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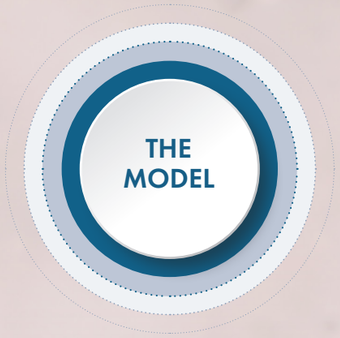
CASE STUDY

Impact Hub Case Study:
Total Grassroots Engagement – The Carter Center's Leadership in the Guinea Worm Eradication Program

By Charlie Euchner

Dracunculiasis (aka Guinea worm disease), a painful affliction with no vaccine or medical treatment, was causing millions to suffer in poor and isolated communities in sub-Sahara Africa.

Eradicate the disease.



The Carter Center coordinates and supports a range of partners to implement interventions to prevent the spread of the disease.

Key Lessons

- Enacting behavioral change requires sustained, long-term engagement.
- Trust and incentives are essential for enlisting community members and volunteers.
- Committed high-level political leadership can drive progress at all levels of society.

When Jimmy Carter was president of the United States, an aide named Peter Bourne talked to him about addressing a hideous affliction primarily in rural communities in Africa called dracunculiasis, or Guinea worm disease. The disease caused crippling pain and disability in those infected. Carter declined to commit resources to the disease, as there were no American victims.

"It's a despicable disease.
And it was in such remote villages
that no one wanted to take on the task.
So we decided to take it on"
- Jimmy Carter, 1986[1]

In 1984, Bourne, now a health official at the United Nations, again asked Carter to take on the disease. The former president had in 1982 started the Carter Center, a nonprofit organization committed to reduce human suffering and strengthen human rights worldwide. One of the organization's priorities was to fight neglected diseases. Carter said yes.

Because the populations affected by dracunculiasis were poor and isolated, no national government or health organization had ever launched a substantial effort to eradicate the disease. There was no vaccine. Prevention depended on keeping people from coming into contact with water sources infected by the worm, which required people to change entrenched behaviors and customs.

To achieve this, the Carter Center launched the Guinea Worm Eradication Program and began working to engage, coordinate, and support governments, community leaders, and various local stakeholders. It became a hub that enabled networks across society to implement necessary changes.

When the Carter Center formally kicked off its work in 1986, 3.5 million people in 21 countries suffered from Guinea worm disease annually.[2]

In 2022, only 13 cases were documented worldwide. The Guinea worm disease was on its way to becoming only the second disease ever to be eliminated (smallpox was eradicated in 1980).[3]

The Problem

Dracunculiasis appears to be as old as civilization itself. The disease was found in the calcified remains of a 3,000-year-old mummy of an Egyptian girl. According to the Carter Center, the mention of "the fiery serpent" in the Old Testament of the Bible is a reference to the disease.[4]

The disease results from infection by the Guinea worm, which releases larvae in stagnant water. The larvae infect microscopic crustaceans called cepepods. Humans drink water or eat undercooked fish containing the cepepods. When the crustaceans die, they release the Guinea worm larvae into the intestine. Those larvae mate, and the female offspring grow into meter-long worms resembling long pieces of spaghetti. A year after first entering a human host, the worms seek to exit the body, burrowing through skin, typically in the legs or feet, and producing cripplingly painful ulcers. To mitigate the burning pain, an infected person often sticks the wound in a pool of water, allowing the worm to release its larvae and begin the cycle again.

In addition to the debilitating wounds, victims also suffer fever, nausea, diarrhea, and vomiting. They can become permanently disabled or, in rare cases, die. An outbreak can cause an entire village's economy to shut down for months.

A parasitologist examines a worm under a microscope in Bongor, Chad. Multiple examination methods are used to confirm specimens are Guinea worms. © The Carter Center

"It's one of those problems that once you see it, you can't unsee it," said Adam Weiss, the director of the Guinea Worm Eradication Project at the Carter Center. "Even some of the most stoic men in South Sudan, this brings them to their knees. They cry. They don't want to admit it, but they do. It's something you can't walk away from."

Once a person is infected, the only treatment is to slowly extract the worm – an inch a day – using a stick and dripping water to trick the worm into leaving the body more quickly. If the worm breaks, however, the part remaining in the body could cause potentially fatal infections.

A health worker extracts a Guinea worm from the knee of a South Sudanese woman. © The Carter Center

The Solution

In theory, stopping Guinea worm disease is simple: prevent people from consuming water infected with larvae. That is hard to implement in practice. Many people lack access to filtered water sources. And because a full year passes from the exposure to contaminated waters and the emergence of the worm through the skin, victims often attribute the disease to other causes and are unaware that water is the source of the ailment.

The Carter Center identified four key interventions:

01

Eliminate all contact with contaminated water and food. Keep people from using contaminated water sources for drinking, cooking, bathing, and recreation.

02

Filter or treat existing water supplies. Provide people with water filters or add larvicide to water sources.

03

Create new clean water supplies. Build freshwater wells not susceptible to contamination.

04

Prevent infected persons from contaminating a water source. Keep victims from soaking their worm wounds in water sources.

These interventions rely heavily on behavioral change – that is, educating villagers in how the disease was spread and convincing them to adopt the interventions. Doing that was beyond the ability of the Carter Center. To be successful, it had to act as a hub that involved and coordinated diverse networks of partners.

Partnerships

The Guinea Worm Eradication Program coordinates various partners – from heads of state to villagers – to implement interventions. Carter himself met with heads of state and health ministers of countries ravaged by the disease, including Angola, Cameroon, Chad, Ethiopia, Ghana, Kenya, Mali, Nigeria, Senegal, Sudan, Yemen, India, and Pakistan. Using his prestige as a former American president, Carter received clearance to establish eradication programs in each country. Program staff collaborated closely with national ministries of health and local public health authorities, whose support was necessary for operating and implementing interventions.

Support came from international humanitarian and global infectious disease organizations such as the World Health Organization, UNICEF, and the U.S. Centers for Disease Control, who were core partners in the program. They provided, among other things, expert guidance, case monitoring, and international certification of disease eradication.

Corporate partners and philanthropic organizations have provided funding and other resources. For instance, Carter enlisted the help of Edgar Bronfman, the CEO of Seagrams, a Canadian multinational conglomerate that was sold in 2000, who used his position as a board member of DuPont, a chemical company, to develop cheap cloth filters that could be used to treat contaminated water.[5] BASF, a German chemical company, donated larvicide.

The most critical set of partners, however, have been community leaders, grassroots organizations, and local volunteers. Since the start of the program, some 300 Carter Center workers deployed to villages and settlement to enlist and coordinate these stakeholders, on whom implementing the interventions depended most. Over the years, thousands of people have contributed to the effort, including volunteers from other humanitarian organizations such as the Peace Corps and local community members.

Two boys drink through pipe filters at Kuse Dam, Terekeka County, Southern Sudan, in 2010. © The Carter Center

Building trust and changing behavior

Volunteers and local stakeholders have performed various roles. They have poured larvicide into ponds; distributed simple water filters for home and business use; prevented infected persons from contaminating water sources; helped victims gather water; reported cases of infection; and worked in clinics and treatment centers.

The Guinea Worm Eradication Program provides volunteers with modest rewards, such as small cash payments and t-shirts. In some cases, volunteering brings prestige in the community or opens up employment opportunities. For instance, some volunteers have been trained in basic health-care skills in places where there were shortages of community health workers and the program set up treatment centers where victims could receive care and be kept from soaking their wounds in water sources.

In some cases, the program has built wells, but many villages lack suitable locations for drilling one. Ultimately, preventing the spread of the disease has depended on winning the cooperation of the entire community to change its behavior.

Carter Center staff have built trust by being in the field for months or years and developing relationships in communities. "You have to build trust," said Weiss. "And that requires not just one visit from President Carter or the minister of health. It takes all of it happening. It doesn't have to be perfect but it has to be systematic."

Trust was necessary to educate communities about the disease and the efficacy of the interventions. Since a full year passes from the exposure to contaminated waters and the emergence of the worm through the skin, victims often attribute the disease to fate, witchcraft, or the uncontestable will of God. Workers often have sought to reason with community members on the basis of faith and values, rather than by making scientific arguments for why they should avoid contaminated waters sources.

"The biggest challenge is just helping people to understand that they don't have to continue suffering from this infection," said Donald Hopkins, a special advisor to the project, in an interview with the Canadian Broadcasting Company.[6] "Once you gain their trust by respecting them and showing empathy, indicating that you're there to help them...then things begin to change."

Elders, faith leaders, and village heads have been especially important for changing norms and beliefs related to the disease.

Their credibility and status have enabled them to educate members of the community and persuade them to comply with the interventions. Prominent national figures also have gone to villages to promote the program. For instance, General Yakubu Gowon, who led Nigeria from 1966 to 1975, visited communities to persuade people to cooperate with healthcare workers.

Perhaps no person has been more important than former President Carter himself. Carter focused public attention on the disease, fundraised, advocated, and directly intervened to persuade a wide range of stakeholders to cooperate.

"When you take on a problem like this, like Guinea worm, you have to sweet talk the ministry officials, the political figures, the nurses, the doctors, the community activists, the farmers, the people who are...most at risk," said Paul Farmer, a global public health leader, in a 2023 interview with NPR.[7] "Carter's had to sweet talk all these people. And that's something that's been very inspiring to many of us."

When cajoling was not enough, Carter used more coercive tactics. For instance, when the prime minister of Ghana resisted making the disease a health priority, Carter said he would begin to call the disease the "Ghana worm." The Ghanaian leader made the disease a priority, and within years it had been eradicated in the country.

Carter Center ambassador Regina Natube leads a lively song and dance to spread the word about cash rewards for reporting possible Guinea worm cases in South Sudan. © The Carter Center

Complications

To achieve its mission, the Guinea Worm Eradication Program has had to adapt to unexpected challenges. These included difficulties getting to some of the worst-affected villages because of conflict and the surprising spread of the disease in dogs and cats.

Sudan was the most prominent example of the first challenge. The country was one of the world's poorest, with only 41 percent of the population having easy access to clean water.[8] In the mid-1990s, it had the highest incidence of dracunculiasis in the world, with an estimated three times as many cases as all other countries combined.

Sudan was also considered the most dangerous country in the world for aid workers, owing to a civil war that lasted from 1983 to 2005. For years, the violence had prevented Guinea Worm Eradication Program workers from accessing villages.

In 1995, former President Carter directly negotiated a six-month ceasefire between the two warring factions. The break in fighting allowed program workers to survey villages and deliver filters and other disease-prevention supplies.

Former U.S. President Jimmy Carter visits a village in Southern Sudan in 2010. During the war that ultimately led to Southern Sudan's independence, President Carter negotiated a cease-fire that allowed health workers to move about safely in the combat zone.
© The Carter Center

A second unexpected challenge was the rise of dogs and cats as carriers of the disease. By 2017, the Guinea Worm Eradication Program had succeeded in reducing the number of reported dracunculiasis cases to just 30.[9] In the past, scattered cases of the disease had been found in dogs and donkeys. Now, after years without any cases in animals, the ailment was suddenly discovered in stray dogs in Chad. At first, the Carter Center's team and its allies did not notice.

"You don't see what you're not looking for," said Weiss.

No consensus existed as to how much the dog problem mattered. The purpose of the program was to eradicate the disease in humans, not all animals. But as the number of cases in dogs increased, the program adopted a "whole health" approach. They expanded their view of the environment from waterways to dogs and cats.

Ultimately, investigators concluded that the dogs contracted the disease by eating fish entrails. Dogs were not known to transfer the disease to humans, but the dogs could leave the larvae in waters used by people. The eventual response was threefold. First, keep dogs away from water. Second, keep dogs away from fish entrails. Third, try veterinary deworming drugs to see if they made a difference.

The effort required sustained discussions and planning with villagers. Dogs played a vital role in farming, hunting, and protection of the home. In some cases, it made sense to tether dogs to keep them away from water sources. The program began offering cash rewards for reporting infected animals and for tethering dogs.

By 2022, infections in animals declined by 21 percent. Chad reported infections in 605 animals, Mali in 41, Cameroon in 27, Angola in seven, Ethiopia in three, and South Sudan in one.

In Chad, Dollar Taissou (bottom right) pulls a Guinea worm from the leg of 2-year-old dog Martoussia. © The Carter Center

The End Game

The Guinea Worm Eradication Program has been a remarkable success. When the program began in 1986, 3.5 million people in 21 countries suffered from Guinea worm disease annually.[10] By 1990, the number of cases worldwide fell to 623,579 and by 2000 to 75,223. By December 2022, only 13 cases were documented worldwide.

Most modern public health triumphs—such as eradicating smallpox or limiting the spread of polio, tuberculosis, or HIV—occurred with breakthrough vaccinations and treatments. The eradication of the Guinea worm disease could happen without a vaccine or substantial financial investment.

Instead, the Carter Center gradually and systematically built global partnerships and facilitated grassroots public health solutions.

Aside from relieving the suffering and disability caused by the disease, ridding dracunculiasis from communities has enabled economic and social development. Farmers have been able to return to the fields. Children could go to school. Clean water supplies not only improve public health but also improve farm production. Education about disease transmission has prepared villagers to confront other diseases that might affect their health and well-being.

A 2013 study by Kelly Callahan and colleagues concluded that: "Eradicating Guinea worm disease has become a powerful, broad-based engine for development. The prevention of NTDs [neglected tropical diseases], and their cost-effective interventions, fuels long-term economic growth and development, and human advancement. The effort to eradicate [Guinea worm disease] is considered one of the most cost-effective health interventions available."[11]

In addition, efforts to combat the disease often have had the side effect of developing local health care capacity. Community surveillance systems for monitoring dracunculiasis cases have been used to track other diseases, including tetanus, lymphatic filariasis, and leprosy. In South Sudan, where less than half of the population had access to health care services, many Guinea Worm Eradication Program volunteers were trained in basic health care skills.

In many cases, women have played a prominent role and developed skills. For instance, in Ghana, the program enlisted more than 6,200 women as Red Cross volunteers that in teams of 10 to 12 went to different villages to implement interventions.

In 2015, former President Carter was diagnosed with brain cancer. He set a personal goal to outlive Guinea worm disease. But in 2019, the World Health Organization changed its projected goal for total eradication from 2020 to 2030.[12]

"It's going to be a slow roll to get to zero," Weiss said. "If we take our foot off the gas in terms of trying to accelerate getting to zero and providing support to those communities, there's no question that you're going to see a resurgent Guinea worm. We're going to make progress, even if it is not as fast as we all want it to be, but that progress continues."

Village volunteer Cezerina Puru Ladu poses with her three-year-old daughter and husband, Garbino, who suffered from Guinea worm disease in 2010. Garbino was the last Guinea worm patient in Senwei village, which is no longer plagued by the debilitating disease. © The Carter Center

References

[1] https://www.npr.org/sections/goatsandsoda/2023/02/23/1158358366/jimmy-carter-took-on-the-awful-guinea-worm-when-no-one-else-would-and-he-triumph

[2] https://www.cartercenter.org/health/guinea_worm/index.html

[3] https://www.amnh.org/explore/science-topics/disease-eradication/countdown-to-zero/guinea-worm#:~:text=Only%20one%20human%20disease%2C%20smallpox,no%20vaccine%20to%20prevent%20it

[4] https://www.cartercenter.org/resources/gallery/images/highres/guineaworm_timeline.pdf

[5] https://www.nejm.org/doi/full/10.1056/nejmp0780895

[6] https://www.cbc.ca/radio/asithappens/eradicating-guinea-worm-disease-1.6728672

[7] https://www.npr.org/sections/goatsandsoda/2023/02/23/1158358366/jimmy-carter-took-on-the-awful-guinea-worm-when-no-one-else-would-and-he-triumph

[8] https://www.cartercenter.org/news/features/h/guinea_worm/guinea-worm-cease-fire.html

[9] https://www.nytimes.com/2018/06/18/health/guinea-worms-dogs-chad.html

[10] https://www.cartercenter.org/health/guinea_worm/index.html

[11] https://www.cartercenter.org/health/guinea_worm/index.html

[12] https://www.nature.com/articles/d41586-019-02921-w

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