SRNA

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Siegel
Rare Neuroimmune
Association

The Siegel Rare Neuroimmune Association (SRNA) **advocates** for, **supports** and **educates** individuals and their families diagnosed with acute disseminated encephalomyelitis, acute flaccid myelitis, MOG antibody disease, neuromyelitis optica spectrum disorder, optic neuritis, and transverse myelitis, and **accelerates** and **invests** in scientific research, therapy development and training of clinician-scientists dedicated to these disorders. Our end goal is to **improve the quality of life of individuals with rare neuroimmune disorders** and redouble our commitment to finding a cure. Together.

Founded in
1994

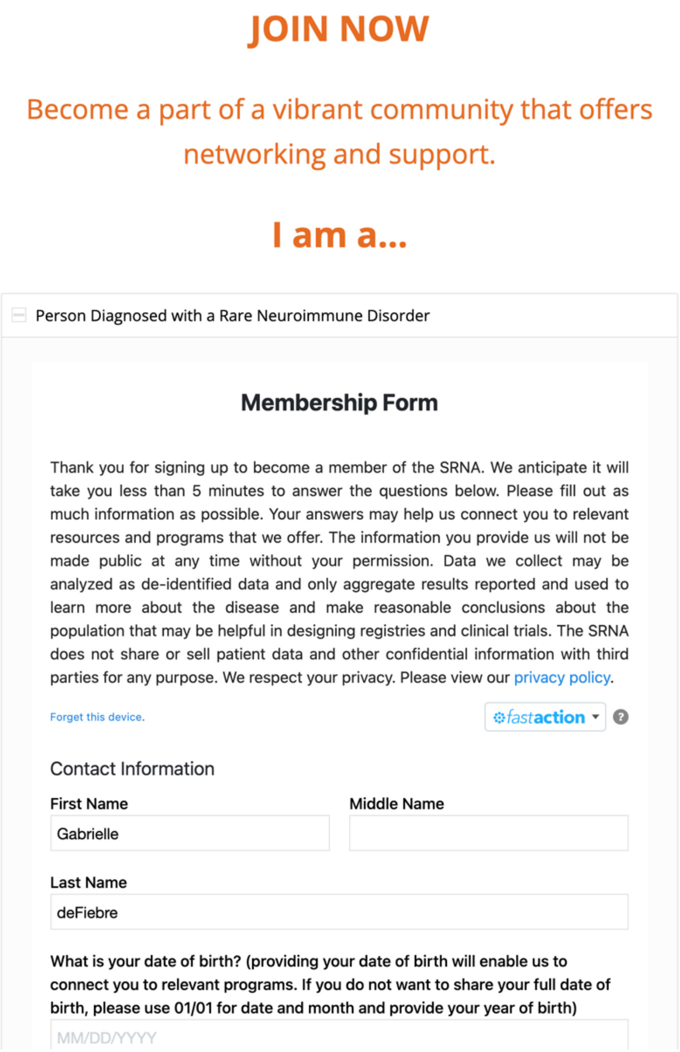
We are a team of
8 staff

Supporting
Over 15,000
people

From over
121 countries

Membership

In 2024, **541 new members joined the association**, including individuals diagnosed with AFM, ADEM, MOGAD, NMOSD, ON, and TM, relatives, and caregivers of people diagnosed, healthcare professionals, and others who have an interest in this cause.



JOIN NOW

Become a part of a vibrant community that offers networking and support.

I am a...

Person Diagnosed with a Rare Neuroimmune Disorder

Membership Form

Thank you for signing up to become a member of the SRNA. We anticipate it will take you less than 5 minutes to answer the questions below. Please fill out as much information as possible. Your answers may help us connect you to relevant resources and programs that we offer. The information you provide us will not be made public at any time without your permission. Data we collect may be analyzed as de-identified data and only aggregate results reported and used to learn more about the disease and make reasonable conclusions about the population that may be helpful in designing registries and clinical trials. The SRNA does not share or sell patient data and other confidential information with third parties for any purpose. We respect your privacy. Please view our privacy policy.

Forget this device.

fastaction

Contact Information

First Name: Gabrielle

Middle Name:

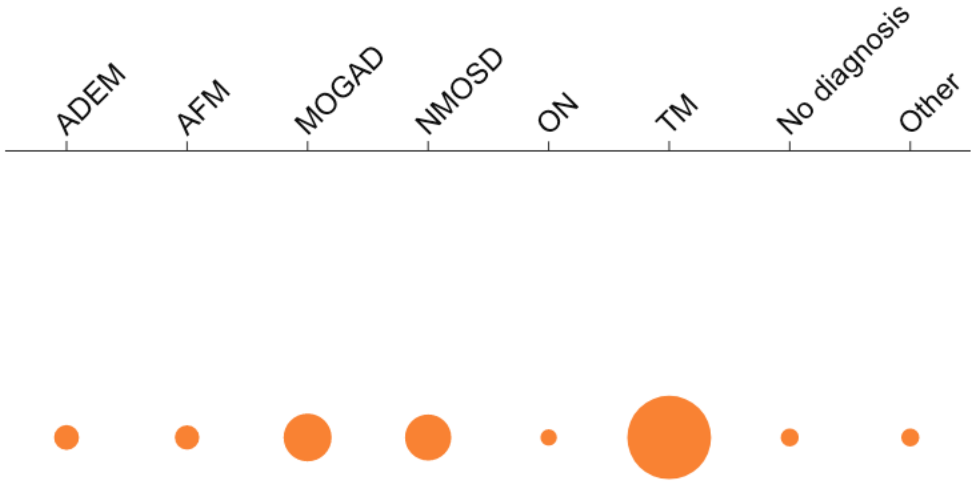
Last Name: deFiebre

What is your date of birth? (providing your date of birth will enable us to connect you to relevant programs. If you do not want to share your full date of birth, please use 01/01 for date and month and provide your year of birth)

MM/DD/YYYY

Privacy Policy: *wearesrna.org/about/privacy-policy*

Membership



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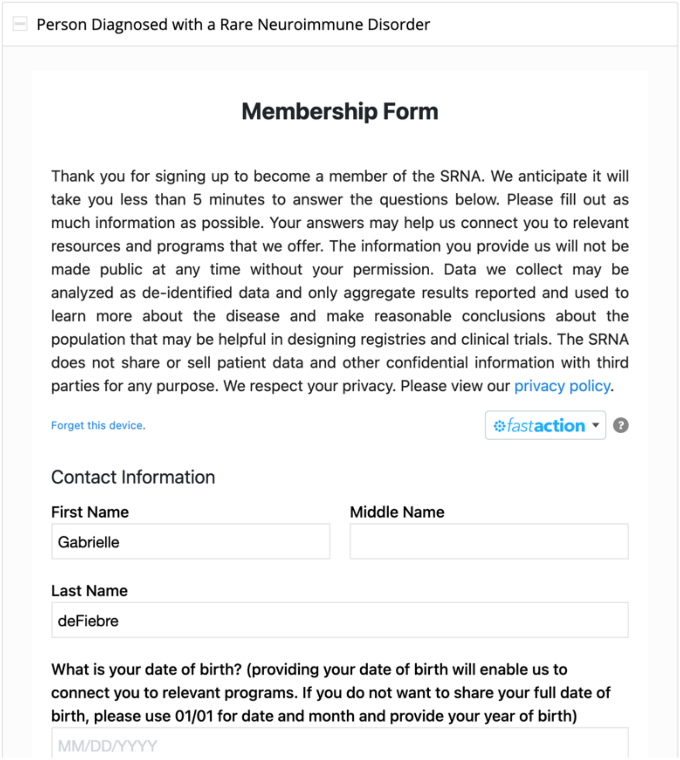
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Connect

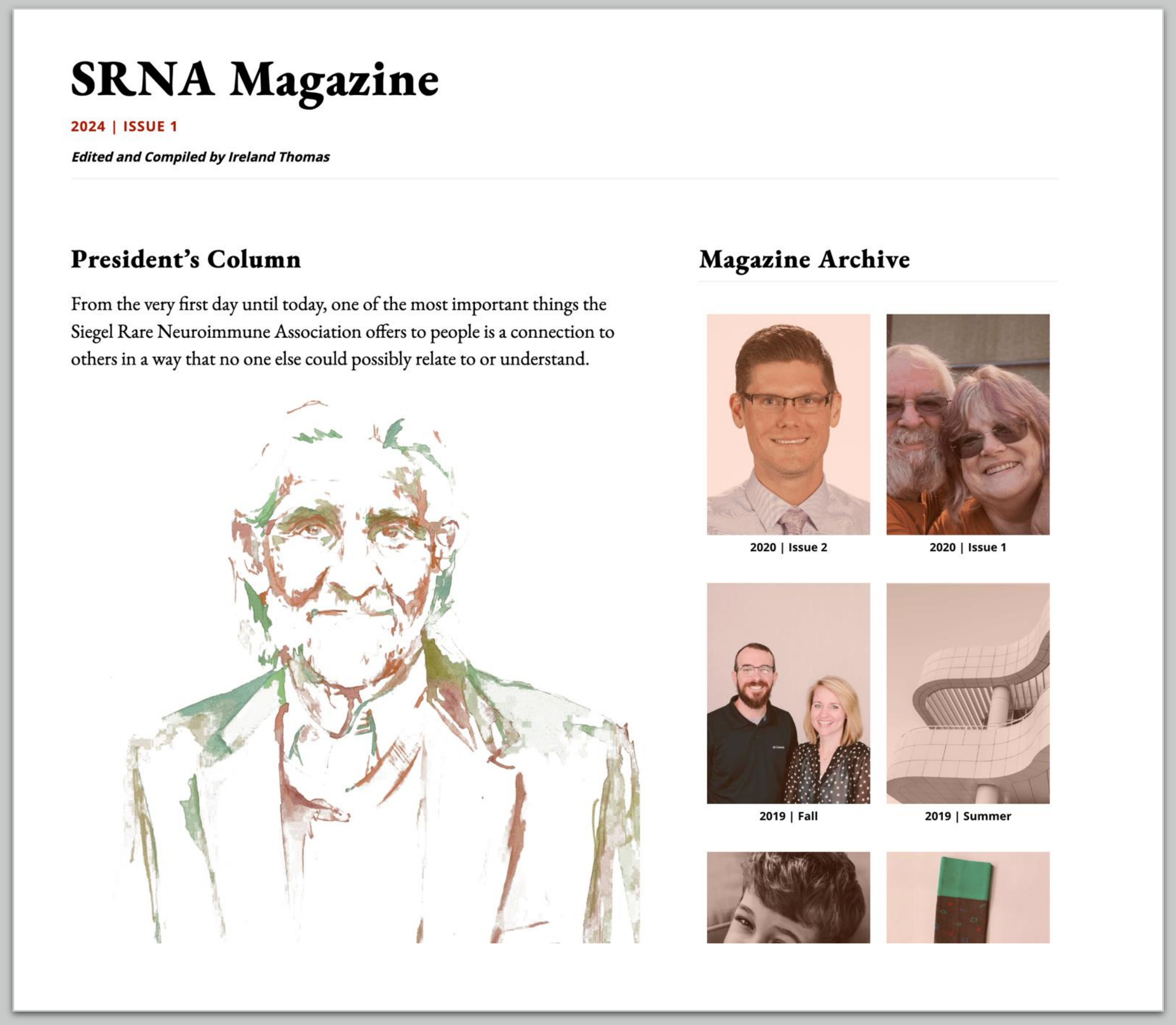
Connect

- Support Group Network and Peer to Peer program
- Personalized support via phone calls and emails
- In 2024, 22 support group meetings were held with over 419 attendees
- In 2024, 35 peer connect requests were made and over 50 documented peer connections were made

Connect

Blogs and Magazines

- Weekly blog posts and quarterly magazine
- Stories from members, research summaries, announcements, event recaps, and time-sensitive information
- Subscription via email in addition to our magazine



SRNA Magazine

2024 | ISSUE 1

Edited and Compiled by Ireland Thomas

President's Column

From the very first day until today, one of the most important things the Siegel Rare Neuroimmune Association offers to people is a connection to others in a way that no one else could possibly relate to or understand.

Magazine Archive

2020 | Issue 2

2020 | Issue 1

2019 | Fall

2019 | Summer

Connect

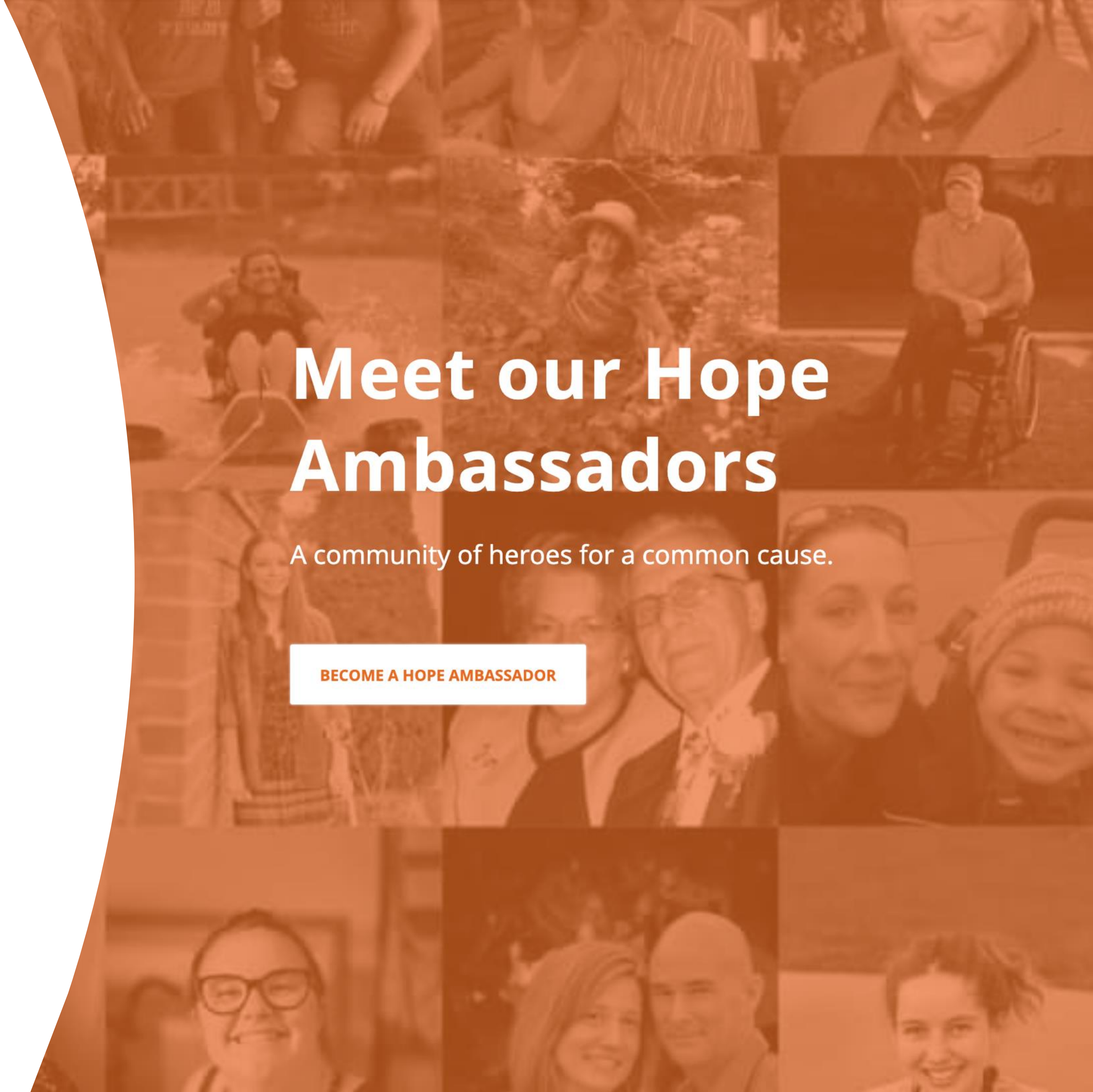
SRNA Quality of Life Family Camp

- Unique opportunity to bring families affected by rare neuroimmune disorders together and connect with medical professionals
- Children, siblings included, connect with peers with similar situations
- 23 families attended our 2025 camp which was held at the Morgan's Camp in San Antonio, TX

Connect

- Launched in 2017 with the 100-day myelife. my hope. Awareness Campaign, our **Hope Ambassador** Network currently features over 130 ambassadors

- Collaborations and partnerships with other organizations to increase awareness and support opportunities



Meet our Hope Ambassadors

A community of heroes for a common cause.

Connect

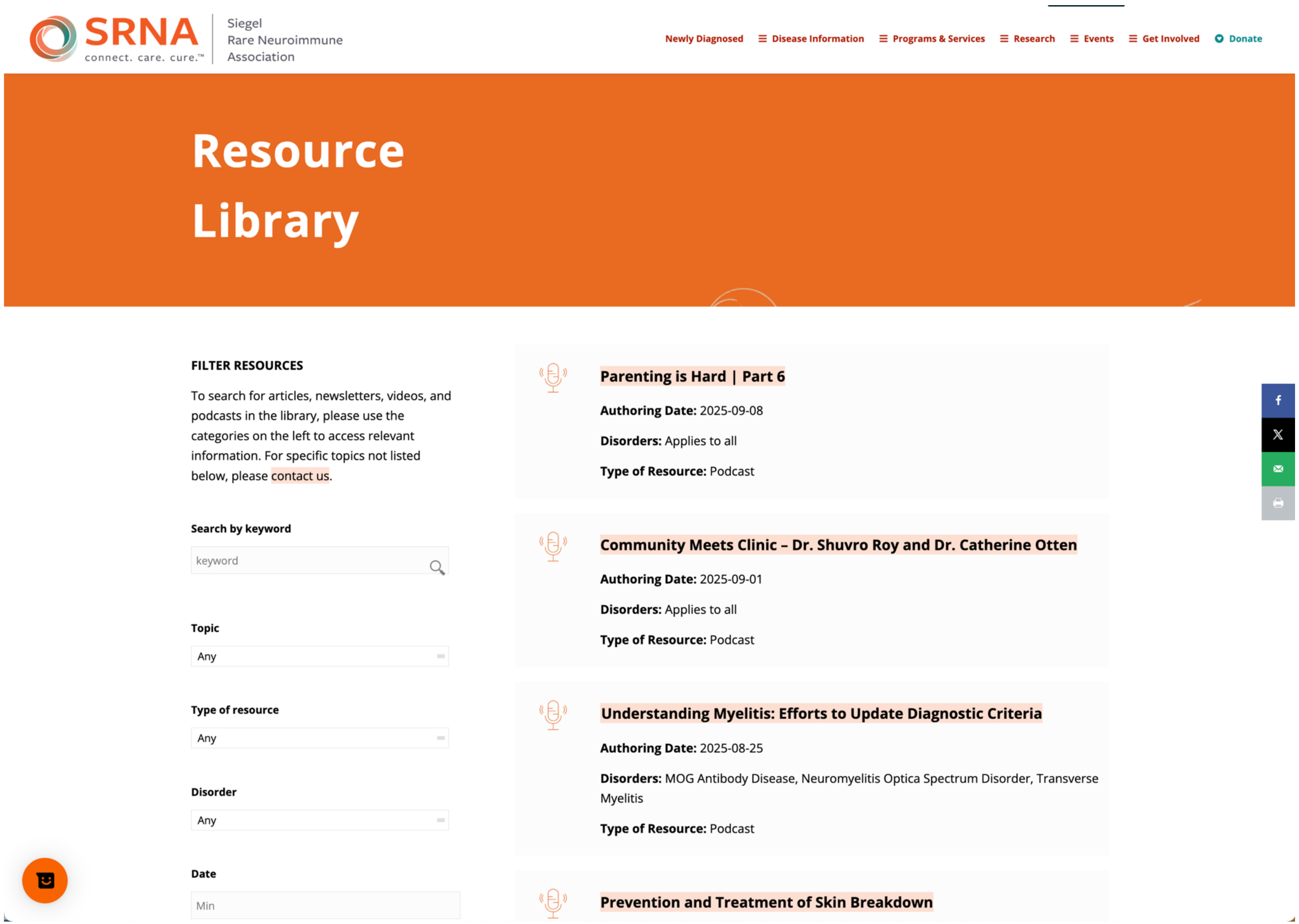
- **Walk-Run-N-Rolls**
  - Organized by community members
  - Raise awareness, fund education and research opportunities
  - Inform local community
  - In 2024, 5 regional events were held with over 330 attendees

Care

Website

- SRNA's website, established in 1997, has become one of the most extensive sources of information on rare neuroimmune disorders, from diagnosis to treatment to ongoing care
- In 2024, atotal of 211,000 active users (compared to 162,000 in 2023) visited the website

Over 868 resources available



Resource Library

FILTER RESOURCES

To search for articles, newsletters, videos, and podcasts in the library, please use the categories on the left to access relevant information. For specific topics not listed below, please contact us.

Search by keyword

keyword

Topic

Any

Type of resource

Any

Disorder

Any

Date

Min

Parenting is Hard | Part 6

Authoring Date: 2025-09-08

Disorders: Applies to all

Type of Resource: Podcast

Community Meets Clinic – Dr. Shuvro Roy and Dr. Catherine Otten

Authoring Date: 2025-09-01

Disorders: Applies to all

Type of Resource: Podcast

Understanding Myelitis: Efforts to Update Diagnostic Criteria

Authoring Date: 2025-08-25

Disorders: MOG Antibody Disease, Neuromyelitis Optica Spectrum Disorder, Transverse Myelitis

Type of Resource: Podcast

Prevention and Treatment of Skin Breakdown

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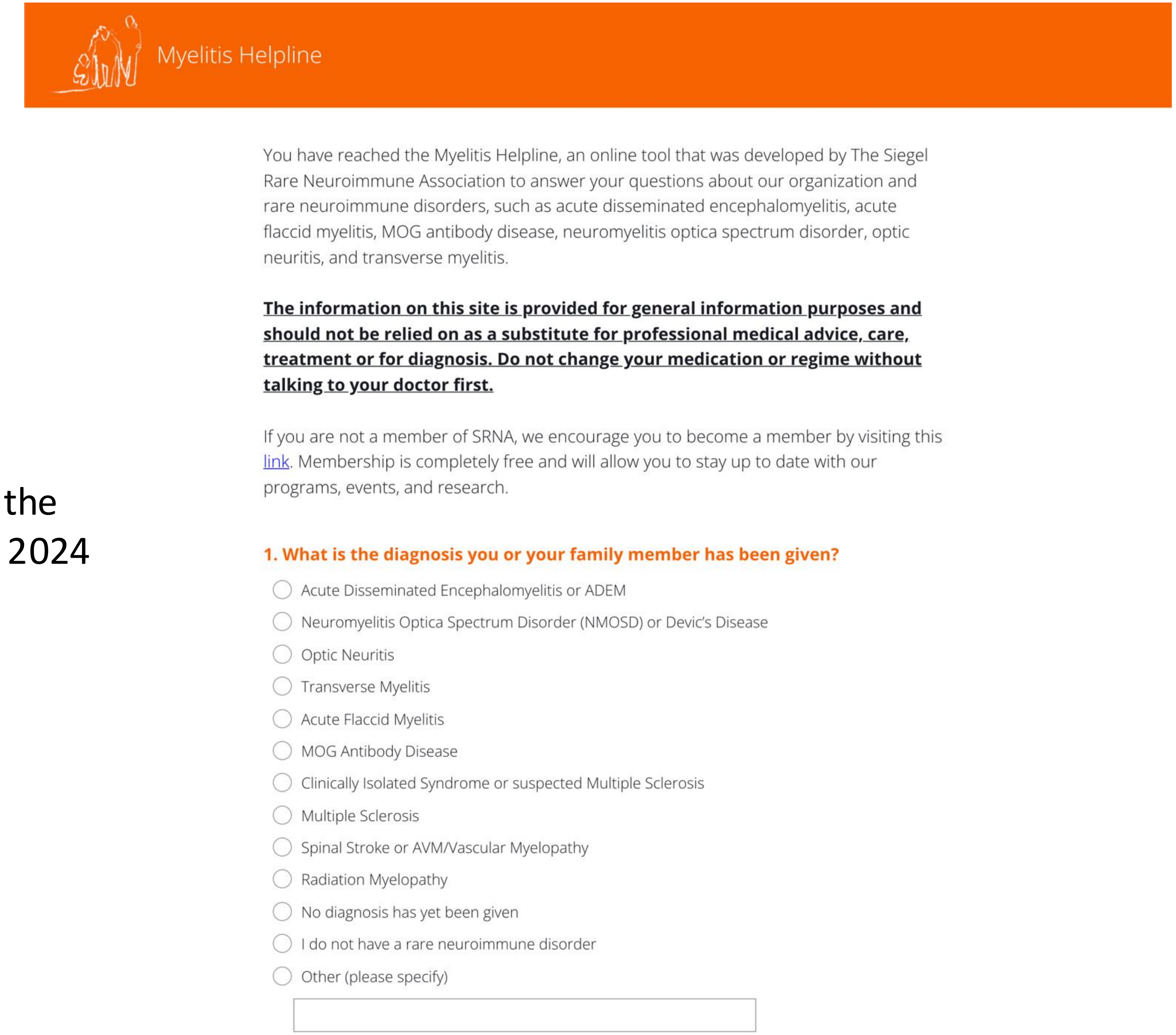
420 individuals supported through the Myelitis Helpline in 2024



You have reached the Myelitis Helpline, an online tool that was developed by The Siegel Rare Neuroimmune Association to answer your questions about our organization and rare neuroimmune disorders, such as acute disseminated encephalomyelitis, acute flaccid myelitis, MOG antibody disease, neuromyelitis optica spectrum disorder, optic neuritis, and transverse myelitis.

The information on this site is provided for general information purposes and should not be relied on as a substitute for professional medical advice, care, treatment or for diagnosis. Do not change your medication or regime without talking to your doctor first.

If you are not a member of SRNA, we encourage you to become a member by visiting this link. Membership is completely free and will allow you to stay up to date with our programs, events, and research.

1. What is the diagnosis you or your family member has been given?

○ Acute Disseminated Encephalomyelitis or ADEM
○ Neuromyelitis Optica Spectrum Disorder (NMOSD) or Devic's Disease
○ Optic Neuritis
○ Transverse Myelitis
○ Acute Flaccid Myelitis
○ MOG Antibody Disease
○ Clinically Isolated Syndrome or suspected Multiple Sclerosis
○ Multiple Sclerosis
○ Spinal Stroke or AVM/Vascular Myelopathy
○ Radiation Myelopathy
○ No diagnosis has yet been given
○ I do not have a rare neuroimmune disorder
○ Other (please specify)

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Rare Neuroimmune Disorders Symposium

- First international symposium held in 1999, with more than 100 attendees from all over the world.
- Since then, yearly symposia, alternating between international and regional engagement every other year.
- One of a kind event that brings together individuals diagnosed with rare neuroimmune disorders and the clinicians and researchers that focus on these disorders.

RNDS OBJECTIVES

BIOLOGY AND CAUSES

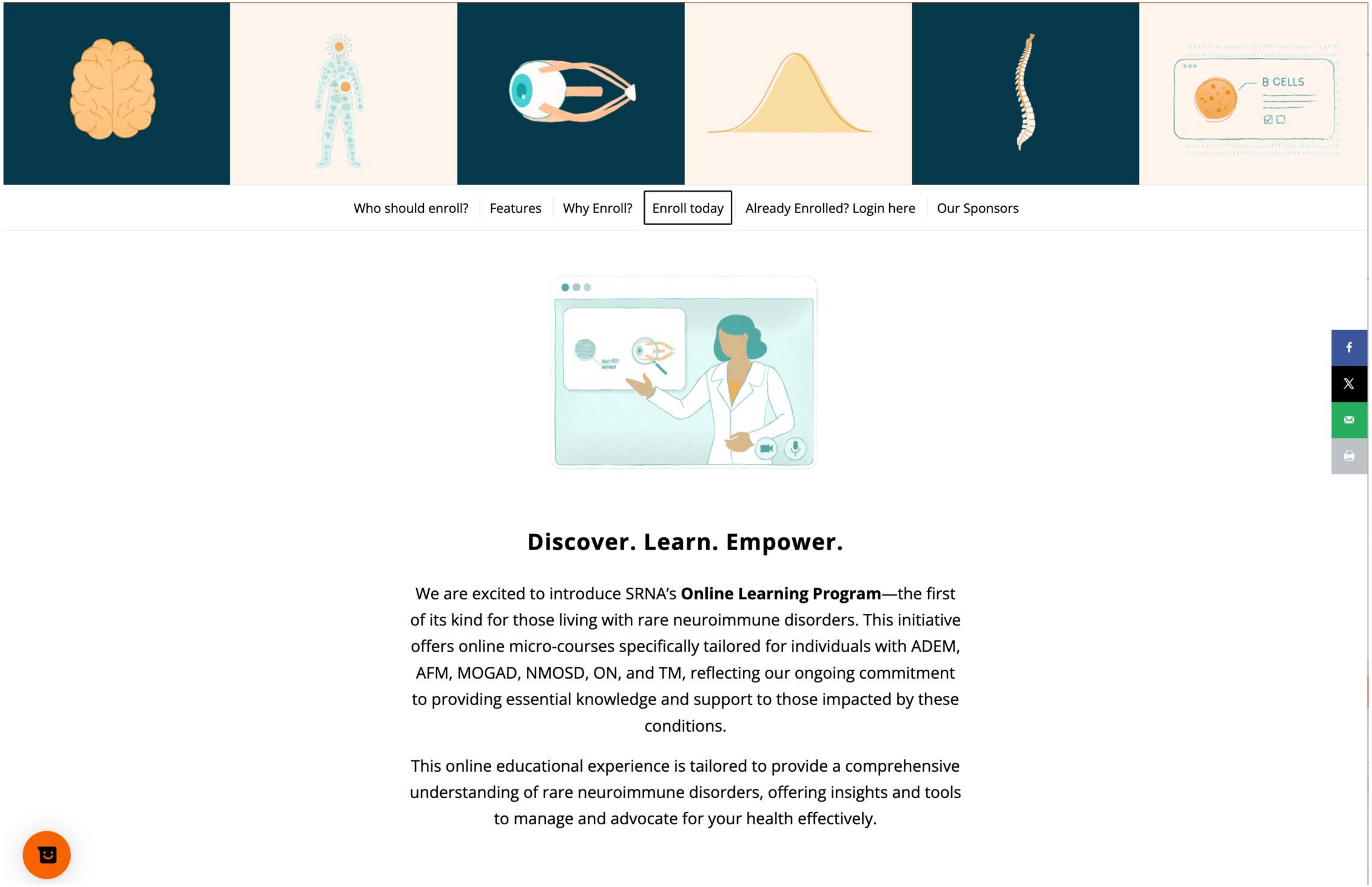
Acquire an understanding of the biology and causes of rare neuroimmune disorders (TM, NMOSD, MOGAD, AFM, ADEM, and ON) and how they relate to each other

MANAGING SYMPTOMS

Learn about the latest medical and surgical strategies to manage the symptoms associated with these chronic rare neuroimmune disorders

RESEARCH AND STUDIES

Gain knowledge on current and future basic science research and clinical studies that will improve the quality of life of our community



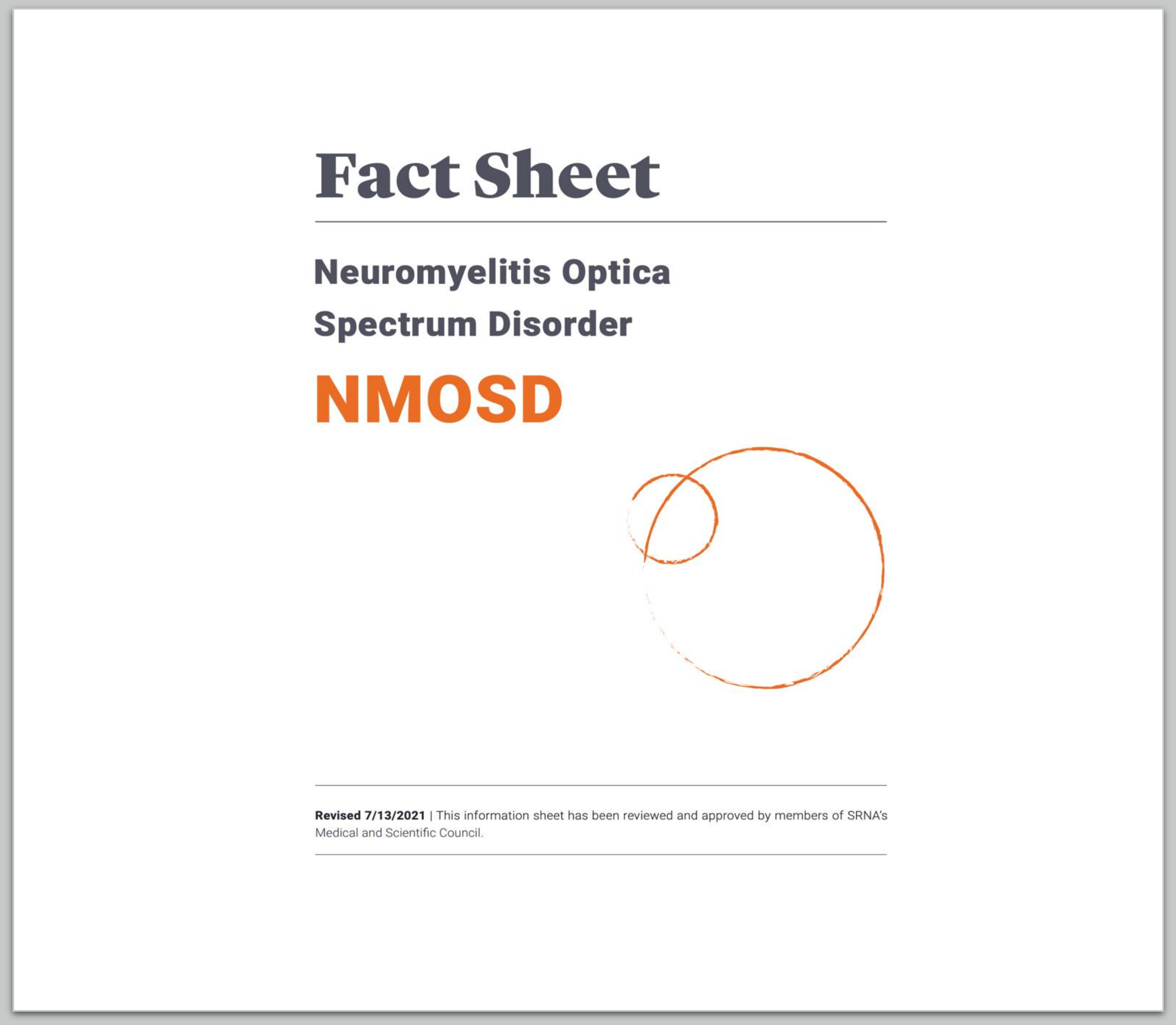
Discover. Learn. Empower.

We are excited to introduce SRNA's **Online Learning Program**—the first of its kind for those living with rare neuroimmune disorders. This initiative offers online micro-courses specifically tailored for individuals with ADEM, AFM, MOGAD, NMOSD, ON, and TM, reflecting our ongoing commitment to providing essential knowledge and support to those impacted by these conditions.

This online educational experience is tailored to provide a comprehensive understanding of rare neuroimmune disorders, offering insights and tools to manage and advocate for your health effectively.

Care

- Disorder Information Sheets available for all disorders
  - All website and printable publications from SRNA are reviewed by members of medical and scientific council
  - In 2022, all information sheets were translated into Spanish



Fact Sheet

Neuromyelitis Optica Spectrum Disorder

NMOSD

Revised 7/13/2021 | This information sheet has been reviewed and approved by members of SRNA's Medical and Scientific Council.

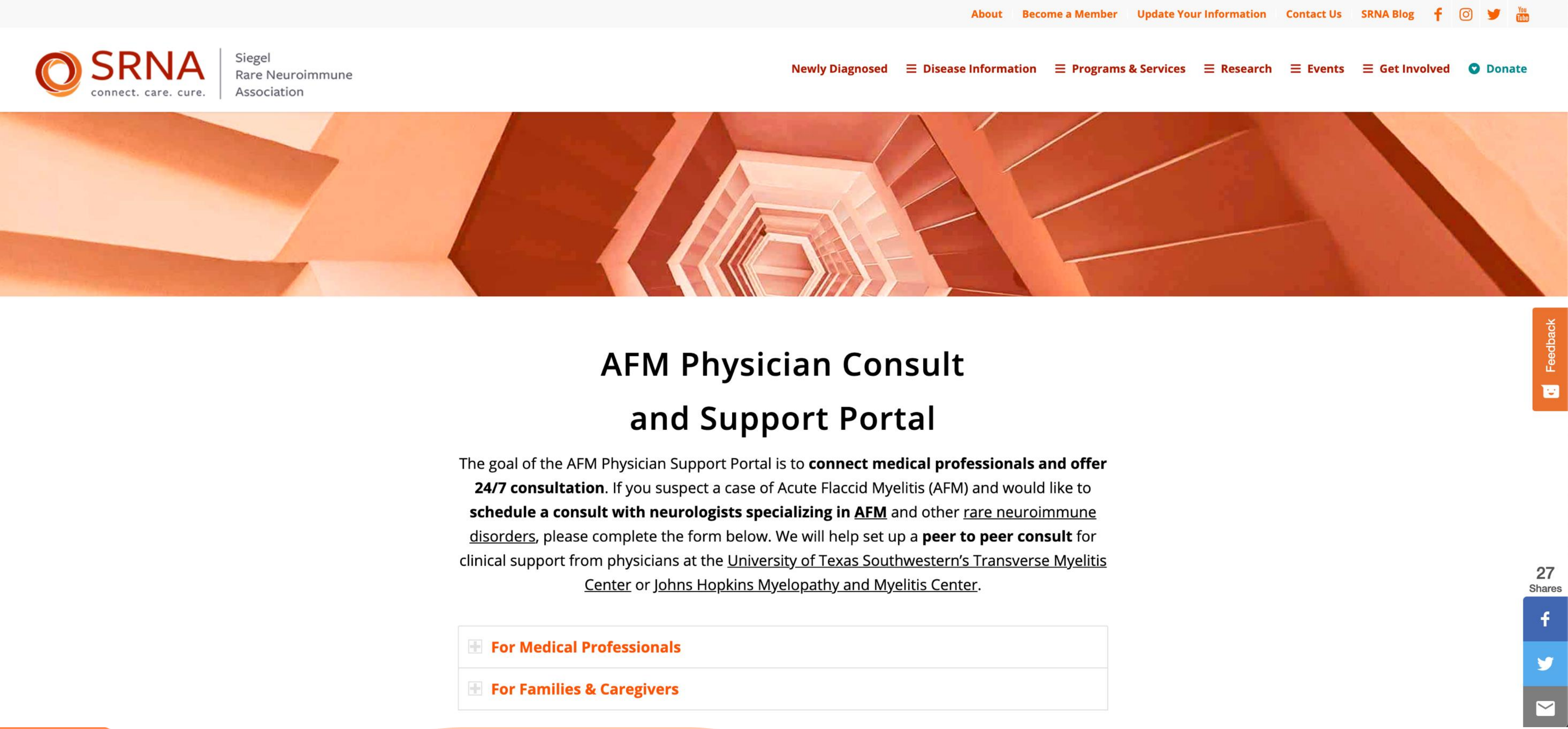

SRNA
Soundwaves

Medical Professional Network

Healthcare professionals and specialized medical institutions finder tool

Centers of Excellence in Rare Neuroimmune Disorders

- SRNA's Centers of Excellence in Rare Neuroimmune Disorders (CERND) designation recognizes medical centers that provide comprehensive care to treating people diagnosed with ADEM, AFM, MOGAD, NMOSD, ON, and TM.
- 17 Centers
  - 5 Pediatric-Only
  - 1 Rehabilitation

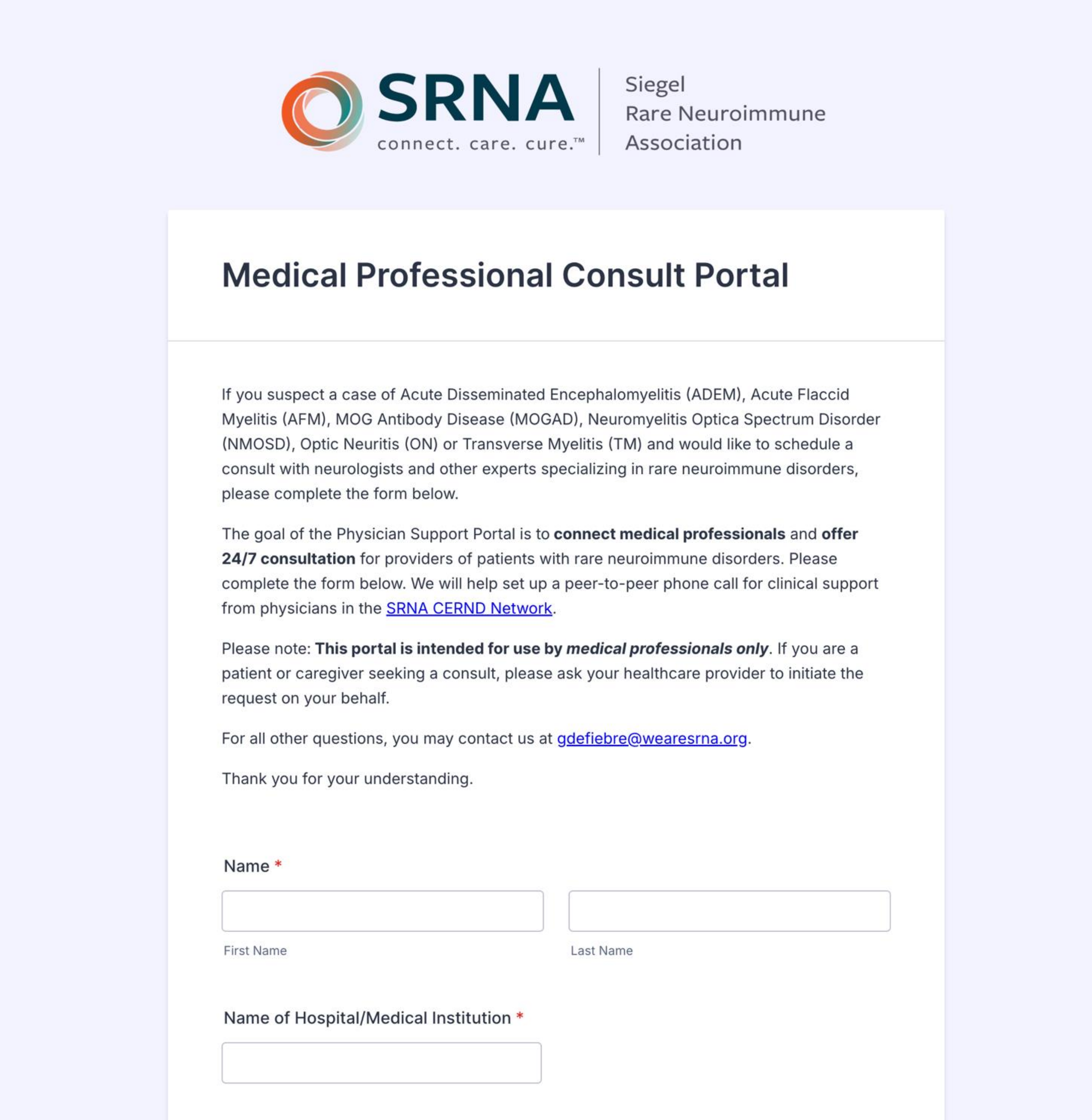


AFM Physician Consult and Support Portal

The goal of the AFM Physician Support Portal is to **connect medical professionals and offer 24/7 consultation**. If you suspect a case of Acute Flaccid Myelitis (AFM) and would like to **schedule a consult with neurologists specializing in AFM** and other rare neuroimmune disorders, please complete the form below. We will help set up a **peer to peer consult** for clinical support from physicians at the University of Texas Southwestern's Transverse Myelitis Center or Johns Hopkins Myelopathy and Myelitis Center.

For Medical Professionals

For Families & Caregivers



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Medical Professional Consult Portal

If you suspect a case of Acute Disseminated Encephalomyelitis (ADEM), Acute Flaccid Myelitis (AFM), MOG Antibody Disease (MOGAD), Neuromyelitis Optica Spectrum Disorder (NMOSD), Optic Neuritis (ON) or Transverse Myelitis (TM) and would like to schedule a consult with neurologists and other experts specializing in rare neuroimmune disorders, please complete the form below.

The goal of the Physician Support Portal is to **connect medical professionals** and **offer 24/7 consultation** for providers of patients with rare neuroimmune disorders. Please complete the form below. We will help set up a peer-to-peer phone call for clinical support from physicians in the SRNA CERND Network.

Please note: **This portal is intended for use by *medical professionals only***. If you are a patient or caregiver seeking a consult, please ask your healthcare provider to initiate the request on your behalf.

For all other questions, you may contact us at gdefiebre@wearesrna.org.

Thank you for your understanding.

Name *

First Name

Last Name

Name of Hospital/Medical Institution *

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Cure

The Eclipse Fund in memory of Pauline H. Siegel

Cure

- We accelerate research to advance our understanding of:
  - the causes and the natural history of these disorders
  - to develop new acute and restorative therapies
  - to improve the quality of life of those affected by these disorders

- SRNA initiated research to date has included:
  - The SRNA Registry
  - Study on experiences with vaccinations
  - COVID-19 survey
  - QoL in NMOSD

SRNA Registry

- 763 participants
  - 65% TM, 10% NMOSD, 1% MOGAD, 5% ADEM and 4% AFM
  - 90% adults
  - 69% in the United States
- 44 people joined the SRNA Registry in 2024

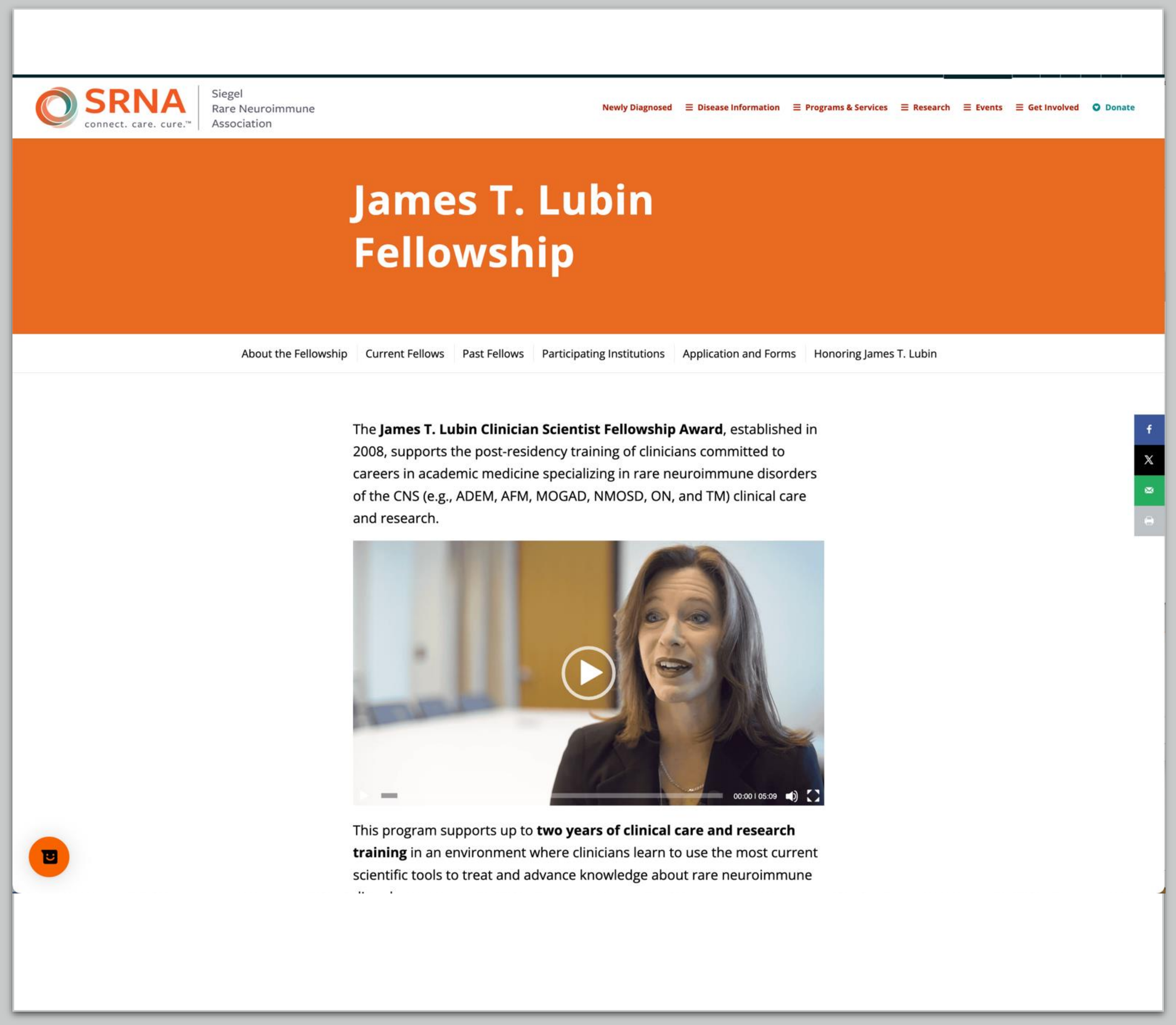
The James T. Lubin Clinician Scientist Fellowship Award

Objectives

- PROVIDE HIGH QUALITY, STATE-OF-THE-ART, COMPREHENSIVE CLINICAL CARE TO PATIENTS WITH ADEM, AFM, MOG-Ab DISEASE, NMOSD, ON, AND TM
- ADVANCE THE RESEARCH AND UNDERSTANDING OF THESE DISORDERS THROUGH CLINICAL RESEARCH AND/OR BASIC SCIENCE RESEARCH
- BECOME AN ACTIVE PARTICIPANT AND FUTURE LEADER IN THE RARE NEUROIMMUNE DISORDERS CLINICAL COMMUNITY

Fellowship

- 10 funded fellows since 2012
- 4 training institutions → now expanded to 7



James T. Lubin Fellowship

The **James T. Lubin Clinician Scientist Fellowship Award**, established in 2008, supports the post-residency training of clinicians committed to careers in academic medicine specializing in rare neuroimmune disorders of the CNS (e.g., ADEM, AFM, MOGAD, NMOSD, ON, and TM) clinical care and research.

This program supports up to **two years of clinical care and research training** in an environment where clinicians learn to use the most current scientific tools to treat and advance knowledge about rare neuroimmune

Current Fellows

Sydney Lee, MD

Autoimmune Neurology Fellow, University of Utah

Dr. Lee is a neurologist who received her medical degree from the University of Saskatchewan. She then completed a Residency at The University of Toronto. For her fellowship, she will conduct a study that compares NMOSD preventive treatments in terms of cost and efficacy in preventing disability and preserving patients' quality of life. First, a group of patients with NMOSD will complete questionnaires, allowing them to identify factors that impact their health and quality of life. This information will then be used to calculate a measurement of quality of life in NMOSD, called a quality-adjusted life year (QALY). They will use economic models to map the course of NMOSD over time and compare the overall cost and effectiveness of each preventative drug. This study will determine the most cost-effective treatment for NMOSD and pave the way toward making these important medications more available to patients.

Rachel Walsh, MD

Clinical Fellow, Boston Children's Hospital

Dr. Walsh is a pediatric neurologist who received her medical degree from Mercer University School of Medicine. She then completed a Pediatrics and Pediatrics Neurology Residency at Stanford Health Care. For her fellowship, she will evaluate the medical information on a large group of pediatric patients (860 patients anticipated) who presented with symptoms of spinal cord dysfunction and were initially diagnosed with myelitis. She will compare patients based on the underlying cause of their myelitis, including those labeled as idiopathic. The study aims to describe the clinical features and long-term recovery from myelitis amongst the different diagnostic groups as well as better characterize the idiopathic cases. Results are expected to help develop classification systems and definitions, predict outcomes early after myelitis onset, and guide future myelitis studies in children and adolescents.

Questions?

info@wearesrna.org

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