



MYOCARDITIS FOUNDATION



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Professor of Pediatrics at Harvard Medical School and Associate Chief of Cardiology at Boston Children's Hospital.

New Mailing Address

The Myocarditis Foundation has moved its business operations to Kingwood, Texas. Please use the below address for all future mail and correspondence.

The Myocarditis Foundation
3518 Echo Mountain Dr., Kingwood, TX 77345
Telephone: (281) 713-2962

Find us online: www.myocarditisfoundation.org



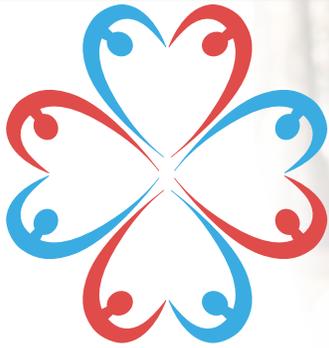
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MYOCARDITIS
FOUNDATION



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

THANK YOU LETTER 2015

The Myocarditis Foundation Thanks You For Your 10 Years of Support!

On September 26, 2015, the Myocarditis Foundation celebrated its 10 Year Anniversary with a group of 75 patients, families who lost loved ones, researchers, adult and pediatric clinicians, at our annual meeting in National Harbor, Maryland.

Fourteen years ago, after a heart transplant due to Giant Cell Myocarditis, a woman and her family could not find any information about myocarditis. There was nowhere for her family to turn for answers. They felt so alone in their journey.

Six years earlier, a Cardiology Fellow at Stanford University, took care of a woman who died of Giant Cell Myocarditis. He felt helpless as there was nothing he could do to save her life. He then made it his life's work to research this catastrophic disease. It was his research that helped to save another young woman from this same disease years later. That woman was Candace Moose and the doctor was Dr. Leslie Cooper.

Together, they founded the Myocarditis Foundation in 2005.

It is because of people like you that we have been able to adhere to our original mission of:

Research, Education, and Support of those affected by Myocarditis...

Our goals remain the same:

- To fund Research Grants that might someday lead to better treatments and especially faster and more accessible diagnostic tests to pinpoint myocarditis
- To educate physicians and the public to raise awareness on and prevent myocarditis victims from being undiagnosed and turned away from medical care because it is "Just a virus". This delay in diagnosis can lead directly to an increase in mortality, often from sudden death due to cardiac arrhythmias.
- To be the resource for myocarditis victims and their families.

In the ten years since inception, we have funded fourteen Research Grants to Post-Doctorate Researchers interested in myocarditis research, totaling almost \$500,000. It is because of your help and financial support that we have been able to reach this point in our quest for putting a stop to this disease's devastation of life.

We print pamphlets on the various forms of myocarditis which are

shared with the public in our awareness campaigns.

Our physicians speak on the disease with other medical professionals, so as to raise awareness to this little known disease that hides behind symptoms of what we may think as a "simple viral infection."

We maintain a presence on Social Media where we reach out to those affected by myocarditis around the world. Our website receives over 30,000 web hits per month.

Our office helps to answer questions or refer them to the best sources for their requests on the disease.

The MF has attained GuideStar's coveted "Gold Star" designation. GuideStar, is a company that evaluates non-profit organizations on board diversity and governance, financial accountability and sustainability. In essence, performing due diligence for donors. The Gold Star rating is an achievement, one that reports to the public that the Myocarditis Foundation has successfully provided a full array of information for public review, including strategy and mission statements, financial statements and detailed program descriptions.

We want to continue to work towards stopping the suffering that this disease causes to so many. The only way we can do that is through your continuing support. Please help us continue our mission and achieve our goal of saving more lives from this devastating disease.

Without your ongoing support, we could never have been able to accomplish what we have. Please help us help others with your donation as we start on our second decade of caring.

We would not be where we are today without your support.

We cannot thank you enough for all that you have done for us so that we can be there to help others.

We want to be there for those who need us. Please make your donation today. Please help make this happen.

May God Bless you for your continued support!

*Sincerely,
Genevieve Rumore,
Executive Director
November 2015*

3rd Annual Family Support/Researcher Meeting Synopsis

By Genevieve Rumore Executive Director Kingwood, Texas

We'd like to share with you the happenings at our recent meeting...

The Myocarditis Foundation recently held its Third Annual Researcher and Patient Family Support meeting at the Gaylord Hotel and Convention Center in Washington, DC. The meeting was held in conjunction with the Heart Failure Society of America's annual symposium. Several researchers and physicians presented their research to the attendees of our meeting and gave updates on the current status of myocarditis in adults and children.

Friday night Jim and Candace Moose hosted a welcome dinner at the Pienza Restaurant in the Gaylord with a delicious Italian food theme of pasta, salad, fruit and cookies. Most importantly, the attendees had the opportunity to meet the others who so similarly were affected by the disease that changed their lives forever. Even though most of the attendees did not know each other before that night, the interactions between them was heartwarming to watch. Dr Cooper, Dr. Price, Dr. McNamara, Dr. Colan, and Dr. Fairweather made themselves available for questions by the attendees.

The evening culminated with a Candlelight Vigil by the Potomac River, conducted by Reverend Brian Barndt, himself a Viral Myocarditis and Heart Transplant Survivor. A poem that was written by a close friend of Tyler Rosenberg was read and an acapella version of "This Little Light of Mine" was started by a parent and joined in by many.

On Saturday morning, the day started with breakfast and then

the physicians spoke on their topics as follows:

- **Dr. Cooper, Mayo Clinic** – "A Ten Year Retrospective on Adult Myocarditis Diagnosis and Treatment"
- **Dr. Price, Texas Children's Hospital** – "A Ten Year Retrospective on Pediatric Myocarditis Diagnosis and Treatment"
- **Dr. Dennis McNamara, University of Pittsburgh** – "Myocardial Inflammation and Recovery: What Have We Learned?"
- **Dr. Steven Colan, Boston Children's Hospital** – Progress in Early Diagnosis of Myocarditis and Why This Matters"
- **Dr. Silvio Antoniak, PhD, University of North Carolina** – "The Role of the Blood Coagulation System in Virus Infections, with a Special Focus on Myocarditis"

After a short break, the Family Speakers spoke on their experiences with Myocarditis as follows:

- **Rev. Brian Barndt** spoke on his experience with Viral Myocarditis and his Heart Transplant
- **Jesse Torrence** spoke about his fight with Giant Cell Myocarditis and his Heart Transplant
- **Kyle Kirsch** spoke about his family's devastating experience on the loss of their young son Quinn, from Viral Myocarditis
- **Kathy Burgauer** spoke about her family's devastating experience with the loss of their adult daughter Ashley, from Viral Myocarditis

A lovely lunch was served and the afternoon session started with Dr. Coralease Ruff, (a grieving parent) and Dr. Kimberly Battle, (a grieving sibling) from the Washington DC Chapter of Compassionate Friends. Together they spoke on Living with Chronic Illness, Coping with the Death of a Child and Coping with the Death of a Sibling. An interactive question and answer period ensued.

After a break, Dr. Michael Bode, the current MF Grant Recipient Researcher, gave us an update on where he was with his research on myocarditis.

Throughout the meeting, families, doctors, and researchers left to be filmed by the videographer that is working with the Foundation to tell our story. The video will start with Candace's story, and her and Dr Cooper's starting of the Foundation. The stories of myocarditis, from the families that have been affected, were filmed during the weekend. The videographer and his assistants commented to Dr. Fairweather, who is working with them on this project, that their lives are forever changed from hearing the stories of strength, courage, and devastation from the families. We are hoping the video snips will be ready to post on the website and u-tube by early 2016.

The evening culminated with a wonderful celebration dinner at the Rosa Mexicana Restaurant where new friends shared in a weekend of education, awareness, and comradery.

Awards were given to Dr. Cooper and Candace for their vision and starting of the Myocarditis Foundation.

Dr. Colan and Dr. McNamara received awards for supporting the Foundation on the Medical Advisory Board for 10 years.

Dr. Elizabeth Schultz and the St Jude Foundation for believing in and supporting the Foundation since inception.

High fundraising awards were given to Cindy and Randy Vanness, Kelly and Kyle Kirsch, and Joseph Rumore and Louis Romano, Jr., for their continuing work at raising awareness and funds to support the MF and research, have helped get us to where we are today.

The families left on Sunday morning and Gen and Joe Rumore remained to staff the MF Booth at the HFSA, sharing information on whom we are and what we do with the attendees to the HFSA. Those who stopped by the booth were cardiologists, cardiac surgeons, researchers, nurses and nurse practitioners, from the USA, Canada, Germany, Russia, India and South America. Most had never heard of us before nor what we do to help those affected by myocarditis from around the world.

We look forward to our 4th Annual Family Support/Researcher Meeting in 2016. The date and venue have not been chosen as of yet. We hope that you will join us for this. Please look for information for it on the Myocarditis Foundation website and Facebook Pages in coming months.



Highlights of the talks

(Continued)

Dr. Leslie Cooper: He first stated that his purpose was to give the attendees hope on where we have been and where we are today

Myocarditis was first termed in Germany in 1837, with very little being studied for the next 100 years.

The incidence and prevalence of myocarditis are not known because there is no widely available test that can be applied at a population level. Expert consensus opinion extrapolating from regional clinical registries and treatment trials estimates that up to 40% of dilated cardiomyopathy results from myocarditis.

If we can identify myocarditis early, we can stop the advance to chronic heart failure which is caused by dilated cardiomyopathy. Studies are being done on various diagnostic tools for early detection.

Dr. Jack Price:
(please see Pediatric Updates)

Dr. Dennis McNamara: The size that a heart becomes from myocarditis, directly relates to how well a person will recover from it. Larger hearts do not do as well with recovery. In addition, the more scarring that the heart has, the less likely for recovery.

As well, women often recover better than men; they are not sure why but there is speculation that it relates to hormonal involvement.

Dr. Steven Colan: While Cardiac Biopsy has been the gold standard for years in diagnosing myocarditis, it is much more useful in diagnosing Giant Cell Myocarditis than Viral Myocarditis. Cardiac Biopsies can miss up to 50 % of Viral Myocarditis due to the patchy areas of distribution and the phase of myocarditis when the biopsy is done. Unless you biopsy the area of the heart where there is a patch of Viral Myocarditis, you will get a false negative.

Cardiac Magnetic Resonance (CMR) has become a primary way to diagnose Viral Myocarditis, and methods to improve its accuracy are being reported. Nevertheless, a more accurate method of diagnosing Myocarditis is needed to adequately test targeted therapy such as immunosuppression and antiviral drugs.

Dr. Silvio Antoniak, PhD: Up to 20% of sudden death in children and young adults under the age of 40 can be attributed to Myocarditis. Most Myocarditis in children, is caused by viruses, and frequently the virus is Coxsackie.

Basic research studies have increased the understanding of Viral Myocarditis and revealed promising pathways for interventions.

Dr. Michael Bode: (Present MF Research Grant Recipient)

He is working on the role of protease-activated receptor-1 in viral infections, such as Coxsackie virus-B3 induced myocarditis. Our Fellowship Grant is helping to support this research.

Dr. Coralease Ruff, PhD and Dr. Kimberly Battle, PhD from Compassionate Friends:

Compassionate Friends is an International Support Group by Peers of bereaved parents and siblings. It started in England in the late 1960's and came to America in the 70's. In their talk they stressed that grief has no time frame. Grief is a normal, natural reaction to the death of a loved one. Grief is a process, not an event. It is a complex process guided by past experiences and a person's religious beliefs.

Grief affects the ability to think, absorb information, make decisions and reason logically. Grief becomes "not normal" when a person is unable to take care of themselves and starts to isolate from others. That is when the person needs to seek help in their grieving process.

Siblings are afraid to express their grief because they don't want to upset their parents further. Parents need to understand this and bring their other children into the process of grieving by doing things together such as celebrating the child's birthday or making their favorite food or dessert, or even doing something that the child who is gone liked to do. You do not want to forget them, they are part of the family whether present now or not. Ask the siblings what they would like to do to honor/memorialize their lost sibling. Ask them to write about their feelings, acknowledge their loss. Encourage them to share their thoughts and feelings.



MF Dr. Ruff of Compassionate Care



MF Family Support Meeting
(Dr. Bode, Kyle and Kelly Kirsch,
Quinn Kirsch Poster, Dr Cooper,
Candace Moose)



MF Kathy Burgauer, bereaved mom



MF Family Support Meeting 2

Chelsey's Tree...a Survivor's Story

Jesse Torrence Washington, D.C.

Back on my grandfather's farm in Ohio where I grew up there's a big, tri-color beech tree – must be about 20 feet tall now. I've grown up with that tree since I was six. It sits outside grandmother's dining room window where we had many thanksgiving and Christmas dinners. For thirty years, my whole family and I have watched that tree eating our turkey and mashed potatoes. We watched it grow so slowly over the years, changing colors like a sunset across the seasons, getting more beautiful and verdant every year. And it watched us too, quietly marking the occasions of our lives – from graduations to weddings to homecoming dances – reaching higher and higher each year towards the sky, spreading its roots deeper and deeper into the Earth with a kind of, graceful, patient certainty, like it knew exactly why it was here – a kind of certainty I wish I had.

That tree survived thirty years of Ohio winters and is now the most beautiful tree on the whole farm.

When it came into our family 30 years ago, we were gathered round on the back yard of the farmhouse, maybe 20 of us, young and old, holding hands, singing, praying, my uncle Gary on the guitar, us little ones squirming around. Grandpa giving a blessing as always. Everyone going around saying their peace.

And a lot of crying. Lots of pain, confusion, I imagine every kind of emotion possible.

Afterwards, we lowered into the ground the red cedar box my grandfather had made, placed that tree on top of it, and asked it to protect its contents for as long as it lived.

Inside that box are my cousin Chelsey's ashes. She died in a car accident when she was seven. She and my Aunt Sue were on their way to pick up her little brother from day care.

I remember Chelsey. She was beautiful, kind, playful. We would have been good friends over the years.

I called my Aunt Sue last week and confessed I didn't know how to "talk about my experience as a survivor" to a room full of people, whose loved ones had not survived.

She said, "Tell the truth."

So, the truth is I feel inadequate up here because I know I can't say or do anything that will bring your loved ones back or lessen that pain for you... or for the family of my donor for that matter.

The truth is I feel guilty for having survived when your loved ones and my donor didn't.

I feel like I have to do something extraordinary with my life now to give full meaning to the sacrifice I have benefited from, even though some days I'd just like to be ordinary.

But most of all, I feel grateful to the countless people – family, friends, medical professional, researchers, fellow victims and survivors, and total strangers who supported me and my family and are part of the reason I have a little more time. And near the top of this list are the folks at the Myocarditis Foundation who are working so hard with such care and compassion each day to bring attention to this disease and to find to find a cure.

Thank you.



So, my story starts about four years ago.

Around March of 2011, I started to notice I was short of breath after just jogging to the car. I thought I was just a little out of shape. I'd been an athlete my whole life, ate well, meditated, did Yoga, took care of myself. I was 31, healthy, fit, with no family history. So later in April, when I began to develop a bad cough they did a routine check of my heart, found nothing, and gave me antibiotics for pneumonia.

I got a little better but then worse over about 10 days. For three nights I couldn't sleep lying down as the fluid backed up in my lungs. I finally dragged myself to the emergency room and was in heart failure by that evening. My family flew in the next day, I was life flighted a few hours later to a nearby hospital. I struggled to breath, gasping for air, feeling

like I was slowly drowning for two more days. When finally all my jokes and bravery were gone, was exhausted and just wanted it to stop, I asked them to knock me out. They immediately obliged, said they'd put me under for just a day or two, let my lungs rest, do more tests, figure it out. I gave my bravest thumbs up and closed my eyes, not knowing for sure if I would wake up. Somehow I think I was OK with that. I had my closest family there and those who weren't I knew they loved me, and they knew I loved them. So I closed my eyes and trusted.

Six weeks later, when they brought me out of the medicated coma, I couldn't lift my arms or even my head off the pillow, couldn't talk, couldn't write, couldn't see well or do much with the left side of my body. Felt like I weighed a thousand

"The reality is that you will grieve forever. You will not 'get over' the loss of a loved one; you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again but you will never be the same.

Nor should you be the same nor would you want to." – Elisabeth Kübler-Ross

pounds, like I was trapped in cement. And, since I was struggling, they had to restrain me, all of which left me almost more scared than before.

Finally, my dad sat down in front of my bed, took my weak little hands in his big, calloused hands, and explained with a somber face that my heart was “Kaput”. You’re gonna need a transplant, son. You also had a stroke and we’re not really sure how bad yet. Now, you know these tubes coming out of your abdomen? They go into this machine here – It’s a bi-ventricular assist device called a Centrimag. It’s what’s keeping you alive, son. Do not pull on those tubes, ya understand? Pretty gnarly, huh? But it’s a step up from the ECMO that you were on before, back when things were uh-h... really bad.

Maybe that’s when I surveyed myself from the neck down and went pale in the face, because then he grabbed my hands even tighter, looked me straight in the eye and added, “We’re gonna walk out of here together one day, son... You hear me? We’re gonna walk out of here together.

Little by little they began to fill me in on what I had missed.

Hoping against hope, my mother never left my side. She sang to me, read to me, prayed for me.

My wife read ever every research paper and reached out to every doctor she could find anywhere in the world, including Dr. Leslie Cooper (who is with us here today), the world’s foremost expert on Giant Cell Myocarditis. He actually called her back, which

of course sent Oana running down the hallway with glee waving her cell phone wildly in the air screaming “Dr. Cooper! It’s Dr. Cooper!”. He soon had my doctors up to speed on my particular form of myocarditis called Giant Cell. My family also got a personal call back from Candace Moose who gave them hope, faith, and critical information, all in her characteristic loving way, and was a real beacon of light my family in a VERY dark time.

Just when they were considering calling it quits for good, my wife convinced the neurologists to let my mother give the voice commands. And this is when I heard her. From inside my strange, Alice in Wonderland like dream world, I heard her voice as clear as day. I was like a helpless

baby trapped in an adult body lying on the floor of my Aunt Billy’s house where I had some of my earliest childhood memories. A strange, male voice would say something, then my mother would repeat it. “Jesse, move your left arm.” Jesse move your left foot.” It felt so eery, like something was off, like a creepy horror movie. Maybe I could sense her fear. But I did as she asked. It was enough to tell them I was still there.

I’ve been told many times now the story of when the doctor broke the news to my parents that my test results were positive for Giant Cell myocarditis, an extremely aggressive form of myocarditis with 70% fatality rate, a 5-6 month progression, and no cure. Well, of course, they

“You will lose someone you can’t live without, and your heart will be badly broken, and the bad news is that you never completely get over the loss of your beloved. But this is also the good news. They live forever in your broken heart that doesn’t seal back up. And you come through. It’s like having a broken leg that never heals perfectly – that still hurts when the weather gets cold, but you learn to dance with the limp.” – Anne Lamott

just broke down standing in the middle of the waiting room. But then a man they’d never met in their life who was there for his mother who’d just had a heart attack, came right up to them – this 6 foot tall black man, as big as a linebacker still in his UPS uniform, he grabbed them both in a giant bear hug and just held them while they cried. He was their angel that day.

The hardest part I think was the waiting. Mostly because it was not a good kind of waiting. We knew we were waiting not just for me to get strong enough to survive a transplant surgery but waiting for someone to die. An untimely death. Preferably someone young and otherwise perfectly healthy. We were hoping without

wanting to hope. Praying that a heart somewhere out there whose body had expired would find the right home.

And finally, on, July 31 in the middle of the night, somewhere in Chattanooga, TN, exactly the “right” person died. He was a match for my blood and tissue type. He was 20 years old. Probably just on his way somewhere. His mother I imagine was soon at his side with a team of doctors, holding his hand, still feeling his warmth, his pulse and hoping beyond hope that he might hear her voice and wake up probably at almost exactly the same hour that my mother and a team of nurses had woken me up in the middle of the night to tell me they had found a heart for me.

I woke up from my surgery, and after four months of not having a pulse, I put my hand right on my chest and felt his heart beat like it might leap right out of my chest.

I whispered to it, “Thank you. You are safe now. I will love you. I will accept you. I will listen to you. I will trust you. I will nourish you. I will protect you. I will become one with you. I will believe in you. I love you.

Maybe this is what his mother might say if she could hold him again. And that’s what I have told this heart every night for four years now and I will continue to till the day it decides to stop beating.

This foundation – I feel like that’s exactly what it does for all of us. And it’s not just what they do but

how they do it. They have held all of us together at different times in different way, all of us who are missing parts of ourselves who walk through the world with scars and secret pains, perhaps feeling only half alive, or half human sometimes. These people know and understand, and they give us hope.

I asked both my Aunt Sue and my mom to pick their favorite from a list of some 15-20 quotes about grief and loss. Interestingly they chose the exact same two. So I thought I’d share them.

May we all dance again one day. Thank you. Jesse Torrence

Logan Sweet Fundraiser

Carolyn Sweet
Bowdoinham, Maine

This year's Logan Sweet Fundraiser was a musical production that took place in June. Studio 48, a local theater, was putting on a production of the Musical 13. 13 is about the struggles and issues that young teenagers face in their teen years. Since Logan would have been 13, the Studio decided to dedicate that production to Logan. The musical was being held at a large local theater that has a large foyer. It was here in the foyer that we were able to have auction tables with many great items from local business and beautiful artwork from local artists. The Myocarditis traveling Exhibit was there in order for people to read Logan's story as well as so many others. Here, they could read and learn about how Myocarditis effects so many people at so many ages. We had brochures and information about Myocarditis in order to help continue to spread awareness.

It was a great turn out and the auction tables brought in many donations. The Studio did a great job with helping to spread awareness and telling Logan's story so that others are aware of what this condition can do to a family without any warning. Before the show, a local news station was able to interview the director of the Studio, Rebecca Beck, as well as myself to further spread awareness of Myocarditis. The more we can get Logan's story out there, the more informed people will be. If my story can help save just one other life, than I know that I am doing my part.



Director's Corner

Hello everyone and thank you for welcoming me to the Myocarditis Foundation as the Director, effective May 2015.

It has been a very busy transition year both because the office has been relocated to Houston, Texas (Kingwood is a suburb of Houston), and the transition from Lindsey to Candace to myself over the first five months of the year. Many changes, but I believe that we will be better than ever moving forward.

I'd like to give you a little background on myself, so that you know me a little better.

I grew up in Staten Island, New York and shortly after my marriage we relocated to Bridgewater, New Jersey for my husband's employment. I am a nurse by profession, and have worked with all age groups from pediatrics in the emergency room to geriatrics as a nursing administrator in a nursing home. My true love though, has always been cardiology.

My heart belongs to cardiology because when I was dating my future husband, he had developed myocarditis, which resulted from the mononucleosis he had shortly before we met. There was not much known about this back then, and my interest from then on has always been cardiology. (We were high school sweethearts, so this love of mine goes back a long way.)

The myocarditis left him with an enlarged heart and cardiomyopathy (weakened heart muscle), and years later, heart failure, which we dealt with medically for years until he received the miracle of a new life, with a Heart Transplant, on Thanksgiving Day 2006, at New York Presbyterian Hospital. Thus, my heart felt connection to Myocarditis.

At one of his post transplant cardiac biopsy appointments, we were introduced to Candace Moose, who also was there for an appointment. My husband and I have both dedicated our future work to finding a way to raise awareness on this disease, to prevent the devastation caused by this disease and prevent the need for cardiac transplantation, which doesn't cure anything, but merely puts you into another medical category.

I had been assisting my husband, behind the scenes, through his annual fundraiser for the foundation for eight years since his transplant and meeting Candace. The Board of Directors made a decision to put me in the Director's position and I am working diligently to help continue the foundation's move forward through the next ten years as it has in its first ten years. Hopefully together we can stop the devastation that this disease causes to so many innocent victims and their families.

Thank you for your support!
Genevieve Rumore
Executive Director
Kingwood, Texas

EVENT

Remembering Rhett at "Paint the Town Rhett"

Vickie Lundy Elgin, Illinois

Early in the year I was asked if there'd be another fundraising event. At the time I was undecided. But for every reason against planning another fundraiser one reason remained constant and present - Rhett. I could not allow the month of May to end without an acknowledgement of Rhett's absence. The second annual "Paint the Town Rhett" paint party, fundraising event was held May 16, 2015 at the Fireman's Hall in Bartlett, IL.

In May of 2013 our lives were forever altered when we were thrust into an elite and exclusive club. A club we never asked to join nor wanted to be members of. We continue to grapple with the horror of the reality of Rhett's death; broken hearted but determined to bring awareness about an unknown cardiac disease called Myocarditis. Like a thief in the night, this disease took the life of our youngest son Rhett, a gregarious, boisterous, compassionate teenager, while he slept.

Our hope and goal is to raise enough money to fund a research grant in Rhett's name to prevent another family from being blindsided when they discover their child/brother with no pulse and not breathing on a typical Wednesday morning; a mother from suffering this tragedy; a father with the inability to save his son; best friends from being stripped of future plans; a brother their birth right of a best friend; a grandparent their future being carried forward. Sadly Rhett's death from myocarditis is not a fluke, isolated incident. That's why the "Not a Blank Canvas: Portraits of Myocarditis" display table is a prominent feature at this event. Guests are encouraged to read each victims story as a reminder of the many lives affected by this deadly disease.

With the help of substantial donations from several corporate sponsors --Colby Red Wine, Buffalo Wild Wings, Noodles and Company, GoPicnic, donations from the Elgin Fire Department (Rhett's dad, Steve is a fire fighter for the City of Elgin), individual donors, and many local business who donated items or services

for raffle prizes – the event raised over \$4100.00 for "May Your Beat Live On" the Rhett P Lundy Memorial and the Myocarditis Foundation, adding to the \$2500.00 earned at last year's Paint the Town Rhett" event.

Rhett was a goofy, fun-loving kid who personified exuberance,

radiated happiness and embraced life. Creating beautiful unique, individual works of art while raising money for a great cause is an amazing combination! "Paint the Town Rhett" a creative twist on a fun night out is a reflection of his life. Paint, drink, be merry, celebrate, honor and remember.



EVENT

Swim for Tyler

Charline Shaw Greenwich, Connecticut

Valerie Shaw a Greenwich High School Swim Team co-captain, organized a special tri-meet to honor and remember her cousin Tyler Rosenberg, who died in 2014 at the age of 19 from Myocarditis. Swimmers from each team (Greenwich High School, Darien and New Canaan) set aside their normal team caps and together, donned "Swim for Tyler" caps to support the Myocarditis Foundation.

Myocarditis is a heart disease marked by the inflammation and damage of the heart muscle, often caused by viruses, that accounts for up to 20% of sudden deaths among teenagers.

Concessions were sold during the meet, with all funds benefiting the Myocarditis Foundation.



Giovanna Pena of Darien, who lost her son Andy, a Darien High School swimmer, to the disease at the age of 14, spoke at the meet and presented a check from the "Andy Smiles Forever Foundation," to the Myocarditis Foundation.

Also present was Lois Rosenberg of Bethany, the mother Tyler Rosenberg. The event was a big success, raising \$3,032 for the Myocarditis Foundation.

EVENT

Tyler's 5K Walk For Myocarditis

Lois and Dan Rosenberg Bethany, Connecticut

We lost our son Tyler to Myocarditis in May of 2014. Tyler's friends approached us about finding a way to remember and honor him, so we decided to have a Myocarditis Foundation fundraiser by holding a 5K walk in his memory. The goals of our walk were to remember Tyler, to create an awareness of this devastating disease, and to raise funds for the Myocarditis Foundation.

We held the walk at a local park in Bethany, CT, where we live. The park has a 1K footpath

around a beautiful lake with a stretch running through the woods. Tyler loved music, so we were able to get a local singer to come and play some of his favorite songs during the walk registration. We then kicked off the walk with our guest speaker, Candace Moose, who spoke about Myocarditis and the devastating impact the disease can have on young people. Tyler's father, Dan and some of Tyler's closest friends also spoke about Tyler, who he was as a son and as a friend. After the walk, we held a

large raffle of items donated by the local business community and had a silent auction of items donated by close friends and family.

Overall, the walk was a huge success. We had a large turnout, and between walk registration fees, donations from the local community, and raffle ticket sales, we were able to raise a substantial amount of money for the Myocarditis Foundation. Equally as important, the attendees were able to learn about the disease from Candace and from the numerous posters that were on display. After the walk, one of the attendees told us that they had explained about Myocarditis to a stranger when asked about his "Tyler's Walk" t-shirt at the grocery store. Lastly, it was great to gather Tyler's friends, family members, and community to celebrate our bright and vibrant son's life.



Candace, Lois and Dan



Tyler Walk banner



Tyler Walk Tshirt

EVENT

Putting His Heart into It

Matt Jones Hale Barns, United Kingdom

The streets of London's Docklands are always busy at the end of a working day, but on 17 June the crowd was swelled by 1,000 red-shirted runners taking part in the British Heart Foundation's, Canary Wharf 10km run. Among them was Matt Jones, Business Development Manager on the Mortgages Digital Accelerator Program.

"This was my first organized race," Matt says. "Although I like to keep fit and enjoy spending time in the gym, I'd never

entered an event like this before. I was free to participate, with entrants supporting the BHF and other heart charities through their fundraising and also through the awareness and publicity the event generates. You didn't have to be a serious runner to enter, although there were many entrants aiming for seriously quick times – there was the choice of a 1km, 5km or 10km course, and walking the route was an option too. Everyone was there to support a cause close to their heart."

This event was of personal significance for Matt. "One of my close friends at the University of Sheffield was a former Hull City academy footballer, who'd left the game after graduating with a degree in Geography to become a teacher" he explains. "Unfortunately, he then fell ill and was diagnosed with Giant Cell Myocarditis, a rare and life-threatening condition that causes inflammation and damage to the muscle of the heart. Steve passed away last year at just 23 years of age. I wanted to raise

money to support research into the condition, leading to better diagnosis and eventually a cure. One of the messages found on his phone after he died said, 'If you are not making someone else's life better, you are wasting time' – that really sums him up and was my motivation for running."

Matt was aiming to complete the 10km in under an hour, but smashed his target to finish in 49 minutes 37 seconds. "I think

EVENT

3rd Annual Sarah Knight Golf Outing

Greg and Susan Knight Marion, Iowa

Cloudy skies and cool temperatures didn't dampen the spirits of almost 200 people who celebrated the 3rd Annual Sarah Knight Memorial Golf tournament on June 12, 2015. Thanks to 118 golfers, many volunteers, generous hole sponsors, cash donations and raffle and silent auction donations, the tournament was a HUGE success. Proceeds totaled just over \$20,000 and will be split equally between the Myocarditis Foundation and Sarah Knight Memorial Scholarship at Western Illinois University. Myocarditis "Not a Blank Canvas" posters filled the room telling the stories of victims and survivors, bringing awareness of Myocarditis. The 2015 Sarah Knight Memorial Scholarship winner shared a few words and thanked the crowd for supporting future educators through the scholarship. It was a day full of smiles, laughter, tears, friends, family and a celebration of Sarah!



David Knight Team



Sarah Knight 2015



Rainshowers



Tyler Knight Team

the adrenaline and emotion carried me through," he says.

Matt didn't just exceed his expectations in the race – his fundraising was also more successful than he could have dreamed of.

"I realized the week before that the event was almost upon me," he says. "I set up my Just Giving page explaining why I wanted to support this cause, and emailed a few colleagues, past and present, to see if they wanted to donate. I

was hoping to raise about £100 and I'd have been really chuffed with £200, but it just took off and my total is currently at £650. Even better, Barclays will match that amount, so I have made an equal donation to the Myocarditis Foundation and the British Heart Foundation."

Matt having completed his run!



2015

November 12th

Not a Blank Canvas Awareness
Event (Dr. Jack Price speaking)
Kingwood/Houston, Texas

November 19th

Cardiology Grand Rounds,
Mayo Clinic
Scottsdale, AZ

November 28th

University of Heidelberg
Medical Center
Heidelberg, Germany

December 3rd

Napes Community Hospital
Napes, FL

December 5th

Pikeville Medical Center
Pikeville, KY

2016

January 8th

2016 Cardiology Grand Rounds,
Mayo Clinic
Rochester, MN

January 22nd

Cardiology Grand Rounds,
University of Utah Medical Center
Salt Lake City, UT

March 1st

Cardiology Grand Rounds,
William Beaumont Hospital
Oakland University
School of Medicine
Royal Oak, MI

March 17th

Mayo Heart Failure Course
Lake Buena Vista, FL

March 30th

Cardiology Grand Rounds,
University of Vermont
Burlington, VT

ANNOUNCEMENT

Myocarditis Foundation "Ask Me Campaign"

Candace Moose, President Myocarditis Foundation Point Pleasant, New Jersey

At our recent Family Support Meeting, Candace Moose rolled out our new Awareness Campaign called the "Ask Me Tee-Shirt Campaign". Candace offered the Tee-shirts that she brought to the meeting for free, to those who wish to help us spread awareness about the disease and the Myocarditis Foundation as well.

The shirt has a picture of our Logo across the front and the words "ASK ME" on the sleeve. Hopefully people will see this and "Ask", what this is about.

In the future, we will be looking at obtaining more, but will be charging for the shirts, shipping and handling, to off set the cost of production. We hope that many more will participate in spreading the word about this devastating disease and what others can do to help.

ASK ME TEE-SHIRT CAMPAIGN

The ASK ME Campaign is designed to stimulate a conversation.

We want to help you be prepared with answers about The Myocarditis Foundation and want you to be prepared with your answer about your myocarditis experience.

The mission of The Myocarditis Foundation is threefold:

- 1. To fund research**
- 2. To educate physicians and the public**
- 3. To support patients and families who have lost loved ones to the disease**

The singular goal of The Myocarditis Foundation is to save more lives from this devastating disease.

You need to be prepared to share your myocarditis story in 30 seconds or less. It is called an "elevator" speech. It should take no more than the time one might have with someone in an elevator. Either people will be interested in learning more or they will not. Decide ahead of time what you are willing to share initially, and what you are willing to share about your experience beyond that. Decide what degree of emotion you are comfortable revealing that could result from sharing your story. Practice in front of a mirror or with your family.

Your goals are:

- 1. To educate the public about the existence of this rare disease that can cause suffering and sudden death in children and young adults**
- 2. To refer the listener to The Myocarditis Foundation for more detailed information.**

ANNOUNCEMENT

Holiday Cards

Genevieve Rumore Executive Director Kingwood, Texas

As the Holidays are quickly approaching, won't you think of supporting the Myocarditis Foundation rather than generic greeting cards with your well wishes to friends and family at this time of giving thanks and holiday greetings.

For just **\$5.00** a card, you will support the MF with a **\$4.00** donation for each card that you send. Your cards are 100% tax deductible.

Inside the card it states "A Contribution Has Been Made To The Myocarditis Foundation" and you can fill in whatever you wish to say.

It sends a message to others about the MF as well as helping support our cause. Don't make this holiday a "generic greeting card moment," make it a "Myocarditis Foundation Moment." Please order today by contacting Diane Aranson at: dijopolo@aol.com

EVENT

Candace Moose Brunch

Candace Moose, President Myocarditis Foundation Point Pleasant, New Jersey

On Sunday Oct. 11, 2015, James and Candace Moose hosted their annual Open House fundraiser for the Myocarditis Foundation at their home in Point Pleasant, New Jersey, for the fifth year in a row. The brunch this year celebrated the Ten Year Anniversary of the Myocarditis Foundation. 65 friends, neighbors, family,

myocarditis patients and myocarditis families who have experience loss, attended. Candace provided a passionate update of what the foundation has accomplished in the past ten years and what still needs to be done in order to save more lives from this disease. Michele Coia-Veston, mother of a

myocarditis angel, presented highlights of the Annual Meeting which had been held two weeks prior in National Harbor, Maryland. Candace was assisted in the kitchen by her son, Brad Moose, and two members of our myocarditis family: Michele Coia-Veston and Gail Chirico.

Offering Hope and Support for Children with Heart Failure

Genevieve Rumore Executive Director Kingwood, Texas

As one of the largest programs in the nation, Texas Children's Hospital, (TCH) in Houston, is leading the way for positive outcomes in pediatric patients with Heart Failure.

Each year, their dedicated team cares for more than 650 cardiomyopathy and heart failure patients. Myocarditis is a major cause of cardiomyopathy, and the mortality rate in children with Myocarditis is 4.2% in children in the US.

Myocarditis is the 2nd leading cause (25%) of Acute Heart Failure in children, with the 1st leading cause being Idiopathic (unknown cause) Dilated Cardiomyopathy; which in effect, could be caused by Myocarditis, thus increasing the percentage caused by Myocarditis.

On July 6th, TCH opened the nation's first Pediatric Heart Failure ICU. On the day that the

ICU opened, there were 4 children being treated for Myocarditis. Texas Children's Hospital demonstrates its commitment to treating children with heart failure by opening this, the nation's first-of-its-kind Heart Failure Intensive Care Unit designed specifically for children. The new and highly-specialized 12-bed unit focuses on the treatment of children with acute heart failure, including patients with myocarditis. Dr. Price reported that by creating a dedicated Heart Failure ICU, the leadership team at Texas Children's hopes to minimize variation in care, design specific treatment protocols, conduct clinical research, and optimize communication between members of the different care teams.

Mechanical assist devices, such as Extracorporeal Membrane Oxygenation (ECMO), a short term option, to allow the heart to rest

and heal itself, (often used in severe acute myocarditis), and Ventricular Assist Devices (VAD), which can be used for a longer period of time or as a bridge to transplant, are both frequently utilized options for children suffering heart failure from acute Myocarditis, at Texas Children's Hospital.

Dr. Jack Price, one of the Myocarditis Foundation Board Members, is an associate professor of Pediatrics-Cardiology and Critical Care, at Baylor, and serves as Associate Medical Director on the Unit.



Dr. Jack Price cutting Ribbon

EVENT

8th Annual Rumore/Romano Golf Outing

Genevieve Rumore Kingwood, Texas

On August 17th, Joe Rumore held his 8th annual golf outing, at the Ballyowen Golf Course in Hardyston Township, New Jersey, to help support myocarditis awareness and to raise funds for research. Joe's dream is that someday researchers will find a tool to diagnose myocarditis in its early stages, preventing the suffering he went through from the lasting heart failure and transplant that he had to endure.

In the last few years Joe has enlisted the help of Lou Romano, another MF Board Member, in helping to continue this event that has raised monies totaling over \$319,000 during the past 8 years. Together they plan the event that brings together so many businessmen, who are very generous in their giving. It is a fun event, where the men get together under beautiful skies in the mountains of New Jersey

(they have always had beautiful weather for the event), and celebrate Joe's new life and as many have said, a very worthy cause. Dr. DeLisa Fairweather spoke about the progress of myocarditis research during dinner and was available for questions thereafter.



Joe Rumore and Ken Kaufman



A great group of attendees.



Dr. Fairweather

