

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.



**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 Vice-President - Chair of the Cardiovascular Department, Mayo Clinic, Jacksonville, Florida

**Candace Moose**, Secretary - Giant Cell Myocarditis survivor and heart transplant recipient. She 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*.

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

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

**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

**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

**Christopher Corso**, Director - Vice-President and Senior Reinsurance Placement Officer XL Catlin Insurance and father to a Myocarditis survivor

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

## Myocarditis Foundation

You Can Help, Please Donate:

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

**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:**  
[info@myocarditisfoundation.org](mailto:info@myocarditisfoundation.org)

### THE MYOCARDITIS FOUNDATION Medical Advisory Board

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

**Bettina Heidecke, MD** - Associate Professor at the University of Zurich, Switzerland Myocarditis Researcher and previous Myocarditis Foundation Fellowship Grant Recipient.

**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 AND GIANT CELL MYOCARDITIS



MYOCARDITIS  
FOUNDATION

*Knowledge  
Nurtures  
Hope. . .*

Your journey is just beginning

The Myocarditis  
Foundation

is here  
to help.

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

## OUR GOAL

The Myocarditis Foundation is a private, non-profit organization, established in 2005, which is dedicated to providing information about myocarditis to medical professionals, patients, and their families, with the goal of saving more lives.

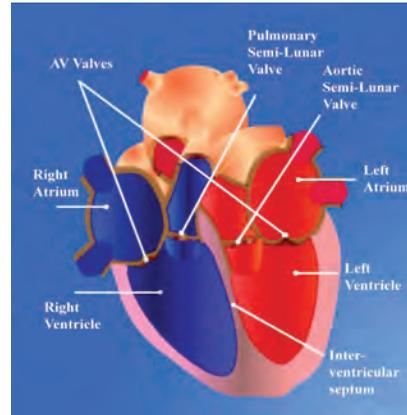
Myocarditis is a poorly understood, often undiagnosed illness which can rapidly progress to heart failure and death. The Foundation attempts to bridge the gap in awareness and understanding of the range of diseases causing inflammation and damage to cardiac tissue, so that effective treatment can be administered in a timely fashion.

The Foundation's primary mission is to provide relevant, accurate and up-to-date information about the nature of myocarditis and its various presentations, to medical professionals and to the public at large. Given both the low occurrence of the disease, and its often severe consequences, it is imperative that physicians become more aware of its existence and clinical presentation as well as the latest information about methods of treatment.

## ABOUT MYOCARDITIS and GIANT CELL MYOCARDITIS

The heart is a four-chambered, muscular pump about the size of an adult fist. Normally, the heart beats 60 to 100 times per minute, pumping blood throughout your body with each beat. Two upper heart chambers called the right and left atria (each is called an atrium) receive blood that returns to the heart from the body. Veins carry this returning blood to the atria. When the muscles of the atria contract, blood is squeezed into the two larger, lower heart chambers called the right and left ventricles. When the muscles of the ventricles

contract, blood is propelled through arteries to the entire body. The pumping of the ventricles creates the pulse you feel in your wrist or neck. The myocardium, the middle layer of the heart wall, is composed of cardiac muscle.



**Myocarditis** is marked by inflammation and damage of the heart muscle. This disease usually attacks otherwise healthy people. Several thousand patients per year are diagnosed in the U.S. Approximately 5 to 20% of all cases of sudden death in young adults are due to myocarditis. There are many causes, including viral infections, autoimmune diseases, environmental toxins, and adverse reactions to medications. Although long-term consequences include death or heart transplantation, many cases of acute myocarditis have no symptoms and are only identified by an electrocardiogram or by blood tests that detect heart injury. The prognosis is variable but

chronic heart failure is the major long term complication. Myocarditis and the resulting disorder of idiopathic dilated cardiomyopathy are the cause of approximately 45% of heart transplants in the U.S.

**Idiopathic Giant Cell Myocarditis (IGCM)**, is a rapidly fatal disorder that may respond to certain immunosuppressive drugs or heart transplantation. However, most cases are not diagnosed until after death or heart transplantation in part due to a lack of awareness of the disease. From 1905 until 1987, all cases of IGCM were described at autopsy, with survival usually less than 3 months from the initial onset of symptoms. By 1993, several cases of patients with IGCM resulted in survival of 1 year or more in association with immunosuppressive treatment. Overall, however, in the late 1980's and 1990's, the average time from the start of symptoms to death or transplantation was only 5 months.

IGCM is so rare it is infrequently considered in patients who present with new onset heart failure. Even today, most cases of IGCM, are only diagnosed at the time of heart transplantation or autopsy. By increasing awareness of IGCM, we hope to increase the frequency of diagnosis and successful medical treatment.

## FOUNDATION ACTIVITIES

*The core activities which support the Foundation's objective are:*

- **Sponsor** conferences and lectures directed to both the public and to physician groups that deal with myocarditis, its causes, symptoms, diagnosis, and treatment.
- **Serve** as a clearinghouse of information about myocarditis, by developing educational materials, pamphlets and publications for use by the public, families, and physicians.
- **Provide** coping strategies to myocarditis sufferers and/or their families.
- **Maintain** a website devoted to educating the public about myocarditis. Information on the site will be relevant to families and professionals alike, and will provide a link to other relevant websites with additional information.
- **Provide** research grants to organizations or to individuals to conduct research into myocarditis.
- **Maintain** a listing and provide a Myocarditis Foundation contact on The National Organization for Rare Disorders (NORD) database.