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## Editorial

# Narcolepsy – Between the dream and reality



“One day I dreamt that I was awake and when I awoke I was sleeping – this phrase might seem funny, but not for those who suffer from Narcolepsy. How many times I thought I was living a real scene and when I woke up I found out that everything was just another dream. Dream, fantasy, things of my mind, like some people used to say, I did not know for sure what was happening: just knew that it was something new, strange and with no apparent explanation. Suddenly, an uncontrollable sleep and there I was, sleeping anywhere, independently of the moment or the situation. Laziness, tiredness, stress, I could not really explain the reason”

This text was written by Antônio Geraldo, a patient with narcolepsy/cataplexy, hospitalized for fractures in both ankles after falling from a stair with 5 meters high due to excessive sleepiness.

We have evolved a lot in terms of knowledge about narcolepsy. We already know the strong correlation between genetics (presence of the allele HLA-DQB1\*0602) and ambient factors (viral infections and vaccinations), resulting in a mechanism of autoimmunity [1–3]. There is also a major knowledge of the illness's physiopathology with the discovery of hypocretin and its connections with the Central Nervous System from the lateral hypothalamus [4,5]. We have evolved also in the pharmacological treatment with the development of new drugs for the control of the excessive diurnal sleepiness and of cataplexy [6,7]. However, the average time for the diagnosis is still above 10 years in men and may be higher than 20 years in women, depending on the country of origin [8].

The main factors responsible for this delay in diagnosis and the beginning of treatment of these patients are the lack of information and basic knowledge among the general population, the failure in recognizing the signs and symptoms by the health professionals, besides the lack of Specialized Centers for the diagnosis and treatment of narcolepsy [9]. This delay in diagnosing takes most of these patients to a life of hopelessness, prejudice and irreparable losses in education and character development [10]. After diagnosis, what we do is treat these patients with medications that improve their sleepiness and the cataplexy. The treatment is still purely symptomatic [6]. We do not modify the high

prevalence of depression, neither, the progressive weight gain which normally might lead to other complications during the disease's evolution.

In this particular sense, some authors describe a higher mortality rate among the narcoleptic population, although the main causes are still undetermined [11]. A doctorate thesis in our department has demonstrated that the aerobic performance of these patients with narcolepsy was worse than the performance found in patients with sleep obstructive apnea. This has led us to imagine a possible alteration in the metabolism of these patients with probable impairment of their quality of life. These data open several new scientific horizons to be researched, but also bring much more responsibility upon diagnosis and treatment of this disease.

Paraphrasing our patient, Antônio Geraldo: “Laziness, tiredness, stress, I could not even explain”. Interestingly, we also cannot explain!

This special text about narcolepsy brings to the reader a very interesting panorama about narcolepsy. We have relevant scientific knowledge, experience with dedicated groups for the treatment and study of patients with narcolepsy, besides several interesting clinical and mysterious cases. We want to invite everyone to read, learn, spread and try to explain

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*Guest Editor*

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