

The Myocarditis Foundation Lobbies Congress for Political Visibility of Myocarditis

The Myocarditis Foundation attended the Rare Disease Legislation Advocates (RDLA) Annual Conference and Lobby Day in Washington D.C. This conference was open to rare disease organizations and their families to learn more about the legislative process and options organizations have to get their voice heard on Capitol Hill.



Lindsey Davis in front of the US Capitol

Collectively, the Myocarditis Foundation was able to meet with fourteen different congressmen (or their staff) from Minnesota, Pennsylvania, and Texas. The Foundation and two families created good contacts in these offices and are now in the beginning stages of creating legislation to bring funding to research and to ensure public awareness and action is taken to diagnose and prevent sudden death related to myocarditis.

The two days following the RDLA Conference and Lobby Day, the Myocarditis Foundation attended the National Institute of Health's Rare Disease Day in Bethesda, MD. This was an excellent opportunity for the Myocarditis Foundation to expose others to myocarditis, what the disease does, and the reason we need to be granted funding at a national level. A family from the DC area who lost a young child to myocarditis also attended the Rare Disease Day. We thank the families who were involved with both of these rare disease events, as they each helped to raise awareness about the impact this disease has on families across the country by simply being in attendee and sharing their stories.

The Myocarditis Foundation encourages each and every family to contact their local representative and talk with them about the experience you had with myocarditis, why it is important to fund medical research at a federal level, and why we need large public awareness campaigns to expose myocarditis in an effort to prevent sudden death in young, otherwise healthy individuals.

Visit www.house.gov/representatives/find/ to find and contact your local representative.



Lita Warmbold sharing her story with fellow conference attendee

Thank you to the families that came to the RDLA Conference and the NIH Rare Disease Day and to the families that continue to support the Myocarditis Foundation in our awareness efforts. Every bit of exposure and awareness helps to save more lives.



A Night to Remember Brad Vanness

On Saturday, February 9th the Vanness family held the fundraiser “A Night to Remember Brad Vanness”, and like their event two years ago, it was an incredible success and a true showing of what a close-knit community is capable of when coming together to honor and remember such a well-loved individual.



From Left to Right: Lindsey Davis, Dr. Leslie Cooper, Amy Vanness (Brad's wife), Cindy Vanness (Brad's mother), Jamie Jackson (Brad's sister), and Randy Vanness (Brad's father)

The Blue Door, a local bar in Kewaunee, WI was packed to capacity as people enjoyed homemade food, drinks, and cheerful memories of Brad. There was standing room only as the night progressed, with everyone in attendance biding on the fantastic auction and raffle items collected by the Vanness family from generous families and businesses in the area. The event raised over \$16,000 for the Myocarditis Foundation's research and awareness programs.

Brad Vanness passed away suddenly from cardiac arrhythmia due to myocarditis on April 18th, 2010 and was just 27 years old. Myocarditis struck this beloved man and left his friends and family at a loss for why this happened to Brad, and wondering what exactly is this horrible disease that takes young healthy people so suddenly and unexpectedly.

Dr. Leslie Cooper and Lindsey Davis, of the Myocarditis Foundation, were honored to attend this unbelievable event and were truly touched by the outpouring of support for the Vanness family and for the Myocarditis Foundation. Dr. Cooper, president of the Myocarditis Foundation and one of the world's leading experts in myocarditis spoke to those gathered at The Blue Door. Dr. Cooper expressed his gratitude to the Vanness family and to the community of Kewaunee for their magnitude of support for the Myocarditis Foundation. In his talk, Dr. Cooper explained what myocarditis is and told his story of why he became passionately involved with myocarditis. Lindsey Davis addressed the Vanness' and the community, “The Vanness family has become one of the Myocarditis Foundation's biggest supporters and while it is tragic we came to know the Vanness' and the town of Kewaunee through Brad's death, it is an absolute honor to know you all and we thank you from the bottom of our hearts for your ongoing support.”

It is with fundraisers like these that the Myocarditis Foundation is able to continue their research endeavors to find ways to better diagnose, treat, and ultimately prevent myocarditis from taking more lives. Many thanks to the Vanness family, their friends, and the Kewaunee community for making myocarditis research possible.



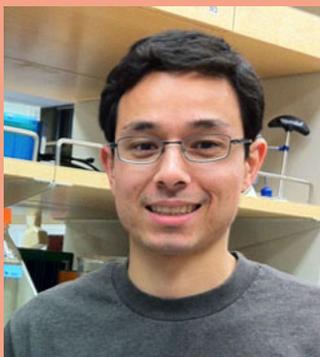
The Myocarditis Foundation Announces its 2012 Grant Recipients for the 2013/14 Grant Cycle

The Myocarditis Foundation is pleased to announce that it will be funding two research fellowship grants for the 2013/14 grant cycle. The Myocarditis Foundation will be funding a research grant awarded to Dr. Chandirasegaran Massilamany of the University of Nebraska, Lincoln in the amount of \$35,000 and have co-sponsored a grant with the American Heart Association awarded to Brian Avanzino of the University of California Davis in the amount of \$50,000, half of which will be funded by the Myocarditis Foundation.

The Myocarditis Foundation's international Medical Advisory Board, made up of leading myocarditis researchers from around the world, selected these two grant recipients from a distinguished field of candidates:

"Regulation of Cardiovirulent Picornaviral Protein Synthesis".

"Our research is aimed at understanding how certain picornaviruses, including Coxsackievirus B3 (CVB3), take over a host cell's translation machinery to produce viral proteins. These viruses produce proteins under conditions when host cell protein synthesis is shut off. We have identified a novel interaction between part of the CVB3 genome and the host cell factors responsible for protein synthesis, and we are investigating how this interaction may influence the kinetics of viral protein production. Insight into the relevance of this interaction will reveal the importance of this element during the viral lifecycle, and ultimately, the ability of the CVB3 to infect its host. Understanding how these viruses use host cell factors may lead to the identification of new targets for antiviral therapies."



by Mr. Avanzino

"Delineating the Role of Cardiac Myosin-Specific CD8 T Cells in Autoimmune Myocarditis".

"Enteroviruses like coxsackievirus B3 (CVB) are common suspects in patients with myocarditis/dilated cardiomyopathy. Previously, it was shown that autoreactive cytotoxic T lymphocytes, also called CD8 T cells, have a role in the mediation of myocarditis induced by coxsackievirus B3. But identification of their target antigens in cardiac tissues continued to be a challenge – this is the challenge, this proposal will begin to address.

The goal of this research is to demonstrate that CD8 T cells can induce autoimmune myocarditis in susceptible mice by recognizing cardiac myosin as the target antigen. The proposed research may provide a basis for future investigations into the role of cardiac-reactive T cells that might be generated in cardiomyopathy patients as a result of exposure to CVB."



by Dr. Massilamany

The Myocarditis Foundation is honored to work with both individuals and their institutions, furthering the expansion of myocarditis research and its network. It is the Foundation's goal to build a greater understanding of the disease and find better ways to diagnose, treat, and ultimately prevent myocarditis, all in an effort to save more lives.

The Myocarditis Foundation would like to thank all the families, businesses, and organizations that have supported the Foundation in 2012, because it is with their efforts that these two grants have been awarded. The Myocarditis Foundation is also honored to be working with the American Heart Association; an organization dedicated to building healthier lives, free of cardiovascular disease and stroke.

For more information regarding the Myocarditis Foundation and its grant program, please visit: www.myocarditisfoundation.org and for more information about the American Heart Association joint grant program, please visit: www.heart.org.



The MYOCARDITIS FOUNDATION

Dear Myocarditis Foundation Friends and Family,

I feel as if we are family, as we have gone through so much together. I write to you today from my retirement with some thoughts about the past and the future.

Myocarditis is a dreadful disease for some, an inconsequential disease to others and a tragic disease for the families of victims who could not survive it. For a rare disease, it causes a disproportionate amount of suffering that does not go away, be it physical or emotional in nature. And yet, the disease receives little attention in the media, smaller still in funding from corporate sponsors, and comparatively paltry government research funding. Support for the Myocarditis Foundation comes primarily from you, those affected by the disease, and we could not survive without you.

Twelve years ago, Dr. Cooper had a vision. He wanted a website where people whose lives had been turned upside down by this disease could go for information, reassurance that they are not alone, and education. He wanted this foundation to be the source of myocarditis research funding and he wanted the investigators we chose to have a life long commitment to this field, to ensure that research would continue beyond our lifetime. Your donations, fundraisers and outreach efforts make this possible and ensure the future of the Myocarditis Foundation as well.

I have made this foundation and my church the charities I currently fund and intend to fund throughout my lifetime and beyond in my will because I believe in the work we do. It has been my pleasure to know so many of you throughout the years, to share with you in good times and in sorrow, and all times trying my hardest to find ways for the foundation to serve you better, while the research we fund works to find a cure.

Now it is time for a new generation with new ideas and youthful energy to take over. Lindsey Davis took over as Director in January 2013. She is the new face of the foundation and as such is available to help you with your myocarditis questions and needs.

Thank you for the gift each of you has been to my life. Thank you also for your altruism in giving so generously to eliminate a disease that has taken so much from you, so that others will not have to suffer like you have. Keep fighting, keep speaking out and speaking up to make the myocarditis voice be heard. Collectively we will make a difference. The life you save will be the cherished one of a family in the future.

Sincerely

Candace Moose, Founder and Retired Executive Director

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.

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

[Find us on Facebook](#)

Research

For Physicians:

We will be accepting applications for Research Fellowship Grants. The stipend will be \$35,000 for the 2014/15 academic year. The deadline for application submission is December 1, 2013. 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

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New Myocarditis Foundation Board Member

The Myocarditis Foundation would like to welcome Louis Romano of River Vale, New Jersey to the Board of Directors. We look forward to working with him and hearing his new ideas for the Foundation as we continue in our mission of awareness and research for myocarditis.

Lou Romano is the owner of HomeWell Senior Care, a home health care agency focused on assisted senior citizens with their activities of daily living. Since 2005 HomeWell has become a community leader in home health care initiatives and currently provides over 7,000 hours of weekly service throughout Bergen County, New Jersey.

A note from Mr. Romano:

“In 2011, I attended the Myocarditis Foundation Golf Outing and the poster board stories (Not a Blank Canvas) truly affected me. I remember getting emotional when reading about the struggles, deaths, and success stories of those with Myocarditis. When Joe Rumore asked me to serve on the board of directors, I immediately jumped at the opportunity. Not only because he is a dear friend, but because I know I can help the Foundation make an impact in the fight against Myocarditis.”



Board Member, Louis Romano



Blogging from the Myocarditis Foundation

Keep up-to-date with all the happenings of the Myocarditis Foundation by following the Foundation's blog! Visit our website: www.myocarditisfoundation.org and click on our Blog to read all the latest research findings, learn about fundraising events, and keep current with myocarditis and Foundation news.

Awareness Items For Sale!

We have

- T-shirts
- Jackets
- Wristbands
- Reusable Shopping Bags



available to sell for our awareness campaign.

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

**Remember,
KNOWLEDGE NURTURES HOPE!**



Knowledge Nurtures Hope



Dr. Cooper's Speaking Schedule

April 25th, 2013 - "Nexus Medicus" International Course –Ulyanovsk, Russia

September 2nd, 2013 - ESC Congress –Amsterdam, NE

May 5th, 2013 - Oklahoma Heart Institute –Tulsa, OK

September 27th, 2013 - American Society of Nuclear Cardiology Annual Scientific Meeting – Chicago, IL

August 10th, 2013- Success with Failure –North Lake Tahoe, CA

October 2nd, 2013 - Cardiology Grand Rounds University of California Medical Center, –San Diego, CA

August 29th, 2013 - St. Elizabeth's University Hospital –Brno, Czech Republic

October 29th, 2013 - American College of Rheumatology and the Association of Rheumatology Health Professionals –San Diego, CA

The Myocarditis Foundation and AHA Partner for Second Collaborative Myocarditis Research Grant



American Heart Association®
Learn and Live

The Myocarditis Foundation has partnered with the American Heart Association (AHA) to co-sponsor a two-year research fellowship grant, to be awarded to an individual working to advance the understanding of the disease and to find better ways to diagnosis, treat, or prevent myocarditis. Applications opened on May 15th, 2013 and the grant will be awarded in December of 2013.

This will be the Myocarditis Foundation's second cosponsored grant with AHA. In December of 2012, the Myocarditis Foundation and AHA cosponsored a grant awarded to Brian Avanzino of the University of California Davis for his research entitled: "Regulation of Cardiovirulent Picornaviral Protein Synthesis".

The Myocarditis Foundation is honored to work with the American Heart Association, whose outreach to the community, the healthcare industry, and other non-profit organizations has significant results in improving the cardiac health of people around the world. We look forward to our ongoing partnership and future with AHA.

The research performed by our talented researchers is what ultimately saves lives from myocarditis. Thank you to each and every individual who has donated and supported the Myocarditis Foundation; your donations further our research program and saves lives from being taken from myocarditis.

Applications opened on May 15th, 2013. For application information, please visit the American Heart Association's website.



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The MYOCARDITIS FOUNDATION

The Myocarditis Foundation and the Heart Failure Society of America's Joint Scientific Symposium



The Heart Failure Society of America (HFSA) invited the Myocarditis Foundation to hold a joint scientific symposium at HFSA's 17th Annual Scientific Meeting in Orlando, Florida on September 22nd at the Peabody Hotel.

This is an extraordinary opportunity for the Myocarditis Foundation to share with heart failure specialists from around the world the most recent research, scientific ideas, and case studies involving myocarditis.

The following is the official agenda for the symposium. *(Please note that only attendees of the HFSA Scientific Meeting may attend this symposium. For more information visit HFSA's website: www.hfsa.org)*

Symposium on Myocarditis

Moderator: *Monte Willis, MD, PhD*, Chapel Hill, NC

3:30 – “Etiology and Prognosis in Acute Myocarditis: When does Cause Matter?” *Leslie T. Cooper, MD*, Rochester, MN

3:45 – “When Should You Consider Endomyocardial Biopsy?” *Stuart D. Russell, MD*, Baltimore, MD

4:00 – “Imaging in Myocarditis: When to Choose CMR, PET and Echo?” *Andrew Howarth, MD, PhD*, Calgary, AB, Canada

4:15 – “Should Myocarditis Ever Influence VAD or Transplant Management?” *Dennis McNamara, MD*, Pittsburgh, PA

4:30 – Panel Discussion and Audience Q and A: *Drs. Cooper, Russell, Howarth, and McNamara*

4:50 – Break

Moderator: *Madeleine W. Cunningham, PhD*, Oklahoma City, OK

5:00 – “When Should I Care If My Cardiomyopathy Patient Has Antiheart Autoantibodies?” *Roland Jahns, MD*, Wurzburg, Germany

5:15 – “Translational Studies of ST2 and Il33 in Human and Murine Models of Myocarditis” *DeLisa Fairweather, PhD*, Baltimore, MD

5:30 – “The Role of Treg and Th17 in Human and Murine Models of Myocarditis” *Peter Liu, MD*, Ottawa, ON, Canada

5:45 – “T Cell Plasticity: Implications for Myocarditis” *Madeleine W. Cunningham, PhD*, Oklahoma City, OK

6:00 – “Bringing It All Together: The International Myocarditis Registry and Bio Bank” *Lori Blauwet, MD*, Rochester, MN

6:15 - Adjourn

Family & Researcher Meetings

In conjunction with HFSA and the Myocarditis Foundation's “Symposium on Myocarditis” in Orlando, Florida, the Myocarditis Foundation will be holding meetings for both our researchers and families. These events will be taking place on September 21st-22nd at the Peabody Hotel.

All of our research grant recipients will be invited to come and present a scientific poster to the HFSA attendees, attend a workshop to enhance their professional skills, and to meet one another and collaborate with other professionals in the myocarditis field.

We also are inviting our families who have been affected by this disease to come, share their story, meet one another, and learn about the accomplishments and future plans for the Myocarditis Foundation.

These plans are in the beginning stages and more information will be provided as details are finalized. Please look for updates on our website, blog, Twitter, and Facebook page.



A YOUNG WOMAN'S ACT TO HONOR HER FRIEND



Alex with her first place medal

When Andy Peña of Darien, Connecticut passed away suddenly from undetected myocarditis at age 14, his family, friends and the whole community were shocked. One of Andy's classmates, Alexandra Ford, was hit especially hard by his death. Alex and Andy had become close friends since the beginning of their high school freshman year. They both ran in the track and field team and attended together the Freethinkers Group, a club where students gather to discuss controversial topics.

On March 10, 2013, Alexandra ran the annual "Celebrate Life" half marathon in Rock Hill, NY and raised \$1,400 for the Myocarditis Foundation in honor of her friend Andy.

"The theme of the half marathon inspired me to raise money for The Myocarditis Foundation, which works to raise awareness and increase understanding of the disease," Alexandra wrote in a letter to her friends and family. The half marathon took place just a few days before the second anniversary of Andy's death. For Alexandra, the theme of honoring her friend by celebrating life was relevant. "The event that helped me to appreciate life more than anything was the unexpected passing of my friend Andy because of the rare heart disease Myocarditis", she wrote. Alexandra, now 16 and a junior in high school, had never run a half-marathon before.

Andy passed on March 25, 2011 from sudden cardiac arrest caused by undetected myocarditis after running on a treadmill. He had had no symptoms.

Alexandra completed the race successfully and placed first in her age group. Andy's parents, Victor and Giovanna Peña, met her at the finish line when she arrived, wearing a shirt created in Andy's memory by the Darien High School Track and Field Team. They are very proud of Alexandra. "She is an impressive and compassionate young woman," Giovanna said, "My husband and I are very grateful to her for doing this in memory of our beloved Andy, not just by raising money for a very worthy cause, but also by helping to spread awareness of the rare disease myocarditis that took our son's life".



Alex and Andy



Alex with Andy's parents, Giovanna & Victor



The MYOCARDITIS FOUNDATION

Not a Blank Canvas: *Portraits of Myocarditis*

*Our
Beloved
Lucy B*

Lucy Boslem, or Lucy B as she was known to many and liked to call herself, was a happy, healthy 8 year old girl who had such a colourful and vibrant personality; she could light up any room that she walked into and did lite up many people's lives.

Lucy was a confident wee girl who would make friends with anyone, no matter what age they were, she would love to befriend them and make them feel involved.

Ten days before we sadly lost Lucy B she had flu like symptoms. However, 3 days before she started to become herself again, laughing and joking and playing with her friends. On 16 July 2011, we were at a family party and Lucy B as always was life and soul of the party - wanting to party on and spend time with her friends and family as long as she could.



Lucy Boslem

South Lanarkshire, Scotland

Lucy went to bed that evening, excited that she was going on holiday the following day. Unfortunately on the 17 July 2011 Lucy took a seizure in her bed. Paramedics believed it to be diabetes however shortly on her arrival to hospital, Lucy's condition deteriorated significantly. After an X-ray Lucy's heart was shown to be enlarged. On 17 July 2011, we lost our Lucy very suddenly with no other symptoms other than a minor cold.

We found out that it was myocarditis a month later that took our beautiful Lucy away. We feel it is so important to raise awareness of myocarditis as if we knew anything about it perhaps our Lucy B would still be here with us today.

Lucy lives on in the heart of her family and friends and we believe her to be looking down on us all, a sparkling little butterfly in the sky.



The Myocarditis Foundation Visits NYC

In December of 2012, Dr. Cooper and Lindsey Davis of the Myocarditis Foundation both found themselves in New York City and took that opportunity to meet with several families and individuals affected by myocarditis. Both Dr. Cooper and Lindsey were delighted to meet with these individuals, get to know them, listen to their experiences, and talk about the successes and the future of the Myocarditis Foundation.

The Myocarditis Foundation Board of Directors knows that it is because of the amazing support from individuals and families that the Foundation continues to make strides in its awareness and research programs; all in an effort to save more lives from myocarditis.

Keep up-to-date with the fundraisers and speaking schedules of the Myocarditis Foundation and let us know if you are located near these events! We love meeting members of the myocarditis community and are more than willing to take time to talk over coffee about your experience and how you can help raise awareness.

Contact us if you would like to set up a meeting!



From left to right: Lindsey Davis, Giovanna Caccialanza & Victor Pena (parents of Andy Pena, a myocarditis victim), and Dr. Cooper in Rockefeller Plaza in New York City

Myocarditis Foundation Fundraising and Awareness Events for 2013

- **February 9th** – Kewaunee, WI: “A Night to Remember Brad Vanness”
- **March 2nd** – Lackawanna, NY: “Lukey Legacy Spring Fever Fundraiser”
- **April 12th** – Macon, GA: “Hearts and Heros Concert” with country music star Colt Ford
- **April** – Danville, PA: Pediatric Update at Geisinger Health Center
- **May 3rd** – South Lanarkshire, Scotland: Lucy B Memorial Fundraiser
- **May 25th** – Madison, WI: Madison Half-Marathon Water Station
- **June 21st** – Marion, IA: “Sarah Knight Memorial Golf Tournament”
- **August 18th** – New Hampshire: Half Ironman participant running to raise money for the Myocarditis Foundation
- **August 19th** – Hamburg, NJ: “Myocarditis Foundation Golf Outing” by Joe Rumore
- **August 25th** – Saugerties, NY: “Rylan’s Cookie Moon is flying high for Myocarditis”



New Address

As of January 1st, 2013 the Myocarditis Foundation has the new address of:

**100 W Main St
Utica, MN 55979**

This is the official mailing address and physical location for the Myocarditis Foundation. Please be sure to mail all donations or other mail to this address, as our previous address will no longer serve the Myocarditis Foundation. Contact us if you have any questions regarding our move.

Major Medical Breakthrough by Myocarditis Researcher Silvio Antoniak

The University of North Carolina at Chapel Hill (UNC) has made a significant medical breakthrough in determining a possible cause of myocarditis, thanks to the research done by Dr. Silvio Antoniak. The Myocarditis Foundation awarded a Research Fellowship Grant to Dr. Antoniak at UNC in 2009. Since then, Dr. Antoniak has made significant strides in his research and has received much interest and publicity from the medical community in his research findings.



Dr. Antoniak

The most recent accomplishment of Dr. Antoniak's is his work on a major medical breakthrough published by UNC Health Care and School of Medicine publication. To read about this medical breakthrough please visit the Myocarditis Foundation's blog and click on the link to read the UNC article.

The Myocarditis Foundation congratulates Dr. Antoniak on his success and ongoing dedication to bringing answers to the field of myocarditis through his important research. The Myocarditis Foundation is proud to be supporting and funding this type of high-quality science and research. It is with the hard work and determination of these dedicated scientists and researchers like, Dr. Antoniak, that we are able to provide answers to the many questions that myocarditis presents to families around the world every day.