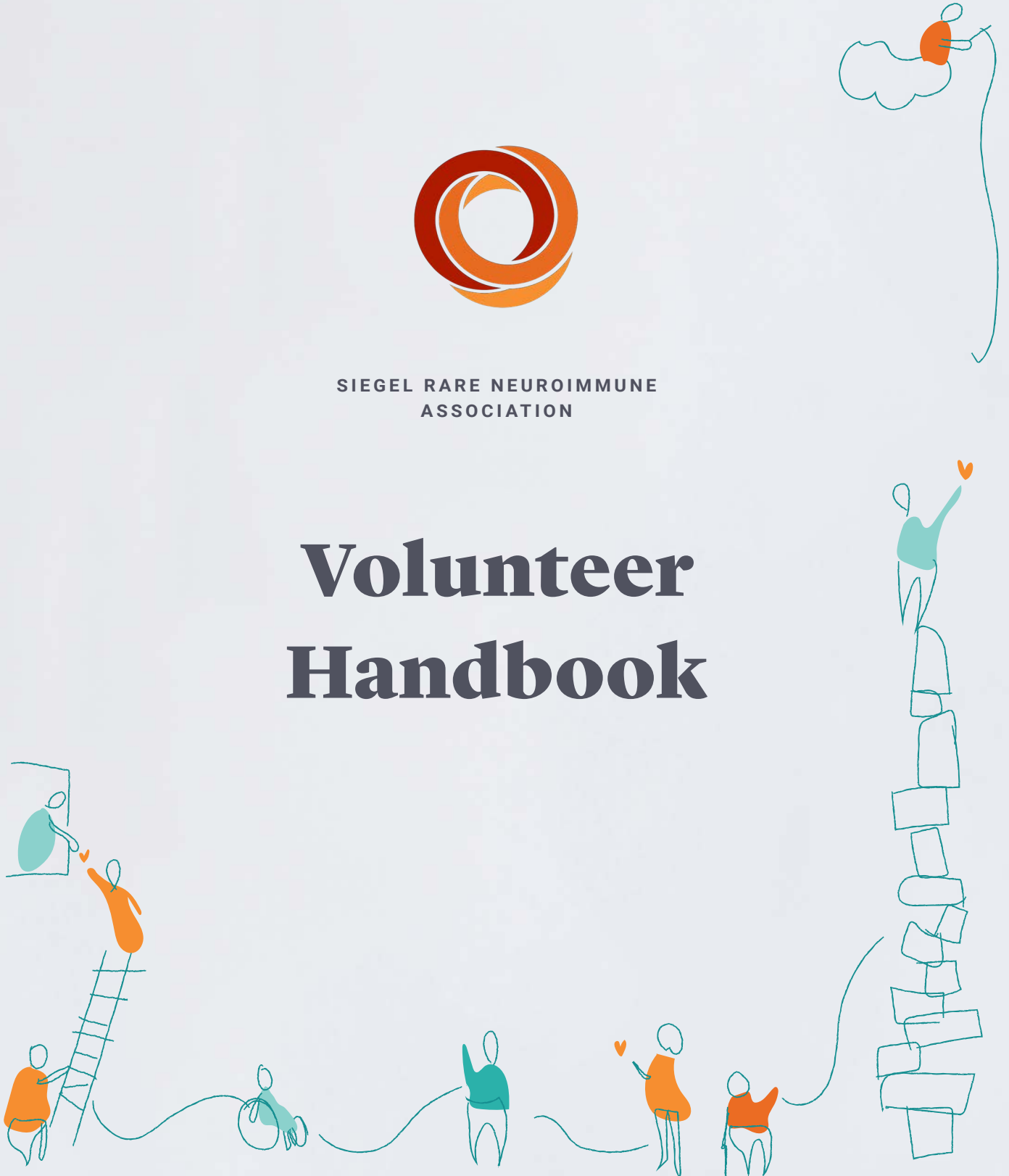




SIEGEL RARE NEUROIMMUNE  
ASSOCIATION

# Volunteer Handbook







**SIEGEL RARE NEUROIMMUNE  
ASSOCIATION**

# Hello and welcome

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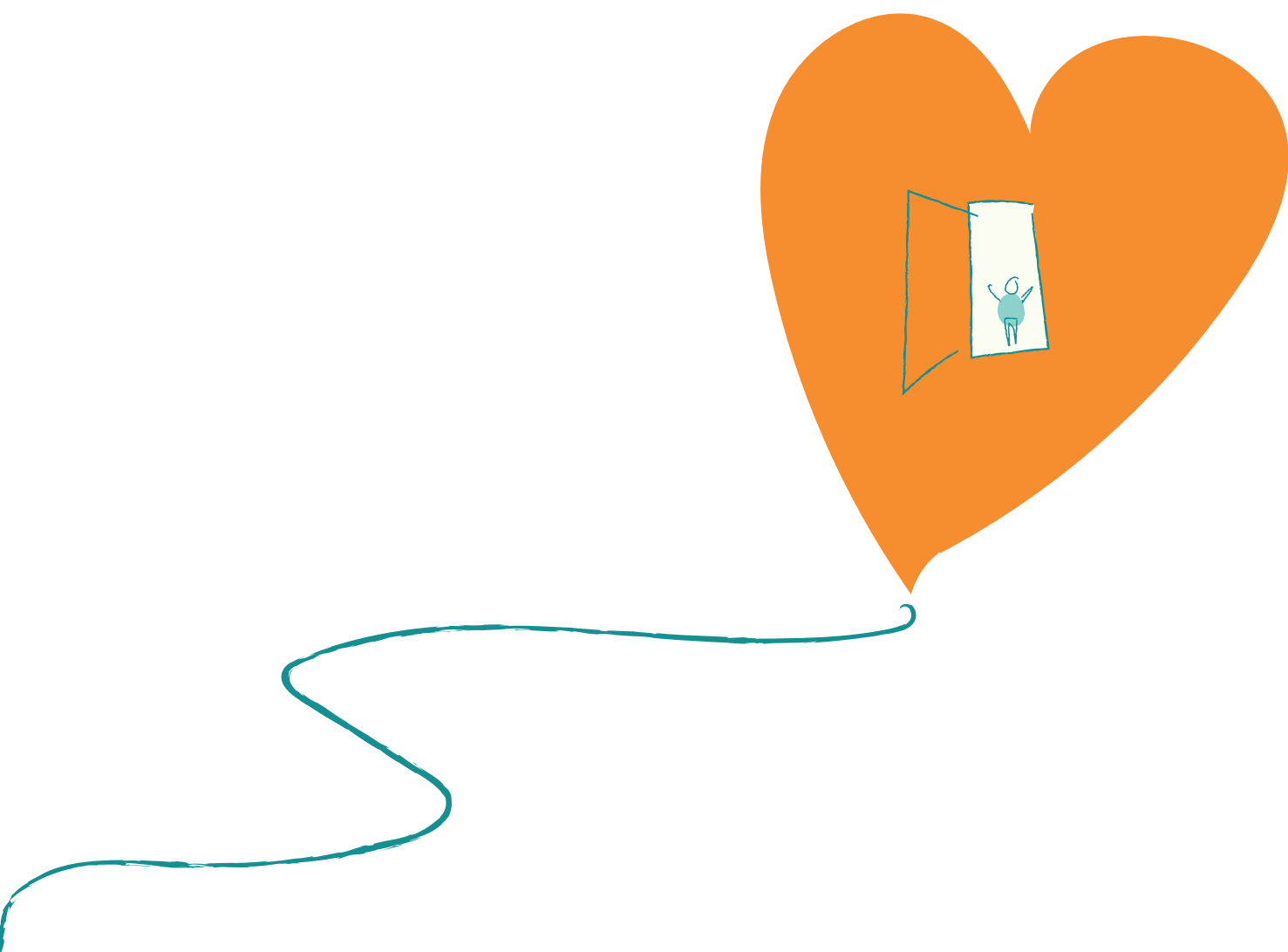
Thank you for choosing to volunteer with The Siegel Rare Neuroimmune Association (SRNA) and for helping to reach and improve the lives of people affected by rare neuroimmune disorders.

**Volunteers are at the very heart of our organization.** You're SRNA's face in the local community. You raise money to fund vital research, education, and community programs and help us deliver them. You tell people we're here for them and your voice helps us shape and improve care for all those affected by rare neuroimmune disorders. You are essential to everything we do.

It is our ambition 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 also help caregivers, families, and our community at large. **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, quarterly magazine, weekly blogs, and monthly Ask The Expert Podcast Series. We offer a network between people with these disorders through local support groups located throughout the world and through our partnership with Smart Patients, while also organizing annual quality of life programs such as family camps for children with these disorders and their families.

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.**

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## **Who is who at SRNA?**



**Angel Simpelo**  
Administrative Assistant



**Jim Lubin**  
Board Member



**Deborah Capen**  
Secretary & Board Member



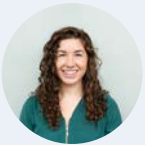
**Linda Malecky**  
Vice President, Treasurer & Board Member



**GG deFiebre**  
Associate Director, Research and Education



**Roberta Pesce**  
Program Manager | Creative Director



**Krissy Dilger**  
Program Associate



**Sandy Siegel**  
President & Board Member



**Chitra Krishnan**  
Executive Director



**Rebecca Whitney**  
Pediatric Program Manager

# 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**





**Every person who  
volunteers for us  
does have one thing  
in common: they're  
absolutely vital to  
our work.**

**—Maggie, 2019 Volunteer**

# Ways to get involved

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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 to connect with others. 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*



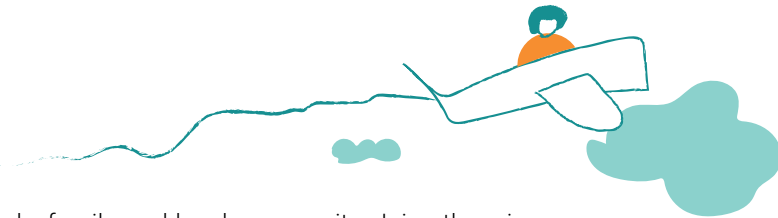
## Start a Walk in Your City

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**

### Mobilize an Awareness Day

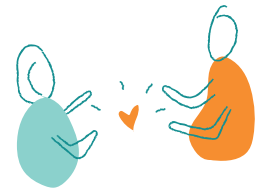


Share your story with your friends, family, and local community. Join others in your community and state who share your experience to petition your local and state government to recognize the lives of those living with and caring for those with a rare neuroimmune diagnosis and the importance of TM Awareness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

### Become a Hope Ambassador

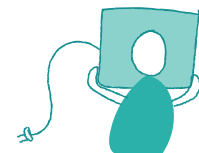
If you've been affected by a rare neuroimmune disorder use your experience to help shape the future of rare neuroimmune disorders by joining SRNA Hope Ambassador's voices.



*"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**

### 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.



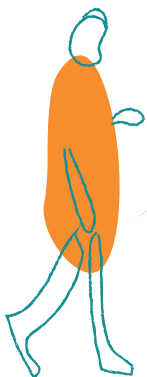
If you'd like more information on any of these opportunities or you want to find out about other ways to get involved, please speak to your SRNA contact. Alternatively visit [wearesrna.org/get-involved](https://wearesrna.org/get-involved).

# 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](mailto: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

Your SRNA contact 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

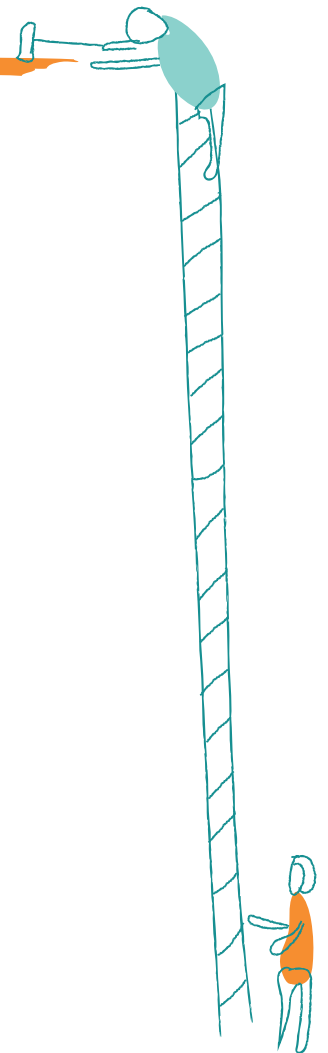
We want to ensure that you feel happy and confident to carry out your role. We ask volunteers to regularly visit our website, read informational emails and magazines, and stay current and knowledgeable about SRNA activities and accomplishments.

## 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 Illinois Support Group Leader

# The essentials

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As a volunteer, you'll need to be aware of the following policies and procedures at SRNA. Please take a few minutes to have a good read through and familiarize yourself with them.



## Expenses

SRNA will reimburse volunteers for any reasonable out-of-pocket expenses. Volunteers must get approval from SRNA contact before making a purchase. We'll only reimburse the amount that you have spent as a result of your volunteering, up to agreed maximum levels. Tickets and receipts must be provided in order to reclaim this money. It remains the decision of the volunteer as to whether they want to claim expenses or not.

## Boundaries

Clear boundaries are important for staff, volunteers, and service users. They enable us to carry out a service according to agreed expectations and ensures that everyone receives the same quality of service. We realize that staff and volunteers may sometimes have contact with people in a personal capacity – as friends, family, or colleagues. In this situation, please take care to avoid any apparent conflict of interest.



## Conflict of Interest

SRNA wants all volunteers to fully recognize the importance of their duty to SRNA's constituents and supporters and the necessity to act in a manner that merits public trust and confidence. It is therefore necessary for volunteers to refrain from engaging in any transaction in which personal interests conflict, potentially conflict, or appear to conflict with those of SRNA.

An actual or potential conflict of interest occurs when a volunteer is in a position to influence a decision that may result in a personal gain for the volunteer or for a relative of that volunteer as a result of SRNA's business dealings. For the purposes of this policy, a relative is a person who is related by blood or marriage, or whose relationship with the volunteer is similar to that of persons who are related by blood or marriage. Participation in any activity prohibited by this policy can result in the termination of volunteer service. While some conflict of interests are easily identifiable, SRNA requests that

all volunteers be aware of examples of conflict of interest to promote the best working environment for SRNA. All public statements on behalf of SRNA should be made by those dedicated to it in an official capacity by a designated SRNA staff member.

The following list of “conflict of interests” is illustrative only and should not be regarded as all-inclusive:

Gifts: Giving or receiving gifts may give the impression of favoritism and could raise expectations of the level of support you can provide in your role. As such, we ask that volunteers don't give or receive personal gifts to or from staff or anyone receiving support services from SRNA. This includes payment for speaking engagements or for participation in workshops or similar activities. NOTE: If a person or organization wishes to make a charitable donation, volunteers are encouraged to connect them to the proper donation channels, or if that is impossible, direct them to the project director so that the donation can be processed correctly.

Improper influence: Volunteers should not, when acting on his or her own behalf or when acting on behalf of another person, business, or organization, attempt to influence SRNA's position on any issue, matter, or transaction nor participate in any discussions pertaining to a related organization.

Confidential information: Inside, personal, or sensitive information should not be used either for the purposes of gaining advantage for one's self, a relative, or another organization or for any other purpose not specifically approved for use by SRNA.

Political activities: Volunteers are encouraged to participate in the political and governmental process. However, except for those authorized to act on behalf of SRNA concerning official affairs, volunteers participating do so as individuals and not as official representatives of SRNA. To avoid any inference of support or sponsorship by SRNA, a volunteer must never represent that his or her political donation, endorsement, or other political activity was made or engaged in with the approval, or on behalf, of SRNA.





### **Confidentiality**

Confidential information is defined as inside, personal, or sensitive information, and may include contact information, health information, or personal experience stories. Volunteers must maintain confidentiality during their time with SRNA. For this reason, when you complete an application form you are also signing a Code of Conduct document that includes a confidentiality statement barring the sharing or disclosing of this information for any unauthorized purposes, including personal benefit. This means that confidential information about people we support, volunteers, SRNA employees, and our work is kept private, unless sharing this information is required by law.



### **Data Protection**

Before we can collect, store, or use data about an individual, the law requires us to ensure that we have that individual's consent to do so. The way we do this is by using what we call 'Data Protection Statements'. Our statements comply with the Data Protection Act. This is a legal act that protects people's personal information. You may, in your work with us, have access to and handle the personal information of the people you are helping. It's vital that you're aware of our policy please ask your SRNA contact for a copy of this, if it's required for your role.

### **Background Checks**

SRNA is involved in working with or supporting children, young people and vulnerable adults in a wide variety of ways. If your role involves working with these people you will be required to undergo a Background Check as part of our policy on safeguarding. Our Community Partnerships Manager will be able to provide you with more information if it's required for your role.





## Code of Conduct

A Code of Conduct agreement must be signed by all volunteers working with SRNA. As a volunteer, you are the face of SRNA and are expected to act professionally and responsibly at all times.

No volunteer should:


- ☐ authorize or use the name, emblem, logo, endorsement, services, or property of SRNA for the benefit or advantage of any person or organization, except in conformance with SRNA policy.
- ☐ accept or seek any financial advantage or gain other than nominal value offered as a result of the volunteer's affiliation with SRNA, or knowingly take any action or make any statement intended to influence the conduct of SRNA in such a way as to confer any financial benefit on any person, corporation, or entity in which the individual has a significant interest or affiliation (see Conflict of Interest section for more detail).
- ☐ disclose or use any confidential SRNA information that is available as a result of the volunteer's affiliation with SRNA to any person not authorized to receive such information. act in a manner that creates a conflict with the interests of SRNA and any organization in which the individual has a personal, business, or financial interest (The individual shall disclose such conflict of interest to the Community Partnerships Manager, Executive Director, or a member of the Board of Directors, as applicable, upon becoming aware of it).
- ☐ commit a theft or inappropriate removal or possession of SRNA's property or that of any volunteer, staff, agent, or visitor, including failing to cooperate fully in any investigation of improper usage of SRNA property.
- ☐ volunteer under the influence of alcohol or illegal drugs.
- ☐ create a disturbance at sponsored activities or in areas which could jeopardize the safety of others, including any violation of any federal, state, or local safety or health law.



## Diversity

We are committed to a policy of treating all volunteers, volunteer applicants, employees, members or clients equally and fairly. We accept volunteers based on their suitability for the role. We won't discriminate against any volunteers because of their age, disability, ethnic origin, gender, marital status, creed, nationality, political beliefs, race, religion, sexual orientation, socio-economic background, or any characteristic protected by law. We are committed to the promotion of diversity and we expect that our volunteers adhere to this policy.

## Harassment Policy



We are committed to providing volunteers with a safe and productive environment and will not tolerate any form of harassment, including sexual harassment. It is unlawful to harass a person because of that person's sex. Harassment can include "sexual harassment" or unwelcome sexual advances, requests for sexual favors, and other verbal or physical harassment of a sexual nature. For example, it is illegal to harass a woman by making offensive comments about women in general. Both the victim and the harasser can be either a woman or a man, and the victim or harasser can be the same sex. Although the law doesn't prohibit simple teasing, offhand comments, or isolated incidents, harassment is illegal when it is so frequent or severe that it creates a hostile or offensive work environment, or when it results in an adverse employment decision (such as the victim being fired or demoted).

It is unlawful and violates policy to discriminate in any way against someone because of their actual or perceived gender identity. Additionally, it also unlawful and contrary to this policy to retaliate against any person objecting to, or supporting enforcement of legal protections against, gender identification discrimination. SRNA is committed to providing a safe environment for transgender and gender non-conforming members.

Any complaint or knowledge of harassment of any kind should be brought to the attention of the Community Partnerships Manager, Executive Director, or the Board of Directors ombudsmen at [ombudsman@wearesrna.org](mailto:ombudsman@wearesrna.org).



## **Liability**

SRNA is not financially or otherwise liable for injury or casualties that occur to anyone while serving as a volunteer for SRNA. Accordingly, volunteers agree to waive any claims against, indemnify, and hold harmless SRNA, its respective officers, directors, employees, sponsors, representatives, and volunteers from any and all liability, including attorney fees, that may accrue on account of, or in any way growing out of, any and all property damage, personal injury, and/or economic loss as a result of or in any way related to or arising out of the volunteer's involvement with SRNA.

## **Dispute Resolution**

If an issue or dispute should arise between volunteers, or between a volunteer or volunteers and staff, the parties involved should first communicate directly with one another in a respectful attempt to reach a mutual understanding. If the parties cannot reach a reasonable resolution, then a volunteer must contact the Community Partnerships Manager, or a staff member to help mediate a resolution.

If a resolution cannot be reached, or if such mediation is unreasonable or impracticable (i.e., because a volunteer has a concern, complaint, or other issue the volunteer feels cannot be resolved by working with a staff member), then the volunteer is invited to contact the Board of Directors ombudsman at [ombudsman@wearesrna.org](mailto:ombudsman@wearesrna.org), an appointed member of SRNA Board of Directors. The ombudsman serves as a public advocate charged with representing the interests of the volunteer by investigating and addressing complaints of maladministration or violation of rights. A volunteer wishing to utilize this process should send an email to [ombudsman@wearesrna.org](mailto:ombudsman@wearesrna.org), which will be received directly by the Board member serving this role.





### **How We Talk**

When you're volunteering for SRNA, you may notice that we use a certain style of language. The way we talk is a key part of our personality and our 'voice' is an important tool for helping people understand who we are and what we do.

It's essential that we maintain one voice – one that's consistent, clear, and easy to understand. One that expresses SRNA's passion for supporting people affected by rare neuroimmune disorders. Whether you're speaking on behalf of SRNA, drafting an email or writing a letter, it's well worth getting to grips with SRNA's 'tone of voice'. Our Community and Partnerships Manager will support you or you can download our style guide from our Volunteer Toolkit.

### **What We Wear**

As a volunteer for SRNA, you're also an ambassador for the organization. You're responsible for presenting a positive image to members, clients and the community. Please use your judgement to dress appropriately for the activities you're asked to carry out. If you're ever unsure about what to wear, just ask our Community Partnerships Manager.



# How much you mean to us

## Acknowledging your contribution

We honor the amazing work of our volunteers with the annual SRNA Distinguished Service Award. Each year a member of our community is honored at the Rare Neuroimmune Disorders Symposium. To learn more about this award, visit [srna.ngo/31c5d](https://srna.ngo/31c5d).

*'The feedback we get shows that they appreciate what we do and are very thankful.'* — **Service Award volunteer**

## Keeping in touch

As a volunteer with SRNA we want to keep you in the loop. You can ask to receive our quarterly 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.



# Dealing with difficulties

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**Problems within your role** If you encounter a difficulty with any aspect of the role, please talk to your SRNA contact as soon as possible for advice and support.

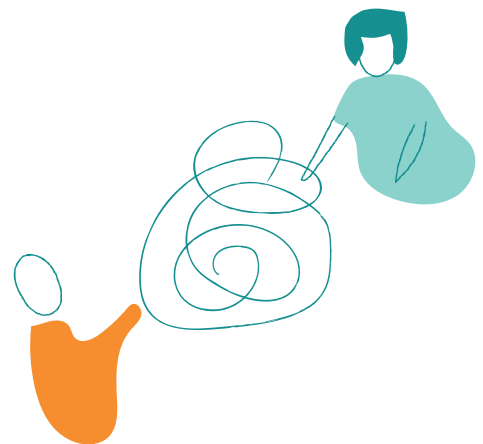
If the role isn't working out as hoped, please let your SRNA contact know. Together you should try to work out any difficulties. If it is agreed it can't work, this shouldn't be seen as a failure. Speak to your contact about finding a more appropriate role, or visit [\[link to volunteer page\]](#) to find out about other opportunities.

## **Dealing with complaints**

Although dealing with complaints can be difficult, it can give us a positive opportunity to improve the way we do things and provide a better service for people affected by rare neuroimmune disorders.

At SRNA we define a complaint very broadly, as 'a statement of dissatisfaction'. This covers any kind of comment – spoken or written – which relates to dissatisfaction, whether or not it's labelled as a complaint, and whether or not it needs a formal response.

We have a centralized complaints procedure to ensure that we capture all feedback. If you wish to make a complaint or you receive a complaint from someone about your service or anything to do with SRNA's work, please email us or just give us a call.









**SRNA**

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