



## A Letter from the President of The Myocarditis Foundation:



This Spring I would like to thank the donors who have made it possible to accomplish our Foundation's mission of support, education and research in the past year. Through your generous gifts of time, money, and in-kind donations we were able to achieve a great number of wonderful accomplishments. First, we funded two new research grants awarded to well deserving candidates dedicated to myocarditis research. We also started an alumni network of past grant awardees and sponsors to encourage mutual support and to help mentor new grant recipients. Another triumph is that we were able to produce two new educational brochures designed for medical providers on pediatric and adult myocarditis. We continue to provide support to physicians and families and offer them up to date information on myocarditis by contacting our office and board members through email and our 800-number. In addition, our web site hosted over 50,000 unique visitors in the past year and our forum for patients and their families to share their experiences with myocarditis is ever growing.

The Myocarditis Foundation relies entirely on your gifts for our day-to-day operations. Ours is the only organization dedicated entirely for the benefit of myocarditis patients and their families. A gift to the Myocarditis Foundation goes directly to help support and educate myocarditis patients, their families, and caregivers. Please consider a gift this year, either as an unrestricted donation to support our current programs or in support of the Foundation endowment that we hope will sustain our mission in future years. In these challenging economic times, a planned gift in the form of appreciated assets, a life-income annuity, or a tax-exempt bequest can allow for a larger gift without affecting your current income.

On behalf of the Board of Directors, I want to thank each of you who have given to the Myocarditis Foundation and tell you how much your generosity has helped the worldwide community we serve.

Gratefully,  
Leslie T. Cooper, MD  
President, MF

### Schedule of Dr. Cooper's speaking events:

June 7th, 2012  
15th Annual Toronto Heart Summit  
Toronto, CA  
Myocarditis Leading to Dilated  
Cardiomyopathy

July 27th, 2012  
University of Cape Town  
Cape Town, South Africa  
Myocarditis

October 12th, 2012  
Medical Grand Rounds  
Mayo Clinic in Arizona  
Scottsdale, AZ  
Myocarditis 2012 Update

July 19th-22nd 2012  
13th Annual Congress of the South  
African Heart Association  
Sun City, South Africa  
Four lectures on Myocarditis and  
Cardiomyopathy

September 21, 2012  
International Symposium on  
Inflammatory Heart Disease,  
Marburg, Germany  
Giant Cell Myocarditis



# The MYOCARDITIS FOUNDATION

## Hold A Fundraiser!

The Myocarditis Foundation has forever dedicated itself to the goal of saving more lives. The only way we can accomplish this is by raising money to award research grants to doctors across the country who dedicate their time to research causes, diagnostic tools, and treatments for myocarditis.

However, we need your help to raise money. Please consider holding an event in your community to help support the continuation of The Myocarditis Foundation and its research!

Any event, large or small, can make a difference. These are just some ideas from events families have held in the past:

- Golf outings/tournaments
- Run/walk/5K/10K events
- Sponsoring a booth at a marathon, town festival, or county fair
- Holding a wine and cheese party in your home
- Have an exercise party
- Have a garage sale
- Hold a local concert

The foundation will be able to supply you with our Not a Blank Canvas posters as well as informational materials. The websites: [networkforgood.org](http://networkforgood.org) and [activenetwork.com](http://activenetwork.com) are great ways for collecting donations for the foundation. If you would like to hold an event or would like more information please contact Lindsey Davis at [lindsey@myocarditisfoundation.org](mailto:lindsey@myocarditisfoundation.org) or call the foundation at 866-846-1600.

### Logan Sweet's 5K fundraiser



left to right: Alex Hall, Carolyn Sweet, Stewart Kravitz, and Sue Hall

*"I do not have to spell check diabetes, and hope someday (I) will not have to spellcheck myocarditis."*

*- Joe Skowronski*

### Dallas Rock & Roll Half Marathon awareness booth in Memory of Mark Austry



left to right: Mary Belkin, Lindsey Davis, and Michael Austry (brother of Mark Austry)

**\*\*The Myocarditis Foundation will be launching a new and improved website in the coming months. It will include all the information on our current website, but will include new sections, more information, and a refreshed layout. We are excited for this change and will keep you updated on our website and facebook page when the change over will happen.**





## Our Story



Andy Pena

It was supposed to be a wonderful weekend. Our family had traveled to Boston to watch our younger son compete at a swim championship meet. On Friday evening March 25, 2011 we had joined over 40 parents and kids from our town swim team for a celebratory dinner at an Italian restaurant. Everyone was happy, laughing, cheering. Our older son Andy was thrilled to be with his close friend, with whom he planned to tour Boston. One month short of turning 15, Andy felt independent, responsible and free. After dinner we all returned to our hotel and while parents gathered together the kids swam and cheerfully played games at the gym pool. Because Andy was very tall, everyone wanted to be on his shoulders during a game of "chicken fight". He was laughing and screaming hard, having a blast lifting and splashing little kids in the water.

Andy was an avid athlete, a swimmer and a runner. The high school outdoor track season was starting and he was eager to run a mile under six minutes. After swimming he jumped on a treadmill and ran hard, determined to reach his goal. His last words to his friend were "Uff, I did it!". He laid down to rest and was suddenly and inexplicably gone, leaving family and friends in immeasurable pain and confusion.

It took more than eight months for the diagnosis to arrive: Chronic Myocarditis. The cause was viral and Andy could possibly have had the disease for weeks, even months. He did not show particularly alarming signs but occasionally mentioned shortness of breath during exercise and at night. He had been diagnosed with seasonal asthma and allergies and used an inhaler to treat these symptoms. We did not know anything about this disease, much less that its symptoms could be confused with respiratory ailments. In memory of our beloved son Andy we plan to work on spreading awareness and funding research on myocarditis and on promoting and funding CPR training.

Victor and Giovanna Peña

Caitie was a wonderful 13-year-old little girl, or others would say young woman, she grew up healthy, happy and an all around joy. Caitie was one of those kids who would try to be nice to anyone she met, even if it meant going against the grain of popularity. She tried including those children who were not being included or befriending those kids who appeared to have no friends. Simple gestures like giving away her cookies during lunch at school seemed small but greatly impacted those with whom she shared those cookies. Proud is just too short a word to describe how we felt about her. She was a straight A student and we took great joy in looking at each other and saying, "Genius." Caitie loved playing the piano and played it beautifully, filling the house with her melodies. The house is so quiet without the sound of her practicing the piano. We are so happy that we were able to help her experience so much in her short life. She traveled as a People to People Student Ambassador to England, France and Italy spreading goodwill among nations. She loved playing lacrosse and baking with family in the kitchen. We enjoyed watching her on the field and dining on her creations. During her time in her Mass Communication class, her catch phrase was "Make it a great day or not, the choice is yours" and she made every day a great one. On November 20, 2007, Caitlyn passed away from viral myocarditis. She had no major symptoms and everything looked like a minor cold. We may never realize the possibilities that might have been discovered had her life continued but we can strive to do something significant with what remains of ours.

Lillian and John Vincent

**"MAKE IT A GREAT DAY OR NOT,  
THE CHOICE IS YOURS"**



Caitlyn Vincent



# The MYOCARDITIS FOUNDATION

## Danielle's Story



Danielle Zoe was born on Nov. 27, 1996 the day before Thanksgiving along with her two sisters, Lexi and Nicki. Danielle was a triplet, a precious gift. She had chubby cheeks, golden curls and huge expressive eyes.

Danielle was an old soul in little girl's shoes. She was sweet and sensitive, was loved so much because a smile never left her face. As a young adult Danielle enjoyed writing, tennis, knitting and ice skating. She had just completed 4th Grade looking forward to starting middle school.

On July 26, 2007, it was a routine summer day at camp. At noon, Danielle went swimming and stepped out shortly with complaints of exhaustion, shortness of breath and chest pain. She went to the camp nurse with complaints of stomach and headaches. She had an elevated pulse, respirations and not much of an appetite. After resting she was sent to her next activity. Danielle returned to the nurse's office. Seemingly anxious, the nurse tried to alleviate her anxiety through breathing techniques. A short time later Danielle's mother was called to pick her up.

When Danielle arrived home she vomited and became lethargic. Paramedics came quickly and transported her to the hospital ER. Within 15 minutes of arrival at the hospital, with resuscitative measures to no avail, Danielle passed away, only four hours after the onset of symptoms.

Perhaps even worse than Danielle's untimely death, was not knowing the cause.

Two months later we were told viral myocarditis. She had an insignificant cold one week prior to her passing. How is it possible to die from a cold? It is incomprehensible.

The sudden and devastating loss of our precious daughter Danielle has left an emptiness in our hearts. However, our hope and goal together with The Myocarditis Foundation is to raise awareness, and educate doctors and specialists alike to help eradicate this disease and prevent this tragedy from happening to other families.

Steve and Karen Hymowitz

Lexi and Nicki

### Myocarditis Fundraising and Awareness Events for 2012:

- **Illinois – Month of April:** Public Health Awareness Event by Becky Wagner
- **New York, NY – April 26<sup>th</sup>** – Windows on the Hudson Event to Honor the Memories of Danielle Hymowitz, Melissa Sofia, Andy Pena, and Logan Sweet
- **Flower Mound, TX – April 28<sup>th</sup>** – Vanessa Hickey Birthday Celebration
- **Darien, CT – April 29<sup>th</sup>** – Zumba Event in Memory of Andy Pena
- **Bowdoinham, ME – May 6<sup>th</sup>** – Logan Sweet Memorial 5K & Fun Run
- **Wauwatosa, WI – May 28<sup>th</sup>** – Marthon Drink Station to Honor Mary Ehrlinger
- **Willmar, MN – June 9<sup>th</sup>** – Stephan Reynolds Memorial Disc Golf Tournament
- **Allen Park, MI – June 18<sup>th</sup>** – Dine to Donate at Applebee's Restaurant
- **Georgia – August:** Andrew Werkhauser College Band Event
- **Leicester, MA – September 1<sup>st</sup>:** 6<sup>th</sup> Annual Devin Kravitz Memorial 5K
- **Hamburg, NJ – September 10<sup>th</sup>:** Joe Rumore Golf Event
- **Texas – September 21<sup>st</sup>:** Nursery School Fundraiser
- **New York State – September 21<sup>st</sup>:** Pig Roast Event
- **Point Pleasant, NJ – September 28<sup>th</sup>:** Sunset on the Manasquan
- **Taylor, MI – September 22<sup>nd</sup>:** Ashley Day Orme Golf Outing
- **Maryland – Fall 2012:** DeLisa Fairweather's event
- **Rochester, MN – Fall 2012:** Wine Event
- **Washington, DC – November:** Meredith Viens Delaware event, Scotch Tasting
- **Connecticut - 2012:** Hospital Event hosted by Annie Schofield
- **New York State - 2012:** Hockey event

#### 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

### Board of Directors

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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

### Consultants to the Board of Directors



# The MYOCARDITIS FOUNDATION

## Myocarditis Foundation Research Network Event

On March 25, 2012, The Myocarditis Foundation held its first ever Research Network Event in Chicago, IL. It was held during the American College of Cardiology's (ACC) annual meeting at the Whitehall Hotel.

The goal of the event was to bring together all of the foundation's researchers, their board of directors, as well as all medical professionals that had an interest in learning more about myocarditis. The foundation held an evening event for all medical professionals allowing them to listen to presentations highlighting the most recent research and interesting case studies on myocarditis.

The event was extremely well received and far exceeded the foundation's expectations. The day began with an all-day board meeting for their Board of Directors, and a collaboration session for their grant recipients. Then in the afternoon, the Myocarditis Foundation had invited several families to come and speak to the board and grant recipients, telling their story of myocarditis. This was an extremely moving experience and left not a dry eye in the room. It reinforced how important the foundation's efforts for raising money for research truly are. We hope that one day we can eliminate these terrifying and heartbreaking stories myocarditis brings to so many families.

The evening event began with all of our grant recipients presenting their research findings through a poster display. This was extremely beneficial to both our grant recipients and to the physicians attending the event, and allowed for a detailed question and answer session to take place for each poster. It sparked a lot of discussion and many future research questions were raised.

The main talks we given by leading physicians and researchers from around the world and included:

- Leslie Cooper, MD, of the Mayo Clinic in Minnesota
- Ulrich Jorde, MD, and Nir Uriel, MD, of Columbia University Medical Center, New York Presbyterian Hospital
- Dennis McNamara, MD, of the Cardiovascular Institute at University of Pittsburgh Medical Center
- Mario Deng, MD, of the Heart Failure Program of UCLA Medical Center
- Bruce McManus, PhD, MD, FRSC, FCAHS, of the University of British Columbia-St. Paul's Hospital; The Heart Center – Providence Health Care
- Lori Blauwet, MD, of the Mayo Clinic in Minnesota and DeLisa Fairweather, PhD, of Johns Hopkins University in Maryland

These presentations created much discussion and brought forth a great deal of crucial information regarding the diagnosis and treatment of myocarditis.

The success of this event made is clear that this is an event that needs to be held each year. The value of the collaboration on research and sharing of diagnosis and treatment protocol is essential to the ultimate goal of the foundation: saving more lives.

The Myocarditis Foundation would like to thank all of their grant recipients, their presenters, their Medical Advisory Board, their Board of Directors, the Thoratec Corporation, and those who continue to support the Myocarditis Foundation.

## *Quotations from Participants:*

Dr. Cooper (Board President):

"The Foundation's first symposium was remarkable for the high number of myocarditis experts present and the unique interaction of patients and families with physician-scientists. These features made for an energizing, dynamic program that connected recent scientific advances with patient needs. The 3 aims of the Foundation- to support families and patients, educate the public and physicians, and advance our knowledge in pursuit of a cure were all met in one memorable evening."

Dr. Nir Uriel (Presenter):

"It was very impressive to see the direction the myocarditis foundation is going and what it achieved until now. Meeting you, Jim Armstrong and others is the main reason we are practicing medicine and pursuing our research. Thank you again for let me be a part of your operation."



left to right: Cindy Vanness, Amy Vanness & Sue Hall



## Research Network Event March 24th, 2012



left to right: Cindy Vanness, Randy Vanness & Sue Hall

Dr. Ulrich Jorde (Presenter):

"Congratulations again on a meeting that was a major (!) success from my perspective. The Myocarditis Foundation has become a major force in advancing the field of inflammatory heart disease, a deadly and common illness in dire need of research funding. I was particularly impressed with the large number of fellows who in difficult economic times without the foundation would not have been able to launch a career that may eventually contribute to a cure for myocarditis"

Dr. Bruce McManus (Medical Advisory Board Member):

The work of the Foundation, the Fellows who have been funded, and the leaders who join in will help us solve some of the issues that underlie myocarditis as it occurs in many settings and with many faces of illness. Thanks for your important leadership, and especially for seeing the value of bringing scientists, clinicians, trainees and the public and patients together.....an exceptional concept that will accelerate the work, and bring more hope and successes.

Clem Weinberger (Board Member):

"It was simply a pleasure to participate with the Myocarditis Foundation this weekend. I was so impressed with the board, grant recipients, and the physicians/scientists presenting in the evening scientific session. I appreciate being asked to participate and look forward to working with you."

Randy Vanness (Guest, lost son to myocarditis):

"From Amy, Cindy, and Randy Vanness... a big Thank You for all you do. Yesterday in Chicago was both wonderful and overwhelming. We got to see that we are not alone in this first hand. Met some wonderful new people and reconnected with Candace and Jim. Got to meet Dr. Leslie Cooper in person and Dr. Mario Deng. Both great guys. We were among parents and families of angels and survivors, transplants recipients, and those that are doing better after being sick, board members, & grant recipients. We really appreciated being included."

Dr. Alan Valaperti (Grant Recipient):

"I write you to thank you and all the Myocarditis Foundation for the great experience at the first Myocarditis Foundation Symposium. The friendly way you organized the Symposium was of big help to make the scientific discussion between the grant recipients, the mentors, and the members of the Myocarditis Foundation easier, pleasant, and really promising for the future of myocarditis research. Sharing myocarditis experiences with relatives of people who suffered from myocarditis or people who had this particular disease was a unique experience to

understand how important is our research supported by the Myocarditis Foundation, to do our best each day and achieve important results which will be of help to cure this rare disease. You and all the members of the Myocarditis Foundation did and are doing a wonderful job, we, the grant recipients, try to do your best to honor your efforts and your financial support."

Dr. Silvio Antoniak (Grant Recipient):

"To meet all the other grant recipients and the board of directors was great.

I learned a lot and got good advice and feedback for my ongoing project and my future directions in the myocarditis research. I was moved by the intimate meeting where the families of myocarditis victims and survivors told their stories; how this disease impacted their lives and how they are urging to find answers why this was happened to them; how to treat the disease and improve the outcome. I am looking forward to stay in touch with the Myocarditis Foundation and their supporters."

Kathleen Simpson (Grant Recipient):

"Meeting everyone involved in the Myocarditis Foundation, including families and staff members, was very rewarding experience. Everyone seemed interested in the research we have been conducting and how our studies are leading to a better understanding of myocarditis. I was thankful for the opportunity to share my research results and also learn about what other grant recipients had accomplished as well."

Kevin Quinn (Grant Recipient):

"Thank you so much for the opportunity to attend the MF conference. It was fantastic to meet with other researchers in the field, and with the cardiologists who manage the disease once diagnosed. The exchange of ideas regarding myocarditis research was extremely valuable, and I am looking forward to collaborating with my newly found colleagues in the near future. Listening to the stories of the persons who either were themselves victims of myocarditis or with the families of those who have lost loved ones to the disease was truly touching and humbling. Again, thank you for a profound experience."

Laure Case (Grant Recipient):

"I would like to thank you for all the support and the wonderfully powerful experience of the Symposium that will stay with me a lifetime."



left to right: Candace Moose & Sue Hall



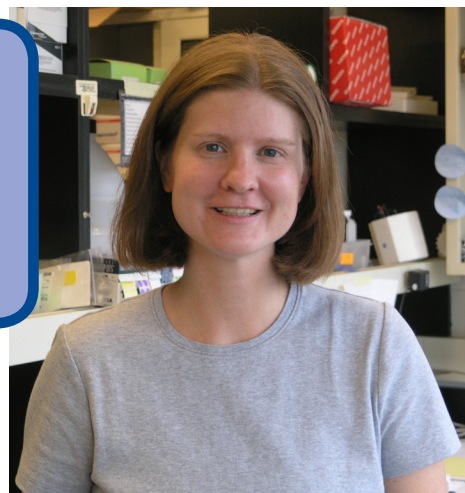


# The MYOCARDITIS FOUNDATION



Kevin Quinn, MD

## The Myocarditis Foundation's 2012-2013 Grant Recipients



Laure Case, PhD

The Foundation is proud to announce the award of two Research Fellowship Grant recipients: Dr. Laure Case from the University of Vermont, and Dr. Kevin Quinn from the University of California in Los Angeles.

Dr. Case's research is titled "Chromosome Y Regulates Susceptibility to Coxsackievirus B3-induced Myocarditis" and is directed toward the Y chromosome and determining the significance it plays in the onset of myocarditis. For over 30 years, Dr. Sally Huber's (mentor to Dr. Case) laboratory at the University of Vermont has utilized the coxsackievirus B3 (CVB3)-induced mouse model of experimental myocarditis to investigate why men are more likely to develop severe myocarditis compared to women. The experiments proposed in Dr. Case's fellowship will identify the critical cell types, for example cardiomyocytes and/or immune cells, which influence myocarditis susceptibility in male mice and may lead to the identification of genes and molecular pathways that can be targeted for mechanistic studies and therapeutic intervention.

Dr. Quinn's pediatric research is titled "Identifying Antiviral Agents to Treat Coxsackievirus Myocarditis" and is primarily directed on the study of different compounds to see which one could be used against enteroviral myocarditis infection. His project has the following 3 goals: 1), To identify the compounds which most actively inhibit coxsackievirus replication in tissue culture cells; 2) To identify the mechanism of action that allows these viral inhibitors to prevent coxsackievirus from completing its lytic cycle; and 3) To test the most active inhibitors in a mouse model of coxsackievirus myocarditis. Those effective in inhibiting coxsackievirus infection in animal models could in turn be evaluated towards application in human patients

The foundation is excited about the prospect of the findings these two researchers can bring to the field of myocarditis. We wish them good luck and look forward to their first update on their research.

## Awareness Items For Sale!

We have

- T-shirts
- Jackets
- Wristbands
- Pens

available to sell for our  
awareness campaign.

Please contact Lindsey at  
[Lindsey@myocarditisfoundation.org](mailto:Lindsey@myocarditisfoundation.org)  
if you would like to buy any items for  
yourself or to sell in your community  
to raise awareness!

Remember,  
KNOWLEDGE NURTURES HOPE!

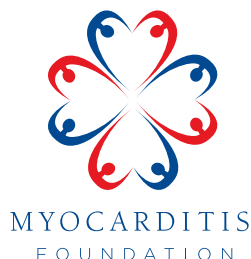
***The Myocarditis Foundation is proud to announce that it will designate a research fellowship grant in the 2013/2014 season in honor of Joseph Rumore Sr. of Pirsippamy, New Jersey. Mr. Rumore has continually raised funds every year for the past five years in his annual golf tournament and has raised more money individually to support the Foundation than any other donor. Mr. Rumore, a myocarditis survivor and heart transplant of six years, serves on the Board of Directors and is truly dedicated to the goals and missions of the Foundation.***





## Webinars

The Myocarditis Foundation hosts a variety of webinars, given by different members of our board or associates. It allows for detailed information to be given to those interested, and also provides a question and answer session for the individuals listening. All webinars are free-of-charge and can be viewed at anytime on our website. If you have an idea for a topic, please email [Lindsey@myocarditisfoundation.org](mailto:Lindsey@myocarditisfoundation.org)



- The effects of Gender in Myocarditis – by DeLisa Fairweather, PhD, - Scheduled for Summer 2012
- Types of Myocarditis- Scheduled for Summer 2012
- Types of Bacteria and Viruses that cause Myocarditis- Scheduled for Summer 2012
- Myocarditis Research – by Leslie Cooper, MD
- Ask Candace – by Candace Moose
- Chronic Myopericarditis – by Leslie Cooper, MD
- The Diagnosis of Myocarditis – by Leslie Cooper, MD
- The Treatment of Myocarditis – by Leslie Cooper, MD
- Coping with Loss During the Holidays – by Chaplain Audrey Lukasak
- Arrhythmias and Sudden Death in Myocarditis – by Leslie Cooper, MD
- Heart Failure in Myocarditis: Acute, Chronic, or Fatal? – by Lori Blauwet, MD
- Viral and Giant Cell Myocarditis – by Leslie Cooper, MD



## Becca's Story

by: Katie Varco- Kent, WA

Rebecca, or Becca as we called her, was truly a beautiful person inside and out. Though only spending twenty-three short years on this earth, she made an unparalleled and unforgettable impact on the lives of everyone she knew.

Becca was taken from us by Myocarditis in February of 2009. At the time, she was a beautiful, healthy young woman with no prior cardiac issues. Becca was working as a medical assistant in a doctor's office with ambitions of attending nursing school.

The days preceding her death, Becca had been fighting off a typical cold. There was no reason to think it was anything more than that until she collapsed the morning of February 5th. The paramedics were called but could not get her heart started again. In the blink of an eye she was gone and our lives had changed forever. Nearly a month went by before all the lab results came back. It was then that we learned about the devastatingly under-diagnosed disease called Myocarditis.

Anyone who knew Becca can tell you countless stories of how she influenced their lives. Her smile could light up an entire room and make your whole day better. Becca was very proud of the life she had created for herself through hard work, her relationship with her family and with God. She truly had the biggest heart, evident to everyone around her.

Even though we were only given a short time to spend with our beautiful Becca, her compassion for others and unyielding love for her family will never be forgotten. Becca has established a permanent place in the hearts of those who knew her. Her sweet memory is what gives us the strength and courage to keep moving forward, knowing that we will one day see each other again.



Rebecca Lianne Varco



# The MYOCARDITIS FOUNDATION

## After Luke's Death, a Push for Myocarditis Awareness

By Timothy M. Kennedy



*Luke's Stepfather Joseph Skowronski shares Luke's story, along with Luke's mother Amy Skowronski and sister Jillian Skowronski.*

WEST SENECA, N.Y. – Luke Gould, a 10-year-old West Seneca boy, passed away unexpectedly November 16, 2011. An active, healthy young athlete, Luke lost his life to an unpredictable heart condition known as myocarditis – which often leads to sudden death.

After his death, the medical examiner could not easily determine a cause of death. Initially, they had notified Luke's family that they were likely to issue an undetermined cause of death. The family struggled with the findings and encouraged the medical examiner to keep the case open. After receiving a request for help from Luke's family, Senator Kennedy called the medical examiner's office and urged them further explore potential causes of death. They agreed to re-examine their findings.

After further review and testing, the cause of Luke's death was found to be myocarditis, an uncommon disease that can be fatal yet often goes undetected and undiagnosed. Now Amy and Joe Skowronski, Luke's mother and stepfather, and Senator Kennedy are teaming up to raise awareness of myocarditis. Luke's family and friends joined Senator Kennedy Thursday at the West Seneca Ice Rink – the rink where the promising young hockey player skated – to announce new efforts in their fight against myocarditis.

Earlier this week, the State Senate passed a resolution, sponsored by Senator Kennedy, to proclaim November 16, 2012 – the one-year anniversary of Luke's passing – to be Myocarditis Awareness Day. Luke's family and Senator Kennedy intend to capitalize on Myocarditis Awareness Day by working to call regional and statewide attention to the disease and the complications it can cause.

Myocarditis often goes undiagnosed, and during autopsies, it is not always immediately detectable. It may affect one portion of the heart, but not others. This means multiple tissue samples may have to be taken and tested. One tissue sample may show signs of myocarditis, but it's possible for other samples from the same heart to look healthy. As a result, some claim that myocarditis may be the culprit in many instances when autopsies of otherwise healthy young people show no conclusive cause of death.

To help prevent families from enduring the pain of not knowing what caused their child's death, Senator Kennedy is going right to the medical examiners. He is sending correspondences to medical examiners across the state urging them to keep myocarditis in mind when faced with the likelihood of issuing an unknown or undetermined cause of death, especially in cases involving the sudden death of a young person.

In the letter, Senator Kennedy writes, "Not knowing the cause of death of one's child is a pain that no person should endure, which is why I have partnered with Amy and Joe Skowronski to spread awareness of myocarditis. As a cause of death of otherwise healthy individuals, especially children, myocarditis can be difficult to detect... Given the story of Luke Gould, I would encourage you to remain aware of myocarditis in future cases of unexplained death in otherwise healthy young people. If there is a case where cause of death is undetermined, we are asking that you consider myocarditis as a cause and examine the tissue evidence closely."

"Lukey was such a happy, energetic and promising boy. We were always very proud of him for everything he accomplished in sports and in school. When Lukey passed away, it broke our hearts, as well as all that met him," said Amy Skowronski. "What made it hurt even worse was not knowing what had caused his death. When the medical examiner told us they were going to declare an undetermined cause of death, we could not accept it. We encouraged them to keep Luke's case open and keep looking for answers. Our family also reached out to Senator Kennedy, who acted quickly in contacting the medical examiner and urging them to re-examine the case. After more testing, they found out that myocarditis had taken Luke's life. Losing Lukey still hurts so much, but just knowing what caused his death has provided us with some sense of comfort.

"We want to thank the County Health Department for going back and reviewing Luke's case, and we thank Senator Kennedy for his support and advocacy," Amy added. "Now we want to prevent future tragedies and save other families from the suffering. It's our mission to increase awareness of myocarditis and to ensure no family has to endure the pain of not knowing what caused the death of their child."



"When we initially heard Luke's story and learned the Skowronski family was on the brink of having to live with an "undetermined cause of death", we knew we had to help," said Senator Kennedy. "Losing a child is painful enough. Not knowing the cause of death of your child is a pain no person should endure. The Erie County Health Department and Medical Examiner's office deserve praise for re-examining Luke's case and conducting further testing. The answers they found helped give Luke's family the sense of closure they needed."

"With the awareness initiatives we're launching with Luke's family, we hope to spark further research into myocarditis to improve diagnosis and treatment and help save lives," Senator Kennedy added. "Our advocacy also aims to ensure medical examiners thoroughly consider myocarditis when reviewing cases of sudden death in otherwise healthy young people."

West Seneca Town Supervisor Sheila Meegan announced the town would keep Luke's legacy prominent in the West Seneca Ice Rink throughout the 2012-13 hockey season, naming Locker Room No. 1 and the home players' bench in his memory.

"West Seneca lost a beautiful young boy, who is missed by so very many. Luke Gould, your love and enthusiasm for the game of hockey goes on this hockey season," Supervisor Meegan said. "On behalf of the town of West Seneca and the West Seneca Hockey Association, we're proud to announce that for the 2012-2013 hockey season, we will place a name plaque on Locker Room No. 1 in his memory, along with the home players' bench. The courage and strength that Luke's love has given his family is truly inspirational and evident today."

For more information on myocarditis and to get involved, visit <http://myocarditisfoundation.org/>. To get involved in local advocacy efforts, you can contact Senator Kennedy's office at 716-826-2683 or [kennedy@nysenate.gov](mailto:kennedy@nysenate.gov).

Senator Timothy M. Kennedy represents the New York State Senate's 58th District, which is comprised of the towns of Cheektowaga, Eden, Hamburg and West Seneca, the city of Lackawanna and parts of the city of Buffalo. More information is available at <http://kennedy.nysenate.gov>.

\*This is a press release from the office of Senator Timothy Kennedy of the 58<sup>th</sup> District of the New York State Senate

## Juanita Jones, Survivor

by: Kiecha Berzins

Juanita Jones finds it a bit ironic that after working as a cardiac nurse for more than 25 years, she changed roles from being a caregiver to becoming a heart patient. Nearly a decade ago, Juanita contracted idiopathic myopathy, a virus that doctors say attacked her heart and caused congestive heart failure (CHF). She suffered with CHF for eight years, during which doctors implanted a biventricular pacemaker, and later, an ICD (defibrillator). But when medical devices and medicines weren't enough to keep Juanita healthy for the long-term, she was put on a transplant list to receive a new heart.

"Being a heart patient has been particularly tough for me," explains the 58-year-old nurse who most recently worked as a case manager at BlueCross/BlueShield of North Carolina. "I have my master's degree in nursing and have taught advanced medical/surgical nursing at East Carolina University. I've worked with very sick heart patients as a clinical nurse specialist. I know what can go wrong when a patient has a heart transplant. But if I wanted to live a quality life, I had to give up control. I needed a new heart."

It was only a matter of weeks before a donor heart became available, and in early 2010, Juanita underwent a heart transplant operation. But it was a slow road to recovery. At one point, she had a blood clot in her lungs, and her body tried to reject her new heart on more than one occasion. It was more than a year before she could begin Cardiac Rehab at WakeMed. "But WakeMed was my first choice," says Juanita. "As a nurse, I'm hard to please, and professionally, I'm qualified to judge the care. I did my research and knew WakeMed was the right place for my rehab."

When Juanita began Cardiac Rehab, she could only do two minutes on an exercise bike, but she slowly progressed and now pedals for 20 minutes or more at a healthy pace. She credits her family's support and the knowledgeable Cardiac Rehab staff for her new lease on life. "They took care of my mind, body and soul. I can't say thank you enough for their dedication to my wellbeing," Juanita says.

When asked how her experience as a heart patient has changed her, Juanita doesn't hesitate to share her thoughts. "Women are programmed to care for everyone else, and many put themselves last on the list of priorities. But we must take care of ourselves, and we shouldn't feel guilty about it. Ladies, listen to your body, and be your own health advocate. It could save your life."





# The MYOCARDITIS FOUNDATION

2201 River Road, #3401 Point Pleasant, NJ 08742  
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To the Family of My Donor:

I have no idea how to write a letter like this. It is something I never imagined I would do. I could sit here all day wondering what I should say and how I should say it without ever finding the right words. So, I guess I'll just begin.

Already I am crying. I'm not sure why. It happens all the time now. For no apparent reason, I will be lying in bed at night with my hand on my chest, or sitting on the couch in the afternoon, or visiting with a friend on the phone—just doing any ordinary thing—and suddenly I am overcome with emotion. It's all mixed up. Happiness, sadness, gratitude, emptiness, fullness, fear, hope, wonder.

It's all there, all at once, and I don't know what to do with it except let it wash over me. My fiancé will lie there with me quietly and share the silence. It is something sacred. I begin to imagine you. I try to distinguish something in the images that come to mind. I wonder who you are, who he was, what he was like, what you are doing right now, what you are feeling. I wonder if you ask similar things about me? I try not to focus on the details, telling myself that he might have been very different from how I imagine. Or maybe, in fact, he was very much the same. Maybe you wish to know something about me. Or maybe you prefer not to know anything. For now, at least, there is a simplicity, a beauty, in not knowing everything. I try not to think with my head but to just feel. It leaves more room for possibilities, more room for what the heart wants to say.



Jesse Torrence and Oona Cheta

Everyone around me seems to realize how fragile life is and that this could have happened to them or their family. It is like an endless stream of adoration and love and revelations about "the meaning of life" from my friends and family, a parade of optimism and hope for all that I might do with the rest of my life now that I have this second chance. It's heart warming and full of expectations.

And, as much as I appreciate it, it gives me mixed feelings. Sometimes, it can make me feel strangely alone, maybe because no matter how hard I try I can't quite communicate to any of them what this really feels like, what this means to have another person's life beating inside me and to sense someone else's grief so far but at the same time so near, to have lost something of myself that was so vital, but gained so much from someone else, someone I don't even know. I feel like no matter how hard I try, I might never be able to completely share this feeling—this sense of connection to something or someone whom I can't quite locate, a person who had a life and hopes and dreams and family and friends like me.

It feels so inadequate to even try to thank you or to console you or to pretend that I know anything about your life or his life and what you have gone through. The best I can do I think is to show you that life—his life—does continue, in some way at least, perhaps in a different body, with a different family, with a different future, but continuing nonetheless. And this heart—his heart—must feel some of the same things that he felt. If you believe that the heart is the seat of our emotions and of so many other things that make us human, then maybe the best I can do is to tell you what this heart says when I listen carefully. Maybe there is something it could say to comfort you, something I do not have the words yet to express.

I know you have suffered greatly this year, and today, especially, you carry a heavy burden, a pain that few of us could ever comprehend. If I could give you one thing this season to make it better, a little easier, it would be so simple. Just love. It was love after all—your family's love, my family's love, his love—that kept this heart alive and somehow made it start beating again when they put it in my chest. And it is love that reminds me every night how alive I am, how alive he is in some way. It is only love that can eventually make sense of this tragedy and joy happening at the same time. It is love that is pouring out of every seam of our lives at every moment of the day and holding it all together.

I feel like this is what we are put here to discover and to expand, and because of his life and your love I have caught a glimpse of it. I hope I never lose it and can share it with the world because we know that tomorrow is not promised to us. Thank you, and God bless you. J

Written by Jesse Torrence

*\*This is an excerpt from the original letter written by Jesse Torrence. To read the letter in its entirety, please visit our website at: [myocarditisfoundation.org](http://myocarditisfoundation.org)*