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A father battles to find cure for his son's illness

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WASHINGTON TWP. – Young Nicholas Antonelle has had nine surgeries in the first four years of his life as he keeps battling with the help and love of many others.

The Long Valley boy is the victim of a lymphatic malformation, one of the manifestations of a category of medical conditions collectively known as vascular birthmarks.

When he was born, the lymphatic vessels above his right eye were not draining properly, causing the fluid to buildup. Although the cause is unknown, the vessels didn't form properly during the first months of life. The fluid had formed a large knot of swelling on his forehead, forcing his right eye closed, by the time Nicholas was born.

It was a heartbreaking experience for his parents, Greg and Elyssa, who had two healthy older boys. Since then, they have traveled to Hackensack, Philadelphia, New York City and Boston as Nicholas' affliction has been treated.

For Greg Antonelle, the personal impact of his son's surgeries has stirred him to take on a role in the fight against the unusual medical condition as executive vice president of the Vascular Birthmark Foundation (VBF).

No one knows what causes the various problems under the umbrella of the foundation. There's no genetic pre-disposition and to date, no explanation as to why.

"In a way, we were lucky," said Mr. Antonelle. "For Nicholas the problem was in the forehead. A lot of these form in the neck. In those cases, babies are often stillborn or need tracheotomies at birth."

Early Signs

When Elyssa was about seven months pregnant, she visited a high risk birth specialist at St. Barnabas Medical center in West Orange for tests. It was there that the first indication of a problem was discovered.

Displayed on a four-dimensional ultrasound was the first indication of the swelling on Nicholas' forehead. Four weeks later another ultrasound showed the same problem and the Antonelles were sent to Hackensack Medical Center.

"They told us it was one of two diagnoses, the other being a hemangioma, a benign tumorous growth," Greg said.

Ten days after the boy was born, Nicholas and his parents were at Wills Eye Institute in Philadelphia.

"They were still using a 1950s textbook. They looked at Nicholas and said there was nothing they could do," Antonelle said.

Serendipity found a more positive answer for the Antonelles in the form of Dr. Milton Waner. Born in South Africa, Waner had moved to the United States and practiced at the Arkansas Children's Hospital in Little Rock.

Elyssa's brother was engaged and his fiancée had an uncle who had heard of Waner. At almost the same time the Antonelles first contacted him, Waner had decided to establish a practice in New York City.

"We were his first appointment at his new office. It was 8:30 a.m., April 4th (2004)," Antonelle said. "He looked at Nicholas and said "I can help him.'""

Some of the surgeries performed at Beth Israel Hospital have been five-hour operations. Waner was able to drain the fluid from the infant Nicholas' forehead, allowing him to open his right eye for the first time. Successive operations have improved the drainage each time.

"About two years ago after the last surgery, one night we heard a scream and rushed into Nicholas' room," Antonelle said.

They found that their son had dislodged a drain that had been installed behind his right ear. A call to Waner's office confirmed that he was overseas, so the family drove four-and-a-half hours to Boston, where Waner's backup physician was located.

Today, Nicholas is a well adjusted pre-schooler. His brown hair hangs over his forehead and few, if any, of his classmates at the Long Valley Christian Nursery School know about the malformation. Nicholas wears glasses like many children, a possible result of efforts made to strengthen his right eye once he could see from it. He still faces additional surgeries in the future.

Gregory Antonelle's involvement with the foundation began almost from the time he met Waner.

"I decided to dig into the research, to find out all I could about this thing had happened to Nicholas," he said.

His research took him to Linda Rozell-Shannon, a New York resident, who started the foundation 15 years ago after her daughter was born with a hemangioma on her lip. That growth was successfully removed by Waner years ago.

"Our goal is to find a cure and a cause," said Antonelle. "And to educate. I don't want people to hear the wrong answers from a textbook that's over 50 years old."

He brings his organizational expertise from running a successful staffing firm, Aimhire of Warren. He's raised \$10,000 from an eBay auction, but has an even larger effort on the immediate horizon.

A seminar by experts in the field of vascular birthmarks is planned for the following day, Saturday, Nov. 15, at the Phillips Ambulatory Care Center in New York City. Waner, co-director of the Vascular and Birthmarks Institute of New York, will be keynote speaker. Waner has co-authored a medical text on the surgical management of vascular lesions of the head and neck.

Nicholas' birthmark could have been in an area of his body less troublesome, such as on the ankle or wrist. But Greg Antonelle has found the luck in what has happened to his son and is setting about to change the way the condition is understood.

"As prevalent as they are, nobody knows about it," he said. "We're going to find a cure and raise that awareness."



Nicholas Antonelle

