

Neglected tropical diseases

How integrated treatment and prevention is paving the way for elimination, improving the lives of millions of people worldwide

Brief



Sightsavers

Now is the time to say goodbye to neglected tropical diseases



Children celebrate during the final trachoma treatment campaign in Yendi, northern Ghana.

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Cover image

A community volunteer gives out treatments to fight neglected tropical diseases in Kudaru, Nigeria.

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A young girl carries a water bucket down a road in Makakoun, Cameroon.

Introduction

Neglected tropical diseases (NTDs) are parasitic and bacterial infections that affect more than 1 billion people worldwide.¹

These painful conditions can cause severe and lifelong physical and visual impairment and are most prevalent in rural regions, poor urban locations and areas of conflict.

As well as physical symptoms, NTDs can trap people into poverty by affecting their ability to work, get an education or interact with others.

The work of Sightsavers and partners shows that these diseases can be prevented, treated and eliminated. Together, we're working to deliver NTD programmes in 32 countries and fighting five debilitating NTDs.

We work with thousands of local volunteers – known as 'community-directed distributors' (CDDs) – to give out millions of donated medicines to people at risk of NTDs and teach them about the importance of good hygiene to prevent infection. Unprecedented support from the pharmaceutical sector, in the form of large-scale drug donations, is fundamental to this work (for more on this see page 15).² We also support a range of interventions that help people with an NTD manage their symptoms.

Often people live in areas where more than one NTD is present so, where possible, we target several diseases together using an integrated approach. We are proud to have supported more than 1.2 billion NTD treatments to date.

The NTDs we are working to eliminate



Trachoma is the leading infectious cause of blindness in the world. Infection spreads through personal contact (via hands, clothes or bedding) and by flies that have been in contact with discharge from the eyes or nose of an infected person. Improving water, sanitation and hygiene (often referred to as 'WASH') can stop the disease from spreading.

The disease starts off as an eye infection similar to conjunctivitis that can be easily treated with medication. If left untreated, repeated infections will turn the eyelashes inwards (trachomatous trichiasis) and scrape against the eye, causing tremendous pain and, eventually, blindness. Those with advanced trichiasis need surgery to save their eyesight.



River blindness also known as **onchocerciasis**, is a parasitic infection that can cause severe skin irritation, itching, visual impairment and irreversible blindness. It is spread by the bite of infected black flies that breed in fast-flowing rivers. Medication can prevent the disease from spreading; it won't cure blindness but it can stop any further sight loss.



Lymphatic filariasis is a parasitic infection that is transmitted to humans by mosquitoes. Those living in at-risk areas are usually first infected during childhood. The disease can result in an altered lymphatic system and the abnormal enlargement of body parts, which is painful and leads to permanent,

physical changes – a condition called lymphoedema. The stigma associated with the disease can have devastating impact on those affected. Although people suffering from advanced lymphatic filariasis cannot be cured, the symptoms can be eased through surgery and care.



Schistosomiasis, also known as bilharzia or snail fever, is caused by parasites released by freshwater snails that can enter people's skin when they come into contact with contaminated water. And, when infected people excrete into the water, the contamination cycle continues. Initial symptoms include a rash or itchy skin, and later a fever.

The disease can be treated using medication, but if left untreated it can go on to damage the intestine, bladder, liver, lungs and spleen. It can also cause anaemia, malnutrition and learning disabilities in children.



Intestinal worms, also known as soil-transmitted helminths, are one of the most common forms of infection worldwide and is often transmitted by eating contaminated fruit and vegetables. People with intestinal worms can become malnourished and more susceptible to disease, chronic illness and infertility.

Medication can treat people with intestinal worms, while improved WASH activities can stop the disease from spreading.

NTDs: facts and figures



More than **1 billion people** are at risk of NTDs³

They are endemic in **149 countries**⁴



Trachoma⁵

137 million people globally are at risk

1.9 million people are living with blindness or visual loss caused by the disease

2 million people urgently need trichiasis surgery to avoid blindness



River blindness⁶

217.5 million people globally are at risk

20.9 million people are actively infected

1.1 million people are living with blindness or visual loss caused by the disease



Lymphatic filariasis⁷

893 million people globally are at risk

120 million people are currently infected

40 million people have symptoms



Schistosomiasis⁸

229 million people globally are at risk

200,000 people die from the disease every year



Intestinal worms⁹

1.5 billion people (around a quarter of the world's population) are infected

This includes **267 million preschool-age children** and **568 million school-age children**



Sightsavers' impact

Sightsavers is supporting **32 countries** to tackle NTDs

We have provided **1.2 billion treatments** since our NTD work began

In 2019, we supported:

142.5 million NTD treatments with donated medicines

43,200 surgeries

The global context

Treating, controlling and eliminating NTDs is a global challenge that requires collective solutions.

In the 2000s, the World Health Organization (WHO) released a strategy to combat NTDs as a group of diseases. Before this, NTDs tended to be addressed separately.

Work to control and eliminate these diseases began accelerating in January 2012, when the WHO published an NTD roadmap, setting targets and associated milestones towards the control, prevention, elimination and eradication of certain NTDs by 2020.¹⁰

On 30 January 2012 – the same day as the roadmap's release – governments, donors, pharmaceutical companies, research institutions and NGOs met in the UK to forge a landmark global agreement to act on NTDs, known as the London Declaration on Neglected Tropical Diseases. The original endorsers of the London Declaration – today collectively

known as *Uniting to Combat NTDs* – have since been joined by more than 80 other organisations from across the world.¹¹

The events of 2012 ignited action in many countries. Progress towards control and elimination gained pace and 32 countries eliminated at least one NTD. This is an incredible achievement, brought about by one of the largest public health initiatives ever seen.¹²

Three years later, in 2015, WHO unveiled a further global action plan against NTDs, calling for better integration with the WASH sector.¹³

On 30 January 2020, eight years to the day of the London Declaration, the first-ever World NTD Day was celebrated. The same year, WHO unveiled a new NTD roadmap designed to drive progress until 2030.¹⁴

Seventy years of treating NTDs

Sightsavers has been working to protect people from NTDs since the 1950s.

This work included surveying northern Ghana and northern Nigeria to establish how many people in those areas were blind and how to prevent others from losing their sight. The survey found trachoma and river blindness to be two of the most common causes of blindness in the region.

This early work also involved some of the very first research into the flies that spread river blindness.¹⁵ Lady Jean Wilson, who co-founded Sightsavers with her husband Sir John Wilson, coined the name 'river

blindness' during a trip to northern Ghana after being bitten by a swarm of black flies.

In the 1980s, Sightsavers was instrumental in multi-country research to develop the best method for providing mass river blindness treatment to communities over a number of years. This resulted in the CDTi approach, which stands for 'community-directed treatment with ivermectin' – the medication used to treat the disease. This now forms the bedrock of river blindness control and elimination work.

It also provides the model on which large-scale treatment distribution for other NTDs (often referred to as 'mass drug administration' or MDA) is based.

The community-directed approach has been successful because it enables people most affected by NTDs to distribute treatment using a method best suited to their circumstances. Because communities have ownership of the process, and CDDs are specifically chosen due to their respected standing, treatment distribution is more likely to continue and be effective. This enables progress to be sustained.

When the success of the CDTi approach for treating river blindness began to take off it became apparent there was a need to ensure MDAs were well-coordinated and best practices shared. This led to the establishment in 1991 of the Non-Governmental Development Organisation (NGDO) Coordination Group for the Control of Onchocerciasis, of which Sightsavers is a founding member, and which assists national programmes. The group has been instrumental in scaling-up treatment. In 2013 the group's name was changed – the word 'control' replaced with 'elimination' – indicating just how far efforts have come in the 20 years since its inception.

Sightsavers has also played a pivotal role in the advancements made on eliminating blinding trachoma. Since the 1990s we have been instrumental in helping to pioneer WHO's 'SAFE' strategy of trachoma elimination (surgery, antibiotics, facial cleanliness and environmental improvements) in endemic countries.

In 2004 we helped to establish the International Coalition for Trachoma Control (ICTC), a group of donors, governments from endemic countries, international development organisations and pharmaceutical companies, which is driving

progress to end trachoma as a public health problem around the world.

A huge amount has been achieved in the fight against trachoma so far. Since 2002, the number of people at risk has fallen by 91 per cent¹⁶, and nine countries have eliminated trachoma as a public health problem¹⁷. In 2018, Ghana became the first country in sub-Saharan Africa to announce elimination. We are proud that Sightsavers-supported programmes played a key role in reaching this historic moment.

In the same year, 151.8 million people were treated globally for river blindness. One out of every four people who received treatment did so through a Sightsavers-supported programme.



Bopda Jean testing skin snips in Yaounde's laboratory.

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Josina Mate (left) prepares to take a dry blood spot sample, while Américo Hanguana (right) enters a survey participant's information into the mobile phone data collection software.

Our key NTD strategies

Disease mapping

Sightsavers has been working with partners to develop stronger, more efficient ways of mapping the spread and transmission of NTDs to ensure treatment and other interventions are as targeted and effective as possible. This includes the Global Trachoma Mapping Project (the largest infectious disease survey ever undertaken), the WHO-led Tropical Data initiative, and the onchocerciasis elimination mapping project (see page 17 for more on our mapping work).

Integrated treatments, distributed by communities

We have helped to mobilise a vast network of volunteer community-directed distributors (CDDs) who are trained to provide medication en masse, often treating several NTDs at once. CDDs are known and trusted by local people and are

effective at raising awareness of how NTDs can be transmitted and prevented, including the need to take preventative medication.

Some CDDs are also trained as case finders so they can identify people with active symptoms who may need further treatment and care. Because children are particularly vulnerable to schistosomiasis and intestinal worms, we also work with teachers to distribute these integrated treatments in schools.

Water, sanitation and hygiene (WASH)

Sightsavers works with partners across various sectors to deliver WASH activities to help shape the behaviours that protect people from NTDs. This includes using latrines and washing hands and faces with water and soap. Other protective measures include boiling or filtering water for drinking or bathing, and safely handling fruit and vegetables.

Digital health

Sightsavers is using digital technology to help eliminate a number of NTDs, and to change the way we work for the better. Digital health initiatives are helping to increase the quality of data being collected and the speed at which it can be accessed. Digital applications are enabling Sightsavers' teams working in remote areas to collect information about people's eye health to improve their quality of care, while real-time monitoring software is keeping the mass distribution of NTD treatments on track.

Our digital health work includes the development and use of the TT Tracker. This is improving the quality of trachoma eye care by enabling health workers to collect and analyse information about patients' operations. It also helps them locate those who are in need of follow-up visits, and gives them an up-to-date view of the surgeries being conducted and their outcomes.

Health systems strengthening

We work to ensure our NTD activities contribute towards the broader sustainable health and development agenda. This includes supporting state and national ministries of health to train surgeons and health care staff, providing equipment, helping to gather data, developing ways to monitor health, streamlining drug supply chains and raising awareness about the causes and treatments of NTDs.

Reaching people who are marginalised, in remote areas or in places of conflict

A large proportion of people who are at risk of NTDs live in remote areas or places of conflict where there is poor access to health care, clean water and sanitation.

Reaching people in these areas can be difficult. To ensure no one is left behind

we support mobile eye health teams who will travel long distances, often through hazardous or dangerous terrain, to reach people in need (read about our work in conflict-affected Yemen on page 19).

We also work to ensure marginalised groups, such as people with disabilities, do not miss out on services. For instance, in some areas we may focus on recruiting local women to be CDDs as they will be more likely than men to be permitted entry into people's homes.

Research

Research is at the heart of everything we do. We conduct research, listen to recommendations, and drive new practices to ensure we are constantly improving NTD programmes. In 2017, Sightsavers was awarded Independent Research Organisation status by Research Councils UK, making us the only international non-governmental organisation working in this field to hold the status in the UK.



A woman and child collect water in Yendi, northern Ghana.

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The dose pole

The dose pole is a simple, lightweight device used to measure the height of men, women and children so that the CDDs can calculate the correct dosage of NTD medication to give them. By measuring a person's height, rather than their weight, drug distributors don't need to carry heavy scales, which are more expensive and can be difficult to read.

The dose pole is often decorated in patterns, colours and markings unique to the community, and can be made from a variety of materials.

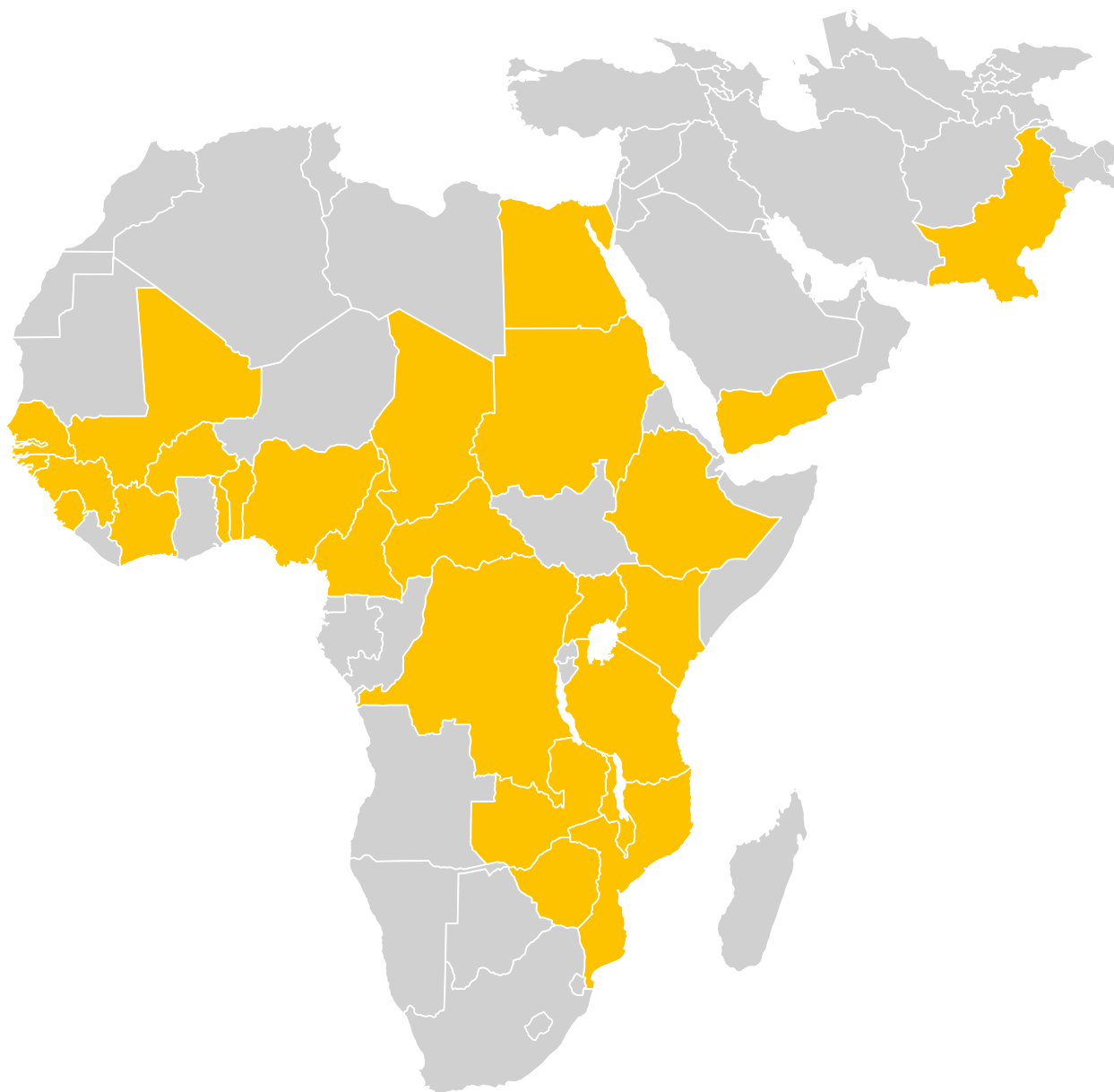
CDD Baraka Ango, from Kudaru in northwest Nigeria, says: "When the community see us with this stick, they will say: 'Health worker, you are coming, we will come and collect our drugs.' They are happy to see us with this stick. I love this stick because it represents us as CDDs in our community."





Dorcas (middle), Baraka Ango (left) and Dunladi Ishaku (right) celebrate as Sightsavers and partners' one billionth treatment for NTDs is delivered in Kudaru, Nigeria.

Where we work



Benin
Burkina Faso
Cameroon
Chad
C. African Republic
Côte d'Ivoire
DRC

Egypt
Ethiopia
The Gambia
Guinea
Guinea-Bissau
Kenya
Malawi

Mali
Mozambique
Nigeria
Pakistan
Sudan
Senegal
Sierra Leone

Tanzania
Togo
Uganda
Yemen
Zambia
Zimbabwe



Community volunteers in Zamfara State Nigeria. L-R bottom row: Maryam Ibrahim, unknown, Aisha Dahiry, Zainab Hamza, Maryam Hamisu. L-R top row: Hannatu Usman, Maryam Umar, Hadiza Ibrahim.

The value of partnerships

We are proud to work with a network of more than 300 partners to prevent, control and eliminate five NTDs in 32 countries.

Sightsavers is recognised as a leader in consortium management – the model used by many NTD programmes, due to their vast size and complexity.

Partnership is essential at all levels of any NTD programme. At the highest levels, Sightsavers and partners work with and support ministries of health and national authorities. But we must also form partnerships at the district and community levels, to make sure our programmes are accepted by the communities we are serving.

Platforms such as the Neglected Tropical Disease NGO Network (also known as ‘the NNN’) enable us to share knowledge and increase the efficiency and effectiveness of our programmes.

Coalitions and networks such as the International Coalition for Trachoma Control allow us to collaborate with other organisations, ensuring work is not duplicated, reaching more people in need with greater efficiency.

Critical to our NTD work is the support we receive from donors, trusts and foundations, corporate partners and fellow international development organisations.

Public-private partnerships have led to remarkable progress against NTDs. For instance, some of the world’s largest pharmaceutical companies have pulled together to create the largest drug donation programme in history.



Support team and trainer Anthony Solomon screens a child at the at the Tropical Data Refresher Training in Oltukai village, Monduli District, Arusha, Tanzania

Programmes

Sightsavers is working to eliminate NTDs through the following ambitious multi-million-pound programmes.

Accelerate trachoma elimination

Accelerate is a huge collaborative effort led by Sightsavers, which aims to support Benin, Botswana, Burkina Faso, Cameroon, Guinea-Bissau, Guinea, Namibia, and Senegal to eliminate trachoma as a public health risk. The programme also aims to make significant progress towards trachoma elimination in Côte d'Ivoire, Ethiopia, Kenya, Nigeria, Tanzania and Zimbabwe.

Accelerate will also build on ground-breaking research into the link between the antibiotic used to treat trachoma and a reduction in childhood mortality, strengthen global and national health systems to sustain elimination, and integrate information and delivery systems with other NTDs for stronger surveillance.

Ascend West and Central Africa

Ascend is UK aid's flagship NTD programme and Sightsavers' largest multiple-disease programme to date. The three-year initiative will make major progress towards eliminating five NTDs by working with communities, ministries of health and partners in Benin, Burkina Faso, Central African Republic, Chad, Côte d'Ivoire, Democratic Republic of Congo, Ghana, Guinea, Guinea-Bissau, Liberia, Niger, Nigeria and Sierra Leone.

Along with consortium partners, Ascend will deliver over 400 million treatments.

GiveWell

This fund is providing preventative treatments for schistosomiasis and intestinal worms to children in Nigeria, Guinea, Guinea-Bissau, Cameroon, and the Democratic Republic of Congo. GiveWell-directed funding has supported the distribution of more than 11.8 million deworming treatments to over 8.7 million school-age children. (See page 19 for more on GiveWell.)

Tropical Data

Since 2016, WHO's Tropical Data project has worked in 44 countries and examined six million people, enabling numerous ministries of health to pinpoint exactly where to provide trachoma treatment and when to stop it because interventions have been successful. It is also helping countries to gather crucial evidence on trachoma elimination to submit to WHO. Sightsavers plays a key role in the programme alongside a consortium of partners.



Silvia Danga enters survey information into the mobile data collection software during the OEM project in Mozambique.

Onchocerciasis elimination mapping (OEM)

This records where river blindness is prevalent and where MDAs would be most effective. In 2019, OEM was piloted in Ghana and Nigeria. It has since been implemented in Mozambique, and is the first time river blindness has been mapped in the country using modern techniques. Sightsavers leads the programme in coordination with local communities, ministries of health, WHO, the Task Force for Global Health, the Bill and Melinda Gates Foundation and many other partners.



Twelve-year-old James undergoes trachoma surgery at an open air site in Kamunyaep village, Kenya.



Zanabu Seidu dances and sings with joy after having her sight restored through surgery.

Success stories

Eliminating trachoma in Africa

In June 2018, Ghana became the first country in sub-Saharan Africa to eliminate trachoma. We have been working with the government to tackle NTDs in Ghana since the 1950s and played a key role in accelerating elimination efforts between 2000 and 2017.

Other African countries are now close to reaching this milestone. Malawi and The Gambia are currently in a two-year surveillance period, after which WHO will confirm trachoma has been eliminated as a public health problem.

Both countries' efforts have been supported by large-scale trachoma elimination programmes co-ordinated by Sightsavers, such as The Queen Elizabeth Diamond Jubilee Trust's Trachoma Initiative, which ran between 2012 and 2019 and significantly contributed to elimination efforts in seven African countries.

The Trust was a time-limited charitable foundation established in 2012 to mark Her Majesty The Queen's Diamond Jubilee. In January 2020, the Trust successfully completed its programmes and ceased operating as a grant-making organisation.

Our one billionth NTD treatment

In December 2017 Sightsavers and partners celebrated a historic milestone: the delivery of our one billionth treatment. This was an integrated antibiotic treatment for river blindness and lymphatic filariasis, which was given to Dorcas, a seven-year-old from Kaduna State in Nigeria, through the UK aid-supported UNITED programme. The programme, which ran between 2013 and 2019, delivered 158 million treatments in Nigeria to tackle NTDs.

Dorcas' grandfather, Simon, was infected with river blindness 30 years ago and is now completely blind.

"I love my grandfather very much and don't want other people to suffer like him," said Dorcas. "I hope that one day, all children will be free from these diseases."

Sightsavers was honoured to have the late Professor Stephen Hawking, whose own father pioneered research on lymphatic filariasis, speak at an event to mark our one-billionth treatment.

He said: "Sightsavers and its partners have taken one billion steps towards combating NTDs... the last mile on the journey to

elimination is always the most difficult... much still remains to be done if we are to reach our elimination targets... During my life I have learned that, if we put our minds to it, success can be within our grasp. I wish Sightsavers good luck with its immense challenges.”

A breakthrough in Yemen

In 2018 Sightsavers started working in Yemen to distribute trachoma treatments. The country has experienced years of civil war and many people are unable to access clean water or sanitation, putting 2.5 million people at risk of trachoma.

More than 444,000 doses of the trachoma treatment were driven by local health officials through conflict zones and past roadblocks to reach the rural Al Hodeidah and Ibb regions in the west of the country. A team of more than 4,000 local volunteers went door to door through 270 villages to ensure the medication was given safely to those who needed it.

Reaping the benefits on river blindness

Programmes supported by Sightsavers have been instrumental in significant progress being made on river blindness in several

countries. For example, in 2018 Uganda announced that four million people in the country were no longer at risk of the disease after it had been removed from 14 out of the 17 areas where it was previously common. Sightsavers has been working to combat river blindness in Uganda since 1954 and has been crucial in supporting the country to reach this milestone.

In 2019, Nigeria – home to around one quarter of all those at risk of river blindness globally – eliminated the disease from Kaduna, Nassarawa and Plateau states, where 4.2 million people had previously been vulnerable. This significant step was taken with support of the UNITED programme.

Recognising the quality of our work on schistosomiasis and intestinal worms

We are proud to be recommended by charity evaluator GiveWell as one of only eight ‘top charities’ globally, in recognition of our work on treating children in sub-Saharan Africa for parasitic worm infections. GiveWell recommends us for the “strong track record and excellent cost-effectiveness” of our deworming work and our standout record of transparency.



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Our plans

In 2020 and beyond, collaboration between partner organisations is more important than ever in the journey to eliminate NTDs. We will continue to work in partnership to ensure health care systems are strengthened from the inside, enabling prevention and treatment for NTDs to reach those who need it, and ensuring the gains that have been made are sustained.

We will also continue to reach out across sectors so that the problems at the root of NTDs – access to clean water, sanitation facilities and education – can be effectively addressed.

In 2020, the profound effects of the COVID-19 pandemic resulted in some

of our NTD programme activities being paused. Sightsavers is working with partners, governments and communities on restarting NTD services when it is safe to do so. We are also adapting some NTD programmes to support the COVID-19 response, using the technical expertise, systems, staff and volunteers developed through our NTD work.

By prioritising innovation and partnership-working, and by responding to the needs and priorities of the communities and countries in which we work, our NTD work will continue to thrive now and in the future, enabling millions of people to enjoy lives that are free of these debilitating diseases.

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Lamik teaches little sister Grace how to wash her hands and face in Chikankata, Zambia.



A group of people walk through a village in the Yendi region of Ghana.

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We work with partners
in developing countries to
eliminate avoidable blindness
and promote equal opportunities
for people with disabilities.

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