

**MUSKEGO NEWS**

# Family of a Muskego 3-year-old with a terminal illness is raising \$1 million for a chance to save her life

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When 3-year-old Olivia (Liv) Stoop of Muskego was very little, she was "obsessed" with her baby dolls that had diapers she could change. When her baby brother Liam was born on May 5, she begged her parents to let her do the same thing: She wanted to change his diapers as one way to care for him.

And she would ponder repeatedly in her cute little voice, "Liam sleeping?" "We take it that she cares about him and wants to make sure he is safe," her mother Erin said.

And she loves to use her play doctor kit and take out her stethoscope to "test her parents' heartbeat." For which, Erin and her husband, Tyler, need to lie on the floor, Liv straddles on top of them and listens to their heartbeat. "She does not have a mean bone in her body," Erin said.

It is a pretty good bet that these young years are going to be the best, most cherished years of Liv's life. This is because on March 28, Liv was diagnosed with Sanfilippo Syndrome Type B, a rare disease that is compared to late-stage Alzheimer's, but for children. "It is 100% fatal," said Erin.

But if there is a chance she and her husband can save Liv's life or even just improve the quality of it, they "absolutely" should try, Erin said.

On Liv's third birthday on Dec. 3, her parents launched a \$1 million fundraising campaign to raise money so promising research can reach the clinical trial. In the 24 hours after Liv's birthday, their GoFundMe page raised more than \$100,000. As of Dec. 9, \$167,520 has been raised.

While there is no guarantee Liv would get enrolled in a trial, she is, however, a good candidate because she was diagnosed young. But the money needs to be raised first, and because it's a degenerative disease, time is of the essence, Erin said.

The family is partnering with the Cure Sanfilippo Foundation to raise money and awareness.

According to the Cure Sanfilippo Foundation website, Sanfilippo Syndrome is a terminal, degenerative disease that causes children to lose all the skills they've gained, and suffer seizures and movement disorders. The general life expectancy is in the child's teenage years.

Almost all never get potty trained and some don't ever try, said Stoop.

"People die in their sleep or pass away from infections or pneumonia as their bodies cannot fight them."

"It is just horrifying," she said.

## **'In constant fear for your child'**

When Erin Stoop found out Liv had Sanfilippo Syndrome, she was 35 weeks pregnant with her youngest child, Liam; she just cried nonstop for more than a week.

Little things got to her. When Liv was born, Stoop would wonder if her child would be into sports.

"I played volleyball, and (my husband) played soccer," she said. Would she play one of those sports? "I had the greatest relationship with my mother, Mary Kohl. We loved to cook together. We were both outdoorsy people, we spent time with our dogs," she said. Or how her wedding dress is kept nicely for her to someday wear.

And then she learned that because this disease was genetic, her son would have a 25% chance of having the same disorder. But she needed to wait to have him tested.

"In times when this should be the best time of your life, it was the worst eight weeks of my life," she said. "You are in constant fear for your child."

Luckily, Liam got tested at 3½ weeks old and did not have the gene for him to have Sanfilippo Syndrome. But he is a carrier, his mother said. Therefore, if his spouse is a carrier, his children would get it.

Erin worries about Liv's future.

Through Facebook, she met a mother, Sheri Sowdon, also from Muskego, who has two boys, Tyler, 19, and Ethan 17, both with Sanfilippo Syndrome.

"I saw a picture of them with feeding tubes," said Stoop. "That was very hard ... Is that where she is headed?"

"It is devastating," said Sowdon. She said that when her sons were both diagnosed, the medical staff told her they were so young, they would have no problem getting into a trial. But when she looked for one, she was told there was no active trial.

Sowdon has seen both her sons cognitively decline to having trouble walking, having seizures and being hospitalized for a bad cold. As toddlers, she said, they were so active. "I try to keep them as active as possible."

"Everything is so expensive for treatment," she said. "We need to get the awareness to fund research. We were so hopeful for a cure, and it did not happen."

## **'These children deserve us to take action'**

Glenn O'Neill, who started the Cure Sanfilippo Foundation with his wife Cara when their daughter Eliza was diagnosed in 2013, said that the million dollars would move forward the research projects related to Sanfilippo Syndrome Type B and closer to clinical trial.

He said that the research has been done and has been promising, but the funds are needed to move it to the trial stage. He said, however, he has no way of knowing how long it will take once the \$1 million is raised.

"The cost of the rare disease is massive," he said. Because it is rare, it is left up to families and patient organizations to raise the dollars. There are no trials for Type B that are enrolling people," he said. "You need to fund the research, the drug tests and the travel for the family."

Sanfilippo Syndrome is caused by a single gene defect that leads to a lack of a necessary enzyme in the body. This lack of enzyme results in the build-up of toxic storage in every cell, and is especially harmful to the brain. The research and the trials in the works, O'Neill said, include gene therapy, substrate reduction and drugs already approved for other diseases that could help children with Sanfilippo Syndrome.

"All of these focus on lessening the build-up of the toxic cellular waste in children's brains and bodies, which reduces neuroinflammation in the brain and prevents the development of

Sanfilippo's many disease symptoms," he said.

Cara O'Neill, who is a pediatrician, emphasized that without the funding, the research will come to a halt. "These children deserve us to take action," she said.

In the meantime, the Stoop family will be fundraising and building up Liv's cognitive skills. She is in speech therapy and occupational therapy. "We want to strengthen these skills before they decline. It will give her a better standard of life. We want to treat her like a normal toddler," said her mother.

Stoop said that if she was not raising funds for research, she would only be doing supportive measures with Liv. Now, she said there is some hope.

"It is our light," she said.

## How to help

To make a donation to Liv's GoFundMe page, visit <https://www.gofundme.com//f/pvzfv-saving-liv>

## For more information

For updates for Liv, visit [www.caringbridge.org/visit/oliviastooptsjourney](http://www.caringbridge.org/visit/oliviastooptsjourney)

For more information on Sanfilippo Syndrome, visit <https://curesanfilippofoundation.org>

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