

Illness becomes part of life

Couple is upbeat despite daughter's rare disease, and dad's brain tumor

By **CATHLEEN F. CROWLEY**
Staff writer

SOUTH GLENS FALLS — Just when Margie and Tony Cottone thought the worst was over, a new nightmare began.

The couple, who grew up in Saratoga Springs and Queensbury, met while working at Hertz-Rent-a-Car in Latham. They married in 2008.

They were living in Georgia and

FAMILY

▼ CONTINUED FROM A1

her forehead turns black and blue.

The first two years for a baby with TAR are the most critical. "If she bumps her head, she could hemorrhage in her brain," Margie said.

Margie and Tony, both 28, returned to their full-time jobs — Margie was a manager at Hertz and Tony was an assistant manager at Taco Bell — but they hated leaving Lexi at day care. In April, the couple moved back to upstate New York to be near family. They now reside in the village.

But a new health crisis awaited them. Two weeks after their move, Margie awoke to find Tony having a seizure. He couldn't talk for 20 minutes, when he finally came out of it, he said he was fine. Margie asked if he knew his birthday and told him to sing "The Star-Spangled Banner." He knew his birthday, but not the national anthem, so she had him sing his favorite Michael Jackson song. He couldn't. They went to the hospital.

Doctors found a plum-sized tumor on Tony's brain.

Margie's first thought after the doctor told her the news: "That figures."

Looking back, there were signs. For years, Tony had attention problems, and around the time of Lexi's birth he started having 20-second episodes during which he couldn't talk. These were diagnosed as panic attacks brought on the stress over Lexi's condition, and he started taking anti-anxiety drugs. It turns out what were thought to be panic attacks were seizures.

The tumor was on the frontal lobe that controls motor and speech. On May 4, a surgeon at Albany Medical Center Hospital removed 15 percent of the mass, but was not able to take out the rest.

Tony developed a massive blood clot in his right thigh while recovering at the hospital. It was so painful, he couldn't talk or think about anything else.

He came home using a wheelchair in mid-May, and though he can walk again is still struggling with speech and memory problems. Tony will have chemotherapy soon. The Stage 2 tumor — a mixed oligoastrocytoma mass — is not cancerous at this point, but is still growing and likely to become cancerous.

Inside

A7 ► Fundraiser to help family.

expecting their second child, but 20 weeks into the pregnancy the couple learned their unborn daughter had deformities. She was missing a bone in her arm, and doctors said she had no toes or fingers. Doctors predicted the fetus would not survive because her lungs were filled with fluid.

The couple prayed, and the baby survived. Alexis was born on Oct. 25 with her dad's black hair and dark eyes. To their delight, she had fingers

and toes. But she was terribly bruised and was missing the radius bone in her forearms.

Lexi, as they call the baby, was diagnosed with thrombocytopenia-absent radius syndrome, a rare genetic disease that affects only 4,000 people. A genetic mutation in Lexi's DNA means that she doesn't produce enough blood cells, called platelets. Most people have 150,000 to 450,000 platelets per microliter of blood — Lexi had 19,000. The shortage means she is vulnerable to infections and bruises easily. When Lexi cries hard,

Please see **FAMILY A7** ►



JOHN CARL D'ANNIBALE/TIMES UNION

TONY AND MARGIE COTTONE with their children, Jayden, 21 months, and Alexis, 7 months, in their South Glens Falls home.

How to help

A fundraiser is being held for the Cottone family. Tickets are \$25. For more information or to donate items for the silent auction, contact Caitlin Cobello at 225-1649 or ccobaldrige@gmail.com.

- **When:** 5 to 8 p.m. Saturday
- **Where:** The Inn at Saratoga
- **Info:** Donations can be sent to Adirondack Trust, ATTN: Fighting Through Thrombocytopenia (TAR) account, 473 Broadway, Saratoga Springs NY 12866

"I'd rather know the life expectancy, but they won't tell me," Margie said.

Tony marvels at how well his wife takes care of the family, which includes 21-month-old Jayden, Lexi's older brother.

"I could never do what she does," Tony said.

Margie says she and Tony work well as a couple because he is so relaxed and she's high-strung,

though she admits to being more high-strung these days.

Despite everything, they are remarkably upbeat. Margie even chuckles as she retell parts of their tragedy.

"I've always been a religious person, so I pray every day — and that helps me," Tony said. "My family is the light of my life."

Lexi's condition qualifies her for Medicaid, and now that neither parent can work the family is eligible for government assistance.

Lexi will eventually have surgeries to lengthen her arms and improve the function of her thumbs. She will also have treatment for her legs, which will become bowed as she grows. But her brain function appears normal, and she smiles and coos like any other infant.

"She been the cutest, happiest baby in the world," said Tony.

► Reach Cathleen F. Crowley at 454-5348 or ccrowley@timesunion.com. Visit her blog at <http://blogs.timesunion.com/healthcare>.