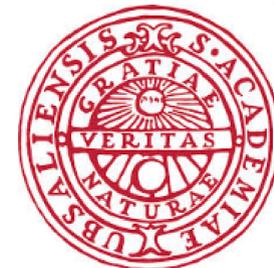


# The National Swedish Register on Narcolepsy, a part of the

## National Swedish Register of Neurology

Attila Szakács<sup>1</sup>. Tove Hallböök<sup>2</sup>.

Anne-Marie Landtblom<sup>3</sup>



1: Department of Children, County Hospital, Halmstad, Sweden 2: Department of Neuropediatrics, Queen Silvia Children's Hospital, Sweden; 3: Department of Neuroscience/Neurology, Uppsala University, Sweden

### Background

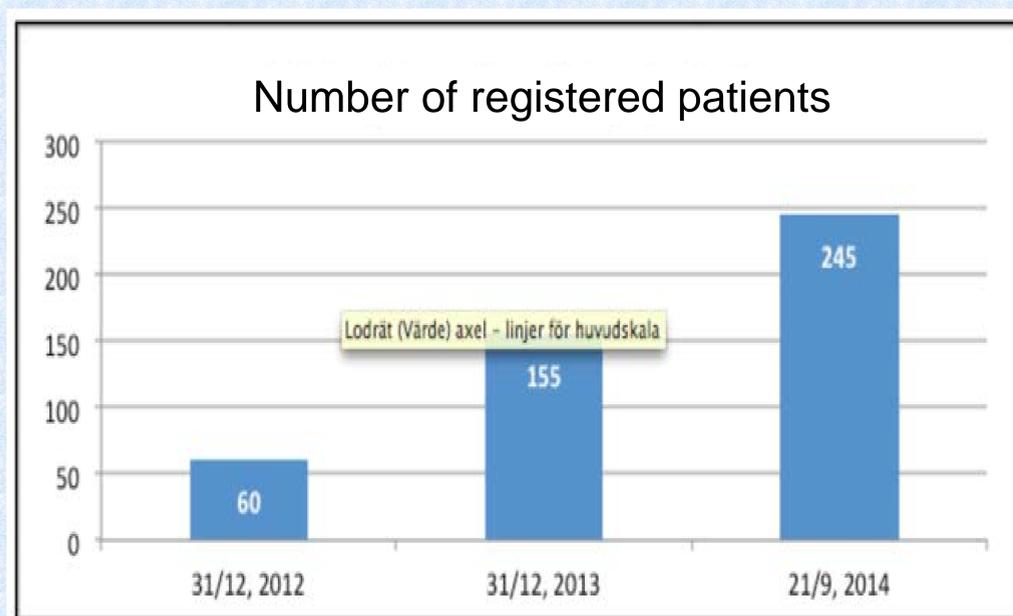
During the vaccination campaign with Pandemrix against H1N1-influenza in October 2009 about 60% of the Swedish population were vaccinated. Adults and children from 13 years of age were vaccinated with one single dose and children below 13 years of age with two doses. From August 2010 an increasing number of children and young adults were reported with Narcolepsy and a connection with the vaccination was suspected.

### Aims

The Swedish Narcolepsy Registry was initiated by the Swedish Food and Drug association and facilitates monitoring of outcome and sideeffects, especially of the drugs with limited documentation for Narcolepsy. It also facilitates followup over time with diagnosis-specific instruments.

### Preliminary results

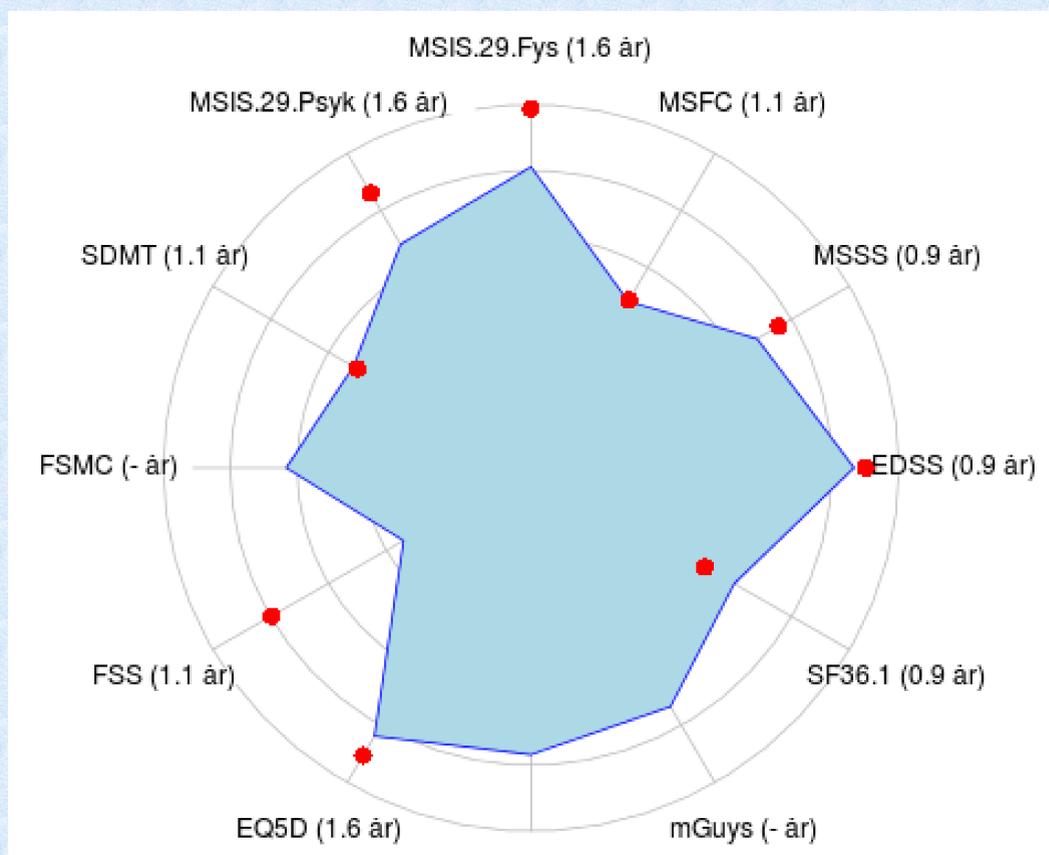
To date, 245 patients are registered at 28 units by 63 register users. This is a significant increase from 140 patients at 22 units at the previous reporting August 2013. The number of registered patients with Pandemrix related narcolepsy is 58. Within the registry, there are 50 registered patients treated with sodium oxybate (Xyrem). The true number in the country is about 90 suggesting a 50% coverage.



Medicines	No. of patients
Methylphenidate	100
Modafinil	60
Sodium oxybate	50
Amphetamine	23
Clomipramine	19
Sertraline	10
Athomoxetine	6
Citalopram	5
Venlafaxine	1
Immune globuline	1
Other	24
<b>Total</b>	<b>299</b>

### Future plans

In the future we hope to connect new users to the registry and support long-term inclusion of all patients with Narcolepsy (prevalence in Sweden is about 4500 patients). The development of PROM (patient reported outcome measures) and a VAP (Visualization and Analysis Platform) could together with training of specialized nurses improved handover between child and adult care and provide a better patient safety and satisfaction.



Functional Clock illustrated with a spider diagram in the Visualization and Analysis Platform (VAP).