



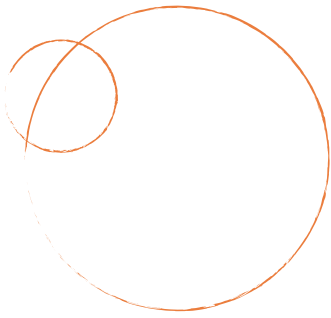
SRNA

Through the years
connect. care. cure.

The Power of Community

CELEBRATING 30 YEARS OF SRNA. TOGETHER.





Since 1994, the Siegel Rare Neuroimmune Association, or SRNA, has stood as a pillar of support and advocacy for individuals affected by rare neuroimmune disorders. It is the place where newly diagnosed individuals and their families find a community of people with similar experiences along with resources, support, and information that help guide them through their journey.

SRNA's journey began as a collective effort of families and individuals impacted by ADEM, AFM, MOGAD, NMOSD, ON, and TM. Over the years, SRNA has evolved into an international organization, steadfast in our commitment to empower, educate, and support our community.

As SRNA approaches its 30th anniversary it marks more than just a milestone; it represents three decades of resilience, growth, and community solidarity. This anniversary is a moment to honor the collective challenges and successes of our community. It's a reflection of our past achievements, and equally, an opportunity to envision and shape the future.

The narrative of SRNA's journey is not just about the organization itself, but, more importantly about the stories of the individuals and families whose lives have been touched by these conditions. It's about the research breakthroughs we've witnessed and the societal shifts we've influenced in our fight against rare neuroimmune disorders.

The 30th Anniversary is an opportune moment to reaffirm our mission, reassess our strategies, and dream bigger. It's about envisioning a world where rare neuroimmune disorders are better understood, more effectively treated, and where those affected lead fuller, more empowered lives.

While we reflect on our past, our eyes are set firmly on the future. This future is built on a foundation of community collaboration and shared vision. Our focus will be on working hand-in-hand with those we serve to co-create services and support programs that truly resonate with their needs.

The next 30 years ask us to think outside the box, expand our reach, and deepen our impact—acting as a springboard into a future where our collective vision shapes a world that is more inclusive, supportive, and empowering for those affected by rare neuroimmune disorders.



Sandy Siegel
President

About the Siegel Rare Neuroimmune Association (SRNA)

The Siegel Rare Neuroimmune Association (SRNA) is a non-profit advocacy organization dedicated to advancing research and clinical care and providing support through networking and education to those affected by rare neuroimmune disorders - acute disseminated encephalomyelitis (ADEM), acute flaccid myelitis (AFM), MOG antibody disease (MOGAD), neuromyelitis optica spectrum disorder (NMOSD), optic neuritis (ON) and transverse myelitis (TM).

We serve as an information resource on rare neuroimmune disorders for our community through our website, magazines, blogs, Ask The Expert Podcast Series, educational events such as symposia and workshops for the exchange of current and up-to-date information regarding the diagnosis, treatment and management of these disorders. We offer a support network between those diagnosed with these disorders through our Peer Connect Program, local support groups located throughout the world, and through our partnership with Smart Patients. Additionally, we organize annual quality of life programs such as family camps for children with these disorders and their families, and through the Pauline H. Siegel Eclipse Fund for research, we catalyze robust research programs and clinical and research careers in academic medicine. We at SRNA hope to grow the number of clinicians and researchers dedicated to the field of rare neuroimmune disorders through our James T. Lubin Fellowship Program. We also collect valuable information about rare neuroimmune disorders through our Registry to make it easier for researchers to learn about the rare disorders and to get in touch with individuals who are willing to participate in future studies.

OUR THREE C'S

Connect individuals affected by rare neuroimmune disorders with each other, and with a network of medical professionals, researchers, and clinician-scientists.

Care for all those affected by offering support, providing education and quality of life programs, and serving as an information resource on rare neuroimmune disorders.

Further our work of finding a **cure** by funding innovative research, training clinician-scientists, developing novel therapies, and investing in academic centers of excellence.

OUR GOAL

To **improve the quality of life** of individuals with ADEM, AFM, MOGAD, NMOSD, ON, TM, and all other rare neuroimmune disorders.



Founded in
1994



We are a team of
9 people



Supporting
15,300+ members



From
121+ countries



By the Numbers

\$1m

invested in clinician
scientist training

We have convened 25 symposia, **uniting over 5,000 individuals diagnosed, families, healthcare professionals, partners, and allies.** These gatherings foster lasting connections and often mark the first meeting for many. Our real impact extends far beyond the event itself; with **over 1.4 million lifetime listens to recordings, our reach continues to grow.**

25

symposia held

We have invested over \$1 million towards the **James T Lubin Fellowship, funding 8 fellows across 5 specialized centers,** including Dr. Haiwen Chen, whose research on MOGAD aims to improve treatment strategies. These fellowships and research investments are instrumental in advancing our understanding of rare neuroimmune disorders, developing better therapies, and ultimately improving outcomes for patients.

800

resources published

We have published over 800 resources to our online library, including podcasts and videos, **providing valuable support and information for those diagnosed, caregivers, and healthcare professionals.**

We have funded the first specialized center and **expanded to 9 Centers of Excellence, ensuring comprehensive care for individuals and families.** These Centers of Excellence play a crucial role in providing specialized care, advancing research, and developing effective treatment strategies for rare neuroimmune disorders.

9

centers of
excellence
certified

13

research
studies
funded

We have **supported 13 research studies, with one subsequently receiving an NIH award of \$1.25 million, demonstrating the transformative and exponential impact these kickstarter investments have.** These research studies are essential for advancing our understanding of rare neuroimmune disorders, developing new treatments, and ultimately improving the lives of patients and families affected by these conditions.

38

awareness walks
hosted

We have held 38 Walk-Run-n-Roll events, **engaging over 20,000 people to raise awareness, fund vital research and support initiatives, and build community support.**

4,900

support request received through
the Myelitis Helpline

In 2016, we launched the Myelitis Helpline. Receiving over 4,900 support requests to date we **offered immediate support, guidance, and critical information** to those affected by these conditions.

692

individuals joined
the SRNA Registry

In 2023, we launched the **first-ever online learning course in the rare disease space**, covering topics from the nervous system to rare neuroimmune disorders, empowering our community with accessible knowledge. This online course provides patients and caregivers with convenient access to education and information about rare neuroimmune disorders. X community members signed up to date.

Since launching our SRNA Registry in 2017, the **self-reported patient database has grown to include 692 individuals, providing valuable de-identified data for researchers and clinicians to improve diagnosis, treatment, and care** for those living with rare neuroimmune disorders.

311

individuals joined the first-ever
online micro-course on rare
neuroimmune disorders



You can learn more about SRNA's work at srna.ngo/2023-ar

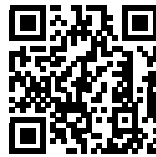


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Siegel
Rare Neuroimmune
Association

Thank you so much for your support!

You may wish to send a check payable to: SRNA, PO Box 826962, Philadelphia, PA 19182-6962
or **donate online at srna.ngo/30-ba**



Note/Memo: 30th Anniversary

SRNA is classified as a 501(c)(3) organization by the Internal Revenue Service. EIN 91-1780467.



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