These days, Liam Steffen is the life of the party.

The 7-year-old first-grader from Savannah, Ga., is a breaststroke competitor on his school swim team and enjoys scoring goals in soccer. Liam loves a challenge — probably because he’s had a lot of experience facing them.

Liam was born with a lymphatic vascular malformation, a noncancerous mass caused by a developmental problem in the lymphatic system. These masses cause swelling in the areas where they form, which, in Liam’s case, was his head and neck. The mass caused his tongue and neck area to expand, which made breathing and eating difficult. At 10 days old, he needed feeding and breathing tubes to stay alive.

“Looking back, those were dark days,” says his mother, Janet Steffen. “At the time, I was told he would never eat, drink or talk on his own.”

Ms. Steffen is a vascular nurse, and she had connections that led her to promising clinical trials and, ultimately, to Nemours Children’s Specialty Care and Wolfson Children’s Hospital, Jacksonville, Fla. That’s where she and Liam’s father, Joe, brought him to see Gary D. Josephson, M.D., a board-certified pediatric ear, nose and throat (ENT) specialist.

Dr. Josephson established a care plan that included a series of surgeries to safely remove as much of the tumor as possible, which improved Liam’s ability to breathe and eat normally like other children his age.

Along the way, pediatric specialists in neurology, radiology, plastic surgery, anesthesiology and oncology worked alongside Dr. Josephson to offer a coordinated care approach.

Board-certified pediatric hematologist/oncologist Eric S. Sandler, M.D., became involved with Liam’s case when a drug typically used to prevent bone marrow transplant rejections showed promise for treating lymphatic malformations. When Liam started taking it, the results were dramatic.

“Liam’s malformation was severe and caused many problems with his tongue and airway, but it stopped recurring when he began the medication,” Dr. Sandler explains. “Through the joint Vascular Anomalies Program between Nemours and Wolfson Children’s Hospital, we provide the specialized care these children need. There are few comprehensive programs like ours that offer this level of expertise.”

Like Liam, children from Georgia have the option of seeing pediatric specialists such as Dr. Sandler at Wolfson Children’s at Southeast Georgia Health System. Outpatient pediatric specialties offered in Brunswick include cardiology, general surgery, hematology/oncology and urology services, as well as physical, speech and occupational therapies. Pediatric otolaryngology (ENT) is expected to be available in the fall.

“It’s nice to know that the specialty care we need is available closer to home,” Ms. Steffen says. Liam will need lifelong care, but he’s doing great. The breathing and feeding tubes are long gone, and his mother reports, “These days he doesn’t stop talking, and he never misses a meal.”