MYOCARDITIS FOUNDATION

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

Mailing Address

The Myocarditis Foundation has moved its business operations to Kingwood, Texas.
Please use the below address for all future mail and correspondence.

The Myocarditis Foundation
3518 Echo Mountain Dr., Kingwood, TX 77345
Telephone: (281) 713-2962

Find us online: www.myocarditisfoundation.org

twitter
twitter.com/myocarditisfndn

YouTube
youtube.com/user/Myocarditisfndn

facebook.com/pages/Myocarditis-Foundation/314590715549

MYOCARDITIS FOUNDATION

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

FAMILY/RESEARCHER MEETING

The 4th Annual Myocarditis Foundation Family Support/Research Meeting to be held September 16th and 17th at the Gaylord Palms in Orlando, Florida

This year we plan on reaching out to even more families and survivors of Myocarditis at our 4th Annual meeting that will be held again in conjunction with the Heart Failure Society of America (HFSA). We are planning for 100 attendees and will be able to only hold spots for the first 100 that register. We are planning again for meals on Friday evening and all day Saturday (breakfast, lunch, dinner).

The weekend will start on Friday September 16th with a welcome dinner, followed by a prayer vigil to remember all those who have been affected (survivors and victims) by myocarditis.

On Saturday September 17th, we will again have our physician specialists, family speakers and two previous researchers all speak on Myocarditis.

We will wrap up the weekend of comradery with a relaxing dinner at a local restaurant.

We look forward to seeing our old friends as well as meeting those whom we only know through phone, email and social media contacts. Please consider joining us for a weekend of healing, support, education and relaxation.

Consider extending your visit to enjoy the surrounding opportunities for fun as well.

The Registration Fee is $100.00 per person.

The Myocarditis Foundation
3518 Echo Mountain Drive
Kingwood, Texas 77345

If you choose to use a credit card, the Registration will be $105.00 to cover our credit card fees.

Your donation is 100% tax-deductable.

Please contact Gen at the Foundation office with any questions.

(281) 713-2962 or
gen@myocarditisfoundation.org

You can also place an ad in our Journal with your loved ones' story, or even just a picture and remembrance.

If you know of any businesses that might wish to help support us by placing an ad or use a business card, etc. for their ad, please see the enclosed flyer. These will help offset the costs of the weekend to the Myocarditis Foundation.

The Myocarditis Foundation is hosting their 4th Annual Patient, Family and Research Meeting in conjunction with the Heart Failure Society (HFSA) Annual Scientific Meeting in Orlando, Florida, on September 16 and 17, 2016. Our meeting brings together the patients and families that have suffered from the disease, doctors who treat the disease, and researchers who are advancing our understanding of the disease. We expect 100 participants at our meeting.

The Myocarditis Foundation, celebrating its 11 Year Anniversary in 2016, strives to save lives by pursing our mission of educating the public and physicians about the disease, supporting patients and families affected by the disease, and funding research to find answers. Please consider helping our mission by placing an advertisement in our program brochure. The Myocarditis Foundation welcomes advertisements from businesses as well as family members who choose to send messages of remembrance, gratitude, or inspiration.

Please email your ad to **Gen@myocarditisfoundation.org** in a PDF Format. Deadline for all submissions is July 21st. Checks should be mailed and made out to: **The Myocarditis Foundation** and mailed to **3518 Echo Mountain Drive, Kingwood, Texas 77345**

Back Page	**$1500**	**8" X 5"**
Inside Cover Pages	**$1000**	**8 "X 5"**
Full Page	**$100**	**8 "X 5"**
Half Page	**$50**	**3.875" X 5"**

The full amount of all ads and any additional donations are tax deductible.

www.myocarditisfoundation.org

Dr. Leslie Cooper's Speaking Schedule

2016

January 8th
Cardiology Rounds at Mayo
Rochester, MN

January 22nd
Cardiology Rounds at
University of Utah
Salt Lake City, UT

March 7th
Cardiology Rounds Oakland
University School of Medicine
William Beaumont Hospital
Royal Oak, MI

March 16-18th
Mayo Heart Failure Course
Lake Buena Vista, FLA

March 30th
Cardiology Rounds,
University of Vermont
Burlington, VT

April 3rd
American College of Cardiology
Chicago, ILL

April 12-17th
Asia-Pacific Heart Failure Meeting
South Korea

June 20th
First Annual MF Gala
New York City, NY

2016 EVENTS

January 30th
3rd Annual Quinn's Cup
Edina, MN

February 9th
MF Awareness Event
Southern California

February 29th
Rare Disease Week
Washington, D.C.

May 15th
Paint the Town Rhett
Elgin, Illinois

June 10th
Sarah Knight Golf Outing
Marion, Iowa

June 20th
First Annual MF Gala
New York City

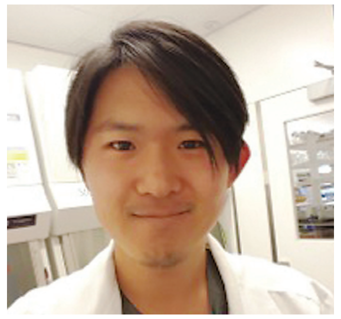
July 17th
Badwal Family 10K Run
London, England

August 1st
9th Annual Rumore/Romano
Golf Outing
New Jersey

September 16th – 17th
4th Annual Family Support/
Researcher Meeting at the
Gaylord Palm Resort
Orlando, Florida

MYOCARDITIS RESEARCHERS

Meet Two of our Myocarditis Researchers



Dr. Jon Sin

Our 2015 Myocarditis Foundation Fellowship Research Grant recipient is Dr. Jon Sin, PhD, of Cedars-Sinai Medical Center. Dr. Sin, under the mentorship of Dr. Ralph Feuer, will be conducting his research project on "Coxsackievirus B Subverts Host Mitophagy to Promote Viral Dissemination and Myocarditis." Coxsackievirus B (CVB) is a common juvenile pathogen that can cause a wide array of inflammatory diseases including myocarditis.

Dr. Sin gave the following response when asked how he became interested in the study of myocarditis research:

"I have been interested in biology ever since I took AP Biology in high school; therefore it was a no-brainer for me to major in biology during my undergraduate studies at the University of California, San Diego. It was here that I had my first exposure to research when I volunteered at the VA in La Jolla and studied Parkinson's Disease. This immediately instilled in me the desire to uncover the mysteries that surround diseases that plague mankind. This path eventually led me to pursue my PhD as I researched viral infections of the heart that result in devastating diseases such as myocarditis and heart failure. Teasing apart the mechanisms by which viruses establish infections in the heart is very fascinating to me, but discovering new potential antiviral therapies is the truly rewarding aspect of my work.

As much as I enjoy my time in the lab, I like to spend my free time on hobbies such as drawing, playing blues music, and visiting the beach, as I soak in the warm southern California sun!"

Dr. Kathleen Simpson, M.D.

One of our 2010 Myocarditis Foundation Fellowship Grant Recipients, Dr. Kathleen Simpson, M.D., of the University of Washington in St. Louis, School of Medicine, was under the mentorship of Dr. Charles Canter, M.D. when she did her research on "Autoimmunity in Pediatric Myocarditis: A Pilot Study."

Dr. Simpson gave the following response when asked how she became interested in the study of myocarditis research:

My interest in pediatric cardiology, and specifically heart failure patients, stems from an appreciation of the fascinating physiology and anatomy involved in caring for children with complex heart disease. After taking care of several children with myocarditis and associated cardiomyopathy, I became interested in better understanding how and why certain children develop myocarditis after exposure to common childhood viruses. Through funding from a research grant from the Myocarditis Foundation, I was able to conduct a research study among several regional children's hospitals to investigate the possible relationship between immune system activation at diagnosis and recovery of normal heart function over time." Dr. Simpson remains involved in Pediatric Cardiology and Myocarditis Research, and recently had another publication, on pediatric myocarditis in the 2016 Journal of Pediatric Cardiology 37:399-404.

We hope that you can attend our 4th Annual Family Support and Researcher Meeting on September 17th at the Gaylord Palms in Orlando Florida, and hear these two dedicated researchers first hand, speak about their research and answer any questions that you might have about it.

EVENT

Sarah Knight Golf Outing

Sarah Knight was a young bi-lingual kindergarten teacher when she became a victim of Viral Myocarditis in September of 2011. Her family started the Sarah Knight Memorial Golf Tournament to raise funds for the Myocarditis Foundation as well as support the Sarah Knight Memorial Scholarship at Western Illinois University. The scholarship is available to bi-lingual bi-cultural elementary education majors.

Sarah's time in the classroom was short, however, her ability to impact young lives endures forever.

SAVE THE DATE
4th Annual Sarah Knight
Memorial Golf Tournament
JUNE 10, 2016
Hunters Ridge Golf Course
Marion, Iowa
Proceeds support the Myocarditis Foundation
and Sarah Knight Memorial Scholarship
See photos from our 2015 event at
www.sarahelizabethknight.com

EVENTS

Myocarditis Foundation Announces Gala Fundraiser in New York City

Matthew, age 12, showing his positive attitude

We are proud to announce that on Monday, June 20, 2016, The Myocarditis Foundation will be hosting its first gala to raise funds to further research a cure and awareness for this often unheard of deadly disease. The event will take place at The Mandarin Oriental Hotel at Columbus Circle in Manhattan. This event will be unlike any other we have held in the past. With its magnificent views of Central Park from the 36th floor ballroom, The Mandarin Oriental will be the perfect way to kick off what we hope to be the first of many major events for the Foundation.

Not only will this gala be a poignant look at this disease, but we will have fun with our silent and live auctions, and music throughout the evening. For those of you who can not attend, make sure to go to our website around 7pm on June 20th. The presentation portion of our gala will be live streamed through our website.

We are currently working on securing our corporate sponsors for the evening. Once this is finalized we will update our website with information on how to go about purchasing tickets. We would love to have our Foundation members join us for this memorable evening. It would be wonderful to see our corporate sponsors and guests have a chance to meet so many wonderful Myocarditis supporters and survivors. You may also contact Lauren Stanco from LCR Events at **914-646-4514 or info@lcrevents.com** to get more information on how to attend, donate an auction item or make a contribution.

Board member, Christopher Corso is the Chairman of this event. This event was crafted to raise awareness for the disease after Christopher's 12-year-old son, Matthew became suddenly ill in May of 2015 with symptoms confusing to many doctors. He was finally diagnosed with Myocarditis which has changed his life. Luckily for Matthew, he won his battle with the disease. Every day he continues to recover from his complications with the illness but, as we know, many others have not been so lucky.

Christopher shared that the emotional support that he received when he reached out the the Foundation last May, impacted him immensely. Christopher attended the Family Support Meeting in September 2015, met with the Board, and decided to join the Myocarditis Foundation. Working towards putting an end to this disease through education and research is what he wants to help us do.

The following are Christopher's thoughts about his experience with Myocarditis and how it became a huge part of his life…

"Life to me is nothing but a test, a ride at a theme park, a journey that you decide if you take a left or right turn…the old cliché, it's what you make of it.

I have always tried to approach life with a focus, I am the type of person who has a lot of confidence, like to lead by example, don't mind marching to my own beat, and definitely live my life with the theme of "never grow up." I try and be positive with a never give up attitude; I always root for the underdog. I try and make good decisions that are well thought out and try not to ever second guess myself on the decisions made. Learn from your mistakes and enjoy life and what you have, not what you don't. Bottom line, life is too short.

All of the above got tested, in May of 2015. My life was turned upside down by the awful disease, Myocarditis. My 12-year-old son, Matthew, became ill and our journey to fight this disease began with a never give up approach. That journey continues today for our family with Matthew's continued recovery. We are extremely thankful to position ourselves against this battle by joining forces with the Myocarditis Foundation. I think we all can agree, that a team approach has a more effective impact than an individual. Not only did I want to help the MF team, but decided to take the battle to another level and join the board with a focus on an annual fundraiser.

Working with my fellow board members and key contacts within my industry of insurance and reinsurance, the event is being positively supported. We are spreading the word about the Myocarditis Foundation, our mission, raising awareness and generating funds in the battle to find a cure. Every day that I come home and tell Matthew that another company or sponsor has joined our battle, he looks over at me and smiles. That smile is the same smile that he showed to me, the nursing staff, doctors, and family during his 30 days in ICU and recovery. It perfectly sums up his approach to life.

Because of Matthew's battle, I have realized how important life really is. Through successful research we can someday prevent the next 12-year-old from being rushed to the Emergency room because we will have found a cure, or alternatively when they arrive at the hospital, we will have found a much more effective way to diagnose and treat Myocarditis. I am confident someday this will occur, with your help – sooner verses later. The Myocarditis Foundation is leading by example and we appreciate your support and interest in being part of the team to fight this battle. Every gala, brownie sale, walkathon, swim event, golf outing, hockey tournament, all contribute to the goal of finding a cure, down to the last penny."

ANNOUNCEMENT

Novel ways to Make Donations to Further our Mission

Micah Vanness, a 2nd grader in Kewaunee, Wisconsin, turned 8 years old on January 22nd . Like any other child he wanted to have a big birthday party with lots of friends invited. Micah and his mom, Amber, talked about not receiving gifts for his birthday this year, but instead he could ask his friends to make a monetary donation to the Myocarditis Foundation in memory of his cousin Brad Vanness. Micah didn't even think twice about it and was more than willing to do this!

Even though Micah was only 2 years old when his cousin Brad passed away from Viral Myocarditis, his mom and Micah say prayers every night to "Bless Brad."

Micah's friends were more than happy to donate to a great cause. Micah's Uncle Randy Vanness (Brad's father), was so thankful when Micah told him what he had asked for in place of gifts, but Uncle Randy was even more shocked with the donation to the Myocarditis Foundation!

A very big Thank You to Micah and his mom for their generosity and selflessness to help others.

Micah with his Uncle Randy

Helping Get Christmas Wrapped Up for Others

Brenda Vonckx, who lost her 19-year-old son Austin to Sudden Death from Viral Myocarditis in September 2014, felt she needed a distraction as the second Christmas without her son was approaching. On a whim, she went to her neighborhood Facebook page and asked if anyone would be interested in having their gifts wrapped in exchange for a donation to the Myocarditis Foundation. The response was overwhelming. Over the course of 2 weeks, she wrapped more than 500 gifts, raising $900.00 for the Myocarditis Foundation. She feels that this year promises to be bigger and better.

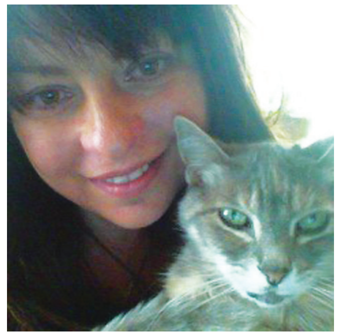
Bake Sale during Community Yard Sale

Brenda also is planning a bake sale to coincide with her community's biannual garage sale on April 9. Neighbors are already signing up to donate sweet treats for the event, and a friend of Austin's was able to get a cotton candy machine donated for the day.

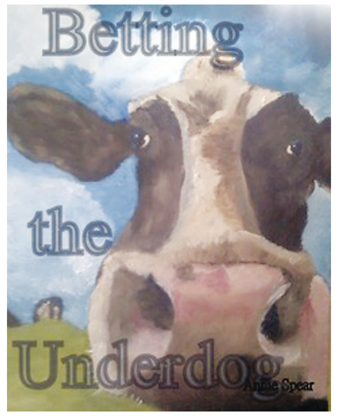
ONE BRAVE YOUNG WOMAN'S STORY

Betting the Underdog

Annie Spear, Putnam, CT



At thirty-two-years old I had congestive heart failure. Three hospitals later I was diagnosed with Giant cell Myocarditis and put on the transplant list. I was given a short life expectancy even with a transplant. I walked out of the hospital a few weeks later with my heart intact. The next year I spent the summer in a coma and lost my short term memory. I was diagnosed with Menengial Ensephelitis. Against all odds I was back to work one year later. Within the first month of being back to work I was stricken with Pulmonary Embolism, Third stage kidney failure, Vasculitis and Systemic Lupus erythmatosis. I was home for Thanksgiving. Less than a year later I had a right atrial, right lung collapse. I sustained the next few years with severe joint pain, pleuricy, Post Traumatic Stress and handfulls of medicine twice daily until I splintered one of the main arteries to my brain. I had stroke symptoms with a left foot drop that made everyday activities even harder than before. My book also talks about the things and people you loose along the way and how that is part of the process of upgrading your life. Through the past nine years I have never for a second lost my faith. In fact that is what has carried me through. I wrote this book in hopes to inspire others. A terminal diagnosis does not have to be a death sentence. If you are brave enough to keep your faith you can conquer anything.



MYOCARDITIS UPDATE

Sports Related Sudden Death

Dr. Leslie Cooper, Chair of the Cardiovascular Dept. Mayo Clinic, Jacksonville, Florida

The majority of Sudden Death is unexplained in the community…

Sports related Sudden Death in the general population is consistently more common than previously suspected. Although regular physical activity benefits cardiovascular health in the long term, there is a small but significant short term increased risk of, dying suddenly during or shortly after exercise.

Sports related sudden deaths in young athletes are highly visible and usually attract considerate public and media attention. Pre-participation screening and emergency response planning (CPR and easily accessed portable external defibrillators), for example, have been associated with a significant decrease in the incidence and mortality of such events in young athletes.

The data linking Myocarditis to sudden death are strong and include autopsy studies and experimental myocarditis models. In clinical practice, Myocarditis is often suspected but infrequently confirmed by cardiac autopsy, which creates a need for noninvasive diagnostic criteria to guide recommendations for athlete participation.

Although acute Myocarditis is associated with the characteristic findings of myocardial injury, (when both of the following criteria are met)…

- A clinical syndrome that includes acute heart failure, angina-type chest pain or myopericarditis of under 3 months duration
- An otherwise unexplained elevation in serum troponins; EKG changes of cardiac ischemia; otherwise unexplained high degree AV Block or arrhythmias; heart wall motion abnormalities; pericardial effusion on Echo or Cardiac MRI imaging.

…there is no sensitive or specific test that can determine when the inflammatory process ends. The acute inflammation associated with inflammation of the lining of the heart or pericardium usually resolves within 3 months. In contrast, Dilated Cardiomyopathy, also associated with acute Myocarditis, often resolves over 6-12 months. Athletes, whom the findings in acute inflammation have resolved, should be screened for arrhythmias before returning to sports participation.

The interval between the onset of myocarditis and retesting before resumption of sports will vary depending on the severity of the initial illness. A reasonable minimum interval for retesting based on experimental models is 3-6 months.

The recommendations that are presented, are as follows:

- Athletes with probable or definite Myocarditis should not participate in competitive sports while active inflammation is present. This recommendation is independent of age, gender, and Left Ventricular Function.
- Before returning to competitive sports, athletes who initially present with an acute clinical syndrome consistent with Myocarditis, should undergo a resting EKG, 24 hour Holter Monitoring, and an exercise EKG no less than 3-6 months after the initial illness.
- It is reasonable that athletes resume training and competition if all of the following criteria are met:
  - Ventricular Systolic Function has returned to the normal range
  - Serum markers of myocardial injury, inflammation and heart failure have normalized
  - Clinically, relevant arrhythmias such as frequent or complex repetitive forms of ventricular or supraventricular ectopic activity are absent on Holter monitor and graded exercise EKGs.

EVENT

Paint the Town Rhett

Fourteen-year-old Rhett was a gregarious, boisterous, compassionate teenager until he became a victim of Viral Myocarditis in May 2013. This 3rd annual FUNdraiser will help to bring his family a step closer to funding a research grant in Rhett's name with the Myocarditis Foundation.

Remembering Rhett

Rhett P Lundy was a freshman at South Elgin High School when he died in his sleep on May 15, 2013 from a devastating heart disease called Myocarditis. This third annual FUNdraiser brings us a step closer to funding a research grant in Rhett's name with the Myocarditis Foundation.

Paint the Town Rhett

Sunday May 15, 2016 11:00 am—4:30 pm
The Lodge on 64 | 41W379 Route 64 | Wasco, IL 60183

June 3, 1998—May 15, 2013

Myocarditis, a little-known disease that claims victims from infancy through elderly, seems most prevalent in those under 35.
www.myocarditisfoundation.org

Facebook Event Page
Stay updated with Event happenings
https://www.facebook.com/events/1703610876521204/
mayyourbeatliveon@gmail.com

Lunch/Paint Package includes: ½ rotisserie chicken, garlic mashed potatoes, vegetable, soup, salad, bread, assorted desserts, tea, water, coffee, plus all art supplies.
(cash bar)
Optional: lunch—or—paint
SEE BELOW FOR PRICING

Program

11:00-11:30	Registration
11:30–1:30	Lunch
11:30–2:30	Silent Auction
2:00-4:00*	Our talented art teacher will demonstrate step-by-step how to create a beautiful work of art as unique as each artist. This fun make-and-take project *(8x10 canvas or two wine glasses*)* supports a great cause—no experience necessary! Keep your work of art, or gift it to a loved one!

**Times are subject to change.*

**Other options are available for guests under 21.*

Entertainment:
Special performance by South Elgin High School Jazz Band/drum line combo*
Rhett was a proud member of the Marching Storm drumline
** Subject to change based on band availability*

Keynote Speaker:
Genevieve Rumore
Myocarditis Foundation Director

SILENT AUCTION | DOOR PRIZES | 50/50 RAFFLE
100% OF THE PROCEEDS WILL HELP FUND THE
RHETT P LUNDY MEMORIAL RESEARCH GRANT

EVENT

Rare Disease Week

The week of February 29th was designated as Rare Disease Week on Capital Hill, with Rare Disease Day specifically around the country on February 29th. With the main office being in Texas now and Candace's satellite office in New Jersey, we were well represented at both functions. Rare Disease Week is a global event, sponsored in the U.S. by the National Organization of Rare Diseases (NORD), of which the Myocarditis Foundation is a member. It is designed to bring awareness of the unique needs of victims of rare diseases and to advocate for legislation affecting of our diseases.

Candace met with NJ Senator Ronald Riser and Gen met with legislative assistants for Senator John Cornyn and Senator Ted Cruz, the Texas Senators, as well as the local Congressman Ted Poe. In Washington, D.C., there were over 300 patient advocates meeting with their legislative delegates and educating them on how they can help positively impact the rare disease community.

There are over 7,000 rare diseases in the world which include Myocarditis and Giant Cell Myocarditis. 1 in 10 people suffer from a rare disease, and over 50% of rare diseases affect children. Both Candace and Gen educated the legislators and their assistants on what Myocarditis is and what it does to those affected by it. All of those whom they met with thanked them for the educational information that they shared and vowed to work on the bills and caucus for Rare Disease which is now in the Senate as well as the House.

Candace with NJ Senator Ronald Riser

Gen with the Texas Delegation at Senator John Cornyn's office

EVENT

Quinn's Cup 2016

January 30th was an awesome day in Edina, Minnesota, for the 3rd Annual Quinn's Cup Pond Hockey Tournament, in memory of Quinn Kirsch. Quinn died of Viral Myocarditis in January 2013 at the age of 8 years old. Living in Minnesota, Quinn's first love was playing Pond Hockey with his friends and family. In fact, he had a rink in his back yard that he played on all the time.

His friends, their families, and even the neighboring towns now come out to support the memory of Quinn and raise funds for Myocarditis Research. It started with about 200 children the first year and has grown so much that the registration had to close this year by mid-December, because they ran out of playing time on the rink space that they had. This year there were over 500 children in the tournament. This tournament has gotten so popular that they are adding a 5th rink for next year's event!

The whole community of Edina comes together to help make this happen. The word about myocarditis was spread on radio and television stations, and throughout the day at the tournament. The towns of Edina and Minneapolis-St. Paul have been well educated on myocarditis thanks to all the work of Kelly and Kyle Kirsch, and Quinn's Cup. Thank you so very much for all that you have done for the Myocarditis Foundation!

Gen Rumore with Kelly and Kyle Kirsch at Quinn's Cup

MYOCARDITIS RESEARCH UPDATE

New Link Between Viral Infections and myocarditis in Infant

Dr. DeLisa Fairweather, PhD,
Assistant Professor; Director of Transitional Research Department of Cardiovascular Medicine, Mayo Clinic, Jacksonville, Florida

A recent study published in the scientific journal "*Pediatric Cardiology*" found that infant myocarditis patients (<12 months old) tested positive for viruses in the blood more often than infants that did not have myocarditis and were otherwise healthy. The greater detection of viruses in the bloodstream in infants with myocarditis was statistically significant with a p value of 0.0001, indicating the likelihood that the viral infection was related to the infant developing myocarditis. However, virus was not detected as often in children older than 1 year who had myocarditis. Virus may be able to replicate (i.e., grow) at a higher rate in infants <12 months old because their immune system is still maturing and is not able to fight off infections as well as older children.

Several "families" of viruses that are known to infect the heart were tested in this study including enterovirus, adenovirus, human herpesvirus 6, and parvovirus B19. Enteroviruses like coxsackievirus have long been believed to cause myocarditis, especially in the United States, because outbreaks of coxsackievirus infection are often associated with children developing myocarditis and because viral infection of animals with coxsackievirus in the laboratory causes myocarditis. The method used to detect viruses in the blood of the infants is called "polymerase chain reaction" or PCR. This method is able to amplify a small amount of virus and determine its genetic "code" so that the researcher or physician is able to tell whether virus is present in the bloodstream and what type or family of virus is present. This technique is commonly used in research laboratories but is not typically used in the United States to determine whether a patient has viral myocarditis. This report suggests that PCR could be added to other clinical diagnostic tests to improve treatment of myocarditis in infants. The PCR test may be able to better identify patients who could benefit from anti-viral therapies.

The chief researcher on this project was Dr. Kathleen Simpson who is an MD and researcher at the Department of Pediatrics at the Washington University School of Medicine in St. Louis, Missouri. Dr. Simpson was a past grant recipient of the Myocarditis Foundation. Each year, the Myocarditis Foundation funds 1 or more research projects focused on clinical or translational myocarditis from young, new investigators to encourage them to pursue a career studying myocarditis. Dr. Simpson has published many studies on myocarditis in children. She will be presenting some of her recent findings at this year's **Myocarditis Foundation Family Support Meeting**, which will be held in conjunction with the Annual Scientific Meeting of the Heart Failure Society of America (HFSA). This year's HFSA meeting will be held at the Gaylord Palms in Orlando, Florida. The Family Support Meeting will be held on the Saturday before the meeting starts on the 17 September 2016. Please join us for the Family Support Meeting and hear more about Dr. Simpson's exciting research.

Publication reference: **Simpson KE**, Storch GA, Lee CK, Ward KE, Danon S, Simon CM, Delaney JW, Tong A, Canter CE (2016) High Frequency of Detection by PCR of Viral Nucleic Acid in The Blood of Infants Presenting with Clinical Myocarditis. Pediatr Cardiol 37:399-404.

"Scientific Abstract: Specific viruses are associated with pediatric myocarditis, but the prevalence of viral DNAemia detected by blood polymerase chain reaction (PCR) is unknown. We evaluated the prevalence of known cardiotropic viruses (enterovirus, adenovirus, human herpesvirus 6, and parvovirus B19) in children with clinical myocarditis ($n = 21$). Results were compared to pediatric controls with similar viral PCR testing. The majority of positive PCR (89 %) was noted in children ≤ 12 months of age at diagnosis compared to older children. Infant myocarditis patients (8/10) had increased the prevalence of PCR positivity compared to infant pediatric controls (4/114) ($p < 0.0001$). Other than age, patient characteristics at diagnosis were similar between PCR-positive and PCR-negative patients. Both PCR-negative myocarditis infants had clinical recovery at follow-up. Of the PCR-positive myocarditis infants, 4 had clinical recovery, 2 developed chronic cardiomyopathy, 1 underwent heart transplant, and 1 died. Infants with clinical myocarditis have a high rate of blood viral positivity, which is higher compared to older children with myocarditis and healthy infant controls. Age-related differences in PCR positivity may be due to differences in host and/or virus characteristics. Our findings suggest that viral blood PCR may be a useful diagnostic tool and identify patients who would potentially benefit from virus-specific therapy."

PEDIATRIC MYOCARDITIS UPDATE

Myocarditis in Children: A Difficult Diagnosis to Make

Jack F. Price, MD,
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One of the most challenging and frustrating aspects of caring for children with myocarditis is making the correct diagnosis in the first place. Acute heart failure and myocarditis are known to mimic the most common diseases of childhood: asthma, bronchitis, and the stomach virus.

In a review of nearly 200 children with a new diagnosis of heart failure at a major children's hospital, approximately 50% had been evaluated by a physician for their symptoms prior to their diagnosis but were given a diagnosis other than heart failure. The most common alternate diagnoses included: pneumonia, asthma, bronchitis, migraine headaches, gastroenteritis, and constipation. Some of those children underwent extensive testing such as CT scans, gallbladder studies, gastric endoscopy, and liver ultrasound. These children were then treated with therapies including antibiotics, asthma inhalers, steroids, and pain relievers. Eventually, all of these patients were correctly diagnosed with heart failure and many of them were found to have myocarditis. It is not known if the delay in diagnosis had any impact on the childrens' subsequent treatment and prognosis.

One of the greatest challenges in pediatric heart failure and myocarditis is to raise awareness not only in the lay public, but also in physicians and nurses who encounter these patients. This is especially difficult when the vast majority of children with symptoms common to heart failure do not actually have heart failure.

However, a few abnormal findings on physical examination may lead caregivers to a correct diagnosis. An abnormal heart sound is commonly identified in children with myocarditis. This sound is called a "gallop rhythm" because it sounds like the hoof beats of a galloping horse.

Another common and abnormal finding is an enlarged liver. This can be felt during examination of the abdomen. These findings coupled with signs or symptoms such as abdominal pain, rapid breathing, fatigue and loss of appetite should alert one to the possibility of myocarditis.

Laboratory studies such as a chest x-ray and blood work may also be helpful. Children with myocarditis frequently have an enlarged heart size on chest x-ray. They may also have evidence of fluid in the lung fields (i.e., congestion). A blood test that is almost always abnormal in children with heart failure resulting from myocarditis is the BNP (B-type natriuretic peptide) concentration. The BNP is a hormone that is secreted in situations causing increased pressure or volume loading on the heart, such as myocarditis.

Raised awareness about the clinical features of myocarditis in children may lead to earlier diagnoses. The impact of more timely diagnosis and treatment is not known at this time.