

# The role of the NGDO Coordination Group for the Elimination of Onchocerciasis

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The NGDO Coordination Group for the Control of Onchocerciasis was launched in 1992, and with the paradigm shift from control of disease to elimination of onchocerciasis transmission, the Group shifted its orientation to that new paradigm in 2013. It also changed its name, replacing ‘control’ with ‘elimination.’ In doing so, the Group has repositioned itself to build on the successes of the past to finish the job it began over 25 years ago.

**Keywords:** Elimination, Onchocerciasis, Resource mobilization, System strengthening

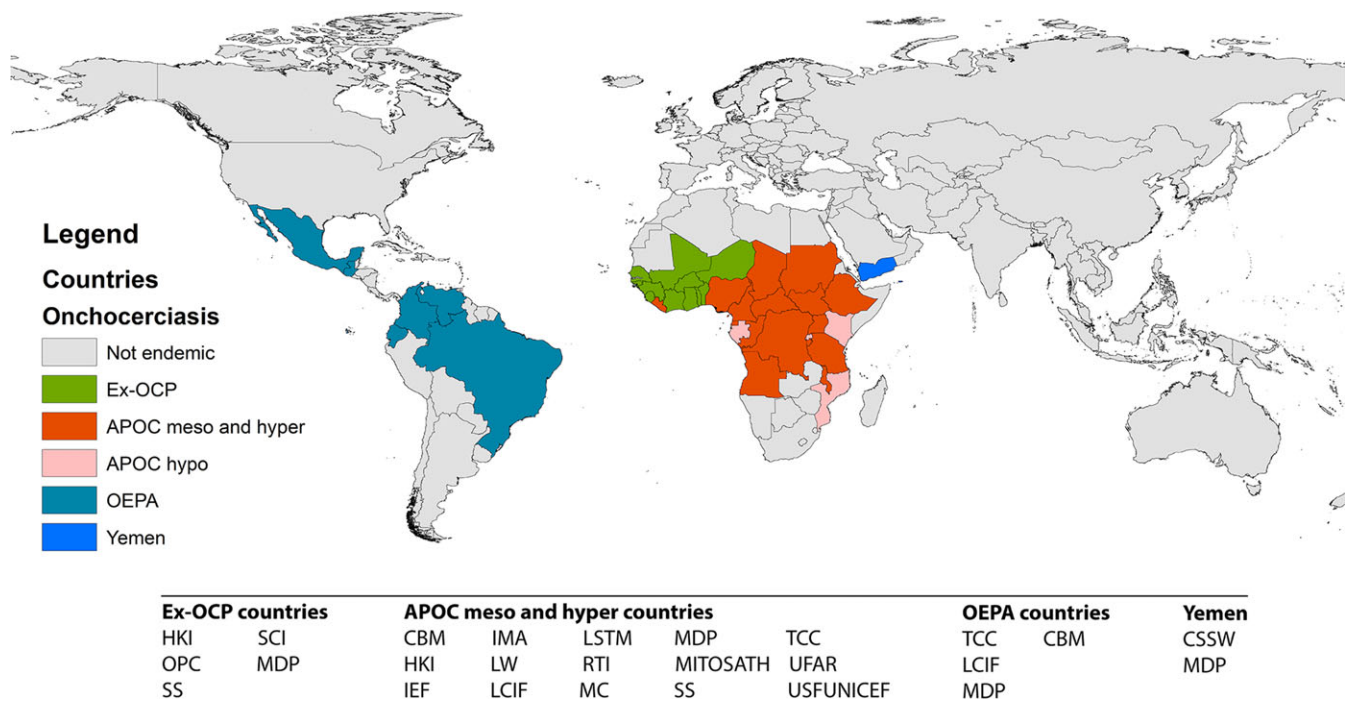
## Introduction

MSD, also known as Merck & Co., Inc., Kenilworth, NJ, USA, in 1987 committed to donating Mectizan<sup>®</sup> (ivermectin), as much as was needed for as long as needed, with the goal of helping to eliminate onchocerciasis. The Non-Governmental Development Organisation (NGDO) Coordination Group for Onchocerciasis Control (‘the Group’) was established by NGDOs in 1992 with the goal of global control of onchocerciasis through mass distribution of Mectizan<sup>®</sup>.<sup>1</sup> The Group members and the countries they have supported are shown in Figure 1. It is the oldest of the NGDO preventive chemotherapy-neglected tropical disease (PC-NTD) support groups that assist national programmes, and the ensuing NGDO groups (e.g. the lymphatic filariasis [LF] and trachoma NGDO groups) have modelled themselves on the Group’s experience. From its inception, the Group supported a broader partnership of all levels of the national health services, together with public-private and multilaterals.<sup>2</sup> The Group facilitated the establishment of the African Programme for Onchocerciasis Control (APOC) in 1995 to enhance the efforts against river blindness in Africa. As a formal member within the APOC partnership governance structure, the Group supported mapping of the disease and the scale-up of Mectizan<sup>®</sup> mass distribution throughout meso- and hyper-endemic areas (microfilaridermia prevalence  $\geq 40\%$ ) in Africa.<sup>3,4</sup> Members of the Group served on the APOC Technical Consultative Committee and attended the Joint Action Forum until APOC’s closure in 2015.

With the paradigm shift in Africa from control to elimination in 2010, the Group changed its name to the NGDO Coordination Group for Onchocerciasis Elimination in 2013, and has revised its terms of reference to adapt to the post-APOC world. The paradigm shift presented new challenges in mapping and expansion of treatment to hypo-endemic areas (microfilaridermia prevalence  $< 40\%$ ) previously untreated, adding new intervention strategy (especially twice per year treatment) where necessary, requiring the delineation of transmission zones/foci, coordination of cross-border and LF overlapping activities, technical resources needed to comply with the revised WHO guidelines on onchocerciasis transmission elimination<sup>5</sup> and raising additional funding to achieve and sustain transmission elimination. On the international scene, the Group is developing an advocacy document for mobilising additional resources. In this article, the authors describe their role in the elimination of onchocerciasis, building on the successes of the past and lessons learned.

## Progress towards WHO Roadmap targets

The initial onchocerciasis elimination target in the WHO Roadmap was to achieve regional elimination of onchocerciasis by 2015 in the six endemic countries in the Region of Americas.<sup>6</sup> Four countries, Columbia, Ecuador, Mexico and Guatemala, have been verified to have eliminated onchocerciasis by the WHO.<sup>6–8</sup> The WHO Africa Region’s target was to achieve elimination of



**Figure 1.** The past and current members of the NGDO Onchocerciasis Coordination Group and the endemic countries they have supported or are supporting. CBM: Christoffel Blindness Mission; CSSW: Charitable Society for Social Welfare; HKI: Helen Keller International; IEF: International Eye Foundation; IMA: IMA World Health; LW: Light for the World; LCIF: Lions Clubs International Foundation; LSTM: Liverpool School of Tropical Medicine; OPC: Organisation pour la Prévention de la Cécité; MC: Malaria Consortium; MDP: Mactizan Donation Programme; MITOSATH: Mission to Safe the Helpless; RTI: RTI International; SCI: Schistosomiasis Control Initiative; SS: Sightsavers; TCC: The Carter Center; UFAR: United Front Against River Blindness; USFUNICEF: US Fund for UNICEF.

onchocerciasis where feasible in 74% of the endemic countries by 2020.<sup>7</sup> Unfortunately, the national interruption of transmission has not been attained in any African country to date, and it is unlikely that this goal will be met. However, transmission has been interrupted and MDA halted in some foci in Mali and Senegal,<sup>9</sup> Uganda<sup>10,11</sup> and Sudan.<sup>12</sup> There is evidence that transmission may have been interrupted in Kaduna, Plateau and Nasarawa states in Nigeria.<sup>13,14</sup> Globally, over 800 000 people are no longer receiving treatment with ivermectin because transmission of onchocerciasis has been interrupted. A new WHO Africa Regional Office-based Expanded Special Project for Elimination of Neglected Tropical Diseases (ESPEN) was launched in 2016 to focus on the five PC-NTDs, including a goal of eliminating onchocerciasis where feasible.<sup>7</sup>

### Challenges of elimination of onchocerciasis

Elimination of onchocerciasis poses numerous challenges. These include the need for integration and coordination with the LF programme, maintaining momentum and commitment from all stakeholders for the end game, use of more sensitive and laboratory-based diagnostics (such as PCR tests of vectors and Ov16 serological tests in children), more intensive use of available drugs, completing the verification dossier and integrating post-elimination surveillance into health systems.

Interruption of onchocerciasis transmission according to the WHO guidelines requires financial, technical and human resources.

Mectizan<sup>®</sup> distribution needs to be expanded into conflict and hypo-endemic areas. The risk of serious adverse events associated with treatment with ivermectin in high prevalence loasis co-endemic areas needs to be mitigated. There is also a need to identify the correct complementary strategies in areas where the scale-up of treatment is required. Perhaps the most challenging issue is the lack of an operational manual to support stopping MDA although, as indicated in other articles in this supplement, Uganda, Ethiopia and Nigeria have prepared their own operational procedures with respect to the WHO guidelines.<sup>15,16</sup>

### Key achievements of the NGDO Coordination Group

Combined support by the NGDO members of the Group has resulted in sustained work for onchocerciasis in all endemic countries, with over 100 million mass treatments with Mectizan<sup>®</sup> per year in the last few years, and provision of funding for country assistance of between US \$5 and US 9 million per year since 2009.

In addition to assisting the Ministries of Health of endemic countries and the afflicted communities in combating onchocerciasis, the Group has had a key role in the governance of international onchocerciasis control efforts, advocacy, fund-raising, delivering other needed health interventions, while safeguarding the achievements of onchocerciasis control and verification of elimination of onchocerciasis. These roles at the international level

have been summarized previously by various authors,<sup>1,2,17–19</sup> documenting lessons learned on expansion from onchocerciasis to control and elimination of NTDs.<sup>19–21</sup> After the closure of APOC in 2015, the Group mobilised additional resources to meet the so-called ‘APOC funding gap’. The Group’s goals are aligned with the United Nations Sustainable Development Goals (SDGs): fighting NTDs (SDG3), leaving no one behind (SDG4), achieving gender equality and empowering women and girls (SDG5), access to water and sanitation (and SDG6), reducing inequality (SDG10), promoting social inclusion (SDG16) and working in partnership (SDG17).<sup>22</sup>

## Repositioning the Group for elimination of onchocerciasis

The Group now aims to serve as an advocate for elimination of onchocerciasis transmission to donors, stakeholders and governments of endemic countries, and to continue to provide direct country support where it is most needed until elimination is achieved. It continues to achieve this task by building on the successes of the past and lessons ‘learned by doing’. The approaches used will be based on a flexible approach to adapt interventions to the epidemiological settings of transmission zones. The outcome should be strengthening of all aspects of the health system to ensure sustained elimination of transmission of the disease and inclusive care for those affected.

## Leadership and governance

Elimination of onchocerciasis calls for strengthening of the current coordination and collaboration not only at national and international levels, but also between public and private multilateral organisations. In 2016 the Group revised its terms of reference to better support the elimination agenda and to adapt to its new role in the post-APOC era. The Group is now more open to new members and partners, and is free to join in order to cast a broader membership net amongst the NTD community. The Group seeks to support elimination activities in countries where there are gaps in funding, working closely with ESPEN in prioritising support for those countries in greatest need and finding new ways of working, particularly in areas co-endemic with LF and loasis. New approaches in monitoring and evaluation that require a laboratory network will need to be scaled-up with training, and resources for reagents and consumables. Treatment coverage will need to be maximised and documented by surveys in accord with recommendations from the WHO NTD Strategic and Technical Advisory Group (STAG).<sup>23</sup> The Group is prepared to use new tools in delineation of transmission zones/foci and more intensive treatment strategies (included limited vector control), where many years of mass treatment has not interrupted transmission.<sup>24–27</sup> Complementary strategies such as these have already been supported by NGDO partners in Cameroon, Ethiopia, Ghana, Nigeria and Uganda, have been used successfully in Sudan and Uganda<sup>15,28,29</sup> and are being used in Benin, Burkina Faso, Ethiopia, Ghana, Mali, Nigeria and Togo.<sup>30</sup> Lessons learned from these countries will be applied as appropriate in different country settings. National independent committees (recommended by the new WHO guidelines) have been encouraged and supported in many countries by the Group members.<sup>16</sup> These

committees are important for accomplishing a key ESPEN goal of ‘putting the countries in the driver’s seat’. The experiences of these committees will form a key knowledge base for expanding the evidence base needed for developing an African operational manual for onchocerciasis elimination.<sup>16</sup> As the end game is reached, coordinated cross-border interventions will become more important.<sup>29</sup> Cross-border meetings and joint activities between Uganda and Democratic Republic of Congo appear to be more effective when arranged at the district level for synchronising implementation, and monitoring and evaluation activities.<sup>16</sup>

Expansion of MDA to countries with conflict and/or post-conflict areas, and where there is also need for expansion of MDA will be supported by NGDO partners with skills in programming in these areas either through a network of national NGOs or directly.

## Advocacy and mobilising additional resources for elimination

The Group will need to support and work with WHO to reposition onchocerciasis as an NTD with an elimination goal within the framework of the next WHO Roadmap. The paradigm shift from control of onchocerciasis to elimination of onchocerciasis transmission will require additional funding for new programming, scaling and sustaining high coverages of MDA and post-treatment surveillance. Innovative and new ways of mobilising resources, such as developing an advocacy document and consortium approach used by the International Collation for Trachoma Control (ICTC) in Africa and the UNITED Programme in Nigeria will be explored.<sup>30–32</sup> MSD/Mectizan Donation Programme (MDP) and the END Fund joint financing to support impact evaluations in African countries is another example of other types of funding strategy.<sup>33</sup>

## Building capacity of the workforce for sustained elimination

The WHO guidelines stipulate that countries set up the independent National Onchocerciasis Elimination Committees (NOECs). Uganda is a good case study on NGDO support to the elimination of onchocerciasis.<sup>15</sup> Similar committees have been supported by NGDO partners in the Americas, Burkina Faso, Ethiopia, Ghana, Guinea, Liberia, Niger, Nigeria, Sierra Leone, Tanzania and Togo.<sup>15,16</sup> NGDO members supporting other countries will facilitate the establishment of similar committees in the remaining endemic countries.

Sustaining geographic coverage rates and treatment coverage rates at 100% and 80%, required to achieve and sustain elimination, will require improving social mobilisation and behaviour change communication. Members of the Group will support the training of more community volunteers to ensure a ratio of one drug distributor to 100 target persons is attained, and the use of the kinship and networking approaches encouraged to reduce the workload and demand for incentives.<sup>34,35</sup> In the elimination agenda, it is also critical to find support for training of the additional health workers needed for an intensive monitoring and evaluation effort, including entomologists, laboratory technicians, coverage survey teams, fly catchers and other mobile workers

who can supervise the volunteer drug distributors, and ensure good data recording and timely reporting.

### Supply chain management

Scaling up MDA for elimination requires improvements in procurement of medicines and supply chain management. The new Joint Application Form drug ordering system shows that supply chain management is between WHO and countries now. NGOs have less and less involvement in this process, but NGOs will be supporting key stakeholders, including MSD/MDP and the health service systems to facilitate the process taking into account the additional challenges for other PC-NTDs. NGOs have provided examples of successful case studies in the UNITED Programme in Nigeria,<sup>36</sup> and in Ethiopia supported by NGO partners. These examples will need to be replicated in other countries.

### Scaling down MDA

There is an urgency to gain momentum in the movement to eliminate onchocerciasis by demonstrating success at a national level. Even though the 11 West African countries in the first Onchocerciasis Control Programme have reported enormous success against the disease, no country in the Africa region has been verified for achieving elimination of onchocerciasis transmission.<sup>37</sup> Four countries in the Americas, however, have been verified by WHO free of onchocerciasis transmission.<sup>38</sup> Data are essential in informed decision-making. The data collection and management is a focus of any elimination agenda as decisions will need to be made in a timely fashion and based on quality data. NGO partners will continue to support improvements in data management and use of innovative approaches such as mHealth.<sup>39,40</sup> Communities have to be prepared for scaling down of MDA. The importance of social mobilisation to support scaling down of MDA will not be overlooked.

### Conclusions

The Group remains relevant in the elimination of onchocerciasis transmission, and committed to supporting and working with communities, endemic countries, WHO (Headquarters and ESPEN) and donors to attain elimination. It is repositioning itself for the challenges of elimination of onchocerciasis transmission through developing a 'blue print' for advocacy and resource mobilisation purposes, and has proposed a plan for its development. Adapting to the elimination scenarios recommended by the NOECs, which allow for flexibility, are our preferred approach.

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