

MYOCARDITIS FOUNDATION



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

MYOCARDITIS UPDATE

Myocarditis Foundation Biobank

With the generosity of our donors, especially over the last few years, we have been able to envision and plan for the first ever Myocarditis Biobank in the world, and will likely start collecting myocarditis blood samples by the end of 2018.

Myocarditis is considered a rare disease and does not have the financial backing to support research of any great magnitude. While many other diseases with larger foundations have had their own biobanks for years, the Myocarditis Foundation is a much smaller foundation with very limited resources.

With your help and with a number of researchers who wish to take their research to the next level, and find the answers/cure for myocarditis, the Myocarditis

collaborators with their participating institutions) has involved a lot of undertaking by many to get things to the point where we can soon likely start to collect

We are very grateful for all of you who so generously have donated your knowledge, time and money so that we can further our mission to educate and fund research on

One cannot begin to understand the work that goes into starting a project such as this and then the ongoing support that it requires.

Foundation is changing all of that. The collaborations that have taken place already in order to get the preliminary plans in place have been monumental. Gaining the support of physicians (both as Principal Investigators and as

myocarditis blood samples from around the world for all ages and cultures.

One cannot begin to understand the work that goes into starting a project such as this and then the ongoing support that it requires.

myocarditis so that we can save lives from this devastating disease.

The Myocarditis Foundation Biobank will collect myocarditis blood samples from patients all over the world along with clinical data and patient demographics. They will be stored collectively where researchers, who after petitioning the Foundation's Medical Advisory Board for use of them and being approved, will have access to them. These researchers will be required to share the knowledge that they obtain through their research with the Myocarditis Foundation as well as naming the Foundation in their papers/reports.

Please look to our Website and Facebook page for more information in the upcoming months.

www.myocarditisfoundation.org

 facebook.com/pages/Myocarditis-Foundation/314590715549



3rd Annual Myocarditis Foundation Gala in NYC, June 21, 2018

The Mandarin Oriental Ballroom in NYC was filled with nearly 400 corporate executives, physicians, researchers, myocarditis family members / survivors, volunteers and sponsors on June 21st for the Foundation's 3rd Annual Gala Awareness and Fundraising Event.

Dr. Leslie Cooper, Co-Founder and Medical Director for the Foundation sent a very moving video message which focused on the current research being done and about the researchers who are relentlessly working to find causes and cures for this insidious disease.

One of the Foundation's first Fellowship Grant Recipients, Dr. Bettina Heidecker, was the Keynote Speaker. Now the Head of Heart Failure and Cardiomyopathies at the Charité' in Berlin, Germany, Dr. Heidecker gave an overview of myocarditis and the Myocarditis Foundation Biobank which will be an invaluable first of its kind resource for researchers worldwide.

Dr. DeLisa Fairweather, a career long myocarditis researcher and member of the Foundation's Medical Advisory Board, also spoke on the research being done in myocarditis and the need to develop a Biobank specific for myocarditis.

Dr. Elizabeth Blume, the Director of the Advanced Cardiac Therapies, Heart Failure, and Heart Transplant Programs at Boston Children's Hospital also spoke.



Myo Logo in Flowers on the table

A very touching moment was when three teenage myocarditis survivors, one Viral Myocarditis (2015) and two Giant Cell Myocarditis (2016) took the stage with Christopher Corso, the Chairman of the event. Dubbed, "The Three Amigos", these young men from various areas of the country have become close friends after meeting at a prior



Dr. Bettina Heidecker



Dr. Elizabeth Blume

Gala and Family Support Meeting for those affected by myocarditis.

The Gala once again raised substantial funds to aid the Foundation's mission to fund research, facilitate education programs / awareness events and provide emotional support to those affected by the disease.

As the National Organization for Rare Diseases (NORD) states, "Alone we are rare, but together we can make a difference."

We thank all the attendees, donors, and sponsors for their ongoing support to help end this disease.

Please follow our Website and Facebook page for information on our 2019 Gala scheduled for June 20, 2019 in NYC.



(left to right) "The Three Amigos" Jackson DeBusscherre, Benjamin Baldwin, Christopher Corso and Matthew Corso (left to right)

The 6th Annual Myocarditis Foundation Family Support Meeting, June 22nd-23rd

The 6th annual Myocarditis Foundation Family Support Meeting was held at the Warwick Hotel June 22nd and 23rd, 2018. This year, our newest Board Member and Family Liaison, Giustina Schiano, helped in the planning of the weekend keeping the needs of each family in mind.

A Friday night dinner started the weekend welcoming everyone, many of whom did not know anyone other than for speaking with the Executive Director, Gen Rumore, on the phone or via email contact. We enjoyed a private dining room where anyone looking would have thought that it was a "Family Reunion" and not a "Support Group" for bereaved families, many of whom were meeting for the first time.

Christopher Corso, the Vice-President of the Board welcomed the group. He introduced those responsible for planning the meeting, the Board Members, Physicians and Researchers in

attendance. Candace Moose, Co-Founder and Secretary of the Foundation, shared her story starting with her battle with Giant Cell Myocarditis and her desire to give back by helping others with the disease, to the start of the Myocarditis Foundation.

A surprise guest, Dr. Leslie Cooper, called via FaceTime from India to say hello to all in attendance. He wished that he was able to attend but was speaking to Cardiologists from all over the world on myocarditis.

Next, Dr. DeLisa Fairweather, a former board member and now Medical Advisory Board Member, spoke on what myocarditis is and answered questions on the disease from those in attendance. Board member, Dr. Doug Luffborough, organized an icebreaker that allowed everyone to introduce themselves and share how myocarditis is a part of their lives.

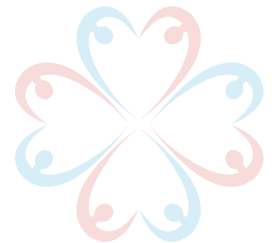
Genevieve Rumore, Executive Director for the Foundation, then gave an update about the education awareness efforts that have been initiated over the last year and introduced our newest Fellowship Grant Recipient, Dr. Paul Hanson, PhD, who spoke about his work studying myocarditis. A panel of experts, including Advisory Board Member Dr. DeLisa Fairweather, PhD; Pediatric Cardiologist and our Pediatric BioBank lead investigator, Dr. Jack Price; Adult Cardiologist and our Adult BioBank lead investigator, Dr. Mario Deng; and Genevieve Rumore, RN, BSN, our Executive Director for the Foundation answered question during a panel discussion on myocarditis and the Foundation.

After lunch, President Joseph Rumore gave an update on the Foundation and our future goals. Finally, Linda Curtis, LMSW, led a

Soul Collage Workshop that was healing and therapeutic for those involved. The sharing of thoughts and experiences continued into the evening. The families were already planning next years' meeting!

We would like to thank each survivor and family member for making this year's Family Support Meeting the best ever, and we want each of you to know that we are here if you need anything between now and then.

There is no set date for the meeting in 2019, but be sure to follow our website and FaceBook Page for updates in the coming months.



Pediatric Cardiology Update

By Jack F. Price, MD

The International Society for Heart and Lung Transplantation held its annual scientific meeting this past March in Nice, France. The meeting attendance was estimated at ~4,000 physicians, scientists, nurses and other healthcare professionals who focus their work on heart failure and cardiac transplantation. Preliminary data from the Myocarditis Registry for Children and Adolescents (MYKKE) study were presented by Dr. Stephan Schubert, from the Pediatric Cardiology department at the Deutsches Herzzentrum in Berlin, Germany.

The purpose of the registry is to collect long-term, clinical information about children with myocarditis and identify associations or predictors of death, hospitalization for heart failure, and major cardiovascular events such as the need for mechanical circulatory support or heart transplant. All hospitals in Germany treating children with heart disease have been invited to participate. The goal is to enroll approximately 1,500 participants over a 10-year period, ending in 2024.

The authors noted that between September 2013 and September 2016, 197 children with suspected myocarditis were

enrolled in the study from 17 different treating centers. A diagnosis of myocarditis was determined by a positive cardiac magnetic resonance image (MRI) and/or a cardiac biopsy. The median age was 13 years (range 0-17 years) and 66% were boys. The majority of children enrolled were teenagers and the incidence of myocarditis by age was: 0 to <2 years (25%); 2 to 12 years (18%); 13 to 18 years (57%). Twenty eight patients (14%) were treated with mechanical circulatory support at a median age of 1.5 years. In 78 % of patients enrolled, cardiac biopsy (29%), MRI (26%) or both (45%) were performed with a positive myocarditis rate of 69%. Heart muscle specimens from biopsy showed "acute" disease in 15% and more chronic disease in the remainder.

Proof of myocarditis had no impact on the ability to wean children off the mechanical circulatory support. Eight children (4%) were eventually treated with a cardiac transplant. Overall death rate was 4.6% with highest rates in the youngest age group (0 to < 2 years). Among patients that were treated with mechanical circulatory support, the death rate was 21%. Patients who didn't receive mechanical circulatory support had a significantly better chance of

survival (97%). Younger age and worse heart function were the strongest predictors of worse outcomes.

In a recent publication of the American Heart Journal (May, 2017), the authors of the study discussed their rationale and study design. Lead author, Dr. Daniel Messroghli, wrote that one of the main goals of the project was to make up for a lack of multicenter data on the signs and symptoms of myocarditis as well as to better understand the

value of current diagnostic tests for myocarditis in children and adolescents. The authors also sought to define age-specific features of myocarditis and determine meaningful criteria for making a diagnosis. The MYKKE study is also designed to include patients with suspected myocarditis rather than patients with confirmed myocarditis only.

Currently, the MYKKE study is including German centers only. The authors plan to eventually expand the study to international centers.



Jack F. Price, MD

MYOCARDITIS RESEARCHER UPDATES

Next MF Fellowship Grant to be named for Rhett Lundy

By Genevieve Rumore, RN, BSN
Executive Director

Rhett Lundy was taken from his family with no previous warning in May of 2013, by Viral Myocarditis, at the age of 14. Myocarditis had shattered their hearts in a million pieces. His absence leaves emptiness in the lives of all who knew him. Not unlike so many other stories of myocarditis that we have heard, Rhett did not wake up from his

normal sleep. His laughter and his ability to lift the spirits of others was silenced forever by Viral Myocarditis.

His family have worked continuously to raise awareness of this disease so that others do not suffer the loss that they and so many others have had to endure. They have had fundraisers to support Rhett's memory and bring a positive from this negative through painting. I had the opportunity to share in one

of their fundraisers a few years ago and saw the support of family and friends who worked to raise funds for a Research Grant in Rhett's name.

This year they have accomplished that goal. The 2018 Fellowship Grant applications will be evaluated in December and as long as the Medical Advisory Board's review of them decides that there is one worthy of receiving a Fellowship Grant from the Foundation (it must be

specifically pertinent to myocarditis research that will make a difference in the near future), the Grant will be named for Rhett Lundy.

Every parent's wish for the researcher who receives a grant with their child's name on it is that they will find an answer to this disease so that others won't suffer as they have. Good luck to all those researchers looking for the answers to this devastating disease.

Myocarditis Foundation and American Heart Association Co-Sponsor Grant



Dr. Lindsey Bazzone, MD, PhD
University of Massachusetts Medical School
Dept. of Medicine/Division of Infectious Disease
Worcester, Massachusetts

Dr. Bazzone was awarded a Co-Funded Fellowship Grant with the American Heart Association (AHA) for the years 2018-2020 for her research entitled "The Role of ADAM in the Immunopathogenesis of Viral Myocarditis."

The Medical Advisory Board members who reviewed her research presentation called it a "useful, logical, and relevant project. Dr. Bazzone's research is the most integrative with a human protein target in both

in-vitro and mouse experiments." The Myocarditis Foundation would like to thank her for her work in myocarditis research and one day we will be able to end the suffering that this disease causes to so many.



Dr. Katelyn Bruno, PhD
Senior Research Fellow
Dept. of Cardiovascular Medicine
Mayo Clinic, Jacksonville, Florida

Dr. Bruno was selected as one of four finalists for the Heart Failure Society of America (HFSA) Young Investigator of the Year Competition for her work on a new biomarker for severity and progression of acute myocarditis. She competed

against 3 other finalists on the quality of her work, her presentation material/presentation skills and her ability to answer questions from the audience. Her competitors each had at least 7-10 more years of experience than Dr.

Bruno, who finished her PhD studies in 2016. We are proud to announce that Dr. Bruno was awarded Runner Up in this prestigious competition.



Dr. Guobao Chen, PhD
2016 MF Fellowship Grant Recipient (2017-2018 academic year)
John's Hopkins University
Baltimore, Maryland

Dr. Chen's research for which he was awarded our Research Grant in 2016, "The Role of PDGFRα+ Cardiac Fibroblast in Myocarditis", has been completed at John's Hopkins University. The results that he was able to achieve with the help of the Myocarditis Foundation were recently published in the September Issue of the European Journal of Immunology. His paper was also chosen as the cover for that issue with the heat map showing the GM-CSF expression in human PDGFRα+ cardiac fibroblasts.

In Dr. Chen's report, he noted that "Heart Failure is a global public health issue with high morbidity and mortality rates, affecting about 26 million people

worldwide. The heart failure survival rate is 50% after 5 years and only 10% after 10 years in the USA. In contrast to other common cardiovascular diseases, heart failure prognoses have shown only modest improvement. The pathophysiology of heart failure is complex and could be triggered by direct injury to the myocardium, such as coronary artery disease and myocardial infarction (heart attack), or an inflammatory disease state such as myocarditis that leads to inflammatory dilated cardiomyopathy.

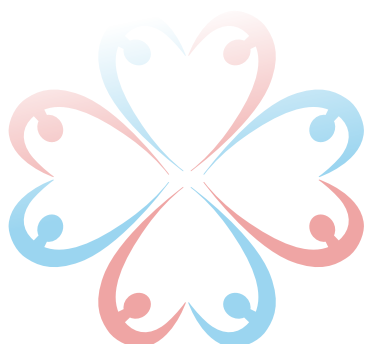
His work was conducted in the research lab of Dr. Daniela Cihakova, MD, PhD, at John's Hopkins University, who actually

was our first Fellowship Grant recipient in 2006!

His research was able to identify a specific cardiac fibroblast subset that drives the development of heart failure of potent producers of inflammatory cytokines and chemokines.

The Myocarditis Foundation would like to express their deepest thanks to Dr. Chen for his interest and myocarditis research that will one day allow us to put an end to this disease!

Congratulations Dr. Chen!

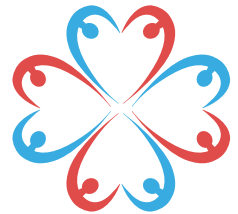


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Myocarditis Foundation and American Heart Association Co-Sponsor Grant (cont)



Dr. DeLisa Fairweather, PhD
Associate Professor of Medicine
Director of Translational Research
Department of Cardiovascular Medicine
Mayo Clinic, Jacksonville, Florida
Myocarditis Foundation Scientific Advisory Board member



HIV-induced Myocarditis is Associated with Pulmonary Hypertension in Men

Hypertension (elevated blood pressure) that occurs in the lung can lead to problems in the heart. Pulmonary arterial hypertension (PAH) is a condition where small arteries in the lung become restricted when lung cells grow until they restrict blood flow. Clinicians and basic researchers are trying to understand what causes these cells to grow leading to lung (pulmonary) hypertension which can develop into heart failure. Certain autoimmune diseases like systemic sclerosis and infections like HIV have been associated with the development of PAH. My lab recently examined published studies to see if sex differences existed in PAH and wrote a review article about our findings (Batten et al. *Biology of Sex Differences*. 2018, 9:15).

This is what we found. PAH that is associated with having an autoimmune disease like systemic sclerosis, systemic lupus erythematosus, rheumatoid arthritis, Sjögren's syndrome, and thyroiditis, for example, occur more often in women with a sex ratio of 9 women to every man. Thus, PAH occurs much more often in women with autoimmune diseases than in men. Surprisingly, PAH that was associated with infections was found to occur more often in men than women. HIV infection is able to cause myocarditis. Although myocarditis is typically caused by infections, especially viral infections, it is also

believed to be an autoimmune disease because of the presence of autoantibodies and autoreactive immune cells called T cells in the bloodstream. Autoantibodies and autoreactive T cells are able to promote heart failure in myocarditis patients.

Two PAH registries have reported that men were twice as likely as women to have HIV-associated PAH. This is the same sex ratio as has been reported for myocarditis. Myocarditis is one of the few autoimmune diseases that occur more often in men than women. Interestingly, all of the patients with HIV associated PAH also had myocarditis. Not only is myocarditis associated with HIV-associated PAH but it is also associated with autoimmune diseases that frequently occur with PAH like systemic sclerosis, systemic lupus erythematosus, and rheumatoid arthritis. More research into this topic is needed to confirm these two studies and to see if myocarditis also occurs in PAH that is associated with autoimmune diseases that occur more often in women like systemic sclerosis.

The association of myocarditis with HIV-associated PAH suggests the possibility that viral infections like HIV may increase the possibility of PAH in men with myocarditis by causing inflammation and scarring of the heart muscle. HIV may cause damage to the small lung arteries resulting in increased blood pressure leading to PAH and myocarditis occurring at the same time in these patients. HIV-induced myocarditis occurs most frequently in Africa

and so further studies in these patients are warranted.

Access to this article is free. If you would like to obtain a pdf copy of the scientific article go to the following link: <https://www.ncbi.nlm.nih.gov/pubmed>.

In the search space write

"Fairweather D and 2018 and sex differences" and the abstract listed below will pop up. Then click on the button on the right top side of the page that says "Read free full text at BMC". When the article pops up, click on the right top button that says "Download pdf" and then save the pdf of the article to your computer.

Biol Sex Differ. 2018 Apr 18;9(1):15. doi: 10.1186/s13293-018-0176-8.

Title: Sex differences in pulmonary arterial hypertension: role of infection and autoimmunity in the pathogenesis of disease.

Authors: Batton KA, Austin CO, Bruno KA, Burger CD, Shapiro BP, Fairweather D*

Department of Cardiovascular Medicine, Mayo Clinic, Jacksonville, FL, USA., *corresponding author

Abstract: Registry data worldwide indicate an overall female predominance for pulmonary arterial hypertension (PAH) of 2-4 over men. Genetic predisposition accounts for only 1-5% of PAH cases, while autoimmune diseases and infections are closely linked to PAH. Idiopathic PAH may include patients with undiagnosed autoimmune diseases based on the relatively

high presence of autoantibodies in this group. The two largest PAH registries to date report a sex ratio for autoimmune connective tissue disease-associated PAH of 9:1 female to male, highlighting the need for future studies to analyze subgroup data according to sex. Autoimmune diseases that have been associated with PAH include female-dominant systemic sclerosis, systemic lupus erythematosus, rheumatoid arthritis, Sjögren's syndrome, and thyroiditis as well as male-dominant autoimmune diseases like myocarditis which has been linked to HIV-associated PAH. The sex-specific association of PAH to certain infections and autoimmune diseases suggests that sex hormones and inflammation may play an important role in driving the pathogenesis of disease. However, there is a paucity of data on sex differences in inflammation in PAH, and more research is needed to better understand the pathogenesis underlying PAH in men and women. This review uses data on sex differences in PAH and PAH-associated autoimmune diseases from registries to provide insight into the pathogenesis of disease.

Keywords: Autoimmune disease; Inflammation; Myocarditis; Pulmonary arterial hypertension; Sex differences; Systemic sclerosis

Myocarditis Foundation visits University of Arkansas

Madison Parrish, who started as a volunteer and then became an Intern with the Myocarditis Foundation helping out in the office has offered to share information on Myocarditis to her sorority and her friends at the University of Arkansas.

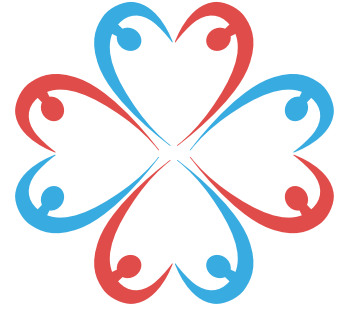
Madison has heard repeatedly that the high-risk age group for viral myocarditis is those from puberty through their 20's, boys have a twice as likely chance than girls of developing it as well. Knowing that most have never heard the word myocarditis until it somehow affects them she offered to share information with those at her school.

In a recent conversation that we had with Madison, she stated: "After working with the Myocarditis Foundation for four years it has become apparent to me how serious this disease is. Seeing first-hand, the effects this disease has on people and their families, has touched me deeply and driven my passion along as others to find a cure. I am more than proud to tell people of my involvement with the Foundation and to hand out information to spread much needed awareness of the disease. I am excited for the day when we can say that there is a cure for this dreaded disease."

We put together a flyer for her to share with other students. The Department of Nursing was very receptive to us and listened to our talk on myocarditis. The Assistant Dean of the Nursing Department willingly accepted our education that we have provided to the Nurse Practitioners and ER nurses this year and stated that she would share it with the Nurse Practitioner Program. She shared that she had not heard before about myocarditis either and was appreciative for the information.

We hope to expand education to the college age population next

year as they often are responsible for their own medical care. The information is to raise awareness so that they are better prepared for their own or their friend's medical needs should they be asked.



Julia Rogers, Tatum Walker, Gen Rumore, Madison Parrish, Amanda Poppell

Letter from the President of the Myocarditis Foundation

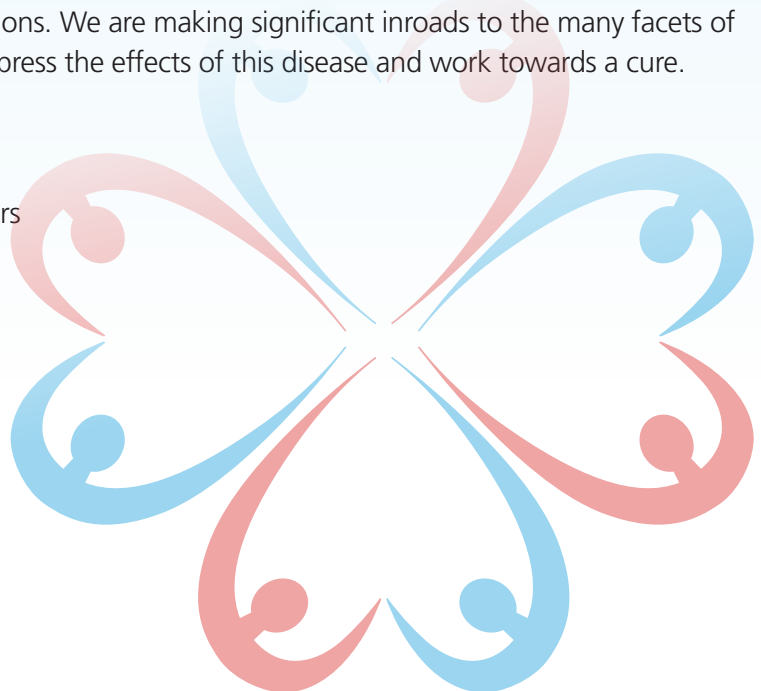
Dear Myocarditis Foundation Family, Friends, and Supporters of the Foundation:

2018 is proving to be a significant year for the Foundation. I would like to share with you some highlights in the Foundation, through the achievement of three milestones:

- We established an Online Myocarditis Community addressing the needs of Myocarditis Families world-wide. There are currently over 200 active participants. The majority of participants are from the U.S.A. and the U.K., but there are a number of additional participants from Canada, Australia and Ireland.
- We have developed an educational program for Emergency Room Nurses and Pediatric Nurse Practitioners, who in turn will share it with the physicians that they collaborate/work with. It is a critical component to inhibit Myocarditis' evasiveness with early detections. Seminars have been developed and are currently being implemented.
- To address the needed advancement of research, the Board is finalizing the establishment of the Myocarditis Foundation BioBank. The BioBank will contain Myocarditis specific blood samples for research and clinical data. We are fortunate to have the backing of leading professionals and institutions implementing this effort. Our funding will support the efforts in three specific areas:
 1. Adult Myocarditis samples with Dr. Mario Deng of UCLA Medical Center being the Principal Investigator.
 2. Pediatric Myocarditis samples with Dr. Jack Price of Texas Children's Hospital being the Principal Investigator
 3. In Europe, our support will fund a Retrospective Study of thousands of samples compiled by premier institutions in Germany, Italy, Switzerland, Spain and the Netherlands. These efforts will be spearheaded by Dr. Bettina Heidecker of the Cherite', in Germany.

Our gains are a direct result of your contributions. We are making significant inroads to the many facets of this rare deadly disease. Together we can suppress the effects of this disease and work towards a cure.

Joseph Rumore
President & Chairman of the Board of Directors
Heart Transplant Recipient 2006



Annual Appeal Letter from Candace Moose

Dear Myocarditis Foundation Friends and Family:

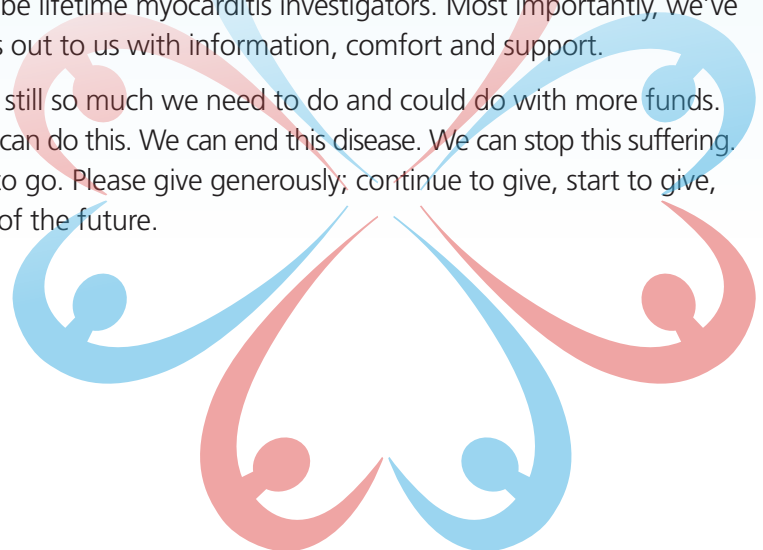
15 years ago, this fall, Dr. Leslie Cooper and I finalized and submitted our application to the IRS requesting nonprofit status for our new foundation. When I called him after my transplant to thank him for his research which saved my life, I asked, "What can I do to thank you?". He said, we need to form a foundation, to raise money for research, to be a resource for patients and families who have experienced loss and to educate physicians and the public about this rare disease. I said, "Let's do it." I was retired, I was recovering, I had time and at least some skill, and I wanted to know more about the disease that had nearly killed me.

In March 2005, we received approval, and we were on our way. Dr. Cooper designed our logo. Friends of Dr. Cooper developed our first website pro bono, and we were in business. In those days, computers were not what they are today. I had access to medical articles through Pub Med, because I was a nurse. I had to pay for the information. The general public did not have any access to information about myocarditis. Imagine how alone the victims felt.

To say we've come a long way is an understatement. The website has been through several iterations and is viewed up to 50,000 times per month both nationally and internationally. It took us 12 years to be able to afford full-time paid staff. I worked for 12 years for free. I am so grateful to Gen Rumore, our Executive Director, who does the work of 6 people. Up until that time, with the exception of some intermittent paid part-time employees and consultants, all of our progress has been made with volunteers including and always with a hard-working, talented Board of Directors. The Board consistently made decisions to advance the science, advance our reach, and advance our programs, rather than pay for staff, until I just couldn't physically carry the load myself anymore. We've raised literally millions of dollars with the help of so many of you and the generous philanthropic and corporate partners who believed in us. We've given over \$600,000 in research grants, while encouraging our researchers to be lifetime myocarditis investigators. Most importantly, we've been available to all and anyone who reaches out to us with information, comfort and support.

Despite what we have accomplished, there is still so much we need to do and could do with more funds. Which brings me to why we still need you. We can do this. We can end this disease. We can stop this suffering. We've come so far, but still have a long way to go. Please give generously; continue to give, start to give, but help us change the outcome for families of the future.

All My Love and Gratitude,
Candace



Speaking Schedules & Events

DR. LESLIE COOPER 2018

October 25-27

Cardiac Symposium
"Update in Diagnosis & Treatment of
Patients with Suspected Myocarditis"
Bogata, Columbia

November 1

Grand Rounds
University of Oklahoma
Norman, Oklahoma

TBA

Cardiology Grand rounds
Intermountain Health
Salt Lake City, Utah

2019

January 28 – February 1

"Arrhythmias & the Heart:
A Cardiovascular Update"
Fairmont Kea Lani, Maui.

February 8-10

"Winter Arrhythmia School"
(as a faculty member)
Mt Tremblant, Quebec, Canada

March 17

Joint American College of
Cardiology and Heart Failure Society
of America Session
"Update in Diagnosis and
Management of Acute Myocarditis"
New Orleans, Louisiana.

April 20

Ponte Vedra Cardiovascular
Symposium
"Myocarditis"
University of North Florida,
Jacksonville, Florida

June 20

MF Gala
Mandarin Oriental Hotel
NYC.

MYOCARDITIS AND RESEARCH UPDATES

Myocarditis and the Heart Failure Society of America 2018 (HFSA)

By Katelyn Bruno, PhD

Dr. Cooper and the Myocarditis Foundation have hosted several scientific sessions at cardiology conferences all over the world over the last 6+ years to educate cardiologist and cardiac care teams about the signs of myocarditis and the suggested treatments. Six years ago, when these sessions were started at a large cardiology conference called the Heart Failure Society of America (HFSA), the myocarditis session always seemed to be placed in a small room far from

the conference with low attendance but that is no longer the case.

This year at the HFSA, which was held in Nashville, Tennessee, Dr. Cooper and Dr. Fairweather were part of an "Update on Myocarditis" session that was held in the largest ballroom of the conference with almost 500 cardiologists present. This session had one of the highest attendances during the conference. The room was so full that every chair was taken, the walls were lined with people

standing to participate in the session and there were a crowd 10 people deep in the doorways that couldn't even get in the room. This is a huge accomplishment with so many attendees wanting to learn more about myocarditis than ever before.

We have come a long way in getting the education to physicians on myocarditis but still have far to go! Looking forward to an even larger crowd next year at the HFSA in Philadelphia, PA, September 14-16, 2019.



Butterfly Garden Dedication



The butterfly is a spiritual symbol for life after death because of its metamorphosis or transformation. They are a deep and powerful representation of life. Many cultures associate the butterfly with our souls. Butterflies are the symbol used extensively by many support groups for the bereaved.

On October 28, 2018, the Austry Family, of Ft. Worth, Texas, hosted a fundraiser for the Myocarditis Foundation with the dedication of a Monarch Butterfly Garden in memory of their son, Mark Stanley Austry.

Their healthy and athletic 32 year old son died over 8 years ago from Viral Myocarditis after completing a half marathon with his older brother. Following Mark's death, the Austry's joined Compassionate Friends, a support group for those that

have lost a child, a grandchild or sibling. While attending a butterfly release in memory of loved ones, they were alarmed to learn that the numbers of migrating Monarch Butterflies had dropped by 90%. They decided to do everything possible to save the Monarch Butterfly and to raise funds for the Myocarditis Foundation, to help their mission of Education, Research, and to provide Emotional Support for those who have been affected by Myocarditis.

The Monarch Butterfly migration is critically endangered because of deforestation in their over-wintering sites in Mexico, weather extremes associated with climate change and most significantly, because of the loss of their breeding habitat. The relentless spraying of herbicides on GMO's is wiping out the once plentiful milkweed,



the only plant that Monarch caterpillars can eat. (100 million acres of milkweed has been lost since 1997). The Monarch will only lay their eggs on the milkweed plant because their toxic leaves make the butterflies taste bad to predators.

It takes 3 generations of Monarchs to travel from Mexico to Canada, but only one generation to make the extraordinary 3,000 mile journey back. Sadly their over-wintering grounds have shrunk from 45 acres two decades ago to less than 1.65 acres today. It is imperative for us to plant milkweed and nectar plants in order to help save this magnificent creature from extinction.

Sunday October 28 was a beautiful day in Fort Worth, Texas for the gathering of friends and family to commemorate the butterfly waystation in memory of Mark Stanley Austry on what would have been their son's 41st birthday. This day holds additional meaning because it also coincides with the "Day of the Dead Holiday" that celebrates the return of the Monarch Butterfly to the fir-clad mountains of

central Mexico. The returning Monarchs are heralded by the Mexican people as a symbol of the souls of their departed loved ones returning to the earth for their annual visit.

On the day of the commemoration, there were many butterflies dining on the nectar of the plants. Many of the gatherers were commenting that they have never seen so many butterflies in one place!

Sharon Austry welcomed and thanked everyone for attending. Gen Rumore, the Executive Director of the Myocarditis Foundation, spoke on myocarditis and what the Foundation uses donation dollars for. Mark's father, Jerry, read a beautiful poem as three dozen Monarch butterflies, that Sharon had obtained from a butterfly breeder, were released.

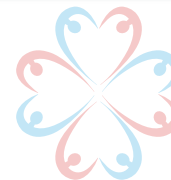
After the ceremony, there was a reception at the Austry home where cookies and cakes shaped like butterflies were served and more discussion on myocarditis occurred.

Thank you, Sharon, for all your hard work. What a beautiful way to memorialize a loved one and attract and feed butterflies!





MYOCARDITIS FOUNDATION



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