



Knowledge Nurtures Hope



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 us at: info@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 Interviral 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



Not a Blank Canvas: Portraits of Myocarditis



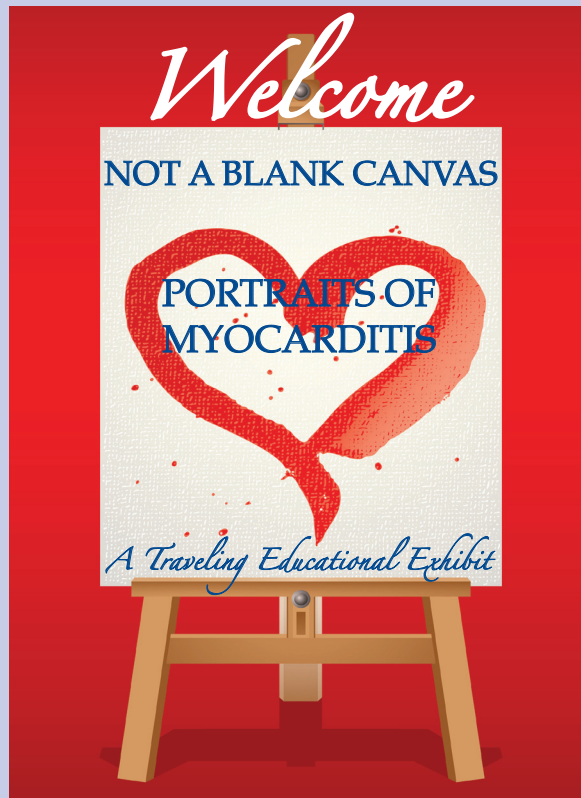
Hana Hornbeck
Phoenix, Arizona

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 survival conversations with ICU physicians and Cardiology. Within days Hana's heart stopped. When she cooled 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 know 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



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 breathe. 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 loss 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 affects 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



Not a Blank Canvas: Portraits of Myocarditis



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 cooled 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 that 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

