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

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

Leslie T. Cooper, MD, Medical Director and Co-Founder, Chair of the Enterprise Dept. of Cardiovascular Medicine, Mayo Clinic, Jacksonville, Florida

Christopher Corso, Vice-President - Senior Reinsurance Officer, AXA XL and father to a Myocarditis Survivor

Francine Andrea, Secretary – Vice-President for Enrollment Management, Student Affairs and Chief Compliance Officer for Felician University

Louis Romano, Treasurer - Owner of Home Well Senior Care, a home health care agency in New Jersey

Candace Moose, Co-Founder, Director - Giant Cell Myocarditis survivor and heart transplant recipient. Candace is a retired nurse, a speaker and advocate for organ donation and is also the author of the book, The Grateful Heart: Diary of a Heart Transplant.

Dr. Jack Price, MD, Director - Associate Professor of Pediatrics, Baylor College of Medicine, Pediatric Cardiologist specializing in Heart Failure and Transplant Cardiology, Texas Children’s Hospital

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

Giustina Schiano - Director - Mother of a Myocarditis Victim and Family Ambassador for the Myocarditis Foundation

Michael Linn, Director - Regional Sales Manager for the Stryker Corporation, Long time supporter of the Myocarditis Foundation

Stephanie Kennan, Director - Senior Vice-President of McGuireWoods Consulting, Daughter of a Myocarditis Victim

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.

Bettina Heidecker, MD - Head of Heart Failure and Cardiomyopathies at the Charite’ in Berlin, Germany; Myocarditis Researcher and previous Myocarditis Foundation Fellowship Grant Recipient.

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

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: info@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

The Myocarditis Foundation
Website Resources
Please call the MF at 281-713-2962, or email Gen at gen@myocarditisfoundation.org. You can also go onto the Inspire.com website and go into the Myocarditis Community Page to speak with others who have been affected by 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.

DEFINITION: What is 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.

ETIOLOGY: What Causes Myocarditis

Accurate diagnosis of myocarditis is challenging due to the variability of presentation and the lack of highly specific diagnostic tools available. Electrocardiograms, Chest X-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.

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?

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.

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 high-risk 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