

BOY FREE OF SYMPTOMS



ERIN COVEY REPUBLICAN-AMERICAN

Andrew King, 10, who has a rare condition called AVM, or arteriovenous malformation, takes practice shots at a hockey net on the deck of his Middlebury family's backyard recently.

Middlebury lad, 10, battles rare disease

BY BILL BITTAR
REPUBLICAN-AMERICAN

AMIDDLEBURY Andrew King took practice shots at a hockey net on the deck of his family's backyard one recent afternoon. There were no signs of the numbness he had felt in his left arm two years ago, when a malformation of blood vessels burst in his spine.

Andrew underwent surgeries for an arteriovenous malformation at age 3 and age 8. Now 10, the Chase Collegiate fifth-grader plays soccer, youth hockey and golf.

"You want him to be able to walk and move," said Tom King, Andrew's father. "Surgery around the spinal cord is something you don't want to take chances with, especially at a young age. We appreciate every moment. It definitely makes you happy that he can do these things. We're very fortunate."

Tom and Ryah King, who also have two daughters, Abigail, 13, and Alessandra, 12, believe more should be done to spread awareness about AVM, which occurs in less than 1 percent of the population.

Dr. Kristopher T. Kahle, attending physician at Yale-New Haven Children's Hospital and assistant professor of neurosurgery and pediatrics at Yale



Andrew King, 10, underwent surgeries for his AVM condition at ages 3 and 8. Now, he is a Chase Collegiate fifth-grader and plays soccer, youth hockey and golf.

School of Medicine, said he does not know why more resources are not put into research and treatment.

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ATTENDING PHYSICIAN AT YALE-
NEW HAVEN CHILDREN'S

tention," he said, "but this has got to be one of the particularly most devastating diseases for how out of the blue it strikes and how devastating it can be."

According to the Joe Niekro Foundation, AVMs affect approximately 300,000 people in the U.S., about 12 percent experience symptoms and 3 percent have ruptures each year.

Natalie Niekro started the Joe Niekro Foundation in 2007 after her father, a longtime Major League Baseball pitcher, died suddenly of a brain aneurysm. "We were basically left on our own,"

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AVM: Started with severe headaches

Niekro said. "When I left the hospital, I just remember how lost I felt. There was no information or guidance for a grieving family. I did research to find support groups and couldn't find anything."

She started a small support group where she lives in Phoenix, Ariz., and JNF now has 34 groups in different states, as well as Canada.

"It helps validate that what they're dealing with is normal," Niekro said. "They provide support for one another. It's a great help for a lot of people. They have to have an outlet."

In addition to surgical procedures to remove AVMs, research is underway for early detection and alternative therapies. Dr. Kahle is taking part in a next generation sequencing to determine if there are mutations and specific genes that can cause the disease.

"Genetic sequencing projects attempt to find causes of diseases," he said. "The two main purposes are diagnosis and therapy."

Dr. Kahle expressed hope that drug therapies can be discovered that could shrink an AVM to avoid risky surgery and to treat areas of the body where surgery is not possible.

Tom King said Andrew first experienced symptoms from his AVM in 2009.

"When he was 3, he had severe headaches," King said. "One moment he was fine, then he was hunched over with a severe headache. After a few episodes, we took him to a pediatrician."

The pediatrician called for an MRI of Andrew's head and neck and the AVM was discovered, King said, adding the mass of blood vessels wrapped around his son's spine.

Columbia Presbyterian Hospital in New York City performed the surgery and doctors thought they got it all out. But part of the AVM was in Andrew's spine, according to King, who said his son complained of numbness in his left hand after hockey practice at age 8.

"You could say he has a spinal stroke," King said. "His whole left arm was numb and his forearm to his elbow was tingling."

Andrew's AVM ruptured and Dr. Robert Spetzler performed surgery at the Barrow Neurological Institute, where the Kings met Natalie Niekro and got involved with JNF to support other families.

"He doesn't have any symptoms now," King said. "Just a weakness on his left side."

Doctors believe they got 98 percent of the AVM out. "We have to keep an eye on it in case it comes back," King said.

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