Experiences during COVID-19 Pandemic Among Those with Rare Neuroimmune Disorders

Informed Consent Form

Introduction

The mission of the Siegel Rare Neuroimmune Association (SRNA) is to support and advocate for individuals and their families diagnosed with rare neuroimmune disorders of the central nervous system. SRNA promotes awareness and empowers patients, families, clinicians, and scientists through education programs and publications. We aim to advance the scientific understanding of and therapy development for these rare neuroimmune disorders by supporting the training of clinician-scientists dedicated to these rare disorders and by supporting basic and clinical research. The disorders covered by SRNA's work include Acute Disseminated Encephalomyelitis (ADEM), Acute Flaccid Myelitis (AFM), MOG Antibody Disease (MOGAD), Neuromyelitis Optica Spectrum Disorder (NMOSD), Optic Neuritis (ON), and Transverse Myelitis (TM).

Purpose of the research

The intention of this research project is to describe the experiences of individuals with rare neuroimmune disorders during the COVID-19 pandemic.

Participant Selection

We are inviting you to participate in this study because you are an individual with a rare neuroimmune disorder (acute disseminated encephalomyelitis, acute flaccid myelitis, MOG antibody disease, neuromyelitis optica spectrum disorder, optic neuritis, or transverse myelitis), or the parent or legal guardian of a child with one of these disorders.

Voluntary Participation

Your participation in this research study is entirely voluntary. It is your choice whether to participate or not. You may change your mind later and stop participating even if you earlier agreed to participate.

Procedures

If you agree to be a part of this study, you will participate in a survey over the phone with a member of the SRNA staff that should not take more than 30 minutes to complete.

Your responses are entirely confidential. All identifying information will be removed and will not be included in analysis of the data.

Risks and Benefits

The risks to participating in this study are minimal. There will be no direct benefit to you.

Reimbursements

You will not be provided with any payment or reimbursement to take part in the research.

Confidentiality

The information you provide will not be shared with anyone outside the research team without your permission. All identifying information will be removed, and you will not be identified in any way in reports of this data.

Who to Contact
If you have any questions or want any additional information about this study, you may contact:

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This research project (IRB# 2368) has been reviewed and approved by the Institutional Review Board of the Institute for Family Health on May 22, 2020. If you wish to find out more about the IRB, contact Saskia Shuman at 212-633-0800.

Certificate of Consent

I have read the foregoing information. I have had the opportunity to ask questions about it, and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Name of Participant: _____

Signature of Participant: _____

Date: _____
Month/day/year