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MADISON NEUROLOGY LLC

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Neurology Care 7 days a Week. Because Your Brain Matters.

Neurosarcoidosis

Patient education guide · Demyelinating & Autoimmune · Madison Neurology LLC

What is it?

Neurosarcoidosis is the nervous system manifestation of sarcoidosis — an inflammatory disease in which immune cells form tiny clumps (granulomas) in body tissues. In the nervous system, it most often affects the coverings of the brain (meninges), the cranial nerves (especially the facial and optic nerves), the pituitary region, and the spinal cord. It affects roughly 5-10% of sarcoidosis patients.

How does it happen?

The cause of sarcoidosis is unknown — an abnormal immune response to an unidentified trigger in genetically susceptible people. Granulomas inflame and can compress neural structures. It is more common in African Americans and in people of Northern European descent.

Common symptoms

- Cranial neuropathies: facial weakness (sometimes both sides), vision loss, double vision
- Headache from meningeal inflammation
- Pituitary/hypothalamic involvement: hormonal changes, excessive thirst and urination
- Myelopathy: weakness, numbness, bladder problems from spinal cord involvement
- Peripheral neuropathy or small fiber neuropathy (burning pain, autonomic symptoms)

How is it diagnosed?

MRI with contrast shows characteristic inflammation of the meninges, pituitary stalk, or cord. Diagnosis ideally requires biopsy confirmation of granulomas (from nerve, meninges, or more accessible sites like lymph nodes or lung), supported by chest imaging (most patients have lung involvement), spinal fluid analysis, and exclusion of infections like tuberculosis.

How is it treated?

Corticosteroids are first-line and usually control inflammation quickly; steroid-sparing immunosuppressants (methotrexate, azathioprine, mycophenolate) and TNF-alpha inhibitors (infliximab — particularly effective in neurosarcoidosis) are used for long-term control. Hormone deficiencies from pituitary involvement are replaced. Seizures, headaches, and neuropathic pain are treated symptomatically.

What does the future hold?

Many patients respond well and enter remission, though the course can be relapsing and some need long-term immunotherapy. Cranial neuropathies and meningeal disease generally respond better than established spinal cord damage. Regular follow-up watches for relapses and medication side effects.

Questions patients commonly ask

Q: I have sarcoidosis in my lungs — is this the same disease?

A: Yes — neurosarcoidosis is the same granulomatous process affecting the nervous system; treating it treats the whole disease.

Q: Will I be on steroids forever?

A: Usually not — steroid-sparing medications take over for long-term control, with steroids reserved for flares.

Q: Is it contagious or inherited?

A: Neither — it's an immune dysregulation condition, not an infection, and family members are not at significant risk.

National support groups & resources

- **Foundation for Sarcoidosis Research** — stopsarcoidosis.org
- **National Organization for Rare Disorders** — rarediseases.org — 1-800-999-6673
- **American Academy of Neurology — Brain & Life patient resources** — brainandlife.org

(Organization contact details were current at the time of compilation; please verify online.)

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