

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. The founding members of the Board of Directors are listed below.



**Leslie T. Cooper, M.D.**, MF President, is a Professor of Medicine and a cardiologist at the Mayo Clinic in Rochester, MN, who has a longstanding interest in treating myocarditis. He edited the textbook, *Myocarditis: From Bench to Bedside*, and leads several clinical studies on the diagnosis and treatment of myocarditis.



**Candace C. Moose**, Executive Director, is a 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*.



**Mario C. Deng, M.D.** is the 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. Additionally, he has authored many scientific publications and most recently served as a board member of the International Society of Heart and Lung Transplantation.



**James A. Moose, MBA**, is a healthcare executive with experience in pharmaceuticals, diagnostics, and medical devices. He has held various management positions at Johnson & Johnson and other major companies. 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.

**Additional Board of Directors**

**Joseph Rumore**: Heart Transplant 2006; former Managing Director of a national insurance company.

**Clement Weinberger, PhD**: former Director of Medical Communications and Training for a major international pharmaceutical company.

**Elizabeth Schultz, M.D.**: Board Certified Clinical Pathologist and current co-director of a private charitable foundation.

**Lori Blauwet, M.D.**: Cardiovascular Diseases Associate Consultant, Mayo Clinic, Rochester, MN

**DeLisa Fairweather, PhD**: Myocarditis researcher, John Hopkins University, Baltimore, MD

**Michael Austry**: Media Executive, Dallas, Tx

**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/charfm.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.*

**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, M.D.**— Professor of Pediatrics at Harvard Medical School and Associate Chief of Cardiology at Boston Children's Hospital.

**Myocarditis Foundation**

**Toll Free**  
**1-866-846-1600**

*You Can Help  
Please Donate:*

By Mail: Myocarditis Foundation  
2201 River Road #3401  
Point Pleasant, NJ 08742

Online: [www.myocarditisfoundation.org](http://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](mailto:candace@myocarditisfoundation.org)

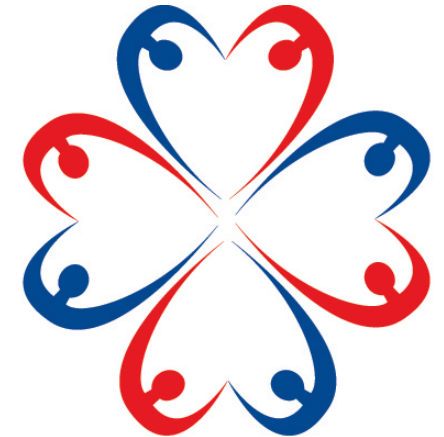
**Internet Resources**

- Children's Cardiomyopathy Foundation:  
[www.childrenscardiomyopathy.org](http://www.childrenscardiomyopathy.org)
- Peripartum Cardiomyopathy Support Network:  
[www.amothersheart.org](http://www.amothersheart.org)
- Parent Heart Watch:  
[www.parentheartwatch.org](http://www.parentheartwatch.org)
- Compassionate Friends:  
[www.compassionatefriends.org](http://www.compassionatefriends.org)
- MayoClinic:  
[www.mayoclinic.org/myocarditis/research.html](http://www.mayoclinic.org/myocarditis/research.html)  
[www.mayoclinic.com/health/myocarditis/DS00521](http://www.mayoclinic.com/health/myocarditis/DS00521)
- American Heart Association  
[www.americanheart.org](http://www.americanheart.org)

**MyocarditisFoundation.org  
Website Resources**

- For Myocarditis Patients: The Patient Survey
- For Patients and Families who have lost loved ones to myocarditis: The Message Board
- For Medical Professionals: Myocarditis resources and research grant information

**BE ALERT TO MYOCARDITIS  
IN CHILDREN:  
A GUIDE FOR PHYSICIANS**



**MYOCARDITIS  
FOUNDATION**

*Knowledge  
Nurtures  
Hope. . .*

Your journey is just beginning

**The Myocarditis  
Foundation**

**is here  
to help.**

[www.myocarditisfoundation.org](http://www.myocarditisfoundation.org)



Myocarditis is a rare, potentially life-threatening inflammatory disorder of the myocardium. It is a common cause of heart failure in otherwise healthy children and accounts for up to one-third of the cases of pediatric dilated cardiomyopathy. The true incidence of myocarditis in children is unknown because some cases are subclinical, and the presentation of those cases severe enough to come to the attention of a pediatrician can vary widely, making a timely and accurate diagnosis challenging. Recognition is even more difficult in very young children because they cannot clearly describe their symptoms. Notably, the initial signs and symptoms are often those of more common pediatric illnesses and may not suggest obvious cardiac involvement. Including myocarditis in the differential diagnosis of children presenting with nonspecific symptomatology when the clinician maintains a reasonable degree of clinical suspicion can be lifesaving. Most children with myocarditis do recover with treatment, but a substantial percentage may progress to serious cardiopulmonary compromise leading to death or heart transplantation. Prompt diagnosis is imperative to allow for rapid and appropriate treatment of these children to optimize disease outcome. Although myocarditis occurs rarely in children, pediatricians should maintain a heightened index of suspicion because of its potential seriousness and high risk of mortality.

### Etiology

In the developed world, the most frequently identified causes of pediatric myocarditis are viral infections of the myocardium. Enteroviruses, most frequently coxsackievirus B, were historically implicated as a common cause of this disease in children, although many other viral entities have since been shown to be causative agents including influenza virus, adenovirus and parvovirus B19. Lyme disease, fungi, protozoa, rickettsiae and other parasites are rare causes of myocardial inflammation as

### Variable Clinical Presentation in Pediatric Myocarditis

- Chest pain/palpitations
- Dyspnea on exertion/exercise intolerance
- Fatigue/lethargy
- Anorexia/poor feeding/failure to thrive
- Abnormal distention
- Fever/malaise
- Mental status changes/near syncopal events

Table 1

are immune-mediated diseases, such as collagen vascular diseases, venoms, toxins and some chemotherapeutic agents.

### Epidemiology

Myocarditis may occur more frequently during seasonal influenza epidemics and particularly during summer and fall with the increased prevalence of coxsackievirus B in the general population. Neonatal myocarditis usually presents acutely, is severe and often fatal with a mortality rate as high as 75%. Infants have an increased risk of myocarditis when exposed to the virus during the first year of life, with the incidence of myocarditis increasing again during late childhood and adolescence. In one study, a review of over 235,000 emergency room admissions to a pediatric hospital identified nearly 30% of confirmed cases of myocarditis were in children younger than three years of age and 25% were in adolescents sixteen to eighteen years. In this older population, myocarditis is a significant contributor to sudden cardiac death as verified on post-mortem examination. Gender differences have been observed in the incidence of myocarditis caused by coxsackievirus B in adolescents where two-thirds to three-quarters of cases are male.

### Clinical Presentation

Signs and symptoms of myocarditis at initial presentation are highly variable in the pediatric population. Children may present with complaints of mild, non-specific flu-like symptoms or with evidence suggestive of cardiac involvement such as acute chest pain. A subset of cases recall history of a viral prodrome followed by the sudden onset of symptoms consistent with cardio-pulmonary involvement such as severe chest pain, respiratory distress (tachypnea, dyspnea) and/or fatigue, pallor, lethargy or cyanosis suggesting hemodynamic compromise. A three-tiered classification of myocarditis is based upon the type and severity of presenting symptoms coupled with the clinical course and outcomes. Fulminant myocarditis appears to be preceded by a viral prodrome in children followed by acute onset of cardio-pulmonary signs and symptoms consistent with severe hemodynamic decompensation. Despite the serious nature of the initial illness, the prognosis for recovery and long-term survival for these cases is excellent if the patients survive the acute episode. Acute myocarditis has a milder, less-distinct presentation but more often progresses to dilated cardiomyopathy and heart failure, requiring cardiac transplantation. Chronic myocarditis, as the name suggests, is persistent, may be latent or progressive, with possible recurrences requiring ongoing medical therapy. The highly variable nature of presentation is determined by the extent of myocardial injury and the patient's own inflammatory immune response.

### Diagnosis

The variable nature of the pediatric myocarditis patient's presenting signs and symptoms makes accurate diagnosis of many of these cases challenging. Often, lack of evidence of cardiac involvement further complicates recognition of the underlying disease. As a result, an accurate diagnosis of myocarditis can be missed at the initial physician encounter. Although many cases resolve spontaneously without further sequelae, others develop persistent, recurrent or latent dilated cardiomyopathy with increased morbidity requiring cardiac transplantation to avoid death. The consequences of a missed diagnosis can be dire highlighting the need for clinicians to maintain a high degree of suspicion for myocarditis while assessing these patients.

**Physical Exam:** Findings on initial exam commonly associated with myocarditis are presented in Table 1. Tachycardia partially compensates for inadequate tissue oxygenation secondary to diminished cardiac output. Decreased peripheral perfusion manifests as cool extremities, weak pulses, pallor, increased time to capillary refill, and/or decreased urinary output. Vasoconstriction initially maintains an age-normal blood pressure, but over time hypotension results as a late finding of cardiac failure. A variety of abnormal heart sounds may be detected including diminished heart sounds, murmurs, gallops and rhythm disturbances. Wheezing, coughing, grunting, nasal flaring, intercostal retraction, rales, dyspnea, tachypnea, cyanosis and hypoxia are evidence of respiratory distress. Hepatomegaly and peripheral edema suggest cardiac failure in severe cases. Non-specific findings include fever, malaise, anorexia, fatigue and lethargy.

### Further Diagnostic Evaluation

Once evidence gathered on presentation and physical exam suggests the need for further investigation of cardiac involvement, the clinician should consider ordering laboratory and imaging studies to confirm the presence of myocarditis and/or to rule-out other cardiac conditions. Further diagnostic evaluation also provides an assessment of the level of cardiac function, alerting the pediatrician of the necessity for proper clinical intervention. Common findings on diagnostic evaluation in pediatric myocarditis are summarized in Table 2.

**Chest Radiography:** Cardiomegaly and pulmonary venous congestion are important findings on a chest radiograph in the myocarditis patient and can help to distinguish a diagnosis of myocarditis from more common respiratory ailments. The above findings, suggestive of heart failure, increase with disease duration and progression, therefore, they may not be evident in cases presenting as fulminant myocarditis. In patients with marked cardiovascular compromise or collapse of unknown cause without evidence of cardiomegaly or pulmonary venous congestion on chest radiograph, a diagnosis of myocarditis cannot be

ruled-out simply on the appearance of a normal chest x-ray. **Electrocardiography:** Electrocardiograms are usually abnormal in pediatric myocarditis patients. Evidence of cardiac involvement may include sinus tachycardia (commonly seen), low voltage QRS complexes, ST-T wave abnormalities, prolonged QT intervals and/or atrioventricular block. Left ventricular hypertrophy with associated repolarization changes are

### Possible Physical Exam Findings in Pediatric Myocarditis

- Tachycardia/ arrhythmias (gallop with S3 impulse)
- Cold extremities/ weak peripheral pulses/ poor capillary refill
- Pallor
- Hypotension (late)
- Abnormal heart sounds/ murmurs (mitral regurgitation)
- Neck vein distention/ peripheral edema (older children)
- Cyanosis/ hypoxia
- Respiratory distress (tachypnea, dyspnea, wheezing, nasal flaring)
- Intercostal retractions
- Fever
- Hepatomegaly

Table 2

observed on ECG as ST segment depression with or without T wave inversions. A variety of tachy and brady arrhythmias including ventricular tachycardia and third degree complete atrioventricular block may be observed in pediatric myocarditis.

**Laboratory Studies:** Biomarkers of cardiac injury including cardiac troponins have a variable diagnostic yield depending on the acuity and severity of the presentation. Viral serologies and peripheral blood and tissue cultures are usually negative and not helpful in achieving an early diagnosis. The endomyocardial biopsy remains the gold standard for diagnosis of viral myocarditis despite the low sensitivity and high rate of false negative test results. Due to the focal nature of myocardial inflammation, biopsy material may fail to include affected areas causing a missed diagnosis due to sampling error. Polymerase chain reaction (PCR) of myocardial tissue for viral genome can increase the sensitivity of the endomyocardial biopsy. The invasive nature of obtaining a myocardial tissue sample poses a significant risk to the patient and should only be utilized when the clinical suspicion is high for a cardiac disorder that is amenable to treatment.

**Echocardiogram:** The echocardiogram is a useful tool for evaluating ventricular function and excluding more common causes of heart failure. Echocardiograms are usually abnormal in pediatric myocarditis. Findings are variable and may include wall motion abnormalities, ventricular chamber dilatation, atrial enlargement, atrio-ventricular valve regurgitation and left ventricular or biventricular dysfunction. Fulminant myocarditis is often associated with an echocardiographic picture of reduced left ventricular systolic function without left ventricular chamber dilatation. **Cardiac MRI:** Contrast-enhanced cardiac MRI may assist in the diagnosis by identifying local sites of suspected inflammation in the myocardium. This test is generally performed in patients with newly recognized ventricular dysfunction without a clear etiology. The prognostic value of MRI tissue characterization is an area of active research

### Possible Diagnostic Findings in Pediatric Myocarditis

#### Chest Radiograph:

Cardiomegaly  
Signs of congestive heart failure (pulmonary venous congestion, pulmonary edema, atelectasis, pleural effusions)

#### Electrocardiogram:

Sinus tachycardia/ arrhythmias (atrial fibrillation, atrial flutter, ventricular ectopy)  
ST - T Wave abnormalities  
Left ventricular hypertrophy (less commonly right ventricular hypertrophy)  
Heart block  
Infarction pattern  
Decreased ventricular voltage  
Atrial enlargement (chronic)

#### Laboratory:

Increased cardiac troponins  
Cardiac enzymes rarely elevated  
Viral titers peripheral blood rarely (+)  
Viral cultures peripheral blood/ biopsy tissue rarely (+)  
Viral genome on biopsy tissue by polymerase chain reaction detectable

#### Echocardiogram:

Dilated left ventricle  
Diminished ventricular function  
Wall motion abnormalities  
Pericardial effusions  
Intracardiac thrombi (rare in infants)  
**Endomyocardial Biopsy:**  
Evidence of inflammation:  
Myocyte destruction  
Fibrosis  
Lymphocytic infiltrates

Table 3

### Conclusions

Children with myocarditis may present to the pediatrician displaying a wide range of signs and symptoms as manifestations

of a variety of clinical states, from occult cardiac disease to full-blown hemodynamic collapse. As a result, a correct diagnosis is often missed at the first physician visit. The lack of early diagnosis of myocarditis may be dire for many of these patients who will progress to dilated cardiomyopathy and heart failure. A delay of specialist intervention will defer a definitive diagnosis and initiation of aggressive treatment that may be life saving and may seriously impact the patient's long-term prognosis. Myocarditis must be considered in the differential diagnosis of any older child with the complaint of chest pain. Although chest pain is a common complaint and rarely associated with cardiac disease in this population it deserves careful evaluation. Young children with respiratory distress, abnormal breath sounds, cardiac murmurs, abnormal rhythm or heart sounds, with or without fever, should have an electrocardiogram and chest radiograph with a low threshold for performing an echocardiograph and/or consultation with a pediatric cardiologist.