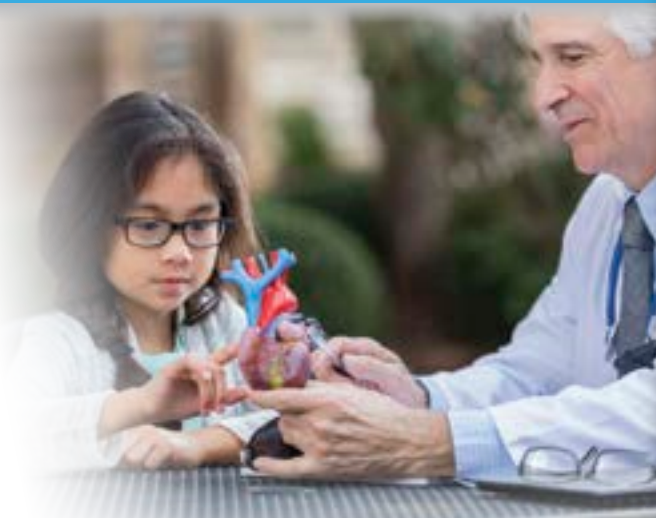


MYOCARDITIS FOUNDATION



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

MYOCARDITIS UPDATE

New Tool Predicts Myocarditis-Related Heart Failure in Men

A study that was funded by the National Institutes of Health and the American Heart Association on Myocarditis-Related Heart Failure in Men, was co-authored by members of the Myocarditis Foundation. Dr. DeLisa Fairweather and Dr. Katelyn Bruno, lead co-authors, and Dr. Leslie Cooper among others, co-authored the study.

The heart inflammation known as myocarditis can have unpredictable outcomes. Typically occurring in young adults after a viral illness, myocarditis can appear with symptoms such as shortness of breath, fatigue and dizziness. The condition may resolve without long term consequences but is a leading cause of heart failure and sudden death. To date, doctors have not had biomarkers or other tests to indicate who's most at risk of dying. But a research team at Mayo Clinic's campus in Florida has identified a new tool to test patients with myocarditis and determine if they are at risk of heart failure.

In the Journal of the American Heart Association, the team found that elevated levels of a protein in the blood, soluble ST2, are a predictor of heart failure in men under 50 years old with myocarditis.

"Our study found that sST2 is a biomarker that can be added to current tests for myocarditis to determine if these patients are in need of life-saving therapies," says the study's co-lead author Katelyn Bruno, PhD.



Dr. Katelyn Bruno

A sST2 biomarker test has already been FDA-approved and is used to gauge other heart conditions, such as heart attack and chronic heart failure, but this finding is the first applied to myocarditis. In animal models of the disease, the team of researchers found that ST2 is the key genetic pathway that leads to heart failure during myocarditis. But the findings also presented a significant twist: researchers found the biomarker is only elevated in men with myocarditis under 50 and predictive of death in this particular group.

Even though both men and women with myocarditis had elevated sST2, the biomarker was not predictive of myocarditis-related heart failure for men over age 50, or women. However, because it's a protein that rises when inflammation occurs, its levels may indicate whether all patients, male or female, are at risk of heart failure from less common variants of myocarditis. Significantly, the study found sST2 levels varied between healthy men and women, even at low levels that aren't indicative of heart failure.



Dr. DeLisa Fairweather

"The body's sex hormones may alter the presence and the effect of the protein," says co-principal investigator DeLisa Fairweather, PhD, in the Department of Cardiovascular Medicine. Those hormones change throughout

life, so the levels and contribution of sST2 may change, as well."

Dr. Fairweather notes more research is needed to know if women with myocarditis are at increased risk of heart failure after menopause.

"This is a biomarker that can impact the clinical care of patients with myocarditis," says Dr. Fairweather. "The study suggests that more research is needed to understand how sST2 levels differ between men and women for other cardiovascular diseases. Moreover, the findings indicate how important it is to analyze all biomedical research results according to sex and age."



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

www.myocarditisfoundation.org

 facebook.com/pages/Myocarditis-Foundation/314590715549

EVENT

4th Annual Myocarditis Foundation Gala Fundraiser, June 20, 2019, NYC



The 4th Annual Gala Fundraiser Event will once again be held at the Mandarin Oriental Hotel overlooking beautiful Central Park in NYC on June 20th. Our major initiative continues to be the funding of the 1st Myocarditis Biobank in the world. Myocarditis, being considered a rare disease, has not been afforded the research tools to advance the science for a cure. The Myocarditis Foundation sees the need to

make available to other global collaborative researchers a blood sample base specific for myocarditis patients from all races and cultures. Together, with the diversification of demographics for research analysis, we can find the answers to this devastating disease.

The Foundation has prestigious American and European Medical Institutions participating.

We look forward to an informative and festive evening.

Please join us at The Mandarin Oriental Hotel on June 20th. Cocktails begin at 6 PM, with the Dinner and Presentations to follow at 7PM.

General Donations and Individual Tickets (\$500.00 each) can be purchased through the Myocarditis Foundation Website under the Donation Button, or if you would like to sponsor a table for 8-12

attendees, **you can contact the Myocarditis Foundation at (281) 713-2962 or Lauren Stanco at (914) 646-4514.**

Help us put an end to this devastating disease which knows no discrimination to age or demographics. Your support will continue to propel us on our Mission of Education, Research and Emotional support for those affected by this disease, with our Singular Goal of Saving Lives.

EVENT

The 7th Annual Myocarditis Foundation Family Support/Research Meetings

**New York City
Friday, June 21, 2019**

The Myocarditis Foundation will once again host a Family Support Meeting at the Warwick Hotel. This will follow our 4th Annual Myocarditis Foundation Gala which is being held at the Mandarin Oriental Hotel on Thursday, June 20, 2019. There will be a Panel Discussion with members of our medical board and medical

advisory board that day. The rest of the agenda is still being finalized.

**Philadelphia, Pennsylvania
Friday, 9/13 - Saturday, 9/14, 2019**

A welcome dinner will be held on Friday evening and the meeting will be held on Saturday, September 14th at the Downtown Marriott in Philadelphia.

As we have done in previous years, our meeting will be in conjunction with the Heart Failure Society of America's Annual Symposium

which is being held at the Philadelphia Convention Center adjacent to the Marriott. We will again have a panel of our physician specialists and researchers available for Q & A. Representatives from the FDA and the National Institute of Health, who will be participating at the HFSA conference, have expressed an interest in hearing from our families about their experience with this rare disease. The Heart Failure Society of America (HFSA) is still working on

the final details of this aspect for our program.

We are looking forward to seeing our old friends and meeting new ones and just being together again at whichever event you decide to attend.

For more information, please contact **Giustina Schiano**, Board Member & Patient / Family Advocate at **Giustina@myocarditisfoundation.org** or **(516) 532-3667**.

Ongoing Myocarditis Foundation Education Initiative

The educational initiative that was started in 2018 with a grant from the St. Jude's Medical Foundation/Abbott Foundation, is being continued through 2019. We have continued to provide myocarditis education to Emergency Room Nurses throughout the United States and Pediatric Nurse Practitioners, but our Executive Director expanded our reach by attending the National Annual Pediatric Nurse Practitioner Conference in New Orleans in March and spoke with almost 2,000 Nurse Practitioners personally, sharing our educational information on "How to Potentially Diagnose Myocarditis by Thinking Outside the Box."

Sadly, more and more doctors are choosing to pursue lucrative specialties rather than Family Practice Medicine or Primary Care, thus the demand for Nurse Practitioners (NPs) with Full Practice Authority (FPA) continues to increase rapidly.

Many of the States that allow FPA are largely rural states, but other states are signing on due to the increased demand for primary care. There are over 222,000 NPs who are alleviating the looming primary care shortage.

The American Association of Nurse Practitioners (AANP) released these numbers as of December 2018:

23 States allow Nurse Practitioners Full Practice

Ability: *Can diagnose, treat and prescribe medications without physician oversight.*

16 States allow Nurse Practitioners Reduced Practice

Ability: *Can diagnose and treat patients but need physician oversight to prescribe medications. They are required to have a Collaborative Agreement with a physician, but that collaborator needs to just be available for collaboration if needed. They do not need to be present when the NP is examining and treating patients.*

13 States allow Nurse Practitioners Restricted Practice

Ability: *These states require physician oversight to diagnose, treat patients, and prescribe medications.*

As you can see, in 39 states at present, the NP plays a huge role in the examining and treatment of patients and this will only increase over time.

While there is currently not a singular diagnostic tool specific for myocarditis and the disease is truly difficult to diagnose, I did share the information that was learned from Dr. Jack Price and other Cardiologists at the Myocarditis Conference held at Texas Children's Hospital. By using these exam techniques and tools we already have which are not often used with children or young adults, we may be able to increase the number of correctly diagnosed cases of myocarditis and save more lives.

A NP who was at the New Orleans conference expressed that she obtained one of the education sheets last year and that she refers to the sheet all the time in her practice and appreciates the education that it had afforded her on the disease.

Dr. Leslie Cooper, had previously shared that in 2016 there were 2.2 million cases of Myocarditis correctly diagnosed

and documented globally. In 2017, the correctly diagnosed global cases of Myocarditis increased to 3.1 million. (Noted in Lancet, November 2018) It is through the education that is being provided not only by Dr. Cooper and other physicians from around the world, but also through the efforts of the Myocarditis Foundation to educate Nurses and Nurse Practitioners here at home in the U.S. that the disease is being correctly diagnosed more frequently.

We still have a long way to go and much more education and awareness to share.

Please help us in our efforts to educate both the medical and public communities through your donations. Please visit our website www.myocarditisfoundation.org and donate today.



Abstract on Myocarditis

One of the Myocarditis Foundation Medical Advisory Board Members, Dr. DeLisa Fairweather is an author on this abstract...

J Exp Med. 2019 Feb 4;216(2):369-383. doi: 10.1084/jem.20180722.

Self-reactive CD4+ IL-3+ T cells amplify autoimmune inflammation in myocarditis by inciting monocyte chemotaxis.

Anzai A, Mindur JE, Halle L, Sano S, Choi JL, He S, McAlpine CS, Chan CT, Kahles F, Valet C, Fenn AM, Nairz M, Rattik S, Iwamoto Y, Fairweather D, Walsh K, Libby P, Nahrendorf M, Swirski FK.

Abstract

Acquisition of self-reactive effector CD4+ T cells is a major component of the autoimmune response that can occur during myocarditis, an inflammatory form of cardiomyopathy. Although the processes by which self-reactive T cells gain effector function have received considerable attention, how these T cells contribute to effector organ inflammation and damage is less clear. Here, we identified an IL-3-dependent amplification loop that exacerbates autoimmune inflammation. In experimental myocarditis, we show that effector organ-accumulating autoreactive IL-3+ CD4+ T cells stimulate IL-3R+ tissue macrophages to produce monocyte-attracting chemokines. The newly recruited monocytes differentiate into antigen-presenting cells that stimulate local IL-3+ CD4+ T cell proliferation, thereby amplifying organ inflammation. Consequently, IL-3^{-/-} mice resist developing robust autoimmune inflammation and myocardial dysfunction, whereas therapeutic IL-3 targeting ameliorates disease. This study defines a mechanism that orchestrates inflammation in myocarditis, describes a previously unknown function for IL-3, and identifies IL-3 as a potential therapeutic target in patients with myocarditis.



EVENT

Second Annual King of Hearts Fundraiser

On Sunday September 23rd, one of our Board members, Giustina Schiano, held a Fundraiser in memory of her son Lee Andrew Hirsch, who passed away from Viral Myocarditis. This was her second annual "King of Hearts" fundraising and awareness event. The luncheon was attended by almost 200 family and friends who came together to honor Lee's memory in hopes that they

could help prevent another mother from going through the sadness and loss that Giustina has had to endure.

The room was filled with love and support for Giustina. The generosity of so many who donated baskets for the silent auction was an additional amazing display of support for Giustina and the Myocarditis Foundation. Thanks to the

generosity of all who supported the event, the 2019 Myocarditis Foundation Fellowship Grant will be named after her son, Lee Andrew Hirsch.

Speakers at the event were Dr. Delisa Fairweather, PhD and Dr. Katelyn Bruno, PhD, myocarditis researchers at the Mayo Clinic in Jacksonville, Florida, who spoke about the Myocarditis Foundation

Biobank and Myocarditis Research being done. Christopher Corso, Vice-President of the Foundation and father of a teenage Myocarditis Survivor also spoke about his passion to end the disease.

Many thanks to all those who attended and supported the Myocarditis Foundation!



Steve and Cynthia D'Auria, Michael and Diane Lee, Genevieve Rumore, Executive Director MF, Joseph Rumore, President, MF

*Clorinda Annarummo, Co-Chairperson
Giustina Schiano, Co-Chairperson and
Mother of Lee Andrew Hirsch*



Southern California / West Coast Fundraiser Event was a Huge Success

On Saturday February 23rd, the Myocarditis Foundation had its 1st Annual Awareness / Fundraiser Event at Ballpark Pizza in Mission Viejo, California.

Diane and Jim Poettgen opened their restaurant to us to help the Foundation raise awareness on Myocarditis. There was a constant flow of customers learning about Myocarditis throughout the day from Genevieve Rumore, the Executive Director. The restaurant was packed for the co-founders of the Foundation, Dr. Leslie Cooper and Candace Moose, and Myocarditis Cardiologist and Researcher, Dr. Mario Deng from UCLA, who also spoke later in the day.

Dr. Doug Luffborough, our west coast Board Member headed up the event and spoke to the attendees.

There were a number of Myocarditis Families there as well, and two of them briefly spoke

about their experiences with Myocarditis (one who lost a son to Viral Myocarditis and one whose daughter was a survivor of Giant Cell Myocarditis). A Myocarditis survivor, who was recently diagnosed, happened to see our post on Facebook and came on over to meet us. As

well, a Giant Cell Survivor who ordered pizza from the "wrong" Ballpark Pizza, was totally surprised when she arrived and saw all the information on Myocarditis!

There was a lot of sharing of information within the room and many happy winners of the 29

Silent Auction baskets that were so generously donated for the event. We look forward to another successful event in sunny southern California in 2020!

A big thank you to the Poettgen's and all those who helped make it a successful day!



*Dr. Doug Luffborough, III
Chairman of the Event*



2018 Myocarditis Foundation 19th Fellowship Grant Recipient



Dr. Taejoon, Won, PhD
Myocarditis Researcher
John Hopkins University

The Myocarditis Foundation is pleased to announce that we awarded a Post-Doctoral Fellowship Research Grant to Dr. Taejoon Won, PhD, from Johns Hopkins Medical School, Maryland for the 2019-20 Academic Year.

Dr. Won's research submission titled: *"Therapy for Myocarditis by Targeting Endothelial PD-L1"*, rose to the top of the research applications this year. Dr. Won is a post-doctoral fellow in the lab of Dr. Daniela Cihakova, MD, PhD. Dr. Cihakova was the first Myocarditis Foundation Grant recipient in 2006 and Dr. Won is our 19th recipient. The grant will be named after a 14-year-old Viral Myocarditis Victim, Rhett Lundy, whose family have been working to raise funds to support the grant in his memory.

His layman's description of his research study:

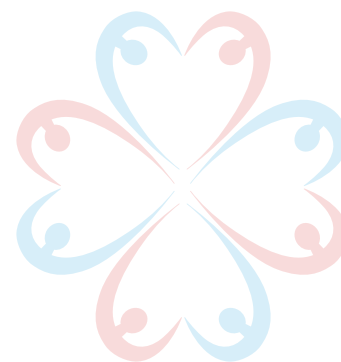
In this proposed research, we will investigate the therapeutic potential of a novel gene therapy for myocarditis treatment. Clinical management for myocarditis is currently limited to controlling symptoms, resulting in the need for new biological therapies based on understanding the pathogenic mechanisms of myocarditis.

Programmed cell death-ligand 1 (PD-L1) is a receptor expressed on immune cells and non-immune cells that suppresses excessive immune responses in peripheral organs including the heart. In some cases of cancer patients, the treatment blocking PD-L1 or its counterpart PD-1 as a cancer therapy has caused fatal myocarditis. It raises a question if

myocarditis can be treated by enhancing PD-1/PD-L1 interaction in the heart. In the proposed research, I will use PD-L1 gene therapy to prevent viral myocarditis in a mouse model. Adeno-associated virus (AAV) is a novel carrier for the clinical gene therapy approach showing no adverse effects and no severe toxicity. The FDA has recently approved the first AAV-based gene therapy. Our laboratory has generated an AAV vector overexpressing PD-L1 selectively in endothelial cells, which are one of the non-immune cells in the heart covering the inside of heart chambers. We will test the therapeutic potential of our AAV-PD-L1 vector in a viral myocarditis mouse model. In addition, to investigate the importance of PD-L1 expression in endothelial cells in controlling

myocarditis development, we will delete PD-L1 expression specifically in endothelial cells using the Cre-lox technology in a viral mouse model. Developing AAV-based PD-L1 gene therapy, our work will open the door to a novel biologically based therapy for myocarditis to selectively suppress inflammation in the heart.

Our congratulations to Dr. Taejoon Won and many thanks for his work in myocarditis research!



Events

June 7

Sarah Knight
Memorial Golf
Tournament
Marion, Iowa

June 8

Lillie's Love, First
Annual Memorial
Golf Tournament
Fredericksburg, VA

June 20

4th Annual
Myocarditis
Foundation Gala
Fundraiser
NYC

June 21

Myocarditis
Foundation Family
Support Meeting
NYC

August 12 Sept. 13-14

Myocarditis
Foundation Golf
Fundraiser
Paramus, NJ

Myocarditis
Foundation Family
Support Meeting
Philadelphia PA

"21 Forever" International Awareness Event and Fundraiser

Yvonne McArthur and her family held an awareness event/fundraiser on Saturday November 3rd at the beautiful Liuna Gardens, on Lake Ontario, Canada. Over 100 attendees can now speak some to what Myocarditis is and share the information with others.

Yvonne lost her 21-year-old son Ryan, to Viral Myocarditis on November 1, 2016, after a valiant 4 ½ month fight with the disease. Yvonne and her family, like so many others, had never heard of myocarditis before it was spoken about to them by the physicians in the ICU. She went to the internet and found the Myocarditis Foundation (MF), where she learned more about the disease.

Yvonne, who does not like to fly, rode in a bus from Canada to NYC with her younger son Brandon, to attend our 2017 and 2018 Family Meeting, and the 2018 Gala. She has verbalized over and over that if it wasn't for the MF, she doesn't know what she would have done. The support that was shown her and Brandon from the MF and by the other attendees at the meetings was monumental in helping her to deal with their devastating loss. The fact that Dr. Cooper sought her out and spoke with her about her son Ryan's "Not a

Blank Canvas", with tears in his eyes, meant so much to her. Brandon was especially thankful that he was able to speak with Dr. Hanson, a young researcher and 2017 MF Fellowship Grant Recipient and fellow Canadian, about his brother and the disease that took him from them.

Yvonne wanted to raise awareness about the disease. She said that the only way to beat this disease is to raise awareness and educate others on the disease.

Her event titled, "21 Forever", was a combination of a tribute to Ryan, awareness event and fundraiser. Brandon, Ryan's younger brother, compiled a video presentation as a tribute to his brother. The MF Founding Video was shown, as well as the slide show of victims and survivors from the 2018 Gala.

The evening started with a bagpipe rendition of "Braveheart", which Yvonne thought was a perfect selection in light of the disease. The young bagpiper (Adam) was the same age as Ryan was when he was struck by Viral Myocarditis.

Gen Rumore, Executive Director of the Foundation spoke briefly about the beginnings of the MF, it's mission of providing education and raising awareness on myocarditis, and about the



Myocarditis Foundation's Biobank. The Biobank has been able to be started through the generosity of our family and friends' donations.

Dr. Hanson, the MF Fellowship Grant Recipient from 2017 spoke about his research and the need to find a universal blood test for myocarditis. A universal blood test would make myocarditis easier to be diagnosed whether you are at a small community hospital or a large teaching hospital. His power-point presentation visually demonstrated his research and the potential for finding that biomarker that could help to diagnose myocarditis in a very timely manner. His lab is presently starting to test his theory on

human myocarditis blood samples that the hospital in British Columbia has been gathering. Dr. Hanson believes that with the help of the Myocarditis Foundation's Biobank's blood samples, the research will be able to move forward in a more-timely manner with the additional number of samples to test his theory on.

Thank you, Yvonne, and thank you for the generosity of so many who participated in or donated items for gift baskets in the silent auction and gift bag raffles, or just who bought tickets and participated in the evening. Clearly the support noted at this event was a testimony to what a wonderful young man Ryan McArthur was.

Speaking Schedules

DR. LESLIE COOPER:

May 9-12

40th Annual Heart Rhythm Scientific Sessions
San Francisco, CA

May 24-28

European Society of Cardiology (ESC) Heart Failure Conference
Athens, Greece

Sept. 13-15

Heart Failure Society of America (HFSA) 23rd Annual Scientific Meeting
Philadelphia, PA

October 10

Mayo Clinic Arizona Grand Rounds
Scottsdale, AZ

October 22-23

Cardiovascular Grand Rounds at Intermountain Medical Center
Salt Lake City, Utah

November 8

Heart Failure Symposium:
Advocate Christ Medical Center
Chicago, Illinois

DR. DELISA FAIRWEATHER:

May 5-9

Chair of the New Investigator Session at the Organization for the Study of Sex Differences Annual Meeting
Washington, D.C.

May 28-29

Subclinical Heart Disease Workshop: "Sex Differences in Inflammation During Atherosclerosis"
Bergen, Norway

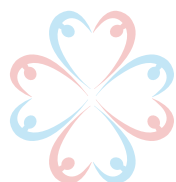
August 12, 2019

Center for Individualized Medicine Grand Rounds at Mayo Clinic, FL
"A New Approach to Heart Disease: Individualized Therapies for Men and Women"

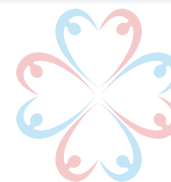
Mayo Clinic, FL

Sept. 12-13

Institute of Gender Medicine Annual Meeting, "Sex Differences in Physiology and Pathology in the Heart: How Sex Hormones Alter Outcome"
Vienna, Austria



MYOCARDITIS FOUNDATION



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Associate Professor, Director of Translational Research, Department of Cardiovascular Medicine Mayo Clinic, Jacksonville, Florida

Mailing Address

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