



**Virtual Scientific Symposium on Neuro-Inflammation in NORSE  
and NORSE Family Conference  
March 4-5, 2021**

**Scientific Symposium on Neuro-Inflammation in NORSE and Related Conditions**

Thursday, March 4, 2021

10:00 am – 12:30 pm Eastern Time

Target audience: Scientists and Clinicians

[Click here](#) to register in advance for the scientific symposium

Agenda

- 10:00 - 10:10 Introduction: Nicolas Gaspard MD, PhD (Université Libre de Bruxelles Hôpital Erasme) Nora Wong PhD (NORSE Institute) Lawrence Hirsch MD (Yale)
- 10:10 - 10:45 Overview of what we know about inflammation in NORSE/FIRES: Annamaria Vezzani PhD (Mario Negri Institute) (25 min + 10 min Q&A)
- 10:45 - 11:20 Single Cell RNA Sequencing: An Unbiased tool for Pathologic Characterization of Human Inflammatory Disease at a Molecular Level: David Hafler MD (Yale) (25 min + 10 min Q&A)
- 11:20 - 11:30 10-minute break
- 11:30 - 12:10 Data blitz/current related projects: 10 min each (7 min + 3 min Q/A)  
Charles L. Howe PhD (Mayo Clinic) Insights from Immuno-profiling  
Sookyong Koh MD, PhD (Emory --> U. Nebraska) Working towards Novel Murine Models of FIRES/NORSE  
Olga Taraschenko MD, PhD (U. Nebraska) The future of interleukin-based therapies for NORSE: anakinra-loaded nanoparticles  
Michael Wilson MD (UCSF) Insights from metagenomics and antibody screening
- 12:10 - 12:25 Discussion: 15 mins
- 12:25 - 12:30 Closing remarks: Lawrence Hirsch MD

After one hour break: Family Conference begins. *\*Use Family Conference registration link below.*

**Family Conference: What Happened – The Who, What, and Why of NORSE and FIRES**

Thursday, March 4, 2021

1:30 pm - 3:45 pm Eastern Time

Target audience: Patients/Families, Clinicians and Scientists

[Click here](#) to register in advance for the Family Conference meeting

## Agenda

- 1:30 - 1:40 Introduction to the NORSE Institute and Family Registry: Nora Wong PhD  
(NORSE Institute)
- 1:40 - 1:50 Current definition of NORSE and FIRES: Lawrence Hirsch MD (Yale)
- 1:50 - 2:05 Who gets NORSE and FIRES and what are the causes? Coral Stredny MD  
(Boston Children's Hospital)
- 2:05 - 2:20 Why do people die from NORSE and FIRES? Olga Taraschenko MD, PhD  
(U. Nebraska) and Sookyong Koh MD, PhD (Emory --> U. Nebraska)
- 2:20 - 2:35 The role of inflammation and emerging treatment options for NORSE and FIRES:  
Eric Payne MD (Alberta Children's Hospital, Canada)
- 2:35 - 2:45 Panel Question and Answer
- 2:45 - 2:55 Break

## **Doctor-Family-Patient Communication**

- 2:55 - 3:10 Challenges in communication during times of uncertainty: Teneille Gofton MD  
(Western University, Canada)
- 3:10 - 3:25 How physicians can improve – Personal communication experiences.  
Two family perspectives: Natalee Gibson and Jason Hallett
- 3:25 - 3:45 Breakout Sessions in groups of 10 people  
Opportunity for feedback to physicians: How do families want information  
communicated to them and what do families want physicians and scientists to study?

Family Conference continues the next day.

## **Family Conference: Loss, Survival, and Hope**

Friday, March 5, 2021

10:00 am– 12:30 pm Eastern Time

Target audience: Patients/Families, Clinicians and Scientists

[Click here](#) to register in advance for the Family Conference meeting

## Agenda

- 10:00 - 10:05 Welcome: Nora Wong PhD (NORSE Institute)
- 10:05 - 10:20 What happens to people who survive? Krista Eschbach MD  
(Children's Hospital Colorado)
- 10:20 - 10:35 Decision making and the role of Palliative Care: Teneille Gofton MD  
(Western University, Canada)
- 10:35 - 10:50 Preparing for the future and discharge planning guide: Erica Sieg PsyD  
(Northwestern)
- 10:50 - 11:00 10-minute break
- 11:00 - 11:30 Breakout Sessions: Resources and support moving forward  
**\*Please identify which breakout session you will attend at time of registration.**

1. Parents of children who survived NORSE / FIRES
  - Moderators: Raquel Farias-Moeller MD (Medical College of Wisconsin) and Coral Stredny
2. Adult survivors and their adult family members
  - Moderators: Erica Sieg and Lawrence Hirsch
3. Resources and support for bereavement
  - Moderators: Teneille Gofton and Kellie Jankowski (Epilepsy Foundation)
4. Support for children / teens / young adults (siblings and children of those affected by NORSE / FIRES)
  - Moderator: Lauren Treat MD (Children's Hospital Colorado)

11:30 - 11:40 Summary of Breakout Sessions

Primary moderator from each session to give overview

11:40 - 12:15 Current and Emerging Research

Nicolas Gaspard MD, PhD (Université Libre de Bruxelles – Hôpital Erasme) Multi-center NORSE study

Teneille Gofton MD Family Registry

Sookyong Koh MD PhD (Emory --> U. Nebraska) and Olga Taraschenko MD PhD (U. Nebraska) Basic research in NORSE

Lawrence Hirsch MD Biorepository

12:15 - 12:30 Final discussion and questions – Goals for the Future

Moderator: Krista Eschbach MD

Questions: Contact Yashwanth Pulluru

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