compcure

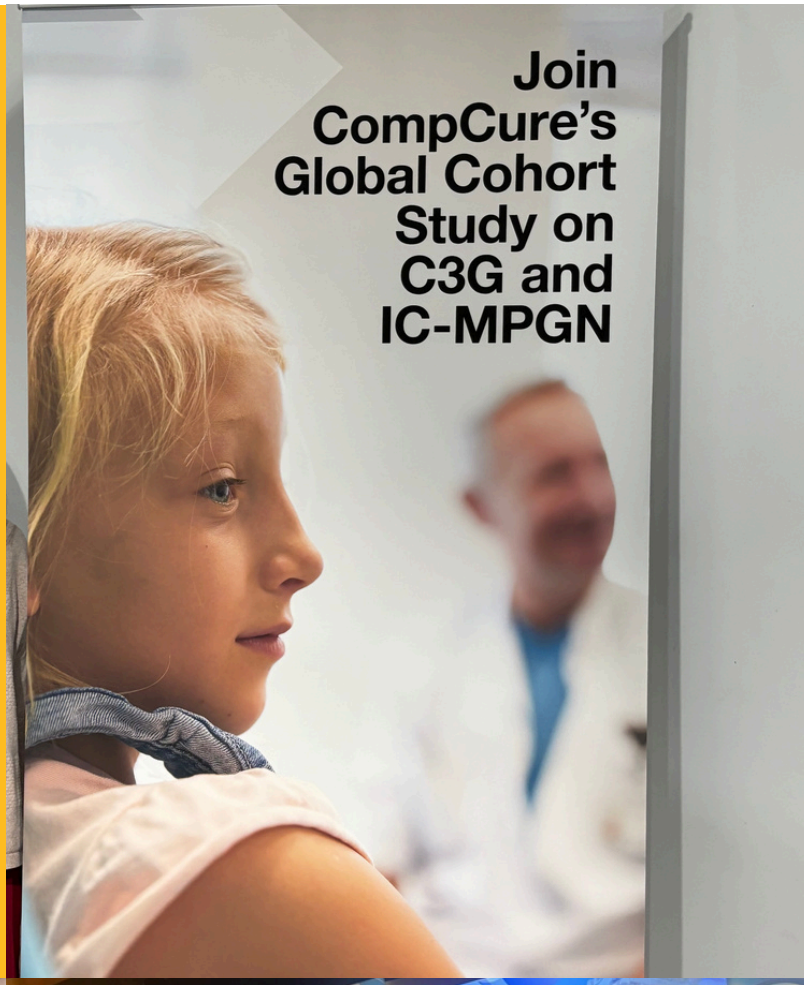
SEP - DEC 25 NEWS

Dear all,

As 2025 comes to an end, we would like to take a moment to express our deep gratitude for the progress we have seen across complement-mediated kidney diseases over the year. We would also like to thank you for the inspiring interactions and productive collaboration we have had with all of you. While we reflect on the progress over 2025, we will highlight some of the major initiatives we have worked on together over the last months.

REGISTRY & COHORT STUDY

The registry and cohort study continue to grow thanks to the collaboration we have with many of you. 350 patients from more than 20 countries have been enrolled. The knowledge and awareness we are generating together is invaluable, as it will inform decisions that will support people and families affected by C3G and IC-MPGN in leading healthy and fulfilling lives. In addition, we are proud that we can contribute to innovation and scientific progress, which is leading to a deeper understanding of complement-mediated diseases.



PRESENCE AT SCIENTIFIC CONGRESSES

In October Giulia Bassanese, CompCure's coordinating manager, attended ESPN in Athens, Greece, where she gave a powerful presentation of the results from the multinational real-world evidence study conducted as part of a collaborative initiative led by ERKNet. It used anonymized data from the CompCure registry. The study collected data from 52 patients with C3G and IC-MPGN treated with proximal complement inhibitors (Iptacopan or Pegcetacoplan) outside clinical trials. Despite presenting with severe disease and limited response to conventional therapies, most patients showed a rapid and marked reduction in proteinuria, normalization of serum C3, and stable kidney function. We are very excited about these results, and extremely grateful for both of these new and efficacious treatment options.
Earlier this year, and as previously communicated, we also had the great pleasure of presenting at four other major scientific congresses: the IPNA Congress in Cape Town, South Africa, the Chinese Spring meeting for Paediatric Nephrology in Shanghai, China, the ERKNet Meeting in Leuven, Belgium, and at the ERA Congress in Vienna, Austria. Furthermore, we had the opportunity to join the ASN Annual Meeting in Houston, USA.

PUBLIC POLICY

In September Marianne Silkjær Nielsen and Sebastian Myrup Hansen joined the Nordic Rare Disease Summit in Copenhagen, Denmark. Marianne Silkjær Nielsen presented at two breakout sessions, which focused on the need for health data and evidence to support research and development of new therapies, and to inform critical regulatory, clinical, and access-related decisions. In rare diseases such data is also rare. It is clear that the only path to quality health data and evidence is based on collaboration across functions and geographies on a Nordic, European and global level. Such collaboration poses several challenges, which were pointed out and discussed, also in the light of the detrimental consequences of not collaborating.

Throughout 2025 we have worked on several initiatives to ensure that C3G and IC-MPGN are represented and prioritized in public policy. In this context, it was an honour to start the year with a presentation at the Kidney Forum, which was organized by EKHA in the European Parliament. Furthermore, we are grateful for the opportunity to support ISN in achieving the significant milestone related to the adoption of the first-ever WHO global resolution on kidney health. It was a pleasure to participate in the panel discussions at the ISN-organized side meeting of the World Health Assembly, and to discuss the specific needs related to rare kidney diseases.

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AWARENESS

Awareness continues to be a core priority for us, as we believe it is essential to empower patients and to support early diagnosis, and timely access to optimal care.
We continue to communicate key updates, activities, and educational content across our digital platforms and we value the engagement from the medical community. In total we have reached more than 25 million people worldwide through social media, television and magazines. Your interaction — whether through sharing content, leaving a comment, or connecting with us at conferences — contributes to strengthening disease awareness and improving the care for patients living with C3G and IC-MPGN, and for this we thank you.

FAMILY WEEKEND

At the end of November, we co-hosted a Family Weekend in Heidelberg, Germany, together with the German Self-help Group for Rare Complement-mediated Diseases and ERKNet. The event brought together over 150 participants - including patients, caregivers, medical experts, and representatives from supporting pharmaceutical companies - from more than 16 countries.
It was a weekend defined by strong emotions, devotion and hope. We could learn from the way patients and families are managing their lives with the diseases, and it was relieving to experience that the challenges are similar, and that no one needs to face them alone. We are grateful to the experts who joined and shared their knowledge on how to navigate the management of these complex conditions. Scientific progress, new therapies, dedicated nephrologists, evidence-based decisions, and a strong international community are important keys to restore health and hope across the diseases.
We thank all the people who joined as well as the people who made this event possible - organizers, presenters, experts and our sponsors Sobi, Novartis, and Alexion. We already started planning the next meeting in 2026.

We are grateful for having all of you as part of our global complement community. A deep and heartfelt thank you for all our interactions in 2025. We are looking forward to continuing our journey towards better kidney health in 2026. We wish you and your loved ones a wonderful holiday season and all the best for the New Year.

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