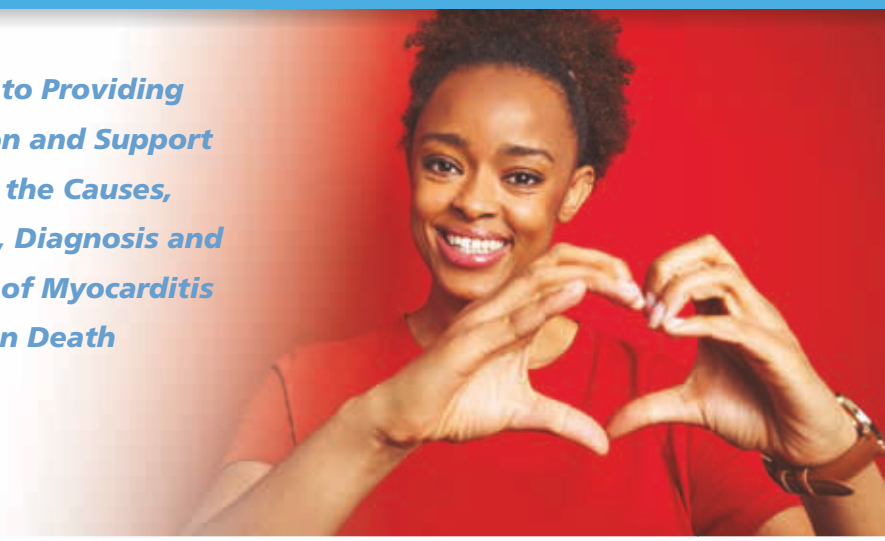
KNOWLEDGE NURTURES HOPE

SPRING 2022 / VOLUME 22 / NUMBER 1

MYOCARDITIS FOUNDATION

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



UPDATE ON COVID-19

# Long-term Cardiovascular Outcomes of COVID-19

Dr. Leslie Cooper discussed the findings of a recent study that found that people who were infected with COVID-19 are at an increased risk of heart disease, even a year after their recovery from infection. The study, published in Nature Medicine, (28, 583-590, 2022) reviewed the health records of more than 150,000 U.S. Veterans, and found that people with prior COVID-19 infections were 60% more likely to develop cardiac issues and was discussed in a recent Mayo Clinic Q&A Podcast.


In the Abstract, the cardiovascular complications of acute coronavirus disease 2019 (COVID-19) are well described, but the post-acute cardiovascular manifestations of COVID-19 have not yet been comprehensively characterized. In this study, it was shown that beyond the first 30 days after infection, individuals with COVID-19 are at an increased risk of incident cardiovascular disease spanning several categories, including **cerebrovascular disorders, dysrhythmias, ischemic** and **non-ischemic heart disease, pericarditis, myocarditis, heart failure** and **thromboembolic disease.**

These risks and burdens were evident even among individuals who were not hospitalized during the acute phase of the infection and increased in a graded fashion according to the care setting during the acute phase (non-hospitalized, hospitalized, and those admitted to intensive care.)

These results provided evidence that the risk and 1-year burden of cardiovascular disease in survivors of acute COVID-19 are substantial. Care pathways of those surviving the acute episode of COVID-19 should include attention to cardiovascular health and disease.

It is extremely important to listen to your body and not to continue to push yourself through any illness, especially after having had COVID-19, without getting it checked out by a medical provider. There is not much known about this, but what is known is that there has been risks and burdens that are evident and should not be overlooked.

RECENT STUDY

# Clinical Guidance on Cardiovascular Consequences of COVID-19

*Read More on this Topic by the American College of Cardiology*

The American College of Cardiology (ACC) has issued an expert consensus clinical guidance document for the evaluation and management of adults with key cardiovascular consequences of COVID-19. This clinical guidance was published in the March 16, 2022 online version of the Journal of the American College of Cardiology.

The document makes recommendations on how to evaluate and manage COVID-associated Myocarditis, Long-COVID, and gives advice on the resumption of exercise following COVID-19 infection. Dr. Ty Gluckman, MD, and co-chair of the expert consensus decision pathway, reported that the best means to diagnose and treat myocarditis and Long-COVID following acute infection, continues to evolve.

The authors of the Guidance, per Medscape Medical News, March 17, 2022, note that COVID-19 can be associated with various abnormalities in cardiac testing and a wide range of cardiac complications. For some, cardiac symptoms of chest pain, shortness of breath, fatigue and palpitations can persist, lasting months after the initial illness, and evidence of myocardial injury has also been seen in both those symptomatic and asymptomatic individuals, as well as after the receipt of the COVID-19 mRNA vaccine.

For clinicians treating these individuals, a growing number of questions exist related to the evaluation and management of these conditions, as well as safe resumption of physical activity. Their report is intended to provide practical guidance on these issues.

As for myocarditis, the report recognizes it as a rare but serious complication of COVID- 19 as well as the COVID-19 mRNA vaccine.

It defines myocarditis as:

- Cardiac symptoms such as chest pain, difficulty breathing, palpitations or syncope
- Elevated cardiac Troponin level
- Abnormal EKG, Echocardiogram, Cardiac MRI, and/or histopathologic findings on Biopsy.

The document makes the following recommendations in regard to COVID-related myocarditis:

- When there is increased suspicion for cardiac involvement in regard to COVID- 19, initial testing should consist of an EKG, measurement of cardiac Troponin, and an Echocardiogram. Cardiology consultation is recommended for those with a rising cardiac Troponin and/or echocardiographic abnormalities. Cardiac MRI is recommended in hemodynamically stable patients with suspected myocarditis.
- Hospitalization is recommended for patients with definite myocarditis, ideally at an advanced heart failure center. Patients with fulminant myocarditis should be managed at centers with an expertise in advanced heart failure, mechanical circulatory support, and other advanced therapies.
- Patients with myocarditis and COVID-19 pneumonia (with an ongoing need for supplemental oxygen) should be treated with corticosteroids. For patients with suspected pericardial involvement, treatment with NSAIDs, colchicine, and/or prednisone is reasonable. Intravenous corticosteroids may be considered in those with suspected or confirmed COVID-19 myocarditis with hemodynamic compromise or MIS-A (multisystem inflammatory syndrome in adults). Empiric use of corticosteroids may also be considered in those with biopsy evidence of severe myocardial infiltrates or fulminant myocarditis, balanced against infection risk.
- As appropriate, guideline-directed medical therapy for heart failure should be initiated and continued after discharge.

The document notes that myocarditis following COVID-19 mRNA vaccination is rare, with highest rates seen in young males after the second vaccine dose. As of May 22, 2021, the US Vaccine Adverse Event Reporting System noted rates of 40.6 cases per million after the second vaccine dose among male individuals aged 12-29 years and 2.4 cases per million among male individuals aged 30 and older. Corresponding rates in female individuals were 4.2 and 1 cases per million, respectively.

In addition, as of February 22,2022, The Centers for Disease Control and Prevention updated its COVID-19 vaccine guidance to recommend that some Americans over the age of 12 who have received a first mRNA vaccine dose, wait up to eight weeks before getting their second dose, instead of the previously recommended three to four.

Several studies suggest that an extended interval between initial dosing may help improve vaccine effectiveness and decrease the small, but potential risk of myocarditis, a rare form of heart inflammation that occurs after vaccination, the agency wrote.

# COVID-19 Myocarditis in Children

***UPDATED ARTICLE FEBRUARY 8, 2022 FROM ORIGINAL OCTOBER 2021 POSTING***

Myocarditis is uncommon in children but occurs more commonly among those with COVID-19. In a recent study published in the Morbidity and Mortality Weekly Report from the Centers for Disease Control (CDC), only 86 children <16 years of age were diagnosed with myocarditis among nearly 65,000 (0.133%) children with COVID-19. During the same time period (March 2020-January 2021), 132 out of nearly 4 million children without COVID-19 developed myocarditis. Although the overall risk was low, the data translate to a risk of myocarditis that is more than 30 times higher among COVID-19 patients. The study reviewed health encounters of more than 900 US hospitals and excluded any patients who had received a COVID-19 vaccine. The methods used for making a diagnosis of myocarditis were not described.

The study also found that COVID-19 patients <16 years of age had a risk of myocarditis similar to that of patients >75 years of age but much greater than all other age groups. In addition, the risk difference for myocarditis was increased in males compared to females. The numbers of cases of COVID-19 myocarditis spiked in April 2020 and again during the COVID-19 surge of December 2020.

The study investigators speculate that the diagnosis of myocarditis among patients <16 years of age may represent cases of the multisystem inflammatory syndrome in children (MIS-C). MIS-C is a clinical syndrome that usually occurs 2-4 weeks after infection with the SARS- CoV-2 coronavirus. It usually manifests with fever, rash, swollen lymph glands and conjunctivitis. In some patients cardiovascular complications are seen including shock, coronary artery dilation and depressed ventricular function. Fortunately, most children who develop MIS-C will recover without chronic cardiac disease.

When SARS-CoV-2 virus infects the muscle cells of the heart, it begins to replicate and damage the cell. The body's immune system is activated and sends lymphocytes and other white blood cells to infected tissues, causing inflammation and producing antibodies against the virus. In some patients, the immune system's response may cause more local tissue injury than the virus itself. Myocardial edema (tissue swelling) with decreased heart function and arrhythmias can result.

The impact of COVID-19 on the heart and the much higher risk of myocarditis among patients with COVID-19 compared to patients without COVID-19 underscores the importance of prevention of spread of the virus. Vaccines against SARS-CoV-2 have been demonstrated to be safe and effective at preventing serious infection. In May 2021, a study published in the New England Journal of Medicine reported a vaccine efficacy of 100% among more than 1,000 fully vaccinated children age 12 to 15 years of age. The children were followed up to 6 months from the second dose. This study was performed prior to the arrival of the Omicron variant and more recent experience in children infected with this variant show that breakthrough infections do occur. Unfortunately, peer-reviewed published data for the efficacy of the vaccine against the Omicron variant are lacking at this time. A larger study of 2,200 vaccinated children 5 to 11 years of age found the vaccine to be safe and had an efficacy of 91%. Currently, the American Academy of Pediatrics and the CDC recommend that all adolescents ages 5 and older receive the COVID-19 vaccine.

*Jack F. Price, MD, FAAP, FACC. Professor of Pediatrics*
*Baylor College of Medicine Texas Children's Hospital Houston, TX*

Recently, rare cases of vaccine-associated myocarditis have been reported in adolescent males usually following the second dose. These boys typically present with complaints of chest pain with or without elevated troponin levels in the blood. As of June 2021, the Vaccine Adverse Event Reporting System (VAERS) reported 1,226 cases of myocarditis after COVID-19 vaccination. The median age was 26 years and the median time to onset of symptoms was 3 days after the vaccination. Cases were reported after both the Pfizer- BioNTech and Moderna vaccines. Among a subset of 323 patients determined to have myocarditis after the vaccines, the vast majority were male (90%) with mild clinical cases and none had died. Upon reviewing the evidence of myocarditis after the vaccine, the Advisory Committee on Immunization Practices of the CDC determined that the benefits of the mRNA COVID-19 vaccines clearly outweigh any risks.

The question of when is it safe for children to return to playing sports and physical activity has received a great deal of attention during the pandemic. The American Academy of Pediatrics has created guidance for pediatricians when recommending return to play for children who developed COVID-19. In general, children who never developed symptoms (chest pain, palpitations, shortness of breath, fainting) while infected may return to play following a period of quarantine. It is recommended that the primary care physician assess the child at least once. For children who were symptomatic, return to activity depends on the severity and resolution of symptoms and may range from 10 days to 6 months. Parents should seek the advice of their primary care team before allowing their child to return to physical activity.

EDUCATION

# Pericarditis Information

While many people have pericarditis, medical professionals are still researching the most effective ways to diagnose and treat the condition. Given these circumstances, it is crucial for those with the condition to understand its complications.

**Pericarditis Symptoms**

Pericarditis stems from an inflammation of the pericardium, a thin sac filled with fluid that guards the heart against infection. When the pericardium is inflamed, its two layers rub against each other and cause chest pain.

Most people feel an intense, stabbing pain with pericarditis, but some experience dull pressure in their chest. This discomfort typically begins on the left side of your breast or behind your breastbone, but it may travel to your neck or left shoulder. Individuals often say that the severity of their pain increases if they take a deep breath, cough, or lie down and decreases if they sit upright or lean forward.

Although chest pain is the most widespread indicator of pericarditis, people experience other signs, as well. Depending on what type of pericarditis you have, you may experience the following additional symptoms:

- Back, neck, or shoulder pain
- Breathing problems when lying down
- Dry cough
- Fatigue or weakness
- Heart palpitations
- Low-grade fever
- Swelling in the abdomen or legs
- Anxiety

**Pericarditis Complications**

If you neglect to seek treatment for pericarditis, your symptoms can transform into long- term health issues with severe implications. Some of the most common complications of pericarditis include:

**Cardiac Tamponade**

This condition occurs when too much fluid enters the pericardium, putting pressure on your heart and prohibiting it from filling correctly. In turn, less blood exits your heart, and you experience a significant drop in blood. Usually, individuals with cancers or tuberculosis develop cardiac tamponade. Those affected by this serious complication may have trouble seeing and feel nauseous or weak. If you have pericarditis and notice these symptoms, seek immediate medical assistance.

**Pericardial Effusion**

Pericardial effusion happens when fluid accumulates in the space between the pericardium. As with cardiac tamponade, this condition puts pressure on the heart and keeps it from pumping correctly. Pericardial effusion can develop quickly or over time and usually comes with chest pain, breathing troubles, nausea, and faintness. If left untreated, pericardial effusion can lead to shock or other serious complications.

**Infection**

Sometimes, bacteria will cause or complicate pericarditis. In these cases, health conditions in other parts of the body can prompt an infection in the heart. Bacterial infection can also trigger an abscess, or an uncomfortable build-up of pus, in the pericardium or heart.

**Myopericarditis**

You may develop myopericarditis if you have an inflamed myocardium or cardiac tissue damage from a heart attack. This life-threatening complication, which is also referred to as post-myocardial infarction and post-heart attack pericarditis, can lead to chronic heart failure and even death.

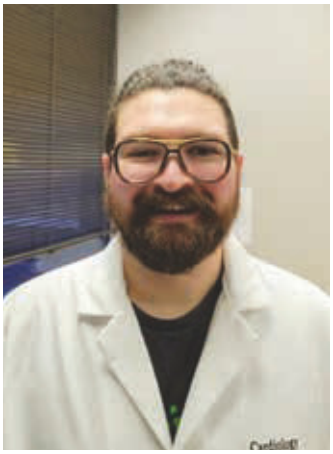
EVENTS

# Health Fair at Kingwood Middle School

On Tuesday March 22nd, the Myocarditis Foundation participated in a Community Health Fair at one of the Middle Schools here in Kingwood, Texas. This was the first event of its kind in 10 years, per Devon Drew, the organizer of the event and the 7th and 8th grade Girl's Health Athletic Coach at Kingwood Middle School. She was excited to see the participation from the community and hopes to keep this event ongoing in the future.

32 Local Businesses participated offering various health information and conducting health screenings for the attendees. This was a great opportunity for the Myocarditis Foundation to get involved in the local community, creating awareness not only about the Foundation and what we do but also to educate parents and middle school age children about the disease.

# Myocarditis Foundation 2021 Fellowship Grant Recipients Announced



*Dr. Andrew Koenig, PhD*

The Myocarditis Foundation is proud to announce that we have two 2021 Fellowship Grant Recipients, Dr. Andrew Koenig, PhD, from Washington University in Saint Louis and Dr. Tahir Kafil, MD, from the Ottawa Heart Institute, in Canada.

Dr. Koenig's research study is titled: ***"Defining the Spatial Proteomic and Transcriptomic Landscape of Myocarditis."*** This Fellowship Grant will be named for Sarah Knight, a 25-year-old bi-lingual kindergarten teacher, who was a victim of Viral Myocarditis. Due to the generosity of her family and friends, this is the second grant to be named for her. They believe that myocarditis research is the key to finding the answers and putting a halt to the disease that takes so many young and otherwise healthy unsuspecting people.

Dr. Koenig's preceptor of myocarditis research is Dr. Kory Lavine, MD, PhD, also from Washington University in Saint Louis.

Dr. Koenig is our 22nd Fellowship Grant Recipient and here is his layman's description of his research:

*Myocarditis is a life-threatening disease and an underdiagnosed cause of acute heart failure and sudden death. In addition to viral, there are a number of different kinds of myocarditis.*

Dr. Kafil's research study is titled: ***"COVID-19 Vaccine-induced Inflammatory Heart Disease Registry and Prospective Cohort Study. (COVID-VIHPR)"*** This Fellowship Grant will be named for Ashley Burgauer, a 27-year-old registered nurse, who was a victim of Viral Myocarditis. Due to the generosity of her family and friends, this grant is being named for her. Her family have made it a passion of theirs to make people aware of this disease and support research to help stop the devastation to families that it causes.

Dr. Kafil's preceptor of myocarditis research is Dr. Peter Liu, MD, also from the Ottawa Heart Institute.

Dr. Kafil is our 23rd Fellowship Grant recipient and here is his layman's description of his research:

*"Myocarditis and pericarditis are inflammatory conditions of the heart muscle and lining. They can occur after viral infections and can occur in patients who are infected by COVID-19. Recently, myocarditis has also been reported following mRNA vaccines for COVID-19. The mRNA vaccines are effective in preventing ICU admissions and deaths from COVID-19 infection. One of their rare side-effects can be myocarditis or pericarditis. Our study is designed to determine the natural history, diagnostic work up, immunological profile, biomarker predictors and sex differences in these conditions."*

*Dr. Tahir Kafil, MD*

***Our congratulations to Dr. Andrew Koenig, PhD and Dr. Tahir Kafil, MD and many thanks for your work in myocarditis research!***

The room was buzzing with the flurry of activity at each booth. The Foundation had a carousel wheel with various colors. Each color had a specific question about the heart and the inflammatory heart diseases, Myocarditis and Pericarditis. After a brief educational lesson on the heart and myocarditis, each person had a chance to spin the wheel, answer a question and win a prize. (Stress ball hearts, heart magnetic clips, Myocarditis Foundation bracelets, and of course stickers and candy!) Everyone was a winner in a multitude of ways.

The Foundation also had invitations to speak at 3 various company's future events and share this much needed information with others.

It was a wonderful evening for all involved!

***If you'd like to participate in events within your community and share this much needed information on myocarditis with others, please email: Melissa@ myocarditisfoundation.org or visit our website for ideas on how to get involved.***

EVENTS

## Brother Honors Brother, a Giant Cell Myocarditis Survivor

When Jackson DeBusschere was 13, he suffered a shocking, unexpected medical crisis. In just a week, he went from being an active student athlete participating in a soccer tournament to needing life support. It was the result of an extremely rare and life-threatening disorder known as giant cell myocarditis. After a long journey, Jackson is now a typical 19-year-old who enjoys sports and is planning for his future.

Jackson is currently a freshman at Cornell University and on the golf team there!

Jackson's battle to overcome Giant Cell Myocarditis was his brother Tyler's inspiration for creating this fundraiser, ultimately supporting the two organizations that were critical in helping our family and Jackson with his road to recovery. Tyler is also an aspiring cardiologist as a result of Jackson's experience and wants to be able to help others in healing their hearts.

With the golf season upon us, Tyler DeBusschere is planning on a second year of Hope Fore! Hearts. Tyler, currently a junior at Strath Haven High School in Wallingford, PA. and a competitive golfer, will be playing in various junior tournaments from March through November all across the Mid-Atlantic region. Giving back to the community and those that have helped his family, is a passion of his, so once again, he wants his golf game to go toward a greater cause - and he needs your help.

Hopefully Tyler will be able to match his birdie (or better) count from last year.

The updated 2022 flyer with fundraiser information and the link to his website can be found here

**hope-fore-hearts.jimdosite.com**

EVENTS

## Sarah Knight 10th Annual Golf Outing Fundraiser

On September 26, 2011, one word – Myocarditis – changed their lives forever. At the time, they did not know the disease or how it steals the lives of children and young adults without symptoms or warning. Now the word strikes fear and sadness in their hearts.

Establishing the Sarah Knight Memorial Foundation in Sarah's honor has helped her family heal and find a way to continue Sarah's legacy. Each year they host a benefit golf tournament to raise funds to further Myocarditis research and fund a scholarship at Sarah's alma mater, Western Illinois University. In nine years they have funded two $40,000 Myocarditis Foundation research grants and are well on their way to funding a third. This year, Sarah's last kindergarten students from Hillcrest Elementary, will be High School Seniors, and perhaps one of them will be directly impacted by "Miss Knight" again.

Dr. Leslie Cooper will be in attendance and speaking to the attendees. If you are in the area, or can be, think about joining the Knight Family at Hunters Ridge Golf Course in Marion, Iowa on June 10th!

To find out more information on the event or to make a donation, go to: **sarahelizabethknight.com**

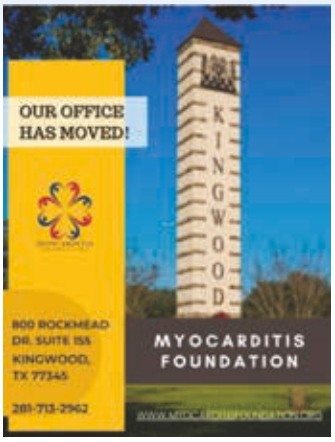
EXCITING NEWS!

## The Myocarditis Foundation has moved to a larger office!

**After 8 years in our previous office, we felt ourselves bulging at the seams. We are now located in the front of Kingwood and more convenient to get to from all the highways.**

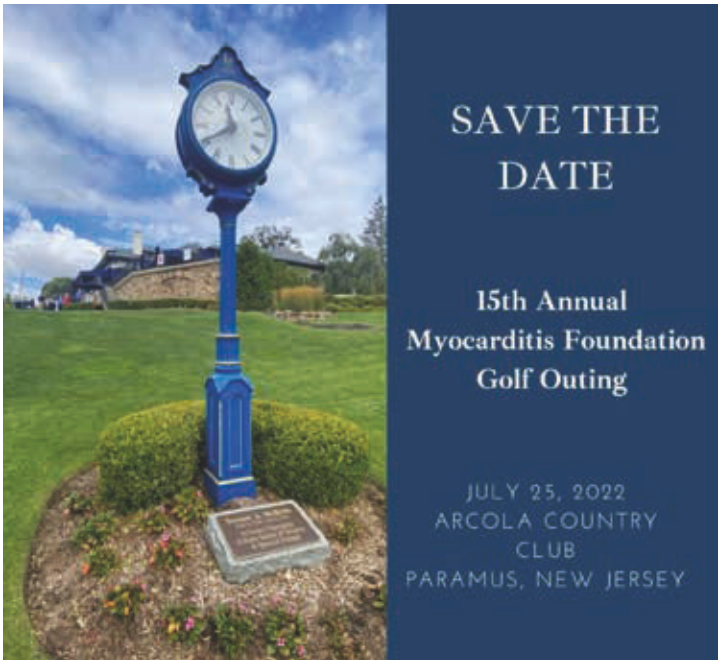
**Our new address is:**
**The Myocarditis Foundation**
**800 Rockmead Drive, Suite 155**
**Kingwood, Texas 77339**

***Please make a note of our new address and stop in to say hi if you are in the area!***



EVENTS

# Myocarditis Foundation 15th Annual Golf Outing




Joseph Rumore, wanting to give back and raise awareness for the disease that took is own heart in 2006, started this golf outing in 2008, as a way to educate others and raise funds for myocarditis research.

Many supporters of the Foundation, friends of Joe's, have attended annually and have brought in many of their own friends who are now supporters of this "looked forward to" event. It has grown annually and has maxed out players the past two years. We recommend that if you are looking to participate in this popular event, you let us know as soon as possible.

Dr. Leslie Cooper will be present at this golf event as well. Maybe we can get him to even "play a few holes" with the participants!

EVENTS

# Kingwood, Texas Education/Awareness Event

On Sunday, February 20th, the Myocarditis Foundation held an Educational Event to raise awareness for Myocarditis. Local businesses and philanthropists supported the event at Kingwood Country Club for 75 local community members.

Gary Kubera, Chairman of the Houston Chapter, spoke on where the Foundation has been, where we are now, and where we are looking to be so that we can put a halt to this dreaded disease that often insidiously attacks people of all ages, but mainly children and young adults.

Genevieve Rumore, a RN and Executive Director of the Foundation, spoke on the Foundation's Mission of Education, Funding Research specific to Myocarditis, and Emotionally Supporting those affected by the disease, with the Goal of "saving lives". The Foundation office in Kingwood, which is a suburb of Houston, receives and answers emails and calls from around the world 24 hours a day and 7 days a week. She reported that over 100,000 people visit the website www.myocarditisfoundation.org a month, with most being new visitors seeking information on the disease. She encouraged the attendees to pay attention to all chest pain, palpitations, and shortness of breath, and have them medically evaluated. Ask, "Could this be Myocarditis?" of your doctors if you have continued or worsening of "viral type symptoms". Advocating for yourself and your loved ones is extremely important in the early diagnosis of the disease.

Dr. Leslie Cooper, Adult Medical Director and Co-founder of the Myocarditis Foundation, along with Dr. Jack Price, our Pediatric Medical Director, spoke on Myocarditis and COVID Myocarditis.

A 21-year-old survivor, De'Aveun Bonds, and his mom Shanee Bonds-Banks, told his amazing story of how he collapsed on the football field, was defibrillated, given CPR, and had a 1% chance of survival, when initially diagnosed in 2016 with Giant Cell Myocarditis. Because of the school staff's immediate reaction and care, and the knowledge and treatment by the doctors once hospitalized, he was here today to share his amazing story.

The afternoon ended with many happy winners going home with the 18 Silent Auction baskets, that helped raise funds to support the Foundation, thanks to the generosity of local businesses.

*De'Aveun Bonds with Gen and Joe Rumore*

The Myocarditis Foundation sincerely thanks all those who help support this event and allowed us the ability to raise awareness and educate people and Emergency Room nurses on Myocarditis. A special thank you to the Kingwood Country Club and its workers who did a stellar job and even donated their tips to help the Myocarditis Foundation.

# MYOCARDITIS FOUNDATION

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