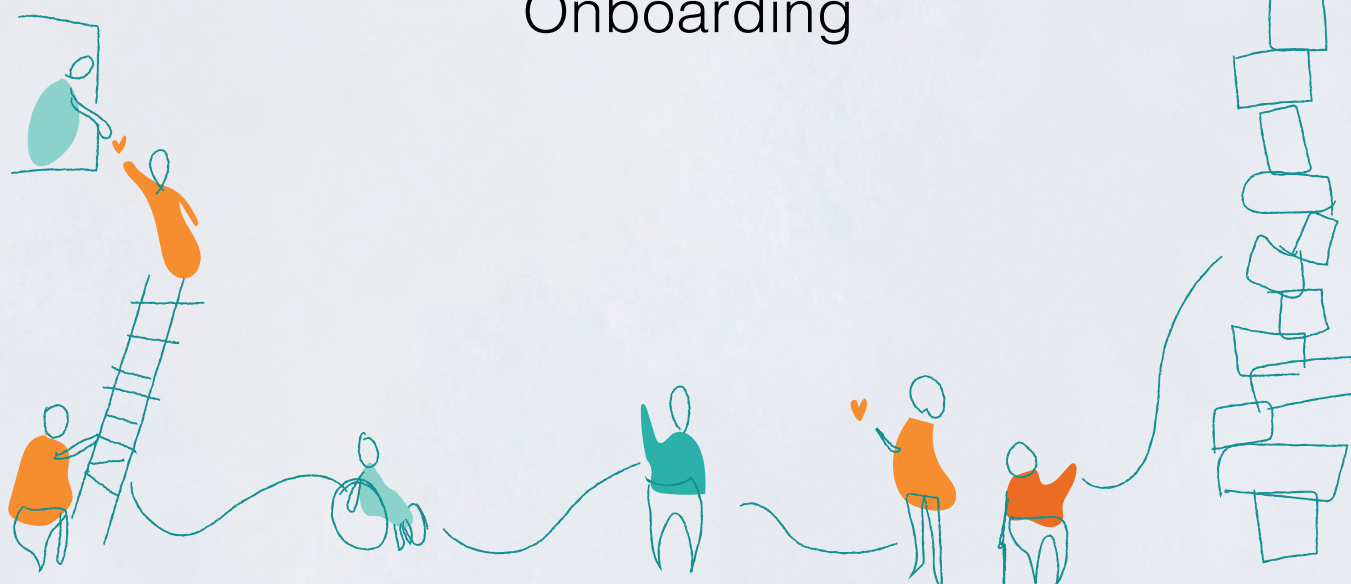




SIEGEL RARE NEUROIMMUNE
ASSOCIATION

Volunteer Handbook

Onboarding





**SIEGEL RARE NEUROIMMUNE
ASSOCIATION**

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Hello and welcome

Thank you for choosing to volunteer with The Siegel Rare Neuroimmune Association (SRNA) and for helping to reach and improve the lives of people affected by rare neuroimmune disorders.

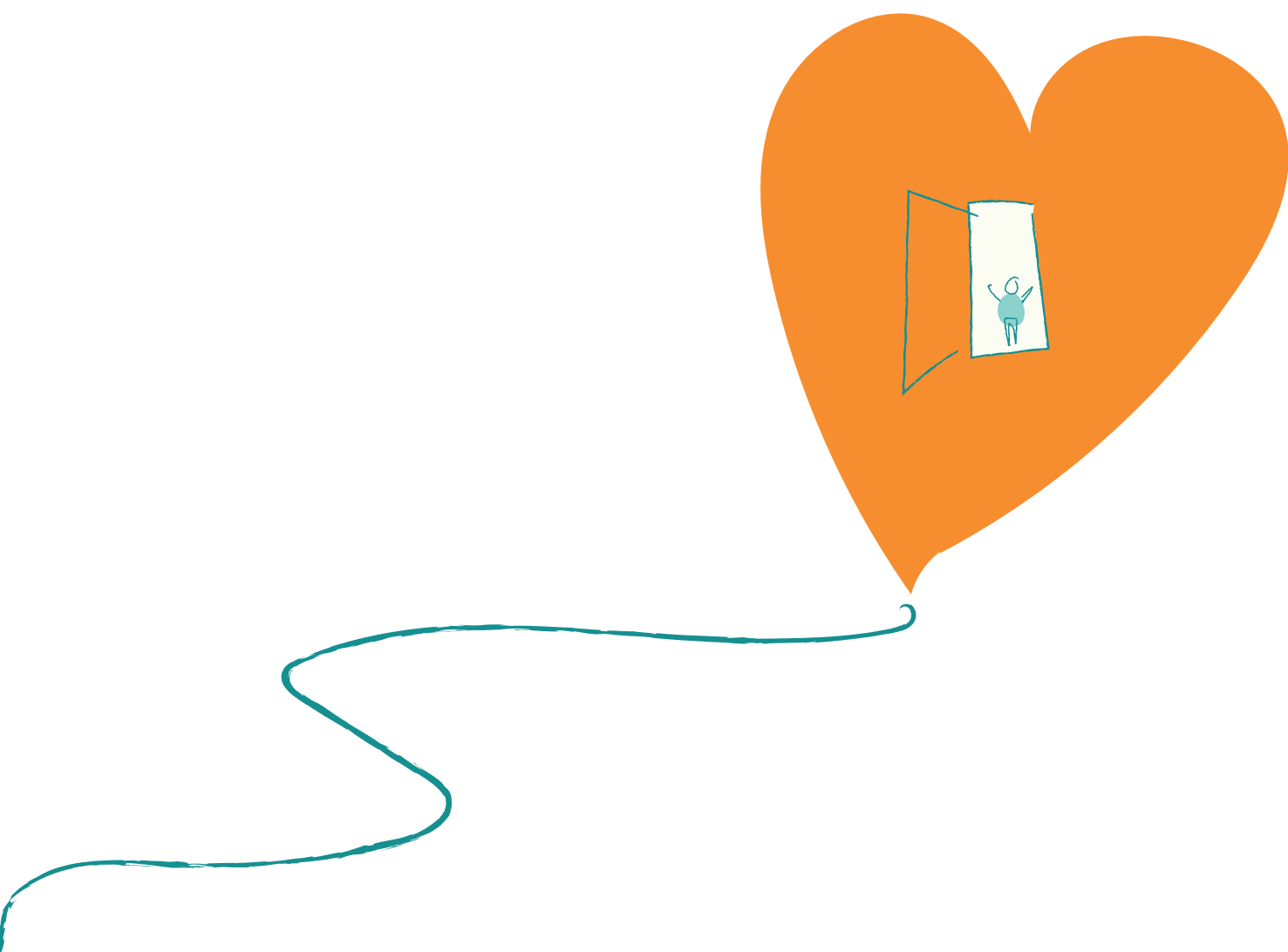
Volunteers are at the very heart of our organization. They are our face in the local community. They tell people that they are not alone. Voices of volunteers help us shape and improve care for all those affected by rare neuroimmune disorders. Volunteers are essential to everything we do. They raise money to fund vital research, education, and community programs and help us deliver them.

We have volunteers from all over the world. They live across the globe - from Arizona to Ontario, Houston to Portland, England to Germany. Volunteers get involved for a variety of reasons. Some want to make a difference in the lives of people affected by rare neuroimmune disorders, others want to develop new skills, and some simply want to meet new people and have fun. Every person who volunteers has one thing in common: they're vital to our work.

We aspire to make sure anyone who gives their time to us feels valued, understood, and proud to be part of SRNA. This handbook is here to explain the things you need to know about volunteering with us. We hope you find it helpful. If you'd like more detailed information on any of the subjects covered, please reach out to us. We'll be more than happy to help you.

Thank you once again for deciding to make a difference.





A little about us



The Siegel Rare Neuroimmune Association (SRNA) is a not-for-profit organization dedicated to supporting children, adolescents, and adults — and their families — who have been diagnosed with rare neuroimmune disorders, including acute disseminated encephalomyelitis (ADEM), acute flaccid myelitis (AFM), MOG antibody disease (MOGAD), neuromyelitis optica spectrum disorder (NMOSD), optic neuritis (ON), and transverse myelitis (TM).

SRNA was founded in 1994 by individuals with rare neuroimmune disorders and their family members—to bring support, insight, and knowledge to those going through similar journeys. Our goal is to help individuals diagnosed with rare neuroimmune disorders and their loved ones become empowered advocates for their health, and to improve the quality of life for the people in our community.

We support, advocate for and educate individuals diagnosed with rare neuroimmune disorders. **We are an information resource on rare neuroimmune disorders for our more than 14,500 members from more than 111 different countries.** We guide people through the system, supporting them every step of the way.

A Focus on Research and Training

A priority for SRNA is to partner closely with physicians to expand the medical professional network for those with rare neuroimmune disorders. We accelerate and invest in scientific research, therapy development, and training of clinician-scientists. We support the post-residency training of clinicians to establish more specialists in these disorders, and support research into causes and potential treatments that will one day help us develop novel therapies. We provide grant support to academic institutions, we help build new Centers of Excellence, and fund novel research ideas.

We also host 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 are here to listen

But we give so much more than just medical help. People need emotional support, so we listen and share information through the Myelitis Helpline, our website, magazine, weekly blogs, and monthly Ask The Expert Podcast Series. We offer a network between people with these disorders through local and online support groups, by offering one-to-one connections through our Peer Connect Program, and through our partnership with Smart Patients.

We are also a major campaigning charity. We want to improve diagnosis and outcomes and work with people affected by rare neuroimmune disorders to enact change.

**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.**

Who is who at SRNA?



Angel Simpelo
Administrative and Creative Assistant



Jim Lubin
Board Member



Deborah Capen
Secretary and Board Member



Linda Malecky
Vice President, Treasurer and Board Member



GG deFiebre
Director of Research and Programs



Roberta Pesce
Director of Strategy | Creative Director



Krissy Dilger
Research and Program Manager



Sandy Siegel
President and Board Member



Chitra Krishnan
Executive Director



Rebecca Whitney
Associate Director of Programs and
Community Support



Lydia Dubose
Community Engagement Manager



Skye Corken
Communication and Engagement Coordinator

A little about you



We currently have volunteers from all over the world. They live anywhere from San Diego to Dallas, Chicago to Orlando, Scotland to Germany. Volunteers get involved for a variety of reasons. Some want to make a difference in the lives of people affected by rare neuroimmune disorders, others want to develop new skills, and some simply want to meet new people and have fun. We don't have a typical volunteer. Every person who volunteers for us does have one thing in common: they're absolutely vital to our work.

Some advice that I could give to someone thinking of volunteering for SRNA is to just take your time and we are here whenever you are ready to take on a role. You don't have to start big. Maybe just start by going to a support group or just listening to someone who is having a hard time. We all have a part to play in this community. It doesn't matter how big or small that part might be. We are all in this together!

- Heidi Bournelis, 2018 NE Ohio Walk-Run-N-Roll organizer



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volunteers for us
does have one thing
in common: they're
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our work.**

—Maggie, 2019 Volunteer of the Year

Ways to get involved

There are oodles of ways for you to get further involved in our work. Here are just a few examples of the opportunities we offer.



Help in your local area

Begin locally! Join a fundraising group or hold your own event to raise money for SRNA.



Become a Support Group Leader

Sharing your experiences and learning together with others who truly understand what it is to live with or care for another with a rare neuroimmune disease can be life-changing. By sharing your struggles and celebrations, learning at educational opportunities, exchanging resources or meeting at awareness events, you experience healing and comfort knowing you are not alone. Start a support group in your area or online to connect with others locally or across the globe. Your own voice is powerful, but just imagine what can be done when we come together as one!

"I got involved with SRNA so I could form a community in San Diego where I had recently relocated to. I wanted to ensure people had the ability to meet with others with similar stories so we could all connect and feel a little less alone. My favorite part of being a SGL is getting to meet so many others with rare neuroimmune disorders and having the chance to be more active with SRNA and to continue raising awareness!." – **Janelle Healy, San Diego Support Group Leader**



Start a Walk in Your City

Join our cheering and motivation squads who provide inspiration and support to the fabulous people who run, walk, and roll to raise money to support research and education. Raise awareness about rare neuroimmune disorders and raise funds to support crucial cutting-edge research. You can also be a marshall, a first aider, or help run the event on the day.

"Volunteering for SRNA is extremely gratifying for me. Having been diagnosed with TM myself, being able to give back to the organization that's leading the way with medical discoveries is the best I can do."

– **Gail Buch, 2018 Arizona Walk-Run-N-Roll co-organizer**

Become a Peer Connect Leader

Sharing experiences with others who truly understand what it is to live with or care for another with a rare neuroimmune disorder can be life-changing. Peer Connect Leaders are trusted individuals who share important information and offer one-to-one support to peers. Our Peer Connect Leaders empower individuals to address condition-related life changes with emotional support and educational materials, offer resources that are scientifically and medically accurate, encourage peers to be their own advocate, and provide an opportunity to build a relationship and offer encouragement to an individual affected by a rare neuroimmune disorder.

"I didn't have the emotional support that I personally needed when I was diagnosed and somehow made it through it all. All I know is that if I had this kind of resource available to me back when I was first diagnosed I think it would've helped me immensely with my mental health so I really want to help others get through their hardships because I know how it is." – **Sal Rasuli, Peer Connect Leader**

Mobilize an Awareness Day

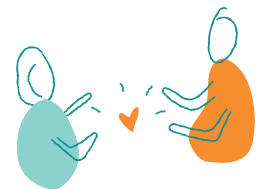
Share your story with your friends, family, and local community. Join others in your community and state who share your experience to petition your local and state government to recognize the lives of those living with and caring for those with a rare neuroimmune diagnosis and the importance of TM Awareness days and events.

"I was able to petition the state of Georgia for a Transverse Myelitis Awareness Day and it was passed on February 15, 2012. House Resolution 809 declared that day Transverse Myelitis Awareness Day. It is my hope and dream that the cause and cure for TM will be found in my lifetime." – **Kim Harrison, Former Support Group Leader in Georgia**

Become a Hope Ambassador

If you've been affected by a rare neuroimmune disorder use your experience to help shape the future of rare neuroimmune disorders by joining SRNA Hope Ambassador's voices.

"I'm probably more confident now than I was before I got NMOSD. I'm not afraid to stand up in front of a room of people and talk about issues that are important to us all. It's a way for me to be a part of the changing face of rare neuroimmune disorders in this country." – **Heather Reynolds, SRNA Hope Ambassador**

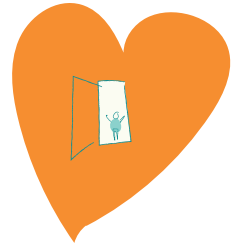


Share your story through our "This is Me" Campaign

We at SRNA are committed to raising awareness about ADEM and all other rare neuroimmune disorders. We have recently launched our "This is Me" Campaign to challenge the social issues and understanding around rare diseases & disabilities and aims to break the silence by supporting people diagnosed with rare neuroimmune disorders to tell their own stories. We encourage you to share your story. By bringing your voice to the forefront, we can empower communities, researchers, physicians, and governing entities to understand your disorder and all rare neuroimmune disorders better.

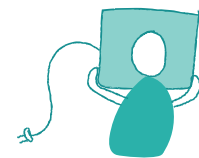
You are your own most powerful advocate. Your own voice is the most effective in relaying your story and it must be heard. You matter. Join us today!

"I want people to know that they aren't alone, and that there is hope for a recovery and a normal life. Everyone's path is unique, and you are in a race with no one but yourself. View each challenge as a way to prove to yourself that you will keep getting up no matter how many times you fall." - **Christopher Godfrey, "This is Me" Ambassador**



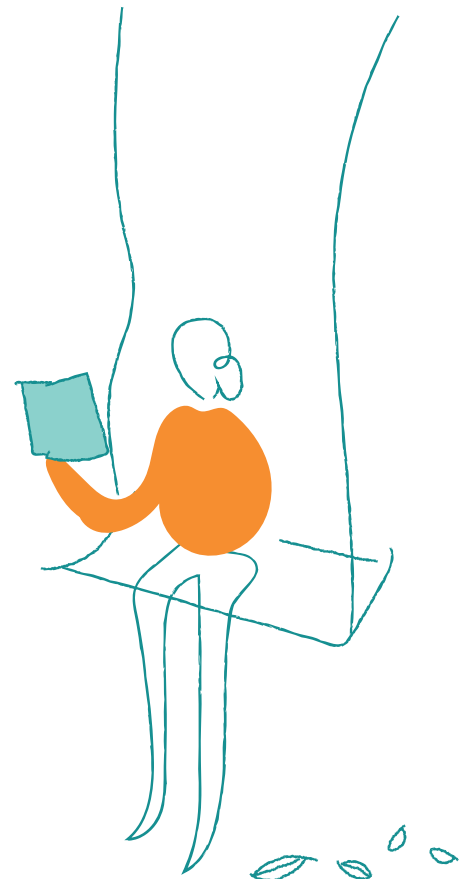
Become a Virtual Office Volunteer

Put your skills to good use or learn new ones whilst volunteering for SRNA right from your computer. We offer several resources for our community, including blogs, an SRNA Magazine, podcasts, video recordings from past symposia, information fact sheets, and more. Do you have a background in writing? Do you speak multiple languages? Do you like to be organized? We are looking for volunteers to assist with transcription, translation, and editing. If you'd like more information on any of these opportunities or you want to find out about other ways to get involved, please reach out to us at volunteer@wearesrna.org.



“Sharing is Caring. My wish for those watching my video story is to leave this space a little more hopeful and optimistic. Always pick yourself back up no matter what, and look for the silver lining in everything. If you look hard enough, you will be pleasantly surprised at what you find with an open heart and mind. It's pretty scary at first, so be kind and loving with yourself along this journey of life. Know you are never alone.”

– Carol Messenger, "This is Me" Ambassador

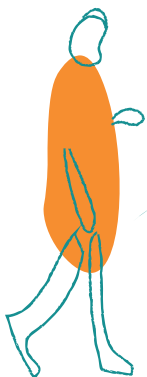


What you can expect from us

We want to make sure that you enjoy your role and get the most out of it.

Our commitment to our volunteers, we will:

- always treat you with **respect, consideration**, and **appreciation**.
- ensure you have a clear idea of your **responsibilities**, including the length of time we'd like you to be involved in a project.
- give you **information, training** and **support** to help you carry out your role.
- provide you with support through **regular meetings** or discussions (the format will depend on your role). offer you fair, honest, and timely **feedback** on your work.
- update you on how your work has **made a difference**.



What we expect from you

We take great pride in, appreciate, and depend upon our volunteers who help us to achieve our goals. We expect high standards from all our supporters, whether they are paid staff or volunteers.

To ensure you get the most out of your role, please do the following:

- ❑ always treat SRNA staff, supporters, and fellow volunteers with **respect, consideration, and appreciation**.
- ❑ act in a **professional** way whenever you represent SRNA in public.
- ❑ act in a way that **doesn't discriminate** against or exclude anyone.
- ❑ be **professional, respectful, and timely in communicating**, whether this is in person, by email, phone, or any other form of communication.
- ❑ be **confidential** and **sensitive** to the experiences of those who seek assistance from SRNA. You agree to become familiar with education tools and materials that offer accurate information to individuals in need and to the general public.
- ❑ **do not offer medical advice** of any kind but direct those in need to the Resource Library, to the Medical Professional Network for locating a medical professional, or to the general email of SRNA at info@wearesrna.org for proper dissemination of an inquiry that may require medical expertise. All volunteers are required to sign a code of conduct agreement.
- ❑ provide as much **notice** as possible if you are unable to fulfill your volunteering commitment, or if you no longer wish to be involved in a project.
- ❑ if you don't fully understand your role and responsibilities, please ask your SRNA contact for **guidance**.



We'll support you

The Volunteer & Community Coordinator will introduce you to your team and anyone else who you might be working with. Please use this opportunity to ask any questions and to highlight any areas you would like further training and support in. If you'll be volunteering with us over a period of time, we recommend a settling in period which gives us both a chance to assess how things are working out.

Training

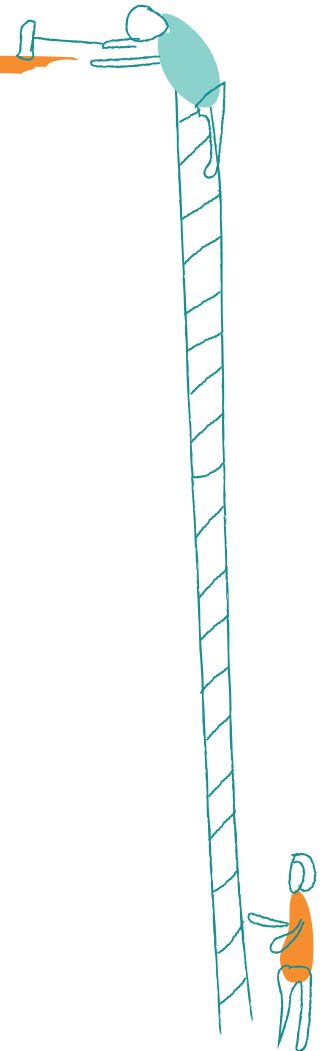
We want to ensure that you feel happy and confident to carry out your role. We ask volunteers to regularly visit our website, read informational emails and magazines, and stay current and knowledgeable about SRNA activities and accomplishments.

Reliability and commitment

It's important that you're reliable and you stick to any arrangements you've made with us. If your circumstances change, please let us know as soon as possible. If you're planning to go on holiday, please let your SRNA contact know that you'll be unavailable for certain dates and when you plan to return.

Support

You'll receive ongoing support from your SRNA contact. As part of your development, please make a note of how each task you carried out went, what you did and if there were any issues that arose. Most volunteers will have a review meeting and the frequency of these will vary depending on the nature of your role and your time commitment. The review meeting, in person or by phone, will focus on how the role is going, what support you need and, if necessary, update you on what's happening at SRNA. It should be an opportunity for volunteers and staff to raise issues and for you to talk constructively about your involvement with us.



"I love that SRNA is so hands-on. Many times, volunteering in non-profits means having infrequent and tangential contacts with leadership. That is not true with SRNA."

– Nancy Dove, Illinois Walk-Run-N-Roll co-chair
and Former Illinois Support Group Leader

How much you mean to us

Acknowledging your contribution

We honor the amazing work of our volunteers by highlighting your stories and voices throughout the year, offering opportunities to connect with the volunteer community, and more.

'The feedback we get shows that they appreciate what we do and are very thankful.' — **SRNA Volunteer**

Keeping in touch

As a volunteer with SRNA we want to keep you in the loop. You can ask to receive our magazine, which is jam-packed with the latest information about everything we're up to. Once a year you'll receive our Annual Report – this will let you know all of our key achievements over the previous 12 months.





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