Jimmy Carter closes in on decades-long goal: Eradicating Guinea worm

Former president has played pivotal role in fight against neglected tropical diseases.

Caption

Credit: The Carter Center

By Katherine Landergan

When cancer cells had invaded Jimmy Carter's body in 2015, another target was atop the former president's mind: a pale, stringy worm that was sickening people in remote parts of Africa.

During an Atlanta press conference to discuss Carter's cancer diagnosis at the time, one reporter asked what he wanted out of life's last chapter. One of his wishes, he said, was to see the Guinea worm disease finally be eradicated.
"I'd like for the last Guinea worm to die before I do," said Carter, with a grin.

At one point in his life, Carter's answer may have seemed unlikely for a Georgia peanut farmer who became governor and then president.

But Carter, who turns 99 Sunday, dedicated much of the last four decades to eliminating neglected tropical diseases in impoverished parts of the world. As Carter rests in hospice at his modest ranch-style home in Plains, he's incredibly close to achieving his Guinea worm goal.

When the Atlanta-based Carter Center began its worm eradication program in 1986, about 3.5 million people in Africa and Asia were afflicted. So far in 2023, there have been just half a dozen human cases of Guinea worm.
Carter's colleagues say the former president's focus, political prowess, press connections and fundraising skills have played a big role.

"He's driven. Once his mind had locked on the idea of getting Guinea worm to zero, then the operative principle was, 'whatever it takes,'" said Dr. Donald Hopkins, who worked for decades leading Guinea worm eradication at the Carter Center.

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Carter is the oldest-living president in American history, and his lengthy post-presidency has been busy and impactful. In 1982, two years after being voted out of the White House, Carter and his wife Rosalynn founded the Carter Center, which has defended human rights and democracy and tackled illnesses around the globe.

Today, the nonprofit has its sights on eliminating six diseases: Guinea worm, river blindness, trachoma, schistosomiasis and lymphatic filariasis, as well as malaria on the island of Hispaniola. Behind the names of those diseases are some horrifying symptoms, seemingly pulled right from a nightmare.

Schistosomiasis, for example, is contracted through a parasite that lays thousands of eggs that tear tissues of internal organs, and that can cause bloody urine, bladder dysfunction, kidney and liver disease. Trachoma is spread through dirty clothes, hands and flies that are attracted to people's eyes. Eventually, a person's eyelashes turn inward, resulting in scarring and diminished vision, leading to blindness in some cases.

Guinea worm, also known as the "fiery serpent," is named for the stinging sensation as the worm in a person's body comes out through blistered skin.

The disease is contracted when tiny water fleas are consumed, typically through contaminated drinking water. After a person consumes the water, the larvae grows inside a person's stomach, sometimes as much as three feet long. The disease is ancient, and according to the Carter Center is "poised to become only the second disease to be eradicated from earth" after smallpox.

Paige Alexander, the center's chief executive, said Carter didn't want to talk about politics in a recent conversation, but rather the latest Guinea worm count.

"Eradication is at the top of the pecking order when you are talking about diseases and no one thought it could be done," said Alexander. "But we are getting there."

Soon after Carter left the White House in 1981, he began charting his post-presidency. Smallpox had just been eradicated during his presidential administration, with momentum building in health circles to wipe out more diseases.

Hopkins, who was working at the Centers for Disease Control and Prevention at the time, said Guinea worm was such an "obscure, remote disease" that most people had never heard about it even though it affected millions. So in 1986, when Hopkins was asked to speak at an international health conference, hosted by the Carter Center at the Colony Square Hotel in Atlanta, he made sure to talk about it.
Peter Bourne, who served as U.S. drug czar in the Carter administration, was also there and made sure to show Carter a few of Hopkins' presentation slides on Guinea worms.

Carter, helped by his wife, made it a top priority. He was relentless in putting the issue before potential donors, prominent political leaders, heads of international agencies and companies.

"He would visit with the country, talk to the heads of state ... praise them, shame them, whatever was required, show them how their country was lagging behind others," Hopkins said.

He said Carter "could be very insistent, very aggressive, threatening at a press conference in Ghana, for example, to rename the parasite 'Ghana worm' instead of 'Guinea worm' if Ghana didn't get their act together."

Kelly Callahan, now a director of the trachoma control program at the Carter Center, recalls how she had the attention of the former president when she was a peace corps volunteer.

It was 1996, and Callahan was in a highly endemic village for Guinea worm disease in the Ivory Coast. She was working on a project funded by the Carter Center, to make

large water filters that could filter out larvae from the water. Within one year, she and the other workers reduced the number of cases of Guinea worm by 47% in 18 villages.

At a conference in Africa, she displayed her filter frame, explaining how it worked. All of a sudden, Carter walked over.

“My heart was beating. I could not believe it. And he looked at me and he said, ‘Hey, how you doing?’ In the kindest, most gentle and sweetest, softest voice ... and (then said) ‘this is really great work,’” she recalled.

Callahan officially started working for the Carter Center in 1998. Later that year, she was in Kenya, strategizing about how colleagues would safely navigate some war-torn areas. She and Carter stood before a big map, laid out on his conference table.

“’So Kelly, where’s the worst Guinea worm?,’” she recalled him saying. “’Why is it the worst there? How can we get in there? Who can we partner with?’”

They spent two hours strategizing and drawing circles on the map.

“His recall, in every aspect of Guinea worm, in every aspect of disease eradication, has blown me away,” she said. “He’s really motivated many of us to be the best we can be.”

Guinea worm disease is prevented through education and low-tech methods, such as making sure everyone in an impacted community is using nylon filters to drain larvae from the water. People who have the disease are taught to avoid water sources, to prevent the parasite from spreading.

The Carter Center has helped reduce the spread of other infectious tropical diseases. Dr. Kashef Ijaz, vice president for health programs at the center, said that a key next step is addressing the mental health concerns of people suffering from such illnesses.

The center has helped eliminate the transmission of river blindness in Colombia, Ecuador, Mexico and Guatemala through health education and distributing a drug, Mectizan, donated by Merk, a pharmaceutical company. Lymphatic filariasis, a mosquito-borne disease that swells limbs, has been eliminated as a public health problem in large parts of Nigeria, Ethiopia and on the island of Hispaniola. The center also has helped greatly reduce schistosomiasis, a parasitic disease, in Nigeria.

When Carter told that room full of journalists in 2015 that he wanted to outlive the last Guinea worm, Callahan was sitting in the audience. She said tears were streaming down her face.

“At that press conference, he was doing whatever he could, with whatever he had ... to continue to try and make a difference for others,” she said. “I mean, how selfless, how amazingly selfless.”

--Staff reporter Ernie Suggs contributed to this report.