

Spring 2011

Knowledge Nurtures Hope

Vol. 4 No. 1

Kewaunee, Wisconsin Embraces the Vanness Family at "A Night to Remember Brad Vanness"

I've been to a lot of fundraisers. It is one of the things I do for the Myocarditis Foundation. But I have to say that I have never witnessed an event such as the one held on the evening of Feb. 12th at The Blue Door in Kewaunee, Wisconsin. All I can say is Brad Vanness and his family are loved by this community. The event raised over \$21,000. He must have been one exceptionally fine young man. His father told me that 1,000 people came to the funeral home when Brad died one year ago; 300 people attended the church service that followed. Randy said he could feel his son's spirit in attendance throughout the evening.

All of the families were present, including the grandparents, aunts, uncles, and cousins. So was the mayor, the police force, Brad's best man in his wedding, and clearly many, many friends. Brad's father works at the local school-the teachers were there. Brad's mother works at the local bank-her colleagues and



Brad Vanness

customers were there. Brad's beautiful wife's family, Amy's hairdresser clients and vibrant young friends were there. About 400 people came and went over a twelve hour period. Local businesses donated 103 Silent Auction items. Brad's sister Jamie was there making sure the Silent Auction was organized and running smoothly. Brad's grandmother made heart cookies and wrote his name with great care in icing on each one. The mother of the young women who own The Blue Door handmade a heart quilt with Brad's picture stitched lovingly on a patch for presentation to his wife, Amy. There was a loud din of conversation in the always crowded room. Alternately there were tears, meaningful embraces and smiles.

When I talked, the room became silent. I talked about myocarditis, this rare disease no one has ever heard of until it affects their loved one. They wish to this day they had never heard of it and that Brad was safely home with his wife and his dogs where he belongs. It is a difficult disease to understand. The mere mention of it raises more questions than there are answers. As Executive Director of the Myocarditis Foundation I have little to offer except these few things: I know from personal experience what this disease is capable of, so I offer my heartfelt sympathy to the Vanness' and to all the patients and families who contact us. I pray that it is comforting to his wife, his parents and this community to know that at least we at the MF



Front row- Bridget Chaney & Alison Kentgen owners of the Blue Door. Second row - Amy Vanness (Brad's wife), Jamie Jackson (Brad's sister), Randy & Cindy Vanness(Brad's Parents).

are working on it. We are funding research that we hope will someday save lives and prevent families like the Vanness' from such profound suffering. We are educating physicians, we are educating the public and we are working to find new ways to make our website the best it can be. I hope that in the midst of all the grief, this family and this community find some comfort in our efforts. To all who supported the event, I would like to thank you for welcoming my husband and I, to Kewaunee and for all who gave so generously in support of the Myocarditis Foundation I thank you from the bottom of my heart.

Candace Moose, Exec. Director FEB 28, 2011





Knowledge Nurtures Hope



WEDDING DAY PHILANTHROPISTS: COUPLE DONATES TO THE MYOCARDITIS FOUNDATION IN LIEU OF FAVORS

Meet Adrienne Rumore and Dr. Anthony Carreras, who will be married on June 11, 2011

Anthony: Adrienne and I first met in college. I was one year ahead of her. Our relationship is unique in that it has been almost entirely long distance since it started. I have been in graduate school getting my Ph.D. at Rice University in Houston, Texas, the entire time. I've spent holidays and summers in New Jersey with her and she has made several trips to Houston to see me. As you can imagine, we are looking forward to getting married in June.



Adrienne & Anthony

Adrienne: We met in college through friends. Eventually our acquaintance turned into friendship which blossomed into love and got us to where we are today. He's an extremely lovable person and constantly makes me laugh. You know the saying, absence makes the heart grow fonder, which it did, but we are anxious to live in the same state!

Adrienne's father, Joe Rumore, received a heart transplant on his 52nd birthday in November 2006, following a rapid decline due to myocarditis. Joe has served on the Board of Directors of the Myocarditis Foundation for five years. I asked the couple what effect Adrienne's father's health crisis had on their lives.

Anthony: Personally, Adrienne's father's battle with myocarditis has had a significant impact on me. I lost both of my grandfathers when I was very young. I have no memories of them and I have always wished that I had gotten to know them. I am grateful that Adrienne's father is now healthy and going strong. It means a lot to me because we want to start a family. It is very important to us that our children be able to have relationships with all their grandparents.

Adrienne: It was extremely hard on me to see the man I grew up relying on slowly wither away and I felt helpless to help him or stop what was happening. I feel blessed that he will be able to give me away on my wedding day-something I had a hard time admitting might not happen.

Anthony: Using the money we would have spent on favors as a donation to the Myocarditis Foundation will do a lot more good. I think we saw it as a unique opportunity to benefit the lives of other people-other people going through what Adrienne's father went through.

Adrienne: I really can't say it any better. We will put cards on the table letting people know that a donation was made in lieu of favors. I think having someone so close to us battle a life threatening illness has made us more aware of the people around us. It has made us appreciate them more and made us realize what a precious gift life is. Life is meant to be spent with the ones you love, doing the things you love to do.

For the past four years, I have volunteered to help my dad run the Joe Rumore Golf Tournament, held annually in September in New Jersey to raise money for the Myocarditis Foundation. Golf is something that my father loves, has always loved, and helping him orchestrate the fundraiser with my family, to help him give back makes it much sweeter. I know at first people came to participate to support my dad, but after attending several events and learning more about Myocarditis at each one, has really helped spread knowledge about the disease. In the case of Myocarditis, knowledge is power and that is what the day is all about.

The Myocarditis Foundation is grateful for the donation made by this special young couple and we wish them every happiness, success and health in their new life together.

March 23, 2011

New Jersey

Information filed with the attorney general concerning this charitable solicitation and the percentage of contributions received by the charity during the last reporting period that were dedicated to the charitable purpose may be obtained from the attorney general of the state of New Jersey by calling 973-504-6215 and is available on the internet at http://www.State.NJ.US/lps/ca/charfrm.Htm. Registration with the attorney general does not imply endorsement.



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. 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

Board of Directors

Leslie T. Cooper, MD

Director, Gonda Vascular Center Mayo Clinic, Rochester, MN

Mario C. Deng, MD as of April 1,2011 Director of Advanced Heart Failure Program UCLA Medical Center Los Angles, CA

Elizabeth F. Schultz, MD Kiawah Island, SC

James and Candace Moose Point Pleasant, NJ

Clement Weinberger PhD
Prague, Czech Republic and Smoke Rise, NI

Lori Blauwet. MD

Cardiovascular Diseases Associate Consultant, Mayo Clinic, Rochester, MN

Jeff Grant Palm Bay, FL

Joseph Rumore Parsippany, NJ

Medical Advisory Board

Akira Matsumori, MD

Department of Cardiovascular Medicine Kyoto University Graduate School of Medicine

Dennis M. McNamara, MD

Associate Professor of Medicine
Director, Heart Failure Section
Director, Cardiomyopathy Clinic & Heart Failure
Research Program
Cardiovascular Institute at University of Pittsburgh
Medical Center Presbyterian

Bruce M. McManus, PhD, MD, FRSC, FCAHS

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

Steven D. Colon. MD

Professor of Pediatrics at Harvard Medical School and Associate Chief of Cardiology at Boston Children's Hospital

Consultants to the Board of Directors

Lindsey Davis
Rochester, MN

Tricia Tumminello

Financial information about this organization and a copy of its license are available from the State of North Carolina Solicitation Licensing Branch at 800-830-4989. The Myocarditis Foundation is also a license charity in the states of New Jersey & Minnesota. For more information in NJ, please contact The NJ Office of Consumer Protection at 973-504-6215.





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

Research Grant Recipient 2007/2008



Dr. Daniela Cihakova

I received a research fellowship grant from Myocarditis Foundation in 2008. I proposed to study different macrophages populations that are present in the heart during myocarditis. The fellowship grant enabled me to start the project and generate more data to be able to apply for the NIH grant. The line of the research that I started

with the grant from Myocarditis Foundation is still active in our laboratory. We have just finished a manuscript showing how monocytes contribute to Th17 disease pathogenesis during myocarditis.

Dr. Daniela Cihakova

Research Grant Recipient 2010/2011

This has been a great and wonderful opportunity for my research project and future

career. The Myocarditis Foundation research grant is like a very precious food to me. Through this food I can build my own research mind and grow my project to continue my research in this Myocarditis field. I believe that someone will remember my research due to this great grant.

Again, I would like to express my deep gratitude for Myocarditis Foundation's support.

ByungKwan Lim, Ph.D.

Research Grant Recipient 2009/2010

The Myocarditis Foundation research fellowship grant gave me the opportunity to concentrate on my interest to understand the interactions between the coagulation system and the immune system after a virus infection. During my fellowship I investigated the role of the protease activated receptor-1 (PAR-1) in coxsackievirus B3 induced myocarditis. PAR-1, also known as the thrombin receptor, mediates platelets activation and the cross-talk between coagulation and inflammation. In my study, I found that PAR-1 deficiency leads to increased myocarditis after coxsackievirus B3 infection of mice. My research observations were presented at scientific meetings with international researchers and physicians to raise the awareness of virus infection of the heart. In addition, the support by the Myocarditis



Silvio Antoniak Ph.D

Foundation made it possible to initiate a productive collaboration between the McAllister Heart Institute at University of North Carolina at Chapel Hill and one of the leading myocarditis research and clinical centers in Germany, the Charité – Campus Benjamin Franklin in Berlin. I am thankful and appreciate the generous support by the Myocarditis Foundation and its supporters. Beyond the duration of my Myocarditis Foundation fellowship, I hope I can contribute to the knowledge of the myocarditis pathologic mechanism in the future.

by Dr. Silvio Antoniak
UNC McAllister Heart Institute



Dr. Bettina Heidecker

Research Grant Recipient 2007/2008

When I was one of the first two investigators to receive a grant from the Myocarditis Foundation in 2007, I felt extremely honored by the display of trust in our project and by the generous financial support that my lab has received, enabling us to apply highly advanced technology for the discovery of a diagnostic marker for myocarditis. With the honor came a great amount of responsibility and over the last few years, I have been working hard with my mentor and colleagues to successfully complete the goals that I presented in my initial grant application. First, our group was able to further optimize a transcriptomic diagnostic biomarker for myocarditis, which had been initially presented in our preliminary data. The optimized transcriptomic biomarker was further improved by testing some of the most recent bioinformatic algorithms for microarray analysis until the optimal cluster of genes was discovered, which performed with the highest diagnostic specificity and sensitivity. This molecular signature was broadly applicable in other types of cardiomyopathy, including ischemic, idiopathic and secondary cardiomyopathies. Our results will be published March 22nd, 2011 in the specialty journal Circulation.

Furthermore, we have established two enrollment sites for our clinical trial at the University of Miami, in which the goal is to test the diagnostic marker in a population of 150 patients. In this study, we also collected blood from each enrolled patient, to test if peripheral blood mononuclear cells can be used as surrogate for biopsies. Additionally, we have collected a large amount of clinical data and we are currently in the process of applying advanced imaging technologies, such as magnetic resonance imaging, for improved diagnosis on campus.

All this work and effort was made possible by the tremendous support from the Myocarditis Foundation. I would like to use this opportunity again to thank everyone who, through their contributions, continue to make this fantastic organization possible.

Dr. Bettina Heidecker

Heidecker B, Kittleson MM, Kasper EK et al. Transcriptomic biomarkers for the accurate diagnosis of myocarditis. Circulation 2011 March 22;123(11):1174-84

Grief Support Program for Children, Grandmother Volunteers

Since my son's death a year ago, I've discovered a wonderful grief support program for children. The Warm Place offers emotional support to children ages 3 1/2 to 25 that have suffered a death loss. This healing program is offered free of charge to any family in the Dallas-Fort worth Area that has lost a parent, a grandparent or a sibling. I've just completed the training to become a facilitator and am hopeful that this program will not only help countless children deal with their grief but will enable me to help my own grandchildren deal with the devastating loss of their beloved Papa.

Sharon Austry Fort Worth, TX

Webinars

The Diagnosis of Myocarditis*

Will be scheduled in April

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

* Available on website, click on Webinar link

The Webinars are posted at www.myocarditisfoundation.org





Knowledge Nurtures Hope



Summary of Research Grants 2011/2012

"Peripheral Blood Mononuclear Cell and Endomyocardial Gene Expression Signatures of Myocarditis - Identification of Genomic Biomarkers"

Myocarditis, as defined by the inflammation of heart muscle, is a major cause of heart failure with dilated cardiomyopathy. This condition is characterized by infiltration of inflammatory white blood cells into the myocardium with consequent loss of myocytes and development of fibrosis and necrosis. In a significant fraction of patients, the loss of cardiomyocytes leads to ventricular remodeling, permanent ventricular wall dysfunction, dilated cardiomyopathy, heart failure, and/or arrhythmias. Myocarditis is induced by a variety of agents, including genetic susceptibility, toxins, viruses, bacteria, and parasites. In addition, myocardial injury can induce an autoimmune response to heart tissue, which has an important role in the pathogenesis of myocarditis and dilated cardiomyopathy.

Currently there are no validated biomarkers available to detect/predict myocarditis. Although invasive and limited by lack of consensus between pathologists, endomyocardial biopsy still remains the confirmatory test to diagnose myocarditis. In acute myocarditis, the electrocardiogram may show sinus tachycardia with nonspecific ST-segment and T-wave abnormalities. Occasionally, the changes on electrocardiography are suggestive of an acute myocarditial infarction and may include ST-segment elevation, ST-segment depression, and pathologic Q waves. The sensitivity of the electrocardiogram to detect myocarditis is very low. Echocardiography is available as initial evaluation tool. But since there are no specific features of acute myocarditis, it is only useful to rule out other causes of heart failure. Cardiac Magnetic Resonance Imaging is increasing being used as a diagnostic test in suspected cases of acute myocarditis but currently its use is limited to localize sites for endomyocardial biopsy. Cardiac injury associated biomarkers e.g. Troponin I and creatine kinase MB, have been described to be elevated in patients with acute myocarditis but are associated with low sensitivity. So there is a need to develop validated biomarkers to accurately detect/predict myocarditis. High throughput technologies such as whole genome microarrays provide the ability to study the expression of thousands of known and unknown genes in samples from patients at times of specific clinical events. Although studies have described the gene expression signatures of myocardial tissue in patients with new-onset heart failure but currently there are no studies available elucidating the signatures in circulating white blood cells. Since myocarditis is characterized by lymphocyte infiltration of myocardium, using whole genome microarray analysis of circulating peripheral blood mononuclear cells (PBMCs) may lead to the identification of novel biomarkers for the detection/prediction of myocarditis in heart failure patients. So during my fellowsh



Dr. Khurram Shahzad

by Dr. Khurram Shahzad, Columbia University

"IL-1 receptor-associated kinase 4 (IRAK4) epigenetically modulates Nod2- and MDA5-dependent protection in viral myocarditis."



Alan Valaperti Ph.D

able to recognize viral genome.

Over the past two decades, the laboratory of Dr. Peter Liu has extensively mapped the mechanisms of Coxsackie virus B3 (CVB3) infection in the in heart, identifying major determinants of the host immune system in knockout mice. Invading pathogens trigger a large inflammatory response that limits the invaders' proliferation but also damages some of the surrounding tissue. More specialized anti-viral molecules called interferons are self-produced after viral infection and are also supplemented in anti-viral therapies. In the past, an interferon-based therapy has been successfully used in our lab to test its efficacy in CVB3-infected mice.

IL-1 receptor-associated kinase 4 (IRAK4) is a molecule involved in inflammatory processes. Its function in CVB3 infection has not yet been elucidated, but it seems that IRAK4 may also inhibit the production of interferons. We may consider IRAK4 as a really bad guy, since it may simultaneously induce heart inflammation while also inhibiting interferonmediated anti-viral protection in the heart after CVB3 infection.

In our research proposal we want to focus on the host innate immune response in the pathogenesis of viral myocarditis. We are interested in how the interaction between CVB3 and the host immune response alters gene expression. Epigenetic modifications describe alterations surrounding the genes, that is modifications of the players involved in regulation of gene expression. Several heart diseases are related to epigenetic alterations, but, thus far, no correlation has been made between viruses related to myocarditis and epigenetic modulations. Heart-targeting viruses may interact with cellular key players that regulate gene transcription, reducing their anti-viral potential and therefore increasing the susceptibility to heart failure.

We found a dramatic survival difference in CVB3 infected mice lacking IRAK4 compared to their controls. These mice, which demonstrated increased viral clearance, have lower levels of heart inflammation and increased production of protective interferons and interferon-related molecules. We are now aiming to determine the epigenetic modifications triggered by CVB3 infection by using a model of IRAK4 deficiency and assess how they modulate gene expression of two intracellular receptors called Nod2 and MDA5 that are

Studying the imbalance in host innate immune responses triggered by heart-specific viruses will help us to better understand myocarditis mechanisms. Targeted blockade of just IRAK4 may simultaneously ameliorate viral protection and inhibit heart inflammation, reducing acute myocarditis and improving the outcome of chronic myocarditis. Specific treatments focused on epigenetic modulators after viral infection may be a useful tool in developing novel future therapies to cure patients with myocarditis.

Alan Valaperti, Ph.D., University Health Network, University of Toronto, Canada

"Autoimmunity in Pediatric Myocarditis: A Pilot Study"

Among children, myocarditis is an uncommon but serious disease. Recent outcome studies suggest a majority of patients recover normal heart function, but 30% will die or require heart transplantation within 3 years of diagnosis. Some patients will go on to develop significant chronic disease, with dilated and poorly functioning hearts described as dilated cardiomyopathy. Myocarditis is felt to account for 30-35% of patients with dilated cardiomyopathy in Australian and North American pediatric cardiomyopathy registries. Animal and human studies have demonstrated the importance of antibodies against the patient's heart muscle in direct development of disease. The relationship of autoimmunity in the pathophysiology and outcomes of pediatric myocarditis is unknown. Through the collaboration of regional pediatric hospitals encompassing the states of Misssouri, Oklahoma, and Nebraska, we plan to determine the relationship of autoimmunity to outcomes in previously and newly diagnosed pediatric myocarditis. In addition, we will use MRI of the heart to determine specific findings in children and the role of MRI in disease progression and prognosis for children with myocarditis. Improving the understanding of patient immune reaction in myocarditis may lead to improvement in prognosis and treatment in children.



Washington University, St. Louis



and cat.

The MYOCARDITIS FOUNDATION



Knowledge Nurtures Hope



Meet the New Staff

The Myocarditis Foundation is Growing,

XDx. Inc.

Lindsey Davis is the Myocarditis
Foundation's communications coordinator. Lindsey has experience working in the education field and obtained her master's degree in education a few years ago. However, her true passion is working for not-for-profit organizations. She learned about myocarditis a few years ago through Dr. Leslie Cooper, and is honored to be working for such a needed cause. As communications coordinator, Lindsey will be assisting the foundation in all of their newsletters, Facebook and soon-to-be Twitter pages, keeping up with fundraiser ideas, as well as assisting the board with our ever-important research grants. Lindsey currently lives in

Rochester, Minnesota with her fiancé, new puppy,



WITH HEARTFELT GRATITUDE...

The Myocarditis Foundation thanks the following corporate sponsors whose support has provided substantial programming success:

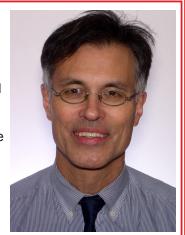
St. Jude Medical Foundation

Boston Scientific

Tricia Tumminello, acting as independent fundraising counsel, brings to the Myocarditis Foundation over thirty years experience in nonprofit leadership, program development, public policy, and fundraising management. Her passion for the Myocarditis Foundation mission comes from personal experiences with her nephew who narrowly escaped death from myocarditis at the age of twenty-two, and two dear friends whose bouts with Giant Cell Myocarditis resulted in heart transplantations. Currently, Tricia is working on Myocarditis Foundation funding development through grants, gifts programs, special events, and donor cultivation, as well as providing guidance for strategic planning and general nonprofit management. Tricia resides in Raleigh, NC with her husband, son, and adopted chow chow.

Dr Deng takes a New Position

The Myocarditis Foundation is pleased to announce that Dr. Mario Deng, Director of Cardiac Transplantation Research at Columbia University Medical Center, and founding member of our Board of Directors, is assuming the Director position of the Advanced Heart Failure Program- including Medical Directorship of Mechanical Circulatory Support and Heart Transplant- at the University of California in Los Angeles (www.uclahealth.org) as of April 1, 2011. Dr. Deng has extensive experience in treating myocarditis and Giant Cell Myocarditis. Many of us who are myocarditis survivors and subsequent heart transplant recipients owe our lives to him, not only for his expansive medical knowledge and professional care but also for his humanity. He will be greatly missed by his patients and their families in the New York area. Dr. Deng is known throughout the transplant community as the co-founder of the FDA-approved, gene- based white blood cell test to rule out cardiac rejection, the AlloMap test, manufactured by XDx Inc, greatly reducing the number of invasive, more costly and at best uncomfortable, routine cardiac biopsy procedures that were previously the gold standard to test for rejection. Dr. Deng will continue to serve on the Board of Directors of the Myocarditis Foundation from the west coast as he has so faithfully done for the past six years. Although we are sad to see him go, we wish him great success in his new position.



Dr Mario Deng

February 16, 2011

Margaux Austin, College Intern. Margaux is finishing her junior year at Appalachian State University in Boone, NC. She is a Public Relations Non-Profit major, and accordingly excited to learn the ins and outs of the non-profit field with the Myocarditis Foundation. She became extremely passionate about community service in high school, when she was given the honor of being President of Millbrook High School's Key Club; within this role she helped organize various fundraising and local service projects. Engaging in these opportunities, inspired her to major in the non-profit industry.



At Appalachian State, she has actively participated with A.P.P.S. concerts, which does the selection. planning, and production of entertainment on Appalachian's campus. She is also a participant of the Wine to Water Club, which is partnered with the non-profit organization that helps to bring awareness and raise funds for people in underprivileged countries, who don't have the luxury of clean water. This year she has been organizing a Toms Shoe Club on Appalachian's campus, and is excited to start planning and gaining awareness for the organization in the coming year. In her free time, Margaux attends RUF (Reformed University Ministries), is captain of her intramural volleyball team, and is taking French class as part of her course work. She enjoys walking and hiking the beautiful Appalachian Mountains of Boone, and of course, cheering on her Mountaineers at football games! Margaux is eager to get experience in the non-profit world, while being involved in the mission of the Myocarditis Foundation.

Myocarditis Foundation Coming Events

Rock'n Roll Half Marathon Information Booth, Dallas TX. Friday and Saturday, March 25 and 26, 2011

Hosted by Michael Austry

Dinner Party to honor Dr. Cooper, Lafayette, NJ, Thursday, April 28th Hosted by Emery and Lillian Castimore,

3rd Annual Celebrate Logan: Live Life WOW Fundraiser, Topsham, Maine Sunday, May 1st Hosted by Jon and Carolyn Sweet;

"Not A Blank Canvas...Putting A Face On Myocarditis"

North Carolina Awareness Event Brier Creek Country Club, Raleigh NC Thursday, June 2nd, 7PM tricia@myocarditisfoundation.org Hosted by Tricia and Vince Tumminello

2nd Annual Tim Burke Golf Tournament, Harrisburg, PA, Saturday, June 4th Hosted by Angela Burke and friends

Fund Night At Friendly's Restaurant August 2011, Bowdoinham, Maine Hosted by Jon and Carolyn Sweet

Devin Kravitz Memorial 5K, Leicester, MA Saturday, September 3rd Hosted by Devin's Family and Friends

Sunset on the Manasquan, Point Pleasant, NJ, Sunday, Sunday, September 18th Hosted by James and Candace Moose

4th Annual Joe Rumore Golf Tournament White Beeched Country Club Haworth NJ Monday, September 19th Hosted by Joe Rumore

Meredith Viens Scotch Tasting in Washington, DC, Saturday, November 5th Hosted by Meredith Viens

Candace Moose, Executive Director



Knowledge Nurtures Hope



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

Where do you start when you didn't to church separately because know that there was an ending?

Ashley was a healthy, vibrant, energetic, enthusiastic, motivated, The meeting ended, Ashley and and fun loving 27 year old with her whole life still ahead of her. She was from Romulus Sr. High in 2001, attended the University of Michigan and then graduated from Henry Ford to know they had made it safely. Community College with a degree in Accounting. She was married Twenty minutes later they sent their in 2007, had recently received a promotion at work, had purchased and was planning to start a family.

for everyone. Ashley woke up went leaving work shortly. to work; she was a Branch Manager Bank in Michigan. After work she a prayer meeting. They had driven love you."

afterward Ashley was heading home for the night.

Mom (Beverly) each drove to the gas station that was just down the road born December 28, 1982, graduated and filled their tanks. They hugged and said their good-byes and each promised to text when they got home

messages to one another upon their safe arrivals. At 9:30pm Ashley called a new home in Trenton, Michigan her husband, Jason, a Police Officer, at work to let him know she was home and going to bed. They said "I love October 12, 2010 was a normal day you and see you soon," as he was

and Assistant Vice President at PNC Then at 9:55pm Mom's phone rang. It was Ashley calling to let her know called me, her sister, Leslie, and we that she had put banana costumes chatted for a while about our day on hold for her new twin niece and then we ended our call with "I love nephew at Target by Mom's work you Chop! Talk to you later." Chop and just wanted to ask if she would was a nickname that we called each pick them up. Mom said she would other. Ashley arrived at our mother's and that she would see her tomorrow. house and changed clothes. They Ashley said, "No you won't, it's my had a small chicken dinner and then date night." Date night was every they were going to church to watch Wednesday night for her and Jason. the members of the congregation's So Mom said, "That's right, well have children while the adults attended a good night, sweet dreams and I



At 10:27pm Ashley posted a message to her friend on Facebook congratulating her on a new baby. She went to her room took off her jewelry, turned on the television to one of the programs she had recorded and laid down for the night.

At 11:45pm Jason arrived home from work and went into the bedroom to let Ashley know that he was home but she was unresponsive. He turned the light on went over to her and saw that she was not breathing, called 911 and started CPR. The Ambulance arrived on site and took over the attempts at resuscitating her all the way to the

At 11:57pm Mom woke to her phone ringing. It was Jason frantically trying to explain what was going on. Mom jumped out of bed and rushed to the hospital and called me to inform me. I called our Dad (Roger) and then called my husband, Shawn. By that time it was just after midnight. Ashley arrived at the hospital and life-saving attempts were performed to no avail. The emergency room doctor pronounced her dead at 12:25am on Wednesday, October 13, 2010. The reason at that time was undetermined.

It was over a month later when the Medical Examiner found her cause of death to be Myocarditis. A disease none of us had heard of. Myocarditis took her from us- our Wife, our Daughter, our Sister, our Aunt, our Niece, and our Friend.

Her life suddenly ended just as it was beginning.

Written in honor of Ashley Dale Orme by her loving sister, Leslie McCarthy

APRIL BRINGS "AWARENESS" AND "FUND-A-GRANT,

FIND-A-CURE" **CAMPAIGNS**

Myocarditis Awareness Days are here! Every day is a good day to tell others about myocarditis! Beginning in April 2011, the Myocarditis Foundation asks you, our readers, to raise awareness both nationally and internationally, among physicians and the public, calling attention to this disease that is one of the leading causes of sudden death in young adults. Myocarditis affects healthy babies, children, youth and adults often causing unrecognized heart damage that leads to heart failure or death. Because it is classified as a rare disease (less than 250,000 cases reported annually), myocarditis has not received the attention in medical training or research funding that other more common diseases garner. Awareness begins with you; tell ten friends and ask them to tell ten of their friends! Give a copy of our brochures to your physicians. Let's see how far the ripple will travel!



Logan, died of Myocarditis May 9th, 2008. He was 6 years old. Every year many people, like Logan die of Myocarditis, an unrecognized killer. The Myocarditis Foundation seeks to hasten progress by increasing wareness and awarding grants to help guarantee that new and innovative research avenues are thoroughly

Knowledge Nurtures Hope

As a part of Myocarditis Awareness Days, the "Fund A Grant, Find A Cure" campaign

has been established. The Myocarditis Foundation is the only nonprofit organization dedicating its resources to improving myocarditis diagnosis and management. Through physician education, public awareness, and funding for medical research, we strive to change the myocarditis landscape and save lives! YOU can have fun and HELP! For each \$35,000 raised, a research proposal will be funded. Visit www.myocarditisfoundation.org for details and suggestions for challenging your friends and family to join you in raising dollars to fund critically needed, innovative myocarditis medical research and awareness for myocarditis and the Myocarditis Foundation. Wear our wristband; chat and tweet about us on Facebook and Twitter; request a "Fund Night" at your favorite local restaurant where a percentage of the days profit is donated to our cause; obtain matching funds from employers; host an "Awareness Day" using your favorite activity and friends: book club, table games (bridge, bunco, Mah Jongg), tennis, golf, cake walk/bake sale, walk/run events, to name a few. Every dollar you raise for "Fund A Grant, Find A Cure" will go to myocarditis research grant awards given by the Myocarditis Foundation in January 2012.

Knowledge Nurtures Hope. Will you join us?

Additional information and support materials (brochures, personalized posters, tee shirts, pins, wristbands, and more) are available by contacting the Myocarditis Foundation at 732-295-3700, Lindsey@myocarditisfoundation.org or at www.myocarditisfoundation.org.

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



Scotch Tastina

Meredith Viens Delaware had written an article in the Myocarditis Foundation's Fall 2010 newsletter "Newlywed Myocarditis Widow Shares Her Heartbreaking Story". Meredith lost her husband, Chris, just six months after being married due to Myocarditis. She ended her article saying "It was just so sudden and so devastating that I want to do what I can to prevent other families from having to go through this." Here is her article about the fantastic fundraiser she held, her story of herself and her husband Chris, and her continued efforts to bring awareness to myocarditis.

The scotch tasting to celebrate the memory of my husband Chris on November 6th was a huge success. We had about 50 people attend and raised a total of \$4,620.00 through tickets sales, the silent auction, and additional donations!!! Part of the money went to the Myocarditis Foundation and the rest went to the scholarship fund we set up in his memory at his alma mater Lynchburg College. This is a huge accomplishment and I am truly grateful for all the generosity and support. I think Chris would have enjoyed it thoroughly and fought hard to win some of the gift baskets for the silent auction!



Chris & Meredith

Chris and I met while working together in 2005. I had a crush on him from that first day, but we didn't start dating until he moved onto a new job 9 months later. We got married October 17th, 2009 on a cold and rainy day. Chris always said it was the happiest day of his life. 6 months, 11 days later, Chris collapsed walking into work and all attempts at revival were unsuccessful.

Chris was one of the most joyful people I have ever known. He loved life, his family, coaching basketball and lacrosse, giving back to his community, and was selfless to a fault. He loved to come home, sit on our porch and have a good glass of scotch while we talked.

The last 10 months have been the worst of my life, I still don't fully understand that he will never come home. Learning to live without Chris is a struggle every day. But I am taking it a moment at a time and have the support of many wonderful friends and family.

I am dedicated to supporting the work of the Myocarditis Foundation to find treatments, cures, tests, whatever we need to prevent others from losing their husbands, wives, sons, daughters, sisters, brothers, and friends. We plan on making this a yearly event on the first weekend in November to celebrate Chris.

THE MYOCARDITIS FOUNDATION IS PLEASED TO ANNOUNCE THAT IT HAS ESTABLISHED A RELATIONSHIP WITH THE AMERICAN HEART ASSOCIATION FOR THE PURPOSE OF CO-FUNDING A RESEARCH GRANT IN MYOCARDITIS.

The grant will be advertised on both the MF and the AHA websites beginning in April. The Myocarditis Foundation has partnered with the AHA to establish a research award for an investigator conducting research related to myocarditis. The award supports a postdoctoral fellow proposing innovative basic, clinical or translational research projects relevant to the etiology, pathophysiology, diagnosis, treatment, epidemiology and/or prevention of myocarditis. The postdoctoral fellowship award will be for a two year project, with funding beginning in January 2012. Please contact AHA or the Myocarditis Foundation for more information.

