KNOWLEDGE NUTURES HOPE

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MYOCARDITIS FOUNDATION

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

EDUCATION UPDATE

How does COVID-19 affect the heart? by Mayo Clinic News Network

The effects of COVID-19 on the lungs are well-known. As the COVID-19 pandemic continues, more information is becoming available about the role the virus, called SARS-CoV-2, has on the heart. "Individuals with known cardiovascular disease are at an increased risk of more severe complications from respiratory viral illnesses, including the flu and COVID-19," says Dr. Leslie Cooper, chair of the Department of Cardiology at Mayo Clinic.

"We know that during severe SARS-CoV-2 infection, heart function may decrease. Sometimes this decrease is a consequence of the systemic inflammatory response to infection, and occasionally, in some people, because of direct viral infection in the heart."

According to Dr. Cooper, there are two dominant cardiac issues related to COVID-19: heart failure, when the heart muscle doesn't pump blood as well as it should, and arrhythmias, or abnormal heart rhythms, that can be related to the infection or to the effect of medications used to treat the virus.

Heart failure can develop due to a systemic inflammatory response to the infection, high lung pressures from lung damage, or occur from heart inflammation known as myocarditis.

"For many people who present with heart failure in the context of COVID-19infection, we don't know if the heart failure is related to myocarditis or to a response to systemic inflammation from COVID-19," says Dr. Cooper.

For older patients, with existing coronary artery disease or hypertension, it is likely heart failure resulting from the increased demand placed on the heart and the body's already decreased cardiac reserve capacity, he says. In younger patients, its likely primary myocarditis caused by the virus.

There has been some debate as to whether medications used to support blood pressure may increase a person's risk for heart failure.

"It is unclear if medicines used to support blood pressure are actually leading to some of the deterioration in heart function," says Dr. Cooper. "But right now, there is no evidence that the commonly used medications for any cardiovascular disorders in the United States will put you at heightened risk of contracting COVID19 or the consequences of infection."

Dr. Cooper advises people to continue their medications, unless their physician has directed them otherwise.

Since COVID-19 is new, there is little data available regarding long-term cardiovascular issues as a result of the virus. Research has already begun at Mayo Clinic, says Dr. Cooper.

"We need to determine the long-term effects of COVID-19 at both a population health level and individual level," says Dr. Cooper, adding funding from the American Heart Association and National Institutes of Health is spearheading research related to COVID-19's cardiovascular impact.

"We know this is a stressful time for everyone because of the economic and social impact of this disease, even if you don't have it yourself," says Dr. Cooper. "And that can put people at heightened risk for all sorts of stress-related illnesses."

For those with known heart issues – whether high blood pressure or other disease -stay focused on good heart health practices.

"Taking care of yourself, being vigilant with hand hygiene, trying to maintain an exercise regimen if you had been before, eating well, are key to maintaining health," he says.

He adds that while we're also being instructed to avoid large group gatherings and maintain social distancing, build in time to stay connected—which will keep your heart emotionally healthy.

"Maintaining social contact through the internet or through the telephone is really important so we don't lose contact and become depressed or otherwise isolated.

"Shortness of breath is very common, and only a minority of people today will actually have COVID-19 infection who develop shortness of breath," says Dr. Cooper. "Now, as before, if people develop chest pain or shortness of breath, they should seek medical attention by calling their health care provider or, if it's severe, 911 for assistance."

EVENT

5th Annual Myocarditis Gala Cancelled due to COVID-19

Sadly, many of us have been affected by the COVID-19 Pandemic. We truly hope though that the majority of you have only been affected by the restrictions that the pandemic has imposed on us as a global community.

One of these restrictions is the cause of our cancelling the 5th Annual Gala. Getting 400 people in a room together is not anything we will be able to do now or sadly, anytime soon.

We were planning to honor our Gala Chairperson, Christopher Corso, who implemented the Gala in honor of his son Matthew. Christopher Corso wanted to help give back to raise awareness and funding for the Myocarditis Foundation so that the Foundation could move forward with research into finding answers to help stop the disease that had changed their lives so dramatically. This Gala event has enabled the Foundation to start our ground-breaking Biobank. COVID-19 has drained many of the medical/research talent to handle the pandemic, but with adjustments and delays our work will resume in search of a cure.

Matthew was stricken with Viral Myocarditis in May of 2015 and has been battling its effects since. Matthew is one of three young men, all of the same age from various areas of the country, who were affected by either Viral or Giant Cell Myocarditis, and who have needed to adapt their lifestyles as high school students to accommodate the needs of their illnesses. All three will be graduating high school this year and we were hoping to get them all together again to celebrate their accomplishments. Congratulations to you all!

We pledge to continue to work towards researching and finding answers for this disease. We are hopeful that you can help us rally around and continue to help support the Myocarditis Foundation in our mission by making donations online via our website: **www.myocarditisfoundation.org** and click on the red Donate Button on the top right hand side of our webpages. Or if you prefer to send a check, please make it out to: The Myocarditis Foundation, and mail it to: **3518 Echo Mountain Drive Kingwood, Texas. 77345**

Please remember to ask your employers if they match donations to Charitable Foundations!

EVENT

Family Support Meeting

The COVID-19 Pandemic has also wreaked havoc on our getting together to support one another and meet with the cardiologists and researchers as we have in the past.

We totally understand the emotional support and being able to speak with these specialists that our meetings bring to us all. The thought of not being able to do it is very upsetting to us at the Foundation, as we believe it would also be for those of you who have attended in the past. It would be extremely helpful for new patients and affected families as well to meet others who have been affected in similar ways and gain the support of others to help them as they navigate the disease process.

We will keep you in touch through our website and through Social Media posts for potential virtual meetings with our doctors and researchers. Stay tuned!

EVENT

NAPNAP Conference Cancellation

The 41st National Conference on Pediatric Healthcare which was to be held on March 25-27, 2020 in Long Beach, California, sadly was also cancelled due to the COVID-19 Pandemic. The Myocarditis Foundation Executive Director was scheduled to attend and provide education on myocarditis to over 1,800 Pediatric Nurse Practitioners. The loss of this educational opportunity would have been a devastating loss in the education of so many front line pediatric care givers. However, the Foundation was able to obtain the mailing list of the attendees.

Thank you to Sophia and Helena Carreras for all your help. We could not have done it without you!

The office staff put together the information that was to be shared, along with an explanation of it into mailing envelopes. With the help of two very young volunteers, who have a few years of experience working with stickers, the mailing envelopes had postage stamps applied. All the educational envelopes have been mailed off to all the attendees, in various states across the United States as well as Canada!

MYOCARDITIS RESEARCHER UPDATES

2019 Fellowship Grant Recipient Announced

Danette Flint, MD
Myocarditis Researcher
Dartmouth-Hitchcock Medical Center

The Myocarditis Foundation is proud to announce our 2019 Fellowship Grant Recipient, Dr. Danette Flint, MD, from Dartmouth-Hitchcock Medical Center. Dr. Flint's research study is titled: "Immune Checkpoint Inhibitor Associated Myocarditis." Dr. Flint's Preceptors are Dr. Javid Moslehi, MD, from Vanderbilt University and Dr. Lauren Gilstrap, MD, from Dartmouth-Hitchcock Medical Center.

The 2019 Fellowship Grant will be named after Lee Andrew Hirsch, a 31 year old victim of Viral Myocarditis from 2015 whose mother and family have been working on raising funds for research so as to prevent others from suffering the loss that they have and to find elusive answers to stopping the disease.

Dr. Flint is our 20th Fellowship Grant Recipient and here is her layman's description of her research.

"Immune Checkpoint Inhibitor Associated Myocarditis:"

Immune checkpoint inhibitors, or ICIs, are a newer drug therapy that target how cancer cells interact with our immune system. ICIs have been approved for treatment of multiple types of cancers and have proven to markedly increase survival for patients, even those with metastatic disease. Unfortunately, because of the way these drugs affect the body's immune system, there are also significant side effects which can target multiple parts of the body, including the heart. When the heart is targeted, inflammation of the heart muscle results, a condition called myocarditis. The illness that results can be so severe that it leads to death. At present, the frequency of ICI associated myocarditis and other related cardiac side effects, such as heart failure and sudden cardiac death, are not well known and individual patient factors that increase or decrease the risk of these side effects have not been examined. In order to provide patients with an accurate and personalized assessment of their individual expected benefit and risk from these drugs, we plan a research project using Medicare data to both determine the rates of these side effects at a national level and identify characteristics that increase or decrease an individual patient's likely benefit or risk with these potentially life-saving, novel therapies.

Our congratulations to Dr. Danette Flint and many thanks for her work in myocarditis research!

MYOCARDITIS RESEARCHER UPDATES

Myocarditis Foundation Awards Another Research Grant

Dr. William Bobo
Myocarditis Researcher
Chair of the Department of Psychiatry and Psychology at Mayo, Jacksonville

Dr. Bobo, Chair of the Department of Psychiatry and Psychology at Mayo, Jacksonville, will be researching the effects of anxiety and depression on quality of life and health outcomes in people diagnosed with myocarditis and those who care for them.

Acute Myocarditis, a potentially life-threatening disease that often develops without warning, is typically associated with ongoing physical challenges among survivors, and striking emotional struggles among both survivors and their identified support givers/caregivers. While other ischemic and non-ischemic heart disease have been studied in relation to anxiety and depression, Dr. Bobo was only able to find one study on those who survived Fulminant Myocarditis and were on circulatory support. He found no reports focused on caregivers.

As such, very little is known about the impact of mental health conditions or symptoms in myocarditis survivors and their caregivers, highlighting a critical knowledge gap.

This project aims to identify people with myocarditis who are risk for clinically significant depression and anxiety.

Our congratulations to Dr. William Bobo and many thanks for his study of this in Myocarditis patents and their families!

Myocarditis In Children: Incidence, Clinical Characteristics And Outcomes

The incidence of myocarditis in children is uncertain but it is estimated that 1 per 100,000 children per year are affected. It has been reported that 0.05% of all pediatric hospitalizations are for myocarditis. Understanding the incidence of myocarditis is problematic because the disease is difficult to diagnose.

The "gold standard" method of making a diagnosis of myocarditis requires a biopsy of the heart muscle. This procedure can be risky in infants and small children. Some institutions are now using cardiac MRI to make the diagnosis. The MRI is less invasive and carries a different risk profile for very sick patients, but we do not know how reliable it is at making the diagnosis in children.

The signs and symptoms of myocarditis can be quite variable. Infants may show signs of listlessness, labored breathing and pallor. Frequently, they become disinterested in feeding or very fussy and difficult to console. Most older children will complain of abdominal or chest discomfort, fatigue or weakness. Respiratory symptoms such as increased work of breathing and wheezing may lead physicians to incorrectly diagnose children with asthma or pneumonia. It is not unusual for some patients to have experienced flu-like symptoms a few days or weeks before seeing a physician. Sometimes, sudden death is the first sign that something is wrong.

Treatment of acute myocarditis is mostly focused on supportive care. Symptoms of breathlessness or abdominal discomfort may be relieved with decongestive therapies such as diuretics. Features of low cardiac output or hypotension may be alleviated with inotropic/vasopressor infusions. In situations of cardiogenic shock, the utilization of mechanical circulatory support can be lifesaving. Although immunotherapies such as intravenous gamma globulin and steroids have been used in children with acute myocarditis, data have failed to demonstrate their benefit for survival or hospital readmission.

The prognosis of myocarditis in children depends, in part, on the age of the patient. The mortality rate in newborn infants has been reported as high as 75%, while estimates in older children generally range from 10-30%. If a child survives the early acute phase of the disease, their chances for long-term survival very good. In addition, some patients may develop a chronic or recurrent form of myocarditis. Pediatric patients hospitalized with myocarditis have a readmission rate of 15%.

Mechanical Circulatory Support Saves Lives In Children With Myocarditis

Many children who develop acute viral myocarditis present to their care team in shock or in impending shock. They frequently have poor circulation, weak or "thready" pulses, and irregular heart rhythms. Their other organs such as the kidney, liver and lungs may also be weakened or injured. These patients are at greatest risk of cardiovascular collapse and death.

Fortunately, mechanical circulatory support (MCS) devices may allow doctors and surgeons to save the lives of children with advanced heart failure caused by myocarditis. An MCS device is a type of artificial heart pump that is inserted into the patients' blood vessels and/or directly into the heart. Basically, it takes over the work of the heart, pumping blood to the body and providing adequate circulation to the failing organs. It also unloads the heart, allowing it to rest and heal while the viral infectious process resolves. Dr. Ivan Wilmot, and others from Texas Children's Hospital in Houston, reported on their experience using MCS in children with acute or persistent myocarditis. They treated 16 children with MCS. Of those patients, 12 of 16 (75%) survived: 5 went on to develop complete recovery of their heart function and 7 were successfully "bridged" to cardiac transplantation. These findings provide further evidence that patients can survive even severe myocarditis if diagnosed and treated in a timely manner. The Houston medical team speculated that MCS allows physicians and surgeons a new way to think about treating acute myocarditis in children.

In a separate multi-institutional study of 195 children supported with MCS in Germany, 28 patients (14%) received MCS (median age 1.5 years). In the MCS group, 50% received a ventricular assist device, 36% extracorporeal membrane oxygenation, and 14% both, with a survival rate of 79%. The weaning rate was 43% (12/28). Nine (32%) patients were transplanted, one had ongoing support, and six (21%) died.

Awareness of the potential recovery of heart function in children with myocarditis, plus the ability to save lives with MCS devices, has fostered an urgency to create more miniaturized versions of heart pumps that can allow for better and safer support of the circulation in small patients. Recently, the Jarvik 2015 ventricular assist device was approved by the FDA for study in small children. This continuous flow pump is designed for long-term use as a bridge to cardiac transplantation in patients with advanced heart failure. The pump is about the size of an AA battery and fits completely inside the patient's body.

Welcome to our new Board Members!

Michael Linn

Mr. Linn is a Regional Sales Manager for the Craniomaxillofacial division of the Stryker Corporation where he manages a team focused specifically on facial trauma/ reconstruction and neurosurgery. He has actively been involved with commercializing Stryker's efforts in the cardiothoracic space, developing and launching products for sternal reconstruction in heart surgery patients. He holds a BS from Bentley University, an MBA and an MS from Saint Peter's University, and several certificates from Harvard University.

"As a longtime friend of a Viral Myocarditis survivor and heart transplant recipient, and a supporter of the Myocarditis Foundation, I have been able to learn extensively about the impact Myocarditis can have and the randomness of the disease state itself. I believe passionately that the efforts of the foundation can serve as a catalyst to reduce such randomness, and work towards more preventative measures to predict and combat Myocarditis."

Please join us in welcoming Mike to our Myocarditis Foundation Family and Board of Directors. We know his youth and creative management style will expand the foundation's influence for years to come.

Michael Linn

Stephanie Kennan

Stephanie Kennan is the Senior Vice President of Federal Affairs, at McGuireWoods Consulting.

Ms. Kennan has worked in the health policy arena for over two decades. Her experience includes working for two members of the U.S. House of Representatives and for U.S. Senator Ron Wyden (D-Or). She also served as Director of Federal Relations for the Maryland Department of Health and Mental Hygiene; as Assistant Director of Government Affairs for the American College of Emergency Physicians; and as a legislative representative for AARP. She also has authored numerous articles concerning health policy and is quoted often in the health care press on current events. She is a graduate of the University of Virginia and earned her MBA from George Washington University and an MA in Creative Writing from Johns Hopkins University.

Her father died at the age of 42 from Myocarditis. Her interest in joining the foundation comes from understanding how important it is to support patients and their families, and to advance the scientific research needed to find treatments and a cure.

Please join us in welcoming Stephanie to our Myocarditis Foundation Family and Board of Directors. We know that her breath of experience and understanding of healthcare will provide additional leadership in moving our mission forward!

Stephanie Kennan

VIRTUAL FUNDRAISERS

Virtual Fundraiser Remembers a Family Member Lost to Viral Myocarditis

Ann's sister Mary Ehrlinger passed away in 2009, at the age of 38 while training for the Madison Ironman, in Madison Wisconsin. Mary loved running and the Madison Half-Marathon was her favorite event which often fell on the same weekend as her birthday.

In her honor every year since, Ann, their family and friends, would man the water station at the Madison Half-Marathon and donate the money they raised to the Myocarditis Foundation in honor/memory of Mary. Unfortunately, this year the event was cancelled due to the COVID-19 Pandemic.

Ann decided that they could still come together and celebrate Mary's memory. So, on Thursday, May 21st, while maintaining "Safer at Home Protocols", they decided to do a "Virtual Happy Hour" where they all got together on a Zoom Call to spend time together memorializing Mary.

Everyone brought their own beverages and snacks and shared time together. Ann invited Genevieve, the Executive Director of the Myocarditis Foundation, to join them and speak about the important work that the Myocarditis Foundation is doing. Information was also shared about making donations via the Foundation website, so that the attendees could make individual gifts if they so choose to do so.

Not only did this raise awareness about Myocarditis and the work that the Myocarditis Foundation is doing, it raised much needed donations for the Foundation. These donations help the Foundation to continue its truly important work in carrying out their mission of raising awareness, funding research, and emotional support for those affected by Myocarditis.

Thank you, Ann, family and friends, for doing this to support the Myocarditis Foundation in memory of Mary!

EVENT

Live Streaming Platform for Video Gamers Supports the Myocarditis Foundation

In April, David Roebuck, a senior Statistics and Predictive Analytics major at Robert Morris University in Pittsburgh, PA., and a competitive NHL Esports player, held a virtual charity stream fundraiser on Twitch to benefit the Myocarditis Foundation. His girlfriend was diagnosed with myocarditis three years ago and has suffered with heart failure since then. He understands that it is a rare disease and needs much more research to find the answers needed to stop it from affecting others. He not only exceeded his fundraising goal but was able to raise awareness for the disease to many others in this high-risk age group. Thank you, David, for your all your support!

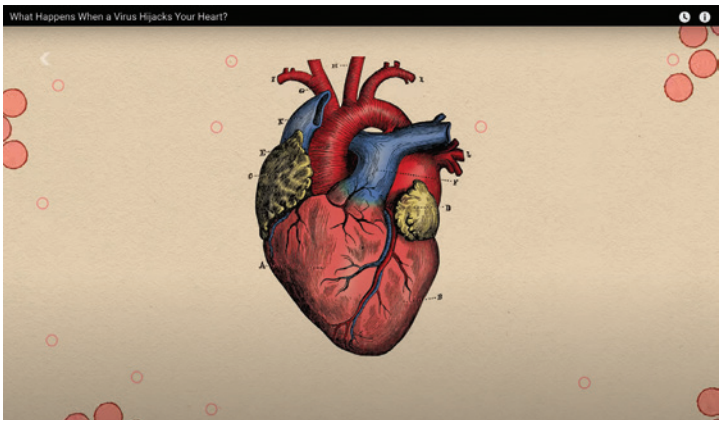
RESEARCH UPDATE

What happens when a virus hijacks your heart?

Dr. DeLisa Fairweather

By DeLisa Fairweather, PhD based on a video interview of DeLisa Fairweather by SICK/SEEKER that was released February 18, 2020,

https://www.youtube.com/watch?v=QePPCRaaTAI



Myocarditis, or inflammation of the myocardium, is a leading cause of sudden death from heart failure in children and young adults worldwide. Many different types of viruses, as well as bacteria and other infectious and non-infectious agents, are known to be able to cause myocarditis. A common virus known to cause myocarditis in the US is coxsackievirus, which targets the gut/intestines leading to a stomach-flu type of illness associated with diarrhea. Other viral causes of myocarditis include HIV, hepatitis B and C virus, influenza and coronaviruses. Coronaviruses are a family of viruses that typically cause symptoms like the common cold, which is caused by other viruses also, and is the family of virus that leads to COVID-19.

One question researchers have had is why do viruses that normally attack the intestines (coxsackievirus), the liver (hepatitis viruses), or the lung (influenza, coronavirus) end up causing inflammation in the heart or heart failure? Recently, researchers have started to better understand why this occurs.

Researchers have discovered that viruses like to target the heart because they use an organelle found in every cell called mitochondria to help them make more viruses and better infect their host (i.e., us!). Mitochondria are what make our cells function because they provide energy to the cell from the food that we eat. Viruses steal that energy to make more viruses. Recently, Dr. Jon Sin, PhD, who is a past recipient of a Myocarditis Foundation Grant, found that coxsackievirus requires mitochondria in order to make more viruses and so they like to go to the heart because heart cells have the second highest number of mitochondria per cell (as many as 10,000)! Only brain cells have more mitochondria (as many as 100,000/cell). The more energy that is needed for a cell to work the higher number of mitochondria that are present in the cell, and a lot of energy is needed to keep the heart pumping! Working together, Dr. Sin's lab and my lab received a National Institutes of Health (NIH) grant to study how the virus's ability to hijack mitochondria could lead to myocarditis.

Another mystery surrounding myocarditis is why people who seem to have recovered from a recent viral infection exercise (typically quite exertional exercise) and then suddenly develop heart problems so that they collapse and sometimes suddenly die. My lab has joined together again with Dr. Sin's lab and Dr. Michael Coronado's lab to study this question. When we exercise, we need a sudden increase in energy, especially with really exertional exercise. Dr. Coronado, PhD has found that when we exercise mitochondria in heart cells split in two and make 2x more energy. But if the virus is in the mitochondria when we exercise what effect does that have on the amount of virus in the heart, inflammation, and a process called 'cytokine storm' all of which could contribute to sudden heart failure. We have submitted a grant to NIH to examine the effect of exercise on myocarditis and hope to hear any day now whether we have received funding to start the study.

RESEARCH UPDATE

Good News About a Study Regarding Exercise Post-Myocarditis!

A Prospective Pilot Study to Identify a Myocarditis Cohort Who May Safely Resume Sports Activities

Dr. Bettina Heidecker is a previous Myocarditis Fellowship Grant Recipient. She is now a Cardiologist and Myocarditis Researcher at the Charite University Berlin, and the University Heart Center in Zurich, Switzerland. In association with other cardiologists, including Dr. Leslie Cooper, of the Mayo Clinic, she is conducting a Prospective Pilot Study to Identify a Myocarditis Cohort Who May Safely Resume Sports Activities.

Myocarditis remains a common cause of sudden cardiac death in young adults. One question that frequently comes up is, "when will it be safe to resume exercise after myocarditis?"

With their first prospective study published in the Journal of Cardiovascular Translational Research (JCTR), they would like to make a start.

Please go to the link below to read their initial Abstract of the Study:
https://link.springer.com/article/10.1007/s12265-020-09983-6

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