

Inflammatory Neuropathy Consortium Constitution

1. Introduction

Neurologists, other experts and patient representatives from Europe and the USA (<http://www.enmc.org/workshop/?id=72&mid=54>) met under the auspices of the European Neuromuscular Centre on 13 to 15 April 2007 in Hoofddorp the Netherlands to consider the management of inflammatory and immune-mediated neuropathy, including Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyradiculoneuropathy (CIDP), multifocal motor neuropathy (MMN), paraprotein associated neuropathy and related disorders. The meeting recognised the need for:

- better education of health care professionals to enable earlier diagnosis and treatment,
- more research into the pathogenesis of the inflammatory neuropathies,
- more trials of treatment for all forms of inflammatory neuropathy,
- more trials in children with inflammatory neuropathies,
- improved outcome measures,
- treatments for symptoms of particular concern to patients, such as fatigue and pain, and
- a strategy for prioritising and undertaking trials of candidate treatments efficiently.

To meet these needs, the meeting launched the **Inflammatory Neuropathy Consortium (INC)**.

2. Mission

To improve the care and treatment of patients with inflammatory and immune-mediated neuropathies.

3. Trial evidence

The INC will maintain an up to date account of the current trial evidence and support the Cochrane Collaboration in maintaining up-to-date systematic reviews of randomised trials. It will maintain a register of relevant ongoing and planned trials.

4. Patient register

The INC will establish and maintain registries of patients with certain uncommon but defined inflammatory neuropathies including their treatments. The initial register will be of MMN and will be retrospective. Prospective registries are planned.

5. Prioritisation of trials

The INC will prioritise interventions for future trials and attempt to facilitate development of prioritised trials.

6. Communication

The INC will

- 6.1 seek status as an ad hoc committee of the Peripheral Nerve Society (appendix 1),
- 6.2 hold meetings open to members of the Peripheral Nerve Society,
- 6.3 set up a page on the Peripheral Nerve Society web site,
- 6.4 seek publication of its recommendations in the Journal of the Peripheral Nervous System, and
- 6.5 provide updates of its activities in the newsletters of the GBS-CIDP Foundation International and other related groups.

7. Liaison

The INC will liaise with interested pharmaceutical companies to achieve its mission. It will work closely with the GBS-CIDP Foundation International and other relevant patient organizations to ensure the relevance of its work to the needs of people with inflammatory and immune-mediated neuropathy.

8. Funding

The INC may apply to the PNS and other organizations for funds to support its activities.

9. Meetings

The INC will meet at the biennial PNS meeting as a minimum and may meet at other times as members desire. Notices of the INC meetings will be posted on the PNS website.

10. Organising Committee

The activities of the INC will be managed by a committee consisting of a chair, one or two vice-chairs, a secretary and ordinary members (see Appendix 2 for a list of the members who have agreed to serve on the committee). Members of the Committee will be appointed by the PNS Board and serve for a term of four years which may be renewable. In order to establish an orderly rotation half of the ordinary members will be selected by discussion, or if necessary by lot, not to serve for a second consecutive term.

11. Membership

Membership of the Consortium will be open to any member of the Peripheral Nerve Society who is engaged in research into the cause or treatment of inflammatory or immune-mediated diseases of the peripheral nervous system. Interested individuals should apply to the Secretary of the Organising Committee.

Appendix 1. Excerpt from the Constitution of the Peripheral Nerve Society

ARTICLE IV. COMMITTEES

Section 1: *Standing and Ad Hoc Committees*: There shall be both standing and ad hoc committees to assist the Board in the conduct of the affairs of the Society. Except as may be otherwise provided in the By-Laws, all committees will be appointed by the Board. Either the President or Secretary-Treasurer shall be an ex-officio member of each with the right to vote.

Appendix 2. Organising Committee

Richard Hughes, London, UK, Chair
David Cornblath, Baltimore, MD, USA, Vice-Chair
Pieter van Doorn, Rotterdam, The Netherlands, Vice-Chair
Michael Lunn, London, UK, Secretary

Peter Hartung, Düsseldorf, Germany
Jean-Marc Léger, Paris, France
Richard Lewis, Detroit, MI, USA
Ingemar Merkies, Rotterdam, The Netherlands
Eduardo Nobile-Orazio, Milano, Italy
Mary Reilly, London, UK
Leonard van den Berg, The Netherlands
Peter van den Bergh, Brussels, Belgium
Ivo van Schaik, Amsterdam, The Netherlands