

Dear all,

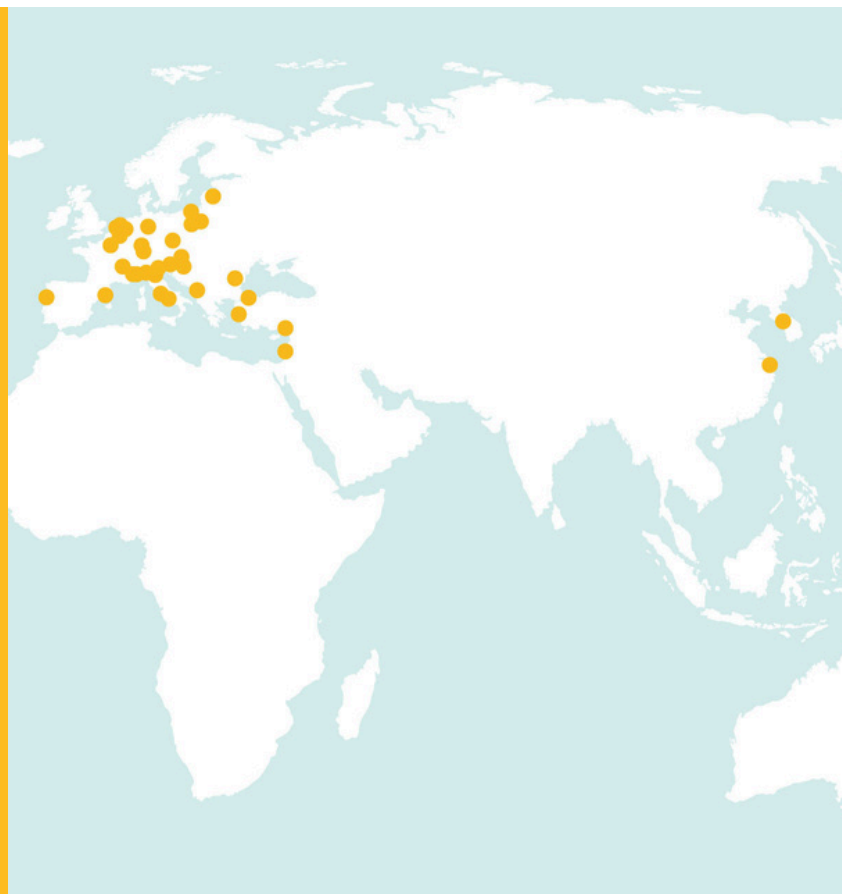
For people and families affected by C3G and IC-MPGN the first months of 2025 have provided new hope, new perspectives and new dreams for the future. We would like to extend our deep gratitude to those of you who have been, and are, involved in the development of the new therapies.

CompCure also had a strong start in 2025 which we are delighted to inform you about in this newsletter.

REGISTRY & COHORT STUDY

275 patients with C3G or IC-MPGN from 37 centers, in 19 countries have now been enrolled in the registry and cohort study. Moreover, we are working on welcoming several additional hospitals from all over the world in the coming months.

We remain fully focused and committed to building a leading global evidence base that will support improved disease understanding, clinical decision-making and better outcomes for patients all over the world. Hence, our multi-center registry and cohort study, positioned as a sub-registry of the ERKRegistry, continue to be core activities for CompCure.



C3肾小球疾病中国协作组

C3 Glomerulopathy Chinese Collaboration Group



LIVE IN CHINA

In April CompCure was officially launched in China. Thanks to a great collaboration with Prof. Hong Xu, Prof. Qian Shen and the skilled team at Children's Hospital of Fudan University we are now able to enroll Chinese patients into our registry and cohort study. The launch was marked by Prof. Franz Schaefer's participation in the Paediatric Nephrology Spring Meeting in Shanghai, China.



PATIENT CONSENSUS SUMMIT & KIDNEY FORUM

CompCure was honored to attend the Patient Consensus Summit and present at the Kidney Forum, organized by EKHA in the European Parliament in Brussels, Belgium in January. Both meetings convened patient representatives, international opinion leaders, and other important stakeholders. During the patient consensus summit five recommendations on how to improve kidney health were developed and subsequently presented by Marianne Silkjaer Nielsen at the Kidney Forum. The policymakers hosting the Kidney Forum agreed to work on the recommendations and allocating funds to early screening for kidney disease ([Read more here](#)). The meeting also generated a lot of media coverage especially through our various collaboration partners, incl. the Danish/Turkish supermodel Tülin Sahin. These collaborations helped us reach more than 20 million people around the world.

PRESENTATION AT IPNA

CompCure was present at the International Paediatric Nephrology Association (IPNA) Conference in Cape Town, South Africa from 19-23 February. PhD. MD. Joanna Śladowska-Kozłowska presented a scientific poster, and we got wonderful opportunities to connect with pediatric nephrologists from all over the world, e.g. through our presence at the ERKNet booth. We believe that these global events are crucial to advancing awareness and collaboration around our core activities.





PRESENTATION AT ESCAPE NETWORK MEETING

In late April, CompCure's coordinating manager, Giulia Bassanese, gave a presentation at the ESCAPE Network Meeting. The ESCAPE network is a consortium dedicated to improving the lives of children with kidney diseases through research. CompCure is profoundly grateful to be part of this international network of highly skilled and dedicated pediatric nephrologists, who are also strongly participating in the cohort study and registry.

FUTURE OUTLOOK



In the future we look forward to discussing and getting your perspectives on how we can further collaborate on improving kidney health at the upcoming conferences, ERA in Vienna, Austria and the ERKNet Meeting in Leuven, Belgium.

In connection with the World Health Assembly, the side event "Kidney Health Matters" will be hosted by Devex in partnership with ISN. This event explores the proposed WHO resolution on kidney health, and Marianne Silkjaer Nielsen will join the panel and discuss opportunities for improving outcomes across rare kidney diseases from a patient perspective ([Read more, and register here](#)).

At the ERA congress we will be hosting the next Steering Committee Meeting to discuss the next important steps for CompCure. In addition, Giulia Bassanese will be giving an oral presentation at the congress following the acceptance of our abstract.

During the summer we will be co-hosting a cross-stakeholder summit in Reykjavik, Iceland along with NephCure and International Society of Glomerular Disease. Here we will address access issues in diagnosis and treatment of C3G and IC-MPGN ([Read more here](#)).

In November, we are organizing an International and German Conference for people and families affected by aHUS, C3G and IC-MPGN in Heidelberg, Germany. This meeting will allow patients and caregivers to connect with each other and share disease experiences. We will also be joined by clinicians, psychologists, and dietitians.

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