KNOWLEDGE NUTURES HOPE

FALL 2017 / VOLUME17 / NUMBER 2

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, NYC, June 22, 2017

On Thursday June 22nd, the Myocarditis Foundation held it's 2nd Annual Gala at the Mandarin Oriental Hotel in NYC. There were over 400 supporters in attendance from all over the world. The Chairman of the event was Christopher Corso, and the Master of Ceremonies was Dr. Doug Luffborough, who kept the evening flowing smoothly.

During the cocktail hour, there was a Silent Auction where the attendees bid on items donated for the event. There were "Not a Blank Canvas" storyboards there for people to read as well. These storyboards shared personal experiences of some of the families in attendance and how they were affected by myocarditis.

There were 33 family members intermixed with supporters whose additional stories of myocarditis were shared.

The evening's speakers included Dr. Leslie Cooper, world renowned Myocarditis Specialist and Dr. DeLisa Fairweather, a Myocarditis Researcher from the Mayo Clinic. Both spoke on the Myocarditis Foundation's 2017 initiative and theme of the gala… starting a Bio-Bank specific for Myocrditis. The Bio-Bank will be the first of its kind for Myocarditis, allowing collaborating researchers to use samples from multiple races, cultures and areas of the world, then to share findings. International collaborators will be eligible for higher research grants needed for clinical trials. The Bio-Bank is expected to be a critically important resource for developing treatment options and to speed progress towards a cure.

There was a slide show of myocarditis victims and survivors showing the personal side of myocarditis.

The night was closed by Joseph Rumore, President of the Foundation, thanking the generosity of the attendees and sharing plans for the future of the Myocarditis Foundation.

The Myocarditis Foundation would also like to thank all of our supporters, committee members, and any and all who helped to make the Gala a huge success.

Dr. Leslie Cooper, Candace Moose, Jeff and Annie Spear

Dr. Leslie Cooper

Dr. DeLisa Fairweather

EVENT

5th Annual Myocarditis Foundation Family Meeting June 23, 2017

The Myocarditis Foundation's 5th Annual Family Meeting was held on Friday June 23rd at the Empire Hotel in NYC. Fifty-five family members were in attendance. We started the meeting with a moment of silence for a prayer for all those that have been affected, and those that are still battling with the disease.

We had the honor of having seven Giant Cell Myocarditis Survivors in a room together, ranging in time frames of a few months from diagnosis to 17 years from when they were diagnosed.

The meeting started with an icebreaker by Doug Luffborough. We had a number of new families present, so this really helped to get everyone more comfortable with each other.

The current MF Fellowship Grant Recipient, Dr. Guobao Chen PhD, from Johns Hopkins University described his current research that is being done. He is working on preventing those affected by Myocarditis from going on to developing Dilated Cardiomyopathy and Heart Failure. He reported that in Myocarditis induced Dilated Cardiomyopathy in children, 60% go on to needing a heart transplant. This is extremely important work that he is conducting and we wish him much success in his research.

The President of the Foundation gave an overview of the direction of the MF, and the starting of Regional Chapters in the near future. A family member of one of these chapters will have a seat on the Board of Directors so that input can be shared more closely back and forth between them.

We had a panel discussion where the attendees could ask the doctors and researchers their questions. We also had smaller discussion groups where the attendees shared their stories throughout the day at the extended lunch period and during the "round table" discussions. Our guest speaker, Dr. Doug Luffborough PhD, shared the story about his childhood and how he was motivated to make something positive from the negativity in his early life.

Dr. Cooper and Dr. Fairweather shared the importance of us starting a Bio-Bank. This is where banked blood and tissue samples from myocarditis patients from all over the world will be housed in one location. Collaborative researchers can access those samples and share their research with each other. We believe that this will lead to a faster realization of a cure. The accessibility of obtaining larger research grants, which are restricted to those that have international collaborative relationships, which we will now have, will become a reality.

The Meeting culminated with a lovely dinner in a private dining room at Bar Boulud Restaurant where we were able to share more about ourselves with our new friends within the myocarditis family. It truly sounded like a large family gathering where there was a lot of interaction and laughter amongst people who were reconnecting after a period of time away from each other.

Contact information was given and will be shared amongst the attendees so that the friendships and support of each other can continue throughout the year. The date for the Gala in 2018 is June 21, 2018, and the date for the Family Meeting will be June 22, 2018. The Gala will be at the Mandarin again, but we are looking for alternative housing and venue site for the Family Meeting. We are looking at possibly having a second Family Meeting elsewhere in the U.S., but this is still in the planning stages.

Family Support Meeting

MYOCARDITIS AND RESEARCH UPDATES

Parvovirus Myocarditis In Children

Dr. Jack Price, Pediatric Cardiologist, Member of the MF Board of Directors, and Clinical Director of the Cardiovascular Intensive Care Unit at Texas Children's Hospital

Many infectious agents are known to cause myocarditis in children. Viruses such as coxsackie B, influenza, herpesvirus 6, and adenovirus have all been described in pediatric myocarditis. Another infectious agent, human parvovirus B19, is often associated with myocarditis and may be one of the most common causes of cardiac inflammation in children.

Parvovirus B19 causes erythema infectiosum, a common childhood infectious disease also known as "fifth disease." It is estimated that approximately 50% of children age 15 years have developed antibodies during an infection with parvovirus B19 at some point in their lives. There is a wide spectrum of clinical characteristics among infected patients ranging from a low-grade fever to severe bone marrow suppression and myocarditis. Children often present to a doctor's office with a classic "slapped cheek" appearance of a rosy facial rash. Other findings include sore throat, runny nose, cough and headache. A diagnosis is usually made based on the presence of the classic rash. A blood test for antibodies to parvovirus may be performed in cases of severe disease or in immunocompromised patients.

The incidence and prevalence of parvovirus myocarditis in children is not reliably known. Because the virus is so ubiquitous, determining its association with cardiac inflammation can be difficult, especially since heart muscle biopsies are so infrequently performed. Dr. Kimberly Molina reported on a series of 19 children diagnosed with parvovirus myocarditis at Texas Children's Hospital and Arkansas Children's Hospital. In Dr. Molina's study, the median age at diagnosis of parvovirus-associated myocarditis was 16 months (range from 6 months to 15 years). The majority of patients were female and the ethnicity was wide-ranging. The most common signs and symptoms were respiratory distress and difficulty feeding/vomiting. Most children were also found to have an enlarged liver and a "gallop" heart rhythm on physical examination. Among children who underwent laboratory testing at the time of presentation, 100% had an abnormally elevated B-type natriuretic peptide level and 78% had an elevated troponin I level. These biomarkers are frequently abnormal in situations of heart muscle injury or heart failure. Furthermore, 89% of children had an enlarged heart on chest x-ray. These findings are similar to other case reports and case series of parvovirus myocarditis in children.

In the cohort studied by Dr. Molina, 5 children survived and recovered with complete normalization of their heart function. One patient survived with persistent heart failure. Eight children survived but required heart transplant and 5 other patients died. One of the key findings of this study was that myocarditis occurring in children with parvovirus is usually severe and not likely to recover. Early treatment of the cardiorespiratory systems with mechanical circulatory support may be life-saving for some.

The heart muscle injury that occurs in parvovirus related myocarditis is caused primarily by inflammation and the body's normal response to infection. In some patients, a transient form of spasm of one or more coronary arteries has also been described. This type of spasm may cause limited blood flow to the muscle of the heart, leading to further injury and scar formation within the muscle. This type of injury can lead to a chronic form of enlarged and weakened heart (dilated cardiomyopathy).

There are no known cures for parvovirus B19 infection. In patients who develop myocarditis and severe heart failure due to this virus, support with a left ventricular assist device or extracorporeal membrane oxygenation (ECMO) may be life-saving or may allow patients to survive as a bridge to heart transplant.

FUNDRAISER

Uncork with Love

Saturday, September 16th was an amazing evening in Muncie, Indiana at the "Uncork with Love" Myocarditis Awareness Event and Fundraiser conducted by The Honor Stride at the Tonne Winery.

Julie Smith, the Chairperson of the event, was a very close friend of Ashley Burgauer, who passed away on August 29, 2013 of Viral Myocarditis. To keep the memory of her friend alive, Julie started The Honor Stride, which raises funds for the Myocarditis Foundation.

Gen Rumore, Executive Director for the MF spoke on Myocarditis and the need to raise awareness on the disease.

"Uncork the Love" was the 4th annual event to raise funds for the Myocarditis Foundation. Not only did it raise awareness about Myocarditis, it was a relaxing evening with great live music under the stars for those who came out to support us. I'd like to thank them sincerely for their efforts and hard work in making the event a huge success.

Julie Smith and Ashley Burgauer Family

Dr. DeLisa Fairweather's Translational Cardiovascular Disease Research Laboratory at the Mayo Clinic, Jacksonville, Florida

The term "translational" refers to the "translation" of basic scientific findings in a laboratory setting into potential treatments for disease.

In Medicine, "Translational Research" is increasingly linking the research fields of Basic Research and Applied Research. Although "Translational Research" is relatively new, it is being recognized and embraced globally.

In her lab, Dr. Fairweather specializes in how sex differences in inflammation caused by environmental exposures can lead to chronic inflammatory disease. Recently, Drs. Fairweather and Bruno published an editorial in the journal Circulation: Cardiovascular Genetics (2017 Oct;10(5). pii: e001950. doi: 10.1161/CIRCGENETICS.117.001950) commenting on how sex differences in cardiac cells called cardiomyocytes contribute to heart failure. Biological sex differences in how cardiac muscle cells stretch and heal after damage between men and women are one reason that myocarditis occurs more often in young adult men than women following viral infections.

As an expert in Myocarditis, Dilated Cardiomyopathy and Heart Failure, Dr. Fairweather leads a research team seeking advances in diagnostic techniques and novel therapies. The Translational Cardiovascular Disease Research Lab is advancing knowledge about the pathogenesis (causes) of disease to discover new diagnostic techniques and novel therapies for patients with Myocarditis and other Cardiovascular and Autoimmune Diseases. Dr. Fairweather is currently writing a paper with Dr. Bruno on how myocarditis can occur in patients with Pulmonary Arterial Hypertension and unexpected disease association. Drs. Fairweather, Bruno and Cooper are writing another manuscript on how sex differences in a particular biomarker that can be found in the blood can predict who will progress from myocarditis to develop dilated cardiomyopathy.

Dr. DeLisa Fairweather, Dr. Katelyn Bruno, Dr. Leslie Cooper, Jessica Mathews, Anneliese Hill

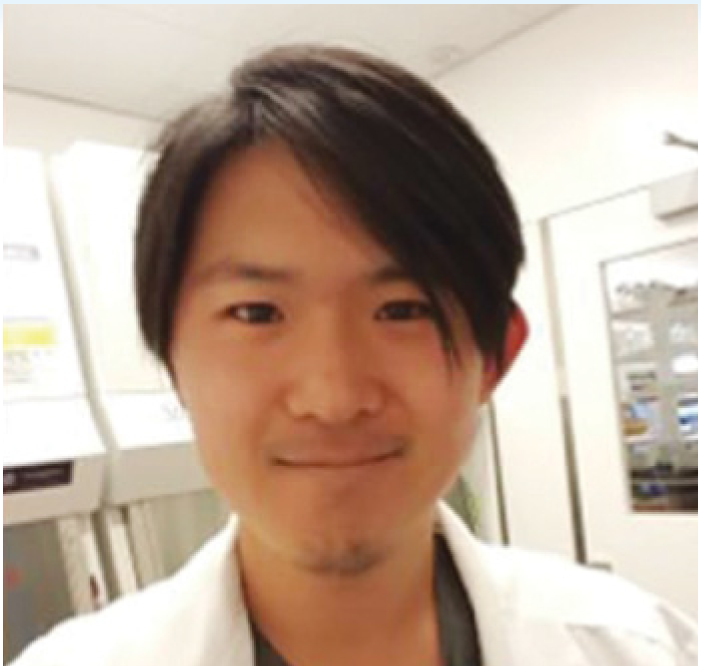
Dr. Fairweather leads her research team who are focusing their efforts on how sex differences in inflammation alter the diagnosis, treatment and prognosis of myocarditis and dilated cardiomyopathy. They are identifying new diagnostic biomarkers and discovering possible new treatments including regenerative medicine with the goal of reducing and preventing disease.

You can view Dr. Fairweather's Lab Website at: **mayo.edu/research/labs/translational-cardiovascular-disease-research**

2015 Myocarditis Foundation Fellowship Grant Recipient

Our 2015 MF Fellowship Grant Recipient, Dr. Jon Sin, has recently shared with us that the work which he was initially awarded the Fellowship Grant for, and continues to research, will be published in the Journal of Virology.

His initial research was on the Coxsackie B Virus (CVB), a common juvenile pathogen that can cause a wide array of inflammatory diseases including meningitis, pancreatitis and myocarditis, all of which can be fatal. Based on his preliminary findings, he was going to utilize a mouse model of CVB infection to test the efficacy of using a mitochondrial fission inhibitor to suppress viral myocarditis. It will take approximately four months before publishing, but once we obtain the research article, we will share the information with you.



Dr. Jon Sin

FUNDRAISER

Sarah Knight Memorial Golf Tournament, June 9th, Marion, Iowa.

Sarah was a 25-year-old bi-lingual kindergarten teacher who died suddenly from Myocarditis on September 26, 2011. After teaching all day and attending a meeting after school, Sarah was working alone in her classroom when she passed away.

In 2013 her family decided to host a golf tournament in Sarah's honor. Their wish and incentive for starting the tournament was to help bring awareness to Myocarditis and to fund research for diagnosis and a cure. They also wanted to establish a scholarship in Sarah's name at Western Illinois University. They find comfort in knowing they are keeping her memory alive!

Sarah's mother wrote: "On Friday, June 9, another record breaking tournament was held in Sarah's honor. They maxed out the course with 144 golfers. The response has been amazing. Total proceeds from the event were a new record of $28,000!"

Susan and Greg Knight

With this year's contribution of $10,000 to the Myocarditis Foundation, we will complete funding a research grant in Sarah's name.

Additionally, the other money was donated to Western Illinois University for a scholarship in Sarah's name that is awarded to a deserving bi-lingual/bi-cultural elementary education major and also to the East Moline School District for their bi-lingual/bi-cultural education program, where Sarah can still have an impact on the students she loved.

The success of our tournament is a result of continued generosity of family and friends. Golfers, volunteers, generous individuals and businesses who sponsor holes and donate raffle prizes, silent auction items and cash all share in making the event a testimony of how much we love Sarah. We did not dream the impact of Sarah's tournament could be so profound and are grateful to everyone who has a part in the success. We are also grateful for Sarah's favorite adage that gave us the courage to try: "What would you attempt to do if you knew you could not fail?"

SUPPORT COMMUNITY

The Myocarditis Support Community Is Now Online

The Myocarditis Foundation has partnered with Inspire, the leading social network for healthcare support, to offer a free online community to allow Myocarditis patients and caregivers to support and connect with each other.

The Myocarditis Support Community lets people share personal experience with others who have faced myocarditis: patients, caregivers, family members and friends. Discussions center around symptoms, treatment, new developments in research, and most importantly, discussions to provide emotional support and enhance caregiving.

Members can create a personal profile page on which they can tell their story, post pictures, or write a diary. Somewhat similar to Facebook, friends can be defined to allow private communications for more sensitive or personal topics.

*Visit **myocarditis.inspire.com** to access the Myocarditis Support Community*

Alternately, the public discussions on inspire can be viewed without signing up.

Participation in the community can be anonymous, or you can share as much of your story as you'd like. To start discussions or leave comments you must register with an email address.

Inspire cannot be used to provide medical treatment advice, for commercial use, for fundraising, or product promotion. Through our partnership, the Myocarditis Foundation is able provide links to key information on the foundation website.

Discussions on the community are moderated by Inspire professionals for adherence to their guidelines for effective participation.

Inspire™
together we're better™

To visit or join the Myocarditis Support Community on Inspire go to Myocarditis.Inspire.com. For further information about the support community you can email **tom@myocarditisfoundation.org.**

FUNDRAISER

10th Annual Myocarditis Foundation Golf Outing
August 14, 2017 at Arcola Country Club, Paramus, NJ

Joe Rumore, Lou Romano Jr.

On Monday August 14th the clouds shielded the strength of the sun on the participants, but did nothing to cloud the events of the day!

The 10th Annual Golf Outing, which was started by Joe Rumore, and now co-chaired by he and Louis Romano Jr., had the largest field of players thus far. The 102 golfers, many who have been with Joe and the annual outing since its inception, played the beautiful Arcola Country Club in Paramus, New Jersey. The coarse was in pristine shape and offered many views of the New York City skyline. The golfers included those who survived myocarditis, families of those that were not able to beat the disease, and many others who support the Foundation looking for a cure.

The day started with lunch on the terrace before the 1:00 pm shotgun start. Anyone driving around the course could see the enjoyment on the golfers faces as they wagered among themselves, savored the cigars, compliments of Lou Romano, Jr., and posed for pictures of their foursomes.

Cocktail hour on the terrace allowed the teams to catch up with each other on the events of the day. The camaraderie of the golfers was evident through the stories and laughs that they shared. During dinner, Dr. Katelyn Bruno, a post-doctoral researcher at the Mayo Clinic, Jacksonville Florida, was the guest speaker. She updated the group about the research being done and the papers being written on it. You could hear the excitement in her voice when she spoke of the positive outcomes being noted in the fight against this disease.

Joe Rumore thanked everyone and shared the growth of the Myocarditis Foundation (MF) with the players and what their ongoing donations have meant to the success of the MF through the years. The golf outing has been the major source of revenue for the MF to award an Annual Fellowship Research Grant to Post-Doctoral Myocarditis Researchers over the years. The golf item raffle prizes, donated by the Pro Shop at Arcola as well as through Golf Galaxy by the MF, brought the players to scan their ticket holdings for the winning tickets. There was an auction for tickets to both the Mets as well as the Yankees, that were donated to the MF specifically for the day. The key prize that everyone wanted to be the winner of was the "Bermuda 2018 at The Reefs Resort" that was donated by Candace Moose. The money obtained from this raffle has always been earmarked specifically for our annual Fellowship Research Grant. The winner was someone that has supported the MF's Golf Outing since it's inception and who is looking forward to visiting the beautiful island of Bermuda next spring.

Gen Rumore, Dr. Katelyn Bruno

Throughout the day, the attendees had access to information on the MF and the ability to read the "Not a Blank Canvas" stories of myocarditis survivors and victims that were on display for them to read.

The success of the outing proved to be the best thus far. Thank you to Lou and Joe for all your hard work on putting this together. We thank Sam Raia, the sponsoring member at Arcola, as well as Jason Hooper and his staff who helped make the day a very pleasant one for all involved. Thank you most of all to Mother Nature, who once again came through with a beautiful day for golf!

252 Attendees Celebrate Lee Andrew Hirsch's Life and Raise Awareness for Myocarditis

On Saturday September 30th at Gargiulo's Restaurant in Brooklyn, NY, 252 people gathered to celebrate the short life of Lee Andrew Hirsch.

Lee's life was cut short because of Viral Myocarditis, which attacked him suddenly in November of 2015 and stole his life at age 31, from so many that loved him.

His mother, Giustina Schiano, was devastated by his loss and wanted to raise awareness about the disease and funding for education and research, to stop it from affecting other families as it did hers. In this undertaking, something that she had not ever done before, she relied on the help of others. They helped her prepare an amazing event that will raise awareness of the disease and work towards the funding for a Myocarditis Fellowship Research Grant in her son's name.

The overwhelming response and outpouring of love that people showed through donations at the raffle tables and toward making the event so special was beyond amazing. In-Kind donations that cut the costs of the evening and made the donation to the Myocarditis Foundation that much stronger, made for a special event.

Giustina went door to door sharing her son's story with others on how his life was so suddenly cut short without warning and the need to educate others on the disease so that others would not suffer the loss and devastation that she and her family had.

Joe Rumore, Candace Moose, Gen Rumore, Giustina Schiano

It was because of her education about the disease to a family friend that prompted him to seek medical care when he started to exhibit viral symptoms that were not getting better. His Viral Myocarditis was diagnosed early and he was able to survive the disease without residual deficits.

It is because of situations like these that will help raise awareness on the ground level about the disease. Because of his sharing of information about the disease to the physicians in the Emergency Room, they now are aware of and will hopefully save another life from Viral Myocarditis in addition to this man's.

If these 252 people share information about Viral Myocarditis to another 252 people, and so on and so on, we can save many more lives from this devastating disease.

We cannot be fearful of saying the word…Myocarditis…

We cannot be fearful of being wrong and scaring someone about potentially having the disease…

It is so much better to say the word, question it, and have the doctors investigate it, examine the person more closely, and work it up, hopefully to say "no, you do not have that…", than to have someone not say anything and to find out months later that that is what someone they knew died from…

**Raise awareness…
raise awareness…
raise awareness…**

Education is the key to early diagnosis and improved outcomes…

Giustina, we cannot thank you enough for the awareness that you have raised already with your efforts and we know that you will save lives because of it…

God Bless you…we know that Lee is so proud of you as are we at the Myocarditis Foundation… Thank you for all that you are doing for us.

INTERNATIONAL NEWS

Myocarditis Board Member is a Speaker at the 7th World Congress of Pediatric Cardiology and Cardiac Surgery Conference in Barcelona, Spain

In July 2017, Dr. Jack Price from Texas Children's Hospital, and a Board Member of the Myocarditis Foundation spoke on "Cutting Edge Perspectives in Pediatric Ventricular Assist Devices." Dr. Price, and a team of physicians from Texas Children's Hospital, spoke to thousands of cardiologists from all over the world on the pros and cons of the usage of Ventricular Assist Devices in children.

While the field of mechanical circulatory support has made great strides in the past years, pediatric mechanical support has not kept pace with the adult mechanical support options. However, that gap is closing rapidly. Texas Children's Hospital is a leader in the usage of these such devices with much success.

Dr. Price spoke to the utilization of VADs in the management of Heart Failure in Children. The number of children awaiting heart transplantation has been rising and mechanical support can be a bridge to transplantation or an answer to end-stage heart failure. They can also be used as a temporary support for a patient affected with myocarditis, allowing the child's heart to rest and heal to a point where the heart can again function on its own.

Sharing of such education to thousands of cardiologists from around the world helped aide in the improved outcomes for those children affected by heart failure, often the result of myocarditis.

Knowledge Nurtures Hope…

INTERNATIONAL NEWS

Global Day of Giving 2017

Myocarditis Foundation Board Member, Christopher Corso, and his company XL Catlin participated in the Global Day of Giving on May 12th by assembling 600 backpacks donated by the Myocarditis Foundation to hold the toiletries that were 100% donated by friends, family, and CVS Pharmacy. The backpacks will be given out to parents when their child is suddenly hospitalized at Boston Children's Hospital.

"This was the same kit my wife and I needed in May of 2015, when our son Matthew was suddenly hospitalized with Myocarditis and was so ill that we did not want to leave his side. These kits are simple to make, make a big difference, and are unfortunately in need," reported Chris. They contain toiletries and other supplies that a person who is blindsided by a sudden hospitalization of a loved one could use. The recipient of these, when they don't want to leave the hospital but still need to brush their teeth, wash their face, shave, etc., will be very appreciative of them.

FUNDRAISER

How One Person Has Made a Difference in Raising Awareness and Funding for the Myocarditis Foundation in Memory of Her Son

There's a lot of truth to the saying "every penny counts" – especially when it comes to fundraising. Whether your event brings in thousands or hundreds, it all plays a critical role in creating awareness and one day finding a way to prevent/cure myocarditis.

Brenda Vonckx, whose 19-year-old son Austin died of viral myocarditis in 2014, realized early on that smaller events are the best way for her to contribute to the cause. She's hosted 8 fundraisers – bringing in a total of almost $8,000 – since September 2015:

Fishing Tournament. A group of Austin's friends got together for a bass fishing tournament in the lakeside community where Austin grew up. The event also included raffle baskets and a 50/50 drawing.

Drag Queen Bingo. The name says it all: It was a fun night of bingo hosted by a drag queen at a place called Hamburger Mary's. The event also included raffle baskets and a 50/50 drawing.

Holiday Gift Wrapping. Thanks to her neighborhood's Facebook page, Brenda was able to advertise and offer gift-wrapping and gift storage services over the Christmas holidays in both 2015 and 2016.

Painting with a Purpose. An art studio in Tampa called Painting with a Twist hosts monthly painting classes where half of all proceeds go to a charity. Brenda did this for the Myocarditis Foundation in both 2016 and 2017. The events also included a 50/50 drawing.

LuLaRoe. One of Brenda's friends is a consultant for this company, which sells women's clothing through multi-level marketing distributors. She hosted two fundraisers on Facebook this year, with both the friend and LuLaRoe corporate donating a portion of sales to the Myocarditis Foundation.

Another way Brenda likes to spread the word about myocarditis is by randomly asking people she encounters in her day-to-day life if they have ever heard of it. When they say no, she pulls a business card-size memorial card she had made in Austin's memory from her purse and tells his story. To date, she has given out nearly 1,000 cards… and she never leaves home without at least a handful.

Brenda moved to a small town in the North Carolina mountains this spring and is busy thinking of more small ways to make a big difference in her new hometown. Email her at **tampaace@aol.com** if you have any questions or want to know more about any of the events listed above. She'd love to hear from you!

FUNDRAISER

Fourth Annual "Paint the Town Rhett" Awareness Event and Fundraiser

Quoting one of the characters from the pilot episode of NBC's This Is Us, "Take the sourest of lemons that life has to offer and try to turn it into something resembling lemonade." Now in its fourth year –"Paint the Town Rhett" FUNdraising event in my son's memory – I've tried making lemonade, from the sourest of life's lemons.

Held at the Moose Lodge in Elgin, IL on May 20, 2017 participants who attended the event ate lunch and a chance to paint two fence panels each. The "lighthouse" theme painting inspired by the Ponce De Leon Inlet Lighthouse after a memorable vacation in Florida in June of 2012. In my online research before our departure I discovered the Ponce de Leon Inlet Lighthouse & Museum in Ponce Inlet, just south of Daytona Beach is open to the public. Visiting this was a must for me, and the always agreeable Rhett didn't object. At the top of the 175-foot tower, visitors can enjoy the magnificent views of the world's most famous beach, Ponce Inlet, and the surrounding inland waterways from the light house gallery deck. But first, you have to ascend the 203 steps to the top. I knew I'd have to climb slowly. Rhett's friend who was traveling with us sprinted to the top. Rhett followed, stopping every 20 or so steps peering down, probably to make sure I was still alive. He'd call out "You ok mom?" or "You got this!"

For many reasons I have fond memories from that trip, one of our last, to Florida.

The American Evangelist Dwight L. Moody wrote, "We are told to let our light shine, and if it does, we won't need to tell anybody it does. Lighthouses don't fire cannons to call attention to their shining-they just shine! "So did Rhett.

Jamie Thomas-Ward, a myocarditis survivor from Champaign Illinois, traveled 3 hours north to share her amazing story of her battle to beat myocarditis and the struggles she endured for months on her road to recovery. Illinois resident, Karen Males, spoke about her beloved brother who died from Myocarditis in 2011, and concluded the event.

Jaime Thomas-Ward and Rhett's Mom, Vickie Lundy

Van Gogh once said, "Great things are done by a series of small things brought together." As we inch closer to funding a research grant in my son's name…

"Together, we have done great things."

Thank you Letter from the Executive Director to our Supporters

November 2017

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 dreadful disease without your support.

While our individual fundraisers are decreasing in quantity, we still depend on donations to carry out our mission of awareness, education, provide funding for research and supporting emotionally those who have been affected by this dreadful disease. Any and all donations are thankfully accepted.

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. Thus, we depend on those that know of us to share your stories and the stories that you know of and why you support the Myocarditis Foundation. Over the past 12 years the Myocarditis Foundation has helped many families with their journey through Myocarditis.

Corporate Grants are also not as fruitful as they have been in the past either.

We are looking at other ways to raise awareness and funding, but the bottom line is we need your help…

If you have an employer who matches donations, please share your donations to us with them. Your donation now doubles and triples, depending on your company, with their help.

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 they be without anywhere to turn for emotional and psychological support as well as information medically on this dreadful 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

Speaking Schedules & Events

DR. LESLIE COOPER:

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

December 15
Myocarditis Event
New Jersey

February 22-February 25, 2018
European Society of Cardiology
Writing Group on
Endomyocardial Biopsy
Serbia

March 16-March 19, 2018
U.S. and Canadian Academy
of Pathology
Vancouver, BC, Canada

April 11-April 15, 2018
Annual Review Course in
Clinical Cardiology
Zurich, Switzerland

May 24-May 27, 2018
Joint Session of ISCP and ISCMF
Kyoto, Japan

June 22-June 24, 2018
Sri Lanka Heart Association
Annual Academic Sessions
Sri Lanka

DR. JACK PRICE:

Nov. 11-15
American Heart Association
(moderator)
Anaheim, California

April 11-14, 2018
International Society for Heart &
Lung Transplantation (ISHLT)
Nice, France

DR. DELISA FAIRWEATHER:

November 3-5
4th World Congress of
Cardiothoracic-Renal Diseases
Lisbon, Portugal

Whitman College

Walla Walla, Washington

February 12-14
Mayo Clinic Symposium on
Regenerative Medicine and Surgery
Scottsdale, Arizona

July 27-29
International Academy of
Cardiology World Congress
on Heart Disease
Vancouver, Canada

2018 EVENTS

January 27
Quinn's Cup
Edina, MN

June 8
Sarah Knight Golf Tournament
Marion, Iowa

June 21
Annual Gala
NYC

June 22
Annual Family Support Meeting
NYC

August 6
Annual Rumore/Romano
Myocarditis Foundation
Golf Outing
Paramus, NJ

INTERNATIONAL NEWS

Viral Myocarditis Survivor and Heart Transplant Recipient Swims in the World Transplant Games in Malaga, Spain

When Rev. Brian Barndt's daughter was 2-years-old, he struggled to explain to her why he couldn't pick her up. A lifelong swimmer who competed at the college level, Brian could barely swim across the pool once and was winded just walking up his driveway. In June of this year, that daughter, now a teenager, cheered him on as he competed in the World Transplant Games in Malaga, Spain. The Transplant Games are an international competition among people who have undergone heart, lung or other transplants.

"Becoming an athlete again was truly a gift, and competing has been a great platform to be able to share with people that transplantation is a life-changing procedure", he says.

Rev. Brian Barndt uses his role and his position in a very positive way to tell his story and make sure that people understand that organ donation is a real gift, and the more people that know about it, the more lives that can be saved.

Please, if you are not already, consider becoming an organ donor. One organ donor can save up to 8 lives. The same donor can also save or improve the lives of up to 50 people by donating tissues and eyes.

Please consider becoming a registered Organ Donor today…

Rev. Brian Barndt and daughter

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