Shining a light on hidden diseases

There is a group of diseases that have plagued humanity for centuries and which today blight the lives of a billion people in 149 countries worldwide. The impact on individuals and communities is immense and yet, until recently, they attracted little attention – and little was done to combat them. That has changed over the past few decades. Efforts are now beginning to show results. But the battle is not yet won.

The Guinea worm is a parasite that has tormented human beings since ancient times. One has even been found, calcified, in an Egyptian mummy. Today, people continue to catch the disease by drinking straight from ponds or other water sources that are infested with minuscule fleas. These fleas have eaten Guinea worm larvae which can penetrate the human intestinal wall. A female larva, having mated with the male, grows in the human body into a meter-long worm that mines through the subcutaneous tissue. Usually heading down to the person’s feet, the worm exudes acid to form a blister and breaks through the skin. Its emergence is excruciatingly slow.

Winding the worm round a stick, daily, is all that can be done to hasten recovery. A patient can be incapacitated for weeks. Children miss school. Adults cannot farm their crops. Worse, to soothe the burning pain, sufferers are drawn to bath in the local water source, whereupon the worm immediately releases thousands of larvae, perpetuating the cycle.

Largely hidden

Guinea worm disease is one of a group of diverse diseases known as neglected tropical diseases (NTDs). NTDs flourish mainly in impoverished environments, particularly in tropical areas. Although they do not cause the same numbers of deaths as tuberculosis or malaria, for example, they not only devastate individual lives, but also damage whole communities and, indeed, national economies by locking so many citizens in the poverty trap.

Previously more widespread, NTDs have gradually disappeared from places where living conditions and hygiene have improved. Today the populations most troubled are the desperately poor, in rural areas and urban slums in Africa, Asia and the Americas, where whole communities still lack adequate access to clean water, good nutrition, sanitation or quality-assured healthcare.

Those who suffer from NTDs are largely disenfranchised. They were described by World Health Organization (WHO) Director-General Dr. Margaret Chan, in the first ever WHO report on NTDs in 2010, as “largely hidden” and “largely silent.”

Controlling diseases

WHO itself helped raise the profile of these diseases a decade ago when the organization’s then Director-General, Dr. Lee Jong-wook, instigated a key “branding exercise” to bring them to the world’s attention. A WHO department nebulously dealing with “Other Communicable Diseases” was scrapped and the “Neglected Tropical Diseases” banner was adopted as a more focused target. There are now 17 diseases classified by WHO as NTDs.

But this was not the first attempt to tackle these diseases. In some cases, efforts had been going on for decades. The global Guinea Worm Eradication Program got rolling in the 1980s at the United States’ federal Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia. In 1982, the former U.S. President Jimmy Carter and his wife Rosalynn founded The Carter Center as a not-for-profit NGO dedicated to human rights and the alleviation of suffering. It has spearheaded the Guinea Worm Eradication Program since 1986, with Dr. Donald R. Hopkins from CDC becoming The Carter Center’s Vice President for Health Programs. Hopkins brought with him the experience of overseeing the smallpox eradication program in Sierra Leone.

The Carter Center helped to develop cost-effective strategies to tackle Guinea worm disease such as providing at-risk communities with fine-mesh cloths to enable them to sieve out the fleas, and pipes with filters that can be used like drinking straws. Health education for the local communities is a vital accompaniment, for example, using a magnifying glass to show people the fleas in the water and explaining the transmission process. The aim is to spark behavior changes. If sufferers stop entering the water source, the cycle can be broken.

Young goat herders in South Sudan drink dam water through a filtration pipe that protects them from Guinea worms. The pipe was provided by The Carter Center as part of its efforts to eradicate Guinea worm disease.
Engaging at the local level

“It’s not about just telling people what to do. It’s immediately challenging traditional beliefs is a non-starter,” said Hopkins. Strengthening. Some African villagers, for example, regarded drinking water as sacred. “But,” said Hopkins, “if you genuinely discuss, engage, convince them that it’s in their interests, they’ll take the necessary action.”

Working in partnership with the ministries of health, teams of village volunteers are required to check that their neighbors understand the transmission cycle, take in hand anyone who becomes infected, administer basic health care, call in medical assistance to stop any burgeoning problem and report all new cases so that progress — and any aberrations — are closely monitored and analyzed.

Another important factor is that standing water sources can be spruced up with a larvicide, such as BASF’s Abate®, to interrupt the cycle. The active ingredient in Abate®, Temephos, is recommended by WHO for use in drinking-water sources at concentrations not exceeding one milligram per liter. BASF has made a long-term commitment to the Carter Center, and Abate® has been supplied, free of charge, for the Guinea Worm Eradication Program for more than 20 years.

Personal commitment

Meanwhile, President Carter has used his high profile around the world to galvanize political leaders. In 1996, he even brokered a truce in the midst of the Bosnian civil war, so that health workers could reach remote areas. This became known as the “Guinea worm cease-fire.”

Even now, in his late 80s, President Carter continues to visit remote African communities with his wife. As he explains: “There were over 250,000 cases with Guinea worm disease when we started out, and only about 3% of the men could write their name, and very few of the women. So we taught them to catch that -- the women, primarily using cartoons and pictures.

The program’s tactics have proved highly effective. In 1998, Guinea worm disease affected approximately 3.5 million people in 23 countries in sub-Saharan Africa. But in 2012, there were just 542 cases reported — a reduction of over 99% — and they occurred only in parts of Chad, Ethiopia, Mali and South Sudan. It looks as if we have done what we set out to do."