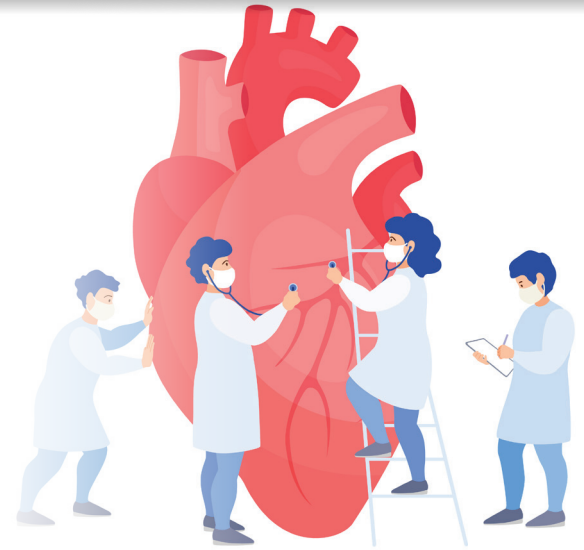


MYOCARDITIS FOUNDATION

*Dedicated to Providing
Information and Support
Related to the Causes,
Symptoms, Diagnosis and
Treatment of Myocarditis
and Sudden Death*



EDUCATION

More awareness is needed... April is Myocarditis Awareness Month

The Myocarditis Foundation is deeply thankful to Governor Greg Abbott for issuing an official proclamation recognizing April as Myocarditis Awareness Month in Texas.

This marks an important first step in raising awareness about myocarditis across the state, but there's still much work to be done in Texas, in our nation, as well as worldwide.

Awareness of the disease needs to be spread to the public, **before** they are faced with the diagnosis. This is to help them question the doctor of a potential myocarditis diagnosis.

When going to the doctor and you have symptoms that initially looks like a viral syndrome, but you are not getting better or getting worse ...you want them to look for early heart failure. Bringing up the words, **"Could this be myocarditis?"** to a doctor, places the ball in their court, for them to rule out that it is not myocarditis. The problem though, to getting this correctly diagnosed, is that there is not

yet a specific diagnostic test for myocarditis.

Education on the diagnosing of myocarditis needs to be spread to the medical community. This is considered a rare disease and was not really taught in medical schools until about the past ten years or so. The symptoms of the disease, very often presents as other viral type illnesses, such as gastric enteritis, the flu, or bronchitis, which all can be symptoms of early heart failure. Ruling out "early heart failure" is key when a person presents with vomiting, diarrhea, cough, wheezing, swelling of extremities, shortness of breath, fatigue, as well as chest pain and palpitations/ fast heartbeat. The symptoms should not be written off as other viral syndromes before evaluation of potential early heart failure is ruled out...this is how you potentially can help diagnose myocarditis until we get a specific diagnostic tool that can be easily done in every hospital around the world.

If vomiting/diarrhea: they should palpate the abdomen for liver enlargement before

saying you have just a "stomach virus"...if the liver is enlarged, it is most likely not a "stomach virus"...

If coughing, wheezing, shortness of breath: they should listen to the heart to evaluate the heart rhythm... is it the "normal lub-dub" or does it sound like a horse galloping, "giddy-up". If these are abnormal, they are "red flags" for potential early heart failure and possibly myocarditis.

Other tests that can help evaluate for myocarditis are:

- Blood tests: BNP, Troponin I, Myoglobin which may be elevated in myocarditis
- Chest X-ray: look for an enlarged heart, vascular congestion, pleural effusion
- EKG: electrical changes, arrhythmias
- Echocardiogram: size of the ventricles, pumping ability
- Cardiac MRI: can reveal myocardial edema and ischemia that often occur in myocarditis. An area of scar can be noted where

the myocarditis affected the heart muscle.

Please be aware that: Myocarditis is the 3rd leading cause of sudden cardiac death in children and young adults.

If you'd like any information on myocarditis to share with others, such as for church, school, and community events, please reach out to us at the Myocarditis Foundation. Please do not wait until you or someone you know has been affected by this disease, let us help educate others now...

We encourage all our supporters to contact their local, state, and federal representatives to ask them to officially recognize April as Myocarditis Awareness Month.



20 Year Anniversary of the Myocarditis Foundation



Congratulations to the Myocarditis Foundation on this momentous milestone!

On March 5, 2005, the Myocarditis Foundation received their official IRS nonprofit approval letter. Dr. Cooper and Candace Moose had been working on all the background materials for several years prior to making the application. Candace benefitted from Dr. Cooper's knowledge about Giant Cell Myocarditis when her Critical Coronary Care Team from Columbia Medical Center in New York consulted Dr. Cooper regarding her case in September 2001.

Candace arrived at Columbia via ambulance in catastrophic heart failure and cardiogenic shock after being transferred between two other hospitals that did not know how to care for her. Dr. Cooper's reputation in the field of cardiology was well

known through his published research and speaking engagements. His specific area of interest was Giant Cell Myocarditis.



Candace Moose

Candace was privileged to be met as a direct admit to CCU by Dr. Mario Deng, a relatively new member of the cardiology team who had experience with her rare diagnosis. The diagnosis of GCM was made

quickly, the treatment recommended by Dr. Cooper was initiated and but by the grace of God, she survived until the transplant and beyond to this day almost 25 years later, so far. Candace survived in large measure because Dr. Cooper's research recommended a treatment protocol that allowed the inflammation in her heart to subside. The treatment acted as a bridge to transplant. Her gratitude for his intelligence, his gifts, his compassion, and his commitment to help patients with a diagnosis that was almost certain death.

Candace contacted him several weeks after she got home and asked him, "What can I do to thank you?" He said that we needed to start a foundation, to be a resource for patients and families, to raise money for research and to educate the public about this disease. The Myocarditis Foundation was born in March of 2005.

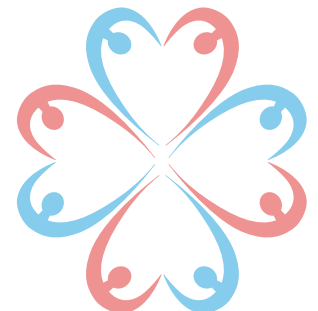
To date over a million dollars has been awarded to mentored scientists to study myocarditis. Our hope has always been that they would become life-long researchers.

Throughout the remainder of 2025, the Myocarditis Foundation will be celebrating this important milestone. In



Dr. Leslie Cooper

coming months, Candace will interview the founding members of Board of Directors, the Medical Advisory Board, prominent researchers, grant recipients, patients who survived and family members whose loved ones did not, each one sharing how the Myocarditis Foundation influenced their journey. Each story will be shared in our various forms of print media and website. Please join us as we reminisce and honor the medical professionals who further defined the science of myocarditis and Giant Cell Myocarditis over 20 years and the members of the Myocarditis Foundation staff who walked with us through our crises.



EVENT

NYC Marathon 2025

The Myocarditis Foundation is excited to announce that we have been selected as an official charity partner of the 2025 New York City Marathon!

This year marks the 55th edition of the world's largest marathon, with an average of 50,000 participants annually. Securing this opportunity has been a long-standing goal for the Myocarditis Foundation, and we want to thank everyone who helped make it happen.

We are honored to be selected as a bronze-level charity partner, which grants us three marathon bibs. These bibs will allow us to select three runners who will represent the Myocarditis Foundation as official marathon athletes. Each of our runners has committed to raising



OFFICIAL
CHARITY PARTNER

tcs

NEW YORK CITY
MARATHON

awareness about myocarditis on and off the racecourse.

Our goal is for each runner to raise a minimum of \$5,000 for the Foundation. In addition to fundraising, they will be spreading awareness by notifying friends and family about their participation in the 2025 NYC Marathon through email, text, social media post, and casual conversations.

We encourage all of our supporters to visit our website and contribute to their fundraising efforts! We were only given three bibs this year, but we hope to increase that number next year if we do well with our fundraising goals. If you think you have what it takes to become a Myocarditis Foundation athlete, please reach out to us to join our waitlist for the 2026 marathon.

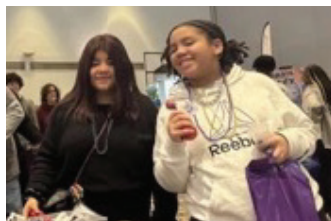
Even though our spots for the NYC Marathon are

filled, you can still get involved in raising awareness and fundraising! If you're healthy and able, we encourage you to participate in local fun runs, 5Ks, half-marathons, or full marathons in your area and choose the Myocarditis Foundation as your charity that you want to run on behalf of. We're more than happy to help you set up a fundraising page and provide support along the way. Please reach out if you're interested and thank you for all your support!



EVENT

Myocarditis Foundation Rare Disease Day Event



On Thursday February 20th, the Humble ISD Mental Health and Wellness Team held a Health Fair that the Myocarditis Foundation participated in.

There were over 600 attendees (parents, grandparents, teachers, school counselors, and children of all ages), many who stopped by our booth. There they could play a game, learn about the heart and myocarditis, and take

away some information to share with others about the disease.

We had Zippy, our mascot, in our booth. He is a zebra, which is a symbol for rare diseases. He greeted our visitors and gave stickers out with his picture on them to the younger visitors along with candy and heart stress balls.

The older children and adults were appreciative of the information that they learned about and were able to take away handouts to share with colleagues, family and friends. Most had never heard of the disease before and welcomed learning about it.

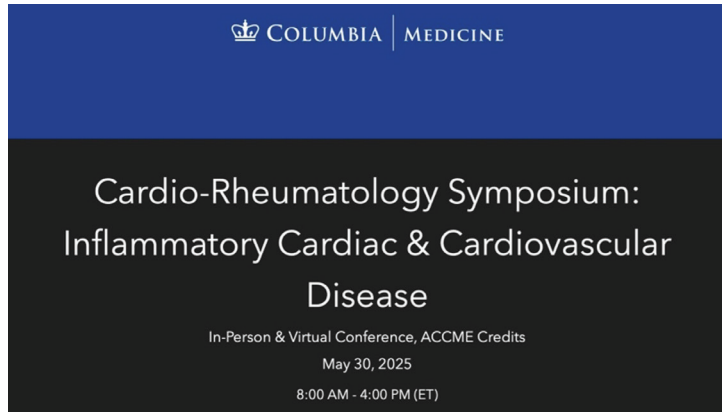


Humble ISD sent around a thank you for our participation and believes that our resources, conversations and connections which we shared will have a lasting impact on their students, families, staff and community.

This was the Myocarditis Foundation's way of helping to raise awareness for myocarditis, in honor of Rare Disease Day, February 28, 2025.



Cardio-Rheumatology Symposium: Inflammatory Cardiac & Cardiovascular Disease In-person and Virtual Conference Friday May 30, 2025, Columbia University Medical Center, NYC



Inflammatory Heart Disease encompasses a number of diseases, including Myocarditis, Pericarditis, and Cardiac Sarcoidosis, among others. There is not much known by most doctors about these diseases, as they are all considered rare diseases and not easy to diagnose. However, when correctly diagnosed early in the disease process, the outlook for recovery is more optimistic.

At this symposium, there will be specialists who know how to best diagnose and treat a full spectrum of cardiovascular diseases. They will share their knowledge base with you which will better help you to understand these diseases, and what is new in their diagnosis and treatments.

Dr. Dor Lotan, a member of the Myocarditis Foundation Board of Directors, is one of the course directors who will be speaking on "Novel Advances in the Management of

Recurrent Pericarditis."

Dr. Leslie Cooper, the Co-Founder of and Medical Director for the Myocarditis Foundation, will also be giving the Keynote Presentation on "Novel Approaches for the Management of Myocarditis."

Program Overview

IN-PERSON & VIRTUAL CONFERENCE

Columbia University Medical Center invites you to join the leading educators from Columbia University, addressing Cardio-Rheumatology an 8-hour, in- person, CME-accredited meeting dedicated to advancing expertise in the dynamic field of cardiorheumatology. This comprehensive educational event will focus on the most current topics, including inflammatory cardiomyopathy, myocarditis, pericarditis, cardiac sarcoidosis and novel therapies for pericarditis. They will also

explore the latest findings on inflammation and atherosclerosis, emphasizing their relevance to cardiology and rheumatology. The symposium will highlight the critical interaction between cardiology and rheumatology, encouraging a multidisciplinary,

team-based approach to managing complex conditions. They will address a range of autoimmune and autoinflammatory disease states involving the myocardium and pericardium, presenting the latest research and therapeutic advancements.

UPCOMING EVENTS (SUMMER)

18th Annual Myocarditis Foundation Golf Fundraiser



11 TH
AUGUST
2025

ARCOLA COUNTRY CLUB
PARAMUS, NEW JERSEY

UPCOMING EVENTS (FALL)

Chili Cook-off

The Myocarditis Foundation's Third Annual Chili Cook-off is tentatively scheduled for November 8, 2025 at Back Pew Brewing in Porter, Texas.

Please consider being a sponsor for a Chili Cooking Team or sponsor

your own Chili Cooking Team and share your special chili recipe. You'd be amazed to learn how many different versions of chili there are from all areas of the country!

Please look for more information on this in the upcoming months.



Winning Team from Chili Cookoff 2024

EDUCATION

Dr. Cooper's appearance on Interviews with the Experts Podcast

Dr. Leslie Cooper, Co-Founder of the Myocarditis Foundation, recently appeared on Mayo Clinic's Interviews with the Experts podcast series to discuss important insights on myocarditis and cardiac sarcoidosis.

In his first episode, Dr. Cooper explored key topics such as the percentage of adults with myocarditis who have a gene variation linked to heart disease, when

doctors should perform a heart tissue biopsy for acute myocarditis, and how Stage B myocarditis can be identified through symptoms and testing.

In his second episode, Dr. Cooper discussed the percentage of patients with cardiac sarcoidosis who also experience lung or thoracic lymph node involvement. He also covered risk factors that increase the likelihood of heart failure or ventricular

UPCOMING EVENTS (FALL)

Myocarditis Foundation Family Meeting (Tentatively in Boston, October 2025)



We are starting to plan our annual Family Meeting and are looking at the Boston area in October 2025. Dates are yet to be determined. We are looking for a venue that will be easily accessible for everyone to get to (plane, car, train, bus). Autumn in the northeast part of our country is very colorful. We will look for special activities that will help bring us all together and allow us to interact and learn a little more about each other.

We are looking forward to seeing some of our previous patients and families, as well as some newcomers to our Family Meeting. For those of you who have never been to our Family Meetings, you will be able to meet our specialists, researchers, and

others, who have been affected by myocarditis and pericarditis. You will hear about the latest research, medications, treatments, as well as be able to speak with and ask questions of our panel of specialists. Being able to meet and interact with others, who have been affected by these rare diseases, is extremely beneficial. Sharing stories and seeing how others have been helped to deal with these diseases has proved very supportive to those who have been newly diagnosed.

We provide speakers that will be helpful in your healing journey, whether it is as a survivor or dealing with the grief of having lost a family member or friend to the disease.



Listen Here!

2024 ACC Expert Consensus Decision Pathway on Strategies and Criteria for the Diagnosis and Management of Myocarditis

The Myocarditis Foundation is very excited to share this recently published article! After peer reviews, and endorsements by the Myocarditis Foundation, the Heart Failure Society of America (HFSA), and the International Society of Cardiomyopathies, Myocarditis, and Heart Failure, the complete article was recently published by Elsevier.

It was after the events of the recent COVID pandemic that myocarditis was identified as a high-priority topic by the American College of Cardiology's (ACC's) Science and Quality Committee and the Solution Set Oversight

Committee. Subsequently, the Writing Committee of the ACC Expert Consensus Decision Pathway (ECDP) on Strategies and Criteria for the Diagnosis and Management of Myocarditis was convened.

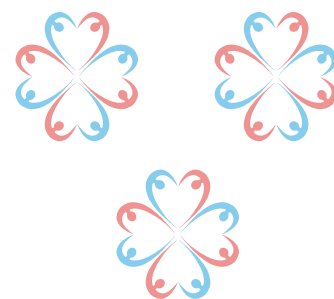
Dr. Leslie Cooper, the Co-Founder of the Myocarditis Foundation, was key to the development of this and was a Vice-Chair on the Writing Committee for the paper.

After many months of collaboration by specialists from around the world, this expert consensus decision pathway was developed to share with the physicians who are not familiar with the disease,

but who truly need to be aware of the potential diagnosis for their patients. It has been found that the earlier the diagnosis is made for patients, the better the outcome and recovery for them.

While the article is geared for physicians, the Myocarditis Foundation wanted the public community to understand the information as well. We have developed a simpler way to better understand the content for the lay person. This synopsis is meant for the public community and not meant to take away from the complete article. It is important to recognize that there is

inadequate healthcare coverage for myocarditis, both for diagnostic care and post diagnosis care. There is also a great need for advocacy, health policy, and interventions for equity for a disease such as myocarditis, that requires advanced therapies when severe. This is a good start that will improve the knowledge base for healthcare providers.



Simplified Lay Person Synopsis:

Recognizing Presentations

- **Classic Symptoms:** Myocarditis typically presents as:
 - **Chest pain** resembling a heart attack.
 - **Heart failure/shock** with symptoms like breathlessness, fatigue, or swelling.
 - **Arrhythmias** causing fainting (syncope) or palpitations.
- **Historical Clues:** Look for recent viral infections, family history of cardiomyopathy, or exposure to toxins that can trigger myocarditis.
- **Clinician Awareness:** Recognizing myocarditis early is crucial since it mimics other conditions like acute coronary syndrome.

Diagnostic Tools: High-Sensitivity Cardiac Troponin (hs-cTn)

- **Role:** hs-cTn detects myocardial injury. It is often elevated in myocarditis but not always.
- **Challenges:**
 - Some patients show normal hs-cTn despite having myocarditis.
 - There's a need for research to confirm if very low hs-cTn levels can reliably rule out myocarditis.

- **Future Potential:** Serial hs-cTn measurements could help track disease progression and recovery.

CMR and EMB as Pivotal Tests

- **Cardiac Magnetic Resonance Imaging (CMR):**
 - **Utility:** Non-invasive test to detect inflammation using T1/T2 mapping and gadolinium-enhanced imaging.
 - **Advantages:** Identifies patterns specific to myocarditis and rules out coronary artery disease.
 - **Limitations:** May be less effective in patients with arrhythmias or delayed imaging post-symptom onset.
- **Endomyocardial Biopsy (EMB):**
 - **Utility:** Helps identify specific types of myocarditis (e.g., giant cell or eosinophilic) and underlying infections.
 - **Risks:** Procedural complications, though rare in experienced centers.
 - **Indications:** Recommended for patients with severe symptoms or those unresponsive to standard therapies.

4-Stage Classification of Myocarditis

- **New Framework** parallels heart failure staging:
 - **Stage A:** At-risk individuals (e.g., those with viral infections, cardiotoxic exposure).
 - **Stage B:** Asymptomatic myocardial inflammation detected through imaging or biomarkers.
 - **Stage C:** Symptomatic myocarditis (e.g., heart failure, arrhythmias).
 - **Stage D:** Advanced myocarditis requiring interventions like circulatory support or heart transplantation.
- **Significance:** This classification helps guide treatment and monitoring.

Research Gaps

- **Progression and Recovery:**
 - Rates of progression from Stage A to C are unclear.
 - Factors determining recovery or irreversibility of Stage D myocarditis are unknown.
- **Chronic Heart Failure:**
 - Long-term risk of developing chronic HF after myocarditis needs further study.

Referral Criteria for Advanced Heart Failure Centers

- **Indications for Referral:**
 - Severe left ventricular dysfunction.
 - Hemodynamic instability (e.g., shock, arrhythmias).
 - High risk of requiring mechanical support or transplantation.
- **Multidisciplinary Care:** Centers specialize in advanced diagnostics, biopsies, and interventions like left ventricular assist devices (LVADs).

Follow-Up Care

- **Monitoring:**
 - Two imaging studies are recommended:
 - An early echocardiogram (2-4 weeks post-diagnosis) to check for progression.
 - A follow-up CMR at six months for detailed assessment.
 - Biomarkers like hs-cTn can help track recovery.
- **Long-Term Surveillance:**
 - Even asymptomatic patients need follow-ups to prevent relapse or chronic complications.
 - Advocacy is needed for insurance coverage of repeat testing.

Genetic Counseling and Testing

- **Importance:**
 - Some forms of myocarditis (e.g., familial or genetically predisposed) are linked to specific gene mutations.
 - Identifying mutations allows screening and preventive care for family members.

- **Cascade Screening:**
 - When a genetic predisposition is identified, family members can be tested to detect risks early.

Return to Physical Activity

- **Strenuous Activity:**
 - Exercise can exacerbate inflammation, so activity is restricted until recovery is confirmed.
- **Guidelines:**
 - CMR, arrhythmia monitoring (e.g., 24-hour Holter), and exercise tests are required to clear patients for strenuous activity.
 - Athletes may resume competitive sports after 3-6 months if cleared by testing.

Future Research Needs

- **Knowledge Gaps:**
 - Social determinants of health impacting disease outcomes.
 - The psychological burden on patients and caregivers.
 - Effectiveness of immunosuppressive therapies.
 - Advanced imaging techniques to improve diagnosis.
- **Registries:** International collaboration to collect patient data could improve understanding of myocarditis.

Management Pathway Summary

1. **Initial Evaluation:**
 - ECG, biomarkers (e.g., hs-cTn), echocardiography, and ruling out coronary artery disease.
2. **Definitive Testing:**
 - Use CMR or EMB for confirmation based on symptoms and risk.
3. **Treatment:**
 - Initiate pharmacological and supportive therapy based on myocarditis stage and severity.
4. **Follow-Up:**
 - Monitor for symptom recurrence, imaging changes, and biomarkers.
5. **Physical Activity:**
 - Gradual return under supervision after diagnostic clearance.

Novel Contributions

- **Updated Lake Louise Criteria for CMR:** Highlights parametric T1 and T2 imaging to detect myocarditis-associated inflammation.
- **Focus on Genetic Factors:** Suggests genetic predisposition might contribute significantly to susceptibility.

MYOCARDITIS FOUNDATION

Board of Directors 2025

JOSEPH RUMORE *President / Chairman of the Board*

Viral Myocarditis Survivor and Heart Transplant recipient, former Managing Director of a national insurance company

MICHAEL A LINN *Director*

Managing Partner of EmGen Enterprises; President of Veramazo; COO of Breathewave Technologies

FRANCINE ANDREA *Director*

Retired Vice-President for Enrollment Management, Student Affairs and Chief Compliance Officer for Felician University

LOUIS ROMANO, JR. *Director*

Owner of Homewell Cares

CANDACE MOOSE *Director and Founder*

Giant Cell Myocarditis Survivor and Heart Transplant recipient

LESLIE COOPER, MD *Chief Medical Director, Founder*

Chair, Dept. of Cardiovascular Medicine; Elizabeth C. Lane, PhD and M. Nadine Zimmerman, PhD, Professor of Internal Medicine named Professorship Committee, Mayo Clinic, Florida

JACK PRICE, MD *Vice-President / Pediatric Medical Director*

Professor of Pediatrics, Baylor College of Medicine, Pediatric Cardiologist Heart Failure and Transplant Cardiology, Texas Children's Hospital

BETTINA HEIDECKER, MD *Research Medical Director*

Head of the Heart Failure and Cardiomyopathies Division at the Charite, Germany Myocarditis Researcher and previous MF Fellowship Grant Recipient

GIUSTINA SCHIANO *Director, Family Ambassador*

Mother of a Viral Myocarditis Victim. Principal Appellate Court Clerk. Appellate Division Second Dept. NYS Supreme Court.

GARY KUBERA *Secretary*

Chemical industry executive and now an industry investment advisor, consultant and an executive coach.

RICK PIACENTI *Treasurer / CFO*

Highly accomplished retired senior executive in oil and gas, transportation, and hospitality industries. Chief Executive Officer of Rick Piacenti Corp, Kingwood, Texas.

DOR LOTAN, M.D. *Director*

Assistant Professor of Cardiology and Advanced Heart Failure, Mechanical Circulatory Support and Transplant Cardiologist at Columbia University Irving Medical Center, NY Presbyterian Hospital, NYC.

Executive Director

GENEVIEVE RUMORE, RN, BSN

Kingwood, Texas

O & PR Manager

MELISSA GRAHAM

Kingwood, Texas

Assistant to the O & PR Manager

JARED BARTON

Kingwood, Texas

Medical Advisory Board

AKIRA MATSUMORI, MD

President, International Society of Cardiomyopathies, Myocarditis and Heart Failure; Visiting Director, Clinical Research Center, National Hospital Organization, Kyoto Medical Center, Japan

BRUCE M. MCMANUS, MD, PhD

Professor Emeritus, UBC Centre for Heart Lung Innovation Founding CEO, PROOF Centre of Excellence Vancouver, British Columbia, Canada

DENNIS MCNAMARA, MD

Professor of Medicine Director, Center for Heart Failure Research University of Pittsburgh Medical Center

DELISA FAIRWEATHER, PhD

Professor, Director of Translational Research, Department of Cardiovascular Medicine Mayo Clinic, Jacksonville, Florida

MARC HALUSHKA, MD, PhD

Cardiovascular Pathologist at Cleveland Clinic; Past President of the Society for Cardiovascular Pathology

WILSON TANG, MD

Professor of Medicine at Cleveland Clinic Lerner College of Medicine; Practicing heart failure and transplant cardiologist at the Cleveland Clinic, specializing in cardiomyopathies and myocarditis.

ENRICO AMMIRATI, MD

Assistant Professor at the School of Medicine at the Vita-Salute San Raffaele University in Milano, Italy; Clinical cardiologist who subspecializes in heart failure and myocarditis at the DeGasparis Cardio Center and Transplant Center at the Niguarda Hospital in Milano, Italy.

JAVID MOSLEHI, MD

Director of Myocarditis at the University of California, San Francisco (UCSF) School of Medicine; Section Chief for Cardio-Oncology & Immunology Dept. at UCSF

Secretary to our Medical Advisory Board

KATELYN BRUNO, PHD

Assistant Professor of Cardiovascular Medicine
Division of Cardiovascular Medicine, Dept. of Physiology & Aging, Center for Regenerative Medicine. University of Florida, Gainesville, FL

Mailing Address: 800 Rockmead Drive, Suite 155. Kingwood, Texas 77339
Telephone: (281) 713-2962

Find us online: www.myocarditisfoundation.org



[twitter.com/
myocarditisfndn](https://twitter.com/myocarditisfndn)



[www.facebook.com/
myocarditis.foundation/](https://www.facebook.com/myocarditis.foundation/)



[Instagram.com/
MyocarditisFoundation](https://www.instagram.com/MyocarditisFoundation)



[Inspire.com/groups/
myocarditis-foundation](https://inspire.com/groups/myocarditis-foundation)
[Inspire.com/groups/
pericarditis](https://inspire.com/groups/pericarditis)