

Trachoma

Eliminating an ancient, blinding disease affecting millions

Brief



Sightsavers

Now is the time to say goodbye to neglected tropical diseases



Twelve-year-old James Ekai reads to his sister from a book written in braille outside of their home in Kalobeya village in the Turkana region of Kenya.

Contents

4
Introduction
.....

6
The history of trachoma
.....

9
Facts and figures
.....

10
Living with trachoma
.....

12
Treatment and prevention
.....

12
Our work
.....

13
Trachoma elimination: one
of the world's largest public
health initiatives
.....

16
Delivering successful programmes
by working in partnership
.....

22
Our focus areas moving forwards
.....

23
References
.....

Cover image

Samuel Seyoum checks Sarem Yibgeta's eyes for signs of trachoma outside her home in Gurage, Ethiopia.

© Sightsavers/Peter Nicholls



Trachoma patients Amina Seif Likula (left) and Jalina Hamis Seif (right) after surgery at the surgical camp in Chunyuu village, Ruangwa, Tanzania.

Introduction

Trachoma, one of the world's oldest diseases, is a painful eye condition that can cause visual impairment and, if not treated, irreversible blindness. It affects millions of people living in the poorest and most rural communities.

The disease is caused by the bacteria *chlamydia trachomatis*. It is spread through contact with infected flies and via hands, clothes or bedding that have been in contact with an infected person.

Symptoms include redness of the eyes, irritation and discharge. If left untreated, repeated infections can cause scarring that can turn a person's eyelashes inwards (a condition known as trachomatous trichiasis). With every blink the eyelashes scrape against the ball of the eye, and can slowly and excruciatingly lead to blindness.

About 1.9 million people in the world are blind or visually impaired due to trachoma, and 137 million people are at risk of losing their sight from the disease.¹ The agonising pain of trachoma and the visual impairment it causes can stop children from going to school and adults from earning a living. This can trap whole communities in a cycle of poverty with the disease leading to an estimated US\$8 billion in loss of productivity.²

Yet trachoma is both preventable and treatable. Through the World Health

Organization's (WHO) 'SAFE' strategy (Surgery, Antibiotics, Facial cleanliness and Environmental improvements), endemic countries are tackling the disease. A huge amount has been achieved so far: the number of people at risk of trachoma has fallen by 91 per cent since 2002³, and nine countries have been validated by WHO as having eliminated trachoma as a public health problem⁴.

However, there is still work to be done. Sightsavers is working with communities, ministries of health, donors, pharmaceutical companies and partners in 27 countries to eliminate trachoma as a public health problem. Through ambitious and effective programmes we aim to help eliminate this disease in most of the countries we support by 2025.

It's a historic time. As more and more countries stand poised to reach elimination targets, the end of this ancient disease could finally be within our grasp.



Dr Amadou checks Gani Dao's eyes for signs of trachoma in the Nikki region of Benin.

The history of trachoma

.....

1



Trachoma can be traced back to the Ice Age. Archaeologists in Australia found skeletons with markings consistent with trachoma-like symptoms. Hieroglyphs in Nubian tombs show a weeping eye next to tweezers – a device sufferers still use today to pluck out eyelashes to relieve the pain. Echoes of trachoma can also be found in ancient Greece: Plato is the first thinker on record to have described trachoma as infectious.

2



Many countries have suffered from trachoma through the centuries. In 1805, Moorfields Eye Hospital opened in London to treat trachoma. The disease had become a serious health issue in the UK and Europe spread by soldiers returning from the Middle East. Charles Dickens depicts the devastation of the disease in his novel *Nicholas Nickleby*.

3



People would try many home remedies to treat trachoma. These included fish bile and ‘bloodletting’ (cuts made near the eye to allow blood to flow). It wasn’t until the 20th century that the bacterial cause of trachoma was discovered, enabling it to be treated with antibiotics and through improved hygiene and sanitation.

4



In the early 1990s, antibiotic trials signalled a breakthrough. Azithromycin is now donated by pharmaceutical company Pfizer under the brand name Zithromax® through a scheme managed by the International Trachoma Initiative. This antibiotic is now used across the world as whole communities are provided with the treatment en masse.

5



WHO established the SAFE strategy to eliminate the disease. In 1996, donors, governments from endemic countries, international development organisations and pharmaceutical companies committed to work together to end trachoma as a public health problem around the world. A group called the International Coalition for Trachoma Control (ICTC), of which Sightsavers is a founding member, was established to implement the SAFE strategy. See more on page 13.

6



In 2012, WHO set out ambitious neglected tropical diseases (NTDs) elimination targets. That year, Oman became the first country to officially eliminate trachoma as a public health problem, indicating the effectiveness of the SAFE strategy. Morocco announced elimination in 2016, followed by Mexico, Cambodia and Laos in 2017. In 2018, Ghana became the first country in sub-Saharan Africa to eliminate the disease. In the same year, Nepal and Iran were declared trachoma-free.

7



Trachoma remains endemic in 44 countries. Sightsavers is continuing to work with a variety of partners to deliver the SAFE strategy, helping consign blinding trachoma to the history books and prevent it from depriving future generations of their sight.



Maryam's story

Maryam lives with her family in northern Nigeria, a country that has the second highest level of trachoma worldwide.

Abubarkar Mohammed, Maryam's father, said he noticed his daughter was having problems with her eyes which were constantly tearing up.



"I don't know what caused it, but it started about three years ago and it's getting worse. She is worried because she sees all her friends doing well without this problem. I am very worried, but I don't have any means of solving the problem."




Trichiasis patient, Maryam Abubakar, after surgery at Gwadabawa health clinic, Sokoto state.




Her father said: "I was so happy when I heard she could be treated. If it was not cured, it would affect her life – it would lead to her going blind."

Maryam was seen by a Sightsavers ophthalmic clinical officer and was diagnosed with trichomatous trichiasis, the advanced stage of trachoma: it causes scar tissue to develop under the eyelid, which eventually causes them to turn inwards. With every blink, Maryam's eyelashes were painfully scraping the surface of her eye. But thanks to support from UK aid, Maryam received sight-saving surgery.


Facts and figures


 **137** million people globally are at risk of trachoma

 **44** countries name trachoma as a public health problem


 **1.9** million people are blind or visually impaired because of the disease


 **US\$8** billion is estimated to be lost in productivity due to trachoma every year

 **2.5** million people urgently need trichiasis surgery to avoid blindness


 **91%** decrease of people at risk of trachoma between 2002 and 2020⁵

Since 2001, Sightsavers has helped to provide...

 **154 million** Tetracycline or Zithromax[®] antibiotic treatments for trachoma infections

More than **463,000** trachoma trichiasis surgeries to restore people's sight 

Our trachoma treatments represent excellent value for money...

 Sight-saving trichiasis surgery costs about **£44**

Providing donated trachoma antibiotics through the mass administration of treatment costs just **15p** per person



Dafiya sits with her daughter-in-law, Abaoulaye, who helps her cope with trachoma.

Living with trachoma

Trachoma disproportionately affects women and children as it is easily passed from person to person through touch. Once the eyelashes start to scrape the eyes, the pain is so intense that many people resort to pulling out their eyelashes to reduce the agony of blinking.

The pain and disability that trachoma causes can lead to a cycle of poverty, limiting many people's access to health services, education and employment. For women living in societies with traditional gender roles, this leads to a further loss of independence and makes it extremely difficult to care for children and other family members.

Trachoma's impact on women and children



Globally, women are up to **nearly two (1.8) times** more likely to be blinded by trachoma than men.



By the time a woman loses her eyesight to trachoma, she has usually been infected **130** times.



60 to 90 per cent of pre-school-age children in endemic countries suffer active trachoma infections.



How trachoma affected three generations of women

Eighteen-month-old Bibie, her mother Mayasa and grandmother Aluna live in a remote village in Ruangwa, Tanzania. All three were diagnosed with trachoma after Sightsavers came to Ruangwa as part of a UK aid-funded trachoma programme.

Aluna, aged 70, was diagnosed with advanced trachoma and was very close to losing her sight completely and permanently. Her 29-year-old daughter, Mayasa, also had advanced trachoma. She had not yet reached the blinding stage of the disease, but discharge in the eye had almost caused her eyelids to shut entirely and she was experiencing excruciating pain on seeing light. Bibie, Mayasa's daughter, also displayed early-stage trachoma symptoms despite being so young.

"I feel bad [about my sight]," said Aluna. "It takes so much time and energy to do so many things, but I have to find a way to do things or we will starve. I cannot wait to have surgery. My life will change

so dramatically if I can see. I really want to see the sun, how it shines, and everything else."

Aluna and Mayasa received surgery at a local health centre. Following the operation, Aluna was no longer in pain and still had some sight. The surgeon said Mayasa's case was one of the worst he has ever seen in a young woman, but after her operation more than 70 per cent of her vision was saved.





Bibie was given antibiotic ointment which cleared up her infection. Thanks to this intervention, she will break the cycle and not have to suffer the same pain and visual impairment as her mother and grandmother.



(Left to right) Aluna, her daughter Mayasa, and Mayasa's baby daughter Bibie, from Likuyu, Ruangwa, Tanzania. All had symptoms of trachoma and were given treatment thanks to a UK aid-funded programme.

Treatment and prevention

Sightsavers uses the World Health Organization-endorsed **SAFE** strategy to help eliminate this disease.

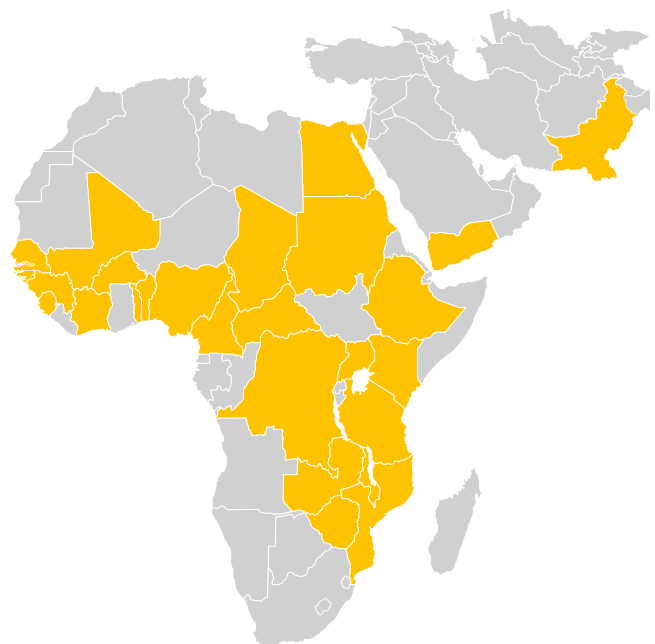
-  **Surgery:** Eyelid surgery stops the eyelashes rubbing against the cornea, treating those at risk of blindness.
-  **Antibiotics:** Zithromax®, donated by Pfizer, is distributed throughout the community to treat active infections.
-  **Facial cleanliness:** Promoting good hygiene and face washing raises awareness of how trachoma is spread.
-  **Environmental improvements:** Proper sanitation for disposal of human waste reduces the number of flies, and clean water helps with face washing and personal hygiene.

The **SAFE** strategy aims to treat existing trachoma cases and prevent new infections from occurring. To be effective, all four elements are needed in the community, including the preventative F&E (facial cleanliness and environmental improvement) aspects, which are often underplayed.

Without water, sanitation and hygiene (WASH) improvements, medical interventions will stall and there is a risk that trachoma could return to a community. For example, a study in rural Ethiopia found that children with dirty faces were 18 times more likely to have active trachoma than those with clean faces.

Our work

Sightsavers has been working to treat and prevent trachoma in Africa and Asia since 2001. With the help of our partners, each year we support thousands of sight-saving trichiasis surgeries and distribute millions of antibiotic treatments through mass drug administration (known as MDA), where treatment is given to whole communities and populations regardless of whether they have trachoma.



Countries where Sightsavers is working to eliminate trachoma

- | | |
|---------------------|---------------|
| Benin | Ethiopia |
| Burkina Faso | The Gambia |
| Cameroon | Guinea |
| Chad | Guinea-Bissau |
| C. African Republic | Kenya |
| Côte d'Ivoire | Malawi |
| DRC | Mali |
| Egypt | Mozambique |
| | Nigeria |
| | Pakistan |
| | Rep. Sudan |
| | Senegal |
| | Sierra Leone |
| | Tanzania |
| | Togo |
| | Uganda |
| | Yemen |
| | Zambia |
| | Zimbabwe |



Tropical Data grader, Misa, screens a child at a trachoma screening camp in a Maasai community in Oltukai village, Monduli District, Arusha, Tanzania.

Trachoma elimination: one of the world's largest public health initiatives

The global effort to control and eliminate trachoma as a public health problem through the SAFE strategy is one of the largest public health initiatives ever undertaken.

When a country believes trachoma has been eliminated as a public health problem, its ministry of health or relevant body must submit evidence to WHO in the form of an elimination dossier. An international committee of experts will then assess the dossier before elimination is validated by WHO.

In 2018, WHO confirmed that Ghana had become the first country in sub-Saharan Africa to eliminate trachoma as a public health problem. Sightsavers began working in partnership to support the country in 2000, when about 2.8 million people there were estimated to be at risk.

By 2020, The Gambia and Togo reported reaching elimination goals and are now embarking on the WHO validation process.⁶

These breakthrough achievements show just what is possible. They are the result of complex coordination between affected communities, governments, frontline health workers, local and international non-governmental organisations, donors, pharmaceutical companies and others. Coalitions and networks such as ICTC ensure work is not duplicated and that partners are collaborating rather than competing, reaching more people in need with greater efficiency.

Overcoming challenges

Eliminating trachoma as a public health problem in countries where it is still prevalent will only be possible if all those who are at risk of trachoma, or already suffering from it, are reached.

War often leaves people unable to access healthcare, clean water or sanitation – the lack of these helps trachoma to thrive. When countries are in conflict there are many obstacles to delivering healthcare, including trachoma programmes. In such circumstances, we try to partner with a local organisation that can deliver on-the-ground services on our behalf.

There are also challenges in treating hard-to-reach groups, such as people from

nomadic communities, who are constantly crossing borders. This requires us to work flexibly and across borders, in collaboration with local partners.

Other obstacles are created by world events, such as the COVID-19 pandemic or the 2014/15 Ebola epidemic in West Africa. Again, a flexible approach is required: one that preserves the gains made on trachoma elimination while ensuring trachoma programmes can support activities to control virus outbreaks.

Protecting our staff, partners and community members during these times is also of the utmost importance.





Reaching nomadic communities

James Ekai is a 12-year-old from a pastoral farming family in Turkana in Northern Kenya. In the hot season, the herd is taken to the mountains for shade and water, but James, his mother Lokitedi and his three younger siblings stay behind in the remote desert village of Kalobeyei. It is in Kalobeyei that health workers found James and diagnosed him with trichiasis, the severest form of trachoma. By this point he was already blind in his left eye.

Reaching remote areas such as Kalobeyei is not easy. Health teams must make long, hazardous journeys to get there, carrying all the equipment they need with them. On arrival they set up makeshift operating theatres wherever they can – under the shade of a tree or in a school or church – before performing a series of straightforward 20-minute operations on people’s eyelids, saving sight and transforming lives in the process.

Surgeon Maurice is aware of the need to act quickly before the trichiasis in James’s right eye becomes so severe he goes permanently blind.

For James and his mother, the day is one of quiet celebration. “I am very happy now,” Lokitedi says. “I’m pleased James will be able to see out of one eye, even if he has lost sight in the other.”

The work in Turkana through Kenya’s national trachoma programme, with support from international partners such as Sightsavers, is putting the systems in place to ensure people like James no longer fall through the gaps.

The Kenyan government is now close to eliminating trachoma in Turkana, when less than 10 years ago, nine per cent of adults there needed trichiasis surgery to avoid permanent sight loss. The country is on course to eliminate trachoma as a public health problem within the next few years.



Twelve-year-old James sits with his mother Lokitedi outside of their home in Kalobeya village in the Turkana region of Kenya.



Caroline Harper speaks at TED2018 - The Age of Amazement, in April 2018 in Vancouver, BC, Canada.

Delivering successful programmes by working in partnership

Sightsavers is committed to working in collaboration with endemic countries, implementing partners and donors to eliminate trachoma through a range of ambitious multi-million-pound programmes.

In April 2018, Sightsavers' CEO Dr Caroline Harper presented a talk at the TED conference in Vancouver in which she urged philanthropists to support trachoma elimination through the newly launched Audacious Project. Dr Harper's TED talk, which has been viewed 1.4 million times, has been the catalyst for philanthropic organisations, including the Bill & Melinda Gates Foundation, Children's Investment Fund Foundation (CIFF), The ELMA Foundation UK, UK aid and Virgin Unite, to set up a new fund worth over \$100 million.

The Audacious Project funds the Accelerate trachoma elimination programme, 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, and make significant progress towards trachoma elimination in Côte d'Ivoire, Ethiopia, Kenya, Nigeria, Tanzania

and Zimbabwe. Accelerate will also build on groundbreaking 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.

The Accelerate programme was supported by the work of the Commonwealth 2018-2020 Fund, which was another monumental collective effort that contributed to eliminating blinding trachoma in Kenya, Kiribati, Nauru, Nigeria, Pakistan, Papua New Guinea, Solomon Islands, Tanzania, Tonga, and Vanuatu. Sightsavers was grant manager of the programme, which finished in May 2020. We worked alongside local partners and country authorities to implement the programme in Kenya, Nigeria, and Tanzania. The Fred Hollows Foundation implemented the fund in the Pacific and Pakistan.

Fighting NTDs in West and Central Africa

Trachoma also forms part of Sightsavers' largest multiple disease programme to date: Ascend West and Central Africa, which is also UK aid's flagship NTD programme. This aims to deliver more than 400 million treatments in 13 countries to treat five NTDs, including trachoma.

This vast and complex programme is managed by a consortium of partners led by Sightsavers consisting of Mott Macdonald, the Schistosomiasis Control Initiative and the Liverpool School of Tropical Medicine.

Learning from previous programmes

The extensive trachoma programmes currently active across Africa and Asia are carrying forward the momentum – and learnings – of previous large-scale trachoma initiatives in which Sightsavers was instrumental.

This includes the UK's five-year Department for International Development (DFID) SAFE programme, which supported ministries in Chad, Ethiopia, Nigeria, Tanzania and Zambia and was led by Sightsavers on behalf of ICTC. It also includes The Queen Elizabeth Diamond Jubilee Trust's Trachoma Initiative, a five-year programme that worked in seven African countries. The Trachoma Initiative was coordinated by Sightsavers on behalf of ICTC, in collaboration with ministries of health, affected communities, and a network of other partners and programmes. The Trust was a time-limited charitable foundation and ceased operating in 2019 after successfully completing its goals.



Emilian reads an eye chart during an eye examination in Kazungula, Southern Zambia. She has a hearing impairment and her daughter helps her communicate.



Islam, who was part of one of the Global Trachoma Mapping Project teams, records data gathered on a smart phone at a village in Khartoum State, Sudan. The data is then sent back to a data collection centre for verification.



Filling the data gap

The Global Trachoma Mapping Project (GTMP), which ran between 2012 and 2016, is the largest infectious disease mapping ever undertaken.

Using smartphone apps to map and collect data, the project tracked how many people across the world were at risk of the blinding eye disease. This initiative was vital in enabling trachoma-endemic countries to be identified and provided key insight on where ministries of health should focus their efforts.

Led by Sightsavers, this groundbreaking, multi-million-pound programme was driven by a 50-strong partnership that included ministries of health, WHO, academics, and other eye health NGOs, and was funded by UK aid and USAID.

More than 550 teams worked in trachoma-endemic countries to collect GTMP data. On average, one person was examined every 40 seconds. The teams visited many remote populations, trekking across snowy mountain ranges in Pakistan,

navigating islands by boat in Papua New Guinea, and crossing vast expanses of desert by light aircraft in Sudan.

Building on that legacy, Sightsavers is now instrumental in delivering WHO's Tropical Data project, which replaced the GTMP. Tropical Data uses the same approach and methodology as the GTMP. Since 2016, the project has worked in 44 countries and examined more than six million people in relation to trachoma. The service also provides support to countries to deliver epidemiological surveys and provide standardised training.

Working in tandem with other NTDs on mapping and conducting surveillance will help the global community in achieving elimination targets for all NTDs.



The Global Trachoma Mapping Project pioneered the use of smartphone apps to map and collect data from 2.6 million people in 29 countries.

Reaching communities in conflict and crisis

Yemen

Yemen has been ravaged by several years of civil war with many residents left without access to clean water and good sanitation.

In 2018, more than 444,000 doses of Zithromax® were driven by local health officials through conflict zones and past road blocks to the rural Al Hodeidah and Ibb regions in the west of the country.

A team of more than 4,000 volunteers went door to door through 270 villages to ensure the medication was given safely to those who needed it. The volunteers chosen were mainly women because they were more likely to be admitted into households where other women and children were present. The trained volunteers also distributed WASH

kits containing soap and hygiene advice donated by WHO to help prevent the spread of the disease.

“

In 2018, more than 444,000 doses of Zithromax® were driven by local health officials through conflict zones and past road blocks





Darfur, Sudan

After years of inadequate healthcare caused by conflict in Darfur, many people there were affected by blinding trachoma.

In 2015, as part of the Global Trachoma Mapping Project, Sightsavers received funding to gather data on trachoma prevalence in Darfur's five states. When the security situation began to improve, Sightsavers, the MENTOR Initiative and partners used funding from the END Fund to carry out the region's first mass drug administration to treat blinding trachoma, working in Central, West and North Darfur states.

In less than a year, 2.55 million treatments were distributed and 3,800 community health volunteers had been

trained to provide treatments, 90 per cent of whom are women.

Simon Bush, director of neglected tropical diseases at Sightsavers, said: "After years of turmoil, communities that were displaced and had their lives turned upside down by violence in Darfur have been strengthened by the knowledge that they are solving the trachoma problem in their communities for themselves.

"Sightsavers is proud to work with the federal and state ministries of health in Sudan and our NGO partners to support the people of this country with this initiative. But while progress is being made, there is more work to be done to protect people from blinding trachoma."





Sightsavers volunteer Issa meets with Mayasa, Bibie and Aluna in Likuyu, Ruangwa, Tanzania.

Our focus areas moving forwards

Finding the last remaining cases

With the end of trachoma in sight, a key priority is finding the remaining people who require surgery, particularly in remote areas where trachoma cases are spread out and where communities are hard to reach. Our approach of going house to house, rather than holding outreach eye camps, is proving far more effective in tracing and treating the remaining cases.

Investing in behaviour change initiatives

Contracting trachoma is often determined by how people live and what they do. We are delivering innovative approaches that aim to change and positively influence people's behaviour, particularly through facial cleanliness and environmental improvements, to help people protect themselves from trachoma.

Innovation and technology

Our mHealth ('mobile health') strategy uses smartphones to collect data and provide training for people running health programmes. We are expanding our mHealth projects to pioneer new innovations, such as patient tracking apps to ensure we provide the best care.

Collaboration with other sectors

As well as ministries of health, Sightsavers is increasingly working with water, sanitation and hygiene (WASH) partners and the education sector to ensure all services in trachoma-endemic areas are integrated.

Data and research

We know that treatment coverage for trachoma is effective: infection levels are falling, but we cannot be complacent about the current data and tools we have. Sightsavers works with partners to conduct research, listen to recommendations and drive new practices to ensure we constantly improve our trachoma treatment programmes.

Leaving no one behind

One of the biggest challenges facing the global trachoma health community is reaching people living in conflict areas. Where possible, we work with our partners to adapt to local circumstances and change our approach to make sure no one is left behind. We're also working to make our NTD programmes more inclusive of people with disabilities.

References

1. WHO (24 July 2020) 'Trachoma: Key Facts' (accessed July 2020). www.who.int/news-room/fact-sheets/detail/trachoma Stats correct as of July 2020.
2. WHO (24 July 2020) 'Trachoma: Key Facts' (accessed July 2020). www.who.int/news-room/fact-sheets/detail/trachoma Stats correct as of July 2020.
3. WHO (24 July 2019) 'Amid continued progress, trachoma elimination programmes set their sights on 2030' (accessed July 2020). www.who.int/news-room/detail/24-07-2020-amid-continued-progress-trachoma-elimination-programmes-set-their-sights-on-2030
4. WHO (24 July 2020) 'Trachoma: Key Facts' (accessed July 2020). www.who.int/news-room/fact-sheets/detail/trachoma Stats correct as of July 2020.
5. WHO (24 July 2019) 'Amid continued progress, trachoma elimination programmes set their sights on 2030' (accessed July 2020). www.who.int/news-room/detail/24-07-2020-amid-continued-progress-trachoma-elimination-programmes-set-their-sights-on-2030
6. WHO (24 July 2020) 'Trachoma: Key Facts' (accessed July 2020). www.who.int/news-room/fact-sheets/detail/trachoma Stats correct as of July 2020.

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

www.sightsavers.org/NTDs

 **SightsaversUK**

 **@Sightsavers**

 **@sightsavers**

 **SightsaversTV**

Bumpers Way
Bumpers Farm
Chippenham
SN14 6NG
UK

+44 (0)1444 446 600

info@sightsavers.org

 **Sightsavers**