

Welcome to
**The International & German
aHUS, C3G and IC-MPGN
Family Weekend**

Program



Selbsthilfe für seltene
komplementvermittelte
Erkrankungen e.V.
MPGN und aHUS



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ERKNet
The European Rare Kidney Disease
Reference Network

Welcome to **The International & German aHUS, C3G and IC-MPGN Family Weekend**

Heidelberg, Germany, 28-30 November 2025

Dear friends and families living with aHUS, C3G or IC-MPGN,

We are delighted to welcome you to our Family Weekend.
The meeting takes place in the Marsilius College.
Address: Im Neuenheimer Feld 130.1, 69120 Heidelberg,
Germany.

A diverse program with interesting presentations awaits you.
The meeting will run in English and in German in two different
rooms.

Friday, 28 November 2025

- | | |
|--------------|--|
| 14:30 | Welcome
Individual Appointments with Experts |
| 15:30 | The Key to a Specific
Diagnosis: The Biopsy
Patrick D. Walker, MD Nephropathologist,
Arkana Laboratories, Arkansas, USA |
| 16:30 | From Blood Test to Treatment:
The Role of Biomarkers
Dr. Jutta Schröder-Braunstein,
UK Heidelberg, Germany
Dr. Tilo Freiwald, UKE Hamburg, Germany |
| 17:30 | Wrap Up and Transfer to the
Center of Heidelberg,
close to the Christmas Market |
| 19:00 | Social Dinner, Kulturbrauerei Heidelberg
Leyergasse 6, 69117 Heidelberg |

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Saturday, 29 November 2025

- | | |
|--------------|--|
| 9:00 | Welcome |
| 9:30 | Current Treatment Options:
Therapies Explained
Dr. Karsten Häffner, UK
Freiburg, Germany |
| 10:30 | Break |
| 11:00 | Back to the Basics: Understanding
aHUS, C3G and IC-MPGN
Dr. Gesa Schalk, KNZ Bonn, Germany |
| 12:00 | Lunch Break |
| 13:00 | Nutrition and Complement Diseases:
Spotlight on Diet
Louise Salomo MD PhD, Copenhagen
University Hospital, Denmark |
| 14:00 | What is Coming Next: Innovation and
Future Treatments
Prof. Gema Ariceta, MD, PhD, University
Hospital Vall d'Hebron, Spain |
| 15:00 | Break |
| 15:30 | The Power of Registries: Shaping
Complement Care
Prof. Franz Schäfer, UK Heidelberg, Germany
Christiane Mockenhaupt, Chair Selfhelp Group
aHUS & MPGN Germany
Marianne Silkjær Nielsen, Founder and Chair
CompCure |
| 16:15 | From Struggle to Strategy:
Mental Health in Everyday Rare
Disease Life
Antonia King, Patient Representative
Dirk Bethe, Psychologist, UK
Heidelberg, Germany |
| 17:00 | Closing Saturday
Walk to the Restaurant |
| 18:00 | Social Dinner, BräuStadel Heidelberg
Berliner Straße 41, 69120 Heidelberg |

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Sunday, 30 November 2025

9:00 **Welcome**

9:10 **Living with Rare Diseases:
Strategies & Support**

Antonia King and other patient
representatives

10:10 **Break**

10:30 **Break Out Sessions:**

Moderated Break Out Sessions:

Topic can be chosen according to interests

- Advocate for yourself and others
– Communication Training with PinT
(Partners in Training) – professional
training with communication expert
- Connecting Body and Soul - Yoga
- The Perspective of Caregivers
- Clinical Trials: As a Last Resort?
- Other Break Out Sessions will
also be available

12:00 **Closing**

12:30 **Lunch & Goodbye**

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MAIN SPONSORS

Novartis:

Building on a 40-year legacy that began in transplant, Novartis is on a mission to empower breakthroughs and transform care in kidney health, starting with kidney conditions that have significant unmet need.

Historically, these conditions have had considerably less funding and research, leading to a treatment landscape largely focused on reactive or end-stage disease management, often with significant physical, emotional, and financial burdens. Our portfolio targets the underlying causes of disease, with an aim to protect kidney health and delay or prevent dialysis and/or transplantation. Our goal is to help patients get back to living life on their terms - whether at work, in school, or with loved ones, and by partnering with patients, advocates, clinicians and policymakers, we aim to raise awareness, accelerate diagnosis and get patients the right care, sooner.

Sobi:

Sobi is an international biopharmaceutical company transforming the lives of people with rare and debilitating diseases.

Inspired by caring, powered by science, we are dedicated to:

- Ensuring every eligible person living with a rare and debilitating disease within our disease areas is given the opportunity to benefit from our approved medicines
- Delivering innovative solutions from our pipeline
- Maintaining our commitment to patients, our employees, and society.

Alexion:

Alexion, AstraZeneca Rare Disease, is focused on serving patients and families affected by rare diseases and devastating conditions through the discovery, development and delivery of life-changing medicines. A pioneering leader in rare disease for more than three decades, Alexion was the first to translate the complex biology of the complement system into transformative medicines, and today it continues to build a diversified pipeline across disease areas with significant unmet need, using an array of innovative modalities. As part of AstraZeneca, Alexion is continually expanding its global geographic footprint to serve more rare disease patients around the world. It is headquartered in Boston, US.

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SUPPORTERS

Healthcare Deutschland GmbH:

Our mission is to improve and ensure the quality of life and therapy adherence of patients with rare diseases through appropriate medical and pharmaceutical measures in the home environment as in close consultation with the treating physicians.

HOSTS

CompCure:

CompCure is a patient- and caregiver-driven non-profit association. We are building a global community that brings together people living with C3G or IC-MPGN, clinicians, leading multidisciplinary experts, industry partners, and other relevant stakeholders with the shared objective of improving outcomes across complement-mediated kidney diseases. Through our various activities and networks, we are working towards a future where C3G and IC-MPGN are fully understood, early diagnosed, and optimally treated.

Selfhelp Group aHUS & MPGN Germany:

We are an association of patients and relatives affected by rare complement-mediated diseases (aHUS, C3G, MPGN). Our goal is to give patients a voice, promote research, and strengthen the exchange between patients, physicians, and scientists.

In addition to professional exchange, we offer a supportive community to help navigate the challenges of everyday life.

ORGANIZING PARTNERS

ERKNet:

ERKNet is the European Reference Network for Rare Kidney Diseases, a consortium of 72 expert pediatric and adult nephrology centers in 24 European countries providing healthcare to more than 70,000 patients with rare disorders of the kidneys.

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