



**SRNA**

connect. care. cure.

Siegel  
Rare Neuroimmune  
Association

- **We know how important research is for improving the quality of life of our community and it remains a top commitment for us as an organization.**
- We continue to do this work through The Pauline H. Siegel Eclipse Fund for research.
- The following is research we have conducted.

# Experiences with Vaccinations

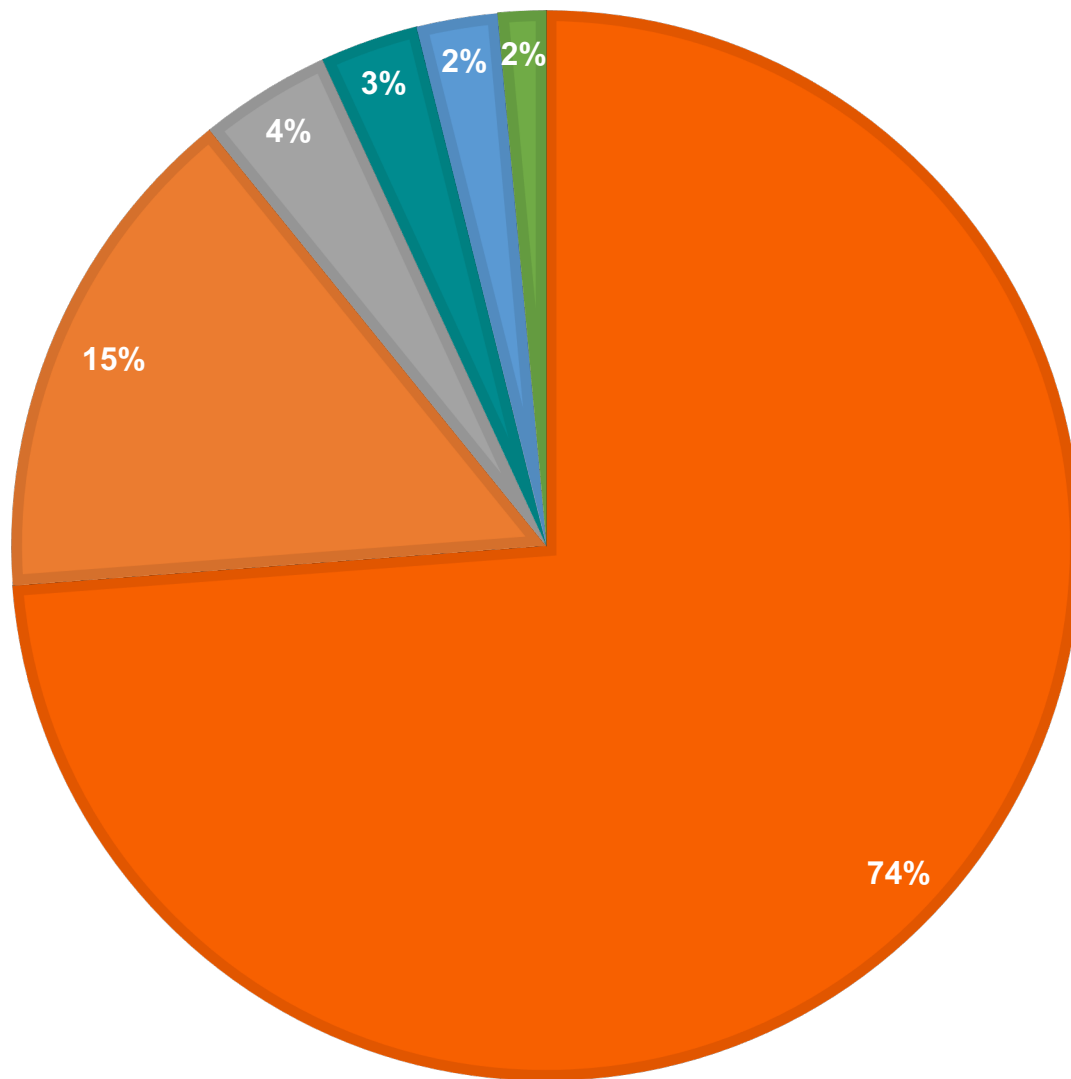
- The goal of the study was to understand and learn from our member community about their experiences with receiving vaccinations before and after a rare neuroimmune disorder diagnosis, with a focus on their experiences *after* diagnosis.

# Methods

- Survey administered using SurveyMonkey and through postal mail.
- Respondents who reported that they experienced a repeat inflammatory attack within 30 days of receiving a vaccine
  - Requested to participate in an interviewer-administered questionnaire over the phone.
- 600 were randomly selected → 223 completed the survey

**Thank you to all who participated in the study!**

■ TM ■ NMOSD ■ ADEM ■ AFM ■ MOGAD ■ Recurrent TM



# Results

- 35 participants (15.7%) reported a vaccination within 30 days before their onset
- 13 of whom received a subsequent vaccination, none had another attack within 30 days of a vaccination
- 65.0% of participants reported that they got one or more vaccinations after their disease onset

# Results

- 6 respondents (4%) of those who had received vaccinations after their onset, reported a subsequent inflammatory attack within 30 days of a vaccination
  - 3 who did not respond reported their diagnosis as TM (2) and NMOSD. The two TM were unsure of antibody status.
  - 2 were diagnosed with TM and unsure of their anti-AQP4 antibody status
    - unsure if new inflammation was confirmed on imaging during this subsequent attack
  - 1 was anti-AQP4 antibody positive
  - 2 respondents received a flu vaccine after this subsequent attack with no issues reported



# Results

- Overall, in the participants in this study who were known to be anti-AQP4 antibody negative, there were no post-vaccine recurrent inflammatory events
- Many respondents were unsure about their diagnosis, did not know their anti-AQP4 antibody status, or were unclear about the difference between a true subsequent inflammatory attack and a worsening of symptoms without new inflammation
- Possibly biased towards overestimating the risk of inflammatory attacks after a vaccination, as those who had an event after a vaccination may have been more likely to respond to the survey

# Results

- About half of those who did not receive any vaccinations after their onset noted that their healthcare provider advised them not to receive a vaccination because of their rare neuroimmune disorder
- More than a third (37.3%) said they did not want to receive vaccinations because they were concerned there are problems with their immune system
- About a third (28%) reported that they did not want to receive vaccinations because they believed a vaccination caused their disorder

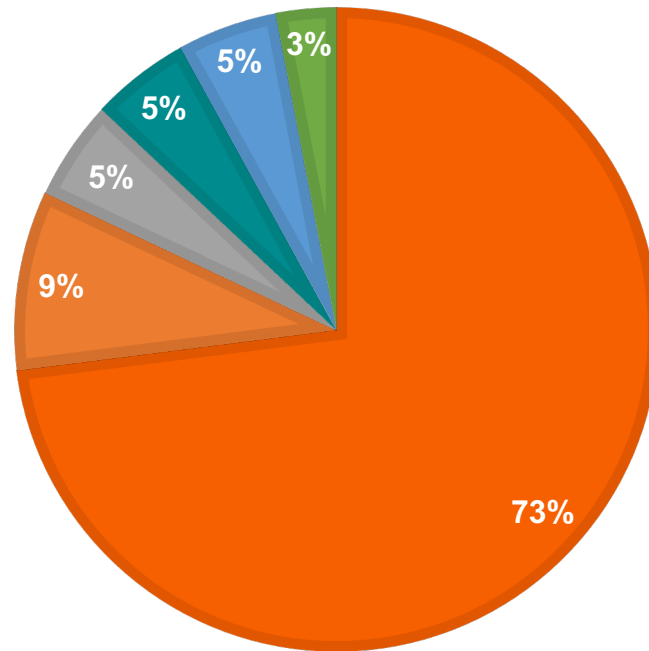
# SRNA Registry

- 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.

# Results

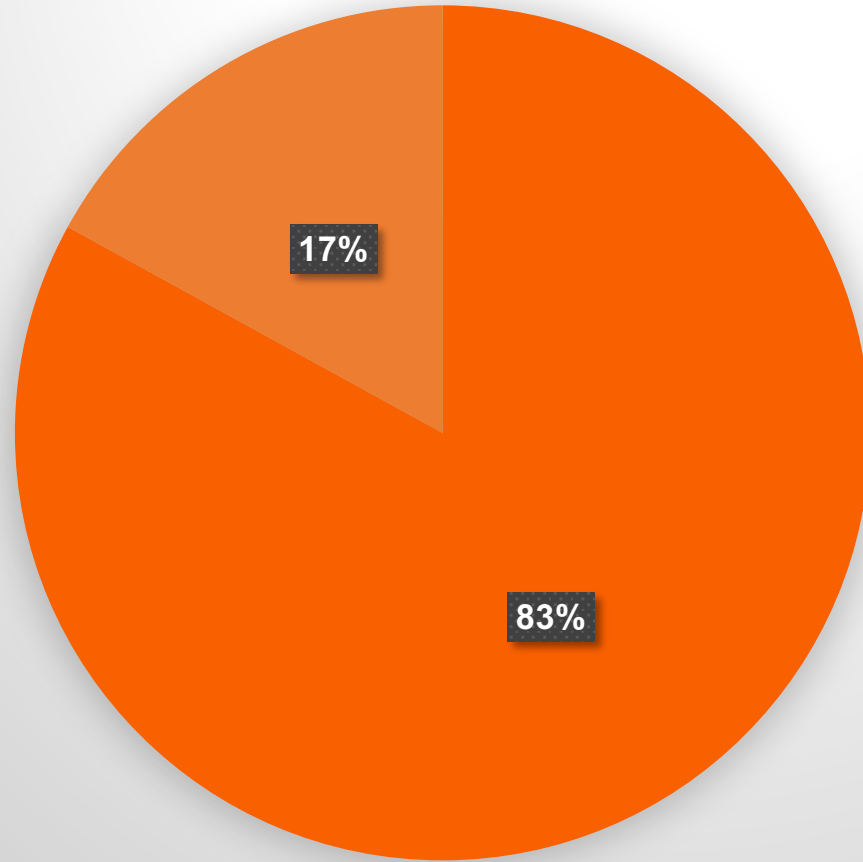
- As of March 2021, there were 531 participants in the registry

■ TM ■ NMOSD ■ ADEM ■ AFM ■ MOGAD ■ Other



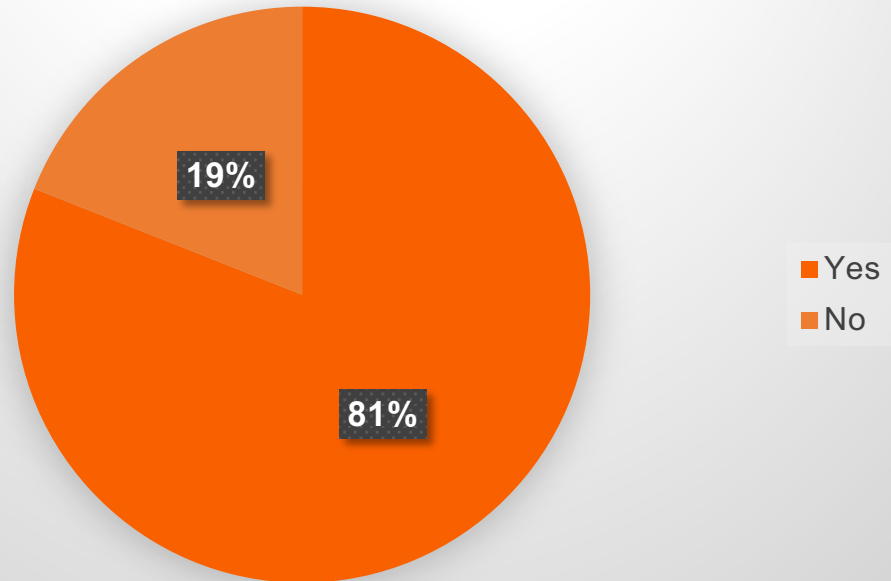
# Results

- 37% were diagnosed less than one week after symptom onset, but for 31% of respondents it took longer than six weeks to be diagnosed
- Less than one-third of participants in the registry received a second acute treatment during their initial inflammatory attack

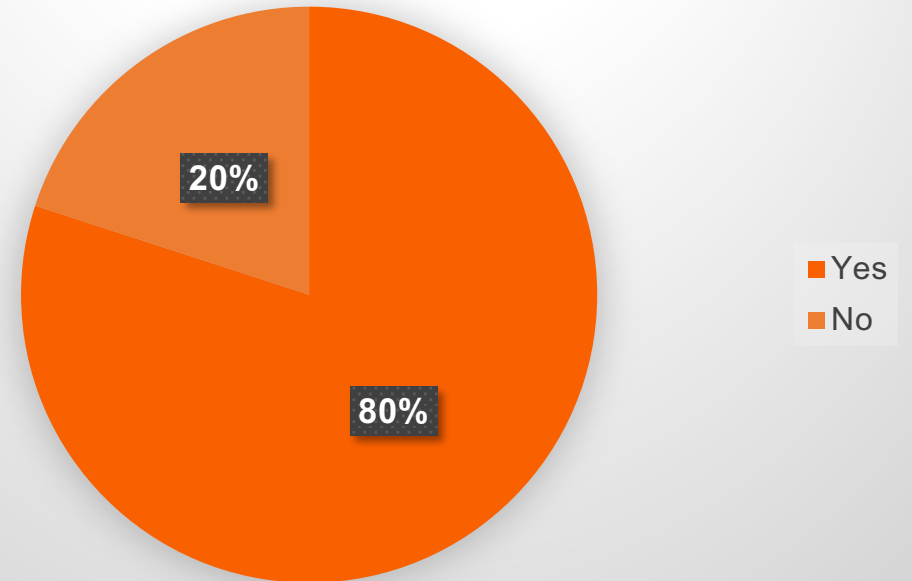


- Received Treatment
- Didn't Receive Treatment

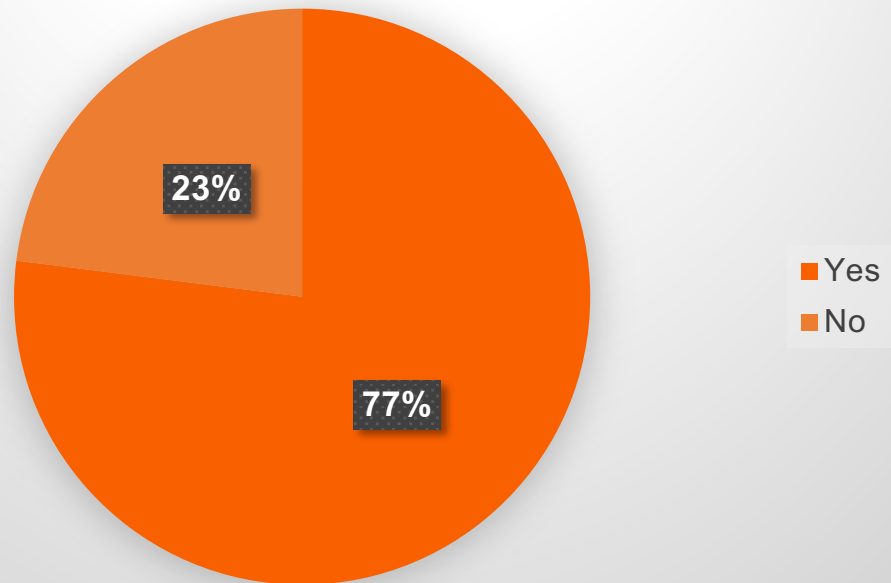
## Loss of Sensation



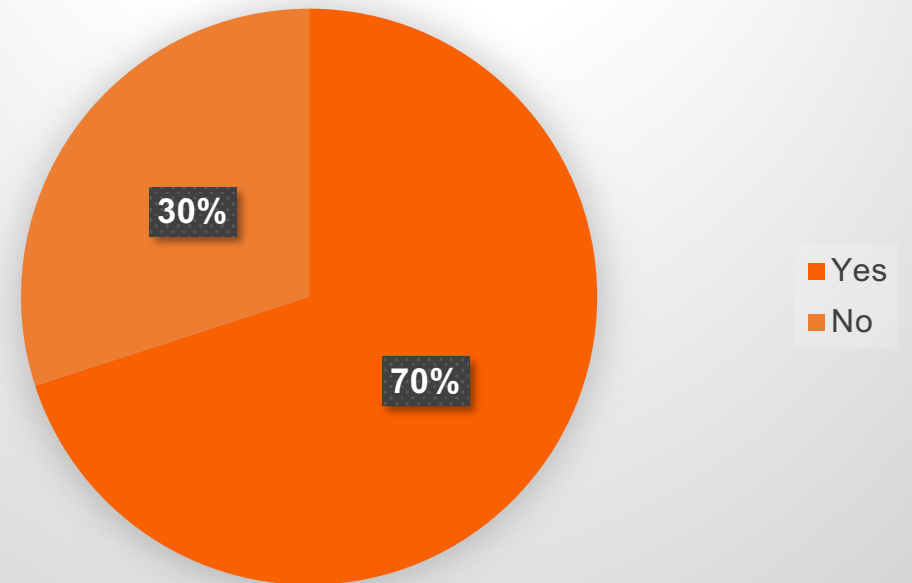
## Weakness/Paralysis



## Neuropathic Pain

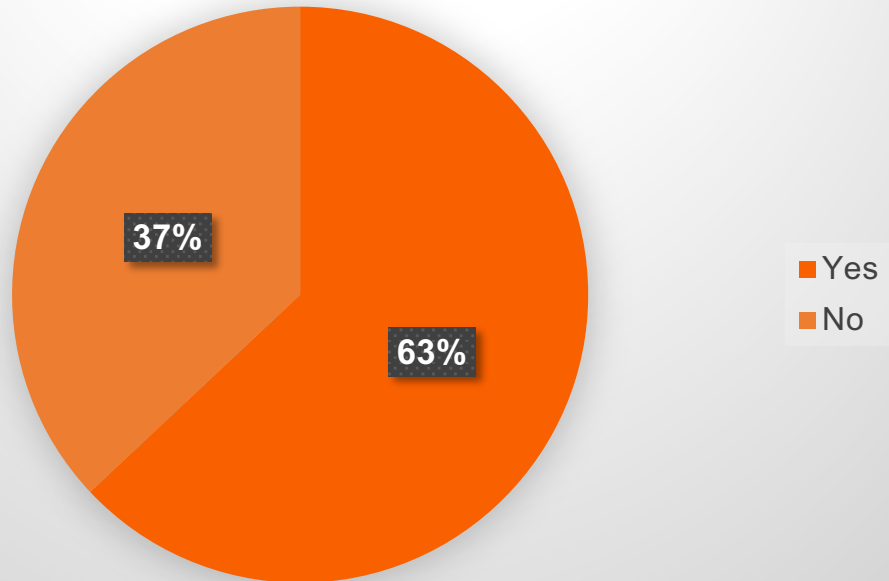


## Bladder/Bowel

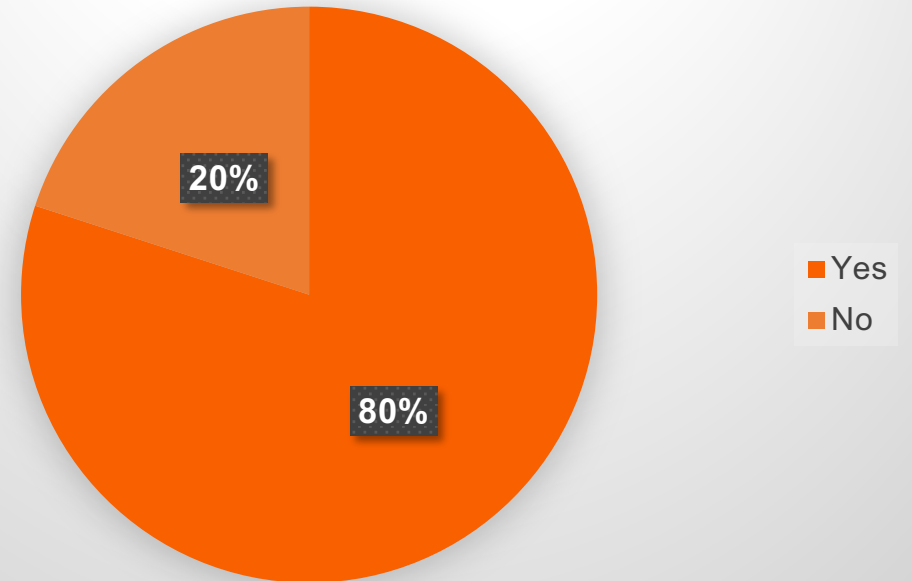




## Spasticity



## Received Rehabilitation

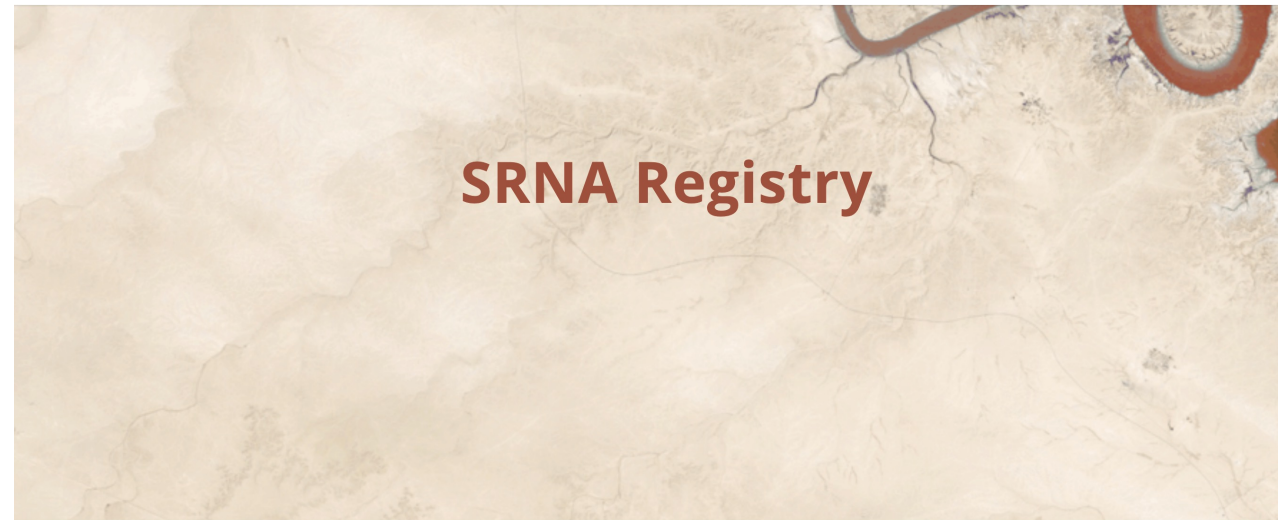


# How to Participate?

- 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.
- When a legal guardian/representative is completing 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.
- This is a voluntary registry.
- The participant may choose someone to help submit their registry information if needed.

# How to Participate?

- 1) Review consent form and assent form if applicable
- 2) Fill out interest form
- 3) Fill out survey sent to your email
- <https://srna.ngo/registry>



JOIN NOW

**About** | [Who can participate](#) | [How to join](#) | [Contact us](#)

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. THANK YOU!

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

# COVID-19 Study

- The goal of the study is to understand and learn from the SRNA member community about their experiences with COVID-19, experiences accessing care during the pandemic, and other potential social challenges (e.g., job loss, issues accessing medication or other supplies)
- Understanding these issues for our community during this pandemic allows us to create relevant programming and inform the medical community about the effects of this pandemic on those with rare neuroimmune disorders
- The study involved participation in an interviewer-guided survey administered over the phone using SurveyMonkey

# Results

- 54.7% were not employed before the pandemic
- 13.7% were unfortunately let go from their jobs due to the pandemic
- 80% had visits that were shifted to virtual visits
- Half of participants had issues accessing medical care
- 5.3% of respondents had a COVID-19 diagnosis, but none were hospitalized