A partnership against epilepsy

Parts of Cameroon have rates of epilepsy that are among the highest in the world. Despite the availability of effective therapies, poverty, a lack of medical resources and superstition about the causes of epilepsy often lead to inadequate treatment and social exclusion for people living with the neurological condition. Novartis is working with a Catholic mission on the ground in a central part of the country to overcome these barriers and improve care.

Photos: Bjoern Myhre, Novartis

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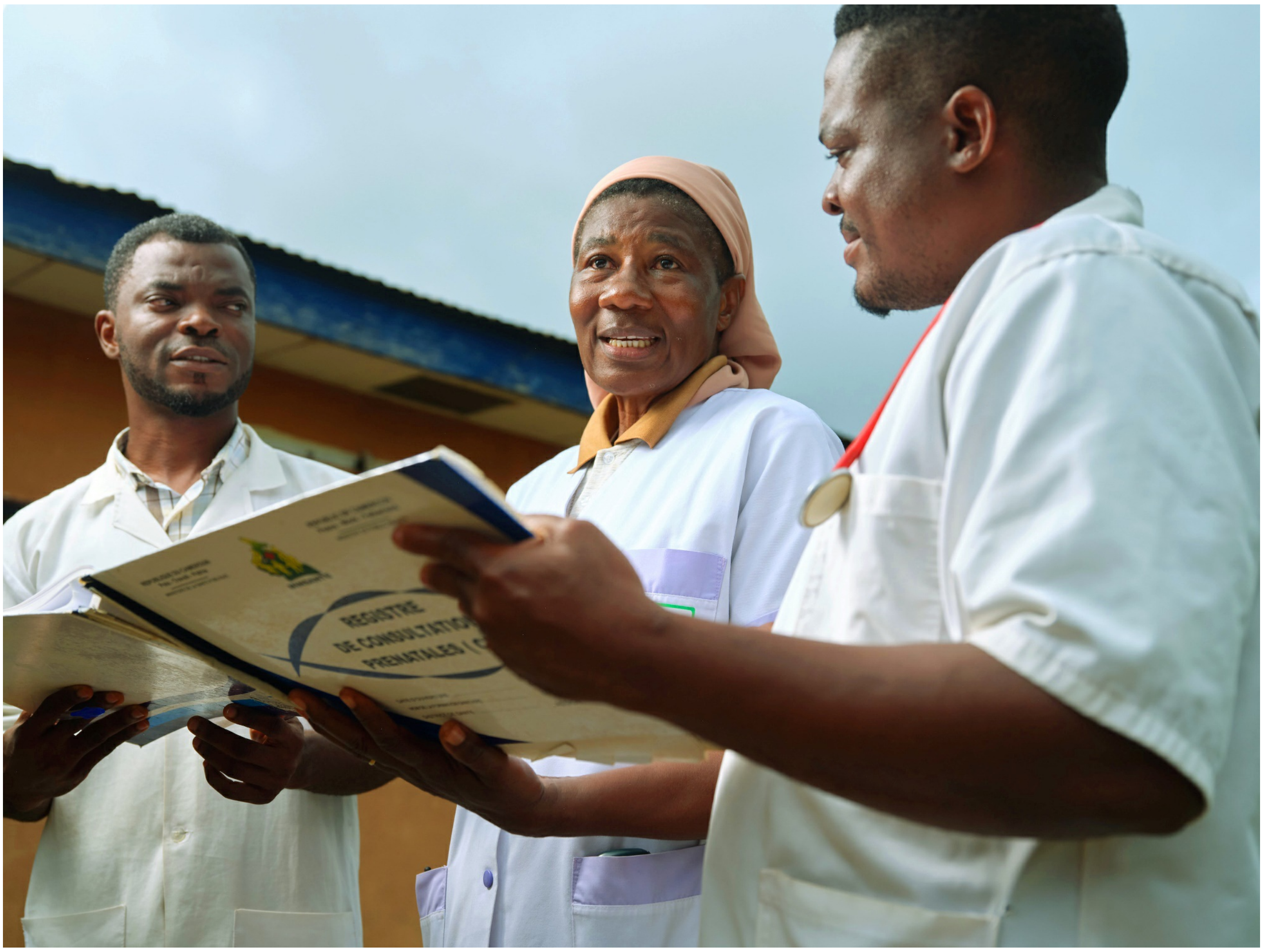
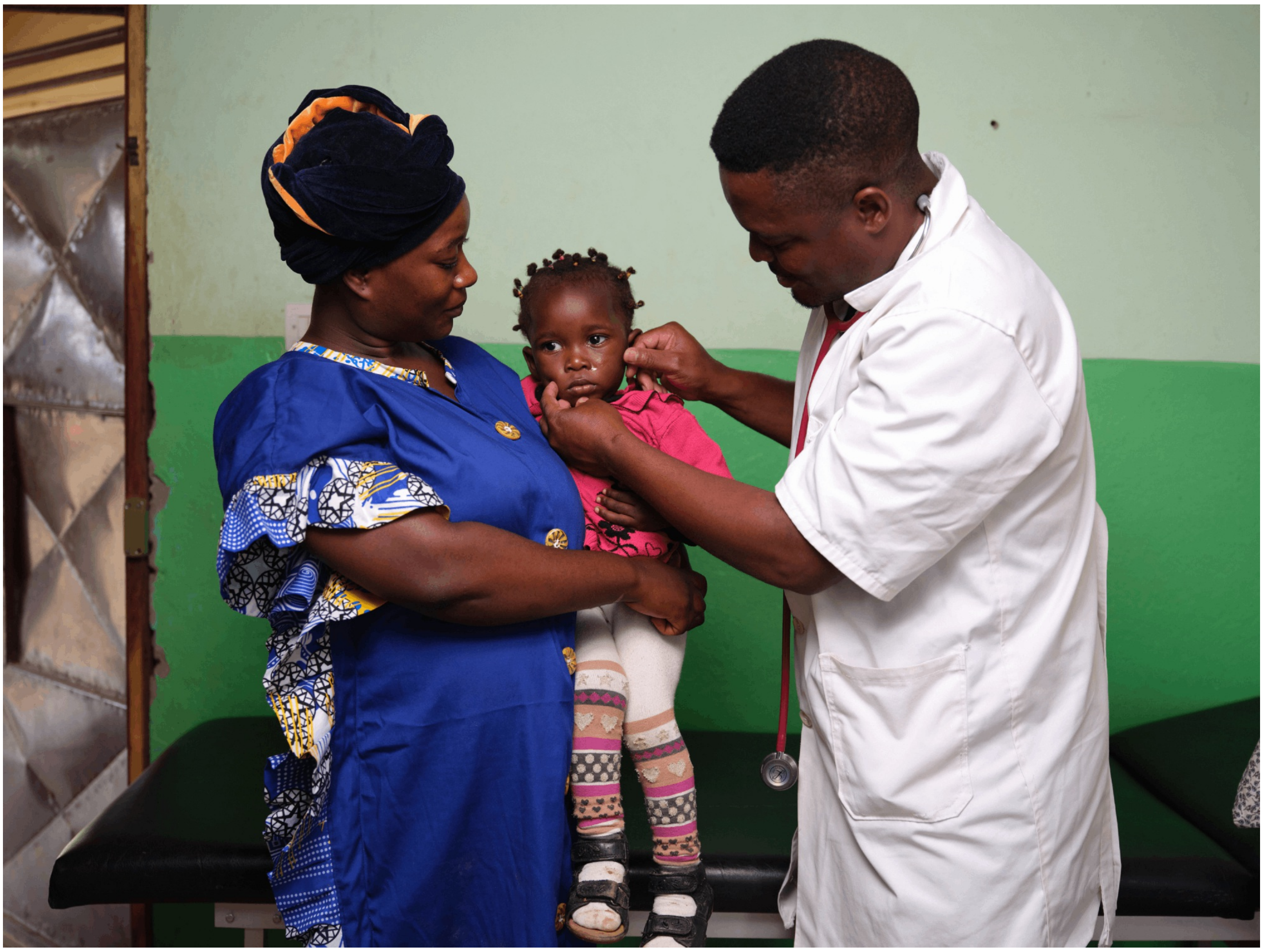


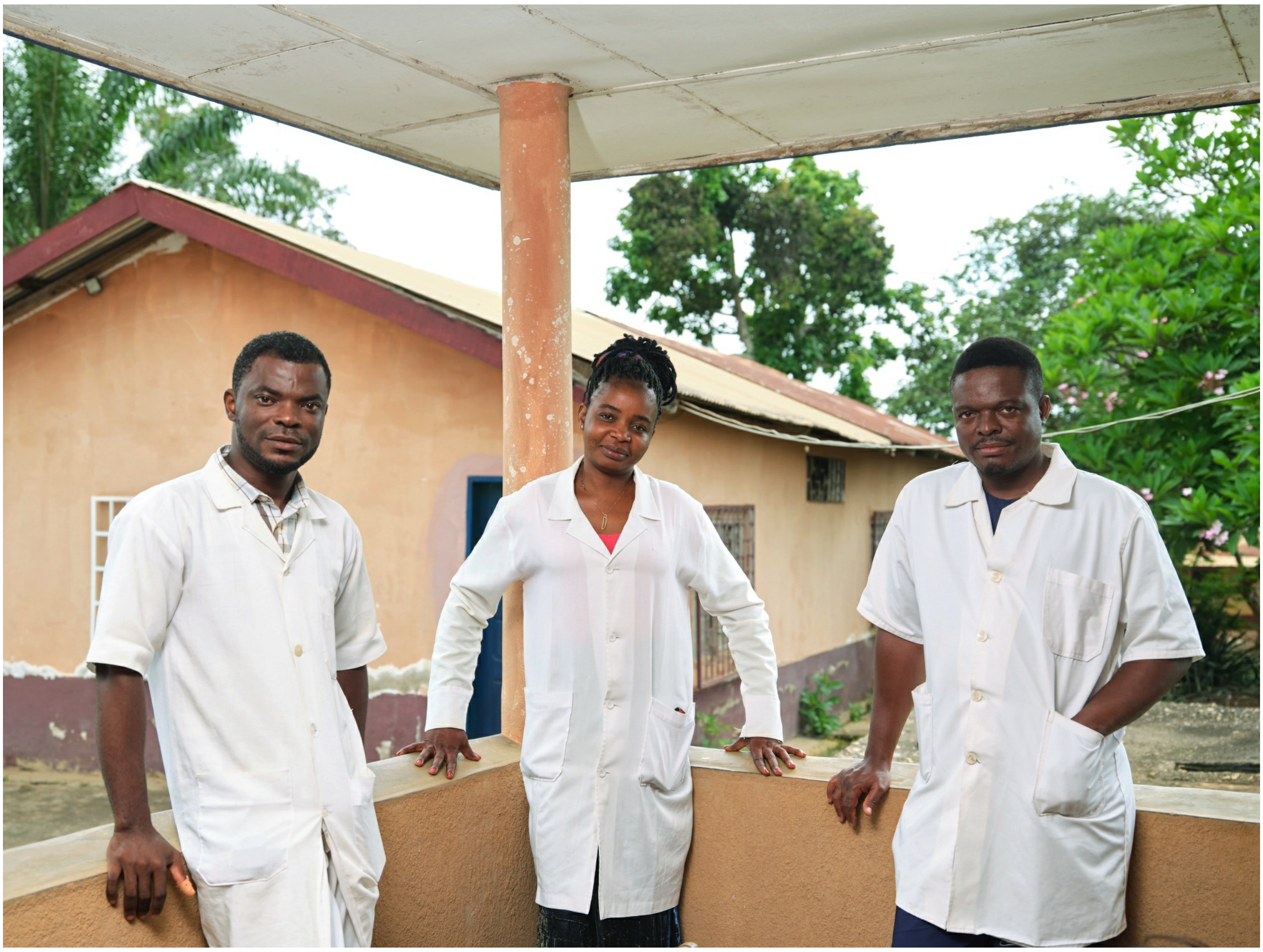
Sister Martine with nurses Thomas Ngue (left) and Richard Bitomo at the Catholic mission's health center in Ntui, in the Grand Mbam region of central Cameroon. Faith-based organizations play a critical role in providing medical treatment, health education and other health services in sub-Saharan Africa (SSA), and Sister Martine has made people with epilepsy a focus of her mission's work. In Grand Mbam, more than 10% of the population lives with epilepsy, a neurological condition that causes recurring seizures. But attitudes toward the disease make it hard to reach patients.

In elementary school, I had classmates with epilepsy. Listening to others I thought, like they said, that it must be some sort of evil spirit taking hold of them. Gradually I started trying to find out who these people are, why they are neglected. We thought the best way to reach these people would be to start visiting the families, given that those who were sick were being hidden. Because we know it's a disease of shame, no parent wants to have the shame of saying, ‘my child has epilepsy’.



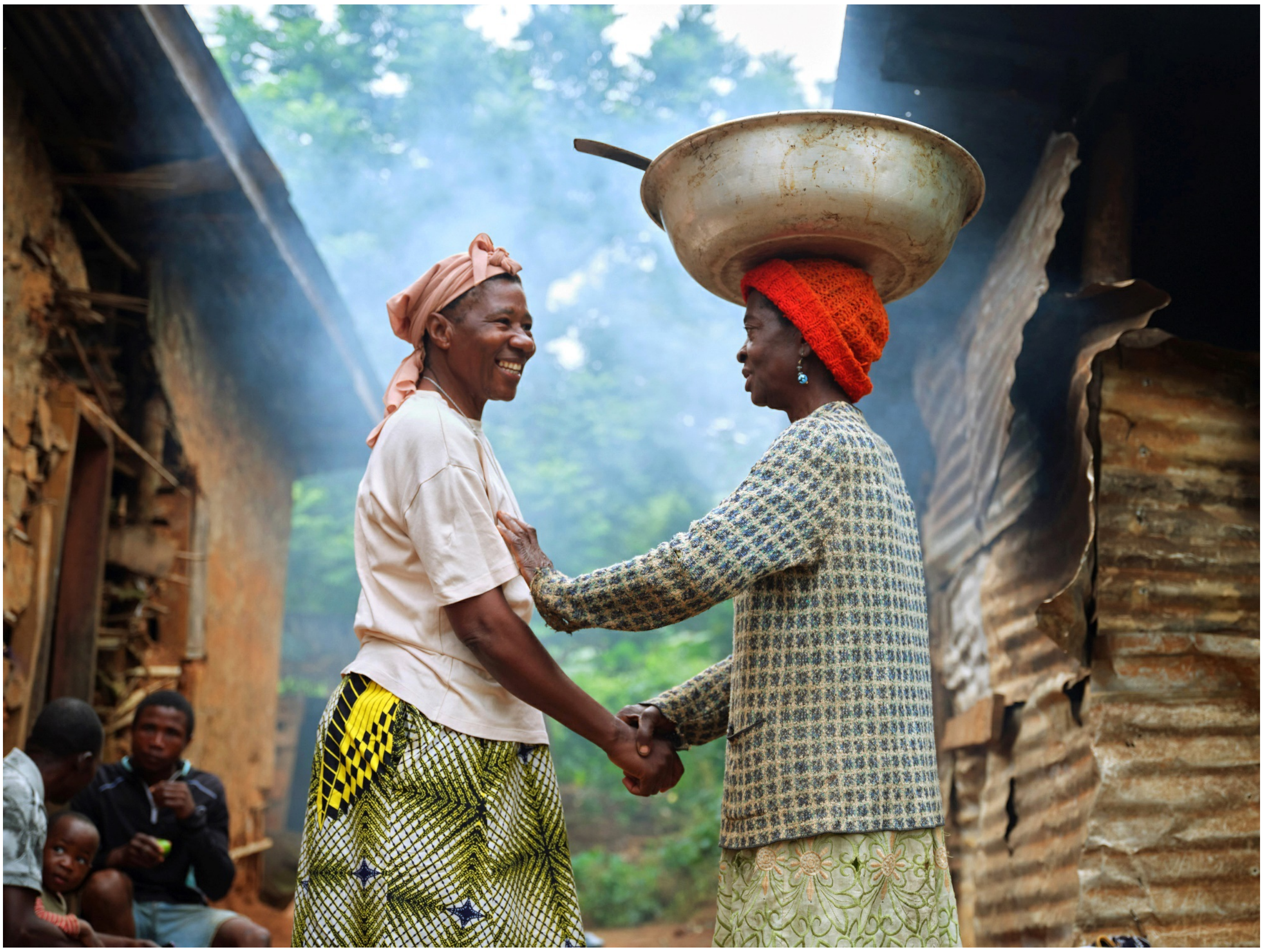
Richard Bitomo examines a child at the health center, which Novartis supplies with epilepsy drugs. Faith-based organizations have close relationships with local communities and networks that reach people in remote areas. For this reason, Novartis has a long history of partnerships with such groups in SSA to help break down barriers to care and treatment — such as stigma and misconceptions — and improve health service delivery. Sister Martine says winning the community’s trust on epilepsy was painstaking.

I can’t tell you it was easy. When you first arrive people look at you as if to say: ‘What is she doing here? Is she coming to snoop around?’ We try to start by having a conversation with the parents to tell them we know there is a sick person in their home, while at the same time trying to convince them that the disease can be treated. When they sense that you speak with conviction and see that you trust them, they will also trust you.



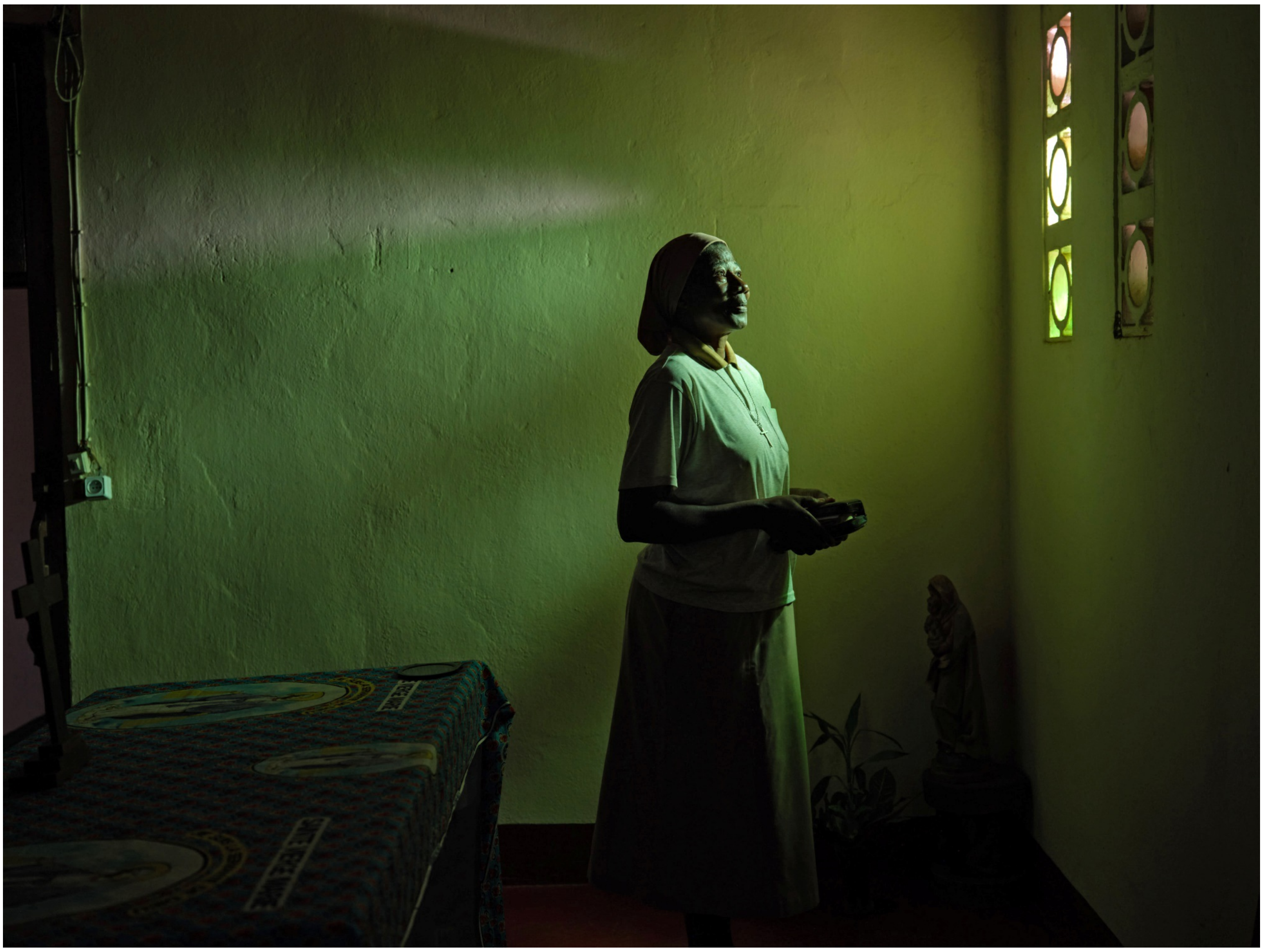
Thomas Ngue, Agnès Ngayina and Richard Bitomo during a break. Novartis also provides training on epilepsy to staff at the health center. The stigma around epilepsy in the rural area of Ntui means people with the disease often drop out of school or struggle to find work. In addition, poverty and lack of experience with modern medicine are further barriers to effective treatment, Sister Martine says.

The families always begin by consulting traditional healers — all of them — before they come to hospital. The difficulty then is understanding that the treatment is a long one. The hardest thing is to be able to ensure that medication is always available for these patients and for them to take them regularly so that they can live balanced lives.



Sister Martine visits Adèle Biloa Ngah (right) in Ntui. Five of Adèle’s 10 children live with epilepsy. The health center has been a lifeline.

People spoke of witchcraft. They made fun of me. But I made the effort to take my children to hospital,” Adèle says. “It’s thanks to the health center that I got all my children back [to a normal life]. Now, if I didn’t tell you my children were ill, you wouldn’t know.



Sister Martine in a prayer room at the mission, where she has spent most of her life.

> It’s a great joy to know that my very small actions can give or renew life, that is to say the strength and courage for people to feel reintegrated into society.

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