



From left to right: Stephanie Austin, Megan Bova, Candace Moose, Cherie Young, Ashley Young and Brittany Bova.

## High School Bands Rock for Myocarditis

Dear Dr. Cooper:

As President of the Myocarditis Foundation, I am writing to inform you and the Board of Directors about the amazing success of five energetic, young activists who worked tirelessly on behalf of our foundation in memory of their loved one. Ashley and Amber Young, college students from Pittsburgh, Pennsylvania, lost their 13 year old sister, Aleigha, suddenly and tragically to myocarditis in March of this year. Ashley's best friend from college, Megan Bova, an early childhood myocarditis survivor, and her sister, Brittany, decided to turn their grief into action.

They planned a fundraising event, a rock concert, to raise awareness about the disease that has touched their lives. The idea for the concert can be credited to their friend, a high school Leadership Club member, Stephanie Austin. The girls invited their friends, advertised by putting up posters, gathered corporate sponsorships,

sold tee shirts and wrist bands, convinced the arena venue to donate the space for free, raffled off Silent Auction items, secured high school bands to play for free, and invited me as a representative of the MF to speak. Approximately 100-200 kids, family and friends attended. The room was electric with energy. Aleigha's mother, Cherie, stood by quietly, still grieving for her daughter, taking in the love and support of the community who turned out to show how much they cared.

Aleigha was participating in a track

and field event during gym class at her middle 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.

The girls are going to make this and other fundraising efforts annual events, as they are trying to raise money for a scholarship in Aleigha's memory at her middle school and for the Myocarditis Foundation to try to save more lives. 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 to be the recipient on behalf of the MF of their tremendous success. May God bless them all.

Sincerely,  
Candace Moose  
Founding Director of The Myocarditis Foundation

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

- **St. Jude Medical** – \$2500. Charitable Grant in support of the Joe Rumore Golf Outing, Haworth, New Jersey, held September 15, 2008
- **XDx, Inc.**, Brisbane, CA; \$2,000 Donation
- **Boston Scientific/Guidant** – \$1000. Charitable Grant in support of The Vintage Celebration, Raleigh, North Carolina, held May 18, 2008.
- **Rite Aid Corporation**, Camp Hill, PA; \$1,000 Donation

# The MYOCARDITIS FOUNDATION



*Anytime Fitness personal trainer Jenö Rab gives heart transplant recipient Joseph Rumore pointers on the Life Fitness elliptical machine.*

## **"Who's got it better than me? I'm a walking miracle,"**

...says Parsippany resident Joseph Rumore, 54, as he works out at Anytime Fitness of Parsippany. Having received a new heart on his birthday, November 24, 2006, Rumore's actions reflect a healthy new lifestyle. "You can choose to be down in the dumps, or you can decide to look at this as an opportunity," Rumore said.

Aside from exercising at least three times a week at Anytime Fitness, Rumore has carefully charted out a life that includes disciplined nutrition, a rigid medication routine, and devoting 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-nine cents of each donated dollar to research grants.

## **Risk Factors**

Every lifestyle choice Rumore makes is influenced by 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, "and where I exercise is crucial to maintaining my health."

Because the anti-rejection medication he takes suppresses his immune sys-

## **Resident Says His New Heart Is Working Out**

tem, Rumore says he has to be much more aware of the environment in which he works out. He looked at a number of gyms before choosing Anytime Fitness of Parsippany. "It was vitally important that I find a facility that not only offered all of the equipment that I needed, but also one that had a controlled environment where I'd have less chance of contracting something," he said.

"One reason I chose Anytime is 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 Jenö is watching out for me. All of this lowers the risk factors and makes me comfortable."

The "paddles" he refers to is the automated external defibrillator hanging on the gym wall. "Jenö" is Jenö Rab, the health club's general manager and personal trainer.

Rumore had always lived an athletic lifestyle, but in 2004, his health declined rapidly. There are various types and stages of myocarditis. Most patients recover from the less severe type of viral myocarditis within weeks. However, the long-term consequences of the more severe myocarditis include chronic heart failure, death or heart transplantation.

## **Symptoms**

Symptoms can be non-existent or may include fatigue, shortness of breath, heart palpitations and chest pain. An electrocardiogram, chest X-ray and blood work can help detect myocarditis, but the only definitive test is a cardio biopsy, which Rumore now routinely undergoes quarterly.

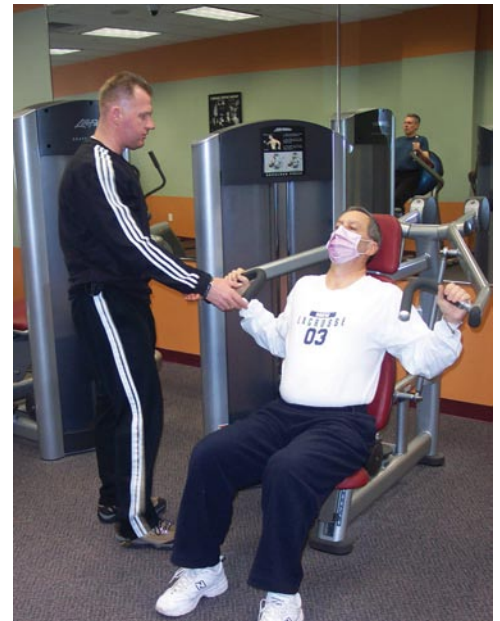
"Too often," he says, "people tend to attribute symptoms to job stress, get-

ting older or having just finished playing a game. People need to be more aware of what their bodies are trying to tell them."

Having listened to his symptoms and to his healthcare providers, Rumore says he feels like he's the luckiest guy in the world. "His attitude is always positive," remarks Bob Messenger, owner of Anytime Fitness of Parsippany. "His energy level is great, and he's always willing to help others. Just sitting and talking with him is really uplifting."

"We can all learn a lot from Joe. 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."

*Reprinted with permission from Parsippany This Week*



*Anytime Fitness general manager Jenö Rab works with heart transplant recipient Joseph Rumore on the Life Fitness shoulder press machine.*

## **1st Annual Myocarditis Foundation Joe Rumore Golf Outing**

The place to be on Monday, September 15, 2008 was the White Beeches Golf & Country Club in Haworth, NJ. Not only was it a great day for golf, but also for massages, good food and a great time. There were memorabilia items, auction items, tournament prizes and 50/50. Dr. Mario Deng, transplant cardiologist from New York Presbyterian Hospital/Columbia, was the guest speaker. He accepted a certificate of appreciation from the Myocarditis Foundation on behalf of the entire team of The Center for Advanced Cardiac Care. If you were unable to attend, please plan to do so next year. A special thank you to our corporate sponsors, St. Jude Medical. The event raised over \$30,000. All proceeds benefit the Myocarditis Foundation.





## Abiah's Heart: One Family's Tragic Myocarditis Story

### Good Friday, March 21, 2008

Abiah awakened about 8:30am with her normal cheerful behavior. After breakfast, she decided to play in the backyard, but after ten minutes, came inside, and lay on the floor because she was hot. Her brother began to fan her. Abiah said that her chest was tight and hurting, she could not breathe. She stood up and then collapsed. Her father called 911. When the ambulance arrived, the paramedics took her vital signs which appeared normal and drove slowly because they felt it was not serious.

By the time her parents arrived at the Hospital they were told that there was something seriously wrong with her heart and she had been airlifted to another hospital. Abiah had arrived at 5:00pm. Her heart stopped beating one hour later. She was resuscitated and placed on life support. Her parents were told that she had a rare viral infection which had affected her heart muscle. Her father asked what virus and he was told they did not know exactly because there were so many and it was hard to narrow down.

### Saturday Morning March 22, 2008

Abiah awakened briefly before she was taken to surgery to correct a damaged blood vessel in her leg. She told her mother that she loved her. This was the last time they saw her alive. Her cardiologist had said that she needed a heart transplant. The hospital was making the arrangements to begin the necessary testing for a compatible heart but, despite their best efforts, Abiah died at 9:00pm.

### Easter Sunday, March 23, 2008

Easter Sunday morning, her parents awoke in indescribable pain with the realization that their daughter was gone. They prayed for strength because they could not face this on their own.

### Monday, March 24, 2008

The next day, her parents went to Abiah's school to inform the Principal. Her mother writes, "I had no idea that she had impacted so many in such a positive way." The school newspaper printed an article entitled, "She Was Everybody's Friend". Now her picture hangs in the school library. She became a part of the school history leaving a legacy of love, peace and compassion.

### Saturday, March 29, 2008

The family traveled to New Orleans, the city from which they had been displaced by Hurricane Katrina, to bury their child. Her funeral service was a celebration of her short life. Her mother reflected, "Much love flowed from heart to heart. She was a beautiful flower that God has chosen for his bouquet. She belonged to Him first."

### July 17, 2008

Patricia M. of Texas, writes, "There needs to be more awareness of this terrible disease in the medical community and more research dollars directed toward finding a cure. Physicians of all specialties and the public, need to be better informed about how to recognize the disease early, so that treatment has a better chance of being successful. Most people have never heard of this very rare disease before it happens to their family, and even fewer realize that it can be the result of a simple viral infection. Please donate today to the Myocarditis Foundation which is committed to funding research in the hopes of discovering better diagnostic techniques and treatment options with the goal of saving more lives in the future."

*Submitted by her mother.*

### Tuesday, February 5, 2008

Fifth-grader, 11-yr.-old, Abiah visited her pediatrician office because she was not feeling well. She had an elevated temperature and a horrible cough. She was diagnosed with bronchitis and given a prescription for antibiotics. She was to return to school 3 days later.

### Wednesday, February 6, 2008

Her dad phoned the pediatrician's office and reported that Abiah was not getting any better. The pediatrician's office responded that it takes up to 72 hours for the antibiotics to work.

### Sunday, February 10, 2008

Abiah was taken to the Emergency Room with a temperature of 103, chest pain and shortness of breath. The chest x-ray did not show pneumonia. She was again diagnosed with bronchitis. The ER physician gave her a different antibiotic.

## Young Man's Brush With Myocarditis

June 2008

My son, 21 years old, had never been in the hospital, much less an emergency room. Two days prior, he had been sick with a flu-like bug, making him tired and achy. Early that morning he was having chest pains, but went to work anyway. Four hours later, he knew something wasn't right. He went to his local doctor. After a short exam, his doctor told him to go straight to the hospital.

When they called him into Triage, he was confused when a nurse told him that his EKG was irregular and she was going to call a doctor to take a look at it. My son looked at her and said, "That must be pretty serious because you are talking about my heart. Can you go get my mom? She is in the waiting room." I

thought, "Why is a healthy 21 year old in the hospital with heart pains?"

While in intensive care for two days, he received pain medications and many tests. They then decided that a cardiac catheterization should be done, my son's first surgery ever. He was sent home and placed on three days of bed rest. It was an extremely intense and scary time. He is back to work now...with a constant, lifetime awareness to always listen to his body and everything it has to say.

*Submitted by his mother, Donna Holland from San Diego, CA.*



# The MYOCARDITIS FOUNDATION

## Myocarditis Patient and Heart Transplant Recipient Wins Silver Medal at the US Transplant Games

Seven years ago Candace Moose, 57, received two immunizations to travel to Africa to do mission work. Several hours later, her heart beat more forcefully, faster and more irregularly. The immunizations had triggered an often fatal autoimmune disease called Giant Cell Myocarditis that subsequently destroyed her heart. Seven weeks later, she received a heart transplant.

Candace Moose first heard about the transplant games in a Support Group meeting while still in the hospital after receiving her heart. She wondered if she would ever be well enough again to be an athlete. When she and her husband moved south three years ago, she joined Team North Carolina and started training for the games. The women's swim team needed a fourth person to compete in the 200 meter medley and relay races. "I swam to show my donor family that I am taking very good care of their son's heart, because without their gift of life, I wouldn't be here today," Candace commented.

The US Transplant Games are sponsored by the National Kidney Foundation and are held in a different city every two years. The Olympic-style event is for athletes who have received life-saving organ transplants of every type—kidney, liver, heart, lung, pancreas and bone marrow. More than 1300 athletes from all 50 states competed for gold, silver and bronze medals in 12 different sports.

6,000 people, from all over the country attended the 2008 games which were held in Pittsburgh, PA, from July 11-16. Transplant athletes, their families and friends, living donors and families who have donated organs all came together to celebrate life. The mission of the games is to demonstrate the success of transplantation, to honor those who have given the gift of life and to call attention to the need for more organ donors. Nearly 100,000 people in the US and close to 3,000 people in North Carolina alone are currently on the list. 18 people die every day from lack of an available organ. One donor can save 8 people's lives and improve the quality of life of 50 others.

Many myocarditis patients require heart transplants in order to survive. In Candace's case, the treatment was successful in decreasing the inflammation, but all that was left of her heart muscle was a scar. As a result, her heart could not beat correctly or pump effectively enough to support her life. She is alive today only because she was given the gift of life.



**Left to right: Candace Moose, Renee Tucker, athlete, and Bill Haskins, team manager.**

## Annie: So Bright and So Loved

Annie Julia Liberati was 22 years old when she died in her sleep with no symptoms from viral myocarditis. I never heard of viral myocarditis before.

Annie was a microbiologist applying to medical school. She was working and living in Blacksburg, Virginia. She just graduated with a dual major in both biology and microbiology from Virginia Tech.

She was coming home in two days to buy a new car. She was so excited. I spoke to her the day before. She had just completed a trip to visit her grandma in California and tour up to San Francisco. She attended a Steelers game and returned to Virginia. She went to work on Monday and Tuesday. She was perfectly fine.

She was so full of life, so bright, and with so much promise. At the Tech Lab she created a kit for third world countries to fight stomach viruses.

We were called on Wednesday, August

22 at 11:00 when Annie did not show up for work. An hour later we were notified she passed away in her sleep. No symptoms, no warning, we were shocked and still are. I can not believe that our bright, vibrant, strong, Annie died. She was not sick, there was no warning.

The autopsy showed that her heart was inflamed and there was damage that compromised the electrical impulses. The cause of death was an arrhythmia caused by a virus.

She was bright, and beautiful, and wonderful. Our hearts are broken with sadness for a loss so deep.

Annie was youngest of 4 children. Her two brothers and sister were all 18 months apart, close in age, and close to each other. She was so much fun, so full of life, and so witty. We all love her and miss her—her radiance, her wit, her warmth, and her joyful laughter.

Viral myocarditis does not even have spell check from google. I in 100,000 young, healthy people die unexpectedly from this insidious disease. Most people get a cold or a fever from a virus. In some people, and it is still not clear why, their autoimmune system joins the virus and attacks the heart. This is what happened to our wonderful Annie.

Currently, there are no indications of whom or why some people get viral myocarditis.

Annie will forever be in our hearts. Every second of every minute, we think of Annie. We love her and miss her and do not understand how a happy, healthy, young woman, so bright and wonderful and so loved could be gone.

*Submitted by her mother.*





## Wine Celebration To Benefit The Myocarditis Foundation A Huge Success

The Myocarditis Foundation held its first fundraising event in the Raleigh area, entitled "A Vintage Celebration" on Sunday, May 18, 2008. James and Candace Moose, founding directors of the Myocarditis Foundation, co-chaired the event. The purposes of the event were to increase awareness of this rare and often fatal heart disease in the local community and to raise funds to support the core activities of the Foundation. Over 100 people attended the event which was sponsored by Don Stacy, owner of D.S. Parada Color Cafe in Falls Point Shopping Center. The evening included wine tasting, wine and food pairing, wine contests, and an art and wine auction. The foundation raised \$13,000. The event would not have been successful without the support of the local business community who generously contributed goods and services. The Raleigh area sponsors included: Art Source Fine Art Gallery and Framing, Atlantic Avenue Orchid and Gardens, The Fresh Market, Whole Foods Market, Empire Wine Distributors, Nollie Jones of UPS Store #4084, Double Data, and Harris Tee-ter. The Foundation also extended a special thank you to its corporate sponsor, Boston Scientific/Guidant, who manufactures cardiac rhythm devices on which myocarditis patients depend to control lethal arrhythmia.

Dr. Patrick Hranitzky, a cardiologist who specializes in electrophysiology from Duke University Medical Center, was honored for his work with patients with inflammatory heart disease who require cardiac rhythm device management. Liz Kravitz, a NC17 television reporter, whose 22 year old brother died of the disease, was also honored for her efforts to raise money for myocarditis research.

The Myocarditis Foundation is a non-profit organization located in Raleigh, NC, 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 underdiagnosed. It can progress rapidly to heart failure, and death or heart transplantation. Several thousand patients per year are diagnosed in the United States. The disease usually attacks otherwise healthy people. Approximately 5-20% of all cases of sudden death in young adults are due to myocarditis.



*Clockwise from above:  
Event Chair, Candace  
Moose with auctioneer  
Tim Hopper during  
wine auction. Below,  
left to right: Mrs.  
Pat Morrison, guest,  
Event Chairs James  
and Candace Moose,  
Sommelier Mike  
Crusenberry, and Mr.  
Jim Morrison, guest.  
Right: Sommelier Mike  
Crusenberry with Event  
Host Don Stacy.*



For more information about the foundation, how to volunteer or for future events, please contact Candace Moose at 919-846-2081. For more information about the Myocarditis Foundation, go to [www.myocarditisfoundation.org](http://www.myocarditisfoundation.org).

### The MYOCARDITIS FOUNDATION Board of Directors

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University of British Columbia-St. Paul's Hospital  
Scientific Director, The Heart Centre-Providence Health Care



## **GRADUATE STUDENT PLEDGES TO STOP MYOCARDITIS SUFFERING THROUGH RESEARCH**

Leah of Pennsylvania writes: "I am currently in graduate school, finishing my Masters degree in Public Health with a goal of pursuing a PhD, hopefully in epidemiology. In preparation for my graduation in one year, I would like to begin to write a publishable paper for graduation on myocarditis and then continue the research throughout my PhD program. I chose the topic because of my intense and personal interest in myocarditis."

"My experience with myocarditis began almost two years ago, but it seems like yesterday to me. My 19 year old brother suddenly become ill. Everyone just thought it was a stomach flu because he had all the symptoms: vomiting, nausea, and cold sweats. My parents left for a trip to Bermuda believing it was just the flu and left my brother in my care. After several days with no improvement, it seemed to me that something did not add up. He had this excessive cold sweat, but no signs of a fever. I had taken him to the same family doctor that day who had examined him a couple of weeks ago. The doctor noted that his blood pressure was off and thought he needed to stop drinking so much caffeine. The doctor seemed concerned but could not give me a definitive answer. Something inside me told me something was seriously wrong, so I immediately rushed him to the Emergency Room. They ran numerous tests but were unable to clearly diagnose him until about 2 days later. They had an idea it was his heart but did not know for sure. He was transferred the following day to a university hospital where the doctors concluded that he had myocarditis. The virus that they believe caused the myocarditis was mono-

nucleosis. At first the doctors told us my brother would need a heart transplant but his heart seem to be holding on. Then he had a defibrillator implanted in his chest and spent about a month in the hospital recovering."

"He is graduating from college in one month. He still has his defibrillator and takes lots of medications but is doing well. His follow up visits include echocardiograms every six months and he is under the supervision of a cardiologist. The doctors are very positive about the future and happy with his progress."

"I made a promise to myself and to my brother in the hospital, that I would do everything I could to prevent any family from ever having to go through this suffering again. I had never even heard of myocarditis in children until that day. Some of the doctors at the first hospital were also shocked by the diagnosis. As I began talking about it more, I came across people who had been affected by this disease. Some of their experiences were not as lucky my own. I am so thankful everyday for my brother and the fact that he is doing well. But every time I see the news and another child and their family has suffered from this disease my heart breaks. I feel that education is the most effective way to treat this disease."

"I am writing to you today to not only share my story, but to see if you have any research topic recommendations, because I would love to begin working on my paper on this disease and possibly continue the research throughout my PhD. If you could email me back and let me how I could get involved, I would greatly appreciate it. Thank you so much for your foundation. Your work is so important!"

## ***The Myocarditis Foundation Announces New Programs for 2008***

### **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 \$30,000 for the 2009/10 academic year. The deadline for application submission is December 1, 2008. Click on the Research tab on our Home Page to access online Research Fellowship Guidelines and Application Form.