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

Myocarditis Foundation Website and Link for Clinical Trials

The Myocarditis Foundation is proud to announce the launch of our newly redesigned website, **www.myocarditisfoundation.org**. With a focus on providing easy-to-navigate functionality, easy-to-understand writing, and a dynamic look, we believe our new website will be an invaluable resource for anyone seeking to learn more about myocarditis and pericarditis or to support our cause.

During the COVID-19 Pandemic, visitors to our website rose from our 45,000 visitors a month to over 100,000 visitors a month, with 85% or more being first time visitors. Thus, we felt the need to undertake this update endeavor making the navigation and updated inclusions of the website at this time.

There is not another website that has such robust, up to date and current information on these diseases as the Myocarditis Foundation's. Our website can be translated into over 100 languages, breaking down language barriers and making it more accessible to people from all over the world.

The office has received many calls from patients and their families looking for a clinical trial that they could become a part of, especially since the COVID Pandemic struck. One of the most exciting features of our new website is the Clinical Trials Section, which provides comprehensive listings of current and upcoming U.S. trials related to myocarditis and pericarditis. This is a resource for anyone seeking to stay informed about the latest treatment options and research advancements and a chance to help participate in them.

At our most recent Board Meeting, Dr. Leslie Cooper commented…As a member of the Myocarditis Foundation Board of Directors, I am thrilled to see our website undergo this exciting redesign. The new website is not only visually appealing but also incredibly user-friendly, with easy-to-navigate pages and clear, concise language that makes it easy for anyone to understand. The clinical trials section is a particularly exciting addition, providing a valuable resource for patients and families who are looking for the latest research advancements. I'm also impressed by the website's ability to be translated into over 100 languages, making our resources and information accessible to a global community. I believe this new website will be an invaluable tool in helping us achieve our mission of increasing awareness and improving outcomes for those affected by myocarditis.

We invite you to visit our new website at **www.myocarditisfoundation.org**. and explore all that it has to offer. Whether you're a patient, family member, medical professional, or supporter, we hope you find our website to be an informative and valuable resource. Thank you for your continued support of the Myocarditis Foundation.

UPDATE

2022 Myocarditis Foundation Fellowship Grant Award

Dr. Jennifer Myers, PhD

The Myocarditis Foundation is proud to announce that Dr. Jennifer Myers, PhD, of the University of Oklahoma has been awarded our 2022 Fellowship Grant Recipient for the 2023-2024 Academic Year!

Her interest in science began at an early age and for as long as she could remember, she loved looking for "clues" and solving problems. Her passion for science led her to a bachelor's degree (summa cum laude) in biomedical sciences at the University of Oklahoma and a doctoral degree in microbiology/immunology from the University of Oklahoma Health Sciences Center.

As a graduate student, working toward her PhD, she joined the laboratory of Dr. Madeleine Cunningham. What she found intriguing in Dr. Cunningham's laboratory, was the translational aspects of human studies in myocarditis.

The goal of her research is to understand the mechanisms and immune phenotypes governing inflammatory heart disease such as myocarditis, and the biomarkers of non-recovery and progression to subsequent heart failure. With no immunomodulatory drugs approved for treatment of myocarditis to prevent permanent heart damage and heart failure or transplant, a more comprehensive understanding of specific immune mechanisms in human myocarditis, dilated cardiomyopathy, and heart failure is needed.

Because her studies are translational, they will make a difference in the lives of those with inflammatory heart disease and lead to better identification of those who will have poor outcomes as well as provide a basis for new treatments. Dr. Myers has found that speaking with patients and their families opens lines of communication between the scientific community and the lay public and opened her eyes to the suffering caused by these devastating heart diseases that can lead to the need for heart transplantation.

"It was a wonderful experience to be given the opportunity to interact with these patients and their families during a Myocarditis Foundation meeting." Outside of the laboratory, I am dedicated to my family, including my husband and two young children, and we enjoy spending time outdoors with our two Labrador retrievers and attending sporting events together.

A "layman's summary" of Dr. Myers' research study on "Autoimmune Mechanisms in Human Myocarditis." is explained below.

Biomarkers to identify myocarditis patients who will not spontaneously recover heart function is an unmet clinical need to inform treatment decisions and prevent progression to dilated cardiomyopathy, heart failure, and transplant. Antibodies that target a person's own heart (autoantibodies) have been reported for years without a full understanding of their role in disease, partly due to a lack of longitudinal studies and more focus on cellular immune responses. Our study is practical, novel, and needed to understand disease-causing heart autoantibodies in myocarditis. We plan to investigate these autoantibodies to identify patients who will have poor outcomes and to determine the genes that are altered in heart cells in response to the autoantibodies present in disease. We will investigate the hypothesis that autoantibodies against the heart protein cardiac myosin will alter genes leading to fibrosis and gene responses leading to cell death in cardiac cells. Our study will provide important new insights into autoimmune mechanisms of myocarditis and biomarkers for development of new diagnostic and treatment strategies.

Dr. Jennifer Myers Research Grant is named in memory of John Phillip Mello, a 26-year-old Viral Myocarditis victim who died in 2017. His family and friends have been working on raising awareness of the disease and funding for a Myocarditis Foundation Fellowship Grant in his name over the past few years since his passing.

Please join the Myocarditis Foundation in congratulating Dr. Myers and welcoming her as the Foundation's 25th Fellowship Research Grant recipient!

FUNDRAISER EVENTS

The 16th Annual MF Golf Outing

Registration is now open for our annual Golf Outing on August 14, 2023 at Arcola Country Club, in Paramus, New Jersey.

Dr. Leslie Cooper will be attending and speaking during the event and at the Awards Dinner after golf. If you would like to attend either for golf and or just for dinner, or to be a sponsor of this very important event, please call Melissa at: **281-713-2962.**

Without our Donor's support we would be unable to continue our Mission of Funding Research, Providing Education to both the public and medical communities, and Providing Emotional Support to those affected by Myocarditis.

FUNDRAISER EVENTS

Hope Fore Hearts Fundraiser 2022 Season

Tyler Debusschere had another winning season of golf and fundraising for the Myocarditis Foundation and the Children's Hospital of Philadelphia Cardiac Center. His big brother, Jackson, fought and won the fight against Giant Cell Myocarditis, several years ago when in high school.

Tyler's brother's fight to overcome Giant Cell Myocarditis and all those who helped to propel him on his road to recovery inspired him to give back to the community and start the Hope Fore! Hearts fundraiser. As an aspiring cardiologist, he was recently accepted to Cornell University where he will be pursuing pre-med studies with a major in Cell & Molecular Biology and a minor in Infectious Disease. He will also be joining his brother, Jackson, as teammates on the Cornell golf team!

Once again, thank you Tyler for all your hard work to help raise funding for two amazing organizations!

EVENTS

Kingwood Middle School Health Fair

The Myocarditis Foundation once again had the opportunity to participate in the Kingwood Middle School Health Fair for children and parents on Wednesday April 12th. The Executive Director, spoke with about 200 middle schoolers, parents, and teachers, non-stop for 90 minutes. We brought our "Gaming Wheel" which attracted the students to participate. After a "brief education" on myocarditis to the lower end of this high-risk age group, they were given the handout geared toward young adults and what they need to know about myocarditis. We encouraged them to share it with their parents and friends. Then they got to participate in spinning the wheel and play in a question-and-answer game for which they received a squishy heart shaped stress ball as a prize.

The children and parents were very attentive as the Executive Director related myocarditis and its symptoms to them on a basis that they could understand.

FUNDRAISER EVENTS

Quinn's Cup Annual Jamboree Hockey Tournament

March 3-5, 2023 was the 10th Annual Event, that started out as a "Pond Hockey" Tournament but has grown to a larger event than could be handled on the pond where it started back in 2014.

Quinn Kirsch was an 8-year-old ice hockey enthusiast who played every chance he got with his friends and older brothers in Edina, MN. On January 7, 2013, after playing on a pond in his back yard, he collapsed suddenly and died. Weeks later his parents found out that it was due to Viral Myocarditis.

To keep his memory alive and raise awareness for the disease that they had never heard of before, his parents and their friends and family started the Quinn's Cup Hockey Tournament in his memory. Kelly Kirsch, Quinn's mother and Chairperson of the event, stated that their event this year was a huge success!

She also shared that "It's amazing how many people read the posters and ask questions about Quinn and Myocarditis. We were very successful in spreading the word & raising more awareness for the disease! We had many people asking about the Myocarditis Information Sheet, that the Foundation sent this year. They were very interested in talking about it. We had one man who attended that was in the hospital for a month with Myocarditis last year. People were much more aware of the disease than in past years."

Quinn's Cup has raised almost $200,000 in support of the Myocarditis Foundation over the past 10 years!

The Myocarditis Foundation gives our heartfelt thanks to the Kirsch Family for all that they have done to raise awareness for the disease and funding so that the Foundation can continue its very important work of Education, Research, and Emotional Family Support for those affected by the disease.

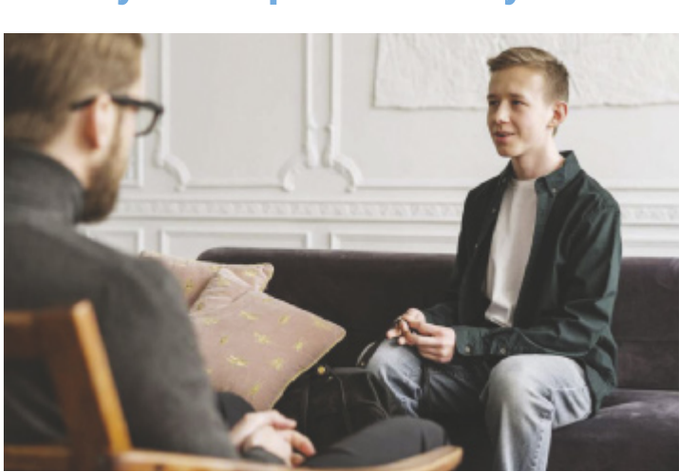
EDUCATION

Please Help Others by Participating in Our Anxiety and Depression Study

The Myocarditis Foundation, in collaboration with the Mayo Clinic, is conducting a study to identify risk factors for anxiety and depression in people with myocarditis and their caregivers.

CAREGIVERS of a current or previous myocarditis patient PLEASE consider participating in this very important study. This vital information will be used to help patients and caregivers worldwide.

If you can think of any caregiver, parent, spouse, friend, or sibling that might be interested please ask them to email Daniel Smith at Myocarditisstudy@mayo.edu or call him at 507-255-0760.



EDUCATIONAL UPDATE

Diagnosis, Risk Stratification and Management of Myocarditis

Dr. Bettina Heidecker

Listen to this podcast with Dr. Bettina Heidecker on a paper she wrote with Dr. Leslie Cooper on this topic.

Myocarditis affects 1.8 million people globally a year. It has been under diagnosed as many believed it to be rare. But we see it more frequently, especially after the COVID Pandemic.

1 to 10 cases of Myocarditis per 1 million COVID vaccines, but Myocarditis from the actual COVID Virus is actually 6 times higher.

To find the podcast from our website, **www.myocarditisfoundation.org** and look under 'About Myocarditis' Blogs for Dr. Heidecker's Podcast link or you can go to SoundCloud and search for **Bettina Heidecker.**

Dr. Leslie Cooper

Dr. Leslie Cooper presented two talks at the First Mayo-Hadassah Heart Failure and Cardiomyopathy Symposium in Israel in March 2023.

To find the podcasts from our website, **www.myocarditisfoundation.org** and look under Blogs for the complete talks:

"Comparison of Myocarditis following SARS-CoV2 mRNA Vaccination and Viral Infections"

"Sarcoidosis"

EDUCATION

Upcoming Family Events

We have had great success not only with our annual "In-Person Family Meetings" and our virtual "Zoom Meetings", which we started during the COVID Pandemic when we could not meet in person.

Our next **Zoom Family Meeting** will be on **Saturday July 29th from 10 am - 12pm, Eastern Time**. So far, we have five specialists who will be joining us on the call to answer your questions and give us the latest news on the areas of Myocarditis, Pericarditis, and the Research being done in these areas.

Please look on our website **www.myocarditisfoundation.org** and Social Media Platforms for more information and how to sign up in the upcoming weeks.

Our next **In-Person Family Meeting** will be on **Friday October 6th and Saturday October 7th, in Cleveland Ohio**. There will be specialists in the fields of Myocarditis, Pericarditis, and Research who will be joining us ready to meet with and speak with our attendees. Please look to our website and Social Media Platforms for more information and how to sign up in the upcoming weeks.

EDUCATION

Monthly Email Newsletter

Did you know that we send out monthly e-newsletters? We encourage you to visit the Myocarditis Foundation website and sign up today! Our foundation is dedicated to raising awareness and providing education about myocarditis, a serious and potentially life-threatening heart condition.

By signing up for our newsletter, you'll receive regular updates about our latest research, events, and advocacy efforts. You'll also hear from individuals who have been affected by myocarditis and pericarditis and learn about their stories and experiences.

Whether you or a loved one have been directly impacted or you simply want to learn more about this important issue, our newsletter is a valuable resource that can help you stay informed and engaged.

So, we urge you to visit the Myocarditis Foundation website today and sign up for our newsletter. Together, we can work to raise awareness and support those affected by this condition.

Candace's Corner

Candace Moose, one of the Co-Founders of the Myocarditis Foundation, has decided this past year to share many of her stories and thoughts of her Giant Cell Myocarditis and Transplant Journey. You can see them monthly on our website, ***www.myocarditisfoundation.org*** *or enjoy them monthly on our electronic newsletter.*

We have attached her initial Blog Post and the most recent Blog Post, which is actually a sort of response to another Myocarditis Survivor and Heart Transplant Recipient's letter to the New York Times.

CANDACE'S INITIAL BLOG...

Giant Cell Myocarditis Survivor Dedicated Her Life to Saving Others

In August 2001 I received two immunizations to travel to Africa to do mission work. Two hours later, my heart started to beat faster, more irregularly and more forcefully. One week later I coded three times, had a defibrillator inserted and was sent home with a diagnosis of viral myocarditis.

The next day I went into cardiogenic shock and though the doctors told my husband there was only a slim chance I would survive the night, if by some miracle I did, my only chance for survival was a heart transplant.

The next day, I was transported via EMT to Columbia Medical Center where Dr. Deng was waiting for me in the Critical Coronary Unit.

He knew immediately it was Giant Cell Myocarditis and he consulted with the world's leading expert, Dr. Leslie Cooper from the Mayo Clinic.

Dr. Cooper's research showed that by giving chemotherapy because of its immunosuppressant and anti-inflammatory properties, GCM patients survive until transplant if a heart were to become available. In all those weeks, I laid in my bed in the CCU praying that I would live to see my children married and my grandchildren born.

The treatment was successful, and a heart did come on October 1, 2001; the heart of a 17 year old boy whose parents made an unbelievably difficult decision to donate their son's organs. I survived only because of a series of miracles: Dr. Deng's immediate diagnosis of Giant Cell, Dr. Cooper's research and treatment recommendations and the gift of a heart from an unknown family who suffered tremendous loss.

I said to Dr. Deng and Dr. Cooper, "What can I do to give back to you what your knowledge, expertise and care have given to me?" Together, we formed the Myocarditis Foundation to help other patients and families in the present. It is our hope that the research we fund will result in more lives saved in the future. I plan to work toward that goal for the rest of the life I am given.

CANDACE'S MOST RECENT BLOG...

The Gratitude Paradox

As so many of you are well aware, I've recently been hospitalized with a respiratory virus. Those most at risk to serious outcomes of this virus are babies and immunosuppressed individuals. It's been a very trying time for me and my family, coping with both the illness and the side effects of the medications used to treat the illness. This is not an unusual occurrence for heart transplant patients. We are always at risk for infections, rejections, vasculopathy and cancer due to the immunosuppression. Every hospitalization forces us to confront our very existence.

On Tuesday, April 18, 2023, the New York Times published an Opinion/Guest Essay entitled, "My Transplanted Heart and I Will Soon Die", written by Amy Silverstein, the author of Sick Girl. Amy has lived 35 years with two different donor hearts. She honored her hearts with "compulsive compliance" with the strictest interpretation of transplant protocols. Despite maintaining "sparkling cardiac health", she is dying of metastatic lung cancer, a consequence of long-term immunosuppressive drugs. Her essay is a cry for better medications, greater life-expectancy from current protocols which she describes as antiquated and more attention to utilization of organs she feels are being wasted given current policies.

I'll let you find and read the entire article if you wish. I would recommend it because she has a lot to say about the state of transplant medicine which impacts us all. She points out a pressure for transplant recipients to not express, much less demand medicines that allow for a longer, healthier life. She feels like this narrative discourages transplant recipients from talking freely about the compromising, life-threatening side effects of medicines we must take. She calls it "the gratitude paradox".

My take on this is that besides our closest family and friends the "miracle" narrative prevents the public from really understanding how difficult being a transplant really is. It must be easy to live this way because we make it look that way. It isn't. I am consistently unreliable in my attendance. I'm often in isolation at home for weeks at a time. And I don't sleep well given the drugs. My family worries, my church supports me in prayer and my best friends thankfully text often.

Amy closes her article by sharing a conversation with her doctor, who sat in front of her crying upon sharing the diagnosis and prognosis of her cancer. With wry humor, Amy said, "I sacrificed my whole body for this heart. I kept her perfect to the end." This forces me to say that it doesn't seem fair.

It is anathema to my personality to see my transplant as anything other than a miracle. However, I can't help but thank Amy for her last-ditch efforts to challenge the heart transplant system, to tell her truth, and for trying to make the transplant world better for those of us still fighting for every day and those to come; I wish her Godspeed.

MYOCARDITIS FOUNDATION

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