Behind the effort to defeat a painful disease
It starts with a painful blister on your leg or foot. When it bursts, a spaghetti-sized worm appears. With help, the worm will come out over the next days and weeks—all 2 feet (60 cm) or more of it. If you break it off, things will only get worse. What you must do is wrap it around a small stick or a piece of gauze and tug gently every day. Guinea worm disease causes weeks of agony before it’s over.

Across the globe, untold millions of people have experienced this torturous and disabling condition. But soon, if all goes as expected, no one will ever face this nightmare again. Much of the credit for this goes to Donald Hopkins, special advisor for Guinea worm eradication at the Carter Center in Atlanta.

Hopkins wanted to be a doctor for as long as he can remember—“even at three or four years old,” he says. He did well in high school and, in 1958, won a full scholarship to Morehouse College, a historically black college in Atlanta. At just 15 years old, he began his freshman year there. In his second year, he first encountered Guinea worm disease. “In the zoology textbook,” he says, “there was a photograph of a woman with a Guinea worm coming out of her body. I never forgot it.”

A health worker extracts a Guinea worm from a patient’s ankle. It’s hard to look at. If a global effort led by Dr. Donald Hopkins is successful, no one will ever have to see or suffer from this condition again.
Guinea worms have afflicted humans for millennia. In fact, archaeologists discovered the preserved remains of a Guinea worm in an Egyptian mummy over 3,000 years old. The Latin name for the worm, *Dracunculus*, means "little dragon," reflecting the fiery pain it causes.

In medical school, Hopkins learned more about Guinea worms. They are a problem mainly in remote, rural areas of Africa and Asia, among the poorest people. The disease keeps people in poverty because they become too weak to work in the fields or to tend their livestock. Affected children are unable to go to school. There is no treatment for the disease and no vaccine to prevent it.

A critical part of the life cycle of the Guinea worm occurs in bodies of stagnant water inhabited by tiny water fleas. The fleas eat the first-stage larvae, which go through two more larval stages inside the insect. To develop further, they must get to the human gut. People drinking from contaminated ponds or other water sources swallow the minute water fleas without knowing it. Inside the human body, digestive acids dissolve the flea, freeing the worm larvae, which tunnel through the wall of the intestine. In the person’s muscles, they grow into adult worms and mate with other Guinea worms. After mating, the males die. Over the course of the next 12 months, the females slither through body tissues on their way to the outer layer of skin.

During that year, hundreds of thousands of eggs develop into immature larvae inside the worm’s body. All that’s left for the female Guinea worm now is to get...
to water so that she can expel her larvae and the cycle can begin again. In the meantime, the human hosts usually know nothing of what’s going on inside their bodies until the worm (or worms) get ready to emerge. They usually come out of the lower legs and feet, though they can end up anywhere.

To get out, the worm secretes an acid that creates a blister, which bursts, revealing the worm and causing such burning pain that the victim wants nothing more than to jump into water to cool the wound. This is just what the Guinea worm needs. Once in water, it releases a mist of larvae, which water fleas eat. When people drink the water, the process starts all over again.

**An Education in Eradication**

After medical school, Hopkins went to Sierra Leone, in West Africa, to direct that country’s campaign to eliminate smallpox. His work was part of a global effort that finally succeeded in 1978. So far, smallpox is the only human disease to be completely stamped out. In 1980, while working for the Centers for Disease Control and Prevention (CDC) in Atlanta, Hopkins attended a meeting at the World Health Organization (WHO) headquarters in Geneva, Switzerland. He recounts, “During the break I was sitting next to a young French physician who had worked in West Africa, in Ivory Coast. We were making small talk. I asked him whether he had seen any Guinea worm disease.” It turned out that he had. Moreover, says Hopkins, the young doctor “had marveled at how Guinea worms declined severely and even disappeared as the government put in clean drinking water. And that just struck me.”

At the time, the WHO and other international agencies were promoting clean drinking water to fight cholera and typhoid and other diseases caused by viruses. But nobody mentioned Guinea worm disease. Hopkins knew that clean water was only part of the answer to bacterial and viral diseases because they had many other ways of spreading from person to person. But with Guinea worm, he says, “You provide clean drinking water, and people use it, and there’s no other way for the disease to be transmitted. This was an astonishing opportunity.”

Hopkins says, “For me the smallpox experience was an inspiration.” It gave him the optimism that Guinea worm disease, too, could disappear from the world. Back at the CDC, he organized a group to systematically track cases of the disease and to start a massive public education campaign.
A Problem of Perception

The group found it difficult to interest international organizations and governments in its work. Hopkins says, “They often didn’t think it was important. They didn’t value the people in the areas where it was occurring because they were mostly rural people. Many people—especially some of the ruling elite—regarded them as among the lowest of the low. So they didn’t care about what kind of diseases they had out there.” Hopkins had seen that attitude before. Indeed, he had experienced it growing up in the 1950s, an African American in segregated Miami. He says, “I can never forget what it felt like being one of those people perceived that way.”

It motivated him and, when he worked in the areas beset by Guinea worm disease, it made him more effective in dealing with the villagers. “It helped me to be able instinctively to put myself in those people’s place and to recognize and avoid in my own behavior the kinds of direct and indirect signals of condescension that I knew they didn’t like.” He’d seen that condescension among some of the foreign health workers on other health projects. The villagers were, he says, “hypersensitive to people coming from the cities and telling them what to do and looking down on them.” He made sure he listened to the villagers and asked questions.

The Road to Success

With no way to treat the disease, eliminating it meant making the sources of drinking water safe. Health workers had to keep people with Guinea worms from entering ponds and other sources of drinking water. And they had to find ways to remove larva-bearing fleas from drinking water. Cloth filters could strain out the fleas. But it wasn’t easy to convince people to use the filters. The villagers didn’t believe their water was the source of the disease. It wasn’t as though they drank cloudy water from a pond and the next day a worm appeared. It was easier for people to believe that everybody was born with Guinea worms.
Sometimes they would emerge; sometimes they wouldn’t. “The most powerful teaching tool was to bring people down to the ponds where they get this water,” says Hopkins. “We’d filter some of it through a finely woven cloth; then backwash the stuff that had been trapped by the cloth into a jar of clear water and hold that up to the light.” The tiny fleas are barely visible, but their jerky movements are noticeable. “People, as I like to say, instinctively do not like the idea they’re drinking water with things swimming around in it,” says Hopkins. “And that helped them to make the connection between the water they were drinking and the Guinea worms.”

In 1986, Jimmy Carter, former president of the United States, joined the fight. He threw the influence and resources of his foundation, the Carter Center, into it. The organization contacted companies that could make and donate the filters needed. Other businesses donated materials to make a drinking straw with a filter that people could wear on a string around their necks. When out in their fields or traveling to another village, they could use the straw to drink from any stream or pond they passed.

Ernesto Ruiz-Tiben, a veteran of campaigns against other tropical diseases, worked with Hopkins. Both Hopkins and Ruiz-Tiben moved from the CDC to the Carter Center to head up the eradication campaign. The center partnered with organizations and government agencies to train field workers and track progress. Its most important effort was mobilizing thousands of volunteers to provide health education to their own communities. The workers encourage people to report suspected cases of Guinea worm infection, preferably before the blister bursts. They treat the patients, clean the wounds, and cause

A CASE OF BAD BLOOD
IT’S BEEN BLAMED ON WITCHCRAFT, on improper behavior, on bad blood, and on countless other causes. Guinea worm disease was a mystery for most of its history. Its long history—a papyrus from 1550 BCE describes the disease and explains how to pull the worm out by winding it around a stick. For thousands of years, doctors treated patients for Guinea worm disease without understanding how it happened. Finally, in 1870, Russian scientist Aleksey Fedchenko solved the mystery, recognizing the critical role the water fleas play in the life cycle of the worm. Without the flea, the worm larva can’t develop to the stage where it can infect a human being. And if nobody swallows the water flea, the larva can’t grow into an adult and reproduce.

For the most part, people in the remote areas where Guinea worm was a recurring problem didn’t benefit from that discovery. The traditional belief was that Guinea worms are in people’s blood from birth. They emerge when the blood goes bad. A massive effort to educate the victims of Guinea worm disease about its real cause has paid off. Now that people in those areas filter the water they drink and guard the sources of that water from re-contamination, the Guinea worm is on the brink of extinction.
the worms to eject their larvae into water that’s then poured harmlessly on the ground. They carefully extract the worms, little by little, wrapping each around a piece of gauze and bandaging the wound between extractions, which take place as often as the patient can stand the pain.

When possible, the volunteers bring Guinea worm victims to local case containment centers. Ruiz-Tiben says, “If you come to the center when you feel like you might have a guinea worm, then we’ll provide a room and a sleeping mat and a mosquito net and we’ll take care of you daily. We have food for you three times a day, and we have showers and latrines.” Patients are rewarded with money for coming. “They come in dirty and hurting from the guinea worm infection. Then a week or two or three later, when the worms are pulled out, they’ve gained weight, they’re clean, and they’re not hurting anymore.” Ruiz-Tiben adds, “We try to make their stay at the case containment center the most pleasant experience possible so that they’ll tell others about the advantages of coming to the center.”

**Getting to Zero**

These methods, which depend mostly on changing people’s behavior, have been extraordinarily successful. In 1986, when the Carter Center became involved, an estimated 3.5 million cases of Guinea worm disease occurred each year, spread over 21 countries in Asia and Africa. In 2016, there were only 25 cases, and they were confined to just three African countries: Chad, Ethiopia, and South Sudan.

Last year, in Chad, several dogs became infected with Guinea worm. Dogs run free in this area. A dog that jumps into a drinking water source to cool the burning can cause a whole new wave of human infections. So the campaign is offering rewards to owners who tie up dogs that shows signs of Guinea worm disease. Volunteers treat the dogs the same way they treat human sufferers, pulling the worm out and caring for the wound. Researchers are testing medications that treat heartworm in dogs to see if the drugs can kill Guinea worms too.

The infected dogs in Chad came as a surprise. However, Ruiz-Tiben says, “They’re kind of a game changer but not a game stopper. This is the hardest part. Dealing with this is very interesting and stimulating but also frustrating because we’re so close and we’ve got to get there. The objective is zero cases. We need to make this parasite go extinct.”

President Carter estimates that they’ve prevented 80 million cases of Guinea worm disease. He has said he hopes Guinea worm will die before he does. He turns 93 on October 1, 2017. With luck, his wish will come true.

**Jeanne Miller** is a frequent contributor to Muse. She looks forward to opening the newspaper someday soon and reading that Guinea worms are gone forever.