




# How to Help Your Patients Enroll in the New-Onset Refractory Status Epilepticus (NORSE) and Febrile Infection-Related Epilepsy Syndrome (FIRES) Family Registry, and Other Rare Epilepsy Registries

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New-onset refractory status epilepticus (NORSE) is a rare clinical presentation of refractory status epilepticus (RSE) that occurs in people without active epilepsy or preexisting neurologic disorder. New-onset refractory status epilepticus does not resolve after 2 or more rescue antiseizure medications, and it presents without a clear acute or active structural, toxic, or metabolic etiology.<sup>1</sup> Febrile infection-related epilepsy syndrome (FIRES) is a subcategory of NORSE and requires a febrile infection between 2 weeks and 24 hours before the start of RSE, with or without fever at the onset of RSE.<sup>1</sup> New-onset refractory status epilepticus/FIRES are becoming increasingly recognized; however, information pertaining to disease course, clinical outcomes, and survivorship remains limited, and mortality and morbidity are variable but often high.<sup>2</sup> The objective of the NORSE/FIRES Family Registry is to (1) provide an easily accessible and internationally available multilingual registry into which survivors or NORSE/FIRES surrogates or family members of people affected by NORSE/FIRES or their physicians can enter data in a systematic and rigorous research study from anywhere in the world where internet is available; and (2) to examine past medical history, outcomes, and quality of life for people affected by NORSE/FIRES.

The NORSE Family registry invites survivors, their loved ones or substitute decision-makers to enter data along with their health care professionals. It is managed using REDCap (Research Electronic Data Capture tool) hosted at Lawson Health Research Institute, affiliated with Western University (London, ON, Canada). All participants must provide electronic informed consent before accessing the online survey. Within the survey we will ask questions about past medical history, clinical presentation, disease course, survivorship, clinical sequelae, and quality of life, among others. If applicable, the survey invites participants to return at 6, 12, and 24 months after disease onset to gather ongoing information on survivorship, long-term outcomes, and quality of life. If participants are already beyond 24 months after disease onset, they are invited to provide data regarding the same variables at the time they are completing the survey. The survey has several features to make data input accessible and user friendly, such as save and return options, email notifications, and detailed instructions for participants. The registry will remain open until 2025. The survey can be accessed at <http://www.norseinstitute.org/norse-registry-2>.



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The NORSE/FIRES Family Registry is a collaborative project developed by members of the NORSE Institute ([www.norseinstitute.org](http://www.norseinstitute.org)). It will allow for the collection of a wide range of clinical and epidemiological variables which will provide a stepping stone for future systematic research. Most importantly, the NORSE/FIRES Family Registry provides an opportunity for families and survivors themselves to contribute directly to NORSE/FIRES research.

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Memorial Fund and all of the families and survivors of NORSE/FIRES who have been paramount in the development of this registry.

## Editor's Note

The table below provides a listing of registries derived from a recent Rare Epilepsy Landscape analysis.<sup>3</sup> More details can be found in the original citation.

Organization	Organization or registry link
Batten Disease Support and Research Association	<a href="https://www.bdsra.org/">https://www.bdsra.org/</a>
Beta-propeller Protein-Associated Neurodegeneration (BPAN)	<a href="https://www.nbiadisorders.org/research/patient-registry">https://www.nbiadisorders.org/research/patient-registry</a>
Bridge the Gap—SYNGAP Education and Research Foundation	<a href="https://www.bridgesyngap.org/">https://www.bridgesyngap.org/</a>
Cardiofaciocutaneous syndrome	<a href="https://connect.invitae.com/org/cfc">https://connect.invitae.com/org/cfc</a>
CFC International	<a href="https://www.cfcsyndrome.org/">https://www.cfcsyndrome.org/</a>
Chelsea's Hope	<a href="https://chelseashope.org/">https://chelseashope.org/</a>
Christianson syndrome	<a href="https://www.brown.edu/hassenfeld/content/international-christianson-syndrome-network">https://www.brown.edu/hassenfeld/content/international-christianson-syndrome-network</a>
Chromosome 9pMinus Network	<a href="https://www.9pminus.org/">https://www.9pminus.org/</a>
DDX3X Foundation	<a href="https://ddx3x.org/patient-registry/">https://ddx3x.org/patient-registry/</a>
DNMI dynamos - Connecting DNMI Families	<a href="https://dnmifamilies.com/">https://dnmifamilies.com/</a>
Dravet Syndrome Foundation	<a href="https://www.dravetfoundation.org/">https://www.dravetfoundation.org/</a>
Dup15q Alliance	<a href="https://dup15q.org/">https://dup15q.org/</a>
FamilieSCN2A Foundation	<a href="https://www.scn2a.org/">https://www.scn2a.org/</a>
Global Pediatric Epilepsy Surgery Registry	<a href="https://www.brainrecoveryproject.org/research/patient-registry/">https://www.brainrecoveryproject.org/research/patient-registry/</a>
Glut1 Deficiency	<a href="https://www.g1dregistry.org/">https://www.g1dregistry.org/</a>
GNAOI	<a href="https://connect.invitae.com/org/gnao1">https://connect.invitae.com/org/gnao1</a>
Hope for hypothalamic hamartomas	<a href="https://www.hopeforhh.org/">https://www.hopeforhh.org/</a>
International Foundation for CDKL5 Research	<a href="https://www.cdkl5.com/cdkl5-international-registry-database/">https://www.cdkl5.com/cdkl5-international-registry-database/</a>
KCNMA1 Channelopathy	<a href="https://www.kciaf.org/registry">https://www.kciaf.org/registry</a>
KCNMA1 Channelopathy International Advocacy Foundation (KCIAF)	<a href="https://www.kciaf.org/">https://www.kciaf.org/</a>
KIFIA	<a href="https://www.kifia.org/research/natural-history-study/">https://www.kifia.org/research/natural-history-study/</a>
LGS Foundation	<a href="https://www.lgsfoundation.org/">https://www.lgsfoundation.org/</a>
Linking Angelman and Dup15q Data for Expanded Research (LADDER)	<a href="https://laddertotreatment.org/">https://laddertotreatment.org/</a>
Lissencephaly Foundation Inc	<a href="https://www.lissfoundation.org/">https://www.lissfoundation.org/</a>
NORSE Institute	<a href="http://www.norseinstitute.org/norse-registry-2">http://www.norseinstitute.org/norse-registry-2</a>
North American AED Pregnancy Registry	<a href="https://www.aedpregnancyregistry.org/">https://www.aedpregnancyregistry.org/</a>
North American SUDEP Registry (NASR)	<a href="http://sudepregistry.org/">http://sudepregistry.org/</a>
Phelan-McDermid Syndrome Foundation	<a href="https://www.pmsf.org/registry/">https://www.pmsf.org/registry/</a>
Project 8p	<a href="https://project8p.org/">https://project8p.org/</a>
PVNH Support & Awareness	<a href="https://pvnhsupport.com/">https://pvnhsupport.com/</a>
Ring14 USA	<a href="http://www.ring14.org/eng/120/clinical-database/">http://www.ring14.org/eng/120/clinical-database/</a>
SLC13A5 Deficiency	<a href="https://www.tessresearch.org/families/">https://www.tessresearch.org/families/</a>
SLC6A1 Connect	<a href="https://www.simonssearchlight.org/research/what-we-study/slc6a1/">https://www.simonssearchlight.org/research/what-we-study/slc6a1/</a>
SUDEP Tissue Donation Program (STOP SUDEP)	<a href="https://www.bcm.edu/healthcare/clinical-trials/h-32343">https://www.bcm.edu/healthcare/clinical-trials/h-32343</a>
SYNGAP1	<a href="https://syngap1registry.iamrare.org/">https://syngap1registry.iamrare.org/</a>
TESS Research Foundation	<a href="https://www.tessresearch.org/">https://www.tessresearch.org/</a>
The Bow Foundation	<a href="https://gnao1.org/">https://gnao1.org/</a>
The Brain Recovery Project: Childhood Epilepsy Surgery Foundation	<a href="https://www.brainrecoveryproject.org/">https://www.brainrecoveryproject.org/</a>
The Cute Syndrome	<a href="https://www.thecutesyndrome.com/">https://www.thecutesyndrome.com/</a>
Tuberous Sclerosis Alliance—Natural History Database	<a href="https://www.tsalliance.org/researchers/natural-history-database/">https://www.tsalliance.org/researchers/natural-history-database/</a>
Wishes for Elliott: Advancing SCN8A Research	<a href="https://scn8a.net/">https://scn8a.net/</a>

Abbreviation: NORSE, new-onset refractory status epilepticus.




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