

Uganda: how goes the nodding syndrome war?

Nodding syndrome has set siege to Uganda's north. In 2012, however, the country struck back, following a sophisticated plan of counter-attack. What ground has been won? Can it hold the line? Can it win the nodding syndrome war? Adrian Burton investigates.

For information about the symptoms and effects of nodding syndrome see *BMJ Open* 2013; 3: e002540

For background information on nodding syndrome see *Emerg Infect Dis* 2013; 19: 1374–1373

For more on Uganda's response plan see *Health Policy Plan* 2015; 1–8

For more on the nodding syndrome-onchocerciasis link see *Int J Infect Dis* 2014; 27: 74–77

For more on the Kampala meeting final report see http://www.who.int/neglected_diseases/diseases/Nodding_syndrom_Kampala_Report_2012.pdf

For more on Uganda's clinical guidelines for the management of nodding disease see *Afr Health Sci* 2013; 13: 219–32

For more on the improvements achieved through treatment, see *BMJ Open* 2014; 4: e006476

For more information on the effects of spraying see *Trop Med Int Health* 2015; 20: 194–200

For more on negative stereotyping by health-care workers see *Afr Health Sci* 2013; 13: 986–91

For more information about patients' and health-care workers' experiences in providing treatment see *BMC Res Notes* 2015; 8: 386

Northern Uganda, epicentre of the nodding syndrome epidemic. It is difficult to know how many children are affected: figures of 1700 to more than 3500 are reported, depending on the consensus case definitions used. In 2011, having asked WHO and the Centers for Disease Control and Prevention (CDC) for assistance in determining what they were dealing with, the Ugandan authorities drew up a two-phase response plan. Covering everything from the training of health-care workers to the establishment of specialised treatment centres and special needs schools, through to spraying against the black fly vector of *Onchocerca volvulus*—the river blindness nematode, with which nodding syndrome has a puzzling but consistently reported association—the plan was audacious for a country with scarce resources. With both phases now complete, is Uganda closer to gaining control? And what happens next?

The first emergency phase of the plan, which ran throughout 2012, made notable headway. "In early 2012, I was tasked to assemble a team and develop a clinical intervention", explains Richard Idro (Makarere University College of Health Sciences, Kampala, Uganda). "We used previous clinical descriptions and our own observations to come up with a strategy for symptomatic management, we developed a training manual for health-care workers, and then ran two associated training courses." The trainees were deployed to three newly formed specialised treatment centres. "There are now 17 such centres across northern Uganda where 3500 patients can receive treatment", adds Bernard Opar (National Coordinator of the Nodding Syndrome Response, Ministry of Health, Kampala, Uganda).

Other advances were made too. "A scientific conference on nodding disease was arranged in Kampala for late July 2012", explains Mwaka Amos Deogratius (also of Makarere University College of Health Sciences). "District task forces were formed to track progress and identify problems at the local level, and a national task force formed to oversee and coordinate all interventions."

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During phase two, which ran from January, 2013, to December, 2014, peer-reviewed clinical guidelines based on the country's growing experience of treating affected children were published. With the cause of the disease unknown, these guidelines focus on providing symptomatic care, aiming first to bring seizures under control—often achievable with sodium valproate and other common anti-epilepsy drugs—and then managing malnutrition, psychiatric problems, and physical and cognitive rehabilitation. "Overall, there has been a big improvement in patient outlook," says Idro. "This is documented in a published paper that examines outcomes after at least 12 months of intervention. With treatment, many children have managed to go back to school." The report even dares to suggest that nodding syndrome, once believed incurable, might be reversible.

2013 also saw the beginning of biannual mass treatment for onchocerciasis, along with the aerial spraying of rivers to reduce the vector black fly population. These actions might have led to the most dramatic success yet: no new cases of nodding

syndrome were reported in 2013—ground that Opar insists is being held. "One of the most important decisions taken by the government was to embark on eradicating onchocerciasis from the area affected by nodding syndrome", he explains. "Due to the civil war that affected the area, the black fly population had increased greatly, and aerial spraying had to be conducted to achieve rapid reduction. This was followed by ground larviciding of breeding sites along the rivers. According to recent surveys, the vector population has been reduced to minimum levels. In addition, parasite reduction in the human population was undertaken to reduce morbidity and eliminate circulating onchocerca microfilaria. The most efficient and rapid way to achieve this was through the mass distribution of ivermectin."

But battles remain to be won. For example, a recent paper expressed concern that many health-care workers develop negative stereotypes towards nodding syndrome: stereotypes that both stigmatise patients and could become an impediment to their care. These include beliefs that the disease is caused by evil spirits (27/40 of health-care workers asked), and that those affected are a burden to society. Another paper revealed continuing shortfalls in access to treatment. "People in some communities report no problems at all accessing drugs", explains Deogratius. "Indeed, medications are brought to their villages by vehicle. Others, however, speak of still having to travel scores of kilometres on foot to reach health facilities that are commonly overcrowded and manned by sometimes insufficiently trained and grumpy health-care workers who frequently have to ration scant supplies of drugs."

The press has reported other problems. For example, in mid-2013, a rehabilitation centre in Kigung District (the country's worst affected area) ran so low on food and drugs that parents had to take their children home, and in September, 2015, Uganda's *Daily Monitor* denounced that funds for battling nodding syndrome had entirely failed to reach Kigung for months on end. Demoralised health-care workers were said to be abandoning their posts because of lack of payment. Indeed, the financing of the fight against nodding syndrome has been dogged by trouble since the start. In 2012, a major row broke out with MPs demanding to know where an earmarked 400 million Ugandan Shillings had gone, with Opar defending that the money had not reached his office a full year after its allocation. It did, however, eventually arrive, and he remains hopeful that such problems have now been overcome. But even if all financial bottlenecks were removed, with just one doctor and 13 nurses for every 10 000 people, how much can Uganda's authorities realistically hope to achieve?

This shortage highlights the crucial role that non-governmental organisations could play in helping to deliver medical services to children with nodding syndrome, yet only one, Hope for Humans (San Antonio, TX, USA), is involved in such day-to-day work. "The authorities do the best they can, and have implemented reforms to enhance health-care funding and delivery", says its co-founder Suzanne Gazda, a US-trained neurologist. "But, the reality is that much remains to be done. Sadly, any changes that do come might come way too late to help the victims of nodding syndrome. Unless we reach them now, with private funding, only suffering and death awaits them."

Since its foundation in 2012, Hope for Humans has tried to steer children away from such a tragic fate, providing care where the Ugandan state cannot. Its first centre opened in the village of

Odek, taking in 41 children for day care. "The children received free medical support, counselling, and special needs education", says Gazda. "By March 2015, we were able to admit most of the children with severe disease for full-time medical care. We have also expanded our programmes to Tumangu in Kitgum District where we have constructed a second care centre where another 40 children can be cared for."

Supported largely by donations, Hope for Humans improves its sustainability by farming. "We grow food for the children, supplementing our budget through the sale of eggs and piglets, and we help the parents by teaching them farming management techniques", explains Christine Henderson, the charity's (Hope for Humans Director of Development). "And importantly, parents know their children are safe, and can go back to work", adds Collines Angwich (Hope for Humans In-Country Director, Gulu, Uganda). Every day, after bathing and breakfast (one of two meals per day), the children take their medication and go to special needs classes. These include physical education, music therapy, reading, drawing, colouring, and story-telling to improve cognitive ability. According to the official response plan, all children in need should receive such specialised education, but so far only Hope for Humans has been able to provide it.

"We also perform monitoring of children in the community or who have gone back to primary school, to find out how they are faring and if they are taking their medication", adds Gazda. Importantly, she agrees with Idro that nodding syndrome is not untreatable. "We need to raise awareness about this. So many parents and health-care workers believe nodding syndrome to be incurable, and children with it to be a burden. With treatment, this does not need to be the case at all."

With the second phase of the response plan now complete, what about the future? "The country will continue to partner and collaborate



Children with nodding syndrome in class: hardly a lost cause

in the search for the cause of nodding syndrome", says Opar. "Funding of treatment will continue, and the program for mass distribution of ivermectin and ground larviciding along the rivers in northern Uganda will be a priority."

"Uganda indeed seems on the right track to stop nodding syndrome", confirms Robert Colebunders (University of Antwerp, Belgium). "We now need to investigate whether the same measures will work in South Sudan, where there is an ongoing nodding syndrome epidemic and where most affected children remain untreated. The evidence that onchocerciasis is linked to different forms of epilepsy, including nodding syndrome, is increasing. The problem of epilepsy in all parts of Africa where onchocerciasis remains insufficiently controlled needs to be addressed."

Fully stabilising treatment for those affected might only come when we better understand the mechanism of the disease, and even then it will probably be a huge struggle for Uganda to make it widely and easily accessible. But with the prevention of future cases now seeming an achievable goal, with results coming in that already affected children can often be successfully treated, and with a pioneering non-governmental organisation showing that their lives can be improved, perhaps it is time to believe that the tide in this war is turning in Uganda's favour.

Adrian Burton

For more on **health-care workers abandoning their posts** see <http://www.monitor.co.ug/News/National/Health-workers-abandon-nodding-syndrome-patients-/688334/2873834/-/4jr7z/-/index.html>

For more information on **Hope for Humans** see <http://hopeforhumans.org>

For more on **onchocerciasis and other forms of epilepsy**, see *PLoS Negl Trop Dis*; published online Aug 13. DOI:10.1371/journal.pntd.0003880