

MYOCARDITIS FOUNDATION



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

EVENT

Family Stories Speak Volumes At The 4TH Annual Gala In NYC

On Thursday, June 20th, Gala Chairman Christopher Corso, brought together 386 friends, family, impacted families, and colleagues representing over thirty companies at the Mandarin Oriental Hotel in New York City for our 4th annual fundraising gala. The evening kicked off with a slide show of impacted families who are currently on their journey to recovery and many that were watching down on us to raise much needed funds to avoid more families being added to this very slide show in the future.

Chris Bressette, an insurance executive with AXA XL, a major sponsor, was the Master of Ceremonies for the evening. Chris provided a summary of how the Myocarditis Foundation was founded, some basic statistics, and ended showing the audience the video from our website giving the 6-minute background of co-founders Candace Moose and Dr. Leslie Cooper.

Directly after the video ended, 7 members of the Myocarditis Family took the stage. They included: Candace Moose, Jackson Debusschere, Jon Sperzel, Joseph Rumore, Matthew Corso, Diane Aranson

and Giustina Schiano. Each person shared an impact statement regarding their personal journey, covering transplants, medical monitoring due to the impact of Myocarditis, and family members who spoke about their loved ones passing.

Dr. Leslie Cooper, co-founder and Medical Director for the Foundation, announced the Foundation's achievement of starting a Myocarditis BioBank. The BioBank will be working with major medical institutions collecting myocarditis specific blood samples, processing them and storing them to enhance research for this rare disease. The BioBank will be the first facility to store myocarditis specific samples for study. This major step forward is a direct result of the Gala sponsors and the participant's generous support.

A video was then shown of patients sharing their stories and how the Foundation has responded to help them through their journey.

The evening ended with a playful recognition of the support from the Gala attendees. Dr. Leslie Cooper, co-founder and Medical Director, Joseph Rumore,



President, Chris Corso, Vice-President and Candace Moose, co-founder and Secretary, led a rendition of Sting's "Message in a Bottle", acknowledging the Foundation's "S-O-S" for help in establishing our BioBank, and

within seconds the audience joined them, capping off a very successful evening.

The Myocarditis Foundation would like to thank the Gala Chairman and the Sub-committee for running a successful event.

(Continued from Pg1)

Many heartfelt thanks as well to our Myocarditis Family who attended, provided a donation, sponsored a table, or took out an advertisement in our Journal.

Many heartfelt thanks to our Myocarditis Family who attended, tried to attend, provided a donation, sponsored a table, and took out an advertisement in our journal. The 4th annual gala raised much needed awareness as well as funds to position us to fulfill our Mission to "Find a Cure", help those impacted, and educate the medical field about this often, deadly disease.

Please go to our website www.myocarditisfoundation.org to watch the video of the evening and see the complete Photo Gallery.



Dr. Leslie Cooper



Joseph Rumore, Candace Moose, Christopher Corso, and Dr. Leslie Cooper



EVENT

Myocarditis Foundation's 1ST Family Meeting For 2019 Was Held in NYC

The Warwick Hotel in New York City was the setting for our 7th year Family Meeting which was held on Friday June 21, 2019.

Some of our families have attended our meetings before but there were four new families in attendance from various parts

of the country, both survivors and sadly those who had lost a loved one. The setting was intimate and comfortable where all the attendees

shared their stories of myocarditis freely and were supported by the Myocarditis Family.

Giustina Schiano, a Board Member and the Patient/Family Ambassador for the Foundation organized and officiated at the meeting. Speakers on our Panel Discussion were Dr. Leslie Cooper and Candace Moose, (co-founders of the Myocarditis Foundation), Dr. Jack Price, (Pediatric Cardiologist at Texas Children's Hospital), Dr. DeLisa Fairweather and Dr. Katelyn Bruno (Myocarditis Researchers from the Mayo Clinic in Jacksonville, FL), Joseph Rumore (President of the MF), and Genevieve Rumore, (Executive Director).

Topics for discussion included the Myocarditis Foundation, (past, present, and future), Research updates, Education updates, and specific questions about the various aspects of Myocarditis for the Panel.



Group picture of attendees

EVENT

Myocarditis Foundation's 2ND Family Meeting for 2019 Held in Philadelphia

Friday, the 13th of September, did not scare away the 50 patients and family members who attended the 1st night of the Myocarditis Foundation's second Family Support Meeting for 2019 in Philadelphia, Pennsylvania.

The Hilton Garden Inn was the site of the meeting which continued on Saturday. Half the attendees were sadly new to our family. The family members who have been with us before, resoundingly affirmed the support that they gain from attending and catching up with

each other and hearing of the new updates on the research being conducted.

The Schiano Family, who lost their son and nephew Lee Andrew Hirsch to Viral Myocarditis in 2015, provided the welcome gift to all attendees. The backpacks, that were provided by the Myocarditis Foundation, were filled by the Schiano Family with various food items that originated in Philadelphia. Lee loved to provide delicious food to others, so what better way to honor his memory than by sharing these yummy treats!

Giustina Schiano, Board Member and Family Ambassador for the Foundation, was the Chairperson for the event which opened with a Blessing by Pastor Lou La Fazio, of Brielle, New Jersey.

The Welcome Dinner was a buffet of various "Tastes of Philadelphia", consisting of Philly cheesesteaks, Italian and Mexican dishes, and ended with desserts and famous Philadelphia Soft Pretzels.

Dr. Leslie Cooper, Co-Founder of the Foundation, spoke about Myocarditis, diagnosis and treatment.

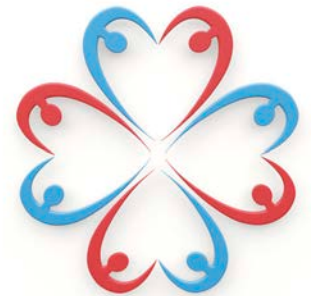
All attendees were invited to share their myocarditis stories with the others. It was a way to introduce themselves and to meet others who were so similarly affected by the disease that changed their lives forever.

Our meeting is truly like a family reunion... a family though that no one would ever want to be a part of and forever held together by the disease that has affected them all in one way or another.

The evening ended with a Candlelight Vigil, conducted by

(Continued Pg 4)

Dr. Taejoon Won, PhD 2018 Fellowship Grant Recipient with Vickie and Steve Lundy



Dr. Jack Price, Dr. Mario Deng, and Dr. Leslie Cooper



Group Picture of Audience

(Continued from Pg3)

Pastor Lou, remembering those we have lost and honoring our survivors.

The meeting had ended for the evening, but no one was looking to leave... The attendees felt very comfortable speaking with the others, as well as the Cardiologists and Researchers who were present to answer any questions they had.

Saturday's meeting opened with Candace Moose sharing the Myocarditis Foundation's beginnings.

The history of the Foundation's education efforts was shared by Genevieve Rumore, Executive Director, with emphasis on the past 2 years' efforts and the training of over 4,000 nurses and nurse practitioners on myocarditis, and how they could "think outside the box" to potentially diagnose early myocarditis. Without a single diagnostic tool to help them, myocarditis remains difficult to diagnose.

The Executive Director continued with explaining the Foundation's Research Fellowship Grant process. A plaque, honoring the Lundy Family for their tireless fundraising efforts, was awarded to Steven and Vickie Lundy. Through their efforts, a third named Research grant was awarded to Dr. Taejoon Won and named in memory of their 14-year-old son Rhett, whom they lost to Viral Myocarditis in 2014.

Dr. Taejoon Won, PhD, the 2018 MF Grant recipient, spoke to the families on his research that is being conducted at Johns Hopkins University, in Baltimore, Maryland. The families were very pleased to learn about the research and what it could mean in the future to help prevent myocarditis from occurring.

After a brief break, Dr. Mario Deng and Dr. Jack Price gave an update on the Myocarditis

Foundation Biobank, how it will work, and what it will mean to our families and on-going research.

The families then split up depending on whether they were survivors or if they had lost a loved one to myocarditis. Those who were survivors went to the Heart Failure Society Association's Family Education Day to participate in interactive educational sessions with leading experts in the field of diseases that can cause heart failure, of which myocarditis is one. Those who lost loved ones, remained at the Hilton Garden Inn, to participate in a workshop and engage and share with others while creating a unique collage of self-expression moderated by Carmela Schiano, a Certified Life Coach. These family members then joined the others at the HFSA to hear representatives from the FDA speak about Clinical Drug Trials

and how to improve involvement of the families/patients in the planning process.

The closing dinner was held at a local restaurant where our families shared that they were looking forward to meeting again next year.

Joseph Rumore, President of the Foundation, thanked the families for attending. A big thank you was also given to Giustina Schiano, a MF Board Member and Family Ambassador, for her tireless efforts in making the Family Support Meeting such a huge success. The Myocarditis Foundation would like to say a big thank you to all of you who attended our meetings.

BPA Linked to Immune Cell Activation in Female Mice

In a new study, researchers on Mayo Clinic's Florida campus found that exposing female mice to the chemical bisphenol A (BPA) increased their risk of myocarditis, a rare inflammatory heart disease usually triggered by a virus.

BPA is commonly found in plastic food and beverage containers; people can ingest BPA when it seeps into what they eat and drink. The Food and Drug Administration states that BPA is safe at the low levels that occur in these exposures. But some concerns remain: for example, people with higher exposures such as workers in plastic-related manufacturing jobs or salesclerks handling BPA-coated receipts could be at risk of adverse effects to the endocrine system.

"We began this study because we know that sex hormones influence the development of myocarditis, so we wanted to explore whether an endocrine disruptor such as BPA could play a role," says principal investigator DeLisa Fairweather, Ph.D., a Mayo Clinic cardiovascular researcher.

In the main experiment, Mayo researchers and collaborators at Johns Hopkins added a human-relevant dose of BPA to the drinking water of female mice for two weeks. Control mice were given drinking water without BPA added. Compared to controls, the BPA-exposed animals experienced an increased incidence of myocarditis after exposure to a viral infection capable of inducing the disease. The scientists attribute this

finding to BPA's ability to alter estrogen receptors.

Dr. Fairweather and team also found evidence of an activated immune response in BPA-exposed animals, namely, an increase in cardiac mast cells, which are associated with cardiovascular disease.

In a separate experiment, the researchers compared female

"Mast cell activation like the kind observed in this study is linked to a variety of major conditions including additional types of heart disease, autoimmune disease, and more," says Dr. Fairweather. "It's possible that plastic exposure could play a role in all of these diseases."

The authors note that further work is needed to confirm their

results in humans. As a next step, Dr. Fairweather and colleagues hope to test whether BPA levels in the blood of myocarditis patients correlate with signs of heart failure. They are also investigating the effect of BPA exposure in male mice.

In addition, because of the ability for viruses to cause myocarditis, the researchers say that elevated BPA exposure just prior to viral infection – as opposed to lifetime exposure – may be important to explore.

The study was published in *Frontiers in Endocrinology*. It received funding from the National Institutes of Health and Mayo Clinic Center for Regenerative Medicine.

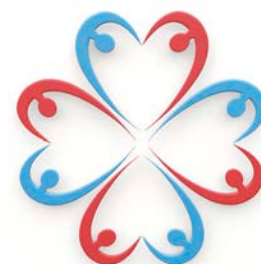


First author Katelyn Bruno, Ph.D., and senior author DeLisa Fairweather, Ph.D.

mice housed in traditional plastic caging with plastic water bottles, to animals housed in glass cages with glass water bottles. In this portion of their study, they did not add BPA to any animals' drinking water. The investigators found that animals in plastic dwellings experienced increased mast cell activation compared to those in glass houses. "This suggests that contact with plastic is all that's needed to induce a response," says Mayo cardiovascular researcher and the paper's lead author, Katelyn Bruno, Ph.D.



Dr. Fairweather's Translational Cardiovascular Disease Research lab works to understand the beginnings of diseases characterized by sex differences. They hope to discover new therapies and diagnostic techniques for patients with myocarditis and other cardiovascular and autoimmune diseases.



Speaking Schedules

DR. DELISA FAIRWEATHER:

December 11, 2019

Invited Speaker: *Transforming clinical care using translational studies in myocarditis/DCM*
Center for Clinical and Translational Science
Mayo Clinic, Rochester, Minnesota

April 14, 2020

Invited Speaker: *The role of mitochondria in the pathogenesis of myocarditis and DCM.*
University of Oklahoma Health Sciences Center,
Department of Microbiology and Immunology
Seminar Series
Oklahoma City, Oklahoma.

May 5, 2020

Invited Speaker: *Using regenerative medicine to heal myocardial inflammation*
Organization for the Study of Sex Differences
Annual Meeting
Del Mar, California

EVENT

Sarah Knight Golf Outing was a Record-Breaking Event

The Myocarditis Foundation cannot thank the Knight Family enough for all that they have done to raise awareness and funds for us to continue our Mission of Education, Research and Emotional Support for those affected by myocarditis.

The Knight Family have been strong supporters of the Myocarditis Foundation since losing their daughter and sister to Viral Myocarditis in September of 2011. They hold an annual Golf Outing in her memory at Hunter's Ridge Golf Course in Marion, Iowa and have set the date for next year's event for June 12, 2020!

Sarah was a teacher in the bilingual/bicultural program at East Moline Schools and their Foundation also supports Students at Hillcrest Elementary

School as well as supporting a scholarship in her name at Western Illinois University. The Knights had worked to raise funds to support a Research Grant in Sarah's name and accomplished that in 2017. Realizing the importance that research plays in finding the answers that can stop this disease from devastating other families, they decided to continue their efforts to fund another Grant in Sarah's name. They accomplished that again in 2019 in addition to supporting their other worthy causes!

Dr. Paul Hanson, PhD, the Researcher who received the initial Grant in Sarah's name, spoke at the event about his research and work on developing a biomarker to provide a simple blood test to diagnose myocarditis.

The Knight Family stated that they never dreamed that the impact that Sarah's Tournament would be so profound. In the words of Sarah Knight, "What would you attempt to do if you knew you could not fail?"

Thank you again to the Knight Family for all that they have done to help us work towards finding the answers to stopping this disease.



The Knight Family

EVENT

12TH Annual Myocarditis Foundation Golf Outing

Arcola Country Club, in Paramus, New Jersey, once again hosted the 12th Annual Golf Outing on Monday August 12, 2019. The day was picture perfect for the 95 golfers who participated, many of whom were repeat supporters.

Louis Romano, Jr, Treasurer of the Foundation, and Joseph Rumore, President, were co-chairs of the event. Lou and Joe spoke about how far the Myocarditis Foundation has come since the event was started in 2008, and where the Foundation is moving forward with our institution of a Myocarditis specific Biobank. They thanked the attendees, many who have been with us every year for the event, stating that the gains that we are making in the Foundation are a direct result of their contributions.

Kevin Breslin, spokesperson for the Breslin Family, a Major Event

Sponsor, stated: "The Myocarditis Foundation is a world class organization and yesterday's golf outing was fantastic and could not have been better."

Renee Cirelli, Marketing Solutions Manager for NJ Advance Media who also was an Event Sponsor, stated the following: "The golf outing was great as always. As part of NJ Advance Media, I have the pleasure of working with the Myocarditis Foundation. Throughout the years of research and progression on the path to find a cure, we have been able to support the Myocarditis Foundation, not only by helping with their raising awareness of the disease but by attending events such as the Annual Gala and the Golf Event. These events are key because it allows everyone to make a human connection and it shows the importance of the work being done by the

Myocarditis Foundation family, of which I am proud to be a part of."

The Myocarditis Foundation would like to thank everyone

who participated or donated in any way for their long-term support and commitment to the Foundation's Mission.



Tom Andrea, Jeff Ellis, Joe Rumore, Mike Lee.

Letter to Help Our Patients During Subsequent Emergency Room Visits



At our recent Family Meeting in Philadelphia, family members of young adults requested a form that could be kept in the wallet by those who previously had been diagnosed with Myocarditis. They specifically requested it for a young adult, as they are the ones often dismissed by Emergency Rooms to wait in the lobby when they present with chest pain or other symptoms that could be attributed to a vast number of everyday diseases. Often, even though they may state that they have been treated for a heart disease and mention the word myocarditis, they are not believed that their current symptoms could be attributed to that and are left to wait hours in a waiting room, if not sent home with a different diagnosis. Often, since the presenting symptoms can be similar to those of everyday viral syndromes, young adults are discharged after not being thoroughly checked out for a

reoccurrence of the disease. The thought process is often one where they do not believe that an otherwise young, healthy athletic person's chest discomfort or shortness of breath can be related to a cardiac issue.

The form would be used when at a different health care facility away from home, (often when

away at college) to show the Emergency Room Triage Nurse / Physician that they indeed had a history of cardiac problems and to not be taken lightly because of their age.

Please go to our website www.myocarditisfoundation.org to print off the form.



Patient Name:

Date of Birth:

Address:

Phone Number:

Allergies:

Medications:

I was diagnosed with:

Date of original diagnosis:

Hospital:

Phone :

Cardiologist:

Phone:

Emergency Contact:

Phone:

It is important to keep acute myocarditis in the differential diagnosis of a patient who presents with new signs or symptoms of acute heart failure (which can initially look like a viral syndrome with vomiting, diarrhea, cough, shortness of breath, fatigue...) especially in children and young adults.

Consider myocarditis in the setting of chest pain or heart failure symptoms.

Tests that may help diagnose Myocarditis include:

- B-type natriuretic peptide concentration (**BNP**) which will be elevated in Myocarditis, but it will not distinguish myocarditis from other causes of heart failure
- **Troponin I** concentration (may or may not be elevated in Myocarditis, especially in children)
- **Chest X-ray** (look for Cardiomegaly, pulmonary vascular congestion, pleural effusion)
- **EKG** (PR depression, decreased voltages, irregular rhythm, Heart block, ST segment changes)
- **Echocardiogram** (depressed left ventricular syst. function, mitral regurg., dilated left ventricle)
- **Cardiac MRI** can reveal myocardial edema and ischemia that often occurs in myocarditis

If acute myocarditis is suspected, referral to a cardiologist is recommended.

Please accept this as a request to acknowledge this patient's history and look to rule out another episode of the disease.

Early correct diagnosis of this disease leads to better outcomes for the patient.

www.myocarditisfoundation.org

UPDATE

Myocarditis Foundation Now Raising Awareness for Pericarditis

The Myocarditis Foundation is working to raise awareness about pericarditis, an underserved, painful and debilitating autoimmune-inflammatory cardiovascular disease. Approximately a third of people with pericarditis, also have heart muscle inflammation, called myocarditis. The Myocarditis Foundation is providing information about pericarditis on its website as an educational reference for patients and caregivers. In addition, the Myocarditis Foundation launched a free online interactive community for pericarditis patients and caregivers to support and connect them with each other.

"The Myocarditis Foundation is a mission-driven organization dedicated to saving the lives of patients with cardiovascular

diseases through education and scientific advancement," said Joseph C. Rumore, President and Chairman of the Board of the Myocarditis Foundation.

Pericarditis, in the acute form, accounts for $\geq 1\%$ of emergency department (ED) visits among patients with ST-segment elevation¹ and up to 4.4% of ED

visits for chest pain.

As documented in: Cardiology 1996; 87(1):60-66)



UPDATE

What exactly is Pericarditis?

There are many underlying conditions that may cause pains in your chest and other complications. About five percent of people who go to the emergency room with non-ischemic chest pain are diagnosed with pericarditis. This condition is still being researched in order to determine the best methods of diagnosis and treatment, but the Myocarditis Foundation is committed to raising awareness in order to encourage better outcomes for affected individuals today and in the future.

What causes Pericarditis?

Pericarditis occurs when the pericardium, a thin membrane around your heart, becomes swollen or inflamed. This can

cause layers of the pericardium to rub against each other, producing sharp chest pains. It can often be hard for doctors to decipher what caused the membrane to become inflamed, but some common causes include:

Viral infections

Trauma

Systemic inflammatory disorders

Certain medications

Complications from a heart attack

What are the symptoms of Pericarditis?

The sharp chest pain caused by the pericardium's layers rubbing against each other is the most common symptom of pericarditis, but you may experience others as

well. The pain in your chest may feel worse if you recline, inhale deeply or cough, while leaning forward can lessen the pain. You may also experience a low-grade fever, fatigue or weakness and heart palpitations.

Whenever you feel chest pains, make sure to visit a doctor immediately or dial 9-1-1 for emergency assistance. While many cases of pericarditis can go away without medical treatment, it can sometimes develop into a more serious condition called cardiac tamponade. This occurs when fluid collects in the pericardium, preventing the heart from filling properly and causing a drop in blood pressure that can be fatal. Receiving an early diagnosis can help prevent these

complications and help ensure that you aren't experiencing a more serious heart condition.

How is Pericarditis diagnosed?

In the United States, there is no consensus on diagnostic guidelines for doctors to follow when pericarditis is suspected. However, the European Society of Cardiology has outlined their criteria, which requires two of the four following symptoms to occur in order to be diagnosed:

Pericardial chest pain
Pericardial rubs, the sound created by the pericardial layers rubbing together
Widespread ST-segment elevation or PR-segment depression based on electrocardiogram findings
Pericardial effusion

Your doctor may also use imaging techniques, such as X-rays of your chest, echocardiograms or an MRI, as well as checking biomarkers of inflammation to further support their diagnosis.

If your symptoms last fewer than three weeks, you will be diagnosed with acute pericarditis. If you experience another episode of pain after a four- to six-week period of no symptoms, then the pericarditis is considered recurring. 20 to 30 percent of patients with acute pericarditis will have recurring symptoms. If the pain persists continually for longer than three months, the condition is considered chronic, which may cause fluid around your heart. Your doctor will work with you to determine the most accurate diagnosis and devise a treatment plan tailored to your specific condition and needs.

Additional information on Pericarditis

If you or a loved one have been diagnosed with pericarditis, it's important to access reliable sources of information about this condition. The sites below offer additional insights, and your doctor may also provide educational resources during treatment.

<https://my.clevelandclinic.org/health/diseases/17353-pericarditis>

<https://www.mayoclinic.org/diseases-conditions/pericarditis/diagnosis-treatment/drc-20352514>

<https://clinicaltrials.gov/ct2/show/NCT03737110>

How is pericarditis treated?

While there are no FDA-approved treatments for pericarditis as of now, there are still some common methods that doctors use to

relieve its symptoms. Over-the-counter (OTC) medications, such as aspirin and ibuprofen, can help reduce inflammation and minimize pain. Colchicine, an anti-inflammatory, may also be prescribed, but should not be taken by individuals with certain pre-existing conditions or who take some medications.

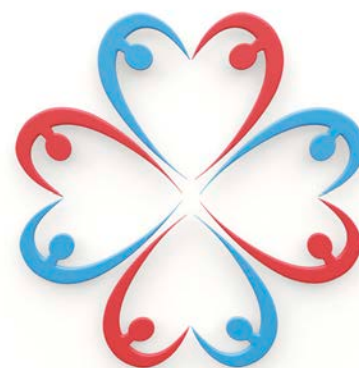
If OTC pain relievers and colchicine fail to produce results, your doctor may use corticosteroids, like prednisone, to eliminate inflammation. However, this treatment will likely be used as a last resort due to the potential side effects associated with corticosteroids. You may also receive antibiotics to clear up any contributing bacterial infections, and in some cases draining of accumulated fluids may be necessary.

Leading the Path to Discovery

While effective diagnosis and treatment are available, there is still much to learn about pericarditis. For almost 20 years, the Myocarditis Foundation has assisted in the effort to help discover cures for all forms of myocarditis and associated pericardial diseases, such as pericarditis. To learn more about these conditions, check out our research library and real life stories from those affected.

Ready to help find a cure?

Contact us today or make a donation to support our work.



PEDIATRIC MYOCARDITIS UPDATE / CLINICAL TRIAL

New Hope for Children With Myocarditis and Chronic Heart Failure

Acute viral myocarditis commonly leads to chronic heart failure in children. Approximately 1/3 of children who survive the acute phase of viral myocarditis will go on to live with diminished cardiac function and chronic heart failure.

A smaller number will require heart transplantation for longer survival.

Evidence-based heart failure therapies are lacking in pediatrics, forcing physicians to prescribe medications that have only been tested in adults. Only a few medical therapies have shown a survival benefit for adults with heart failure. A relatively new medication, sacubitril/valsartan (Entresto®), has been shown to

reduce the risk of death or rehospitalization in adults with chronic heart failure compared to the standard drug enalapril.

This month, the U.S. Food and Drug Administration (FDA) approved the use of sacubitril/valsartan for the treatment of symptomatic heart failure in children >1 year of age. The FDA's decision was based on preliminary findings from the PANORAMA-HF trial in children. In pediatric patients who were treated with sacubitril/valsartan, the cardiac biomarker NT-proBNP was reduced after 12 weeks of therapy. NT-proBNP is a hormone that circulates in high concentration in patients with symptomatic

heart failure. A decrease in the concentration is thought to infer improved cardiovascular outcomes.

Novartis is the pharmaceutical company that produces sacubitril/valsartan (Entresto®) and is sponsoring the PANORAMA-HF trial. The trial is the largest prospective pediatric heart failure medication study to date and is being conducted in 39 countries and 129 clinical sites across North America, Europe, Asia and Latin America. A press statement this week from Novartis stated that the company is committed to the trial completion and collection of 52-week follow up data for the study participants. The trial is expected to be completed in 2021.



Dr. Jack Price

Dr. Leslie Cooper Speaking Schedules

November 7-8, 2019

Heart Failure Symposium
Advocate Christ Medical Center
Chicago, IL

November 15, 2019

Pulmonary Grand Rounds
UF Health
Gainesville, FL

November 21, 2019

UF Health Heart Failure Grand
Rounds:
UF Health
Jacksonville, FL

February 7-9, 2020

Nephrocardiology Conference;
Gaylord Palms Resort
Orlando, FL

February 13-15, 2020

Colombian Society of Cardiology and
Cardiovascular Surgery;
Barranquillo, Colombia

February 13-15, 2020

Heart Failure 2020 Symposium
Los Angeles, CA



*Each year thousands of young lives, like these, are lost suddenly and unexpectedly to the heart disease myocarditis. We at the Myocarditis Foundation work to advance research and spread awareness and education about this devastating disease. Please **DONATE** today.*

EVENT

Austin Vonckx Fundraiser in Tampa, Florida

Brenda Barrett Vonckx has been tirelessly raising awareness and funds for the Myocarditis Foundation over the 5 years since she lost her son Austin at the age of 19, to Viral Myocarditis. Brenda speaks to anyone she can about myocarditis and hands them a small business card with Austin's picture and a few lines about the Myocarditis Foundation, encouraging them to go to our website, find out more about us and asking them to make a donation in his memory. Her fundraisers are often small

intimate groups of friends where she remembers Austin's memory and his love of life, and the importance of finding the answers to stopping this disease we know as myocarditis. Brenda has been a leader in Central Florida and now North Carolina in raising awareness for the Myocarditis Foundation. Thank you, Brenda, for all that you do to help support the Myocarditis Foundation.



Genevieve Rumore and Brenda Vonckx

Events

June 12, 2020

Sarah Knight Memorial Golf Tournament
Marion, Iowa

June 25, 2020

5th Annual Myocarditis Foundation
Gala Fundraiser
NYC

August 17th, 2020

13th Annual Myocarditis Foundation
Golf Outing
Paramus, NJ

Annual Appeal Letter from Candace Moose



Dear Myocarditis Families, Donors and Supporters,
Fall 2019

As we approach the holiday season, I want you to consider placing the Myocarditis Foundation (MF) at the top of your gift list.

Why? Because myocarditis is a rare disease that does not receive the funding it deserves.

Why? Because young, healthy pregnant women, babies, children, and young adults are most commonly the victims.

Why? Because the MF is the only organization worldwide that is dedicated solely to saving more lives from myocarditis.

Why? Most importantly, because one child or loved one who suffers or dies from this tragic, random disease is one too many.

Since our inception in 2005, the MF remains committed to its original mission of:

- Serving patients and families who have lost loved ones
- Funding research grants to advance our understanding of this tragic disease
- Educating physicians and the public about the disease

Our goal remains the same: To Save More Lives

Is there more work to be done? ABSOLUTELY, but we can't do it without your help!

Each time I hear of yet another child or loved one, who has fallen victim, I realize that we are not progressing fast enough.

If you are the kind of person who gives at year-end to charitable organizations, please make the Myocarditis Foundation one of them.

If you have given to us before, please do so again.

If you have given us the same amount every year, please consider increasing your donation.

Consider making a general donation or direct your giving toward one of the following initiatives:

- A donation of \$40,000 will fund a research grant.
- A donation of \$30,000 will fund a part-time Study Manager to oversee our BioBank blood sample collection protocol for one year.
- A donation of \$10,000 will fund an educational program that will allow us to educate more nurses and nurse practitioners about how to identify myocarditis.
- A \$2,000 donation will cover the cost of identifying, consenting, collecting sample and data, shipping, processing and storing one BioBank blood sample which will be made available to researchers.
- A donation of \$500 will pay for much-needed Myocarditis Education to be made available to Emergency Room personnel, facilitating a quicker diagnostic evaluation.

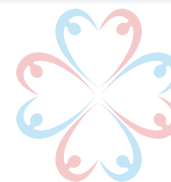
All of these initiatives are geared to saving more lives. Please join us in this fight. We won't rest until we find a cure.

Sincerely,

Candace C. Moose, Co-Founder
Giant Cell Myocarditis Survivor
18 Year Post Heart Transplant



MYOCARDITIS FOUNDATION



Board of Directors 2019

JOSEPH RUMORE

President

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

CHRISTOPHER CORSO

Vice-President

Senior Reinsurance Officer, AXA XL and father to a Myocarditis Survivor

CANDACE MOOSE, RN, BSN, MEd

Secretary and Founder

Giant Cell Myocarditis Survivor and Heart Transplant Recipient

LOUIS ROMANO, JR.

Chief Financial Officer

Owner of HomeWell Senior Care

LESLIE COOPER, MD

Medical Director, Founder

Chair, Enterprise Department of Cardiovascular Medicine for Mayo Clinic

JACK PRICE, MD

Director

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

JOEL ARANSON

Director

Founder and Chairman of National Sporting Good Corporation and father to a Myocarditis Victim

FRANCINE ANDREA

Director

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

GIUSTINA SCHIANO

Director, Family Ambassador

Mother to a Myocarditis Victim

Executive Director

GENEVIEVE RUMORE, RN, BSN

Kingwood, Texas

Director of Communications and Assistant to the Secretary

DR. KATELYN BRUNO

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