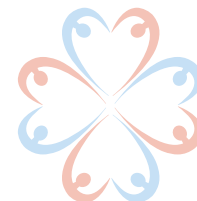


# MYOCARDITIS FOUNDATION



## Board of Directors 2014

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*President and Founder*

Survivor of Giant Cell Myocarditis and heart transplant recipient

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Owner of Homewell Senior Care

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*Director*

Community leader and father to a myocarditis victim

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### **JAIME ROJAS, MS, ATC, LAT**

*Director*

Athletic Trainer and father to a myocarditis victim

### **JOEL ARANSON**

*Director*

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

## Director

### **CANDACE MOOSE, ACTING DIRECTOR**

Point Pleasant, NJ

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

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

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

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

## New Mailing Address

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

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

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



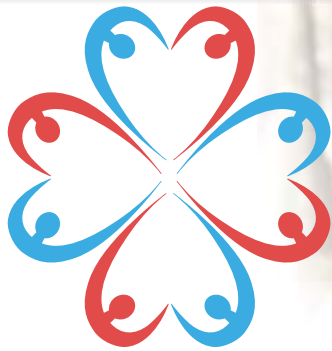
[twitter.com/myocarditisfndn](http://twitter.com/myocarditisfndn)



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



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



MYOCARDITIS  
FOUNDATION



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

ANNIVERSARY

**Myocarditis Foundation Celebrates 10 year Anniversary!**

This year the Foundation celebrates its 10 year anniversary of helping others by providing education, raising awareness to physicians and laymen alike, raising funds to support research for Myocarditis, and supporting patients suffering with the disease and families who lost loved ones to the disease.

Through the help of many very generous supporters, the Foundation has been able to award 14 Research Fellowship Grants, totaling almost \$500,000. Our researchers are adding to the scientific knowledge about Myocarditis, with a goal of developing faster, more accessible diagnostics and more therapeutic treatment options.

Over ten years, the Myocarditis Foundation has developed affiliations with the American Heart Association (AHA), the National Organization of Rare Diseases (NORD) and the Heart Failure Society of America (HFSA).

Our **"Not a Blank Canvas"** poster awareness campaign, detailing real myocarditis victims stories, has significantly increased awareness, thank you to a grant from Boston Scientific. Awareness of the disease is increasing, but there is still much more to do.

Three years ago we started annual Patient and Family Support Meetings, providing opportunities for education and support.

Additionally the Myocarditis Foundation mentors its researchers by bringing them together annually to nurture their interest in myocarditis research.

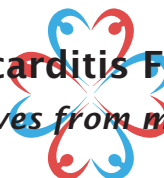
We would like to extend a huge thank you to all of our families who have worked so tirelessly to hold fundraisers on our behalf and to our Corporate Sponsors, Boston Scientific, Bellin Health System, Care One, to name a few but especially St. Jude Medical Foundation, who have been ongoing supporters since inception. Additionally, the faithful support of the Avalon Open Golf group has not gone unnoticed We would not have been able to accomplish so much in ten years without your

support. We could not have raised the awareness nor the research funds without our everyone's support.

To celebrate the success of the Foundation, we are combining our Family Support and Research Meetings this year with the HFSA meetings in Washington D.C. in September. Come and share in our friendships and successes. Please see our "Save the Date" and for further information, please call **Candace@myocarditisfoundation.org**

**mī ō kār dī tīs**  
*let's make the only struggle  
be pronunciation*

**The Myocarditis Foundation**  
*Saving lives from myocarditis*



## EVENTS

# Tufts University's 180 Consulting to Design Marketing Program for the Myocarditis Foundation

A group of staff and volunteers from the Myocarditis Foundation traveled to Medford, Massachusetts in early March to deliver a presentation to a team of students from Tufts University, representing 180 Degrees Consulting.

The Tufts University branch of the international university-based organization, 180 Degrees Consulting, is designing a

marketing program for the Myocarditis Foundation focused on young adults, one of the most vulnerable populations to inflammatory heart disease.

A special thanks to Sue Hall and Staurt Kravitz for presenting their myocarditis stories with the students. The students were inspired by their very moving stories.

## ANNOUNCEMENT

# Big Hearts Auction

*As told by Ashley's mother, Kathy Burgauer...*

Ashley Burgauer was a registered nurse, a daughter, a sister, an aunt, a cousin and a beautiful friend to many whose life suddenly ended one Thursday afternoon to a disease they had never heard of. Ashley was found unresponsive at home in bed and taken to the hospital where she was pronounced dead. Nine weeks later the autopsy reported

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

Join us for live music, drinks and a silent auction at the Fickle Peach in Downtown Muncie, Indiana on August 22nd. We will be raising awareness for Myocarditis.

For more information go to: [bigheartsauction.com](http://bigheartsauction.com)

## OUR EXPERIENCE

# Andrea Stone

On a Monday, my 11-year old daughter, Sarah, called me from school because she had a fever and needed to be picked up. She vomited at home and felt bad on Tuesday.

I recall that she complained about a pain in the middle of her back between her shoulder blades. At about 3 a.m. on Wednesday morning, she woke me up saying she had a really pain in her back, but she took some Advil and slept in my bed. She stayed home from school again on Wednesday. Wednesday night at about 11:00 p.m. she was still complaining about her

back pain, but the new symptom of chest pain and shortness of breath appeared.

We decided to take her to the ER thinking that her vomiting may have caused some acid damage to her esophagus or maybe she had pneumonia. The ER doctor thought she might have a tear in her esophagus, so he did an EKG. Her EKG results weren't normal, so he ran her troponin levels which were at 28, which is very high. We were transferred to the Children's Hospital via ambulance and were directly admitted to the ICU at 6:00 a.m. on Thursday morning.

## OUR EXPERIENCE

# North Carolina Father Faces Significant Transplant Expenses

July 25, 2015 marks Brian Barndt's, 10 year anniversary milestone of his heart transplant at Duke University. In 2005, he partnered with the National Foundation for Transplants to reach the goal of \$35,000 to invest in his health as a heart transplant recipient. That goal was reached, and the funds paid for all transplant related costs for over 6 years. It was an incredible relief for him not to live under the excessive financial burden of paying for the medical expenses necessary to maintain good health. The fund allowed him to focus on providing for his family and serving as a full-time pastor and chaplain for the past 10 years. A transplant is not a cure, but a life saving measure that requires diligence and hard work to maintain the health of the organ.

Brian is asking you to consider joining his team and contributing

to the National Foundation for Transplants (NFT). Your gifts are tax-deductible and can only be used for transplant-related expenses.

### You can help in the following ways:

- Send a tax-deductible donation via check or credit card. Please make your check payable to NFT North Carolina Transplant Fund, and **remember to write "in honor of Brian Barndt" on the memo line.** Donations can be mailed to **5350 Poplar Avenue, Ste. 430, Memphis, TN 38119.**
- Visit [www.transplants.org](http://www.transplants.org) to make a secure online donation. Click **"Find an NFT Patient"** to search for his name.

For any questions about NFT, feel free to contact the staff at **800-489-3863.** Brian thanks you!



They did an echo cardiogram which was normal on Thursday and followed up with a cardiac MRI on Friday morning. Sarah was very fortunate that the damage that was found was very minor. She didn't have any arrhythmias the entire time they were monitoring her.

We were shocked when the cardiologist told us we could go home on Friday evening. After reading the stories on this site, I was so worried, but I wanted to share because I think there are many minor cases of myocarditis that are missed by doctors and never diagnosed.

If one of those minor cases happen to be caught, the prognosis can be much less scary than in some of the tragic cases shared here. Sarah had a follow up with her cardiologist a few days after she was discharged. In three months, she will have another visit. Eventually she may have another cardiac MRI just to make sure there is no long term damage.

Sarah is now back to school and even doing volleyball again. We had lots of people praying for her return to health. Seeing her back to her routine is a true blessing.

EVENTS

# The 8th Annual Joe Rumore Golf Tournament

The 8th Annual Joe Rumore Golf Tournament will be held on Monday August 17, 2015 at the Ballyowen Golf Club in Hamburg, New Jersey.

Joe suffered with Myocarditis as a young adult, only to survive and live with the complications of Heart Failure in his 40's. Despite years of intense medical management, Joe was succumbing to the disease in 2006 when he was blessed with the gift of life, a heart transplant, on Thanksgiving Day. He decided then, that he would make it his life's work to prevent others from going through what he and his family had gone through for many years.

Joe started the golf tournament in 2008 to raise awareness about Myocarditis. Through the generosity of his family and friends he has been able to fund many research grants for the Foundation.

Last year Joe was extremely happy when Lou Romano joined the Board and now co-sponsors the event with him. With Lou's help, last year was the most successful fundraiser that we've had and for the first time attracted a major corporate sponsor.

Please save the date, August 17th , and join them for a glorious day of golf in the hills of the Crystal Springs Resort in Hamburg, New Jersey. Lunch, Dinner and giveaways are provided. We look forward to you joining us.

Please contact: [jrumores@yahoo.com](mailto:jrumores@yahoo.com) for further details.

EVENTS

# Myocarditis Awareness Month

Randy Vanness, one of our Board Members who lost a child to Myocarditis, has worked diligently on getting awareness out there on Myocarditis – what it is, what it does to victims and their families, and the need for research to find a specific test for quick detection of the disease.

Randy was able to get the attention of the Governor of Wisconsin, the state where he lives, to declare April as Myocarditis Awareness Month. This will broaden the awareness throughout the state of Wisconsin, and hopefully this will be the start for

other states to join in and raise the awareness there as well.

Thank you Randy so very much for all of your persistence, dedication and hard work.



## 2015

### February 2015

Myocardial and Pericardial  
Disease Conference  
European Society of Cardiology  
**Tel Aviv, Israel**

### March 13th -16th

American College of  
Cardiology Meeting  
**San Diego, CA**

### March 23rd -24th

Cardiology/Cardiac Surgery  
Summit  
**Rochester, MN**

### April 5th -11th

German Cardiovascular Society  
Meeting  
**Berlin, Germany**

### April 16th-18

Mayo Conference  
Case Studies for the Heart  
**Manhattan, NY**

### April 24th-26th

Mayo Conference  
Imaging Adult Heart Disease  
**Jacksonville, Florida**

### May 22nd-25th

World Congress on  
Acute Heart Failure  
**Seville, Spain**

### May 28th-31

Mayo Samsung Meeting  
**Seoul, Korea**

### June 11th-14

University of Arizona  
Grand Rounds  
**Tucson, AZ**

### September 19th

Heart Symposium  
**Pikeville, KY**

### September 26th -29th

Heart Failure Society Conference  
**Washington, D.C.**

## EVENTS

# The 3rd Annual Sarah Knight Memorial Golf Tournament

The 3rd Annual Sarah Knight Memorial Golf Tournament will be held Friday, June 12, 2015. Sarah's birthday, a day she loved to celebrate, is June 13th. The event has been planned close to her birthday to give friends and family a chance to celebrate a special girl. Our inaugural event in 2013 was a huge success with 100 golfers on the course. The tournament grew in 2014 and we're expecting even bigger and better things this year.

The tournament is held at Hunter's Ridge Golf Course in Marion, Iowa. Golfers enjoy a fun-filled day that includes lunch and dinner. Volunteers ensure the success of our event and provide wonderful assistance. Generous friends, family and local businesses donate raffle prizes and silent auction items. Many non-golfers join us for socializing and dinner. It truly is a celebration of Sarah.

### A young woman with so much to give...

An infectious laugh, a great sense of humor and a magnetic personality, Sarah Knight could make friends wherever she went. Sarah was a loving, caring and compassionate daughter, granddaughter, sister, teacher, and friend. Just 25 years old, her future was bright and she was loved by many. On September 26, 2011, all that changed when Sarah died unexpectedly from a little known disease, Myocarditis.

On September 26, 2011, Sarah spent a typical day as a kindergarten teacher. She taught during the day, attended a meeting in the late afternoon, and in the evening was working in her classroom on her lesson plans. Around 7:30 p.m. the school custodian discovered Sarah unresponsive, lying on her classroom floor. Thanks to a very diligent coroner, who was

determined to find the cause of Sarah's death, the family learned three months later that she had died of Myocarditis.

Inspired by other families and their efforts to raise funds for the Myocarditis Foundation, and also to continue Sarah's legacy as an educator, the Knight family launched the Sarah Knight Memorial Golf Tournament in 2013. Proceeds from the event are split evenly between the Myocarditis Foundation and the Sarah Knight Memorial Scholarship at Western Illinois University.

Complete event information is available at [www.sarahelizabethknight.com](http://www.sarahelizabethknight.com). To sign up to golf or make a donation, select the "Register for Golf or Make A Donation" button on the website homepage. If you would like to make a contribution for the raffle or silent auction, you may select the "Contact Us" link.

## EVENTS

# Tyler Rosenberg Walkathon Saturday June 20th, 2015

Myocarditis is a little known, but devastating disease that took the life of our 19 year old son Tyler. Myocarditis is a relatively rare disease that attacks otherwise healthy people and is felt to be responsible for up to 20% of all cases of sudden death in young adults. In some instances healthy young people go to sleep and just don't wake up the next day, or they are involved in an athletic activity and just collapse on the field. It can be caused by a viral or bacterial infection, autoimmune diseases, environmental toxins and reactions to medication. Survivors are sometimes left with damaged hearts, a lifetime risk of relapse, or even in need a heart transplant.

On the Myocarditis Foundations website, [www.myocarditis-foundation.org](http://www.myocarditis-foundation.org) please read the many stories of people that either died or with luck and appropriate medical care, survived.

Typically, in myocarditis, a common virus attacks the heart muscle causing inflammation. Sometimes the body's own antibodies respond by attacking the injured heart muscle cells, mistaking them for the virus and causing further damage. The heart is left with scarring, gross enlargement or chambers that are so dilated they lose their pumping ability. All of these problems can lead to heart failure and sudden death.

Tyler's myocarditis, was most likely caused by a virus from an upper respiratory infection or the flu. What occurred, we will never know. He was asymptomatic until the day he collapsed at home and then died later that day at Yale New Haven Hospital. When he was first brought to the emergency room he was diagnosed with a massive blood clot in his lungs and treated for that. We didn't find out until almost three

months later in the autopsy report that he never had a clot, and in fact died of viral myocarditis.

Most cases of myocarditis have no symptoms but if there are, they range from fatigue, shortness of breath during activity, palpitations, chest pain, abdominal pain, loss of consciousness, and sudden death. Patients may experience some, all, or none of these symptoms. It is commonly mistaken for a case of stomach flu, or an upper respiratory illness.

Because the signs and symptoms vary so widely, and are similar to other conditions, it is often misdiagnosed (as what occurred in Tyler's case).

The only definitive test for myocarditis is a heart muscle biopsy, although some diagnostic information can be gathered through, chest x-rays, echocardiograms and blood tests.

## Rare Disease Legislative Advocate Conference

Rare Disease Week on Capital Hill took place in Washington D.C. from February 23rd -27th . Candace Moose, our President of the Board of Directors, attended with patients and families who have been affected by Myocarditis.

The annual event is sponsored by Rare Disease Legislative Advocates. The Myocarditis Foundation team

visited their Congressmen to ask for support for rare disease legislation, of which Myocarditis and Giant Cell Myocarditis are considered part of. The event is held every year and we look forward to having more of those that have been affected by Myocarditis and Giant Cell Myocarditis attend with us.



*Candace, Jamie Thomas-Ward, a Myocarditis survivor, and Michele Cola-Veston, mother of a young man who died from Giant Cell Myocarditis*

## Fund Raising Walk at The Bethany Veterans Memorial Park 265 Beacon Rd Bethany, CT.

We wish to remember Tyler Rosenberg, to educate, create awareness, and raise money for the Myocarditis Foundation. The foundation is tasked with distributing accurate information to medical professionals, patients and their families. They hope to further the scientific advancement of both the diagnosis and treatment of the disease with the goal of saving more lives. [www.myocarditisfoundation.org](http://www.myocarditisfoundation.org). The Foundation is small and in need of your support and is the only organization that we have found that is pursuing the above goals. We ask for your support.

**Please join us in raising money to support awareness of this silent and deadly disease.**



## In Memory of Jeffrey T. Grossman, Esq.

Our son, Jeffrey Grossman, lost his life to giant cell myocarditis on May 3, 2013, only weeks beyond his 46th birthday, after exhibiting signs of weakness and fatigue for a short period of time. He was barely 46 but had accomplished and contributed so much.

Jeff was loved and nurtured by parents and family and was a loving caring child and son. His childhood and formative years were filled with friends, family, sports and studies. Throughout the years, Jeff and his dad would always flash the #1 sign to each other whenever they would say goodbye, a sign we are certain he is still making.

Jeff's four years at Penn State were among those he found the most enjoyable and rewarding. Jeff had a deep attachment to the university and kept abreast of all things Penn State, especially Nittany Lion football. After graduation from Penn State came Temple Law School, with more studying and honing of skills. He went on to establish and develop the successful Grossman Law Firm in Philadelphia, where he thoroughly enjoyed a unique camaraderie with both clients and colleagues.

He shared his love with his family and friends, adored his two daughters, and had a special place in his heart for his parents. With his warmth and easy manner, he made friends readily and was respected and admired by many. The outpouring of heartfelt sadness and sense of loss at his passing was beyond words.

Jeffrey Grossman packed a great deal into his short 46 years, but we'll remember him most as the son he was and the man he became. He is forever loved, missed and #1.

### Holiday Open House & Boutique for Myocarditis Foundation

In Jeff's memory, Pilates Core Center in Cherry Hill, NJ, owned by Jeff's stepmother, Diane Grossman, and her business partner, Sylvia Byrd-Leitner, held a Holiday Open House & Boutique on November 19, 2014 to raise awareness and funds for Myocarditis Foundation. The studio's teachers and administrative staff donated their time and talent for the event, and all money collected for classes was donated to Myocarditis Foundation. Penny Solomon Wearable Art donated beautiful hand painted scarves and ties with all proceeds benefitting the Foundation; a percentage of the sales of jewelry by Wireworks, Goddaughters and Stella & Dot and tote bags by Aran Rose Designs also was donated; and Pilates Core Center raffled off private sessions and group class packages to generate funds for the Foundation.

It didn't stop there. Diane Grossman and Jeff's parents, Herb Grossman and Diane Aranson, set up a First Giving donation page so family and friends all across the country could join in the fundraising effort. Between November 19 and December 31, 2014, \$5,000 was raised in Jeff's memory.





**The Myocarditis Foundation**  
**3<sup>rd</sup> Annual**  
***Patient, Family and Researcher Meeting***

Join us at the **Gaylord Marriott Resort and Conference Center**  
National Harbor, MD, on

**Friday and Saturday, September 25 and 26, 2015.**

The conference will be held in conjunction with the  
**Heart Failure Society of America Annual Meeting.**

Welcome Buffet Dinner, Friday from 5:00-8:00pm

Candle Light Vigil, Friday 7:30pm

Conference Saturday, 8:00-4:00

MF 10<sup>th</sup> Anniversary Dinner Saturday, 6:00 pm;

All meals provided free of charge. Some travel scholarships available.

***Due to space limitations, only the first 100 reservations will  
be accepted.***

Hotels within walking distance of The Gaylord and in a variety of price points can be explored by searching [www.nationalharbor.com](http://www.nationalharbor.com). Area attractions and discounted hotels within a short driving distance can be found on discount travel websites. National Harbor is a 20-minute cab ride from Washington.

**Send your non-refundable conference reservation fee of \$50. per person, limited to three persons per family, by August 1<sup>st</sup>, to Candace Moose, 2201 River Rd, #3401, Point Pleasant, NJ 08742. All are encouraged to sell program brochure ads. Honor your loved one with an ad. Angel and Survivor ads range from \$25. to \$100. For business ad information email Candace. Email completed ad to [Candace@myocarditisfoundation.org](mailto:Candace@myocarditisfoundation.org) by August 1<sup>st</sup>.**

***Save the Date!***

**September 25 and 26, 2015**

***National Harbor, MD***

ANNOUNCEMENT

## The Quinn M. Kirsch Memorial Grant: 2015 Research Grant Named in Memory of Quinn M. Kirsch

The Myocarditis Foundation is pleased to announce that they have named their 2015 research grant in memory of a little boy from Minnesota who died 2 years ago of myocarditis. The Quinn M. Kirsch Memorial Grant was awarded to Dr. Michael Bode of UNC/ Chapel Hill, North Carolina who is conducting research under the mentorship of Dr. Nigel Mackman.

Quinn Kirsch was an 8 year old boy who collapsed suddenly in his home after an ordinary day of

activities, and died later that day at the hospital. The Medical Examiner's diagnosis of Myocarditis was shocking as Quinn did not exhibit any symptoms. Mr. Mrs. Kirsch chose to memorialize Quinn by donating funds to the Myocarditis Foundation to support a research grant in the hopes that someday with scientific advancement, other families would not have to experience the pain of losing a child to this disease.

To raise the \$35,000 to cover the cost of the grant, Quinn's parents, siblings, friends and school held several fundraisers. The primary event was the 2nd annual Quinn's Cup Hockey Tournament, which was held on January 10th 2015.

Quinn's Cup was a huge success, with 30 teams and almost 400 skaters. Hundreds of fans came out to cheer on the players, and support a good cause. Quinn's Cup mission is three-fold: To raise

awareness of Myocarditis and how it impacts its victims, raise funds for the Myocarditis Foundation, and finally to provide a venue for Quinn's family, friends, teammates and classmates to celebrate Quinn's life while doing something he loved – play hockey on an outdoor rink.

His parents, Kelly and Kyle Kirsch invite you to follow them for updates at: [www.quinnscup.org](http://www.quinnscup.org) and [@quinnscup](https://twitter.com/quinnscup).

ANNOUNCEMENT

## Bettina Heidecker, M.D., 2007 MF Research Grant Recipient

Dr. Bettina Heidecker was one of the Myocarditis Foundation's first Research Fellowship Grant Recipients in 2007. The title of her research was "Gene Expression Profiling for Detection of Myocarditis."

Dr. Heidecker came to the United States, from Austria, as a medical student in 2004. In 2006, Dr. Heidecker went to Johns Hopkins as a post-doctorate fellow in the cardiovascular laboratory of Dr. Joshua Hare, a renowned clinician-scientist in heart failure and cardiomyopathies. Dr. Heidecker's experience at Dr. Hare's lab has shaped her research career. It was in his lab that she discovered her deep interest in cardiology. Hare provided her with autonomy, professional guidance, and inspiration to pursue clinically relevant research in the field of transcriptomic biomarkers in myocarditis and heart failure.

At Dr. Hare's lab, she discovered a transcriptomic biomarker that detects myocarditis with very high accuracy at disease onset. This takes us one step closer to saving lives by earlier detection of the disease.

Dr. Heidecker's work was recognized by the American Heart Association, the Heart Failure Society of America, and the Myocarditis Foundation, winning her multiple prestigious awards including the Samuel A. Levine Award and Jay N. Cohen New Investigator Award.

Dr. Heidecker has expressed in a 2015 European Heart Journal article that, the Myocarditis Foundation was especially helpful for her through its financial support and the mentorship of Dr. Leslie Cooper and DeLisa Fairweather, PhD."

Today she practices cardiology and conducts clinical research at the University of California, San Francisco (UCSF). Dr. Heidecker is an International Lecturer in Cardiology at the Aston Medical School in Birmingham, UK. She is also Director of the Scientific Advisory Board of Heart Genomics.





## “For My Mother”

Before my mother’s diagnosis in May, I had never heard of or given thought to diseases like Myocarditis. When you are young you like to believe that these things are not real, and that they could certainly never happen to my mom. My mother has always been the healthiest, well-fit person you could find. Our own family doctor likes to joke that she was the “healthiest sick person” she’d ever met, and that was the truth. It was always my thought that my mother was going to keep on moving at high speed forever, no slowing down. But on May 1st, 2014, my mother was taken to the hospital after suffering crushing chest pains. She had been struggling with a cold for days before, which for my mother meant that she was lethargic and weak, something my family was unfamiliar with. After her diagnosis she was so scared, and it was sobering to find my mother, the pillar of good health and fitness in our family, afraid of her own heart.

The strain of virus that caused such a change in my mother was Cocksackie B, which initially meant nothing to me. It was the villain that could have taken my mother from me if she hadn’t been so healthy to start with, and I tried so hard to put it out of my mind as she and her heart initially started to function normally again. But the virus recurred in late September. We didn’t believe it was going to recur at all, especially after four months of finally feeling normal again. After the second incident, we learned that her heart had scarring and decreased function. I had just started college at this point, and I couldn’t handle the idea of my mother being taken from me before I could make her proud.

My piece was prompted by an assignment in my digital art class, as part of a typography project. Our assignment was to find a cause that we felt deeply about and make a graphic that would inform others. I struggled with this assignment for over a week

before I started researching Myocarditis. It was a foreign concept to me, and the scariest thing in my life, and I had originally believed that knowing more would make it harder to face. But it didn’t. The information that I learned and put into my

graphic made it easier to face the disease I’d before only considered as a malicious villain. I hoped that by making this piece, I could make it easier for others to face and understand Myocarditis. But most of all, this piece is for my mother, the bravest person I’ll ever know. I hope to keep making her proud of me for a long time to come.

*Alayni Frizzell*



## Myocarditis Foundation Co-Sponsors the Myocardial and Pericardial Disease Working Group in Tel Aviv, Israel

Myocarditis Foundation Co-Sponsors the Myocardial and Pericardial Disease Working Group in Tel Aviv, Israel

The Myocarditis Foundation was a co-sponsor of the European Cardiology Society's 11th Myocardial and Pericardial Disease Working Group, which was held February 6th-7th in Tel Aviv, Israel.

Dr. Leslie Cooper gave a presentation on Myocarditis to over 250 physicians in attendance

from all over the world, and each physician in attendance also received information on the Myocarditis Foundation.

The Foundation had a booth in the Exhibit Hall with additional information on Myocarditis for the attendees.

This meeting was very successful at increasing awareness to physicians throughout the world about the Myocarditis Foundation.



## 2015 Events

### January 10th

Quinn's Cup Hockey Tournament  
**Edina, MN**

### February 23rd – 27th

Rare Disease Legislative Advocate Conference  
**Washington, D.C.**

### March 9th -11th and March 19th -22nd

Lukey's Legacy Hockey Tournament  
**West Seneca, New York**

### March 16th

Rare Disease Day in New Jersey

### April 11th

A Night To Remember Brad Vanness  
**Kewaunee, WI**

### May 16th

Paint the Town Rhett  
**Elgin, IL**

### June 6th

Stephen Hughes Fundraiser  
**Hull, United Kingdom**

### June 12th

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

### June 20th

Tyler Rosenberg Memorial Walkathon  
**New Haven, CT**

### August 17th

9th Annual Joe Rumore Golf Tournament  
**Hamburg, New Jersey**

### August 22nd

Big Hearts Auction  
**Muncie, IN**

### September 5th

9th Annual Devin Kravitz Memorial 5K  
**Leicester, MA**

### September 26th

Myocarditis Foundation Family Meeting  
10 Year Anniversary Celebration  
**National Harbor, Washington D.C.**

### September 29th

World Heart Day

### October 11th

Open House on the Manasquan  
**Point Pleasant, New Jersey**

### Ways You Can Support the Myocarditis Foundation

- Shop at Smile.Amazon.com and choose the Myocarditis Foundation as your charity
- Send Tribute Cards in place of greeting cards (see our website for more information)
- Ask friends and family to donate to the Myocarditis Foundation this holiday season
- Hold a local Fundraiser or Awareness Event in your town
- Ask for brochures to hand out at your local clinic/hospital
- Attend the annual Myocarditis Foundation Patient and Family Support Meeting

*A Night To Remember*  
**BRAD VANNESS**

*The Brad Vanness Memorial  
Fundraiser for "The Myocarditis Foundation"*  
[www.myocarditisfoundation.org](http://www.myocarditisfoundation.org)

**Sat. April 11, 2015**

**At Lakehaven Hall  
Kewaunee  
3 PM to Midnight**

*Something for Everyone!*



**Baskets & Silent Auction items  
Food • Refreshments • Live Music**

Every year children and young people, like Brad, DIE OF MYOCARDITIS, an unrecognized killer!

**Greatest Hits**

**Polka Band  
3:30 - 6:30**

**Antique  
Rockshow  
7:00 - 11:00**

*Come and join us to share  
some memories and help raise funds  
and awareness to fight the disease  
that took Brad's life.*



**and always remember to...Dream BIG**

## Farrah's Story - My Epic

I had just started my first semester of my sophomore year at college in August of 2013, and had a completely normal day. I was in the kitchen with my roommate about to make dinner and suddenly I broke out in sweat from head to toe and felt like my chest collapsing in on itself. The pain kept on radiating across my chest wrapping around my back and eventually spread down my left arm. Since we no idea what was going on I did not go the hospital immediately. I couldn't sit still because of the pain, and once I began vomiting, we decided to go to the hospital.

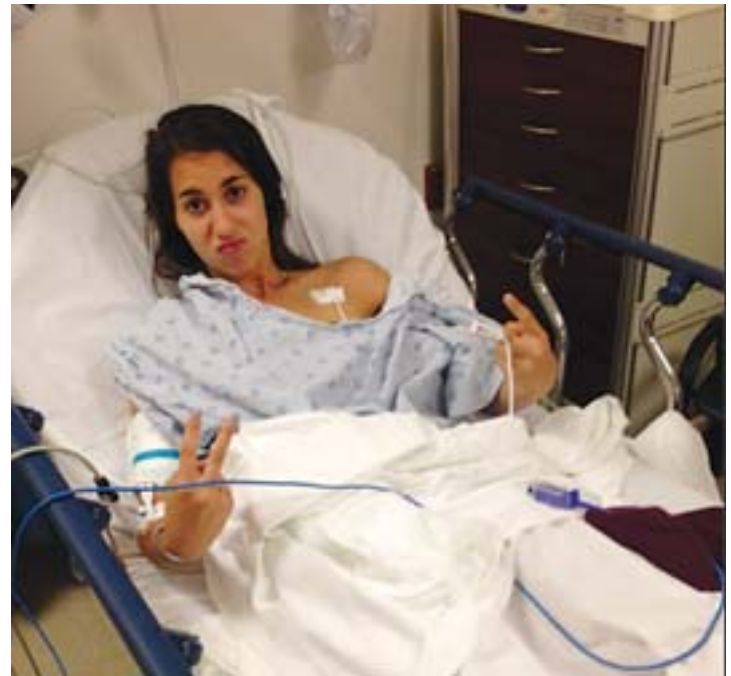
My diagnosis was myocarditis and pericarditis, and the doctors could not figure out what caused it. Heart disease does not run in my family, I was a highly active kid, ate well, there seemed to be no logical reason to why I would have inflammatory heart disease. It was not until the next morning that it struck me what had just happened. I was tired, weak, and confused because my life literally changed in an instant. I went down to being a part time student in school and did the best I could with the lowest energy levels I've experienced while having chest pains.

By the time January came around, I felt like my quality of life had dwindled down to a point of both physical and mental exhaustion. I went back to my cardiologist and had an MRI done which determined that I had chronic myocarditis and he suspected that it could have been caused to an autoimmune attack. After that evaluation, I had to withdraw from school, start taking steroids and immunosuppressant's, and have IVIG infusions.

I immediately started to feel more energy after the IVIG treatments with random flares of chest pain, but little by little I began to get my life back together and was back in school, exercising, and living like a normal kid in college.

By November 2014, I was cleared by my cardiologist to start working out again, which was the greatest news I have ever heard. Now I am back in school as a full time student, working, and just successfully completed a 10k with one of my best friends in college.

Now that I am on the other side of things, and life is better than ever I must say that there is a need to raise awareness for Myocarditis. It is such a spontaneous disease in its nature and no one ever suspects that they could have this disease in its initial onset. As a community we need to work together to raise the awareness for this disease so further research can be done to help answer many unanswered questions for the victims of this disease. To this day I have no idea why or how it happened, but with the advancement of knowledge in scientific research, I believe there is much to be discovered about this disease.



*My sister Leila was trying to make light of the situation at the hospital so she took pictures of me acting all tough when I was confined to a hospital bed.*



*My roommates and best friends, Macy and Danielle, were my biggest supporters throughout this who experience. This is a picture of us at the Richmond Heart Walk in September 2013.*

*I got to wear the red had because I was a survivor!*



*Here is the whole heart walk team, we called ourselves the Myocardinosaur.*