

## MYOCARDITIS FOUNDATION



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

### EVENT

## 2nd Annual Gala and 5th Annual Family Meeting, NYC, June 22-June 24, 2017

The 2nd Annual Gala Fundraiser Event will again be held in NYC at the Mandarin Oriental Hotel on June 22nd, followed by the 5th Annual Family Support Meeting on June 23rd -June 24th.

On the Morning of June 22nd, we will start the Family Weekend at the outdoor audience of the TODAY Show, on Rockefeller Plaza, with the hopes of getting the Foundation's Banner on world television. Anyone interested in participating is welcome to come join us. Please go to the TODAY Show website and sign up as a participant with the Myocarditis Foundation. The more, the merrier! They will not let you on the set without having you registered first for security purposes. Please wear any Myocarditis Foundation apparel

or any apparel that memorializes a loved one's awareness event. We hope to make a big enough impact with the hope of getting some air time to speak a little about the Myocarditis Foundation, it's mission and goal.

Later that day, the Gala will start at 6pm at the Mandarin Oriental Hotel, overlooking Central Park. Attendees will be greeted with our "Not a Blank Canvas Stories" in the hope that they will see the devastation that this disease can cause and the successes it can provide when early assessment and diagnosis is made.

**The Keynote Speaker will be Dr. Leslie Cooper, Co-Founder of the Myocarditis Foundation.**

The event will contain both a silent and live auction as well as a

live ask for donations. Our major initiative this year is to raise funding for an international Bio-Bank. Myocarditis is a rare disease, and as such, is not afforded the research tools to advance the science for a cure. The Myocarditis Foundation sees the need to make available to other global collaborative researchers, a blood sample base specific for myocarditis from patients of all races and cultures.

The Bio-Bank will collect and store these samples in one location, allowing collaborative researchers to access them for advancing the science of a cure for myocarditis. We feel that this will fast forward the efforts of researchers to put a stop to this disease and the suffering that it causes to so many otherwise

healthy children and young adults.

On Friday June 23rd, the Family Support Meeting will be held at the Empire Hotel, NYC. We are changing it up a little this year as the doctors were not available to attend the Heart Failure Society of America (HFSA) meeting. By combining it with the Gala, we were able to secure the availability of families to hear them and speak with them, one on one. The evening will end with a dinner at Bar Boulud. An optional breakfast and 2 hour private sightseeing tour of NYC will be on Saturday morning, ending at 12 noon.

Anyone interested in attending can contact **Gen Rumore at (281) 713-2962 or gen@myocarditisfoundation.org**

### WEBSITE UPDATE

## Website Modernization / St Jude's Medical Foundation Grant

The St. Jude's Medical Foundation has awarded the Myocarditis Foundation with a Grant to renovate and modernize the Myocarditis Foundation Website, making it easier for visitors to the site to navigate through it obtaining the needed information that they came there looking for.

Over the past quarter, we have done a major renovation and modernization of the Myocarditis Foundation Website. In this age

of technology with over 160,000 unique visitors to our website per quarter, we needed our website to function perfectly and quickly. The website is functionally easier to navigate, and is now fully capable with mobile devices. It continues to offer the most current medical information about the disease. Please stop by [myocarditisfoundation.org](http://myocarditisfoundation.org) and check us out. There have been some bugs that we need to

work out so please let us know if you encounter any so that we

can fix them. We welcome your feedback!



## "A Night to Remember Brad Vanness" April 8, 2017

This event, is held every other year by one of our Myocarditis Foundation Board Members in memory of his son Brad, who died in 2010 after being misdiagnosed as "the flu".

Randy has been a constant advocate for the Myocarditis Foundation and supporter in raising awareness for Myocarditis, so that others get the proper diagnosis and don't suffer the

devastation that his family has.

His event brings out many supporters from Kewaunee, Wisconsin and mixes fun with the awareness and fundraising...



Randy and Cindy Vanness and Gen Rumore

### MYOCARDITIS RESEARCH UPDATE

## 2016 Fellowship Grant Recipient

The Myocarditis Foundation is pleased to announce that Dr. Guobao Chen, PhD, is the 2016 Fellowship Grant Recipient for the 2107-2018 Academic Year. Dr. Chen was the second place finalist in last year's Fellowship Grant applicants, but came in above all the others in the 2016 submissions.

Dr. Chen is from Johns Hopkins University School of Medicine and his mentor is Dr. Daniela Cihakova MD, PhD. Dr. Cihakova was the very first MF Fellowship Grant recipient in 2006. Dr. Chen is now conducting myocarditis research in Dr. Cihakova's Lab and his research submission is entitled: "The Role of PDGFRα+ Cardiac Fibroblast in Myocarditis."

### Dr. Chen's layman's summary of his research project is as follows:

Despite that most patients recover from acute myocarditis, an estimated 9-16% of myocarditis cases progress to dilated cardiomyopathy, which is one of the most common causes of non-congenital heart failure in young individuals. Effective treatments for chronic dilated cardiomyopathy patients are limited, leaving heart transplantation as the only option for end stage heart failure. Thus, to stop the disease progression from myocarditis to dilated cardiomyopathy is

critical for patients to recover from myocarditis.

We have adapted an experimental auto-immune myocarditis mouse model, to investigate the mechanism behind the disease progression from myocarditis to dilated cardiomyopathy. We have found a specific group of heart cells that is receiving the signaling from a pathological factor IL-17A. After receiving the signal from IL-17A, these cells will produce a number of other pathological factors to exacerbate the disease progression from myocarditis to dilated cardiomyopathy. We have also detected the same group of heart cells in human myocarditis patients and they were found to be expressing the pathological factors that were found in our mouse model. Similarly, the same specific group was also found in ischemia patient biopsies and our myocardial infarction (Heart Attack) mouse model. Thus, our discovery provides an excellent opportunity to develop specific treatment to halt the disease progression from myocarditis to dilated cardiomyopathy. We have designed delicate therapeutic methods to specifically target the immune function of this group of cells without killing them, which will minimize the side effects of systemic immune suppression and preserve other functions of these cells that might be important for the recovery from myocarditis.



### A short story about how Dr. Chen joined Dr. Cihakova's Lab at Johns Hopkins:

As previously an immunologist, I was first attracted by the sophisticated immune interactions between different cell types in the heart that were previously published by members of Dr. Cihakova's Lab. From there, I went on to read more about myocarditis and diseases involving heart inflammation. It was after that when I became more and more interested with this topic. Later, in a routine conversation with my mum, she told me that her doctor suspected

that she might have had myocarditis before, as her left ventricle was abnormally large. All these things strengthened my decision to dedicate my research career on developing treatment for myocarditis and other heart diseases.

The Myocarditis Foundation extends their best wishes to Dr. Chen for much success in his myocarditis research. It is our prayer that we will one day find a treatment or a cure for this devastating disease, that takes so many of our young and otherwise healthy children and young adults.



## Newest Myocarditis Foundation Board Member, Francine Andrea

The Myocarditis Foundation would like to introduce and welcome Francine Andrea to you as our latest member of the Myocarditis Family Board of Directors!

Ms. Andrea is the Vice-President of Enrollment Management, Student Affairs and Chief Compliance Officer for Felician University. In her role, she serves as a member of the President's Council and provides leadership, vision and strategic direction in the planning, development, execution and assessment of a comprehensive and effective strategic plan aligned with the University's goals and objectives. She has served in senior roles at a number of Colleges and Universities, in state government and in numerous consulting roles in higher education throughout the Northeast.

Ms. Andrea has been a follower of the Myocarditis Foundation for

10 years as well as a supporter of its efforts. She too has been touched by myocarditis. A dear friend of hers, much like a brother to her, required a heart transplant 11 years ago due to the long term side effect of heart failure from the disease.

She watched him decline over the years prior to his transplant and sees the need to put a stop to the devastation that this disease causes for so many.

She looks forward to working with us to raise awareness and generate funds for research to put an end to myocarditis as we know it today.

Please join us in welcoming Francine to our Myocarditis Foundation Family and Board of Directors. ***Thank you so very much Francine, together we can make a difference!***



### MYOCARDITIS RESEARCH UPDATE

## Visit To Dr. Fairweather's Myocarditis Research Laboratory, Mayo Clinic Jacksonville, Florida

On Friday March 31st, some of the Myocarditis Foundation Board Members visited and toured the Myocarditis Research Laboratory of Dr. DeLisa Fairweather. It has been said that "A picture is worth a thousand words", and that is so true.

To begin with, Dr. Fairweather conducted a presentation on her research of "Sex Differences as a Tool in Myocarditis Research".

Why do more men develop Myocarditis and Dilated Cardiomyopathy (DCM)? Dr. Fairweather believes that males response to a virus causes worse myocarditis, due to higher levels of testosterone.

She believes that an early diagnostic tool needs to be developed so that myocarditis can be detected before it goes to DCM. (1 to 3 months after myocarditis strikes is when DCM develops in animal models and most adults.) In children, DCM can happen quickly because they do not have a well developed

immune system. Diagnosis by biopsy is difficult the further out from the initial infection you go because the inflammation is gone by then. The earlier the diagnosis is made, the better the outcome for the patient.

In her lab, they use animal and cell culture models to study how coxsackievirus leads to myocarditis and the mechanisms that can be targeted to diagnosis and treat the disease. It was amazing to see an echocardiogram being done on a mouse with the same machine that is used on humans. The probe is only fractionally smaller, but the skill that Dr. Bruno has working with them is nothing short of amazing!

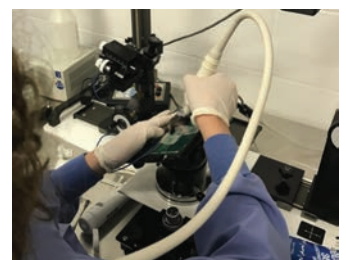
They are so caring to the mice making sure that they are well cared for. In fact, the other labs at the Mayo Clinic wanted to know what they do in Dr. Fairweather's lab that the mice are so happy, not stressed and produce proliferately. Their model



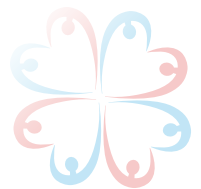
*L to R Jennifer, Dr. Fairweather, Erica, Dr. Bruno, Anneliese*

is now used in the other labs as the standard protocol for studying myocarditis.

Seeing each aspect of the research process shed a brighter light on how important each part of the process actually is. Many thanks to Dr. Fairweather, Dr. Bruno, Erica, Anneliese and Jennifer for sharing their very important pieces of the research puzzle with us.



*(Picture of Echocardiogram by Dr. Bruno on a Mouse Model)*



## EDUCATIONAL EVENT

# Pediatric Myocarditis Seminar Hosted At Texas Children's Hospital

On Saturday, March 25th, the Myocarditis Foundation teamed up with the Texas Children's Hospital to provide an educational seminar on "Myocarditis, Cardiomyopathies and Sudden Death in Children: An Update for Community Health Care Professionals."

Dr. Jack Price spearheaded and chaired the event which has been over 6 months in the making.

Dr. Jeffrey Tobin, Chief of Cardiology at St. Jude's Children's Research Hospital and co-director of the Heart Institute at LeBonheur Children's Hospital in Tennessee, was the Keynote Speaker. Dr. Tobin previously served as Chief of Cardiology at Texas Children's Hospital from 2003-2009.

Many pediatricians and Emergency Room Physicians gave up their Saturday to learn more about this catastrophic disease that disproportionately affects so many children and young adults.

The room was focused on the speakers and many insightful questions were asked of them. You could hear a pin drop with the exception of whomever was speaking at the time.

The MF shared some "Not a Blank Canvas" poster board stories with the attendees to make

realize just how important quick and correct diagnosis is for improved outcomes to this disease. It put faces to the stories of the victims and survivors that helped make it very real for them.

Many comments of "thank you so much for doing this" were shared as the attendees left at the end of the day.

The attendees verbalized that they will not look at what they think is a "common childhood disease" the same way again.

We are planning to present this information to other facilities in the future, so that they too can gain the knowledge to correctly diagnose myocarditis.



*Dr. Tobin and Dr Price, Dr Price introducing the Seminar*



## EDUCATIONAL EVENT

# Myocarditis Awareness Shared With Students at Northeastern University in Boston, Massachusetts, Nov 15, 2016

The National Organization of Rare Disorders (NORD), a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them, such as the Myocarditis Foundation, has developed a Speakers Bureau Data Base. The Speakers Bureau, is a resource for teachers, college and medical school professors, student groups and community members who are seeking speakers to talk about rare diseases in the classroom or at community events. NORD wants to facilitate opportunities for patients and caregivers to share stories about their journey to diagnosis and search for treatment, especially for students preparing for healthcare careers. NORD hopes that the patient voice will raise awareness of rare diseases and

promote earlier diagnosis for patients, many of whom go without accurate diagnosis.

On Monday, November 14, 2016, Christopher Corso (a Myocarditis Foundation Board Member and father of a Myocarditis Survivor), spoke with approximately 70 students at Northeastern University in Boston, Massachusetts about Myocarditis... how it has affected his family as well as what is needed to be done to develop an early diagnostic tool specific for myocarditis, the importance to educate physicians on the need for early correct diagnosis, and about the research that has been done and is ongoing to finding out why some people develop the disease and others do not...why it affects boys more than girls...why it

seeks out and affects otherwise healthy athletic children, and why it is the 3rd leading cause of Sudden Death in children and young adults.

Even though Viral Myocarditis and Giant Cell Myocarditis are considered rare diseases (less than 200,000 documented cases a year in the U.S.), there is a belief that many more people are affected, either by a mild case that is not diagnosed or when found on autopsy and was not documented in hospital record numbers.

Raising awareness to the general public of the disease as well as educating the medical community about the presenting symptoms, and developing an early diagnostic tool specific for myocarditis are all key to improved outcomes from the disease.

The Myocarditis Foundation says a big "Thank You" to Christopher Corso for sharing his story and information on this disease to these future medical community students!



*Chris Corso*



## FUNDRAISER

# Elvis Returns to Spring City, Tennessee, to Help Support The Myocarditis Foundation

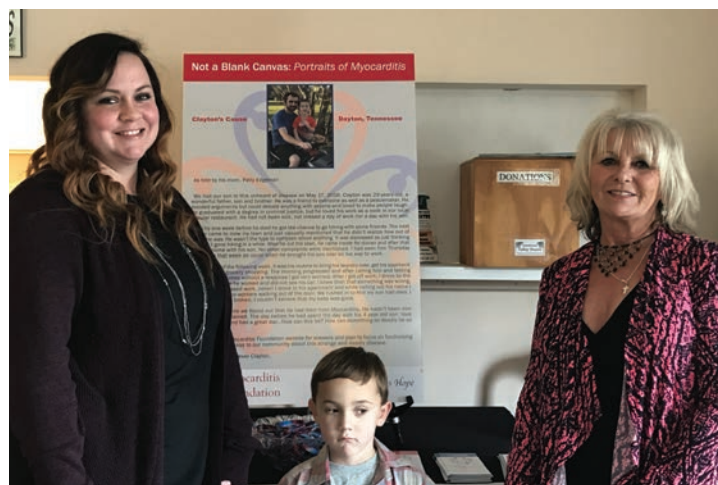
Patty Edgeman, mother of a Viral Myocarditis victim Clayton Edgeman, wanted to do something to raise awareness for the disease that took her son on May 17, 2016 without warning.

Clayton, was a hard worker who never missed a day of work in his life until this day when he did not arrive at work as scheduled. His mom and co-workers knew that something was wrong and went looking for him. They found him unresponsive in his apartment and after three months learned that it was viral myocarditis that took his young life leaving behind a 4 year-old son.

Patty reached out to our website and contacted us for more answers. She wanted to do something in Clayton's memory so that others would learn about this disease and what could be done to help stop it from devastating others like it did to her family. She asked what could she do as an awareness event/ fund raiser, and was referred to our Fundraising Guidelines on our website. After speaking with

a dear friend of 40 plus years, her friend Priscilla offered to help by enlisting in her son, Matt Cordell, who is a national and international entertainer and Elvis Impersonator/ Singer. Matt donated his time and beautiful gift from God, his voice, to help raise awareness and funding to help the Myocarditis Foundation in Clayton's memory. The Tennessee Valley Theatre donated the venue for the event as well.

Matt put on a 2-hour show as Elvis Presley, that his daughter Madison, also a singer, sang in with him. Matt sang many Elvis Presley songs from the 2,500 songs that Elvis recorded over the years. This is his family business back in Pigeon Forge, Tennessee, where his mom, Pricilla, was also a singer. His dad, Ken, works the lighting and wife Tashia helps with the sound system. Matt has been around the country and on cruises performing, and has come in first place in multiple Elvis competitions. He also does charity work such as this fundraiser and performs in



*Patty and Grandson*

nursing homes when able with his busy schedule.

The Myocarditis Foundation was present and spoke about the disease, the Foundation, where we've been and where we are going with research, education, and support for those going through the disease, with our singular goal of saving lives. There were auction items that were donated and raffled off with the Grand

Prize of a La-z-Boy Recliner, that

was donated by the La-z-boy company for the event. There was a lot of verbal interaction with the audience after the show with much education and awareness on the disease, not to mention pictures with "Elvis".

The Myocarditis Foundation greatly thanks Patty and her family and friends for making the evening such a success. We know that Clayton is very proud of his family for what they have done to raise awareness and funding for the Myocarditis Foundation.

## FUNDRAISER

# Quinn's Cup, January 28, 2017

The fear of softening ice, due to slightly warmer than usual temperatures in Edina, Minnesota, did not deter Quinn's Cup from going on. The community of Edina pulled together and moved the venue with just a few days to prepare for the Pond Hockey Tournament, that is held in honor/memory of Quinn Kirsch. Quinn was an 8-year-old boy who loved hockey and died from Viral Myocarditis suddenly after playing pond hockey with his dad on January 7, 2013. Quinn's Cup is a FUN event that emphasizes the love of outdoor hockey, and celebrates Quinn.

Quinn's Cup 2017 had 52 teams and 650 skaters from local communities participate in the event. The event benefits the Myocarditis Foundation, which is dedicated to providing education and support related to the causes, symptoms, diagnosis and treatment of Myocarditis and Sudden Death.

In 4 years the event has raised and donated almost \$100,000 to the Myocarditis Foundation.



*MF Table and Sponsors Banner*



*Kyle and Kelly Kirsch*

## Speaking Schedules & Events

### DR. COOPER

**May 12**

Heart Rhythm Society,  
Sudden Death in Myocarditis  
**Chicago, Illinois**

**May 16**

Myocarditis for Primary Care,  
VA Hospital  
**Jacksonville, Florida**

**June 22nd - 24th**

Myocarditis Foundation Gala  
and Family Support Meeting  
**NYC**

**July 24th - 28th**

Success with Failure:  
Strategies for the Evaluation and  
Treatment of Heart Failure  
**Hawaii**

**August 3**

Mayo Cardiovascular Course  
The Heart of the Matter,  
Myocarditis  
**Overview, Sedona, AZ**

**August 27**

European Society of Cardiology  
Hot Issues in Myocarditis  
**Barcelona, Spain**

**August 29**

European Society of Cardiology  
Myocarditis Made Easy  
**Barcelona, Spain**

**September 16**

American Society of  
Nuclear Cardiology

**November 2**

American College of  
Rheumatology  
**San Diego, California**

**November 11**

Cardiac Sarcoidosis,  
Sarcoidosis Foundation Meeting  
**Jacksonville, Florida**

**December 1**

Myocarditis, University of Chicago  
**Chicago, Illinois**

**December 7-8**

Myocarditis, Mayo Clinic  
Echocardiography Course  
**Chicago, Illinois**

### DR. FAIRWEATHER

**July 14-16**

The 22nd World Congress on  
Heart Disease "Sex Differences in  
Biomarkers of Heart Failure"  
**Vancouver, Canada**

**November 3-5**

5th World Congress of  
Cardiothoracic-Renal Diseases  
"Sex Differences in Cardiac  
Inflammation: a Tool for  
Biomarker Discovery"  
**Portugal**

### DR. PRICE

**July 16-21**

World Congress of Pediatric  
Cardiology and Cardiovascular  
Surgery,  
**Barcelona, Spain**

**September 16-19**

Heart Failure Society of America

**November 11-15**

American Heart Association  
(Moderator)  
**Anaheim, California**

## 2017 EVENTS

**May 20**

Paint the Town Rhett  
**Elgin, Illinois**

**May 21**

Christopher Widjaja Concert  
**Livingston, New Jersey**

**July 8**

Motorcycle, Car and Truck Ride for  
Myocarditis  
**Kewaunee, WI**

**June 9**

Sarah Knight Memorial Golf  
Tournament  
**Marion, Iowa**

**June 22**

2nd Annual Gala Fundraiser  
**NYC**

**June 23**

5th Annual Family Support  
Meeting  
**NYC**

**August 14**

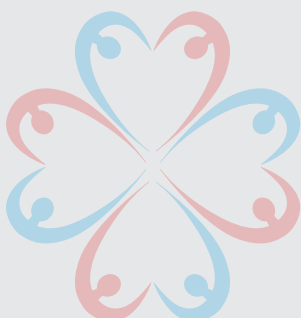
Myocarditis Annual  
Golf Tournament  
**Paramus, NJ**

**September 16**

Honor Stride, Ashley Burgauer  
Event  
**Muncie, Indiana**

**September 30**

King of Hearts,  
Lee Hirsch Event  
**Brooklyn, NY**



## EDUCATIONAL EVENTS

### March 4, 2017 Heart Failure Management Conference at the Houston Methodist DeBakey Heart and Vascular Center

The Myocarditis Foundation participated in an education event for patients with Heart Failure and Mechanical Assist Devices while waiting for Heart Transplants at the DeBakey Heart and Vascular Center in Houston Texas.

Some of these patients were victims of myocarditis who were learning to live with the long term side effect of Heart Failure. The attendees expressed the value of the information that they learned at the various booths, of which the Myocarditis Foundation was one of them.



Dr. Jack Price and Madison Parrish

## NEWS

### International Conference and News Flash

In early December 2016, Dr. Leslie Cooper, Dr. DeLisa Fairweather, and Dr. Bruno from the Myocarditis Foundation, along with hundreds of other cardiologist from around the world, including some of our Medical Advisory Board, traveled to Kyoto, Japan for the International Society of Cardiomyopathies and Heart Failure. Dr. Cooper and Dr. Fairweather were presenters at the conference, speaking on Myocarditis.

The ISCHF, was established in 2007 and has held regional and international congresses, established working groups and task-forces to facilitate much-needed cooperative research in these fields among their members worldwide and with other societies and related groups in the fields of cardiomyopathies and heart failure. (Myocarditis is a major cause of cardiomyopathy and heart failure.)

Their goal is to advance the scientific understanding of cardiomyopathies and heart failure, clarify the etiology of these diseases, and promote and organize scientific activities through publications, symposia, workshops and seminars, and actively participate in other congresses.

In January, 2017, Dr. Leslie Cooper was appointed the Vice-President of The International Society of Cardiomyopathies and Heart Failure (ISCHE)! As well, the name of the Conference has been changed to the International Society of Cardiomyopathies, Myocarditis and Heart Failure.

The Myocarditis Foundation would like to congratulate Dr. Cooper on this esteemed appointment and we know that he will help to ensure that there will be ground gained in our fight against myocarditis.



## Giant Cell Myocarditis Update

While we all know that Giant Cell Myocarditis is a rapidly fatal disorder that may respond to certain immunosuppressive drugs or heart transplantation, most cases are not diagnosed until after death or heart transplantation, in part due to a lack of awareness of the disease. Dr. Leslie Cooper has made it his life's work to research and treat Myocarditis and Giant Cell Myocarditis. Over the past number of years, Dr. Cooper has traveled the globe speaking on Myocarditis and Giant Cell Myocarditis. Physicians know that they can contact him when they have a diagnosed case to discuss treatment options. Dr. Cooper reports that almost on a daily basis he receives calls from all over the world speaking with physicians who are treating Myocarditis and especially, Giant Cell Myocarditis. I have to truly believe that the education that is being shared, is raising the awareness about Myocarditis, and especially Giant Cell. Just in the past few months, I have heard of success stories with regard to patients with diagnosed Giant Cell Myocarditis. They have been able to be discharged after treatment was started and improvement was noted. Because they were diagnosed quickly, some have not required the use of mechanical assist devices either. These are all positive signs with respect to awareness about the disease. Please read Benjamin's story, as he is a 14-year-old who recently was diagnosed with Giant Cell Myocarditis and has a wonderful story to tell...

## Not a Blank Canvas: *Portraits of Myocarditis*

### Benjamin's Story Gower, Missouri



Ben (14) was on his way to being state champion in all four areas of Taekwondo and preparing for his next tournament in Kansas City when he came home from school on a Monday, November 14, complaining he didn't feel well and was sick to his stomach. He felt fine the next morning and went to school as usual. Sitting in History class, he put his head down and felt his heart beating really fast and asked his teacher to feel it. She immediately sent him to the office, who sent him to the school nurse. The nurse called me and said he had a heartbeat of 250 and I needed to come get him and take him to the emergency room. We live in a rural area and the closest emergency room is 30 minutes away. We arrived in emergency and I began to have a clue that this was serious when there were about 5-6 staff in his room. They tried medicine to bring the heart rate down but ended up shocking him twice in an hour. He was then transported to KU medical center. He was in the Pediatric ICU for four days, he continued to have an irregular rhythm with PVCs. The team tried to do an ablation but could not do it at this time. He

was discharged with a life vest and scheduled for a pet scan the day before Thanksgiving.

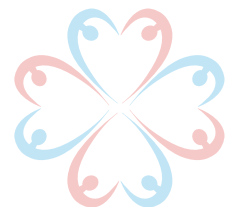
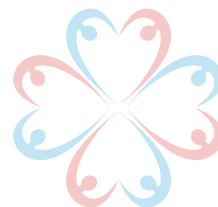
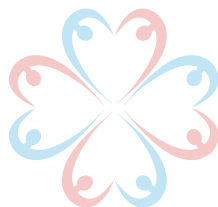
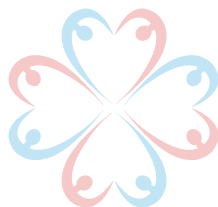
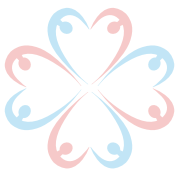
Ben was scheduled to try the ablation procedure again on Tuesday, November 29. Dr. Reddy said the ablation couldn't be done because the Pet Scan showed inflammation all over his heart. He then ordered a heart biopsy. He said he wanted to know what was going on. Thank God for this doctor! The pediatric doctors told us they rarely order a biopsy of a child's heart. Due to Dr. Reddy and the team at Mid America Cardiology we knew what was wrong, it was Giant Cell Myocarditis. They immediately started steroid treatment and Ben received a pacemaker and defibrillator. Due to his age of 14, Ben was transferred to Children's Mercy for continued treatment. I had emailed Dr. Cooper upon learning of Ben's diagnosis and he called and left his phone number for consultation. The doctors (Dr. Birnbaum and team) followed the recommended course of treatment of steroids and immune suppression. What Ben thought was going to be an overnight stay for an ablation turned into 15 days in ICU.

Ben's Story is a miracle. He recently had another Pet scan and it showed very little inflammation and he has been released to do some activity. He currently is on the High school golf team and is teaching younger students Taekwondo and beginning to participate again himself. We have been asked many times how can we go from such a diagnosis to almost back to normal routine in only 5 months. God answers prayers and works miracles through doctors such as Dr. Cooper, Dr. Reddy and Dr. Birnbaum! It was also through aggressive testing to know what was affecting the heart and a quick correct diagnosis, that Ben is alive today without a transplant. We thank the team at Mid America Cardiology, and Dr. Cooper's therapy regime, which saved Ben's life from this often deadly disease.



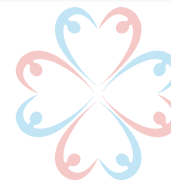
Myocarditis  
Foundation

*Knowledge Nurtures Hope*





# MYOCARDITIS FOUNDATION



## Board of Directors 2017

### JOSEPH RUMORE

*President*

Myocarditis survivor and heart transplant recipient, former Managing Director of a national insurance company

### LESLIE COOPER, MD

*Vice-President, Medical Director, Founder*

Chair of the Cardiovascular Department, Mayo Clinic, Jacksonville, FL

### CANDACE MOOSE, RN, MSN

*Secretary and Founder*

Giant Cell Myocarditis Survivor and Heart Transplant Recipient

### LOUIS ROMANO, JR.

*Chief Financial Officer*

Owner of HomeWell Senior Care

### DELISA FAIRWEATHER, PHD

*Director*

Associate Professor, Director of Translational Research, Department of Cardiovascular Medicine Mayo Clinic, Jacksonville, Florida

### JACK PRICE, MD

*Director*

Associate Professor of Pediatrics, Baylor College of Medicine  
Associate Director, Advanced Heart Failure Unit, Texas Children's Hospital, Houston, Texas

### JOEL ARANSON

*Director*

Founder and Chairman of National Sporting Good Corporation and father to a myocarditis victim

### FRANCINE ANDREA

*Director*

Vice-President for Enrollment Management, Student Affairs and Chief Compliance Officer for Felician University

### CHRISTOPHER CORSO

*Director*

Vice-President and Senior Reinsurance Placement Officer XL Catlin Insurance and father to a Myocarditis survivor

## Executive Director

### GENEVIEVE RUMORE, RN, BSN

Kingwood, Texas

## Director of Communications and Assistant to the Secretary

### DR. KATELYN BRUNO

Director of Communications and Assistant to the Secretary, Myocarditis Researcher at the Mayo Clinic, Jacksonville, Florida

## Medical Advisory Board

### AKIRA MATSUMORI, MD

Professor of Medicine, Department of Cardiovascular Medicine, Kyoto University Graduate School of Medicine, Kyoto, Japan.

### BRUCE M. MCMANUS, PHD, MD, FRSC, FCAHS

Professor & Director, The James Hogg iCAPTURE Centre, University of British Columbia-St. Paul's Hospital Scientific Director, The Heart Centre-Providence Health Care, Vancouver, British Columbia, Canada.

### DENNIS M. MCNAMARA, MD

Associate Professor of Medicine Director, Heart Failure Section; Director, Cardiomyopathy Clinic and Heart Failure Research Program, Cardiovascular Institute at University of Pittsburgh Medical Center Presbyterian, Pittsburgh, PA.

### STEVEN D. COLAN, M.D.

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

### DR. BETTINA HEIDECKER, MD

Associate Professor at the University of Zurich, Switzerland  
Myocarditis Researcher and previous MF Fellowship Grant Recipient

## Mailing Address

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

**3518 Echo Mountain Dr., Kingwood, TX 77345**

**Telephone: (281) 713-2962**

**Fax (281) 608-7252**

Find us online: [www.myocarditisfoundation.org](http://www.myocarditisfoundation.org)



[twitter.com/myocarditisfndn](https://twitter.com/myocarditisfndn)



[youtube.com/user/Myocarditisfndn](https://youtube.com/user/Myocarditisfndn)



[facebook.com/pages/  
Myocarditis-Foundation/  
314590715549](https://facebook.com/pages/Myocarditis-Foundation/314590715549)