

# THE SRNA REGISTRY

The Siegel Rare Neuroimmune Association has created a patient registry. The purpose of this registry is to help advance research about rare neuroimmune disorders, collaborate with researchers from around the world, and identify participants for clinical trials.

Many of our members have shared information about their diagnosis, treatment, and outcomes over the years. The information you shared continues to help us guide our programs and research.

The SRNA Registry has been designed to learn more about the natural history of rare neuroimmune disorders, treatments, and outcomes using standardized tools.

## Who Can Participate?

Individuals diagnosed with:

- Acute Disseminated Encephalomyelitis
- Neuromyelitis Optica Spectrum Disorder
- Optic Neuritis
- MOG Antibody Disease
- Transverse Myelitis
- Acute Flaccid Myelitis
- Other related disorders (multiple sclerosis, spinal stroke, HTLV I and II, anti-NMDA receptor encephalitis, etc.)

Consent to participate must be provided by an eligible adult participant or a legal guardian if the participant is under the age of 18 or is an adult who is unable to provide consent for him/herself.

Parents or a legally-authorized representative can also enroll on behalf of patients who are deceased. When a legal guardian/representative is completing The SRNA Registry, an additional signature is required for participant assent, which is required if an individual is 7 years of age or older and is cognitively able to provide assent.

## Contact us

For more information and questions about The SRNA Registry, please contact SRNA's Director of Research and Programs, GG deFiebre, at [gdefiebre@wearesrna.org](mailto:gdefiebre@wearesrna.org).

## More info and how to join

[srna.ngo/registry](https://srna.ngo/registry)

