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'It just kept growing': How a New Milford organization helped a child in need of a lifesaving procedure

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NEW MILFORD — For a young girl who recently went through a major 12-hour surgery to fix a massive venous malformation on the left side of her face, Nagalem Alafa was full of energy.

In a New York City store, the 5-year-old girl smiled broadly and offered high-fives as her father, Matios Alafa Haile and their interpreter talked about her recent lifesaving surgery.

After meeting Nagalem with her mother in Ethiopia, an official from the U.S. Agency for International Development reached out to New Milford-based nonprofit, Healing the Children Northeast, to see if they could help Nagalem get the growth removed. In June, she arrived in New York City with her father and an interpreter for the surgery. None of them had been to the United States before.

The New Milford-based nonprofit is one of 16 chapters of the national organization, Healing the Children, which was founded in 1979. The northeastern regional chapter was founded in 1985 and has been operating out of New Milford ever since.

The organization primarily provides medical and dental services to children throughout the world who lack these resources, its website states. With three programs that provide domestic services, send medical teams overseas, or bring international children to the U.S. for treatment, the chapter says that from 1985 to 2020, it has helped more than 55,000 children and young adults.

Nagalem is one of these children.
Nagalem and her father are from a small rural village in southwest Ethiopia, where their family farms corn and teff, a grain. Nagalem is the youngest of five children and was born with abnormally developed veins in her face that continued to grow as Nagalem did until the malformation was larger than her head.

It spanned from her cheekbone down under her jawbone to her neck, according to Dr. Teresa O, a pediatric and adult facial plastic surgeon who performed the surgery with Dr. Robert Rosen and her husband, Dr. Milton Waner.

Venous malformations, which develop before birth, can occur in various parts of the body and grow as children age. Nagalem's malformation could have eventually cut off her air supply or ruptured.

“It just kept growing and growing,” Nagalem's father said through his translator, a young woman from Ethiopia's capital city, Addis Ababa, named Kalkidan Gebremariam.
Patrick Brady, the USAID Representative to the African Union, first came upon Nagalem at another charity’s screening site. He said the size of the malformation was shocking.

They told Brady they were going to have to turn Nagalem away— she wouldn’t be able to have the surgery in Ethiopia.

But Brady couldn’t stop thinking about the little girl, so he reached out to Healing the Children Northeast.

**Nonprofit medical work**

While the nonprofit is based in New Milford, its reach extends from New York to Maine, with volunteers across the country, according to Casey Saussy, a board member who has played an integral part in Nagalem’s journey.

Saussy now lives in Connecticut but originally got involved with Healing the Children Northeast while living in North Carolina.

Missy Law, the organization’s program director who started working at the New Milford offices in 1985, said the nonprofit has provided many decades of medical and social services to the region, including yearly college scholarships, donations to the local food nonprofit Camella’s Cupboard, and aid with medical bills.

The organization has brought children to regional hospitals like New Milford, Danbury, and New Britain, as well as hospitals in New York City and Boston over the years, Law said.

But their domestic medical reach has been less robust since HIPAA laws made it illegal to share an individual’s protected health information, she added.

Law said they used to get tips from school nurses about local children in need. Now, parents must actively seek out their help.

On top of that, Law said it’s become harder to find open operating rooms.

“Today, it’s harder for the nonprofit to do medical work on their own,” Law said.
“Today it’s kind of hard to even get the hospitals to volunteer their services,” Law said. “Most of our kids that we’ve brought in within the past couple years have known somebody that is with the hospital.”

Law has fostered several of the organization’s children herself, and said social media has helped her keep in touch. Another inbound family stayed in New Milford with their conjoined twins after receiving medical aid.

“I remember almost all of them,” Law said.
Nagalem's journey

With Brady’s help, the nonprofit organized Nagalem’s surgical and trip logistics with New York doctors. The surgery took place at Lenox Hill Hospital on June 23 while Nagalem’s father anxiously awaited news.

Healing the Children Northeast ended up covering all personal and travel-related expenses for the family. The surgery was done pro-bono and lodgings were covered by the Waner Children’s Vascular Anomaly Foundation.

After two successful procedures to remove the malformation, some additional dental work, and an “all clear” from her doctors, Nagalem and her father are headed back to Ethiopia next week.

Navigating endless hours of medical meetings, surgeries, follow-ups and discussions with a language barrier was no easy task. Gebremariam said it could be difficult and emotional to translate for Nagalem’s father. She had not previously worked as a translator but offered her services for the trip.

“I think it was amazing that we had Kalkidan,” said O. “I think that was a great luxury and benefit for all of us.”

Brady also said that managing medical expectations and continued medical care once Nagalem arrived back home were difficult hurdles, especially with geographic, language, and access barriers.

Before her surgery, Nagalem’s family kept her close to home, according to her father. Although she did not seem to face stigma from her community, the family wanted to protect her.

Haile, Nagalem’s father, said he was “full of joy” that Nagalem would be able to play like other children without restraints when they arrived back home.

After the surgery, he said Nagalem looked in the mirror and asked where the growth was.

Within a few days, Nagalem had perked up— singing, eating, and playing.
“I give it all to God,” Haile said of his daughter’s recovery. “I am so happy now, thanks to God.”

Saussy said getting to know Nagalem, her father, and their translator through the entire process been “life-changing.”

She wrote in an email that she was “humbled by the trust Nagalem’s parents had in the promise that we could remove the venous malformation so that she could live a long, healthy life.”

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Reach Currie on

Currie Engel covers health issues and the towns of New Milford and Brookfield for the News-Times. A graduate of Princeton University and Columbia Journalism School, she has worked for publications like The Houston Chronicle, Harper’s Magazine, and TIME. When she’s not reporting, Currie is usually reading, running, and singing, but usually not at the same time.

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