Sarcoidosis: A Snapshot

What is sarcoidosis?

Sarcoidosis is a debilitating chronic illness where organ(s) throughout the body become **inflamed**.[1]

Often, clumps of immune cells called **granulomas** form. This can cause permanent organ scarring and damage, and worsen other medical conditions.[1,2]

~5-10% of people progress to **advanced sarcoidosis**, where their condition worsens long-term and can even be fatal.[2,3]

By the numbers

~1.2M
people are affected by sarcoidosis[4]

~200K
are in the U.S.[5]

20-60
is the age range when sarcoidosis is most likely to occur[6]

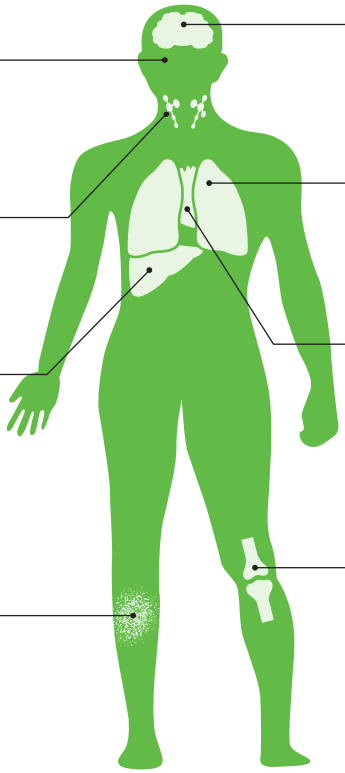
30-50%
of people with sarcoidosis need systemic therapy to treat it[7]

The year they're diagnosed, the average person loses:

8% of their earnings **&** **26** work days[8]

Sarcoidosis can strike anywhere

While sarcoidosis most commonly manifests in the lungs, it is a whole-body disease that can affect almost any organ.



12-23% of cases affect the **eyes**

12-15% of cases affect the **lymph nodes**

12-20% of cases affect the **liver**

16-32% of cases affect the **skin**

3-9% of cases affect the **nervous system**

89-95% of cases affect the **lungs**

2-5% of cases affect the **heart**

1-7% of cases affect the **bones and joints**

Source: Moor CC, Kahlmann V, Culver DA, Wijsenbeek MS. Comprehensive care for patients with sarcoidosis. *J Clin Med*. 2020;9(2):390. doi:10.3390/jcm9020390

1. Sarcoidosis overview. Cleveland Clinic. https://my.clevelandclinic.org/health/diseases/11863-sarcoidosis-overview. Published February 4, 2015. Accessed June 16, 2022. **2.** Baughman RP, Wells A. Advanced sarcoidosis. *Curr Opin Pulm Med*. 2019;25(5):497-504. doi:10.1097/mcp.0000000000000612. **3.** What is sarcoidosis? Foundation for Sarcoidosis Research. https://www.stopsarcoidosis.org/what-is-sarcoidosis/. Accessed May 12, 2022. **4.** Denning DW, Pleuvry A, Cole DC. Global burden of chronic pulmonary aspergillosis complicating sarcoidosis. *Eur Respir J*. 2012;41(3):621-626. doi:10.1183/09031936.00226911. **5.** Baughman RP, Field S, Costabel U, et al. Sarcoidosis in America: Analysis based on health care use. *Ann Am Thorac Soc*. 2016;13(8):1244-1252. doi:10.1513/annalsats.201511-760oc. **6.** Sarcoidosis. Mayo Clinic. https://www.mayoclinic.org/diseases-conditions/sarcoidosis/symptoms-causes/syc-20350358. Published January 30, 2019. Accessed June 16, 2022. **7.** Statement on sarcoidosis. *Am J Respir Crit Care Med*. 1999;160(2):736-755. doi:10.1164/ajrccm.160.2.ats4-99. **8.** Arkema EV, Eklund A, Grunewald J, Bruze G. Work ability before and after sarcoidosis diagnosis in Sweden. *Respir Med*. 2018;144. doi:10.1016/j.rmed.2018.09.016.

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A disease of unknowns...

Our ability to fight sarcoidosis is still lacking in many ways, making it an especially difficult disease for patients and physicians alike. Many people are left feeling frustrated and alone as they struggle to find answers and keep it from taking over their lives during their most productive years.

AWARENESS: Since sarcoidosis is rare and symptoms vary widely, people can go for years **without knowing they have it**.[1]

DIAGNOSIS: There are **no definitive tests or biomarkers**, so it may take many doctor's visits to rule out other options before receiving a diagnosis.

TREATMENT: There are **no approved medicines** specifically for sarcoidosis.[9] Steroids are the main treatment option, but they don't work well for everyone and can cause or worsen other health problems like depression, weight gain, heart disease, and diabetes.[10,11,12]

MANAGEMENT: Most doctors have **almost no training on sarcoidosis** and lack the tools to manage treatment effectively over time. The measures that do exist don't capture what's most meaningful for patients, like fatigue or ability to work.

...and inequities

All of these challenges are magnified for Black individuals, women, and people with a lower income, who are disproportionately impacted by sarcoidosis and disparities in care. **Black women** in particular bear the greatest burden of the disease.

Nearly **3x** **more likely** to develop sarcoidosis[13]

Tend to have more **chronic and severe** forms of the disease[13]

More likely to experience **poor lung function**[14]

Higher rates of **hospitalization** and **mortality**[13]

Less likely to have access to **quality care**[15]

"When it comes to sarcoidosis, the people who are at great risk of having bad outcomes are often the same people who have the greatest need to work. They are the breadwinners and caregivers of their households, so their greatest fear is that they won't be able to continue working."

– DR. KEITH ROBINSON

But there is hope

While the exact causes of sarcoidosis are unknown, research suggests that **inflammatory pathways** are likely a driving force. We are working to better understand these pathways and find promising targets for future medicines, which could redefine the standard of care and help us take back control from this devastating disease.

9. Grunewald J, Grutters JC, Arkema EV, Saketkoo LA, Moller DR, Müller-Quernheim J. Sarcoidosis. *Nat Rev Dis Primers*. 2019;5(1). doi:10.1038/s41572-019-0096-x. **10.** El Jammal T, Jamilloux Y, Gerfaud-Valentin M, Valeyre D, Sève P. Refractory Sarcoidosis: A Review. *Ther Clin Risk Manag*. 2020;16:323-345. doi:10.2147/TCRM.S192922. **11.** Sharp M, Brown T, Chen E, Rand CS, Moller DR, Eakin MN. Psychological burden associated with worse clinical outcomes in sarcoidosis. *BMJ Open Respir Res*. 2019;6(1). doi:10.1136/bmjresp-2019-000467. **12.** Khan NA, Donatelli CV, Tonelli AR, et al. Toxicity risk from glucocorticoids in sarcoidosis patients. *Respir Med*. 2017;132:9-14. doi:10.1016/j.rmed.2017.09.003. **13.** African American women & sarcoidosis. Foundation for Sarcoidosis Research. https://www.stopsarcoidosis.org/aaws-campaign/. Accessed June 16, 2022. **14.** Rabin DL, Thompson B, Brown KM, et al. Sarcoidosis: Social predictors of severity at presentation. *Eur Respir J*. 2004;24(4):601-608. doi:10.1183/09031936.04.00070503. **15.** Hena KM. Sarcoidosis epidemiology: Race matters. *Front Immunol*. 2020;11. doi:10.3389/fimmu.2020.537382.

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