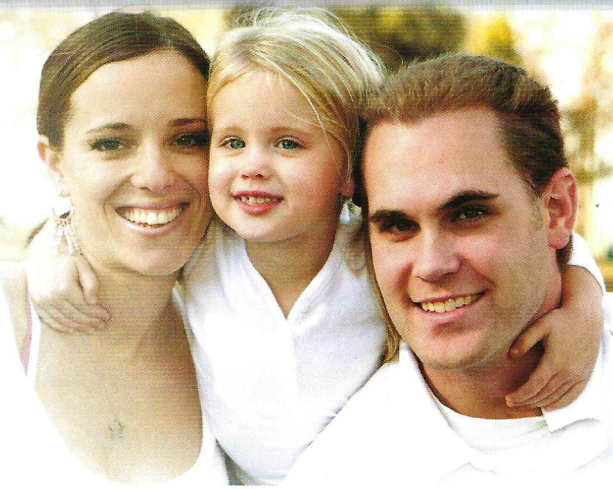


## MYOCARDITIS FOUNDATION



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

### Australia Patient and Family Support Meeting and World Heart Federation Newsletter

Written by: Katelyn Bruno

The Myocarditis Foundation held a Patient and Family Support Meeting May 3, 2014 at the Royal Automobile Club (RAC) in Melbourne Australia. Board member and myocarditis physician, Dr. Leslie Cooper, a board member and myocarditis physician from Mayo Clinic, and Katelyn Stafford-Bruno, a myocarditis researcher and PhD candidate in Dr. DeLisa Fairweather's Laboratory at Johns Hopkins University, hosted the meeting. This meeting brought together families that have been affected by myocarditis from all over Australia.

The event started with a cocktail hour and hors d'oeuvre to allow the families to meet, get to know each other and talk openly with Dr. Cooper and Bruno. Dr. Cooper then gave a presentation explaining myocarditis and the pros and cons of the various diagnostic techniques used. Bruno then gave a presentation about the goals, purpose and

challenges of the Myocarditis Foundation and how others can get involved to help spread awareness and increase fundraising to help fund research. The floor was then opened to each of the patients and families to tell their story of how myocarditis has affected their lives. This was a truly touching part of the evening when some patients found similarities in their struggles. One family shared their story about the loss of their child for the first time. Plans were then made to look into establishing a branch of the Myocarditis Foundation in Australia to allow for local Annual Family Support Meetings and to increase awareness in the community and with Australian physicians. These family support meetings are an extremely important part of our foundation's mission and we look forward to expanding our foundation all over the world.



*The Myocarditis Foundation Booth at the World Heart Federation. From left to right: Katelyn Bruno, George Cooper, Becca Lank, and Dr. Leslie Cooper.*

While in Australia Dr. Cooper and Bruno attended the World Heart Federation (WHF) Annual Meeting held in Melbourne May 3-7th, 2014. The Myocarditis Foundation sponsored a scientific session chaired by Dr. Cooper along with four of the top myocarditis and perimyocarditis experts in the world. The session was very well attended with over 400 adult and pediatric cardiologists from all over the world in attendance. The Myocarditis Foundation also had a booth in the exhibit hall at the WHF meeting where they gave out information about the diseases, brochures on how to diagnosis adult and pediatric myocarditis and the most current research being done in the field. Increasing awareness in the medical community is another vital mission of the Myocarditis Foundation to help



*Dr. Cooper and Bruno with some of the attendees of the Myocarditis Foundation Patient and Family Support Meeting in Melbourne Australia.*

*(Continued on Page 2)*



## Dr. Cooper's Speaking Schedule

### 2014

#### July 16th

The Mayo Clinic

"Cardiac Sarcoidosis"

**Rochester, Minnesota**

#### August 1st

Sedona, AZ Mayo

Heart of the Matter Conference,

"Myocarditis"

**Sedona, Arizona**

#### September 12th

The Mayo Clinic

two separate talks on  
vascular disease

**Rochester, Minnesota**

#### September 16th

Cardiology Grand Rounds at the

Lubin Cardiovascular

Institute of Alberta

**Calgary, AL, Canada**

#### September 17th

The 18th Annual Scientific Meeting

of the Heart Failure Society of

America; Moderator: "Emerging

Roles for Advanced Imaging in

Unexplained Cardiomyopathy"

**Las Vegas, Nevada**

#### October 12th

Myocarditis Foundation

Fundraising Brunch

**Point Pleasant, New Jersey**

#### October 23rd

The 11th ESC Myocardial Pericardial

Disease Working Group Meeting:

"Giant cell Myocarditis" and will

be participating in the debate:

"All Patients with clinically suspected

myocarditis shall be biopsied

**The Dead Sea, Israel**

### 2015

#### January 10th

Major League Soccer's Medical

Symposium "Sudden Cardiac Death"

**Fort Lauderdale, Florida**

#### April 8th-11th

German National Cardiovascular

Society, "When to Perform an

Endomyocardial Biopsy"

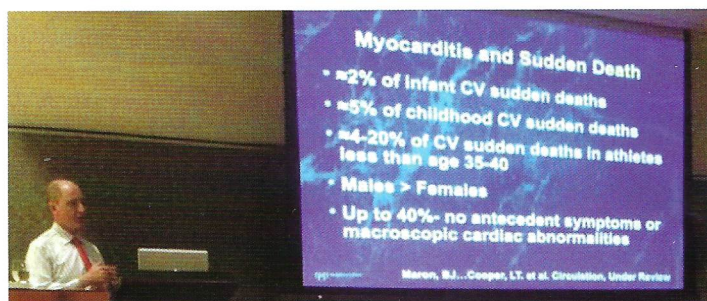
**Mannheim, Germany.**

### COVER STORY

## Australia Patient and Family Support Meeting *(Continued from Page 1)*

prevent myocarditis from going undiagnosed or misdiagnosed.

Dr. Cooper and Bruno's trip to Australia was very successful for the Myocarditis Foundation and we look forward to future trips, the possibility of establishing the first satellite branch of the Myocarditis Foundation in Australia and building awareness of myocarditis throughout the world.



*Dr. Leslie Cooper giving a presentation at Family Support Meeting about Myocarditis*

### OUR EXPERIENCE

## Ashley's Story

Ashley Burgauer, 27, was a registered nurse, a daughter, a sister, an aunt, a cousin and a beautiful friend to many, who's life suddenly ended one Thursday afternoon to a disease we had never heard of.

Ashley's immune system was weak, but she always overcame any virus that came along. Ten months before Ashley died, she started to get sick on a regular basis, with viruses that would a healthy person could fight off. She continued to stay strong in spirit and mind trying to deal with never feeling good and tired all the time, with regular visits to her doctor. She had complained of abdominal pain, which her GI doctor thought it could be an ulcer flaring up again and ordered up an endoscopy for the next week. That endoscopy never took place as she died two days later. Ashley had stopped over with her dog to visit on that Thursday morning and make plans for the Labor Day weekend. My husband

and I had plans to be out of town that day and when we left we told her good bye and would see her later that afternoon to pick up her dog and would meet her at our lake home. When we got home that afternoon her car was still in our driveway and upon entering our home, thought she was taking a nap, which was not unusual for her to do. Much to my horror, I found her unrespon-

sive in our bed. She was taken to the hospital by the EMS and pronounced dead.

Nine weeks later the autopsy reported she had died from Myocarditis. Our world as we knew it has changed, but my desire to make people aware of this disease has become a passion of mine.

*Kathy Burgauer, Ashley's mother  
Muncie, IN*



*Ashley Burgauer*

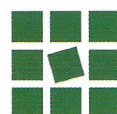
### SUPPORT

## St. Jude Medical Foundation Thank You

The Myocarditis Foundation would like to thank St. Jude Medical Foundation for the generous general operations grant that they awarded to help the Myocarditis Foundation continue in their daily operations and awareness programs. Support from St. Jude Medical Foundation has been a

large part of why the Myocarditis Foundation is able to achieve all of its programs since its inception in

2005 and we are honored to receive an operations grant again in 2014.



**ST. JUDE MEDICAL™**  
**FOUNDATION**



## ANNOUNCEMENT

# The Myocarditis Foundation Launches Tribute Cards



The Myocarditis Foundation is announcing the launch of their Tribute Cards! Tribute Cards are given for any reason that one might purchase a greeting card; however, it includes the acknowledgement of a donation made to the Myocarditis Foundation. Tribute Cards can be given for any reason including Memorial Cards, Birthdays, Anniversaries, Graduations, Thank You, Mothers Day, Fathers Day, or any other Holiday or Occasion.

Please consider sending a Myocarditis Tribute Card for your next significant holiday or occasion. Minimum Donations begin at \$5.00 and are tax deductible. Please follow these simple steps to send a **Tribute Card**:

Please call or email Diane Aranson at **561-213-2775** or **DiJoPolo@aol.com** with the

- Your name
- Your address
- Person and/or occasion you will be honoring
- Donation amount

The Tribute Card(s) will be mailed to you directly, at no cost

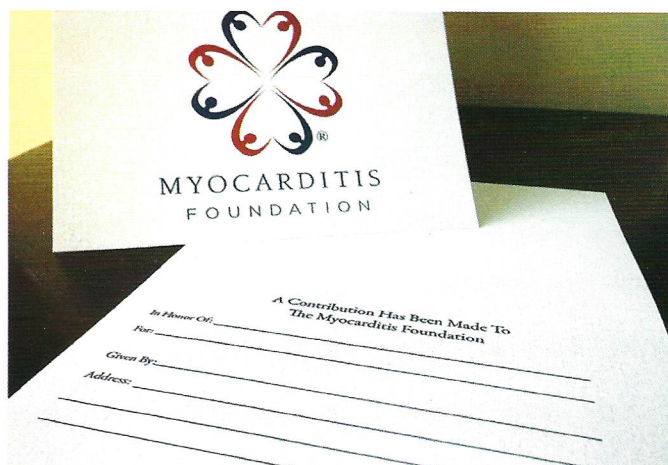
Make a donation to the Myocarditis Foundation by mail or online. If submitting a donation online, be sure to mention that it is for a tribute card. Checks can be made out to: The Myocarditis Foundation and mailed to:

7022 S Revere Pkwy  
Suite 240  
Centennial, CO 80112

Mail your Tribute Card to your friend, niece, nephew, aunt, uncle, sister, brother, mother, father...or whoever is celebrating a special occasion! They will be honored that they inspired you to make a donation to the Myocarditis Foundation and are helping to save lives!

Diane Aranson has been designated as Tribute Card chairperson for the foundation. Diane lost her son in 2013 to Giant Cell Myocarditis and her husband Joel is on the Myocarditis Foundation's Board of Directors. She will mail out your Tribute Card and track all donations for the foundation. The Aranson's will be donating all postage relating to the mailing of your Tribute Cards and the Myocarditis Foundation is supplying the Tribute Cards.

Contact Diane for more information. **GET STARTED TODAY!!**



Myocarditis Foundation tribute cards are now available

## FAMILIES

# Thank You to our Myocarditis Families

A heartfelt thank you to all our Myocarditis Families who have supported us thus far in 2014 through donations, awareness events, and fundraisers. The Myocarditis Foundation could not survive without your ongoing support, it truly makes a difference in achieving our mission of awareness and research; all to save more lives from myocarditis.

**The Reynolds Family**

**The Kirsch Family**

**Paige and Kevin Veronie**

**The Martin Family**

**Our Lady of Grace School**

**Becky Wagner**

**Buffalo Wild Wings of  
Crystal City**

**The Vanness Family**

**The town of Kewaunee, WI  
Kewaunee Grade School  
Student Council & Students**

**Michele Butkus**

**The Lundy Family**

**The Knight Family**

**The Sweet Family**

**Friends & Family of Mary  
Ehrlinger**

**Friends & Family of John  
Domingues**

**The Roark Family**

**The St. Laurence School &  
Students**

**Stuart Kravitz**

**Friends & Family of Ashley  
Burgauer**

**The Rojas Family**

**The Sweet Family**



Family and friends of Sarah Knight at the 2nd Annual Sarah Knight Memorial Golf Tournament in Marion, IA



Madison Half-Marathon runners in memory of Mary Ehrlinger



## Quinn's Cup

On January 11th, the city of Edina, MN came together to honor and remember Quinn Kirsch. Eight-year-old Quinn tragically passed away suddenly on January 7, 2013 due to myocarditis. Quinn loved playing outdoor hockey and it was Quinn's hockey coach that came up with the idea for a hockey tournament to remember and celebrate Quinn.

Quinn's Cup is a pond-hockey tournament for the Twin Cities' 10 and under hockey teams to come and play a friendly tournament, focused on having fun and the love of hockey. Over 250 kids played while parents and siblings cheered them on. There was also food, raffle prizes, games, and of course hugs, memories, tears, and smiles remembering Quinn.

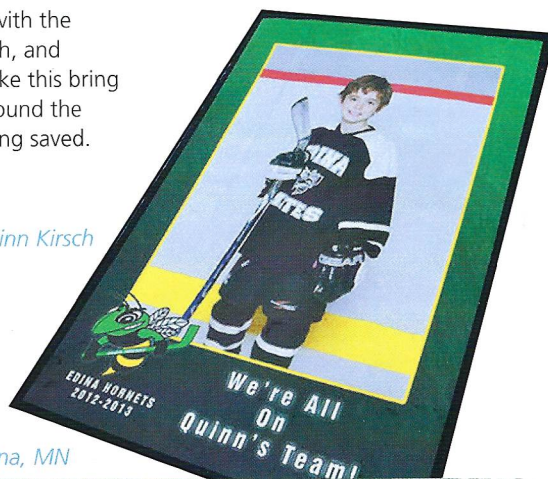
The event was attended by several local news agencies and the Minnesota Wild (Minnesota's pro-hockey team) featured the event on their website and

created a video honoring Quinn and explaining the disease. Goldie the Gopher, the official mascot for the University of Minnesota, even came and signed autographs and posed for pictures with the kids. Dr. Leslie Cooper, president and founder of the Myocarditis Foundation (MF), and Lindsey Davis, Director of the MF attended the event. They both gave talks explaining the disease and the mission of the Myocarditis Foundation. Despite the cold temperature that day, it was a fun-filled event focused on raising money for the Myocarditis Foundation and above all, honoring Quinn's memory.

All proceeds of Quinn's Cup came to the Myocarditis Foundation and in the end, near \$13,000 dollars was raised. The Myocarditis Foundation is honored by the outpouring of support from the Kirsch family, their many friends, and the loving community they are such a large part of. Quinn will always be

remembered and with the awareness, research, and education events like this bring to communities around the world, lives are being saved.

Quinn Kirsch



Young hockey players at Quinn's Cup in Edina, MN



## Quinn

Quinn is the youngest of our four boys. He was fun, funny, loving and athletic. He loved his big brothers, the cabin, road trips, playing catch with dad, and snuggling with mom. Quinn was happy and energetic – and full of life! He was in third grade, and had just started piano lessons, excited to follow in his brothers' footsteps. Quinn had lots of good friends and enjoyed doing just about anything with them. His favorites were playing hockey and soccer – but he was good at everything he tried, a real natural. We had just bought a new puppy, Lucky, for Christmas – mostly because Quinn wanted a puppy so badly, and he adored her.

On January 6, 2013 Quinn had a very normal day – it included hockey practice with his team, running errands with his dad Kyle, and more hockey on the backyard rink with dad and big brother Jack. After dinner that evening, Quinn and I made brownies – they were baking in the oven. He was playing with Lucky when he collapsed near the kitchen – we thought he was kidding around. Kyle performed CPR and was able to revive him; we called 911, they came immediately, rushing him to the Children's Hospital Minneapolis. Efforts to revive Quinn were unsuccessful, and after 6 horrific hours they told us... "it's over". Our beautiful son was gone in an instant. The horror of that night, and the aftermath, are something no family – no child – should have to endure. Weeks later, we learned Quinn had viral myocarditis, and it was catastrophic. His heart didn't stand a chance. He had no symptoms whatsoever, no indications that something was wrong.

Quinn was one month from his 9th birthday. The house is too quiet without him. Our family will never be the same – but we can try to make a difference in Quinn's name.

We support the Myocarditis Foundation in their efforts to spread awareness about this horrible disease through our pond hockey fundraiser – Quinn's Cup. This fun event honors his memory while supporting the foundation in their efforts.

We miss and love you Quinn

Kelly & Kyle Kirsch  
Edina, MN





## International Outreach

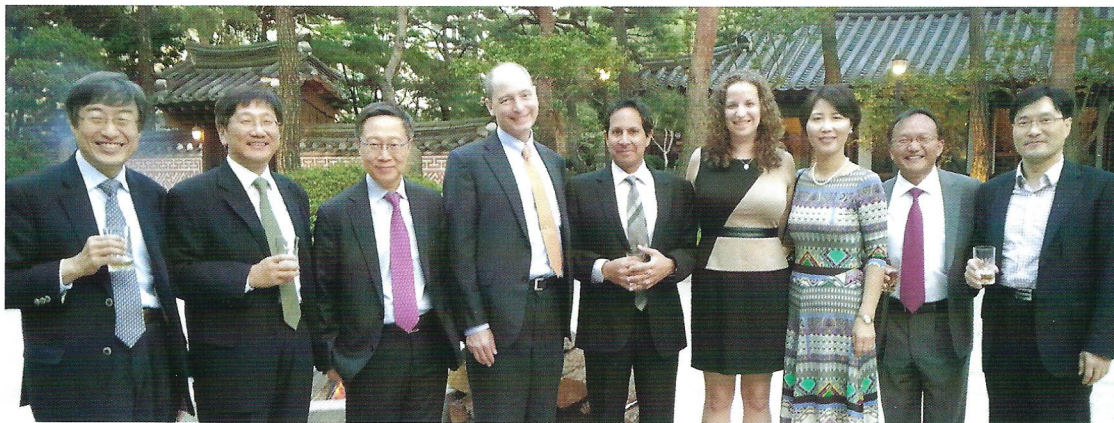
The Myocarditis Foundation actively supports international outreach to help educate physicians and the public about this deadly disease. In 2014 Dr. Cooper spoke or will speak on myocarditis at the Asia Pacific Heart Failure Society in Indonesia; the Indonesian Cardiovascular Society; the Samsung Medical Center in Seoul, South Korea; the World Heart Federation Meeting in Melbourne, Australia; and the European Society of Cardiology's Myocardial and Pericardial Working Group meeting at the Dead Sea Israel.

Dr. DeLisa Fairweather spoke on myocarditis at a scientific meeting in Berlin Germany. She also performed collaborative research in Seoul, South Korea; Berlin, Germany; and Marburg,

Germany. In addition to outreach to the professional medical and scientific communities, Leslie Cooper and Katelyn Bruno spoke at the Myocarditis Foundation's Family Support Meeting in Melbourne, Australia.

Active scientific collaborations between the Myocarditis Foundation board members and international colleagues are ongoing in Pretoria South Africa and Brno in the Czech Republic. These are in addition to the research efforts ongoing in South

Korea and Germany. During the rest of 2014 and 2015 these collaborations should result in a number of high impact publications. The results from these publications will form the basis for additional research grants to help prevent and treat myocarditis.



*The Myocarditis Foundation and Samsung Medical Center Collaboration Dinner in Seoul, South Korea*

## AWARENESS

### High Schools Across the Country Raise Awareness for Myocarditis

In just the past few months we have heard of several different middle and high schools from all across the US who have held myocarditis awareness events and fundraisers to honor individuals in their communities who have passed away due to myocarditis. In Denver, Colorado students at Smokey Hill High School gave a presentation about the disease and a young girl in the community who passed away due to myocarditis. The students also bought baked goods and ended up donating \$25 to the Myocarditis Foundation. It was an excellent way to bring awareness to a disease that often affects young, healthy individuals! Thank you Smokey Hill High School students!

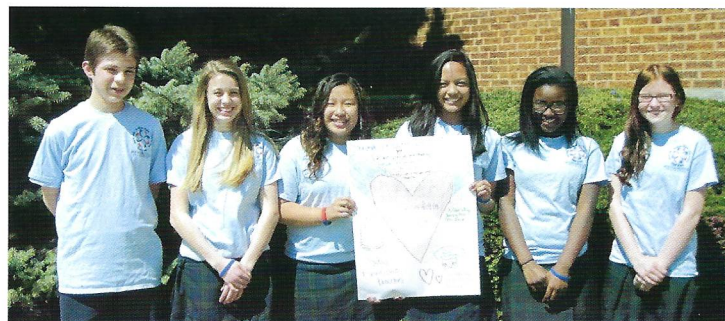
In Kewaunee, Wisconsin a school dance was held at the local community grade school. While the dance was not designed as a charity dance, the students came together and decided to donate \$250 of the proceeds to the Myocarditis Foundation. They wanted to support their school custodian, who's son, Brad Vanness, passed away due to

myocarditis. The Myocarditis Foundation is humbled by the outpouring of support by these young students who want to show their love and support for their fellow community members. Lastly, the St. Laurence School in Elgin, Illinois has been particularly active in raising money for the Myocarditis Foundation in memory of a fellow student, Rhett Lundy, who passed away due to myocarditis. They have written essays about the disease (read the essay our website blog), sold t-shirts and wristbands, which raised \$346, and students even took it upon themselves to go around with a jar asking for donations, which raised \$50.

These students want to be sure their friend and fellow classmate is not forgotten and the community knows about the disease that took his life so suddenly.

Every awareness event has the potential to save lives from this

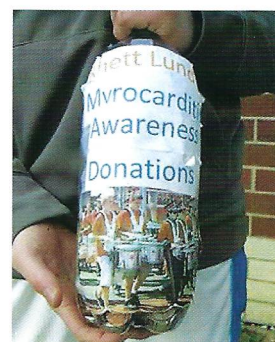
disease and every penny raised helps to fund the Myocarditis Foundation so that they may continue in their mission of support, awareness, and research. Thank you to all these amazing young students and the communities they are a part of!



*Smokey Hill High School Awareness Presentation*



*St. Laurence School Early Action Club*



*Money Jar by St. Laurence student, A. Dunn*





## THE MYOCARDITIS FOUNDATION Research Fellowship Grant Program

The Myocarditis Foundation is pleased to announce that it is accepting applications for two (2) Scientific Research Fellowship Grants this year in the areas of both Adult and Pediatric Myocarditis.

### **Purpose of the Myocarditis Foundation's Research Program:**

To advance medical knowledge of the disease and to develop more accurate diagnostic methods and life-saving therapies, with the goal of saving future lives.

- The Grant Overview, Grant Requirements and Guidelines, and the Grant Application are available at [www.myocarditisfoundation.org](http://www.myocarditisfoundation.org) or by emailing: [Lindsey@myocarditisfoundation.org](mailto:Lindsey@myocarditisfoundation.org)
- The amount of the grant is \$35,000 for salary only.
- The deadline for grant submission is December 1, 2014.
- All applicants must select a preceptor with a proven track record of research in myocarditis.

### **Application Deadline: December 1st, 2014**

If you have any questions, please contact Lindsey Davis at:

Email: [Lindsey@myocarditisfoundation.org](mailto:Lindsey@myocarditisfoundation.org)

Phone: 732-295-3700

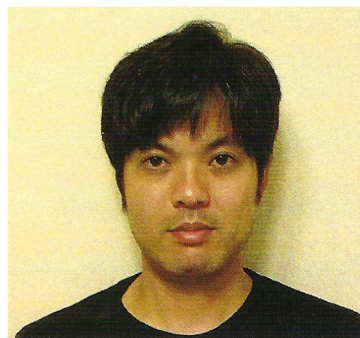


## The Myocarditis Foundation Announces its 2013 Grant Recipient for the 2014/15 Grant Cycle

The Myocarditis Foundation is pleased to announce that it will be funding a research fellowship grant for the 2014/15 grant cycle. The Myocarditis Foundation will be funding a research grant awarded to Dr. Yuji Nagatomo of the Cleveland Clinic in the amount of \$35,000. Dr. Nagatomo is under the mentorship of Dr. Wilson Tang of the Cleveland Clinic.

In December 2013, the Myocarditis Foundation's international Medical Advisory Board, made up of leading myocarditis researchers from around the world, voted to award a fellowship grant to Dr. Nagatomo after selecting his application from a distinguished field of candidates.

Dr. Nagatomo's research project is titled *"Autoimmunity in Suspected Myocarditis and Recent-Onset Cardiomyopathy: The significance of IgG3 autoantibody against 1 adrenergic receptors"*. Below is a layman's summary of his research.



*"Over the years, there has been extensive research work surrounding the presence of antibodies that attack the components of the adrenaline system, which may directly or indirectly affect the function of the heart. Termed "autoantibodies", they may stimulate the system and activate the flight and fight response that drives the heart to get weaker over time. Preliminary findings have suggested that removal of one specific type of autoantibodies, IgG3, appears to be most effective in facilitating recovery of heart function. The objective of this study is to determine how common this subtype of autoantibody that acts against the adrenergic system is found in patients with new-onset heart failure or suspected myocarditis, and to see how these autoantibodies (and its subtype) directly influence the adrenaline system by looking at how they stimulate the blood cells. We believe that this research will provide novel insight into the pathology of myocarditis and lead to the development of new treatment modality for this potential therapeutic target."*

**– Summary by Dr. Nagatomo**

The Myocarditis Foundation is honored to work with Dr. Nagatomo and the Cleveland Clinic, furthering the expansion of myocarditis research. It is the Foundation's goal to build a greater understanding of the disease and find better ways to diagnose, treat, and ultimately prevent myocarditis from taking more lives.

The Myocarditis Foundation would like to thank all the families, businesses, and organizations that have supported the Foundation in 2013. It is with their generosity and support that research grants are able to be awarded each year.

## 2014 Events

**January 11th**

**Edina, MN**

"Quinn's Cup Hockey Tournament"

**February 22nd**

**Prince George, VA**

"Keith Martin Memorial Banquet"

**March 8th**

**Houston, TX**

Wedding of Paige and Kevin Veronie

**March 28th**

**Edina, MN**

Our Lady of Grace School's Teacher Raffle

**Month of April**

**Kewaunee, WI**

Donation Box at Lakeshore Lighthouse in memory of Brad Vanness

**April 4th**

**Crystal City, VA**

Buffalo Wild Wings Awareness Day

**April 17th-19th**

**Bali, Indonesia**

"Asian Pacific Congress of Heart Failure" myocarditis talks and informational booth

**April 23rd-May 25th**

**Nanaimo, BC**

Donation of commission in memory of Dominique Butkus

**May 3rd**

**Melbourne, Australia**

Myocarditis Foundation Patient & Family Support Meeting

**May 4th-7th**

**Melbourne, Australia**

"World Heart Federation-Congress of Cardiology" myocarditis talks and informational booth

**May 16th**

**Elgin, IL**

"Paint the Town Rhett"

**June 7th-8th**

Point Pleasant, NJ: Myocarditis Foundation 2nd Annual Patient and Family Support Meeting

**June 13th**

**Marion, IA**

"2nd Annual Sarah Knight Memorial Golf Tournament"

**June 13th-14th**

**Bowdoinham, ME**

"Community play OLIVER!"

**August 16th**

**Muncie, IN**

"Honoring Friends with Big Hearts" Silent Auction

**August 18th**

**Hamburg, NJ**

"The Myocarditis's Annual Golf Tournament"

**August 30th**

**Leicester, MA**

"8th Annual Devin Kravitz 5K"

**September 14th-17th**

**Las Vegas, NV**

"The Myocarditis Foundation's Researcher's Mentoring Meeting" and HFSA Annual Meeting with myocarditis talks and informational booth

**September 29th**

**World Wide**

World Heart Day

**October 12th**

**Point Pleasant, NJ**

"The Myocarditis Foundation's Fundraising Brunch"



## The Myocarditis Foundation's 2nd Annual Patient and Family Support Meeting

The Myocarditis Foundation was honored to be able to hold its annual Patient and Family Support Meeting for the second year in a row. This meeting has proved to be invaluable to the patients and families affected by myocarditis, as the Myocarditis Foundation provides the opportunity for these individuals to come and meet several myocarditis experts, learn about the newest research, and meet others who know all too well the exact difficulties and pain this disease can bring to patients and their families.

This year's meeting kicked-off with a sunset cruise down the Manasquan river where families were able to interact with each other and members of the Myocarditis Foundation's Board of Directors, share their experiences,

and ask questions in a casual atmosphere. The highlight of the evening was a memorial service for all of those who had lost someone to myocarditis. Each family received a butterfly and when their name was called they came up, announced the name of their loved one, and then released their butterfly. It was a moving experience and was a perfect way to honor the many lives myocarditis has taken.

The next morning, breakfast was served and families were able to once again talk with one another until the start of the meeting. The meeting began with a talk by Director, Lindsey Davis highlighting the accomplishments of the Myocarditis Foundation and explaining the need for continued fundraising and support from the myocarditis community. Following

Mrs. Davis was a talk by myocarditis expert Dr. Leslie Cooper of the Mayo Clinic. This was one of the highlights of the meeting, as Dr. Cooper was able to explain the disease in detail, highlight some of the ongoing research, and answer the questions posed by the patients and families in attendance. Katelyn Stafford, a PhD candidate and myocarditis researcher in Dr. Fairweather's lab at Johns Hopkins University, was the next guest speaker providing information on the cutting-edge research being done around the world trying to find better ways to diagnose and treat myocarditis.

The Myocarditis Foundation had asked Paul Groce and Michele Coia-Veston to both present their myocarditis stories at the meeting. Mr. Groce, a survivor of myocarditis,

told his harrowing story of the onset, diagnosis, and long recovery of such a debilitating disease. Mrs. Coia-Veston lost her son Nino after a reoccurring case of myocarditis in her son's transplanted heart. Her story was tragic and heartbreaking, but showed the true love and support needed by friends, families, and communities when we lose someone to this terrible disease. We thank Mr. Groce and Mrs. Coia-Veston for their time, bravery, and strength in sharing their stories.

The third scientific talk of the meeting was by MF board member and pediatric cardiologist and heart failure expert Dr. Jack Price of Texas Children's Hospital. Dr. Price was able to explain myocarditis in children and some of the new treatments used at



*The families in attendance at the 2nd Annual Myocarditis Foundation Patient and Family Support Meeting*



# Boston Scientific

## Advancing science for life™

*Thank You to Boston Scientific for the generous grant to make this year's Patient and Family Support Meeting Possible*

Texas Children's Hospital for those diagnosed with myocarditis and heart failure. The meeting's talks concluded with a special guest speaker, Chris Ann Waters who is a grief expert. She talked with the families who had lost someone about coping mechanisms and working your way through the grief process. Ms. Water's resources are posted on the Myocarditis Foundation's website.

The Myocarditis Foundation's Patient and Family Support meeting concluded with lunch and awards ceremony. The Myocarditis Foundation awarded three certificates of appreciation to families who have made significant strides in the political activism for myocarditis, autopsy results, heart failure, and rare disease legislature. Michele Coia-Veston, Giovana

Caccialanza, and the Skowronski Family all received awards honoring their political gains with their local, state, and national governments.

The Myocarditis Foundation would like to thank Boston Scientific for a generous grant they awarded to the Myocarditis Foundation to make this meeting possible. Bellin Health Care Systems of Green Bay, WI also donated significant funds to ensure all parts of this important Family Meeting were covered, allowing for the Myocarditis Foundation to continue using its funds to support a mission of saving lives. In-kind donations were also made by the Firefly Restaurant at the White Sands Resort and Joe Leone's catering; both of the Point Pleasant community.

Above all we would like to thank the many families who continue to support the Myocarditis Foundation in all that we do. We could not provide support and recourses to families or fund our awareness and research programs without support from our myocarditis families. One participant shared "The service on the boat with the butterflies was a very nice way for all of us to share our grief and help support each other. I think it really drew everyone close together as a big family, which is what we are." We couldn't agree more, we love and cherish our myocarditis family.

One woman who attended summed up the experience perfectly: "After the Myocarditis meeting I had learned more about the disease. The statistics and heart diagrams on the slides helped me to better understand heart dysfunction, heart failures and sudden deaths. Listening to the testimonies caused me to appreciate even more the hard work the Foundation is doing to save lives and educate individuals. Continue striving to increase awareness in the medical field as well as the public. I need to do more and I will do more. I love you guys very much!"

The Myocarditis Foundation hopes to hold a Patient and Family support meeting every year in the United States, with the location changing each year. Please check our website and Facebook page for updates about happenings of the Foundation and for upcoming events. In the meantime, all talks are posted on the Myocarditis Foundation's YouTube channel.



*Butterflies from the memorial butterfly release to remember those who have passed away due to myocarditis*



## Myocarditis Foundation Membership

Members will gain access to the Myocarditis Foundation's official Medical and Research Blog; updated monthly by myocarditis experts and researchers, highlighting the newest medical updates. Our experts and researchers will be explaining

ongoing projects, medical breakthroughs, new research, published papers, and more all in easy to understand terms and explanations. We want to give our supporters the most accurate and up-to-date information we can provide.

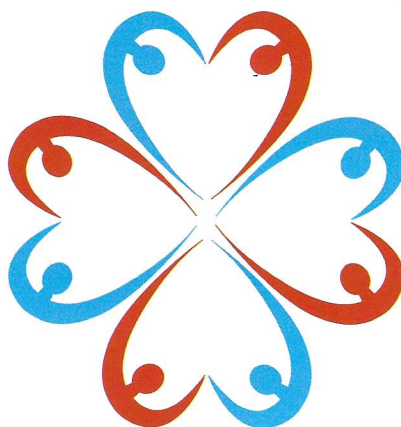
## World Heart Day!

The Myocarditis Foundation has partnered with the World Heart Federation to celebrate World Heart Day. The Myocarditis Foundation is asking all of its families and supporters to take September 29th and spread the word about myocarditis in your community. The Myocarditis

Foundation can supply you with brochures and flyers, and will be selling Puravida bracelets to support the Myocarditis Foundation and its mission of awareness and research. Visit our website or Facebook page for more information.

# How you can help save lives from myocarditis?

- Hold a fundraiser or awareness event in your community
- Shop at **Smile.amazon.com**
- Bring brochures to you family doctor or local clinic
- Encourage friends and family to like our FB page or visit our website to learn about this disease
- Make a reoccurring donation through your employer and/or your company
- Donate your credit card reward points



**MYOCARDITIS**  
FOUNDATION



## Paul's Story: How I survived myocarditis

My myocarditis story begins like so many others. I came home from a weekend road trip from Canada. I called a friend and had a short conversation with him. I started to draft a paper for school. I remember feeling somewhat excited to write this paper, because it was the last assignment that I had to do, until my graduation from Law School.

I remember typing, and all of sudden, I had a partial out of body experience. I remember feeling as though, one foot was still inside my body, and the other foot had left my body. I thought to myself, "This is really strange; I should probably go to bed."

As I was sleeping, I became ill, no chest pains, just vomiting and cold sweats. Thinking that I just had the flu or a cold, I continued to try to sleep. Around 3 a.m. I woke up. I found myself sprawled out on the floor. I picked myself up, and continued to sleep. At 5 a.m. my alarm went off. I forced my eyes open, because I had no energy to open my eyes, and then crawled out of bed. On my hands and knees, I crawled to the bathroom, and tried to take a shower. I attempted to take a shower, but realized that I was too weak to do so, and I began to draw water for a bath.

I crawled into the bath tub. I went unconscious in the bathtub because the next thing I recall was "waking up" out of the bathtub, and it being very cold water. I thought to myself, "How long have I been asleep?"

I got out of the tub, and went back to my bedroom. I called my internship, and told them that I am feeling under the weather, but I hope to make it for work in the afternoon. The rest of the day becomes a struggle for me. Numerous times I tried to walk to get some water, and I never could make it to the sink in time. Each time, I end up on the floor,

"waking up" and feeling disoriented. I kept thinking that I had the flu, and that I was "tired" and this is why I keep finding myself on the floor. It wasn't until I hurt my ribs and jaw, that I finally realize that I am not "falling asleep" on the floor, but that was passing out.

I called my dad, who is a doctor, and told him about my day. He told me to go to the hospital. I called a friend, and he picked me up. When I arrived at the hospital, the intake person does not take my story too seriously. I explained that I have been "passing out" all day. An hour later, when the doctors check my weight and heart rate, then they realize that something was wrong.

My heart rate was between 25-30 beats per minute. I remember the doctors telling me to stay awake, and to focus. They wanted to

know if I had a history of heart problems. I told them that this was the first time something like this happened. I remember throwing up.

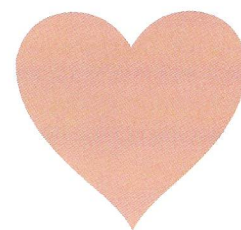
My parents drove to the hospital, which took a while since they live in another state. The next day I was in a lot of pain, and I had gotten aspirational pneumonia, fluid in my lungs, and swelling in my brain. They put a temporary pace maker in. However because of the lack of oxygen levels in my blood, they decide to put me on a respirator, and I am induced into a coma.

A few days later I am taken from New Hampshire, to Massachusetts General Hospital. I am not sure how long I was in the coma for, but I remember waking up in Massachusetts. I was in the ICU for at least a week and half, and then began to make a comeback.

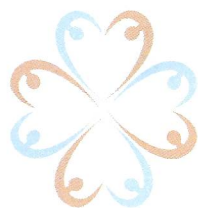
About a week and half later, I was out of the hospital, and was recovering. As soon as I came back from the hospital, I had to prepare for graduation, and I decided to go through with studying for the Bar Exam.

Recovery was difficult, and is still on going. In July I took the Bar Exam and in October, I found out that I had passed.

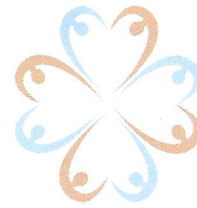
There isn't a day that goes by that I don't think of all the survivors and victims of myocarditis. It truly is a devastating illness, and like most people, I had never heard of it.







# MYOCARDITIS FOUNDATION



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## New Mailing Address

The Myocarditis Foundation has moved its business operations to the Denver area of Colorado. Please use the below address for all future mail and correspondence. All phone numbers and email address remain the same.

## The Myocarditis Foundation

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