

Title: Networking Event in Münster: Advances in Research on the rare Susac Syndrome

In mid-June, a groundbreaking networking event focused on the understanding, diagnosis and treatment of Susac Syndrome took place in Münster, Germany. The event brought together individuals affected by the syndrome, EURORDIS, clinical and basic research experts, as well as early career scientists, laying the foundation for new insights and progress in understanding this rare and underexplored condition.

Several European countries and EUSAC centers were involved in the organization of this important networking event, which was supported by the EJP-RD networking Support Scheme. Approximately 70 participants, including clinical experts, basic research experts, patients, and patient representatives, attended in-person or online, contributing to the expansion of knowledge about the Susac Syndrome and strengthening collaboration in this field.

Susac Syndrome is an immune-mediated disorder characterized by the occlusion of small arterial blood vessels in the brain, the retina, and inner ear. This leads to the development of a clinical triad consisting of encephalopathy, sensorineural hearing loss, and visual disturbances. The syndrome is often misdiagnosed as Multiple Sclerosis and consequently treated incorrectly.

The exact cause and origin of the Susac Syndrome have not yet been fully elucidated. Therefore, the exchange of information and collaboration among experts are of great importance. The networking event in Münster provided a platform for presentations, workshops, and the sharing of insights. Speakers covered a wide range of topics, including clinical features, patient care, and current research approaches. An important initiative was the establishment of the i-Susac network, aimed at facilitating closer collaboration among experts. Significant steps forward are the planned creation of a dedicated patient registry and a biobank, where blood and cerebrospinal fluid samples from Susac Syndrome patients will be collected and categorized according to specific criteria. This database will assist researchers in gaining a better understanding of the causes and disease processes of the Susac Syndrome, potentially leading to more effective therapies. The Neurology department of Münster University Hospital is already making an important contribution with its existing biobank. "We currently have stored samples from 80 patients with Susac Syndrome," explained Dr. Catharina Groß, the scientific laboratory manager who played a key role in organizing the event.

This networking event marks a significant milestone in the research and treatment of the Susac Syndrome. Through the exchange of knowledge and collaboration among experts, diagnostic accuracy will be improved, and innovative approaches to therapy development will be pursued. „I believe that this meeting really created a momentum and we will remain committed to grow the i-Susac network“, explained Dr. Barbara Willekens, neurologist and researcher from Antwerp, Belgium who co-organized the event. This dedicated network of medical professionals, individuals affected by the syndrome, and researchers will contribute to improving the lives of people with Susac Syndrome.