

Dear all,

Looking back at the first four months of 2026, it has been a busy and exciting period, marked by a broad range of activities, which we hope you will enjoy reading about in this newsletter.

REGISTRY & COHORT STUDY

Our registry continues to evolve. It now includes more than 400 enrolled patients from 52 hospitals in 20 countries. This is a major accomplishment, and we would like to express our deep gratitude to everyone who contributes.

SCIENTIFIC CONFERENCES

[ESPN Research Conference in Florence, Italy from 12-15 March](#)

During this conference, data from CompCure's registry was presented. Current challenges in complement-based diagnostics were discussed, and potential associations between serum C3 trends, disease progression, and patient outcomes were explored.

[Die Deutsche Gesellschaft für Nephrologie \(DGfN\) in Weimar, Germany from 25-28 March](#)

We gave a plenary presentation about immune-mediated glomerulopathies, where we presented real-world data on the use of ipcatopan and pegcetacoplan in patients with C3G and IC-MPGN.



**57. Jahrestagung der
Gesellschaft für Pädiatrische
Nephrologie**

25. bis 28. März 2026
congress centrum weimarhalle

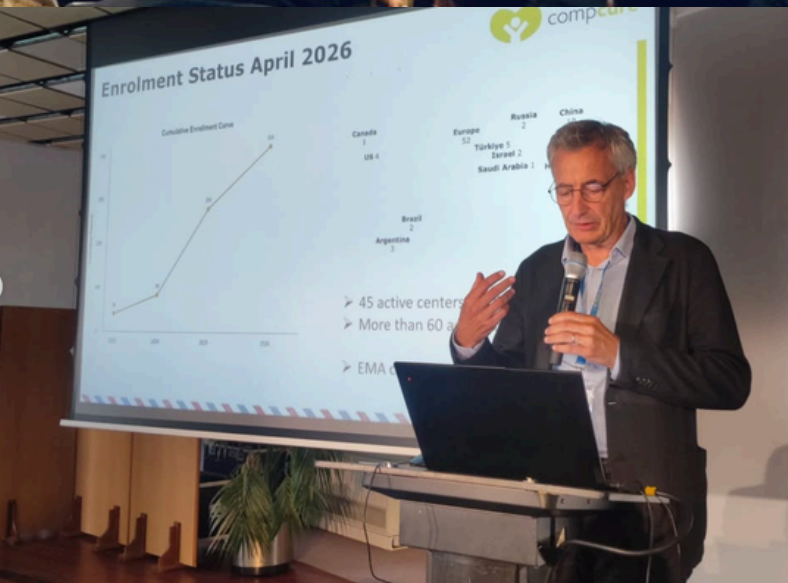


The data highlighted promising results, particularly in terms of proteinuria reduction, normalization of serum C3 levels, and stabilization of kidney function, supporting the growing role of proximal complement-targeted therapies in routine clinical care.

World Congress of Nephrology, WCN, Yokohama, Japan from 28-31 March
Marianne Silkjaer Nielsen gave a presentation about evidence generation. Furthermore, she met with leaders and representatives of Japanese patients-, nephrology- and public health organizations, with whom she discussed opportunities for collaboration.

ERKNet Meeting in Lyon, France from 4-6 May

An update on CompCure's scientific activities was provided, with emphasis on the registry and cohort study.



AWARENESS, INPUT TO GUIDELINES AND CLINICAL PRACTICE

Raising awareness about C3G and IC-MPGN continues to be a major priority. It is encouraging to see how the interest, understanding and attention to complement-mediated kidney diseases are evolving.

Webinar on Complement Targeted Therapy, 18 March

Dagens Medicin in Denmark, Norway, and Sweden hosted a webinar on “Complement Targeted Therapy”, which was sponsored by Sobi and CompCure. Fadi Fakhouri took a deep dive into the clinical study data of pegcetacoplan and iptacopan, and Marianne Silkjaer Nielsen presented a multi-disciplinary approach to evidence generation.



BONNIER HEALTHCARE EVENT **Dagens Medicin**

Welcome to our Nordic webinar on **Complement Targeted Therapy**

Meet the experts, and participate in Q/A session

Fadi Fakhouri, Anette Bruchfeld, Marianne Silkjaer Nielsen, Stefan Jacobsson

March 18th, 2026
LIVE from 15:30-17:00 CET

Sign-up for free

Sponsors: **Sobi** **compCure**

Learn more about the VALIANT phase 3 study from keynote speaker Professor Fadi Fakhouri from Lausanne University Hospital, Switzerland.



KDIGO Controversies Conference on Complement-Mediated Kidney Diseases in Rome, Italy from 16-19 April

This conference was organized to prepare for updates to the existing guidelines.

Our patient community was represented competently and strongly by Hyo Jin Heinz and Lindsey Fuller.

Furthermore, Giulia Bassanese joined the meeting, where she, amongst others, supported evidence-based discussions based on CompCure's registry.

The strong collaboration among all participants is very encouraging, and we look forward to the publication of the official recommendations later this year.

PATIENT SUPPORT & EDUCATION

Many patients and families are asking for information about C3G and IC-MPGN, and for guidance on how to manage the diseases and the associated challenges.

Based on all these requests, we developed a booklet. In addition, to supporting patients, we hope it can also support clinicians in their efforts to inform and educate patients and families living with C3G or IC-MPGN.

The booklet is written by patients and caregivers, together with nephrologists and other experts in complement-mediated kidney diseases.

We are grateful that so many people contributed to the booklet, which has already been downloaded more than 300 times through our website.

The booklet in English is available on our website, free of charge.

We are in the process of getting it translated into other languages. We will keep you informed, when these versions are available.

Living with the Rare Kidney Diseases C3G and IC-MPGN

A Guide for Those Affected by Patients, Caregivers, Nephrologists, and Other Experts





In the coming months, representatives of CompCure will be at the ERA Congress in Glasgow, Scotland from 3-6 June, please join our focused oral presentations. We will also be attending the ESPN Annual Meeting in Bordeaux, France from 30 September to 3 October. We hope that we will be able to connect with many of you at these events.

SAVE THE DATE

PATIENT AND FAMILY WEEKEND

From 27–29 November we will co-host a Family Weekend in Heidelberg, Germany, together with the German Self-Help Group for Rare Complement-Mediated Diseases and ERKNet. You are welcome to extend the invitation to patients and families living with aHUS, C3G and IC-MPGN. You can find more information on our website about this event, as well as register.

aHUS, C3G and IC-MPGN

Patient & Family Weekend

27 - 29 November 2026

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