



# EUROPE'S SECOND SCN8A & SCN2A CONFERENCE & FAMILY GATHERING

26-27 MAY 2023, KØGE - DENMARK

# EUROPE'S SECOND SCN8A & SCN2A CONFERENCE & FAMILY GATHERING - DAY 1 -

Comwell Køge Strand Hotel  
Strandvejen 111, 4600 Køge - Denmark

FRIDAY, 26th May 2023

🕒 8:30 - 9:00

## REGISTRATION

🕒 9:00 - 9:05

## CONFERENCE WELCOME

🗣️ Mads Ravnborg, Director of the Danish Epilepsy Center, Denmark

🕒 9:05 - 9:15

## WELCOME FROM THE DANISH AND GERMAN TEAM

🗣️ Elena Gardella, Dianalund, Denmark

🗣️ Rikke Møller, Dianalund, Denmark

🗣️ Walid Fazeli, Bonn, Germany

session 1 - chairs: Elena Gardella, Rikke Møller

🕒 9:15 - 9:45

## MONOGENETIC EPILEPSIES: WHAT'S NEW IN 2023

🗣️ Markus Wolff, Zurich, Switzerland

🕒 9:45 - 10:30

## SCN2A PHENOTYPES AND LONG TERM EVOLUTION

🗣️ Walid Fazeli, Bonn, Germany

🗣️ Katherine Howell, Melbourne, Australia

🕒 10:30 - 11:00

## COFFEE BREAK

session 2 - chairs: Walid Fazeli, Markus Wolff

🕒 11:00 - 11:45

## SCN8A PHENOTYPES AND LONG TERM EVOLUTION

🗣️ Elena Gardella, Dianalund, Denmark

🗣️ Roberto Previtali, Dianalund, Denmark

🕒 11:45 - 12:15

## GENE VARIANT EFFECTS ACROSS SODIUM CHANNELOPATHIES

🗣️ Andreas Brunklaus, Glasgow, UK

🕒 12:15 - 12:45

## SCN PORTAL

🗣️ Dennis Lal, Cleveland, US

🕒 12:45 - 13:45

## LUNCH BREAK



session 3 - chairs: Rima Nabbout, Dennis Lal

- L
13:45 - 14:15
**SCN2A/SCN8A MIXED FUNCTIONS: RECENT DISCOVERIES, UNDERLYING MECHANISMS, TRENDS IN THERAPY**

 Rikke Møller, Dianalund, Denmark
- L
14:15 - 14:45
**THERAPEUTIC APPROACHES FOR SCN2A/SCN8A DEES**

 Madeleine Oudin, Boston, USA
- L
14:45 - 15:15
**SCN2A ASO PRECLINICAL DATA**

 Steven Petrou, Melbourne, Australia
- L
15:15 - 15:45
**DEVELOPING THE FIRST GLOBAL GUIDELINES FOR THE TREATMENT OF SCN8A: WHAT WE KNOW AND WHAT WE NEED TO LEARN**

 Gabi Conecker, Washington DC, USA
- L
15:45 - 16:15
**COFFEE BREAK**

session 4 - chairs: Katherine Howell, Andreas Brunklaus

- L
16:15 - 16:35
**THE SCN2A/SCN8A FRANCE EXPERIENCE**

 Rima Nabbout, Paris, France
- L
16:35 - 16:50
**SCN8A/SCN2A HPOs**

 David Lewis Smith, Glasgow, UK
- L
16:50 - 17:05
**CLINICAL SIMILARITIES ACROSS SODIUM CHANNELOPATHIES**

 Sopio Gverdtseteli, Dianalund, Denmark
- L
17:05 - 17:20
**EFFECT OF FENFLURAMINE IN SCN8A-DEE**

 Angel Aledo Serrano, Madrid, Spain
- L
17:20 - 17:35
**LEV THERAPY IN SCN8A-DEE**

 Angelica Pisati, Dianalund, Denmark
- L
17:35 - 17:50
**GROWTH ATTENUATION THERAPY: PROs AND CONs**

 Phil Zeitler, Aurora, USA (ONLINE)
- L
17:50 - 18:10
**HOW KETOGENIC DIET MAY BE BENEFICIAL IN CONTROLLING NEURONAL EXCITABILITY**

 Ilaria Rivolta, Milan, Italy
- L
18:10 - 18:30
**DISCUSSION**

# EUROPE'S SECOND SCN8A & SCN2A CONFERENCE & FAMILY GATHERING - DAY 2 -

Comwell Køge Strand Hotel  
Strandvejen 111, 4600 Køge - Denmark

SATURDAY, 27th May 2023

🕒 8:15 - 8:30

## WELCOME

session 1 - chairs: Elena Gardella, Cinzia Scarcelli

🕒 8:30 - 9:30

## TAKE HOME MESSAGES FROM DAY 1

- 🗣️ Elena Gardella, Dianalund, Denmark
- 🗣️ Rikke Møller, Dianalund, Denmark
- 🗣️ Walid Fazeli, Bonn, Germany

🕒 9:30 - 10:00

## SCN2A AND SCN8A COST-ANALYSIS AND QOL STUDIES

- 🗣️ Adam Strzelczyk, Frankfurt, Germany (ONLINE)

🕒 10:00 - 10:30

## COFFEE BREAK

SCN2A/SCN8A: beyond the seizures  
session 2 - chairs: Maaïke Studemund, Walid Fazeli

🕒 10:30 - 10:45

## SLEEP DISORDERS IN SODIUM CHANNELOPATHIES

- 🗣️ Francesca Furia, Dianalund, Denmark

🕒 10:45 - 11:00

## MOVEMENT DISORDERS IN SCN8A-DEE

- 🗣️ Margherita Aluffi Valletti, Dianalund, Denmark

🕒 11:00 - 11:15

## TRANSITION CARE IN SCN8A

- 🗣️ Caterina Ancora, Dianalund, Denmark

🕒 11:15 - 11:40

## BRIDGING THE GAP BETWEEN PROFESSIONALS, SCIENTISTS AND PATIENTS

- 🗣️ Torie Robinson, London, UK

🕒 11:40 - 12:00

## THE UNMET NEEDS OF RARE FAMILIES

- 🗣️ Cinzia Scarcelli, Milan, Italy

🕒 12:00 - 13:00

## LUNCH BREAK

session 3 - chairs: Stefania Dantone, Rikke Møller  
Patient organizations / Future directions

- 🕒 13:00 - 13:15 **THE SCN8A EUROPEAN FEDERATION**  
🗣️ Gregori Cabanach, Marseille, France
- 🕒 13:15 - 13:45 **THE DIFFERENT EXPERIENCES AND FUTURE CHALLENGES OF RECENTLY FOUNDED SCN2A ASSOCIATIONS IN ITALY, GERMANY AND GEORGIA**  
🗣️ Stefania Dantone, Padova, Italy  
🗣️ Maaïke Studemund, Hamburg, Germany  
🗣️ Zhana Chokheli, Tbilisi, Georgia
- 🕒 13:45 - 14:15 **SCN2A AND SCN8A SIMONS SEARCHLIGHT REGISTRY**  
🗣️ Michelle (Misia) Kowanda, Zurich, Switzerland
- 🕒 14:15 - 14:30 **CONCLUDING REMARKS**

## YOUR PERSONAL NOTES



## ENDORSED BY



## SCIENTIFIC COMMITTEE

Elena Gardella, Dianalund, Denmark  
Rikke Møller, Dianalund, Denmark  
Walid Fazeli, Bonn, Germany

## ORGANIZING COMMITTEE

Elena Gardella, Dianalund, Denmark  
Stefania Dantone, Padova, Italy  
Cinzia Scarcelli, Milan, Italy  
Svenja Kaden, Heidelberg, Germany  
Francesca Furia, Dianalund, Denmark  
Laila Doktor, Dianalund, Denmark

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