



EUROPE'S FIRST SCN8A & SCN2A CONFERENCE & FAMILY GATHERING

10-11 SEPTEMBER 2021, BONN - GERMANY

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

University Hospital Bonn - Biomedizinisches Zentrum I (BMZ I)
Gebäude 13, Großer Hörsaal, Venusberg-Campus 1 - 53127 Bonn

FRIDAY , 10th September 2021

- 🕒 9:00 - 9:30 **REGISTRATION**
- 🕒 9:30 - 9:35 **WELCOME TO THE UNIVERSITY HOSPITAL BONN**
🗣️ Janbernd Kirschner, Bonn, Germany
- 🕒 9:35 - 9:45 **INTRODUCTION & CONFERENCE WELCOME**
🗣️ Walid Fazeli, Bonn, Germany - Elena Gardella, Dianalund, Denmark
Anna Homann, Meppen, Germany - Roland Waegner, München, Germany
- 🕒 9:45 - 10:30 **GENETIC EPILEPSIES AND BASIC MECHANISMS OF SODIUM CHANNELOPATHIES**
🗣️ Holger Lerche, Tübingen, Germany
- 🕒 10:30 - 11:00 **QUALITY OF LIFE: LESSONS LEARNED FROM DRAVET SYNDROME**
🗣️ Adam Strzelczyk, Frankfurt, Germany
- 🕒 11:00 - 11:30 **COFFEE BREAK**
- SCN2A (parallel session):
- 🕒 11:30 - 12:00 **SCN2A: PHENOTYPIC SPECTRUM**
🗣️ Walid Fazeli, Bonn, Germany
- 🕒 12:00 - 12:30 **SCN2A: FUTURE THERAPIES**
🗣️ Steve Petrou, Melbourne, Australia (ONLINE)
- SCN8A (parallel session):
- 🕒 11:30 - 12:30 **EUROPEAN SCN8A PATIENT ADVOCATES**
🗣️ Cinzia Scarcelli, Milan, Italy - Roland Waegner, München, Germany
Ben Clay, Liverpool, UK (ONLINE)
- 🕒 12:30 - 14:00 **LUNCH BREAK**

SCN2A (parallel session):

🕒 14:00 - 15:00

MEET THE OTHER SCN2A FAMILIES

🗣️ Kris Pierce, Australia (ONLINE) - Anna Homann, Meppen, Germany
Stefania Dantone, Padua, Italy - Jenny Burke, USA

SCN8A (parallel session):

🕒 14:00 - 14:30

SCN8A: PHENOTYPIC SPECTRUM AND CURRENT THERAPIES

🗣️ Elena Gardella, Dianalund, Denmark

🕒 14:30 - 15:00

SCN8A: GENOTYPE-PHENOTYPE CORRELATIONS

🗣️ Rikke Møller, Dianalund, Denmark

🕒 15:00 - 15:30

COFFEE BREAK

SCN2A (parallel session):

🕒 15:30 - 16:00

SCN2A: CURRENT THERAPIES

🗣️ Markus Wolff, Berlin, Germany

🕒 16:00 - 16:30

SCN2A: NATURAL HISTORY STUDY

🗣️ Markus Wolff, Berlin, Germany - Walid Fazeli, Bonn, Germany

SCN8A (parallel session):

🕒 15:30 - 16:00

SCN8A: NATURAL HISTORY STUDY AND PROGNOSTIC FACTORS

🗣️ Elena Gardella, Dianalund, Denmark

🕒 16:00 - 16:30

SCN8A: FUTURE THERAPIES

🗣️ Miriam Meisler, Michigan, USA (ONLINE)

END OF PARALLEL SESSIONS

🕒 16:45 - 17:15

THE ROLE OF PATIENT ORGANISATIONS: DATA, RESEARCH AND CLINICAL TRIALS; LESSONS FROM THE CUTE SYNDROME FOUNDATION

🗣️ Hillary Savoie, USA

🕒 17:15 - 17:45

SCN2A & SCN8A: IS THERE A COMMON SEIZURE SEMIOLOGY?

🗣️ Nicola Specchio, Rome, Italy

🕒 17:45 - 18:15

LEAVE YOUR QUESTIONS FOR TOMORROW'S SESSIONS (ONLINE & IN PERSON)

🗣️ Family groups

🕒 19:30 - 22:00

DINNER

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

University Hospital Bonn - Biomedizinisches Zentrum I (BMZ I)
Gebäude 13, Großer Hörsaal, Venusberg-Campus 1 - 53127 Bonn

SATURDAY, 11th September 2021

- 🕒 9:00 - 9:15

INTRODUCTION

🗣️ Walid Fazeli, Bonn, Germany - Elena Gardella, Dianalund, Denmark
- 🕒 9:15 - 9:45

DRAVET SYNDROME - TAKE AWAYS FOR THE SCN2A/8A JOURNEY

🗣️ Luis Miguel Aras, Bilbao, Spain
- 🕒 9:45 - 10:15

SUDEP, WHAT WE KNOW

🗣️ Torbjorn Tomson, Stockholm, Sweden (ONLINE)
- 🕒 10:15 - 10:45

SUPPORTIVE TECHNOLOGIES

🗣️ Luis Miguel Aras, Bilbao, Spain
- 🕒 10:45 - 11:00

COFFEE BREAK
- 🕒 11:00 - 11:30

GENERAL Q & A

🗣️ Elena Gardella, Dianalund, Denmark - Walid Fazeli, Bonn, Germany
- 🕒 11:30 - 12:30

MEET THE EXPERTS

🗣️ SCN8A: Gardella + SCN2A: Fazeli (one-to-one consultation)
- 🕒 12:30 - 14:00

LUNCH BREAK
- 🕒 14:00 - 14:30

CBD AND FENFLURAMINE

🗣️ Alexandra Klotz, Freiburg, Germany
- 🕒 14:30 - 15:00

KETOGENIC DIET

🗣️ Mette Schou Larsen, Dianalund, Denmark (ONLINE)
- 🕒 15:00 - 15:30

WRAP-UP, TAKE AWAYS, WHAT'S NEXT AND GOODBYE

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

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