

MYOCARDITIS
FOUNDATION



Dedicated to Providing Information and Support Related to the Causes, Symptoms, Diagnosis and Treatment of Myocarditis and Sudden Death.

“ANYTHING IS POSSIBLE”

Myocarditis Survivor Competes in IRONMAN World Championship in Kona, HI



Hamish Deery at the finish line

Hamish Deery of Melbourne, Australia is a family man, friend, business executive and was in the best shape of his life when myocarditis changed his life. Hamish was training for and competing in Ironman races across Australia when on the day of the Long-Course Championships in 2012 he was suddenly struck with myocarditis. His heart was only pumping at 50% but his brilliant team of physicians were able to diagnose and begin treatment for his case of myocarditis. Hamish then faced a challenging 5 months of uncertainty and recovery but on March 28th, 2013 Hamish was cleared by his doctor and began training again; this time “to inspire, to fundraise, to show anything is possible”.

On October 11th, Hamish competed in the Ironman World Championship in Kona, HI. To go from a diagnosis

of myocarditis to competing in the world’s ultimate feat of athleticism is the utmost proof that “anything is possible”. Throughout Hamish’s training, he was able to raise \$2,000 for the Myocarditis Foundation from friends and family who supported him in his recovery and training. Below are Hamish’s words on why he chose to pursue his life-long goal no matter the circumstances.

“For me, sport provides a metaphor for life. I have always been inspired by the everyday sportsman, rather than the elite. Those “everyday heroes” who have the courage to stand at the start line despite the prospect of failure, and to commence on a journey to explore their limits and define their own success.

When I was diagnosed with Myocarditis, and I faced the prospect of no longer participating in triathlons, I decided that if I was given the opportunity again, that more than ever I needed to live those values, even if I needed to redefine my own limits and success. Part of that was dedicating my racing to raising awareness of Myocarditis.

I was very fortunate that I was still able to compete and progress to qualifying for the World Championships. It gave me a wider platform, and it was a humbling experience. But more importantly, it re-enforced the metaphors I see in sport and life: to participate, to examine our limits, define our own success, while being part of a community that values those who have the courage to finish last as much as those who finish first.”

Hamish finished his Ironman race in 10 hour 23mins, was 131 in his division (out of around 360) and placed 631 overall.

Congratulations and thank you to Hamish for proving “anything is possible” and giving hope to myocarditis survivors across the world. You are an inspiration and we are honored to share your story.

To read Hamish’s personal recount of his race-day, visit our website: www.myocarditisfoundation.org/blog



Hamish 5 km into the bike-section of the Ironman World Championship

The Devin Kravitz 5K

The Devin Kravitz Memorial 5K has been held in Leicester, MA for the past eight years and continues to bring awareness to myocarditis. We thank the friends and family of Devin Kravitz for your ongoing support and dedication to myocarditis research, and a special thank you to the Devin Kravitz 5K Committee:

- Janet King**
- Elizabeth Kravitz**
- Danielle Porter**
- Michelle Pingeton**
- Mark Pingeton**
- Robyn Goldberg**
- Richard Kravitz**
- Karen Lemerise**
- Sue Hall**
- Stuart Kravitz**

Below are a few words from Stuart Kravitz, a long-time Myocarditis Foundation supporter and father of Devin Kravitz who was tragically lost to myocarditis at the age of 22:

"Our hope is to stop this horrible disease from claiming any more lives. We at the Devin Kravitz Memorial Race Committee will continue to raise awareness and funds to stop this horrible disease. We only wish we could do more."

The next Devin Kravitz Memorial 5K will be September 5, 2015"



Worcester Polytechnic Institute participants

2014 & 2015 Events

- January 11th**
Edina, MN
"Quinn's Cup Hockey Tournament"
- February 22nd**
Prince George, VA
"Keith Martin Memorial Banquet"
- March 8th**
Houston, TX
Wedding of Paige and Kevin Veronie
- March 28th**
Edina, MN
Our Lady of Grace School's Teacher Raffle
- Month of April**
Kewaunee, WI
Donation Box at Lakeshore Lighthouse in memory of Brad Vanness
- April 4th**
Crystal City, VA
Buffalo Wild Wings Awareness Day
- April 17th-19th**
Bali, Indonesia
"Asian Pacific Congress of Heart Failure" myocarditis talks and informational booth
- April 23rd-May 25th**
Nanaimo, BC
Donation of commission in memory of Dominique Butkus
- May 3rd**
Melbourne, Australia
Myocarditis Foundation Patient & Family Support Meeting
- May 4th-7th**
Melbourne, Australia
"World Heart Federation-Congress of Cardiology" myocarditis talks and informational booth

- May 16th**
Elgin, IL
"Paint the Town Rhett"
- June 7th-8th**
Point Pleasant, NJ
Myocarditis Foundation 2nd Annual Patient and Family Support Meeting
- June 13th**
Marion, IA
"2nd Annual Sarah Knight Memorial Golf Tournament"
- June 13th-14th**
Bowdoinham, ME
"Community play OLIVER!"
- August 16th**
Muncie, IN
"Honoring Friends with Big Hearts" Silent Auction
- August 18th**
Hamburg, NJ
"The Myocarditis's Annual Golf Tournament"
- August 30th**
Leicester, MA
"8th Annual Devin Kravitz 5K"
- September 14th-17th**
Las Vegas, NV
"The Myocarditis Foundation's Researcher's Mentoring Meeting" and HFSA Annual Meeting with myocarditis talks and informational booth
- September 29th**
World Wide
World Heart Day
- October 11th**
Kona, HI
"IRONMAN World Championship" Hamish Deery racing on behalf of the Myocarditis Foundation

- October 12th**
Point Pleasant, NJ
"The Myocarditis Foundation's Fundraising Brunch"
- October 25th**
Victoria Park, London
"Badwal Family Fun Run"
- November 8th**
Pembroke Pines, FL
Cambridge Preschool 20th Anniversary Event
- November 19th**
Cherry Hill, NJ
"Pliates Core Center Holiday Open House and Boutique"
- January 10th, 2015**
Edina, MN
"Quinn's Cup"
- April 11th, 2015**
Kewaunee, WI
"A Night to Remember Brad Vanness"

Ways You Can Support the Myocarditis Foundation

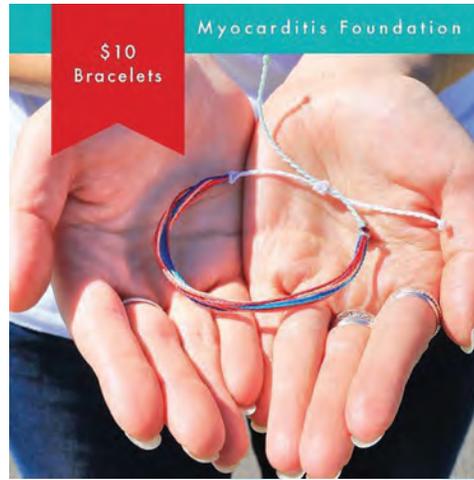
- Shop at Smile.Amazon.com and choose the Myocarditis Foundation as your charity
- Send Tribute Cards in place of greeting cards (see our website for more information)
- Ask friends and family to donate to the Myocarditis Foundation this holiday season
- Hold a local Fundraiser or Awareness Event in your town
- Ask for brochures to hand out at your local clinic/hospital
- Attend the annual Myocarditis Foundation Patient and Family Support Meeting

ANNOUNCEMENT

Silvio Antoniak Grant Recipient

The Myocarditis Foundation is honored to announce that Silvio Antoniak, one of the Myocarditis Foundation's research grant recipients of 2009, has been awarded two prestigious awards from the Heart Failure Society of America and from the American Heart Association. Silvio Antoniak won HFSA's Jay N. Cohn Basic Science Award and was selected by the AHA 's Council on Arteriosclerosis, Thrombosis, and Vascular Biology to receive the Travel Award for Young Investigators, based on the high score of an abstract he authored. Congratu-

lations to Dr. Antoniak and a heartfelt thank you for his continued work on myocarditis research and bringing myocarditis research into the spotlight of national organizations and medical journals from around the globe.



The Myocarditis Foundation will be selling our PuraVida Myocarditis Awareness Bracelets again for the holiday season. Supplies are limited, so be sure to place your order soon! The photo is an actual representation of the bracelet and displays the red and blue hues representing myocarditis awareness. Email: info@myocarditisfoundation.org to order your bracelet!

AWARENESS

Remembering Our Mother, Kamaljit Badwal

Kamaljit Kaur Badwal, our beloved mother was born in Punjab, India on October 6th, 1952, the eldest to four brothers. In 1967 at the age of 14, her parents migrated the family to London, UK. Here she attended Mayfield Girls School; married at 25 and later had 4 children.

Kamaljit had a real zest for life; dreams to travel the world, a lover of fashion, a highly skilled embroidery designer, having worked on gowns for the royal family, an amateur Indian classical dancer and an avid fan of Indian cinema. She was a loving daughter, sister and mother; she had her whole life ahead of her.

On Saturday June 29th 1991, all of this was suddenly snatched from her. In the early hours of that day, her husband discovered her lying on her bedroom floor not breathing. On arrival of the paramedics, she was pronounced dead, leaving behind a devastating and empty hole in her family's lives. Kamaljit left behind two daughters, aged 12 and 9, and a 6-year-old son. She was 38 years old.

The post-mortem report indicated cause of death from a rare heart condition called Myocarditis, a condition that strikes without warning, shattering so many lives.

The following years we had a lot of growing up to do but we

believe it's time we shared our story, we believe it's time to share the devastating impact myocarditis can have on families and friends.

As a family we had never heard of Myocarditis until our mother's untimely passing. Together we have learned that this condition, despite being rare, has affected thousands across the globe.



Kamaljit Badwal

London Fun Run

The Badwal Family of London held a Fun Run in London's Victoria Park to commemorate Kamaljit Badwal who passed away suddenly to myocarditis in 1991. The family had over twenty runners all running for myocarditis awareness and each runner wore a t-shirt to tell the world about myocarditis. In the end, over \$4,000 was raised for the Myocarditis Foundation! A huge thank you to the many friends

and family of Kamaljit who helped bring awareness to the London community and supported the Myocarditis Foundation in our mission of saving more lives from myocarditis. Continue to check our Facebook page and website for more events from the Badwal family, as they are just getting started in raising myocarditis awareness in memory of Kamaljit.



Kamaljit Badwal's friends and family at their memorial Fun Run in London

2015

January 10th

Major League Soccer Medical Symposium
Fort Lauderdale, FL

January 16th

Utah Cardiac recovery Symposium
Salt Lake City, UT

February, 6-7th

The 11th Meeting of the Myocardial and Pericardial Diseases Working Group of the European Society of Cardiology (rescheduled from October)
Dead Sea, Israel

April 6th

St. Elizabeth's Hospital
Brno, Czech Republic

April 8th

German Cardiovascular Society
Mannheim, Germany

April 16th

Mayo Cardiology Symposium
New York, NY

May 17th

Samsung University Hospital Mayo-Samsung Cardiology Symposium
Seoul, Korea

June 12th

Cardiology Grand Rounds, University of Arizona
Tucson, AZ

September 24th

Cardiology Grand rounds, University of Wisconsin
Madison, WI

ANNOUNCEMENT

Dr. Leslie Cooper and Dr. DeLisa Fairweather Move to Mayo Clinic Jacksonville

Myocarditis Foundation board members and myocarditis medial experts, Drs. Leslie Cooper and DeLisa Fairweather are moving to the Mayo Clinic in Jacksonville, FL. This was a wonderful

opportunity for both Cooper and Fairweather to advance their careers, continue in their research, and bring a strong focus of myocarditis treatment and research to the clinic.

Myocarditis families and patients can continue to reach Dr. Cooper through the Myocarditis Foundation.

AWARENESS

7th Annual Myocarditis Foundation Golf Outing

In August, The Myocarditis Foundation hosted its 7th Annual Golf Outing at Ballyowen Golf Club in Hamburg, New Jersey. This event continues to be the largest and most popular fundraiser throughout the year. The Event Sponsors, HomeWell Senior Care and Care One, LLC, both Senior Care companies based in New Jersey, paved the way for another successful outing as over 100 golfers and attendees helped raise over \$35,000 towards the research and treatment of Myocarditis.

Lou Romano, Foundation Board Member and President of HomeWell Senior Care, was very excited about the turn out and participation. "To have an organization like Care One sponsor our event, along with golfers, board members and volunteers from all over the

country truly demonstrates the growing support in the fight against this awful disease. On behalf of the Board, I would like to thank Care One and all other participants for their generosity and commitment to the many patients and families affected by the heart disease Myocarditis." A big thank you to personal friend of the board, Gus Dovi who provided all the professional

printing for the golf event gratis. This event could not reach the level of success that it does without the ongoing support from community members and local businesses. The Foundation has already booked next year's event with the goal of it becoming bigger and better each year. For sponsorship opportunity, please contact the Foundation office for more details.

Pictured left to right: Gus Dovi, Joe Rumore (Foundation Trustee), Ron DiLorenzo, and Pat Perno



CareOne sponsored this year's Myocarditis Foundation Golf Event

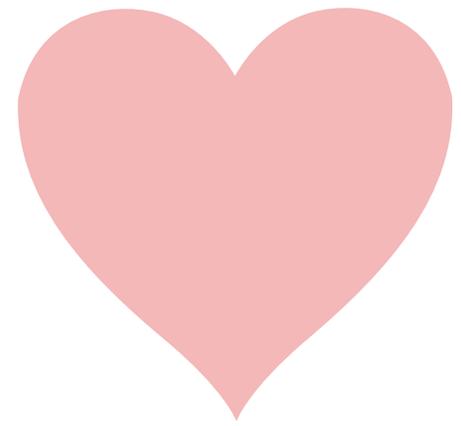
"The Grateful Heart" Guest Speaking Event

Well known author, speaker & Myocarditis Foundation Executive Director Emeritus, Candace C. Moose spoke at The Woman's Club of Brielle on Oct. 29, 2014 to promote the awareness of Myocarditis. At 49 yrs. old Candace was diagnosed with Giant Cell Myocarditis and is a survivor and heart transplant recipient. Candace put her experience of being a heart transplant recipient into a beautiful and heartfelt book: *The Grateful Heart: Diary of a Heart Transplant*.

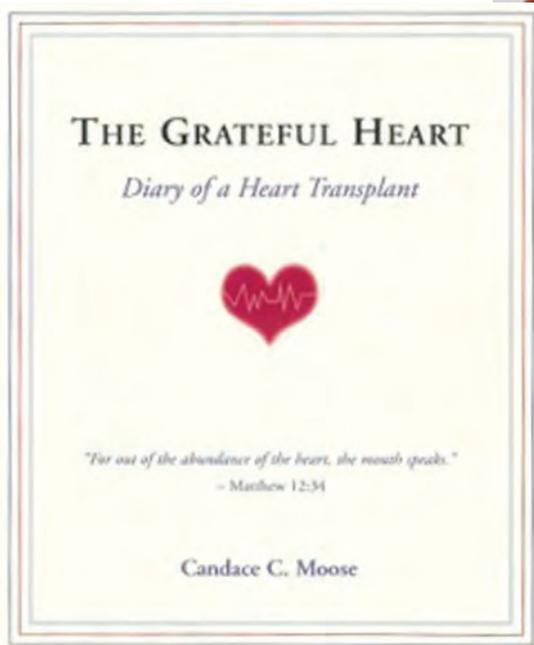
The Woman's Club Literature Committee read her book *The Grateful Heart* and Candace spoke at their club. The ladies generously gave a donation to the Myocarditis Foundation and several members purchased copies themselves. Thank you to the Woman's Club of Brielle for making this event possible and for bringing awareness to myocarditis.



Candace Moose
signing her book
"The Grateful Heart"



Candace Moose with Nancy Erickson, Chair of Literature



"A Grateful Heart: Diary of a Heart Transplant"

Candace Moose, Giant Cell Myocarditis survivor due to a heart transplant and co-founder of the Myocarditis Foundation, wrote a beautiful and eloquent book tracking her experience of her heart transplant. Candace's book, *"The Grateful Heart"* highlights the ups and downs of the journey of heart transplantation as well as how she addressed the big questions that come with a rare disease that goes from a near-death experience to the transplantation of a new heart. It is a beautiful read, one that can speak to anyone about the power of positive thought, close friends and family, and an amazing staff of medical professionals.

This heartfelt book was re-released on October 22, 2014. The Myocarditis Foundation is selling Candace's book for \$30, which includes shipping and a small donation to the Myocarditis Foundation. To order your book, simply email: info@myocarditisfoundation.org with your information and make a donation on our website for the book.

You can read a full review of *The Grateful Heart* on the Myocarditis Foundation's website: www.myocarditisfoundation.org/the-grateful-heart

Thom's Story

It was the first day of November 2013, and life was so beautiful! My best friend (and son's godmother) of over 30 years, Jean, was visiting from Colorado with my daughter, Katie, and I in New York for the first time in over two years. She had flown in on Halloween afternoon, and we had a laugh-filled day reminiscing about everything and looking forward to spending the following evening with my 21-year-old amazing son, Thomas Dean, at his college in Fredonia, NY, where he was a senior majoring in English. Thom's birthday had been exactly one week before on October 25th, and we planned to take him out to dinner. We had the best evening I could have imagined, and Thom looked happier and healthier than I had seen him in a long time. After a difficult start in his freshman year adjusting to dorm life and all of the craziness that went with it (which he never was comfortable with), he was a senior and had an air of confidence and purpose that just filled my heart with joy! Life was good, my kids were doing great, and I was with my best friend; life couldn't be any better!

I was awakened suddenly at 4 a.m. by a phone call telling me to get to the hospital near my son's campus that was an hour and a half away. They couldn't tell me anything on the phone, and Katie, Jean, and I made that long, long drive not knowing what we would be facing but hoping it wasn't anything too serious, because we had just left him hours before, and he was fine. I was just grateful to have them with me, because if it had been any other night of the year I would have been all alone. When we arrived at the hospital, we were met immediately by campus staff and told that Thom had collapsed in his dorm room while playing a video game and was unable to be revived, and our

Thom was gone. To say that it was a shock could not nearly describe our emotions! We had just left him hours before, and he was perfect! How could my son have died and WHY??? That was the question that would plague us for over four months. We were told we would have to wait for the toxicology report, which could take up to six months, but I knew that would show nothing, because I knew my son and knew that he would barely have more than one beer let alone anything else. Finally, over four agonizing months later and after practically begging the coroner's office, we were told that Thom passed away from myocarditis, something that I had never heard of, even though I work in the medical field. Thus began our education on this sadistic killer and the many lives it has destroyed. I believe it was the efforts of a local family that

enabled us to get an actual answer, Amy and Joe Skowronski who lost their 10-year-old son, Luke, just two years before to myocarditis, who have made coroners in our state aware of myocarditis and to look for it in cases of sudden death. I will be eternally grateful to them, for not having a reason or something to fight against now would be unimaginable!

Thom was an amazing young man who touched so many lives in his 21 years. He grew up with a divorced mom and was always so exceptional and mature beyond his years in the way he looked at life and managed to be the male figure in his sister's life. I could go on for pages and pages about what made him so special, but I will just say that he was a unique young man who loved books, philosophy, acting, gaming, and making us laugh, and he touched the lives of so

many people with the extreme wisdom he had for one so young. If he had been a lesser person, he might have been a victim of bullying when he was younger, because he was always a little different than the average kid, but he always managed to find a group of extremely loyal and adoring friends whose lives he impacted so positively and in such a beautiful way that he will never be forgotten! After his death, we were able to self-publish a book with his writings and our memories of him to raise money for his scholarship fund at Fredonia, and to celebrate his life and to hopefully raise some money to fund myocarditis research, we have established a Facebook group in his honor called Team T.H.O.M. - The Heartbreak Of Myocarditis. If anyone would like to learn more about Thom's inspiring life, please join us in our group!



CORPORATIONS

Thank you to our Corporate Sponsors

Thank you to the many corporations and businesses who have supported the Myocarditis Foundation. It is through your support that we are able to fund our research and awareness programs, but also are able to raise awareness within your communities of those you know personally who have been affected by the heart disease myocarditis.

St. Jude Medical Foundation - pioneering heart failure disease management with innovative solutions that help reduce hospitalizations and improve the quality of life of patients. sjmfoundation.com

Boston Scientific - a leading innovator of medical solutions that improve the health of patients around the world. Their products and technologies are used to diagnose or treat a wide range of medical conditions. bostonscientific.com/en-US

Bellin Health System - a community-owned not-for-profit organization responsible for the physical and mental health of people living in Northeast Wisconsin and the Upper Peninsula of Michigan. They exist to serve others through patient care excellence and innovative programs designed to influence health in our region. bellin.org

Care One - with services that include post-hospital care, rehabilitation, assisted living, long-term care and a variety of clinical specialty programs, CareOne offers compassionate care in gracious, professionally managed centers and communities. CareOne's outstanding programs and services are conveniently located at 29 different centers throughout New Jersey. care-one.com



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FAMILIES

Thank You to Our Supporters

A heartfelt thank you to all our Myocarditis Families who have supported us thus far in 2014 through donations, awareness events, and fundraisers. The Myocarditis Foundation could not survive without your ongoing support, it truly makes a difference in achieving our mission of awareness and research; all to save more lives from myocarditis.

- The Reynolds Family**
- The Kirsch Family**
- Paige and Kevin Veronie**
- The Martin Family**
- Our Lady of Grace School**
- Becky Wagner**
- Buffalo Wild Wings of Crystal City**
- The Vanness Family**
- The town of Kewaunee, WI**
- Kewaunee Grade School Student Council & Students**
- Michele Butkus**
- The Lundy Family**
- The Knight Family**

- Friends & Family of Mary Ehrlinger**
- Friends & Family of John Domingues**
- The Roark Family**
- The St. Laurence School & Students**
- Stuart Kravitz**
- Friends & Family of Ashley Burgauer**
- The Rojas Family**
- The Sweet Family**
- The Badwal Family**
- Hamish Deery**
- Friends and Family of Jeffrey Grossman**
- The Cambridge Preschool**
- The Devin Kravitz 5K Committee**
- Friends and Family of Thomas Dean**
- South Elgin High School**
- The Winans Family**
- The Avalon Open Golfers**
- Bruce and Bev Gordon**



Rojas family relatives at the Cambridge Preschool Event in Pembroke Pines, FL





MYOCARDITIS FOUNDATION



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New Mailing Address

The Myocarditis Foundation has moved its business operations to the Point Pleasant. Please use the below address for all future mail and correspondence.

The Myocarditis Foundation

3518 Echo Mountain Dr., Kingwood, TX 77345

Toll-free US & Canada: 1-866-846-1600 • Telephone: (732) 295-3700

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