

By The Carter Center



Edirisa Wangwenyi, one of the first village volunteers who distributed ivermectin to fight onchocerciasis in Uganda, stands in his home, which is filled with health education materials and inspirational posters.

In the early 1990s, fear dominated the community of Jawe parish, found in Mbale district, Uganda. The Jawe clan's neighbouring parishes, Buryango and Bulweta, were being plagued by an unknown ailment that attacked a person's skin and eyes. The disease left its victims unable to care for themselves or their families.

At a community meeting in 1993, parish member Edirisa Wangwenyi told the attendees about the disease that was attacking their neighbours. He said the disease plagued sufferers with skin like that of a lizard — very hard, dry, and peeling off like a snake's skin. Its victims scratch themselves nonstop every day and tear apart their bodies with stones and broken pieces of pots. He described the sufferers as a cursed race and warned all not to associate with them to avoid getting their sickness. The community members heeded Wangwenyi's instructions, although many themselves had unknowingly already been infected by the disease — onchocerciasis.

Five years later, the Jawe subcounty chief received a box containing ivermectin tablets and was told that they combated onchocerciasis. The parish chief selected Wangwenyi to distribute the medicine. Wangwenyi soon

learned that he and many others in his parish also had the dreaded disease. The instructions he received were clear: "Begin treatment with yourself".

Wangwenyi walked house to house to distribute the ivermectin, taking several months for distribution. Many people refused to take it, and some experienced side effects. Wangwenyi had to assure the people that the side effects would pass, and that he too was taking the ivermectin. Treatment coverage in the community was low for some years, in part because of resistance to taking the drug.

In the second year of distribution, two people per parish were chosen to assist Wangwenyi, and communities were empowered to make decisions on how to run the programme. The Carter Center came to assist the Uganda Ministry of Health in the programme and worked to strengthen community structures through a kinship system. The use of kinship structures increased distribution and community acceptance, and over the years the terrible manifestations of onchocerciasis disappeared as treatment coverage improved.

Recently, Wangwenyi expressed his gratitude to The Carter Center and other donors for their unending support. "The prisoners of onchocerciasis have been set free," he said.