KNOWLEDGE NURTURES HOPE

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MYOCARDITIS
FOUNDATION

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

UPDATE ON COVID-19

Myocarditis Following COVID Vaccine

There has been so much confusion on what is the true incidence of Myocarditis post COVID-19 vaccination over the past few years. As you know, research takes time. Information needs to be collected and evaluated before the information can be documented and shared.

Dr. Bettina Heidecker, one of our Myocarditis Foundation Board members, conducted a study with 17 other myocarditis researchers across Europe and the United States on the incidence of Myocarditis following COVID-19 vaccine. This publication put into perspective the incidence, presentation, diagnosis, pathophysiology, therapy, and outcomes. It is supported by the Heart Failure Association of the European Society of Cardiology (ESC) and the ESC Working Group on Myocardial and Pericardial Diseases. It was recently published in the European Journal of Heart Failure 2022, and we will share some of the highlighted points with you below.

As we know, the rapid spread of coronavirus 2019 (COVID-19), which overwhelmed healthcare systems around the world within weeks, required the rapid development and introduction of novel methods of disease prevention and treatment. Vaccines that used a broad range of different technologies had been developed with an unprecedented speed, were tested in large randomized clinical trials, and utilized broadly once Emergency Use Authorization had been granted to reduce the spread of the infection with the goal of achieving immunity across the entire population. As of recently, more than 10 billion doses have been administered worldwide.

One of the most discussed complications of the vaccines affecting the heart is myocarditis and/or pericarditis. The goal of this current review article is to provide clinicians and scientists with an objective and comprehensive overview of the data regarding the clinical presentation, diagnosis, pathophysiology, and management of myocarditis following the most widely utilized COVID-19 Vaccines.

Rates of vaccine-associated myocarditis vary by age and sex with the highest rates in males between 12 and 39 years. The clinical course is generally mild with rare cases of left ventricular dysfunction, heart failure and arrythmias. Mild cases are likely underdiagnosed as Cardiac MRI is not commonly performed even in suspected cases, and not at all in asymptomatic and mildly symptomatic patients. CMR is the best non-invasive diagnostic tool with endomyocardial biopsy being restricted to severe cases with heart failure and/or arrythmias. In all age groups studied, the overall risks of COVID-19 related hospitalizations and death are hugely greater than the risks from post-vaccine myocarditis.

While they overall believe through the studies that COVID-19 Vaccines are very

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UPDATE ON COVID-19

Myocarditis Following COVID Vaccine (continued)

safe, there is a low but consistent, tangible rate of post-vaccination myocarditis and/or pericarditis identified in several national and international level studies. Whilst there can be no room for complacency, fortunately, the majority are mild and not associated with hospitalization or severe complications. This risk must be balanced against the much greater risk of death, pulmonary, vascular, and cardiac complications by the COVID-19 virus itself.

Overall, the risk/benefit ratio hugely remains in favor of vaccination for most classes of ages, especially in older adults.

For the medical community, a key red flag is in identifying affected individuals (i.e., particularly young men) presenting with chest pain, palpitations, or shortness of breath within 7 days of the second dose of an mRNA vaccine. Management is largely supportive for most affected individuals unless there is evidence of heart failure or major arrhythmic episodes.

However, there is a greater need to better understand the mechanisms if cardiac injury from these vaccines. Why and how precisely do COVID-19 vaccines cause myocarditis and myo/pericarditis, and how do they differ from COVID-19 infection related myocarditis?

In those that have developed myocarditis after the first dose of the vaccine, there needs to be more evidence on when they should receive a second dose of the vaccine.

Also, there is not a clear sense of the long-term implications of post-vaccine myocarditis.

Future work should focus on the mechanistic basis for myocarditis and in identifying those at an increased risk of adverse outcomes in need of closer long-term monitoring.

Please go to the Blog section of our website, **www.myocarditisfoundation.org** to read the full article.

EVENTS

2022 Family Meeting at National Harbor, Maryland

Our Family Meeting was successfully held on Friday September 30th & Saturday October 1st, despite the havoc that Hurricane Ian caused to our Agenda.

While a few of our participants, as well as a few of our speakers, had to back out of attending due to emergencies at home due to the storm, we had a very successful meeting. Other specialists stepped in to help us out which we sincerely thank them for.

There were only two families who were previous attendees. Most of our attendees had never attended the Foundation's in-person meetings before and expressed their thanks for bringing them together with others who are dealing with similar situations. They had no idea how much that having this opportunity to participate and speak with other families, specialists, and researchers would mean to them when they signed up to attend.

Not only were the families impacted positively, the specialists and researchers were as well. Only two of our speakers had knowledge of how our meetings are planned out around our patients and families as well. They too, were so grateful for the knowledge given them about our family and patient stories, and how we support them. Our corporate sponsors, who were initially planning on only participating on Friday and for a short time on Saturday, asked if they could stay for the entire meeting. They were so touched by the family stories and what the Foundation was doing to help them navigate through their concerns related to myocarditis. They decided to stay for the whole meeting and participate in the break-out round table discussions both for the survivors and the families who lost loved ones.

We had much more interest from the medical community, which I attribute to the recent outpouring of interest in myocarditis, post pandemic. Dr. Cooper shared that all the corporate sponsor representatives who attended and participated, later approached him at the HFSA to relate their positive feedback on the meeting. We are looking forward to planning for even more corporate sponsorships in the future. Not only can they help us carry out our mission but for them to also learn more about the Myocarditis Foundation and what we do to help those who are affected by the disease.

We look forward to our next in-person Family Meeting, which is being planned for early October 2023 near the Huntington Convention Center of Cleveland, Ohio.

The tentative dates are: Friday October 6th & Saturday October 7th, 2023.

Come see and hear from our other families, specialists and researchers, and plan to see the Rock & Roll Hall of Fame while you are there!

EVENTS

The 15th Annual Myocarditis Foundation Golf Outing was a Huge Success!

Monday July 15th was the 15th Annual Myocarditis Foundation Golf Outing at Arcola Country Club in Paramus, NJ. We had 120 golfers, many of whom were returning supporters of the Foundation. 30 additional supporters joined us for the dinner, raffle / silent auction portion of the evening.

We could not have accomplished the success of our fundraiser, a day of golf and fun, without the support our sponsors, participants, and volunteers.

The sponsors of the event included:

Town Title, Morgan Stanley The Trilogy Group, MSPC Certified Public Accountants, the Linn Family, RT Specialty Group, Peter Christou / First Trust, Home Well Cares, Jordan Wright, Quality Auto, Cardiol Therapeutics, Inc., Kiniksa Pharmaceuticals, NJM Insurance Group, Albergo Law Group, Liberty Contracting, B&M Market, Whalen & Ives, John Philip Foundation, James & Candace Moose, Joseph & Genevieve Rumore, Michael A. Linn, Mike Petruccelli, Sr., Jack Conover, and Donald Onorato.

Dr. Leslie Cooper was to be our Guest Speaker, but unfortunately was unable to attend. Instead he sent his speech which was shared by Genevieve Rumore, the Executive Director. He spoke of his personal experience with a Giant Cell Myocarditis (GCM) patient when he was in his medical residency that became the focus of his professional energy thereafter. His work in GCM research led to treatments that have made dramatic improvements in the lives of GCM patients. From GCM usually being diagnosed on autopsy, it now has an overall survival rate of 90% at 1 year after diagnosis.

Candace Moose, Co-Founder of the Myocarditis Foundation, spoke about how Joseph Rumore came to join the Myocarditis Foundation soon after its inception and all that he has done to help move the MF forward over the past 16 years that he has been a part of it. The entire room gave him a standing ovation for his work at the Foundation and the 15 years of the Golf Outing's success. It has become the largest fundraiser for the MF and looked forward to by so many repeat participants.

The John Philips' Foundation attendees spoke about their friend, John Mello, for whom their foundation was formed for and who died a few years ago of Viral Myocarditis. They spoke about how the Myocarditis Foundation was able to help and support them in the early days of dealing with their loss. They now work on helping raise awareness and research dollars to prevent others from suffering the effects of myocarditis.

UPDATE

Congratulations To Dr. Delisa Fairweather, PhD. And Dr. Katelyn Bruno, PhD. On Their Distinguished HFSA Fellowship Designations

Fellowship is one of the most distinguished designations the Heart Failure Society of America (HFSA) can offer its members. It is a tremendous recognition of professional achievement and contributions to the society. The designation is based on outstanding credentials, achievements, and contributions to heart failure medicine.

Dr. Fairweather, PhD., is Director of Translational Research in the Dept. of Cardiovascular Medicine at Mayo Clinic in Jacksonville, Florida. She has worked with the Myocarditis Foundation for many years and is on our Medical Advisory Board. She has recently received a RO1

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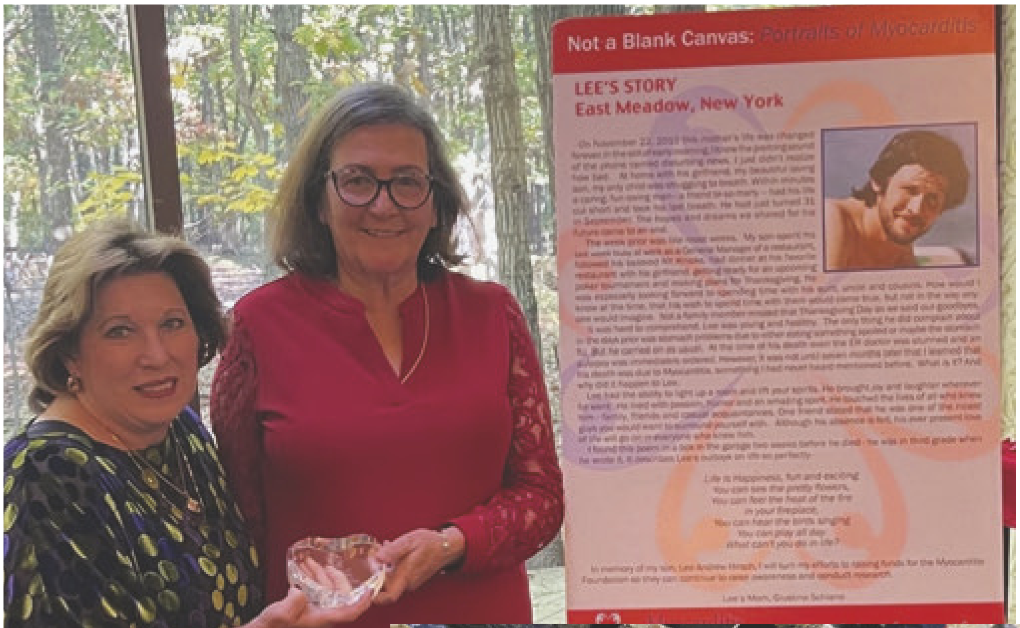
EVENT

The King of Hearts Fundraiser, in Celebration of a Life Well Lived!

Sunday October 16, 2022 was the 3rd King of Hearts Fundraiser in memory of Lee Andrew Hirsch, which was held at Nicotra's Ballroom in the Staten Island Hilton, NYC, to benefit the Myocarditis Foundation. There were 133 attendees who participated in the festivities. So many generous donations were made from 114 donors to enable the 104 amazing gift baskets for the raffle tables! It took a village of family and friends to put this all together, with Giustina Schiano as the chairperson.

Featured Guest Speakers included:

- Dr. Leslie Cooper, MD, the Foundation's Chief Medical Director, and Co-Founder, who is the Chair of the Cardiovascular Medicine Dept, at Mayo Clinic, Florida.
- Dr. Danette Flint, MD, Cardiologist and Myocarditis Researcher at Dartmouth-Hitchcock Medical Center, who was awarded the Myocarditis Foundation's Fellowship Grant in 2019, in memory of Lee Andrew Hirsch.
- Candace Moose, Co-Founder of the Myocarditis Foundation, a Giant Cell Myocarditis Survivor and Heart Transplant Recipient.



The Myocarditis Foundation presented an award to Giustina Schiano for all her efforts in raising awareness for Myocarditis and the funding needed for Dr. Flint's fellowship grant. The funding enabled Dr. Flint to have dedicated research time during her critical care fellowship and early faculty career to pursue research on a larger scale, using a database of more than 40,000 patients. She will be submitting a manuscript for publication this month on her research. The funding provided by the Myocarditis Foundation in honor of Lee Andrew Hirsch has had and will have a domino effect, promoting ongoing research beyond its initial scope.

Some comments from the attendees were: It was a first-class affair; they were impressed that the Myocarditis Foundation was present and engaged in the event; Please don't wait two years for the next one, we want to see you again next year!

The Foundation thanks Giustina Schiano for all her efforts to make this such a successful event!

UPDATE

Congratulations To Dr. Delisa Fairweather, PhD. And Dr. Katelyn Bruno, PhD. (continued)

Grant from the National Institute of Health to further her research. Funding for this type of grant is extremely competitive, and only 10% of the grant requests are funded. Often an RO1 grant is behind many "best practices" and interventions considered "standard of care". Her RO1 grant research is on Sex Differences in Mitochondria.

Dr. Katelyn Bruno, PhD., is an Assistant Professor of Cardiovascular Medicine in the Division of Cardiovascular Medicine (Department of Medicine), Department of Physiology and Aging and Center for Regenerative Medicine at the University of Florida. She too has worked with the Myocarditis Foundation in various capacities for several years and is currently the Secretary to the Medical Advisory Board.

The Myocarditis Foundation would like to congratulate and thank them both for all that they have done to further the science of Myocarditis.

FUNDRAISER

A Big Sister's Gift to the Myocarditis Foundation

Little Brother:

Mark Ryan Summers was a 17-year-old high school senior set to graduate that year, Class of 2012. He was into everything tech and was amazing with a computer. He loved playing card games with his friends and was the best son and brother his family could ask for.

Mark wasn't feeling well for a few days, so on Tuesday February 7th his mom took him to the ER because he was complaining of some chest pain along with just feeling sick. They did an EKG, and were told that everything was good. The ER sent him home with the advice of taking some cold meds and Tums.

On Sunday February 12th, 2012 Mark passed away peacefully in his sleep. While his family believes that everything happens for a reason, had those doctors at their local hospital been more aware of Myocarditis in children and young adults, then maybe things would be different today and Mark would have been physically at their wedding.

If only those doctors had done a Troponin Level or looked further to see the real cause of Mark's chest pain…

On the other hand, maybe the damage to his heart was already too much. They will never know…

This is why the Summers' family feel the work of the Myocarditis Foundation is so important. Awareness is key!

They enjoy talking about Mark any chance they get… it keeps his memory alive in all of them. It also keeps the awareness of Myocarditis going!

Big Sister:

Jodi, Mark's older sister, was planning her wedding to an amazing man named Adam. Although Adam had only met Mark a few times, he knew how important he was to their family. Adam talks about him to others to spread the awareness as well.

Mark's mother, Susan Summers and his sister Jodi have been huge supporters of the Foundation since finding it when Mark passed away back in 2012. Adam and Jodi decided that for their wedding, they would ask guests not to bring cards filled with money or to bring gifts. They felt that everyone's presence on that day was truly a gift in and of itself.

However, if their guests felt the absolute need to gift them with something, they asked them to please donate to the Myocarditis Foundation in memory of Mark.

The Myocarditis Foundation received over $3,000 in memory of Mark!

Jodi and Adam are extremely thankful to everyone that donated and very proud to do their part in raising support for the Myocarditis Foundation so that they can continue to do all that they do for patients and families affected by Myocarditis.

Congratulations and many thanks to the new Mr. & Mrs. Adam Pattisall.

EDUCATION

Myocarditis Study

The Myocarditis Study on Anxiety and Depression, in conjunction with the Mayo Clinic, continues to enroll participants. At our recent Family Meeting, in National Harbor, Maryland, we heard from many of our participants that not only do the patients, but the caregivers as well, have been suffering from the stress of dealing with myocarditis. We truly need to show how impactful this disease is all around.

PLEASE consider participating in this very important study. Even as a caregiver of a current or previous myocarditis patient. This vital information will be used for Worldwide help of Myocarditis Patients and Caregivers.

This research study is being done at the Mayo Clinic and has zero effect on your clinical care or any caregiver's future health care at Mayo Clinic. With that said, if you can think of any Caregiver, parent, spouse, friend, sibling that might be interested please give them Daniel Smith's contact information. Thank you so much for your time and completing the study.

Daniel G. Smith
Associate Clinical Research Coordinator

Department of Psychiatry & Psychology

Smith.Daniel3@Mayo.edu or **507-255-0760**.

BOARD OF DIRECTORS

Myocarditis Foundation Welcomes New Member To Their Board Of Directors

Jamie Giani , Director

Millie Rose

Jaime Giani has been following the Myocarditis Foundation for a few years since the loss of her 5-year-old daughter, Millie Rose, to Viral Myocarditis and Sepsis in 2019. She was devastated as any parent would be and decided that she wanted to raise awareness for myocarditis and support the mission of the Myocarditis Foundation in memory and honor of Millie Rose.

Jaime is an attorney and federal court administrator in Arkansas. She is married to Patricio and has two other children, Nora and Gio.

Please join us in welcoming Jaime to our Myocarditis Foundation Family and Board of Directors. We know that her breath of experience and understanding of legal matters will provide additional leadership in moving our mission forward!

MYOCARDITIS
FOUNDATION

Donate Today!

Dear Friend of the Myocarditis Foundation,

This past year we have had a flood of visitors to our website looking for information on myocarditis as well as a large increase in emails and phone calls into the office for information that they can't obtain anywhere else.

We pride ourselves not as a "donation" based website, but as the most current, relevant information and help site. We do not ask for donations as others so often do such as…"If you liked what you have learned, please consider making a donation to ….".

The Myocarditis Foundation website is packed with information, and we would hope that people would understand that the only way we can continue to provide help this way to those that reach out for it is through donations.

We don't have any other form of revenue other than a few corporate grants that we solicit for various specific events, and those are not guaranteed.

If we had even a dollar from everyone that visits our website, we would be so much more secure in ensuring that we could continue to do what we do, for the thousands that need us.

Perhaps this has happened to you recently or in the past?

When people are lucky enough to be given the diagnosis of myocarditis and discharged home, they always comment that they do not receive much information at all, just to "take it easy".

Then they go to the computer and type in myocarditis. They find us at the Myocarditis Foundation, our website, email, and phone number. They so frequently tell us that they have learned more from us and our website than they have from the doctor or the hospital.

Sadly, the state of our economy after the COVID Pandemic has hurt our donation numbers and the dollar amounts of them as well. We are asking this year, if you could spare even a small amount as a donation on a monthly recurring basis, not only would it help keep our mission going but it would help those thousands of people who seek out the information and help that they so desperately need about myocarditis while they are going through it.

Please remember these statistics:

Myocarditis is the 3rd leading cause of Sudden Death in Children & Young Adults and accounts for 45% of Heart Transplants in the U.S.

We've lost too many to this dreaded disease…please help us stop this.

Please be there for us,
for those that suffer,
and for the families of those that have succumbed.

To continue our commitment to battling myocarditis, & bringing a 24/7 service response, we need your help.

Myocarditis Foundation is recognized as a Platinum level charity.

I hope you will consider making-a-donation today to support our ongoing efforts.

THANK YOU!

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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JUSTIN GODOWN, MD
Medical Director of Pediatric Cardiomyopathy and Cardio-Oncology; Assistant Professor & Practicing Pediatric Cardiologist at Monroe Carell Jr. Children's Hospital at Vanderbilt, Nashville, TN

Secretary to our Medical Advisory Board

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