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On the Brink: Guinea Worm | A Long Crusade

## **Dose of Tenacity Wears Down a Horrific Disease**

By DONALD G. McNEIL Jr.

OGI, <u>Nigeria</u> — Whatever secrets the turgid brown depths of the Sacred Pond of Ogi may keep, there is one they betray quite easily: why it is so infuriatingly hard to wipe even one disease off the face of the earth.

Ogi is one of the last areas of Nigeria infested with Guinea worm, a plague so ancient that it is found in Egyptian mummies and is thought to be the "fiery serpent" described in the Old Testament as torturing the Israelites in the desert.

For untold generations here, yardlong, spaghetti-thin worms erupted from the legs or feet — or even eye sockets — of victims, forcing their way out by exuding acid under the skin until it bubbled and burst. The searing pain drove them to plunge the blisters into the nearest pool of water, whereupon the worm would squirt out a milky cloud of larvae, starting the cycle anew.

"The pain is like if you stab somebody," said Hyacinth Igelle, a farmer with a worm coming out of a hand so swollen and tender that he could not hold a hoe. He indicated how the pain moved slowly up his arm. "It is like fire — it comes late, but you feel it even unto your heart."

Now, thanks to a relentless 20-year campaign led by former President <u>Jimmy Carter</u>, Guinea worm is poised to become the first disease since <u>smallpox</u> to be pushed into oblivion. Fewer than 12,000 cases were found last year, down from 3 million in 1986.

Mr. Carter persuaded world leaders, philanthropists and companies to care about an obscure and revolting disease and help him fight it. His foundation mobilized volunteers in tens of thousands of villages to treat the drinking water the worms live in.

But the eradication effort has already taken a decade longer than expected. And sometimes, when the world beyond their farthest sorghum field or camel-grazing spot takes an interest in them, the villagers fight the message.

Guinea worm's Latin name is dracunculiasis, or "affliction with little dragons," but in Africa it is often called empty granary because of its tendency to erupt at harvest time, rendering farmers unable to work. It ought to be almost ridiculously easy to wipe out, because it has a complex life cycle in which humans, worms, fleas and shallow ponds each must play their parts perfectly. Any missing link disrupts the chain of transmission.

Wells can be drilled to prevent the afflicted from plunging their limbs into the village's drinking water. Or local water sources can be treated with a mild pesticide that kills the fleas that swallow the worm larvae and are, in turn, swallowed by the humans. Or every family can faithfully pour its water through a filter cloth each day, or drink through filtering straws. With unremitting effort, experts at the Carter Center now estimate, purging the last nine African countries of the disease could take five more years. Dr. Ernesto Ruiz-Tiben, technical director of its campaign, says he is sure that, at long last, victory is in sight.

Nigeria is in the homestretch. Last year, it reported only 121 new cases, down from estimates of 650,000 two decades ago.

Dr. Ruiz-Tiben has been fighting it for 22 years. And for all the success, he groans, "sometimes it's like dragging a dead elephant through a swamp by its tail."

A Pond's Dangers

In 2001, Jacob Ogebe, a field officer for the Carter Center Guinea Worm Eradication Program, was trying to track down every pond in the area surrounding Ogi. He treated each with Abate, a mild pesticide that left the water potable, but killed the microscopic fleas that carry Guinea worm.

But slowly, he realized that Ogi's villagers were misleading him. He heard rumors of a sacred pond, but no one would take him to it. "They kept leading me to other places," he said. "Then one day, I was treating another pond, and I got lost and discovered it."

Though it is only a triangular puddle about 20 feet on each side in a heavily trodden grove of trees, the villagers revere it. "We have laws here, so no one dirties it," Gabriel Egba, the pond's high priest, said in an interview on its edge.

The rules are painted on a metal sign. The sacred water may not be sold or bartered. Any animal that drinks must be killed. Anyone who bathes, fishes, urinates or dips an oily pot in it is to be fined. Fines range from 35 cents to a live goat.

The pond teems with whiskery fish, turtles and snakes. More important, villagers say they believe that the souls of their ancestors also dwell in it, and Mr. Egba officiates at the sacrifices of roosters and rams for anyone wishing to talk to them.

After Mr. Ogebe found the pond, he said, villagers tried to dissuade him from treating it. "Some of them offered me money to hide it," he said. "But I told my boss at the Carter Center. Then, each time I went to the village, people followed me around. There were threats on our lives."

But by November 2003, the Carter Center's office in Jos, the regional capital, had persuaded village leaders to treat it. Nigeria's political leaders,

constantly on the defensive against foreign accusations that the government here is inept or corrupt, had developed a sudden interest in the country's increasingly successful Guinea worm eradication campaign. The Carter Center's office was able to send in its biggest gun, short of a visit from Mr. Carter himself: Gen. Yakubu Gowon, who ruled Nigeria from 1966 to 1975.

For General Gowon, whom Mr. Carter had met in 1997 and asked to join his work, the Guinea worm campaign had become a point of personal pride. At 32, he took power in a coup against military rulers who had overturned Nigeria's first democratic government, and he crushed a war of secession in Biafra that cost a million lives. Now in his 70's, he is an elder statesman with his own foundation, the Gowon Center, modeled on Mr. Carter's.

He feels, he said, "a sort of guilt" that he did nothing about the disease while he was in office. "It was never reported in those days," he said. "If we had known, I would have done something about it."

On the day of his visit to Ogi, he was greeted politely beneath the village's central tree and was personally invited to pour the Abate into the pond. But when he and the other dignitaries walked the several hundred yards through tall grass to it, they found many of the village's women forming a human wall around it.

"They had colors rubbed on their faces to show resistance," like Indian war paint, Mr. Ogebe said. "They were chanting songs of their refusal."

Sarah Pantuvo, General Gowon's Guinea-worm eradication director, said the women shouted: "This disease is a curse from our ancestors, it has nothing to do with the pond water! If we let you touch anything, the ancestors will deal with us. We heard them crying all night!"

"I was very angry," Ms. Pantuvo said.

But General Gowon tried to defuse the situation, telling the women: "You, the women who fetch water from this pond, were not consulted about treating it? You should have been."

He assured them that the Abate would not harm the fish, and he told them that if their ancestors were benign, they would not want their children to be sick, and would like the pond treated.

But the women would have none of it. "Why don't you go treat AIDS instead?" they shouted.

Finally, he backed down, saying he would return when the women were ready.

That evening, he visited Matthew Ogbu Egede, the paramount chief of the area around Ogi. Chief Egede was mortified.

"I am a Christian," he said in an interview. "I don't believe in anything about juju. These people objected out of ignorance. The devil made them object."

He convened a meeting of "the elites," a local chiefs council. Furious, they ordered the village to accept the pesticide treatment and pay a fine of "one very mighty native cow, plus goats, yams and kegs of palm wine," Chief Egede said. The council sent the general an effusive letter of apology.

"As Socrates of the old Greek people took a cup of hemlock poison from his people for the love of his state, so have you borne our people's churlish misbehaviour," it said, further comparing him to William Tyndale, who translated the Bible into English and was martyred for heresy, and to St. Polycarp, who smiled as he was burned at the stake.

Mr. Ogebe was allowed to treat the pond. Slowly, cases of Guinea worm disease died out in the area.

The mud hut in Ogi called the Guinea Worm Containment Center recently housed four patients, including Mr. Igelle, the farmer. There they are given buckets of water to cool their burning limbs, and three simple meals a day to keep them from working in the fields, where they might be tempted to soak a painful blister in a drinking pond.

Each sufferer had at least one yardlong worm painfully emerging, a few agonizing inches a day, carefully wound around a twig or bit of gauze.

"I blame myself, because I drank that water," said Mr. Igelle, 55, admitting that he had drunk from a stagnant pond when the water his wife had carefully filtered had run out as he worked in his far-off yam field. "Now my children go to the field to fetch food, and I tell them not to drink."

Though Mr. Igelle may be one of Ogi's last cases, migrant herders and farm laborers still pass through, and any one of them could have picked up a worm in the last year. It could come back.

A Cause in Need of a Leader

That such a mighty struggle would erupt over one pond gives a sense of how daunting a disease eradication campaign can be. Without a relentless leader, it will go nowhere. In the case of Guinea worm, that role is played by Mr. Carter, who in 1986 was hunting for projects for his new foundation.

He had a chat with a former aide, Dr. Peter Bourne, who was then leading a very ambitious effort, ultimately abandoned, by the <u>United Nations</u> to bring clean drinking water to every village in the world.

"He had slides of Guinea worm to show me," Mr. Carter said. "I was intrigued."

Soon after, on a human rights mission to Pakistan, he mentioned the disease to Mohammad Zia ul-Haq, then the president, "General Zia didn't

know anything about it," he said, "but his prime minister had come from a village with Guinea worm."

It turned out that 2,000 villages did, but villagers never reported it, thinking it was "a curse of God, or some confluence of planets, or came from drinking goat blood."

President Zia told a general to wipe it out, and in 1993, Pakistan became the first country to do so.

Mr. Carter himself first saw the worms in Ghana in 1988, in a village where 300 of 500 inhabitants were disabled by it.

"My most vivid memory was of a beautiful young 19-year-old-or-so woman with a worm emerging from her breast," he said. "Later we heard that she had 11 more come out that season."

He arranged for a well to be drilled, "and when we went back a year later, they had zero cases — zero."

But drilling, at \$1,500 a well, is prohibitive. Filtering out the larvae-carrying fleas is cheaper. At a 1989 lunch with Edgar M. Bronfman, the Seagram's liquor heir, Mr. Carter explained the technique with a damask napkin. Mr. Bronfman, who held a major stake in the DuPont chemical company, had its scientists develop a tough but fine mesh.

Other donations followed: Abate larvicide from the BASF chemical company, pipes with steel mesh filters from a Norwegian power company, \$16 million from the Bill and Melinda Gates Foundation.

When Mr. Carter started organizing his campaign, his experts estimated that eradication would take 10 years. Asked if he worried that the worms would outlive him, he grinned and shook his head.

"I don't have any doubt that it will be eradicated during my active service," he said. "The discouraging thing is the extreme cost. I have to keep explaining to donors why it costs so much for these last few cases."

An Army of Volunteers

While his campaign could not have succeeded without a large vision and contributions to match, the eradication of a disease ultimately depends on the dedication of workers in the field.

In rural Nigeria, as is true everywhere when literacy rates are low and telephones rare, everything must be done face to face. Twenty years ago, the Carter Center began its campaign by surveying 95,000 villages in Nigeria alone, sending someone to each one to ask if it had any cases of Guinea worm.

In each of the 6,000 villages that did, a team had to be formed to visit the authorities, explain the campaign and ask them to pick a "Guinea worm volunteer," someone who could read and write, would be willing to track each case, teach others how to roll worms out on a stick and keep their larvae out of drinking water.

The volunteers are unpaid. "They get a T-shirt, and people look up to them," said Dr. Cephas Ityonzughul, a consultant for the Carter Center's program in central Nigeria.

Supervisors like Mr. Ogebe are also unpaid but may get the use of a bicycle or motorbike, which in rural Africa are major status symbols. They also receive a Carter Center backpack full of sterile bandages.

Part of their job is to fight folk-medicine habits that sometimes die harder than any disease.

In a village north of Ogi, a traditional healer, Yahaya Sarki, demonstrated his own "worm treatment." Plucking a short iron blade from his straw roof, he whetted it on his stone doorstep and heated it on a hot coal. Then he mimed how he would plunge it into the emerging worm's head.

"The idea is to burn the worm to death," Dr. Ityonzughul explained, "but as soon as you touch it, it recoils and tries to find an exit elsewhere. It's very brutal, and it frequently causes tetanus. In 2002, we lost two volunteers to it. But in northern Nigeria, it's used in almost all cases. I've given up fighting it. No matter what I say, they do it anyway."

"Besides," he added of the victims, "it incapacitates them. They can't walk, so they don't put it in the water."

People also pick off their dressings, saying "the worm must breathe," he said. He has tried paying them a few cents to keep wounds bandaged, but it rarely works.

Still, he is not easily put off his mission, though tactics are not always as public and confrontational as they were in Ogi.

"We have paid people to put Abate in the sacred ponds secretly," he admitted.

He described a northern village that practiced both ancestor worship and Islam, which considers dogs unclean.

"They refused the Abate," he said, adding with a grin: "But someone killed a dog and threw it in their sacred pond. People stopped drinking the water — and Guinea worm cases went down."