



National Institute of
Neurological Disorders
and Stroke

NIH Counter**ACT**
Program

Status Epilepticus after Benzodiazepines: Seizures and Improving Long-term Outcomes

February 28 - March 1, 2023



Status Epilepticus:

The Family Perspective

Nora Wong, PhD, Executive Director, NORSE Institute

Status Epilepticus after Benzodiazepines: Seizures and Improving Long-term Outcomes



Disclaimer

The views expressed in this presentation are those of the author and do not reflect the official policy of NIH.

Disclosure

This certifies that I, Nora Wong, has no financial relationship that is relevant to the subject matter of the presentation.



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Doctor-family communication is incomplete, especially in the acute phase.

Most research focuses on the acute phase

Limited data on long-term outcomes may affect **end-of-life recommendations**



Proposed consensus definitions for new-onset refractory status epilepticus (NORSE), febrile infection-related epilepsy syndrome (FIRES), and related conditions

Lawrence J. Hirsch, Nicolas Gaspard, Andreas van Baalen, Rima Nababout, Sophie Demeret, Tobias Loddenkemper, Vincent Navarro, Nicola Specchio, Lieven Lagae, Andrea O. Rossetti, Sara Hocker, Teneille E. Gofton, Nicholas S. Abend, Emily J. Gilmore, Cecil Hahn, Houman Khosravani, Felix Rosenow, Eugen Trinka
First published: 05 February 2018



International consensus recommendations for management of new onset refractory status epilepticus including febrile infection-related epilepsy syndrome: Statements and supporting evidence

Ronny Wickstrom, Olga Taraschenko, Robertino Dilella, Eric T. Payne, Nicola Specchio, Rima Nababout, Sookyong Koh, Nicolas Gaspard, Lawrence J. Hirsch, the International NORSE Consensus Group
First published: 23 August 2022



Incomplete doctor-family communications

- What families hear from doctors: “Seizures” and “We don’t know”
- Discrepancy between doctor’s vs. family’s view of patient condition grows
- Families unprepared for final decisions, outcomes and rehab requirements
- Doctors may not be fully aware of long-term patient outcomes



Current focus:

Etiology, biomarkers, phenotyping and treatment comparisons

Expand to:

Common language and measures

Long-term outcomes

Collaborative infrastructure

**AES – NORSE Institute Seed and Infrastructure Grants
Applications due March 23, 2023**

CURE Epilepsy grants



International NORSE/FIRES Family Registry

PI: Teneille Gofton, MD, Western U. Canada

Families can register living and deceased patients online

Currently 84 patients enrolled

In English, French, Spanish, Simple Mandarin. Hindu and Portuguese soon.

Link on www.norseinstitute.org



Collaborative NORSE/FIRES Biorepository

Director: Lawrence J. Hirsch, MD, Yale

Donating centers do not need IRB to send samples. Shipping paid by Yale.

Analyses: Cytokine, genetic, single-cell RNA sequencing, neuropathology studies (Yale), metagenomic and auto-antibody analyses (UCSF)

Results made publicly available

Remaining samples shared as decided by Biorepository Steering Committee



Biorepository Steering Committee

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PI's: Sara Hocker, MD and Ronny Wickström, MD, PhD

Krista Eschbach

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Working Guideline for Communications

- Give unified, candid explanations of what is known and not known
- Have families articulate what they understand and their values
- Printable NORSE brochure www.norseinstitute.org
- Request autopsy
- Request organ donation: transplant and NORSE/FIRES biorepository at Yale
- Provide diagnosis codes, Rx, therapy and referrals for rehab
- Discharge planning guide www.norseinstitute.org



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Thank you.