

# RIVER BLINDNESS

The  
beginning  
of the end

Working together to eliminate onchocerciasis



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Page 4

Line 1: Dr. Guido Kluxen

Line 2: CBM

Line 3: The Carter Center

Line 4: RTI

Line 5 and 6: Mectizan Donation Program

Page 7, 14 and 16: Adrian Hopkins

Page 9: Sightsavers

Page 10: The Carter Center

Page 12: Jon and Hannah: Laura Dean, COUNTDOWN/LSTM

Michel: Mectizan Donation Program

**The Non-Governmental Development Organisation  
(NGDO) Group for Onchocerciasis Elimination**

# FOREWORD

**For over 40 years, a large global partnership has been battling river blindness (the medical term is onchocerciasis), one of the most devastating of the neglected tropical diseases (NTDs). Huge progress has been made to control the disease; however, it remains among the most prevalent of the NTDs and continues to cause visual impairment, blindness and debilitating skin disease among some of the poorest people on the planet.**

In 1987, the pharmaceutical company MSD (known as Merck & Co., Inc., Kenilworth, NJ, USA in the United States and Canada) announced a breakthrough medicine to treat river blindness and given regularly, Mectizan® (ivermectin MSD), relieves symptoms and preserves sight. In announcing a decision to donate the medicine to support global river blindness programmes the company also established the Mectizan Donation Programme (MDP), now the longest-running, disease-specific mass drug donation programme and public/private partnership of its kind. Mass drug administration (MDA) or Preventive Chemotherapy (PC) is a treatment strategy based on treating all eligible people in the population based on a community (not an individual) diagnosis.

Whilst impressive progress has been made, with some countries declared free of the disease and areas in other countries also free, if treatment was to stop before transmission has been interrupted the recurrence of symptoms, disease and disability are still of great concern, especially across large areas of sub-Saharan Africa.

As we approach 2030, the United Nations Sustainable Development Goals (SDGs) with their pledge to 'leave no-one behind' are the overarching framework for all development work with poverty reduction, gender equity and disability highlighted as central cross-cutting themes for the most

marginalised populations. The World Health Organization (WHO) is responding to these goals with their focus on equity. Universal health coverage as well as innovation and partnership are key entry points for NTD work. Effectively positioning onchocerciasis-elimination in this context is essential moving forward.

Diverse partners with shared commitments, must strengthen efforts to eliminate onchocerciasis to prevent new cases of visual impairment, blindness and skin disease, building on and protecting the huge successes already achieved. To do this, we will need additional partners and key financial commitment. Increased advocacy is essential outlining the need to support a comprehensive and inclusive 'continuum of care' ranging from promotion to prevention, treatment and rehabilitation to establishing quality services for those already disabled by the disease and its consequences. All services must be available, accessible, acceptable and affordable for all.

For many individuals and their families, river blindness will remain a lifelong, inescapable burden. We must act now to prevent the disease returning and stop millions of others needlessly suffering the same outcome. With a concerted final push, elimination of the disease is achievable, realistic, and cost effective, with the potential to bring huge public health and socio-economic benefits in currently remaining endemic areas. Realising these benefits, we must eliminate river blindness once and for all.

This document serves as a framework to address these concerns, identify unique opportunities and alert the international community to the exciting possibility of the elimination of transmission of the disease, but also serves as a wake-up call to the consequences of not continuing the effort. Slowing the momentum would result in disease recurrence, the waste of 40 years of important research, and major stakeholder inputs, creating a major reversal of a public health success.

**With a concerted final push, elimination of the disease is achievable, realistic, and cost effective, with the potential to bring huge public health and socio-economic benefits.**



# WHERE WE ARE NOW

- 17.4 million DALYs averted through Mectizan treatment
- Four million community drug distributors trained
- A wide network of international partners is in place
- Elimination is a reality in an increasing number of countries

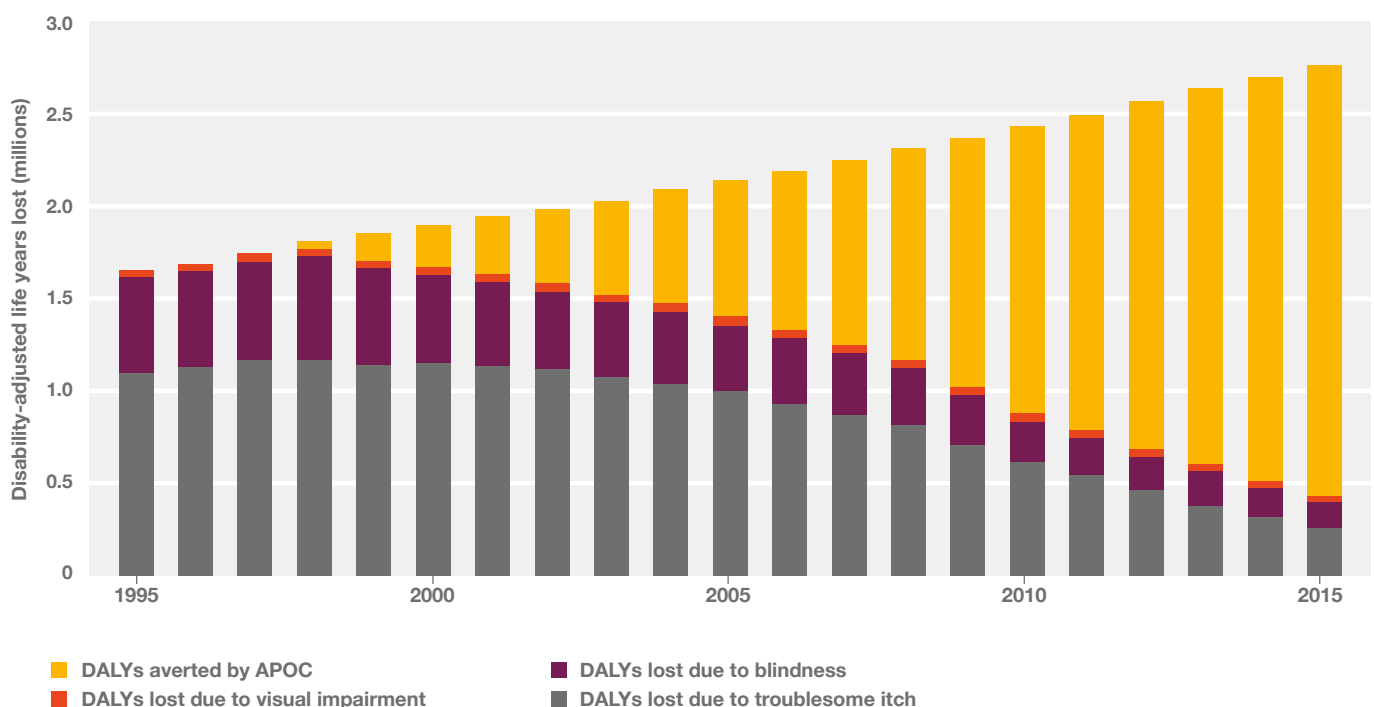
River blindness affects people living in mostly remote and underserved rural communities in some of the poorest areas of the world. It can cause irreversible blindness and severe skin disease in those who have very little to start with and making them poorer.

It is spread by a biting black fly that breeds in fast flowing rivers. An infected person will have larval stages of the parasite in their skin. The fly feeds by puncturing skin until it bleeds and then sucks up the blood and the larval stages of the parasite at the same time. After a week or so the fly needs another blood meal so bites the next person. During the bite transformed larvae leave the black fly and enter the wound of the skin of a new host. The larvae grow into adult worms which form nodules, a raised bump often under the surface of the skin that can last for many years. The adult worms mate, creating thousands of young larvae which then migrate through the skin causing all the troubling symptoms.

After several months, an infected person will begin to itch, an horrific experience that continues day and night – most end up with skin wounds, caused by the vigorous scratching lacerating the skin and causing infection.



## The impact of 20 years of control under APOC



The effect most associated with river blindness is of course loss of sight. The migrating larvae travel to the eye penetrating most of its layers. When the larvae die they cause inflammation that leads to corneal opacities and/or the retinal damage. Without treatment, this will eventually lead to blindness. The impact of these long-term effects reduces work productivity and creates social isolation.

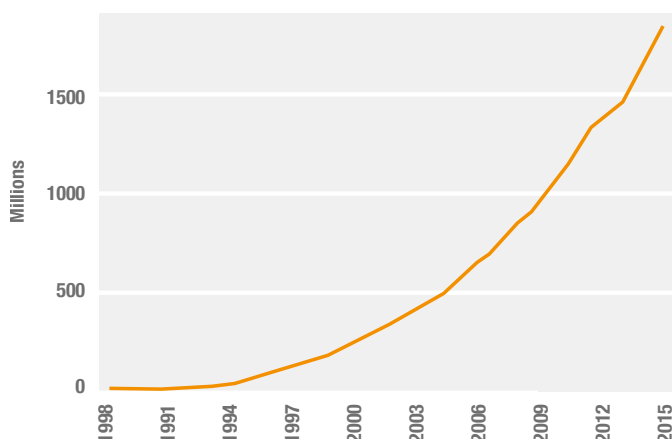
In 1995 it was estimated there were more than 120 million people at risk of infection; 17 million people were infected; 800,000 people were visually impaired, and 270,000 people were blind as a result. Approximately 6.5 million people suffered from severe itching or dermatitis and disfiguring skin lesions. The remarkable effects of the various programmes and the success of these control efforts have been shown by modellers working with data from the African Programme for Onchocerciasis Control (APOC). It has helped to dramatically reduce the number of disability-adjusted life years (DALYs) lost.

## Disease control

In 1974, the Onchocerciasis Control Programme (OCP) in West Africa, (a partnership between donors to a World Bank Trust Fund, WHO, UNICEF and UNDP) was established. Using mostly helicopters, insecticide was sprayed every week into rivers to kill the breeding black flies, and it worked. The disease stopped spreading and millions of hectares of land that had been abandoned were released. Areas by rivers, the most fertile arable land came back into use to feed millions of people as new cases were prevented. However, this method was expensive, it did not cover all endemic areas, and needed to be carefully monitored for its effect on the environment, as well as for insecticide resistance. New infections were reduced but there was no relief for those who already had the disease.

In the 1980's, the pharmaceutical company MSD developed the drug Mectizan® (ivermectin MSD) which destroys the larvae but not the adults, and pledged to supply as much as needed for as long as needed to treat the world for river blindness. The early efforts were led by Dr William Campbell and his team, an achievement for which he later shared the Nobel Prize for Medicine in 2015.

Cumulative Mectizan Treatments Approved



Mass treatment with Mectizan became the main strategy for the control and elimination of the disease. In 2017, 203.8 million treatments were approved for river blindness elimination in 26 countries in Africa and in Brazil, Venezuela and the Yemen.

## Partnerships

In Africa, the OCP ended in 2002 having made huge inroads into elimination using mostly vector control but from 1988 combined with Mectizan® treatment. In 1995, APOC, a partnership between donors, endemic countries, WHO and NGOs, was created to help non-OCP-supported countries develop programmes to control river blindness. At the heart of the APOC strategy was the innovative community-directed treatment with ivermectin (CDTI). Communities planned their own distribution systems making decisions about how and when the Mectizan® was distributed. CDTI was a major development of early MDA programmes and is unique, due to the responsibility given to communities to manage their own programmes, so strengthening health systems from the “bottom up”. Dosing was simplified by the use of an innovative dose pole easy to use in a community setting. This global partnership has trained and mobilised an army of community-based health volunteers, developing a structure to permit communities to take ownership of their own programmes, assisting with both technical and financial support, working together to ensure the medicines reach all in need even in the remotest villages and despite conflict and other crises. Seeing a need to expand NTD programmes across Africa, in 2016 the WHO created ESPEN (the Expanded Special Project for the Elimination of NTDs), broadening the NTD agenda and absorbing APOC activities.

In the Americas treatment began in the six endemic countries in 1992 using twice a year Mectizan initially under the “River Blindness Foundation” (together with other NGOs), which after amalgamation with The Carter Centre and together with the cooperation of PAHO created the Onchocerciasis Elimination Programme of the Americas (OEPA) to coordinate efforts in Latin America.

This diverse partnership of smart organisations and determined countries, including many millions of US dollars donated by the international community, has made massive progress in controlling the disease. OCP and APOC were costly but enormously successful partnerships and without the continued efforts, many of the gains may be lost.

**In 2017, 203.8 million treatments were approved for river blindness elimination in 26 countries in Africa and in Brazil, Venezuela and the Yemen.**



## Progress to elimination

Major progress has been made on the control of onchocerciasis. There are now very few new cases of blindness or severe skin disease except in conflict areas where instability has had severe impact on programmes and where access is difficult. Control measures have been so successful that we can envisage the next step – the elimination of transmission of the disease. Elimination of transmission is a major step beyond control, and beyond elimination as a public health problem. It implies that transmission is brought to such a low level the parasite can no longer be transferred by the black flies and the disease will die out.

### In the Americas

Between 2013 and 2016, Colombia, Ecuador, Mexico and Guatemala have all been verified free of onchocerciasis by WHO. Treatment is only ongoing amongst Yanomami Indians living in the Amazon forest around the Venezuela Brazil border.

### In Africa

While no country in Africa has yet been verified free of the disease, countries including Ethiopia, Mali, Niger, Senegal, Sudan, Uganda and Nigeria have stopped, or are close to stopping, treatment in some areas. The formation of national onchocerciasis elimination committees (NOECs), first established in 2008 in Uganda, has proved instrumental in making sure all elimination activities are well coordinated, evidence based and in support of communities and governments for sustained success.

### In Yemen

Approximately 500,000 people are at risk in 8 wadis (river valleys). The disease is almost exclusively a severe skin manifestation called Sowda. Treatment of affected patients has been going on for some years, however it is necessary to do mass treatment of all people including those without symptoms as many of these are carrying the disease as well. Vector control may be possible in the future. Political Instability has been a major setback to the National Elimination Plan, although mass drug administration has begun in some areas.

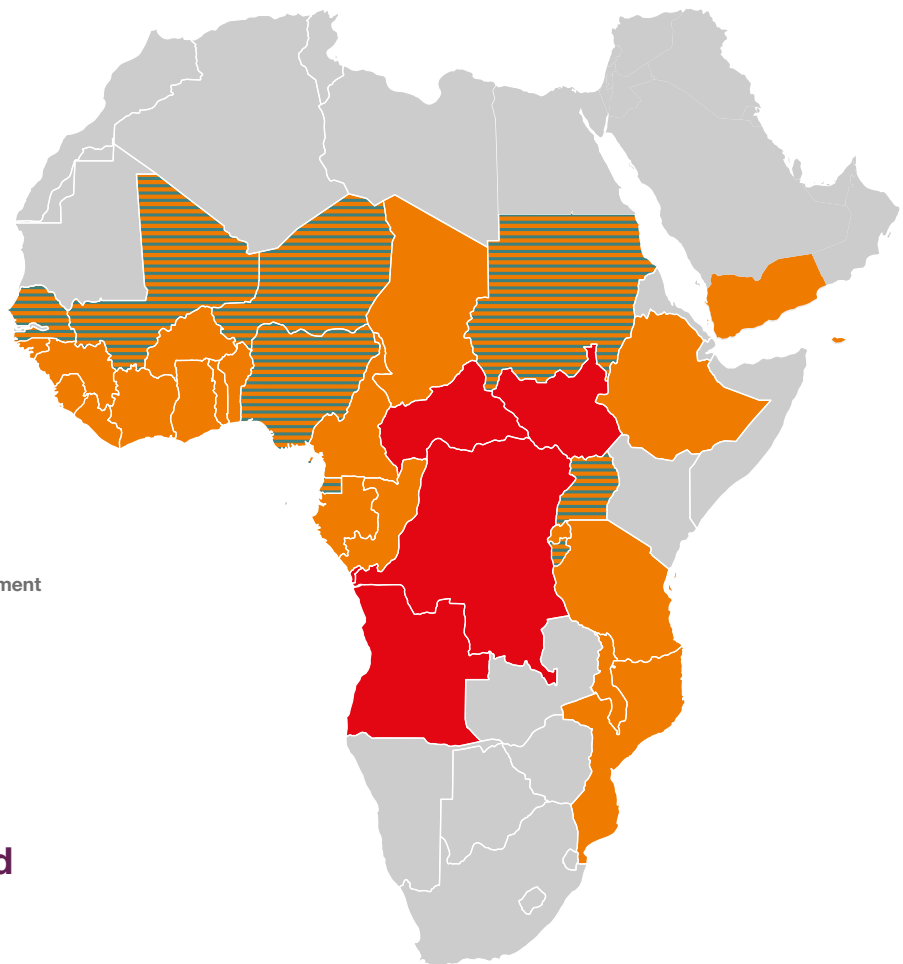
### Onchocerciasis distribution in the Americas



- Elimination verified by WHO
- Some areas eliminated, others close to stopping treatment
- Treatment ongoing
- Increased coverage required

**Between 2013 and 2016, Colombia, Ecuador, Mexico and Guatemala have all been verified free of onchocerciasis by WHO.**

### Onchocerciasis distribution in Africa and Yemen





**“It’s the community drug distributors that are the heroes of this programme. Around 4 million volunteers have been trained over the life of the African programme – 4 million people within thousands of communities in Africa who have been sensitised as to the need for those communities to support themselves, if given the tools to achieve elimination. It’s those individuals, the health volunteers, that are the backbone of all these achievements.”**

Simon Bush, Director of Neglected Tropical Diseases, Sightsavers



**Paul Fadul**  
26, South Sudan

“I volunteered as a community drug distributor for two years then was promoted to supervisor. I am doing this job because I want to help the community – to ensure everyone who is eligible takes the medicine and anyone who refuses understands its importance for prevention. People know the signs and symptoms but not the cause of the disease. Health is a top priority, if you are healthy, your family will be, and you can provide for them. Eliminating the disease will improve the life of the community. I’m excited to be able to contribute to the elimination of onchocerciasis.”



**Baraka Ango**  
35, Nigeria

“I’m a volunteer community drug distributor, trained to provide treatment to my local community and educate them on ways to avoid the spread of infections. We work in pairs, giving medication. A person infected with river blindness cannot work in the fields, get involved in the community or visit their friends. It affects their social life entirely. We don’t get paid, it is not about money. I find joy in protecting our people from river blindness and protecting the future generations of our village.”



**Opera Geoffrey**  
49, Uganda

“I have worked as a CDD in Masindi, Uganda since 1995. I travel to people’s houses to tell them how important the medication is. I don’t want my community to suffer with sickness when the drug is available. It’s important that everyone takes the medication because we are coming close to eliminating onchocerciasis and we don’t want people to remain with vectors or worms in their body. Donors have done a lot and assisted communities who have suffered, and I would say bless them without them we would be dying innocently without knowing what’s killing us.”

# WHY WE NEED TO ACT NOW

**The elimination of transmission of the disease can only be achieved if the endemic countries and international donors remain committed. This shift from control to elimination requires major changes in thinking, planning, funding and national support. It is vital to protect the achievements already made. Unless onchocerciasis is eliminated, the resurgence of disease, once control activities are scaled down, is inevitable.**

The last miles have never been more important. There remains evidence of significant old untreated disease particularly in remote and unstable environments, presenting an ever-present danger of resurgence. The hope is that by 2025, nearly all countries will be on a path to elimination of the disease. WHO is developing further milestones for the achievements of SDG 3.3 (90% reduction in the burden of NTDs by 2030). But the suffering goes beyond that of the affected individual. The disease has a devastating impact on livelihoods limiting access to education and preventing men, women and

- To prevent disease recurrence
- To protect health and the achievements already made
- To strengthen health systems and help achieve the SDGs

children from being able to work and lead fulfilled lives. As we shift to the elimination of transmission, we must also build a sustainable future for those affected, focusing on a 'continuum of care' ensuring that even when the disease is eliminated, patients and care givers receive the support they most need. The success so far of the river blindness programme has been unprecedented. But this is by no means the end.

## Protecting the investment by the international community

As the symptoms, signs and consequences of the disease gradually disappear it has been more difficult to maintain interest and financial support for the programme. It is essential that we continue to achieve good Mectizan® coverage until elimination has been reached and that people are encouraged to continue taking the drug. Financial support for the vital Mectizan® distribution, and the years of post treatment surveillance necessary, may be lost during this critical period.



**“We believe elimination of river blindness is very possible in the near future, but success will require the strong commitment of the remaining endemic countries and the many international partners in this public health initiative,”**

**said former U.S. President Jimmy Carter, whose Carter Center has been a leader in the international campaign to eliminate the parasitic disease since 1996.**

**“We’re committed to fulfilling our pledge to donate Mectizan® to fight river blindness for all who need it, for as long as it is needed. The success we’ve seen over the past 30 years gives us hope that the complete elimination of this public health burden is possible. Through creative partnerships, innovative approaches to distribution and effective programme management, we’re well on our way.”**

**Ken Frazier, Merck Chairman and CEO**

## Preventing recurrence of the disease

Even with a good control programme, low level transmission can still continue. This transmission would automatically increase again if treatment was stopped before full elimination has been achieved and we could return to the situation during the last century with potentially no new tools to fight the disease if Mectizan resistance develops.

In Africa the foci are large and often overlap. Populations and flies migrate bringing back the infection from outside the area and so complicating elimination efforts. In the Americas the foci of infection were small, isolated and widely separated from each other reducing the possibility of infection from outside.

Although Mectizan® is free to the user, people in several endemic regions still do not have good access to treatment. Reasons include political instability and inaccurate data resulting in underestimation of Mectizan® needs.

Many countries in Sub-Saharan Africa have experienced conflict, from Sudan to Angola. Conflict has led to destruction of infrastructure, breakdown of primary health care and massive migration of qualified personnel to more stable areas. These factors lead to a slower scale up of treatment and often a poor geographical coverage (the area that needs to be treated) and therapeutic coverage (the proportion of people in the area actually treated). The areas without proper treatment coverage could remain as possible sources of recurrent infections in disease free areas. Working in conflict and post conflict areas is very worthwhile but demands greater flexibility and will cost more.

Human and fly populations are mobile. The black fly has been recorded as travelling over 400 Km using the seasonal winds in West Africa. Infected black flies could reinvade areas where transmission has been interrupted. It is important to make sure migrating flies do not start a new cycle of infection. Local transmission can occur where coverage is inadequate or where displaced infected populations move into a previously river blindness free area but where black flies are still present. This transmission can also occur across national or regional boundaries and cross border collaboration is vital to prevent such cross-border transmissions.

## Using donated Mectizan® in the most effective way

Mectizan® has been donated for over 30 years. Mass distribution has led to clearance of the disease verified by WHO in four countries in Latin America and some foci in Africa.

A rational use of Mectizan® will ensure that transmission is interrupted in the most effective way possible. This may also involve use of different strategies such as combining Mectizan distribution with vector control, or with other medication. There is major progress in the development of longer acting microfilaricides (that kill the larvae) but the discovery of other medication that safely kill adult worms is still some way off. In the meantime, it is imperative to use Mectizan® effectively to promote elimination and reduce the risk of recurrence.

## Strengthening health systems

Where lymphatic filariasis (LF) and river blindness are co-endemic both programmes benefit as Mectizan® is distributed more widely – including in previously untreated areas of low prevalence. There needs to be good coordination at national and district levels. Community directed distributors (CDDs), the backbone of CDTI, ensure good coordination of these treatment programmes at the implementation levels. The community ownership and participation has played a major role in strengthening health systems from the bottom up. It was estimated that with CDTI 50% of the population who received ivermectin in the APOC programme areas lived more than 20 Km from the nearest functioning health centre – APOC was therefore one of the first programmes to tackle at least one aspect of universal health coverage.

Co-infection with *Loa loa* or eye worm (another filarial infection) has provoked rare but important serious adverse events presenting further barriers to achieving elimination goals in a number of Central African countries. It causes poor adherence to CDTI in affected communities, however, this is slowly changing as new diagnostic and therapeutic measures are tested within the routine health system structures. Onchocerciasis may be associated with the risk of developing epilepsy and has been linked with the severe nodding and Nakalanga syndrome in highly endemic communities. Effective control of onchocerciasis has led to a reduction of symptoms in some areas.

## Achieving the Sustainable Development Goals: Leaving no one behind

Eliminating river blindness will contribute to tackling many of the Sustainable Development Goals, set out by the United Nations in 2015. Incorporated into the global development framework (SDG3.3) – the control of NTDs is critical to the push to end a continuing cycle of poverty, disease and disability. It is important to recognise that no SDG can be reached in

isolation. Tackling NTDs generally and specifically river blindness will assist in directing much needed investment to the poorest and most marginalised communities, removing one of the most serious barriers to development and strengthening local capacity for sustainable and inclusive health systems.



### Jon

Jon was just 14, when he sought treatment for symptoms caused by his river blindness. During Liberia's conflict, access to medicines was difficult. He was never given Mectizan® at the health clinic, and when the medicine arrived in his community, the distributors wanted money for it. He had no money to pay, so he went back to the hospital. The medicine he received made him itch and didn't stop his visual deterioration. Jon documented his story in chalk on a wall in his house – over time, Jon lost his sight completely. Jon's wife left him and took their children. He describes the challenges of living alone with his blindness. His roof leaks and he often sleeps on a wet floor, he faces difficulty finding food.

### Hannah

Hannah loved going to school, she wanted to be a doctor. In 1991, as a teenager, she started to experience severe itching on her skin and problems with her eyes. Liberia was in conflict, medicine was difficult to find. Hannah's mother sought care for her daughter as far away as Guinea and Ivory Coast, but it became too expensive. Then, in 1994, Hannah lost her sight. She struggles to move around in the community feeling 'afraid' and 'ashamed'. Contribution to the household is difficult for Hannah, and her siblings often exclude her. Hannah's mother has become her primary carer – giving up work, not going to church, she says she can't go because she is afraid to leave her daughter alone.

### Michel

Michel lives in the Central African Republic along the Ouham River in the north-west of the country. He lost his vision in the early 1990s due to river blindness. He was a young man then with hopes of continuing his education, but his family threw him out saying he was a drain on their very meagre resources. "I was working in Bossangoa at the time, part of a prevention programme supported by CBM", says Adrian Hopkins who worked with the Ministry of Health at the beginning of the programme. "I returned to the country 20 years later and met with Michel. He said he recognised my voice from previous consultations." Michel has been taking ivermectin for the itching but unfortunately it was too late to save his sight. This area has been plagued with civil disturbance and war and treatment has not always been as regular as it should have been, but Michel says that since the programme began, there have been no new cases of blindness in his community – too late for him, but not for others.

**SDG 17**  
**PARTNERSHIPS**  
**FOR THE GOALS**

**SDG 8**  
**DECENT WORK AND**  
**ECONOMIC GROWTH**

**SDG 5**  
**GENDER**  
**EQUALITY**

**SDG 4**  
**QUALITY**  
**EDUCATION**

**SDG 2**  
**ZERO HUNGER**

**SDG 1**  
**NO**  
**POVERTY**

**SDG 10**  
**REDUCED**  
**INEQUALITIES**

**SDG 9**  
**CLEAN WATER**  
**AND SANITATION**

**SDG 3**  
**GOOD**  
**HEALTH AND**  
**WELLBEING**



# UGANDA: A MODEL FOR SUCCESS



Uganda, with a population of 41.5 million people has been fighting river blindness since the middle of the last century. Recognising the severity of the disease early on, a country wide effort was launched to tackle it. While control of river blindness has been successful,

transmission is still an issue, yet the 2020 target for nationwide elimination of onchocerciasis remains within reach.

Back in the late 1950s an estimated 1.18 million people living in Uganda were at risk of river blindness, around 40% of that number were believed to be already infected. The black flies carrying the disease were found mainly near the Victoria Nile River, the Murchison Nile from the Atura River ending in Murchison Falls, and the Rwenzori focus that extended into the Democratic Republic of the Congo (DRC).

In 1952, vector control efforts began on the Nile River. Some 20 years later, in 1973, the fly had been eliminated along a 70km stretch between Lake Victoria and Lake Kyoga. Consequently, vector control was initiated in other areas of the country alongside MDA (then diethylcarbamazine citrate or DEC) in certain foci. The drug was provided to patients at health facilities until 1992.

In 1989, the Uganda Foundation for the Blind began mass treatment with ivermectin in Budongo. Following this, Uganda Ministry of Health with support from the River Blindness Foundation (RBF) established a nationwide programme. Mapping of onchocerciasis was conducted in 1993 and rapid epidemiological mapping for onchocerciasis (REMO) in 1997. Between 2005 and 2006, Uganda piloted the possibility of eliminating river blindness and applied twice-yearly ivermectin treatment in the Wadelai focus using CDTi. Both rounds attained treatment coverage of at least 90% of the eligible population. In addition, combining vector control and ivermectin treatment in some foci proved to be an effective approach for rapid transmission interruption.

## A national elimination policy (2007 to present)

The Uganda Ministry of Health crafted a new policy for nationwide transmission elimination that was launched by the president of Uganda, His Excellency, Yoweri Museveni, in January 2007. The renamed Uganda Onchocerciasis Elimination Program (UOEP) had several charges. First,



twice-per-year ivermectin treatment was adopted except where once-per-year had been clearly effective in breaking transmission. Second, a molecular laboratory based on the Guatemala model was established to help monitor progress towards elimination. Third, an independent technical advisory committee, the Uganda Onchocerciasis Elimination Expert Advisory Committee (UOEEAC), was established to help the ministry progress towards nationwide elimination.

The first assignment of the UOEEAC was to formulate national guidelines for determining elimination in Uganda. After interruption of transmission has been attained and interventions stopped, the focus moves to at least 3 years of post treatment surveillance (PTS) activities in line with the WHO guidelines.

Official communication about interruption of transmission and the 3-year PTS period is provided to concerned districts and communities. If these PTS criteria are met, the UOEEAC recommends that the focus concerned be declared 'transmission eliminated' and its population considered free from risk of river blindness.

**“Uganda has demonstrated success in elimination of Onchocerciasis. Out of 17 foci, 7 have already eliminated the disease and a population of 3,783, 847 is free of Onchocerciasis. We need to continue the elimination effort globally and also addressing elimination of transmission across the borders.”**

Dr. Aceng Jane Ruth, Minister of Health, Uganda

### What has been achieved?

Uganda is closing in on its goal of eliminating river blindness nationwide by 2020. Six foci, Mpamba-Nkusi, Mount Elgon, Itwara and Imaramagambo (in 2016) and Kashoya-Kitomi and Wambabya-Rwamarongo (in 2017) have eliminated transmission of River Blindness. More than 1 million people living in these districts are no longer at risk. Based on WHO guidelines, this is the largest population ever declared free of river blindness.

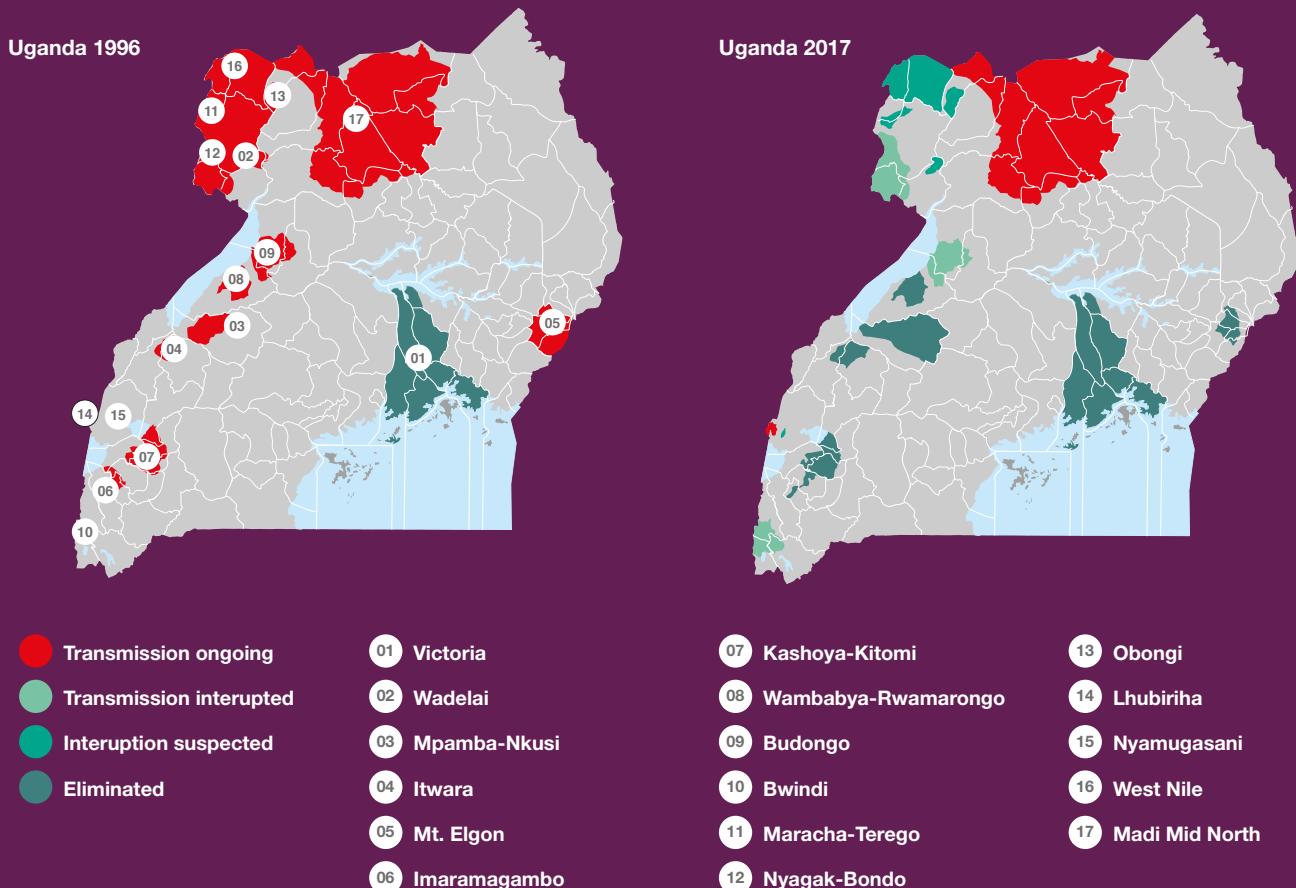
Transmission of the disease continues in only two of Uganda’s original 17 focus areas: the large Madi-Mid North focus (with a population of 1 437 565) and the smaller (population 135 046) Lhubiriha focus. The Madi-Mid North and Lhubiriha foci share a border with the Republic of South Sudan and DRC, respectively.

### Lessons learned

The original approach to the elimination of river blindness transmission in Uganda was to liberally advance from a single annual dose of ivermectin to twice-per-year treatment supplemented with vector control/elimination to accelerate the program toward success by 2020. A single annual dose of ivermectin administered with adequate coverage may not break transmission if the force of transmission is high.

Uganda has possible cross-border transmission with the DRC in the Bwindi, Lhubiriha and Nyagak-Bondo foci as well as with the Republic of South Sudan (RSS) in the Madi-Mid North focus. Unless the transmission status of river blindness in DRC and RSS is known, the WHO guidelines will not allow these Uganda foci to be declared as transmission interrupted or eliminated.

The Uganda Ministry of Health has recently established effective coordination with its DRC counterparts and in 2016 epidemiological and entomological joint surveys were performed in border areas. Discussions have also begun with RSS health officials to develop similar surveys and other coordinated activities. Uganda has made every effort to treat the refugees with ivermectin but obtaining adequate treatment coverage among these highly mobile populations will be a challenge.





## WHAT WE NEED TO DO

- **Set up national elimination committees**
- **Conduct elimination mapping**
- **Develop detailed strategies specific to each focus of infection**
- **Maintain and expand treatment coverage**

### Expanding the evidence-base and developing new tools

Major progress has been made in the elimination of river blindness using existing tools. Four countries have been declared free of the disease by WHO, treatment has been stopped in some foci in Africa, notably in Uganda, Sudan and most recently in Nigeria. However, to facilitate and accelerate the process, research and development is still needed. Whereas OCP and APOC were excellent programmes controlling the disease in many areas as a public health problem, and in some foci probably even eliminating transmission, a major shift in approach is needed to achieve sustained elimination of transmission on a wide scale. This involves the use of new tools, new medicines, and further mapping of river blindness to identify all areas of the disease where it has not been treated in the control programmes. Some of these approaches include:

> **Better diagnostics** to better identify infected people. Amongst others a test to show the presence of live adult worms would be really useful.

> **Development of laboratory** capacity with human resources and appropriate equipment to carry out the analysis needed to stop treatment.

> **New drugs:** safe and easy to use macrofilaricides (to kill adult worms) suitable for MDA would have a massive impact on eliminating the disease. Research is ongoing but medicines for widespread use are not yet available. Other more effective longer lasting micro-filaricides (killing mf) e.g. the recently FDA approved drug Moxidectin, could also play a significant role in reducing the time line but the strategies for its use need to be established.

> **The best MDA strategy** for use in previously untreated low prevalence areas needs to be assessed and the potential use of alternative strategies.

> **Although the new “Loascope” is useful in Loa loa areas** how to use the tools programmatically needs to be determined.

> **Establishing post elimination strategies** to signal possible reinfection from other foci.

> **Programmatic challenges, to ensure success.** How to combine NTD programmes without loss of specific strategies for elimination, overburdening of CDDs with other programmes etc.

> **National ownership of programmes**, with the creation of National Onchocerciasis Elimination Committees and increasing domestic financing.



**“Impressive progress has been made toward elimination of onchocerciasis. To see this through to the end, we need continued partnership with endemic countries and coordinated effort for maximum impact.”**

**Katey Owen, Director, Neglected Tropical Diseases, Bill & Melinda Gates Foundation**

### Elimination Mapping

Major strides have been made in mapping and controlling river blindness. Thanks to the excellent work done during the APOC REMO mapping exercise, we already know where the high and mid prevalence areas are. But to achieve elimination without danger of resurgence, we now need also to know where the low prevalence areas are, as well as areas that have not received Mectizan® for either onchocerciasis or lymphatic filariasis, so they too can be treated to reach geographical coverage in ALL endemic areas.

ESPEN is working on mapping all areas not yet under treatment that may need to be included in the transition from control to elimination.

### Alternative strategies for elimination

Alternative strategies to augment CDTI where required already exist, but where and when to use them depends on epidemiological, technical, and logistical issues, including funding. None of the strategies are as simple as annual distribution of Mectizan. The current strategy in most of Africa is to maintain coverage of over 80% of the total at-risk population every year. But regular monitoring is needed to maintain progress and in some areas this level is not attained. New treatment strategies, extra training and additional supply needs can be more accurately assessed once the full magnitude of the transition from control to elimination is laid out.

**> Twice yearly and even more frequent distribution** of ivermectin has been used to great effect. Countries in Africa are encouraged to change strategy if possible where transmission is going.

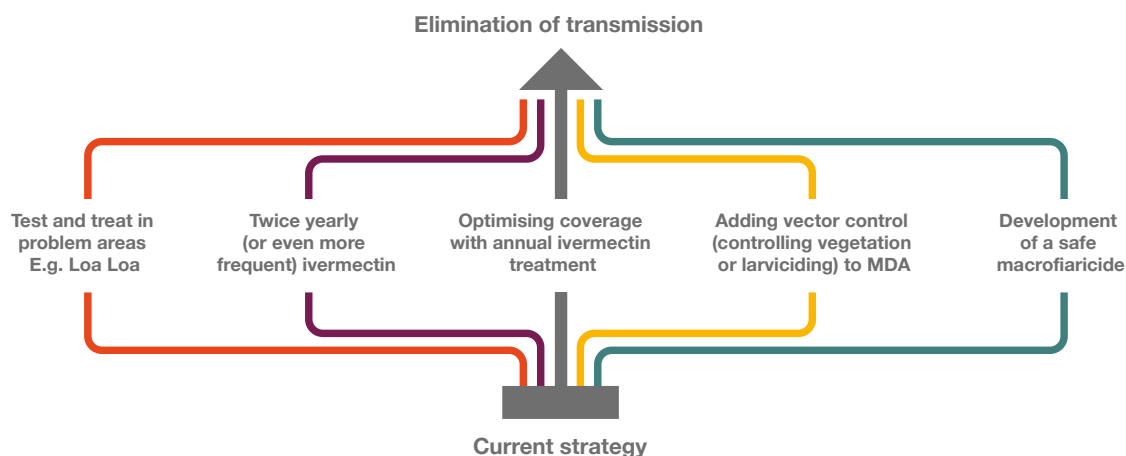
### To assist national decision making

**> WHO updated guidelines** on how to validate stopping MDA were published in January 2016. However, national programmes need to assess how to apply them in their specific circumstances. WHO has now established a Technical Advisory subgroup to develop guidance for country programmes and advance the operational research agenda.

**> A first priority is the creation of National Onchocerciasis Elimination Committees (NOEC)** in all endemic countries, with a broad spectrum of expertise from national and international members, to assist and guide national programmes to achieve elimination of the disease. The main roles of NOECs are to review national program progress, to assess remaining gaps and to guide and make recommendations to the national programmes on programmatic and technical approaches in the following aspects:

- Determining and assessing the real geographical coverage; the number of treatments delivered and the number of people who successfully take the treatments or have access to them.
- How best to improve population estimates for drug requisitions?
- The optimal methods for trapping and monitoring vectoral capacity and distribution of blackfly populations in different areas.
- Analysing factors causing persistent foci of infection and use of alternative strategies.
- How to plan and execute at the national level the implementation of the WHO guidelines on stopping MDA.
- How to build country capacity and improve access to the necessary laboratory facilities or trained personnel to carry out the tests.
- Decision making on alternative treatment strategies where they appear necessary to achieve elimination.

### Onchocerciasis: Alternative treatment strategies



**“When the World Bank catalyzed the partnership to reduce the horrifying toll of River Blindness, it was our first health project – because it was so clearly a driver of poverty and a barrier to development. The same creativity, boldness and commitment of that first effort is now needed again in this final push towards eradication, and we are fully committed to working with countries, our international partners and the private sector to ensure that we ‘put the last mile first’ to collectively defeat this scourge.”**

**Timothy G. Evans, Senior Director and head of the Health Nutrition and Population Global Practice, World Bank Group**

## A focus on the patients

Patients who have suffered with the effects of onchocerciasis still need a continuum of care. This must be provided through strengthening the national Primary Health Care system. Guidance for many of these problems already exists at WHO.

**> Ensuring no one is left behind.** Inclusion of blind and visually impaired individuals, their carers, as well as those affected by epilepsy and other onchocerciasis complications in elimination and post-elimination strategies.

**> The stigma and mental health burden caused by chronic disease.** This includes the individual, family and community level impacts on the mental wellbeing of people affected by blindness, visual impairment and chronic skin disease.

**> High levels of epilepsy are often found where there are high levels of onchocerciasis.** These patients will need long term care in the community.

**> Individuals who systematically do not take the treatment.** Explore the barriers to the uptake of treatment.

**> Avenues for treatment at the health facility.** Rapid diagnostics could result in individual (often non-compliant) patients getting alternative treatment e.g. with Doxycycline and also could care for patients with severe skin disease.

**> Inclusion of individuals and disadvantaged groups** who may not present for treatment.

## Strengthen Partnerships

The process of onchocerciasis elimination must be fully owned by national governments including establishing national policy, creation of partnerships for research and technical support as well as domestic financing. Technical support by a well-established partner base and some international funding is still necessary for many countries. WHO (and ESPEN in Africa) offers technical support to national programme managers as well as a more regional overview assisting with cross-border issues.

## How much does it cost?

The elimination of transmission of onchocerciasis is a long-term project. Most countries are well past the halfway mark of a 15 to 20-year programme. Countries differ considerably in their size, costs of communication and logistic challenges and the degree of integration of the programme in the national health system.

The unit costs per district below are average costs and will vary considerably from country to country and sometimes within countries, but these are based on financial reporting and budgets from some of the partners, so are based on actual figures. They do not include salaries for regular staff doing MDA as part of their health activities but may include a small bonus payment.

Some costs occur at a national level such as an annual review meeting. This is usually both a review and planning meeting for the next year sometimes part of a broader NTD meeting. But some work will need to be done at a national laboratory and elimination mapping will also be on a national scale.

Unit Costs per health district, population 150,000	Average cost per treatment per year in US dollars
Total per district	12500
Per capita cost \$	0.08
Other National costs	
Annual Review and National Elimination Committee costs	10000
Approximate Elimination Mapping Cost per Evaluation Unit (District)	40000
Setting up a National Laboratory	55800

The donation of Mectizan® is a major part of the success of this programme. Treatments shipped for onchocerciasis treatment and combined treatment with LF in 2017 were 186 million with an estimated market value of 781.2 million US dollars.

**Alternative strategies to augment CDTI where required already exist, but where and when to use them depends on epidemiological, technical, and logistical issues, including funding.**

## Global status of River Blindness (2018)

Country	Districts	Population	Districts requiring MDA		Districts under MDA		MDA required but not yet Started	
			Districts	Population	Districts	Population	Districts	Population
Angola	164	28,689,085	50	5,255,695	35	3,630,439	15	2,089,374
Benin	77	11,887,254	51	7,137,443	51	7,137,443	0	0
Burkina Faso	70	20,244,079	6	1,409,805	6	1,409,805	0	0
Burundi	46	10,315,043	11	2,410,859	11	2,410,859	0	0
Cameroon	189	24,757,603	113	11,496,760	113	11,496,760	0	0
Central African Republic	17	5,456,720	10	2,676,865	10	2,676,865	0	0
Chad	100	13,548,122	30	3,965,234	29	3,881,801	1	83,433
D.R. Congo	519	95,113,450	266	43,909,541	262	43,323,553	4	585,988
Rep. Congo	43	4,486,381	23	729,915	17	636,783	6	93,132
Cote d'Ivoire	83	25,077,810	68	18,285,145	62	16,722,488	6	1,562,657
Equatorial Guinea	18	1,075,494	0	0	0	0	0	0
Ethiopia	839	96,223,314	188	17,834,293	188	17,834,293	0	0
Gabon	51	2,066,520	27	730,704	0	0	27	730,704
Ghana	216	30,176,772	126	13,534,524	102	11,161,622	24	2,372,902
Guinea	38	11,480,322	24	7,083,264	24	7,083,264	0	0
Guinea-Bissau	117	1,918,861	33	542,905	17	215,315	16	327,590
Kenya	290	48,023,943	0	0	0	0	0	0
Liberia	15	3,094,538	15	3,094,538	15	3,094,538	0	0
Malawi	29	16,358,324	8	4,089,580	8	4,089,580	0	0
Mali	75	19,747,160	20	5,894,346	20	5,894,346	0	0
Mozambique	159	27,843,860	0	0	0	0	0	0
Namibia	34	2,358,961	0	0	0	0	0	0
Niger	42	19,692,458	0	0	0	0	0	0
Nigeria	774	188,261,047	480	107,279,819	455	100,420,389	25	6,859,430
Rwanda	30	12,266,868	0	0	0	0	0	0
Senegal	76	15,622,526	8	969,153	8	969,153	0	0
Sierra Leone	14	7,404,862	12	5,842,131	12	5,842,131	0	0
South Sudan	79	14,423,705	48	9,107,153	46	8,648,128	2	459,025
Sudan	2679	39,580,000	5	501,181	4	400,000	1	101,181
Tanzania	185	52,907,463	28	6,544,522	28	6,544,522	0	0
Togo	40	7,667,337	32	5,222,062	32	5,222,062	0	0
Uganda	117	39,635,841	24	8,106,780	24	8,106,780	0	0
Zambia	103	15,657,044	0	0	0	0	0	0
Yemen	Some treatment ongoing, 8 wadis to be mapped in detail – est. 500,000 people at risk							
Brazil	Ongoing treatment in Amazonas Focus - 12,787 people under treatment							
Venezuela	Ongoing treatment in South Focus - 14,079 people under treatment							

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