

Dear all,

2025 has almost come to an end and we would like to thank all of you for being part of our community, and for your participation in the many activities we have carried out together. It has been an incredible year for people and families living with C3G and IC-MPGN as new and transformative therapies are becoming available, and as our community is becoming stronger. As we look back on what we have achieved together, we are happy to share some of the highlights with you.

## REGISTRY & COHORT STUDY

The registry and cohort study keep expanding at a rapid pace. And we are beyond grateful for your contribution to CompCure's registry. At the moment we have enrolled 350 patients into our registry. This helps us on the important path to ensure early diagnosis and optimal treatment for patients affected by C3G and IC-MPGN. The knowledge our consolidated data brings to our community is of critical importance. It helps inform meaningful decisions, which can support patients and families in leading healthy lives while sustaining their kidney function as long as possible.



## NORDIC RARE DISEASE SUMMIT

In September Marianne Silkjær Nielsen and Sebastian Myrup Hansen joined the Nordic Rare Disease Summit in Copenhagen, Denmark. Here we had the opportunity to meet and learn from many other organisations and experts working with rare diseases outside the kidney field.



It was very inspiring to see how much passion and dedication there is to improving care and awareness across more than 7000 rare diseases — most of which still lack treatment options.

During the summit Marianne Silkjær Nielsen represented CompCure in two breakout sessions about the importance of Health Data and Access.

A highlight of the summit was the participation of Her Majesty Queen Mary of Denmark, patron of Rare Diseases Denmark, accompanied by the Danish Minister for the Interior and Health Sophie Løhde.

We are grateful to all participants for their dedication to improving outcomes for people living with rare diseases.



**Driving Patient Consensus Summit**



**Presentation at ESPN**

## **PUBLIC POLICY**

Awareness remains a key focus for us. Through the year we have discussed the importance of early diagnosis and optimal treatment for C3G and IC-MPGN in the European Parliament at the Kidney Forum, and at a side meeting of the World Health Assembly organized by ISN, the International Society of Nephrology. Furthermore, we have been present at five scientific congresses throughout the year - the IPNA Congress in Cape Town, South Africa, the ERKNet Meeting in Leuven, Belgium, the ERA Congress in Vienna, Austria, the ESPN congress in Athens, Greece, and at the ASN Annual Meeting in Houston, USA.



A significant milestone this year was the first-ever global kidney health resolution adopted by the World Health Organization. We were truly relieved and encouraged to see this important step forward, knowing it has the potential to improve the lives of hundreds of millions of people worldwide affected by kidney diseases.



**Kidney Forum in EU Parliament**

## AWARENESS

In the past months we have experienced the resilience and courage of the patients and caregivers who have shown an immense bravery by sharing their personal story of how it is to live with C3G and IC-MPGN. These stories have helped both our community and others understand what everyday life is really like for people living with these two rare kidney diseases. The videos of these patient and caregiver stories have been posted on our social media channels (Facebook, Instagram, LinkedIn and YouTube).

Raising awareness of complement-mediated kidney diseases continues to be one of our major focus areas. In this context, we are delighted to share that we have reached more than 25 million people worldwide through social media, television and magazines.

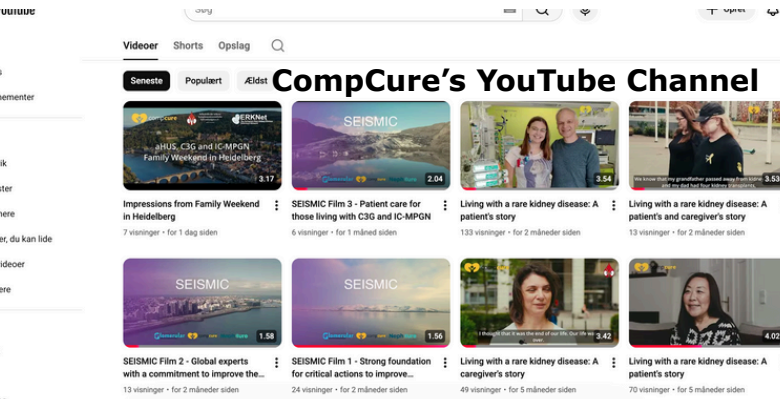
In addition, we keep sharing relevant stories and updates on our social media channels. We are very grateful for all the interactions, likes and re-sharing of our posts - your engagement helps us raise awareness and reach more people.



**Articles in The Parliament and "Nierenpatient"**

Europäische Patientenkonferenz in Brüssel

## Konsensuspapier zu chronischen und seltenen Nierenkrankheiten



**NIKEI, financial times of Japan**



**National Turkish TV**

BİRAZDAN

Tülin Sahin'le MODA





## **FAMILY WEEKEND**

At the end of November, we had the incredible pleasure of co-hosting the aHUS, C3G and IC-MPGN Family Weekend together with the German Self-help Group for Rare Complement-mediated Diseases and ERKNet in Heidelberg, Germany. It was a weekend defined by strong emotions, devotion and hope. We could learn from the way other patients and families are managing their lives with the diseases.

It was relieving to experience that the challenges are similar, and that we do not need 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.

And we are especially thankful to the more than 150 participants who joined us from over 16 different countries. In addition, we thank all the people who made this event possible - organizers, presenters 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 over 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.**

**Follow us on social media**

