



**FOR IMMEDIATE RELEASE**

Contact: Eileen Masciale  
631-665-2163  
publicity@marfan.org

**National Marfan Foundation Benefit to be Held on April 22 at Cipriani 42<sup>nd</sup> Street**

PORT WASHINGTON, NY, April 15, 2010 – The National Marfan Foundation will hold its 10<sup>th</sup> annual benefit, *Heartworks: The Marfan Gala*, on Thursday, April 22, 6 pm, at Cipriani 42<sup>nd</sup> Street. At the gala, the NMF will honor Dr. Herbert Pardes, President and CEO of NewYork-Presbyterian Hospital and Healthcare System, and Dr. Duke Cameron, Professor of Cardiac Surgery and Pediatrics at Johns Hopkins Hospital in Baltimore, with a Hero with a Heart Award. In addition, a special Founder’s Award will be presented to Karen Murray, President of VF Sportswear, who is the corporate host for the evening.

Mayor Michael Bloomberg, who is honorary chair of Heartworks for the 9th consecutive year, will be on-hand to present the Founder’s Award. Ann Reinking, the Tony Award-winning choreographer and Broadway star, serves as Artistic Chair.

The evening will feature entertainment by Broadway legend Tommy Tune. NBC’s Hoda Kotb will serve as master of ceremonies, with WNBC’s Janice Huff leading the live auction.

*Heartworks* has raised nearly \$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.

“As we celebrate our 10<sup>th</sup> Heartworks, we are proud to honor Karen Murray with a Founder’s Award for her vision, passion and commitment to the NMF. A dedicated volunteer, she has been able to build excitement for this event among her family, friends and colleagues in the fashion industry. Their support has given it glamour and has made it a fundraising success,” said Carolyn Levering, president and CEO of the NMF.

At the event, the NMF will also honor the past recipients of the Hero with a Heart Award as part of a Circle of Honor.

The NMF is grateful to the gala committee for their devotion to making *Heartworks* a success.

## **Hero with a Heart Award Recipients**

Dr. Herbert Pardes, who has had a distinguished career in psychiatry, heads one of the leading centers in the U.S. for the diagnosis and treatment of patients with Marfan syndrome and related disorders. NewYork-Presbyterian Hospital has a long history of offering the comprehensive multi-disciplinary care that people in the Marfan population turn to for expertise in cardiology, cardiac surgery, orthopedics, ophthalmology and genetics. In addition to the exceptional clinical care offered at NewYork-Presbyterian, the medical experts there have also been on the forefront of critical research on Marfan syndrome that has led to a better quality of life and a longer lifespan for those who are affected.

Dr. Duke Cameron, Director of Pediatric Cardiac Surgery at Johns Hopkins, is a member of the NMF's Professional Advisory Board who is sought after by many parents when their children with Marfan syndrome require surgery to repair their fragile aorta. In addition, he has conducted extensive research on aortic surgery in Marfan syndrome. Currently, Dr. Cameron is involved in a major NMF-funded multi-center study comparing valve-sparing surgery and valve-replacement surgery.

“Dr. Pardes and Dr. Cameron are so deserving of this honor,” said Levering. “Individuals and families with Marfan syndrome and related disorders certainly benefit from their medical expertise and their commitment to providing the highest quality of patient care.”

## **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 or visit [www.marfan.org](http://www.marfan.org).

\* \* \*

### **2010 Circle of Honor**

Ben Carpenter, Greenwich Capital  
Paul Charron, former chairman of Liz Claiborne  
Dr. Richard Devereux, New York-Presbyterian/Weill Cornell  
Dr. Hal Dietz, Johns Hopkins Hospital  
Susan Falco and Randy Falco  
Heather Holmes Floyd  
Dr. Valentin Fuster, Mt. Sinai Hospital  
Dr. Leonard Girardi, New York-Presbyterian/Weill Cornell  
Dr. Antonio M. Gotto, Jr., Weill Cornell Medical College  
Dr. O. Wayne Isom, New York-Presbyterian/Weill Cornell  
Allan Larson  
The late Dr. Victor A. McKusick, Johns Hopkins Hospital  
Merck & Co.  
Karen Murray, VF Sportswear  
Tony Award winner Ann Reinking  
Dr. Mary Roman, New York-Presbyterian/Weill Cornell  
Dr. Paul Sponseller, Johns Hopkins Hospital  
Michael L. Weamer, American Heart Association

4/10

# # #