from other donors in terms of our independence and neutrality.

Our focus was on strengthening the Kiribati Ministry of Health's COVID-19 preparedness and response, particularly for critically ill patients, supporting critical care and reviewing what kind of support might be useful in the future to enhance primary healthcare.

Impact of climate change

Living and working in the capital, Tarawa, very quickly brought home the very real impact of climate change. It is very crowded and if you drive down the only main road on the island at high tide, the ocean is literally crashing over each side which is pretty eye-opening in terms of planetary health.

A huge number of the current health issues in Kiribati are directly linked to climate change. Rising sea levels is one of the major things that is having a huge impact, particularly on people's access to fresh water which in turn affects their ability to sustain agriculture.

Not being able to grow fresh fruit and vegetables, means most people end up on a very basic diet of rice and whatever protein they can catch from the ocean, which is often deep fried. This is leading to higher incidences of cardiovascular and renal disease.

> "We could instantly see how climate change is changing people's lives and presenting huge challenges."

To witness first-hand what climate change is doing to people's lives and especially their health - you see this in the community, and it is reflected in the hospital and the clinics as well - is quite a powerful insight.

Because the islands are shrinking, there is no room for them to expand or to build anywhere, so everyone is living in cramped quarters, which in turn leads to an increase in communicable diseases such as tuberculosis. There are

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also a lot of scabies outbreaks, especially in children, with the increased risk of streptococcal infection and all the implications for long-term health that goes with that. If you add in the high incidence of diabetes, it starts to explain why so many people end up with such poor renal function.

COVID-19

The biggest challenge we had anticipated - supporting the country to deal with a major outbreak of COVID-19 - never actually eventuated. Luckily, cases were pretty much contained to Tarawa. There were the odd few cases detected in the community but then lots of the other islands never saw the virus and were locked down in their own separate ways.

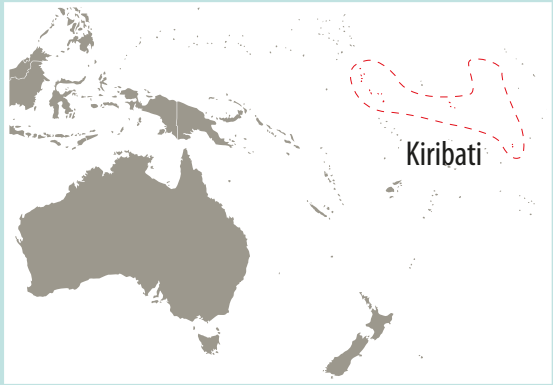
This actually gave us more time to properly assess the country's primary and secondary healthcare systems. The areas that would really benefit from some more support include diabetes and other non-communicable diseases, women's, neonatal and child healthcare and communicable diseases such as tuberculosis and hepatitis B.

Working with limited resources

In reality, there are very few resources available for healthcare. In Tarawa at least there is a hospital, they can do surgery and basic healthcare is available to anyone who needs it, but in the outer islands, which vary from being a 20-minute boat ride to a 14-day trip at sea, there is next to nothing, not even doctors. There are amazing nurses who staff the local clinics. They have had a year's extra training so are known as medical officers, but they have to do everything from diagnosis through to emergency care with very little in terms of medical supplies, equipment, or expertise to support them; not much more than a rudimentary building and some basic medicines.

One of the best aspects of my time in Kiribati was working with the local doctors, nurses and other staff. They were always so positive despite having so few resources to work with. Their approach to things was phenomenal, they were always laughing, always smiling and so receptive. They were just fantastic.

KIRIBATI



Kiribati (pronounced Ke-ree-bas), is a vast but vulnerable island nation made up of three archipelagos in the centre of the Pacific Ocean.

With a total land mass of just 811 km^2, spread over 3.5 million km^2 of sea, only 21 of Kiribati's 33 islands and atolls are inhabitable. More than half the population of 120,000 live in cramped conditions on the main island of Tarawa. The increase in the frequency and intensity of storms and tropical cyclones, the intrusion of salt water with sea level rises, coupled with declining rainfalls and higher temperatures, is rapidly depleting the country's freshwater supplies, directly affecting people's wellbeing, health, and the ability to grow food.

Without climate change adaptation efforts, most of Kiribati's inhabitable islands are expected to be inundated by 2050.

The i-Kiribati, as the people of Kiribati are known, have already started losing their homes and resources critical to their livelihoods, such as coral reefs and fisheries. This is directly impacting their health. There are high rates of non-communicable diseases, with diabetes a particular concern, exacerbated by high rates of obesity. Due to overcrowding, communicable diseases such as TB, hepatitis B and leprosy are also present in significant levels. With the shift away from the traditional diet, acute malnutrition appears to be increasing in children. The country ranks last in life expectancy out of all 20 nations in Oceania. It has the highest infant mortality rate at 88 per 1,000 live births.

SUPPORTER PROFILE

Alice Montague, chief executive, The Clare Foundation: Auckland

When the war broke out in the Ukraine, the Clare Foundation turned to Médecins Sans Frontières because they wanted to work with a trusted organisation that would be on the ground and working alongside Ukrainians quickly.

We were looking for a partner that was well-established, well-respected, professional and could operate very efficiently in challenging situations. So Médecins Sans Frontières was a great fit for us because we could have confidence that they were going to be where the need is greatest.

The foundation is a progressive philanthropic organisation established in 2020 after Anna Stuck decided she wanted to help create a better future for her children and the generations to come.

Anna and our trustees aim to drive extraordinary change for people and the planet. We rely on a small team who are passionate about generating the most momentum and impact possible. Our key areas of focus are the environment, oral health, youth wellbeing and women.

Although the foundation mostly supports work in Aotearoa New Zealand, in times of crisis we pride ourselves on being able to pivot to rapidly generate support for international emergencies and for the organisations we know we can help make a difference.

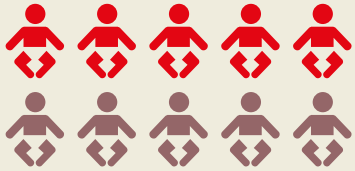
With more than 50 years' experience delivering emergency medical responses all over the world, Médecins Sans Frontières was definitely our 'go-to" when the conflict broke out in Ukraine earlier this year and we were looking at how we could quickly and efficently provide support to the people of Ukraine.

For more information about becoming a Major Donor, please visit **msf.org.nz/donate/other-ways-donate/major-donors**

NIGER

POPULATION: 26 MILLION

MSF STAFF: 1,485



Without treatment at least **50 PER CENT** of children with SCD will **DIE** before their **FIFTH BIRTHDAY**

Advancing care for children with sickle cell disease

Therapeutic patient education sessions are an important part of the package of care for sickle cell disease. Here, Aicha and her son Ibrahim (right foreground) receive information about SCD as they wait with other mothers and children for their follow-up consultation at Madarounfa district hospital, Niger.

In southern Niger, Médecins Sans Frontières has stepped up its collaboration with the Ministry of Health to provide advanced care for sickle cell disease, a life-threatening genetic blood disorder that overwhelmingly affects children in sub-Saharan Africa.

Ibrahim was only eight months old when he started to suffer repeated bouts of pain and fever. Soon after, he was diagnosed with sickle cell disease (SCD).

"He was admitted to hospital for two days," Ibrahim's mother, Aicha Lawali, says of her infant son. "They gave him a blood transfusion and then referred him to hospital for a consultation. That's where I was told he had sickle cell disease."

Ibrahim is one of more than 280 children currently being cared for in regions the SCD program at Madarounfa district hospital supported by Médecins Sans Frontières.

One of the most common genetic diseases worldwide (300,000 babies are born with it each year), SCD is also the most common haemoglobin disorder. Its hallmark is abnormal sickle-shaped red blood cells caused by a mutation in the haemoglobin, the protein carrying oxygen in the cells. Unlike normal round blood cells, sickle cells are hard, and tend to be sticky, clumping together and blocking blood flow. They also have a much shorter lifespan than normal blood cells.

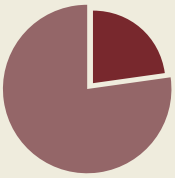
Early death without treatment

At least half of all children born with SCD will die before their fifth birthday unless they are treated.

Ibrahim's first diagnosis was followed two weeks later by a second. "I was told he had the SS gene [indicating sickle cell anaemia]," said Aicha. Sickle cell anaemia is the most common presentation and severest form of SCD.

SCD has many symptoms, including pain crises caused by poor blood circulation and lack of tissue oxygenation, especially the bones. These so-called vaso-occlusive crises, because they involve blocked blood vessels, can be very frequent and intense and affect vital organs. SCD also increases susceptibility to infections. Moderate anaemia is typical in SCD, but in sickle cell anaemia the lack of haemoglobin is severe. Affected children experience fatigue, dizziness, and shortness of breath, and may deteriorate quickly.

Thankfully, Ibrahim was correctly diagnosed early.



Niger Ministry of Health estimates that SCD affects **23 PER CENT** of the population

NORMAL BLOOD CELL

SICKLE BLOOD CELL

NORMAL RED BLOOD CELLS live for approximately **120 DAYS,** but sickle cells live only **10 TO 20 DAYS**

Without diagnosis or treatment, children and their families become trapped in a cycle of medical emergencies and short-lived recovery, according to paediatric advisor Dr Inma Carreras, who is based in Dakar, Senegal.

"You see these patients repeatedly coming and going, for blood transfusions, pain management and intravenous antibiotics. They are always very sick. They are not growing. They have distended bellies because their organs, especially their spleen and liver, have become unusually enlarged due to different complications related to SCD," Dr Carreras says.

> "There's a moment when these children disappear. It's a huge tragedy."

Stem cell or bone marrow transplants are the only cure for SCD, but it is possible to manage symptoms and significantly reduce complications, as the team at Madarounfa hospital has shown these past two years.

Evolving care from 'simple' to 'advanced'

Médecins Sans Frontières has been collaborating with the Nigerien Ministry of Health in Madarounfa since 2014, providing free general and intensive care as well as therapeutic feeding for children aged up to five years. In February 2020, the services were reorganised with the addition of a dedicated outpatient clinic for chronic diseases, offering ongoing management for children, and their families.

For SCD, this involved a 'simple package' of care encompassing diagnosis, patient education, monitoring and follow-up, prevention of sickle cell crises and other complications through malaria prophylaxis, vaccination and antibiotics, and the timely treatment of complications.

This means Ibrahim is not just treated for SCD but for any other health complication such as the cold and malaria that he presented with on his third follow-up.

"They gave me tablets and syrups to look after him," explains Aicha. "His drugs would be too expensive for us if I had to buy them all."

In the first two years of the clinic, over 200 children came under the ongoing care of the 'simple package' treatment, while the joint Médecins Sans Frontières and Ministry of Health team completed preparations to deliver the next level of care.

It wasn't until 1995, exactly 85 years after SCD was first reported, that hydroxyurea was identified as the only drug effective in treating the disease and reducing related crisis events. Nearly 30 years later this remains the case. In Madarounfa, being able to offer treatment with hydroxyurea, and a laboratory testing regimen to monitor a child's response to the dosage, represents a major advance in the level of care available for children such as Ibrahim.

To achieve this, throughout 2021, the team, supported by advisors in the Médecins Sans Frontières medical department, developed advanced tools and protocols, and strengthened lab systems. Hydroxyurea in paediatric formulation was costed, and supply secured. Clinical staff received ongoing education in the care of sickle cell patients, and the outpatient department lead doctor was able to undergo training at a specialty SCD unit in Dakar.

Although the collaboration in Madarounfa is dedicated to free care for children under five, the advanced package embeds a longer-term view, aimed at ensuring that children like Ibrahim at most risk of severe complications can grow with fewer obstacles to live longer, active lives.

"Once a child has been included in the [advanced] program, they will continue to receive follow-up until the age of 15," says the doctor in charge of the paediatric and pathology service, Dr Souleymane Ousmane Yanoussa.

Expanding care for chronic disease

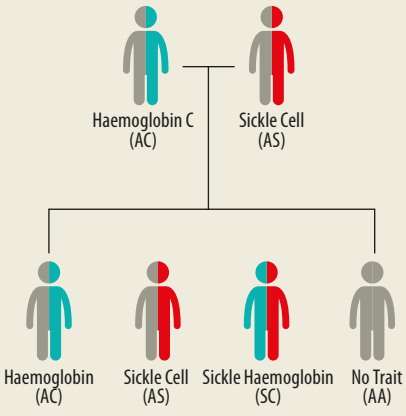
Chronic diseases are on the rise in children worldwide, and Médecins Sans Frontières continues to seek models of care that can help establish ongoing support and treatment for children like Ibrahim that we see in our waiting rooms. In Madarounfa, collaborating with the Ministry of Health and the National Centre for SCD, we look forward to further developing our program, learning more as we link in with other efforts in the region. As our understanding of what we can replicate elsewhere grows, so too can our contribution to ensuring more children with lifelong diseases survive into adulthood with greater quality of life.

SICKLE CELL: AN INHERITED TRAIT

SCD is caused by the sickle cell gene, but not all people with the gene have SCD. People with a single copy of the gene are healthy carriers of only the sickle cell trait, but if both parents carry the trait their child has a 25 per cent chance of developing the disease.

In an evolutionary twist, this same gene is protective against malaria, which is why it continues to survive and be passed on among people living in malaria-affected regions such as sub-Saharan Africa.

In Madarounfa district hospital, rapid testing is now able to identify whether a child has the severest form of SCD, sickle cell anaemia, or another form of the disease.



FIELD WORKER

NAME: Jessa Pontevedra

HOME: Auckland, NZ

Field role: Project medical referent

Our medical doctors can be responsible for a range of activities, including supporting and training host country doctors, and establishing and managing mobile clinics. Frequently working closely with local health authorities and community organisations, they also require strong cross-cultural communication and resource management skills.

Médecins Sans Frontières Experience:

Twenty missions over the past ten years, mainly in emergency teams in many countries. Currently working in Angola as interim medical referent for the emergency cell of Operational Centre Geneva.

March to June and July 2022: Ukraine

A Médecins Sans Frontières doctor examines a patient during a consultation in Médecins Sans Frontières mobile clinic in Zaporizhzhia. © MSF.

"Ukraine is a very resilient country, full of resilient people"

Tell us about your assignment in Ukraine.

The first time I was sent to Ukraine was at the beginning of this year to help set up our emergency response in the eastern side of the country. We were looking at the gaps in and strains on the healthcare system and doing our best to respond to these gaps. I set up two projects. One was for internally displaced people who were trying to flee the conflict zone, these were in the cities of Dnipro and Zaporizhzhia. The other project was more for the people who chose to stay, this project is in the Donetsk region, in the east of the country.

Could you share an example of the impact of the project?

The projects are continuing to provide access to essential care such as medications for non-communicable diseases like diabetes for both the population on the move and those who choose to stay through mobile clinics.

What where some the challenges you faced establishing this project?

With an emergency of such magnitude and in a context that's not so straight forward, finding our space and footing at the very beginning of the conflict was quite challenging.

What stood out for you most about this assignment?

The resilience of the population and resourcefulness and capacity of Ukrainians left a deep impression on me. It is a very resilient country full of resilient people. I was in a car one day with one of our Ukrainian colleagues, we were driving in the eastern region about 25km from the front line. You could hear the shelling not too far away, but I saw these ladies planting flowers on the sidewalk. So, I turned to my colleague, and she very simply said, 'It's springtime and summer is not long. Life goes on, we need the streets to be pretty too'. This and many other examples of efforts to make sure normal life can go on but with the intention of making things better for themselves and others is what I'm continually taking from this mission.

What do you do when not on assignment with MSF?

When I'm not on mission, I divide my time between being home in Auckland, working within the public health system and my farm in The Philippines, where I am trying to do regenerative farming/ permaculture.

ON ASSIGNMENT

Note: This list of field workers comprises only those recruited by Médecins Sans Frontières Australia. We also wish to recognise other Australians and New Zealanders who have contributed to Médecins Sans Frontières programs worldwide but are not listed here because they joined the organisation directly overseas.

AFGHANISTAN
Andrew Dimitri
Medical doctor
NSW

Gail Page
HR officer
SA

Sarah Gnanaseharam
Nurse
NSW

Joanne Clarke
Paediatrician
NSW

BANGLADESH
Arunn Jegan
Head of Mission
NSW

Carmen Macdonald
Paediatrician
ACT

Nicolas Morris
Nurse
WA

Thomas Hing
Logistics Team Leader
NSW

CENTRAL AFRICAN REPUBLIC
Patrick Baffoun
HR Officer
NSW

CHAD
Emma Roney
Epidemiologist
VIC

Isaac Chesters
HR Officer
QLD

HAITI
Lisa Searle
Medical Doctor
TAS

IRAQ
Douglas Kerr
Mental Health Coordinator
NSW

Paul Blackery
Medical Doctor
QLD

JORDAN
Luke Morris
Logistics Coordinator
TAS

KENYA
Sunil Satyavrata
Logistics Team Leader
QLD

Adam Pettigrew
Logistics Coordinator
NSW

KIRIBATI
Lindsay Croghan
Logistics Team Leader
QLD

LEBANON
Anita Williams
Medical Doctor
VIC

LIBYA
Anna Haskovec
Logistics Coordinator
NSW

NIGERIA
Prue Coakley
Head of Mission Assistant
NSW

Candice Lynch
Medical Scientist
NSW

PAPUA NEW GUINEA
Malaika El Amrani
Nurse
NZ

Dominic Roberts
Logistics Team Leader
QLD

PHILIPPINES
Virginia Lee
Medical Coordinator
NSW

William Johnson
Logistics Coordinator
NSW

POLAND
Rodolphe Brauner
Head of Mission
QLD

SOUTH SUDAN
Angela Van Beek
Midwife
QLD

Shaun Cornelius
Logistician
NZ

Tasnim Hasan
Medical Doctor
NSW

Audrey Badaoui
Nurse
NSW

Simon Reid
Paediatrician
NSW

Verity Kowal
Communications Officer
NSW

Emily Young
Nurse
SA

SYRIA
Kitrina Norrish
Medical Scientist
NZ

UGANDA
Kiera Sargeant
Medical Coordinator
SA

UKRAINE
Carol Nagy
Medical Coordinator
TAS

Kathrine Charlton
Nurse
QLD

YEMEN
Shelley Cook
Nurse
VIC

Esther Choi
Midwife
NSW

Caterina Schneider-King
Administration-Finance Coordinator
VIC

Kaylene Tomkins
Medical Doctor
WA

Alyson Penny
Midwife
QLD

John van Bockxmeer
Medical Doctor
WA

Brian Moller
Information And Legal
QLD

Hashim Ali
Logistician
VIC

MULTIPLE/OTHER
Lucy Butler
Administration-Finance Coordinator
NZ

Megan Graham
Administration-Finance Coordinator
SA

Katie Dabbs
Nurse
VIC

In July Médecins San Frontières was among those who successfully called on the United Nations Security Council to renew the cross-border resolution UNSCR 2585. The resolution, which was extended for a further six months, creates the only pipeline for lifesaving cross-border aid into northwest Syria, allowing urgent distributions of food, medical and other supplies such as this one carried out in Idlib, Syria in 2020. @MSF.