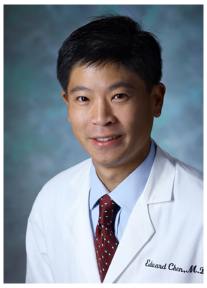
JOHNS HOPKINS
MEDICINE

Sarcoidosis News

A publication of the Johns Hopkins Sarcoidosis Center **Spring/Summer 2026**

A Note from the Directors



As winter gives way to spring (finally!), we are reminded of the importance of renewal, connection and community.

We hope everyone stayed safe and warm through this year's snowstorms. Thankfully, Punxsutawney Phil predicted that winter may soon be winding down, and we are looking forward to April, which brings longer days, spring flowers and Sarcoidosis Awareness Month.

We are excited to join the Life and Breath Foundation for the **Take a Breath for Sarcoidosis Walk/Run on Saturday, April 25**. Events like this are a wonderful way for patients, families and supporters to come together, raise awareness and celebrate the strength of the sarcoidosis community. If you are interested in participating or learning more, please visit **lifeandbreath.org**.

We are also pleased to share that our Patient Advisory Board is planning its **Third Annual Say Sarcoidosis Patient Education Event**, scheduled for August 22. This event is designed for patients and caregivers to learn from experts, connect with others living with sarcoidosis and hear the latest updates in care and research. To register, visit **saysarcoidosis.org**.

Most importantly, during **Sarcoidosis Awareness Month**, we want to recognize the strength and resilience of our sarcoidosis patients and families. Your experiences, advocacy and willingness to support one another continue to inspire our work every day.

SAVE THE DATE

Third Annual

SAY SARCOIDOSIS
PATIENT EDUCATION EVENT
August 22nd, 2026

At the Johns Hopkins Sarcoidosis Center, we are honored to partner with you in advancing research, improving care and building a community grounded in compassion, knowledge and hope. Thank you for being part of this journey with us.

In good health,

Edward Chen, M.D.
Co-director, Sarcoidosis Center

Michelle Sharp, M.D., M.H.S.
Co-director, Sarcoidosis Center

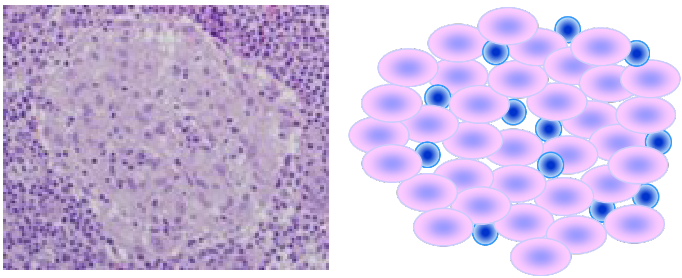
Inside

PATIENT EDUCATION:
THE 5 Ws OF SARCOIDOSIS

Many patients wonder what causes sarcoidosis, and so do we.

WHAT

Biopsies from patients show that sarcoidosis causes granulomas. These are tiny, microscopic clusters of white blood cells. Granulomas also form when the immune system responds and tries to contain an infection or cancer. Pathologists look for clues that it is something other than sarcoidosis, such as microbes (bacteria, fungi, mycobacteria), cancer cells or devitalized/necrotic tissue. The types of cells found in sarcoidosis granulomas are mostly epithelioid macrophages, with smaller numbers of lymphocytes, and even lesser numbers of other cells.



Left: *Picture taken with a microscope of a sarcoidosis granuloma showing epithelioid macrophages (cells with faint-blue oval nuclei) and lymphocytes (cells with dark-blue round nuclei);* ***Right:*** *Diagram of a sarcoidosis granuloma showing larger epithelioid macrophages (pink) and smaller lymphocytes (blue)*

WHERE

Sarcoidosis causes granulomas to form in affected parts of the body, such as lymph nodes, lungs, skin, liver or heart. The granulomas take up space where they form. In the skin, sarcoidosis can cause a raised nodular rash. More severe granulomatous inflammation can lead to pain, such as if lymph nodes become very swollen, or problems with how an organ works. In the liver, this can lead to abnormal blood test results.

WHEN

Sometimes, sarcoidosis is found by accident in patients without symptoms who have tests for another reason (e.g. chest X-ray taken after a car accident). For other patients who experience unexplained symptoms such as shortness of breath, tests may detect nodules and infiltrates in the lungs. A diagnosis of sarcoidosis is made if a biopsy finds granulomatous inflammation, no evidence of cancer and cultures do not find signs of infection.

WHY

We do not know what causes granulomas to form in sarcoidosis. When the immune system is active, several chemical signals called cytokines are released into the blood stream, causing white blood cells of the immune system (macrophages and lymphocytes) to become activated. One of the important cytokines involved in sarcoidosis is tumor necrosis factor (TNF), which is a “key ingredient” for causing activated white blood cells to find their way into lymph nodes and other parts of the body to form granulomas. High levels of TNF can also cause patients to feel fevers, fatigue, musculoskeletal aches and lose weight. Medications such as prednisone “shut down” inflammation by causing white blood cells to make less cytokines such as TNF. Some newer “biologic” medications have been engineered to block specific cytokines such as TNF and can be used to treat sarcoidosis.

WHO

Sarcoidosis seems to happen more frequently in some parts of the world, such as in northern Scandinavia and the southeastern U.S. There may be genetic reasons why some people develop sarcoidosis. Research studies show that the chance of finding sarcoidosis is five times higher within the family of a patient with sarcoidosis (parent, sibling, or child) compared to the chance of finding sarcoidosis among the general population. Even so, sarcoidosis remains an uncommon medical condition.

Official statistics still consider sarcoidosis a rare disease. However, we do not know how many people have sarcoidosis that is "silent" and is only discovered by accident through tests obtained for other reasons. By raising awareness for sarcoidosis, we hope to gain a better understanding of who is affected by sarcoidosis and how it affects them, develop better ways to diagnose and treat sarcoidosis, and discover a cure.

PATIENT ADVISORY BOARD SPOTLIGHT:
ARLENE PRINCE

When were you diagnosed with sarcoidosis?

I began my treatment 10 years ago. Before that, I had a terrible cough for several years and went to multiple doctors without any improvement or diagnosis. As time went on, I felt like I would never get rid of the cough and I was not able to speak without coughing. To compound that, I was always extremely dizzy and had terrible headaches. I became very frustrated.

The year before I was diagnosed, I became very ill. My doctor finally ordered a lung biopsy. The results were pulmonary sarcoidosis in every biopsy taken. I was then sent to a neurologist and diagnosed with neuro-sarcoidosis. From then on, I began to plan my future. It was a great relief knowing I was going to get treatment for my symptoms.

What is your advice for patients who have been recently diagnosed with sarcoidosis?

My advice is to follow your doctor's instructions. Take all of the medications as prescribed and never miss a dose. You will get stronger and begin the journey to feeling better.

I have had my medications changed several times and I go to a number of doctors, but I am happy. Each day is a challenge, but I believe that hope and perseverance will make me a much stronger person.

Join the movement to raise awareness and support for those living with sarcoidosis!

Launched in 2025, the "Say Sarcoidosis" campaign is driven by the Johns Hopkins Sarcoidosis Patient Advisory Board and its partners to provide free education and awareness about sarcoidosis. We invite you – patients, caregivers and advocates – to get involved in one of our committees.

- Event planning (Help us plan another amazing patient education event!)
- Fundraising
- Communications
- Patient support group

Your experience and dedication can make a real difference! To learn more about the Patient Advisory Board or patient support group, email sarcoidosis@jh.edu.

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Learn more at hopkinsmedicine.org/pulmonary/patient-care/sarcoidosis.

PATIENT SUPPORT GROUP

1st Monday of Every Month
5:30 to 7 p.m.
Via Zoom:
jhjhm.zoom.us/j/93227201153

May 4 – Balancing Act: Managing Sarcoidosis Treatment and Side Effects
presented by Dr. Kristen Mathias

June 1 – Cardiac Sarcoidosis
presented by Dr. Nisha Gilotra

July 6 – Holiday
No support group in observance of the 4th of July holiday.

Visit **saysarcoidosis.org** for a complete schedule.

Scan here to join:

SUPPORTING OUR MISSION

The mission of the Sarcoidosis Center is to build a multi-disciplinary center that provides excellent patient-centered care; educates the next generation; and helps advance research to find the cause and a cure of sarcoidosis.

If you are interested in supporting our mission, please visit **secure.jhu.edu/form/pccm** or contact:

Caroline Jelavich • cjelavi1@jh.edu
Department of Medicine Development Office

If you prefer not to receive fund-raising communications, call 1-877-600-7783 *or email* FJHMOptOut@jhmi.edu. *Include your name and address so that we may honor and acknowledge your request.*