

Dear all,

Today is C3G and IC-MPGN day. Please help us make C3G and IC-MPGN seen, heard, and understood.

We hope you have enjoyed the summer holidays with your loved ones, and that this newsletter finds you well and in good health. We are happy to share with you some of the activities we have been involved in during the last four months.

REGISTRY & COHORT STUDY

Our registry continues to grow. It now includes more than 443 enrolled patients from 52 hospitals in 20 countries. We are very thankful for everyone who contributes. Our team continues to support centers, who are interested in joining the registry, with local legal, ethics, and documentation guidance to ease the process of joining. We are also working on strengthening the practical side of implementing the workflows in the registry, biobank and histopathology archive. That way, it will be easier for the centers to contribute to the registry once they are fully onboarded.

SCIENTIFIC CONFERENCES

ERA Congress in Glasgow, Scotland, 3-6 June

It was a great pleasure to attend the ERA Congress. Both CompCure's coordinating manager, Giulia Bassanese, and Marianne Silkjær Nielsen gave oral presentations at the congress. Marianne's presentation focused on the survey about the socioeconomic burden related to C3G and IC-MPGN.

She emphasized there is a strong need for further consideration when it comes to vocational, educational, income, and functional life-related difficulties, both public policy and in routine clinical care. We are grateful that so many of you participated in the survey.





PATIENT ADVOCACY BOARD

The Patient Advocacy Board, which ensures that the patient perspective is represented and heard in all the activities we are involved in, keeps expanding. This year, we were delighted to welcome five new patient advocates from five different countries. They are Julie Gibbs from England, Claudia Lóbo from Portugal, Zina van der Marel from Netherlands, Ane Merino from Spain, and Claudia Robustelli from Italy. All of them are either patients or caregivers. Over the last months, several members of our patient community have been involved in activities aimed at supporting reimbursement concerning new therapies. By joining forces, we can learn from each other, strengthen our individual voices, and back our efforts with more comprehensive knowledge and evidence. The preparation of the upcoming patient and family conference is intensifying, and we thank many of you for providing input on the agenda and core themes of the meeting.

PUBLIC POLICY

Cardiovascular-Kidney-Metabolic Policy Forum: Addressing the Disproportionate Impact of CKM Conditions on Women's Wellness

We are proud that CompCure's Patient and Family Community Lead, Antonia King, could join this year's Cardiovascular-Kidney-Metabolic Policy Forum during the World Health Assembly. Together with global experts she helped drawing attention to the important issue of women living with cardiovascular, kidney, and metabolic diseases that are being diagnosed too late which leads to delayed access to treatment.

Antonia participated in a panel discussion sharing her personal experience with the announced topics. She highlighted the importance of early diagnosis, screening and timely treatment in complement-mediated diseases.

She talked about the need for a holistic approach to cardiovascular-kidney-metabolic diseases and the impact on patients' wider health.

She also emphasized the disproportionate socioeconomic burden rare kidney diseases can place on women, affecting caregiving responsibilities, fertility, employment, mental health, and overall quality of life. Thank you to GloPAKH and partners for putting women's health on the agenda across borders and organ systems.

KIDNEY INTERNATIONAL PUBLICATIONS

Real-World Outcomes of Pegcetacoplan Treatment in C3G and IC-MPGN, 16 June

Many are wondering how the new and targeted therapies work in real life. Based on CompCure's registry data and input from the CompCure consortium of participating nephrologists, we could contribute to the discussions with a publication in Kidney International on the real-world use of pegcetacoplan in patients with C3G and IC-MPGN. The results showed that among 25 patients, researchers observed a rapid and sustained reduction in proteinuria, improved kidney function, and normalization of serum C3 levels in almost all patients. No serious adverse events during follow-up, and two patients with kidney failure experienced such significant improvements in kidney function that they were able to stop dialysis. A big thank you to everyone who contributed to this publication. Our collective knowledge and experience are critical to inform decisions on how to optimally manage the diseases. **You can read the publication by clicking on the text above.**

SEISMIC: A Multi-Stakeholder Summit Addressing Access Issues in Diagnosis and Treatment of C3G and IC-MPGN, 27 August

Conclusions from the SEISMIC summit, that took place in Iceland last year in July 2025, were also published in Kidney International.

It was a multi-stakeholder meeting that addressed the various access barriers in diagnosis and treatment of C3G and IC-MPGN, specifically in context of the new proximal complement-inhibitors, which have potential to improve the prognoses of both diseases. The recommendation from this group was to support early diagnosis and improved disease management through involvement of experts, early initiation of the new proximal complement inhibitors, and improved disease understanding.

We hosted the meeting together with NephCure and International Society of Glomerular Disease. A huge thanks to Carla Nester and Marina Vivarelli for leading the meeting, and to everyone who contributed with valuable input and support to people and families affected by C3G and IC-MPGN. **You can read the publication by clicking on the text above.**

Real-World Outcomes of Iptacopan in C3G and IC-MPGN, 3 September

A study recently published in Kidney International Reports presents real-world outcomes of iptacopan treatment in 28 patients with C3G or IC-MPGN, approximately two-thirds of whom would not have been eligible for previous clinical trials.

Proteinuria decreased by a mean of 56% at six months, kidney function remained stable overall, and no serious adverse events were reported during 293 treatment-months.

The findings suggest that iptacopan may represent a promising therapeutic approach for patients with C3G and primary IC-MPGN, including outside the controlled setting of a clinical trial. As the responses varied between patients, it also highlights the need to further understand the underlying disease mechanisms, and to develop biomarkers that can help guide more individualized care.

By bringing together experts in C3G and IC-MPGN across CompCure, ERKNet and international centres, this growing collaboration helps generate the knowledge needed to improve care for people living with these very rare diseases. We sincerely thank all participating patients, clinicians, and centres. **You can read the publication by clicking on the text above.**

FUTURE OUTLOOK



ESPN Annual Meeting in Bordeaux, France, 30 September - 3 October

We look forward to seeing many of you in France. Here we once again hope to connect, share knowledge, and learn from each other during the event.

Giulia Bassanese will give a presentation with the headline “Serum C3 Trajectories Are Associated with Disease Outcome in C3 Glomerulopathy (C3G) and Primary Immune Complex-Mediated Membranoproliferative Glomerulonephritis (IC-MPGN)”.

Patient & Family Conference, Heidelberg, Germany, 27-29 November

We are extremely grateful and pleased to announce that Anna Schubart, who led the development of iptacopan, and Pascal Deschatelets, who led the development of pegcetacoplan and co-founded Apellis, will join us at this event. This is a unique opportunity for our complement community to learn directly from two of the scientists who helped turn complement research into new and transformative treatment approaches.

The registration page is still open if you would like to join us for the Patient & Family Conference which we will co-host together with the German Self-Help Group for Rare Complement-Mediated Diseases and ERKNet. Here you can connect with other patients and families living with aHUS, C3G, and IC-MPGN, share experiences, support one another, and learn more about the diseases from experts.

Whether you have joined us before or are considering attending for the first time, you are very welcome. You can register through our website.

If you have limited opportunities we can support financially on travel and accommodation. Feel free to contact us at info@compcure.org if this is something you would like to explore. We would love for you to join us.

C3G & IC-MPGN Awareness Day, 25 September

Today we mark this special day to create awareness on C3G and IC-MPGN. This will be done on our social media channels - Facebook, Instagram, YouTube and LinkedIn. We encourage you to do the same to help raise awareness about these rare kidney diseases by resharing or creating your own content.