



## The Myocarditis Foundation Launches its New Website

On October 11th, 2012, the Myocarditis Foundation launched a brand new website. Months of hard work finally paid off as we unveiled the website with much appreciation and positive remarks from those viewing it for the first time. The Myocarditis Foundation worked tirelessly collecting new content and incorporating innovative ideas and could not be happier with the results.

The Myocarditis Foundation hopes that this new website will help to increase awareness, further generous donations, provide more information to those seeking answers, deliver support for people all over the world, and also bring together the myocarditis research community.

This new website includes features like a blog (updated weekly), discussion forum, researcher's private forum, "share your story" section, translation for over 60 languages, social media links, You Tube channel, two new surveys, and in-depth information regarding myocarditis. Please visit the new website yourself and see all the new and improved features the Myocarditis Foundation has added.

Thank you for those who donated to help fund this gigantic, and much needed project!

[myocarditisfoundation.org](http://myocarditisfoundation.org)

The screenshot shows the homepage of the Myocarditis Foundation website. At the top is a blue navigation bar with links: Home, About Myocarditis, Research & Grants, Real-Life Stories, Forum, Blog, About Us, Get Involved, and Contact. Below the navigation bar is a large hero section featuring the Myocarditis Foundation logo on the left and a photograph of an elderly woman smiling at a baby on the right. A 'DONATE' button is overlaid on the top right of the hero image. Below the hero image is a tagline: "Dedicated to Providing Information and Support Related to the Causes, Symptoms, Diagnosis and Treatment of Myocarditis and Sudden Death." Below the tagline are four small thumbnail images with red captions: "I HAVE MYOCARDITIS", "I LOST SOMEONE TO MYOCARDITIS", "I'M A HEALTHCARE PROFESSIONAL", and "I'M A RESEARCHER". At the bottom left, there are social media sharing buttons for Tweet (2), Like (98), Google +1 (3), and a red heart 'DONATE' button. To the right of these buttons is a text box with the text: "103 have shared this with their friends". Further right is a newsletter sign-up form with fields for "Your Name..." and "Your Email Address...", a red "SIGN UP TODAY!" button, and a small note: "We respect your privacy".

Homepage of the new Myocarditis Foundation website



# The MYOCARDITIS FOUNDATION

## The Myocarditis Foundation Holds its First Annual Wines of South Africa Fundraiser

Dr. Leslie Cooper and Dr. Lori Blauwet, board members of the Myocarditis Foundation, held the first annual “Wines of South Africa” fundraising event in Rochester, MN this past October. Dr. Blauwet spent the past year living and working in South Africa and had visited countless wineries while there, bringing back home rare bottles of South African wine. She then donated many of the wines to the Foundation in hopes of raising money for the Myocarditis Foundation.

The night began with a talk from Karin Rost, a Giant Cell Myocarditis survivor. She reminded people why the research the Foundation does is so important and how grateful she is to be able to live her life to the fullest.

The night proceeded with professional food and wine pairings from South African wine expert, Roy Goslin. The evening concluded with a live auction of rare and usual bottles of wine paired with generous donations from the Rochester community including a trip for two to South Africa!

All proceeds of the event went to fund the Myocarditis Foundation in their efforts to achieve their goals and missions.



Table of rare South African wines for the live auction



Lori Blauwet at Contantia Mist Winery in South Africa



Lori Blauwet talking to South African wine expert, Roy Goslin



## Videos Needed!

The Myocarditis Foundation is collecting videos of patients and families who have been affected by myocarditis. We want to share with the world the devastating impact myocarditis has on both survivors of the disease and families who have lost loved ones to it. We will use the videos to further our awareness campaign in our mission to save more lives.

These videos will be put on the Myocarditis Foundation YouTube channel. We have a couple of videos currently posted, so please visit our website [www.myocarditisfoundation.org](http://www.myocarditisfoundation.org) for ideas.

These can be simple, short videos, made on cameras, phones, or camcorders. Once you have a video, please email it to Lindsey at: [Lindsey@myocarditisfoundation.org](mailto:Lindsey@myocarditisfoundation.org). We look forward to seeing your videos soon!

### Research Grant Application Deadline - December 2012

The Myocarditis Foundation is pleased to announce that it is accepting applications for two (2) 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 more lives.

- ♥ The Grant Overview, Grant Requirements and Guidelines, and the Grant Application are available at [www.myocarditisfoundation.org](http://www.myocarditisfoundation.org).
- ♥ The amount of the grant is \$35,000 for salary only.
- ♥ The deadline for grant submission is December 1, 2012.
- ♥ All applicants must select a preceptor with a proven track record of research in myocarditis.

If you have any questions, please contact Lindsey Davis at: [Lindsey@myocarditisfoundation.org](mailto:Lindsey@myocarditisfoundation.org) 732-295-3700

### Sunset on the Manasquan Fundraiser

Candace and Jim Moose hosted their annual fundraiser "Sunset on the Manasquan" this past September. Seventy people attended and the event made \$12,000, with all proceeds going to continue to fund the Myocarditis Foundation in their efforts to further their mission and goals.

Miles Shen, an ongoing myocarditis activist, played violin accompanied by his fellow Princeton University student on the piano. The guest speaker for the event was Giovanna Pena, who tragically lost her son in 2011. Her talk touched many people as she explained the profound effect this disease has on people and their families. Lastly, Hildegard Herb sold her handmade jewelry and donated all proceeds to the Myocarditis Foundation.

We look forward to next year's Sunset on the Manasquan and hope that it continues to be a successful event in the years to come.

### The Myocarditis Foundation's Annual Golf Event

Joe Rumore, board member of the Myocarditis Foundation and heart transplant recipient due to myocarditis, held the 5th Annual Myocarditis Foundation Golf Event which raised \$24,000 for the Myocarditis Foundation's mission and goals. Sixty golfers attended his New Jersey event, all of which came to show their support to the Foundation. Candace Moose, Executive Director of the Myocarditis Foundation and Giant Cell Myocarditis survivor, addressed this loyal group of supporters on this year's accomplishments of the Foundation and acknowledged what their support has meant to the Foundation.

Once again this yearly event helps the Myocarditis Foundation support research by providing grant funding. We can't thank the friends, family and associates enough for the support they provide the Foundation each year.. It is because of them that we are able to further the research that helps to answer all the unanswered questions that myocarditis presents.



# The MYOCARDITIS FOUNDATION

## The Kravitz Family Hosted the 6<sup>th</sup> Annual Devin Kravitz Memorial 5K Run/Walk

The Kravitz family held its 6<sup>th</sup> Annual Devin Kravitz Memorial 5K Run/Walk event this past September. Devin Kravitz passed away from myocarditis in October of 2006 and his family and friends have made it their goal to raise awareness for myocarditis in their hopes that they can “stop this horrible disease from claiming any more victims.”

This year they had over 300 people in attendance and had over 50 kids participate! They also received recognition from the University of Massachusetts. The Kravitz Family was mentioned when the President and CEO of UMass Health Care, John O’Brian, credited them with contributing to the awareness of Myocarditis, which has since saved more lives.

The Myocarditis Foundation would like to thank the Kravitz family for their outstanding awareness events and the money they have donated to the Myocarditis Foundation over the past six years. We could not fund the research we do or work to increase awareness without the support of families like theirs.



*Sue Hall and son Alex Hall, a myocarditis survivor, were among the runners in the 5K*

## Myocarditis Fundraising and Awareness Events Past and Upcoming:

### Past 2012 Events:

- **March 24th – Chicago, IL:** The Myocarditis Foundation Research Network Event
- **April 2011 – St. Louis, MO:** Public Health Awareness Event by Becky Wagner
- **April 26th – New York, NY:** Windows on the Hudson Event Honoring the Memories of Danielle Hymowitz, Melissa Sofia, Andy Pena, and Logan Sweet
- **April 28th – Flower Mound, TX:** Vanessa Hickey Birthday Celebration
- **April 29th – Darie May 28th – Wauwatosa, WI:** Marathon Drink Station to Honor Mary Ehrlinger
- **June 9th – Willmar, MN:** Stephan Reynolds Memorial Disc golf Tournament
- **June 18th – Allen Park, MI:** Dine to Donate at Applebee’s Restaurant in Memory of Ashley Orme
- **September 1st – Leicester, MA:** 6th Annual Devin Kravitz Memorial 5K Run/Walk
- **September 1st – Burnham, PA:** Memorial Motorcycle Ride
- **September 10th – Hamburg, NJ:** Joe Rumore Golf Event
- **September 21st – Texas:** Nursery School Fundraiser
- **September 22nd – Abilene, TX:** Myocarditis Awareness Event, with guest speaker Dr. DeLisa Fairweather
- **September 22nd – Taylor, MI:** 2nd Annual Ashley Day Orme Golf Outing
- **September 22nd – Buffalo, NY:** Pig Roast Event
- **September 27th – Marburg, Germany:** International Symposium of Inflammatory Heart Disease
- **September 28th – Point Pleasant, NJ:** Sunset on the Manasquan hosted by Jim and Candace Moose
- **October 6th – Burnham, PA:** Hot Dog Bash
- **October 26th – Mechanicsburg, PA:** Myocarditis Awareness Night
- **October 27th – Rochester, MN:** Wines of South Africa Fundraiser hosted by Dr. Leslie Cooper and Dr. Lori Blauwet
- **October 27th – Irving, TX:** Mark Austry Memorial Golf Event
- **November 8th – Irving, TX:** Chase Charity Fair

### Upcoming 2012/2013 Events:

- **February 9th, 2013 – Kewaunee, WI:** A Night to Remember Brad Vanness
- **April 2013 – Danville, PA:** Pediatric Update at Geisinger Health Center
- **April 12th, 2013 – Macon, GA:** Hearts and Heros Concert with Country Music Star Colt Ford
- **June 21st, 2013 – Marion, IA:** Sarah Knight Memorial Golf Tournament

Please email Lindsey at: [Lindsey@MyocarditisFoundation](mailto:Lindsey@MyocarditisFoundation) to add your event to our list!

### New Jersey

*Information filed with the attorney general concerning this charitable solicitation and the percentage of contributions received by the charity during the last reporting period that were dedicated to the charitable purpose may be obtained from the attorney general of the state of New Jersey by calling 973-504-6215 and is available on the internet at <http://www.State.NJ.US/lps/ca/charfrm.Htm>. Registration with the attorney general does not imply endorsement.*



### 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 2013/14 academic year. The deadline for application submission is December 1, 2012. Click on the Research tab on our Home Page to access online Research Fellowship Guidelines and Application Form.

[www.myocarditisfoundation.org](http://www.myocarditisfoundation.org)

1-732-295-3700

## THE MYOCARDITIS FOUNDATION

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Rochester, MN



# The MYOCARDITIS FOUNDATION

## The Myocarditis Foundation Attends the International Symposium on Inflammatory Heart Disease in Marburg, Germany September 20th-21st, 2012

The Myocarditis Foundation was asked to attend and provide support as a patron of Dr. Bernhard Maisch's Symposium of Inflammatory Heart Disease in Marburg, Germany. Dr. Leslie Cooper, president of the Myocarditis Foundation, was a guest speaker as well as many other world-renowned physicians from around the globe. It was a wonderful opportunity for this group of physicians and researchers, who specialize in this small area of inflammatory heart disease, to come together and discuss their ideas, research, and case findings. Topics of discussion included not only myocarditis and Giant Cell Myocarditis, but also pericarditis and cardiomyopathy.



*Dr. Cooper giving his talk on myocarditis at the symposium in Marburg Germany*

Lindsey Davis, Communications Coordinator of the Myocarditis Foundation, attended the symposium to represent the Foundation and to provide information about the services the Foundation offers and to give materials to these doctors and researchers from all over the world. The foundation was well received and a great interest was sparked in the work the Foundation does with not only their researchers, but also the many families affected by myocarditis. By having the foundation participate in this meeting, they have begun to reach out to the international community and can further their services to people around the world. The Myocarditis Foundation also made the beginning steps in creating partnerships with other organizations in countries across the globe. It is their hope through these growing partnerships they can find ways to support one another not only fiscally, but with ongoing research as well.



*Dr. Cooper and Lindsey Davis, Marburg Germany*

Opportunities like this could not happen without the support of the many families who donate to the Myocarditis Foundation. The Foundation would like to thank everyone for their continued support and look forward to attending symposiums in the future in an effort to spread awareness and bring further attention to this diseases that has such a pronounced impact on so many families.





## Introducing Myocarditis Foundation E-Newsletters

Along with the launch of the Myocarditis Foundation's new website, we will also have the availability of sending out a monthly e-newsletter! This will arrive at the beginning of each month, highlighting upcoming events, stories from the past month, and a letter from one board member per month, describing the work they are doing to further the mission of the Myocarditis Foundation.

If you are interested in signing up for the e-newsletters, please do so on our website's home page. If you would no longer like to receive the paper bi-yearly newsletter and instead switch to our monthly e-newsletter, please fill out the included card and mail it back to the foundation.

## Dr. Cooper's Speaking Schedule

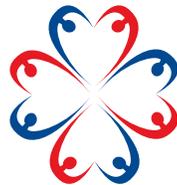
**November 5<sup>th</sup>, 2012** - Myocarditis: State of the Art American Heart association annual Scientific Sessions - **Anaheim, CA**

**December 7<sup>th</sup>, 2012** - Heart and Vascular Center Lehigh Valley Health Network - **Allentown, PA**

**January 15<sup>th</sup>, 2013** - University of Pittsburgh Medical center Cardiology Grand Rounds – **Pittsburgh, PA**

**February 20<sup>th</sup>, 2013** - Department of Cardiology Grand Rounds of The University of Texas MD Anderson Cancer Center - **Houston, TX**

**April 26<sup>th</sup>, 2013** - Ulyanovsk State University Nexus Medicus Conference State-of-the-art lecture: Myocarditis – **Ulyanovsk, Russia**



MYOCARDITIS  
FOUNDATION

## The Myocarditis Foundation Receives a Grant from the Asahi Kasei Kuraray Medical Company

The Myocarditis Foundation is honored to announce its acceptance of a \$5,000 grant from the Asahi Kasei Kuraray Medical Company in Tokyo, Japan. Asahi Kasei is a company dedicated to the advancement of science and technology in the medical field, and is a comprehensive leader in blood-related healthcare systems. The Foundation is grateful to have made this valuable connection with a company dedicated to saving more lives through their innovation of disease treatment and preventative medicine.

This generous grant from the Asahi Kasei Kuraray Medical Company will help the Myocarditis Foundation follow in its mission of providing relevant, accurate, and up-to-date information about the nature of myocarditis and its various presentations to medical professionals and the general public.

The Foundation thanks the Asahi Kasei Kuraray Medical Company for their award of this grant and look forward to working together in the future.

**AsahiKASEI**



# The MYOCARDITIS FOUNDATION

## Myocarditis Foundation Reusable Shopping Bags by *ChicoBag*™ ChicoBags for Sale!



The Myocarditis Foundation has partnered with the company ChicoBags to create an exclusive Myocarditis Foundation ChicoBag. ChicoBag specializes in offering fashionable, environmentally friendly reusable shopping bags that are designed to be unforgettable. The bags are the size of a regular plastic grocery bag, but can be used over and over and stuff into its own pouch to be carried easily wherever you go! ChicoBags are sold at specialty grocery stores around the country, but now you can have your very own with the proceeds going to support the Myocarditis Foundation!

We will be able to ship them the third week in December, just in time for the holidays! We will sell them each for \$20 or 6 for \$100. If you are interested in ordering, please email Lindsey at: [Lindsey@MyocarditisFoundation.org](mailto:Lindsey@MyocarditisFoundation.org).

## A Fundraiser for MY O CAR- WHAT?

Myocarditis, what a tongue twister of a word. A word that I never heard of until October 2010. A word that still I wish I had never heard of, I mean at least the way that I had to learn about it. Myocarditis broke my heart by being the criminal that stopped my sister's heart.

From the day my sister, Ashley Dale Slone-Orme, passed away until now, I have made it my goal to help raise funds and awareness for the Myocarditis Foundation. I can't control what happened and I can't control too much of the future. But I can control, plan and organize a fundraiser.

You may ask, "A fundraiser, why do you do it?" I do it because I don't want anyone to experience Myocarditis the way that my family and I did. I want people to know in advance. I want people to be aware. I want people to be informed. I don't want anyone to feel the heartache that I have to endure. By raising funds and awareness it's my way of remembering my sister. It's my way of keeping her in conversation. It's my way of helping others that want to keep going. It's my way of helping those living with Myocarditis. It's my way to continue to cope and to help others dealing with a loss to cope too.

Since I've lost my sister I have held the following events:

- ~ The Ashley Dale Orme Golf Outing and Silent Auction at the Lakes of Taylor sponsored by The Olympia Group
- ~ 50/50 Raffle
- ~ Dine to Donate & Bake Sale Event at Applebee's Allen Park
- ~ Cedar Point Tickets Raffle
- ~ Dinner Benefit and Chinese Auction at the Taylor Meadows sponsored by The Olympia Group
- ~ Nominated the Myocarditis Foundation for a charity funding from the North West Suburban Mothers of Multiples Group

...and I'm still not done. Some ideas I have for additional events are a Road Rally, a Black Tie or Masquerade Ball, a Mom to Mom Sale, a Limo Bus Casino Trip, a Mini Golf Tournament, a Bowl-a-thon, a Car Wash, a Lemonade Stand. The possibilities are endless.

So, if you are thinking of fundraising for Myocarditis, you should. It's the first step that's the scariest but once you've put together your first event the rest are so much easier. Be sure to enlist your friends and family to help you, typically they are ready, willing and able. Plus, so many places assist you from start to finish, the golf courses, the restaurants, the local businesses. The feeling you have once you've sent in the donations is uplifting. It doesn't bring a loved one back but it does make your heart smile. And a smiling heart is a beating heart. My heart is smiling thinking of your thoughtfulness and desire to host a fundraiser for this worthy cause.

Thank you and best of luck with your fundraiser.

Sincerely,

Leslie McCarthy  
Brownstown, Michigan



*Ashley Dale Slone-Orme- Sister of Leslie*

*McCarthy: The reason I Fundraise*



# Remembering Melita

By Lita Warmbold



Melita Warmbold

Our daughter, Melita passed away September 21, 2011, so this past year my husband and I have spent the majority of our time simply trying to heal, learning to accept and live in our new reality the best we can. The entire process has been more of a wave we have ridden, as opposed to an experience we willingly participated in.

The first wave being “What happened?”, “Why her?” and the answer being one we didn’t even know existed: Myocarditis, Viral Myocarditis. The second being “How?” The answers came crashing down on us and more of the reality became apparent. The over use of antibiotics, the lack of knowledge in the medical community regarding presentations and treatment of Myocarditis, the list goes on. As we became more aware of Myocarditis and those that have been affected by it, primarily due to the Myocarditis Foundation, those around us wanted more information and the process of giving back began.

Our daughter went to a wonderful daycare and the staff, parents and administration were the most concerned about accurately understanding what happened. Therefore we decided to have an event for a speaker to come in and address those interested in additional information. The church that the daycare is a part of offered the space and the Myocarditis Foundation offered the speaker, Dr. DeLisa Fairweather. We decided to sell T-Shirts at the daycare and at a local retail shop to raise money that could be given back to the Myocarditis Foundation. We chose to hold the speaking event the evening before the one-year anniversary of our daughters passing. We had approximately 35 people in attendance and raised about \$2,000. The following day a memorial bench dedication was given at the daycare and a carnival for all the kids was given in honor of our daughter. Though our goal for both attendance and dollars given was larger than the actual amounts, we have come to pray for acceptance that the seed of knowledge was planted in those who were in attendance.



T-Shirts made for fundraising in honor of Melita

Every second of every day we long for our daughter with an ache so tremendous it overwhelms us, we have had to reconcile every single action and decision we made the day our daughter passed. Whatever we can do to minimize this for another parent is our goal.



Brian Barndt at the 2012 Transplant Games

## Myocarditis Survivor’s Medal Count

Brian Barndt from Wake Forest, NC, attended the US Transplant Games in summer 2012 and added 8 more swimming medals to achieve his impressive total of 20 medals overall from both the US and World Transplant Games in 2006, 2008 and 2012. Brian suffered from Viral Myocarditis in his youth and required a heart transplant in his 30’s. He is a pastor and father of two. Go Brian! Continue to inspire us all.



## Girl's Death Inspires Three Prong Attack on Disease that Claimed her Life

By Jen Wagner



Balloon launch in memory of Cathrynne Wagner

Cathrynne was only 2 ½ when she succumbed to Myocarditis. She hadn't been sick three days when she went into cardiac arrest. What appeared to be a simple stomach virus was actually a virus invading her heart. How could a stomach virus lead to her death? How could it be so hidden that her parents and three doctors couldn't see it?

That is what my husband, Tom, and I have been asking for the last 6 months. Our daughter was healthy one day, sick the next, and then gone. It left us reeling. How did we not see this coming? We questioned our parenting. We talked to the coroner, her pediatrician, and the Myocarditis Foundation.

We were not about to let Cathrynne die and do nothing about it. So, we launched activities that paid tribute to Cathrynne, raised money to help fund research for a cure, and raised awareness of the disease.

### Memorial

Cathrynne's birthday came on Labor Day. She would have been three years old. Rather than let the day come and go with sadness, we decided to celebrate her birthday. Tom's cousin decided to organize a motorcycle ride for Cathrynne. With the roar of engines, they would ride to our house on the day of her birthday party. After they arrived, our family and friends, all dressed in pink t-shirts we had made with her image on them, would eat a potluck meal and talk about her life. Sitting nearby was a display of countless pictures of her and information about the disease. After eating the meal, we released pink butterfly balloons into the sky with postcards attached. The postcards included info about the disease, her story, and notes written to her that would travel to heaven on the balloons.

We also began "Gifts from Angels." Instead of spending the holidays being sad about loved ones being in heaven, grieving families can now purchase a gift for or from their lost loved one and send it to a child spending the holidays in the hospital. It not only comforts grieving families, but it makes the holidays brighter for sick children.

### Fundraising

As mentioned earlier, a motorcycle ride was organized in Cathrynne's honor. The motorcycle club accepted riders of all kinds for \$10/person. Every motorcycle rider was able to purchase a t-shirt to wear on the ride. Between the funds raised by the motorcycle club and a donation from the local VFW, we were able to raise \$3,000 on that day. If possible, we hope to make the motorcycle ride an annual fundraising event and call it, "Ride for Rynne."

To memorialize Cathrynne, we decided to create t-shirts and wristbands with Cathrynne's image and name on them. From the minute we mentioned on Facebook that we had t-shirts and wristbands made, we have had continuous orders for them. We made \$600 in profits from the t-shirts and bracelets alone! All of this money was raised to fund Myocarditis research.

Cathrynne's grandmother, Peg, wanted to raise as much money as she could to help fund research on the disease. So, she planned a raffle and auction in Cathrynne's honor. The day included a hot dog meal, a ticket raffle, a Chinese ticket-style auction, a 50/50 drawing, and face painting/sand art for children. All of the raffle items and food were donated by families and businesses in her local area. When the day was done, she had raised over \$4,000 for myocarditis research. The best part of all is that the money raised that day was entirely profit because everything was donated!

### Education and Activism

Since Cathrynne's death, we have set up a table at our local community days. People could view the "Not a Blank Canvas" poster series, pick up fliers, ask questions, and make a donation to the foundation.

Since Cathrynne died of a disease that is so rare and unheard of, we contacted the CEO of the major medical center in our area and brought to their attention that she died of a disease that no one recognized until after she had died. After what seemed like months, the Chairman of Pediatrics at the hospital wrote us a letter thanking us for making



them aware of the need for education of their doctors and committed to bringing an expert in for their annual pediatric conference. He also offered our family the opportunity to participate in Children's Miracle Network to advance awareness of myocarditis and to raise funds for the disease.

In response to efforts in NY State to raise awareness for the disease and not let another child die of "undetermined causes" like Luke Gould, we contacted our PA senator and representative to ask them to nominate a Myocarditis Awareness Day in Pennsylvania. We decided that April 28<sup>th</sup> would be a good choice because it was the day before Cathrynne died and if there had been awareness of the disease and a cure, she might have survived her trip to the ER the next day. We are currently in the planning stages of this day with Representative Adam Harris. This day will end at a local restaurant, which will donate a portion of their profits for the day to the Myocarditis Foundation and a candlelight vigil at Cathrynne's grave.

Cathrynne's death has affected many in our area. Two high school students from our area have chosen to complete their Senior Project on Myocarditis. Both are hosting "Gifts from Angels" boxes in their local high schools. They both have different ideas of how they will spend their time. Their ideas include an all-night volleyball game, a candy sale, and a letter writing campaign.

While we have just joined the fight against myocarditis, our efforts prove we can be mighty. With each awareness activity we give this cowardly killer one less place that it can hide. Once it is out in the open, we can fight it with a cure. Cathrynne can't come back, but we can pay tribute to her life and use our grief as fuel to stop this from happening to another child.



*Wagner family receiving a check for the motorcycle ride fundraiser*

## Sarah Knight

By Susan & Greg Knight of Marion, Iowa



*Sarah Knight*

On September 26, 2011, one word – myocarditis - changed our lives forever. At the time we did not know the disease or how it steals the lives of children and young adults without symptoms or warning. Now the word strikes fear and sadness in our hearts.

Our daughter, Sarah, was the kind of person who would light up a room. Her energy and enthusiasm for life were contagious. Her BIG laugh was something we loved most about her. Sarah was a bi-lingual kindergarten teacher just starting her second year of teaching. She had a passion for children and poured her heart and soul into her career. She truly loved her students and worked hard to make learning fun.

On September 26, 2011, Sarah spent a typical day as a kindergarten teacher in East Milone, IL. 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 lying on her classroom floor where she had simply laid down and died. The weekend before she and her boyfriend were home to visit. We went to a college football game, shopped for Halloween decorations for her classroom, spent time laughing and enjoying each other's company. Twenty-four hours after she left home, she was gone. No illness, no symptoms, no worries in the world the day before. We could not have suffered a bigger shock.

Thanks to a very diligent coroner, who was determined to find the cause of Sarah's death, we learned of myocarditis. Since then we have met other families devastated by this disease. We hope Sarah's story will bring an awareness of myocarditis and help support research so that no more precious lives are lost. Sarah brought joy to many people during her short time on this earth. Our world is much too quiet now; there are no words to express the hollowness we feel without her.



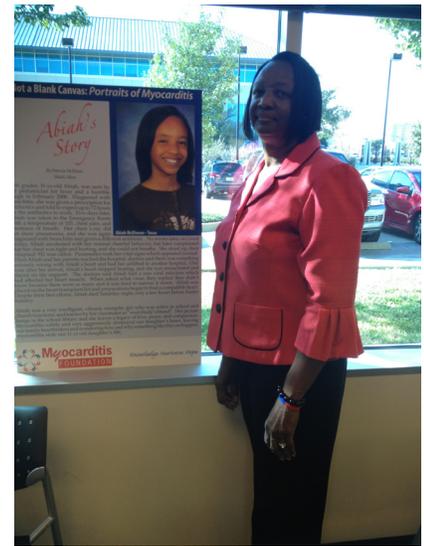
## Charity Fair

Patricia McElveen, employee of Chase Bank, created a booth for the Myocarditis Foundation at the Chase Charity Fair, held on November 15<sup>th</sup>, 2012 in Irving, TX. The Charity Fair was an opportunity for Chase Employees to showcase their favorite non-profit organizations, and ask for donations from fellow employees. Then, Chase will match up to \$1,000 per employee's donations.



*Patricia McElveen with her co-workers at the Chase Charity Fair in Irvine, TX*

Patricia became involved with the Myocarditis Foundation in 2008 when her eleven-year-old daughter, Abiah, died suddenly of myocarditis. Patricia shares, "Myocarditis subtly and very aggressively destroyed our daughter's heart, leaving our family heartbroken and wondering how and why something like this can happen." Patricia and her family are now advocates for myocarditis awareness, always finding ways to get the word out about this horrible disease on behalf of the Myocarditis Foundation.



*Patricia McElveen with her daughter Abiah's poster*

Patricia was able to share her story with over 100 employees at the Charity Fair, raising medical awareness and asking for donations for the Myocarditis Foundation.

## Wedding Donation Made by Young Couple

Ronnie and Leah met through a mutual friend about 2 years ago and were wed in October of this year in Lehigh Valley, Pennsylvania. The couple chose to donate to the Myocarditis Foundation in lei of wedding favors for their guests.

When Leah was asked why she and Ronnie chose to donate to the Myocarditis Foundation she responded, "The Myocarditis Foundation has a special place in my heart. My younger brother was diagnosed with Myocarditis in 2006, at the age of 18. It was determined his Myocarditis was caused from the Mono virus. He went through an extremely long recovery. Last year we found out that his heart had fully recovered. The Myocarditis Foundation was there for my family when we needed them most. They answered any and all questions and also provided information and hope for the future."

Leah continues, "My hopes are that one day there will be a way to detect Myocarditis earlier. My brother's symptoms resembled nothing more than the flu. I have a heath background and for some reason I just knew something wasn't right so I was able to convince him to go to the hospital. We got to the hospital just in time, his heart, kidneys, and lungs were already failing. I hope that future research will provide early detection methods and hopefully one day a cure. I think the most important aspect to fighting Myocarditis is awareness. Many people do not know what Myocarditis is, yet alone the symptoms. I hope that the Myocarditis foundation can continue to educate people on this disease can continue to be a resource for those who need them."

The Myocarditis Foundation in honored to be part of such a monumental event in Leah and Ronnie's lives, and are overjoyed at the news of Leah's brother's recovery. The Myocarditis Foundation wishes the couple a beautiful future filled with love and happiness.