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Secretary to our Medical Advisory Board

KATELYN BRUNO, PHD

Assistant Professor of Cardiovascular Medicine

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

MYOCARDITIS FOUNDATION



2024 Family Conference "Reflecting & Connecting" July 11-14. Dallas, Texas

The Myocarditis Foundation is thrilled to announce the dates of our 2024 family meeting! This family meeting will be held July 11th through July 14th in Dallas, Texas, at the Statler Hotel, 1914 Commerce Street, Dallas, Texas, 75201.

Please join us to experience reflecting and connecting with others who have been affected by myocarditis. There will be a welcome reception & memorial candle lighting ceremony, myocarditis & pericarditis specialists, and researchers available for your questions, updates on latest information. activities focused on well-being, as well as a fun event on Friday night.

Many find the myocarditis journey more understandable and bearable when shared with those who understand. Some have been on this journey for years, while others have barely begun. Hand in hand, we walk this road together, offering one another support and hope.

We are honored to share this weekend with you, knowing you will be touched in some way through your experience, whether by a speaker, a workshop, or a fellow "traveler" seated next to you at a meal.

Please join us to experience reflecting and connecting with others who know and understand myocarditis.

IMPORTANT CONFERENCE DETAILS:

Registration:

There is no fee to attend. We just ask that you pay your travel expenses. There is scholarship funding available through corporate grant funding for rooms. Please make your reservations as soon as possible as space is limited and the discounted room rate cutoff is May 31st.

Call Melissa for the room link information (281)-713-2962.

HOTEL ACCOMMODATIONS:

The Statler Hotel is perfectly located in the heart of downtown Dallas. It is registered in The Historic Hotels of America and offers one of the best views of Dallas. The Statler will be providing a room block of rooms for the nights of July 11 – July 13, at the discounted rate. The rate is for Deluxe King and Double Queen rooms, (limited number of Queen Rooms available).

You will need to place a credit card on file to secure your room and for any incidental charges, if any. It is important to reserve your room as soon as possible and contact Melissa Graham at **Melissa@ myocarditisfoundation. org** with your confirmation details to receive the scholarship.



RESEARCH Two Fellowship Grants Awarded for the 2024 Academic Year



One of the 2023 Fellowship Grants was awarded to Dr. Swati Sharma, of the University of North Carolina, Chapel Hill, for her work on: "The Protective Role of Platelet Protease- activated Receptor4 (PAR4) in Coxsackievirus (CVB3) Myocarditis".

Dr. Sharma came to the United States from India, in December of 2021. Based on her preexisting background in blood coagulation and willingness to learn about viral infections and their impact on coagulopathy, she applied to Dr. Antoniak's lab at the University of North Carolina, Chapel Hill, to continue her scientific training. The Antoniak Lab gave her an opportunity to expand her knowledge and learn about infection induced procoagulant phenotype. Under Dr. Antoniak's guidance she learned about myocarditis and developed an interest in this understudied field.

Dr. Sharma's proposed work will provide an important bridge towards her own independent research interest investigating the effects of viral infections on the blood coagulation and their role in inflammatory heart diseases.

(Dr. Silvio Antoniak was the 2009 Fellowship Grant Recipient from the Myocarditis Foundation for his study on Viral Myocarditis.)

Dr. Swati Sharma's Layman's explanation of her Myocarditis Research Project

Inflammation of heart is one of the leading causes of sudden death in children and young adults. Inflammation can be caused by viral infections. An abnormal immune response to initial viral infection is a major driving factor. We currently lack effective treatment approaches for virus-induced heart inflammation. In infections. small circulating blood cells called platelets, that are usually involved in limiting blood loss during injury, are activated. Importantly, platelet overactivation can also lead to the formation of blood clots that cause heart attacks and strokes.

In this application, I will show that platelets play an active role in preventing virus-induced inflammation of the heart by changing the immune response to the virus. Here, I intend to show that platelet activation protects against virus- induced heart inflammation. I propose that viral infection activates the platelets, through the receptor PAR4. Platelet activation is needed to release platelet components, especially small RNA fragments. One of these RNA fragments is miR223. miR223 can reduce heart inflammation by enhancing pathways that are anti-inflammatory.

One of the cells responding to platelet miR223 are immune cells called macrophages. I intend to show that platelets activation limits disease by increasing macrophage miR223 levels. Thus, reducing the inflammation in the heart in a mouse model of viral-induced heart inflammation. Moreover, I will show a potential therapeutic approach by using platelets to deliver miR223 as treatment of viral-induced heart inflammation. Thus, this project will reveal a new way of protecting the heart against viral infections, preventing inflammation of the heart, and reducing the number of patients requiring heart transplantation. My research will help patients in the US to live longer and healthier lives.

Congratulations to Dr. Swati Sharma on the award for her myocarditis research study!



Our second 2023 Fellowship Grant was awarded to Dr. Simon Vanhentenrijk, MD, Pharm D, of the Cleveland Clinic for his work on: "Leveraging Cutting-edge PHIP-Seq Antibody Profiling to Differentiate Autoantibody Patterns in Myocarditis".

Dr. Vanhentenrijk came to the United States after his training as a Cardiologist in Belgium.

He always wanted to know the deeper understanding of 'how and why' the heart reacts to different stimuli. His particular interest in heart failure and heart muscle diseases led him to join the highly competitive research lab of Dr. Tang at the world-renowned Cleveland Clinic. Being part of the translational research group motivates him to yield scientific excellence in the field of antibody-antigen reactions at the level of the heart muscle cells. With his pharmaceutical

background, Dr. Simon Vanhentenrijk also feels the urge to create new ideas on how to develop drug therapies in myocarditis.

As a dedicated father of three lovely children, Dr. Simon Vanhentenrijk says he feels deeply connected with the purpose of the Myocarditis Foundation that continuously strives to expand scientific boundaries to save the lives of young individuals. He feels humbled, and yet passionately driven, to help increase our insights on 'how and why' inflammation of the heart muscle often has such devastating outcome and how we can overcome this.

Dr. Simon Vanhentenrijk's Layman explanation of his Myocarditis Research Project

The goal of his translational research project is to use a novel, state-of-the-art technique, called Phage Display Immunoprecipitation Sequencing (PhIP-Seq) in patients with myocarditis. This technique will help us understand the interplay of antibodies in cardiac autoimmune diseases by building an extensive library of distinct human peptides. The advantage of the PhIP-Seq platform is to perform an unbiased, high-throughput assessment of antibodies potentially linked to specific conditions.

A previous feasibility study using PhIP-Seq was done in Dr. Tang's lab on sera from patients with suspected autoimmune cardiomyopathy, systemic sclerosis, systemic sclerosis with heart failure with preserved ejection fraction, and healthy controls. In this pilot study with a targeted approach based on our prior work on B1-adrenergic receptor antibody epitopes (research done by former laureate of the Myocarditis 2024 FOUNDATION UPDATES
Two New Board Members Welcomed to the Myocarditis Foundation

Foundation grant: Dr. Yuji Nagatomo), a patient with suspected autoimmune cardiomyopathy, whose antibodies binds to both extracellular loop (ECL) 1 and 2 of b1-adrenergic receptor, showed a reduced LVEF (47%), indicating a mild dysfunction of the heart.

This project also provides the framework of the multicenter Myocarditis Biobank (that Dr. Tang is currently co-leading) that can leverage both retrospective and prospective cohorts with the following components: 1) detailed clinical phenotyping that can be extracted from Electronic Health Record and captured in Redcap; 2) extraction of review of primary data sources including advanced imaging (cardiac MRI or PET) and endomyocardial histological specimens; 3) retrospective tissue/imaging retrieval and deep phenotyping; 4) patient outreach for prospective blood sampling and longitudinal follow-up through surveys. Procedures developed in this project will better define the myocarditis study population and will also greatly catalyze the foundation of the Myocarditis Foundation Biobank in terms of developing scalable processes of broad clinical phenotyping, patient enrollment, biospecimens collection, and longitudinal follow-up.

Dr. Simon Vanhentenrijk's research grant is named in memory of Sarah Knight, who died of Viral Myocarditis at the age of 25 in 2011, and whose family and friends have been working on raising funds for Myocarditis research in the years since her passing.

Congratulations Dr. Simon Vanhentenrijk on the Myocarditis Foundation's Fellowship Grant Award for your myocarditis research study!



Rick Piacenti is a highly accomplished retired senior executive with more than 40 years of success within the oil & gas, transportation, and hospitality industries. His areas of expertise include debt and equity financing, financial reporting, human resources, personnel development, and contract negotiation. He has been an advisor for both the World Compassion Network and the RRP Cancer Foundation, two other non-profits, starting from 2015.

He has been very active with the Myocarditis Foundation for over the past seven or so years and was the major sponsor of our local Awareness and Fundraising event in 2022 as well as a major sponsor in our First Annual Chili Cook-Off which was held recently in the fall of 2023. His areas of expertise include debt and equity financing, financial reporting, human resources, personnel development, and contract negotiation. We see him as a tremendous help in establishing regional support operations, here in Texas.

Please help us welcome him to the Myocarditis Foundation Board of Directors!



Dr. Dor Lotan is an Assistant Professor of Cardiology and Advanced Heart Failure, Mechanical Circulatory Support and Transplant Cardiologist at Columbia University Irving Medical Center, NYC.

Recently, he has been appointed as the director of the newly

formed Pericardial/Myocardial Disease Center at Columbia University Irving Medical Center, New York Presbyterian Hospital, New York. The Mission of the clinic is to provide comprehensive care for patients presenting with any type of pericardial disease, including resistant, recurrent pericarditis, constrictive pericarditis, as well as patients suffering from myocarditis.

Dr. Lotan has published several scientific medical papers in peer-reviewed journals and published three book chapters, among them in a cardiovascular medicine textbook by the European Society of Cardiology. He has also been a guest lecturer at numerous international medical conferences.

His qualifications, experience, and dedication make him an ideal addition to the Myocarditis Foundation Board of Directors, placing patient care at the forefront of our shared mission.

Please join the Myocarditis Foundation in welcoming Dr. Lotan to our Board of Directors!

ANNOUNCEMENT Specialty Clinic Formed at New York Presbyterian Hospital



Exciting news for myocarditis and pericarditis patients in the New York City area! The Myocarditis Foundation is delighted to announce the formation of a specialized clinic at New York Presbyterian Hospital, led by the esteemed Dr. Dor Lotan. With a wealth of experience and expertise in advanced heart failure therapies, cardiomyopathies, and myocardial and pericardial diseases, Dr. Lotan aims to provide comprehensive and multidisciplinary care through the newly established Pericardial/Myocardial Disease Center at Columbia University Irving Medical Center. If you or someone you know is seeking expert assistance, appointments with Dr. Lotan can be scheduled at (212) 305-4600 by requesting the pericardial clinic. Join us in welcoming Dr. Lotan as he brings his vast knowledge to benefit the myocarditis and pericarditis care communities.

EVENT Myocarditis Consensus Meeting – March 23rd, 2024



Carla Giordano (Italy), Marc Halushka, (USA and Medical Advisory Board Member), Sarah Parsons (Australia), and Joseph Maleszewski (USA) – all members of the consensus groups.

On a rainy March Day in Baltimore, 100 cardiovascular pathologists and cardiologists, from around the world, met in person or virtually to discuss myocarditis. The event was the culmination of a two-year process to develop new or revised criteria for the heart tissue diagnosis of myocarditis led by the Society for Cardiovascular Pathology and the Association for European Cardiovascular Pathology. These criteria are 1) the first ever for certain tissue types and 2) an advancement over criteria that are more than 35 years old for heart biopsy tissue. The event included basic science, introductions of two new sets of criteria, clinical studies of these new criteria, and a lively, interactive discussion. We achieved strong agreement on diagnostic criteria for larger heart tissues including hearts seen at transplant or when a left ventricular assist device is placed. We found there is still work to be done for achieving strong consensus for heart tissue biopsies as a result of the discussion, but with a new path forward. The meeting concluded with clearing skies and a celebration of what was accomplished. These new criteria will help pathologists and clinicians make the correct diagnosis of myocarditis to help with finding better treatments for patients.

The organizers of the meeting thank the Myocarditis Foundation for their generous support of the meeting.

The Myocarditis Foundation banner was prominently displayed at the entrance of the event location.



EDUCATION Cardiogenic Shock



Dr. Jack Price

The Journal of the American College of Cardiology recently published a paper, co-authored by Dr. Jack Price, MD, the Pediatric

Medical Director for the Myocarditis Foundation.

There has been a lot of research on Cardiogenic Shock in adults, but outcomes of children with Cardiogenic Shock are lacking. This paper talks about a study done for children hospitalized with acute decompensated heart failure.

Cardiogenic shock (CS) represents the most severe form of acute heart failure. It is a low cardiac output state resulting in tissue hypoxia and life-threatening end-organ hypoperfusion. A group of pediatric cardiology specialists at various institutions, studied Acute Decompensated Heart Failure (ADHF), from a single-center retrospective cohort from Texas Children's Hospital over the period of January 1, 2004, to December 31, 2018. Their paper was recently published in the Journal of American College of Cardiology, and some interesting data related to myocarditis was found.

 Approximately 1 in 4 children who are hospitalized with heart failure present in shock.
 Of them, 24% have myocarditis.

- Children presenting in shock are >3 times as likely to have a diagnosis of acute myocarditis as the cause of their heart failure compared with patients presenting without shock.
- Compared to other causes of acute heart failure (e.g., cardiomyopathy, congenital heart disease, etc.), myocarditis is not significantly associated with in-hospital mortality.

EVENT Peer Support Program



Have you experienced the challenges of myocarditis firsthand? Whether you're a survivor or have lost a loved one to this complex condition, your story holds immense value. The Myocarditis Foundation is proud to announce the launch of our new **Peer Support Program,** connecting individuals impacted by myocarditis with a supportive community.

Share your journey, empower others:

- Offer hope and understanding: By sharing your lived experience, you can provide encouragement and valuable insights to those navigating similar challenges.
- Connect with individuals on a deeper level: Your story can create meaningful connections and foster a sense of shared understanding within the myocarditis community.
- Make a difference: Your participation can empower others to cope with their diagnosis, navigate treatment options, and find strength in shared experiences.

We welcome volunteers who:

- Have been diagnosed with myocarditis or have lost a loved one to the condition.
- Are comfortable sharing their story in a sensitive and supportive manner.
- Are passionate about advocating for increased awareness and understanding of myocarditis.

Flexible volunteering options:

- Offer one-on-one support: Provide personalized encouragement and guidance to individuals seeking peer support through confidential phone calls or emails.
- Speak at patient support groups: Share your story in a group setting, offering insights and answering

questions from individuals impacted by myocarditis.

• Participate in virtual events: Connect with individuals from across the country through online webinars and panel discussions.

Join us in building a supportive community:

By sharing your story, you can make a profound difference in the lives of others facing myocarditis. To learn more and sign up for the **Peer Support Program**, please contact **Melissa at** *Melissa@myocarditisfoundation.org* or call (281) 713-2962.

Together, we can raise awareness, offer hope, and empower individuals living with myocarditis.

EVENT

Myocarditis Foundation 2024 Golf Outing Registration



Monday, August 12, 2024, Arcola Country Club Paramus, New Jersey

Event Highlights:

Complimentary Shopping: Each golfer will enjoy a personalized shopping experience, featuring premium golf merchandise.

Lunch: Indulge in a grilled lunch prior to the start of the

outing. We will offer several on course food and beverage stations.

Arcola Country Club: Nestled in the heart of Paramus, Arcola Country Club boasts unparalleled beauty and exclusivity, offering a picturesque backdrop for your golfing experience. The outing format will be individual play, two best balls per foursome. Caddie costs are fully covered.

Post-Game Events: After the game, unwind and socialize at our lavish cocktail hour followed by dinner. Enjoy the premium silent auction items, raffle prizes, and awards ceremony.

Join us for a day of golf, camaraderie, and philanthropy as we come together to make a difference in the fight against myocarditis.



Honoring Joel Aranson

At this year's Myocarditis Foundation Golf Outing, we gather not only to enjoy a day of golf but also to pay tribute to a remarkable individual who played a significant role in our organization's journey.

Joel Aranson, a beloved member of our Board of Directors, dedicated himself wholeheartedly to the cause of myocarditis awareness. Joel's passion and commitment stemmed from a deeply personal experience: the loss of his son-in-law to Giant Cell Myocarditis in 2013. Joel was unwavering advocate, serving on the Myocarditis Foundation's Golf Outing Committee and Finance Committee. His leadership, generosity, and tireless efforts have left an indelible mark on our organization and the lives of those affected by myocarditis.

As we gather on the greens of Arcola Country Club, we fondly remember Joel's legacy and honor his invaluable contributions to our cause. Though he may no longer be with us, his spirit and dedication continue to inspire us to strive for a future free from the grips of myocarditis.

Clinical Trials / Education Clinical Trials, what They Are and Why They Are So Important ...



Clinical trials are research studies that test a medical, surgical, or behavioral intervention in people. These trials are the primary way that researchers determine if a new form of treatment or prevention, such as a new drug, diet, or medical device, is safe and effective in people.

There are 4 Phases of Clinical Trials:

Phase I Clinical Trial:

Doctors do a phase I clinical trial to learn if a new drug, treatment, or treatment combination is safe for people. They may have already tested it in laboratory animals. These trials usually last several months to a year. They usually have 10 – 30 volunteers. Doctors collect information on the dose or treatment, when and how often you take it, any side effects, or problems, and how the treatment affects you or side effects.

Phase II Clinical Trial:

A phase II clinical trial tells doctors more about how safe the treatment is and how well it works. A Phase II clinical trial lasts about 2 years. Volunteers sometimes receive different treatments. For example, a phase II trial could have 2 groups.

- Group 1 People who receive the usual treatment for the condition. This is also called the standard treatment. It is the best treatment known.
- Group 2 People who receive the usual treatment plus the new treatment doctors are studying.

Or a phase II clinical trial could have 3 groups. Volunteers in each group get a different dose of the treatment doctors are studying.

If the phase II clinical trial shows the treatment works and is as safe as the regular treatment, doctors can do a phase III trial.

Doctors use a computer program to put volunteers into different groups. The computer does this at random, which means by chance. Each volunteer has an equal chance of going in any of the groups. The name for this process is "randomization."

Using a computer to put volunteers in groups keeps the research staff from possibly changing the clinical trial results. They might do this if they chose who went in which group. For example, they might think a certain volunteer would benefit from the new treatment. So, they might put that person in the new-treatment group. But this could change the clinical trial results. Randomization helps avoid this. It is very important to use randomization when a clinical trial compares 2 treatments or more.

Phase III Clinical Trial:

A phase III clinical trial tests a treatment that worked well for volunteers in a phase II clinical trial. Doctors use phase III to compare the new treatment with the standard treatment. They want to know if the new treatment is better, has fewer side effects, or both. So, they put volunteers in different groups. The volunteers in each group get a different treatment. Phase III clinical trials can take many years. They may have several thousand volunteers. These must include men, women, and people of different ages and ethnic groups, if possible. This helps doctors learn how the treatment works in different people.

If a phase III clinical trial shows the treatment works well, doctors might begin using it with people outside the clinical trial. For example, if they learn that a certain amount of exercise lowers your cancer risk, they publish a report. This shares the information with other doctors. If the researchers or sponsor learn a new medicine is safe and effective, they can ask the government to approve it for people to use. In the United States, they ask the Food and Drug Administration (FDA). The FDA looks at the results of the clinical trial's phases. They approve the treatment if the results meet their standards.

Phase IV Clinical Trial:

Doctors can prescribe a drug for their patients after the FDA approves it. But the FDA may require the sponsor to keep studying that approved treatment. In these clinical trials, doctors may check if the treatment benefits people as much as it did earlier. They also look for more possible side effects. These clinical trials are called phase IV clinical trials.

In a Phase IV clinical trial, doctors might study the drug or treatment in different doses, or with other drugs or treatments. Or they might study how it works if people take it at different times. They might study it in different people than earlier clinical trials did. For example, they might study how well it works for children or older adults. Doctors can also study how well a drug or treatment works overtime.

Drug makers may do phase IV clinical trials even if the FDA does not ask them to. They might do this to get FDA approval to use the drug in a new way.

Phase IV clinical trials can also check the safety of drugs or treatments being used now. They do this to make sure drug makers report any new or serious side effects. The FDA may take away a drug's approval if new research shows it is not as safe or effective as earlier testing showed. Doctors cannot prescribe it any longer if this happens.

It has taken many years to get to the point of clinical trials for finding treatments for Myocarditis and Pericarditis. There are two Pharmaceutical Companies who are working on or have developed treatments for Myocarditis and Pericarditis who have or had recent clinical trials.

Kiniksa Pharmaceuticals recently had a clinical trial for the use of Arcalyst in the treatment of recurrent pericarditis. This was approved by the FDA and now is the only current treatment for recurrent pericarditis.

Cardiol Therapeutics announced recently that they have exceeded 50% enrollment in their Phase II ARCHER trial for a treatment for acute myocarditis.

Cardiol Therapeutics also has recently achieved full patient enrollment in its Phase II MAVERIC -Pilot Study investigating a drug for Recurrent Pericarditis.

Please go to our website to access information about these Clinical Trials and others.

EDUCATION Why Do I Have to Limit Exercise After Myocarditis?

After treatment, many patients live long, full lives free from the effects of myocarditis. For others, however, ongoing cardiovascular medication or even a heart transplant may be needed. Overall, dilated cardiomyopathy which can result from myocarditis accounts for up to 45 percent of heart transplants in the U.S. today.

I liken healing from myocarditis to healing from a broken bone. When you break a bone and are told by the doctor that it needs to be casted to allow it to heal properly, you don't question them. You allow them to cast it and you just deal with the limitations it puts on you.

Sure, people's bones can heal even if not casted, but they won't probably heal as well nor work as well after it does eventually heal. The same goes for a healing heart that you stress by exercise.

You cannot place your heart in a cast to allow it to rest and heal itself. Your heart needs to continue to work and pump blood throughout your body so that you can continue to live. The only true treatment for everyone affected by myocarditis is Cardiac Rest. Cardiac Rest is not making the heart work harder than it needs to (by keeping the heart rate within the normal range of 60-100 beats per minute) which allows the heart to heal the best that it can. Sometimes there are other symptoms that may need to be taken care of (i.e. elevated blood pressure, frequent palpitations, heart failure, etc....), but most people only require cardiac rest.

Unfortunately, most of the people who develop myocarditis are young, athletic, and otherwise healthy individuals. When they start to "feel better", they think that they can resume exercising to overall get "stronger again". They do not realize that it takes 3-6 months for the heart to heal itself after developing myocarditis. Just like it usually takes 8 weeks for a bone in a cast to heal, 3-6 months is the time the heart needs to heal since it still must work while it is healing itself.

Trust me, I have spoken to so many patients who tell me that even though they are feeling better, every time they try and exercise, the pain in their chest comes back or they have more palpitations, and in general feel worse again. Please listen to the experts who have determined that 3-6 months is the usual time frame that a heart needs to heal itself. Sometimes it may take longer, depending on the severity of the case of myocarditis that you have.

Cardiac rest means: no exercise (light walking, is usually permitted, but you need to clear that through your cardiologist), not speed walking, distance walking, running, or jogging, no lifting weights, energy drinks, caffeine, smoking, recreational drugs, anything that can increase the heart rate and make the heart work harder.

The area of the heart muscle affected by the myocarditis remains irritable to stimulation during this 3-6 month period and a person is more prone to developing lethal cardiac arrythmias during this time as well as the possibility of the heart enlarging (cardiomyopathy) to try and accomplish what you are asking of it to do, pump more blood and work harder while it is sick and trying to recover..

Healthy lifestyle changes can also support proper heart function. Eating fresh fruits and vegetables and healthy options for protein. Your doctor may recommend that you reduce sodium in your diet, avoid alcohol, limit fluid intake and quit smoking.

Giving up the exercise to allow the heart to heal the best that it can, will benefit you down the line. The thought of living with an enlarged heart and heart failure is worse than giving up the 3-6 months needed to best allow the heart to heal. Your doctor can clear you for increasing exercise again by conducting a few tests to see how your heart responds to the stress of exercise after this period of cardiac rest.

Genevieve Rumore, RN, BSN Executive Director Myocarditis Foundation