



Heart of Iowa Chapter-NMF
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For Immediate Release



National Marfan Foundation

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Drink for a Cure, May 16, in West Des Moines

New, Fun Event to Benefit Heart of Iowa Chapter of the National Marfan Foundation

Des Moines, Iowa – The Heart of Iowa Chapter of the National Marfan Foundation (NMF) is holding its first **Drink for a Cure** on Saturday, May 16, at the Rock Bottom Restaurant and Brewery, 4508 University Avenue, West Des Moines. This fun event will feature beer and wine sampling, food, live entertainment, games, prize drawings, a silent auction, and a one-of-a-kind beer brewed just for the event.

Tickets, which are \$40 in advance and \$50 at the door, may be purchased by e-mailing tkdean11@mchsi.com or by calling 263-1948 or 252-1892.

“We invite you to come join us as we raise our glasses to toast the lives of those we have lost to Marfan syndrome, as well as those we hope to save as we drink for a cure,” said Teri Dean, president of the Heart of Iowa Chapter-NMF and mother of a young man affected by Marfan syndrome. The group hopes to raise \$10,000.

All proceeds will go to the Heart of Iowa Chapter-NMF, specifically to support the 25th Annual National Marfan Conference. The local chapter is co-hosting the conference with the Twin Cities Chapter at the Mayo Clinic in Rochester, MN, August 6-9. For many attendees, this conference represents their first opportunity to access comprehensive information and medical treatment, as well as the ability to network with others affected by Marfan syndrome.

Marfan Syndrome

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 Marfan syndrome is its effect on the aorta, the main artery carrying blood away from the heart.

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 70's due to advances in cardiovascular surgery, increased options in medical therapy and better diagnosis. Without a proper diagnosis and medical management, they are at risk of aortic dissection and sudden death.

Approximately 200,000 people in the U.S. are affected by Marfan syndrome or a related disorder.

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.

The Heart of Iowa Chapter carries out the mission of the NMF throughout Iowa. The group educates doctors, emergency department personnel, coaches, school nurses, athletic directors, parents and the general public about Marfan syndrome so that *everyone* with this disorder receives the best care possible. For information about Marfan syndrome, visit www.heartofiowa.org or contact the National Marfan Foundation at (800) 8-MARFAN (www.marfan.org).

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