**STANFORD HEALTH CARE – SARCOIDOSIS PROGRAM**

**SARCOIDOSIS PATIENT INFORMATION**

What is sarcoidosis?

Sarcoidosis is a disease in which the body’s own immune system causes damage to its own organs. This kind of disease is sometimes called “auto-immune”. Damage from sarcoidosis can occur in any part of the body.

In people with sarcoidosis, inflammation occurs in what are called “granulomas” (masses of inflammatory tissue). Over time, if sarcoidosis is not treated, these granulomas may replace healthy organ tissue and cause scarring and fibrosis (hardening) of the affected tissue.

What are the signs and symptoms of cardiac sarcoidosis?

* Irregular heartbeats, which can feel like fast or skipped heartbeats
* Fluid retention, which can cause swelling in the legs or abdomen
* Shortness of breath or cough
* Dizziness/fainting

How is cardiac sarcoidosis diagnosed?

There is no single test for sarcoidosis. The diagnosis is based on a detailed medical history and physical exam and may also include blood, urine, and other tests.

Tests used to evaluate cardiac sarcoidosis may include:

* EKG (electrocardiogram): Patches, called electrodes, are placed on the skin to get a picture of the electrical activity of the heart. The EKG may show abnormal heartbeats or electrical signals from changes in the heart muscle.
* Echo (echocardiogram): A healthcare provider will place gel on the chest and move an ultrasound probe back and forth across the chest to look at the heart. Sound waves are used to show the shape of the heart and movement of blood through the heart.
* Blood/urine tests: A sample of your blood or urine may be sent to the lab for tests. The tests may tell if your organs, such as your liver or kidneys, are working correctly.
* Cardiac MRI (magnetic resonance imaging): This scan uses magnets and a computer to take pictures of your heart. The MRI shows detailed pictures of your heart and major blood vessels. Intravenous (IV) dye may be given to help your caregivers to get better pictures.
* PET (positron emission tomography) imaging:

Stanford Healthcare has developed a protocol using PET scans to diagnose and monitor sarcoid activity in the heart. This test involves the injection of a small amount of radioactive sugar into an IV followed by a PET scan. The scan shows the amount of inflammation present in the body. The doctor can use this information to help with the initial diagnosis as well as to check the disease status. The scans may be done every few months to determine the response to treatment and to guide medication management.

\*\*\*It is **EXTREMELY IMPORTANT** for the dietary instructions to be followed prior to the PET scan in order for the test to provide accurate results. A strict **No Carbohydrate** diet needs to be consumed the **entire day** before the test followed by an 8 hour fast prior to the test.

See attached “Sarcoid Patient Preparation for Nuclear Medicine” sheet for specific diet instructions. This sheet given out by nuclear medicine states the No Carbohydrate diet is to be followed after 2pm. It is recommended that you follow the No Carbohydrate diet the entire day prior to your PET scan, starting with breakfast the day before the test.

How is sarcoidosis treated?

Treatment is designed to minimize inflammation, relieve symptoms, and prevent complications.

Medications:

(See “Common Medications/Supplements Used to Treat Cardiac Sarcoidosis”)

Medications are used to decrease inflammation in the body, treat symptoms, and reduce side effects.

* Steroids: Decrease inflammation.
* Methotrexate: Decreases inflammation and allows for lower long-term steroid doses.
* Antibiotics: Used to prevent infections due to weakened immune system function from steroids and methotrexate.
* Supplements: Folic acid, calcium, and vitamin D help prevent side effects.
* TNF Inhibitors: Reduce (inhibit) Tumor Necrosis Factor (TNF) an inflammation causing substance in the body, which is elevated in people with sarcoidosis

Surgery:

* Pacemaker/Defibrillator: Some people may require a pacemaker, a defibrillator, or both devices to maintain a normal heart rhythm. These are small devices placed under the skin.
* Heart transplant: During a heart transplant, your diseased heart is removed and replaced with a donor heart. There are a small number of patients with severe disease who need a heart transplant.

What do I need to do?

* Take medications as prescribed.
* Contact your healthcare provider with any questions or concerns you have.
* Maintain regular office visits and bring a complete updated medication list to each appointment.
* Have testing done as recommended by your health care team.