

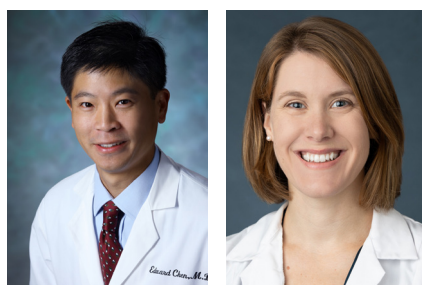


# Sarcoidosis News

A publication of the Johns Hopkins Sarcoidosis Center

Fall/Winter 2025

## A Note from the Directors



Autumn has finally arrived, providing us with some relief from the hot and humid weather that lingered into early October. The new season also ushers in a few exciting announcements about the Sarcoidosis Program.

### Staff News

–Welcome, **Kristen Mathias, M.D., M.H.S.**, who joined the sarcoidosis team in August. In her short time with us, she has already made a positive

impact on reducing wait times to our clinic.

–Congratulations, **Kayla Nyakinye, C.R.N.P.**, (pictured at right), who received the 2025 Clinical Excellence Award for Non-Physicians from Johns Hopkins Medicine's Miller Coulson Academy. The honor is awarded annually to a non-physician provider who exemplifies clinical excellence.



### Recap: Say Sarcoidosis Patient Education Event

Our second annual Say Sarcoidosis Patient Education Event was a huge success! More than 300 individuals participated either in person or virtually. Many thanks to our Patient Advisory Board and event committee who organized a memorable event with valuable information and resources. If you missed this year's event, you can view videos at [saysarcoidosis.org/events](https://saysarcoidosis.org/events).



As always, we invite you to reach out to us with any feedback or ideas you may have at [sarcoidosis@jhmi.edu](mailto:sarcoidosis@jhmi.edu).

In good health,

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

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

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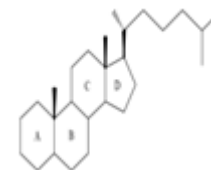
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## PATIENT EDUCATION: STEROIDS

### KNOW THY ENEMY (MEDICATIONS WE LOVE TO HATE)

**S**teroids are a family of hormones. Glucocorticoids are the family of steroids that includes prednisone, which is used to treat a wide range of medical conditions, including sarcoidosis.

All steroids share a common chemical “backbone” structure of four fused rings (*pictured at right*). Different chemical side chains (bold lines) control which cell receptors they bind and define the main medical effects for each steroid family.



Each steroid family has a main effect, but can also cause side effects that are features from other steroid families. This includes salt and fluid retention; weight gain; changes to the skin, hair and body composition; changes in mood and behavior; and bone density. Learning about other steroid families may help us understand the possible side effects from prednisone.

**Corticosteroids** includes cortisol (the natural corticosteroid made by the adrenal glands) and several synthetic corticosteroids. This family of steroids is divided into two classes:



**1) Glucocorticoids** reduce inflammation. They also are part of the body’s “stress response” to maintain blood sugar levels. *This may explain why some patients experience diabetes when taking prednisone.*

The adrenal glands will reduce or stop making cortisol when a patient takes corticosteroids. Adrenal insufficiency is when the adrenal glands are slow to ramp up cortisol production after corticosteroid medications are stopped.

**2) Mineralocorticoids** help manage salt and water balance, and elevate blood pressure, but can have a negative effect on bone density. *This may explain why some patients experience swelling in the legs and feet when taking prednisone.*

**3) Sex hormones** – Testosterone and estrogen are the main examples of these. They control development of reproductive organs and maintaining secondary sex characteristics, including body composition (hair, skin, bone, and distribution of fat and muscle) and possibly behavior.

Scientists have discovered “crosstalk” between different steroid families. Testosterone can increase the production of cortisol, and glucocorticoids can partially bind to cell receptors for sex hormones. *This may explain why some patients experience changes to their mood, hair and body composition when taking prednisone.*

**4) Anabolic steroids** are synthetic compounds whose main effect is to build muscle mass (outlawed by many sports organizations). Anabolic steroids can increase the number of androgen receptors. *This may explain why some patients experience changes to their behavior and increased hunger when taking prednisone.*

## PATIENT ADVISORY BOARD SPOTLIGHT: ROBIN GOBLE

### When were you diagnosed with sarcoidosis?

My symptoms – fatigue, vertigo, double vision and headaches – began in 2019 and progressively got worse. My primary care doctor tried to treat the symptoms as best they could, but nothing worked. I saw an ENT for my vertigo and they ordered an MRI, which showed severe inflammation around my cervical spine. I was immediately admitted to Johns Hopkins for testing. After six days in the hospital, I was diagnosed with neurosarcoidosis, a complex, multi-system inflammatory disease.

My initial regimen was a powerful combination of therapies designed to quickly halt the progression of inflammation caused by the disease: Renflexis (Infliximab), CellCept and high dose prednisone. Eventually I was weaned off prednisone and the CellCept was replaced with Methotrexate.



*Robin currently serves as the membership chair of the Sarcoidosis Program's Patient Advisory Board.*

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

For people newly diagnosed with sarcoidosis, know that you are not alone. Reach out to support groups to find others who understand the symptoms of your disease. It can be lonely; fatigue often keeps us from socializing and participating in activities the way we used to.

Get a good team of doctors who understand sarcoidosis. They will have resources to help you find information and manage your disease.

Most importantly, take care of yourself. Self-care is not selfish. Rest when you need to. Pay attention to nutrition. Try to walk – even if it is for 10 minutes. Celebrate the small wins!

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

The Johns Hopkins Sarcoidosis Patient Advisory Board invites patients, caregivers and advocates to get involved through event planning, communications, support groups and fundraising. To learn more or join the board, email [sarcoidosis@jh.edu](mailto:sarcoidosis@jh.edu).

## ADVANCING DISCOVERY, INSPIRING HOPE

The **Sarcoidosis Discovery Fund** continues to fuel ground-breaking research across neurosarcoidosis, cardiac sarcoidosis and pulmonary sarcoidosis, empowering Johns Hopkins fellows and early-career faculty to pursue bold, patient-centered investigations that are transforming care. With donor support, our scholars are identifying new biomarkers, refining treatment strategies, and uncovering how environmental and immune factors shape disease progression. Each award helps launch a career devoted to improving outcomes for patients with this complex and often overlooked condition.

Continued partnership is vital to sustaining this momentum. Your gift to the Sarcoidosis Discovery Fund helps drive innovation, train the next generation of leaders and bring us closer to a cure.

To learn more about partnering with us on this important mission, email Caroline Jelavich, senior development officer, at [cjelavi1@jh.edu](mailto:cjelavi1@jh.edu).



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Learn more at [hopkinsmedicine.org/pulmonary/patient-care/sarcoidosis](https://hopkinsmedicine.org/pulmonary/patient-care/sarcoidosis).

## PATIENT SUPPORT GROUP

## SUPPORTING OUR MISSION



**1st Monday of Every Month**  
 5:30 to 7 p.m.  
 Via Zoom:  
[jhjhm.zoom.us/j/93227201153](https://jhjhm.zoom.us/j/93227201153)

**Dec. 1 – Hepatic Sarcoidosis**  
*presented by Dr. Michelle Ma*

**Jan. 5 – Veterans: What We Can Learn to Understand Sarcoidosis**  
*presented by Dr. Mohamed Seedahmed*

**Feb. 2 – Multisystem Sarcoidosis**  
*presented by Dr. Michelle Sharp*

Visit [saysarcoidosis.org](https://saysarcoidosis.org) for a complete schedule.

Scan here to join:



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](https://secure.jhu.edu/form/pccm) or contact:

**Caroline Jelavich • [cjelavi1@jh.edu](mailto: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](mailto:FJHMOptOut@jhmi.edu). Include your name and address so that we may honor and acknowledge your request.*