

# The MYOCARDITIS FOUNDATION



4708 Norbury Place, Raleigh, NC 27614 • 866-846-1600 • 919-846-2081 • [www.myocarditisfoundation.org](http://www.myocarditisfoundation.org)

## THE MYOCARDITIS FOUNDATION IS MOVING TO NEW JERSEY

Please contact us at the new mailing address after  
December 1st, 2009

The Myocarditis Foundation  
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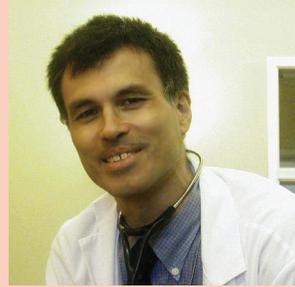
Dr. Leslie Cooper

### ***2nd Annual Myocarditis Foundation Joe Rumore Golf Outing Event a Hole in One!***

***The 2nd annual Myocarditis Foundation Joe Rumore Golf Outing was held on Monday, September 21st, 2009, at White Beeches Country Club in Haworth, NJ. The event raised over \$25,000. Joe wishes to thank all of the participants, sponsors, and donors that gave so generously and contributed to the success of the event.***

***Dr. Leslie T. Cooper, Chief of Vascular Medicine at Mayo Clinic, Rochester, MN, and President of The Myocarditis Foundation was the guest speaker.***

## SPOTLIGHT ON THE BOARD OF DIRECTORS



**Mario C. Deng, M.D.**  
**Founding Member of Board  
of Directors**

Dr Deng is the Director of Cardiac Transplantation Research in the Department of Medicine and Division of Cardiology at New York Presbyterian Hospital/Columbia University. He received his medical education at Stanford University and in Germany where he authored the seminal textbook on Heart Transplantation.

In 2000, he accepted the position at Columbia University, where his research focus in recent years led to the approval of a novel gene-based blood test to determine rejection in heart transplant.

Among many other honors, Dr. Deng served on the Board of Directors of the International Society of Heart and Lung Transplantation from 2001-2005. He is widely published in medical journals and has authored several books.

Dr. Deng's bedside manner is as novel as his research. He believes that patients should be empowered to make decisions about their own healthcare, while the healthcare team provides background expert and empathetic options counseling. It is his belief that patients' outcomes actually improve when they are involved in the decisions that affect their own lives.

Dr. Deng has extensive experience in taking care of myocarditis and Giant Cell Myocarditis patients and has served as a member of the Board of Directors since 2005. He feels strongly about his commitment to serve the Foundation because he believes that by offering accurate information to patients and their families who experience inflammatory heart muscle disease empowers them to develop expertise and informed decision-making capacity on their own behalf.

Dr. Deng is the father of two daughters, both Cambridge University educated scientists with PhD's in Physics. Dr. Deng enjoys Salsa dancing in his spare time with his wife, Dr. Federica Raia, a PhD professor of Geology Education at New York University.

Written by Candace C. Moose, 10/14/2009

## ***Planned Giving***

You can contribute to the long term success of The Myocarditis Foundation by adding a statement to your will. Direct your lawyer to include a statement bequeathing a gift of a stated amount or percentage of your estate to be directed to the Foundation. Together we can make a difference.



# MYOCARDITIS

## Giant Cell Myocarditis Patient Gets Married in CCU

I was a very healthy, fit and exercise-conscious 45 year old. On July 1, 2002, I was scheduled to go to Washington, D.C. on business. At 6:00 am, I went on a 22 mile bike ride, showered and was off to my office in Chicago to work a few hours before my 3:00pm flight to Washington, D.C.

I distinctly remember on that day, my friend stopped by and asked me how I was. I told her I was feeling "great."



**Skip & Judy's Wedding Day**

Before I boarded the plane, I bought an extra large iced decaf at Starbucks. In the middle of the trip, I started to feel palpitations. I thought maybe they had given me a caffeinated drink in error, as an explanation for the palpitations. When I deplaned, I was feeling a little disoriented.

I arrived at the hotel and called Skip (at that time, my boyfriend of 14 years) and told him that I didn't feel well.

The next morning I was feeling better, but not 100%, so I decided to skip my exercise routine.

The next day was July 4, 2002. When I got up I tried to get out of bed to walk to the bathroom, but I was so dizzy that I had to crawl back to the bed. Then I heard Skip yelling my name. I opened my eyes and he told me that I had passed out. Skip drove me to the emergency room. I assumed I had a virus and that they would send me home with a prescription. Wrong!!

After the nurse took my vital signs, she called in a specialist who I later

learned was a cardiologist. After some tests, he told me he thought I had myocarditis and that I would probably need a pacemaker. My first question was, "Will I still be able to ride 40 miles on my bicycle?" He said, yes, and that it would even be a better ride.

Very fortunately, the emergency room cardiologist called upon another heart specialist. This doctor had recently attended a conference where Dr. Leslie Cooper of the Mayo Clinic presented information on a condition called giant cell myocarditis (GCM). Dr. Cooper is the world's foremost expert on GCM and had created a treatment plan for the condition. The local doctor contacted Dr. Cooper who told him that it looked like a textbook case of GCM and recommended a heart biopsy. I was at a small local hospital, so the biopsy was sent to Johns Hopkins for analysis and didn't come back for four days.

In the meantime, I was in the ICU cardiac unit, disoriented, deteriorating, and not knowing what was happening. When the biopsy results came in it confirmed that I had GCM. I was airlifted to a major Chicago area hospital, Loyola Medical Center. That night I went into cardiac arrest and Skip was told that I might not make it through the night.

The next day I woke up in the heart transplant unit on full life support with an implanted ICD. I was hooked up to a pump in my groin and was told not to move my legs or risk paralysis.

I was started on Dr. Cooper's GCM treatment plan. My understanding of GCM was that it was an extremely rare autoimmune condition in which my body attacked my heart, as if it were a foreign entity.

The whole thing was absolutely surreal. I kept thinking that this was a nightmare and that I would wake up and it would be July 4 all over again. I had lots of tests to evaluate me as a candidate for a heart transplant. I accepted the fact that some people die young and that I was going to be one of them. I had my lawyer come to the

hospital to prepare a will.

I was still on life support when I told Skip that I wanted to get married. It still brings tears to my eyes when I remember his response: "Judy, I've always wanted to marry you." What a guy. He didn't even think twice. Close friends and relatives were invited and the doctors gladly let us use their conference room for the occasion.

As the days approached the wedding day, I was improving. I came off life support and as soon as I was able. I took my first walk on Saturday, July 13. Everyday thanks to Dr. Cooper's treatment plan, my heart function showed improvement.

I was married in my hospital gown, that was truly the happiest day of my life.

Seven years have passed and I am now 52 years old. Seven years ago, I, for sure, would never have thought I'd still be here.

I work full time, and lead a pretty normal life. But I won't tell you that everything is rosy. I fear a recurrence and the medical literature supports my fear. I do my best to manage the disease, and not let it manage me.

I owe my life to God, to my wonderful doctors, particularly Dr. Cooper, to my devoted husband, Skip, for all of his support, and for taking one day at a time, working towards wellness.

Judy Sommers  
Chicago, IL





# MYOCARDITIS

## Three Cheers for Erin!



ERIN: First day of Junior Year of High School

My healthy, energetic and athletic daughter Erin Strickland was looking forward to her freshman year of High School. Erin had made the Senior Large Level 5 (advanced) Stingray All-star cheerleading squad, the Varsity competition Cheerleading squad at her High School and she would be cheering for the Freshman Football and Basketball teams.

On September 12, 2007 Erin broke out in a rash. The Doctors suspected an allergic reaction. She was treated with a cortisone shot and ointment. Erin's energy level dropped but we just dismissed it as the results of a busy schedule.

The rash worsened and then she developed a fever. On Oct 1, 2007, the fever went to 103.6 and Erin was admitted to the hospital was treated for suspected staff scalded skin and scarlet fever. Erin was discharged with an antibiotic.

Erin continued to be active but still did not have the energy she was use to having. On Wednesday January 23, 2008 her stomach began to cramp. Thursday afternoon she began to vomit. Her Doctors suspected a stomach virus. On Sunday Jan. 27th

at 5:00 a.m. I took Erin to ER where she was treated for dehydration for 12 hours and was told to go home and follow-up with a GI specialist. I insisted she was in too much pain and too ill to go home. When the nurse brought a wheel chair to the room to help Erin to the car Erin vomited violently and the nurse then was able to find a Doctor to admit her. Once admitted the doctor said she thought she saw Erin's heart in the stomach x-ray. There just so happened to be a Cardiologist on the floor at the time so he immediately did an echocardiogram and saw Erin's heart was enlarged. This was the cause of the vomiting.

Erin was then transferred to Egleston Children's CICU. Because of the recent bizarre illnesses on Monday they did a heart biopsy and found the Giant Cell Myocarditis. There was fluid around her heart and her lungs had begun to fill with fluid. They had to put in a tube to drain the fluid from her lungs.

The transplant team came in and immediately began working her up for a transplant. We were informed that GCM was extremely rare and was usually not found until an autopsy was performed. I informed the Doctors that obviously God had a different plan because God allowed them to find it on Erin. The Doctors thought I had lost my mind.

Some time soon after the Doctors advised us that if Erin had to have a heart transplant she would have to go to University of Alabama, Birmingham(UAB). Friday February 8th she was transported to UAB via a Jet. A couple of days after arriving in Birmingham her heart function went down to 15% and a team of Dr's came in and explained that they were going to move her to CICU and order a Berlin Heart from Germany. Erin would have go through a surgery and be kept asleep for two or three days. Dr. Bourge came in and explained that the Berlin Heart would take a week to arrive in Birmingham but that Erin was in CICU so that if

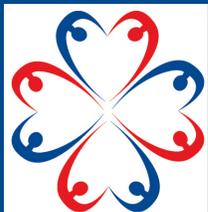
needed she could be placed on life support in a matter of minutes. He then said... "Maybe this is the Lord's way of telling us we are moving too fast". Praise God it was!!!! Erin got better and on Thursday February 28th had an ICD implanted and was released from UAB on Friday February 29th.

Erin has had to adjust to a less active lifestyle and has to take 20 pills each day. She has 3 wires running from the ICD to her heart and must try and protect them from being damaged. I am so grateful that she is alive Had I taken Erin home from the ER that Sunday and tried to follow up with a GI specialist I suspect Erin would not be alive today.

My hope and prayer is that through further research and education no child will have to die or suffer from GCM.

Erin's Mom  
Lynda Strickland  
Atlanta, GA





## ***This little heart of mine, I'm gonna let it shine....***

I was 22. Stoked on life. I had just graduated from the University of California, San Diego. In my time spent at the University I had somehow managed to work for brilliant minds, cloning genes for developmental studies, training dolphins for the military, and learning about life from cells to social situations. I was on to my next adventure- Australia. I had always dreamed of going there and I had landed a volunteer position with the University of Queensland in Brisbane, where I would be helping to track dolphin populations in Moreton Bay.

I had saved up enough money and with a ticket purchased by dear old dad and a hesitant "okay to go" from my mom, I was off. I arrived and worked long hours on a small craft with two others. I was the photographer. We had a few weeks downtime on the project. I decided to take a trip to Northern Australia. When I arrived, I realized I was not feeling so well. I kept my head up and decided that exercise would be the cure all. A few days later I got a soar throat and decided that I should take it easy.

As the days went by I was only feeling worse and worse. A new friend of mine took me to the Doctor's office and they told me to rest and so I did, but strangely at night I could not lay down I had to sit cross legged and fall asleep with my head in my lap and periodically I would wake up and rush to the restroom. I was very ill. The next night I went to the ER, I waited 2 hours and paid 180 dollars, in order to be told I most likely had bronchitis.

A few days later on August 5, 2008 I decided I needed to visit the chemist in order to be given medicine. I

walked from the bus to the chemist, a distance of about 100 feet and knew something was very wrong. I arrived and the girl that greeted me and asked if I wanted an ambulance. I said no, I had already been to the hospital.

Minutes passed and the next thing I knew she was next to me and I was coming out of a seizure and I had struck my head on the isle. The girl called an ambulance.

I arrived at the hospital and kept going into shock. People were saying my name, telling me to relax, I am terrified of needles so it wasn't easy. An older doctor came in and asked me what happened in the past week. I told him about my trouble at night and he immediately diagnosed me with myocarditis. I was flown that evening back to Brisbane to Prince Charles Hospital. I was loaded onto a stretcher then onto a plane and I fell asleep for about an hour and a half of the two-hour flight.

I arrived at the hospital and joked with the night staff. In the next couple of days I was restless. My father would soon be arriving and I was excited to show him how I was making improvement. Before he arrived I had been taken off of dopamine and was no longer improving, that afternoon they consulted me for heart surgery and I said, "No"

I was given a moment alone and I took that time to talk to my heart. I focused all my energy on that little heart of mine and said, "You better get better" and after 13 days in the hospital I was released and told that I had made the most amazing recovery they had ever seen. I have learned that I am a very



**Aubrie O'Rourke**

strong individual. I learned that life is precious occurrence.

I learned that I am not invincible. I live with the above story everyday. I wish for anyone who is experiencing this situation that there is nothing as powerful as positive thinking.

I am very lucky to be alive. It was the quick response of the medical team and my own will to recover that allowed me a second chance at life. I am currently working on my PhD studying the evolution and development of marine organisms and I am working toward becoming a pilot. I have written a book to share my story and to spread hope, it is entitled "CALAFIA" and it is an acronym that stands for "create a life about finding it all". Please live and love greatly and always listen to your heart.

Aubrie O'Rourke  
San Diego, CA

The Myocarditis Foundation is proud to announce their receipt of two charitable grants from the following corporate sponsor:

• **St. Jude Medical**

\$5000 in support of the FIESTA! 2009, held on May 1st, 2009 in Raleigh, NC and another \$2500 in support of the 2nd Annual Joe Rumore Golf Outing in Haworth, NJ, on September 21, 2009.



## The Myocarditis Foundation Announces Programs for 2009

### 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.

### Message Board

#### For Families Who Have Lost Loved Ones to Myocarditis:

Click on the Message Board tab on our Home Page and to receive your protected password for our online Support Group. Share your experiences with other families who know what you are going through.

### Research

#### For Physicians:

We are accepting applications for Research Fellowship Grants. The stipend will be \$35,000 for the 2010/11 academic year. The deadline for application submission is December 1, 2009. Click on the Research tab on our Home Page to access online Research Fellowship Guidelines and Application Form.

**[www.myocarditisfoundation.org](http://www.myocarditisfoundation.org)**  
**1-866-846-1600**

## The MYOCARDITIS FOUNDATION

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**The Plasmonics** From left to right: Jim Moose, Rodney Kirby, Mark Faust, Greg Hargis, Ken Lundy, Lloyd Tucker and Frank DeLucia

## FIESTA! 2009

### Myocarditis Foundation Benefit A Huge Success!

The Myocarditis Foundation held its second fundraising event in the Raleigh area, entitled FIESTA! on Friday May 1st, 2009. James and Candace Moose, founding directors of the Foundation chaired the event. The purposes of the event were to increase awareness of this rare and often heart disease in the local community and to raise funds to support the programs and services of the Foundation. Over 100 guests were entertained by music from the band, "The Plasmonics", the Talecris Biotherapeutics entry in the 2007 Triangle Area Corporate Battle of the Bands. The event raised over \$25,000.

The event was held at North Ridge Country Club in Raleigh. The evening included Mexican food, music, and dancing. The event would not have been possible with the help of volunteers and local artists and businesses that donated time, goods and services. The Raleigh area business sponsors included: Art Source Fine Art Gallery and Framing, Atlantic Avenue Orchid and Garden Center, The Fresh Market, Empire Wine Distributors, Double Data, Dr. Mike Peters and Eye Care Associates, Knight's Play Golf Center, Todd Baemer of Falls Golf Complex, Saks Fifth Avenue, Kim Hopper Designs, Caring Sole Reflexology, Body N Sync, Transformations for Health, Hair Entheos, D.S. Parada Color Café, Master Baker Joy Nogales, Homewood Nursery and artists Heather Durham and Mike Frenza. Many other individuals gave generously as well. The Foundation also received a grant from St. Jude Medical, manufacturers of cardiac rhythm devices on which myocarditis patients depend to control lethal arrhythmias.

The special guest speaker for the evening was Dr. Cheryl Cammock, a pediatric cardiologist from Winston Salem, NC, who spoke about her experiences with children with myocarditis and the special challenges that she faces in treating this every vulnerable population. Candace Moose also spoke about her experience with Giant Cell Myocarditis and how that led to the formation of the Foundation.

The Myocarditis Foundation is an international web-based non-profit organization that is dedicated to increasing awareness and hastening progress in understanding this rare disease. Myocarditis is a disease that is marked by inflammation and scarring of the heart muscle. It is poorly understood and often under diagnosed. It can progress rapidly to heart failure, lethal arrhythmias, and death or heart transplantation. Several thousand patients per year are diagnosed in the United States, many on autopsy. The disease attacks otherwise healthy people. Approximately 5-20% of all cases of sudden death in young adults in due to myocarditis.



**Candace Moose, Event Host**



**Mr & Mrs Bruce Nogales**



**Mrs Carol Delucia & Mrs. Sherry Leider**



**Mrs. Felicia Jackson**



**left to right: Mrs Karen Long, Mrs Annette Kennedy, Mrs Donna D'Orazio and Mr Bruce Kennedy**