# ASK THE DOCTOR

## What You Need To Know About Marfan Syndrome

*by Dr. Alan Braverman*

(NAPSA)—You or someone you care about may be among the 200,000 people in the United States with Marfan syndrome or a related disorder, yet not even know it. Experts agree that half of those affected are not diagnosed. Yet people with this potentially fatal condition can live a normal lifespan once it's properly diagnosed.

It is important for people to know about Marfan syndrome so that all who are affected can get the treatment they need to avoid a sudden early death.

Dr. Braverman

I know all too well how dangerous this condition can be. While in medical school, I diagnosed my brother with Marfan syndrome and realized it was the cause of my father's early death of an aortic dissection.

Here's what you should know so your family can avoid a similar tragedy:

**What Is Marfan Syndrome?**

Marfan syndrome is a disorder that primarily affects the bones and joints, eyes and blood vessels. People with the condition are frequently tall, with disproportionately long arms, legs, fingers and toes. They may have an indented or protruding chest bone and curved back and they're nearsighted at an early age. Marfan syndrome also puts the aorta at risk of enlarging, tearing or rupturing, which can lead to sudden death. If someone you know has the signs of Marfan syndrome, urge him or her to see a doctor familiar with the disorder.

**Who Gets It?**

Marfan syndrome affects both sexes and all races equally. The condition is inherited from a parent in about three-quarters of cases but can occur spontaneously.

**How Is It Diagnosed?**

Common, painless tests include an echocardiogram, an electrocardiogram and an eye exam. A geneticist may review the family medical history. A genetic test can also be helpful; however, in the United States, insurance does not always cover it.

**How Is It Treated?**

There's no cure but there are treatments to minimize and even prevent complications. Preventing a fatal aortic tear is of utmost importance. People with Marfan syndrome take medications and avoid strenuous and competitive exercise to protect their aorta. Still, they are required to have their aorta monitored every year to check for enlargement. When the aorta gets to a certain size, surgery is done to avoid a tear or rupture.

Advances in medical care are helping people with Marfan syndrome live longer and enjoy a good quality of life. Most can work, go to school and enjoy active hobbies.

With early diagnosis and appropriate management, the life expectancy for someone with Marfan syndrome is similar to that of the average person.

**Where Can I Learn More?**

The National Marfan Foundation (NMF) has a comprehensive Information Resource Center that offers extensive information about Marfan syndrome and related disorders, as well as guidance on finding doctors who are experienced with Marfan syndrome and connections to support networks. Contact the NMF at www.marfan.org or call (800) 8-MARFAN.

• *Dr. Braverman is the director of the Marfan Syndrome Clinic at Washington University School of Medicine and chair of the National Marfan Foundation's Professional Advisory Board.*