

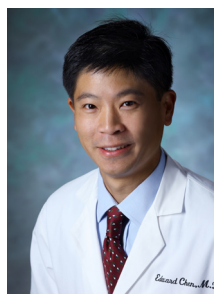


Sarcoidosis News

A publication of the Johns Hopkins Sarcoidosis Center

Fall/Winter 2024

A Note from the Directors



August marked a busy month for the Sarcoidosis Center!

We were honored to host the Americas Association of Sarcoidosis and Other Granulomatous Disorders (AASOG) Annual Conference on August 15 and 16. The theme, "The Art of Working Together for Progress," focused on how multidisciplinary care, research and education in sarcoidosis can improve the quality of medical care for our sarcoidosis patients, reduce health disparities and improve the understanding of this disease by patients and doctors. It was a wonderful event that brought together sarcoidosis experts from across the globe.

On the heels of the AASOG conference was our first "Say Sarcoidosis" patient education event on August 17. More than 350 individuals attended in person or virtually, and learned about the latest developments in sarcoidosis research and treatment. Many thanks to our Patient Advisory Board and others from the Sarcoidosis Center who organized a memorable event with valuable information and resources. If you were unable to participate, we invite you to watch a recording of the event at youtube.com/@SaySarcoidosis/videos.

As always, we invite you to reach out to us with any feedback or ideas you may have at sarcoidosis@jhmi.edu.

In good health,

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

Michelle Sharp, M.D., MHS
Co-director, Sarcoidosis Center



Congratulations, Dr. Sharp!

During the 2024 AASOG Conference in August, Dr. Michelle Sharp received the Rising Star Award for her contributions to the field of sarcoidosis, including clinical care, advocacy and education. An excerpt from her nomination said, "She is a true advocate for her patients, and her research and leadership are outstanding in this area."

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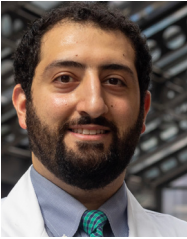
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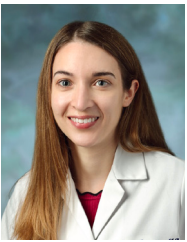
4 Patient Support Group Supporting Our Mission

SUPPORTING THE NEXT GENERATION OF SARCOIDOSIS EXPERTS

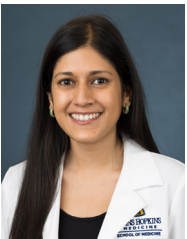
In addition to providing patient-centered care, the mission of the Sarcoidosis Center is to educate the next generation of sarcoidosis experts. Below is an update on some of our most recent trainees.



Ali Mustafa, M.D., completed his fellowship in pulmonary and critical care medicine at Johns Hopkins in June 2024. With support from the Sarcoidosis Discovery Fund, Dr. Mustafa completed a project with Michelle Sharp, M.D., MHS, and published a study showing how air quality can affect the well-being of patients with pulmonary sarcoidosis. He started a new position with Virtua Health in New Jersey, where he aspires to build a new sarcoidosis



Jana Lovell, M.D., served as chief cardiology fellow at Johns Hopkins this year. The Sarcoidosis Discovery Fund supported her training under Nisha Gilotra, M.D., to find better ways to categorize patients with cardiac sarcoidosis. She is pursuing an additional year of training in advanced heart failure and transplant cardiology to hone her skills treating patients with sarcoidosis and other inflammatory causes of heart failure.



Kristen Mathias, M.D., MHS, joined the Sarcoidosis Center after completing the graduate training program in clinical investigation at the Johns Hopkins Bloomberg School of Public Health. Under the mentorship of Dr. Sharp and armed with her background as a rheumatology fellow, Dr. Mathias's goal is to "level the playing field" by addressing disparities and inconsistencies in medical care received by patients with sarcoidosis with a special focus on medicines and medication toxicity.



Anjali Wagle, M.D., is a cardiology fellow whose mission is to improve the understanding of sarcoidosis by patients and their doctors. Under the mentorship of Dr. Gilotra, her research involves a collaboration with the Johns Hopkins Whiting School of Engineering to use artificial intelligence to improve medical care for individual patients with cardiac sarcoidosis by identifying which patients are more likely to respond to treatment and which patients may be at risk for complications.

For more information on how to support our mission or to make a gift to the Sarcoidosis Discovery Fund, contact **Caroline Jelavich** at cjelavi1@jh.edu. Your partnership in supporting this fund will improve patient care and outcomes; invest in the growth of sarcoidosis experts; and advance research.

PATIENT EDUCATION: WHAT IS CARDIAC SARCOIDOSIS?

Sarcoidosis is an inflammatory condition that can affect multiple organs. In cardiac sarcoidosis, tiny collections of immune cells form granulomas in the heart tissue and can interfere with normal functioning.

Symptoms

Sarcoidosis affecting the heart can cause a person's heart rate (pulse) to be abnormally fast or abnormally slow, and can also cause the heart rhythm to be irregular or skip beats. Problems with the heart rate or rhythm can cause dizziness, chest pain or breathlessness during activity. Sarcoidosis can also injure or damage the heart muscle, causing it to become weak. If this happens, patients can experience leg swelling, fatigue and breathlessness when lying flat.

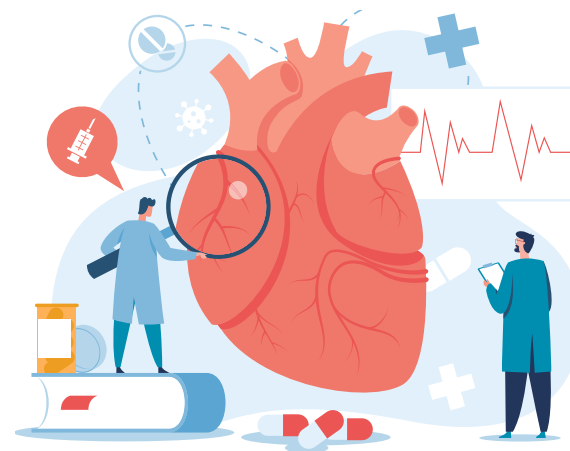
Diagnosis

Patients who experience chest pain, irregular heart rate, unexplained breathlessness or unexplained dizziness could be experiencing signs of cardiac sarcoidosis. Initial tests may include an electrocardiogram (ECG) and echocardiogram (EKG). In some cases, a cardiac monitor worn for one or more days is needed to look for problems with the heart rate or rhythm.

Patients with risk factors for heart disease or a family history of heart disease may need additional testing to look for more common causes of heart problems, such as coronary artery disease. If any of these initial tests are abnormal, a referral to cardiologist is recommended. Often, a specialized MRI or FDG-PET scan of the heart is needed to confirm a diagnosis of cardiac sarcoidosis.

Treatment

Like other forms of sarcoidosis, cardiac sarcoidosis is treated with medications that suppress inflammation. Some patients will need additional medications to alleviate heart failure and heart rhythm problems. Severe cases may need placement of a cardiac device, such as a pacemaker or defibrillator.



PATIENT ADVISORY BOARD

The Johns Hopkins Sarcoidosis Patient Advisory Board (PAB) was established in 2020 with the goal of increasing sarcoidosis awareness and knowledge; improving access to care; understanding and navigating patient needs and challenges; and helping promote clinical and scientific research. The PAB meets quarterly and helps plan patient support group meetings and the annual patient education event.

If you are interested in joining the board, submit your application at saysarcoidosis.org.





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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:

jhjm.zoom.us/j/93227201153

Nov. 4 – What's New in Vaccines?

presented by Dr. Olivia Kates

Dec. 2 – Navigating Sarcoidosis: Ask Us a Question

presented by the Patient Advisory Board

Jan. 6 – Occupational Exposures and Sarcoidosis

presented by Dr. Nancy Lin

Feb. 3 – Cardiac Sarcoidosis

presented by Dr. Nisha Gilotra

March 3 – Joints and Muscles in Sarcoidosis

presented by Dr. Kristen Mathias

Scan here to join the meeting:



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 in 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 fundraising 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.