



## Newsletter

### Dutch ALS congress

On Friday October 8th 2010 a Dutch ALS congress will be held in De Reehorst in Ede. The title of the congress is: "AL(le)S uit de kast"  
The congress is initiated by the ALS Centre Netherlands together with the Dr G.J. van Hoytema Stichting. The congress is for all people professionally involved in the care of ALS patients. [Read more](#)

### Krista Kuitwaard wins PJ Dyck award



During the congress of the Peripheral Nerve Society in Sydney, Krista Kuitwaard, resident in Neurology at ErasmusMC in Rotterdam, was awarded the Peter James Dyck prize. This award is named to one of the most important researchers in peripheral nerve disorders and is awarded yearly to a young and promising researcher in the field of peripheral neuropathies. [Read more](#)

### Zon-Mw projects: n-of-one trials



ZonMW has awarded two research grants for n-of-one trial related projects. The first project of dr. S. Weinreich (VU Medical Centre), will start the development of an 'n of 1' trial service, integrated in the Dutch health care (assessment) system. The aim is to promote equitable pharmaceutical care for patients with rare diseases and to generate evidence on the efficacy of promising, off-label drugs. The second project of dr. G. Drost and prof. dr. G.J. van der Wilt (St Radboud UMC), examines the use of informative priors in the hierarchical Bayesian model. Aggregation of a number of N-of-1 trials using a Bayesian approach is useful to estimate treatment effectiveness for a group of patients. Herewith, they aim to build a robust evidence base for (off-label) drugs in rare diseases, so that coverage decisions can be made. [Read more](#)

### Agenda

#### September

12 American Neurological Association Meeting (ANA)

25 European Federation of Neurological Sciences Congress (EFNS)

#### October

08 Dutch ALS congress

12 World Muscle Society Congress (WMS)

#### November

10 Meeting Belgian Dutch neuromuscular studyclub

#### January

14 ISNO symposium neuromuscular disorders

### Deadline Prinses Beatrix Fonds Year award 2010

Deadline for submission of a paper for the Prinses Beatrix Fonds Year award is October 15<sup>th</sup> 2010. For more information on submission of a paper: [Read more](#).



### Jan 14th 2011: ISNO symposium neuromuscular disorders

On Friday January 14th 2011, the yearly ISNO neuromuscular disorders meeting will take place in Amsterdam. For program information and registration, check the website of [Boerhaave](#).

### New trials

[click here for all trials](#)

Disorder	Treatment	Centre	Start date
CIDP	Dose-finding study IVIg in CIDP	ErasmusMC	01/01/2010
GBS	Multicenter trial: 2nd IVIg treatment in GBS	ErasmusMC	01/01/2010
Duchenne	RCT: Idefenone	LUMC	01/02/2010
SMA	Genetic and clinical markers in SMA	UMCU	01/03/2010
Kennedy disease	Genetic and clinical markers in Kennedy disease	UMCU	01/03/2010
MMN	Comparison intravenous vs. subcutaneous IVIg	UMCU	01/04/2010
Duchenne	Phase I/IIa: exon skipping PRO044	LUMC	01/08/2010