

This Networking event has received funding from the European Union's Horizon 2020 research and innovation programme under the EJP RD COFUND-EJP

**SCN8A & SCN2A CONFERENCE  
& FAMILY GATHERING**  
**26-27 MAY 2023, KØGE - DENMARK**



**Congress Venue**

Comwell Køge Strand Hotel  
Strandvejen 111, 4600 Køge (Denmark)

**Scientific committee**

Elena Gardella, Walid Fazeli, Rikke S. Møller

**Organizing committee**

Stefania Dantone, Elena Gardella, Cinzia Scarcelli, Svenja Kanter, Francesca Furia, Laila Doktor

Friday, May 26, 2023	
8:30 - 9:00	Registration – Francesca Furia
9:00 - 9:05	Welcome from the medical director of the Danish Epilepsy Center - Mads Ravnborg
9:05 - 9:15	Welcome from the Danish team (Elena Gardella, Rikke Møller), the German team (Walid Fazeli) and the family representatives
<b>Session 1 –</b>	
9:15 - 9:45	Monogenetic epilepsies: what's new in 2023 – Markus Wolff (Germany)
9:45 - 10:15	Gene variant effects across sodium channelopathies - Andreas Brunklaus (Glasgow-UK)
10:15 - 10:45	SCN Portal - Dennis Lal (Boston-USA)
10:45 - 11.15	Coffee break
<b>Session 2 –</b>	
11:15 - 12:00	<i>SCN2A</i> phenotypes and long term evolution - Walid Fazeli (Bonn - DE) and Katherine Howell (Melbourne - AU)
12:00 - 12:45	<i>SCN8A</i> phenotypes and long term evolution - Elena Gardella (Dianalund - DK) and Roberto Previtali (Dianalund-DK, Milan-IT)
12:45 - 13:00	Discussion
13:00 - 14:30	Lunch
<b>Session 3 -</b>	
14:30 - 15:00	<i>SCN2A/SCN8A</i> mixed functions: recent discoveries, underlying mechanisms, trends in therapy - Rikke Møller (Dianalund-DK)
15:00 - 15:30	Therapeutic approaches for <i>SCN2A/SCN8A</i> DEEs - Madeleine Oudin (USA)
15:30 - 16:00	Developing the first global guidelines for the treatment of <i>SCN8A</i> : what we know and what we need to learn - Gabi Conecker (USA)
16:00 - 16:30	Coffee break
<b>Session 4 –</b>	
16:30 - 16:50	The <i>SCN2A/SCN8A</i> France experience - Rima Nabbout (Paris-FR)
16:50 - 17:05	Transition care in <i>SCN8A</i> - Caterina Ancora (Dianalund-DK, Padua -IT)
17:05 - 17:20	<i>SCN8A/SCN2A</i> HPOs - David Lewis Smith (Glasgow - UK)
17:20 - 17:35	Clinical similarities across sodium channelopathies – Sopio Gverdtsiteli (Dianalund-DK)
17:35 - 17:50	Effect of Fenfluramine in <i>SCN8A</i> -DEE -Angel Aledo Serrano (Madrid-ES)
17:50 - 18:05	LEV therapy in <i>SCN8A</i> -DEE - Angelica Pisati (Dianalund-DK, Genoa -IT)
18:05 - 18:20	Growth Attenuation Therapy: Pros and Cons - Phil Zeitler (USA) ( <i>online</i> )
18:20 - 18:30	Discussion

Saturday, May 27, 2023	
8:15 - 8:30	Welcome
<b>Session 1</b>	
8:30 - 9:30	Take Home Messages from Day 1 – Elena Gardella (Dianalund-DK), Walid Fazeli (Bonn-DE), Rikke Møller (Dianalund-DK)
9:30 - 10:00	SCN2A and SCN8A cost-analysis and QoL studies - Adam Strzelczyk (Frankfurt-DE) <i>(online)</i>
10:00 - 10:30	Coffee break
<b>Session 2 SCN2A/SCN8A: beyond the seizures</b>	
11:00 - 11:15	Sleep disorders in sodium channelopathies - Francesca Furia
11:15 - 11:30	Movement disorders in SCN8A-DEE - Margherita Aluffi Valletti (Dianalund-DK, Genoa -IT)
11:30 - 11:45	Cognitive function and psychological support - Anne Vagner (Dianalund - DK)
11:45 - 12:10	Bridging the gap between professionals, scientists and patients – Torie Robinson (UK)
12:10 - 12:30	The unmet needs of rare families- Cinzia Scarcelli, Milan IT
12:30 - 13:30	LUNCH
<b>Session 3 - Patient organizations / Future directions</b>	
13:30 - 13:45	The SCN8A European Federation - Gregori Cabanach (Marseille, FR)
13:45 - 14:15	The different experiences and future challenges of recently founded SCN2A associations in Italy, Germany and Georgia- S. Dantone- M.Studemund - Z. Chokheli
14:15 - 14:45	The experience of Simons Searchlight Foundation- Jane Hong (USA)
14:45 - 15:00	Concluding remarks (Elena Gardella, Walid Fazeli)

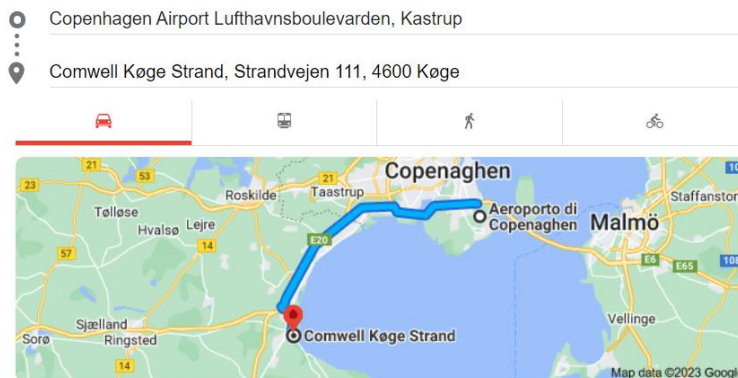


## Congress Registration

Registration is out of charge. To register please send an email to [ffu@filadelfia.dk](mailto:ffu@filadelfia.dk) indicating the number of people, the dates of arrival and departure and if you need any type of support not provided by the hotel. Registrations are open until April 25th. Later registrations can be accepted depending on the structure's availabilities.

## How to reach the Congress Venue

The Comwell Køge Strand Hotel can be reached from Copenhagen's airport:



- **By car:** 39-minutes drive from Copenhagen airport through E20 motorway (46,6 Km)  
Public parking is possible at a location nearby for free.
- **By train:** 66-minutes trip from Copenhagen airport to Nørreport St. and from Nørreport St. to Køge St.  
Train tickets are available on: <https://www.dsb.dk/en/> (search route from CPH lufthavn to Køge st.).

Københavns Lufthavn St. (Metro)  
Metro M2  
Nørreport St. (Metro)  
Gåtur  
Nørreport St.  
Shift  
Nørreport St.  
S-tog E  
Køge St.

## Hotel Reservation

All the participants / families should contact the hotel and make their reservations (the code for booking is FILADELFIA). They should indicate the dates for their staying and pay in advance. Rooms with special prices are available for the night of 25-26 May. The deadline for reservation is April 25th. On April 26th, the pre-reservation of the rooms not booked & paid will be canceled. From April 26th, the room booking will be available without a guarantee of availability. The cancellation of the pre-reservation of the rooms will be free of charge until 24 hours before the reservation date.

A limited number of family rooms is available and the hotel has no elevator to the rooms on the first floor. Families can arrange separately the booking of extra nights (standard price) and eventually other specific requests (special meals, additional beds, ...). Children not needing restoration can have a special quote only including accommodation.