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**Shriners Hospitals for Children and Oregon Health & Science University to Host
27th Annual National Marfan Foundation Conference, July 14-17, 2011**

***Shriners Hospitals for Children to Receive Scientific Leadership Award at
July 16 Awards Luncheon***

PORT WASHINGTON, NY, June 22, 2011 — Shriners Hospitals for Children and Oregon Health & Science University are co-hosting the 27th Annual National Marfan Foundation (NMF) Conference on July 14-17, 2011. The NMF Annual Conference enables people with Marfan syndrome and related connective tissue disorders, and their families, to meet leading Marfan syndrome researchers and physicians and learn about new medical and genetic research firsthand. At the Conference, the NMF will celebrate 30 years since its inception.

On July 16, at the NMF awards luncheon to be held at the Portland Marriott Downtown Waterfront, Shriners Hospitals for Children will receive the Foundation's prestigious Scientific Leadership Award. Shriners is being recognized for its patient care and research accomplishments and for its ongoing commitment to the basic science that will lead to a better life for people with Marfan syndrome and related disorders in the future.

Lynn Sakai, PhD, Senior Investigator, Portland Shriners Research Center, and Professor of Biochemistry & Molecular Biology, Oregon Health & Science University, is spearheading the conference initiative. A member of the NMF's Professional Advisory Board since 1997, Dr. Sakai is a leading Marfan syndrome researcher whose work laid the foundation for the identification of fibrillin, the culprit in Marfan syndrome, and led to advanced work that pointed to the candidate gene for Marfan syndrome.

More than 400 individuals, primarily affected people and their families, are expected to attend the conference to learn about Marfan syndrome and related disorders and network with other people with these conditions.

“The NMF is looking forward to a very successful conference this year in Portland, where so much of the seminal research for the understanding of Marfan syndrome has been conducted,” said NMF President and CEO Carolyn Levering. “We are happy to bring our conference back to the Pacific Northwest so our members in this part of the country can participate more easily. I’m sure they will find it is a life-changing experience.”

NMF Conference has Family Focus

The NMF Annual Conference begins with evaluation days on July 14-15 when people who have a diagnosis or suspect that they have Marfan syndrome or a related connective tissue disorder can be evaluated by medical experts from all over the country (by appointment only). The “health fair” offers people who do not have access to medical experts at home an opportunity to be evaluated by knowledgeable doctors from the host institutions and other leading Marfan syndrome clinics around the country. Echocardiography and eye exams will be conducted by OHSU physicians and staff on July 14, and orthopedic and genetic evaluations will be conducted at Shriners Hospitals for Children on July 15.

General conference sessions are on July 16, with medical presentations and a panel discussion led by researchers and physicians who have special expertise in Marfan syndrome and related disorders. They will address a range of topics, including cardiac, orthopedic, pulmonary and ophthalmic issues, cardiac surgery in adults and children, and pain management.

After the general plenary session, conference attendees can attend small-group workshops about specific medical concerns led by physicians and other medical professionals. On July 17, workshops about psycho-social concerns will be offered.

To make it easier for affected individuals and families, the NMF offers conference scholarships, which are funded by the NMF membership through three funds: the Heaney Angels Fund, Weiss Scholarship Fund and Julie Kurnitz Memorial Fund. Awards are based on financial need and priority is given to those who do not have access to specialty Marfan care at home and have never attended an NMF Conference before.

The National Marfan Foundation is grateful for the generous support of the conference from Andersen Construction, Bank of the West, Beattie Charitable Trust, Chetco Shrine Club, Klamath Falls Shrine Club, OHSU Foundation, Rose City Camp No. 77, Sherman Jr./Sr. High School and Union County Shrine Club.

Marfan Syndrome and the National Marfan Foundation

Marfan syndrome is a potentially fatal genetic disorder of connective tissue. Marfan syndrome and related connective tissue disorders affect approximately 200,000 Americans. Because connective tissue makes up the entire body, the disorder manifests itself in many body systems, including the skeletal system, eyes, lungs, blood vessels and heart. Many people with Marfan syndrome and several of the related disorders experience an expansion of the aorta. Without proper monitoring and medications to reduce the stress on the aorta, affected people are at high risk for aortic dissection or rupture, which could result in sudden death.

Studies about the increased life expectancy for people with Marfan syndrome provide great hope and optimism, but only through increased awareness, earlier diagnosis and proper treatment can people with the disorder expect to live a normal life span.

The NMF was founded in 1981 to provide accurate and timely information about the disorder to patients, family members and physicians; to serve as a resource for medical information and patient support; and to support and foster research.

To obtain additional information about the conference and to register, please call the NMF at 800-8-MARFAN or visit the NMF on line at www.marfan.org.

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*Note to Editors: One-on-one interviews with Marfan syndrome and affected individuals and families can be arranged prior to the conference or on-site.
Please contact Eileen Masciale (631.665.2163 or publicity@marfan.org) to schedule.*