



DEAR ALL

2024 has been a wonderful year for CompCure

GRATITUDE

We would like to express our deep gratitude to everyone who has contributed to better outcomes for people and families affected by a complement-mediated kidney disease.

During the year we have had several opportunities to connect with nephrologists, patients and families from all over the world. The interactions have been insightful, enjoyable and touching. They have allowed us to better understand how we can support continues scientific progress and improvements of the entire patient journey.



ERKNet

The European Rare Kidney Disease Reference Network



PROGRESS

The foundation of the impact and the progress we are experiencing with CompCure is established by Franz Schaefer and his wonderful team in Heidelberg. Here we would like to call out Giulia Bassanese and Joanna Sladowska-Kozlowska. Thanks to their strong commitment, we have managed to connect with centers from all over the world. We are grateful for the trust and participation from all the 26 hospitals and dedicated nephrologists who support us, and contribute to our registry, which currently counts 186 patients. We are in active dialogue with additional 90+ hospitals, and we will look forward to welcoming many of them and their patients in the new year.

PATIENT CONFERENCE

The close connection with patients and families is essential to us. It was a great pleasure to **co-host the aHUS, C3G and IC-MPGN patient conference in Berlin, Germany** together with the German self-help group for complement-mediated diseases.

Over 65 participants from across Europe and beyond joined and shared insightful perspectives, personal experiences, and care for each other and our evolving community. It was very heartwarming, and also inspiring for our activities at CompCure.





Antonia is already working successfully on connecting with patients and families from all over the world. We hope to meet many C3G, IC-MPGN and aHUS families in person during our next patient and family conference, which will take place in November 2025 (stay tuned – more information will follow shortly).

ORGANIZATION

Another highlight was the Steering Committee Meeting in Valencia, Spain.

It is reassuring to experience the level of united expertise, and the potential of productive collaboration during these meetings. We aligned on the strategy for the next three years. Here the global expansion plans, which we are already executing on, and a patient task force, which is currently being established, are just two exciting highlights. Along those lines, we are delighted that Antonia King could join CompCure on a part time basis as Patient and Family Community Lead.

AWARENESS

The general awareness of CompCure and the activities we are undertaking to improve outcomes in C3G and IC-MPGN have increased substantially over the year.

This is primarily through our strengthened online and social media presence, which is carefully curated by Sebastian Myrup Hansen with support from Bent Lomholt and others. Overall, we have reached more than **4 million people in 2024**. This is also based on our collaboration with other renal associations, and support from the Turkish model and Unicef ambassador, Tülin Sahin.



The outlook for 2025 looks promising for CompCure.

We will kick-off the year by hosting a Patient Consensus Meeting in Brussels, Belgium with attendance of patient representatives, nephrologists and public policy specialists.



Our aim is to develop a consensus statement, which can be broadly supported by individuals, patient- and HCP organizations with focus on kidney diseases. The consensus statement will include 3-5 specific asks to policy makers, which will also be presented at the Kidney Forum organized by EKHA on January 28th in the European Parliament.

By February the Nelia app will be launched with our support. Here patients will get access to a tool that can help them keeping track and manage their disease. Furthermore, the users will be able to contribute to a better understanding of how it is to live with the diseases by submitting patient-reported outcome.

Another exciting event on the early 2025 horizon is the **IPNA conference in Cape**

Town, South Africa. Here CompCure got an abstract approved. Furthermore, we will have opportunities to interact with the global community of pediatric nephrologists, e.g. at the **ERKReg booth**.

Last, but not least, we are grateful that our partnerships with Novartis and Sobi have been / are in the process of being extended. We thank both companies for their support to CompCure, and for all their efforts in developing approved therapies for C3G and IC-MPGN patients.

On behalf of the whole CompCure team, I wish everybody a wonderful holiday season, and all the best for a healthy, happy and fulfilling New Year.

Best wishes,
Marianne Silkjaer Nielsen

CompCure

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