

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



MYOCARDITIS
FOUNDATION

UPDATE

**COVID-19 One Year Later...
What Do We Know About It and Your Heart?**

Coronaviruses are known to cause respiratory or intestinal infections in humans and animals. According to data from previous coronavirus epidemics (SARS and MERS), these viral infections lead to mainly pulmonary complications such as pneumonia.

Fast forward to 2020 and now we have the (SARS-CoV-2 Virus) which causes COVID-19, and in some instances myocarditis.

The effects of COVID-19 on the lungs are well known. COVID-19 was initially believed to be a respiratory illness that only caused respiratory symptoms, at times severe, many times relating to a person's age and medical co-morbidities. As the COVID-19 Pandemic progressed, more information was learned about the cardiac effects as well.

One of the leading causes of myocarditis is a viral infection, such as influenza. When the COVID-19 pandemic hit the U.S., fear grew about the potential impact that it could cause to myocarditis rates, especially among young athletes. This worry fueled many debates over the resumption of NCAA athletics seasons. But as more and more data became available throughout the year the theories changed to believe that myocarditis may not actually be a huge byproduct of the virus.

In a published study in September 2020, researchers believed that up to 15% of COVID-19 patients suffered from myocarditis. However, in a more recent study published in JAMA Cardiology, Dr. Jonathan Kim, MD, Chief of Sports Cardiology at Emory University School of Medicine, found that few cases of inflammatory heart disease (of which one is myocarditis) were found. However, while there were few instances of myocarditis, something abnormal kept showing up on cardiac imaging, even for patients with mild or moderate COVID-19 cases.

Dr. Leslie Cooper, Chair of the Mayo Clinic Department of Cardiovascular Medicine and a founder of the Myocarditis Foundation, reported the following: "In all these imaging findings and MRI's, we're seeing something else. Now we do not know what that something else is, it could be an edema, extra fluid from leaky blood vessels. We also don't know the clinical impact. Do you get a higher risk of death, or a higher risk of heart failure if you exercise following COVID-19?"

At present, there are at least 10 MRI registry studies in the U.S. looking at pinpointing the long-term damage from a cardiology standpoint from COVID-19. Dr. Kim reported that certainly with the rigorous

screening recommendations that are out there (in college and professional athletic programs), he believes that we should have more information coming out shortly.

The 3 to 6 month recommendation for athletes to not exercise and have cardiac rest is not necessarily based on rigorous evidence. This is clearly time that will allow the inflammation to resolve itself. Intense physical activity following a myocarditis diagnosis could make the inflammation worse, increasing the risk substantially of dangerous heart rhythms and sudden cardiac arrest. In terms of why for some it is 3 months and others it is 6 months may just be dependent on how significant of a clinical myocarditis course that individual athlete had. In that time period there would be testing before the athlete is able to go back into play.

For young athletes who have had a COVID infection, regardless of the symptoms, be mindful in the weeks following the infection for shortness of breath from activity, palpitations or chest pain. If you develop one of those symptoms you should seek medical evaluations for cardiac or pulmonary reasons.

Current reports state that 40-50% of COVID-19 hospitalized patients still feel shortness of breath 2 months after discharge.

Clearly, science needs more time to understand the myocarditis and COVID-19 relationship. In the meanwhile, caution is the key. One of the challenges in myocarditis is that the prevalence, even before the COVID-19 pandemic, is not truly known because the majority of cases go undetected because the patients do not even know themselves that they had it.

Dr. Cooper's advice is to pay attention to your stamina and condition and always consider what could be happening.

References:

1. *Walter, Kenny; (March 10, 2021); HCP Live: Science Needs More Time to Understand Myocarditis and COVID-19*
2. *Saleh, Ahmed; Matsumori, Akira; Abdelrazek, Sherif; Eltaweel, Sara; Salous, Amjad; Neumann, Franz-Josef; Antz, Matthias; Myocarditis Involvement in Coronavirus Disease 19; Springer Nature 2020*



INTRODUCTIONS

Myocarditis Foundation Office Staff



Melissa Graham

Melissa Graham has been with the Foundation, behind the scenes, since the later part of 2018. Melissa's position has transitioned and helped the office grow over the past two and a half years. She is responsible for the office operations, the implementation of our outreach programs and the management of our social media needs. Many of you have benefited from her help for your fundraising efforts and special projects. Melissa works closely with our vendors, especially our SEO contractor who has been helping us update and grow our website. Melissa helps direct you to the correct person for your needs and is always ready and willing to go the extra mile to get a project done. Melissa is an integral part of our success. Welcome and thank you Melissa for all that you do!

Additions to the Myocarditis Board of Directors



Dr. Heidecker

Dr. Heidecker has been on our Medical Advisory Board since 2016 and has now transitioned to our Board of Directors.

Following her clinical training in the United States, Dr. Heidecker returned to Europe, where she joined Thomas F. Lüscher, MD as a cardiologist at the University Hospital Zurich. With his support, she established a clinic for myocarditis, a highly productive research team and a biobank for myocarditis. Many publications in the field of myocarditis resulted from that time.

In 2018, Dr. Heidecker accepted a position in the division of cardiology at the Charite, University Hospital Berlin led by Ulf. Landmesser, MD, where she became the head of heart failure and cardiomyopathies at the Campus Benjamin Franklin. Myocarditis continues to be her main subject of research, with the goal to detect the disease at an early stage and to treat it with a personalized approach to get the best possible outcome for each individual patient.

The Foundation is very happy to now have her as a member of our Board of Directors!

Gary Kubera has been following the Myocarditis Foundation for a few years while participating in events and monitoring its growth. Hearing the stories of its victims as well as survivors, has inspired him to want to make a difference and contribute to the work of the Foundation. Gary has spent over 30 years as a chemical industry executive and CEO before (semi) retiring in 2017. By bringing his background as an industry investment advisor, consultant and executive coach to the Myocarditis Foundation Board of Directors, he hopes to help the mission grow. Gary is a graduate of The University of Chicago and Ithaca College. He lives in Houston, Texas, with his wife Debi.

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



Gary Kubera

EVENTS

Zoom Calls to Connect Patients and Families with Our Cardiologists and Researchers

The year 2020 put a halt to many things including getting together with Family and Friends for all of us. Fear of contracting the COVID Virus was on everyone's minds, but more so in those of us who have had negative outcomes before with viruses.

We can appreciate that it means so much for people to get

together and discuss a disease that very few people understand or actually have had to deal with. We are a Family, as such, and it affected us very negatively by not being able to get together and hug and share that we understand how you feel, etc. We had to figure out a way to do it without being in person somewhere.

With the help of modern technology, we were able to meet virtually in October where approximately 37 family members joined us to "Chat" with Dr. Leslie Cooper and Dr. Jack Price and ask questions of them that I am sure many others had wanted to hear the answers to as well. COVID was only known about for a little over six months, and high on the topics wanted to

be discussed. Little was known about it but what they did know was that it was a virus, and it was affecting people's hearts which is very near and dear to all of us.

On review of the meeting, we had many very positive comments and asks of when the next one will be. So, on January 9th we held another "Chat" including one of our Researchers, Dr. DeLisa

Three Additions to the Myocarditis Foundation Medical Advisory Board

The Myocarditis Foundation is pleased to announce the addition of three esteemed Cardiologists and Researchers to the Foundation's Medical Advisory Board. Dr. Tang is with the Cleveland Clinic, Dr. Ammirati is with the DeGasparis Cardio Center and Transplant Center at the Niguarda Hospital in Milan, Italy, and Dr. Godown is a Pediatric Cardiologist at Monroe Carell Jr. Children's Hospital at Vanderbilt in Nashville, Tennessee.

All three of the new Board Members are extremely enthusiastic to participate in the Medical Advisory Board. We at the Myocarditis Foundation look forward to their scientific knowledge and expertise in the field of myocarditis. Please join us in welcoming Dr. Tang, Dr. Ammirati, and Dr. Godown to the Myocarditis Foundation!



Dr. Tang

Dr. Tang is Professor of Medicine at Cleveland Clinic Lerner College of Medicine at Case Western Reserve University. He received his M.D. degree from Harvard Medical School, internal medicine residency training at Stanford University Medical Center, and cardiology fellowship training at the Cleveland Clinic. He is a practicing heart failure and transplant cardiologist at the Cleveland Clinic's Heart, Vascular and Thoracic Institute, specialized in cardiomyopathies and myocarditis, as well as kidney- and cancer-related heart diseases. As a clinician-scientist, Dr. Tang's translational research focuses on understanding the cellular and molecular mechanisms that contribute to disease progression in heart failure and cardio-renal and inflammatory heart diseases, including some research work supported by the Myocarditis Foundation Postdoctoral Fellowship looking at the role of autoimmune mechanisms of myocarditis and dilated cardiomyopathy. He has published over 650 peer-reviewed scientific manuscripts and book chapters and has been elected as member of the American Society of Clinical Investigation in 2013 for his contributions to mechanistic understanding of cardio-renal syndromes, as well as the Association of American Physicians in 2018 for studying the contributing role of diet and microbiome in cardiovascular diseases.



Dr. Ammirati

Dr. Ammirati is a clinical cardiologist who subspecializes in heart failure in Milano, Italy. He is an attending physician at the De Gasparis Cardio Center and Transplant Center at the Niguarda Hospital in Milano, Italy, and Assistant Professor at the School of Medicine at the Vita-Salute San Raffaele University in Milano. Niguarda Hospital is one of the largest and important hospitals in all of Europe.

With a background in immunology and heart transplantation, he has developed an expertise in myocarditis and has published over 140 manuscripts, which include several manuscripts on myocarditis in major journals such as *Circulation*, *Journal of American College of Cardiology* and *Lancet*. He has systematically studied many patients with myocarditis, obtaining endomyocardial biopsy in patients with fulminant presentation, resulting in one of the largest cohort of patients with myocarditis and several important manuscripts that have re-defined how we approach these patients. For example, in a paper that was published in the *Journal of American College of Cardiology (JACC)* in the summer of 2019*, he studied the myocardial biopsies samples from 220 patients with myocarditis. These data have reinforced the critical role that direct myocardial tissue examination makes in patients with myocarditis.



Dr. Godown

The Myocarditis Foundation is pleased to announce the addition of Dr. Justin Godown, to our Medical Advisory Board. Dr. Godown is a Pediatric Cardiologist at Monroe Carell Jr. Children's Hospital at Vanderbilt in Nashville, Tennessee. His patient care emphasis is in pediatric cardiomyopathy, heart failure, and heart transplantation and he has authored over 60 peer-reviewed publications in the field of pediatric cardiology. Dr. Godown's research focuses on novel data strategies to expand analytic possibilities in pediatric heart failure and heart transplantation. He is actively involved in a number of multi-center research initiatives to study heart failure in children.

Dr. Godown's expertise in the area of pediatric myocarditis will be an invaluable addition to the Myocarditis Foundation.

Fairweather and another Cardiologist/Researcher from Germany, Dr. Bettina Heidecker. This time we grew in numbers to 85 and included attendees from 6 countries around the world. It was another success and plan to do them at least 3-4 times a year. It also helps those that would not be able to travel and attend an in-person meeting.

Our next "Chat" will be on Saturday May 1st from 10 am – 12 pm, Eastern Time and will include other distinguished Cardiologists, adult and pediatric, from around the country and world. We will not only have Dr. Jack Price from Texas Children's Hospital but also a new Medical Advisory Board Member, Dr. Justin Godown, Medical Director of Pediatric Cardiomyopathy and

Cardio-Oncology at Monroe Carell Jr. Children's Hospital at Vanderbilt, Nashville, Tennessee. In addition to Dr. Leslie Cooper, of Mayo Clinic, we will have 2 prestigious cardiologists from Italy who are well known in their study of Pericarditis. Dr. Massimo Imazio, Director of Cardiology at the University Hospital of Udine, Italy, a national referral center for advanced heart failure and cardiac

transplantation. Also participating will be another new Medical Advisory Board Member, Dr. Enrico Ammirati, a clinical cardiologist who subspecializes in myocarditis at the DeGasparis Cardio Center and Transplant Center at the Niguarda Hospital in Milano, Italy.

We are proud to be able to continue our important mission of patient family support.

NORD and GuideStar Updates

The 2021 year started out as a Platinum Year all around for the Myocarditis Foundation!

In 2018, the National Organization of Rare Diseases (NORD) adopted a set of operating practices to ensure that its member organizations maintain ethical standards and integrity from industry and other influences. Their qualifications require members to have proof of tax-exempt status, bylaws, a Conflict of Interest Policy for both Board and Staff, an annual Operating Budget, programs that involve research, education, a website that fully reflects your mission and your diverse patient

voices, a Privacy Policy, a Board that must meet at least twice annually and a Medical Advisory Board. The Member must disclose how donations are used. We have met all their requirements and have been awarded their Platinum Seal of Excellence.

GuideStar is the world's largest source of information about nonprofit organizations. It serves to verify that a recipient organization is established, and that the donated funds go where the donor intended for them to go. In 2013, GuideStar implemented three seals based on the information a nonprofit provides in its profile: Bronze,



Silver and Gold. In 2016, a new seal that allowed nonprofits to share progress and results for their mission, GuideStar Platinum, was introduced. Seals need to be earned in order, starting with Bronze and working the way up to Platinum. In Platinum, one metric must be from the previous year, showing



success from the prior year. In 2021, we attained the GuideStar Platinum Seal of Transparency based on our metrics monitored from 2020 and 2019. Please go to our website and click on our GuideStar Transparency icon to learn more about us.

PERICARDITIS UPDATE

Exciting News for the Pericarditis Community!

On March 18, 2021, Kiniksa Pharmaceuticals received approval from the U.S. Food and Drug Administration (FDA) of ARCALYST (rilonacept) for the treatment of recurrent pericarditis and reduction in risk of recurrence in adults and children 12 years and older. ARCALYST is the first and only FDA-approved treatment for people living with recurrent pericarditis who are age 12 years



or older. ARCALYST specifically targets the cytokine interleukin-1 (IL-1a and IL-1b), which has been implicated as the driver of

inflammation in recurrent pericarditis. For more information on this product approval, please visit www.ARCALYST.com.

Thank you to Kiniksa for your unwavering advocacy on behalf of patients suffering from recurrent pericarditis and their families! We thank you and all the patients, investigators, and study teams who participated in, and contributed to, the conduct of the RHAPSODY clinical trial. We look forward to furthering our partnership to help support the pericarditis community.

INTERNATIONAL MYOCARDITIS SYMPOSIUM

International Society of Cardiomyopathy, Myocarditis and Heart Failure (ISCMF) Symposium

The International Society of Cardiomyopathy, Myocarditis and Heart Failure is dedicated to expanding knowledge and understanding of heart disease through collaboration and conferences.

At the General Assembly held on December 3, 2016 a change of the name of ISCHF to the International Society of Cardiomyopathy, Myocarditis and Heart Failure (ISCMF) was proposed and approved. Myocarditis was added to the name because a need was identified for "myocarditis" to be

recognized more widely and to encourage research on myocarditis.

The ISCHF has held regional and international congresses and established working groups and task forces to facilitate much-needed cooperative research among their members and other societies in the field of cardiomyopathy and heart failure. Networking programs have been initiated, such as the "Global Network on Myocarditis".

Dr. Akira Matsumori, President of the ISCMF, is an esteemed member of our Medical Advisory

Board. Their 2021 Conference was held virtually in February due to the travel restrictions caused by the COVID Pandemic. Dr. Akira Matsumori, Dr. Leslie Cooper, Dr. DeLisa Fairweather, and Dr. Katelyn Bruno, who are all involved in our Foundation participated and shared their research and knowledge with the other participants from around the world.

Some of the topics that were discussed were: Atrial Fibrillation and Heart Failure, COVID-19 from various areas around the

world, New insights in the treatment of Heart Failure with medications used for other diseases (SGLT2 Inhibitors); Potential Biomarkers for Myocarditis; Cardiomyopathy and Myocarditis; Biomarkers and Genetics for Heart Failure, Myocarditis and Cardiomyopathy; Advances in using Regenerative Medicine as a Therapy for Myocarditis, and a Biomarker of Inflammation in Heart Failure with Myocarditis.

Myocarditis Foundation and How You Can Help.

The Foundation Office has been increasingly involved in speaking with patients and families over the past year with many of them reaching out to us after finding us on the Internet. The Myocarditis Foundation website, in recent times, has received over 40,000 visitors a month. We have spoken with over 1,200 contacts during the past 2 years, most being in 2020 specifically. We take pride in being able to provide individual assistance and help to answer questions, provide emotional support, as well as help to point them in the right direction to gain the help that they need. We help connect new patients and families to speak with others who have been through the disease process so that they do not feel so all alone. We provide this service on a 24/7 basis with very quick response. We help patients and families with information to advocate for themselves.

Did you know that we are on FaceBook, Twitter, Instagram and YouTube? We share much needed information with the public community on our Social Media platforms, but we are a small organization. If you could "like" what we post and "share" it with your friends on your pages, then ask them to "like" and "share" it with their friends, we can get the information out to many more people all over the country and world, and thus multiple the numbers who can benefit from the information on Social Media.

I also share this information to express how needed our work at the Foundation is by so many. Our donations have declined over the past year, mainly due to the COVID Pandemic. Many fundraiser events that were planned, had to be cancelled. Other events that would have been planned, were not.

The Myocarditis Foundation is still a very much a needed service for so many. Our Mission is carried out through donations from people like yourselves, many who have been affected by the disease and many who have been helped through the efforts of the Foundation Office and the Myocarditis Foundation Website.

Where would all these people go if we were not there to help them? We frequently hear from many of them that the help they received from us has been so very valuable and they don't know what they would have done if they didn't find us.

We ask that you help us by making a donation today. Your donation will help to allow us to continue our efforts.

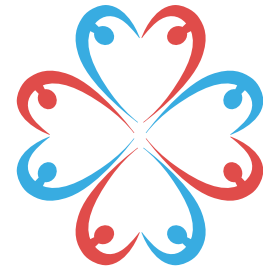
DONATE at: www.myocarditisfoundation.org

We utilize volunteers to help us in our efforts whenever we can and thus our administrative costs are well within the acceptable range for nonprofits. 89 cents of every dollar earned is spent on the mission.

If your employer matches donations, please share that you made a donation with them. Every little bit helps!

Thank you so very much!

***Genevieve Rumore
Executive Director***



**MYOCARDITIS
FOUNDATION**

Fundraisers

Tyler Debusschere's brother, Jackson, fought and survived Giant Cell Myocarditis a little over 5 years ago.

His younger brother Tyler is raising awareness for the disease and funding to support both the Children's Hospital of Philadelphia and the Myocarditis Foundation.

Please help by donating to Tyler's efforts.



HOPE FORE! HEARTS




Hi, my name is Tyler Debusschere and I am currently a sophomore at Strath Haven High School in Wallingford, PA. I am a competitive golfer, playing in various junior tournaments from March through November all across the Mid-Atlantic region. Giving back to the community and those that have helped my family is a passion of mine, so this year I want my golf game to go towards a greater cause - and I need your help!!!

Please consider donating any dollar amount that you choose for every birdie (or better) that I make in a tournament round this upcoming season. At the end of the year, all proceeds will benefit both the Children's Hospital of Philadelphia Cardiac Center and the Myocarditis Foundation.

To sign up to donate, email me at debusschere@comcast.net with your name and dollar amount per birdie. Over the course of the season, I will be posting my scores on a public document which can be accessed at the following link: https://docs.google.com/document/d/1X3ORMQB0h_Qj4Xt_jByVCAG9pl7aSe0lzL3EjXkd3_U/edit?usp=sharing

Once I complete all of my tournaments, I will let you know the final birdie count upon which all proceeds will be collected and distributed to the above organizations.

Thank you in advance for your support!




Sarah Knight, was a 25-year-old Kindergarten teacher, who died suddenly from Viral Myocarditis. Thanks to a very diligent coroner, who was determined to find the cause of Sarah's death, her parents learned of myocarditis. Since then, they have been bringing an awareness of myocarditis to others and helping to support research so that no more precious lives are lost. They are holding their 9th Annual Sarah Knight Golf Outing, on June 25th, 2021 in Marion, Iowa. This date would have been Sarah's 35th Birthday...

There are many ways to participate in their memorial event. Please visit their website at www.sarahelizabethknight.com to learn more.

Sarah Knight Memorial Golf Tournament



Hunter's Ridge Golf Course, Marion Iowa

June 25, 2021



Fundraisers

Joseph Rumore, was a teenager many years ago when he was struck by mononucleosis. He later developed chest pains and shortness of breath, and after evaluated by many doctors was told he “probably had a virus but would be OK”. He was also told that he “had an enlarged heart”, but that was because he was an athlete. Fast forward twenty- five years later, he woke up one day in full blown heart failure and was told that he would need a heart transplant in the near future. That day came eight years later when the medication that he was taking no longer worked. That was almost 15 years ago, and the Foundation will be holding its 14th Annual Golf Outing on August 9th, 2021 in Paramus, New Jersey, at the beautiful Arcola Country Club, with scenic views of New York City.

This year the Myocarditis Foundation Golf Outing will have a new format including a complimentary Greyson shopping experience, multiple beverage and food stations throughout the course, a lavish cocktail party style dinner including a raw bar, and premium raffle prizes and awards. Dr. Leslie Cooper, our Co-Founder and world-renowned myocarditis specialist, will be our guest speaker.

Please follow us on social media for exciting future announcements about the outing.

14th Annual Myocarditis Foundation Golf Outing



Monday August 9th, 2021

**Arcola Country Club
Paramus, New Jersey**

Shotgun Start 12:00 pm

Guest Speaker:

Dr. Leslie Cooper, Mayo Clinic

***Plus, there are a few other
special appearances planned***

To Register, please go to: www.myocarditisfoundation.org/events/golf

For Questions, please email: Melissa@myocarditisfoundation.org



MYOCARDITIS FOUNDATION

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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.

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

KATELYN BRUNO, PHD

Instructor of Medicine and Research Associate at Mayo Clinic, Dept of Medicine, Jacksonville, FL and Instructor of Biology at the University of North Florida

Mailing Address: 3518 Echo Mountain Dr., Kingwood, TX 77345

Telephone: (281) 713-2962 Fax (281) 608-7252

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