

Welcome

NOT A BLANK CANVAS

PORTRAITS OF
MYOCARDITIS

A Traveling Educational Exhibit



Myocarditis
FOUNDATION

Knowledge Nurtures Hope



Myocarditis FOUNDATION

The Myocarditis Foundation strives to improve the medical outcome for myocarditis patients through programs to raise awareness, educate physicians and the public, and fund important medical research. It is the only nonprofit organization dedicating all of its resources at no charge to advancing the understanding and management of myocarditis.

- A 501 (c)(3) nonprofit organization formed in 2005 by a Giant Cell Myocarditis and Heart Transplant Survivor, a Mayo Clinic cardiologist whose expert Giant Cell Myocarditis knowledge and innovative treatment protocol stabilized her condition, and a Columbia University at New York City cardiologist whose expert knowledge in advanced heart failure and cardiac transplantation saved her life.



Candace Moose, R.N.
Founder



Leslie T. Cooper, Jr. MD
Founder



Mario C. Deng, MD
Founder

LEADERSHIP BY MYOCARDITIS EXPERTS

The following people volunteer to provide governance and guidance:

OFFICERS AND BOARD OF DIRECTORS:

President: Joseph Rumore, Myocarditis and Heart Transplant patient; former Managing Director of a national insurance company; Kingwood, Texas

Vice-President: Christopher Corso, Reinsurance executive at XL Catlin and father to a Myocarditis Survivor, who continues his battle today; Attleboro, MA

Secretary and Founder: Candace C. Moose, RN, BSN, MEd; Giant Cell Myocarditis patient, Heart Transplant patient and Author of “The Grateful Heart”; Point Pleasant, New Jersey

Treasurer: Louis Romano, Owner of HomeWell Senior Care, a home health care agency; Hackensack, NJ

Director: Giustina Schiano, Mother of a Myocarditis Victim, Community Leader and MF Family Support Advocate; East Meadow, NY

Founder, and Medical Director: Leslie T. Cooper, Jr. MD, Chair of the Cardiovascular Department, Mayo Clinic, Jacksonville, Florida

Director: Jack Price, MD, Associate Professor of Pediatrics at Baylor College of Medicine and the Clinical Director of the Cardiovascular Intensive Care Unit at Texas Children’s Hospital; Houston, TX

Director: Joel Aranson, Founder and Chairman of National Sporting Good Corporation and father to a Myocarditis Victim; Boca Raton, FL and Verona, NJ

Director: Douglas Luffborough, III, PhD, Community Leader who holds a PhD in Leadership Studies. Heart inspired speaker, Author and Education Client Partner; Chula Vista, CA

Director: Francine Andrea, Vice-President for Enrollment Management, Student Affairs and Chief Compliance Officer for Felician University

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Abiah's Story

By: Patricia McElveen
Abiah's Mom



Abiah McElveen • Texas

Fifth grader, 11-yr-old Abiah, was seen by her pediatrician for fever and a horrible cough in February 2008. Diagnosed with bronchitis, she was given a prescription for antibiotics and told to expect up to 72 hours for the antibiotics to work. Five days later, Abiah was taken to the Emergency Room with a temperature of 103, chest pain, and shortness of breath. Her chest x-ray did not show pneumonia, and she was again diagnosed with bronchitis and given a different antibiotic. Six weeks later, on Good Friday, Abiah awakened with her normal cheerful behavior, but later complained that her chest was tight and hurting, and she could not breathe. She stood up, then collapsed; 911 was called. Paramedics took her vital signs which appeared normal. When Abiah and her parents reached the hospital, doctors said there was something seriously wrong with Abiah's heart and had her airlifted to another hospital. One hour after her arrival, Abiah's heart stopped beating, and she was resuscitated and placed on life support. The doctors said Abiah had a rare viral infection which had affected her heart muscle. When asked what virus, they replied they didn't know because there were so many and it was hard to narrow it down. Abiah was placed on the heart transplant list and preparations began to find a compatible heart. Despite their best efforts, Abiah died Saturday night, only a few hours before Easter Sunday.

Abiah was a very intelligent, vibrant, energetic girl who was active in school and church functions, and known by her classmates as "everybody's friend". Her picture hangs in the school library and she leaves a legacy of love, peace, and compassion. Myocarditis subtly and very aggressively destroyed our daughter's heart, leaving our family heartbroken and wondering how and why something like this can happen; myocarditis stole our 11 yr old daughter's life.

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Our Story

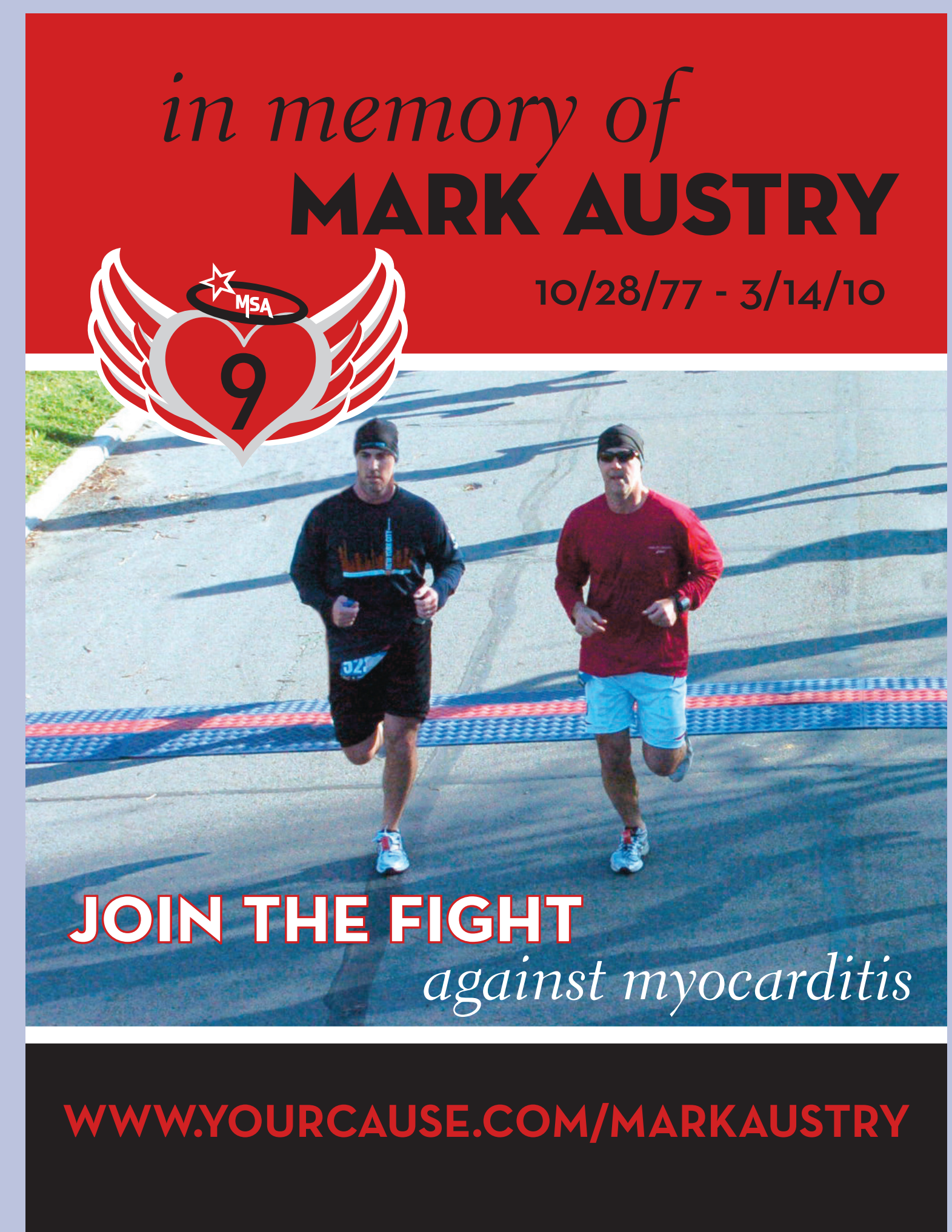
On March 25, 2011, dozens of the 14,000 runners in the Dallas Rock N Roll Half Marathon ran in memory of Mark Austry who collapsed and died at the finish line at last year's race. His brother who is the runner in the family talked Mark into running with him last year. They finished the race, Mark got a drink of water, and Michael glanced at his watch to check his time and heard Mark fall. Paramedics tried unsuccessfully to revive him. Mark, the youngest of three brothers, a 32-year-old husband, father of two, and son was an accomplished athlete in several sports including baseball and golf, but that didn't save him.

Mark's sudden death has left his family in tremendous pain. Mark's mother, Sharon Austry, calls the disease, "a thief in the night", though not an ordinary thief that steals possessions, but a thief that takes your most precious and irreplaceable possession, then cruelly breaks into your happy life leaving every holiday a pile of broken dreams. She writes that not a day goes by that they aren't reminded of the enormity of their loss, like when Mark's three year old daughter Isabella asks for her father or when Mark's absence is noted in Anna's second birthday pictures.

Michael spoke to the cardiologist after the autopsy revealed viral myocarditis. The cardiologist stated that he did not know how Mark got the disease and that it could not have been prevented. Michael researched myocarditis and found the Myocarditis Foundation website where he learned that the disease is the third leading cause of sudden unexpected death in otherwise young, healthy individuals including athletes.

This year, the Austry family, including Mariana, Mark's wife and a host of supportive friends and neighbors, staffed a Mark Austry Tribute Booth at the Dallas Half Marathon Expo registration desk. Michael said it was just too painful to run the race but that he was hoping to raise awareness for myocarditis and money for a Myocarditis Foundation research grant.

Michael has honored his brother by naming his new baby girl, Devin Mark, after her uncle.



The LAST Picture Taken: In Memory of Mark Austry
Dallas, Texas

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Brian Barndt • Wake Forest, NC

A Survivor's Story

heart2swim

Brian Barndt, a Wake Forest, North Carolina resident and Total Immersion Swimming certified coach, knows something about determination. He suffered from heart disease for nearly two decades before receiving a heart transplant in 2005. As a student swimmer and polo player at UNC-Wilmington in 1990, Brian contracted a virus that damaged his heart. The doctors were able to control his disease with medication, but he knew a heart transplant was in his future. “My body did well 10 years after the virus, but in 2000, I started to decline”.

First, he had a defibrillator implanted in his chest, a device designed to deliver a shock to his heart if a life-threatening arrhythmia occurred. The once athlete water polo player could not even swim the length of the pool. He fought his fear of transplant surgery, and got in line for a new heart. Six weeks after the surgery he was back in the pool.

After receiving new life through the transplant, Brian has returned to swimming with a passion! Brian has competed in transplant athletics, winning seven gold medals at the 2006 and 2008 U.S. Transplant Games as a member of Team NC, and 3 silvers and 1 bronze medal at the 2009 World Transplant Games in Australia. Brian also competes in triathlons, and was member of the first all-heart transplant relay team to complete an Iron Distance triathlon race. The 3-man “Tin Men” relay team, whose name is loosely based on the Tin Man character from the Wizard of Oz who just wanted a heart, have received their hearts and now want to use them, their motto: 3 Hearts, 2 Lungs, 1 Goal. Brian is also the first heart transplant recipient to swim in the annual Escape from Alcatraz

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A Survivor's Story

On May 27, 2010 (my birthday), our son, Casey, called from school saying he had chest pains. He'd had very mild intestinal symptoms the week prior and was somewhat lethargic afterward, so I already had mother's intuition something wasn't right. My husband had near-total blockage of LAD at 37, so I was suspicious and immediately went into action, despite paramedics saying he was probably dehydrated, "Drink Gatorade and rest." I called family doctor who examined and sent him for blood work and EKG just in case. Casey was fine afterward when we went out for my birthday dinner.

When we got home, the doctor called saying get him to the ER right away. Casey's blood cardiac Troponin level was 7 and climbed as high as 13 (normal is 0.2!), indicating ongoing heart muscle damage. They said he was having a heart attack. How could my 16-year-old be having a heart attack? He went by ambulance to Ohio State University's Ross Heart Hospital. My husband was in Japan and flew home-an agonizingly long trip with no communication. I was scared and doctors weren't saying much. Cardiac catheterization showed clear coronaries. Next, cardiac MRI showed myocarditis, assumed viral from the brief illness.

Casey received medications (still taking today) and had to rest a lot. I felt so blessed to leave that hospital with my child; at times I thought I wouldn't--words can't explain that fear. At home, I researched and realized exactly how blessed we are! Our son has youth on his side and hopefully will heal completely--last scan showed cardiac healing of around 75%. He might have scar tissue for life. We won't know more until June.

My son's getting ready for prom and will be acting in a play on May 27. I know I'll cry again on my birthday, but this time tears of joy! I truly hope the Myocarditis Foundation can raise awareness and fund research so others may have this kind of outcome. My heart aches daily for those lost to this insidious disease.

Mike & Libby Blevins, Ohio



Casey Blevins • Ohio



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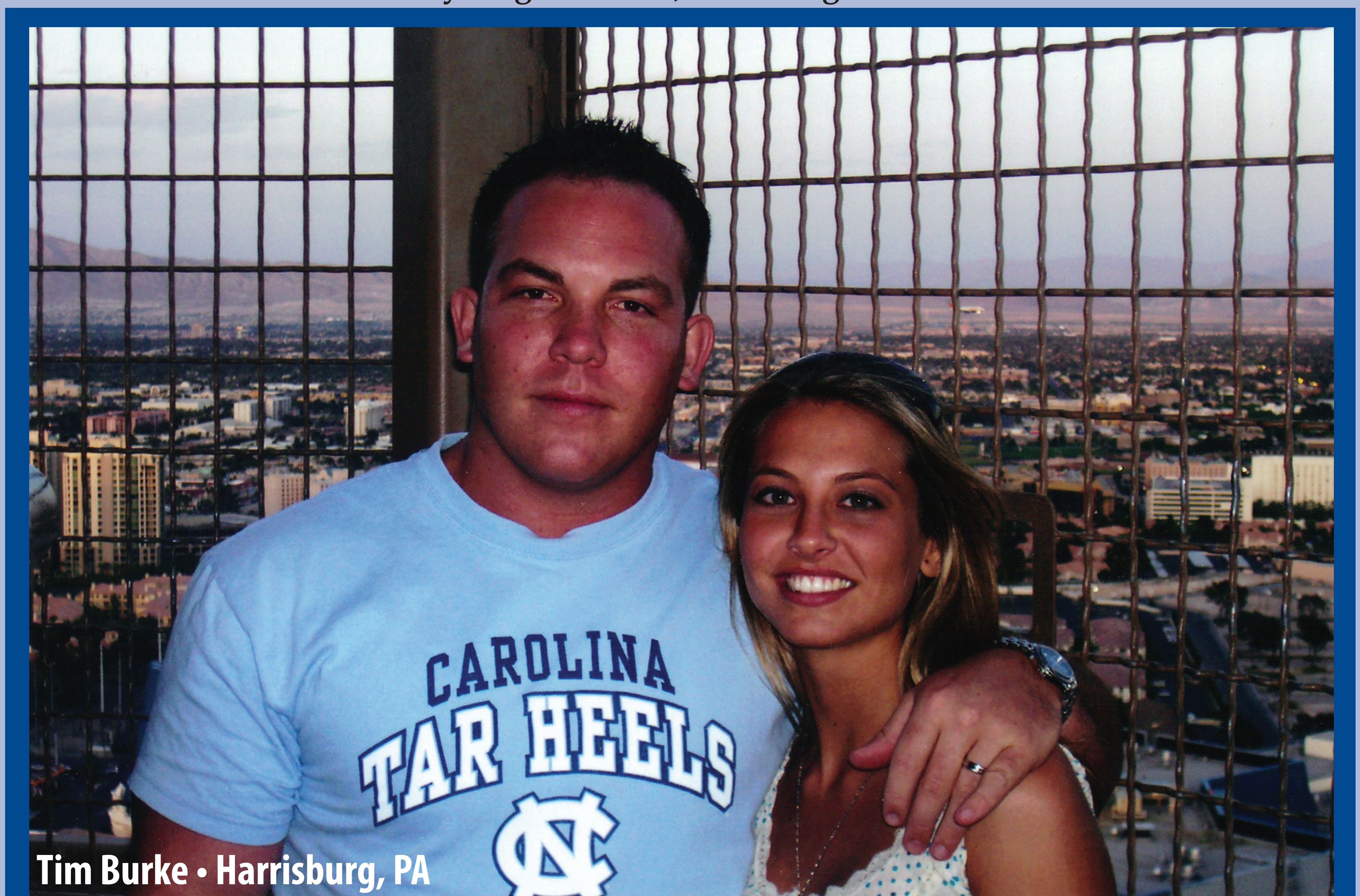
Tim's Story

On February 16, 2010 my life was suddenly forever changed. In the early morning hours I was woken up by my husband, Tim, struggling to breath. Approximately fifteen minutes later he was gone. My wonderful, loving husband of only two years was gone. All of the hopes and dreams that we shared were gone. It was so hard to comprehend because he was not sick. He was active, exercised regularly and was in good shape. How was this possible? The coroner called later that morning and explained that Tim's death was a result of complications from Myocarditis. At the time of his death he had six weeks of scar tissue around his heart and he was three weeks into heart, liver and kidney failure. Also sometime in the recent past he had suffered a mild heart attack. Tim was only 30. I was completely stunned by what the coroner had found.

Myocarditis? What is Myocarditis? That is what I and everyone else in my life began asking. It does not seem possible that there is a disease that can take someone's life without presenting much more than flu-like symptoms. The week prior to his death he told me that he was "not feeling right." He had experienced occasional lightheadedness, nausea, and had less of an appetite. We thought he may have been getting the flu but he had started to feel better. Unfortunately this disease does exist and though it's considered rare, it effects far too many people and in many cases goes undetected until sudden death occurs.

The fact that Tim lost his life will never make sense to me but I am committed to continuing to raise money for The Myocarditis Foundation. Hopefully through the hard work of individuals to raise money and awareness for this cause progress through research will be made in leaps and bounds. There needs to be a time when this disease is more often than not diagnosed before it is too late. Please educate yourself and others about this disease.

by Angela Burke, his loving wife



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Our Story

After having our first son, Cole, in 2007, Daron and I knew that we wanted more children. We were ecstatic to learn that we were expecting again in February of 2009. We soon found out that we would be blessed with another little boy who we decided to name Owen.

On October 21, Owen made a grand entrance at 37 weeks and 5 days. He was 7 pounds, 4 ounces, and 20 inches long. At first we were congratulated on a very happy, healthy baby boy.

However, within a few hours, it became clear that Owen was having problems breathing. By the next day he was flown to Levin Children's Hospital in Charlotte, North Carolina, for extra help. Despite their best efforts, Owen was not showing improvement. Owen's lungs became worse as the days passed, and the doctors felt that he may be fighting a virus. Five days later we came in to find his bed surrounded by doctors and nurses. He had gone into complete heart failure and was not expected to make it through the night. Later, we would learn that his diagnosis was Enteroviral Myocarditis.

Since that day Owen has overcome extraordinary circumstances and has proven to be a very special little man. Regardless of what "the books" say, Owen is still with us and has gifted our family with days of laughter and wonderful smiles. He reminds us that life is precious.

We are so thankful to God for the gift of our little Owen. This experience has taught us much about having faith, trusting God, and the true power of prayer. Owen definitely has a long road ahead, but we remain hopeful and know that God will continue to lead us through this journey.

Kristan Cardwell, Mom



Owen Cardwell • Albemarle, NC

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Leslie T. Cooper, Jr., MD

When I was a cardiology fellow at Stanford University, I had a patient, a young woman who died of Giant Cell Myocarditis. I remember feeling helpless as there was no treatment available that could have changed the course of her life. After her death, myocarditis and specifically Giant Cell Myocarditis became the focus of my medical research. Many years later, I am happy to report that advances in treatment, diagnosis and protocol have saved more lives from this disease; however, we still have a long way to go. Far too many families lose loved ones prematurely from this tragic disease. In 2001, I received a call from Dr. Mario Deng at Columbia Medical Center asking me to consult on a case regarding a 49 year old woman who he suspected had Giant Cell Myocarditis. Though Candace was too ill to be enrolled in the Giant Cell Myocarditis Treatment Trial I was leading, an alternative therapy was recommended that successfully enabled Candace to live long enough to receive a new heart. In her recovery, she called and asked what she could do for me, and I said that we needed to form a foundation, to raise money for myocarditis research and to be a clearinghouse of information for physicians, patients and families who lost loved ones. The Myocarditis Foundation was officially approved as a 501C3 nonprofit in 2005.

Six years later, our website draws over 30,000 web hits per year. Affected patients and families hold awareness events and raise money for research all over the country. We have given over \$300K away to aspiring myocarditis investigators who have made great strides in advancing our understanding of this disease. Until we have faster more effective diagnostics and treatments, we have more work to do.

I am the founding President of the Board of Directors and plan to continue to serve and mentor the next generation of leaders in the field of myocarditis so that they can continue the work we have begun through the Myocarditis Foundation.

**Dr. Leslie Cooper, Director of the
Gonda Vascular Center
Mayo Clinic, Rochester, MN**



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My Story



Matthew Day • Baltimore, MD

My heart ordeal began back in the summer of 2005. I was an active 21 year old working days and taking a few summer courses at night. I was determined to graduate school, make the most money I could, and let nothing stand in my way. Family, dating, friends, church were not high on my priority list. I just wanted to finish school.

Gradually over several days, a pain in my stomach kept increasing in intensity; but I ignored it thinking it would go away. I had a fishing trip planned for the afternoon and I really wanted to go, so I picked up some stomach medicine at the drug store, which made me feel better, and packed my gear.

While out on the boat, the pain came back with vengeance. My friend took me back to shore and I had to crawl out of the boat. Not sure what was going on, I called my parents and we went to see a doctor. Unfortunately, the tests came back with no definitive answers. They sent me home with some medicine and told me to take it easy for a few days - I should get better. The next morning, I woke up and the pain was still there. My parents decided I needed to go to the nearby community hospital. I was reluctant to go, but said goodbye to my dog and told her I would be back later that evening.

After three hours in the Emergency Department, the doctors still had no answers, but admitted me to the hospital. A number of doctors came in to exam me, but said nothing. My condition kept getting worse, and I was moved to ICU. This is when I get scared. I did not want to go to the ICU because that is where the really sick people are. A CT scan was ordered, and when they gave me the contrast liquid I was so thirsty I drank it quickly. I remember the nurse saying, "I have never seen someone drink the contrast so quick and then ask for more." While taking me to radiology, my body began to shut down. They rushed me back up to the ICU, hooked me up to a ventilator, and then waited. I really don't remember much beyond this point, but I was told that a cardiologist came in to examine me and told my parents, "There is nothing we can do for your son. He is going to die", and then he walked out of the room.

My family was in shock and could not believe this was the end. They call every doctor they could find and successfully transferred me to another hospital. The first two weeks were touch and go. They pumped me full of all kinds of medicines; every organ in my body was damaged. My kidneys and heart were affected the most. I needed kidney dialysis for a while. I was discharged 26 days later. In 2006, I experienced episodes of cardiac arrhythmia and had a pacemaker implanted.

My heart has eventually recovered and today I am a fairly healthy 26 year old man. Emotionally, it will take years to recover from this experience. The worse part is not knowing what happened to my body. The doctors diagnosed my mysterious illness as Congestive Heart Failure, but have never given me any more information on what was the cause or why my body crashed. I tell my story to bring an awareness to heart related diseases. These illnesses and diseases do not only affect the elderly any longer. People of all ages need to take better care of themselves and look at what is truly important. I have been changed. I have learned to value my family and friends over the desire to only make money and get ahead, but how I learned these lessons is something I hope to never experience again. I mourn losing my old self, but am thankful for what I have found.

2011: Matt is a seminary student at Lutheran Theological Seminary in Gettysburg, PA

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Mario Deng, MD



I became familiar with Giant Cell Myocarditis while practicing Heart Failure/Heart Transplant medicine in Germany. A young, previously healthy woman died of GCM while waiting on the list for a new heart. Two years later, I was the doctor on call at Columbia Medical Center/New York Presbyterian Hospital when Candace Moose was transferred from another hospital via EMT in profound heart failure with a diagnosis of viral myocarditis. I suspected GCM immediately and ordered a heart biopsy which confirmed my fear. The early diagnosis and immediate change in treatment allowed Candace to live long enough to receive a new heart. Throughout her illness and recovery, we formed a special bond which continues to this day.

With her husband, and others, we formed the Myocarditis Foundation in 2005 to raise money for research, to be a support for patients and families who have lost loved ones to the disease and to educate physicians and the public about the disease. I have been on the Board of Directors since the inception of the foundation and plan to continue to serve for years to come because I believe it is important as I have a personal commitment to raising awareness about inflammatory heart muscle disease.

**Dr. Mario C. Deng, Director of the Advanced Heart Failure Program at
University of California in Los Angeles
May 2011**

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Jeremy's Story

My older brother, Jeremy, was a seemingly healthy 14 year-old who was active, healthy, and bright. He was on the academic honor track at his high school, participated in varsity hockey and cross country, and was an exceptional role model for myself and our younger sister, Lauren. His drive to succeed, good nature, and kind heart made us all proud to have him as a big brother and son. After going to a movie with his friends one Thursday night in 1994, Jeremy began to have flu-like symptoms. His pediatrician advised us to give it a couple of days, and let the virus run its course. On Sunday, when Jeremy's mild symptoms suddenly became more severe, we brought him to the emergency room, and Jeremy ended up in the intensive care unit before there was enough time to grasp the severity of the situation. Jeremy experienced a severe episode of rhabdomyolysis, which resulted in kidney failure and a fatal disruption in his heart rhythm. We later learned that Jeremy's illness was a result of viral myocarditis. This devastating disease abruptly ended Jeremy's life prematurely, with no warning sign. Although Jeremy is no longer with us, I'll always be the middle child, as his legacy lives on in us through the lessons we learned from him and in the many ways in which he touched our lives.

By Brian Fishman, Jeremy's younger brother who was age 10 when Jeremy died.



Jeremy Fishman • Arizona

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My Psalm

David Green • Christchurch, New Zealand



David awarded an honorary Finisher's Medal for the Christchurch City Marathon. My sense of humour has me amused with the irony of receiving this when I would probably set off my Pacemaker if I just ran across the road!

In April of 2005, I was a fit and healthy 49 year old father of five and grandfather of one, and taught Mathematics at a boys College in Christchurch, New Zealand. I enjoyed tinkering in the garage with my vintage Ford and 'inventing' gadgets, usually toys. I was training for the local half-marathon in June and would regularly complete a 1 hour 40 run.

At the end of April within the space of one week of feeling less energetic, stomach pains and feverish sweats at night, I was admitted to hospital, a walking dead man with a heart ejection fraction of 19%. On the first day in hospital after it was confirmed that it was not a coronary attack but myocarditis, things were going down fast and I was put on a Heart Balloon Pump for five days straight. By mid-May, after a second round of the Balloon Pump, it and various other lines were removed. Medical opinion indicated that there were 'hours to live'.

So many people had been praying and one such prayer read to me was Psalm of David 118, vs 17: I shall not die, but live and declare the works of the Lord.

My kidneys had not been functioning for 4 days when, inexplicably, some kidney function returned. Even after surviving a night when my heart exceeded 200 beats per minute, there was huge concern that I would not survive further rounds of shock treatment. Finally, massive doses of Amiodarone settled my heart.

A Pace-maker/Defibrillator was fitted before I left hospital in early July and I was on steroids, immunosuppressants and other assorted medications. I had the absolute love of a wife who would not let go, and the total commitment of family, friends, community, and hospital staff. By the start of 2006, even with an ejection fraction of around 20% I was able to resume teaching part-time. Diagnosis: Giant Cell Myocarditis, meaning my non heart-transplant survival is, as many have suggested, MIRACULOUS!



David and grand-daughter Sarah. She was such a delight for all during my stay in Hospital, and an example that love and support of family and friends is powerful medicine.

Not a Blank Canvas: *Portraits of Myocarditis*

Monday, St Patrick's Day 2008: Alex, my 15-year-old son, came home and just said, "Hey Mom, it was weird today. I had chest pains and felt dizzy and short of breath." Our pediatrician examined Alex that day; EKG and a chest x-ray were negative and she advised to take it easy. And so our story began.

Tuesday: Alex complains of a stomach ache but assures me he is ok to stay at school; doctor said call if pain gets worse.

Wednesday: stomach ache moves higher up and Alex calls from school to say he can't walk home because of leg pain and weakness; dr. said he most likely has a virus and to keep him home on Thursday and call if anything changed.

Thursday: we're up at 4AM; Alex is weak, pale and not breathing well; off we go to the ER – 5 minutes away – and he is getting worse; he can't walk and one look at the doctors' faces tells me it's bad; medicines, IV, hook up to monitors, and tons of questions; Alex is calmer than me; within minutes, Alex is being transported to the University of Massachusetts; a large team of medical people are waiting for us upon arrival; lots of questions, tests, monitors going crazy, defibrillator pads are put on Alex and he is rushed to ICU; I tell Alex he is gonna have to fight.

6:15 AM: Alex needs to go to Children's Hospital in Boston – they have a machine that MIGHT save his life; Life Flight is grounded because of the rain, a special transport team is on the way.

My cousin, a priest, is called to bless him. We all hold hands and pray for Alex; I thought this would scare him, instead he tells Father Bill, "Thank you". Alex's lungs are filling with fluid and a breathing tube is put in. I promise him I won't leave his side until he opens his eyes again and tells me "I love you".

Upon arrival at Boston's Children's Hospital, Alex is placed on ECMO, a heart lung machine. We spend hours in the waiting room, getting updates every 15 minutes. Finally, we get to see him around 5 PM. Alex needs a cardiac biopsy. We're told it's risky but very important to determine what they're dealing with. I find the chapel and pray; we wait.

Days turn into weeks and Alex is still on ECMO. Doctors are worried about brain damage. Blood clots form in the tubes and Alex has to be taken off ECMO. Alex does amazingly well, and the doctors decide to let him slowly wake-up. He can't talk because of the breathing tube, but he makes a shape of a heart with his hands and then does what looks like his fingers running fast and then he makes it look like he broke something. We figured out that he is asking if his heart is broken and still running fast. I know then that his brain is still intact. When the breathing tube comes out, Alex gasps for a breath, looked at me, and said, "Love you Mom!" This is the best gift ever!

One Year Later: Alex missed the end of school but had a tutor and was able to go on to the next grade at school in September, and celebrate his 16th birthday. My life will never be the same ... in some ways for the better. Alex is doing amazing! He is on no medicine at all. He even played soccer this fall. Alex's cardiologists call him a Myocarditis legend. I call him **my miracle**!

Sue, Alex's Mom



Alex Hall

Worcester, Massachusetts

My Miracle

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Jolanda Heskes • The Netherlands

Jolanda's Story

My sister, Jolanda, and I grew up in a typical Dutch family. In 1996, Jolanda was 27, active and fit. She seemed to have it all: a loving husband, a home of their own, two cars, a big dog, a job she liked, and she was pregnant with their first child. It was a boy. I was looking forward to becoming an aunt.

Six months into her pregnancy, Jolanda fell ill. She was short of breath, extremely tired and was turned off by food. The midwife explained that my nephew-to-be had grown so much that he pressed against her lungs and that there was nothing to be worried about. It sounded logical, but it turned out to be wrong information.

She was home alone for the weekend because her husband was abroad for work. My parents stopped by and were very worried about the way Jolanda looked. My mum called the midwife and Jolanda's GP who said my mother was overly concerned. So they took my sister home with them. She seemed to be doing a little better in their care, but Monday morning Jolanda was rushed to the hospital. The x-ray showed her heart was enormously enlarged; the doctors were doing everything they knew and she seemed to improve.

The call came in the middle of the night. Jolanda had had an attack of some kind. When we arrived at the ICU, she looked strange and swollen; she was so cold. Her doctor said her organs were failing. I asked him if he could take some of mine and make her chances better, but he said no. It was hopeless. The doctors had tried everything, but did not know what was killing her. Jolanda and her unborn child died at half past five pm on December 3rd 1996.

On autopsy, Giant Cell Myocarditis was found. The doctors had never thought of that diagnosis because it is so rare and had never been seen in a pregnant woman. Her cardiologist showed us a thick book about heart diseases; he called it "the bible of the heart". It only had a few lines on the disease that killed my sister. **Back in 1996, my sister's cardiologist told me there was one doctor in the whole world who is trying to cure Giant Cell Myocarditis.** I later searched the internet and found Dr. Leslie Cooper on The Myocarditis Foundation website. Dr. Cooper still can't answer our "why" question but it is good to know he is working hard to do so. And it is good to see he has already come so much further than those few lines in "the bible of the heart".

I cannot help him with his research, but I realized I can do something. I'll be running the NYC marathon this year. I intend to raise as much money as I can for myocarditis research to help Dr Cooper and The Myocarditis Foundation find the answers to the "why-question" and hopefully save many lives.



Brenda Running

Brenda Heskes , Jolanda's Sister



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Garret's Story

Garret Lee Hodges was a loving, funny and smart 15 year old boy. He was our first born child, a big brother, a grandson, a nephew, a cousin and friend to many. Garret loved life, family and friends. He also loved his hobbies with a passion; dirt bike riding, Xbox, air soft and texting friends.

Dates and times are not clear in my memory as we were in such a fog for so long. That first morning Garret called me to let me know he didn't feel good; he had a headache and wanted to stay home. He stayed home that day, played Xbox, texted friends, and rested. The next day he was feeling worse, he was running a fever of 103 degrees and started vomiting. Nursing advice was to treat him for the flu. The third day, he continued to be tired, feverish and still slightly vomiting. Same nursing advice, it was flu season after all. We went to the doctor that morning. They were quite concerned thinking he was dehydrated so they started giving him IV fluids which (unknowingly) caused his damaged heart to work too hard. He went from the Dr.'s office to the hospital in the slowest ambulance ride ever. They took him right in and I remember the attending doctor saying "we have a really sick kid here". They were going to get him stabilized and take him to ICU. The ER doctors still did not know what was taking our son. Garret's heart stopped on the elevator. It was a couple of months before we received the diagnosis of Viral Myocarditis; it was determined with a heart biopsy.

It is so important to our family that others do not have to suffer as we have. Awareness and education are key! The loss of our son has made us so aware that nothing is in our control. Garret walked into the doctor's office that day and did not come home.

We all have lost a true treasure, our son Garret.



Garret Lee Hodges • Graham, WA



Not a Blank Canvas: *Portraits of Myocarditis*



Hana Hornbeck
Phoenix, Arizona

Hana's Story

The first time I heard the word Myocarditis was the day my 14 year old, healthy daughter was hospitalized in Phoenix. This was my first shock to be followed by many more. As it turned out Hana was suffering from Giant Cell Myocarditis or GCM. We would not find this out till it was too late to save her heart due to the fact GCM can only be detected through a heart biopsy. GCM is extremely rare and lethal. Heart failure progressed in Hana and she was rushed to UCLA. Aggressive drugs, countless blood tests, procedures, constant monitoring and numerous surreal conversations with ICU physicians and Cardiology. Within days Hana's heart stopped. When she coded and was gone for a few minutes, a young anesthesiologist performed CPR and I know saved her so we could make it to the next step.

Hana went from different life support bridges in a whirlwind of 3 open heart surgeries back to back due to complications. We now knew that a heart transplant was the only option. How could this happen to a young athlete and captain of the cheer squad? She went on the list for heart transplant and Hana existed on a very scary and I can say painful device called BiVAD at UCLA from October 2009 till December 30th 2009. That was the day she was transplanted. I thank God for her strength to get through this and for her donor and their family, I can only express the gift they gave saved me as well. We were finally able to return home to Phoenix in April 2010.

Hana is an amazing young woman and I want to share her story. What she experienced was so unexpected. She is back in school and was back to cheering 7 months after her transplant! Currently, she is getting ready to compete in the Miss Teen Arizona Pageant coming up November 2011. She has already won in my eyes and I am her biggest fan!

Barbara Hornbeck, mother, Phoenix, AZ



Myocarditis
FOUNDATION

Knowledge Nurtures Hope

Not a Blank Canvas: *Portraits of Myocarditis*

Michael's Story

Michael Robert Kern is a face of Myocarditis. A good looking, healthy 25 year old, full of love, life and laughter, Michael had been married less than two years when he died suddenly of Viral Myocarditis. He had very mild flu-like symptoms for 2 days. The first day, he went to work and felt like he was coming down with a cold. He took a cold tablet before going to bed. The following day, he went to work, came home and felt it was his stomach bothering him and not a cold. He didn't feel like eating much and took pink bismuth liquid before going to bed at 10:30 PM on a Thursday night, but he did tell his wife that there was something "different" about how he felt. His wife told him to go to the doctor the next day if he was not feeling any better. A little after midnight on Friday the 13th, 2007, he jerked up in bed and fell over. His wife thought he was dreaming, he fell halfway off the bed and his wife struggled to get him on the floor, pinching him to try to wake him. She realized he was

not breathing and called 911, then called us after the medics arrived. When we arrived, they were putting Michael into the ambulance. They took him to the major trauma center rather than the local hospital so we held a small bit of hope, even though we knew if he had stopped breathing; too much time had passed for him to survive. At the hospital, we were told that he had left ventricular arrhythmia and was pronounced dead. The doctor suspected Viral Myocarditis and after autopsy the cause of death was verified. There was no heart muscle enlargement; the Medical Examiner said that he was perfectly healthy which makes the finality of death more difficult to accept. We had never heard of myocarditis before this happened. We know now, unfortunately, one of the symptoms is sudden death. Our beloved son is a face of Myocarditis and through awareness, if other lives are saved, then his death will not have been in vain.



Michael Kern • Charlotte, NC

Rest in peace Michael. We love and miss you everyday. ~ Sylvia Kern, Mother



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BEATING MYOCARDITIS

James Conrad Moore • Chino Hills, California



I'm 18 years old. I'm in my first semester of college. My favorite activities are hunting, fishing and playing guitar. The most important things in my life are family, hard work and having fun.

My Myocarditis story begins when I was just not feeling good one day. I couldn't fall asleep because my chest hurt. I went to the hospital later that night. Eventually the doctors figured out that I had myocarditis. For the next couple of weeks, I was stuck in the hospital being monitored and having a lot of blood tests done. I was in a ton of pain, and it was scary to hear that not much could be done to get me healthy because Myocarditis is caused by a virus and not much is known about it.

My recovery took about a year and a half, but it seemed like forever to me. I was very weak and felt exhausted all the time. Slowly I started to get my energy back. At first I took short walks, then jogging, and now I am back to running and lifting weights. Once in a while I have bad days when I am in a lot of pain and I feel like I was back in day one of recovery, but I push through it. I forced myself not to worry about it and keep going. Recovery was very tough and stressful at times, but I tried my best to be positive.

Myocarditis has definitely changed my life. I was 17, very athletic and perfectly healthy. Then I felt sick one day and ended up in the hospital wondering if I would see tomorrow. My first day home when I was out of the hospital, I walked outside and looked at the blue sky, the trees, heard the birds chirping and I really started to appreciate

life more. I try to live every day to the fullest now. I was curious about the disease so I searched online and found the Myocarditis Foundation website. I wanted to raise money for the Foundation because it was scary for me to hear the doctors tell me that there is no way to treat it or prevent it. I hope that sometime in the future doctors will be able to tell other victims of the disease that Myocarditis CAN be treated.

My plan was to try to get people to sponsor me to go on a 16 mile hike. It wasn't an easy task for me at the time, but I had family and friends along with me for motivation. We raised a good amount of money. It felt good to know that I was helping to fund research that could help people fight through Myocarditis and be healthy again. Everyone had a good time on the hike and they felt good about themselves too.

I'm doing great now. I've been riding my bike, hiking the Sierras, and my heart doesn't hurt at all. Being in the hospital so long and having myocarditis made me lose almost all my muscle mass on my arms and legs, but I am back to lifting weights and as soon as I get my muscles back, my body will be just as it was before getting sick. I feel very lucky to have survived and not have any permanent damage done to my heart. With the help of the Myocarditis Foundation, I believe that more people will be as lucky as me and Myocarditis won't be such a deadly threat as it is now.

Sept 2010



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My Story

Candace Moose • Point Pleasant, New Jersey

In August 2001 I received two immunizations to travel to Africa to do mission work. Two hours later, my heart started to beat faster, more irregularly and more forcefully. One week later I coded three times, had a defibrillator inserted and was sent home with a diagnosis of viral myocarditis. The next day I went into cardiogenic shock and though the doctors told my husband there was only a slim chance I would survive the night, if by some miracle I did, my only chance for survival was a heart transplant. The next day, I was transported via EMT to Columbia Medical Center where Dr. Deng was waiting for me in the Critical Coronary Unit. He knew immediately it was Giant Cell Myocarditis and he consulted with the world's leading expert, Dr. Leslie Cooper from the Mayo Clinic. Dr. Cooper's research showed that by giving chemotherapy because of its immunosuppressant and anti-inflammatory properties, GCM patients survive until transplant if a heart were to become available. In all those weeks, I laid in my bed in the CCU praying that I would live to see my children married and my grandchildren born. The treatment was successful and a heart did come on October 1, 2001; the heart of a 17 year old boy whose parents made an unbelievably difficult decision to donate their son's organs.

I survived only because of a series of miracles: Dr. Deng's immediate diagnosis of Giant Cell, Dr. Cooper's research and treatment recommendations and the gift of a heart from an unknown family who suffered tremendous loss. I said to Dr. Deng and Dr. Cooper, "What can I do to give back to you what your knowledge, expertise and care have given to me?" Together, we formed the Myocarditis Foundation to help other patients and families in the present. It is our hope that the research we fund will result in more lives saved in the future. I plan to work toward that goal for the rest of the life I am given.

**Candace Moose, Giant Cell Myocarditis Survivor, Heart Transplant,
Founding Director of the MYOCARDITIS FOUNDATION
May 5, 2011**



Knowledge Nurtures Hope

Not a Blank Canvas: *Portraits of Myocarditis*

“Who’s got it better than me? I’m a walking miracle.” These are the words of New Jersey heart transplant patient Joseph Rumore, 57. Having received a new heart on his birthday, November 24, 2006, Rumore’s actions prove that he means what he says,

“You can choose to be down in the dumps, or you can decide to look at this as an opportunity,” says Rumore.

Aside from exercising at least three times a week, Rumore has carefully charted out a life that includes disciplined nutrition, a rigid medication routine, and devoting much of his time to the Myocarditis Foundation, an organization seeking to find a cure for the disease that destroyed his original heart. As a member of the foundation’s Board of Directors, Rumore uses his business background to help the organization administer a program that returns ninety-five cents of each donated dollar to research grants and education.

Lives by Risk Factors

Every lifestyle choice made by Rumore is decided upon by weighing the risk factors involved. This includes decisions on where he walks, works, plays, dines and exercises.

“Exercise is one of the most important things I had to integrate into my life,” he says. Because the anti-rejection medication he takes represses his immune system, Rumore says he has to be much more aware of his environment.

“I chose to exercise at the gym because of how clean both the staff and the members keep the place. Also, their cardio machines let me monitor my heart rate, and they have the paddles. I also know that the personal trainers are watching out for me. Rumore explains. “I lead a perfectly active life.”

Otherwise Healthy Life

Rumore had always lived an athletic lifestyle and never had clogged arteries or any of the other conditions usually associated with heart disease. He says that when he was playing a college basketball game in the late seventies, he started feeling ill. A subsequent cardiogram showed an abnormality, but everything soon went back to normal, and he didn’t give it any more thought.

Then, in 1989, his symptoms of fatigue and lethargy returned. His wife, Genevieve, a nurse, pushed for more high-profile tests. The results showed congestive heart failure, with a possibility of myocarditis. Rumore continued to live as comfortably as possible on medication under the watchful eye of Genevieve.

Then, in 2004, his health declined rapidly. His heart ejection fraction went as low as 9 percent. Ejection fraction is the measurement of the capacity of the heart to pump. A normal ejection fraction is 50% to 70%. In 2006, Joe received a donor heart and began the long road of recovery. Rumore’s ejection fraction with his new heart is 63%. “We can all learn a lot from Joe”, adds a friend. “He’s living proof that we can overcome great odds with a plan and a great attitude. He’s not only an inspiration for other transplant patients, but an inspiration for all of us”.

A Survivor's Story



Joe Rumore • Parsipanny, New Jersey



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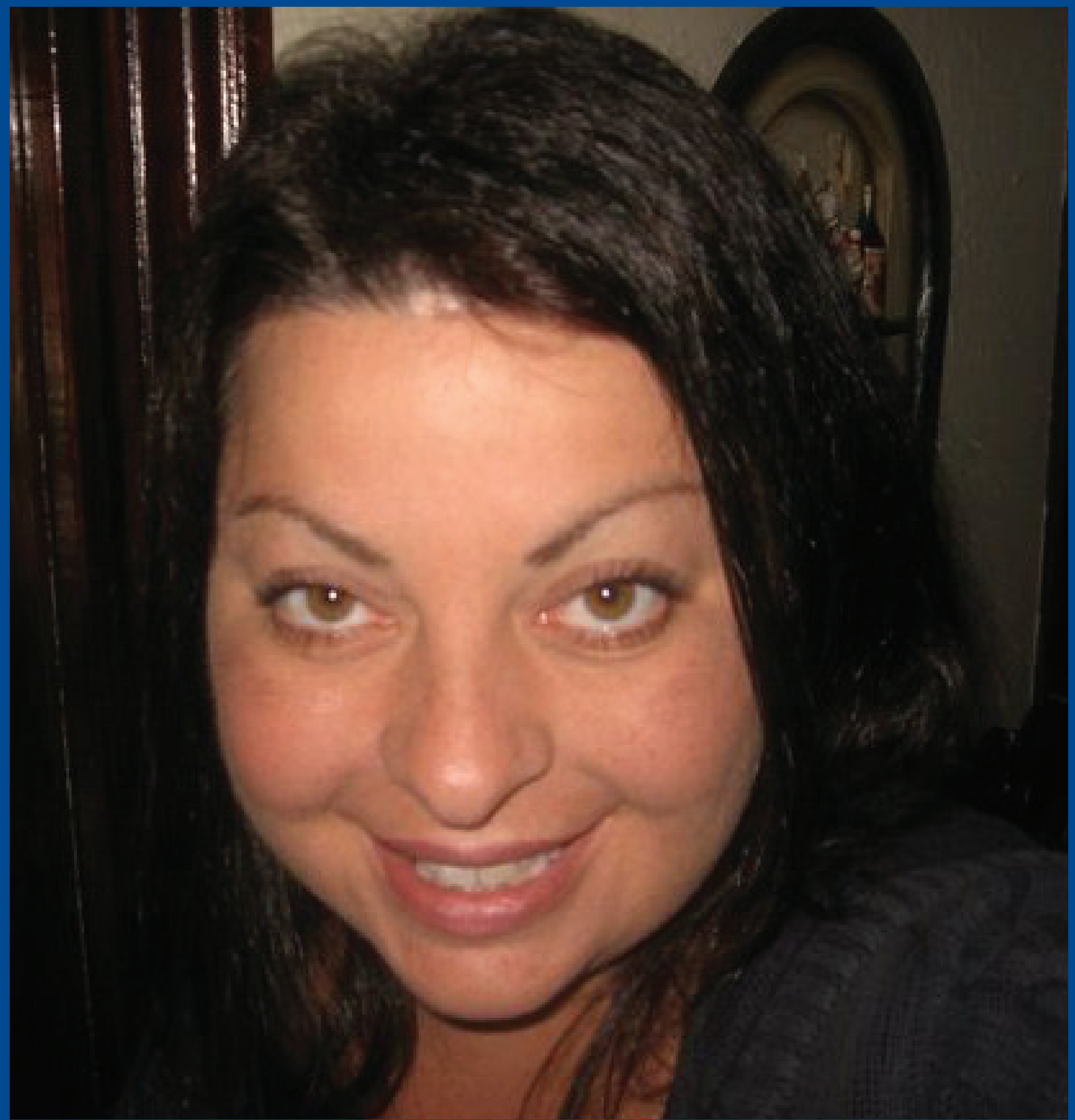
My Story

I checked in to emergency room at the local hospital. A man in a white coat stood face to face with me and asked if I was having chest pains or shortness of breath. My reply was yes. He looked at me in disbelief and told me to have a seat in the waiting room it would be an hour or so before I was called. I was thirty two years old and in good shape

no one would believe I had a heart problem. I left and drove to Dr. Guilbert's office thirty minutes away in the snowstorm. I was rushed out of his office by ambulance and taken to the city hospital. I had congestive heart failure that night. They did emergency surgery to install a heart pump. I was then rushed to Tufts in Boston where I had a new heart pump installed and a biopsy. I was diagnosed with Giant Cell Myocarditis and placed on the transplant list. Against all odds I left the hospital weeks later with my own heart at full function.

Eighteen months later I was back at Tufts in a coma for months. I arrested several times. They called the CDC in hopes of answers. I was finally diagnosed with Meningeal Encephalitis and cerebritis. My immune system attacked my brain. I was treated with steroids, antiviral agents and Cytoxan eventually fully regaining my memory.

One year later I was rushed out of Dr. Guilberts office again. I had Pulmonary Embolism, and chronic kidney disease stage III, systemic lupus erythmatosis, lupus nephritis, vasculitis. The next year I had a right atrial collapse, pleurisies, and pericarditis with bibasilar atelectasis. Against all odds and expectations I am still here. My secret you ask? Positive thinking and an unshakable faith.



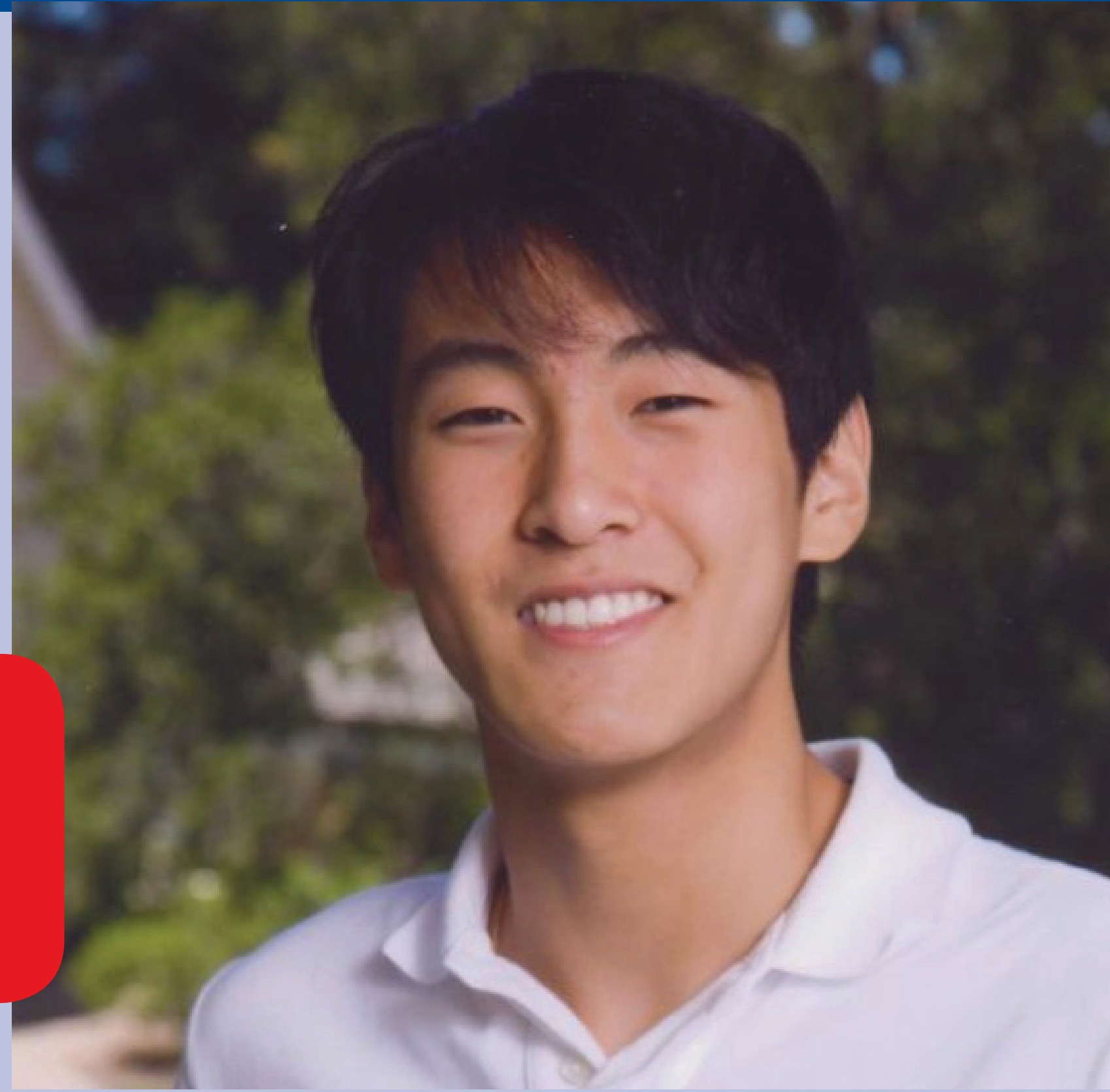
Annie Schofield • Putnam, Connecticut

Not a Blank Canvas: *Portraits of Myocarditis*

MY STORY

A Piano and Violin Virtuoso and Myocarditis Activist

Miles Shen • Atherton, California



In December 2009 when I was a 17-year-old high school student, I contacted the Myocarditis Foundation to explain I had done a project on Myocarditis and decided to raise awareness about this disease by hosting a chamber music concert at my school. In addition, I produced a CD of my piano performances and sold them to raise money, and donated the proceeds to The Myocarditis Foundation.

I became interested in myocarditis by chance. My Anatomy class teacher at the Menlo School asked everyone in the class to write down 5 diseases they are most afraid of getting. Based on this information, our teacher assigned each student a different chronic disease. Over the course of the month, we lived as though we actually had our diseases. My aunt had a very mild version of myocarditis when she was young. I got some insight from her. Today, she is hardly experiencing any problems.

I learned Myocarditis is not well understood due to lack of research. Because all research requires money, I decided to incorporate my personal interest in music by making and selling CD's. This CD was recorded at home on my own little 'recording studio'. I spend hours some days recording just one or two pieces. The work is very intense because mistakes happen often. But in the end, all the work pays off. I am proud of the product.

I feel the project was rewarding at both personal and far-reaching levels. At the personal level, this project helped me take greater initiative. I did all the planning, reservations, CD sales, and sent the invitations. At the far-reaching level, I feel rewarded with the opportunity to help those truly in need. I hope my contributions go a long way. Thank you for listening! I will be sure to continue my work. If anyone wants more CDs, I have plenty left.

NOTE: Accompanied by his friend, a pianist, Miles played his violin at a Myocarditis Foundation fundraiser in September 2010 at the home of James and Candace Moose. He continues his activism on behalf of the Foundation despite a grueling academic course load at Princeton University in New Jersey.



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Our Story

Forever Be in Our Hearts

*By: Carolyn Sweet
Logan's Mom*



Logan Sweet • Bowdoinham, Maine

The loss of a child is a road that no parent should have to travel, but on May 9th, 2008, at 6:47pm, Logan, our 6 year-old son, collapsed in our den and, despite my efforts to revive him, he died instantly in my arms. He was a healthy boy who lived a normal, active life.

The autopsy report indicated that his heart was 75% larger than normal. Later we learned the cause of his death was Viral Myocarditis.

This was a total shock to all of us. For months, I walked through life in a fog. How would I continue to live? It has been three years since that devastating moment. One of my biggest fears when Logan died was that people would forget him; that his friends and teachers at school would forget how much fun he was, how easily he laughed, and how enthusiastic he was to learn.

The school has since honored Logan by naming an award after Him.

To make sure that Logan would be remembered, I made a large quilt from Logan's pictures, artwork and his favorite shirts, all sewn together. This beautiful memory quilt sits on our bed right now, a constant hug from Logan.

Next, we had a beautiful bench installed at the school playground, dedicated to Logan by his family. It is a place for anyone to sit and be where Logan loved to "Laugh, Play and Love" – the inscription on the bench plaque.

Lastly, to keep Logan's memory alive, we created the LoganSweet Foundation with the mission to raise awareness of Viral Myocarditis, and to promote good health and eating habits, as well as, the importance of living a healthy and happy lifestyle.

I continue to need to stay connected to my memories of Logan, no matter how painful it seems at that moment. Sharing stories of Logan with my husband, my family and my friends gets me through the pain. Crying is my connection to Logan. My love for him grows with every good cry. I find I am renewed, and I know that my continued strength comes from him. I have also found peace, peace in the precious eyes of my other children. They are proof that love never dies and that life does go on.

I hope Logan is looking down on us with a "huge heart" at all that we have done, and continue to do, to keep his memory and love alive. I miss him more than words can say. I think about him every day, and I know that he will be Forever In Our Hearts. I love you Logan.



Knowledge Nurtures Hope

Not a Blank Canvas: *Portraits of Myocarditis*

It was Christmas Eve 2007 and whilst wrapping the last of our Christmas presents, I turned to my husband Gary and said how blessed we were. We were both healthy and happy and we had a beautiful little boy Angus who was 18 months old. I was pregnant with a new baby due in two months; I had just turned 36 and was in the prime of my life.

My Story

I struggled through Christmas Day, feeling exhausted, with family at our place for lunch. I saw my doctor and he thought I was coming down with a virus. Later that afternoon I decided to take Angus for a walk in his pram. As I was pushing him up a steep hill I got a burning pain in my chest. Once I got to the top of the hill I collapsed over the pram and tried to get my breath. My husband immediately took me to the hospital.

Doctors ordered a blood test to check cardiac troponin levels and were alarmed to see that they were very high. They thought I was having a heart attack. I was put into critical care as I rapidly declined to the point that my every breath was a painful struggle. They really didn't know what was happening to me. After a few echocardiograms they diagnosed viral myocarditis. The team of specialists decided it was best for both the baby and I, to deliver by caesarean section. My poor husband was told that I might not make it.

Tiny little Ava Lee was born 7 weeks early. She went off to special care with Gary and I went back into Intensive Care. I was breathing a lot easier and after three weeks in the hospital I slowly built up enough strength to go home. My echocardiogram looked good so the cardiologist thought I would make a good recovery over the next 6 months or so.

Once at home life was really tough. I didn't have the energy to be looking after a newborn and a toddler. After two weeks of struggling at home my cardiologist ordered another echocardiogram immediately and saw that I was in heart failure. My heart was really large. He decided that I needed a heart biopsy. The biopsy showed that I had a very rare condition called Giant Cell Myocarditis. This was the worst possible outcome. I started very heavy immunosuppressant intravenous therapy that made me so sick. They decided to implant a defibrillator. When stable, I went home with all my drugs.

Giant Cell Myocarditis is a nasty condition that most people don't survive. There were no survivors in Australia. After 6 weeks of the intensive drug therapy my next biopsy showed that the Giant Cells had gone. I was warned I would never be cured as GCM is an immune system disorder that could reoccur.

I realize my life is a gift and I cannot take it for granted. So many people don't survive and it is by God's Grace that I did; I intend to make it a good one however long that may be.

DONNA TAYLOR
AUSTRALIA



Not a Blank Canvas: *Portraits of Myocarditis*

Our Story



Brad Vanness • Kewanee, Wisconsin

We lost our son Brad to Cardiac Arrhythmia due to Acute Myocarditis on Sunday, April 18, 2010. He was 27 years old and only sick for two days. His wife, Amy, took him to the ER on Friday, April 16th. Brad and Amy told the ER staff that he had chest pains, a racing heart, and abdominal pain. When he got there he immediately vomited; at that point the focus of the ER staff was on his stomach and the flu-like symptoms even though both Brad and Amy had told them of the chest pains numerous times. After spending 5 hours in the ER, Brad was discharged with the explanation of “Severe Abdominal Pain - Cause Unknown”.

On Saturday, Brad had an uncomfortable day, but was feeling somewhat better. On Sunday, April 18th, Brad and Amy spent the day watching television together and he was feeling better. About 8 p.m., Amy went to a friend’s house and Brad was going to make supper for them. He was outside talking with her when she left. She told him she would be home in about an hour. When Amy came home at about 9:15 p.m. she found that Brad had died while she was gone.

It took the pathologist about a month to find out it was Myocarditis. Brad was a great young man with a promising future! We had never heard of this awful disease before this, and we turned to the Myocarditis Foundation for information on what had happened to our son.

We feel the need to help others become more educated on this disease, especially the doctors. A benefit was held in February 2011 in Brad’s memory and enthusiastically supported by the Kewanee community. Over 400 people, including the mayor and law enforcement officers, attended the event and proceeds were given to the Myocarditis Foundation for awareness and education programs. It is our hope that by educating individuals and healthcare workers, this tragedy may be prevented from happening to other families.

Randy and Cindy Vanness, Amy Vanness,
Jeremy and Jamie Jackson



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Aaleigha's Story

Ashley and Amber Young, sisters from Pittsburgh, Pennsylvania, lost their 13 year old sister, Aaleigha, suddenly and tragically to myocarditis in March of 2009. The girls and their college friends, one an early childhood myocarditis survivor, turned their grief into action and organized a Rock Concert fundraiser. The girls invited their friends, advertised with posters, gathered corporate sponsorships, sold tee shirts and wristbands, convinced the local arena to donate the space and local high school bands to play for free! What an event; with nearly 200 in attendance, the room was electric with energy! Cherie Young (mother), grieving for her daughter yet so proud of her family's and friends' efforts, took in the love and support of the community who turned out show how much they cared. The concert

was a huge success and proceeds were used to create a scholarship in Aaleigha's memory at her middle school and fund myocarditis medical research through the Myocarditis Foundation's research grants program.

Aaleigha was participating in a track and field event during gym class at her school when she collapsed while running the final leg of a relay. Though resuscitation efforts were initiated immediately, she died at a hospice several weeks later, having never regained consciousness. Initially, the doctors were not sure of the diagnosis, but a heart biopsy revealed myocarditis and other heart problems.

Candace Moose, Founding Director of the Myocarditis Foundation, who attended the event stated. "I am so grateful to have met these wonderful young people, to have been invited to share in their grief and in their activism, and finally for the Myocarditis Foundation to benefit from their tremendous efforts and success! May God bless them all."



Aaleigha Young
McDonald, Pennsylvania



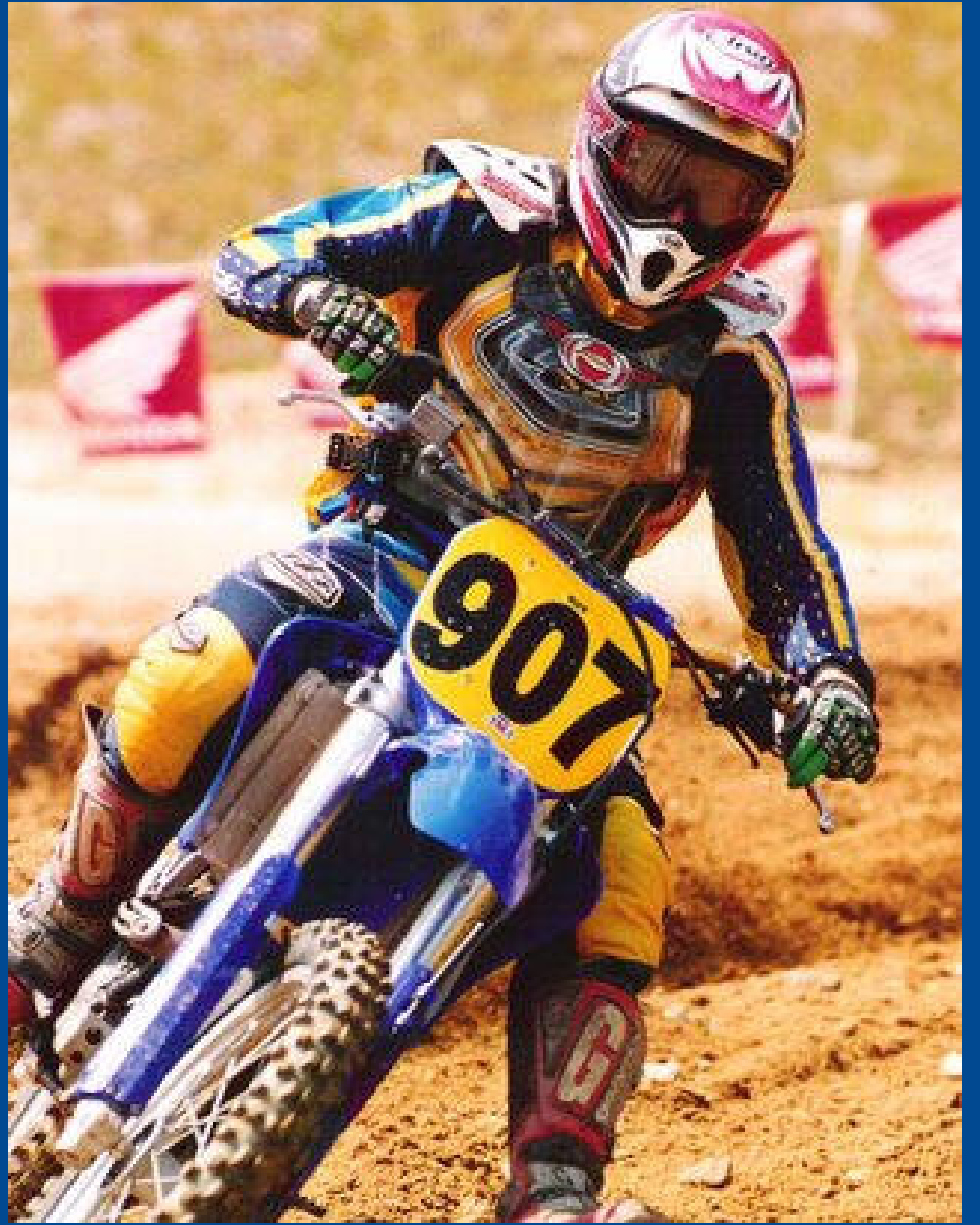
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Devin's Story



Devin Kravitz • Leicester, MA

Devin Kravitz, born January 31, 1984, grew up in Leicester, Massachusetts. A very active kid, he played Little League, soccer, and Pop Warner football. He was a member of the Greenville Baptist Youth Group and loved going on retreats with the church.

Devin had the need for speed. His greatest recreation love was dirt bikes. In 1999, he started racing with the New England Sports Committee and became an expert rider in his third year of competition, not an easy accomplishment. His professional race number, 907, was retired in his honor.

Devin graduated from Leicester High School in 2002 and went on to Quinsigamond Community College part time taking courses in criminal justice. He also spent time on the Leicester Volunteer Fire Department. Devin worked in the carpentry and electrical fields with local companies and spent a lot of his time helping family and friends with their home improvement projects. In September 2006, he was selected for the Police Academy and would have started in December 2006.

On October 25, 2006, Devin passed away in his sleep from cardiac arrest due to Myocarditis of viral origin. He was 22 years old. Heart disease comes in many forms and it does affect the young and old alike. Often time's simple tests can prevent death, especially in young people.

Devin leaves behind his Mother Janet, his father Stuart, his sister Elizabeth, his fiancée Danielle, and who he would have enjoyed tremendously, his baby boy Austin, born on May 30, 2007.

Since his death, his family and friends, along with the community come together for the Devin Kravitz Memorial 5K Road Race, DK5K.org. The event is always held Labor Day weekend in his home town, to raise awareness of Myocarditis and to raise money for research. All proceeds from the event are donated to The American Heart Association and The Myocarditis Foundation.



Knowledge Nurtures Hope

Not a Blank Canvas: *Portraits of Myocarditis*



Becca's Story

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



Not a Blank Canvas: *Portraits of Myocarditis*

Melisa Sofia: The biggest heart in school



Melisa Sofia • New Milford, NJ

Melisa Sofia loved snatching paper out of the computer printer and drawing pictures of her family. She strummed a hot-pink guitar. She sang Miley Cyrus' "The Climb," then gave up Miley for Justin Bieber. She begged to have her nails painted and have "Good Night Moon" read to her. She rebelled against the jeans her mom wanted her to wear. Melisa was to begin practicing to be a cheerleader for the Mighty Mites football team.

"She was the sweetest, most pure-hearted child," Melisa's dad, Robert Sofia said.

The seemingly healthy 6 1/2-year-old died in her sleep the morning of June 23, 2011, less than 48 hours after her last day of kindergarten. The medical examiner found the cause to be a disease her parents had never heard of: myocarditis, inflammation of the heart muscle. Melisa's death left many thunderstruck.

Melisa Sofia was born Nov. 12, 2004, at New York-Presbyterian Hospital. Melisa was 6 months old when the family left the Bronx for a tidy expanded Cape on a northern New Jersey cul-de-sac.

It was on the cul-de-sac where she learned to ride a bike and played with her friends and brother Robert. They shared a bunk — Melisa and her collection of stuffed animals on the bottom, little Robert on the top.

Robert Sofia, Melisa's father shared this story, "A man came up to me, in the long procession at the funeral and bowed to me. I've come here to tell you that Melisa would always play with my daughter and protect her from the kids who were making fun of her. And that his daughter said Melisa had the biggest heart in the school."

After that heart gave out, Melisa's mother wondered whether the family should keep the house.

After all, it was upstairs in the pink-walled bedroom where her mother found Melisa lifeless on that blur of a morning in June. It was downstairs, on the entryway's granite floor, where police officers frantically tried to revive Melisa. They thought the better of leaving. This is where her memory lives on.

Copy consolidated from article published Aug. 14, 2011

Jay Levin, Staff Writer, The Bergen Record

New Milford, NJ



Knowledge Nurtures Hope

Not a Blank Canvas: *Portraits of Myocarditis*



Alice Fried
British Columbia, Canada

My Story

On July 6, 2010, it was just another normal day - I enjoyed a morning bike ride. My daughter came home from school and I promised we would go to see the new movie, *Twilight*. I remember feeling like I might be catching a cold. We headed to Chilliwack BC, to get a bite to eat before hitting the movies. I tried to have a cigarette, but I had this weird feeling that I couldn't inhale. I tried to eat; I couldn't get a bite down, so I told my daughter that we needed to go home so I could lie down.

As we approached home, I began to feel pressure in my chest. While I laid on the couch, the pressure became so intense, like a semi-trailer was on top of me. My daughter kept saying "Mom, let me call 911", and of course, I kept saying no. Then I started to feel sharp pains shooting through my back, and my face and neck felt stiff. The pressure and pain got worse; I was having difficulty breathing and my daughter called 911.

At the hospital, numerous tests were performed and I was told I had had a heart attack. Arrangements were made to send me to a hospital in Burnaby, BC for an angiogram. One week later, I had the angiogram and the cardiologist said my arteries looked fine, but I

had Myocarditis. My first question was "What is Myocarditis"? "It is an inflammation of the heart's muscular wall. Myocarditis can occur with no symptoms, and is often misdiagnosed". The doctor said I was very lucky, as "a very large percent of people who get this disease do not know they've had it until found later on an autopsy. Inflammation occurs when there is an infection and the body sends more blood to those areas to fight the infection".

I was released the following day, with instructions: strict bed rest, no sports or anything strenuous, no cigarettes. Five weeks later, my ejection fraction (heart function) was 50%, and I still had the infection, but it was going away. I was told I could not go back to work yet, but should gradually work on getting my energy level back.

It is now May 2011 and I am back working, but find that I get tired easily and if I lift something heavy or do strenuous activity, I get a little warning sign - sort of a flutter in my heart. I thank the wonderful doctors who took care of me, and the many friends and family who continue to pray for me.

Alice Fried, British Columbia, Canada

Not a Blank Canvas: *Portraits of Myocarditis*



Vanessa's Story

Vanessa Hickey • Flower Mound, TX

Vanessa noticed a rash on her chest April 1st 2011. Although she had been training for a 7 mile run, she was experiencing occasional fatigue and upset stomach. The rash kept getting worse and she was also noticing shortness of breath with exercise and went to the doctor 3 times over the next few weeks. After celebrating her 40th birthday with friends, she woke up throwing up from what we assumed was a stomach bug. She was

also having a little lightheadedness and slight chest pains, so we took her to a medical clinic. After a chest X-ray, an EKG, and 2 bags of fluids, they still thought it was a nasty stomach bug and sent her home to rest.

The symptoms continued to worsen so she went to our family doctor 2 days later. The doctor couldn't get a pulse, so he sent her down to the ER. As they were preparing to remove what they thought was an infected gall bladder, her blood pressure dropped at an alarming rate. They put the surgery on hold while starting aggressive antibiotics to treat what they thought was a septic gall bladder. After checking her blood work, they believed she had a heart attack and then did an angioplasty to look for blockage. There was no blockage so they did an Echo to find her heart was only functioning at 12%.

She was transferred to UTSW and thanks to the knowledge of their heart failure team, they performed a risky heart biopsy and diagnosed her with a very rare auto-immune disease called Giant Cell Myocarditis. She was put on the heart transplant list, but her body began to react very positively to the treatment thanks to Dr. Leslie Cooper's research on the disease. After 3 weeks in the Cardiovascular ICU, we are happy to say Vanessa has made a miraculous recovery and is at home with her own heart, which is now functioning normal with little or no scar tissue.

Not a Blank Canvas: *Portraits of Myocarditis*



Our Daughter

Danielle Hymowitz • New City, NY

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

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Ashley's Story



Ashley Dale Orme • Michigan

Myocarditis took more than one person from our life; it took a Wife, Daughter, Sister, Aunt, Niece and Friend

Where do you start when you didn't know that there was an ending? Ashley was a healthy, vibrant, and fun loving 27 year old with her whole life still ahead of her. She was born December 28, 1982, graduated from Romulus Sr. High in 2001, attended the University of Michigan and then graduated from Henry Ford Community College with a degree in Accounting. She was married in 2007, had recently received a promotion at work, had purchased a new home in Trenton, Michigan and was planning to start a family.

October 12, 2010 was a normal day for everyone. Ashley woke up went to work; she was a Branch Manager and Assistant Vice President at PNC Bank in Michigan. After work she called me, her sister, Leslie, and we chatted for a while then we ended our call with "I love you Chop! Talk to you later." Chop was a nickname that we called each other. Ashley arrived at our mother's house and changed clothes. They had dinner and then they went to church. They had driven to church separately because afterward Ashley was heading to her home.

The meeting ended, Ashley and Mom each drove to the gas station that was just down the road and filled their tanks. They hugged and said their good-byes and each promised to text when they got home.

Around 11:45pm Jason, her husband, arrived home from work and went into the bedroom to let Ashley know that he was home but she was unresponsive. He turned the light on and saw that she was not breathing, called 911 and started CPR. The Ambulance arrived on site and took over the attempts at resuscitating her. Once Ashley arrived at the hospital the emergency room doctor pronounced her dead at 12:25am on Wednesday, October 13, 2010. The reason at that time was undetermined.

The Medical Examiner found her cause of death to be Myocarditis. A disease none of us heard of. Myocarditis took her from us- our Wife, our Daughter, our Sister, our Aunt, our Niece, and our Friend.

Her life suddenly ended just as it was beginning.



Knowledge Nurtures Hope

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Our Son

Andy Peña • Darien, Connecticut

It was supposed to be a wonderful weekend. Our family had travelled 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 where “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



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Caitlyn Vincent • Baltimore, MD

Caitlyn's Story

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 Vincent

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

-CAITLYN VINCENT

Not a Blank Canvas: Portraits of Myocarditis

Lukey's Story

An infectious smile, wit, as well as a magnetic personality, Luke Anthony could make friends wherever he went. Lukey was a loving, caring, and compassionate son, brother, grandson and friend.

Lukey is an angel now, passing of myocarditis on November 16, 2011, Luke was ten years old. Luke was a gifted artist as well as athlete, and was always on the go.

His favorite school subject was art, and he was able, even from a very young age, to draw incredible pictures and art projects. Lukey maintained his studies, but I suspect the rest of the school day was another avenue to socialize and make friends.

Lukey excelled in sports as well, playing baseball, soccer, and hockey in our town leagues. He never stopped moving, and when he made a save as a hockey goalie, you could see that smile under his mask, and the pride he felt, as did we all. Lukey's future seemed so bright, and he was loved by so many.

On November 15, 2011 Luke kissed Mom good night and told her he loved her, Luke did not awaken on November 16. How could this happen? Luke was a happy, active, vibrant ten year old boy with no symptoms of any illness, and a future as bright as the sun waiting for him to embrace

it. Our world stopped turning on this day, as we were living every parents worst nightmare, the loss of a child. Our families hearts all have a void, missing his smile, his laugh, his unending energy with every breath.

Initially deemed unknown cause, efforts from NY Senator Tim Kennedy allowed Lukey's case to remain open and myocarditis be found as cause of Luke's sudden passing.

The Myocarditis Foundation has provided much comfort to our family these past months. Our current efforts, which are guided by an angel, are focused on establishing autopsy guidelines and raising awareness of this disease.

Every moment of every day, Lukey is missed by so many, our hearts are broken . . . our resolve is not.

Fly High Lukey!

Joe & Amy Skowronski



Lukey Gould
West Seneca, NY

Not a Blank Canvas: *Portraits of Myocarditis*



Cathrynne Wagner
Burnham, Pennsylvania

Rynne's Story

Cathrynne was such a joy to everyone who knew her. Her smile could light up a room and she always knew exactly what she wanted. She was beauty and spunk in a small package. On a Thursday afternoon, Cathrynne started vomiting. We gave her fluids to keep her hydrated, but the next morning, when she was still throwing up, we took her to the pediatrician. He believed she had a stomach virus and prescribed medication to settle her stomach. After getting the medicine, she started to keep down fluids and had a typical lazy day at home.

Saturday, she was still keeping down fluids, but was not eating solid foods. She stopped throwing up, but she still seemed weak. Since she was keeping down fluids, we expected her to start to tolerate solid food the next day; however, on Sunday morning, she was even weaker. Her breathing became labored and her heart began to beat rapidly. We rushed her to the emergency room.

The doctors ran tests and took x-rays. They informed us that she had pneumonia and needed to be taken by helicopter to a children's hospital. Just as the helicopter arrived, our sweet little girl went into respiratory arrest. The doctors, nurses and flight team worked valiantly for more than an hour and a half to revive her.

No one could tell us how something like this could happen so suddenly to an otherwise healthy child. Every day, children have stomach viruses and parents never think that it will take their children. We were left with our grief to wonder what caused this to happen to our family.

Six weeks later, we received the autopsy results. A silent killer, rarely anticipated, had damaged her little heart. Myocarditis had taken our little girl.

Jennifer Wagner

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Melita's Moments



Our daughter was named after myself, her mother, Lita & her grandmother, Olita (her best friend). She was the lifelong dream of my husband Chris, his “Baby Girl”. On September 21, 2011, 18 days past her 3rd birthday, I had kept her home from daycare because of “flu-like” symptoms. I had taken her to the Pediatrician mid-day when she had showed signs of her blood pressure dropping, we were sent home with a prescription for nausea and told to give it a day and what we hoped was a virus would pass. At 5pm that afternoon Melita took her last breath, seconds later in my arms her heart stopped. It took an excruciating 90 days to determine the cause of our daughters passing, viral myocarditis. Like too many other Parents we do not want our daughter to be forgotten, nor do we want the sum of her life to be of her death. My husband is military and in regards to our daughters passing the military truly stepped up to take care of their own. With the small life policy the military provided we covered the funeral expenses and the remainder we donated. We donated to her daycare, and took donations in place of flowers at her funeral to purchase outdoor water fountains & benches for the playground. We also donated a small amount to our local church for their new child care facility. We felt it only right to give back to the people who helped us educate, and develop our beautiful, joyous, bright charming and tenacious little lady. Our daughter taught her friends and family to love unconditionally, and have faith and trust God regardless of the outcome. These moments as well as others where we have had the opportunity to share and to help heal and minister to other’s we call Melita’s Moments and our lives have been filled with many. By working with the Myocarditis Foundation increasing awareness and providing funding for research, we hope that our lives as well as others will be filled with many more.

Melita Warmbold
Abiline, Texas

Chris and Lita Warmbold



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My RESEARCH

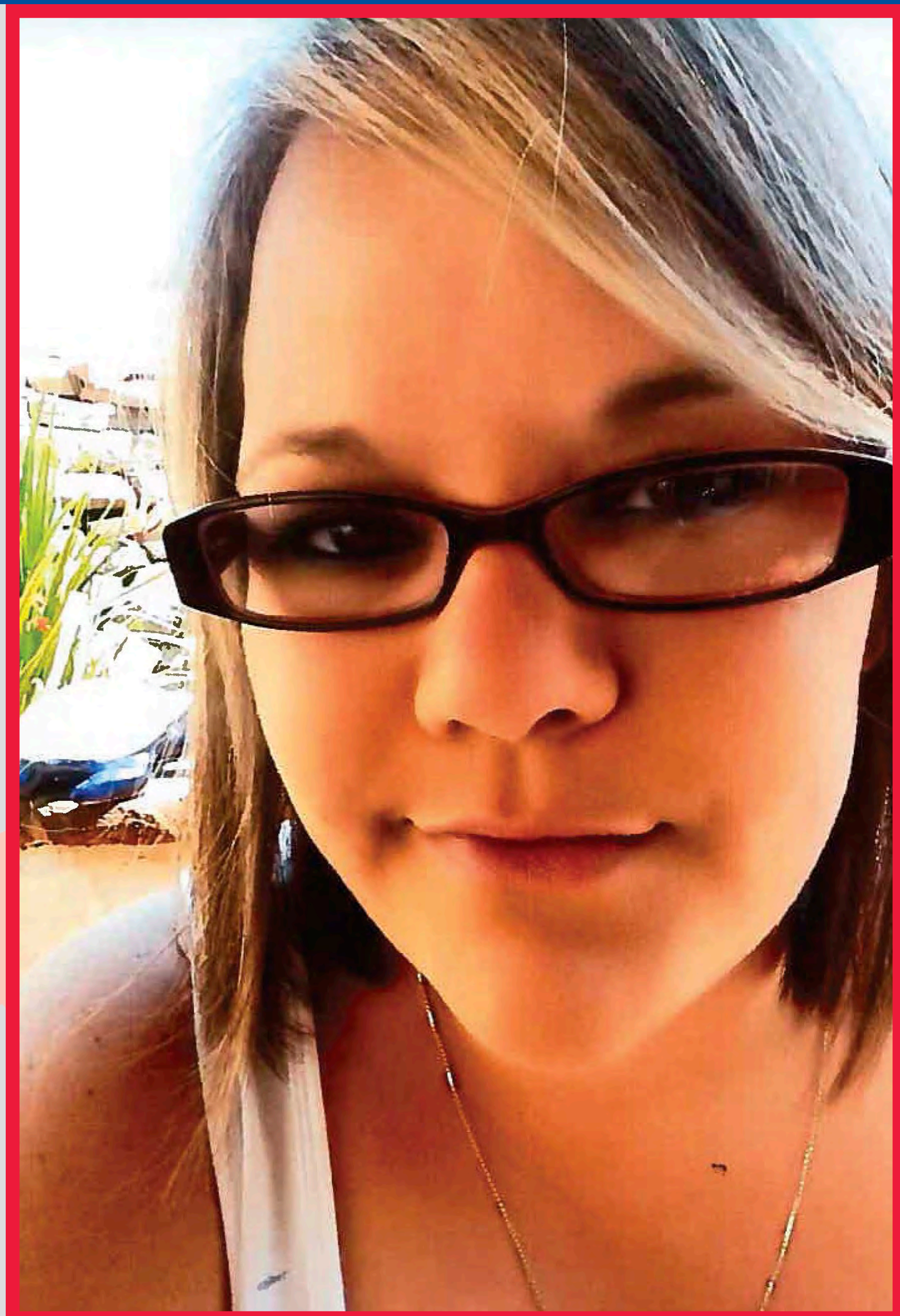
“Viral infection with cardiotropic viruses such as coxsackie virus B3 (CVB3) led to a massive myocardial inflammation called myocarditis. The major late-consequence of viral myocarditis is dilated cardiomyopathy with heart failure presentation. Although virus itself can be responsible for myocardial injury, there are more evidences that an over-bursting immune reaction, rather than a direct virus mechanism, is accountable for deleterious damage of the heart.” Research Finding

The Myocarditis Foundation research fellowship grant gave me the opportunity to concentrate on my interest to understand the interactions between the coagulation system and the immune system after a virus infection. During my fellowship I investigated the role of the protease activated receptor-1 (PAR-1) in coxsackievirus B3 induced myocarditis. PAR-1, also known as the thrombin receptor, mediates platelets activation and the cross-talk between coagulation and inflammation. In my study, I found that PAR-1 deficiency leads to a reduced innate immune response during coxsackievirus B3 infection of mice. The reduced early innate immune reaction was associated with uncontrolled virus replication and more acute myocarditis that led to a greater impairment of heart function in PAR-1 deficient mice. My data suggest that PAR-1 activation is necessary for an effective innate immune response after coxsackievirus B3 infection. My research observations were presented at scientific meetings with international researchers and physicians to raise the awareness of virus infection of the heart. In addition, the support by the Myocarditis Foundation made it possible to initiate a productive collaboration between the McAllister Heart Institute at University of North Carolina at Chapel Hill and one of the leading myocarditis research and clinical centers in Germany, the Charité – Campus Benjamin Franklin in Berlin. I am thankful and appreciate the generous support by the Myocarditis Foundation and its supporters. Beyond the duration of my Myocarditis Foundation fellowship, I hope I can contribute to the knowledge of the myocarditis pathologic mechanism in the future.



By Dr. Silvio Antoniak
McAllister Heart Institute
University of North Carolina, Chapel Hill
Spring 2011

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Shannon Mauldin Story El Reno, Oklahoma

Shannon, was a healthy 31-year-old mother, wife, daughter, sister, and aunt, who every one depended on for one thing or another. Shannon was only 31 but had been on her job for 12 years starting at the bottom working her way up the corporate ladder. She was a financial advisor for the elderly and their families. She knew all aspects of this part of life for the elderly. Many times as her mother I would be visiting at her work and saw her go into her purse and give a resident money for one thing or another.

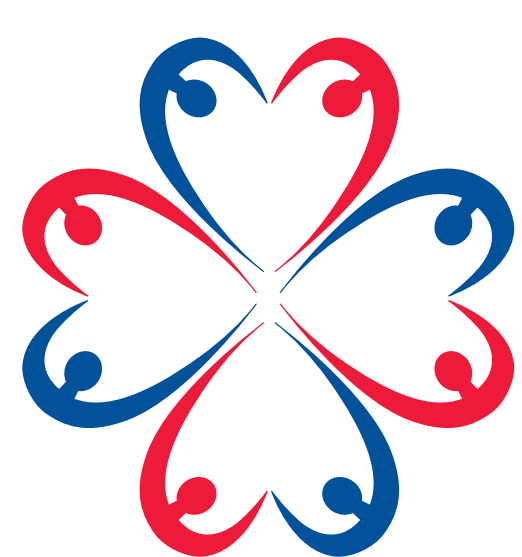
Shannon was a success story. She became a mother to a son at age 16 and worked very hard to provide for him all he needed and most all he wanted. She was never able to have any other children although she desperately wanted more. She was the sister to only one sibling and the only aunt to one niece. She was also

the best friend any one could ask for. She was the sweetest daughter her father and I could have ever wished for. She was kind, giving, and put every one else's needs before her own. She was madly in love with her husband. She loved all animals, but most of all her dogs Maggie and Mattie.

Shannon also loved life and the lake. The last holiday she had was the 4th of July 2015. We all spent it together at the lake enjoying family, food and fireworks. On the Sunday as we packed to leave, Shannon said in the most sincere tone of voice "Mom I just love this place, I never want to leave." On the way home that day is when I noticed something not quite right with her. When we arrived home she came in and for the first time in years I took her temp. It was 101.7. The next day she called in sick, which she never did, and went to an urgent care center. The doctor treated her as if she had the flu, gave her a shot and sent her home. The next day, Tuesday, she was short of breath, had a fever and tightness in her chest. Her mother-in-law took her to the Emergency Room and at that time we knew how serious it was. She was transported by ambulance to the nearest heart hospital and a pace maker was placed. Shannon kept getting worse and on a Friday early morning at 4 a.m. she had a heart attack.

As a mother, this is some thing you never want to see. Shannon was placed on the ECMO machine. She never regained a pulse. She is missed each and every day.

The reason I want to share her story is because Shannon was always giving to others. If her story can help another family, maybe just maybe, it will help her friends and family heal. This horrible disease strikes the most unlikely people and a cure needs to be found and found fast.



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Knox Peterson Schwarz was a vibrant, joyful, and loving 2 1/2-year-old boy. He loved chasing after his big brother and sister and swinging at the park.

A stomach virus had been going around our school and two members of the family had already gotten it, so we were not surprised when Knox threw up a couple of times. He was fine the next couple of days, and then vomiting returned along with diarrhea. We kept him resting and gave him plenty of fluids to keep him from getting dehydrated. That night, he seemed much better as his vomiting and diarrhea stopped. He did seem more lethargic than usual and went to bed early.

The next day he continued to improve, or so we thought. He even ran around a little and played with his siblings even though he seemed a little more tired than usual. That night, Knox fell asleep on the couch while we were watching a movie as a family. He was breathing heavier than normal with a strange sound but we thought maybe he was just congested. He had a doctor's appointment scheduled first thing in the morning, so we thought we could ask her about this then.

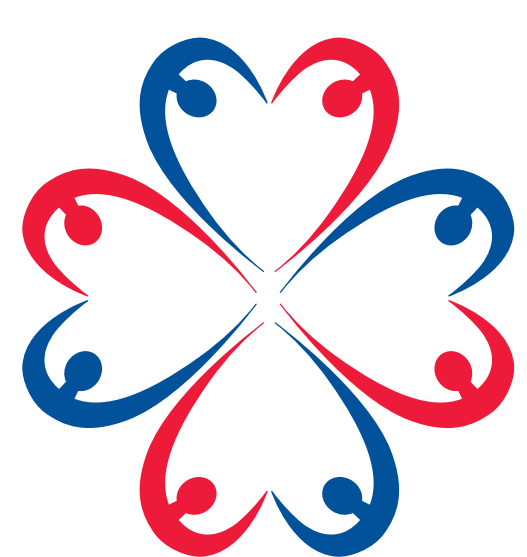
In the middle of the night, I woke up to change Knox's diaper and his breathing seemed to be more labored. I knew something was wrong and took him to the emergency room immediately. The doctors were concerned with his oxygen level and high heart rate and admitted us. They started treating Knox for pneumonia, giving him I.V.s with antibiotics and oxygen. He eventually had to be put on a ventilator to try and improve his oxygen. The doctor decided to give Knox an EKG on his heart and the result was abnormal. He consulted with the cardiologist, and for whatever reason decided against giving him an echocardiogram. It wasn't until hours later, when Knox's condition started to deteriorate, that they finally performed an echocardiogram. The doctor was finally able to see that Knox had an enlarged heart and suspected myocarditis. They wanted to transfer us to the local children's hospital that had an ECMO machine to keep him on heart and lung support. Knox was never stable enough to be transferred and ended up passing away after an hour of chest compressions.

We will never know why the doctors decided to cancel the first echocardiogram that was sitting outside his room, ready to be used. We will always wonder if, had it been detected earlier, this may have gotten him to the hospital with the ECMO machine in time to save his life. We are still awaiting official results from the medical examiner, but his preliminary cause of death is listed as myocarditis, something we had never even heard of before that November day.

We will always miss our beautiful and vibrant boy. His love and joy lit up our lives. We hope to set up a foundation in his honor asking people to do random acts of kindness in his name.



Cedar Park, Texas



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Rian Jones-Cook
Delanco, New Jersey

Rian was a Thanksgiving baby, born on November 16, 2015. Our family gathered and celebrated his arrival with food and festivities. Each holiday that followed, we realized he liked celebrations. He was never fussy and always alert. Rian went to his doctor for his routine monthly checkup at the end of February. He had a runny nose and the doctor just said to use saline drops to help keep his nose clean. He seemed better, but on March 6, 2016, he became irritable and I held him close. It was unlike him to cry so much. Suddenly he let out a scream and his arm dropped. I tried to wake him but no response. We called for help...The police came...



Then the ambulance.

He was alive.

Then, the sirens.

Then the longest ride ever.

The medics saying "oh no."

The hospital doctors working on him for 3 hours.

"His heart is not beating on its own. Do you want us to stop?" the doctors asked.

"No," I said. We'd still be there if it were up to me.

Finally, a decision was made that Rian was gone.

I was numb. I don't really remember a lot more after that.

It took 3 months to get the full results from his organs to find out what happened to my little king. When they called to tell me it was myocarditis (inflammation of the heart) I didn't know what that was.

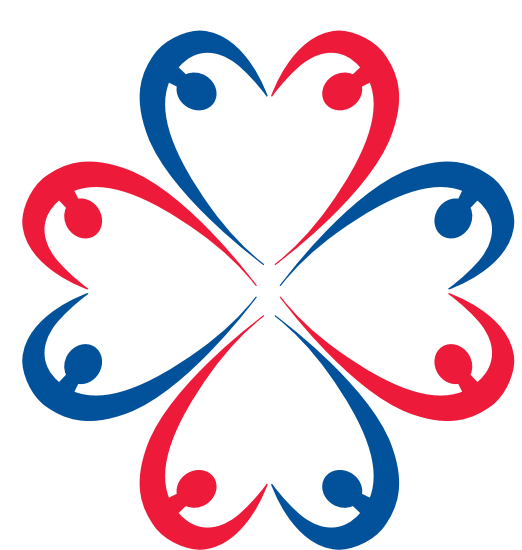
My baby Rian died because a virus attacked his heart.

How could this be?

My oldest son Richeon and I are writing a book on loss and healing thru a mother and brother's journey. The attached writing in blue is an excerpt from the children's book we are working on together. It will be published in early 2017 and we hope it will comfort others who have lost a beloved child. I hope that Rian's story will help people dealing with myocarditis to understand that they are not alone.

A portion of the proceeds from the book sales will be donated to the Myocarditis Foundation. We need to raise awareness about this disease to both the medical and public communities so that others do not suffer the anguish and suffering that we and others have had to endure.

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Ryan McArthur
Ontario, Canada

He was only 21 years old. He was brave.
He was a fighter and a warrior.
He died a sudden and tragic death to Myocarditis.

His name was Ryan and this is “His” Story.

On May 31, 1995 I was blessed, when I gave birth to my son, Ryan McArthur. He was a perfectly healthy and happy baby boy. Ryan was highly intelligent, studious and self-disciplined in high school. He graduated on the Honor Role, and was destined for success in his future. While in school, Ryan still found the time to learn how to play the drums, hold down a part-time job and coach a flag football team. He was very active, very healthy and very athletic. With Ryan’s hard work, dedication and commitment to his academics, he was named to the Dean’s Honors List and graduated Mohawk College at the top of his class, in May 2016.

The week of June 13, 2016 Ryan caught a head cold, with common flu like symptoms. He rarely ever got sick and never complained. He stated that he was just feeling tired and had a “cold”. In subsequent days he carried out his normal activities...played baseball with friends, went shopping for clothes, got a new haircut, still “fighting his cold”.

At 6:20 am, on June 22, 2016, our lives would change forever. We heard a loud bang on the floor of Ryan’s bedroom and a cry for help. “Help me! Help me!” We ran into Ryan’s room and found him on the floor. We called 911 and rushed to the hospital. Upon arrival they did an extensive medical history. He regularly worked out at the gym. He never drank alcohol, did drugs or smoked a day in his life. How could this be happening?

The waiting at the hospital was excruciating. After what seemed like an eternity, the doctors gave us an update. A blood clot had broken away from Ryan’s heart and traveled to the left side of his brain. He required emergency brain surgery to repair the clot. The surgery was a success. However, Ryan remained in a coma for 18 days following the surgery. We prayed that he would wake up. And on the morning of July 11th, Ryan opened his eyes and smiled!!

We were also told that Ryan had the heart of an 80-year-old and it was functioning at only 10%. We were told that an airborne virus had attacked his heart and that Ryan had a tough road ahead. We had so many questions. We were so confused. How could this happen to such a healthy, happy and bright young man with his whole life ahead of him. We were devastated.

Ryan spent the next 4.5 months in the ICU. He fought daily and he never gave up. The plan of care, was always to get Ryan strong enough for a heart transplant. Ryan’s determination never faltered. He never gave up hope. His progress in the ICU was remarkable. He was called, “The miracle of the hospital”.

Unfortunately, Ryan’s health deteriorated the last week of October, 2016. His heart could no longer hang on. It wasn’t strong enough. And Ryan took a turn for the worse. On Ryan’s last night, he was surrounded by all his family. I put my hand on his chest and I felt his heartbeats drop, one by one. I saw a tear roll down his cheek, from the corner of his eye. His heart stopped and within seconds it started again. I thought God was giving him back to us. He continued to fight, right to the end. The doctor unplugged the heart monitor, and I felt Ryan’s heart beat one last time. That night, my heart broke as well.

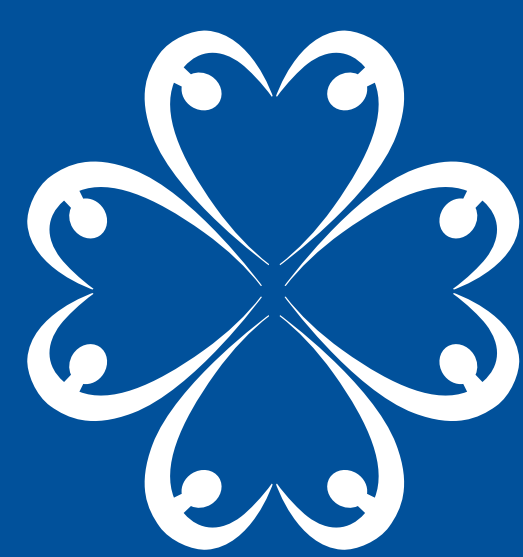
We love Ryan so much. We want everyone to hear about his courageous battle with this horrid disease. As a mother, I would have changed places with my son in a moment. I asked God to “take me instead”.

I want no other family to ever go through this experience. Myocarditis took our healthy, happy, amazing son away from us at only 21 years old. He never got to fulfill his dreams. He never got to fall in love, to get married or to start a family. He had so much potential. So much talent. So much to look forward too. His life was cut short by this disease and our lives will never be the same. We want to keep Ryan’s memory alive forever.

Ryan’s favorite inspirational quote by Tom Brady of the New England Patriots...

“I didn’t come this far to only come this far, so we’ve still got further to go.”

We need to work together to help the Myocarditis Foundation find the cure and stop this suffering and loss of life it causes.



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Gracie's Story... St. Louis, Missouri

Sept 6, 2017 is a day our family will never forget. Before this date, Gracie was happy, healthy and rarely sick. We were in the back to school routine and suffering with the usual back to school cold and cough that was going around. We took our children to the pediatrician where Gracie was diagnosed with the croup and given an oral steroid medication to help her breathing. Everyone else seemed to be getting better, but Gracie seemed to get better for a day and then she took a turn for the worse. Gracie's cough was worse, she was vomiting and she was very very tired which was unusual for her. She did not have a fever. She would be sitting on the couch and just fall asleep and was hard to wake up. We were worried so we took her back to the pediatrician. They told us they wanted us to go to the Emergency Room (ER) and get some tests done as they were worried that she was so sleepy. We took her to the ER and they ran some tests and started an intravenous line (IV). They told us they thought she might have pneumonia. We thought we would get antibiotics and go home and that is when our journey began.

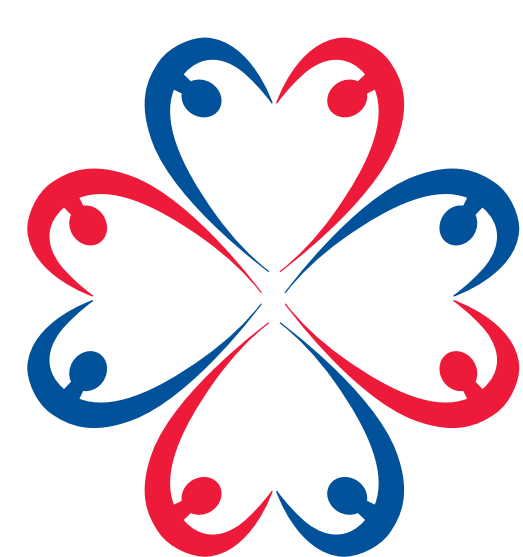


The next thing we knew they told us they were going to transfer her to Saint Louis Children's Hospital. We knew at that moment that things were very serious. They immediately took us to Children's Pediatric Intensive Care Unit (PICU) and then things took a turn for the worse. Gracie's room filled with doctors and nurses and they took us out of her room and down the hall. Gracie had gone into cardiogenic shock and cardiac arrest. She was diagnosed with viral myocarditis and tested positive for the corona virus. They put her on ECMO and a ventilator and told us they did not know what her prognosis would be. They said that if she did get better that she may need a heart transplant. She had so many IV lines and medication pumps it was hard to count. We prepared ourselves for the worst and we prayed. She was put in the Cardiac Intensive Care Unit on ECMO for 5 days and a ventilator for 6 days. Those were the longest days of our lives. We prayed and prayed and God answered our prayers. Gracie was getting stronger and they took her off of the ECMO and the ventilator and gradually off of her medications. After several weeks in the Cardiac ICU and weeks of physical and occupational therapy, Gracie was getting stronger each day. Gracie had to get her strength back so that she could walk.

Gracie is our little miracle and was able to finally go home. Her doctors are very hopeful that she will have no lasting effects from this terrible illness. We are so thankful to God and our wonderful Children's Hospital, all of the doctors, nurses, staff and resources that the hospital had for us. We are so blessed to have Gracie with us today and to have the support of our hospital, friends and family. We will never think of a cold the same way again.

We want to share Gracie's story to raise awareness of this horrible illness that we had never even heard of. We hope and pray that through raising awareness and funds for research, that others someday will not go through what our family went through.

Gracie's Mom & Dad



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Not a Blank Canvas: *Portraits of Myocarditis*

Kyle Hansen Story Oak Park, Illinois

Driving home from our summer vacation in July, 2017, I started to feel lousy. My throat hurt, my head hurt and I knew I was coming down with something. I saw my primary care physician who prescribed antibiotics over the next few weeks but my condition worsened. On a Friday afternoon, later that month, I began to retain water, my stomach began to distend and my urine output was very low. At that point, I went to the emergency room.

I was admitted into a local community hospital and underwent testing. I was eventually diagnosed with Myocarditis. However, the hospital did not have enough means to support my condition and I continued to deteriorate... quickly. At one point, a chaplain came in to pray with me, as my life was hanging by a thread. My family members requested that I be transferred to a facility in the Chicagoland area better equipped to manage my care. I was granted the transfer and the University of Chicago Medicine Hospital agreed to take on my care. I was immediately transferred to their world-renown Advanced Heart Failure & Cardiac Transplant division.

At U of C Medicine, I was put on an Extracorporeal Membrane Oxygenation, or ECMO machine. The machine pumps and oxygenates a patient's blood outside of the body, allowing the heart and lungs time to rest and recover while they are being administered life-saving medications. During the surgery to install the ECMO machine, the doctors took a biopsy of my heart and changed my diagnosis to Giant Cell Myocarditis.

I was fighting for my life and was told that there was a good chance that I would need a heart transplant to live. It was a very, very surreal time for me. Up until then, I had been a very healthy 52-year-old mother of 3, and now I was told I might need a new heart and could be facing a lengthy hospital stay.

During the week I was on the ECMO device, and by the grace of God, my heart started to pump on its own. My doctors told me that my heart had recovered enough to remove me from the ECMO device, which occurred surgically a few days later. Thereafter, the drip medications were reduced or eliminated. The lines and drainage tubes were eventually removed. I was finally cleared to leave the hospital after a month of being in the intensive care unit.

I was incredibly weak, scared and in a state of bewilderment that this had happened to me. Even today as I write an account of my journey, it almost feels like this happened to someone else and I am watching a movie about it.

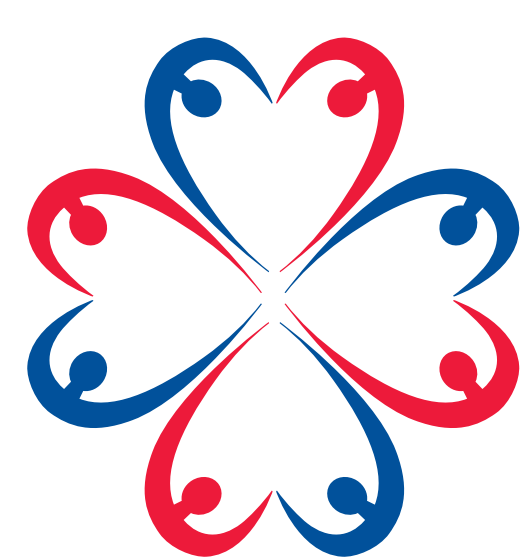
Four months post-release, according to the doctors, I am making a miraculous recovery with my own heart, and I never miss a day to thank God and my medical team for where I am at. Within a few months of being home, I even walked a 5K with my friends and family, all wearing Kyle "True-Grit" bright red t-shirts in honor of my recovery. It was quite an accomplishment considering I couldn't hold a hair dryer when I was first released.

My recovery has been steady, but the journey is long and continuous. I worry about every irregular heart-beat and any unusual sensation in my chest. Not a moment goes by that I'm not aware that I have Giant Cell Myocarditis. I remain on the heart transplant list in case my condition takes a turn for the worse.

I take numerous medications to support and strengthen my heart. They make me jittery, weak and fatigued. I also have steroid-induced diabetes. I follow the doctor's plan and I try not to complain too much about this new lifestyle. I am enrolled in a cardiac rehabilitation program. I have since returned to work on a limited basis and I am beginning to feel like I am leading a mostly "normal" life again.

The doctors say that my heart will never fully regain its former strength and functionality but I am working hard to get back to as close as possible. All of these side effects are minor. I have no complaints...I feel blessed to be alive.

I hope my story brings hope to those who read it. And for those who have lost a loved one to myocarditis, my heart breaks for you. I am truly saddened by each and every loss. It's a terrible disease and the common thread in each story seems to be a lack of a timely diagnosis. I went untreated and undiagnosed for almost three weeks. It appears that raising awareness about myocarditis is paramount to helping more people survive. I hope to do my part in this fight and to help save the precious lives of those who might suffer.



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Drew Hazlett Story Orlando, Florida

“My name is Andrew Hazlett, but I go by Drew, and my Myocarditis story all started in May of 2017 when I was 18 years old. My family all got sick with the flu and my little sister ended up with pneumonia.

After everyone got better, I got sick again with coughing, sweating and shortness of breath at night, which required me to sleep sitting up. My parents thought I had pneumonia like my sister.

My mom made my dad take me to an urgent care where an X-ray was done. The doctors discovered that I had an enlarged heart and possible fluid around my lungs. The doctor rushed me to Florida Hospital Orlando where they specialize in cardiac care. I was put on medications and lots of tests were done. I had a Swan Ganz Catheter put in my neck to monitor the pressures in my heart. I spent 2 weeks in the ICU and on the cardiac unit. During this time, it was my high school graduation. My school, Lake Nona High School in Orlando, coordinated with the hospital so that a live stream of the ceremony came into my hospital room and I could be a part of it. Even though my diagnosis was still a mystery I seemed to be getting better and went home with medications and an external defibrillator in the beginning of June.

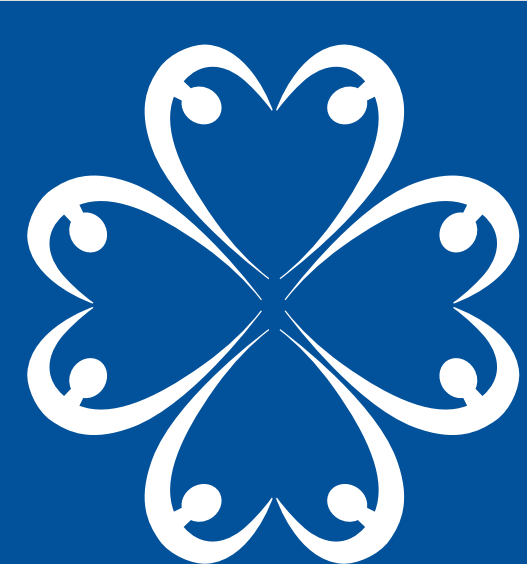
On June 13th I took a turn for the worse with an abnormally high heart rate and was rushed by ambulance back to Florida Hospital Orlando. At this time it was determined that I had cardiomyopathy caused by Myocarditis. Two days later after having another Swan Ganz Catheter put in my neck and a Balloon Pump in to help my heart I crashed and had to be placed on an ECMO machine (that would do the work for my heart and allow my heart to rest and heal) to save my life. I ended up in the CVICU (cardiovascular ICU) and remained on ECMO for 5 days. After that I had to be put on a BiVAD (BiVentricular Assist Device). This machine was a bridge to a heart transplant which required me to stay in the CVICU for over 80 days. I had the best nurses, doctors, surgeons and staff surrounding me. It was tough being a teenager hooked to lifesaving machines and living in a hospital for so long but I was blessed to have my friends, family and our community supporting me through it all.

On August 20, 2017 we got the call that the perfect heart was found for me and my transplant began at 7:00 p.m. that evening. My new heart began beating at 12:04 a.m. on August 21, 2017 which was the same day as the solar eclipse. My mom said they sang “Total Eclipse of the Heart” to me.

I had some complications post transplant, like extra fluid around my heart and lungs, and my other organs suffered from all the trauma of having 2 major open heart surgeries so close together. I ended up on dialysis and spent an additional 2 weeks in the CVICU. Once I got a little better I was transferred to the cardiac unit where I spent an additional week recovering. During this time Hurricane Irma came thru the state of Florida and since we were predicted to lose power my family and the hospital staff decided it was in my best interest to keep me in the hospital a couple extra days where they had back up generators if the storm got too bad.

I finally came home on September 14, 2017 and have been getting better and stronger ever since. I have monthly biopsies, go to clinic, have labs drawn, attend cardiac rehab 3 times a week and take around 20+ life saving medications twice a day. My family and I are very grateful for my medical team, the donor’s family and everyone who supported us on this journey.

We want to give back and do more to raise awareness about Myocarditis. We hope to one day help other families who might be going through something like I did.



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BEAU'S STORY Temperance, Michigan

Our life forever changed July 15, 2017.

Before that Beau was a happy two-year-old who didn't get sick often. He loved the outdoors no matter how cold it was. If the sun was shining he would say, "mom the sun is out, I go out and play?" And there I would sit, drinking my coffee and watching him play early in the mornings. He had a smile that would melt your heart, and the best belly laugh. He was smarter than his age due to growing up with two older brothers. He loved riding on the tractor and lawnmower with his dad and the bond he had with his dog was like no other.

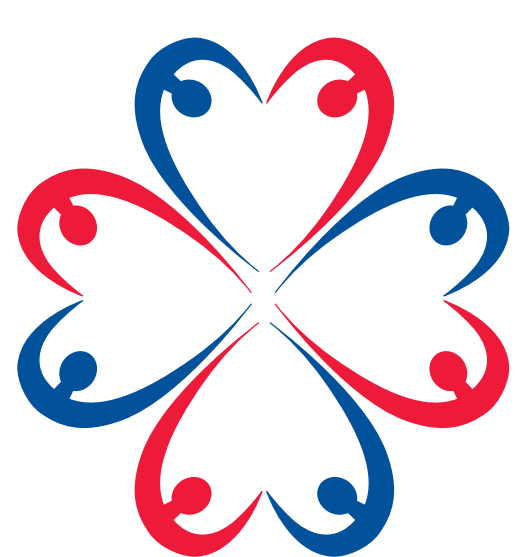
On July 5, 2017 after being up late from a family 4th of July party, Beau woke up with a red swollen eye. I called the doctors right away and got him in. They didn't know what it was, but put him on a strong antibiotic and wanted to see him back in ten days. We left two days later for a family vacation to Tennessee. Beau's eye was better the morning we left, but I continued the antibiotics as directed. We had a great time in Tennessee enjoying the mountains. We were there for six days. He was playing and enjoying every minute of it. We came home on July 12, 2017. Everything seemed normal with Beau.

The next day we were outside almost all day playing and by evening he said he peed his pants. That was unusual for him because he was really good about going to the potty when he had to go. Well he didn't pee his pants, he had diarrhea. I got him in the shower and told him it was ok, we would rest for the rest of the night. He only had it for a short time, not even overnight. The next morning July 14, I had to return to work at a daycare where Beau also went with me. I told him he'd have to stay home with his dad in case he was still sick, we didn't want to get any other kids sick. When I returned home from work my husband said he took more naps than normal. I thought it was because we had been on vacation for six days with no nap schedule so of course he's tired. Not too long after I got home he went right outside and played. We ate his favorite meal that he picked out, pork chops and rice with green beans. He ate it all. He went back outside and played with his brother.

That early morning of July 15, he woke up around three a.m. saying his belly hurt. I checked his temperature and he had no fever. I gave him some Motrin and rocked him back to sleep. We fell asleep on the couch. He woke up three hours later puking. I thought he had the stomach bug. Still no fever. We cuddled on the couch for a few hours, but every time I'd try to get him to drink something it would come right back up. By noon I decided to take him to the ER because he couldn't keep anything down. My older son who was 11 and I took him while my husband and my ten-year-old stayed home. I told them I'd call if they said it was anything serious.

We got to the hospital and checked in. We didn't have to wait long and they called him back. I set him down on the bed and he acted like he was going to puke again. I grabbed the bucket the nurse gave me and he started having a seizure. Everything happened so fast. They thought it was just a febrile seizure and he would come out of it. They were wrong. He stopped breathing. They called code blue and pushed me out of the room. They worked on him for almost 2 hours and couldn't get his heart to beat on its own. Our whole family waited in a tiny room for almost 2 hours and then the worst sight ever was seeing the whole team of doctors who were working on our son come in crying telling us they don't know why our two-year-old was dead. All they could tell us was his heart was very sick.

Five months after he passed we got his autopsy and it said Acute Lymphocytic Myocarditis (likely viral). Until then we had no idea what that was, we never heard of it. Beau was taken two months before his third birthday. He was cut short of a future because of Myocarditis.



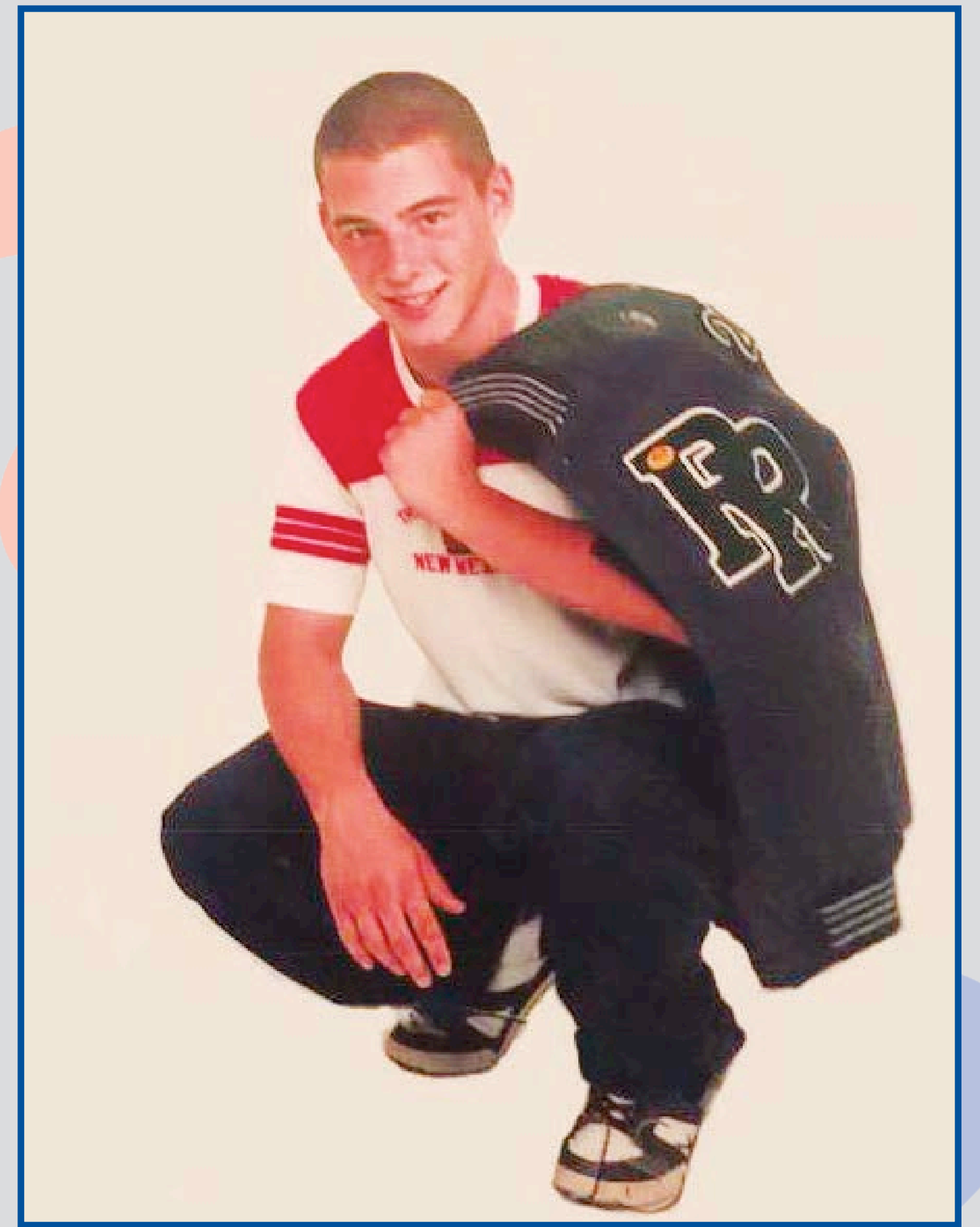
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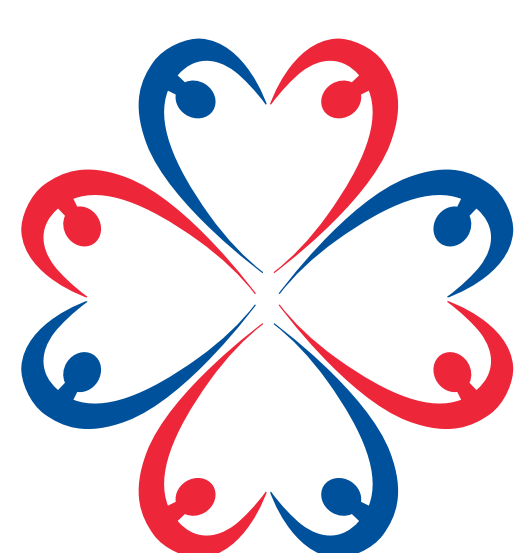
Jeremy Scott Coffee Rio Rancho, New Mexico

On September 11, 1987, our brother and my parent's only son was born. Jeremy was a mischievous, good natured child. He had a knack for getting out of his car seat as a toddler and a tendency to climb extremely tall trees. Jeremy always did things in his own way, whether that was wearing cowboy boots with shorts or building forts in the middle of the desert with his friends. Jeremy was a natural athlete and was generally good at any sport he tried, but settled on football in high school. Jeremy was friendly, goofy, thoughtful, and honest with a bit of a rebellious streak. He worked throughout high school in the restaurant industry and later in different industries and positions making friends pretty much anywhere he went.



In late October of 2016, Jeremy came down with what he first thought was the flu. He still worked and hung out with friends. He expected to be better in a few days, but his symptoms only intensified. Jeremy resisted going to the doctor because he was sure it was just a flu and would run its course soon. A week passed and Jeremy was still feeling very ill. After a lot of convincing he said if he didn't feel better he'd go to see the doctor the next day. Jeremy passed out in the bathroom that afternoon and his dad took him to the emergency room where the E.R. doctor discovered that Jeremy's heart wasn't working properly. Jeremy was immediately transferred to the ICU. It was in the ICU our family first heard the word "myocarditis" and what was going on with Jeremy's heart. Within hours it was determined he was "the sickest patient in New Mexico" and the ultimate goal was to get him transferred to a hospital that could care for someone in his condition. Jeremy's heart began to struggle more and it was decided he'd be put into a medical coma and would need an ECMO machine to help Jeremy's heart circulate blood. From there the medical team and his family searched for a hospital that could accommodate him as well as a life flight team that could transport him to another state. This process took almost a week. Eventually, Jeremy ended up at the University of Colorado hospital in Aurora, Colorado. Jeremy spent almost two weeks in the cardiac ICU. Jeremy's condition in Colorado was a roller coaster of ups and downs, his condition would improve and worsen daily, sometimes multiple times in a day. The goal was always to get Jeremy healthy enough to get a heart transplant. Unfortunately, his kidneys and liver began to show distress and eventually to shut down despite the medical interventions. He went into septic shock and medications did not seem to help much. On November 21, 2016 Jeremy had a series of strokes that rendered him unresponsive. Over excruciating discussion his family decided to set Jeremy free on November 22, 2016. His fight was over.

Jeremy was just 29 years old when he lost his life to myocarditis. He was strong. He was a fighter. To this day, we have a hole in our lives that can never be filled. A disease we had never heard of took our brother, our son, our friend away from us. Our family wants everyone to hear Jeremy's story. We don't want another family to lose someone they love to this disease.



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Leanna Mae Knopik Sarasota, Florida

In early June, 2012, Leanna was treated for flu-like symptoms by her pediatrician, however, the symptoms never really went away. Leanna's energy was low and she complained of shortness of breath when climbing the stairs in our home.

On her schedule, the week of Father's Day that year, was a week-long mission trip to WV where teens and crew leaders from 6 states repair the homes of impoverished families. Leanna was still suffering from the flu-like symptoms just prior to that trip, so I took her to her doctor two days before she was to leave.

Her doctor checked her out, said it was a virus but "nothing spooky". He cleared her to go on the trip but insisted that she rest as much as possible.

Two days later (on a Saturday), Leanna got on a bus with many other kids and rode to WV.

Her symptoms worsened. She could not keep anything down and was miserable. She and I texted constantly.

On Tuesday, I arranged a flight and flew her home. I picked her up in Tampa and took her straight to her pediatrician's office. There they checked her vitals and could not get a reading on her blood pressure. Her doctor suggested we take her to the ER. We thought she was just severely hydrated.

Once at Sarasota Memorial Hospital, they replenished her fluids but her vitals were still not where they needed to be. The head of pediatrics came down to evaluate and the next thing we knew, they were air lifting Leanna to All Children's Hospital (now Johns Hopkins ACH).

After being at JHACH for a few days, she was intubated to take the load off her heart.

Maybe a week after that, they installed an LVAD and she was put on the transplant list. A heart became available very soon after the LVAD was installed but we declined it...We wanted to give the LVAD a chance to do its job. Another suitable heart did not come along after that.

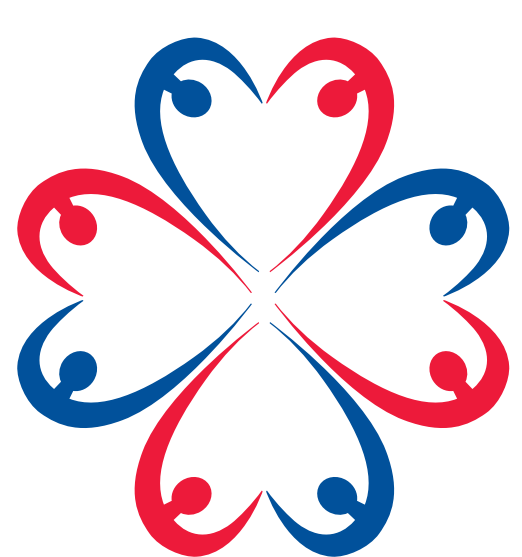
About 4 weeks after being admitted to the hospital, following another surgery to install an assist device, she had a seizure. The neurologist did not recommend surgery given her fragile state so we had to make a decision.

On July, 19, 2012. We disconnected Leanna from all the machines and she passed away.

Please help us educate and raise awareness on this disease so that others do not suffer the sadness that this disease has caused our family...



Beth Knopik



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Ke'Mora's Story... Indianapolis, Indiana

Ke'Mora was blessed with good health. My daughter has never had to stay in the hospital and only visited to get yearly check-ups and shots for school.

On September 20, 2018 she came home from school and threw up. We thought maybe she had over heated at school and let her rest the rest of the evening. For the next 5 days she barely moved. It was hard for her to even shower due to lack of energy. She said her chest hurt, she felt dizzy, and nauseated.

After day 5 my husband and I decided to take her to the emergency department. At that point she could barely walk but we encouraged her that the stomach bug wasn't affecting her legs and she trudged in the hospital with me. I still feel really upset that I didn't know she was that weak.

The doctor looked her over and still he even thought it was a stomach bug. He did mention that her heart rate was abnormal but when he checked her chart the check in nurses had recorded a normal heart rate.

No EKG or scan were offered instead he gave her a rapid strep test that came back negative.

He sent us home with instructions to bring her back if she ever got a fever or didn't feel better in two days.

Exactly two days later she went into cardiac arrest in the back seat of the truck while I was driving. She spent 15 minutes on the side of the road with no pulse and barely breathing.

The EMTs got a pulse after shocking her heart and took her back to the emergency department. At the hospital she went out 3 more times before she was placed on life support and a ventilator.

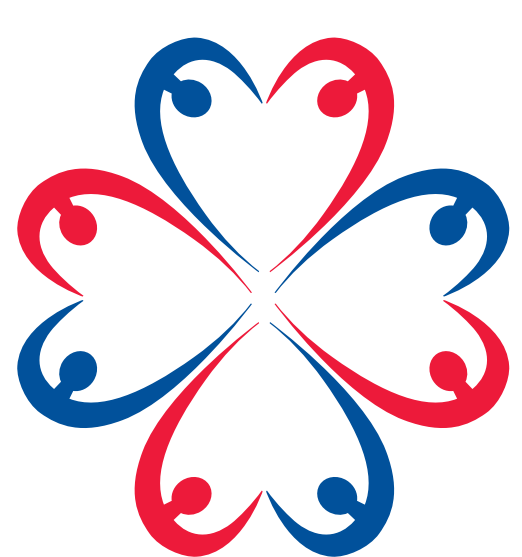
After a week in ICU she was released to a floor called the step-down-unit. She started therapy and learning to do basic things again like eating and washing her face.

Once all her medication was reduced and she was medically stable they released her to inpatient rehab where she learned to shower, wash her hair, and walk again.

She has started back at school half-days until she regains her strength. She still goes to outpatient therapy 3 times a week. She also is taking heart medication and blood pressure medication. We are not sure if she has to be on them for the rest of her life.

I'm so thankful she got another chance at life. God really blessed our family.

We need to raise awareness about this disease called Myocarditis, so other children do not almost die before they are diagnosed and treated!



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Lillie's Story... Fredericksburg, Virginia

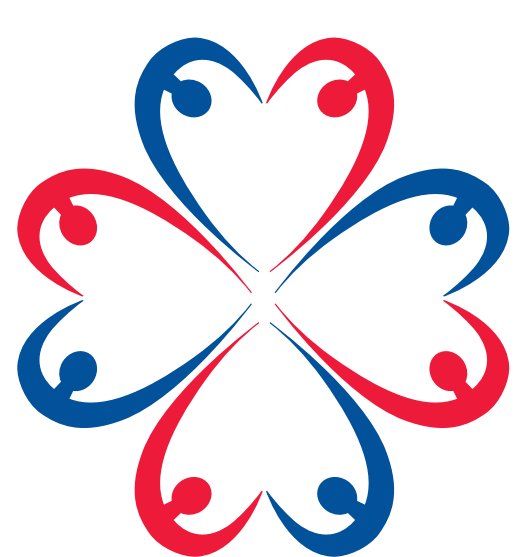
Lillie Nicole Hall was a vibrant, happy and very loving 3-year-old little girl. She had just started her first dance class – this princess loved music and expressing it in her moves! There wasn't a creature she didn't love or a human she was afraid of. Lillie loved life and enjoyed every minute of her very short lived life. Her memory will live on in our hearts forever.

A stomach virus had been going around and a few children she had come into contact with had it so her Mommy wasn't surprised when Lillie woke up not feeling well. At first her parents thought it was "excited exhaustion"....too much candy, soda, and twisty rides from her trip to Kings Dominion the day before. Her Mommy kept her resting and gave her plenty of fluids. It appeared as though she was improving, but she spiked a high fever and the vomiting and diarrhea returned. A doctor's appointment was scheduled for the next day. Once there, on Friday, October 20, 2017, the doctor did a chest x-ray because she was concerned that Lillie may have pneumonia. They were told she had a viral infection and she was given a shot of antibiotics. The doctor told them to monitor her and if she wasn't better by Monday to bring her back. They left the doctor's office and went straight home. That afternoon Lillie wanted to walk with her Mommy to get her "Bubba" off the school bus – she seemed a little better. They returned home after a short walk to and from the bus stop and Lillie climbed up in her favorite comfy recliner, blanket in hand and started to watch television. Within the next hour Lillie suddenly let out a cry for help, "my arms hurt" and her breathing was labored. There was no time to call for an ambulance. Mommy swooped her in her arms; Daddy contacted emergency officials to notify them that they were in route to the hospital emergency room, five minutes from their home, but seemed like the longest ride of their life. A ride Mommy and Daddy will never forget. They were met by emergency personnel upon their arrival and Lillie was rushed into a treatment room, but it was too late. Our precious Lillie was gone.

We will never know if what the doctor did was sufficient enough for Lillie at the time or if perhaps, there were other measures that could have or should have been taken. It all happened so quickly, we later thought, certainly her condition should have been able to be diagnosed right away but unfortunately that wasn't the case. For months, we waited to hear the news of what happened to Lillie, what caused the distressed breathing, what caused her poor little heart to be in such distress. Finally, the autopsy report, Lillie died of Myocarditis (inflammation of the myocardium (muscular layer of the wall of the heart) – our baby died because a virus literally attacked the biggest part of her being, her heart!

We will forever miss our beautiful little girl, her love and happiness lit up our world. "Lillie's Love" has been formed in her memory and we plan to host many fundraisers and bring awareness to this horrible disease. We hope that people will not only contribute to the Myocarditis Foundation, but also join us in the many events we plan to hold in her memory as well. A portion of the proceeds from these events will be donated to the Myocarditis Foundation. We need to raise awareness about this disease to both the medical and public communities so that others do not suffer the anguish and pain that we and others have had to endure.

We are unsure which pain is worse – the shock of what happened or the ache for what never will.



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Never look back unless you are planning to go that way (Henry David Thoreau)... and he did not look back

Shivam's Story... Grayslake, Illinois

This is the story of our beloved son Shivam Chetan Chokshi, who died at the age of 21 due to **Lymphocytic Myocarditis** on July 25th, 2018, his half birthday.

On January 25, 1997 we were blessed when we welcomed our healthy and happy baby boy into our life. Growing up, Shivam was always known for his silly nature and high energy. As he grew older, he took all his energy and crafted it into discipline. He was intelligent, studious and relentless in all that he did in high school. While in high school, Shivam still found the time to play football and wrestle, hold down a part-time job and was involved in Boy Scouts. He was very active, healthy and athletic. He graduated with high honors and was destined for success in his future at DePaul University.

During his college years, Shivam studied Finance and Accounting and added an abundance of activities to his plate. At DePaul, he served in a variety of leadership roles but greatly enjoyed mentoring with the EDGE program, being an Orientation Leader, and working as a Chicago Quarter mentor. With Shivam's hard work, dedication and commitment to his academics, he was named to the Dean's Honors List and was scheduled to graduate early in December 2018 with a full time offer at an investment bank waiting for him.

On July 21, 2018 Shivam came home to celebrate his dad's birthday. We all had a great time and we were so glad to have all of our favorite people together. I ordered an ice cream cake for my husband and Shivam had the smallest piece even though he loved ice cream cake. I offered him another piece and he looked at me and said "mom, I don't want it, I'm not feeling well". His asthma was acting up, which was normal for him as he grew with pediatric asthma. He used his inhaler and he was fine. That evening, my daughter drove him back to his apartment in the city. He complained to his girlfriend that he had a hard time breathing and she offered an inhaler to him. He used his nebulizer, which is a larger treatment for asthma. He had no other issues from Sunday to Wednesday of that week. He even went to the gym on July 23rd and 24th without any health issues.

On July 25th, our lives changed forever. As an investment banking intern, it was common for him to be at work in the evening. We were talking in our family group chat about how my daughter found another apartment to lease very close to him. He said he was so excited to share the city and be neighbors with her. He read our last message at 7:37 PM. At around 8:30 PM my daughter and I got a call from his co-worker that Shivam had a seizure. He had fallen, and they were performing CPR on him and taking him to the hospital. It was strange - Shivam never had a seizure before so this didn't make sense. We were informed that they were taking him to Northwestern Memorial Hospital in Chicago. We reached the hospital around 10:19 PM. According to the doctor, our boy left us at 10:07 PM, but that was when they stopped performing CPR. It was likely he was already gone before they even made it to the hospital. We did not have time to say goodbye to him. His life was cut short by this disease and our lives will never be the same.

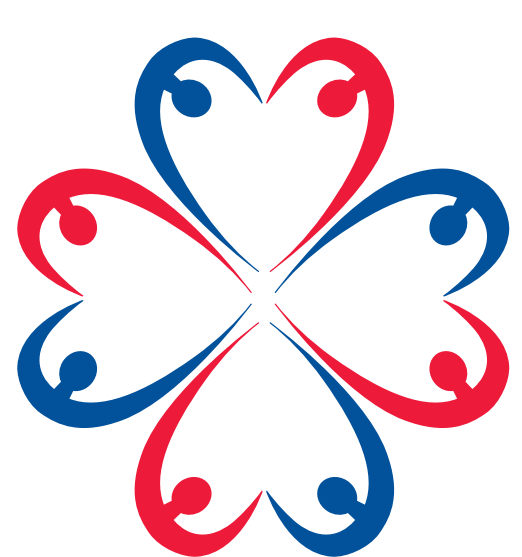
The question that hits us the most is why? He was such a healthy boy. He regularly worked out at the gym and played sports. How could this be happening? As a mother, I would have traded places with my son in a moment. I asked God to "take me instead".

3 months after his passing, we received the autopsy report and were told he passed away due to **lymphocytic myocarditis**. It was random, and it was rare. It gave us a sense of closure but still left us with so many questions about what this disease is and how it works. HIS EKG/ECG were normal, along with all of his bloodwork that was completed during his physical in May 2018.

Myocarditis took our healthy, happy, amazing son away from us at the age of 21. He never got to fulfill his dreams. He never was able to start a family. He had so much potential, so much talent, so much to look forward to. He wanted to live more than anyone else I have ever met. Everything he did was for his family and for his future.

As Shivam often referenced Eleanor Roosevelt's quote, "Great minds discuss ideas; average minds discuss events; small minds discuss people". He had the biggest dreams and hoped to build a school in India where children who cannot afford to pay for school can still get an education. We hope to fulfill that dream one day.

Although Shivam is no longer with us, his legacy lives on in us through the lessons we learned from him and in the many ways in which he touched our lives. We love him very much.



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Our Research

As a part of our mission, the Myocarditis Foundation annually funds promising research to investigate the mechanisms of myocarditis in order to increase medical understanding and support development of diagnostic and treatment protocols to improve disease outcome. Grant proposal applications are available on the Foundation website; proposal review and selections are made by the Foundation's Medical Advisory Board. To date, over \$600,000 has been awarded for myocarditis research.

The Role of Monocytes in Autoimmune Myocarditis. (A study of the body's immune cells), Daniela Cihakova, MD, PhD, Johns Hopkins University, Baltimore, Maryland, 2008; this investigation has received additional funding from the National Institute of Health. Dr. Cihakova now has her own lab and is mentoring other researchers on myocarditis.

Gene Expression Profiling for Detection of Myocarditis. (A study investigating a diagnostic marker for myocarditis), Bettina Heidecker, MD, The University of Miami, Florida, 2008; research results published in *Circulation* 2011 March 22; 123(11) 1174-84. Dr. Heidecker is now an Associate Professor at the University of Zurich, Switzerland and travels internationally speaking on myocarditis. She now is a member of the MF Medical Advisory Board.

Thrombin-PAR-1 Signaling in Viral Myocarditis. (A study of the inflammatory response in Myocarditis), Sylvio Antoniak, PhD, McAllister Heart Institute, University of North Carolina-Chapel Hill, 2010

Peripheral Blood Mononuclear Cell and Endomyocardial Gene Expression Signatures of Myocarditis – Identification of Genomic Biomarkers. (A study of white blood (immune) cells response to myocarditis), Khurram Shahzad, MD, Columbia University Medical Center, New York, 2011

Autoimmunity in Pediatric Myocarditis: A Pilot Study. (A study of children's immune reaction to myocarditis), Kathleen Simpson, MD, Washington University, St. Louis, MO, 2011. She continues her study of myocarditis and is a pediatric cardiologist in the St. Louis Missouri area.

Coxsackie Virus B Subverts Host Mitophagy to Promote Viral Dissemination and Myocarditis.
Dr. Jon Sin, PhD of Cedars-Sinai Medical Center

The Role of PDGFR α + Cardiac Fibroblast in Myocarditis. Dr. Guobao Chen, PhD of Johns Hopkins University School of Medicine who works in Dr. Cihakova's Lab (she was our first Fellowship Grant Recipient in 2006)

Personalizing Myocarditis Diagnostics through Novel Biomarkers. Dr. Paul Hanson, PhD University of British Columbia/St Paul's Hospital



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VINCE AND TRICIA TUMMINELLO

WACHOVIA BANK

BRIER CREEK BRANCH, A WELLS FARGO COMPANY