

MYOCARDITIS
FOUNDATION

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



EDUCATION

Myocarditis Foundation 20th Anniversary Celebration (2005-2025)

On behalf of the Myocarditis Foundation, we want to extend our deepest gratitude to everyone who joined us for our 20th Anniversary Celebration on August 9th. We were proud to honor two extraordinary individuals, **Candace Moose** and **Dr. Leslie Cooper**, whose vision, dedication, and leadership have shaped the Foundation into what it is today.

20-year members of our Board of Directors and Medical Advisory Boards also were highlighted at the event. **Dr. Bruce McManus**, **Dr. Dennis McNamara**, **Dr. Akira Matsumori**, **Dr. Elizabeth Schultz**, and **Dr. DeLisa Fairweather** have all been very helpful throughout our 20 years of myocarditis researcher support.

In addition, there were two surprise awards given. One was to **Joseph Rumore**, a Board Member who has been on the Board of Directors since shortly after the Foundation's inception. Joseph met Candace in late 2006 after he had a heart

transplant for severe cardiomyopathy post viral myocarditis as a young adult, 36 years earlier. Over the years, Joseph has served as the Treasurer, President, and finally as the Chairman of the Board, helping to guide the Foundation to where it is today. It was he who started the Annual Golf Outing Fundraiser in 2008, which has raised significant funding over the years to support our Myocarditis Research Fellowship Grants, our education efforts, and patient support.

The other was to **Genevieve Rumore**, an RN and Certified Emergency Room Nurse, who has been our Executive Director for the past 10 years. Genevieve helped raise awareness of and educate the Nursing and Public Communities on myocarditis. Her knowledge and work in the field of emergency room and cardiac care, proved that an educational program was needed for front line caregivers. With the oversight of Dr. Jack Price, she started one which has educated over 20,000 nurse

practitioners. Actually, the pediatric nurse practitioner association now comes to her to ask if she will continue to share her education with their convention attendees for next year's convention!

There were a number of patients, family members, researchers, and supporters in attendance, who shared in the celebration of this momentous milestone. So much has been done over the past 20 years to raise awareness of and support research for myocarditis, as well as help those who have been affected by the disease. There is still much to be done, and we will continue our mission until there is no longer a need!



EDUCATION

Educational Updates on Myocarditis and Pericarditis

Over the past twenty or so years, research has increased in the field of inflammatory heart disease (myocarditis and pericarditis). Researchers and cardiologists from around the world have gotten together and realized that there needs to be more consistent ways to diagnose and treat both these diseases. Work has been done over the past few years to develop guidelines to improve what is known and to be able to share it with other practitioners.

This year has proven to be monumental in getting those guidelines finalized. More is being researched about them, and clinical trials are now being conducted for treatments which has never been done before to this extent.

At the end of 2024, the American Academy of Cardiology released the Expert Consensus Decision Pathway on Strategies and Criteria for the Diagnosis and Management of Myocarditis.

This summer, the European Society of Cardiology published guidelines to improve the diagnosis and care of patients with myocarditis and pericarditis.

The American College of Cardiology recently released new 2025 guidelines that change how pericarditis should be diagnosed and managed. These updates bring important shifts in both treatment and follow-up, especially for patients who struggle with repeat flare-ups.



2025 ACC Guidelines



2025 ESC Guidelines

CELEBRATION

Congratulations to our Director of Research

Dr. Bettina Heidecker, one of our first Fellowship Grant recipients in 2007, has just been awarded a full professorship at the Charite University in Berlin.

Dr. Heidecker's newly established professorship in the Department of Cardiology is a Professorship for Cardiomyopathies as she works to strengthen Heart Failure Research.

Dr. Heidecker's appointment strengthens the Charite's research profile in an area of high clinical and societal relevance. Her scientific work focuses on inflammatory and non-ischemic cardiomyopathies, in particular myocarditis – a frequently underestimated disease that can lead to heart failure or sudden cardiac

death, especially in young people.

Before joining Charité in 2018, she led a specialized myocarditis clinic and research group at University Hospital Zurich. She also serves on our Board of Directors of the Myocarditis Foundation, an international organization dedicated to advancing research and knowledge transfer in myocarditis.

Congratulations Dr. Heidecker!



CELEBRATION

Welcome to our newest Board Member

Deipanjan "Deip" Nandi, was recently added to the Myocarditis Foundation's Board of Directors. He has vast experience in Children's Myocarditis, Heart Failure, Mechanical Support, and Transplant Cardiology. He is at

Nationwide Children's Hospital at Ohio State University in Columbus, Ohio, where he is currently an Associate Professor of Pediatric Cardiology and is the Medical Director of the Pediatric & Adult

Advanced Cardiac Therapies (PAACT) Program. The Myocarditis Foundation welcomes Dr. Deipanjan Nandi!



Understanding the Emotional Aftermath of Myocarditis

Myocarditis Survivors Face High Risk of Depression, New Study Finds



MYOCARDITIS SURVIVORS FACE HIGH RISK OF DEPRESSION

For many survivors of myocarditis, the journey doesn't end when their heart starts to heal. A new study - funded in part by the Myocarditis Foundation and published in *Frontiers in Psychiatry* - has found that nearly **45% of myocarditis survivors experience clinically significant depressive symptoms**, often years after their initial diagnosis.

Led by researchers at Mayo Clinic and Florida State University, this study

is one of the most comprehensive examinations of the emotional and psychological toll myocarditis can take. Using detailed surveys and advanced machine learning techniques, the team explored which factors were most strongly linked to depression in survivors. What they found was striking: **psychosocial challenges - like poor emotional wellbeing, reduced resilience, and**

low quality of life - were more predictive of depression than even physical symptoms or family history of mental illness.

The research included 96 adult participants, many of whom had recovered physically from myocarditis but continued to struggle with anxiety, trauma, and mental health. The study utilized tools such as the CES-D for depression, the Beck Anxiety Inventory, and the Impact of Events Scale to

get a full picture of each individual's experience. The results strongly suggest that surviving myocarditis doesn't just affect the body - it deeply impacts the mind and spirit as well.

This research has powerful implications. It urges clinicians and caregivers to expand the lens through which they view myocarditis recovery, emphasizing the importance of **mental health screening and support**. Survivorship care plans should integrate resources for emotional healing, including therapy, support groups, and resilience training. For patients and families, the message is clear: if you're struggling, you're not alone - and there is help.

The Myocarditis Foundation is proud to have supported this vital research and remains committed to improving the lives of all those affected by myocarditis.

FUNDRAISERS

Fundraiser in Memory of Austin Vonckx

Since 2014, Brenda Vonckx has hosted annual fundraisers in memory of her son Austin, who passed away at just 19 from myocarditis. At this year's event on August 16th at AR Workshop Tampa, friends gathered to craft signs, trays, and other projects raising \$1,350 for the Myocarditis Foundation.

For Brenda, these events are a way to turn grief into action, honoring Austin's memory while supporting research and awareness. Each year, her community comes together to create, connect, and carry forward Austin's spirit of love and hope in the fight against myocarditis.



FUNDRAISERS

18th Annual Myocarditis Foundation Golf Outing

On August 11th, 2025, the Myocarditis Foundation hosted its 18th annual golf outing at the beautiful Arcola Country Club in Paramus, New Jersey. The day was sunny and perfect for golf, providing an ideal backdrop for our largest annual fundraiser. This event plays a crucial role in advancing the Foundation's mission of raising awareness, funding research, and supporting those affected by myocarditis.

This year, we were thrilled to welcome 100 golfers and sponsors, who helped us raise an incredible \$154,000. Funds that will directly fuel new research grants and expand the support we provide to those affected by myocarditis. We extend our heartfelt thanks to everyone who attended and sponsored the event. Your support helps make all of this possible. A special thank-you goes to Arcola Country Club for being

such a gracious and supportive host, helping us put on this important event seamlessly as well as a thank you to everyone who volunteered with us and especially to our generous

sponsors. If you're interested in sponsoring or attending next year's event, be sure to subscribe to our electronic newsletter and follow our social media pages for updates.



FUNDRAISERS

Lee Andrew Hirsch King of Hearts Fundraiser

On Sunday, September 28th, there was a very special event planned by one of our Myocarditis Foundation's Directors, Giustina Schiano. Giustina lost her son, Lee Andrew Hirsch, 10 years ago suddenly to Viral Myocarditis. She knew nothing about this disease that took her only child and vowed to do whatever she could to raise awareness of and funding for research so that others may not suffer as she has. The 4th King of Hearts Fundraiser welcomed almost 140 attendees, with 43 of

them never hearing about Myocarditis or attending one of her fundraisers before. As usual, Giustina's event was an enormous success due to the hard work and dedication to her efforts by her family and friends.

The evening was filled with heartfelt stories and a sense of community as guests learned more about the impact of Myocarditis and the important work being done by the Foundation by the guest speakers, Dr. Leslie Cooper, Chair of the Cardiovascular

Department at the Mayo Clinic, Jacksonville, Florida, and Co-Founder and Medical Director of the Myocarditis Foundation and Dr. Dor Lotan, Founder and Director of the Pericarditis / Myocardial Disease Center at Columbia University, Irving Medical Center at NY Presbyterian Hospital. He is also a Director on the Myocarditis Foundation Board of Directors.

Guests enjoyed the inspiring program, delicious food, and amazing raffles and silent

auction items, all coming together to support Giustina's mission. The generous contributions made throughout the night will go directly toward advancing research and educational outreach, reinforcing the Foundation's commitment to saving lives and supporting families affected by the disease. As the event concluded, there was a collective feeling of hope and determination, with attendees leaving not only more informed but also united in the effort to make a difference.



FUNDRAISERS

Fundraiser in Memory of John Phillip Mello

The John Phillip Foundation proudly held its 6th annual golf tournament and fundraising dinner at the Acushnet River Valley Golf Course on September 20, 2025, in honor of John Phillip Mello, who unexpectedly passed away in 2017 from Myocarditis. The dedicated Foundation Board, sponsors and volunteers were excited to host this event. Having played in pouring rain, and even one year in a hurricane, this year the weather was perfect. The 140 golfers, many of whom have attended each year, were eager to support the Foundation, out of admiration, love, and respect for John, his contributions to his

hometown, and to his family. Greeted by the numerous volunteers, all the participants enjoyed a beautiful day of golf and a warm dinner at the Century House. This community rallied around this event, with generous donations from sponsors providing numerous baskets for raffle and silent auction items making this a resounding success!

The event included an update from Francine Andrea, a member of the Myocarditis Board of Directors, on recent advances surrounding Myocarditis and updates regarding the work of the Myocarditis Foundation.



The John Phillips Foundation and its community have become a member of the "Myocarditis Board Family". A wonderful partner, their continuing contributions to fund research and the mission of the Myocarditis Foundation has been exceptional. At the conclusion of Francine's remarks, the John Phillips Foundation again presented her with a check for the Myocarditis

Foundation in the amount of \$20,000 for the intent of funding another research grant, education, and awareness of this under-recognized cause of sudden cardiac death.

The Myocarditis Foundation cannot thank this Foundation, the family and friends of John, and the Acushnet community enough for their generous support. Together we are making strides in saving lives.

FUNDRAISERS

Family Meeting October 23-25, Jacksonville, Florida

This year we had many new families attend with a few repeat families that helped them better understand how the Foundation helps those affected by the disease. Our basic meeting outline was the same: Thursday evening, meet and greet, relax with some light food choices, and then "Share your Story" as to why you chose to participate and attend the meeting. We had a "Candlelight Vigil" where everyone shared who they were lighting their candle for, their honor or their memory.

On Friday we showed the video that was made by Candace Moose on "How the Myocarditis Foundation

was Started", a little basic review on Myocarditis and Pericarditis, and the importance of Journalling (writing down your thoughts to help you better understand your feelings and help you better deal with what you are going through and cope). We also had some medical speakers on the topics of "Covid Vaccines and Myocarditis", "Returning to Play after the Diagnosis", Genetics and Myocarditis as well as a Talk on "Are Pediatric Patients Just Little Adults?". Of course, there was scheduled time with Dr. Leslie Cooper, for those who had personal questions about the disease.

Friday evening brought some lighthearted fun to the "Family Conference / Retreat", and we went to have an evening of "Fun and Fajitas" at Top Golf. There was a lot of laughter throughout the evening.

Saturday started with a session of Chair Yoga, and more speakers on "Sex Differences and Environmental Triggers in Myocarditis", "Using Artificial Intelligence to

Identify Mechanisms and Biomarkers in Myocarditis", updates on the Clinical Trials that are occurring in Myocarditis and Pericarditis, and a speaker on "When Life Shifts: Grief, Uncertainty, and Coping with Myocarditis."

We'd like to thank our supporters of the event, Kiniksa and Cardiol Therapeutics for their continuing help in allowing us to carry out our mission!



NYC Marathon 2025

Jordan Issacs, a viral myocarditis survivor, has been working with the New York Road Runners Club for 2 years to get the Myocarditis Foundation added as an official charity partner for the New York City Marathon. We had registered 3 runners for this year's marathon, Michael Conte, Pardis Khorasani, and Blake Guerrieri, which was on Sunday November 2nd.

They have raised over \$24,000 for the Myocarditis Foundation. Jordan had t-shirts made with our branding, and they were worn by the runners in the race and given to those who were there supporting them and cheering them on. A huge thank you to Jordan and our runners, Pardis, Michael, and Blake!



Pardis Khorasani

Michael Conte

Blake Guerrieri

EDUCATION

Education Event

On Friday May 30th, 2025 the Myocarditis Foundation had the pleasure of attending the "Inflammatory Cardiac & Cardiovascular Disease Symposium", at NYP Hospital, that was Chaired by Dr. Dor Lotan, one of the Myocarditis Foundation's Board of Directors.

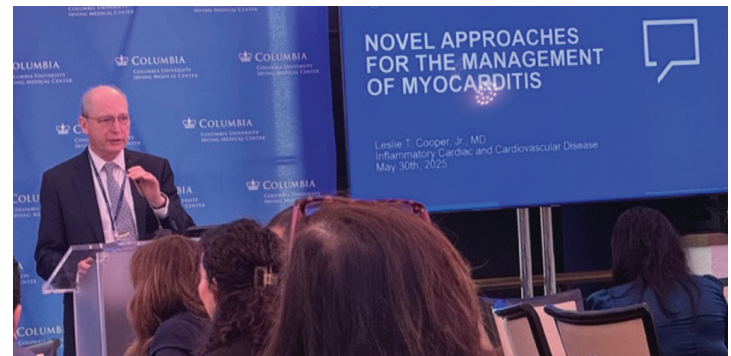
The welcoming remarks, started with "Cardiology and Rheumatology: An Integrated Approach" and was discussed jointly by Dr. Lotan and Dr. Liebowitz, both from NYP Hospital.

The two Keynote Speakers were Dr. Leslie Cooper, from the Mayo Clinic, who spoke on "Novel Approaches for the Management of Myocarditis" and Dr. Paul Ridker, from Harvard, who spoke on "Beyond

LDL Reduction & Traditional Risk Factors: Atherosclerotic Disease". Dr. Dor Lotan, of NYP Hospital, also spoke on "The Novel Approaches in the Management of Recurrent Pericarditis."

Other topics related to Inflammatory Cardiac and Cardiovascular Disease that were discussed were: Cardiac Sarcoidosis, Amyloidosis, Myocardial involvement in Kawasaki Disease, Immune Checkpoint Inhibitor Myocarditis, and the utilization of MRI, PET scan and CT scan and their role in diagnosing inflammatory cardiovascular diseases.

The amazing attendance was 100 in-person attendees and almost 300 online attendees, from around the world. Continuing Education Hours were offered for those who participated.



We were so very pleased to see the number in attendance who were interested in learning more about these diseases and how they relate to inflammatory cardiomyopathy.

The Myocarditis Foundation also had a table with additional information about Myocarditis and the Foundation.

Thank you to all who participated in the update of these diseases at the Symposium!



Can Artificial Intelligence Help Diagnose Myocarditis Or Pericarditis? What Patients Should Know...

(This Information Was Posted In A New Yorker Magazine Article)

Artificial Intelligence (AI) is rapidly changing how doctors gather and process medical information. In recent years, new AI tools have been developed that can scan large amounts of data, suggest possible diagnoses, and even flag conditions that human doctors may have overlooked. A recent article from *The New Yorker* explored the rise of these technologies in medicine and asked an important question: if AI can diagnose patients, what role do doctors play?

For patients and families affected by myocarditis, this is a timely topic. While AI holds promise, it's important to understand both its strengths and its limitations.

The Promise of AI in Medicine

AI models are designed to process information at a speed and scale no human can match. They can sort through thousands of symptoms, lab results, and case studies to suggest possible diagnoses. In some cases, AI has even highlighted conditions that had been missed by clinicians, giving patients new leads to investigate.

For patients living with rare or complex conditions like myocarditis or pericarditis, this can feel encouraging. Having more tools in the diagnostic toolbox means more opportunities for early recognition and treatment.

The Limits of AI

But AI comes with clear limitations. While it has access to medical knowledge, it lacks the investigative reasoning and human insight that doctors bring to each case. AI can sometimes misdiagnose, oversimplify, or even "hallucinate" by creating incorrect information. It also cannot consider the full picture of a patient's life, history, and unique circumstances in the way a physician can.

This is especially critical for conditions like myocarditis, which can present with a wide range of symptoms and requires careful evaluation by trained specialists.

Why Doctors Still Matter Most

AI should not replace the role of doctors. Instead, it can be seen as a supportive tool. For instance, raise new questions, suggest possibilities, or speed up

the diagnostic process. Ultimately, however, the final judgment and care plan should always come from a qualified physician.

For patients, the most important thing to remember is this: AI may offer insights, but your doctor brings the experience, context, and investigative skills that no algorithm can replicate.

Takeaway for Patients

If you're navigating a diagnosis like myocarditis or pericarditis, you may encounter news about AI in medicine. While these tools are exciting, they are best used in partnership with your doctor's expertise and not as a replacement. Patients should never rely solely on AI for medical decisions but can view it as one more resource in their journey toward answers and care.

MYOCARDITIS FOUNDATION

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

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

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Pediatric Cardiologist and Associate Professor of Pediatric Cardiology and is the Medical Director of the Pediatric & Adult Advanced Cardiac Therapies (PAACT) Program at Nationwide Children's Hospital, Ohio

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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

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