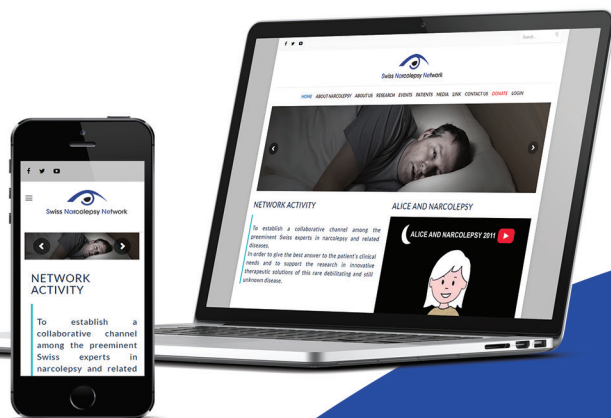


Website



Swiss Narcolepsy Network

Member of



Swiss Narcolepsy Network

Narcolepsy

Living with a rare disease
Information for patients
Relatives and interested parties

Contacts

Swiss Narcolepsy Network
c/o Villa Saroli
PO Box 5269
Viale Stefano Franscini 9
CH-6900 Lugano

+41 (0)79 259 62 69
info@snane.ch

www.snane.ch

Further information

Download the information brochure from
www.snane.ch

Self test: www.Swissnarcolepsyscale.ch



What is Narcolepsy?

Narcolepsy is characterized by excessive daytime sleepiness, including irresistible sleep attacks, overwhelming affected persons in the most inappropriate situations. Many patients also experience short episodes of sudden muscle weakness known as cataplexies, which are triggered by strong emotions, mostly laughter. About half of the patients report symptoms of paralysis (sleep paralysis) or dream-like perceptions (hypnagogic hallucinations) when falling asleep or waking up. Some narcolepsy patients also describe a fragmented night sleep and nightmares.

Narcolepsy is a neurological disease that affects brain centers controlling the regulation of sleep and wakefulness. The cause is thought to be an autoimmune process that leads to the destruction of the hypocretin-forming brain cells in the hypothalamus.

Current studies indicate that only persons with a genetic predisposition (HLA-DQB1*06:02) exposed to an environmental trigger, such as infectious diseases or vaccinations, are at risk of developing narcolepsy.

Narcolepsy can occur at any age, but young adults are most frequently affected. The symptom severity can vary considerably. Cataplexies may develop weeks or years after the onset of excessive daytime sleepiness. In children, the disease is commonly associated with remarkably long nocturnal sleep or as re-occurrence of previously resumed daytime napping; irritability and motor restlessness mimicking ADHD are important clinical features at that age; cataplectic attacks can appear as paroxysmal ptosis, mouth opening and tongue protrusion. The diagnosis, especially the early detection of the disease, is therefore not always easy. Once the disease has onset, it persists for a lifetime. Medication helps to relieve the symptoms, but a cure is still not available.

The Swiss Narcolepsy Network

Swiss Narcolepsy Network (SNaNe)

The Swiss Narcolepsy Network (SNaNe) was founded in Bern on January 20th 2017 by leading Swiss experts in the field of narcolepsy.

The committee includes:

- Prof. Dr. med. Claudio Bassetti, Bern, President
- Prof. Dr. med. Mehdi Tafti, Lausanne, Vice-President
- Dr. med. Fabrizio Barazzoni, Lugano, Treasurer,
- Prof. Dr. med. Ramin Khatami, Barmelweid
- PD. Dr. med Alexander Datta, Basel
- Dr. med Silvia Miano, Lugano
- Prof. Dr. med. Johannes Mathis, Bern
- PD Dr. med. Philipp Valko, Zürich
- Dr. med. Sigrid von Manitius, St. Gallen

SNaNe Mission Statement

SNaNe's mission is to build stronger co-operation among leading Swiss experts in the field of narcolepsy, with the aim of providing the best possible diagnosis and treatment for affected patients. In particular, SNaNe supports research into innovative therapeutic solutions.

Activities of the SNaNe:

- Promotion of cooperation between specialists from different disciplines
- Coordination of local networks and referring physicians
- Psychosocial services to support patients and their families (patient information)
- Quality Assurance
- Education (knowledge transfer for professionals and the population)
- Bridge to international organizations such as the European Narcolepsy Network (EU-NN)
- Providing support to patients and relatives in their interactions with representatives of the healthcare system

