Does your doctor suspect you may have CARDIAC SARCOIDOSIS?

Cardiac Sarcoidosis (CS) is a rare form of sarcoidosis in which clusters of white blood cells, called granulomas, form in the tissue of the heart. Due to its high mortality rate, early detection and prompt initiation of treatment are critical. Note: Most patients respond to treatments favorably when treated appropriately and early.

POSSIBLE SYMPTOMS*

*Most common symptoms are palpitations, light headedness, chest pain, and syncope (drop in blood flow to the brain).

**Breathing Problems:**
- Shortness of breath**
- Coughing
- Chest Tightness
- Wheezing

**Feeling Lightheaded/Fainting**

Irregular Heartbeats (Arrhythmias):
Can feel like palpitations/skipped beats.
The types of arrhythmia are:
- Tachycardia
- Atrial fibrillation
- Atrial flutter
- Bradycardia
- Ventricular fibrillation
- Premature contractions

**Leg Swelling**: Usually occurs in late-stage CS

***POSSIBLE COMPLICATIONS***

- Arrhythmias:
  Abnormal heartbeats or rhythms
- Pericarditis:
  Causes inflammation of the covering of the heart and chest pain (rare)
- Heart Blocks:
  Blockage of electrical impulses that regulate heart rate, preventing blood flow.
- Heart Attacks
  When a blockage prevents blood and oxygen from reaching part of the heart.
- Heart Failure
  When the heart is unable to pump blood through the body.

**How do you know you have Cardiac Sarcoidosis?**

**Step 1: Screen**
If you’re experiencing the symptoms above, talk to your doctor about an EKG/ECG test to assess your heart rhythm and flow. Based on symptoms and assessment by your doctor, current guidelines recommend EKG/ECG to test your heart rhythm and flow. Some physicians may require additional testing to determine if you should continue to the confirmation testing as described in Step 2.

**Step 2: Diagnose**
Based on the test results, you will need to seek a specialist to confirm, using one of the following tests: Cardiac MRI is recommended, otherwise FDG PET scan to detect myocardial damage and ongoing inflammation is then recommended.

**Step 3: Treat**
If diagnosed, your specialist and providers will determine a specialized treatment plan, or if treatment is required at all, based on the severity of your case. Most patients respond to treatments favorably when treated appropriately and early.

**How is it treated?**

Less Severe/Early-stage Detection
- No treatment required, but regular observation recommended
- Oral Medications
  Immunosuppressants/anti-inflammatory medications and beta blockers are among some of the medications that can help manage symptoms.
- Pacemaker or Implantable Cardiac Defibrillator (ICD)
  Can manage or correct heart rhythm

Most Severe/Late-stage Detection
- Ablation
  Creates scar tissue to stop parts of the heart muscle from triggering irregular rhythms
- Heart Transplant
  Only in the most severe cases.

Treatments vary based on the severity of the case, which is why early diagnosis is so important.

**Who has Cardiac Sarcoidosis?**

While only 5% of sarcoidosis patients are officially diagnosed with CS, studies indicate that up to 30% of all sarcoidosis patients may actually have CS.

The average age at diagnosis is approximately 50 years old.

Ongoing studies are being conducted that may further refine the guidelines above. FSR will be sure to update them as indicated.

To view a full list of resources, please visit www.stopsarcoidosis.org/cardiac-sarcoidosis-resources/ or scan the QR code.