

Mysterious nodding disease afflicts young Ugandans

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In this photo taken Monday Feb. 20, 2012, a mother shows the burnt arm of her child suffering from nodding disease at their home in the Kitgum district, Uganda. Uganda this week hosts a four-day international conference on nodding syndrome that health officials believe will lead to a clearer understanding of the mysterious disease. The disease is called nodding syndrome, or nodding head disease, because those who have it nod their heads and sometimes go into epileptic-like fits. The disease stunts children and destroys their cognition, rendering them unable to perform small tasks. (AP Photo/Stephen Wandera)

(AP) — Augustine Languna's eyes welled up and then his voice failed as he recalled the drowning death of his 16-year-old daughter. The women

near him looked away, respectfully avoiding the kind of raw emotion that the head of the family rarely displayed.

"What is traumatizing us," he said after regaining his composure, "is that the well where she died is where we still go for drinking water."

Joyce Labol was found dead about three years ago. As she bent low to fetch water from a pond a half mile from Languna's compound of thatched huts, an uncontrollable spasm overcame her. The teen was one of more than 300 young Ugandans who have died as a result of the mysterious illness that is afflicting more and more children across northern [Uganda](#) and in pockets of South Sudan.

The [disease](#) is called nodding syndrome, or nodding head disease, because those who have it nod their heads and sometimes go into epileptic-like fits. The disease stunts children's growth and destroys their cognition, rendering them unable to perform small tasks. Some victims don't recognize their own parents.

Ugandan officials say some 3,000 children in the East African country suffer from the affliction. Some caregivers even tie nodding syndrome children up to trees so that they don't have to monitor them every minute of the day.

Beginning Monday, Uganda hosts a four-day international conference on nodding syndrome that health officials believe will lead to a clearer understanding of the mysterious disease.

World Health Organization officials in Uganda said the conference will be attended by about 120 scientists from all over the world. Anthony Mbonye, of Uganda's Ministry of Health, said the conference will allow scientists to share knowledge about the disease.

Scientists are working to find the cause of the disease, which is stretching health care capacities here and testing the patience of a community looking for answers as to why it attacks mostly children between the ages of 5 and 15, why it's concentrated in certain communities, and whether it is contagious.

The U.S. Centers for Disease Control and Prevention, which has been investigating nodding syndrome at the request of the Ugandan government, has ruled out 36 possible causes since 2009 and is carrying out a clinical trial for potential treatments. In mid-February the lead investigator said on a visit to Uganda that there is now "clear evidence that this is an epidemic" about which very little is known.

"We did repeated exams on several of these children and found that some of the children had stayed the same, some of the children had gotten worse, none of the children had improved," said Scott Dowell, director of CDC's Division of Global Disease Detection and Emergency Response.



In this photo taken Monday Feb. 20, 2012, a Ugandan family shows the grave of a family member who died of nodding disease in Kitgum district, Uganda. Uganda this week hosts a four-day international conference on nodding syndrome that health officials believe will lead to a clearer understanding of the mysterious disease. The disease is called nodding syndrome, or nodding head

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Researchers are focusing on the connection between nodding syndrome and the parasite that causes river blindness, Dowell said, though it is not yet clear there are any links. Onchocerciasis, or river blindness, has been around for a long time, but nodding syndrome is somewhat new, he said. "And we also know that there are many parts of the world that have onchocerciasis but have no evidence of nodding syndrome."

Many residents here in the northernmost reaches of Uganda, nearly 300 miles from Kampala, say they think the disease is rooted in violence. Locals have said it's the only explanation for the disease's prevalence in places most affected by the legacy of a brutal war carried out by Joseph Kony, the leader of the Lord's Resistance Army, a rebel group. Kony and the group have waged a campaign of murder, rape, and the abduction of boys and girls who go on to become killing machines or sex slaves.

"We the Acholi have suffered a lot, and I am asking why," said Benjamin Ojwang, an Anglican bishop in the area. "In the absence of Kony, we were beginning to find relative peace. When are our people going to rest?"

A disease as strange as nodding head gives people a sense of hopelessness and helplessness, said N.K. Okun-Okaka, a retired veterinarian who has the status of a village elder.

"They can only do something about it if they know the cause, how it is spread. My heart goes out to these children. We feel very sorry and we feel like we do not live in the modern world," he said.

Ugandan health officials have known about the disease for nearly 10 years. By 2006, after Kony was repulsed from Ugandan territory, health care providers had diagnosed several cases of epilepsy without stopping to ask why.



In this photo taken Monday Feb. 20, 2012, a Ugandan child suffering from nodding disease shows their burned arm at their home in the Kitgum district, Uganda. Uganda this week hosts a four-day international conference on nodding syndrome that health officials believe will lead to a clearer understanding of the mysterious disease. The disease is called nodding syndrome, or nodding head disease, because those who have it nod their heads and sometimes go into epileptic-like fits. The disease stunts children and destroys their cognition, rendering them unable to perform small tasks. (AP Photo/Stephen Wandera)

"This thing is old," said Emmanuel Tenywa, a World Health Organization official in northern Uganda. "After the war there were so many cases of epilepsy. That's how this thing started."

Yet serious steps to manage the disease were taken only in the last year after a group of parliamentarians accused the authorities of criminal negligence. The government then announced a \$2.2 million plan. But the cash has been slow to reach treatment centers.

Sick children have remained stuck in villages where biting poverty sometimes combines with the inattention of caregivers. Children have been badly burned after falling in fires. Others have died falling into water, like Languna's 16-year-old girl. And it is common to see children tethered to trees by caregivers too busy to look after them.

In Languna's household alone, eight children suffer from the disease, including a 12-year-old boy whose growth is so stunted he looks half his age. Languna has given up on all of them.

"We lost a child who was so promising," he said. "But what pains us more is that these ones you see are destined to (die)."

Investigators said they are not certain the disease is non-communicable, but they advise against alarm.

In the absence of definitive answers, some here have been taking matters in their own hands by isolating the sick. At the Okidi primary school, which Labol attended before she drowned, teachers once attempted to segregate the children and then dropped the idea after being criticized. Since 2007 there have been 141 cases of nodding disease at the school, with seven ending in death.

Now sick children rarely come to school, science teacher Paska Atto said.

Luke Nyeko, the Kitgum chairman, is frequently stopped by parents demanding to know what exactly their [children](#) are suffering from or

why they cannot be cured.

"I feel very bad, very bad," he said of encounters with distressed parents. "It's a bit tricky because you can't go and lie to them. We just tell them that we don't know the condition."

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