

ANEmone

Acute Necrotizing Encephalopathy Multidisciplinary Outreach Network
Connecting Families, Clinicians and Scientists around a Rare Genetic Disease

Practical Information:

- Families participating in the InflammaNUP clinical study will have shuttle services available during the ANEmone meeting (Monday to Wednesday) to visit CHU Montpellier (Gui de Chauliac) for a consultation with Dr. Pierre Meyer and a small blood sample, provided informed consent is given.
- We kindly ask all participants, staff and volunteers to wear a mask during the ANEmone meeting
- Useful telephone numbers are
 - Crown Plaza +334 67722222
 - Nathalie Arhel: +336 6820 7571
- For dietary needs or stay-related questions, contact the Crowne Plaza directly

Sunday 27th April 2025: Arrival Day

Arrival at the Crowne Plaza hotel
190 rue d'Argencourt, 34000, Montpellier, FRANCE
Light dinner at the hotel

Monday 28th April 2025: Day 1

Breakfast at the hotel

Session 1:

9.15am - 9.30am	Welcome to ANEmone <i>Nathalie Arhel, CNRS Research Director, Montpellier, France</i>
9.30am - 10.30am	ANE International: A historical overview, support for families, introducing the ANE families. <i>Kim Smith, founding member of ANE International, Sydney, Australia</i>
10.30am-11am	Introducing the Medical Doctors and Researchers <i>Round table</i>

11am Coffee break/rest

CONTACT:

Nathalie.arhel@cnrs.fr
gestion@irim.cnrs.fr

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Monday 28th April 2025: continued

Session 2:

11.30am-12noon

MIRCEM: National Referral Centre for Neuro-Inflammatory Diseases

Kumaran Deiva, Professor in Neuropediatrics, Kremlin Bicêtre Hospital, Paris, France

12 noon- 12.30pm

Key differences in the severity and treatment of sporadic ANE versus hereditary ANE1

Ming Lim, Professor in Neuropediatrics, Evelina Children's Hospital, London, UK

12.30pm Lunch at the Hotel

Session 3

2pm-2.30 pm

Molecular Biology of RANBP2

Alexander Palazzo, Professor of Biochemistry, University of Toronto, Canada

2.30pm - 3pm

Sharing experience from an ANE1 family

- My ANE journey

Tobin Chisnall, ANE warrior, age 13

- Perspectives of a physiotherapist & mother

Sarah Chisnall, ANE Interational Family, New Zealand

3pm- - 3.45pm

Question and Answer Panel

Moderation by the speakers

3.45pm Coffee Break / Rest

4.30pm - 5pm

Clinical Study on ANE1 (InflammaNUP) and influenza A virus-triggered inflammation

Sophie Desgraupes, Research Fellow, Montpellier, France

5pm - 5.45

Question and Answer Panel

Moderation by the speakers

Free time / Rest

7.30pm Evening Dinner at the hotel

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Tuesday 29th April 2025: Day 2

Session 4

9am - 9.30 Focus on new tools for clinical research on ANE1: Whole exome sequencing
Hsiu-Yi Chen, Research fellow, A-star Institute Infectious Diseases, Singapore

9.30am - 10am Focus on new tools for clinical research on ANE1: Induced pluripotent stem cells
Vanessa Sancho-Shimizu, Reader in Paediatrics Infectious Disease, Imperial College London, UK

10am - 10.30am Focus on new tools for clinical research on ANE1: Nasal epithelial cells & personalised medicine
Theo Moraes, Head of Respiratory SickKids Hospital, Toronto, Canada,

10.30am Coffee Break / Rest

Session 5

11am - 11.30 The Grayson Legacy Trust
Faye & Craig Ansell, ANE International Family, Graysons Legacy, London, UK

11.30am - 12.15pm Question and Answer Panel
Moderation by the speakers

Lunch at the hotel

Session 6

2pm - 3.30pm Feedback from small group discussions, additional time for Q&A
All together

3.30pm - 4pm Closing remarks and Future perspectives for ANE Families
Jared Chisnall & Kim Smith, founding members of ANE International, New Zealand & Australia

4pm Coffee break / Rest

7.30pm Evening Dinner at the hotel

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Wednesday 30th April 2025: Departure

Breakfast at the hotel

Check out from the Crowne Plaza hotel and travel home

Medical and Scientific Participants:

ARHEL Nathalie, PhD, CNRS, Montpellier, France
BARZAGHI Federica, MD, Policlinico of Milan, Italy
BARBARIA Weim, MD Habib Bougatfa Hospital, Tunisia
CHEN Hsiuyi, PhD, A*STAR ID labs, Singapore
DEIVA Kumaran, MD, APHP, Paris, France
DESGRAUPES Sophie, PhD, CNRS, Montpellier, France
DILENA Robertino, MD, Policlinico of Milan, Italy
LIM Ming, MD, Evelina children's hospital, London, UK
MEYER Pierre, MD, CHU Montpellier, France
MORAES Theo, MD, Sickkids Hospital, Toronto, Canada
PALAZZO Alexander, PhD, University of Toronto, Canada
SANCHO-SHIMIZU Vanessa, PhD, Crick Institute, London, UK

We wish to sincerely thank the many sponsors and funding bodies who support this event:

