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Newton man struggles with rare disease

By JESSICA LOWE NDN Staff Writer

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Days are tough for Larry Norcross. The 47-year-old Newton man starts his mornings feeling ill, nauseated and often vomiting. His balance is off. He can no longer drive. He can no longer work. Even the simplest tasks like watching one of his four children in a school or athletic activity is daunting.



With all that, Tammy, his wife of almost 22 years, said her husband and her family hold out hope for a cure for Larry's disease.

"We just keep praying for a miracle," said Tammy, who spoke on behalf of Larry because he was too ill to conduct an interview.

Diagnosis

The Norcross' long journey began in 1997 when Larry, a sales man for a local Newton company, began feeling ill on plane rides, then dizzy and suffering from severe headaches. He insisted something was wrong and doctors first believed it was something as simple as allergies.

When Larry collapsed, Tammy knew it was something more serious.

And it was.

A CT scan showed that Larry had a tumor in his brain. In December of 1997, Larry had brain surgery with his wife — who was pregnant with their fourth child — by his side.

"We didn't pay attention to what it was at first. He had a tumor. They got it out. The doctors told us it wasn't cancer and that it slow growing and hopefully we didn't have to deal with it again until he was an old, old man," Tammy said.

Unfortunately for the Norcross family, the doctors were wrong.

In the spring of 2000, a scan showed that the tumor had grown back. This time the Newton family traveled to the Mayo Clinic in Rochester, Minn., where Larry began receiving radiation treatment to shrink the tumor.

The Norcross family took a collective sigh of relief believing Larry was on the road to recovery. Again, their relief was short lived.

"We sit there thinking the tumor is gone. We were told it was not cancer so we thought everything was great," Tammy recalls. "He wasn't feeling sick so we thought we were in the clear."

During a routine scan in 2005, doctors found a second tumor in Larry's brain.

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After finding a second brain tumor, Larry faced yet another brain surgery.

"It kind of rocks your boat to find another brain tumor," Tammy said. "He had brain surgery again and it did not go well. They could not remove the tumor. I shutter to think what happened in that operating room."

Tammy said the second brain surgery was a blow to the family when they learned there was little the doctors could do.

"It was devastating to go through," said Tammy. "It was a long, painful and expensive biopsy and they didn't get the tumor out."

This time the doctors suspected Larry was suffering from a rare disease known as Von Hippel-Lindau (VHL), which is a rare genetic disorder that affects multiple organs and causes tumors to grow in the brain, eyes, spine, pancreas, kidneys, adrenal glands and other areas in the body rich in blood vessels.

Tammy said the disease is caused by a mutation in the VHL tumor suppressor gene, which produces a protein that helps regulate cellular growth.

"We had no idea what this was. We had never heard of it. I've never met anyone with VHL," Tammy said. "We did a history of Larry's family and there is no sign that someone else has had VHL."

Treatment

After learning the tumor could not be removed the Norcross family began to look into treatment options for the disease that is attacking Larry's major organs.

Tammy said there is no known cure.

"There's no cure. That's frustrating part. We have no plan of attack," Tammy said. "We hope we can hold out til there's new technology or a new treatment. I read somewhere they hope to have a cure by 2025 but 15 years is a long time to wait when you are so sick."

Although no cure exists, Tammy said Larry has taken part in some clinical drug studies and is receiving an IV treatment which is used on cancer patients to reduce tumor size and slow growth.

"The last scan showed little change," she said. "Best case scenario we hope the Avastin has slowed things down."

Faith, Family and Friends

With tears in her eyes, Tammy said it's been difficult for her family during the 12 years since Larry's first brain tumor was discovered.

"He has four tumors of size now and multiple tumors up and down his spine," she said. "He's sick of being sick. It's really hard."

The most challenging part of the ordeal for Tammy has been watching an active husband and father retreat because of his illness.

"I've lost my partner even though he's here. He was a very active dad and husband and helped a lot with the house and the kids and provided for the family," she said. "He can't do most of the things he used to even watching the kids at their activities or talking is tough. When you don't feel good you don't have much to converse about."

Tammy said their four children — Leah, 17, Lauren, 15, Luke, 14, and Logan, 11 — have grown up quickly and taken on many responsibilities their peers haven't had to.

"I'm very proud of them. They all deal with it differently," she said. "They miss their dad laughing and playing with them like he used to."

Despite the challenges the Norcross family faces, Tammy said they manage to keep a stiff upper lift thanks to the support of their family, friends, church family and community.

"I find myself in tears a lot because I'm so emotional and overwhelmed by the generosity of the people around us," she said. "It's been difficult and I wouldn't wish this upon anyone but we have been so blessed with so much love and support."

The Newton woman said people — sometimes complete strangers — lend a helping hand to keep the family afloat.

"The lawn gets mowed. I never have to worry about the kids getting picked up from soccer practice or swim team practice. People still bring meals to the house," she said. "It's hard to be on the receiving end of all that. I wonder and think 'Have I been this generous?' or 'Would I even know what to do in this situation for someone else?' It's overwhelming."

That overwhelming generosity extends to a fundraiser planned for Saturday. A spaghetti dinner and silent auction will be from 6:30 to 8:30 p.m. at the McCann Center at Sacred Heart Catholic Church, 1115 S. Eighth Ave. East in Newton. All the proceeds will go to help cover the cost of Larry's mounting medical bills.

"I just hope someday we can pay it forward," she said. "I look forward to the day that Larry is well and we can pay everyone back for their generosity. We could not have survived this without the kindness of our family, friends, church and community. I would like nothing more to be able to pay it forward."

While the Norcross' wait for the opportunity to pay it forward they also wait for a cure.

"We're still praying for a miracle," she said. "We pray that they figure out a way to stop the tumors from growing."

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