Neglected tropical diseases (NTDs): a diverse group of communicable diseases that prevail in tropical and subtropical conditions in 149 countries – affecting more than one billion people and costing developing economies billions of dollars every year (WHO)

ACRONYMS

AICHM  Africa Inland Church Health Ministries
ATCP  Amhara Trachoma Control Programme
CAR  Central African Republic
CBID  Community Based Inclusive Development
CDTI  Community Directed Treatment with Ivermectin
CLTSH  Community Led Total Sanitation and Hygiene
DFAT  Department of Foreign Affairs and Trade (Australia)
DfID  Department for International Development (UK Aid)
DID  Disability Inclusive Development
DMDI  Disease Management Disability and Inclusion
DRC  Democratic Republic of Congo
ESPEN  Expanded Special Project for the Elimination of NTDs
F&E  Facial cleanliness and Environmental Improvements
FCT  Federal Capital Territory
GTM  Grarbet Tehadiso Mahber
HANDS  Health And Development Support
IADC  Italian Agency for Development Cooperation
LF  Lymphatic Filariasis
LGA  Local Government Area (Nigeria)
MDA  Mass Drug Administration
MDP  Mectizan Donation Program
NNN  NGDO NTD Network
ORDA  Organization for Rehabilitation and Development of Amhara
PCT  Preventive Chemotherapy
PNSOV  Programme National pour les Soins Oculaires et Visuels
S&A  Surgery and Antibiotics
SAFE  Surgery, Antibiotics, Facial cleanliness and Environmental Improvement
SDGs  Sustainable Development Goals
TT  Trachomatous Trichiasis
WASH  Water, Sanitation and Hygiene
WHO  World Health Organisation
The 2012 WHO Roadmap on NTDs set out a path for the control, elimination and eradication of a defined set of Neglected Tropical Diseases. As we approach the end of the decade, the global community can reflect on significant progress made toward these goals.

**Trachoma:** Over this time, CBM has supported over 20 million treatments of azithromycin and over 150,000 surgeries. This has contributed to the significant fall in the number of people globally requiring intervention for blinding trachoma – from 325 to 142 million.

In Sub Saharan Africa, Ghana remains the only country to have validated the elimination of trachoma as a public health problem but several other countries are expected to reach this milestone soon. Burundi could be on track to declare elimination by 2022; in 2019, with CBM’s support, the Ministry of Health identified just one district requiring further MDA. Kenya, Uganda and Malawi, where CBM worked with support from the TRUST, are not far from reaching elimination.

Other countries have further to go – in Ethiopia where 44% of the global burden of active trachoma is found, CBM’s focus on inclusive F&E (Facial Cleanliness & Environmental Improvement) is helping ensure success is accelerated and sustained.

In DRC, which has only recently started work on trachoma, CBM is supporting the Ministry of Health to set up the first trachoma surgery programme – to urgently start to tackle more than 50,000 TT cases in the country.

**Onchocerciasis (river blindness):** Over the last nine years CBM has supported over 150 million treatments with Mectizan®. With others, this has contributed to the fact that there are very few new cases of oncho blindness globally.

However, the challenges to achieving interruption of transmission remain – a shortage of laboratory capacity and the scale of the task of mapping previously untreated areas, among others.

Despite this, Nigeria, the country with the most cases of onchocerciasis on the continent, presents great cause for hope – as with a number of other states, several CBM supported states are likely to be able to stop treatment in the next few years.

With the start of the new decade, a new WHO Roadmap for 2021-2030 is under development. While elimination efforts will remain central, the new Roadmap also aims at a paradigm shift with a strong focus on crosscutting approaches that reflect the full continuum of care. CBM fully supports this new direction as it reflects our long term goal of making NTD work comprehensive and inclusive, reflected in CBM’s active role in the NNN “Disease Management, Disability and Inclusion” (DMDI) working group. Advocating for a human rights and pro-poor approach, our work addresses the requirement for effective access to care for all those affected by these disabling and disfiguring diseases.

As we look forward to this new phase, I would like to express CBM’s sincere appreciation to all the donors and partners who make this work possible.

Dr Babar Qureshi
Director Inclusive Eye Health & NTDs
The map represents areas covered by treatment in the campaign Jan – Dec 2018. CBM carries out additional TT surgeries under its Inclusive Eye Health programmes in these and other countries.

### Key to Neglected Tropical Diseases

- **ONCHO**: Onchocerciasis
- **LF**: Lymphatic Filariasis
- **SCH**: Schistosomiasis
- **STH**: Soil Transmitted Helminths
- **TRA**: Trachoma

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**CBM: NTD PROGRAMMES**

**CHAD**

Trachoma TT surgery in four regions.
Partner: Koumra Hospital, Funding: CBM, Lions Club International Foundation

**NIGERIA**

Integrated MDA – 4 states; TT surgery – 2 states.
Funding: END Fund, DFAT, DfID, Queen Elizabeth Diamond Jubilee Trust, NZ Aid, Sightsavers

**CAR**

MDA – 29 districts.
Funding: END Fund, CBM

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Funding: End Fund, CBM
The map represents areas covered by treatment in the campaign Jan – Dec 2018. CBM carries out additional TT surgeries under its Inclusive Eye Health programmes in these and other countries.

**SOUTH SUDAN**
- **DISEASES COVERED**
  - Oncho
  - LF
  - Trachoma
- Oncho/LF – 6 counties expanding to 18 in 2019.
- TT surgery in IDP camps.
- Funding: End Fund, CBM

**PAKISTAN**
- **DISEASES COVERED**
  - Trachoma
- TT surgery, F&E.
- Partners: Pakistan Sindh Institute of Ophthalmology, and COAVS.
- Funding: DFID & FHF

**ETHIOPIA**
- **DISEASES COVERED**
  - Trachoma
- Covering 20 districts in SNNPR and Amhara Regions with strong focus on F&E.
- Partners: ORDA, GTM.
- Funding: CBM, IADC, DFAT, NZ Aid

**BURUNDI**
- **DISEASES COVERED**
  - Oncho
  - STH
  - Trachoma
- Oncho MDA – 11 districts; Trachoma impact survey – 12 districts.
- TRA MDA – 1 district.
- Funding: CBM, END Fund

**KENYA**
- **DISEASES COVERED**
  - Trachoma
- TT surgery and F&E.
- Partners: AICHM, Meru County Government.
- Funding: Queen Elizabeth Diamond Jubilee Trust
NIGERIA

CONFLICT AND COLLABORATION

Since Boko Haram started their insurgency in 2009, working in Yobe State has become a challenge for CBM partner HANDS, but not one it has been defeated by. Yobe lies in the very north of Nigeria and is the 6th largest state with a population of 3 million people. CBM started work in Yobe in 1997, with MDA for onchocerciasis. Once peaceful, it now forms part of an area straddling Cameroon, Chad and Nigeria in which the insurgency has killed an estimated 25,000 people and many more lives have been devastated through abduction, displacement, trauma and hunger.

While the NTD programme has been affected, the fact that work continues is a testament to the excellent collaboration and trust built between the HANDS team, the Primary Health Care Management Board, the NTD Unit in Yobe State and most importantly, affected communities. Together, they have found ways to continue providing much needed services. Plans are flexible, depending on the current security situation; there is a strong reliance on local up to date information and staff keep a low profile – using local vehicles and dressing appropriately. HANDS and State MoH staff rarely travel to the remotest areas, so to monitor the drug distribution, they rely on the dedicated Front-Line Health Facility staff with whom they maintain close communication.

To ensure surgeons are not put at risk, TT surgical cases from insecure areas are transported to safe centres. Despite the challenges, an impressive number of surgeries has been achieved. 2,700 of the 4,000 target were completed in nine months, although some areas remain too insecure to access at present.

2,700 TT CASES OUT OF 4,000 TARGET, COMPLETED IN 9 MONTHS

‘The huge success can be attributed to the resilience of the whole team, pushing for completion of activities against all difficulties’

HANDS Programme Officer
Okewu Emmanuel
LEAVING NO ONE BEHIND

With an estimated population of over three million, CBM and its partner HANDS have been supporting the Ministry of Health in NTD control and elimination in the Federal Capital Territory (FCT) since 2000. FCT comprises the burgeoning city of Abuja and thousands of surrounding villages. The task of school-based MDA for schistosomiasis and STH requires a high level of mobilisation and organisation to reach the plethora of government, private and religious schools.

In line with the SDG commitment to ‘leave no one behind’, CBM and its partner HANDS took steps in 2018 to ensure that children with special needs were not excluded from the deworming programme. Four schools were specifically targeted including two schools for the blind.

Mrs Harmony, the Principal of a school for children with disability in Bwari Council, ensured full cooperation, noting that this was the first time that the school had participated in a deworming programme. Dr Nebe, the Head of the National Schistosomiasis and STH Control Programme, witnessed the distribution and was excited to see the children benefitting for the first time. In response to the difficulties that some students had in swallowing the tablets, she promised to raise the need for a paediatric oral suspension.

HANDS Programme Manager, Rinpan Ishaya said… ‘We’ve not heard reports of such schools being targeted before, so we are very happy to have included them.’

Dr Nebe (centre) explains the importance of deworming to children and teachers.

Mrs Harmony and other staff oversee deworming at a school for children with disability in Bwari.
ETHIOPIA

TRACHOMA SAFE – MAKING A DIFFERENCE WITH F&E TRACHOMA ELIMINATION PROGRAMMES

Ethiopia is the country with the largest burden of trachoma globally – 44% of all active trachoma. In 2018, Ethiopia also counted for over 62% of all TT surgeries done globally. Within the SAFE strategy, F&E is important to underpin S&A interventions and ensure elimination is sustained. For the last six years, CBM and partner ORDA have been complementing the work of The Carter Center, by investing in F&E activities in Amhara Region through the Amhara Trachoma Control Programme (ATCP).

Work has focused on community ownership, advocacy for sustained behaviour change and support for the development of accessible WASH infrastructure. In some of the target districts, baseline levels of TF were as high as 73% when this support started.

Over this time, over 630 protected water points were constructed to provide communities with safe and accessible water. To improve hygiene, almost 20,000 pit latrines were constructed, most with handwashing facilities. Regarding behaviour change, over 130 Trachoma School Clubs were established to promote facial cleanliness, engaging children to teach their peers. It is estimated that over 840,000 adults and 150,000 children have benefitted during this period from an investment of over 4.7 million Euro.

The drivers of change in trachoma prevalence are complex and any reduction in prevalence cannot be attributed to one specific intervention alone. However, it is encouraging that in districts that have had at least 5 years of intensified F&E interventions, the observed reduction in the active trachoma has been on average over 50% with some as high as 70%.

The ATCP is also a great model of collaboration as it works in close partnership with the communities, with government at all levels and other NGOs.

Collaboration, we believe, means that improvements are more likely to be sustained.

Collaboration:

- Construction of water points with government Water Resource Development offices
- Facial cleanliness and environmental improvement with communities using CLTSH approach and partners from WASH & Education sectors
- Communities proactively participate at all stages from planning to evaluation

ETHIOPIA CARRIES 44% OF THE GLOBAL TRACHOMA BURDEN

MORE THAN 630 PROTECTED WATER POINTS BUILT

‘Now my family fetches at least 120 litres of clean water per day… my children are healthy because they wash and bathe. I’m not afraid to catch diseases like trachoma… because we have clean water and we know how to protect ourselves.’

Improving WASH has had some unexpected benefits beyond the reduction in trachoma: Aman is fifty and has been disabled from birth. He lives in Wagehmera zone in Amhara region. Due to the social stigma of his physical disability, even though he could walk with a stick, Aman was not allowed to go to school and neither did his parents seek medical help. ‘In my community this is often seen as God’s punishment.’ Aman was the main provider for his family, but his income was not enough to meet their needs.

When CBM’s partner ORDA supported the Mybulit spring development, Aman was hired by the community as guard for the water point. Not only does he receive a small monthly salary but he earns additional money by fetching water for families.

‘The work of ORDA/CBM changed my life.’
DRC

DISTRIBUTION IN BENI BUTEMBO DURING THE EBOLA EPIDEMIC

The province of North Kivu is one of the most densely populated in DRC, around 8 million people live there. Its north eastern town of Beni Butembo has been the centre of the worst Ebola epidemic in DRC since the first outbreak in 1976.

Since August 2018, around 2,000 people have so far died from the Ebola epidemic. While MDA has continued, the effect on the programme has been strongly felt.

NTD drug distributors work out of a sense of duty to their communities and are respected for that. However, the epidemic has seriously challenged their motivation and inevitably led to a reduction in their numbers.

Vincent from Butembo Health Zone has been a drug distributor for three years. He continued, despite the challenges. ‘Some distributors resigned because they could get paid to work on the Ebola campaign, others left due to fear.’

Suspicion and resistance to mass health interventions has been understandably high – some have refused to take the tablets from the hands of distributors despite the strict hygiene measures. In some cases, communities refused the distribution altogether and even chased the distributors away. This has had a negative impact on MDA coverage rates achieved this year.

Papy Kendakenda, the Assistant Supervisor for the NTD team in Beni says: ‘It is essential that we continue the treatment and we are proud of what is being achieved despite all the challenges.’

‘Since we were chosen by the communities, we do have their respect. Even so, we had to raise awareness before we were able to turn the tide.’

Vincent

LEARNING FOR EFFECTIVE TT PROGRAMMES

Lessons drawn from CBM’s other programmes, will be important in DRC:

Community-centred approach: wide engagement of local leaders, community agents, women’s groups and former patients is needed to ensure everyone has access to services and no one is left behind.

Effective counselling: layering counselling opportunities at all levels from mobilisation to surgery, increases the confidence of patients to make informed decisions for surgery, or to take alternative options.

Strong documentation: ensuring no one is missed can be achieved by effective community mobilisation and systematically mapping all households covered. Instilling a strong culture of documentation from the outset is important.

Ownership: Trachoma Task Forces at district level, as well as National level, are key to achieving elimination. Composed of a range of stakeholders they promote strong ownership and can leverage local government to support complementary activities such as water provision or school based hygiene and sanitation education. District Task Forces also help make transition to local government control a natural process.

Post-operative follow up: an essential component of quality assurance which needs to be included from the start to cultivate a culture that ensures patients receive follow-up care even after transition.

TT SURGERY STAKEHOLDER WORKSHOP

While MDA is already being integrated with other drug treatments, the estimated TT backlog of around 50,000 cases presents a greater challenge – currently DRC has no practising TT surgeons.

With the support of CBM, the National NTD Programme conducted a 3 day stakeholder’s workshop in July. The purpose was to agree the approaches and norms to be used in DRC, particularly for the training of surgeons – who will be the critical resource for success. The workshop brought together ophthalmologists from the National Eye Care Programme (PNSOV), NGOs, and WHO ESPEN.

By the end of the three days, important steps had been made. The strong engagement of PNSOV will be vital to ensure quality surgery and a strong spirit of collaboration between NGOs working in different parts of the country, will help ensure efficient use of resources and shared learning.

From 2019, CBM will initially target up to 4,000 cases in Sud Ubangi, complementing the integrated MDA programme.
SOUTH SUDAN

REDDUCING THE RISK OF STIGMA AND DISABILITY FROM NTDs

South Sudan has suffered decades of civil conflict and is believed to have one of the highest burdens of NTDs in the world. Health infrastructure and services have collapsed and providing aid in this divided society has become a great challenge.

Over the last two years, CBM renewed its partnership with the South Sudan National Health Authority and has been able to restart its NTD programme after the most critical period of the civil conflict. In 2017 work began in 3 counties delivering drug treatments against onchocerciasis and LF. These areas had some of the highest prevalence rates but were also accessible, despite the ongoing conflict.

The distribution was very successful with 74% of the targeted population treated. In 2018 distribution increased to six counties with co-funding from the END Fund. Since the restart of the programme, CBM has supported the treatment of more than 1 million people.

THE NTD PROGRAMME AS CATALYST FOR HEALTH SYSTEMS STRENGTHENING

In 2018, the NTD programme was integrated with the Boma Health Initiative, contributing to the rebuilding of public health services. BHI ensures a standard package of basic health care services is available through community health workers who are trained to detect and report disease morbidity. This improves the provision of specialised care – an important first step to reducing the stigma surrounding NTDs.

In 2018, CBM was the driving force behind the creation of an Onchocerciasis and Lymphatic Filariasis Elimination Committee, a body of national and international experts to advise on the elimination of NTDs within South Sudan – a key aim for country’s health authorities.

CBM aims to expand its support in South Sudan; our goal is an environment in which the population is no longer at risk of the disabling and stigmatising effects of NTD infections.

KENYA

NEARING THE END

CBM’s 5-year support from the Trust Trachoma Elimination Programme ended in April 2019. CBM has been working with a local partner AICHM and the County of Meru, to manage the programme of surgeries and support improvements in hygiene and sanitation.

The programme relies on Community Health Volunteers (CHV) to take health messages into homes and identify possible cases of TT. Each young volunteer visits around 80-100 households, under the supervision of the Public Health Officer (PHO) and Community Health Education Workers (CHEWs).

Through this house to house approach 3,434 people have been identified with TT and operated on during outreach camps. In addition, environmental improvements have been a key part of the CHV’s message and as a result of their enthusiasm and hard work, latrines have been built and 35 villages proudly declared Open Defecation Free (ODF).

Inspired by this success, the County has initiated its own project to replicate the activities in areas not covered by the Trust funding.

Achieving Facial Cleanliness remains a challenge in the drier areas of Meru County due to water scarcity. However, since 2016 the County has been leading efforts on improving access to water by providing storage tanks in schools and public institutions. It has also drilled over 100 boreholes, although more are required to ensure that trachoma will not return.

Following one further round of MDA – we hope that Meru will start surveillance and be joined by other counties, before certification for elimination of trachoma.
ONCHOCERCIASIS: NUMBER OF PERSONS TREATED WITH IVERMECTIN: 23,078,687

NUMBER OF PERSONS TREATED THROUGH MDA: 48,649,262

SCHISTOSOMIASIS: NUMBER OF PEOPLE TREATED WITH PRAZIQUANTEL: 2,968,917

SOIL TRANSMITTED HELMINTHS: NUMBER OF PEOPLE TREATED WITH ALBENDAZOLE AND/OR MEBENDAZOLE: 7,176,881

TRACHOMA: NUMBER OF SURGERIES PERFORMED: 24,096

NUMBER OF PERSONS TREATED WITH AZITHROMYCIN: 6,149,215

LYMPHATIC FILARIASIS: NUMBER OF PERSONS TREATED WITH IVERMECTIN/ALBENDAZOLE: 23,984,179
Clinical Officer James leads Babiwemba (70) from the outreach clinic in Namutumba, Uganda, after a successful TT surgery (support from Queen Elizabeth Diamond Jubilee Trust).