

The SRNA Registry

Assent Form

Introduction

The mission of The Siegel Rare Neuroimmune Association (SRNA) is to help individuals and their families who have one of the rare neuroimmune disorders.

Purpose of the research

The purpose of this study is to let The SRNA Registry collect and share information on people with diseases like you have, such as acute disseminated encephalomyelitis, acute flaccid myelitis, neuromyelitis optica spectrum disorder, MOG antibody-associated disease, optic neuritis, or transverse myelitis.

A registry is a place to collect and store detailed information about individuals with a specific disease or disorder. In this case, The SRNA Registry is for individuals with rare neuroimmune disorders (acute disseminated encephalomyelitis, acute flaccid myelitis, neuromyelitis optica spectrum disorder, MOG antibody-associated disease, optic neuritis, or transverse myelitis).

What you will do if you participate

If you participate, you will share your medical information with The SRNA Registry. You will fill out forms on paper or on a computer. You may have a parent, guardian, or someone else help you enter the information.

You will be asked to update the registry information at least once a year. The SRNA Registry will send you a reminder each year.

If you are younger than age 18 when you enter the study, we will ask to provide your own consent once you reach age 18.

What are the risks of being in this study?

There may be questions that you feel uncomfortable answering. You do not have to answer any question that you do not want to answer.

We will protect your privacy by removing information that might identify you from any data that is shared. We will assign the information a code number. The key to the code will not be shared. However, there is a small chance that you might be identifiable from the information in the registry.

Why you might want to participate

Being in this study will not benefit you yourself. However, your participation can help doctors understand diseases like yours better. We hope that such research will eventually improve the diagnosis and treatment of these disorders.

Right of refusal and right to withdraw

You do not have to take part in this study if you don't want to. You don't have to do every part of this study if you don't want to. If you start the study but don't want to continue, you can stop at any time you want. No one will be angry if you stop.



Institutional Review Board (IRB)

Approval Date: 08/22/2019

Expiration Date: 08/21/2020

Administrative Approval: SS

Southwestern Medical Center (UTSW)

Dr. Benjamin Greenberg at UTSW is partnering with SRNA to share data about registry participants with TM who want their information shared. Dr. Greenberg is the Director of UTSW's Transverse Myelitis and Neuromyelitis Optica Program. Dr. Greenberg's study, entitled Comprehensive Outcomes Registry Exploring Transverse Myelitis Study (CORE TM Study), will create a registry focused on short and long-term outcomes, and further inform the development of an outcomes measure for use in clinical trials. The CORE TM Study will collect similar information as the SRNA Registry, but will also include review of medical records. The CORE TM study is only enrolling individuals with TM. **If you would like SRNA to share your information and responses with UTSW, please check yes below.** Dr. Greenberg's team will contact you and may ask for additional information and medical records. **If you do not want your information shared, please check no below.**

I give permission for SRNA to share my data with Dr. Greenberg's team at UTSW

_____ YES
_____ NO

Who to Contact

If you have any questions or want any additional information about this study you may contact:

Gabrielle deFiebre, MPH
The Siegel Rare Neuroimmune Association
1787 Sutter Parkway
Powell, OH 43065-8806
<http://www.wearesrna.org/>
gdefiebre@wearesrna.org
855-380-3330 ext 6

This research project (IRB# 2302) has been reviewed and approved by the Institutional Review Board of the Institute for Family Health on July 31, 2018. If you wish to find out more about the IRB, contact Saskia Shuman at 212- 633-0800.

Certificate of Assent

I have had this study explained to me in a way that I understand, and I have had the chance to ask questions. I agree to take part in this study.

Name of Minor: _____

Signature of Minor: _____

Date: _____
Day/month/year



Institutional Review Board (IRB)

Approval Date: 08/22/2019

Expiration Date: 08/21/2020

Administrative Approval: SS