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Beyond Swollen Limbs, a Disease's Hidden Agony

By DONALD G. McNEIL Jr.

LÉOGÂNE, Haiti — Like many surgeons, Dr. Yves Laurissaint is a man supremely sure of himself.

"I've trained a lot of other surgeons to do this operation," he said as he sliced open the engorged scrotum of 68-year-old Gesner Nicé, emptied more than a pint of clear liquid, then began trimming away with a cauterizing scalpel, filling the operating room with the acrid smell of burning skin. "But they don't do it. They say it's too complicated."

Mr. Nicé, a woodcutter, has lymphatic filariasis, a disease in which clusters of four-inch worms as fine as blond hairs nest in the lymph nodes, the body's drainage system, stretching them until lymph fluid can only drain downward.

To anyone who has visited poor tropical countries or seen pictures of the disease, the instantly recognizable symptom, which afflicts both men and women, is elephantiasis: legs so swollen that they resemble an elephant's.

But 10 times as common is the symptom that is almost never spoken of: the engorged scrotums, known as male hydrocele (Greek for water bulge). In cities like Léogâne, more than a quarter of the men are tormented by the condition, their scrotum swelling to the size of a softball, or a basketball in severe cases.

The operation that Mr. Nicé received will help alleviate his suffering. But one great tragedy of lymphatic filariasis (pronounced lim-FAT-tick fill-ahr-EYE-us-sis) is that it is not curable.

Still, it is one of a handful of diseases world health experts hope to eliminate within a generation, because its spread can be prevented with deworming drugs that can even be distributed in household salt, an approach that wiped out the disease in China.

But the task is daunting, not merely because 120 million people in 80 countries have the worms, but also because of the stigma and secret shame that the affliction causes, particularly in men, turning filariasis into a disease the world hardly knows. Even where it is endemic — 40 million people suffer its symptoms

ON THE BRINK: FILARIASIS *Tormented and Ashamed*

in the world's most downtrodden places — it is cloaked in ignorance and misunderstanding.

"It's tied in with grinding poverty — where you find it maps almost perfectly

spontaneously — as it did in Barbados — when countries prosper and the poor are able to afford window screens to block the mosquitoes that transmit the disease and local governments cover the sewers where they breed.

As common as filariasis remains, it is not easily contracted and is no threat to tourists. Unlike malaria, which can be transmitted by a single bite, it usually



Erik S. Lesser for The New York Times

Antoinette St. Fab, left, and her mother, Marie Denise Bernard, in Léogâne, Haiti. Their swollen legs are a symptom of lymphatic filariasis.

with the poorest of the poor," said the Rev. Thomas G. Streit, director of the University of Notre Dame's tropical disease program in Léogâne. "And it's just heartbreaking."

Dr. Jaime Z. Galvez Tan, former chairman of the Global Alliance to Eliminate Lymphatic Filariasis, a partnership of health agencies, donors and drug companies, called it "the disease at the end of the road."

Imported from Africa with the slave trade, filariasis was long called "Barbados leg" and found as far north as Charleston, S.C. It can disappear

requires hundreds of bites from mosquitoes carrying male and female worms, which must crawl into the puncture, find each other in the victim's body and then mate.

A Crushing Burden

In poor countries like Haiti and Guyana the disease hangs on. It does not kill, but it crushes people's spirits and often leaves poor farmers unable to work, which can mean starvation. The most pitiable can be spotted on rural roads, shuffling slowly along in oversize pants.

In central Nigeria, Dr. John Umaru, a



Photograph by Vanessa Vick for The New York Times

THE PROBLEM

Lymphatic filariasis is caused by a parasitic worm, which is carried by 120 million people in 80 countries. Forty million have the symptoms of the disease. The most recognizable is elephantiasis, a swelling of the limbs.

Shehu Iliya, above, who lives in Gwamlar, Nigeria, and has a severe case of filariasis, said people treated him as if he were dead.



Photographs by Erik S. Lesser for The New York Times

THE TREATMENT

Workers in Port-au-Prince, left, clean sea salt before spraying it with a deworming drug and bagging it. The treated salt is then sold at a loss to Haitians. Blood tests for worms, right, in Léogâne, Haiti, are done after dark, because baby worms swarm in the blood only then, when mosquitoes bite.

worm-disease expert for the Carter Center, said he had seen a man “with a hydrocele down beyond his knee who made a pouch and strapped it around his neck so he could carry it.” He had heard of another who needed a wheelbarrow.

“Some guys just go off in the bush and cut it open,” he said. “They can’t live with it anymore. But then they often die of bleeding or infection.”

In Mr. Nicé’s case, his hydrocele, was about the size of a grapefruit, Dr. Laurissaint said. He could not lie down comfortably, walking hurt and he was embarrassed. “I can still climb coconut trees,” Mr. Nicé boasted from the operating table. (His hourlong operation was performed under local anesthesia.) “And even if you see in me an old man, I can still perform like a young man. I have nine children.”

As for those with swollen legs, there is little relief. All they can do is to wash their legs and feet daily to forestall infections as the skin breaks and elevate them to relieve the swelling.

The limbs cannot be surgically drained because the lymph fluid swells all the tissue instead of filling a pouch. The damage is permanent, because the overstretched lymph nodes do not shrink again; the worms eventually just die inside them.

For people with elephantiasis, big pants will not hide their affliction. Funguses that erupt between toes stink and draw flies. Children can be mocking. Lovers can be cruel.

Antoinette St. Fab, 30, sells rice and oil in an outdoor Léogâne market. Both her legs are swollen, but the left is enormous, almost a foot thick.

“In the past, I used to carry things like spaghetti and canned milk on my head and walk around selling them,” she said. “But I can’t do that anymore.”

Because she now washes her legs frequently and smears antibiotic cream on them, she rarely has the fevers of infected ulcers anymore. But the pressure hurts, and she has trouble finding even flip-flops to wear. She tries to hide her legs under ankle-length skirts, but she must slit them very high to walk.

Her husband left her when he realized that her legs would not shrink, she said. As her new boyfriend, a handsome out-of-work carpenter, sold goods nearby, she said, “I don’t know if he will leave me, too.”

The other market women can be vicious. “I stepped on someone’s foot by accident, and she said, ‘Hey, yam leg, don’t put your fat foot on me.’ I told her: ‘Oh, be quiet. God gave me this leg. Do

you think that if I went to the store to buy a leg, this is the one I'd choose?"

Ms. St. Fab asked doctors to cut the leg off, but they refused, telling her a disfigured limb was better than none. Even if they had, the swelling could begin anew, higher up.

The worst known case was an Egyptian woman whose leg weighed 130 pounds, more than the rest of her. It literally anchored her to the floor of her sister's house.

Treating symptoms can be costly. Hydrocele operations run from \$30 to \$120 in different countries. A program to teach washing and disinfection techniques costs about \$17. But these steps do not aid in eradication, which is complicated and costlier still, because it means treating millions of people with deworming drugs every year, drugs that do not cure the disease itself, but prevent its being passed on by killing the baby worms that mosquitoes transmit.

Five years ago, the World Health Organization adopted eradication by 2020 as a goal, and progress toward it for the next five years will cost about \$1.5 billion, the Global Alliance said. But that estimate assumes that billions of deworming pills will be donated by GlaxoSmithKline and Merck, that technical advisers will be lent by the Centers for Disease Control and Prevention in Atlanta and that American graduate students and local people will work for no pay.

It also presumes continued financing from the biggest donors, including the Bill & Melinda Gates Foundation, the World Health Organization and Unicef.

Even with money, eradication is tricky. When not placed in salt, deworming drugs must be handed out yearly in remote villages.

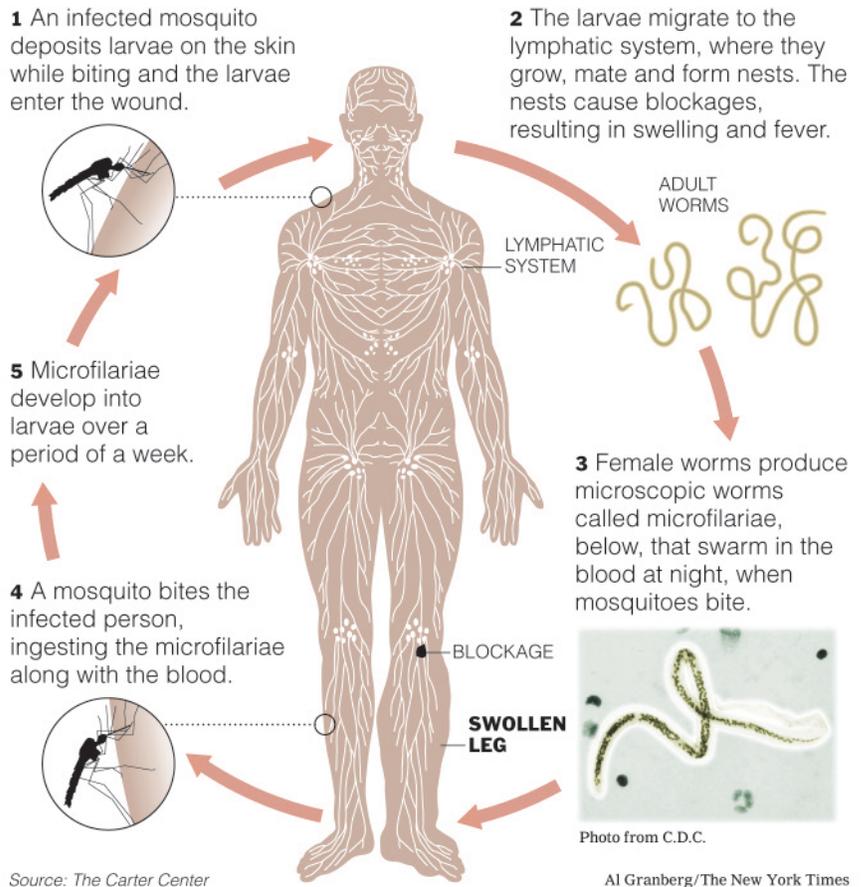
"Bush laboratories" with microscopes and equipment to draw blood and track the effort must be set up.

Adding to the challenge, some "night bleed" tests must be done after dark, because baby worms swarm in the blood only then, when mosquitoes bite.

A Climate for Disease

At Notre Dame's guest house here, all the window grilles have one extra bar—twisted into the S-shape of the filarial worm. It is called Residence Filariose.

The Life Cycle of Lymphatic Filariasis



"If I get a donor who'll give a million dollars, I'll rename it after him," Father Streit joked.

Léogâne, a coastal city of 150,000, has a perfect climate for the disease: as a sugarcane area, it is full of rum distilleries. Culex mosquitoes, which carry the worms, lay their eggs in filthy water; the pools of cane squeezings and sewage are ideal nurseries.

But ignorance also abets the disease's spread, for the embarrassment filariasis causes does not lend itself to easy public discussion. During a week in Haiti, a reporter was told by many people with filariasis that they had swellings because they were kicked in a soccer game or by a

horse, or fell out of a tree or sat on a bewitched rock.

Ms. St. Fab said her mother, who also has elephantiasis, told her she got it from

jumping rope too much as a schoolgirl.

SeBien Diogi, 80, a local voodoo priest, said gwopye—Creole for gros pied or fat foot—was caused by a white powder sprinkled on the ground, for which he sells a brown-powder antidote. Other folk healers suggest leeches and corn-mush poultices.

Even if infected people have a proper understanding of the disease, the adult worms are frighteningly hardy, too big for deworming drugs to kill and too deep in the body to remove surgically. Modern drugs aim to destroy the baby worms, called microfilariae.

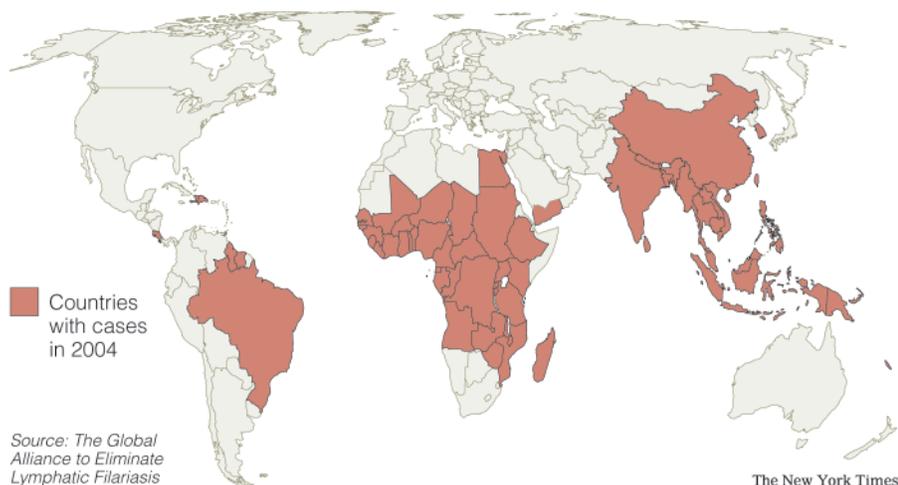
Several drugs—all first developed for deworming cattle and pets—will kill the worms. They include Glaxo's albendazole, Merck's Mectizan (sold under the name Heartgard for dogs) and diethyl-carbamazine, which is made cheaply by several companies, none of which donate as Glaxo and Merck do. But they are now available in only a quarter of the villages in the world where they are needed.

When he began working in Haiti in 1981, Dr. Patrick J. Lammie, co-director of the C.D.C. effort to eliminate filariasis in the Americas, the treatment was a 12-day

The Disease

- As numbers of adult worms accumulate in "nest balls," lymph vessels stretch and their fluid cannot drain.
- This creates "elephantiasis"—legs so engorged that they resemble an elephant's.
- But 10 times as common, though it is rarely spoken of, is the disabling swelling of the scrotum.

The Range of Lymphatic Filariasis



course of diethylcarbamazine.

“We went house to house giving people a pill every day for 12 days,” he said. “It was a miserable experience.” Even now, with one annual dose, the task is gargantuan. Adult female worms breed for about six years before they die, so every infected person in the world must be dewormed annually for six years.

A Huge and Complicated Task

“Let’s say you were trying to make rats extinct, but there was no such thing as rat poison,” explained Dr. Frank O. Richards Jr., a C.D.C. parasitologist. “Instead, all you had was a form of once-a-year birth control. You’d have to find a way to make sure that every single female rat in the world got a dose every year until she reached menopause. Eventually rats would die out—but you see how hard the job is. If just a few rats somewhere stayed untreated, it could bounce back.”

Also, the drugs work better when taken together, which complicates logistics.

An alluring aspect, however, is that people like their side effects: they kill other worms. Within days, mothers see their toddlers pass hookworms, schoolboys with schistosomiasis stop urinating blood and adults see their lice and scabies fall off.

“People feel a lot better,” Dr. Richards said. “Mectizan is sometimes called ‘the poor man’s Viagra.’ People stop itching, they feel great, and—voilà! I’ve heard of babies named Mectizan.”

But a big annual dose makes everyone sick for a day or two, and in dangerous countries like Haiti, pill-distribution days can draw gangs of thugs. Officials would prefer a slower, gentler method: adding

diethylcarbamazine to household salt.

Thanks to several donors, Haiti has a salt program, but for a poor country, it is relatively expensive. The program employs about 50 people to buy local sea-salt brewed in beach pits, pick out rocks and twigs, wash it by hand, spray it with diethylcarbamazine and iodine and then rebag it.

It costs 26 cents to make each bag of salt, said Jean Marc Brissau, manager of the plant in Port-au-Prince. But it must be sold for at a loss, for 10 cents, to compete with the grimy local salt, or no one will buy it.

Getting people to accept treated salt can take time, but it is effective. China eliminated the disease by ordering villagers to use it.

Despite the costs and the obstacles, Dr. Lammie and others, like Dr. Marie Denise Milord, national director of Haiti’s campaign against filariasis, remain optimistic. Haiti hopes to wipe out the disease by 2012. “If the world will keep helping,” she said, “we will eliminate it.”

Correction issued by The New York Times: This article referred imprecisely to the benefits of two drugs that kill the worms that cause it. As the article noted, the drugs, albendazole and Mectizan, kill other parasites as well. But they do not kill the worms that cause the bladder and intestinal disease schistosomiasis.



Vanessa Vick for The New York Times

On the Brink

This is the fourth in a series of articles about five diseases—polio, guinea worm, blinding trachoma, lymphatic filariasis and measles—that are extinct in the developed world but stubbornly persistent in some poor nations. As the diseases hover on the brink of eradication, doctors and scientists face daunting obstacles as they struggle to finish the job. The articles will be online, with multimedia presentations, including a video interview about filariasis with Donald G. McNeil Jr. in Haiti. Names and addresses of organizations that accept donations to help combat the five diseases are also at nytimes.com/health.

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