The MYOCARDITIS FOUNDATION

Fall 2011 *Knowledge Nurtures Hope* Vol. 4 No. 2

Vanessa's Giant Cell Story

It all began on April 1st, 2011, with a seemingly innocent chest rash. A couple of weeks later, Vanessa went to her primary doctor who diagnosed it as hives and gave her a pack of steroids. She had also been tired so they did blood work. This showed she was anemic, so she began taking iron supplements. The rash continued to get worse so she went back to the doctor and received a stronger dose of steroids. The next visit was to the dermatologist who thought it was eczema and gave her a steroid shot along with some cream.

Aside from the rash she was feeling okay except for an occasional upset stomach. The increased fatigue began making exercise difficult. She had run a 7 mile race in late March but a few weeks later (after a little time off from running), she had a hard time making it around the block. After a tennis match on Friday April 29th, she was a bit winded, but otherwise fine. She went out to dinner with friends that night to celebrate her 40th birthday, and woke up at 2am the next morning throwing up. It seemed like the same stomach bug we pass around the family every year, so we didn't think too much of it. She then also started feeling light headed and had a little chest pain, which we first thought could be additional symptoms of the stomach bug. On Sunday, our concern began to grow since the bug usually runs its course quickly. Since our regular doctor was closed, we visited a local walk in clinic. They kept her for a while; did a chest X-ray, an EKG, and gave her 2 bags of fluids, but they didn't find any other concerns.

Vanessa wasn't feeling any better on Monday morning, so we went back to her primary doctor again. She was very light headed, winded, nauseated, and had cold sweats. The doctor couldn't get a pulse from her so he sent her down to the ER. They thought she had an infected gall bladder and were preparing her for surgery when her blood pressure rapidly dropped, and she was crashing in the ER. They thought she was septic and started major antibiotics. The surgery was put on hold until they figured out what was going on.

After checking her blood work they told her she had had a heart attack and then did an angiogram to look for blockage. Although no blockage was found, the doctors realized her heart was not doing well. She was not allowed to eat or drink anything for 2 days while they tried to figure out what was going on with the gall bladder. They didn't want to do surgery with the condition of her heart, and after 2 days of antibiotics the gall bladder calmed down. Now they were trying to figure out what was going on with the heart. It was only functioning at 12% and her organs weren't functioning properly, so she was starting to retain all the IV fluids she was getting. The cardiologist suspected viral myocarditis and decided she needed to be transferred to UTSW (University of Texas Southwestern). She got there on Friday, and they immediately started to work. They discovered blood clots all over her body (both legs, an arm, neck, and both major veins in her abdomen). The team of 6 heart failure doctors started to suspect something more. They did a risky heart biopsy, and that is when we found out the devastating news that she had a very rare disease called Giant Cell Myocarditis. Basically it's an auto immune disease where the body attacks the heart. They immediately started working her up for a heart transplant. There is a very small pool of people with this disease so unfortunately there is not a lot of research for a cure. Less than 300 cases of giant cell myocarditis have been reported in the last 100 years, and most are diagnosed at autopsy. Everything I was finding on the internet about this disease was very frightening and not very hopeful. Some of the findings showed that it usually hits otherwise healthy individuals with no previous heart conditions. Up until 23 years ago, there were no patients who survived without a transplant. Today there are at least 28 people who have survived more than 1 year without a heart transplant.

Vanessa and Todd Hickey with their three children

The top notch team of doctors at USTW, led by Dr. Patel, began to consult with Dr. Cooper at the Mayo clinic. After preparing for a very long wait on the transplant list, Vanessa begin to react extremely well to the treatment. After 3 weeks in the hospital (2 in CVICU) we are happy to say Vanessa has made a miraculous recovery. She is at home with her 3 kids and husband….and with her own heart!! Her heart function is back to normal and has little or no scar tissue. She is still a little weak, but getting more back to normal every week. She is so thankful for all her prayer warriors that helped her get this far. The long term side effects of this disease and the medicine are somewhat unknown, so please keep the prayers coming. The doctors are even in awe of the miracles happening!!!! If you would like to read more about her journey visit caringbridge.org/visit/vanessahickey

Todd Hickey, Flower Mound, TX

MY HEART RENEWED

By: Jamie Simpson

The Simpson Family, November 2010

It was Easter morning, 3am to be exact. I woke up in a cold sweat with my heart beating so hard it felt as though it was going to burst out of my chest. I thought I was having anxiety about getting up early with the kids and getting everyone out the door to early service Church. As the Church service went on I began to feel worse, feverish, chills, nausea, and dizzy. I told my husband that I thought I had the flu.

The next day the "flu symptoms" got worse, I had my niece take me to the ER that night. I went in stating I had chest pains with flu symptoms. They did some blood work, and sent me home and said I had a virus. They never checked my heart; of course they did not I did not fit the profile for a heart patient. I was a 34 yr old female with no major surgery's or illness, not over weight, healthy, active, not diabetic, only a low thyroid.

The next day I was even more miserable, I would take a sip of water and end up vomiting. By the next night I was on the floor in so much pain, shiverring, telling my husband that I could barely breathe. He put the boys in the car and dropped me off at the ER.

They checked my vitals in the ER and I was rushed to a room with many nurses sticking me, asking me questions, hooking me up to machines, and giving me baby aspirin. It was like a movie. The doctor came in and said that my blood work and EKG showed I was having a major heart attack or have had one and they were rushing me to surgery because I was not getting enough oxygen. They said it was a miracle that I even walked through the door. I had only been there for 15 minutes and I was off to surgery for my heart! I was in shock, and so was my husband who received the phone call from the ER doctor.

They took me to surgery; I woke up in ICU with a temporary pacemaker coming out of my groin. The doctor came in and said that my arteries all looked amazing but my heart was extremely enlarged and not beating on its own. They told me I had MYOCARDITIS. Myocardiwhat???? They said that it is usually a virus or autoimmune disease that attacks the heart.

During my stay at the hospital I had an unexplainable peace that could only have come from God. I was so thankful that I had Jesus to cling to. He was my focus. I used the time in the hospital to draw close to him, to hear him, listen to him and to see his presence. Everyday I saw his hands upon my family and me. He surrounded us in his love. The outreach from family and friends was unbelievable. People all over were in prayer for our family.
Monday morning came and off to surgery I went and they were able to insert a permanent pacemaker. Then I started to feel better. After 8 days of being in the UCI unit I was more than ready to go home. I practically begged to go home, but I was in for a surprise. I thought I would be back to myself even though they told me it would take 6-8 weeks. I was young and active so I assumed recovery would be fast. Boy was I wrong. I was so weak. I was in pain, my chest was so heavy and I was so out of breath even while I was sitting. I felt as if I was a 90 year old woman with 2 small children to look after. The side effects from all the steroids and heart medications were almost unbearable. It was ironic that the medicine that helps you is wreaking havoc on your body. At my first checkup I received the news that my heart was relying on the pacemaker 100%. About 3 weeks later it was at 11%. God was healing me and answering prayer. After 8 weeks I was finally able to move my left arm and began to be able to do more daily routines.

I was starting to feel good, then one night the chest pain came back and I found myself in the hospital once again with heart failure. The doctors ran more tests and said it was still the myocarditis and my heart was still very weak. The news was disappointing, but I received it with gratefulness for all the knowledge that the doctors have that brought me this far!

One of the hardest parts of my diagnosis is the if's and why's. Everyday I am thankful for the extra bit of strength I have to hold one of my children, play and laugh with them, to care for my family and bless others. As of today we still do not have answers of why I have myocarditis. I know that God is doing a good work within me. My heart feels weak but HE is strong. I am thankful for being alive. I am thankful for my journey, even through the pain and what ifs.........

Jamie Simpson, Ladera Ranch, CA

KAMRYN'S STORY

Kamryn on Easter 2010

My baby girl Kamryn Faith was only 16 months old when she passed away from myocarditis on 8/28/2010. Our story sounds very similar to all of these. There were no symptoms, or warnings that would have caused me to be alarmed prior to 8/27. She was breathing differently than normal, but not enough to cause me to panic (just enough for me to notice). I took her to an ER. They ultimately said she had bronchiolitis, and sent her home with instructions to return if she got worse or to follow up with pediatrics on Monday. I never went home. I took her to another ER in town, and they saw that her heart was enlarged. They recommended that she be transferred by ambulance to a hospital with a pediatrics wing.

When we got in the ambulance it was the last time I ever held my baby girl. When we got to the next hospital 45 minutes away she had already gotten worse. The doctors there assumed that she had swallowed something and completely focused on that. They never once looked at her heart. They kept telling me she would be ok as I stood there for hours watching my baby die. (I know that now but did not then).

They decided they needed to take a look inside her lungs to rule out whether or not she swallowed something. By the time they got her to surgery she was so weak because she had been struggling all night to breathe. I asked, " Is she going to be ok to go into surgery?" They said Yes." I asked, "Why is her heart beating so fast?" They said it was because she was fighting them so hard. (That whole night she kept trying to turn over and lay on her stomach but they would not let her so every 5 minutes or so she would try and they would turn her back over).

About 20 minutes into the surgery I started to see her doctors and nurses running at full speed back to the OR. I knew that something was wrong. It took another 20-30 minutes before they came out and told me that she was in heart failure and that they were doing everything they could to save her. But they wanted to prepare me for the possibility that she may not make it. They left. The next time I saw them they told me that my little Kamryn Faith had died. Now what? I have 3 older kids (15, 12, and 5). My husband was deployed to Afghanistan. It was only 2 weeks until he was coming home. He left when she was 8 months old and he will never see her again. I couldn't even begin to imagine how I was going to tell him that she was gone. The last time I talked to him was at the second hospital and he didn't even know that we had been transferred or that she had gotten worse.

I had to tell the kids, my parents, his parents, all while trying to keep it together enough to talk to the coroner and a host of other people the hospital sent my way. I got to go see Kamryn, talk to her and all I could say was how sorry I was because I was supposed to take care of her and now she was gone. Everyone keeps telling me there was nothing I could do, but I am having a very hard time believing that. Just by reading all of your posts I see that this disease is one that strikes without warning. Thank you all for sharing your stories. Mine is just beginning, and I hope that things have become easier for you all with time. People keep telling me that will happen, so I hope it's true.

Keenna Murphy, Chesapeake, VA

Schedule of events
Dr. Cooper is Speaking at:

October 11th: Genomic and Proteomic Studies in the Management of Myocarditis, Australian Medical association Annual Conference, Canberra, Australia

October 14th: Talk 1: Myocarditis: Diagnosis and Treatment. Talk 2: When to Perform an Endomyocardial Biopsy. Annual Meeting of the Ecuadorian Cardiology Society, Manta Ecquador.

December 6th: Cardiology Grand Rounds, Washington University, St Louis. MO.
Update in Myocarditis

January 5th: 2012.Cardiology Grand Rounds, Ohio State University. Columbus OH.
Update in Myocarditis

January 14th: Big Island, Hawaii. Mayo Clinic Annual Cardiology Review Course.
Update in Myocarditis.

The Myocarditis Foundation
Research Fellowship Grant Program 2011

The Myocarditis Foundation is pleased to announce that it is accepting applications for two (2) Research Fellowship Grants this year in the areas of both adult and pediatric Myocarditis.

Purpose of Myocarditis Foundation Research Program:

To advance medical knowledge of the disease and to develop more accurate diagnostic methods and life-saving therapies with the goal of saving more lives.

- Grant Overview, Grant Requirements and Guidelines, and Grant Application are available at www.myocarditisfoundation.org
- The amount of the grant is $35,000 for *salary only.*
- The date for submission is December 1, 2011.
- The applicant must select a preceptor with a proven track record in research of myocarditis.

Any Questions, Please Contact:

Dr. Leslie Cooper, President of Board of Directors, cooper.leslie@mayo.edu
Candace Moose, Executive Director, candace@myocarditisfoundation.org

Andrew in Australia a week and a half after his second case of myocarditis

Andrew's Survival Story

Hey there! My name is Andrew Werkheiser, I am 19 years old, and I am a student at Mercer University in Macon, Georgia. I'm majoring in Marketing and Management and minoring in Photography. I recently graduated from EMT school and will be getting nationally certified within the month. I have also been accepted to undergo fire fighter training and will be accepted into the Macon Bibb Emergency Management Association on my 21st birthday. I guess you could say I'm a business man who likes saving lives. I don't think when my dad told me I could be anything I wanted to be, he thought I would just pick everything. I went to a small Catholic High School in Roswell, Georgia and write to you about myocarditis and how it affected my life.

It all started at 2:00 AM (only an hour after I had gotten to sleep after studying for a psychology test.) I woke up and was a bit restless. Who isn't in college dormitory bunk beds? I was experiencing pain, similar to a growing pain, in both of my arms. I figured I had just knocked them both out from laying on them. I thought I could shake them for 2 minutes, then I'd be good to go. I rolled onto my back and tried to sit up when my chest started to burn and feel like it was compressed from every angle. Being a first responder at the time, I knew that chest pain, arm pain, and a newly noticed neck pain wasn't exactly the best combination. But I was 18. Who cares? I just was sleeping wrong. Eventually my chest felt like it was on fire, like kerosene was sweeping through my veins. Still being stubborn, I refused to call an ambulance and instead relied on one of my trusty fraternity brothers who got me to the hospital quicker than anyone else would have.

Of course I was taken in immediately because chest pain isn't something to mess with. After a ton of tests and hoping that the 100 mph speeds I knew my parents were traveling at didn't land them in the bed next to me, a nurse came in and informed me that the results weren't back, and I certainly wasn't going to make my psychology exam in 4 hours.

Once the doctor arrived the grins, smiles, hand shakes, and soft voice couldn't have made what he was about to tell me any easier to hear. He said (with the most horrible sort of Arnold Schwarzenegger evil doctor voice), "Andrew, we have found enzymes in your bloodstream that are signs of your heart dying." He then proceeded to head out the door. My world crumbled. I couldn't believe what I heard and how it wouldn't stop replaying in my head. Here I am, a kid who loves life and I may not live to see my next birthday? For me it was never a "why me" or "why now" sort of thing. It was more like a, "come-on God you got to be kidding me." I just couldn't get over the thought that all I want to do is save other people's lives and I'm stuck in a bed not being able to do a thing to save my own. I began to bawl. I cried like a little baby and called my dad to tell him what I had just heard. My mom called shortly after, and I lost it all over again.

Finally, I began to relax after what seemed like hours of prayer and decided to kick back and put on some good old "Comedy Central." As I flipped to the channel, I was as happy as I could be to see a stand up comedy show. They have always been my favorite. I found out that I was going to be just fine but had suffered a heart attack and could have another, which of course I did that night. Due to many crazy complications in Macon, I was transported to Atlanta in an ambulance. That was two hours of heaven; every question I've ever had, was answered. In Atlanta, they ran more tests including a cardiac cath test and prepared me to be released from the scariest week of my life (Or so I thought.)

About a year and a half later, I was back on top of the world. Working hard in school, loving life, and almost forgetting about a virus that had almost taken my life. The summer of 2011 was finally here, I was getting ready to ship off to Australia for a 6 week internship, and was having just plain fun. The second I got off the plane I knew I wasn't feeling well. I just assumed it was the horrible flight and a cold that I could sleep off. The next day, I had a headache but, for the most part, the Motrin was doing its job. I was getting around and meeting new people just fine. That night, I slowly started to slip into old habits of constantly checking my pulse. I had a plain and simple "bad feeling." I very unhappily told my new friends it would be best for me to stay in that night. I tried to relax, watch some t.v. ,and fall asleep. I got the sudden urge to take Bayer and drink lots of water. I fell asleep for about half an hour and woke up to another "worst nightmare." This time I knew exactly what was happening and there was no adrenaline from fear to block out any pain. On top of that, I was just plain angry. I was so frustrated that this was happening AGAIN especially while I was in Australia. I was supposed to be making memories that would last a lifetime. I stumbled to the lobby and again was stubborn. I called a taxi instead of an ambulance. I guess it has something to do with working in EMS and not wanting to be the patient in the back. As I arrived at the hospital, I thankfully was quickly taken in and immediately given pain meds as well as anti-inflammatory medication. I had two more waves and then finally was able to rest and recover. Many were baffled at how I had come to get this horrible virus again and were worried I had Giant Cell and needed a transplant. However, after talking me into a horrifying biopsy, we came to find out that I in fact did not have Giant Cell, but instead had come down with a completely different form of myocarditis.

After returning home, I visited the Mayo Clinic in Minnesota and left with the same unanswered questions that I arrived with. As of now, I am playing it safe and going day by day trying to stay healthy and not slip back into this again. I truly can't afford to do so as next time I may not be so lucky. Through it all, I can promise you I felt the power of prayer from my friends, family, church, and high school. I will never forget all the people who have told me they prayed for me and I will be forever thankful because it is due to them that I am still here. I can tell you my faith was strong before this, but nothing like it is today.

Andrew Werkheiser, Roswell, GA

Adventures in Myocarditis


Karin skydiving in May 2011

The year was 2007. In mid March I hiked the Grand Canyon and was starting to train for a summer triathlon. One ordinary day while walking the dog, I became extremely short of breath. I stopped, bent over, rested my hands on my thighs, caught my breath, and continued on, (thinking I must be catching a cold.) This shortness of breath returned on other occasions but was inconsistent, and I ignored it. Running on my treadmill one day in early April, I became so short of breath I had to stop after 60 seconds. Biking up hills, I used to kick my husband's butt, now I could barely climb them.

Finally, I went to see my local doctor. She diagnosed me with a right bundle branch blockage and told me to return in two weeks for a treadmill stress test. In the meantime, I was not to exercise, (advice I ignored.) I thought I did great on the stress test, so imagine my frightened shock upon being informed immediately that I had to be seen at Nasseff Heart Center in St. Paul, MN, 30 miles away, in 30 minutes. Following many tests at Nasseff Heart Center, the team of experienced cardiologists were mystified, and a heart biopsy was finally done. The cardiologists had seen nothing like my results. Dr. Uma Valeti had done work at the Mayo Clinic in Rochester, MN, and knew of a cardiologist there, Dr. Leslie Cooper, who might provide a diagnosis and suggest treatment. By this point I was hospitalized in St. Paul, and was very short of breath. I was transferred to St. Mary's hospital in Rochester, where I became Dr. Cooper's patient. The diagnosis was giant cell and granulomatous myocarditis. I started on a regimen of medications and began to improve. Due to ventricular fibrillation, I had an ICD implanted several months later. After a year of drug therapy, many medication dosages were tapered and some were even eliminated.

In January 2009, a year and a half after my initial diagnosis, I felt a bit short of breath walking up the incline of our driveway (probably just tired or too much sodium, I thought.) On my home treadmill again, I began to feel lightheaded during an exercise session and stepped off . The next thing I knew I felt my head slam on the floor. My ICD had shocked me. Tests indicated a recurrence of giant cell myocarditis. Once again I became so short of breath that it was difficult to even walk 10 feet. All my life, I have been exceptionally healthy, which is probably why I initially thought I was coming down with a cold. I hadn't had a cold in so many years and really didn't remember what cold symptoms felt like. I also remember having earlier episodes of lightheadedness, which I dismissed. I will be forever angry with myself for not seeing a doctor sooner. I detest having to take drugs, hate the feel and appearance of the ICD bump on my chest and daily evidence of a foreign body planted in me. To me these things are signs of weakness, imperfection, and failure. However, with Dr. Cooper's knowledge and help, these things have saved my life. Since my recurrence, I have been back on a full medication regimen with no tapering. Teaching third grade keeps me busy. While I may not have quite the energy I did, I have found a new normal. Over the summer I completed two sprint triathlons. Things on my bucket list, including skydiving, are getting checked off. I can once again walk my dog without experiencing shortness of breath.

Karin Rost, River Falls, WI

The Myocarditis Foundation Announces Programs for 2011

Myocarditis Patient Survey

For Patients:

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

Discussion Forum

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

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

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

Find us on Facebook

Research

For Physicians:

We will be accepting applications for Research Fellowship Grants. The stipend will be $35,000 for the 2012/13 academic year. The deadline for application submission is December 1, 2011. Click on the Research tab on our Home Page to access online Research Fellowship Guidelines and Application Form.

www.myocarditisfoundation.org

1-732-295-3700

The MYOCARDITIS FOUNDATION

Knowledge Nurtures Hope

"BE ALERT TO MYOCARDITIS IN CHILDREN: A GUIDE FOR PHYSICIANS"

New Myocarditis Foundation brochure detailing myocarditis in children is now available free.
Give a copy to your pediatrician or family physician.
Contact Lindsey@myocarditisfoundation.org

Diaper Drive

What is the best way to get people to come out and hear you speak? Give them something for free. When my daughter first told me about hosting a diaper drive in memory of Kamryn's birthday, I thought, "Oh yea, they'll come for the free diapers and then leave." Reluctantly, I purchased diapers and wished them well. That was April of this year (Myocarditis Awareness Month, but we didn't know that then): a week after what would have been Kamryn's 2nd birthday. Not only did they give out diapers and wipes, but they had a birthday cake to go along with the festivities. It was a joyous occasion and along with the family, their church family, friends and a few marines from Camp Pendleton, they pulled it off.

She was so excited when she called to tell me about it. They ran out of diapers at one point, but the donations kept coming in. She was also excited that people actually took time to listen to what they were saying about Myocarditis. She only had limited information that she had gotten from the site as we had not reached out to the foundation for help.

Fast forward 4 months to another city... August 13th and 14th was Diaper Drive number two. There is a city-wide festival in one of the parks in our hometown of Champaign, Illinois. I thought, "What better way to reach lots of people at one time?" But, I was going to need help and that's where the foundation stepped in. When I explained to them what I wanted to do, they assisted by supplying the printing, handouts, and giveaways at no cost to us. We just had to focus on getting the word out that we needed donations of diapers and wipes. Once I got the posters and flyers from the foundation, it was mass mailing time. We mailed posters and flyers to 50 churches asking for donations and to post the information where they did business. An attorney friend also volunteered to have their firm as a drop off site for diapers and wipes. We couldn't get any better than that! To my surprise, we did. A local news reporter saw the poster and wanted to know more. She contacted the family in Champaign, set up a TV interview (the interview is posted on the Discussion Page of the foundation's website), and we got newspaper coverage of the event.

Once the interview aired on the evening news, people wanted to know more. They came out, got information about Myocarditis and the word was out! We serviced between 60-75 (actually lost count) babies, but gave out Myocarditis brochures to old and young alike. For the older children, we handed out cake pops with a red heart that Granny called "Kamryn Heart Pops". As a family, we are determined to get as much information out as possible.

Becky Wagner,
St. Louis, MO

Kamryn's
1st Birthday Party,
April 2010

Meet Our New Board Member...
DeLisa Fairweather, PhD

DeLisa Fairweather, PhD
Assistant Professor
Johns Hopkins University

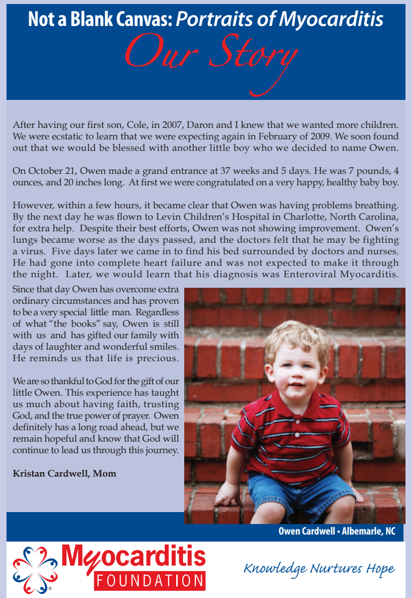
My interest in myocarditis started during my PhD studies in Australia. I was intrigued by the question of how infections could cause autoimmune disease, and in particular the autoimmune heart disease myocarditis. After finishing my PhD in Australia I continued this quest at Johns Hopkins University, eventually in my own laboratory. My lab focuses on understanding how infections and toxins cause myocarditis, dilation and heart failure, and why men develop heart disease differently than women. Answers to these questions will help us work out how to prevent disease and to develop better treatments. As a young researcher I am enthusiastic to see breakthroughs in myocarditis and to make more people aware of its importance. I would like to offer my expertise in models of myocarditis to the Foundation and to further research endeavors through teaching and mentoring.

Announcing The Myocarditis Foundation's Traveling Exhibit "Not a Blank Canvas: Portraits of Myocarditis"

What better way to show the world the impact myocarditis has than telling the stories of those people affected by this devastating disease. The Myocarditis Foundation has been hard at work compiling stories and pictures of people whose lives have been touched by myocarditis.

These posters are now available to be shipped to fundraisers across the country. It is an overwhelming experience reading the stories from these remarkable people. In just the couple of events at which they were featured, we have seen an amazing response. Myocarditis is no longer some obscure, unknown disease; it is now a very real and personal disease that has disrupted lives across the world. It is the faces of babies, children, teenagers, and adults, needing to tell their myocarditis story. Through this outstanding exhibit we hope to further raise awareness because after all, knowledge nurtures hope!

If you are interested in creating a poster or using the exhibit at an upcoming fundraiser, please contact Lindsey at: Lindsey@myocarditisfoundation.org



Not a Blank Canvas: *Portraits of Myocarditis*

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.

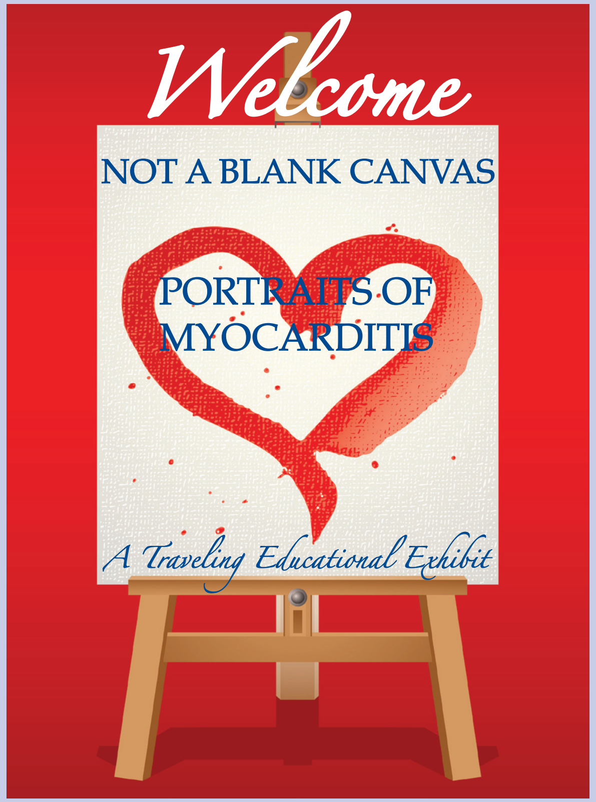
Since that day Owen has overcome extra ordinary circumstances and has proven to be a very special little man. Regardless of what "the books" say, Owen is still with us and has gifted our family with days of laughter and wonderful smiles. He reminds us that life is precious.

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.

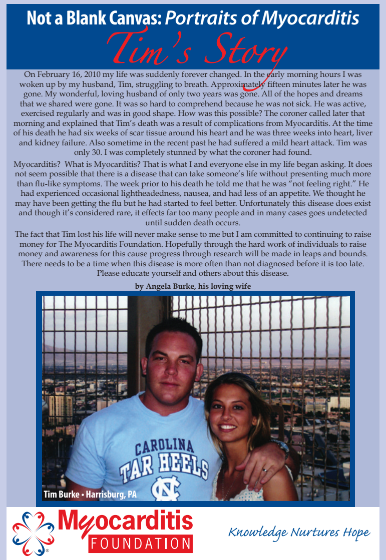
Kristan Cardwell, Mom

Owen Cardwell • Albemarle, NC

Myocarditis FOUNDATION *Knowledge Nurtures Hope*



Myocarditis FOUNDATION *Knowledge Nurtures Hope*



Not a Blank Canvas: *Portraits of Myocarditis*

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

Tim Burke • Harrisburg, PA

Myocarditis FOUNDATION *Knowledge Nurtures Hope*

Not a Blank Canvas: *Portraits of Myocarditis*

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

Hana Hornbeck
Phoenix, Arizona

Hana's Story

Myocarditis FOUNDATION *Knowledge Nurtures Hope*

Not a Blank Canvas: *Portraits of Myocarditis*

My Story

Candace Moose • Point Pleasant, New Jersey

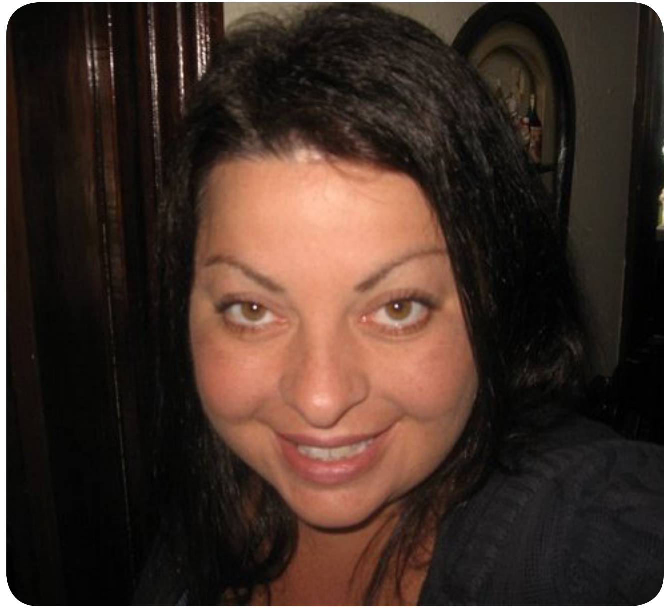
In August 2001 I received two immunizations to travel to Africa to do mission work. Two hours later, my heart started to beat faster, more irregularly and more forcefully. One week later I coded three times, had a defibrillator inserted and was sent home with a diagnosis of viral myocarditis. The next 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

Myocarditis FOUNDATION *Knowledge Nurtures Hope*

Incurable Optimist



Annie Schofield

The automatic doors opened leading into an emergency room from hell. It was the middle of a snowstorm so the waiting area was full of people coughing and wheezing. After I checked in a man wearing a white coat asked me if I was having chest pains or shortness of breath. “Yes” I responded. Then he stood face to face and asked the same question this time in disbelief. “Are you having chest pains or shortness of breath”? “Yes” I answered again. He smirked and told me to go back to the waiting room. I was thirty two years old, well dressed and in good shape. Who would have thought I was in danger?

I had a bad feeling about this small hospital that I had never been to before so I left. I drove straight to my doctor’s office. Dr. Guilbert has been my Primary Care physician for almost ten years so we were well acquainted. It only took him a few minutes to figure out I was in grave danger. I was rushed out of his office by ambulance to the city hospital where I sat all day and night in emergency listening to the heart monitor go haywire for hours on end. I was in unbearable pain. I could no longer stand it. I knew something was really wrong. The last thing I remember I laid down on the floor. That night I had congestive heart failure. During emergency surgery they installed a heart pump. I was then rushed by ambulance to Tufts Medical Center in Boston about an hour away. I was told they were better equipped to handle my situation. On arrival I was prepped to have surgery again. They needed to install a new heart pump. Something was wrong with the first. At the same time I experienced my first heart biopsy. It’s a very strange feeling something I will never forget. They pull a sheet over your body and face as if you were dead. Then they drill a hole in your neck for the catheter. The wire goes zipping up and down to your heart to bite a tiny piece off. This scared me so that I kept my hand outside the sheet on the rail of the bed and wiggled my fingers the whole time. I was hoping someone would see to know that I was still alive. I lay on deaths door for what seemed like an eternity. I had hours left until they were going to give me a tracheotomy. While I was waiting my Mother came and sat by my bed. She started to say the rosary aloud. In minutes an overwhelming feeling of release came over me. By the time she was done my oxygen levels had raised to the point I did not need the trach. From this point I progressed beyond any expert’s beliefs.

I was diagnosed with Giant Cell Myocarditis and put on the transplant list. I was told I would need a transplant within a year’s time. Even with the transplant it was likely to return. Survival rate was not good but better with the transplant. I would have to take Cyclosporine and Cellcept for the rest of my life. The side effects include protruding gums and extreme facial hair. At this point I giggled. Really are you kidding me? I’m Italian the last thing I need is more facial hair. There is one thing the experts did not take into consideration. I am a positive thinker. I did not see a transplant in my future. I pictured myself leading a normal life. I knew I was going to be just fine. Sure enough I left the hospital a few weeks later with my heart working at full function. There was no lasting damage. I left them all scratching their heads.

My one year anniversary I celebrated by walking a half marathon in Bermuda. I had also returned to work determined to lead a normal life. However on my one year and a half anniversary things were not so well. After getting a full body massage at a spa I started to lose my energy and memory. I am told I was going about daily functions but had absolutely no memory of this. I was eventually brought to Dr. Guilbert’s office again. I don’t remember the appointment but Dr. Guilbert says he will never forget it the blank look on my face. I did not know my own name or what country I was in.

Off to Tuft’s I go again. I spent a few months in a coma. No one could figure out what was wrong meanwhile they kept a close watch on my heart. I arrested several times during this episode. Tuft’s contacted the government CDC in hopes for an answer. I was treated with steroids, antiviral agents and Cytoxan a mixture sure to cure any of your ailments. I was diagnosed with Meningeal Encephalitis with Cerebritis. I eventually came to and was sent to rehab. There I had to regain my memory, my motor skills, walk and regain my body strength. I also lost the sensation in my right hand from being shackled down in the coma. Several shock therapies later I was told I will regain it or I won’t, time will tell. Against all odds I was able to do this. I pictured myself leading a normal life. This is what I truly saw for my future. I really believed this. Once I regained my mind I was able to put all the pieces back together again.

I was released from rehab in November. A month later on Christmas day my husband of ten years told me he had moved in with another woman while I was in the coma. Not the Christmas gift I expected but in hind sight it was indeed a gift. Now I had to fight the good fight by myself. My doctors did not like the fact I was living alone. I spent more time with my family than I ever had. My dad has a saying that goes something like this, “When times are good everyone wants to be your friend but when things get hard no one knows who you are”. My family stayed in my corner. I still lived by myself an hour away from them. I wasn’t worried. I knew with everything I had I was going to be alright. Thanks again to my unshakable faith, positive thinking and hard work I returned back to work one year later.

The first month of returning to work I was covered head to toe with a rash. Then my right foot started to swell so bad I could hardly walk. By the second month my breathing was also restricted. Off to Dr. Guilbert’s again. Sure enough he figured it out once again. Thank God for Dr. Guilbert! I had a blood clot in my leg that broke off into a Pulmonary Embolism. I was rushed to the hospital again. It was there I was diagnosed with chronic kidney disease stage III, systemic lupus erythmatosis, lupus nephritis, vasculitis, pulmonary embolism, lupus cerebritis. I left the hospital a week later this time with more meds and blood thinners.

I knew that returning to work again was not a good idea. My time here is limited. I never did any of the things I really wanted to. I had so many dreams when I was younger yet I settled for an unfulfilling life. I decided not to go back to work. I would spend whatever time I have here doing things I love and helping people. That gives me peace and happiness. It fulfills me. That’s what I want my legacy to be.

The next few months’ things started looking up. Christmas Eve I met the most wonderful, loving, caring man. He walked into my life at a time I was rock bottom. I had gained 50 pounds from all the steroids. Lost most of my hair from the Cytoxan and I was certainly not in the best of health. He fell in love with me anyway and for that I am truly grateful.

May 2011 I was admitted to Tuft’s again this time with a right atrial collapse, pleurisies, and pericarditis with bibasilar atelectasis. This time I came home with oxygen but every time gets easier especially being surrounded by the right people.

It is not what happens to us that make us who we are; it is how we respond to those events and what we choose to do about our feelings. Choose to stay positive even when all odds are against you. Most importantly never lose faith. It will bring you though anything.

Annie Schofield, Putnam, CT

Meet Another New Board member... Michael Austry

Michael Austry (right) running the Half Marathon in Dallas with brother Mark just before crossing the finishing line

Michael Austry was introduced to Myocarditis on March 14, 2010 when his youngest brother Mark collapsed and died after crossing the finish line with him at the White Rock Lake Rock and Roll Half Marathon in Dallas, Texas. Mark was 32 years old and the married father of two young daughters.

Since learning that the cause of Mark’s death was Myocarditis, he has been an avid supporter of and fundraiser for the Myocarditis Foundation. On the year anniversary of Mark’s death, Michael used his race contacts at the White Rock Lake Rock and Roll Half Marathon to secure a donated booth at the race expo to help raise awareness and funds for the cause which was covered extensively in the local print and television media. He also turned his participation in the St. George Iron Man into a personal fundraising tool and raised over $6,000 for the Foundation.

Michael is the owner of a publishing representative firm in Dallas and manages print advertising for various national magazines. Through his work relationships, he is hopeful some of the magazines will help by running public service announcements about Myocarditis as space is available.

Michael is married to wife Danielle and has a one-year old daughter named Devin Mark in memory of his beloved brother.

Jeff Grant, Retired Emeritus, Founding Director of The Myocarditis Foundation :With Gratitude
"Life with a Wry Sense of Humor and a Diagnosis of GCM"

Jeff Grant was 38 years old in 2000 when he experienced an episode of tunnel vision while walking down the hall at work. He went to a Walk In Clinic who discharged him and refunded his money, sending him instead to the hospital. The hospital put him on a heart monitor and within minutes, called in a cardiologist who performed a battery of tests, including a heart biopsy. He was discharged one week later with a defibrillator and a diagnosis of idiopathic myocarditis.

One week later, his cardiologist called he and his wife into the office and explained that Stanford University had read his biopsy as Giant Cell Myocarditis and that he was likely to die within 3-12 months. The doctor referred him to Dr. Cooper at the Mayo Clinic who sent him to his alma mater, the University of Kentucky, where he was admitted and treated with OKT3, heavy chemotherapy protocol designed by Dr. Cooper. Jeff said, "Do I have time to take a vacation to Disney first?" He was told he couldn't work for one year.
He worked 20 hours per week for several years, fully expecting to die at any moment, and when he didn't, he decided that he might as well have fun. He finally came to the conclusion that his chances of dying weren't any different from the rest of the population, so he decided to live it to the fullest. He doesn't put things off that he wants to do. He believes that people who had the chance to survive, do so because they have a positive attitude. And besides, he admits, "I like a good fight!"

Ten years later, he is slower, he has less stamina, but he feels like he can do anything he wants. He feels lucky that the disease damaged the electrical system of his heart because he has a medication and a device that now control the lethal arrhythmias. He says he is just too stubborn to die. Jeff's website, GCMinfo.org, was the only source of information available to me when I recovered from GCM and my heart transplant in 2001 and it was the precursor to and model for the Myocarditis Foundation. We are forever grateful for his pioneering efforts and altruistic spirit that set the stage for the future. As he retires from the Board of Directors, he does so with one foot still firmly planted in our foundation's heart.

Candace Moose, September 22, 2011

Webinars

Coping with a Loss Due to Myocarditis
Scheduled in the new year

Hosting a Fundraiser
Scheduled in October 2011

Chronic Myopericarditis
September 2011
Presenter: Dr. Leslie Cooper, Chief of Vascular Medicine at the Mayo Clinic and President and Founder of The Myocarditis Foundation

The Diagnosis of Myocarditis
May 2011
Presenter: Dr. Leslie Cooper, Chief of Vascular Medicine at the Mayo Clinic and President and Founder of The Myocarditis Foundation

The Treatment of Myocarditis
February 2011
Presenter: Dr. Leslie Cooper, Chief of Vascular Medicine at the Mayo Clinic and President and Founder of The Myocarditis Foundation

Coping with Loss During the Holidays
December 2010
Presenter: Chaplian Audrey A. Lukasak, M-Div, BCC, CT Mayo Clinic, Rochester, MN

Arrhythmias and Sudden Death in Myocarditis
November 2010
Presenter: Dr. Leslie Cooper, Chief of Vascular Medicine at the Mayo Clinic and President and Founder of The Myocarditis Foundation

Heart Failure in Myocarditis: Acute, Chronic or Fatal?
September 2010
Presenter Information: Dr. Lori Blauwet Cardiologist, Mayo Clinic, Rochester, MN

Viral Myocarditis
July 2010
Presenter: Dr. Leslie Cooper, Chief of Vascular Medicine at the Mayo Clinic and President and Founder of The Myocarditis Foundation

The Webinars are posted at
www.myocarditisfoundation.org

Myocarditis Fundraising and or Awareness Events in 2011:

- February 12th: Dream Big Fundraiser to honor Brad Vanness, Kewaunee, WI
- March 26th: Rock and Roll Marathon booth in Dallas, TX to honor Mark Austry
- St. George's Iron Man Competition to honor Mark Austry
- April 28th: Dinner to Introduce Dr. Cooper, Augusta, NJ
- May 1st: Live Life WOW, Logan Sweet Foundation, Topsham, Maine
- Hana Hornbeck, Myocarditis T-Shirts sale to raise awareness in Phoenix, AZ
- June 2: Not a Blank Canvas Premiere, Raleigh, NC
- June 4: 2nd Annual Tim Burke Golf Tournament in Harrisburg, PA
- Jennifer Burke, Myocarditis T-Shirts sale to raise awareness in North Las Vegas, NV
- July 23rd: Lakes of Taylor Golf Tournament to Remember Ashley Orme, Detroit, MI
- August 13: Kamryn's Diaper Drive, Champaign, IL
- August 15: Mark Austry Memorial Golf Tournament, Lanta Golf Club in Dallas, TX
- August 20: SLUG Magazine awareness event to honor Mia Bella Brickey and the Myocarditis Foundation in Salt Lake City , UT
- September 3: Devin Kravitz Memorial 5K, Leicester, MA
- September 17: Sunset on the Manasquan, Point Pleasant, NJ,
- September 19: Annual Joe Rumore Golf Tournament, White Beeches Country Club in Haworth, NJ
- October 1st: The Avalon Open Golf Outing in Avalon, NJ
- November 6th: Remember Jolanda by Brenda Heskes, New York City Marathon
- November 5: Evening of International Intrigue to remember Chris Delaware, Alexandria VA

Interested in adding your fundraiser to the list or holding your own fundraiser? Please contact Lindsey at Lindsey@ myocarditisfoundation.org.

The Myocarditis Foundation Hosts First Myocarditis Symposium for Cardiologists

The Myocarditis Foundation will host its first Myocarditis Symposium on Saturday, March 24th, 2012, in Chicago, IL, at the Whitehall Hotel from 6:00pm-9:00pm. The symposium will take place during the American College of Cardiology annual meeting. Dinner will be provided. If you would like to attend this event, please contact Candace Moose, Executive Director, for more information.

Myocarditis Foundation Endowment Campaign:

The Myocarditis Foundation announced today that it has begun a two million dollar Endowment Campaign. The funds will be used to secure the future of the Foundation. To make a donation to the fund, please contact Candace Moose, Executive Director via email at Candace@myocarditisfoundation.org

Awareness Items For Sale!

We have

- T-shirts
- Jackets
- Wristbands
- Pens

available to sell for our awareness campaign.

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

Remember,
KNOWLEDGE NURTURES HOPE!

The MYOCARDITIS FOUNDATION
2201 River Road, #3401 Point Pleasant, NJ 08742
732-295-3700 • www.myocarditisfoundation.org

Losing My Son Jonathan

On May 21, 2011, my son Jonathan and I were discussing radio host Harold Camping's prediction for The Rapture which was predicted to happen on that date. We lightheartedly bantered back and forth about the time of this event, Jonathan recalling one time and I another. I ask him to give me a hug "just in case" at which he chuckled. Then he wrapped his arms around me, and gave me a hug. I reminded him, "Now remember, don't you leave without me!" This merely elicited another smirk from Jonathan before he headed out the door with his Starbucks apron in his hand. I recall having some uneasiness that day, but I wasn't sure why. I surely didn't believe The Rapture was really going to happen that day, did I? "Tell Mom I had the time wrong," Jonathan passed along later that day.

Little did I know that on June 4, 2011, exactly two weeks later, Jonathan would leave this world. If the coroner was correct, it took at least 3 weeks for Jonathan's heart to enlarge to twice its normal size. That indicates that Jonathan's heart was already enlarged when we had the above conversation. How could I have known that would be the last hug I would receive from my son?

Jonathan's girlfriend recalls him mentioning some chest pain and shortness of breath when Albertson's was entering labor negotiations and employees were threatening to picket. But, Jonathan thought it was anxiety. Since Jonathan's chest pain seemed to worsen with "Monster-type" drinks, his girlfriend suggested that he discontinue them, which he did. Apparently because his chest pain improved, Jonathan thought he was fine.

On June 1st, Jonathan called me at work and said he felt like he was coming down with the flu. He asked me to bring home Gatorade. Jonathan's sister had tested positive for Strep a few weeks prior, and his girlfriend had a sore throat and an ear infection recently, so when I got home I checked his throat: no spots. I told him, "Since we've have Strep going around, if you get a sore throat you should see a Doctor". He said he didn't have a sore throat, just ached, and had a slight temperature (under 100 degrees said his girlfriend). He said he thought it was "just the flu" and he would stay home from work the next day (June 2nd) and get some extra rest.

Jonathan returned to work June 3rd. Later we learned that he had coughed up a little blood at work. They told him to go home, but he decided to finish his shift. He promised a friend at work that he would see the Doctor the next day if he didn't feel better (his insurance cards were found on his desk the next day). He returned home briefly to meet his girlfriend, then they met with another friend for dinner. Twice Jonathan became ill during dinner, but he decided he felt well enough to go to a movie. Although he didn't feel great during the movie, he looked better and said he felt better on the way home. Jonathan returned home a little after midnight. He said he was tired because he hadn't slept well the night before, so he went on to bed. His sister recalls hearing him up once during the night going to the bathroom, but they didn't see each other nor did they talk.

Jonathan Iacuaniello:
July 29, 1987 - June 4, 2011

On Saturday morning (June 4th), Albertsons called trying to reach Jonathan because he had not arrived for his work shift, and they had been unable to reach him on his cell phone. I took our home phone to his room, where I found Jonathan in his bed. I knew the minute I saw him that something was very wrong. Jonathan passed away in his sleep earlier that morning on June 4, 2011.

The coroner gave us the diagnosis a few days later: Sudden Death, Myocarditis, Probable Viral Etiology, Cardiac Hypertrophy, manner of death "natural". Jonathan did not have the flu the last couple of days. His heart was in the process of shutting down. My life has turned in the direction that many others have. I have tried desperately to find answers to what took the life of my child, and I struggle daily to move forward without him. I knew nothing about Myocarditis prior to June 2011. Now I know there are many people who are living daily with Myocarditis who are fighting for their very lives.

Each day I try to remember what we had: twenty-three wonderful years with Jonathan. What a blessing that is in itself. All the love we had for him and the love he had for us. His laughter, his smile, his energy (we called him "Tigger" when he was a child, because he bounced so much). His imagination and his enthusiasm for life (movies, games, dining out, time with family, time with friends, and more). I hope some day the memories and positive factors of his life will outweigh the pain of losing our beloved son at such a young age.

We love you Jonathan, and miss you every single day. Love, Mom

Nancy Iacuaniello, Escondido, CA