The MYOCARDITIS FOUNDATION

Winter 2013 Knowledge Nurtures Hope Vol. 6 No. 1

The Myocarditis Foundation's 2013 Family Support Meeting and Researcher Workshop

On September 23rd, the Myocarditis Foundation (MF) held its first official Family Support Meeting and Researcher Workshop in Orlando, Florida. The Myocarditis Foundation held these two events in conjunction with the Heart Failure Society of America's (HFSA) Annual Scientific Meeting.

Top: Candace Moose, Karen Hymowitz
Bottom: James Moose, Sue Hall, Carolyn Sweet, Kristen Stephens, and Sally Adair

The Family Support Meeting commenced along with the Researcher Workshop on the morning of September 23rd. The Myocarditis Foundation's Family Support Meeting's goals were to provide information and answer questions in a safe, open atmosphere for families and patients; and also to allow for families of loved ones and survivors to share their stories. Dr. Leslie Cooper, Dr. Lori Blauwet, Dr. Monte Willis, and Candace Moose all gave talks, followed by talks from survivors and families of loved ones: Jeff Grant, Carolyn Sweet, Kristen Stephens, and Katie Kendjorsky. This meeting was highly emotional, filled with tears, hugs, and smiles; and many families shared that this meeting brought "a sense of peace" to them and their family. This is a meeting the Myocarditis Foundation hopes to hold each year in an effort to provide ongoing support to the families and patients affected by myocarditis. All of the Family Support Meeting talks were recorded and available for viewing on the Myocarditis Foundation's website.

Next door to the Family Support Meeting, the Myocarditis Foundation's Researcher Workshop was being held simultaneously. The Myocarditis Foundation graciously received a grant from St. Jude Medical Foundation, which allowed for the Myocarditis Foundation to invite all of its past and present research grant recipients to attend a workshop to help them advance in their professional career while fostering a love for myocarditis research. The Researcher Workshop began with presentations from grant recipients: Dr. Laure Case, Dr. Chandirasegaran Massilamany, Dr. David Marchant, and Dr. Bettina Heidecker. Following the grant recipient talks, were professional talks given by Dr. Madeline Cunningham, Dr. DeLisa Fairweather, Dr. Leslie Cooper, and Lindsey Davis. These professional talks were aimed at offering tools, advice, and information to help these researchers succeed in the field of myocarditis research.

Following both meetings, the two groups came together to share a lunch and to continue to tell the stories of the families who's amazing fundraisers fund the critical research the Myocarditis Foundation's researchers complete. Lindsey Davis, Director of the Myocarditis Foundation, also awarded certificates of appreciation to Jeff Grant for his dedication and help in founding the MF, Giovanna Caccialanza for her ongoing support and successful fundraisers in memory of her son Andy Pena, and to Katie Kenjorsky for her dedication and fundraising successes in memory of her mother Barbara Henry.

Lindsey Davis and Dr. Leslie Cooper presenting Giovanna Caccialanza a Certificate of Appreciation at the Family Support Meeting

The Myocarditis Foundation would like to thank all of the families, patients, researchers, speakers, and board members who were in attendance at the Orlando meetings. Also a sincere thank you to those who continue to donate to the Myocarditis Foundation and to St. Jude Medical Foundation; these events would not be possible without your generous support. This was an unbelievable event that brought so much peace, understanding, and scientific knowledge to those affected by myocarditis and to those who will bring new understandings to this disease.

Julian's Story

Julian Rosario-Valentin

Julian was a beautiful person inside and out. He was full of life and love. He made our family what it was. His charming personality made anyone that met him fall in love with him. He was always making people laugh and putting on a show. He was a very active little boy. He played baseball since he was 3-years old and he absolutely loved to dance, since before he could even walk. Julian also became a big brother in July 2011 and he lived for his little sister. Their bond was so strong. We never would have thought we'd lose such an important person so soon.

Julian passed away on September 8th 2012 after complaining of only a headache. He had been at the doctor just two days before he passed for a physical and he was perfectly fine, he wasn't the least bit sick.

On the day of September 8th, I had Julian at the doctor for his headache by noon. Julian had thrown up in the waiting room and once they called his name they brought us into one of the exam rooms. He was laying down and he looked very pale and very weak but he was talking to me and telling me that he was okay. The doctor tried to take blood, she pricked him about 3 times and couldn't get much if any blood at all so she told me calmly to take him to the hospital for a brain scan. I then started to panic but I told Julian and myself that everything was going to be okay. As soon as we pulled up to the Emergency room doors Julian was gasping for air and just seconds after they got him into the trauma room his heart stopped beating. They tried to revive him for 40 minutes but they couldn't.

That day, an enormous part of me died. Nothing seemed real and it still to this day doesn't. I'd give anything to change what happened that horrific day.

Three months later we were told that his cause of passing was Acute Myocarditis, something I had never even knew existed until now and I knew right away that I needed to know more, I needed to do something. Our family has a huge void that can never be filled and a little girl who will grow up without her beautiful, one-of-a-kind brother. We have decided to start a foundation that will forever keep Julian's memory alive and that will raise awareness to this silent killer that many people have no idea about. We plan to share stories, hold events and fundraisers for the Myocarditis Foundation. This is now a part of our lives forever and we will keep fighting until the end.

Cait Valentin, Julian's Mother

Dr. Cooper's Speaking Schedule

January 7th – Vanderbilt University School of Medicine in Nashville, TN: "Cardiovascular Research Seminar"
January 8th – Vanderbilt University School of Medicine in Nashville, TN: "Cardiology Grand Rounds"
January 17th – University of California, San Diego: "Cardiology Grand Rounds"

April 18th – Bali Nusa Dua Convention Center in Bali, Asian Pacific Congress of Heart Failure Scientific Meeting: "Advances in the Pathophysiology and Treatment of Myocarditis"
April 18th – Bali Nusa Dua Convention Center in Bali, Joint Session with the American College of Cardiology: "Imaging and Heart Biopsy in Acute Dilated Cardiomyopathy"
April 19th – Bali Nusa Dua Convention Center in Bali, Joint Session with the American College of Cardiology: "Recent Advances in Imaging of Cardiac Inflammation"

May 5th – Melbourne, Australia, World Heart Federation's World Congress of Cardiology Scientific Sessions: "Joint Session on Myocarditis" (topics to be determined, please see our website for updated information)
May 17th and 18th – Samsung Medical Center in Seoul, South Korea (topic to be determined, please see our website for updated information)

Colorado Rapids Sidekicks Raise $10,000 for the Myocarditis Foundation

Carly Davis, Lindsey Davis, and Buddy George (from left to right) volunteered on behalf of the Myocarditis Foundation for the Colorado Rapids Sidewalk Sale and Silent Auction

The Colorado Rapids and the Rapids Sidekicks held the fundraiser and sidewalk sale “Open Closets, Open Hearts” on September 14th at Dick’s Sporting Goods Park in Denver, Colorado. This event was held to raise funds and awareness for the Myocarditis Foundation in honor of Elysa Rojas, daughter of the Rapids’ Head Athletic Trainer, Jaime and his wife, Jana. The Rapids team came together to support Jaime and his family in this time of tragic loss and heartbreak. Elysa was just shy of her third birthday when she was tragically lost to viral myocarditis in January 2013.

Open Closets Open Hearts Sidewalk Sale

The Rapids Sidekicks, a group dedicated to supporting charitable organizations through a special relationship with Denver Rapids players, hosted the sidewalk sale and auction of new and gently used athletic gear and memorabilia prior to the Rapids’ home match versus FC Dallas. “The Rojas family has been very close to our hearts for along time, and we were thrilled to kick start their vision of carrying on Elysa’s legacy with such a successful event,” said Kersten Mullan, wife of defender Brian Mullan, who heads the Sidekicks group. “We owe a huge thanks to the Myocarditis Foundation, the Colorado Rapids, and all the individuals and organizations that donated items to the sale, and the fans that contributed.”

Lindsey Davis, Director of the Myocarditis Foundation, was in attendance of the event, along with several volunteers of the Myocarditis Foundation. “The Myocarditis Foundation is extremely honored and humbled by the support of the Rapids team and their fans. The Rojas family, and so many other families just like theirs are the reason we continue our fight every day to bring awareness to this disease, and we can’t thank everyone enough for coming together to support our cause.” said Lindsey.

The Open Closets, Open Hearts Sidewalk sale included gear donated by not only Colorado Rapids players and coaches, but also items donated by the US Soccer Federation, FC Dallas, Real Salt Lake, Florida International University soccer, Bumpy Pitch apparel, and former Rapids players. There was even a jersey signed by the entire US Woman’s Soccer team that was auctioned off to a lucky winner. The outpouring of support by the soccer community was truly touching and made the event a success. Please visit the Rapids website and facebook page to read more about the event and the Rojas family.

Love and well wishes go out to the friends and family of Elysa Rojas. They, and the many other families affected by myocarditis, are the reason the Myocarditis Foundation is able to spread awareness and fund research so that more lives can be saved from the disease myocarditis.

The MYOCARDITIS FOUNDATION

Myocarditis Foundation Awarded a Kroenke Sports Charity Grant

On August 17th, 2013 the Myocarditis Foundation was awarded a $2,500 grant from the Colorado Rapids Teammates for Kids Foundation and the Kroenke Sports Charity of Denver, CO. The Myocarditis Foundation was nominated when a family of the Rapids soccer team lost their young daughter earlier this year to myocarditis. The team sprang into action and dedicated their 2013 season to raising awareness of myocarditis.

The Teammates for Kids Foundation is a national non-profit that is dedicated to helping kids. They focus on helping children in the areas of health, education, and inner-city outreach. Teammates for Kids was started in 1999 by Bo Mitchell and Garth Brooks, with the goal of giving all kids, all around the world, an even start. More than ten years later, Teammates has raised over $80 million to help children in over 60 countries around the globe.

The Kroenke sports Charity is the official charity of the Denver Nuggets, Colorado Avalanche, Colorado Rapids, and Colorado Mammoth. Kroenke Sports Charities is committed to improving the lives of families and children in Colorado. They are dedicated to investing in the education, heath, and sports programs for the Colorado community and works to support nonprofit organizations aligned with their mission. During the 2010-11 season, Kroenke Sports Charities and Teammates for Kids awarded grants totaling $30,000 to nonprofit organizations.

Kroenke Sports Charity awarding a check to representatives of five charities, including the Myocarditis Foundation at the Colorado Rapids Half-Time Ceremony

Lindsey Davis, Director of the Myocarditis Foundation, attended the August 17th home game for the Rapids and accepted the grant during the halftime program. The Myocarditis Foundation was among five charities that were awarded grants from the Teammates for Kids program. The Myocarditis Foundation is honored to be awarded this grant and look forward to a long relationship with the Colorado Rapids and their associated charities.

Myocarditis Foundation Fundraising and Awareness Events for Winter 2013/2014

November 2nd – Lorton, VA: “Kamryn’s Diaper Drive”

Nov-Dec – Nanaimo, BC: “Dominique’s Dream

November 30th – Pinellas Park, FL: “Julian’s Memorial Fundraiser and Statue Unveiling”

December 28th – Willmar, MN: “3rd Annual Stephen Reynolds Alumni Hockey Game

January 11th – Edina, MN: Memorial Pond Hockey Tournament

Email Lindsey@myocarditisfoundation.org to learn more about holding an event and to get your event posted to our website.

Knowledge Nurtures Hope

Myocarditis Patient Survey

For Patients:

Click the Myocarditis Patient Survey tab on our Home Page and complete the online form. The purpose of the questionnaire is to try to capture the impact that myocarditis has had on your life. Your perspective is vitally important to others who are trying to understand the seriousness of the disease.

Discussion Forum

For Patients and Families Who Have Lost Loved Ones to Myocarditis:

Click on the Community Discussion Forum tab on our Home Page to join our online Support Group.

Visit our Facebook page
Join in discussions & find out about current events

Find us on Facebook

Research

For Physicians:

We will be accepting applications for Research Fellowship Grants. The stipend will be $35,000 for the 2014/15 academic year. The deadline for application submission is December 1, 2013. Click on the Research tab on our Home Page to access online Research Fellowship Guidelines and Application Form.

www.myocarditisfoundation.org
1-732-295-3700

THE MYOCARDITIS FOUNDATION

Board of Directors

Leslie T. Cooper, MD
Director, Gonda Vascular Center
Mayo Clinic, Rochester, MN

Monte Willis, PhD, MD
Associate Professor
McAllister Heart Institute, Chapel Hill, NC

James and Candace Moose
Point Pleasant, NJ

Clement Weinberger PhD
Prague, Czech Republic and Smoke Rise, NJ

DeLisa Fairweather, PhD
Myocarditis Researcher
John Hopkins University, Baltimore, MD

Lori Blauwet, MD
Cardiovascular Diseases Associate Consultant,
Mayo Clinic, Rochester, MN

Joseph Rumore
Parsippany, NJ

Micheal Austry
Dallas, TX

Louis Romano
River Vale, NJ

Director

Lindsey Davis
Rochester, MN

Medical Advisory Board

Dennis M. McNamara, MD
Associate Professor of Medicine
Director, Heart Failure Section
Director, Cardiomyopathy Clinic & Heart Failure Research Program
Cardiovascular Institute at University of Pittsburgh Medical Center Presbyterian

Akira Matsumori, MD
Department of Cardiovascular Medicine
Kyoto University Graduate School of Medicine

Bruce M. McManus, PhD, MD, FRSC, FCAHS
Professor & Director, The James Hogg iCAPTURE Centre
University of British Columbia-St. Paul's Hospital
Scientific Director, The Heart Centre-Providence Health Care

Steven D. Colon, MD
Professor of Pediatrics at Harvard Medical School and
Associate Chief of Cardiology at Boston Children's Hospital

Financial information about this organization and a copy of its license are available from the State of North Carolina Solicitation Licensing Branch at 800-830-4989. The Myocarditis Foundation is also a licensed charity in the states of New Jersey & Minnesota. For more information in NJ, please contact The NJ Office of Consumer Protection at 973-504-6215.

For Elysa

Elysa Louise Rojas is a sweet, bright and beautiful little girl who was taken from our earth far too soon as a result of Viral Myocarditis. Over the course of very routine-looking childhood illness, Elysa's condition took a turn for the worse. Less than 9 hours into medical intervention in the ER and PICU, Elysa's heart suddenly went into an irreversible arrythmia. Healthcare providers had never considered Elysa's heart to be a possible cause for her illness and were absolutely shocked when her heart suddenly stopped functioning. While the medical treatment she received was perfectly appropriate for 99% of cases presenting as she did, this medical intervention in fact worsened her condition and actually initiated the fatal heart arrythmia that abruptly ended her life just prior to her 3rd birthday. Her family and friends were left with so many questions, completely heartbroken and wondering how this could happen to the healthy little girl who brought so much joy and sunshine to their lives. Her family is establishing a foundation based upon Elysa's initials, dedicated to improving **E**ducation of healthcare providers and the community, providing **L**ight to families affected by pediatric cardiac conditions and promoting **R**esearch around the diagnosis and treatment of myocarditis. Through the work of "For Elysa," our hope is to continue to fulfill the bright future and promise of our sweet angel.

Thank You

A big thank you to the many families and organizations who have made 2013 such a success for the Myocarditis Foundation. A special thank you to:

St. Jude Medical Foundation
Kronke Sports Charities
Denver Rapids
Rapids Sidekicks
Ellie and Ty Moose
The Winans Family
Rylan Otoyic-Martin's family and friends
The Boslem Family
The Rojas Family
The Knight Family
Luke Gould's family and friends
Ashly Orme's family and friends
Andy Pena's family and friends
The Vanness Family
The Moreland Family
Mark Summers' family and friends
Nathan Roark's family and friends
Kevin Gollogly's family and friends
Mark Austry's family and friends

Susan and Greg Knight at their highly successful Sarah Knight Memorial Golf Tournament in Iowa

Blogging from the Myocarditis Foundation

Keep up-to-date with all the happenings of the Myocarditis Foundation by following the Foundation's blog! Visit our website: www.myocarditisfoundation.org and click on our Blog to read all the latest research findings, learn about fundraising events, and keep current with myocarditis and Foundation news.

West Coast Cycle for Myocarditis


Carly Davis entering into California on her bike ride down the West Coast

On July 24th, 2013 four students from Pacific Lutheran University (PLU) embarked on a month-long bike-ride down the West Coast of the United States. Carly Davis, Kyle Curtin, Ryan Read, and Chiara Rose-Whitt departed from Pacific Lutheran University in Tacoma, Washington and rode the entire length of Highway 101 to the boarder of Mexico in San Diego, California, all while raising awareness and funds for the Myocarditis Foundation.

Carly became interested in myocarditis when her older sister, Lindsey Davis took the job as Director of the Myocarditis Foundation. Carly decided to combine her love of the outdoors and adventures with raising money in honor of the many patients and families affected by myocarditis. The four students had graduated in the spring of 2013 and they decided this epic adventure would be a perfect way to pay tribute to their four years of college.

They rode every day, seeing new sites, meeting new people, and telling those they met about the disease myocarditis. At the end of their trip, they raised over $900 for the Myocarditis Foundation. You can read about all of their adventures and see the beautiful photos on their website: westcoastcycleformyocarditis.wordpress.com

Myocarditis Foundation's YouTube Channel

The Myocarditis Foundation is now on YouTube! Visit our homepage and click on the YouTube icon to view the Myocarditis Foundation's channel.

You will find videos submitted by families in honor of a loved one or inspiring videos of survivors. The Myocarditis Foundation also has posted all the talks from our first annual Family Support Meeting. If you would like to add a video, please contact us.


Ryan Read, Carly Davis, and Kyle Curtin stopping to take in the view on their cycle adventure for myocarditis

Local residents raise awareness, funds for Myocarditis Foundation

By Breanne McCarthy

POINT PLEASANT — On Saturday evening, Point Pleasant resident Candace Moose held a fundraiser in her home to help raise funds and awareness for the Myocarditis Foundation [MF].

Dr. Leslie Cooper [from left], medical director of the Gonda Vascular Center at the Mayo Clinic in Rochester, Minn., and co-founder of the Myocarditis Foundation, presented Tyson Moose, 5, of Westfield, Clancy Chichetti, 14, of Woodcliff Lake, and Elizabeth Jane Moose, 8, also of Westfield, with certificates of appreciation after the children raised $1,175 for the foundation during a bake sale held in Point Pleasant over Labor Day Weekend. *Photo courtesy CANDACE MOOSE*

Mrs. Moose said myocarditis is inflammatory heart disease which is the cause of sudden death in approximately 5 to 20 percent of healthy young people, and said the number may even be higher.

She said she originally got involved with starting the foundation seven years ago after she was diagnosed with myocarditis. Her diagnosis came more than 12 years ago.

"I am a victim of the disease," she said. "I had a catastrophic form of the disease 12 years ago which led to a heart transplant."

Mrs. Moose said after being diagnosed she went through seven weeks of multiple critical events and visited three different hospitals.

She then came across a doctor — Dr. Leslie Cooper, who is also the medical director of the Gonda Vascular Center at the Mayo Clinic in Rochester, Minn.

Mrs. Moose said Dr. Cooper's research helped her by treating her with chemotherapy to "turn down" her immune system, which then acted as a bridge for a heart transplant.

While in recovery, Mrs. Moose was so grateful to Dr. Cooper that she asked what she could do to pay him back. He said a foundation needed to be set up to spread awareness because — at the time — little information about the disease had been available online.

Mrs. Moose then worked pro bono as director of the foundation until this past January. She said she felt a bit tired after dedicating seven years toward the foundation and said she wanted to bring in someone with fresh ideas to fill her position.

The foundation seeks to increase awareness of the disease through its website, myocarditisfoundation.org, and by hosting events all over the country.

"The MF exits to educate physicians and the public about this rare disease, to raise money for research and to support the patients and families who have been affected by the disease," she said. "The goal is the foundation is to save more lives from the disease. The MF is the only organization nationally or internationally that is exclusively dedicated to this disease."

Over the years, she has held several fundraisers to raise awareness of the disease.

Continued

Continued

Local residents raise awareness, funds for Myocarditis Foundation

Mrs. Moose said her grand-daughter, Ellie Jane Moose, 8, had seen her on television while on Fox 5 News in October 2012 doing a segment on myocarditis, and became convinced she was a celebrity and wanted to raise money for her cause.

So over this past summer, her granddaughter Ellie and her two helpers, brother Tyson Moose, 5, and Clancy Chichetti, 13 — who are all summer residents of Point Pleasant — decided to hold a fundraiser.

The children held a bake sale at the Water's Edge community in the borough over Labor Day Weekend and raised $1,175 for the foundation.

To commemorate the children's efforts, the Mooses held a fundraiser event Saturday evening at their home.

Friends and neighbors were invited, including those from local churches, local vendors and local families who have experienced the loss of a child due to the disease.

There were no ticket prices, however, donations were being accepted and there was an auction of some donated goods to help raise funds.

At the event, Dr. Cooper gave the three children a certificate of appreciation showing the foundation's gratitude for their efforts.

For more information on myocarditis, visit myocarditisfoundation.org.

Courtesy of Star News Group

Board News

The Myocarditis Foundation is excited to announce that we are expanding our board of directors. We are looking for board members with the following skills: fundraising, marketing, law, professional athletes or coaches, and finance. We would like to draw from both the general public and people who have been affected by myocarditis. Board members are expected to: attend a minimum of two in-person meetings a year and monthly phone conference meetings, serve on at least one committee, be a donor and pay their own way to the meetings, and help to promote awareness of myocarditis. We are looking for all ages, races, and can reside anywhere in North America.
We are also thrilled to announce that for 2014: Dr. Leslie Cooper of the Mayo Clinic will serve as our Medical Director, Mrs. Candace Moose will be the Board Chair, and Ms. Lindsey Davis will continue as our director.

If you would like to be considered for board membership or know someone we should reach out to, please contact our governance consultant, Carol Weisman, carol@BoardBuilders.com or 314 863 4422.

Myocarditis Foundation and Heart Failure Society of America Joint Symposium on Myocarditis

Lindsey Davis managed the booth at the HFSA Annual Scientific Meeting

The Myocarditis Foundation was asked by the Heart Failure Society of America (HFSA) to hold a joint symposium on myocarditis at their annual scientific meeting. Dr. Leslie Cooper, President and Founder of the Myocarditis Foundation and Professor of Medicine at the Mayo Clinic, selected the speakers and topics for the event held on September 22nd in Orlando, Florida.

The speakers included experts from around the world who specialize in myocarditis and all presented on topics of myocarditis diagnostics, treatments, or research. This symposium was open to all attendees of the HFSA meeting, as was attended by approximately 250 physicians and researchers.

In addition, the attendees were also able to browse the many research projects completed by grant recipients of the Myocarditis Foundation. Each of the Myocarditis Foundation's researchers were able to display a poster of their research and answer questions about their research prior to the start of the symposium. This was an excellent way for the Myocarditis Foundation to showcase the many research projects that they are able to fund, as well as bring awareness to the exceptional quality of the grants the MF awards each year.

The HFSA's meeting ran from September 22nd through September 25th, featuring talks from experts around the world on topics related to heart failure. HFSA was extremely generous and granted the Myocarditis Foundation a free booth in their Exhibit Hall. Lindsey Davis, Director of the Myocarditis Foundation, along with MF volunteer Audrey Davis, managed the display booth for the length of the meeting. The booth was extremely well attended and proved to be effective in providing the heart failure community an understanding of the Myocarditis Foundation's mission and the many resources it has for both the medical community as well as their patients. Hundreds of physician, nurses, researchers, and other healthcare professionals stopped by, asked questions, and took information for their offices and patients around the world

The Myocarditis Foundation was honored to be part of the Heart Failure Society of America's annual conference and look forward to an ongoing partnership dedicated to the awareness and research around sudden death, heart failure, and myocarditis.

Dr. Leslie Cooper speaking at the HFSA and MF Joint Symposium

Couple Donate to the Myocarditis Foundation in Lieu of Wedding Favors

Paige Veronie contacted the Myocarditis Foundation in August of 2013, expressing her desire to donate to the MF in lieu of wedding favors for her and Kevin's upcoming wedding. Paige tragically lost her sister, Meghan, to myocarditis and wanted to be sure that the organization that has supported them and countless other families were recognized and honored as part of their wedding. Below is a short interview with Paige and Kevin as they explain their connection with the Myocarditis Foundation. Best wishes to the happy couple and we wish you a lifetime of love and happiness.

Q: When and how did you and Kevin meet?

A: Kevin's older brother, Keith, and my older sister, Meghan, were best friends and when Kevin and I were just 12 years old they decided that we would marry each other. We didn't officially meet until my sister's 21st birthday, when we were freshman in college. Kevin's brother had passed away the year before so Meghan made it her mission to set us up. When we finally met for the first time there was an instant connection. It wasn't exactly love at first sight, but there was a strange bond between us that we didn't even recognize yet.

Paige and Kevin

Q: When and where is the wedding?

A: March 8, 2014 at Royal Oaks Country Club in Houston, TX

Q: Why did you choose to give to the Myocarditis Foundation in lieu of wedding favors for your wedding?

A: Our wedding has been a long time coming and we want it to be the most special day of our lives. Wedding favors are nice but we want people to remember what is important to us on our wedding day. The Myocarditis Foundation is very close to our hearts. My sister, Meghan, passed away four years ago from Myocarditis. She was 23 years old and so full of life. It has been a tough road for my whole family, including Kevin. He thought of her as a sister and misses her as much as I do. We believe what the Myocarditis Foundation is doing is very important and will always do anything we can to support this organization.

Q: What are your hopes for the future of the Myocarditis Foundation and for the disease itself?

A: Our hope for the foundation is growth. The mission of the MF is very important. More people need to know about the disease and how it affects patients and their families. Many lives have been turned upside down because of this disease and very few people even know about it. The research on diagnosis and cures is also imperative so that this disease will hurt less people in the future.

How You Can Help

The Myocarditis Foundation is dedicated to supporting the patients and families affected by myocarditis and is the only organization that awards 100% of its research grants to myocarditis-specific research.
Consider donating to the Myocarditis Foundation today! Visit our website to donate online or to find more ways to support the Myocarditis Foundation in advancing their awareness and research programs.

Myocarditis
An Essay Written by Keri Behles in Memory of Fellow Friend and Classmate, Rhett Lundy

You are at your best friend's funeral. Your friend was perfectly healthy, besides a heart condition which they had medication for, got good grades, and never did any drugs, so how could something like this happen as if out of no where? When the autopsy results came back it was discovered that your best friend had myocarditis. Your best friend had been misdiagnosed with a common heart condition. You just lost your best friend to a curable disease, a disease that is rare and often misdiagnosed. Myocarditis foundation has been funding research that could've saved your best friend's life if more people knew about the disease and donated towards research for it.

Myocarditis, by definition, is a disease marked by inflammation and damage of the heart muscle. Myocarditis, although curable, is a very deadly and terrifying disease as it, more often than not, has no symptoms. So someone standing right next to you could have myocarditis and not even be aware of it, they could even believe that they have a completely different type of heart defect or disease. Myocarditis can only be identified by an electrocardiogram or by blood tests that detect heart injury. Research is still being done to find the best way to diagnose and treat myocarditis.

The Myocarditis Foundation is dedicated to "increase awareness of this disease among medical professionals and the public in order to advance the development of accurate, rapid diagnostic methods and safe, effective therapies that minimize or eliminate myocarditis progression to heart dysfunction, failure, and sudden death." The money donated to this foundation will go towards research focused on finding better and safer treatment options, more efficient diagnostic tools, ways to prevent contraction of the illness, and making the public aware of this disease. The research this foundation funds could save thousands of peoples lives. By being able to diagnose patients properly and correctly, giving them specialized treatment, and working on finding a cure this disease can become nonexistent.

Last year, at South Elgin High School, a student died, three days before his birthday, from myocarditis. His name was Rhett and he was a shy boy who played snare drum on the drumline. His family was completely unaware of his heart condition. Rhett was only fourteen years old when he was killed by myocarditis. He still had a whole life to live when it was suddenly stolen from him. He wanted to ask the girl he liked out, go to prom, graduate high school, go to college, and live his life, but unfortunately his chances to do these opportunities was taken away from him by a disease he had no idea he had.

Some critics might believe that the American Cancer Society is more important than the Myocarditis Foundation because it affects more people, but I would argue that although more people are affected by cancer, thanks to foundations like American Cancer Society, many cancers can now be cured, where as myocarditis is a disease that still needs research in order to just simply diagnose it correctly. Most cancers, thankfully, can be easily diagnosed through specific tests, however myocarditis has to be tested with very precise and complicated tests, and even then finding the disease is very difficult, and it is often times confused with various different heart related diseases. Although the Myocarditis Foundation still needs a large amount of research toward the disease myocarditis, more people are diagnosed with cancer than myocarditis, so the rate of death is higher than the rare myocarditis. However, even if the rate of death from cancer is higher than myocarditis, the rate of survival is much higher as well, and the long-term problems are less severe than myocarditis, as a person with myocarditis could have a chronically enlarged heart, and may need a heart transplant.

Myocarditis, although a rare disease, is a very random, invisible to the human eye disease that could kill someone before they even know they have. It is a contagious disease that can kill someone suddenly, without any form of symptoms. Unfortunately, this disease is hard to diagnose correctly from the lack of symptoms, and does not have any specialized treatment, nor a cure or any form of prevention.