

## **A FITTING GIFT FOR TYLER PARENTS OF BOY FELLED BY RARE DISEASE PUSH FOR RESEARCH IN HIS MEMORY**

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A year and a half after he died, Tyler John Vranick's fifth birthday, in some ways, was the most special of them all, his parents said.

The Commack child, dubbed "The Enigma Baby" because of a mysterious disease that robbed him of the strength to move or breathe on his own, died in January 2005. Just one month later, Columbia University doctors solved the enigma and posthumously diagnosed Tyler with a rare disease known as SMARD1.

Now, to coincide with his birthday last Monday, Tyler's parents are rallying support for a new research fund established by Columbia's Motor Neuron Center in the boy's name. They say finding a cure for the disease that took their only son is the best gift they could ever give him.

"Instead of just feeling sad all the time, I kind of felt like we had to do something," said Josephine Vranick. "It makes me feel like I'm doing something positive. And that's really what he was all about ... making people see the light."

During his short life, Tyler touched people throughout the country, who rallied in support of the cherub-faced boy whose giggles belied endless discomfort. Although able to feel sensation in his small frame, Tyler was born with barely the strength to move a muscle.

Tyler breathed through a hose connected to his throat and required around-the-clock monitoring to make sure he didn't suffocate on his own mucus.

Despite their desperate efforts and countless trips to various pediatric neurologists, Tyler's parents never got an answer to what was ailing their son while he was alive. Josephine Vranick said maybe it was better that way.

"We still had hope all the way up until the end," she said. "When you know the final diagnosis, that this is what the outcome is going to be, it kind of takes away your hope."

SMARD1 stands for spinal muscular atrophy with respiratory distress, type 1. The genetic disorder's symptoms are similar to the more common spinal muscular atrophy, but it is characterized by severe and progressive weakness of the muscles, particularly those used in breathing, Columbia doctors say.

"These kids are bright and alert, but they're kind of stuck in their bodies," said Dr. Wendy Chung, Columbia's director of clinical genetics, who diagnosed Tyler with SMARD1.

Chung said that although there are only about 50 documented cases of SMARD1 in the world, the number of cases is probably much higher. But with no laboratory in the United States performing clinical tests for the disorder, many cases are never diagnosed.

Chung said it's likely that some victims of sudden infant death syndrome, or SIDS, were SMARD1 sufferers. But until doctors learn more about the disease, "we're at the beginning of a very, very long journey" to find a cure, she said.

"It's one of the difficulties always with rare diseases," Chung said. "Until you have a diagnostic test, you can't even tell who has it."

After taking some time to "lick our wounds and get our heads together," Steven Vranick said, he and his wife decided last month to commit themselves to fighting the disease as doggedly as if Tyler were still here.

"We didn't want his life and his legacy to be in vain," he said.

Vranick said his hope is that Tyler will become "the face" of SMARD1, much like Lou Gehrig is the face of ALS, amyotrophic lateral sclerosis. A fundraiser hosted by the Vranicks two days before Tyler's birthday raised \$10,000 for research.

With his heart-melting smile and courage beyond his years, Vranick said, there could be no better poster boy for the illness.

"My son went through things that adults couldn't handle, and he did it with a smile," he said. "My son never gave up, and we'll never give up trying to find a cure."

For more information or to make donations to the Tyler John Vranick Fund for SMARD1, visit [www.columbiannc.org](http://www.columbiannc.org), or e-mail [CarnivalForLife71506@yahoo.com](mailto:CarnivalForLife71506@yahoo.com).

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