

NEWS FROM TURKISH ASSOCIATION OF THE FIGHT AGAINST PNH AND aHUS DISEASES

Our first “**Patient-Specialist Meeting Camp**” was held and completed by our association between 15 th.-16 th. February 2025 at the meeting rooms of Istanbul University, Faculty of Medicine.

The meeting was held in a total of 6 sessions, two of which were parallel.

- In the PNH session, Prof. Dr. Mustafa N. Yenerel gave information about the symptoms of PNH disease, the pre-diagnosis stage, the diagnosis period and the treatment process to PNH patients. In the second part of the session, an interactive process was created and patients' questions about symptoms, diagnosis and treatment were answered.
- In parallel with the first session, a similar study was conducted by two nephrologists Prof. Dr. Alaattin Yıldız and Prof. Dr. Alev Yılmaz. Hus-aHUS patients were informed and their questions were answered. In the last part of the session, one-on-one evaluations were made for pediatric patients at the Information Desk conducted by Prof. Dr. Alev Yılmaz.
- In the afternoon session, information was given about the joint drug development studies for the both of the diseases PNH and aHUS diseases. Prof. Dr. Mustafa Yenerel conveyed important information about the clinical trials of new drugs carried out both within the body of Istanbul University Faculty of Medicine and in the world, and the effects and differences of these drugs.
- The other session, a seminar was given by Dr. Lecturer Irmak POLAT on the psychological-emotional problems experienced by patients and their families who have been exposed to any chronic or rare disease and the methods of coping with them.

- In the last session, Lawyer Berkay Özdemir gave information about the methods related to overcoming the legal problems experienced by the patient during access to the drug. In addition, an interview was held on the concepts and rights of the disabled and disabled.

As an association, all of our patient organization Members and our community were invited to the Meeting Camp.

Within the scope of the invitation;

- The participation of the patient and their relatives was provided free of charge.
- Patients and their relatives coming from outside the city were provided with free accommodation for one night.
- Coffee breaks and lunch were served as compliments all day long.
- All participants received the **book "Conversations with PNH/aHUS Expert"** as a gift.
- **"A Special Child, PNH" and "A Special Child, aHUS" books were presented** to our pediatric patients.
- Camera-photo footage was taken during the entire meeting and sessions were recorded for screening for patients who could not attend the meeting on our **Education Channel** in the future.



TURKISH ASSOCIATION OF THE FIGHT AGAINST PNH AND AHUS

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Our patient organization was invited to the National Pediatric Nephrology Conference in Antalya/ Turkey between 10th.-13th. April 2025 , and we had the chance of meeting with the leading pediatric nephrologists all over Turkey and shared information about aHUS CAB and aHUS Alliance Action , to raise awareness among Turkish professors.

Prof. Dr. Christoph Licht from University of Toronto was one of the invited speakers at the Conference who made a great speech about the functions of the kidney and kidney related diseases.



Our patient organization became the representative of C3G and IC-MPGN rare kidney diseases on behalf of Compcure Association Europe. We will be happy to represent C3G and IC-MPGN patients in Turkey.