

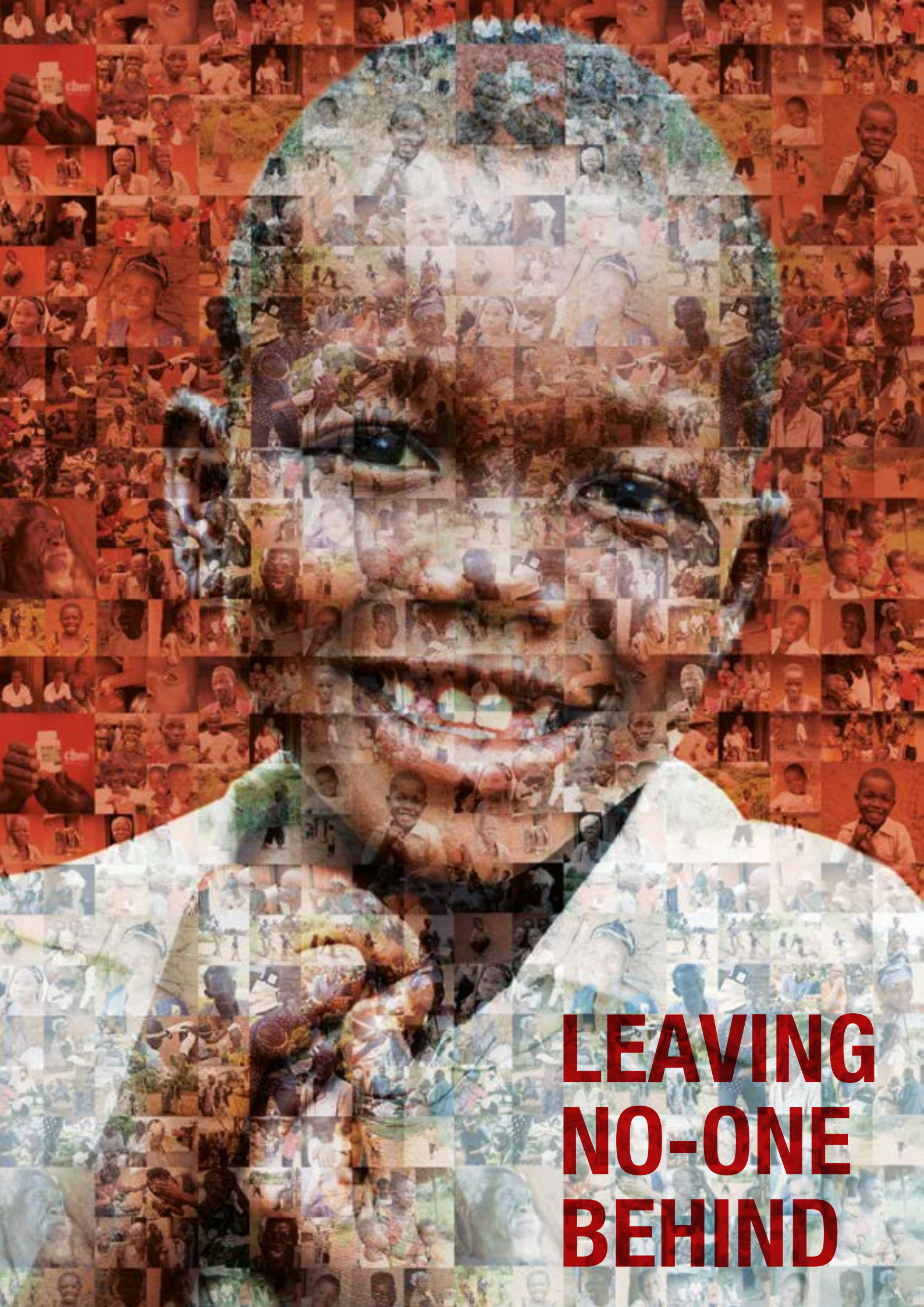


# A JOURNEY TO END NTDs

Elimination and Care

2017





**LEAVING  
NO-ONE  
BEHIND**



# FOREWORD

**By defining our goal more clearly – by making it seem more manageable and less remote – we can help all people to see it, to draw hope from it, and to move irresistibly toward it.**

JFK, JUNE 10, 1963

**M**ore than one in seven people on the planet is affected by, or at risk from Neglected Tropical Diseases (NTDs) – that’s more than the population of Europe and the United States combined. Collectively, there are 18 diseases and between them, they cause blindness, immobility, disfigurement and great pain. Typically, they don’t kill quickly although they shorten people’s lives, and will prolong suffering from generation to generation if nothing is done to stop them. The elimination of these diseases has often been described as the ‘best buy’ in public health.

Over 600 million children live in areas where NTDs are transmitted; this limits not only their potential, but that of their entire communities. The responses required are often simple, but in order to break the cycle of neglect, we must address the needs of those that have been and are being forgotten most.

In 2015, the United Nations (UN) identified 17 sustainable development goals (SDGs) in its global pledge to ‘leave no one behind’. NTDs have the most direct relevance for SDG 3, the health goal, and their important role has been highlighted with an NTD indicator (3.3). Together with the WHO we see NTDs as a proxy for poverty and inequity assisting in targeting our efforts and investments to the most marginalized, to increase Universal Health Coverage (UHC, 3.8). NTDs impact on so many areas of life, making them relevant to literally all the SDGs, and efforts to eliminate NTDs will have a direct impact on progress towards 2030.

CBM has been involved in the elimination of NTDs from the beginning. Working together with international donors, NGOs and national and local organisations and networks, CBM supports numerous NTD programmes across the world.

“A Journey to End NTDs – Elimination and Care” records what we have achieved over the last year and where we are now. It presents our plan of action for the coming years, bringing our ‘traditional’ NTD work together with ‘Disease Management Disability and Inclusion’ (DMDI), Community Based Inclusive Development (CBID) and Livelihoods. We care for those affected and we’re working to enhance community and government ownership through national health system strengthening, community engagement and cross-sectoral action. Ultimately, we are working to free future generations from these menacing diseases, improving prevention and treatment, without forgetting those for whom prevention and treatment are too late because they already have a disability.

But none of these goals can be reached with a ‘business as usual’ approach. We need to redouble efforts to assist governments in driving progress towards Universal Health Coverage, particularly as the elimination of many of these NTDs cannot be achieved in isolation when they are linked to so many other pressing health and development issues.

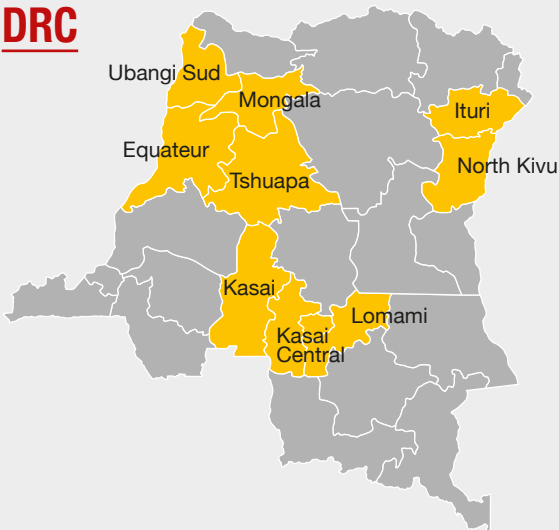
Together we can win the battle to end NTDs, together we can make them ‘neglected’ no longer.



**Dr Babar Qureshi**  
**Director Neglected Tropical Diseases**

# CBM: KEY PROGRAMMES 2017

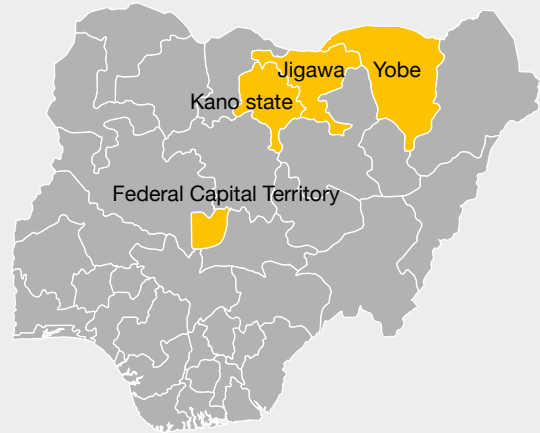
## DRC



CBM continues to support MDA in 120 Health Zones (External funding: END Fund) and has mapped for trachoma. (Funding: USAID/RTI)

- DISEASES COVERED**
- ONCHO
  - LF
  - SCI
  - STH
  - TRACHOMA

## NIGERIA



After supporting MDA for onchocerciasis in 4 states for over 20 years – with other NTDs increasingly integrated – it is likely that treatment can be stopped in many districts by 2020. (External funding: APOC, DfID, DFAT Australia). CBM has mapped trachoma in Yobe and Jigawa states and is planning for MDA and TT surgery. (Funding: Queen Elizabeth Diamond Jubilee Trust)

- DISEASES COVERED**
- ONCHO
  - LF
  - SCI
  - STH
  - TRACHOMA

## ETHIOPIA



In Ethiopia, CBM is supporting local organisations ORDA and GTM to tackle facial cleanliness and environmental improvements (F&E), two components of the SAFE strategy, by strengthening community engagement.

- DISEASES COVERED**
- TRACHOMA



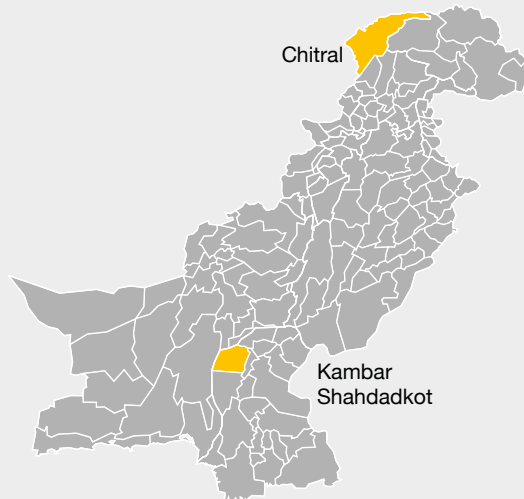
## KENYA



In Kenya, with funding from Queen Elizabeth Diamond Jubilee Trust, CBM is supporting TT surgery with local partner AICHM; F&E is implemented with the government.

**DISEASES COVERED**  
**TRACHOMA**

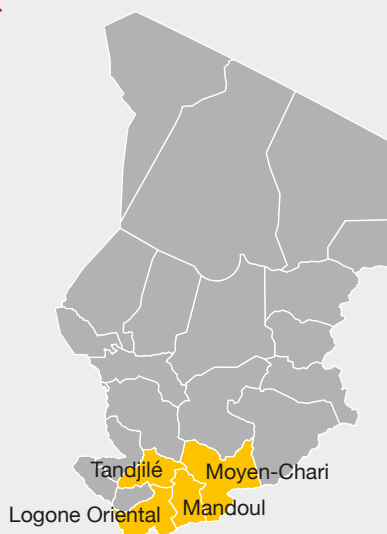
## PAKISTAN



A CBM funded MDA programme for trachoma has just been launched in 2 states.

**DISEASES COVERED**  
**TRACHOMA**

## CHAD



CBM is supporting Trichiasis (TT) surgery through Koumra Hospital. (External funding: Lions Club International Foundation)

**DISEASES COVERED**  
**TRACHOMA**

## STRENGTHENING MECTIZAN DISTRIBUTION

CBM is expanding its involvement in Mectizan distribution in five countries: DRC, Nigeria, Burundi, CAR, South Sudan. The programme includes support to National Programmes to strengthen data management, supply chains, distribution systems and coverage surveys.

# NTDs AND DISABILITY

**Neglected tropical diseases spare no-one. They disproportionately affect women and children, impair physical and mental development, lead to chronic disability, and are a significant contributor to healthy life years lost.**

NTDs flourish under conditions characterised by poor housing and sanitation, unsafe water, and limited access to basic health care. While current attention focuses on prevention and treatment, less attention has been paid to addressing the needs of those already affected. In addition to physical suffering and disability, people affected also often face social exclusion and have high rates of associated mental ill health (often considered the greater disability). This is particularly true of diseases that have visible physical symptoms, such as Trachoma, Onchocerciasis or Lymphatic Filariasis.

Typically, NTD programmes have followed a vertical approach with a single-disease focus. Up to now, the increasingly important dimensions of disease management, disability and inclusion (DMDI) have been widely lacking. Recognising the links between NTDs and disability is hugely important if programmes are to meet the physical as well as psycho-social needs of those affected. To do this, they will need greater financial resources so that comprehensive and inclusive approaches can be effectively implemented.

## CBM'S INVOLVEMENT

For more than 30 years, mass drug administration (MDA) has been a great success in preventing NTDs, however, CBM's experience and studies show that there must be a stronger focus on preventing and treating NTDs, in particular on the many barriers they must overcome to be accepted in society. CBM's work to address these needs is based on a continuum of care approach that goes beyond efforts to prevent or cure an infection, but responds to the broader needs of individuals and communities. Stigma, discrimination and exclusion are a common experience for those affected and health systems where NTDs are endemic are often weak, especially at grass-roots level. On the back of its NTD programmes, CBM has introduced additional services, such as community based inclusive development (CBID) programmes, which offer livelihood support, or mental health services and self-help groups. To further promote, support and mainstream this approach CBM actively participates in the "Disease Management, Disability and Inclusion" (DMDI) working group of the NTD-NGDO-Network (NNN). The holistic, human rights based DMDI approach aims to ensure universal access and inclusion for all through treatment and care.



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## DISABILITY INCLUSIVE NTD PROGRAMMES AND TRAINING

With decades of experience in inclusive eye health, CBM and its partners are uniquely placed to ensure the rights of people with disabilities are recognised and upheld. In Uganda, CBM was involved in the Queen Elizabeth Diamond Jubilee Trust Trachoma Initiative until early 2017. The programme identified TT patients through house to house visits carried out by village health workers (trained by CBM). They also identified people who have mobility issues – people who can't walk and can't leave their house – and provided wheelchairs for them. By providing transport to the TT camp, CBM ensured they could benefit from the programme that would have otherwise been inaccessible. In the area of mental health, CBM is collaborating in a pilot project in Nigeria, to address NTD stigma and depression. CBM plans to train Community Drug Distributors in the identification of mental health issues brought on as a result of diseases such as LF, and then to give psychological and emotional support or refer them for further help. In Ethiopia, using comprehensive SAFE, CBM is working to make water, sanitation and hygiene (WASH) inclusive by building community latrines accessible for people with disabilities.

# TRACHOMA

**One of the oldest and biggest NTD programmes CBM is involved with, is the elimination of trachoma – the world’s leading infectious cause of preventable blindness. Globally, around 190 million people are still at risk of trachoma, 1.9 million people are blind or visually impaired, and 3.2 million people urgently need surgery to avoid blindness.**

CBM is focusing its work in some of the most endemic countries such as Ethiopia and Nigeria. It is increasing efforts to scale up SAFE interventions drawing on its technical expertise in trichiasis-surgery (TT), community engagement and increasingly close collaboration with WASH sector expert organisations for effective F&E work. Amhara Regional State in Ethiopia has one of the highest trachoma rates in the world. In 2014, CBM launched the

second phase of the Amhara Trachoma Control Programme (ATCP) in collaboration with the Organization for Rehabilitation and Development in Amhara (ORDA). A recent evaluation of the second phase revealed that a strong community ownership resulted in enhanced community

awareness of trachoma and the need to increase SAFE interventions – training village health workers, setting up local WASH communities, educating children in anti-trachoma school clubs, and the construction of community water supply schemes. CBM also partners with The Carter Centre to provide the S and A components.

In 2 states in Pakistan, a CBM funded MDA programme for trachoma has just been launched. In Chad, CBM is conducting TT surgery through local partner Koumra Hospital. In Kenya, elimination is in sight: with funding from the Queen Elizabeth Diamond Jubilee Trust, CBM supports local partner AICHM to provide TT surgery with F&E provided in collaboration with the local Government.

## CBM SCALE-UP 2016

### OVER 4 MILLION DRUG DONATIONS

- Almost 23,000 TT surgeries
- 40 surgeons trained in TT
- 1,180 community & health workers trained in F&E

#### SAFE STRATEGY



**SURGERY**



**ANTIBIOTICS**



**FACIAL  
CLEANLINESS**



**ENVIRONMENTAL  
IMPROVEMENTS**



**SUSAN NKIROTE MBABU** is a health worker with CBM and part of the trachoma programme team in Meru County, Kenya – “she’s extraordinary,” they say. During the day, she teaches at the local nursery school. Once school is out, she goes by another name – Mwenye Huruma – literally translated, means “humble and caring”, and that’s just what she is. There are around 33 villages in Kathelwa Community, each with around 200 households – and Susan visited them all to find new cases of trachoma. The majority of people with TT are elderly and cannot read. They needed surgery but many had traditional beliefs and resisted treatment because they were afraid. Susan helped them understand that surgery could change their lives for the better and enable them to work again – and now, some of them are.

**“I have sleepless nights when I see people suffer with their disability – when help is available, but they cannot access it.”**



25-year-old **FAISAL SALLAU** and 26-year-old **SULEMAN GARBA** are CBM Community Drug Distributors. They’ve been volunteering for the last 6 years. Each year they distribute Azithromycin (trachoma), Ivermectin (oncho) and Albendazole (LF) and attend an annual one day refresher course to make sure they keep up-to-date with new practices. They also provide basic education on personal hygiene and encourage the children to keep their faces clean. “When we started there were 4 of us, now there are 6 volunteers. We do it to help the people in our communities who cannot help themselves,” says Faisal.



# ONCHOCERCIASIS

**Onchocerciasis – or River Blindness – is an infection that causes severe eye and skin disease often with debilitating itching. Ultimately the parasitic worms cause irreversible blindness. Transmitted by the bite of a black fly that breeds near fast-flowing rivers or streams, it's the second most common infectious cause of preventable blindness. While onchocerciasis is not a direct cause of mortality, the socioeconomic consequences are severe and extend beyond the infected individuals, affecting families and communities as a whole.**



**ALBERT MUKENYI** is 74-years-old, and blind. He lives with his family in a village in central DRC. "I was a great hunter," he says, "now I sit and do nothing." His grandson, Marceil is 9-years-old. He collects food and water for his grandfather. "I like to help, but sometimes I would prefer to play football with the other children," he says. Albert maybe blind, but he's thankful now, "I know the medication comes from people without asking for anything. We couldn't afford it. It prevents my children and grandchildren from going blind. Thank you."



**AGNES OCHAI** occupies a position of great importance in the global fight against onchocerciasis. Since the 1980's she has suffered a form of Oncho that is highly stigmatized, called 'leopard skin'. "I was shunned by my community and some of my family members," she says. But she's used her own experience to start helping other people in her village, becoming a CBM Community Drug Distributor, and reaching out to other women at risk of exclusion. Agnes is an incredibly selfless and brave woman who has shown unwavering personal courage and strength in unimaginably hard circumstances.

**"NTDs are diseases of the poorest people who have little political voice. CBM has been working on these diseases for many years, in some of the most difficult areas of the world."**

**ADRIAN HOPKINS, FORMER CBM ADVISOR AND DIRECTOR OF THE MECTIZAN DONATION PROGRAM**

and integrating people with irreversible blindness within their communities. In heavily infected areas this was a major cause of disability. At that time, there was no suitable prevention or treatment available. In 1987 the pharmaceutical company Merck (MSD) made a remarkable commitment with a new medicine called Mectizan® (Ivermectin). This donation through the Mectizan Donation Program (MDP) **"as much as needed for as long as needed"** was an unprecedented development in public health.

In 2016 alone, CBM treated almost **34 million** people living in areas where Onchocerciasis is prevalent, working in countries such as Nigeria, DRC and Burundi. In 2017, CBM expects to increase treatments for oncho, restarting

In many parts of Africa in the 1980's, CBM's work with people with visual impairment included areas where River Blindness was a major disease. Rehabilitation revolved around treating complications

its programmes in CAR and South Sudan, that were interrupted due to conflict. Within CBM's programmes more than 65,000 people received training to lead and manage drug distribution in their own communities. This enables them to ensure all eligible people are reached, drugs are administered correctly and accurate records are kept.

CBM is a founding member of the NDGO Coordination Group for the Elimination of Onchocerciasis and was one of the organisations that together with governments of endemic countries and WHO, developed programmes to prevent disability and now to eliminate the disease. River

Blindness is now controlled in 34 endemic countries and is at a point where elimination (interruption of transmission) is within sight in many places. However, the very last miles can be the most difficult and require more resources.

**CBM SCALE-UP 2016**  
**ALMOST 34 MILLION**  
**DRUG DONATIONS**  
**OVER 65,000**  
**COMMUNITY DRUG**  
**DISTRIBUTORS**  
**TRAINED**



# LYMPHATIC FILARIASIS

**Lymphatic filariasis (LF), is the most common disabling disease globally with over a billion people at risk. It is a parasitic disease caused by microscopic, thread-like worms (microfilariae) and is transmitted through the bite of infected mosquitos.**

**947 million people in 54 countries** worldwide remain threatened by LF and require preventive chemotherapy to protect them from this parasitic disease. In the year 2000 it was estimated that **120 million people** were infected, of whom about a third are disfigured or incapacitated.

LF often leads to feelings of shame and low self-esteem, which – along with social restrictions – increase the likelihood of depression, anxiety and other mental disorders. Many sufferers hide within their communities and have to be found and persuaded to accept treatment. The burden of disease associated with LF may be twice as high if depressive illness is taken into account.

The global momentum to eliminate LF has developed over the last 20 years. Generous donations of medicines have contributed to the interruption of the transmission of the

disease, in many formerly endemic areas. In 2016 alone, CBM treated almost 22 million people for LF in Nigeria and DRC. CBM treats LF where it is co-endemic with river blindness, distributing Albendazol and Ivermectin. These

drugs will ensure people are treated for onchocerciasis, LF and intestinal worms.

**CBM SCALE-UP 2016**

**ALMOST 22 MILLION  
DRUG DONATIONS**

**OVER 177,000  
COMMUNITY MEMBERS  
TRAINED IN WASH  
INTERVENTIONS**



**FATIMA HUSSENI** is 55-years-old. Her husband has LF. His mobility and therefore his capacity to work to support his family is affected. The large extended family has received annual treatments for NTDS for many years. “We appreciate all that CBM and HANDS (CBM partner organisation) have been doing for us”, she says. Fatima knows how to prevent the spread of disease, “volunteer drug distributors give us advice and we hear messages on the radio to inform us,” she says. “We pray that soon, the tests will show that these diseases are no longer here and that we can stop taking the drugs,” she says.



**JIDDA MUHAMMAD ASSAKIN** has

suffered with Lymphatic Filariasis since 1990. “At first, the impact of the disease was devastating on me,” he says. “People would avoid me, fearing I would infect them.” Because of the disease, Jidda hasn’t been able to work. “We have exhausted all our lifetime savings in

seeking medical care both in and out of Nigeria. But thanks to the MDA programme and support from CBM, I have been able to receive the treatment and care I need,” he says.

# **CBM ACTION 2018 – 2021**

## **MOVING FORWARD TOGETHER**

**The global alliance against NTDs is one of the largest and most successful public health initiatives in history. But without the continued development and implementation of effective, comprehensive and integrated programmes, the devastation brought by NTDs upon individuals, families and communities will continue to affect generation after generation.**

### **2021 GOALS**

CBM has been working on these diseases for many years in some of the most difficult areas of the world – our commitment to contributing to their elimination and to the care for those affected includes:

- ✔ **Achieving ‘stopping mass community treatment’ – a key elimination milestone – in specific areas in four countries**
- ✔ **Expanding comprehensive Trachoma SAFE programmes in five countries**
- ✔ **Fully integrating with Government-led national programmes in all countries**
- ✔ **Establishing referral systems for other eye conditions in all trachoma programmes**
- ✔ **Establishing referral systems for Mental Health and Community Based Inclusive Development (CBID) programmes in selected NTD programmes**
- ✔ **Training all CBM programme staff in disability inclusive development (DID)**

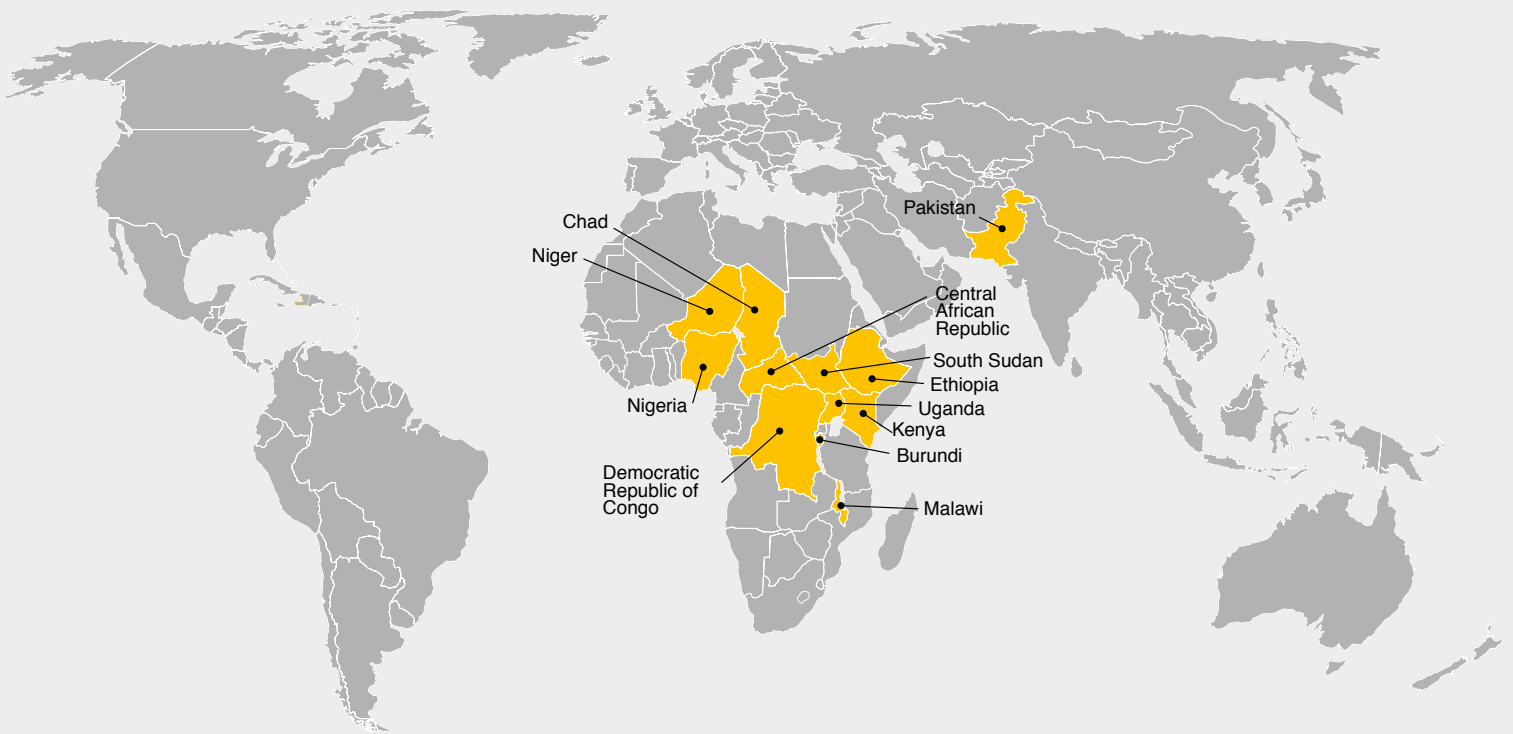


We know that every country has unique needs and challenges, but stepping up efforts to strengthen health systems in the important dimensions of disease management, disability and inclusion (DMDI), is needed everywhere.

By focusing on these goals, we are on the brink of accomplishing something extraordinary. As we look forward to 2030 and achieving the Sustainable Development Goals, we can look forward to a world where NTDs are not only “not neglected” but many will have been eliminated, freeing future generations from the risk of disability and providing capacity to address the complex needs of those still affected.



## CBM SUPPORTS WORK WITH NTDs IN 12 COUNTRIES



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