

THE MYOCARDITIS FOUNDATION Board of Directors

The Foundation board is comprised of medical professionals with experience in myocarditis and lay persons who have been touched by the disease.



Candace Moose, President - Giant Cell Myocarditis survivor and heart transplant recipient. She is a retired nurse, wife, mother and grandmother, a speaker and advocate for organ donation and is also the author of the book, *The Grateful Heart: Diary of a Heart Transplant*.



Leslie T. Cooper, MD, Medical Director and Vice-President - Chair of the Cardiovascular Department, Mayo Clinic, Jacksonville, Florida

DeLisa Fairweather, PhD, FAHA, Secretary -Assistant Professor, Director of Translational Research, Department of Cardiovascular Medicine, Mayo Clinic Jacksonville, Florida

Joseph Rumore, Treasurer - Myocarditis survivor and heart transplant recipient. He is a former managing Director of a national insurance company

Dr. Jack Price, MD, Director - Associate Professor of Pediatrics at Baylor College of Medicine and the Clinical Director of the Cardiovascular Intensive Care Unit at Texas Children's Hospital

Louis Romano, Director - Owner of Home Well Senior Care, a home health care agency

Joel Aranson, Director - Founder and Chairman of National Sporting Good Corporation and father to a Myocarditis victim

Randy Vanness, Director - Community leader and father to a Myocarditis victim

Jaime Rojas, Director - Athletic Trainer for a pro soccer team and father to a Myocarditis victim

Founding Board of Directors

Leslie T. Cooper, MD - Chair of the Cardiovascular Department, Mayo Clinic, Jacksonville, Florida

Candace Moose - Giant Cell Myocarditis survivor and heart transplant recipient.

Mario C. Deng, MD - Director of the Advanced Heart Failure Program, including Medical Directorship of Mechanical Circulatory Support and Heart Transplant at the University of California in Los Angeles. He is an advanced heart failure and transplantation cardiologist.

James A. Moose, MBA - Healthcare executive with experience in pharmaceuticals, diagnostics, and medical devices. Mr. Moose is currently retired and provides consulting services in addition to his work for the Myocarditis Foundation.

Jeff S. Grant - Retired founding board member, is a computer programmer, and a Giant Cell Myocarditis patient, currently undergoing treatment.

Medical Advisory Board

Akira Matsumori, MD - Professor of Medicine, Department of Cardiovascular Medicine, Kyoto University Graduate School of Medicine, Kyoto, Japan.

Bruce M. McManus, PhD, MD, FRSC, FCAHS -Professor & Director, The James Hogg iCAPTURE Centre, University of British Columbia-St. Paul's Hospital Scientific Director, The Heart Centre-Providence Health Care, Vancouver, British Columbia, Canada.

Dennis M. McNamara, MD - Associate Professor of Medicine; Director, Heart Failure Section; Director, Cardiomyopathy Clinic and Heart Failure Research Program, Cardiovascular Institute at University of Pittsburgh Medical Center Presbyterian, Pittsburgh, PA.

Steven D. Colan, MD - Professor of Pediatrics at Harvard Medical School and Associate Chief of Cardiology at Boston Children's Hospital.

New Jersey

Information filed with the attorney general concerning this charitable solicitation and the percentage of contributions received by the charity during the last reporting period that were dedicated to the charitable purpose may be obtained from the attorney general of the state of New Jersey by calling 973-504-6215 and is available on the internet at http://www.State.NJ.US/lps/ca/charfrm.Htm.

Registration with the attorney general does not imply endorsement.

North Carolina

Financial information about this organization and a copy of its license are available from the State of North Carolina Solicitation Licensing Branch at 800-830-4989.

Myocarditis Foundation You Can Help, Please Donate:

By Mail: The Myocarditis Foundation 3518 Echo Mountain Drive Kingwood, Texas 77345

Online: www.myocarditisfoundation.org

Click DONATE Link

The Myocarditis Foundation (MF) seeks to increase awareness and hasten progress in understanding myocarditis by awarding grants to help guarantee that new and innovative research avenues are thoroughly funded and explored. Please donate now.

The MF is a private, non-profit organization that exists to educate physicians and the public about this rare disease and support the patients and their families who have been affected by the disease. Copies of our materials will be available without charge. All of the money donated to MF will go directly to programs and services.

For more information: candace@myocarditisfoundation.org

Internet Resources

Children's Cardiomyopathy Foundation: www.childrenscardiomyopathy.org

Peripartum Cardiomyopathy Support network: www.amothersheart.org

Parent Heart Watch: www.parentheartwatch.org

Compassionate Friends: www.compassionatefriends.org

MayoClinic:

www.mayoclinic.org/myocarditis/research.html www.mayoclinic.com/health/myocarditis/dS00521

American Heart Association: www.americanheart.org

MyocarditisFoundation.org Website Resources

For Patients and Families who have lost loved ones to myocarditis: The Message Board

For Medical Professionals: Myocarditis resources and research grant information

ADULT MYOCARDITIS: RECOGNITION AND DIAGNOSIS



Knowledge Nurtures Hope. . .

Your journey is just beginning

The Myocarditis Foundation

is here to help.

www.myocarditisfoundation.org







DEFINITION: What is Myocarditis?

Myocarditis is a rare, sometimes fatal disease characterized by inflammation of the heart muscle. Although it is an important cause of dilated cardiomyopathy (enlarged weakened heart muscle that can't pump well) worldwide, often progressing to heart failure and transplantation, myocarditis remains poorly understood and is often undiagnosed. Most cases of myocarditis result from a prior viral infection, although many other causes have been identified. The true incidence of myocarditis is unknown due to diagnostic difficulties.



ETIOLOGY: What Causes Myocarditis

Most cases of myocarditis result from viral infections, although many other infectious and non-infectious agents have been considered rare causes of the disease. About 20 viruses have been associated with myocarditis and dilated cardiomyopathy. A rare and particularly deadly form of myocarditis called, Giant Cell Myocarditis, is associated with pre-existing autoimmune disease and hypersensitivity reactions to drugs in a small group of patients.

SIGNS AND SYMPTOMS: When to Suspect Myocarditis

Signs and symptoms of myocarditis at initial presentation can be highly variable ranging from non-specific complaints to acute diffuse heart failure. Patients may recall a recent history of gastrointestinal illness or seek medical attention for mild, non-specific viral flu-like symptoms. Most commonly, the initial presentation is of sudden onset heart failure with severe chest pain, difficulty breathing, fatigue, palpitations, lethargy, decreased exercise tolerance and or syncope (dizziness.)

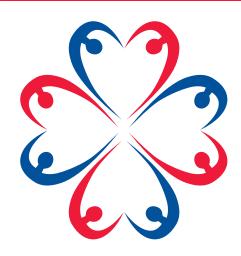


DIAGNOSIS: How is Myocarditis Detected?

Accurate diagnosis of myocarditis is challenging due to the variability of presentation and the lack of highly specific diagnostic tools available. Electrocardiograms, ChestX-rays, Echocardiograms, and more recently Cardiac Magnetic Imaging (MRI) have been used for assessing suspected myocarditis cases. Endomyocardial Biopsy (a biopsy of the heart muscle) remains the gold standard for a definite diagnosis of acute myocarditis in patients in whom the benefits outweigh the risks of such a procedure.

THERAPY: What are the Treatment Options for Myocarditis?

The primary treatment is supportive care based on guidelines and recommendations published by major cardiovascular organizations in North America and Europe. Administration of intravenous cardiac medications or the insertion of a temporary pacemaker may be necessary. In severe cases, extracorporeal membrane oxygenation (ECMO) or a ventricular assist device (VAD) may be necessary in the acute phase to allow the heart to recover or to serve as a bridge to transplantation. Immunoglobulin or corticosteroids have been used in some acute cases to inhibit the immune response. Following the acute phase, surviving patients may recover completely or have long-term deficits. In severe cases, cardiac transplantation may offer the best chance for long-term survival. Patients with acute myocarditis should refrain from competitive sports until cleared to do so by their physician.



CONCLUSION:

Although myocarditis is a relatively rare disease that in many cases resolves without further problems, the importance of recognition, early diagnosis and prompt treatment in highrisk individuals cannot be overstressed. A substantial number of patients suffer significant cardiac damage leading to life long morbidity or death when an accurate early diagnosis eludes the doctor. The doctor should maintain a high degree of suspicion for the presence of an inflammatory process when examining patients whose presenting signs and symptoms warrant further cardiac evaluation.



For further information please visit the Myocarditis Foundation website at: www.myocarditisfoundation.org