KNOWLEDGE NURTURES 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

COVID-19, Your Heart and Exercise… Be Vigilant About Listening to Your Body Right Now

2020 has proven to be a challenging year in many ways for all of us. Following the guidelines set by specialists in the field of infectious disease was thought to be the answer to keeping us safe.

Dr. Leslie Cooper, M.D., reports that the most important thing is prevention. Using personal protective devices such as a mask, frequent handwashing, and social distancing remain the foundation of preventing transmission and thereby illness.

Along with prevention, fresh air, sunshine and exercise was what many people strived for during this pandemic. People wanted to use the time to "get healthier" in ways that they could within the restrictions designated. Many people took up bike riding with their families. In fact, the availability of purchasing a bike was extremely difficult for months after the pandemic was in full force.

One of the problems that we are experiencing is that COVID-19 does not always present with symptoms. It is documented that over 20% of infected patients have no symptoms.

80% of those with what is considered a mild case, presents with what looks like a normal flu or bad cold. The symptoms usually last for 2 weeks.

Those with severe infection, which are approximately 20% of those infected, develop trouble breathing from viral pneumonia. Many of these need to be admitted to the hospital. People with complications generally recover within 3-6 weeks.

A former competitive cyclist started taking bike rides at lunchtime with his wife. They would ride on secluded trails behind their house in Georgia. One day, he could barely make it up a small incline that he was able to do a million times before. It was hot and humid so he attributed his difficulty to the weather being oppressive. Then, when he was going up the last climb, he developed severe shortness of breath; his heart was pounding and he needed to rest for ten minutes before continuing.

He called and made an appointment with his doctor who did a COVID test, which came back positive. He was told not to ride nor exercise until he was better and reevaluated. After that ride, he struggled with breathlessness every time he tried to do anything. He would feel 85-90% fine while he was resting, but as soon as he did any type of activity like walking around his yard or walking up a set of stairs, he would be exhausted for hours.

In short, exercise can make COVID-19 worse. For cyclists and other active people who generally turn to physical activity to boost circulation and feel better faster when they are a little under the weather, this is new and urgent news, says Jordan Metzel, M.D., a sports medicine physician at the Hospital for Special Surgery in New York City. He goes on to say that this is against his personal exercise

(continued on pg 2)

COVID-19, Your Heart and Exercise…(continued)

philosophy that it is okay to exercise through minor sickness symptoms. COVID-19 plays by a different set of rules when it comes to sports and exercise.

This is what you need to know:

Be vigilant, and listen to your body…

Exercise is still very important for your health. Not only does regular activity keep your immune system strong, but it also helps to prevent the underlying conditions that might increase your risk of more severe coronavirus complications, such as obesity, high blood pressure and diabetes.

So, definitely keep moving, but pay attention to how you feel. "Be especially mindful of unusual symptoms and check in with your doctor if you have shortness of breath, chest pain, palpitations, lightheadedness, leg swelling, muscle pains and or unexplained fatigue", states Dr. Makia, M.D., of Life Bridge Health Sports Cardiology, in Baltimore, Maryland.

It has been found that even mild cases of COVID-19 can hurt your heart. Myocarditis, an inflammation of the middle layer of the heart wall, can weaken your heart and lead to heart failure, abnormal heartbeat, or even sudden death.

An equally scary COVID-19 related cardiovascular concern is blood clotting, especially when sitting for prolonged periods of time, like a long car ride. Dehydration also raises the risk of blood clotting with COVID. Though you want to take it easy and avoid working out if your're COVID positive, low intensity activity like walking, or at least avoid prolonged sitting, can provide some protection against Deep Vein Thrombosis (DVT).

Remember, pay attention to anything unusual and get it checked out with a doctor, especially if you have been COVID positive.

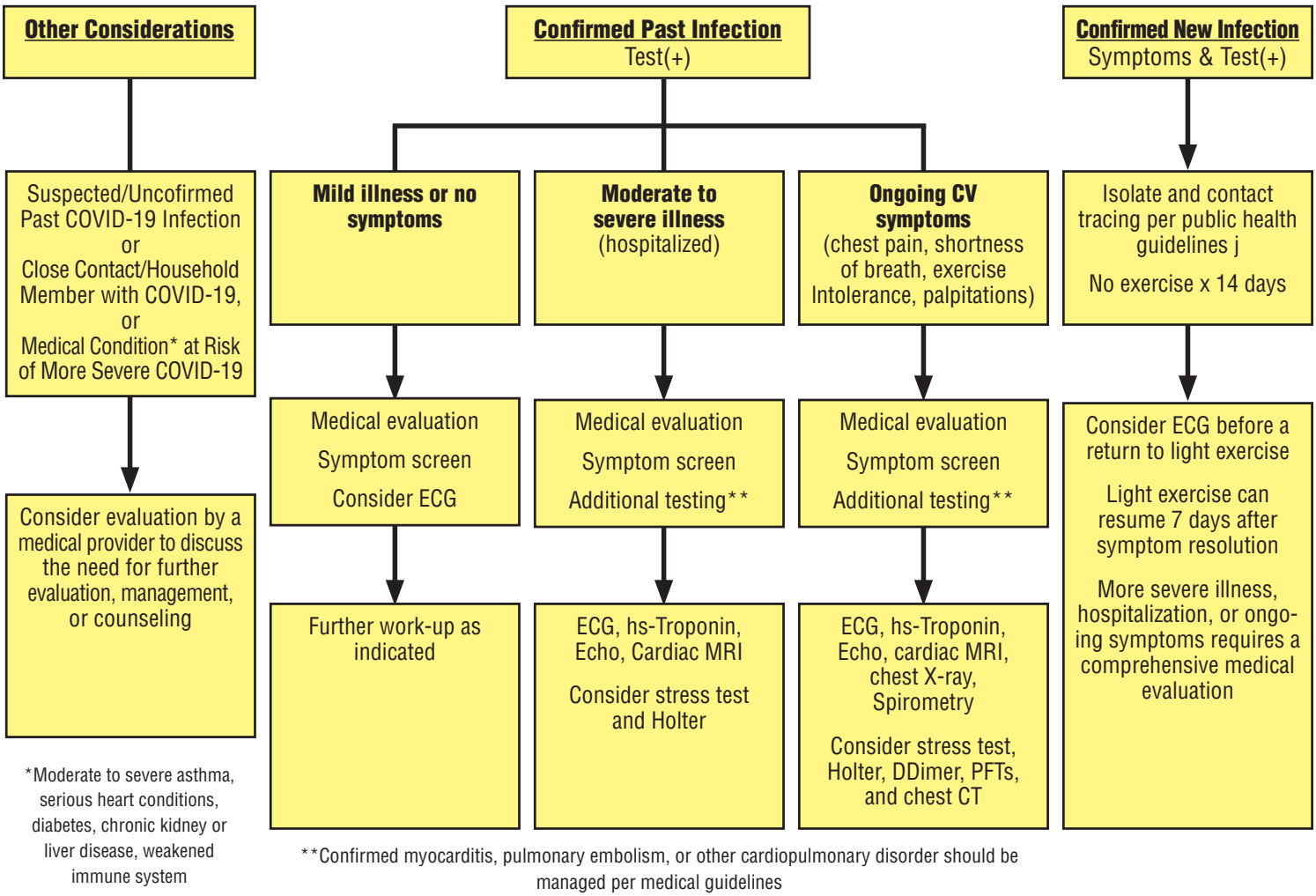
Thank you to the following for this information:

Dr. Leslie Cooper, M.D., Mayo Clinic

Dr. Jordan Metzel, M.D., Hospital for Special Surgery, NYC

Dr. Sural Makadia, M.D., Life Bridge Health Sports Cardiology, Baltimore, Maryland, Seattle Children's Hospital

Cardiopulmonary Considerations for Student-Athletes during the COVID-19 Pandemic



*Moderate to severe asthma, serious heart conditions, diabetes, chronic kidney or liver disease, weakened immune system

**Confirmed myocarditis, pulmonary embolism, or other cardiopulmonary disorder should be managed per medical guidelines

Recognizing Cardiomyopathy in Children

Dr. Jack Price

In layman's terms, cardiomyopathy is a disease of the heart muscle. As a result of a defect, the heart muscle becomes weakened, swollen, or lopsided, making it harder for the heart to pump blood. "Cardiomyopathy is eight times more common in infants than in any other demographic," says Dr. Jack F. Price, MD, Pediatric Cardiologist at Texas Children's Hospital. Here, the Myocarditis Foundation and Price explain cardiomyopathy and what is known about how it affects children.

What Is Cardiomyopathy?

Like myocarditis, cardiomyopathy may lead to congestive heart failure, which is caused by the buildup of fluids in the heart, lungs, or other organs. According to Price, there are three main types of cardiomyopathy, including:

- **Dilated:** This is the most common form of cardiomyopathy. The heart becomes enlarged and weakens, and as a result, it is unable to adequately pump blood to other organs.
- **Hypertrophic:** In this form, the muscle wall is thicker than it should be. Though the heart can pump, it can't relax properly and therefore can't draw enough blood into the heart.
- **Restrictive:** The muscle itself appears normal but is stiff and poorly compliant. This leads to the upper chambers of the heart, called atria, becoming enlarged. Pressure builds up in the atria and eventually transfers to the lungs.

Unfortunately, cardiomyopathy comes with the risk of sudden heart failure and death. This is especially dangerous in youth athletes or any children who regularly exert themselves. To prevent this, there is a growing movement to screen student-athletes for cardiomyopathy before allowing them to participate in sports. "When a patient tests positive," says Price, "we often restrict them from participating in sports and even physical education classes depending on the severity of their illness."

Signs and Symptoms

Price says that symptoms of cardiomyopathy in children vary depending on the age group. In infants, symptoms include:

- Less interest in feeding
- Painful, labored breathing
- Sneezing and coughing
- General fatigue
- Failure to thrive

In addition to these symptoms, older kids often complain of abdominal pain, vomiting, and diarrhea. They may also become disinterested in the activities they normally enjoy and begin to avoid exercise. "The symptoms of dilated cardiomyopathy are very similar to those we see in advanced forms of myocarditis," adds Price.

Incidence in Children

In the United States, pediatric cardiomyopathy tends to be rare, with an estimated 1.1 cases per 100,000 children under the age of 18. About half of these cases are dilated cardiomyopathy. Meanwhile, 20–50% of cases are hypertrophic cardiomyopathy, with restrictive cardiomyopathy accounting for only about 5% of cases in children.

Further, male and African American children have the highest incidence of all pediatric cardiomyopathy cases. In terms of age, it's most likely to be diagnosed in the newborn period, early adolescence and young adulthood. The reasons, however, are tough to identify. "Most forms of cardiomyopathy are caused by a genetic mutation," says Price, "so it can be passed in families." More often, however, the patient is the first in their family to have cardiomyopathy – the result of spontaneous mutation.

Update On Myocarditis In Children

Incidence, Clinical Characteristics, And Outcome

Every year, roughly one in every 100,000 children is diagnosed with myocarditis. Though we know a lot about myocarditis in adults, the medical world still has a limited understanding of how it affects children. "We probably have an underestimation of the prevalence of myocarditis in children, simply because it's so hard to identify," explains Dr. Jack F. Price, MD, Pediatric Cardiologist at Texas Children's Hospital. Here, the Myocarditis Foundation and Price explore the incidence, clinical characteristics, and outcomes for children with myocarditis.

Incidence in Children

Though researchers estimate that the myocarditis rate in children hovers around 0.001%, Price says that estimate is likely lower than it should be. "That's because there are probably a lot of children who are impacted by myocarditis without ever receiving a diagnosis," he says.

Though it's difficult to confidently say how many children have myocarditis, it's easier to pinpoint when they are most at risk. It's thought that newborns are vulnerable because they don't have a fully-developed immune system, so they can't effectively fight off the viral infections that cause myocarditis. Newborns are also at risk of exposure to pathogens while in utero. There's also another spike in incidence around puberty and at the onset of adolescence. "In older kids, it's more difficult to explain," adds Price, "though some researchers speculate that hormones might play a role."

Clinical Characteristics

Because myocarditis is so rare in children, few caregivers are aware of its signs. "That makes it all the more challenging for physicians, nurse practitioners, and pediatricians to recognize and treat it," says Price.

The symptoms of myocarditis can be misleading, however. The earliest signs usually mimic those of a typical viral infection. Children might present with a low-grade fever, runny nose, cough, and other symptoms that are easily mistaken for a common cold or mild flu. It's only after one or two weeks that they start showing more typical signs of heart disease, such as:

- Shortness of breath
- Reduced appetite
- Fatigue and listlessness
- Chest and abdominal pain
- Disinterest in activities usually enjoyed

Treatment and Outcome

Unfortunately, there are not many treatment options for myocarditis. Most doctors simply focus on symptom relief and supportive care. For instance, breathlessness and abdominal discomfort can be helped with diuretics. In more extreme cases, a form of mechanical circulatory support might be necessary. The mechanical support is typically only a temporary measure, but it can be used long-term if the patient doesn't show signs of recovery.

Further, Price believes that "kids have a much better chance of complete recovery than adults do." Unlike adult patients, children don't usually have to fight other issues like chronic kidney disease, diabetes, or high blood pressure.

EVENT FUNDRAISER

13th Annual Myocarditis Foundation Golf Outing Fundraiser

The 13th Annual Myocarditis Foundation Golf Outing was held on Monday August 17th, 2020 under sunny skies at the beautiful Arcola Country Club Golf Course in Paramus, New Jersey.

Lucky number 13 was certainly lucky for the Foundation! After months of restrictions due to the Pandemic, the event was held with the restrictions that were required of players and participants as a total outdoor event.

The golf outing was the most successful that we had with more corporate sponsors and participants than ever before. This success was due to the efforts of the Golf Committee, consisting of Joseph Rumore, Louis Romano, Joel Aranson and Michael A. Linn.

Dr. Leslie Cooper was the anticipated guest speaker, but due to the COVID Pandemic, he was not able to participate. The Executive Director for the Foundation, Genevieve Rumore, stepped in and spoke about the recent issues and concerns that have surfaced about Covid-Myocarditis.

Many of the participants were repeat supporters, although there were many new faces to the event, all of whom we hope to see again next year.

The Myocarditis Foundation could not have provided this day of golf and fun without the support of our sponsors, participants, and volunteers. Many thanks to those who made this day possible and to everyone for supporting the Myocarditis Foundation!

VIRTUAL EVENT

In Memory of Austin

Austin Vonckx went off to college in August of 2014 to enjoy every minute of it with his friends, his classes, his dorm life, his "new found freedom, of sorts" being out on his own.

He would text or call his mom about the events of his day, but the one call he made in the wee hours of September 14th was different. He said that he had a headache, felt dizzy, and was really tired for the past few days. His mom thought that it was just a college freshman getting acclimated to everything new in his life and told him to make sure that he ate and got his sleep. They talked and laughed about the events of his day until 48 minutes into the conversation when his mom heard a gurgling noise and then silence. Austin was gone.

A healthy, young, active 19-year-old, taken in the prime of his life, by Viral Myocarditis.

His mom has worked continually on keeping his memory alive by spreading awareness to everyone that she can. She has had at least one fundraiser annually to raise funds for research with the goal of one day ending suffering and sudden death from this insidious disease. Austin has a saying that he was "going to eat life", meaning that he wanted to do everything he could do, join every club that he could join, make every friend he could make, etc. "Eat Life" is now the tagline that they use for all their fundraising events in memory of Austin.

Austin also practiced his signature from the time he could write.

When his mom went to get his things from school, she noticed a notebook with pages of his signature in it. She added his signature to the coffee mugs that they had made for their last event. Austin, your signature and tagline will live on forever along with your memory.

A huge "Thank You" to his mom Brenda Vonckx, for all that she does for the Myocarditis Foundation!

About Pericarditis

The Myocarditis Foundation often receives requests for information on Pericarditis, as it can be seen alongside Myocarditis in patients. To help those of you that are affected by Pericarditis, the Myocarditis Foundation has contracted with Inspire.com, for pericarditis sufferers , like myocarditis sufferers, to engage with others that are dealing with this rare, often not well understood disease.

Talk with others affected by Pericarditis by going to: ***Inspire.com/groups/pericarditis***

Also, just as there was no where for those affected by Myocarditis to turn to before 2005, when Candace Moose founded the Myocarditis Foundation, a woman who is affected by recurrent pericarditis is in the process of starting a pericarditis foundation called, the "Pericarditis Alliance." The website was recently launched, ***www.pericardiancealliance.org*** and Dr. Allan Klein, a cardiologist who specializes in pericardial diseases is on their Board of Directors.

Founded in 2020 by a team of volunteers, the Pericarditis Alliance provides a much-needed advocacy and information forum for pericarditis patients and healthcare providers. Their goal is to grant funding for ongoing research into pericarditis, to fund activities to educate patients and the healthcare community, and to provide a space for patients to find information about the disease. Pericarditis is classified as a rare disease, affecting three per 10,000 people annually. Approximately 15-30% of individuals that have pericarditis will experience the condition again; another small percentage of them will develop recurrent or chronic pericarditis. It is estimated that each year in the United States, 40,000-50,000 people suffer from chronic pericarditis.

MYOCARDITIS INFORMATION

An Overview of Pericarditis

Dr. Allan Klein, Cleveland Clinic

One of the types of heart inflammation the Myocarditis Foundation researches is called pericarditis. Very often, the best way to treat pericarditis is to address the condition that caused it – but first, you need to find out what that is. "Pericarditis has a variety of causes, some more common than others," says Dr. Allan Klein, M.D., Director of the Center for the Diagnosis and Treatment of Pericardial Diseases at Cleveland Clinic. "Understanding the causes is essential to treating the underlying condition."

An Overview of Pericarditis

Before exploring the causes, it helps to begin with an understanding of what pericarditis is. In short, pericarditis is inflammation of the pericardium, the thin protective membrane that surrounds and supports the heart. It often causes chest pain, shortness of breath, abnormal heart rhythms, and other potential symptoms as well. There are also several subtypes, including:

- Acute pericarditis: This form begins suddenly but typically does not have a long duration (less than 3 months). It can lead to recurrent pericarditis (improves after 4-6 weeks but then recurs) or incessant (lasts more than 4-6 weeks).
- Chronic pericarditis: This form can last for more than three months.
- Constrictive pericarditis: This form occurs when the pericarditis causes scar tissue and calcification. The bands of stiff, hard tissue compress the heart and prevent it from filling properly and cause heart failure.

Most cases are mild and can improve on their own, but more severe cases may require anti-inflammatory medication or even pericardiectomy. Early diagnosis is key to preventing long-term complications.

The Most Common Causes

According to Klein, the majority of pericarditis is caused by a viral illness. He estimates that about 80% of cases begin this way. The virus itself can be something as simple as a common cold or flu. If the virus gets into the bloodstream, it can travel to the heart and infect the pericardial tissue, causing inflammation and swelling.

Klein also estimates that another 5 percent of pericarditis cases occur after a cardiac injury. "For example," he says, "if you have open-heart surgery where the doctors have to open the pericardium, that surgical trauma can cause pericardial inflammation (post-pericardiotomy syndrome)." The injury might also be the result after a heart attack or other trauma such as an EP procedure (atrial fibrillation ablation, or pacemaker insertion).

Though viral infections and heart injuries are the most common causes of pericarditis, they're not the only possible sources. Autoimmune disorders like lupus, AIDS, tuberculosis, or rheumatoid arthritis are responsible for their fair share of cases. Other causes including cancer or hypothyroidism might be responsible for the inflammation.

Who Is at Risk?

Though they aren't causes of pericarditis by themselves, there are a few risk factors that can increase a person's chance of getting it. One major factor is steroid use. "If you introduce prednisone (Medrol dose pack) then take them away too quickly, the withdrawal can increase your risk," says Klein. Blood thinners can also cause bleeding inside the pericardium, resulting in hemorrhagic pericarditis.

Another at risk for recurrent pericarditis includes those that are undertreated the first time. "A lot of pericarditis we see will get better with time and medications such as NSAIDs, colchicine and sometimes prednisone," explains Klein, "but sometimes it can evolve into a more complicated condition." Those cases may need new biologic medications such as interleukin-1 blockers including anakinra or rilonacept.

Dear Donors to the Myocarditis Foundation,

The year 2020 will go down in the books as a very challenging year for the Myocarditis Foundation.

Not only the fact that fundraisers were cancelled due to the restrictions that the COVID Pandemic caused, but also that it added challenges to the disease itself, with so many suffering the effects of COVID Myocarditis and or fear of it.

So many around the world and especially within our country depend on us for direction. Our visitors to our website has reached over 30,000 monthly during the past few months, and many others call our Foundation Office and email us monthly with questions looking for any little bit of hope that their loved one can beat this disease.

We can't afford to stop carrying out our Mission of Education, Emotional Support of those affected by Myocarditis, and Funding Research for Myocarditis.

Many have told us how helpful it is to speak to someone who knows about the disease, who has been through the fight, or who can help them in finding where to turn to for answers.

Please help us continue our Mission by donating today.

Any charitable contributions you make for the rest of the year 2020, is eligible for a 100% tax deduction under the ***CARES Act legislation****.*

Thank You Very Much!

We Wish You All A Happy and Healthy New Year!

www.myocarditisfoundation.org

How Can I Help Spread The Word About Myocarditis and The Myocarditis Foundation?

Many of you have offered to help raise awareness about Myocarditis. We have put together some information that perhaps you could share with others at community functions, school functions, work functions, health fairs, just to name a few. While the world is still battling the Coronavirus, we may not be readily doing these events, but hopefully in the near future we will.

Please send me a note telling me of your interest.

I can share what I have written up and when you have an event where you'd like to share our information at, please let me know. We can send you pamphlets, etc. then.

Thank you for your interest and willingness to help.
Gen@myocarditisfoundation.org

Myocarditis Education On Our Website

Since early 2018 the Myocarditis Foundation has been working on getting Emergency Rooms across the country to participate in this free education on Myocarditis. Most Emergency Rooms contacted, felt that they could not ask their nurses to participate in any other education than the hospital required mandatory education. Thus, we are offering it to you independently, for your general knowledge and to improve your skills when caring for your patients, or when families and friends contact you for your help from time to time.

With so much happening in our world today related to viruses, we feel the need to share this extremely important information. Whether you work in the Triage Area of the Emergency Room, a Pediatrician or Family Practice Office, your own Independent Practice, or you are a nursing professional looking for information on the disease, **please go to our website www.myocarditisfoundation.org and under the heading of "For Clinicians and Researchers", click on "Learn More" and then click on "I'm a Healthcare Professional"**.

Thank you for wanting to expand your knowledge of Myocarditis and for your future ability to raise awareness of the disease with your colleagues, family and friends.

Because its early symptoms can mimic other viral diseases, Myocarditis remains a difficult disease to diagnose. But by utilizing these tools we believe that many more cases will be diagnosed early and can have much more positive outcomes for many.

Thanks very much,
Genevieve Rumore
Executive Director

MYOCARDITIS FOUNDATION

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Mailing Address
3518 Echo Mountain Dr., Kingwood, TX 77345
Telephone: (281) 713-2962
Fax (281) 608-7252

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