

# March 18: 1<sup>st</sup> European Narcolepsy Day

Sleep experts in 25 European countries will ask local and national media to pay special attention to Narcolepsy on March 18.

The 1<sup>st</sup> European Narcolepsy Day is an initiative of the European Narcolepsy Network and is formally supported by the European Sleep Research Society. The European Network will add lustre to this day with the release of a small *art book* as well as a *cartoon* on narcolepsy. Additional information about narcolepsy and the Network can be found below and local experts will be happy to provide supplementary information.

Narcolepsy is characterized by excessive daytime sleepiness, attacks of muscle weakness induced by emotions, and a disturbed nocturnal sleep. It is a devastating disorder that usually starts during adolescents. Its early diagnosis and treatment can prevent detrimental psychosocial consequences for the individual patient and their families. This is the main reason to ask attention for the disorder on the European Narcolepsy Day.

Excessive daytime sleepiness has been recognized as a major hazard to public health. It has a profound impact on quality of life, causes impairment of sustained attention hampering school achievements and bearing an increased risk for road and work accidents.

The European Narcolepsy Network (EU-NN), founded in 2008, consists of a group of European clinical and scientific experts in the field of narcolepsy. The objectives of the EU-NN are the promotion of European scientific research of narcolepsy and its borderland, and the optimization of medical care in this field in the broadest sense.

Narcolepsy is a rare (5 : 10.000 inhabitants) but important disorder from a scientific as well as clinical point of view. The discovery that it is caused by a selective loss of hypocretin-producing cells has shed a complete new light on physiological sleep regulation. It also opened new research avenues concerning interactions between sleep, metabolism, endocrine function and the autonomic nervous system.

Europe, and the individual European centres, can only achieve a leading position in this field through close collaboration. Experts, clinicians as well as basic researchers, are spread all over Europe. On their own they see too few patients or may have too limited facilities to perform research with significant impact. Adequate patient numbers, and application of cutting-edge techniques, can only be realized through collaboration.

The EU-NN provides the opportunity to solve these issues and facilitates 'cross fertilisation' and synergistic collaboration. The core tools are the available database and biosample bank. Guidelines for the entry of data guarantee its standardisation and quality, and its modular structure enables the collection of prospective data. The database will also be formally launched on March 18.

A first result of the European collaboration is the recent paper in the *Journal of Clinical Investigation*: Cvetkovic-Lopes V, Bayer L, Dorsaz S, Maret S, Pradervand S, Dauvilliers Y, Lecendreux M, Lammers GJ, Donjacour CE, Du Pasquier RA, Pfister C, Petit B, Hor H, Mühlethaler M, Tafti M. Elevated Tribbles homolog 2-specific antibody levels in narcolepsy patients. *J Clin Invest.* 2010 Mar 1;120(3):713-9. This is the first study identifying reactive autoantibodies in human narcolepsy.

**The current EU-NN board members are:**

Dr. Gert Jan Lammers, president; Prof. Claudio Bassetti, vice president;  
Prof. Geert Mayer, secretary; Dr. Ramin Khatami, treasurer;  
Prof. Yves Dauvilliers; Prof. Mehdi Tafti; Prof. Thomas Pollmächer

On behalf of the board,  
Gert Jan Lammers, president