



National Marfan Foundation • 1981–2011

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**National Marfan Foundation Benefit to be Held on
April 7 at Cipriani 42nd Street**

PORT WASHINGTON, NY, April 5, 2011 – The National Marfan Foundation will hold its 11th annual benefit, *Heartworks: The Marfan Gala*, on Thursday, April 7, 6 pm, at Cipriani 42nd Street. At the gala, the NMF will honor Jeffrey LeSage, U.S. National Managing Partner, KPMG, and St. Jude Medical with 2011 Hero with a Heart Awards.

Mayor Michael Bloomberg, who is honorary chair of *Heartworks* for the 10th consecutive year, will provide the opening remarks. The corporate host of *Heartworks* is Karen Murray, President, VF Sportswear.

The evening will feature entertainment by Broadway performer Megan Hilty (*Wicked*, 9 to 5). Hilty recently garnered the lead role in Steven Spielberg's new NBC pilot *Smash*, which will be produced by Dreamworks and UMS.

WNBC-TV's Jane Hanson will serve as master of ceremonies. Her WNBC-TV colleague, Janice Huff, will co-host.

Dinner chairs are Benjamin Carpenter; Hal C. Dietz, III, MD, Johns Hopkins Hospital; Randy & Susan Falco; Leonard Girardi, MD, New York Presbyterian Hospital; Alix McLean Jennings & Ezra Jennings; Tony Award-winning actor and choreographer Ann Reinking; Mary J. Roman, MD, New York Presbyterian Hospital and Michael L. Weamer, CAE, American Heart Association.

Heartworks has raised more than \$7 million for the NMF to date. The proceeds from the event are earmarked for Marfan syndrome research, support for individuals and families affected by the disorder, and public awareness and education.

“The NMF has a life-saving mission and, because of the generosity of our friends and supporters in New York City we can continue our programs that enhance the quality of life and extend the lifespan of people with Marfan syndrome and related disorders,” said Murray, who serves on the Board of Directors of the NMF. “We are grateful to Mayor Bloomberg, along with our many sponsors, for making *Heartworks* a successful fundraiser year after year.”

Hero with a Heart Award Recipients

Jeff LeSage, is a leader in the business world and a leader in the fight against heart disease. He has been involved in the American Heart Association for several years years and now serves as chairman of the board of the AHA’s New York City Chapter. His dedication to fighting heart disease extends to the National Marfan Foundation and its efforts to enhance the lives of those in the Marfan syndrome and related disorders community.

A supporter of the NMF’s *Heartworks* gala, Jeff embodies the generosity of spirit of his company, KPMG, which has become an important partner to the NMF in its life saving programs and services.

St. Jude Medical, which has an extensive product portfolio that includes mechanical heart valves that are a mainstay of treatment for people with Marfan syndrome, is playing a critical role in advancing the surgical field as it relates to Marfan syndrome.

In 2004, the NMF initiated a research study entitled *Aortic Valve Operative Outcomes in Marfan Patients* to examine the outcomes associated with two types of aortic valve operations for people with Marfan syndrome. The goal of this multi-center study it to obtain vital data that will enable physicians and patients faced with a difficult choice to determine the appropriate course of surgical treatment.

St. Jude Medical has been at the forefront of support for this research, taking the lead in providing funding to enable researchers to gather and analyze data over the course of several years. The investment that St. Jude Medical is making in this research will reap benefits for people with Marfan syndrome and related disorders today and in generations to come.

“We are thrilled to pay tribute to KPMG’s Jeff LeSage and St. Jude Medical at this year’s *Heartworks* gala,” said Carolyn Levering, NMF President and CEO. “Our corporate partners are so valuable to us as we continue to fight against Marfan syndrome and work to make life better for all those who are affected.”

Marfan Syndrome and the National Marfan Foundation

Marfan syndrome is a connective tissue disorder that affects the heart, blood vessels, eyes, bones, joints and lungs. It is often, but not always, characterized by a tall stature and disproportionately long legs and arms. Other skeletal manifestations are curvature of the spine, a protruding or indented chest and loose joints. The most serious problem associated with the Marfan syndrome is its effect on the aorta, the main artery carrying blood away from the heart. In affected people, the aorta is prone to progressive enlargement, which can lead to tears in the aortic wall that require surgery. If aortic enlargement and tears are left undetected, the aorta may rupture, leading to sudden death.

The life expectancy for people with Marfan syndrome who are diagnosed and treated is now in the 70s due to advances in cardiovascular surgery, increased options in medical therapy and better diagnosis.

Currently, there is a critical clinical trial under way on a medication, losartan, which has been shown to prevent and even reverse aortic enlargement in mice with Marfan syndrome. The study, which is being funded by the National Heart, Lung, and Blood Institute, is examining losartan vs. atenolol, a beta blocker, in people with Marfan syndrome age six months to 25 years. It is being conducted at study sites throughout the U.S., in Canada and overseas.

Approximately 200,000 people in the U.S. have Marfan syndrome or a related connective tissue disorder. In most cases, the condition is inherited; one-quarter of people with Marfan syndrome are the first in their family to be affected.

The National Marfan Foundation is a non-profit voluntary health organization dedicated to saving lives and improving the quality of life of individuals and families affected by the Marfan syndrome and related disorders by:

- Educating affected individuals, family members and the health care community about Marfan syndrome.
- Advocating for and funding clinical and molecular research into the early detection and treatment of Marfan syndrome.
- Providing a network of local and special-interest support groups to help affected people and their families share experiences.

Tickets to *Heartworks*, which start at \$500, are available by calling 516-883-8712, ext. 24. For more information on the Marfan syndrome, call 800-8-MARFAN, ext. 24, or visit www.marfan.org.

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