



Newsletter

Treatment for postpolio syndrome

Recently a Cochrane review was published on the treatment of the postpolio syndrome (PPS). PPS is a condition that can affect polio survivors years after recovery from an initial paralytic attack by the polio virus. PPS is characterised by progressive or new muscle weakness or decreased muscle endurance in muscles that were previously affected by the polio infection and in muscles that seemingly were unaffected, generalised fatigue and pain. These symptoms often lead to a decline in physical functioning. A group of Norwegian and Dutch neurologists and rehabilitation physicians, including prof. dr. Marianne de Visser and prof. dr. Frans Nollet put all the information together. [Read more](#)

Rare Disease Day May 15th 2011

On May 15th 2011 the fourth Rare Disease Day will be held in Artis, Amsterdam for all people with a rare disease and those who encounter it on a daily basis. The purpose of Rare Disease Day is to raise awareness for all people in the Netherlands that have a rare disease. On this day, hundreds of children and adults with rare diseases come together to talk about their specific problems. Children and adults have the opportunity to meet each other, to enjoy a day out, and to be inspired to take action themselves. [Read more](#)

European Union Committee of Experts on Rare Diseases (EUCERD)

The European Union Committee of Experts on Rare Diseases (EUCERD) is charged with aiding the European Commission with the preparation and implementation of Community activities in the field of rare diseases, in cooperation and consultation with the specialised bodies in Member States, the relevant European authorities in the fields of research and public health action and other relevant stakeholders acting in the field. The EUCERD will foster exchanges of relevant experience, policies and practices between these parties. Two members in this committee represent rare neuromuscular disorders: prof. dr. M. de Baets (Maastricht) and prof. dr. K. Bushby (Newcastle). [Read more](#)

Agenda

May

- 28 European Neurological Society meeting
- 28 European Society of Human Genetics Conference

June

- 25 Peripheral Nerve Society Biennial Meeting

August

- 31 European Conference on Post Polio Syndrome

September

- 10 European Federation of Neurological Sciences Congress (EFNS)
- 25 American Neurological Association Meeting (ANA)

October

- 11 International congress of Human Genetics
- 18 World Muscle Society Congress (WMS)

Jan 13th 2012: ISNO symposium neuromuscular disorders

On Friday January 13th 2012, the yearly ISNO neuromuscular disorders meeting will take place in Amsterdam. Save this date in your agenda. The program will soon be available on the [ISNO website](#).

New trials

[click here for all trials](#)

Disorder	Treatment	Centre	Start date
Becker	Epidemiology and natural course	LUMC	01/11/2010
CIDP	IVIg dose finding study	ErasmusMC	01/01/2011
SMA	RCT: olesoxime (TRO19622) or placebo	UMCU	01/01/2011
Duchenne	DbI blind plac. contr. dose comp. study: exon skipping PRO051	UMCN	01/01/2011
Duchenne	Phase I/IIa: exon skipping PRO044	LUMC	01/04/2011