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.

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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.

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

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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.

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Internet Resources
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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
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.

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 2% 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.

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.

ETIOLOGY: What Causes Pediatric Myocarditis

Myocarditis may be caused by infections in the heart, autoimmunity 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 erythematos, 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 transplantation is performed.

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-proBNP are frequently elevated. A chest x-ray may reveal lung congestion or an enlarged heart. The electrocardiogram (ECG) is abnormal in about half of patients, 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 dilated 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.

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.

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 membrane oxygenation (ECMO) or a ventricular assist device (VAD) may be necessary in the acute phase to allow the heart to rest or 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.

ETIOLOGY:

What Causes Pediatric Myocarditis?

- Viruses: Coxsackie B, adenovirus, parvovirus B19, hepatitis B and C viruses
- Autoimmune disorders
- Systemic lupus erythematos, celiac disease, sarcoidosis
- Giant cell myocarditis

DIAGNOSIS:

- Clinical findings: respiratory distress, decreased cardiac function
- Blood tests: troponin I, BNP, NT-proBNP
- Chest x-ray: lung congestion, enlarged heart
- ECG: abnormalities, decreased voltages
- MRI: inflammation of heart muscle

EXPECTED OUTCOMES:

- Transplant-free survival rates: 40%-80% over 5 years
- Predictors: symptoms at presentation, arrhythmias, clinical improvement

THERAPY:

- Supportive care
- Intravenous cardiac medications
- ECMO or VAD
- Immunoglobulin (IVIG) or corticosteroids
- Medical therapy
- Cardiac transplantation

DEFINITION:

What is Myocarditis?

- Inflammation of the heart muscle
- Causes: viruses, autoimmunity disorders, hypersensitivity reactions

DEFINITION:

What is Pediatric Myocarditis?

- Inflammation of the heart muscle in children
- Causes: same as in adults, plus additional factors

SIGN SYMPTOMS:

- Acute viral myocarditis: nonspecific, variable symptoms
- Clinical manifestations: respiratory distress, decreased cardiac function

THE INFORMATION IN THIS BROCHURE SHOULD NOT BE CONSIDERED OR USED AS A SUBSTITUTE FOR MEDICAL ADVICE, DIAGNOSIS OR TREATMENT. IF YOU HAVE OR SUSPECT THAT YOU HAVE A MEDICAL PROBLEM OR CONDITION, PLEASE CONTACT A QUALIFIED MEDICAL HEALTH CARE PROFESSIONAL. THE MYOCARDITIS FOUNDATION DOES NOT WARRANT THE ACCURACY OR COMPLETENESS OF THE INFORMATION IN THIS BROCHURE. REFERENCES AVAILABLE UPON REQUEST.