



FOR IMMEDIATE RELEASE
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**Baylor College of Medicine and University of Texas Health Science Center at Houston
to Host 26th Annual National Marfan Foundation Conference,
July 8-11, 2010**

Dr. Denton Cooley, Pioneering Cardiac Surgeon, to be Honored at July 10 Awards Luncheon

PORT WASHINGTON, NY, JUNE 14 — Baylor College of Medicine and The University of Texas Health Science Center at Houston (UTHealth) are co-hosting the 26th Annual National Marfan Foundation (NMF) Conference on July 8-11, 2010. 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.

Dr. Denton Cooley, the pioneering cardiac surgeon who established the Texas Heart Institute, will receive the Foundation's prestigious Antoine Marfan Award at the NMF awards luncheon at the InterContinental Hotel on July 10. Dr. Cooley is being recognized for his innovative and outstanding contributions to cardiovascular surgery and the surgical care of people with Marfan syndrome.

Dianna Milewicz, MD, PhD, President George H.W. Bush Chair of Cardiovascular Medicine and Professor and Director of the Division of Medical Genetics, The University of Texas Medical School at Houston, and Joseph Coselli, MD, Chief of the Division of Cardiothoracic Surgery and Professor of Surgery in the Michael E. DeBakey Department of Surgery at Baylor College of Medicine, are spearheading the conference initiative. Both doctors have a long-time commitment to the National Marfan Foundation and are among a select group of clinicians and researchers who serve on its Professional Advisory Board (PAB); Dr. Milewicz has served as PAB Chair since 2004.

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 Houston, where the host institutions provide both world-class clinical and research experience with Marfan syndrome and related disorders,” said NMF President and CEO Carolyn Levering. “We are also thrilled to have the opportunity to honor Dr. Cooley, whose surgical advances are life-saving for people with Marfan syndrome and related disorders.”

NMF Conference has Family Focus

The NMF Annual Conference begins with Marfan syndrome evaluation days on July 8-9, 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). Held at Baylor College of Medicine, the clinic offers people who do not have access to medical experts on Marfan syndrome at home an opportunity to be evaluated by Marfan-knowledgeable doctors from the host institutions and other leading Marfan syndrome clinics around the country.

General conference sessions are on July 10, 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 and ophthalmic issues, options in aortic surgery, and special concerns for children. There will also be a presentation about the disorders that are related to Marfan syndrome and a special research update.

On that day, the conference will also offer small-group workshops where attendees can discuss specific medical concerns with physicians and other medical professionals. On July 11, workshops about psycho-social concerns will be held.

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 from the Baylor College of Medicine, Dr. Scholl Foundation, The Fondren Foundation, Loeys-Dietz Foundation, St. Jude Medical, Terumo Cardiovascular Systems Corp., The University of Texas Health Science Center at Houston and W. L. Gore & Associates.

Critical Marfan Research in Houston

“The medical institutions in Houston have made significant contributions to the advancement of patient care worldwide, and they continue to do so for the Marfan syndrome and related disorders community,” said Levering.

Texas Children’s Hospital is one of 27 sites participating in a critical clinical trial related to the treatment of aortic enlargement in people with Marfan syndrome. The trial – which is funded by the National Heart, Lung, and Blood Institute and several other partners and conducted by the Pediatric Heart Network and other centers with leading Marfan clinics – is studying the effects of a commonly prescribed blood pressure medication, losartan, versus atenolol, the beta-blocker treatment that is the current gold standard of treatment for Marfan syndrome. Losartan has been shown to reduce aortic enlargement in mice with Marfan syndrome; the current study is on children from six months old to adults aged 25. Dr. John Jefferies, Assistant Professor, Pediatric Cardiology, Texas Children’s Hospital and Baylor College of Medicine, is the lead investigator at Texas Children’s Hospital for this study.

Dr. Coselli and his colleagues at Baylor College of Medicine are playing a leading role in the NMF-funded study, *Aortic Valve Operative Outcomes in Marfan Patients*. This research, which compiles data from 20 surgical centers in the U.S. and abroad, is comparing the results of two types of aortic surgery common in Marfan syndrome. In one procedure the aortic valve is replaced; in the other, the aortic valve is spared. The investigators are hoping to answer questions about the long-term effectiveness of each procedure and which types of patients are better suited for each surgery.

In addition, UTHealth and Baylor College of Medicine, along with four other centers throughout the country, are participating in GenTAC, the National Registry of Genetically Triggered Thoracic Aortic Aneurysms. This registry is collecting clinical data and samples on patients with aneurysms and dissections that are caused by genetic alterations. Among the patients being enrolled in the registry are those with Marfan syndrome, Loeys-Dietz syndrome and other genetic conditions that cause aortic aneurysms. The samples and data will be made available to qualified investigators to enable research to determine best medical practices and to advance the clinical management of genetic thoracic aortic aneurysms, and other cardiovascular complications.

The registry is being headed by Dr. Milewicz at UTHealth, and Dr. Scott Lemaire, Professor of Surgery, and Dr. Jeffries, at the Baylor College of Medicine.

Dr. Milewicz is also conducting extensive research in her lab at UTHealth's Medical School on the genetic basis of vascular disease. Her studies involve recruiting and characterizing families with multiple members with vascular disease, specifically aortic aneurysms and dissections and cerebral aneurysms; mapping genes causing familial vascular disease and identifying the defective gene at mapped loci; and using cell biology to understand how defective genes alter smooth muscle cell function, in particular focusing on pathway analysis. UTHealth's teaching hospitals include Children's Memorial Hermann and Memorial Hermann-Texas Medical Center.

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 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.*