

#### MMS Bulletin #92

Vernachlässigte Krankheiten

## It will take some convincing...

# Onchocerciasis - an innovative disease control solution meets a minor hitch

Von Andy Crump

Onchocerciasis is the world's second leading infectious cause of blindness. Rarely life-threatening, the disease causes chronic suffering and severe disability. Adding to the problem is the fact that the disease often occurs with epilepsy.

In a dilapidated old church in a poor rural village, a young boy lies prone, semicomatose on a mat woven from banana leaves. A small gap in one, almost closed, eyelid provides a vacant view of his impoverished and troubled relatives. In Masindi, in north-western Uganda, this sight is dreaded but frighteningly commonplace. Mothers and fathers are faced with regular trauma as their children become the victims of epilepsy.

Several other children are suffering from what is referred to locally as Nakalanga syndrome, principally a hyposexual dwarfism usually associated with mental disturbances. Here especially, and elsewhere in parts of Africa where onchocerciasis and epilepsy are found together, and where belief in spirits is deep-seated, there is a worrying anecdotal link between the two. Unfortunately, little research has been carried out to establish if there is indeed a link, but results so far suggest that there is indeed an association. However, in Masindi, the uncertainty is a major concern to communities as well as to programme managers striving to combat onchocerciasis.

## River Blindness hinders development

In Africa, onchocerciasis constitutes a serious obstacle to socio-economic development. It is often called River Blindness because of its most extreme manifestation and because the blackflies that transmit the disease abound in riverside areas, where they breed in fast-flowing waters.

Fertile riverine areas have frequently been abandoned for fear of the disease which is caused by a parasitic worm, Onchocerca volvulus, which lives in the human body for up to 14 years. Each adult female worm produces millions of microscopic larvae (microfilariae), that migrate

throughout the body to cause a variety of symptoms.

The parasites are transmitted via the bite of infected blackflies (Simulium spp.) that carry immature larval forms of the worms from human to human. In the body, adult worms lodge in nodules under the skin, releasing large numbers of microfilariae into surrounding tissues. Immature worms move through the body and after dying, cause a variety of conditions including serious visual impairment, severe itching and depigmentation of the skin, lymphadenitis and general debilitation.

The disease destroys the skin of those infected, disrupts the education of children who are driven to distraction by maddening and unrelenting itching, steals their childhood as they become forced to look after elderly relatives blinded by the disease, and ruins the marriage prospects of thousands of young women where beauty and healthy skin are their most prized assets.

In a significant region of west Africa, control has been brought about through vector control, spraying of insecticide to control blackflies. The Onchocerciasis Control Programme in West Africa (OCP) was a major control initiative launched in 1974 in an area encompassing 11 countries. Jointly sponsored by the WHO, World Bank, UNDP and FAO, plus a coalition of 20 donor countries and agencies, the OCP successfully achieved its objectives and was wound up at the end of 2002.

OCP's principal method for controlling onchocerciasis involved interrupting transmission by eliminating the vector. Simulium larvae were killed by aerial spraying of insecticides over breeding sites in fast-flowing rivers. Following interruption of transmission, the reservoir of adult worms dies out in humans after 14 years.

To complement vector control activities, the OCP also distributed a drug, ivermectin. The development of ivermectin in the 1980s revolutionised the prevention and control of onchocerciasis. The drug provides a safe, effective means for killing microfilariae in infected people. A single dose of the drug (which is being supplied free on a global scale, for as long as it is needed, by the manufacturer, Merck & Co. Inc.) needs to be taken annually.

The number of tablets that a person should take can be calculated simply by measuring their height using a simple measuring stick. The drug rids the human body of the immature forms of the parasitic worms that cause the devastating symptoms of the disease. Yet the adult worms remain unharmed, meaning that the annual dose must be taken repeatedly, for 14 years or until the adult worms die naturally.

For the system to work, all members of a community who are eligible must take the drugs. Those who don't comply jeopardise their fellow community members by remaining as a potential source of infection.

# A revolution called "community directed treatment"

The development in the 1990s of innovative community directed treatment (ComDT) programmes, through which affected communities themselves collect and distribute ivermectin and meet all the costs, has heralded a revolution in the treatment of onchocerciasis, as well as promising the same for other diseases.

ComDT empowers affected communities to take control of their own health care. Volunteers are selected by the community and, after 2-3 days of comprehensive training from health workers, assume responsibility for collecting ivermectin tablets from a local distribution point and delivering correct dosages to all eligible members of their community. They monitor, treat or refer side-effects, make detailed records and report back to the health centres. Days and method of distribution are determined by the community.

ComDT achieves far better coverage than similar programmes run via the formal health sector. National and local authorities, with donor and non-governmental organisation support, now simply have to organise the delivery of the donated drugs to local health centres for collection.

Following the success of the OCP, the same co-sponsors and donors created the African Programme for Onchocerciasis Control (APOC) in 1995. APOC's objective is to create, by 2007, sustainable community-directed ivermectin distribution systems which will ultimately cover 59 million people in 17 non-OCP countries in Africa where the disease remains a serious public health problem and where some 15 million people are infected.

In a few isolated foci, APOC also aims to eliminate the blackfly through insecticide spraying. Throughout Africa, the outstanding success of community-directed treatment, a process initiated through TDR's pioneering research work and now driven forcefully forward by APOC, should lead to the elimination of onchocerciasis on the continent.

It is clear that ComDT works extremely well. Even in war-ravaged countries where poverty is rife and resources scarce, such as Sudan, ComDT is succeeding, delivering ivermectin to villagers in even the remotest of areas. In Sudan, it is reported that ComDT is now actually delivering anti-epilepsy drugs to these villagers at the same time.

## Is ivermectin worsening epilepsy?

What is also clear is that APOC and the National Onchocerciasis Task Forces (NOTF) in countries such as Uganda, Sudan and the Central African Republic are facing a significant problem. How to convince those who believe that ivermectin is inducing or worsening epilepsy attacks that this is, in fact, not the case. In Masindi, several village dwellers remain convinced that onchocerciasis causes epilepsy claiming the drug either brings on the condition or at least makes it worse. Others, both in Masindi and in villages in other endemic countries, believe that ivermectin, in fact, helps cure or alleviate epilepsy.

Those who believe ivermectin is detrimental, are, naturally, refusing to partake in the distribution programme. In doing so, they are placing at risk their fellow villagers who do take part, as well as introducing a major stumbling block in the campaign to eliminate onchocerciasis from the African continent - a goal that is entirely reachable if affected communities, health systems, governments, industry and international agencies work together in a collaborative effort.

Fortunately the other benefits of ivermectin, which also kills a variety of intestinal worms, motivate those without visible lesions or signs of onchocercal infection problems to take the drug. Nevertheless, loving parents faced with a child struck down by epilepsy will take some convincing. And as is proving the case in Masindi, the task will not be an easy one.

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## "You can tackle anything"

What the success of the campaign against river blindness in West Africa demonstrates is that with the right approach, "you can tackle anything" in Africa, including HIV/AIDS, says Dr. Ebrahim Samba, the Africa regional director of the World Health Organization (WHO). The fruitful outcome of the river blindness campaign carries a number of lessons that are "applicable to any programme in Africa." These include:

- A shared vision: "Among the elements that contributed to success were, number one, a real shared vision, by the beneficiary African countries at the highest level and the non-African partners."
- Precise definition and realistic plan: The problem needs to be identified in scientific terms, followed by "a realistic, appropriate plan and strategy built for that problem."
- Long-term approach: An effort of two, three, five years is a "waste of time." The campaign against river blindness was planned for 20 years, but went on for almost 30 years.
- **Good technical team:** A team of technical experts and managers who can implement the broad vision, while also managing the human and financial resources of a complex, costly and lengthy programme. "Any abuse of resources, however small, could rupture the whole activity. So there has to be consistent, transparent management of the programme."
- Enduring support: There must be ongoing political and financial support for the work of the team carrying out the programme. "The river blindness programme was lucky in that none of the partners bowed down, over the whole period. Some of them came in without being solicited as partners. I say 'partners' and not 'donors and recipients,' because everyone contributed -- the African contributed, the non-African contributed."

Similarly, for the current efforts to combat HIV/AIDS, Dr. Samba concluded, "There should be a shared vision. There should be a commitment over a long time - it is much more complicated than river blindness, so it needs 30 years, minimum. There should be dedicated, good staff selected for their competence, not for political or other considerations. And there needs to be a corresponding commitment of funding over time."

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