

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 $14^{\rm th}$ and $15^{\rm th}$ 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 - one more reason to visit the German capital with the whole family! You can find a hotel recommendation in the appendix.

#### Program of the English speaking session:

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

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13:00	Registration, get-together and lunch snacks		
14:00	<ul> <li>Talks and discussions Part I:</li> <li>Diagnostics and therapy for children – Prof. Dominik Müller (Charité Berlin)</li> <li>Where can you get a second opinion? (ERKNet) - Joanna Sladowska-Kozlowska (Heidelberg University Hospital)</li> <li>How do we advance research? The CompCure Register – Marianne Silkjær Nielsen</li> </ul>		
15:30	Coffee break		
16:00	<ul> <li>Talks and discussions Part II:</li> <li>The complement system: What is the problem with aHUS/MPGN/C3G? – Dr. Arthur Dopler (Ulm University)</li> <li>Therapies for C3G/MPGN and aHUS – Dr. Evelyn Seelow (Charité, Berlin)</li> <li>Pregnancy with aHUS/MPGN/C3G – N.N.</li> </ul>		
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
9:30	Patient stories and discussion about further steps for better research - Marianne Silkjær Nielsen
10:30	Coffee break
11:00	Talk about nutrition for kidney patients – Dietologist has been requested
12:00	Lunch and networking

For registration, please fill out the application form in the attachment and send it as soon as possible to <a href="mpgn@ahus-selbsthilfe.de">mpgn@ahus-selbsthilfe.de</a>, so that we can plan the capacities on site.

Visit our website (in German) for further information: <u>www.ahus-selbsthilfe.de</u>

## **Application form**

#### For the Patient's Conference on aHUS and C3 Glomarulopathy/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 <a href="mailto:mpgn@ahus-selbsthilfe.de">mpgn@ahus-selbsthilfe.de</a>

Name (main participant):		
Email:	Phone:	
Are you a registered member of our patient's group?	□ YES □ NO	
Name (accompanying person):		
Child 1: Name:	Age:	Should we take care of your child during the talks? □ YES
Child 2: Name:	Age:	Should we take care of your _ child during the talks? □ YES
Child 3: Name:	Age:	Should we take care of your child during the talks?
<b>Do you need an individual conversation with a doc</b> We will try to arrange an appointment and let you kno <b>Further comments:</b>	U	
Further	Information:	
<b>How to get to the conference site:</b> The Integral meeting center is located a 5-minute-walk minutes from Berlin Central Station). Please note that t		
Hotels nearby (up to 900 m walk): 1. Pegasus Hostel Berlin: <u>https://www.pegasu</u> possible	<u>ıshostel.de/</u> - fro	om 90€ per night, at least 2 nights booking

- 2. **Hotel Comenius**: <u>https://hotelcomenius.com/</u> from 200 € for 2 persons in a double room, 173 € single room
- 3. **KiezBox**: <u>https://kiez-box-berlin.hotel-mix.de/</u> 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

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