



# HEALTH AWARENESS

## Marfan Syndrome Research Provides Hope and Optimism

(NAPSA)—An estimated 40,000 plus Americans have a life-threatening condition called Marfan syndrome—about half of those affected don't even know they have it. Fortunately, scientists are working hard to understand and treat it.

A connective tissue disorder, it affects the heart and blood vessels, bones, eyes and other body systems. People with Marfan syndrome are often tall and thin, with disproportionately long arms and legs, extreme joint flexibility, an indented or protruding chest bone and a curved back.

The life-threatening part is the effect on the aorta, the large blood vessel that carries blood away from the heart. In affected people, the aorta is fragile and prone to expand. It can even tear or rupture, leading to a sudden early death. People with Marfan syndrome can have a long life span, however, if they are diagnosed and treated—and the earlier the better.

### Research Provides Hope

There is now great optimism as researchers learn more about Marfan syndrome. One promising study is specifically looking at how two drugs affect aorta enlargement in Marfan syndrome. Researchers at centers throughout the U.S. and in Canada are currently enrolling patients from 6 months to 25 years of age.

Justin Phillips has Marfan syndrome, as do two of his three sons, Gregory and Douglas. The boys participated in a clinical trial when they were just 8 and 10 years old.

"Participating in the trial did not require any extra effort on our part," said the boys' mother, Jennifer. "They were already seeing the cardiologist regularly, taking



**Justin Phillips and his sons, Gregory and Douglas, are helping researchers find a cure for Marfan syndrome.**

medication and getting echocardiograms. There was only one extra appointment. It was an easy decision for us to get involved."

Jennifer and Justin were fully confident in the trial. As Jennifer noted, "The two study drugs are already on the market and we knew their record of safety. It's really a matter of finding out how they affect the Marfan aorta, and we wanted to do our part."

Douglas and Gregory were happy to be involved in the study. In fact, they are the ones who urged their father to enroll in an adult study.

### Getting Involved

If you or someone you care about has Marfan syndrome, you can participate in this critical research study, too. Log on to the National Marfan Foundation website, [www.marfan.org](http://www.marfan.org), and click on "Clinical Trial." Other research opportunities are also available on this site. For answers to questions about children participating in research, visit [www.nhlbi.nih.gov/childrenandclinicalstudies](http://www.nhlbi.nih.gov/childrenandclinicalstudies).