



## **How Can I Help Spread the Word About Myocarditis and the Myocarditis Foundation?**

### ***Myocarditis is considered a Rare Disease. What does that mean?***

- It is one of over 7,000 known rare diseases
- It affects less than 200,000 people in the U.S. at any given time
- Altogether rare diseases affect an estimated 25-30 million Americans, approximately 1 in 1,500 people.

Myocarditis was never taught about in medical schools until the past few years because it is considered a rare disease. Because of this, most doctors do not know much about it and often do not think of it when evaluating patients.

Dr. Leslie Cooper, Co-Founder of the Myocarditis Foundation, was key in getting it taught recently in medical schools and there are now questions on the medical board exam about it as well.

The physicians on our Board of Directors and Medical Advisory Board are key in spreading the word to Cardiologists around the world.

Often times, the doctors who initially see patients with myocarditis are front line clinicians in Pediatrician Offices, Family Practice Offices, Urgent Care Facilities, Emergency Rooms, etc. and they are not familiar with or thinking about this disease as a potential diagnosis.

***(July, 2020)***

***I am Not a Medical Person So How Can I Help to Raise Awareness  
About This Disease?***

Educating the general public will help alert doctors to thinking about the potential of myocarditis as a diagnosis.

Most people who are affected by myocarditis have never heard about the disease or even heard the name mentioned until it has affected them or someone they know in some way.

Because the main cause of the disease in developed countries are viruses, the disease often presents with symptoms that can be confused as “being just a virus”. People are often misdiagnosed with flu, gastroenteritis (stomach virus), bronchitis, asthma, pneumonia, anxiety, dehydration, among other things. Often people are seen 2 or more times before a correct diagnosis is made.

More often than not, the above diagnoses are the correct diagnoses. But, by mentioning the word “Myocarditis”, it will cause the doctor or clinician to stop, and think about the potential diagnosis of myocarditis.

***(Myocarditis Foundation July/2020)***

## ***What Can I Tell People About Myocarditis?***

- Myocarditis is the 3<sup>rd</sup> Leading Cause of Sudden Death in Children and Young Adults.
- Myocarditis accounts for 45% of Heart Transplants in the United States.
- Myocarditis is the 20<sup>th</sup> Leading Cause of Death Worldwide.
- The easiest way is to share your story. People love to hear personal stories...it makes them real.
- If myocarditis is diagnosed early, the person has a better chance of survival.
- There is no specific diagnostic test for it like there is for say, strep, but there are other blood tests that can help to rule out it as a potential diagnosis.
- Giving a good history of how exactly you feel when sick is important..."This is the worst that I have ever felt", "Everyone else in my family had this virus but they're all better and I am still suffering with it"...
- If you do not feel better and in fact start to feel worse, go back to the doctor or visit an emergency room (better if it is one in a larger teaching hospital)...
- Make sure that the doctor does a complete physical exam when you are ill...have them listen to heart, lungs, abdomen, including palpating your liver...an enlarged liver is not normal with a "stomach virus".
- While this disease can affect people of all ages, the high-risk age group for this disease is from puberty through your early 30s, and it affects boys twice as frequently as girls.

***(Myocarditis Foundation July 2020)***

- **Our Mission is three-fold:**
  - Raise awareness and educate both the medical and public on it
  - Raise funds for research specific to myocarditis
  - Provide emotional support for those affected by the disease
- In order to be able to do all these things, the Foundation is supported solely by donations. 89 cents of every dollar go towards our mission.
- We have awarded 21 Fellowship Research Grants to Myocarditis Researchers in the 15 years we have been a Foundation (Incorporated as a 501c3 in 2005)
- We are starting a Myocarditis Specific Biobank, where blood samples of myocarditis patients will be stored for researchers to request samples from for their research.
- For more information, and to make a donation, please go to our website: [www.myocarditisfoundation.org](http://www.myocarditisfoundation.org)

### ***How and Where Can I Share This information?***

**Set up a table at:**

- **Church Functions**
- **School Functions**
- **Community Functions (Health Awareness, Walks, Runs, Farmers Markets, Holiday Markets, etc.)**

**We can send you pamphlets that you can share with participants for further information.**

**Thank you.**

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