



Selbsthilfe für seltene  
komplementvermittelte  
Erkrankungen e.V.

MPGN und aHUS



We are a German patient group for complement diseases aHUS and C3 Glomerulopathy/MPGN.  
In cooperation with the foundation CompCure we cordially invite patients and caregivers!

## Complement Weekend: International Patient's Conference on aHUS and C3 Glomerulopathy/MPGN

on 14<sup>th</sup> and 15<sup>th</sup> of September 2024 in Berlin, Germany

Address: Begegnungszentrum Integral, Marchlewskistraße 25e, 10243 Berlin

The annual patient day for aHUS and MPGN/C3 glomerulopathy is a unique opportunity for patients and care-givers to find out more about these rare diseases, learn about new therapies, ask doctors questions and exchange ideas with one another. This year we would like to invite those affected from all over Europe for the first time and offer a parallel session in English alongside with a German session. Participation including meals is free of charge. We will engage German speaking teachers, who also speak English, so you can bring your child with you. You can find a hotel recommendation in the appendix.

### Program of the English speaking session:

#### Day 1: Saturday, 14<sup>th</sup> September 2024

|       |   |
|-------|---|
| 13:00 | Registration, get-together and lunch snacks   |
| 14:00 | Talks and discussions Part I:<br>- Diagnostics and therapy for children – Prof. Dominik Müller (Charité Berlin)<br>- Where can you get a second opinion? (ERKNet) - Joanna Sladowska-Kozłowska (Heidelberg University Hospital)<br>- How do we advance research? The CompCure Register – Marianne Silkjær Nielsen |
| 15:30 | Coffee break  |
| 16:00 | Talks and discussions Part II:<br>- The complement system: What is the problem with aHUS/MPGN/C3G? – Dr. Arthur Dopler (Ulm University)<br>- Therapies for C3G/MPGN and aHUS – Dr. Evelyn Seelow (Charité, Berlin)  |
| 17:30 | Break / individual discussions with the doctors   |
| 19:00 | Snacks and networking (till 20:30)  |

#### Day 2: Sunday, 15<sup>th</sup> September 2024

|       |  |
|-------|--|
| 9:00  | Get-together and coffee  |
| 9:15  | Talk and discussion: What my kidney disease has taught me – Adrian Ley (author of the podcast FunktioNIEREN, Vienna) |
| 9:45  | Patient stories and discussion about further steps for better research - Marianne Silkjær Nielsen                    |
| 10:15 | Coffee break   |
| 10:30 | Talk and discussion: How nutritional recommendations do not become serious bans – Barbara Contzen (Dietologist)      |
| 11:30 | Networking   |
| 12:00 | Lunch  |

For registration, please fill out the application form in the attachment and send it as soon as possible to [mpgn@ahus-selbsthilfe.de](mailto:mpgn@ahus-selbsthilfe.de), so that we can plan the capacities on site. Visit our website (in German) for further information: [www.ahus-selbsthilfe.de](http://www.ahus-selbsthilfe.de)

# Application form

**For the Patient's Conference on aHUS and C3 Glomerulopathy/MPGN on 14<sup>th</sup> and 15<sup>th</sup> September 2024  
im Begegnungszentrum Integral, Marchlewskistraße 25e, 10243 Berlin, Germany**

Participation including meals is free of charge. Please send the completed form as soon as possible, as we have to plan the capacity on site, by email as a completed PDF file or as a photo [mpgn@ahus-selbsthilfe.de](mailto:mpgn@ahus-selbsthilfe.de)

**Name (main participant):** \_\_\_\_\_

Email: \_\_\_\_\_ Phone: \_\_\_\_\_

Are you a registered member of our patient's group?  YES  NO

**Name (accompanying person):** \_\_\_\_\_

|                             |            |   |                              |
|-----------------------------|------------|---|------------------------------|
| <b>Child 1: Name:</b> _____ | Age: _____ | Should we take care of your child during the talks? | <input type="checkbox"/> YES |
| <b>Child 2: Name:</b> _____ | Age: _____ | Should we take care of your child during the talks? | <input type="checkbox"/> YES |
| <b>Child 3: Name:</b> _____ | Age: _____ | Should we take care of your child during the talks? | <input type="checkbox"/> YES |

**Do you need an individual conversation with a doctor during or before the conference:**  YES  NO

We will try to arrange an appointment and let you know the slot shortly before the conference.

**Further comments:** \_\_\_\_\_  
\_\_\_\_\_

## Further Information:

### How to get to the conference site:

The Integral meeting center is located a 5-minute-walk from the subway station Weberwiese (U5 line, 9 stops or 15 minutes from Berlin Central Station). Please note that there is only paid parking in the area.

### Hotels nearby (up to 900 m walk):

1. **Pegasus Hostel Berlin:** <https://www.pegasushostel.de/> - from 90€ per night, at least 2 nights booking possible
2. **Hotel Comenius:** <https://hotelcomenius.com/> - from 200 € for 2 persons in a double room, 173 € single room
3. **KiezBox:** <https://kiez-box-berlin.hotel-mix.de/> - 137 € single room, 151 € double room

Please book hotel rooms as soon as possible, as cheap accommodation options in Berlin are scarce.

**Contact for urgent questions on site:** phone +49 151 53 06 18 06 (also SMS) / E-Mail: [mpgn@gmx.de](mailto:mpgn@gmx.de)

**We are looking forward to meeting you in Berlin!**