ERKNet The European Rare Kidney Disease Reference Network

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

aHUS, C3G, & IC-MPGN Patient and Family Conference

Turning Innovation into Better Lives, Together

27-29 November 2026
Marsilius Kolleg, Im Neuenheimer Feld 130.1, 69120 Heidelberg, Germany & Online

Dear friends and families,
We are delighted to welcome you to our patient and family conference.
An exciting and comprehensive program awaits you.

The meeting will run in English and German, with separate meeting rooms for each language, both in person and online.

High-level agenda

Subject to minor changes

Friday, 27 November

Arrival possible as of 16:30

17:00	**Welcome: Turning Innovation into Better Lives, Together**
17:15	**Inhibiting progression of chronic kidney disease: What can I do myself?** *Professor Jürgen Flöge, RWTH Aachen University*
18:00	**Standards of Care in aHUS, C3G, and IC-MPGN** *Dr. Giulia Bassanese, University Hospital Heidelberg* *Dr. Aleksandra Vujović, University Medical Centre Ljubljana*
18:45 - 19:30	**Informal Networking and Patient-Driven Discussions** *Refreshments provided*

There will be no childcare offered on Friday.

We thank our main sponsors for making this event possible

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Saturday, 28 November

Arrival possible as of 8:30

9:00	**Welcome & Meeting Objectives**
9:15	**The Complement System, the Diseases, and How They Are Diagnosed, Followed-Up, and Treated?** *Dr. Evelyn Seelow, Charité Berlin*
10:00	**The Patient Journey: What To Expect and What To Do?** *Lindsey Fuller, Patient Advocate, Co-Founder of C3G Warriors and Mary Baliker, Patient Advocate, Healthcare Consultant*
10:45	Break
11:15	**From Science to New Treatments: Discovering and Developing Pegcetacoplan** *Pascal Deschatelets, Inventor of Pegcetacoplan, and Co-Founder of Apellis,* *moderated by Marianne Silkjær Nielsen, Founder and Chair, CompCure*
11:45	**From Science to New Treatments: Discovering and Developing Iptacopan** *Anna Schubart, Researcher and Key Scientist Behind Iptacopan,* *moderated by Marianne Silkjær Nielsen, Founder and Chair, CompCure*
12:15	Lunch Break
13:15	**Real-World Evidence: How Registries Can Help Turn Innovation Into Better Lives** *Professor Franz Schaefer, Founder of the European Reference Network for Rare Kidney Diseases (ERKNet), University Hospital Heidelberg and* *Marianne Silkjær Nielsen, Founder and Chair, CompCure*
14:00	**Mental Health and Support Systems** *Impulses and Facilitation by* *Dirk Bethe, Psychologist, University Hospital Heidelberg and* *Antonia King, Patient and Family Community Lead, CompCure*
14:45	Break
15:15	**Workshop: Practical Tips and Tricks for Everyday Life**
15:45	**Reflexions and Conclusion**

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16:30	Bus Transfer to Old Town Heidelberg
18:30	**Networking Dinner Wirtshaus am Markt Heidelberg,** Hauptstraße 190, 69117 Heidelberg Please register in advance before November, 14 through the registration form or write to ak@compcure.org

Sunday, 29 November

Arrival possible as of 8:30

9:00	**Welcome & Recap**
9:15	**Introduction to Our Partners and Sponsors**
9:45	**Family Planning** *Dr. Evelyn Seelow, Charité Berlin*
10:30	**Education and Employment: Challenges and How To Navigate Them** *Lindsey Fuller, Patient Advocate, Educator and* *Andre Heinz, Chief HR Officer*
11:15	**Workshop: What to Take Away**
11:45	**Closing Remarks: Connecting the Dots Towards Better Care** *Marianne Silkjær Nielsen, Founder and Chair, CompCure*
12:15	**Lunch & Goodbye**

Childcare will be offered for children aged 5 to 12.
On Saturday you can bring your child(ren) at 8:45; the program for children starts at 9:00 and ends at 16:15. On Sunday you can bring your child(ren) at 8:45; the program for children starts at 9:00 and ends at 12:15. If you need childcare and you have not already completed the registration form, please let us know (ak@compcure.org). There will be a separate program for teenagers, and more information will follow.

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