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.

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:
info@myocarditisfoundation.org

MyocarditisFoundation.org
Website Resources

- Discussion Forum
- Up-to-Date Medical information
- Resources for Medical Professionals
- Real-Life Stories
- Events & Speaking Schedules

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.

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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.

PEDIATRIC MYOCARDITIS

MYOCARDITIS FOUNDATION

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. The disease can affect the muscle cells of the heart (myocytes), the heart valves and blood vessels, and the specialized electrical conduction pathways within the heart.

Most patients recover completely from acute or sudden myocarditis. In newborns, myocarditis can be severe due to an immature immune system. Other organ systems may also be affected in this group of patients. Myocarditis is an important cause of sudden death in young athletes.

When the muscle cells of the heart weaken from myocarditis, the heart chambers may enlarge. This form of heart disease is called dilated cardiomyopathy. Children with dilated cardiomyopathy may develop symptoms of heart failure, sometimes necessitating a heart transplant. Heart failure resulting from myocarditis-induced dilated cardiomyopathy is a significant cause of disability and death in children.

DEFINITION: What is Pediatric Myocarditis?

Myocarditis is inflammation of the heart muscle. When myocarditis affects patients younger than 18 years of age, it is called pediatric myocarditis.

In newborns the disease can be especially severe because of an underdeveloped immune system. Myocarditis can present in young athletes as sudden death. The incidence of dilated cardiomyopathy in children ranges from 0.57 to 0.76 cases per 100,000 children. Myocarditis is associated with dilated cardiomyopathy in 27% to 46% of cases. Dilated cardiomyopathy is the primary indication for childhood heart transplantation. Therefore, heart failure resulting from myocarditis-induced dilated cardiomyopathy is a significant cause of disability and death in children as well as adults.

ETIOLOGY: What Causes Pediatric Myocarditis

Myocarditis may be caused by infections in the heart, autoimmune disorders, hypersensitivity reactions to drugs and toxin exposure. Viruses are the most common cause of myocarditis in children. Less common infectious agents include bacteria and protozoa. Coxsackie B was the first virus associated with myocarditis. Many other viruses have also been implicated in children including Adenovirus, Parvovirus B19, hepatitis B and C viruses and HIV. The heart can be damaged by the virus itself or by the body's immune defense against the virus. Drugs including some antibiotics, antipsychotics and anticonvulsants may rarely cause hypersensitivity reactions resulting in inflammation of the heart. Scorpion bites have been associated with myocarditis primarily in India. Autoimmune disorders associated with myocarditis include: systemic lupus erythematosis, celiac disease, and sarcoidosis. Finally, Giant Cell Myocarditis is a rare but serious cause of acute dilated cardiomyopathy and heart failure carrying a high risk of death unless heart tranplantation is performed.

SIGNS AND SYMPTOMS: When to Suspect Pediatric Myocarditis

Clinical manifestations of acute viral myocarditis are usually nonspecific and highly variable. They range from mild flu-like symptoms to sudden death. Many infants and children with myocarditis present with fulminant features such as rapid and labored breathing, wheezing, grunting, low blood pressure, cool extremities and decreased urine output. Older children may complain of fatigue, fever, vomiting and muscle aches a few days before developing more severe symptoms such as shortness of breath and exercise intolerance. More advanced symptoms include rapid heart rate, erratic and weakened pulse, pale color, sweating and dizziness.

DIAGNOSIS: How is Pediatric Myocarditis Detected?

A physical examination may reveal signs of respiratory distress or decreased cardiac function. Clinical findings may include: rapid respiratory or heart rate, retracting chest wall respiratory muscles, nasal flaring, distended neck veins, weakened pulse, irregular heart rhythm, cool extremities, enlarged liver, low blood pressure. Some patients may develop a change in their mental status, becoming confused, disoriented or non-interactive. Blood tests for cardiac injury may help establish a diagnosis of myocarditis. Blood levels of troponin I and B-type natriuretic peptide (BNP or NT-pro BNP) are frequently elevated. A chest x-ray may reveal lung congestion or an enlarged heart. The electrocardiogram (ECG) is abnormal in about half of cases and may show decreased electrical voltages or an irregular heart rhythm. An echocardiogram (Echo) is usually nonspecific but may reveal decreased left and/or right ventricular pump function. Magnetic resonance imaging (MRI) may detect inflammation of the heart muscle and give additional information about the size and function of the heart.

Once a diagnosis of myocarditis is suspected and other common causes of cardiomyopathy have been excluded, a cardiologist may perform a cardiac catheterization to retrieve tissue samples from the inner lining of the heart. This is called an endomyocardial biopsy. The biopsy is the gold standard for diagnosis of myocarditis but its use is limited by risks associated with the procedure. Tissue obtained by this procedure may also yield clues about the identity of the causative agent. The Pediatric Cardiomyopathy Registry, a study funded by the National Heart, Lung and Blood Institute, has reported that only one-third of children have a defined cause of their cardiomyopathy.

THERAPY: What are the Treatment Options for Myocarditis?

The primary treatment of myocarditis is supportive care based on guidelines and recommendations published by major cardiovascular organizations in North America and Europe. There are specific guidelines for the management of heart failure in children and standards of care for heart transplantation and pediatric cardiomyopathies. Children with a new diagnosis of myocarditis usually require hospitalization for treatment of heart failure and arrhythmias. Administration of intravenous cardiac medications or insertion of a temporary pacemaker may be necessary. In severe cases, extracorporeal memrane 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 (IVIG) 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 cardiac function. Some patients may develop a slow and progressive course of dilated cardiomyopathy with diminishing cardiac function and heart failure symptoms. In severe cases cardiac transplantation may offer the best chance for long-term survival.

EXPECTED OUTCOMES: What is the Prognosis for Myocarditis Patients?

Although many children recover from myocarditis with no serious consequences, severe forms of myocarditis are associated with significant morbidity and mortality worldwide. Children with fulminant myocarditis are more likely to achieve a complete recovery if they survive the acute phase. Children who develop cardiomyopathy and progress to end-stage heart failure, despite optimal medical therapy, may be candidates for cardiac transplantation.

Transplant-free survival rates are highly variable, ranging from 40%-80% over 5 years. A recent study demonstrated improved 1 and 5 year survival rates of 90% and 83%, respectively. Predictors of outcome in children with dilated cardiomyopathy include severity of symptoms at presentation, the presence or absence of arrhythmias and the rate of clinical improvement. After therapy, post-transplantation survival rates are 80% at 1 year and 70% at 5 years.