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Two-year-old Appleton girl wages battle for her life

By Cheryl Sherry

Post-Crescent staff writer

When 3-year-old Faith Meltz plays dolls, they imaginarily throw up at times. While most parents might question the oddness of the action, hers do not.

Yes, the imaginary is all too real in the Appleton home of Brian and Shannon Meltz, where Faith's younger sister, Hailey, who turned 2 on Monday, has an inoperable brain tumor. Throwing up, feeding tubes and a chemotherapy port installed in her tiny chest are all part of the new normal for Faith and her family.

Although chemotherapy buys them time, it is not a cure.

What will Hailey's health be like when she turns 3? Or 5? Or 10? No one knows. Getting there will be an emotional roller-coaster for the Meltz family, which has gone on the offensive in an effort to boost awareness and research into Pediatric Low-Grade Astrocytoma, or PLGA, the disease holding their daughter hostage.

"There are cases where some kids handle it beautifully and the tumor for whatever reason decides not to grow and they have a stretch of time where they are basically fine," Brian said. "And then there's a lot of cases where that's not the case. So it's really hit or miss."

Rather than dwell on the negative, Brian and Shannon have decided to put up a fight for their daughter's life and the lives of other children with PLGA. In the meantime, Hailey will continue her visits to Children's Hospital in Madison for the next year and a half, part of a 70-week clinical trial chemotherapy regimen. The ordeal is something Hailey and her parents have grown to hate.

"When we get into the parking lot, she starts screaming and crying," Brian said.

"The biggest thing for me is she doesn't understand what's happening," Shannon said. "I'm holding her down while they access her port and she's just saying, 'No, no, no.' It just breaks your heart. Yet she doesn't know anything else. This has been her life."

Using their arsenal of tricks, Brian and Shannon finally calm Hailey down during treatment, until the portable pump is removed from the port that's permanently installed in her chest. Only when Hailey is safely buckled back into her car seat and heading home does the crying come to an end, and the little girl returns to being just a little girl.

Then starts a new week of dread. "Oh, Tuesday's coming and we have to go to Madison and it's going to be a long day," Shannon said. "And it's never going to end. So you just try to take it one day at a time and get through."

Hailey, then 20 months, was diagnosed with the brain tumor in June. It also is referred to as JPA or Juvenile Pilocytic Astrocytoma. It is the most common kind of childhood brain tumor. Although it is a non-malignant tumor, it can be life-threatening depending on its location in the brain and whether or not it can be completely removed during surgery.

Hailey's tumor involves the hypothalamus and is causing an extremely rare condition called diencephalic syndrome. Despite adequate nourishment, Hailey cannot gain weight. There are only a couple hundred documented cases of this syndrome in medical journals.

Brian and Shannon continue to hope the chemotherapy they are pumping into her body shrinks the tumor just enough to at least temporarily give her a chance to gain some weight. Hailey currently weighs just under 21 pounds.

Although scientific discovery and technology have converged to turn the tide in the fight against cancer, Dr. Mark Kieran, director of Pediatric Neuro-Oncology at the Dana-Farber Cancer Institute in Boston said, "Even with medicine's many advances, low-grade astrocytomas remain largely under-researched and under-funded, with treatments unchanged for 20 years. ... Little is known about low-grade gliomas (central nervous system tumors), as attention and funding focused on these types of tumors has lagged behind that of high-grade gliomas."

Seventy percent of the patients living with the disease have a high likelihood of growth and cognitive abnormalities. Thirty percent of patients do not live.

"It was devastating," said Brian upon finding out little research was being done to find a cure for PLGA. "You are already at the lowest point you've ever been in your life when you experience a diagnosis of something like this with your child. Then you start thinking, 'OK, how do we fix it? What's the treatment? Tell me there's something I can do to take this away. Tell me there's research that can at least get us there quicker.' Well there isn't even that. ...

"We have days where it just hits you so hard. This is our life now, and there's no light at the end of the tunnel — yet," Brian said. "If there were a light it would be much easier to go through this. ... This is never what I would wish for my child, for either of my children. It's just not fair, but life isn't fair. Our only option at this point is to try to change it. We have to try to change it."

Hailey's story

In 2005, Faith Meltz became the big sister of the newly born Hailey Jaye Meltz. Beside the usual fussy moments, Hailey was a happy and healthy baby girl. Her parents even remarked how easy Hailey was compared to Faith.

Around her first birthday, Hailey's weight dropped significantly. Her parents and pediatrician Dr. John Edwards of ThedaCare Pediatrics in Appleton agreed Hailey's weight had not caught up with her height, and her fussiness when it came to feeding was something she'd probably grow out of. She had also begun coughing while drinking a bottle, couldn't handle solid baby food and was vomiting immediately after eating.

It later was discovered Hailey was aspirating or breathing liquids into her lungs every time she drank. Finally, the Meltz's thought, here was an answer to the continuing low body weight and aversion to food and drink. Brian and Shannon began doing exercises with Hailey to improve her oral coordination and resolve the aspiration.

Months went by, but Hailey's condition did not improve, so Edwards referred the 15-month-old to a gastroenterologist at Children's Hospital, who immediately admitted her, placed a feeding tube in order to put weight on the 19-pound baby and ran a battery of tests.

Everything came back normal except that Hailey had very large adenoids. Again, Brian and Shannon thought they might have found an answer. Hailey had gained a pound and a half on the feeding tube and her adenoids were removed. But the vomiting and aversion to food continued.

Over the next few months, Hailey was poked and prodded and tested and underwent a procedure to dilate the pylorus, the

opening of the stomach to the intestines. Her symptoms remained the same and her gastroenterologist advised repeating the procedure and getting a just-in-case MRI, which was done at Appleton Medical Center.

It was Edwards who later broke the news to Brian and Shannon that Hailey had a sizeable brain tumor. The Meltz's 10-month struggle finally was explained.

"I wouldn't even be able to describe how dramatic and how hard a day that was," Brian said. "He told us immediately following the (MRI), they found the mass in her brain. It was about three centimeters, a pretty sizeable mass for a little kid. And it's been a whirlwind ever since."

A biopsy of the tumor later determined it was incurable.

"(A biopsy) is considered minor brain surgery, but it was the worst thing for Hailey," Brian said. "To see your little daughter screaming and crying and head wrapped and not able to get comfortable and vomiting and hooked up to all these machines, it was just miserable. But we are glad we did it, because we did find out with all certainty what type of tumor it is."

Fighting to find a cure

Soon after Hailey's diagnosis, Shannon and Brian realized they had only one choice — to try and do something about their situation.

"We feel we have no option; the alternative is unacceptable, to lose our daughter and to lose the concept of the family we are trying to create," Brian said.

Brian, 34, works as a real estate investor. Shannon, also 34, works as a project coordinator for Ingenuity First, a division of ThedaCare. The rest of their time is spent with their girls, and focusing on their new mission — finding a cure for PLGA.

They hooked up with Fight PLGA (formerly Fight JPA), a grassroots organization started by Linda Janower, a retired communications CEO, who launched a Web site in November 2005, a year after her granddaughter was diagnosed with the disease.

"(Researchers) haven't even studied the molecular makeup of this tumor," Shannon said. "All the money right now is focused on that, how does it grow and what cells is it made of? There are drugs out on the market right now that could help but they just don't know. That's the quickest path."

"We are trying to raise money and awareness and funds to advance research to bring this to the forefront so we can hopefully find a cure, or at least more effective treatments and eventually a cure. ... It really starts with raising money," Brian said.

"There's potential of something better out there. And that's what drives us. We could save our daughter. We could save our family and thousands like her around the country. ... Giving up is not an option. That's our mission."

"There are brilliant people out there, and they haven't had the resources to fight," Shannon said. "We will find the resources."

In the meantime and through Hailey's nightmarish treatments, the Meltzes hope their daughter knows how much they love her.

"We are doing this to help her," Shannon said, tears rolling down her cheek. "You dream about (your children) growing up happy and healthy, going to college and someday finding someone to love them and then having kids. Is Hailey going to have a chance like that?"

"We hope."
