

# MYOCARDITIS FOUNDATION



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

## PEDIATRIC MYOCARDITIS UPDATE

### Advancing Medical Understanding of Pediatric Myocarditis is Critical to Saving Lives of Children Across the U.S.

*Dr. Jack Price, Texas Children's Hospital*



When people think of heart disease, they rarely picture a young child. Instead, most view it as a disease that strikes older adults...and that is one of the reasons why pediatric myocarditis, a leading cause of sudden death in children, frequently goes undetected by pediatricians and emergency room doctors.

Another reason, is that the symptoms are frequently very similar to the flu or the common cold, which pediatricians deal with every day.

This is one of the most frustrating and scary parts of myocarditis. The symptoms mimic normal childhood diseases, which make it hard for pediatricians and emergency room doctors to detect the illness.

Myocarditis is the inflammation of the heart muscle and typically

attacks otherwise healthy people, including children and young adults. When myocarditis affects patients younger than 18 years of age, it is called pediatric myocarditis. In infants, the disease can be especially severe because of their underdeveloped immune systems.

In children, the cause is almost always a virus and usually one that is normally present in the community, such as influenza. For most children, the virus results in a common cold, nothing more. But for others, and doctors aren't sure why, it can turn into a disease that attacks the heart.

Some children are vulnerable and other children aren't...and it's not only that the virus attacks the body, it's the body's immune response to the virus as well. In some cases, there are minor or no symptoms and the disease resolves itself without medical intervention. In more serious cases, typical symptoms include labored breathing, a rapid heartbeat, sweating for no obvious reason, fatigue, change in exercise tolerance, wheezing, low blood pressure, cool extremities and decreased urine output. Older

children may complain of fever, vomiting and muscle aches a few days before developing more severe symptoms, which can include shortness of breath and an inability to exercise.

failure in patients suffering from pediatric myocarditis.

This disease tends to strike most often during infancy (under 1-year-old) and mysteriously during

*This disease tends to strike most often during infancy (under 1-year-old) and mysteriously during puberty and early adolescence.*

Doctors need to be on the lookout for clues that signal an illness more serious than a common cold. First among those clues is the sound of a child's heartbeat. If the heart makes a galloping rhythm, like the sound of a horse running, that should be a tipoff. If the lungs are making crackling noises or the doctor detects an enlarged liver or kidney during the physical exam, these red flags should also trigger more diagnostic tests, including a chest x-ray that can reveal an enlarged heart.

Doctors can also use a blood test known as B-type Natriuretic Peptide (BNP) which almost always will return results indicating heart

puberty and early adolescence. Doctors are not sure why the prevalence is higher in older children, especially in males. Research is being done to try and explain that.

Once properly diagnosed, treatment varies depending on how far the disease has progressed, whether there has been any heart damage and if so the extent of that damage. When caught early, doctors essentially "support the organs that are failing." This could mean intravenous heart medication, an artificial heart pump, or if the kidneys are failing, dialysis. It's actually potentially reversible, if you

*(continued on page 2)*

## Advancing Medical Understanding *(continued from pg1)*

can support the patient through this vulnerable period, (caught early and adequately supported.)

Because it is difficult to diagnose, it is also difficult to know exactly how many children contract pediatric myocarditis. Some children may never display serious symptoms and so are never diagnosed, while others may be misdiagnosed. Tragically, some children die suddenly without ever

being diagnosed.

The Myocarditis Foundation is working to change that. The organization provides accurate information to medical professionals, patients and their families about the disease. Dedicated to the scientific advancement of both the diagnosis and treatment of the disease, the foundation also raises money for medical research and education.

The Myocarditis Foundation in conjunction with the Texas Children's Hospital in Houston, are planning a physician education seminar next spring to educate community and emergency room physicians of the disease's symptoms, methods for earlier detection and referral, as well as treatment, to improve outcomes for sufferers and to ultimately save lives.

Advancing medical understanding of this disease is critical to saving the lives of children across the United States.

Pediatric myocarditis is one of the leading causes of sudden death in children. It is commonly found on autopsy in patients who have died suddenly. It is our goal to educate the medical community, to catch this disease before it claims young lives.

### Myocarditis Research Update

## Promising Research on Myocarditis Offers Hope

*Dr. DeLisa Fairweather, Mayo Clinic*

It is difficult to diagnose, tough to treat, and if left undetected, it can kill.

The big question is why do some get myocarditis and others don't.

A clue is found by looking at both environmental causes and the immune response. Since the disease is often confused with other heart conditions and often diagnosed as the flu, asthma or pneumonia, many cases go undetected and doctors receive little training on diagnosing and treating myocarditis. The need to expand understanding of the disease through research, then, is critical.

We have been studying the disease for years, using animal models that closely resemble human patients to better understand how some people's immune response leads to the development of acute or chronic myocarditis. It's a really good model to study what's happening with people who develop the type of inflammation of the heart that leads to acute or chronic myocarditis. Many people get the disease but never get symptoms, while for others it's much more severe.

Also key to the research is learning more about the differences between men and women. Men are more likely to develop a severe form of the disease. While some women are susceptible, they often develop a different level of inflammation.

Because heart disease in men and women is different, we should develop treatments that are more effective for men and women, which would result in more personalized or tailored treatment.

The research is also aimed at developing more precise, non-invasive diagnostic tools. Current tools, such as an echocardiogram, tell doctors if the heart is dilated or not pumping properly, while cardiac MRIs detect areas of the heart that don't move normally, have poor blood supply or are scarred. Neither provide a clear picture of the level of inflammation of the heart... only a heart biopsy can do that, and that is an invasive, painful procedure.

The Mayo Clinic's team of researchers are working on developing a non-invasive method to detect inflammation in the heart. This will allow



doctors to more easily diagnose patients with myocarditis, while also determining whether certain treatments are effective in reducing that inflammation. This, in turn, will help bolster research efforts that could ultimately lead to prevention of the disease.

Because we are imaging a particular type of immune cells, if this type of inflammation is there, we know patients are more likely to progress from myocarditis to

dilated cardiomyopathy. If we can identify people at higher risk, then they can be more carefully monitored and provided treatments that might prevent progression.

For the thousands of people who contract myocarditis each year, this promising research offers hope for the development of new diagnosis and treatment strategies that will save lives.



## Thank you Letter from the Executive Director to our Supporters

November 2016

Dear Myocarditis Families and Supporters,

I do not know how to thank you for all your support, financially as well as emotionally, to the Myocarditis Foundation. We could not have done what we have been able to do this year to raise awareness and educate others about this dread disease without your support.

We are dependent on donations to carry out our mission of awareness, education, provide funding for research and supporting emotionally those who have been affected by this dread disease. With being considered a rare disease, not many are aware of us and our mission, but when myocarditis affects them, we are where they turn to.

I would like to share with you some statistics that we have observed thus far during 2016:

- Our website hits have been increasing constantly. We have been well over 30,000 hits a month this year with a number of months close to 40,000 hits a month.
- Our webhost denotes that the number one site (over 275,000 hits) that the visitors visit is, "What is Myocarditis?" which takes them to "Discover Myocarditis Causes, Symptoms, Diagnosis and Treatment."
- At the Myocarditis Foundation, I receive many desperate phone calls and emails from people whose children and family members have been afflicted with myocarditis...some are survivors, many with complications, and others who want to know why their child or mother/father of their children have died suddenly from something that they had never heard of before. So often I hear the words, "But why, they were never sick a day in their life..." "Please you need to do something, we need research to find the answers..."

Over the past 11 years we have been able to help so many people that have been affected in various ways by myocarditis and its aftermath. We are in need of your donations to the Myocarditis Foundation so that we can continue our website for those who have been affected by this dread disease, to access and gain up to date information that would otherwise not be available to them, and to maintain our foundation so that they can contact us by phone or email for more personal information as needed.

In this environment, soliciting Corporate Grants for a rare disease are not as viable as they have been in the past.

We are looking at enhancing the dynamics of our website to raise awareness and funding for research, but the bottom line is that we need your continued help.

If you have an employer who matches donations, please share the information about your donation to us with them.

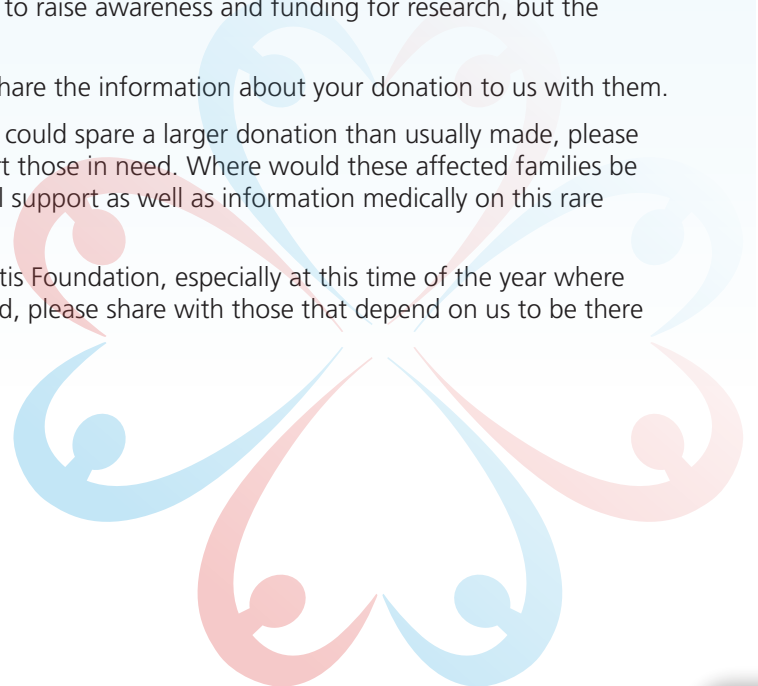
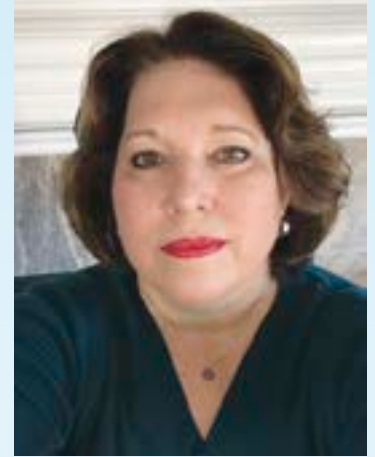
If you have been blessed with being financially secure and could spare a larger donation than usually made, please think of us. What a better foundation than ours to support those in need. Where would these affected families be without anywhere to turn for emotional and psychological support as well as information medically on this rare disease called myocarditis, if we are not there for them?

Please consider sharing your generosity with the Myocarditis Foundation, especially at this time of the year where charitable giving is asked of us all. If you have been blessed, please share with those that depend on us to be there for them...

Thank you and God Bless You All.

Sincerely,

Genevieve Rumore  
Executive Director  
The Myocarditis Foundation





## First Myocarditis Foundation Fundraiser a Huge Success !

On Monday evening June 20th, over 300 attendees participated in our first Gala at the Mandarin Oriental Hotel in New York City. Over twenty seven re-insurance companies and countless other supporters came together at the Mandarin Oriental for an emotional and educational evening to support the Myocarditis Foundation. Christopher Corso, the event's chairperson, spearheaded this event after joining the Myocarditis Foundation's Board of Directors at the end of 2015. With the support of many of his colleagues in the re-insurance industry, family and friends, the event took shape. A Silent Auction, Live Auction, and a Live Ask all helped to make the event very successful for the Foundation.

Over 300 people were introduced to what exactly myocarditis is and educated on how it impacts those affected by the disease. Our "Not a Blank Canvas" storyboards were placed around the room that held the cocktail hour and silent auction items. Reading the stories most definitely impacted the attendees before they went into the dinner where they heard the speakers talk about the disease.

Christopher Corso shared the story of his 12-year-old son's experience and survival with Viral

Myocarditis. You could have heard a pin drop in the room during the time that the speakers were speaking. No one left their seats...everyone was engrossed in what they were hearing. You could even see the staff of the facility paying attention to those speaking. Our guest speakers included Dr. Leslie Cooper and Dr. Jack Price, of our Board of Directors, as well as Candace Moose, Founder and Secretary of the Board and Joseph Rumore, President of the Board's closing remarks and thank you to all who took the time to attend and support the Foundation.

We believe the funds raised will enhance the speed of our research efforts.

The 2017 fundraiser is already in the planning stages and is set for Thursday June 22, 2017, again at the Mandarin Oriental in New York City. Please look for more information that will be coming in the future months on our website.



*Matthew and Christopher Corso*



*Myocarditis Logo and Table*



*Gen and Joe Rumore*



*Candace Moose and Dr. Leslie Cooper, Founders of the Myocarditis Foundation*

*Attendees in room listening attentively to the speakers*





## EVENT

# 2016 4th Annual Family Support Meeting

Despite the Zika Virus, that had an impact on a number of attendees and speakers for us, the 4th Annual Family Support Meeting went on. Forty-five attendees came together to hear our esteemed physicians and researchers speak on the latest updates in the realm of myocarditis. (Dr. Leslie Cooper of the Mayo

Clinic, Dr. Jack Price of Texas Children's Hospital, Dr. Betsy Blume of Boston Children's Hospital, and Dr. Dennis McNamara of the University of Pittsburgh).

Four of our families shared their very personal experiences with myocarditis to all of us as well. Brenda Vonckx spoke of the loss of her 19-year-old son Austin;

Sam Widjaja spoke of the loss of his 10-year-old son Christopher; Jeff Grant spoke of his win over Giant Cell Myocarditis; and

Christopher Corso spoke of his 12-year-old son Matthew's continued fight against viral myocarditis.

There were past affected families as well as new faces to the event.

We wish that we could say that there is no new families to attend, that we just get together to rekindle our support of one another, but until that happens we will continue to support those as they need it.

In 2017 we are planning the 5th Annual Family Support Meeting the weekend after the Gala in New York City. More info will be posted on our website as becomes available.



*Pastor Tom Unrich (at dinner) officiant for the Candlelight Vigil, speaking with attendees Andrew Mei and Christopher Corso*



*Carson and Sam Widjaja, Joe Rumore*



*Group of attendees at dinner*



*Andrew Mei, Dr. Leslie Cooper, Boni and Jeff Grant*



*Group of attendees*



*Christopher Corso, Kelly and Kyle Kirsch*

## Giant Cell Myocarditis Survivor with a keen awareness of his body, his mother's intuition, and a quick diagnosis and to thank for his life...

*Dominick Oliver, Pennsylvania*

Call it a mother's intuition – and an athlete's keen awareness of his own body...both may have saved Dominick Oliver's life.

A survivor of a rarer form of Myocarditis known as Giant Cell Myocarditis (GCM), Oliver's symptoms started during the end of his sophomore year of college when he began feeling sick with flu-like symptoms – fatigue, nausea, a lack of strength. As much as he tried to dismiss it as just a common cold, he had a feeling something more was wrong. The flu-like symptoms persisted until the then, college football player felt his health and strength slipping away...“I was lifting weights one day with my friend and the next time I tried to do the same exercises, my strength plummeted,” he remembers. “It was almost overnight.”

When Oliver told his mom how he was feeling, she decided that he needed to have some bloodwork drawn and got him to a hospital. The test results indicated that something might be wrong with his heart. After a series of tests, the doctors determined that he had some type of serious heart condition. He was quickly transferred to the University of Pittsburgh Medical Center's Presbyterian Hospital. The first night there, he underwent a series of additional tests and was initially diagnosed with Viral Myocarditis, an inflammation of the heart that can lead to heart failure and sudden death.

If that wasn't bad enough, the news got even worse...

After a few days without responding to treatment, doctors conducted a heart biopsy and determined that he had Giant Cell Myocarditis (GCM), a much more severe and frequently fatal form of the disease. “During all of this time, we were being educated on

Myocarditis and the doctors and nurses all said, ‘Be thankful you don't have Giant Cell,’ ” Oliver remembers... And then he did have it.

“When you are 20 years old and hear that even with proper treatment, the rate of survival even with a heart transplant is still slim, you're going to be a little rattled,” Oliver notes. “My parents were in the room so I tried to keep it together. I didn't want them to see how frightened I was. So many thoughts started rushing through my head but none more frightening than coming to the realization that I was completely helpless. There was no controlling this situation.”

Medically known as Idiopathic Giant Cell Myocarditis (IGCM), this even more rare form of Myocarditis, is caused by widespread infiltration of giant cells in the heart that are

abnormal. With proper treatment the rate of survival even with heart transplantation is less than 50 percent one year after symptom onset.

The disease typically strikes young, otherwise healthy adults. Symptoms can include flu-like illness, swelling of the ankles, chest pain, heart palpitations, fatigue and shortness of breath. Patients may experience irregular heartbeats, which can cause sudden lightheadedness or loss of consciousness. Symptoms usually develop very suddenly. Congestive heart failure often also occurs. Making the diagnosis even more difficult is that Giant Cell Myocarditis can only be accurately identified through a heart biopsy. Cardiac biopsies can only be done at transplant centers.

The exact cause of Giant Cell Myocarditis is unknown. Since 20 percent of cases occur in people

with autoimmune disorders, medical researchers theorize that this may be a factor in developing Giant Cell Myocarditis. Autoimmune disorders are caused when the body's natural defenses against “foreign” organisms attack healthy tissue.

By increasing awareness of Myocarditis in general, and the education of physicians about the disease, the diagnosis of Myocarditis and Giant Cell Myocarditis is becoming a little easier to recognize and properly diagnose. Oliver is one of the few lucky ones. When it was determined that he had Giant Cell Myocarditis, his doctor in Pittsburgh consulted with Dr. Leslie Cooper, chief of cardiology, then at the Mayo Clinic in Rochester, Minn. A founder of the Myocarditis Foundation, and national and international expert on Myocarditis, Dr. Cooper has devoted his career





## Giant Cell Myocarditis Survivor *(continued)*



to the study and treatment of this disease. The two doctors collaborated to develop a treatment plan that included rest and medication. Oliver was hospitalized for more than a month – allowing his heart to get stronger and the medicine to take effect. He was also put on the heart donor transplant list – just in case.

“It was then that, being so young, I realized that my life was never going to be the same,” Dominick remembers.

Although being in the hospital for all that time took a toll – he weighed 210 pounds upon admission and just 173 pounds when released – he has since made a nearly full recovery. Today, Dominick is 31 years old and lives in the Pittsburgh area, with his wife, Dana. He is a fundraiser for Chatham University. His only lingering health issue is high blood pressure.

“Fortunately, I was an athlete and more in tune with my body,” he says. “That, and my mom’s intuition, honestly saved me. My saving grace was a quick diagnosis.”

“It’s not the easiest thing to cope with,” Dominick adds. “The horrible stories that you hear and the fact that there are not many happy endings, sometimes you feel a little guilty. But mostly, I feel really, really blessed.”

### EVENT

## Heart Failure Society of America (HFSA)

The HFSA is the first organized effort by heart failure experts from the Americas to provide a forum for all those interested in heart function, heart failure and congestive heart failure (CHF) research and patient care.

Heart failure is often a side effect of cardiomyopathy and myocarditis, and many myocarditis cardiologists and physicians attend this annual conference to gain insight and education on the latest treatments and findings on heart failure.

At the Heart Failure Society of America’s Meeting (HFSA), (with which our Family Support

Meeting was held in conjunction of), Dr. Leslie Cooper had a Myocarditis Symposium which was well attended by those at the conference. Cardiomyopathy and Heart Failure are often a side effect of Myocarditis and an important aspect of its treatment.

The Myocarditis Foundation had a Booth in the Exhibit Hall where the 2,000 attendees of the HFSA visited to gain information on the various topics, and treatments presented at the conference. Dr. Bruno, Annalease Hobbs (an assistant from Dr. DeLisa Fairweather’s myocarditis research lab at the Mayo Clinic in

Jacksonville) and myself, were in the booth to answer questions from the physicians, nurse practitioners and researchers who visited us. We shared in the research that is currently being conducted as well as thoughts on future planned projects for myocarditis research.

Dr. Leslie Cooper, who frequently stopped by to speak with our

visitors, collaborated on future research projects as well with them. Dr. Bruno commented that this was the most interactive HFSA/Myocarditis Booth that they had ever had!

I believe that this shows the increase in awareness of the disease and the Foundation’s presence globally.



*Both pictures have Dr. Katelyn Bruno, myocarditis researcher, explaining the present research being conducted to visiting physicians and researchers*

## Dr. Leslie Cooper's Speaking Schedule

### 2016

#### December 2nd - 4th

International Society of  
Cardiomyopathies and Heart Failure  
**Kyoto, Japan**

### 2017

#### February 20th - 24th

Cardiology at Cancun:  
Topics in Clinical Cardiology  
**Cancun, Mexico**

#### May 12th - 13th

Heart Rhythm 2017:  
The Heart Rhythm Society's 38th  
Annual Scientific Sessions  
**Chicago, Illinois**

#### 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**

### 2017 EVENTS

#### January 15th

Awareness Event in Memory of  
Clayton Edgeman  
**Tennessee**

#### January 28th

Quinn's Cup Pond  
Hockey Awareness Event in  
Memory of Quinn Kirsch  
**Minnesota**

#### February 27th

Rare Disease Week  
**Washington D.C.**

#### February 28th

Rare Disease Day

#### March 25th

Myocarditis Education Seminar  
for Medical Community at  
Texas Children's Hospital  
**Houston**

#### June 22th

Myocarditis 2nd Annual Gala  
**NYC**

#### June 23rd - 24th

Myocarditis Foundation  
5th Annual Family Support  
Meeting  
**NYC**

#### August 14th

Rumore/Romano Myocarditis  
Foundation Golf Outing  
**New Jersey**

### EVENT

## Mayo Researchers Collaborate with Researchers in the Czech Republic for Myocarditis Research

Dr. DeLisa Fairweather and Dr. Katelyn Bruno, members of the Myocarditis Foundation's Board, along with Dr. Lori Blauwet of the Mayo Clinic have traveled to Brno, Czech Republic to work on

collaborations with physicians and researchers at St. Anne's University Hospital and Masaryk University. Drs. Fairweather and Bruno analyzed sera biomarker of myocarditis that could assist with

diagnosis and potentially predict progression of disease. This is just one of the many sites around the world where myocarditis research is being conducted.



Front Row: Dr. Katelyn Bruno, PhD Dr. Lori Blauwet, MD Dr. Lenka Spinarova, MD, PhD  
Back Row: Dr. Jan Krejci, MD, Dr. DeLisa Fairweather, PhD

### EVENT

## International Society of Cardiomyopathies and Heart Failure (ISCHF) December 2016

Dr. Akira Matsumori, an esteemed member of the Myocarditis Foundation's Medical Advisory Board, is the Chairman for this International Heart Failure Conference in Kyoto, Japan, December 2-4, 2016.

Dr. Leslie Cooper, founding member of the Myocarditis Foundation and world renowned specialist in the field of Myocarditis, is on the Executive Committee for this conference and will be a key speaker on myocarditis throughout the conference. Topics that he will be speaking on

are: "The Global Burden of Myocarditis", "The Role of Viral Infection in the Pathogenesis of Cardiomyopathies, Heart Failure and Myocarditis", "Recent Advances in Imaging of Myocarditis".

Another speaker at the conference is our very own Dr. DeLisa Fairweather, an esteemed myocarditis researcher from the Mayo Clinic, previously from John Hopkins University. She will be speaking in the conference section on "Sex Differences in Cardiomyopathy", specifically on the "Pathophysiology of Heart

Failure in Men and Women", and is the Chairman for the Symposium on "Prevention and Treatment of Cardiomyopathies and Heart Failure by Life Style Changes".

Dr. Bruce McManus, of Vancouver, Canada, another member of our Myocarditis Foundation Medical Advisory Board will be speaking at this conference, along with numerous esteemed physicians and researchers from around the world who specialize in cardiomyopathy, myocarditis and heart failure.



## EVENT

# Sarah Knight 2016 Golf Outing

Sarah's Mom shares the success of her daughter's annual memorial golf outing that supports the Myocarditis Foundation as well as two school associations that were dear to her daughter Sarah's heart...

The 2016 Sarah Knight Memorial Golf Tournament was a record breaker! It was a beautiful sunny day with temperatures in the 90s. We filled the course with 121 golfers and shattered our previous number of hole sponsors with a total of 30 regular and 31 gold sponsors. The silent auction and raffle were a huge success bringing more revenue than ever! Total proceeds from the event were just over \$27,000, more than we ever dreamed possible.

\$10,000 will be donated to the Myocarditis Foundation where we are close to funding a

research grant in Sarah's name. \$10,000 will be donated to East Moline School District for their bi-lingual/bi-cultural education program, where Sarah can still have an impact on the students she loved. \$7,000 will be gifted to Western Illinois University where our endowed scholarship is granted to a deserving bi-lingual/bi-cultural elementary education major year after year.

The inspiration for the golf tournament came from families who shared their fund raising success stories on the Myocarditis Foundation Facebook page. When Sarah died we knew we had to do something to keep her spirit and love for children alive. With the virtual support of other Myocarditis families, our tournament was "born" and has far surpassed our dreams. Sarah's favorite saying was "What would



*Sarah Knight's "Not a Blank Canvas Poster" with one of Sarah's best friends since childhood, Stephanie McCracken*

you attempt to do if you knew you could not fail?" Gather up your friends, family, virtual family and dream bigger than you ever thought possible!



## EVENT

# 2016 9th Annual Myocarditis Foundation Golf Outing

On Monday, August 1st, the Myocarditis Foundation hosted their 9th annual golf outing, co-hosted by Joseph Rumore and Lou Romano, Jr.

The outing was held this year at Arcola Country Club, in Paramus, New Jersey. Despite the rains that occurred in the days prior to the event, the sky cleared and it was a beautiful day for the 100 golfers who participated. Through the participants continued generosity towards the Myocarditis Foundation (MF), the proceeds raised were the most ever for the Myocarditis Foundation in its 9-year history of the event.

This event was started after Joseph Rumore received his second chance at life, from a generous family on Thanksgiving Day, 2006. His own heart was irreparably damaged from Viral Myocarditis and he only had days to live without this generous gift

of life. His life's goal is to raise awareness, education and funding for research into myocarditis, so that one day others will not have to go through the same suffering so many have already gone through.

Dr. Leslie Cooper, of the Mayo Clinic, met with the golfers during lunch and spoke before the 1:00 PM shot-gun start. Dr. DeLisa Fairweather, also of the Mayo Clinic, spoke during dinner about the research that is being done to find an early detection tool for myocarditis. With such a tool, the medical community will be able to have a more definitive way to rapidly diagnose this disease helping to provide for much better outcomes.

The proceeds from the event will fund another Fellowship Research Grant from the Myocarditis Foundation.



*Joe Sr. and Joe Jr.*



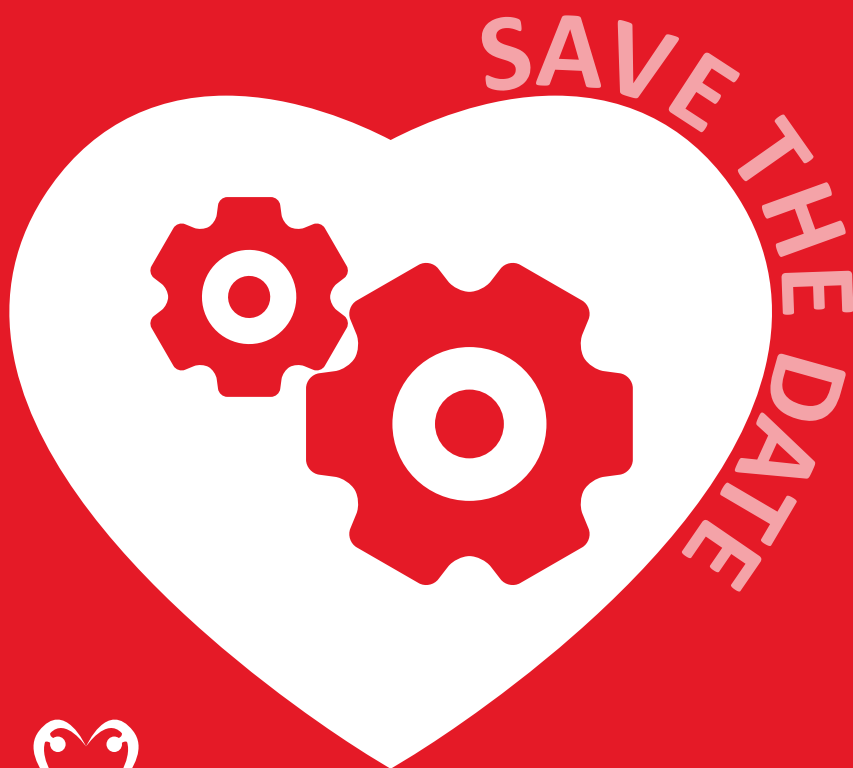
*Lou Romano, Jr. and Joe Rumore, Sr., Hosts of the event*



*Tom Andrea and Dr. Leslie Cooper*

# PEDIATRIC MYOCARDITIS SEMINAR

3|25|2017



## EVENT

### Myocarditis Foundation and Texas Children's Hospital Partner in Educational Event

The Myocarditis Foundation will partner with Texas Children's Hospital next spring as hosts of an educational conference on the topic of pediatric myocarditis, sudden death and heart failure. Leaders in the field of pediatric cardiology and heart failure will present the latest research, innovations and data related to myocarditis in children.

In addition, fundamental features of the disease including diagnostic evaluation, treatment and follow up will be discussed. The target audience will include pediatricians,

family physicians, emergency room physicians, nurses and nurse practitioners. The event will be held Saturday, March 25, 2017 at Texas Children's Hospital. Registration and detailed information will be available soon through the Myocarditis Foundation. (281) 713-2962

Please share with your pediatricians or any first line diagnosticians about this conference. Seating is limited and continuing medical education units will be provided through Texas Children's Hospital.

## PLEASE JOIN US

for a 1-day seminar on the clinical presentation, diagnosis and treatment of acute myocarditis. The program includes presentations from leading experts in the field.

Continuing education credits for physicians and nurses will be provided.

**PRESENTED BY:**  
The Myocarditis Foundation  
and Texas Children's Hospital

For more information or to register, please contact Genevieve Rumore at [genevieve@myocarditisfoundation.org](mailto:genevieve@myocarditisfoundation.org) or 281-713-2962.

SPACE IS LIMITED | REGISTRATION FEE



## National Organization of Rare Disorder - (NORD) Summit October 17-19, 2016

This was the 5th and largest Summit that NORD has held since their inception 33 years ago. In the 1970's and early 1980's, patients and families living with rare diseases felt alone and forgotten. Very little was being done to study these diseases or develop treatments. The leaders of several rare disease patient organizations formed an ad hoc coalition to focus attention on this problem. That coalition became NORD in 1983.

This is much how the Myocarditis Foundation became about; there was no information out there for those who were afflicted by the disease and Dr. Leslie Cooper and Candace Moose made the Myocarditis Foundation happen.

NORD is a 501(c)(3) patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them (like the Myocarditis Foundation.) NORD, along with its more than 250 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research and patient services.

There were over 600 registered participants that attended and heard from key people at NORD and the Food and Drug Administration (FDA). There were family speakers as well who shared their rare disease stories and what they have done to advocate and raise awareness for their particular disease as well as rare diseases in general.

Throughout the course of the first two days, two themes emerged loudly and consistently as necessary for continued progress: collaboration and involving the patient in every step along the way. Collaboration is

the key to making progress over rare diseases. Nord's resounding thought process is, "Never underestimate the power of one, but together we are a force to be reckoned with."

The majority of rare diseases are neurological and pediatric based, they are somewhat different than myocarditis which often strikes and takes the person in the blink of an eye. Just like myocarditis, we all have the same roadblocks... misdiagnosis, lack of awareness, need for funding, and time (to be diagnosed and treated before decline.)

This year there was a round table breakout session where I networked with others about the importance of educating the medical community on our rare diseases.

Pharmaceutical advances in the rare disease world has never been better. Over 50% of new drugs that have been approved lately by the FDA have been towards helping out the rare disease community.

NORD speakers highly recommended that the most important things that patient groups can do consist of the following:

- First and foremost is to support those afflicted with a rare disease, so that they know that they're not alone
- Raise funding for medical research into the disease
- Educate others about the disease to raise awareness both in the medical and the public communities

Doesn't this sound familiar? This is exactly the Myocarditis Foundation's mission, which we carry out every day in every way we can.

The third day, which was specifically for the member disease groups of NORD, was very helpful in the concerns that we as a rare disease foundation deal with on a daily basis. NORD has started educating medical students of every discipline (doctors, nurses, physician assistants, etc.) on learning about rare disease, with the help of the rare disease foundations. They will also be starting a Rare Disease Video Library, "Journey to Diagnosis", where physicians and medical students will be able to view 2-3 minute videos on a specific disease that are made by

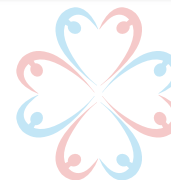
the individual foundations and submitted to NORD. It is recommended to include 3 parts: an interview with a doctor about the disease, interview with the patient or family, and finally an interview with a representative from the foundation explaining what the foundation does for the patient, family and disease. I will be looking at doing this for the Myocarditis Foundation in the very near future.

*"Alone we are Rare, Together we are Strong...and Together we make a Difference..."*  
NORD





# MYOCARDITIS FOUNDATION



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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.

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

**Fax (281) 608-7252**

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



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