

**16<sup>th</sup> - 17<sup>th</sup> May 2025**  
**3rd SCN2A & SCN8A**

scientific conference & family gathering

scientific lead: Walid Fazeli (Bonn/Germany) and  
Elena Gardella (Dianalund/Denmark)

# Conference program



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[www.scn2a.de](http://www.scn2a.de)

[www.scn8a.eu](http://www.scn8a.eu)

[www.scn2a-italia.it](http://www.scn2a-italia.it)



### Location

Kranz Parkhotel in Siegburg/Bonn - Germany  
[www.kranzparkhotel.de](http://www.kranzparkhotel.de)  
Booking under: [info@kranzparkhotel.de](mailto:info@kranzparkhotel.de)  
Booking code: EU Conference



### Registration

Registration is free of charge and includes catering during the conference, as well as dinner on Friday.

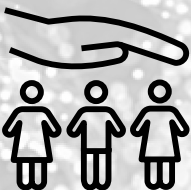
<https://lets-meet.org/reg/b7f4598e20ab473313>



### Support - travel grants

We are pleased to announce that we will cover 70,00€ per participant per night (up to a maximum of 3 nights).

For additional travel grants, please send your inquiry to [info@scn2a.de](mailto:info@scn2a.de).



### Child care

We offer non-medical child care during conference hours at the hotel. This service is available for both affected children and their siblings.

Please register separately at:  
<https://www.leo-kinderevents.de/scn2a>

## Programm

### 3rd SCN2A & SCN8A Scientific Conference and Family Gathering

Siegburg/Bonn (Germany) (16th - 17th May 2025)

#### THURSDAY, May 15th 2025

Time	Subject	Speaker
18:00 - 19:00	Welcoming of participants	

#### FRIDAY, May 16th 2025

Time	Subject	Speaker
08:00 – 09:00	Registration of participants	
09:00 – 09:15	Welcome and Introduction	Walid Fazeli (Bonn) Elena Gardella (Dianalund) Patient advocacy groups
1st session (Chairs: Markus Wolff/ Patient advocacy groups) <b>CLINICAL SPECTRUM</b>		
09:15 – 09:35	Precision medicine in DEEs - current status	Ingrid Scheffer (Melbourne)
09:35 – 09:50	SCN8A – clinical spectrum	Elena Gardella (Dianalund)
09:50 – 10:05	SCN2A – clinical spectrum	Katherine Howell (Melbourne)
<b>DISEASE MECHANISMS</b>		
10:05 – 10:25	Genetic mechanisms of sodium-channelopathies	Rikke Møller (Dianalund)
10:25 – 10:45	Targeting aberrant dendritic integration to treat cognitive comorbidities of epilepsy	Heinz Beck (Bonn)
<b>Coffee break (10:45 – 11:15)</b>		
2nd session (Chairs: Elena Gardella/ Patient advocacy groups) <b>BEYOND SEIZURES</b>		
11:15– 11:35	Movement disorders in childhood and adolescents	Anne Koy (Cologne)
11:35 – 11:45	Movement disorders in SCN2A	Vanessa Kasto (Bonn) Walid Fazeli (Bonn)
11:45 – 11:55	A joined wearable and video analysis data approach to phenotype people with SCN2A and SCN8A	Sunanjay Bajaj (Houston) Dennis Lal (Houston)
11:55 – 12:05	Episodic ataxia in SCN2A	Sopio Gverdsiteli (Dianalund) Walid Fazeli (Bonn)
12:05 – 12:20	Analysis of over 30,000 phenotypic annotations in individuals with SCN8A-related disorders	Ingo Helbig (Philadelphia)
<b>Lunch break (12:20 – 13:30)</b>		

3rd session (Chairs: Walid Fazeli/ Patient advocacy groups)		
TREATMENT		
13:30 – 13:40	SCN8A: anti-seizure medication	Elena Gardella + Team (Dianalund)
13:40 – 13:50	SCN2A: anti-seizure medication	Beattie Goad (Melbourne) Daniel Fritzen (Bonn)
13:50 – 14:05	Partial allele-specific knockout by CRISPR rescues Scn8a DEE mice	Wenxi Yu (Michigan)
14:05 – 14:20	Gene therapy approaches for the treatment of SCN8A DEE	Manoj Patel (Virginia)
14:20 – 14:35	The Regulatory Landscape of DEE Clinical Trials: - to basket or not?	Orrin Devinsky (New York)
Industry session		
14:35 – 14:55	Update on Stoke Therapeutic's Investigational Therapy for Dravet Syndrome	Stoke Therapeutics (Brian Werneburg)
14:55 – 15:15	Update in drug development for DEEs	Praxis Precision Medicine
15:15 – 15:30	Bexicaserin in DEEs	<i>t.b.c.</i>
Coffee break (15:30 - 16:15)		
4th session (Chairs: Rikke Møller/ Patient advocacy groups)		
SHORT COMMUNICATIONS		
16:15 – 16:25	Improving parental classification of seizures and seizure-like events in children with SCN2A/8A DEEs	Orrin Devinsky (New York)
16:25 – 16:35	Development of clinical and genetic inclusion criteria for high risk disease modifying therapies in SCN2A	Tobias Brünger (Houston) Dennis Lal (Houston)
16:35 – 16:45	Sleep disturbances in SCN2A	Sarah Krämer (Bonn)
16:45 – 16:55	Sleep disturbances in SCN8A	Francesca Furia (Dianalund)
16:55 – 17:05	MRI findings in SCN2A	Daniel Bamborschke (Bonn)
17:05 – 17:15	Functional characterization of SCN8A variants and pharmacological response: Insights for precision medicine	Anthony Frosio (Milan)
17:15 – 17:25	Prediction tools reliability in SCN8A-related disorders	Francesca Furia (Dianalund) Roberto Previtali (Dianalund)
17:25 – 17:35	NDEEMA across sodium channelopathies	Sopio Gverdtsiteli (Dianalund)
17:35 - 17:45	Cenobamate in sodium channelopathies	Marina Trivisano (Rome)
End of Day 1		

**SATURDAY, May 17th 2025**

Time	Subject	Speaker
09:00 – 09:05	Introduction	Walid Fazeli (Bonn) Elena Gardella (Dianalund) Patient advocacy groups
1st session (Chairs: Katherine Howell/ Patient advocacy groups) <b>SUMMARY DAY 1</b>		
09:05 – 09:20	SCN2A	Walid Fazeli (Bonn)
09:20 – 09:35	SCN8A	Elena Gardella (Dianalund)
09:35 – 10:00	Discussion on Day 1	
<b>PALLIATIVE CARE</b>		
10:00 – 10:20	Empowering Caregivers: Perspective on supporting medically complex children	Kacie Craig (The Cute Syndrome Foundation)
10:20 – 10:45	Pediatric palliative care	Martin Staudt (Munich)
10:45 – 11:00	Discussion on both talks	
<b>Coffee break (11:00 – 11:30)</b>		
2nd session (Chairs: Walid Fazeli/ Patient advocacy groups) <b>MISCELLANEOUS</b>		
11:30 – 11:50	Detail-oriented visual processing and reduced perception of global patterns in the <i>Scn2a</i> <sup>+/-</sup> rat model of autism spectrum disorder	Angelina Tadic (Trieste)
11:50 – 12:15	Parental mosaicism in DEEs - implications for families	Elisabeth Mangold (Bonn)
12:15 – 12:45	QoL and Burden of illness in SCN2A- and SCN8A-associated disorders	Adam Strzelczyk (Frankfurt) Elena Gardella (Dianalund) Walid Fazeli (Bonn)
<b>Lunch break (12:45 – 14:00)</b>		
3rd session (Chairs: Elena Gardella/ Patient advocacy groups) <b>PATIENT ADVOCACY GROUPS</b>		
14:00 – 14:15	How can PAOs grow and strengthen their capacity to support research? Opportunities through philanthropic foundations	SCN2A Germany
14:15 – 14:30	Connections that count: partnering with professionals at every stage of the journey	Leah Schust Myers (SCN2A Family Foundation)
14:30 – 14:45	Building scientific advocacy through collaboration with other DEEs and rare diseases	Luismi Aras (SCN8A Spain)
14:45 – 15:00	Concluding remarks	Walid Fazeli (Bonn) Elena Gardella (Dianalund) Patient advocacy groups
<b>End of the conference</b>		

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