My Mission: Tell People about Marfan Syndrome

(NAPSM)—"God kept me here for a reason," said Michael Redd, 41, of Georgia. "To tell people about Marfan syndrome."

Michael's wife, Teresa, added, "If we can save a life, we will tell anyone our story."

It's a story that could have ended when Michael was 14 years old, when he had his first aneurysm. Michael had many of the physical signs of Marfan syndrome early on. He was tall and gangly, had hypermobile joints and hammer toes, and had eye issues that are common in people with Marfan syndrome. He felt different and was called a "friendly giant." Yet he had never been diagnosed with Marfan, a connective tissue condition that affects many parts of the body.

Michael survived the surgery for the brain aneurysm, but serious medical issues followed, culminating with chest pain in 2014 that led to aortic surgery, which is common in people with Marfan. Still the underlying cause had not been identified and Michael was lucky to be alive. Aortic dissection (a tear in the large artery that carries blood away from the heart), can be fatal if not treated quickly. However, emergencies can be prevented with the right medication and monitoring, as well as surgery before a potentially fatal event.

It wasn't until a month after aortic surgery that Michael, had genetic testing. Marfan syndrome, a genetic condition, was confirmed. After learning about Marfan and thinking of his family medical history—other relatives who had many of the same physical features and died early deaths due to aneurysm—Michael knew that the diagnosis made sense.

Signs and Symptoms

Every person's experience with Marfan syndrome is slightly different. Some features of Marfan syndrome are easier to see than others. These include long arms, legs, and fingers; tall and thin body type; curved spine; chest sinks in or sticks out; flexible joints; flat feet; crowded teeth; and stretch marks on the skin that are not related to weight gain or loss.

Harder-to-detect signs of Marfan syndrome include heart problems, especially those related to the aorta, the large blood vessel that carries blood away from the heart to the rest of the body. Other signs can include sudden lung collapse and eye problems, including severe nearsightedness, dislocated lens, detached retina, early glaucoma, and early cataracts. Special tests are often needed to detect these features.

More On Marfans

About 1 in 5,000 people has Marfan syndrome, including men and women of all races and ethnic groups. About 3 out of 4 people with Marfan syndrome inherit it, meaning they get the genetic mutation from a parent who has it. And there is a 50 percent chance that a person with Marfan syndrome will pass along the genetic mutation each time they have a child.

Michael Redd (far right) believes it's his mission in life to tell people about Marfan Syndrome.

A Family Issue

The next step was for Michael to get his two young daughters tested. Both Michelle and Mariah were then confirmed to have Marfan.

The family takes Marfan syndrome seriously. They are grateful that they know what it is and are aware of the signs of an emergency. And they have sought out the medical care of an expert physician on Marfan syndrome, Dr. Glen Iannucci, Director of the Aorta & Vascular Program at the Children's Heart Center, Children's Healthcare of Atlanta, who helped them understand the condition. Teresa calls Dr. Iannucci a "God-sent angel."

"With an early diagnosis and proper medical management, people with Marfan syndrome can live a long lifespan," said Dr. Iannucci, who oversees the care of Michelle and Mariah. "I would recommend that anyone who has the outward signs of Marfan talk to their doctor and get evaluated. Treatment of Marfan has come a long way in the past 25 years. Medical management can make the difference between life and death."

Michelle, who is a seventh grader and wants to be a lawyer when she grows up, thinks it's "really cool" to tell her story about Marfan and has shared information on the condition with her friends.

"There are more people like me out there," said Michelle. "I tell other kids it's going to be okay."

Learn More

For further information about the signs of Marfan syndrome and how to get evaluated and treated, visit The Marfan Foundation website, Marfan.org.