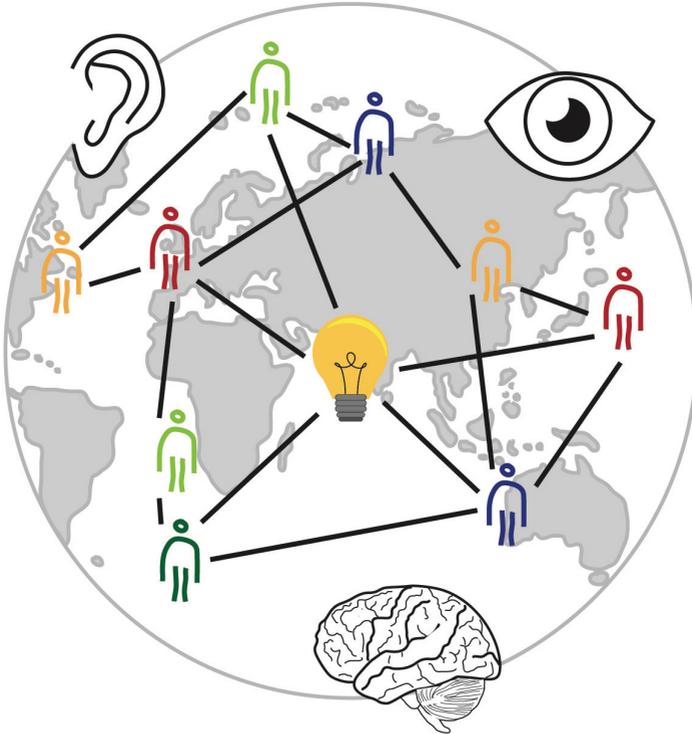


Department of Neurology with Institute of Translational Neurology  
University and University Hospital Münster, Germany



## Networking Support Scheme

Susac syndrome from bench to bedside – bridging the knowledge gaps by uniting basic research with the clinic

15<sup>th</sup> to 16<sup>th</sup> of June 2023 in Münster, Germany



## Impressum

### Herausgeber

Department of Neurology with Institute of Translational Neurology  
Albert-Schweitzer-Campus 1, Gebäude A1  
48149 Münster  
T +49 251 83-46811

### Redaktion

Catharina C. Gross,  
Department of Neurology with Institute of Translational Neurology

### Gestaltung

GB Unternehmenskommunikation

### Titelfoto

Eva Dawin,  
Department of Neurology with Institute of Translational Neurology

### Stand

Juni 2023



# Susac Syndrome Networking Event

We would like to invite you to the [Susac Syndrome Networking Event](#) from the 15th to 16th of June 2023 at the [Hotel Kaiserhof](#) [www.kaiserhof-muenster.com](http://www.kaiserhof-muenster.com) in Münster.

The aim of this networking event is to improve recognition, understanding, treatment and research on [Susac syndrome](#), a rare autoimmune disease affecting the [brain](#), [retina](#) and [inner ear](#). Within this meeting, [clinical and scientific experts](#) in the field will exchange current [knowledge and address knowledge gaps](#) on (i) causes and pathophysiology of the disease, (ii) improvement of diagnosis and prognosis, and (iii) treatment options. This event will serve as a starting point to set up an [International Susac Consortium \(I-SuSaC\)](#) to lay the groundwork for future scientific collaborations for the patients' benefit. This meeting will result in a consensus agreement on [harmonization of a clinical data respiratory](#) combined with [standardized sample processing](#) for a joined Susac biobank.

The voice of the patient will be presented by a patient report and a representative from [EURODIS – Rare Diseases Europe](#) [www.eurordis.org](http://www.eurordis.org)

This Networking event has received funding from the European Union's Horizon 2020 research and innovation programme under the EJP RD COFUND-EJP N° 825575.



A handwritten signature in black ink, appearing to read 'H. Wiendl'.

Univ.-Prof. Prof. h.c.  
Dr. med.  
[Heinz Wiendl](#)  
Director  
Department of  
Neurology with Institute  
of Translational Neurology

A handwritten signature in black ink, appearing to read 'C. Gross'.

Dr. rer. nat.  
[Catharina C. Gross](#)  
Scientific Head CSF- and  
Laboratory Diagnostics  
Neurology, Work Group  
Leader, Department of  
Neurology with Institute  
of Translational Neurology

# Program

Thursday 15<sup>th</sup> of June 2023 – What do we know about Susac syndrome?

- 09.00 – 09.10 [Welcome and introduction to the meeting](#)  
Catharina C. Gross, Münster, Germany; Barbara Willekens, Antwerp, Belgium
- 09.10 – 09.40 [Key note lecture I – Lessons learned from rare diseases](#)  
Heinz Wiendl, Münster, Germany  
Chair: Thomas Papo, Paris, France
- 09.40 – 10.15 [The voice of the patient](#)  
Chair: Ilka Kleffner, Bochum, Germany
- 09.40 – 09.55 [One among 500 - my experience with Susac syndrome](#)  
Patient report
- 09.55 – 10.15 [The added value of patient organizations](#)  
Simone Boselli, EURORDIS
- 10.15 – 10.30 Coffee Break
- 10.30 – 11.45 [Bedside session I – Current knowledge on clinical features](#)  
Chairs: Barbara Willekens, Antwerp, Belgium;  
Jan Bauer, Vienna, Austria
- 10.30 – 10.40 [Diagnostic criteria defining Susac syndrome](#)  
Ilka Kleffner, Bochum, Germany
- 10.40 – 10.50 [Update on epidemiology and clinical presentation of Susac syndrome](#)  
Jan Dörr, Berlin, Germany
- 10.50 – 11.00 [Optical coherence tomography and fluorescence angiography in Susac syndrome](#)  
Marius Ringelstein, Düsseldorf, Germany

- 11.00 – 11.10 [Cognitive outcomes in Susac syndrome](#)  
Guy Laureys, Gent, Belgium
- 11.10 – 11.25 [Neuro-otology of Susac syndrome](#)  
Todd Hardy, Sydney, Australia
- 11.25 – 11.45 [Round table and audience discussion including future perspectives](#)
- 11.45 – 12.00 Break
- 12.00 – 12.50 [Bedside session II – Optimizing patient care](#)  
Chairs: Ilka Kleffner, Bochum, Germany;  
Todd Hardy, Sydney, Australia
- 12.00 – 12.10 [Treatment options in Susac syndrome](#)  
Barbara Wokke, Rotterdam, the Netherlands
- 12.10 – 12.20 [Pregnancy in Susac syndrome](#)  
Barbara Willekens, Antwerp, Belgium
- 12.20 – 12.35 [Experience in setting up a country wide patient registry](#)  
Thomas Papo, Paris, France
- 12.35 – 12.50 [Round table and audience discussion with future perspectives](#)
- 12.50 – 13.45 Lunch
- 13.45 – 14.15 [Keynote lecture II – Experiences from the COVID-19 Network – REDCap: chances and challenges in setting up web-based platforms](#)  
Maria Pia Sormani, Genua, Italy  
Chair: Heinz Wiendl, Münster, Germany

# Program

Thursday 15<sup>th</sup> of June 2023 – What do we know about Susac syndrome?

14.15 – 15.00 **Bench session I – Current knowledge on the pathophysiology and tools for future research**

Chairs: Beatrijs Wokke, Rotterdam, the Netherlands;  
Nicholas Schwab, Münster, Germany

14.15 – 14.25 **The role of CD8 T cells in the pathophysiology of Susac syndrome**  
Catharina C. Gross, Münster, Germany

14.25 – 14.35 **Benefits of brain tissue research – multiplex microscopy and transcriptomics to decipher the pathophysiology of neuroimmunological diseases**

Jan Bauer, Vienna, Austria

14.35 – 14.45 **Everything flows – multiparameter flow cytometry for classification of neuroimmunological diseases**

Andreas Schulte-Mecklenbeck, Münster, Germany

14.45 – 15.00 **Round table and audience discussion including future perspectives**

15.00 – 15.20 **Coffee Break**

15.20 – 16.15 **The future – Young investigator session on current research I preclinical**

Chairs: Caroline Loos, Antwerp, Belgium;  
Catharina C. Gross, Münster, Germany

15.20 – 15.30 **On the search of Susac-specific antigens**

Eva Dawin, Münster, Germany

15.30 – 15.40 **Generation of iPSC-derived microvascular endothelial-like cells to study immune cell/endothelial cell interaction**

Dominik Krüger, Münster, Germany

15.40 – 15.50 [10 x spatial transcriptomics of brain biopsies to investigate CD8-mediated processes in the CNS](#)

Katharina Mair, Vienna, Austria

15.50 – 16.00 [Exosome sequencing in Susac syndrome](#)

Clémence David, Paris, France

16.00 – 16.15 [Round table and audience discussion including future perspectives](#)

16.15 – 17.00 [The future – Young investigator session on current research II clinical](#)

Chairs: Eva Dawin, Münster, Germany;

Guy Laureys, Gent, Belgium

16.15 – 16.25 [Misdiagnosis and differential diagnosis: the role of MRI](#)

Caroline Loos, Antwerp, Belgium

16.25 – 16.35 [Audiovestibular testing in Susac syndrome](#)

Maria Van de Kerckhove, Gent, Belgium

16.35 – 16.45 [Impact of pregnancy and contraception on the course of Susac syndrome](#)

Annika Radermacher, Bochum, Germany

16.45 – 17.00 [Round table and audience discussion with future perspectives](#)

17.00 – 17.10 [Closure and summary of the day](#)

Catharina C. Gross, Münster, Germany;

Barbara Willekens, Antwerp, Belgium

18.00 Dinner

# Program

Friday 16<sup>th</sup> of June 2023 – Where to go – Workshops on future perspectives of the consortium

09.00 – 09.15 **Bench Session II - Pre-clinical models to study causality of immune-mediated processes in neuroimmunological diseases**  
Roland Liblau, Toulouse, France  
Chair: Jan Bauer, Vienna, Austria

09.15 – 10.00 **WS 1: Clinical and paraclinical outcome measures – defining a common data set**  
Lead: Barbara Willekens, Antwerp, Belgium;  
Ilka Kleffner, Bochum, Germany; Roland Liblau, Toulouse, France

10.00 – 10.30 **WS 2: Dealing with clinical data sets in rare diseases – dos' and don'ts from collection to analysis**  
Lead: Barbara Willekens, Antwerp, Belgium; Maria Pia Sormani, Genua, Italy; Thomas Papo, Paris, France

10.30 – 10.45 Coffee Break

10.45 – 11.30 **WS 3: Biobanking efforts towards an international Susac biobank**  
Lead: Catharina C. Gross, Münster, Germany;  
Jan Bauer, Vienna, Austria; Guy Laureys, Gent, Belgium

11.30 – 12.00 **Conclusions and to dos for the future (e.g. joint research applications)**  
Catharina C. Gross, Münster, Germany;  
Barbara Willekens, Antwerp, Belgium

12.00 – 13.00 Lunch and departures

# General information

## Local organization

Dr. Catharina C. Gross, PhD

Univ.-Prof. Prof. h.c. Dr. Heinz Wiendl, MD

Department of Neurology with Institute of  
Translational Neurology

University and University Hospital  
Münster, Germany

## Co-organization

Dr. Barbara Willekens, MD, PhD

Department of Neurology

Antwerp University Hospital, Belgium

## Meeting venue

Hotel Kaiserhof

[www.kaiserhof-muenster.com](http://www.kaiserhof-muenster.com)

Bahnhofstrasse 14

48143 Münster

If you are interested in joining the meeting please contact Claudia Mendes [claudia.mendes@ukmuenster.de](mailto:claudia.mendes@ukmuenster.de)

For those who cannot attend the meeting in person there will be a remote option via Zoom. If you would like to join the meeting via the remote option please contact Claudia Mendes [claudia.mendes@ukmuenster.de](mailto:claudia.mendes@ukmuenster.de) until the 13th of June.



**Department of Neurology with Institute of Translational Neurology**  
**University and University Hospital Münster, Germany**  
Albert-Schweitzer-Campus 1, Gebäude A1  
48149 Münster  
T +49 251 83-46811