

# **The Swedish Experience - Quality of Life in Patients with Restless Legs Syndrome: Enquiry in Sweden During 2006 Among Members of the Swedish RLS Association (RLS Förbundet)**

Sten Sevborn,<sup>1</sup> Angelika Alsfasser,<sup>2</sup> Jan Ulfberg<sup>3</sup>

<sup>1</sup> Swedish RLS Association

<sup>2</sup> Restless Legs e. Vereinigung, Rheinlandpfalz, Germany

<sup>3</sup> Uppsala University, Sleep Disorder Centre, Avesta Hospital, Sweden, Inland Hospital/division Tynset, Norway.

During 2006/2007 we performed a postal enquiry among the members of the Swedish Restless Legs Syndrome (RLS) Association to show their quality of life. The questionnaire, which contained more than 300 questions, was sent by regular mail to all members in 2006 to be returned in a prepaid envelope to Mr. Sevborn. Of 1.000 members 805 returned the questionnaire. The study was completed during 2007.

The results of this study provide an insight into the problems with which RLS patients have to live, but they also show to what extent life can be improved once the disorder is diagnosed and treated.

The age of respondents was between 20 and 96 years, and the age of RLS onset between 1 and 93 years, the majority of respondents were women (71%). A total of 84% of RLS sufferers reported bilateral symptoms and a majority reported being affected by symptoms in more than one part of the body; 54% reported problems in the lower parts of the legs, 21% in the thighs, 18% in the arms and 7% in the trunk. RLS sufferers noted the severity of symptoms on a scale of 0 to 10 in the morning, afternoon, evening and night, where 0 represented no symptoms and 10 very severe symptoms. Over 300 responders indicated that they had very severe symptoms. Treatment with dopaminergics was reported to be effective: the mean values of severity dropped to one third of the value before treatment initiation.

Seventy-one responders had been or were still on the sick list due to their RLS; the length of time on sick leave varied from 1 to 156 months. A total of 30 patients received a sickness allowance due to their RLS.

The length of time RLS sufferers waited to receive a diagnosis varied between 0 and 70 years, and the number of visits to a doctor prior to diagnosis varied between 1 and 20. Forty-nine percent (49%) of respondents stated that they were well treated by their doctor compared to 23% who complained that they were badly treated. A positive RLS diagnosis was made by the primary care doctor in 52% of cases, by a neurologist in 20% of cases and by another type of doctor in 27% of cases.

The pharmaceuticals used for the treatment of RLS were divided into the following groups: dopamine agonists, dopamine precursors, opioids, antiepileptics, and others. The treatment most used for RLS symptoms, at all times of the day, were dopamine agonists, followed by dopamine precursors. A total of 494 of 805 respondents reported taking medication for diseases other than RLS. The intake pattern of these medications varied strongly over the day. Antidepressants ranged 7th. Citalopram, tryptizol and sertralin were the most used substances. With regard to improving sleep, 32% used hypnotics more or less regularly, with zolpidem or zopiklon being used by the majority. Only 36% believed that the hypnotics worked well, therefore, 64% were not satisfied with hypnotics. Alcohol, spirit, wine and beer were reported to have more deteriorating than improving effects on the RLS symptoms. For nicotine there was no significant difference between the numbers of respondents who noted deterioration and those who noted an improvement. With regard to blood donation, 138 respondents were previously active blood donors, and 10 respondents reported to continue to give blood regularly. Iron supplementation was not taken as recommended.