

2023

The Myocarditis Foundation Presents

**The Patient Family Support
and Researcher Meeting**

Hampton Inn, Downtown
Cleveland, OH
October 6 & 7, 2023

THE MYOCARDITIS FOUNDATION

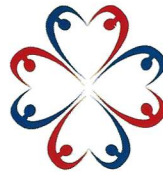
The Myocarditis Foundation is a non-profit organization dedicating to providing information and support related to the causes, symptoms, diagnosis and treatment of myocarditis and sudden death. By working collaboratively with medical professionals and the general public, we are able to increase awareness and fund research to find ways to better diagnose, treat, and prevent myocarditis from claiming more lives.

We would like to thank the generosity of our Program Supporters in helping make the Family Support Meeting a success.

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AND SPECIAL THANKS TO OUR GUEST SPEAKERS:

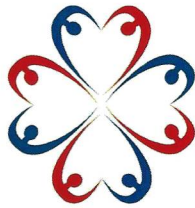
Dr. Leslie Cooper, MD
Dr. Jack Price, MD
Dr. Wilson Tang, MD
Dr. Katelyn Bruno, PhD
Shahnawaz Amdani MD
Dr. Mark Bechter, MD
Dr. Andrew Hamer, MD
Dr. Tahir Kafil, MD



www.myocarditisfoundation.org

The Myocarditis Foundation 800 Rockmead Drive
Suite 155
Kingwood, Texas 77345

Disclaimer: The Myocarditis Foundation is not a health care provider; this meeting is provided solely for general informational purposes and should not be used in place of a visit or consultation, or of otherwise securing the advice of a physician or other health care or professional services provider. By attending this meeting, you acknowledge that the Foundation is not engaged in rendering legal, medical, counseling, or other professional services or advice.



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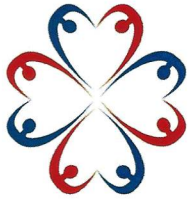
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Katelyn Bruno, PhD



CHAIRMAN'S UPDATE 2023

On behalf of the Myocarditis Foundation and our medical professionals, I'd like to welcome you to our annual Family Support meeting.

While COVID has had a dramatic impact on our lives, it has also brought to light Myocarditis awareness. The Foundation has continued our efforts through the limitations of COVID restrictions, working on our mission of Research, Education and Family Support, with progress being made on all fronts.

We adjusted to the world of COVID shutdowns by offering Virtual Family Support meetings, but we understand the importance of meeting face-to-face and speaking one-on-one with myocarditis specialists, researchers, and others affected by the disease.

Our online Myocarditis Community through Inspire.com, has increased to over 785 participants for myocarditis, and over 338 for pericarditis, which is a 76% increase over last year's numbers. Inspire gives them an outlet to express themselves with others in similar circumstances.

We have granted 25 Fellowship Grants to new researchers of myocarditis, since our inception in 2005, totaling over a million dollars in impactful research.

There are currently 10 Clinical Trials in the U.S. that are being conducted on Myocarditis, with 138 being conducted around the world.

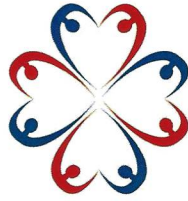
We are fostering the use of new medical technology to update and re-write most of the historic research. We see the development of our Biobank/Patient Registry helping to advance research and diagnostic capabilities.

We have maintained our position of a Platinum GuideStar rating. This rating quickly identifies us as a Non-Profit operating with the highest level of integrity. It also advises that we run the Foundation at a very low Administrative Operating Ratio indicating your donations a going directly to the stated mission.

Unfortunately, Myocarditis has had a significant impact on our lives and those of family members. As a family with commonality, we will share our experiences supporting one another and hopefully find some comfort knowing we are not alone. I look forward to our presentations and discussions.

It is my hope we provide some answers and support one another which will enable us to move forward with helping others.

Joseph Rumore
Chairman



September 14, 2023

Dear All:

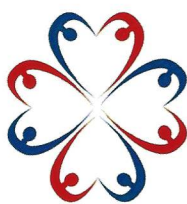
Your presence at this meeting means you have experienced myocarditis, a disease you likely knew nothing about until this trauma occurred. I'm so sorry for however this disease has impacted your life. Know these two things: You are not alone and you are in the right place to have your questions answered by the experts, to receive support from fellow participants who have experienced what you have been through and to meet the Myocarditis Foundation staff and Board of Directors and Medical Advisory Board who have been working for almost 20 years to find a cure for this disease. Welcome.

None of us chose this path, but together we can hopefully travel toward an uncertain future together, and ease each other's burdens.

I'm so very sorry I can't be with you this year due to a significant family illness that requires me to stay close to home. Know that my heart is with each and every one of you, old friends and new friends I've yet to meet. You are now a member of our MF family. Our desire is to be helpful to you and supportive of you. Stay with us as long as you like, but always keep in touch so that we can keep you abreast of the progress being made in our understanding of myocarditis.

We pray that you will be inspired to join us in the fight to eliminate this disease. Our hope is that future research will produce better, faster, more widely available diagnostics and more treatment options. Tell your story to anyone who will listen, host fundraisers for the foundation, and give generously to help us win this fight.

Love,
Candace Moose, Co-Founder

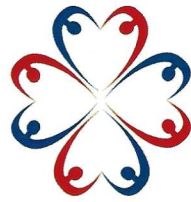


Guest Speaker

Dr. Leslie Cooper, MD
Cardiologist
Chair of the Cardiovascular Dept.
Mayo Clinic, Jacksonville Florida

Co-Founder and Medical Director of the Myocarditis Foundation

- Dr. Cooper's clinical interests and research focus on clinical and translational studies of rare and undiagnosed cardiomyopathies, myocarditis, and inflammatory cardiac and vascular diseases such as giant cell myocarditis, cardiac sarcoidosis, eosinophilic myocarditis, and Takayasu's arteritis.
- He has published over 257 original peer-reviewed papers as well as contributing to and editing books on myocarditis. In addition, he has spent years working with clinicians and researchers around the world to further diagnosis, treatment, and care for myocarditis and cardiomyopathies.
- In addition to his clinical and research work Dr. Cooper is a fellow of the American College of Cardiology, the American Heart Association, and the European Society of Cardiology Heart Failure Association, The International Society for Heart and Lung Transplantation and the Society for Vascular Medicine and Biology.

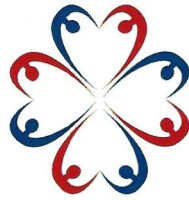


Guest Speaker

Dr. Jack Price, MD
Pediatric Cardiologist
Founding Director of the 1st Pediatric Cardiovascular
Intensive Care Unit at Texas Children's Hospital
Houston, Texas

Pediatric Medical Director of the Myocarditis Foundation

- Dr. Price serves as a senior attending physician and cardiologist in the Heart Center at Texas Children's Hospital. He sees mostly heart failure and transplant patients on the inpatient team but also cares for patients in general cardiology clinics. He is an advocate for children with heart disease and strives to provide patient and family-centered care that is current, evidence-based, and trustworthy.
- As a faculty member of the Baylor College of Medicine, Dr. Price has served in several educational leadership roles at the medical school and regularly teaches students and trainees at affiliated hospitals. His research interests focus mainly on pediatric heart failure. He has presented abstracts of his research at national and international scientific meetings and received the Outstanding Pediatric Cardiology Research Award from the American Heart Association. He has authored more than 155 scientific manuscripts, book chapters and review articles.

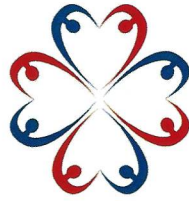


Guest Speaker

Dr. Wilson Tang, MD
Cardiologist
Research Director of Heart Failure and Cardiac
Transplantation Medicine
Cleveland Clinic

Member of the Myocarditis Foundation Medical Advisory Board
Principle Investigator for the MF Biobank / Registry

- Dr. Tang's specialty interests include cardiomyopathy, heart failure including heart transplantation and mechanical circulatory assist devices, cardio-renal diseases, and cancer-related heart diseases.
- Dr. Tang is a clinician-scientist interested in clinical translational research, with joint appointments with the Department of Cellular and Molecular Medicine and the Genomic Medicine Institute at Cleveland Clinic's Lerner Research Institute.
- He leads the Cleveland Gene Bank Study as well as the Cleveland Heart and Metabolic Prevention Study to investigate novel mechanisms in the development of heart diseases.
- Dr. Tang has authored over 668 published peer-reviewed manuscripts in medical and scientific journals and chapters in medical textbooks. He currently serves in the Editorial Boards for Journal of the American College of Cardiology (JACC) Heart Failure, JACC Cardio-Oncology, Circulation Heart Failure, and American Heart Journal.



Guest Speaker

Dr. Katelyn Bruno, PhD, FHSA
Myocarditis Researcher
Assistant Professor of Cardiovascular Medicine
Department of Medicine & Department of Physiology and Aging
Deputy Director, Center of Regenerative Medicine
Director, Bruno Translational Cardio-Immunology Laboratory
University of Florida

Secretary to the MF Medical Advisory Board

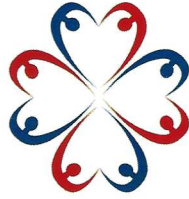
- Dr. Bruno's lab is working to identify immune mechanisms contributing to myocarditis and dilated cardiomyopathy utilizing novel animal models to discover new diagnostic tools and therapeutics. Specifically, her recent work involves studying multiple novel potential drug targets, utilizing a new regenerative medicine therapy (secretome), and developing a pediatric myocarditis mouse model to study differences based on patient age.
- Before starting her independent laboratory at the University of Florida Dr. Bruno trained under and worked with Dr. Fairweather at Mayo Clinic Florida for over 10 years. Drs. Fairweather, Cooper, and Bruno still actively collaborate on important work studying myocarditis, dilated cardiomyopathy, and heart failure.



Guest Speaker

Dr. Tahir Kafil, MD
Cardiologist
Myocarditis Researcher
Cleveland Clinic

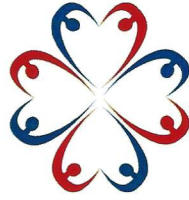
- Dr. Tahir Kafil completed his Internal Medicine Residency and Adult Cardiology Fellowship at Western University. He subsequently completed his Advanced Heart Failure and Cardiac Transplantation Fellowship at the University of Ottawa Heart Institute. During his time in Ottawa he helped establish the Post-Vaccine Myopericarditis Clinic. He is a co-Investigator in the CIHR-funded COVID-VIHPR study assessing rare cardiovascular complications of COVID-19 vaccination. For his research work he was awarded the prestigious Myocarditis Foundation's Fellowship Grant.
- Under the Myocarditis Foundation's Fellowship Grant, his research was on COVID-19 Vaccine-Induced Inflammatory Heart Disease.
- He is presently pursuing further training in Echocardiography and Advanced Cardiac Imaging at the Cleveland Clinic Foundation in Cleveland, USA.
- His research interests are in Myopericarditis, Cardiovascular manifestations of Autoimmune Diseases, and Cardiac Sarcoidosis.



Guest Speaker

Dr. Andrew Hamer, MD
Cardiologist
Chief Medical Officer and
Head of Research & Development for Cardiol Therapeutics

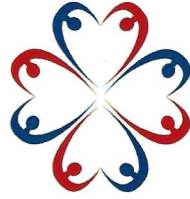
- In addition to his many years as a Cardiologist, Dr. Hamer has co-authored many high-quality peer-reviewed scientific publications reflecting his considerable experience as a clinical trialist, having served as a principal or co-investigator for 40 multi-centre clinical trials in therapies for acute coronary syndrome, heart failure, hypertension, cholesterol disorders, atrial fibrillation, and diabetes.
- Currently, Cardiol Therapeutics has two Phase II Clinical Trial in progress.
 - A Phase II Clinical Trial for Myocardial Recovery in Acute Myocarditis
 - A Phase II Clinical Trial for Recurrent Pericarditis



Guest Speaker

Dr. Mark Bechter, MD
Cardiologist
Vice President of Operations & Patient Advocacy
Kiniksa Pharmaceuticals

- Dr. Bechter has been with Kiniksa since January 2023. Prior to this, he was the Vice-President of Aeglea Bio-Therapeutics in the UK, and Medical Director and Chief Scientific Officer for a number of other Healthcare groups and Pharmaceutical Companies.
- Kiniksa's Mission is to develop safe, effective, and transformative treatment options for patients with debilitating diseases. As the VP of Operations & Patient Advocacy at Kiniksa, he is working to help patients affected by inflammatory heart disease, of which both Pericarditis and Myocarditis are.
- Kiniksa has recently developed a medication to treat recurrent Pericarditis. Arcalyst (rilonacept) is the first and only FDA-approved treatment, at present, to treat recurrent Pericarditis and reduce risk of flares in people 12 years and older.



Guest Speaker

Dr. Shahnawaz Amdani, MD., F.A.C.C.
Cleveland Clinic

- Dr. Amdani is a pediatric Cardiologist specializing in Pediatric Heart Failure and Heart Transplantation at Cleveland Clinic.
- He did his Pediatric Cardiology Fellowship at Children's Hospital of Michigan and a Fellowship in Advanced Heart Failure and Transplant Cardiology at Washington University Medical Center in St. Louis.
- He recently published a paper on Cleveland Clinic's experience with "Myocarditis after COVID Vaccine in Those with a History of Myocarditis".



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Not a Blank Canvas: *Portraits of Myocarditis*

Kacey Koenigs, Black River Falls, WI



On Friday, December 30th, 2016, I called my Mom from the floor of my room sweating and crying because I felt like I was about to pass out. The room was going dark, I was lightheaded, my heart was racing at speeds it had never reached before, and I wasn't able to yell to my sister and Dad that were just one floor below me. For over a week prior to this, I had not felt right, but I had just finished my first semester at college and figured I was just tired and recovering from the stress of it all. Christmas Day was the first day that I noticed that it was my heart that was beating funny and causing me to feel lightheaded, dizzy, and nauseous. My parents figured it was a form of stress or anxiety from the end of my semester and decided to just watch it for a few days. The feeling kept coming back so my Mom took me into the clinic in my town three days later. While I was there, they performed an ECG and everything came back normal except that my heart rate was between 110-120 beats per minute. The normal heart rate is 60-100 beats per minute so mine was just a little fast. The doctor told me to go home, rest, and drink water because it probably was just stress and dehydration.

Two days later was when my Dad found me on the floor of my room pale, ice cold, and sweating. By the time my Dad got to me, I couldn't see him at all even though he was right in front of me, but I could hear him talking to me and trying to keep me from losing consciousness. Immediately, my parents took me to our local ER. When they got me hooked up to the machines, they found that my heart rate was fluctuating at sky high rates. I laid there for three hours as my heart rate jumped all over at rates from 130 to 290 beats per minute. Everytime my heart rate went over 200, the machine would start beeping and I just laid there knowing that the alarms going off were for me. I was in Ventricular Tachycardia and the doctors could not get my heart to come out of it. They tried countless ways to get the rhythm to break before they gave me medications through an IV. The first medication they tried didn't work so they doubled the dose and gave it to me again, but that still didn't work. The next medication they gave me helped more than the first but it was still unable to completely stabilize my heart, so they decided to transfer me to a bigger hospital. My parents watched as the doctors gave their 18-year-old daughter baby aspirin, loaded up the paddles, and took her away by ambulance with the sirens blaring to a hospital an hour away.

I spent that night in the ICU at Gundersen Lutheran Hospital after they did an echocardiogram of my heart. The first doctor that came to us at Gundersen Lutheran told us that she thought I had a defect in my heart that I was born with. With this news, I sat there astounded. I had been an athlete my entire life and had always been an exceptionally healthy kid. I played volleyball throughout high school, went to State for track, and had been a dedicated figure skater since I was three years old. How could something have taken this long to show up with my heart after being so active? The next day that question was answered when the fifth doctor to see me determined that I had Myocarditis. Since it was New Year's Eve, the doctors there decided that I needed to be transferred to another hospital that was able to do an MRI sooner and was able to provide me with more intensive care. So, they loaded me in the ambulance for another ride to a new hospital that was two and a half hours away.

I arrived at UW-Madison Health that evening and spent New Year's Eve in the Cardiac ICU with my family. On New Year's Day, the doctors came in to talk to us and they told me that my Troponin levels were extremely high at 39. They also determined that I had fluid in my lungs because they had been giving me so many fluids through an IV, but the good news was that my heart rate was fairly stable. On January 2nd, they took me for the MRI and later a CT scan. The results from those tests confirmed the diagnosis of Myocarditis. After that, I spent the next few days in the hospital recovering. The day before I was released, a heart transplant doctor came in to speak with me and tell me I was being treated as a heart failure patient. It was the most humbling and terrifying moment of my life. Once I was released, I returned home with a month to regain strength before returning to college. I was able to return to college on time with a lower class load and restrictions on daily life.

At the time, it was believed that after six months I would be fully recovered and able to return to normal life since I was diagnosed as a mild case of acute Myocarditis. However, in the following six months, the areas affected by inflammation on my heart did not improve. After discovering that, I was referred to Mayo Clinic to see the expert, Dr. Leslie Cooper. After my MRI in May 2018 showed still no improvement in the areas that were affected by inflammation, it was determined that as of now it is believed to all be scar tissue on my heart. This scar tissue causes me to still have periods of Ventricular Tachycardia that make me feel like I am going to pass out but medications help with that. After a year and a half of no physical activity, I have finally been released to slowly return to being active, but there will always be some limitations on my abilities because of the scar tissue. There are so many unknowns and mysteries about the causes and repercussions of Myocarditis that make this disease terrifying, but I am slowly learning how to live with the effects from this disease. I am extremely thankful to still be here with the support of my family and friends while I continue to live with the effects of Myocarditis. I am also thankful for Dr. Leslie Cooper and the Myocarditis Foundation for bringing awareness and research to this disease.



**Myocarditis
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Knowledge Nurtures Hope

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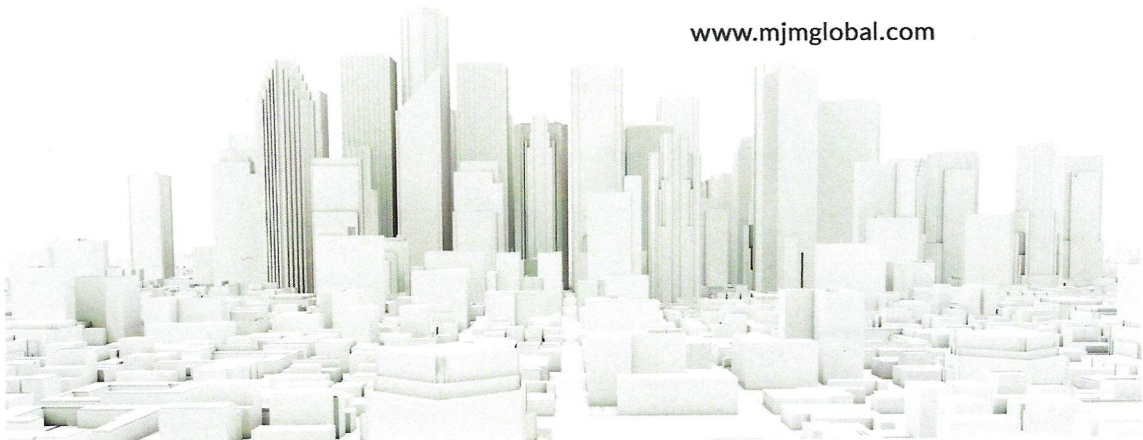
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Myocarditis tried its best to take this joy from our family, but we were lucky enough to have beat it thanks to the generosity of a Family who donated their loved one's heart and other organs at the time of their own sorrow.

We support the Myocarditis Foundation and the work it does to raise awareness, educate on the disease, and encourage research in myocarditis, so that others won't have to suffer the effects of long-term heart failure and the need for a transplant to survive.

Don't let this disease take another families happiness from them...

Please become an Organ Donor...Donatelife.net

Please support the Myocarditis Foundation...
www.myocarditisfoundation.org

The Rumore Family

Not a Blank Canvas: Portraits of Myocarditis

Rhett Porter Lundy
June 3 1998 – May 15 2013

A gleam in his eye, laughter in his voice, and a contagious smile best describes our 14-year old son Rhett, who was a gregarious, boisterous, compassionate teenager until he was ripped from our lives when myocarditis took his life in the early morning hours of Wednesday the May 15, 2013, shattering our hearts in a million pieces.

Tuesday May 14th began and ended as any typical weekday. Unbeknownst to me 11:00 PM that night would be the last time I would see my son alive when he gave me a hug and kiss and got ready for bed.

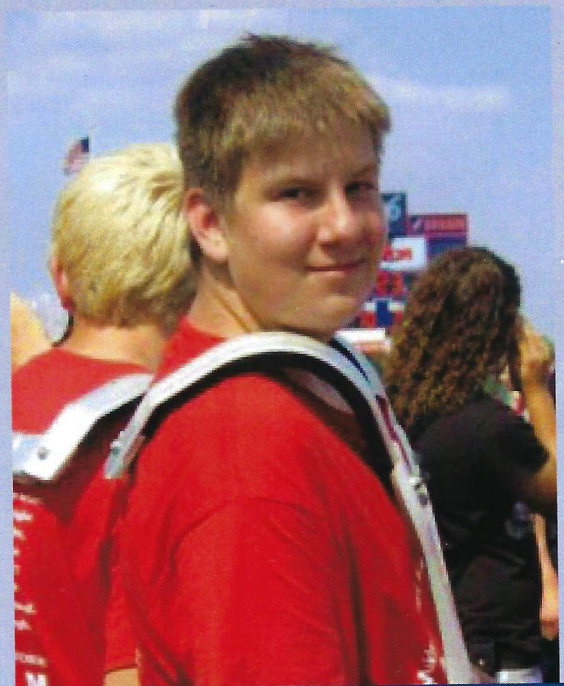
Rhett arrived home from school that afternoon excited and nervous about his second interview for his first summer job as a pool attendant working for the city. He returned from the interview excitedly announcing that he got the job ... just as soon as he passed the drug test scheduled for Friday after school. That was to be a busy week for Rhett; the end of school year was quickly approaching and many classes like Honors Biology had assignments due. Tuesday evening Rhett worked meticulously on the desert diorama for Biology which was due the following day, strategically placing the plastic cacti, and rubber snakes and spiders in the sand to resemble a desert scene.

Wednesday morning May 15th, when Rhett was not awake at his typical time, my husband went to wake him. I knew something was terribly wrong when I heard his dad cry out "Rhett, oh God Rhett!" His training and experience as a paramedic couldn't have fully prepared him to find his son unresponsive that morning, but he told me call 911 and immediately began CPR. Less than an hour later Rhett was pronounced dead at the hospital.

Rhett was a diligent student, interested in math, science and engineering. He loved playing video games and was intrigued by game design and animation. In addition to being a strong student, he completed his freshman year with a 4.2 GPA, he was a talented percussionist and a proud member of his high schools drum line, and a member of the boy's bowling team. Rhett loved animals and had developed an interest in the political process and enjoyed debating with others. Family, friends and casual acquaintances all recognize that love and joy permeated Rhett's life. He brought laughter to others, and possessed the ability to lift the spirits of those around him. His absence leaves emptiness in the lives of all who knew him.

Like a fire that has long been extinguished, left behind are smoldering embers. As any firefighter can attest, those embers can sometimes reignite. Nothing will extinguish the smoldering embers of the grief we experience every day from Rhett's death.

The Lundy Family
Steve, Vickie, and Ryne



Rhett Lundy • Elgin, IL



Myocarditis
FOUNDATION

Knowledge Nurtures Hope

Not a Blank Canvas: *Portraits of Myocarditis*

Kyle Hansen Story Oak Park, Illinois

Driving home from our summer vacation in July, 2017, I started to feel lousy. My throat hurt, my head hurt and I knew I was coming down with something. I saw my primary care physician who prescribed antibiotics over the next few weeks but my condition worsened. On a Friday afternoon, later that month, I began to retain water, my stomach began to distend and my urine output was very low. At that point, I went to the emergency room.

I was admitted into a local community hospital and underwent testing. I was eventually diagnosed with Myocarditis. However, the hospital did not have enough means to support my condition and I continued to deteriorate... quickly. At one point, a chaplain came in to pray with me, as my life was hanging by a thread. My family members requested that I be transferred to a facility in the Chicagoland area better equipped to manage my care. I was granted the transfer and the University of Chicago Medicine Hospital agreed to take on my care. I was immediately transferred to their world-renown Advanced Heart Failure & Cardiac Transplant division.

At U of C Medicine, I was put on an Extracorporeal Membrane Oxygenation, or ECMO machine. The machine pumps and oxygenates a patient's blood outside of the body, allowing the heart and lungs time to rest and recover while they are being administered life-saving medications. During the surgery to install the ECMO machine, the doctors took a biopsy of my heart and changed my diagnosis to Giant Cell Myocarditis.

I was fighting for my life and was told that there was a good chance that I would need a heart transplant to live. It was a very, very surreal time for me. Up until then, I had been a very healthy 52-year-old mother of 3, and now I was told I might need a new heart and could be facing a lengthy hospital stay.

During the week I was on the ECMO device, and by the grace of God, my heart started to pump on its own. My doctors told me that my heart had recovered enough to remove me from the ECMO device, which occurred surgically a few days later. Thereafter, the drip medications were reduced or eliminated. The lines and drainage tubes were eventually removed. I was finally cleared to leave the hospital after a month of being in the intensive care unit.

I was incredibly weak, scared and in a state of bewilderment that this had happened to me. Even today as I write an account of my journey, it almost feels like this happened to someone else and I am watching a movie about it.

Four months post-release, according to the doctors, I am making a miraculous recovery with my own heart, and I never miss a day to thank God and my medical team for where I am at. Within a few months of being home, I even walked a 5K with my friends and family, all wearing Kyle "True-Grit" bright red t-shirts in honor of my recovery. It was quite an accomplishment considering I couldn't hold a hair dryer when I was first released.

My recovery has been steady, but the journey is long and continuous. I worry about every irregular heart-beat and any unusual sensation in my chest. Not a moment goes by that I'm not aware that I have Giant Cell Myocarditis. I remain on the heart transplant list in case my condition takes a turn for the worse.

I take numerous medications to support and strengthen my heart. They make me jittery, weak and fatigued. I also have steroid-induced diabetes. I follow the doctor's plan and I try not to complain too much about this new lifestyle. I am enrolled in a cardiac rehabilitation program. I have since returned to work on a limited basis and I am beginning to feel like I am leading a mostly "normal" life again.

The doctors say that my heart will never fully regain its former strength and functionality but I am working hard to get back to as close as possible. All of these side effects are minor. I have no complaints...I feel blessed to be alive.

I hope my story brings hope to those who read it. And for those who have lost a loved one to myocarditis, my heart breaks for you. I am truly saddened by each and every loss. It's a terrible disease and the common thread in each story seems to be a lack of a timely diagnosis. I went untreated and undiagnosed for almost three weeks. It appears that raising awareness about myocarditis is paramount to helping more people survive. I hope to do my part in this fight and to help save the precious lives of those who might suffer.



Myocarditis
Foundation

Knowledge Nurtures Hope

Not a Blank Canvas: Portraits of Myocarditis

Austin Lee Vonckx

August 21, 1995 - September 14, 2014
Trinity, FL

*Taken in the prime of his life and at
the top of his game*

Austin was 4 weeks into his freshman year at Florida Gulf Coast University and enjoying every minute of it... his friends, his classes, his dorm, his freedom... life was great. His daily texts and random calls to his mom always confirmed that he had landed exactly where he was supposed to be.

That all changed in the early morning hours of September 14, 2014. Austin called his mom at 3:06 a.m. with a headache that was making him dizzy when he tried to sleep. He also casually mentioned that he'd been "really tired" for the past few days. His mom chalked it up to being a new college freshman and reminded him to eat and sleep.

Austin proceeded to tell his mom about his day, which included paddleboarding

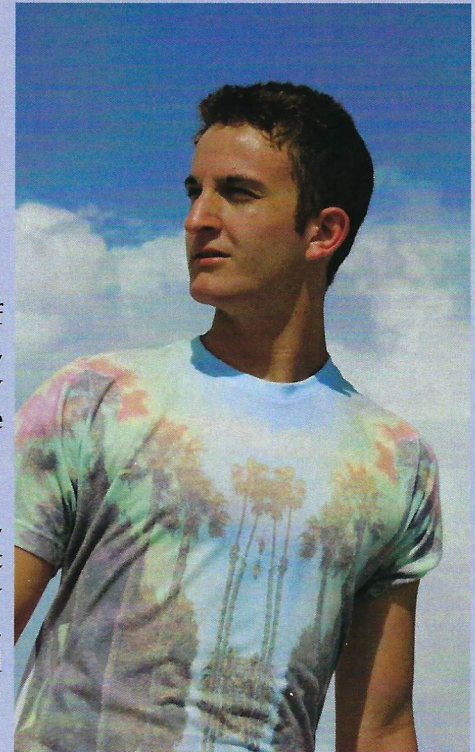


FGCU orientation in June 2014

on the campus lake, playing football on the lakefront beach and playing video games in his room with friends until 2:00 a.m. They talked and laughed as they typically did until - 48 minutes into the conversation - a loud gurgling noise came across the line, followed by complete silence. The paramedics found Austin lying on his dorm room bed, on his back, with his cell phone still in his hand. Viral myocarditis literally took his life in the middle of a sentence.

Another beautiful life stolen by this dreadful disease: a 19-year-old who was passionate about the Green Bay Packers and the Tampa Bay Rays... who enjoyed fishing, sports, Eminem, fantasy football and collecting signed memorabilia... who treasured his pets and was fascinated by cats... who was a faithful, fun-loving friend who spent his days making people laugh... who cherished his PS4 and could beat anybody at Madden... who was loved beyond measure and adored beyond words by his mother Brenda, brother Eric and father Don.

Austin's new home is in the hearts of all who loved him. And his memory will always be kept alive, as his friends and family work to spread awareness and raise money for ongoing research - with the goal of one day ending suffering and sudden death from this insidious disease.



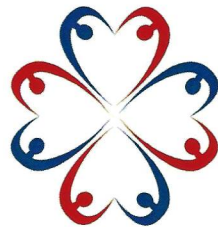
Enjoying the beach in Sanibel Island just weeks before his death



Myocarditis
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Knowledge Nurtures Hope

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Not a Blank Canvas: *Portraits of Myocarditis*

Ke'Mora's Story... Indianapolis, Indiana

Ke'Mora was blessed with good health. My daughter has never had to stay in the hospital and only visited to get yearly check-ups and shots for school.

On September 20, 2018 she came home from school and threw up. We thought maybe she had over heated at school and let her rest the rest of the evening. For the next 5 days she barely moved. It was hard for her to even shower due to lack of energy. She said her chest hurt, she felt dizzy, and nauseated.

After day 5 my husband and I decided to take her to the emergency department. At that point she could barely walk but we encouraged her that the stomach bug wasn't affecting her legs and she trudged in the hospital with me. I still feel really upset that I didn't know she was that weak.

The doctor looked her over and still he even thought it was a stomach bug. He did mention that her heart rate was abnormal but when he checked her chart the check in nurses had recorded a normal heart rate.

No EKG or scan were offered instead he gave her a rapid strep test that came back negative.

He sent us home with instructions to bring her back if she ever got a fever or didn't feel better in two days.

Exactly two days later she went into cardiac arrest in the back seat of the truck while I was driving. She spent 15 minutes on the side of the road with no pulse and barely breathing.

The EMTs got a pulse after shocking her heart and took her back to the emergency department. At the hospital she went out 3 more times before she was placed on life support and a ventilator.

After a week in ICU she was released to a floor called the step-down-unit. She started therapy and learning to do basic things again like eating and washing her face.

Once all her medication was reduced and she was medically stable they released her to inpatient rehab where she learned to shower, wash her hair, and walk again.

She has started back at school half-days until she regains her strength. She still goes to outpatient therapy 3 times a week. She also is taking heart medication and blood pressure medication. We are not sure if she has to be on them for the rest of her life.

I'm so thankful she got another chance at life. God really blessed our family.

We need to raise awareness about this disease called Myocarditis, so other children do not almost die before they are diagnosed and treated!



**Myocarditis
Foundation**

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Not a Blank Canvas: *Portraits of Myocarditis*

Christopher

We once had a perfect life, a completely bright future and lots to look forward to. Our perfect life was shattered after a tragedy that will scar us for the rest of our lives.

Christopher was our first son. He had a younger brother who loved him very much too. Christopher was very loving and kind to his parents and his friends. He was always loved everywhere he went.

Ever since he was born, Christopher had shown signs of quality of a person we could only dreamed of. He was very persistent and hard working. He showed great interests in everything he laid his eyes and hands on. He was tri-lingual by the time he started walking. By the age of 6, he knew the facts of all dinosaurs, memorized the names of our presidents, knew the facts of every states in the United States and countries in the world. He was also a very accomplished pianist. Three months before he left us, he won the spelling bee championship of Hoboken NJ. One week after his passing, we received a letter from John Hopkins Center for Talented Youth congratulating us that Christopher had won the High Honor award.

More importantly Christopher showed abundant love for God and other human beings. He was always very appreciative of what he had and we were able to afford for him. He volunteered himself to anybody he saw needing help (and gained many great friends along the way). I learned a lot to be a better human being from him. My wife and I counted our blessings for having him, and had very high hope for his future. He literally gave us the best 10 years of our lives.

On July 3rd 2015, a day before his favorite holiday, he complained of discomfort and fever. The whole day he rested at home and watched TV with us. We gave him fever reducer and lots of water. In the evening he threw up and felt very weak. Near midnight he struggled to breathe and showed signs of seizure. By the time the ambulance arrived, I was already performing CPR on him. An hour and a half of attempted resuscitation, we lost him.

For many months after his passing, I was struggling to come to terms with the loss. Even now writing this is painful. How could life give us such a perfect son, but then just took him away without any warning, and without even giving us a chance to say good bye. Chris' passing took away a big part of our lives.

A few months later, the medical report eventually showed that he died from Viral Myocarditis. This prompted us to learn more about this terrible disease. It will be a lifelong promise of us to educate others about this disease and hopefully raise awareness and funding to prevent this kind of loss on other parents.



Christopher Wijaja • New Jersey

Not a Blank Canvas: *Portraits of Myocarditis*

LEE'S STORY New York, New York

On November 22, 2015 this mother's life was changed forever. In the still of early morning, I knew the piercing sound of the phone carried disturbing news. I just didn't realize how bad. At home with his girlfriend, my beautiful loving son was struggling to breath. Within minutes a caring, fun loving man - a friend to so many - had his life cut short and took his last breath. He had just turned 31 in September. The hopes and dreams we shared for his future came to an end.

The week prior was like most weeks. My son spent his last week busy at work as a General Manager of a restaurant, followed his beloved NY Knicks, had dinner at his favorite restaurant with his girlfriend, getting ready for an upcoming poker tournament and making plans for Thanksgiving. He was especially looking forward to spending time with his aunt, uncle and cousins. How would I know at the time, that his wish to spend time with them would come true, but not in the way anyone would imagine. Not a family member missed that Thanksgiving Day as we said our goodbyes.

It was hard to comprehend. Lee was young and healthy. The only thing he did complain about in the days prior was stomach problems due to either eating something spoiled or maybe the stomach flu. But he carried on as usual. At the time of his death even the ER doctor was stunned and an autopsy was immediately ordered. However, it was not until seven months later that I learned that his death was due to Myocarditis, something I had never heard mentioned before. What is it? And why did it happen to Lee.

Lee had the ability to light up a room and lift your spirits. He brought joy and laughter wherever he went. He lived with passion, humor and an amazing spirit. He touched the lives of all who knew him - family, friends and casual acquaintances. One friend stated that he was one of the nicest guys you would want to surround yourself with. Although his absence is felt, his ever present love of life will go on in everyone who knew him.

I found this poem in a box in the garage two weeks before he died - he was in third grade when he wrote it. It describes Lee's outlook on life so perfectly-

*Life is Happiness, fun and exciting
You can see the pretty flowers,
You can feel the heat of the fire
in your fireplace,
You can hear the birds singing
You can play all day.
What can't you do in life?*

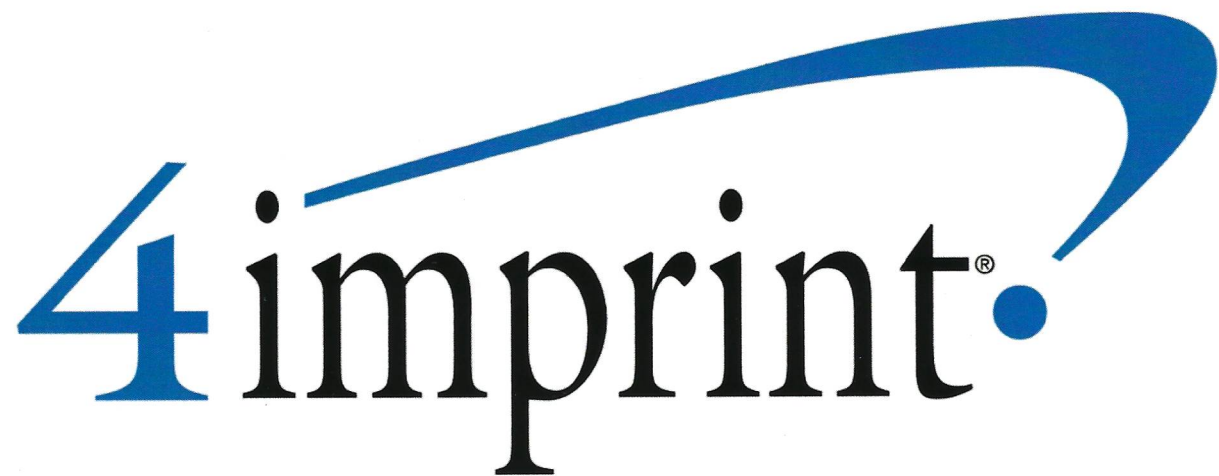
In memory of my son, Lee Andrew Hirsch, I will put my efforts in raising funds for the Myocarditis Foundation so they can continue to raise awareness and research.

His Mom, Giustina Schiano



Myocarditis
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The Myocarditis
Foundation would like
to thank 4imprint for
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YOU have the power to Donate Life...



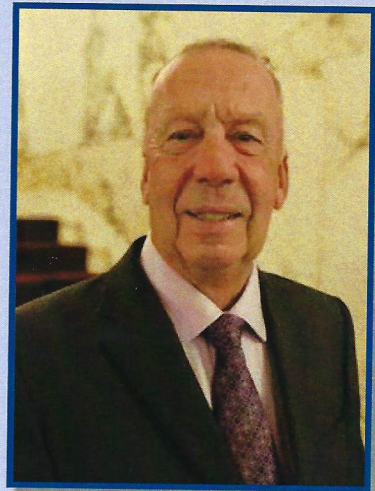
Candace Moose's birth heart was irreparably damaged due to **Giant Cell Myocarditis**. She is here today and was able to start the Myocarditis Foundation in 2005 thanks to an organ donor family, who gave their 17-year-old son's heart to someone who needed it when he could no longer live due to brain death.

Through the founding of the Myocarditis Foundation, we were able to raise awareness of the disease, educate both the medical and public communities about the disease, provide research funds specific to the disease, and provide emotional support to others who have been devastated by this disease. The Foundation also helps patients find the specialists that they need when presented with a disease that most doctors have never seen in their practices.

Joseph Rumore's birth heart was irreparably damaged due to Viral Myocarditis. He is here today because a husband donated his wife's heart when she developed brain death. Joe was able to start the Myocarditis Foundation Golf Outing in 2008 to raise awareness for Myocarditis. So far, they have raised over a million dollars for the research of Myocarditis, **Viral and Giant Cell Myocarditis**.

Together they have lived to see their children grow up, marry, and see their grandchildren born, which neither would have been able to do without the saving chance of a **new life due to organ donations**.

Together with Dr. Leslie Cooper, the Boards of Directors and Medical Advisory Board, they have grown the Myocarditis Foundation to what it is today and hope to see the day when this disease will not have the devastating outcomes that it has had in the past.



Do you know:

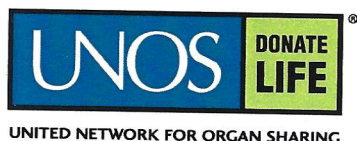
- Every 9 minutes, another person is added to the national transplant waiting list.
- 17 people a day die while waiting for an organ transplant.
- 1 out of 3 deceased donors is over the age of 50.

Each organ donor can save up to 8 lives due to organ donation and heal up to 75 lives through tissue donation.

In 2021, nearly 20,400 donors brought new life to recipients and their families...

Think about what these people can accomplish in their new lives and see in their lifetime with their new gift of life thanks to the generosity of a donor...

Plan ahead...don't take your organs with you, heaven knows we need them here!



Become an Organ Donor

**It is an honor
to support the
Myocarditis Foundation**



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