



CEDARS-SINAI MEDICAL CENTER.

NEWS

8700 Beverly Blvd., Room 2429A ■ Los Angeles, CA 90048-1865
Office (310) 423-4767 ■ Fax (310) 423-0435

Media Contact: Kelli Hanley
E-mail: kelli.hanley@cshs.org
Telephone: 1-310-423-3674

FOR IMMEDIATE RELEASE – June 17, 2004

HIGHLIGHTS: Thousands of people do not know they have Marfan syndrome, a potentially fatal genetic disorder of the connective tissue that affects the heart, lungs, bones and eyes. Without diagnosis and treatment, they are at risk of sudden death. To help identify and care for these patients, and give them the hope of a normal life-span, Cedars-Sinai has established a Marfan Center and will co-host the National Marfan Foundation's 20th Annual Conference from July 7-10, 2004, at the Beverly Hilton Hotel, in Beverly Hills.

CEDARS-SINAI MEDICAL CENTER TO HOST 20TH ANNUAL NATIONAL MARFAN FOUNDATION CONFERENCE, JULY 7-10, 2004

LOS ANGELES, CA (June 17, 2004) – For the first 20 years of her life, Angela Gates struggled to deal with a medical condition that no one could identify. Not only was she taller and thinner than the kids at school, but she had unusually loose joints, exceptionally long fingers and toes, and poor eyesight. But when she had to have surgery to correct an indented chest bone at the age of 13, Angela knew something definitely had to be wrong.

It would take another seven years for Angela to find out that she had Marfan syndrome, a potentially fatal genetic disorder of the body's connective tissue, affecting the bones, ligaments, eyes, lungs, heart and blood vessels. The disorder, she was told, would require careful monitoring throughout her life especially because it also affected the aorta, the large artery that carries blood away from the heart, which could cause it to enlarge and tear, resulting in sudden death.

To help identify and care for patients like Angela with Marfan Syndrome, Cedars-Sinai Medical Center recently established a Marfan Center and will co-host the National Marfan Foundation's 20th Annual Conference from July 7-10, 2004, at the Beverly Hilton Hotel, in Beverly Hills. Patients and their families will get the most up to date information about the disorder, meet leading Marfan syndrome researchers and physicians, and learn about new medical and genetic research.

“Although there is no cure for Marfan syndrome, an early diagnosis, proper treatment and careful management of the disorder can give patients with the condition a relatively normal life-span,” said David Rimoin, M.D., Ph.D., Director of the Medical Genetics Institute at Cedars-Sinai. “Unfortunately, we know that thousands of people do not even know they are affected.”

Dr. Rimoin, a medical geneticist at Cedars-Sinai and an expert on Marfan syndrome, diagnosed Angela some 17 years ago. He told her that she would need to be under the care of a cardiologist and sent her to Robert Siegel, M.D., Director of the Cardiac Non-Invasive Lab at Cedars-Sinai, who put her on medication to lower her blood pressure and reduce the stress on the aorta. Having been under his care for the years since her diagnosis, Angela also sees specialists for checks on her lungs, bones and eyes.

“I've chosen not to let this disorder beat me,” said Angela. “I take care of myself and choose to live as normal a life as possible.”

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The National Marfan Foundation conference opens at Cedars-Sinai Medical Center on July 7-8, giving people who suspect they have the Marfan syndrome an opportunity to be examined by physicians who specialize in diagnosing and treating the disorder. (These exams are by appointment only.) The general conference sessions take place July 9-10, with medical presentations at the Beverly Hilton Hotel. These sessions will feature leading Marfan syndrome researchers and physicians who will address various aspects of the Marfan syndrome, including current genetic research, surgical advances, drug treatments and answer questions from conference attendees.

Marfan syndrome and related connective tissue disorders affect an estimated 200,000 people in the U.S. alone. Although it is mostly hereditary, 25 percent of people are the first in their family to have the disorder. Angela, for example, has no known relatives who had Marfan syndrome. But because she has the genetic mutation for the disorder, she and her husband decided to adopt their first child, six-and-a-half years ago.

Although an increasing number of people with Marfan syndrome can be identified with new molecular tests, most people still require a multi-faceted clinical exam to make the diagnosis, including appointments with:

- ◆ a medical geneticist who examines the family history and coordinates the patient's care
- ◆ a cardiologist, who evaluates the heart and blood vessels using an echocardiogram and ultrasound
- ◆ an ophthalmologist, who does a "slit-lamp" eye exam to look for lens dislocation
- ◆ an orthopedist, who examines various aspects of the skeleton and bones

"This is a disorder that can be diagnosed and managed effectively with the right treatment," said Dr. Rimoin. "At the Marfan Center at Cedars-Sinai, we apply a multi-disciplinary approach to diagnose and treat this condition."

Because Marfan syndrome is a disorder of the connective tissue – the glue that essentially holds the body together – it affects various parts of the body, causing differing degrees of impairment in the bones, eyes, skin, lungs and heart of a given individual. For example, it's not uncommon for people with Marfan syndrome to have extreme near sightedness, develop early glaucoma and/or a dislocated lens, which can result in a detached retina.

Bones are another part of the body that can be greatly affected by the Marfan syndrome, frequently – but not always – causing patients to be very tall, thin, and extremely loose-jointed and flexible. The sternum or breastbone can also either protrude or "cave in." Often this can restrict lung function, causing respiratory problems and making patients susceptible to pneumonia and other complications. Patients can also experience scoliosis or curvature of the spine.

But the most dangerous complication from the Marfan syndrome results when faulty connective tissue causes the wall of the aorta to become weak and stretch. When the aorta expands, the chance that it will tear or even rupture increases, causing sudden death.

"An early diagnosis and the necessary medical treatment interventions such as medications to lower blood pressure can save a person's life," said Dr. Siegel. "If people have signs of the Marfan syndrome, they should speak with their doctor."

Cedars-Sinai Medical Center is one of the largest non-profit academic medical centers in the Western United States. For the fifth straight two-year period, Cedars-Sinai has been named Southern California's gold standard in health care in an independent survey. Cedars-Sinai is internationally renowned for its diagnostic and treatment capabilities and its broad spectrum of programs and services, as well as breakthroughs in biomedical research and superlative medical education. The Medical Center ranks among the top 10 non-university hospitals in the nation for its research activities.

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