

Dear all,

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

The past four months have been busy and exciting with steady progress across several activities. In this newsletter, we are pleased to share key updates, highlights, and input from our growing community.

REGISTRY & COHORT STUDY

Our registry continues to grow. It now includes more than 443 patients from 52 hospitals in 20 countries. A huge accomplishment, for which we would like to express our deep gratitude to everyone who contributed.

Our teams are continuing to support interested centers through local legal, ethics, and documentation processes. We are also working on strengthening the practical implementation of the registry, biobank, and histopathology archive workflows, so that centers can participate more smoothly, once their local setup is completed.

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 focused oral presentations at the congress.

Giulia's presentation centered around the diagnostic gaps in C3G and IC-MPGN. She highlighted the needs for more standardized and comprehensive diagnostic approaches, to enable improved disease classification and better patient care. Marianne's presentation focused on a survey about the socioeconomic burden related to C3G and IC-MPGN from the perspective of patients and families.



63rd ERA CONGRESS

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Challenge Your Thinking





She emphasized that there is a strong need for further consideration of the vocational, educational, income, and functional life-related challenges associated with C3G and IC-MPGN, both from a public policy perspective, and in routine clinical care. We are grateful that so many patients participated in the survey.

The ESCAPE Network Meeting, Heidelberg, Germany, 11-12 June

We are proud to collaborate with the ESCAPE Network, which has supported CompCure since the beginning with guidance, expertise, and participation in our activities.

At the ESCAPE Network Meeting Giulia Bassanese provided an update on CompCure's registry.

PUBLIC POLICY

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

Antonia King, Patient and Family Community Lead at CompCure, participated at the side event of the World Health Assembly organized by GloPAKH, Mended Hearts Europe, the Partnership to Advance Cardiovascular Health and the International Atherosclerosis Society. As part of a panel discussion, Antonia shared her personal experiences and highlighted the importance of early diagnosis, screening, and timely treatment in complement-mediated diseases. She also emphasized the need for holistic approaches to care and drew attention to the disproportionate burden that rare kidney diseases can place on women, including the possible impact on caregiving responsibilities, fertility, employment, mental health, overall socio-economic status, and quality of life.



PUBLICATIONS IN KIDNEY INTERNATIONAL

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

The conditions for treating C3G and IC-MPGN are changing with the increasing availability of proximal complement-inhibitors. In collaboration with ERKNet and 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 research suggests that pegcetacoplan may represent a promising therapeutic approach for patients with C3G and primary IC-MPGN, including outside the controlled setting of a clinical trial. Key findings after six months of treatment included: 81% reduction in proteinuria; improvement or stabilization of kidney function, with an increase in eGFR of 12 ml/min/1.73 m²; two patients with kidney failure recovered sufficient kidney function to discontinue dialysis; and no serious adverse events reported during 222 cumulative patient-months of exposure.

Importantly, many of the patients had previously experienced limited or non-sustained responses to conventional therapies.

A huge thank you and congratulations to Giulia Bassanese, Marina Vivarelli, Franz Schaefer, the CompCure Consortium, all collaborating investigators, and centers for this important contribution. **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

The conclusions from the SEISMIC summit have also been published in Kidney International. The SEISMIC summit was a multi-stakeholder meeting addressing access barriers in diagnosis and treatment of C3G and IC-MPGN, specifically in context of the proximal complement-inhibitors that offer disease-modifying efficacy to patients. The meeting was hosted by NephCure, International Society of Glomerular Disease, and CompCure.

A huge thanks to Carla Nester and Marina Vivarelli for productively 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

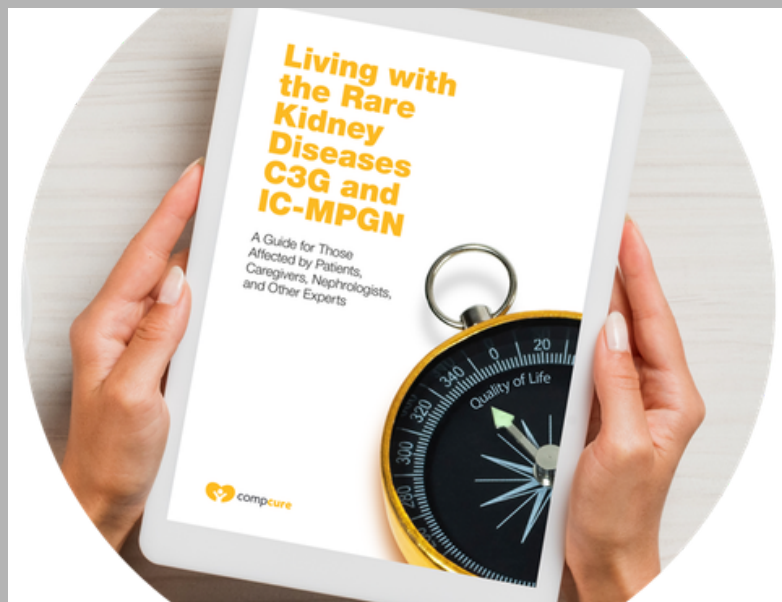
Recently this encouraging article was published on the real-world outcomes of iptacopan in 28 people living with C3G or IC-MPGN, some of which would not have been eligible for previous clinical trials.

The results show: 56% mean reduction in proteinuria at 6 months, stable kidney function during follow-up, normalized serum C3 in 74% of patients by month 3, and good toleration of iptacopan, with no serious adverse events reported during 293 treatment-months.

The responses varied between patients, highlighting the continued need to better understand who responds to treatment, and why, and to develop biomarkers that can help guide more individualized care. The study was made possible through international collaboration and data from ERKNet and CompCure. We sincerely thank all participating patients, clinicians, and centres. **You can read the publication by clicking on the text above.**

BOOKLET EDUCATING ABOUT C3G AND IC-MPGN

We are delighted that the booklet has been so well received by patients and families around the world, and we are deeply grateful to everyone who contributed. We are still in the process of getting it translated into other languages. For now, the booklet is available in English through our website - free of charge.



PATIENT ADVOCACY BOARD

The Patient Advocacy Board plays a central role in direct patient support, in strengthening, and coordinating efforts, e.g. in important hearings and initiatives to secure access to new medicine, and in ensuring that the patients and family perspectives are represented across our various activities. The board brings together patients and caregivers from 11 countries, and each member contributes with insights from their own lived experiences as patients or caregivers and from the communities they represent. It is a pleasure to welcome five new patient advocates who have joined the board since the beginning of the year. 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.

Over the past months, several members of our Patient Advocacy Board have provided valuable and coordinated input to support access and reimbursement related discussions across countries. It is important for us to recognize the tremendous amount of work done by so many people in our community to ensure that the new products become broadly available across countries to patients who need them.

FUTURE OUTLOOK



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

We look forward to attending the ESPN Annual Meeting, and we hope to see many of you there. 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.

The registration page is still open for patients and families who 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.

It is still possible to join for patients and families living with aHUS, C3G and IC-MPGN. More information is available on our website, as well as register.

C3G & IC-MPGN Awareness Day, 25 September

Today we mark this special day to create awareness on C3G and IC-MPGN.

To help raise awareness and strengthen understanding of these two rare kidney diseases, we have created a new film that has been shared across our social media channels on Facebook, Instagram, YouTube, and LinkedIn.

We hope you will join us in raising awareness of C3G and IC-MPGN, whether by sharing our content or creating your own. Together, we can help make these rare diseases better known, understood, and treated.