

## MYOCARDITIS FOUNDATION



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

### EVENT

## 3rd Annual Myocarditis Foundation (MF) Gala New York City June 21st

The Myocarditis Foundation is pleased to announce that the 3rd Annual Gala Fundraiser will be held on Thursday June 21st, at the Mandarin Oriental Hotel in NYC, 80 Columbus Circle at 60th Street between Broadway and Columbus Avenue.

Cocktails and the Silent Auction start at 6 PM and the Gala program starts at 7 PM.

Family members who are attending will once again be asked to share their myocarditis stories with the guests at the corporate tables where they will be seated. Hearing

a persons' story first hand, is very moving and impacts others greatly. They, much like most who encounter Myocarditis, have likely never heard of or know very little about the disease.

Biobank will be the fastest, most direct way of finding answers to this disease. We are finalizing the operating structure and look forward to collaborating with researchers from around the world,

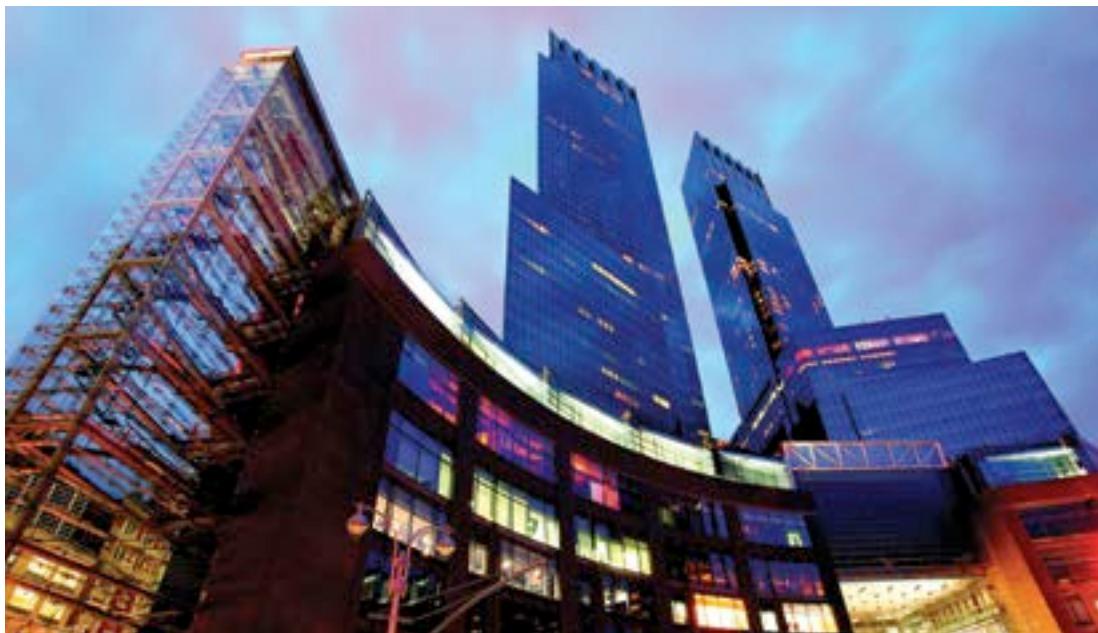
***"Alone we are Rare, but  
Together we can make a difference."***

Because of last year's Gala success, we have been able to move forward with our plans for the International Myocarditis Biobank, the only one in the world. The

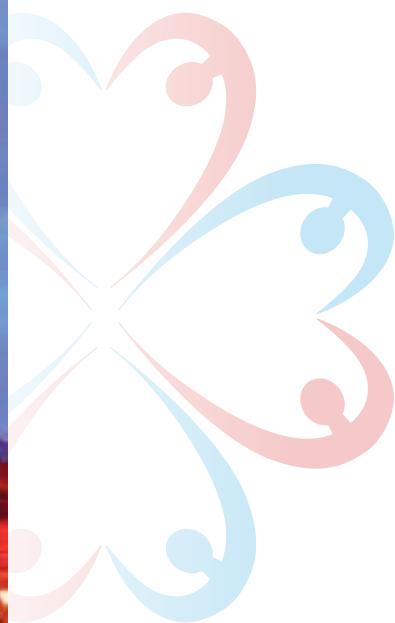
utilizing these human myocarditis samples to find answers. Research is part of our mission with the singular goal of saving lives.

Please help support the Gala in any way possible so that we can stop this devastating disease.

Please contact Gen at the Myocarditis Foundation **(281) 713-2962** or [gen@myocarditisfoundation.org](mailto:gen@myocarditisfoundation.org) for more information or to register/obtain your tickets for this very worthy charitable event. You can also register via the Foundation website.



The Mandarin Oriental Hotel



# Family Support Meeting, June 22-23 Warwick Hotel, New York City

The Myocarditis Foundation is pleased to announce that we are having our 6th Annual Family/Researcher Meeting on Friday evening, June 22nd, through Saturday evening June 23rd, at The Warwick Hotel, 65 West 54th Street, New York City.

The Warwick is a beautiful, historic, recently renovated hotel in mid-town Manhattan with larger than average hotel rooms. The weekend will start with a welcome dinner on Friday evening and the meeting will be all day on Saturday with breakfast and lunch provided. The meeting will culminate with a relaxing farewell dinner at a local restaurant.

We have been working on our panel of specialists and researchers who will be present for one on one and group questions.

## We anticipate the following esteemed speakers:

- **Dr. Jack Price**, a pediatric cardiologist, Co-Director of the Heart Failure Intensive Care Unit at Texas Children's Hospital, and member of the MF Board of Directors. He is also the Principal Investigator of the Myocarditis Foundation's Pediatric U.S. Biobank samples.

## MYOCARDITIS AND RESEARCH UPDATES

### Dr. DeLis Fairweather's Lab awarded funding for Myocarditis Research

By Dr. DeLis Fairweather, PhD

Dr. DeLis Fairweather's laboratory at Mayo Clinic in Jacksonville, Florida has been awarded funding to examine whether regenerative medicine therapy could reduce or prevent myocarditis and dilated cardiomyopathy. Myocarditis sometimes progresses to dilated cardiomyopathy, or an enlarged heart, which may result in the need for a heart transplant. There are different types of regenerative therapies being studied to prevent disease. Dr. Fairweather's lab is studying a type of regenerative therapy called "exosomes". Exosomes are vesicles or packages that are released from all cells in the body. The "packages" contain proteins

- **Dr. DeLis Fairweather**, a myocarditis researcher at the Mayo Clinic, Jacksonville, and member of the MF Medical Advisory Board. Her lab has recently been awarded funding to look at a potential way to reduce or prevent myocarditis and dilated cardiomyopathy.

- **Dr. Paul Hanson**, a myocarditis researcher and our most recent MF Fellowship Grant recipient. Dr. Hanson's research rose to the top of the research applications this year, with his research submission titled: "Personalizing Myocarditis Diagnostics through Novel Biomarkers." Dr. Hanson will give us an update on his research study.

- **Dr. Mario Deng**, a member of the Founding MF Board of Directors and who presently is working with the Advanced Heart Failure/Mechanical Support/Heart Transplant division of UCLA Hospital. Dr. Deng will also be the Principal Investigator for the Myocarditis Foundation's, Adult U.S. Biobank samples.

We will be honored to have these prestigious members of the medical and research communities attend our family meeting. They

will be available for your questions as well as their updating us on updates in the field of myocarditis.

While our agenda is still in the planning stages, it will prove to be a very supportive event for our myocarditis family members.

We will be having a dinner at a nearby restaurant on Friday evening where we can rekindle old friendships or sadly make new ones by welcoming new members to the group. The Saturday program is a full day meeting that will culminate with a dinner at a restaurant near the Warwick.

Please contact Gen at the Myocarditis Foundation to register for the event. **(281) 713-2962** or email at: [gen@myocarditisfoundation.org](mailto:gen@myocarditisfoundation.org)

To stay at the Warwick, use this link to reserve hotel rooms: [warwickhotels.com/new-york/](http://warwickhotels.com/new-york/)

<https://gc.synxis.com/rez.aspx?Hotel=78109&Chain=22256&group=062018MYOC>

Should you incur any problems such as no rooms available, please contact Gen at **(281) 713-2962** or [gen@myocarditisfoundation.org](mailto:gen@myocarditisfoundation.org).

We are looking forward to another successful meeting and seeing you there.



that have been found to inhibit immune responses like the type that occur during myocarditis. However, no one has studied whether exosomes are able to reduce or prevent myocarditis. Dr. Fairweather's study has yielded beneficial results suggesting that this regenerative therapy may be effective in myocarditis patients. The research team which includes Drs. Fairweather, PhD, Katelyn Bruno, PhD, and Leslie Cooper, MD, plan to use these preclinical findings to begin the first clinical trials of this promising new treatment in myocarditis patients in the next year or two. The next step in the research is to determine whether

exosomes could reduce or prevent dilated cardiomyopathy in order to prevent the need for a heart transplant and/or to serve as a "bridge" to transplant. If this

new therapy is found to prevent heart failure from myocarditis and cardiomyopathy it could be used to save lives from this devastating disease.

*Dr. Katelyn Bruno and Dr. DeLis Fairweather*



## The World's Smallest Heart Pump By Jack Price, MD, FAAP, FACC

Smaller may be better when it comes to heart pumps, especially in children. The Abiomed Impella 2.5 is the world's smallest ventricular assist device (VAD) and has recently been approved by the Food and Drug Administration for use in patients with cardiogenic shock. This type of acute heart failure is common in patients with myocarditis. The good news is that acute heart failure caused by myocarditis is often reversible when an accurate diagnosis is made and when supportive treatments are rapidly employed.

The Impella 2.5 pump is usually inserted through the main artery

in the leg and advanced up across the aortic valve with the tip resting in the left ventricle. A tiny motor (4mm in diameter) pulls blood into the tip of the pump and expels it into the ascending aorta, thus unloading the failing heart and allowing for recovery of function. A patient's blood pressure and vital signs may be optimized, providing improved blood flow to the rest of the body, including vital organs such as the brain and kidneys. This procedure can be performed by a cardiologist in the cardiac catheterization laboratory and does not require a surgeon.

The device is designed for temporary support and is recommended for use  $\leq 6$  days, although there are reports of much longer use. The pump is capable of providing up to 2.5L per minute of blood flow to the body. The size and pumping capability allow it to give adequate cardiovascular support to patients as small as young adolescents.

Technological innovation has led to the creation of smaller and more durable heart pumps, and physicians are now implanting these devices much more frequently. In a recent report on

national utilization of short-term mechanical circulatory support devices, the authors note that the use of such devices increased by 1,511% from 2007 to 2011. Hospital costs and mortality rates associated with short-term devices have decreased. Short-term heart pumps may allow patients to be successfully bridged to recovery of cardiac function or to transition to a long-term device as bridge to transplant.

A video of the Impella device can be found at the following link:  
<http://www.abiomed.com/impella/impella-25>

## EDUCATIONAL EVENT

## Minneapolis Children's Hospital Myocarditis Updates May 2018

Kelly and Kyle Kirsch, the parents of Quinn Kirsch (2005-2013), have reached out to Minneapolis Children's Hospital to raise awareness on Myocarditis and educate the physicians, nurses, and first responders on the presenting symptoms of Myocarditis and how to deal with it once it is a potential/definitive diagnosis.

With the help of a friend on the hospital's Board, the Myocarditis Foundation will be presenting at Grand Rounds on May 24th to the hospital's medical and nursing staff

and as well at a luncheon to follow for first responders in the community on Myocarditis.

Dr. Jack Price, Pediatric Cardiologist and Myocarditis Foundation Board Member, will be speaking at Minneapolis Children's Hospital Grand Rounds on "Myocarditis and How to Best Diagnose It" and later at the luncheon on the "Clinical Signs and Symptoms of Myocarditis and New Onset Heart Failure". It is very important for the first responders and emergency room and other physicians to

understand how to plan the appropriate initial diagnostic evaluation of myocarditis and heart failure, and how to implement the initial management of such, which will be shared with the group.

Also speaking at the luncheon will be Dr. DeLisa Fairweather, a Myocarditis Researcher from the Mayo Clinic in Jacksonville, Florida. The title of her talk is: "Novel Regenerative Medicine Therapies for Myocarditis and Dilated Cardiomyopathy (DCM)." Myocarditis progresses to DCM in

a subset of patients and is a leading cause of heart failure in children and young adults. New regenerative medicine therapies are being developed to reduce sudden heart failure during Acute Myocarditis and to prevent progression to DCM. Regenerative therapies may also serve as a bridge to transplant for DCM patients with Chronic Heart Failure. Preliminary data in preclinical trial models identify how regenerative therapies reduce Myocarditis/DCM.

## ANNOUNCEMENTS

## New Medical Advisory Board Member:

Dr. DeLisa Fairweather, PhD, has served on the Myocarditis Foundation Board of Directors for the past six years making important contributions to the direction of the Foundation. We are now pleased to share with you that Dr. Fairweather has moved from the Board of Directors to become a member of our Medical Advisory Board as of January 2018.

Dr. Fairweather is Director of Translational Research and Associate Professor of Medicine in the Department of Cardiovascular

Medicine at Mayo Clinic in Jacksonville, Florida. She also holds a joint appointment as an Associate Professor in the Johns Hopkins Bloomberg School of Public Health in Baltimore, Maryland.

Dr. Fairweather presents data on myocarditis at National and International scientific meetings, has received funding from the National Institutes of Health (NIH) and the American Heart Association (AHA) to research myocarditis, serves as a reviewer of myocarditis grant applications

for NIH and AHA study sections, and serves as a reviewer with expertise on myocarditis for numerous scientific journals. She is also a member of the Scientific Advisory Board for the International Society of Cardiomyopathy, Myocarditis and Heart Failure and the International Academy of Cardiology.

We look forward to her scientific knowledge and expertise on Myocarditis as a member of our Medical Advisory Board. Welcome to your new role Dr. Fairweather!



*Dr. DeLisa Fairweather*

## EDUCATIONAL EVENT

# The Myocarditis Support Community is Active

In October 2017 the Foundation launched a partnership with Inspire, the leading social network for healthcare support. Inspire provides a free online community to allow Myocarditis patients and caregivers to connect and support with each other.

Since being launched, 134 members have enrolled, the majority from the US and the UK – with some members from as far away as Albania and Singapore. While female participants outnumber males about 2 to 1, the ages of participants are almost equally represented among people in their 20's, 30's, 40's, and 50's.

Messages on the community forum, which can be anonymous, include personal stories sharing trials and successes with Myocarditis

treatment, how to provide support for loved ones, comparison of symptoms and treatments as well as overall encouraging and supportive outreach.

Some recent posts include:

- Helping my girlfriend through these hard times
- Selecting the right cardiologist
- 2-year-old with Myocarditis
- Does anyone have the same symptoms?
- Thankful I found a Myocarditis community

Optionally, participants can post details about their personal experience with Myocarditis in a profile page, and further, in an ongoing journal. A few members



commercial use, for fundraising, or product promotion. Through our partnership, the Myocarditis Foundation is able to provide links to key information on the foundation website.

Discussions on the community are moderated by Inspire professionals for adherence to their guidelines for effective participation.

To visit or join the Myocarditis Support Community on Inspire go to [Myocarditis.Inspire.com](http://Myocarditis.Inspire.com). For further information about the support community you can email [tom@myocarditisfoundation.org](mailto:tom@myocarditisfoundation.org)

## EDUCATIONAL EVENT

# Myocarditis Foundation 2018 Education Initiative

The Myocarditis Foundation with the help of a Grant by the Abbott Foundation (Previously St. Jude Medical Foundation), has taken on an Education Initiative to educate and raise awareness on Myocarditis to Pediatric Nurse Practitioners and Emergency Room Nurses in 2018.

A double-sided, laminated, 8 ½ x 11-inch document was provided to the over 1600 Pediatric Nurse Practitioners who were attending the Annual Convention of this March in Chicago. The document contained an educational update on Myocarditis on one side with “Making the Diagnosis” tips on the reverse side. Since Nurse Practitioners must collaborate with a physician, we believe that this information will have reached over 1600 Pediatricians/Physicians as well.

In April, Gen Rumore, the Executive Director and former Certified Emergency Room Nurse, attended the Southeast Regional Emergency Nurse Conference in Charlotte, NC. She shared

information not only about Myocarditis but about the Myocarditis Foundation as well. Gen knows from experience that Emergency Room Nurses, especially the nurse entrusted in the Triage area (where those seeking treatment are initially evaluated and categorized as Urgent, Non-Urgent, and Fast Track), play a very important role in deciding on the care to be given and often make suggestions to the physicians on possible diagnoses. They too were given the educational laminated document that was provided to the Pediatric Nurse Practitioners, which will hopefully also be shared with the Emergency Room Physicians with whom they work with.

Lastly, the Myocarditis Foundation will be requesting Emergency Room Nurse Managers to allow their nurses to participate in an educational screening on Myocarditis, then reading a packet of Myocarditis information. They are asked to complete a post test to see the results of what was



Gen Rumore, Executive Director of Myocarditis Foundation, sharing Myocarditis Information with Emergency Room Nurses at their Annual Southeastern Regional Conference in Charlotte, NC

known before as well as after the educational offering was completed. A certificate for an hour of “Continuing Education” will be provided for all those who participated. The goal is to have 250 Hospital ERs participate (5 per State) in this aspect of our Initiative.

Overall, we believe that we will have reached both Community based Nurse Practitioners/Physicians as well as Emergency Room Nurses/Physicians in a very large number. We feel that this should improve the likelihood of sooner and more correct diagnosis for many, and inevitably improving their outcomes.

## Myocarditis Foundation Awards 17th Fellowship Grant

The Myocarditis Foundation is pleased to announce that Dr. Paul Hanson, PhD, from Vancouver, British Columbia, Canada, is the 2017 Fellowship Grant Recipient for the 2018-2019 Academic Year. Dr. Hanson was the second-place finalist in last year's grant applicants (2016) but rose above all other applicants in the 2017 submissions.

The Myocarditis Foundation's International Medical Advisory Board (MAB), reviews the applications and subsequently make the recommendation as to whom the grant should be awarded to. Dr. Hanson's research submission, titled: "Personalizing Myocarditis Diagnostics through Novel Biomarkers" received very high grading and very positive remarks from our MAB. To achieve a more accurate and personalized diagnosis for myocarditis, Dr. Hanson under the supervision of Dr. Bruce McManus PhD, MD, has learned from valuable mouse models of viral myocarditis and will be applying that knowledge to human myocarditis diagnostic development.

Dr. Hanson has discovered increased amounts of certain proteins associated with

heart-muscle-failure in the setting of viral infection (myocarditis) in mice when compared to the hearts of healthy uninfected mice. Importantly, these particular proteins could be detected even in sections of the heart without the characteristic inflammation and tissue damage usually considered necessary for diagnosis. Further, this pattern of increased protein expression appears to be specific to viral myocarditis as compared to other causes of heart failure. Their preliminary work in human heart muscle has revealed increased amounts of these same proteins in human myocarditis, suggesting that they are biomarkers of viral myocarditis, or in other words, biological hallmarks of this particular disease state.

Following on this work, down the road, they anticipate being able to detect fragments of these proteins generated during the disease process in the blood of patients with myocarditis. If this approach is successful, they may be able to develop a blood test that will improve the ability to diagnose myocarditis.

Dr. Hanson's Fellowship Grant has been named after a Viral Myocarditis victim, Sarah Knight,



*Dr. Paul Hanson, PhD*

whose family has been raising funds to support research into myocarditis since she passed away from it in 2011. We thank the Knight Family for their efforts to raise funds to support this grant, and the work of Dr. Hanson in studying myocarditis.

Dr. Hanson will be attending and speaking on his research at our upcoming Family Meeting in June.

### UPDATE

## Myocarditis Bio-Bank

In late 2016, the Myocarditis Foundation collaborated on and worked to plan the development of the first ever "Myocarditis Registry and Bio-Bank". Seeking the financial assistance of attendees during the "Live Ask" portion of the 2nd Annual Gala Fundraiser last June, the Foundation was able to move forward with their innovative plan and start the process. As this will be the first ever such Bio-Bank globally, the Foundation knows the importance of developing international

collaborations to obtain the most diverse samples of myocarditis. The Foundation is collaborating with various institutions from the U.S., European Block, Asia and Africa. We believe that these collaborative efforts will bring about early detection and medical treatments for the disease.

The Principal Investigator for the adult arm of the North American study will be Dr. Mario Deng, Professor of Medicine at the David Geffen School of Medicine

at UCLA, and Cardiologist at the Ronald Reagan UCLA Medical Center.

The Principal Investigator for the pediatric arm of the North American study will be Dr. Jack Price. Dr. Price is a Professor of Medicine at Baylor College Medical School and Co-Director of the Pediatric Heart Failure ICU at Texas Children's Hospital in Houston, as well as a member of our Board of Directors.

The Principal Investigator of the International arm of the study is Dr. Bettina Heidecker. Dr. Heidecker, a previous MF Fellowship Grant Recipient in 2007 and Cardiologist/ Myocarditis Researcher, has recently been appointed head of the heart failure and cardiomyopathies clinic at the Charit, in Berlin, Germany.

This project requires very in-depth preparation and we are hoping that we will be able to start collecting myocarditis samples before the end of 2018.

## Recent Awareness Events/Fundraisers

### Loganton, Pennsylvania

Rachel Lehman, a high school senior at Sugar Valley Rural Charter School, was deeply touched by a worker at the school who lost a 2½ year old granddaughter to Viral Myocarditis. After hearing about this disease, she went online to the Myocarditis Foundation's website and began to read about the disease and the "Real Life Stories" that have been shared by patients and family members. It touched her so deeply that she wanted to help raise awareness and educate others on the disease so that perhaps it could help prevent even at least one death from this rare disease that touches people of all ages and nationalities. Rachel made this her Senior Project and had T-Shirts and key chains made which she sold in memory of those who have suffered from the disease. She planned a "picnic dinner" where

she shared information from the Myocarditis Foundation. She will be presenting to over 50 attendees at the Senior Symposium on April 21st, speaking about Myocarditis and presenting all that she has learned and done on a trifold presentation board. The Myocarditis Foundation thanks Rachel for her initiative to educate others and to speak out about this rare disease.

### Edina, Minnesota

Eight-year-old Quinn Kirsch died suddenly in January 2013. It was later learned that he had died from Viral Myocarditis. Quinn's hockey coach knew of Quinn's love of playing ice hockey and suggested that they hold a pond hockey tournament to keep his memory alive.

Quinn's Cup was started in 2014 with 250 children and three rinks. The event raised nearly \$13,000 for the Myocarditis Foundation

that year. Quinn's Cup has grown in size every year since. On Saturday January 27th, there were 60 teams of children, 720 of them, skating on 5 rinks for the 5th Annual Quinn's Cup Pond Hockey Tournament. They have raised an amazing \$135,000 in the five years since its inception. The Quinn's Cup mission statement parallels the Myocarditis Foundation, as well as provides a venue for Quinn's family, friends, teammates and classmates to celebrate Quinn's life while doing something he loved, play hockey on an outdoor rink.

This year, a first time visiting parent/grandparent whose child had participated in the Tournament, sent a touching email to Quinn's father. He stated that he was deeply touched by the incredible energy and impact that Quinn has had on the lives of so many others in his short lifetime. As he was walking through the area he

heard a father explain to his daughter that sometimes people's hearts are not strong enough to go on. The young girl said, "I think he's here anyway", which caused him to stop and let that thought sink in. He also stated in the email to Quinn's dad, "What you and your family have created, what you nurture in Quinn's memory is so big and powerful. At a time when there is so much noise and negative energy swirling in the world around us, it provides a quieting sense of joy. No doubt your son would have been humbled and pleased."

Quinn, no doubt, is very proud of what his parents, family and friends have done for so many others in his memory.

Thank you from the Myocarditis Foundation to the Kirsch family and all those who helped and/or participated in this special event, in memory of Quinn.

### ANNOUNCEMENTS

## New Members to the Myocarditis Foundation Board of Directors:

The Myocarditis Foundation would like to announce the addition of two new Board Members, Giustina Schiano and Dr. Douglas Luffborough, III.



*Giustina Schiano*

Giustina Schiano's adult son Lee, was taken suddenly by Viral Myocarditis in 2015. Giustina, like so many others of us, had never heard of this disease before it wreaked havoc and devastation to her family. Giustina was

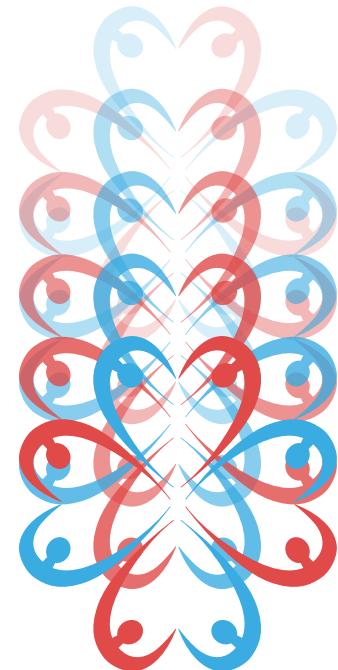
encouraged by her family to attend our annual Family Meeting in 2016, only months after she lost her only child. Her family learned about it from our website and put Giustina in touch with the Foundation. She traveled to Florida by herself, not knowing what to expect, just what she had learned from speaking with the Foundation. She was welcomed by the other members of the Myocarditis family and she soon found that she was no longer alone in what she had been going through. The Board elected Giustina to the Board to represent the needs of all Myocarditis families. Family support is one of the three cornerstones of the Foundation's mission. Our family's voices will be paramount under Giustina's guidance.



*Dr. Luffborough*

Dr. Luffborough, or "Dr. Luff" as he likes to be called is no stranger to the Myocarditis Foundation. As a long-time friend of one of our Board Members and speaker at previous Myocarditis events, Dr. Luff lost a child to heart disease and has an extended family member that is still fighting viral myocarditis. He brings to the Foundation, not only personal experience but years of business expertise in the non-profit industry.

We welcome both Giustina and Dr. Luff to the Foundation and know that they will be key figures in moving the Foundation forward in our mission.



# Speaking Schedules & Events

## DR. JACK PRICE

### April 11-14

International Society for Heart and Lung Transplantation  
Nice, France

### May 24th

Minneapolis Children's Hospital  
Grand Rounds  
Minneapolis, Minnesota

## DR. DELISA FAIRWEATHER

### April 30th

11th Annual Meeting of the Organization for the Study of Sex Differences "Sex Differences in Viral-induced Myocarditis"

Atlanta, Georgia

### May 24th

Minneapolis Children's Hospital  
Grand Rounds "Novel Regenerative Medicine Therapies for Myocarditis & DCM"

Minneapolis, Minnesota

### July 27-29

International Academy of Cardiology  
Annual Scientific Sessions 23rd  
World Conference on Heart Disease  
"Prevention of Myocarditis/DCM using Regenerative Medicine Therapy"

Boston, Massachusetts

### Sept. 20-21

International Congress and Expo on Cardiology "Prevention of Cardiomyopathy using Regenerative Medicine Therapy"

Toronto, Canada

### Oct. 18

Mayo Clinic Dept. of Cardiovascular Medicine Grand Rounds

Jacksonville, Florida

## DR. LESLIE COOPER

### April 11-15

Annual Review Course in Clinical Cardiology  
Zurich, Switzerland

### May 24-27

Joint Session of ISCP & ISCMF  
Kyoto, Japan

### June 22-24

Sri Lanka Heart Assoc. Annual Academic Sessions  
Sri Lanka

## UPCOMING MYOCARDITIS FOUNDATION EVENTS:

### May 12th

Third Christopher Widjaja Memorial Benefit Recital  
Livingston, New Jersey

### June 8th

Sarah Knight Golf Tournament  
Marion, Iowa

### June 21st

3rd Annual Myocarditis Foundation Gala  
New York City, New York

### June 22-23rd

6th Annual Family Support Meeting  
New York City, New York

### August 6th

Myocarditis Foundation Golf Outing  
Paramus, New Jersey

### September 23rd

Lee Andrew Hirsch Memorial Event  
East Meadow, New York

## ANNOUNCEMENTS

## Medical Advisory Board Member and Previous MF Fellowship Grant Recipient:

Dr. Bettina Heidecker, MD, the MF 2007 Fellowship Grant Recipient and a member of the Myocarditis Foundation's Medical Advisory Board, has recently been asked to join the Charit Campus Benjamin Franklin in Berlin as the head of heart failure and cardiomyopathies. The Charit University Hospital complex is one of Europe's largest clinics and has a long history with the first of its hospitals established in 1710.

More than half of Germany's Nobel Prize winners in medicine and physiology have worked there. Dr. Heidecker will be working alongside highly esteemed physicians and cardiologists. She will not only work in the clinical setting caring for patients with heart failure and cardiomyopathies but will be teaching the next generation of physicians about myocarditis and its many forms of clinical presentation. Dr. Heidecker's plan is to also establish a research laboratory at the Charit, to continue her work looking for an early detection tool for myocarditis and improved therapies for the disease.

While at the University of Zurich, where she worked as a non-invasive cardiologist since 2015, she established a specialty clinic for myocarditis. Dr. Heidecker, with her clinical research team, also introduced a screening algorithm that increased the number of detected cases with myocarditis per year significantly. The data



Dr. Heidecker

will be published in an upcoming Journal of the American College of Cardiology Heart Failure.

Dr. Heidecker has earned many awards internationally dating back to 2000 and is a very highly published author on myocarditis and cardiomyopathies and also has written book chapters on Acute Fulminant Myocarditis (along with Dr. Leslie Cooper, of the Mayo Clinic) and a chapter in The Handbook of Genomic Medicine (along with Dr. Joshua Hare, of the University of Miami).

Dr. Heidecker will also be the principal investigator of the European arm of the Myocarditis Foundation's "Myocarditis Registry and Bio-Bank".

The Myocarditis Foundation wishes all our best to Dr. Heidecker and we look to her to be one of the major players in myocarditis care and research in the next 20 years.

Congratulations Dr. Heidecker!

## UPDATE

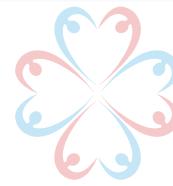
## Gold Star Rating

The Myocarditis Foundation has maintained its impressive Gold Star Rating and attained an 8% Administrative Expense Ratio for 2017. We thank the many Volunteers and Contributors who

helped us attain our excellent results. Our full financial results are posted on our Website and on GuideStar.



# MYOCARDITIS FOUNDATION



## Board of Directors 2018

### **JOSEPH RUMORE**

*President*

Myocarditis survivor and heart transplant recipient, former Managing Director of a national insurance company

### **CHRISTOPHER CORSO**

*Vice-President*

Vice-President and Senior Reinsurance Placement Officer XL Catlin Insurance and father to a Myocarditis Survivor

### **CANDACE MOOSE, RN, BSN, MEd**

*Secretary and Founder*

Giant Cell Myocarditis Survivor and Heart Transplant Recipient

### **LOUIS ROMANO, JR.**

*Chief Financial Officer*

Owner of HomeWell Senior Care

### **LESLIE COOPER, MD**

*Medical Director, Founder*

Chair, Enterprise Department of Cardiovascular Medicine for Mayo Clinic

### **JACK PRICE, MD**

*Associate Professor of Pediatrics, Baylor College of Medicine*

Director of the Heart Failure ICU, Texas Children's Hospital, Houston, Texas

### **JOEL ARANSON**

*Director*

Founder and Chairman of National Sporting Good Corporation and father to a myocarditis victim

### **FRANCINE ANDREA**

*Director*

Vice-President for Enrollment Management, Student Affairs and Chief Compliance Officer for Felician University

### **GIUSTINA SCHIANO**

*Director and Family Advocate*

Mother to a Myocarditis Victim

### **DOUGLAS LUFBOROUGH III, PhD**

*Director*

Father of a victim of Heart Disease and extended family member of a Myocarditis Survivor

## Executive Director

### **GENEVIEVE RUMORE, RN, BSN**

Kingwood, Texas

## Director of Communications and Assistant to the Secretary

### **DR. KATELYN BRUNO**

Director of Communications and Assistant to the Secretary, Myocarditis Researcher at the Mayo Clinic, Jacksonville, Florida

## Medical Advisory Board

### **AKIRA MATSUMORI, MD**

Professor of Medicine, Department of Cardiovascular Medicine, Kyoto University Graduate School of Medicine, Kyoto, Japan.

### **BRUCE M. MCMANUS, PhD, MD, FRSC, FCAHS**

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

### **DENNIS M. McNAMARA, MD**

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

### **STEVEN D. COLAN, M.D.**

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

### **DR. BETTINA HEIDECKER, MD**

Associate Professor at the University of Zurich, Switzerland Myocarditis Researcher and previous MF Fellowship Grant Recipient

### **DELISA FAIRWEATHER, PhD**

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

## Mailing Address

The Myocarditis Foundation has moved its business operations to Kingwood, Texas.

Please use the below address for all future mail and correspondence.

**3518 Echo Mountain Dr., Kingwood, TX 77345**

**Telephone: (281) 713-2962**

**Fax (281) 608-7252**

Find us online: [www.myocarditisfoundation.org](http://www.myocarditisfoundation.org)



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