



The International Pediatric MS Study Group - IPMSSG

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MOTIVATION FOR FOCUS ON PEDIATRIC MS

DUTCH/ROTTERDAM SITUATION

- working on aggressive variants/BMT
- (desperate) questions by 3P (patients, parents , professionals):
gap in knowledge, limited pool for research
- growing international attention
- scientific: unique window into MS risk factors



WHY IPMSSG?

Rare disease in children

No approved therapies or **standardised clinical** practices

Limited **pool** for research

Only **network** to serve the global pediatric MS clinical and research community

Pediatric MS offers a unique and vitally important **window into MS risk factors**, genetics and immunology



Vision

... “to optimize worldwide care, education and research in pediatric multiple sclerosis (MS) and other acquired inflammatory demyelinating disorders of the central nervous system.”
(IPMSSG Charter, 2013)

Mission

To **improve the care** of children with multiple sclerosis and acquired demyelinating diseases worldwide, **promoting clinical initiatives, education and research.**

Timeline and Key Activities

- *Inaugural meeting*
- *Consensus publications*
- *Decision to formalize international collaboration*

Forming 2004-2007

- *International Pediatric MS Research Meeting*
- *Pilot project*
- *Outreach*

Growing 2007-2009

Initiating 2009-2011

- *Charter with guiding principles for collaboration*
- *100+ members*

Key Activities

- *IPMSSG Clinical Trials Summit*
- *Research Writing Group*

- *Implementing the strategic plan*
- *Establishing the new infrastructure*

Guiding 2011-2013

Evolving 2013-2015

2015 +

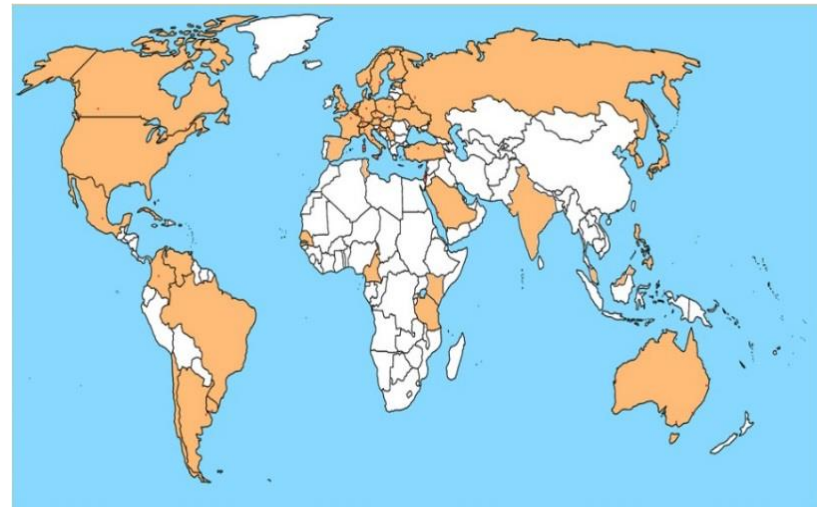
- *Protocol reviews*
- *Charter revision*
- *Boston 2014*

2004: meeting of < 20 clinicians

- Consensus:
 - What is MS?
 - How do we manage?

2014: > 135 members from 36 countries

- Charter and Strategy
- Clinical Care
- Clinical Trial
- Education and Outreach
- Research





*1st European meeting on pediatric MS
Rotterdam April 16-17, 2009*

What Impact Has It Had?

- Better patient care for all children with MS
- Early Diagnosis (definitions)
- Treatment; given a choice (consensus)
- Evidence- treatment trials (summit)
 - Drug companies want/need our involvement
- Addressing the child's needs - cognition
- National networks - USA, UK, Holland, Canada, Poland, Norway
 - Minimum standard of care for all children

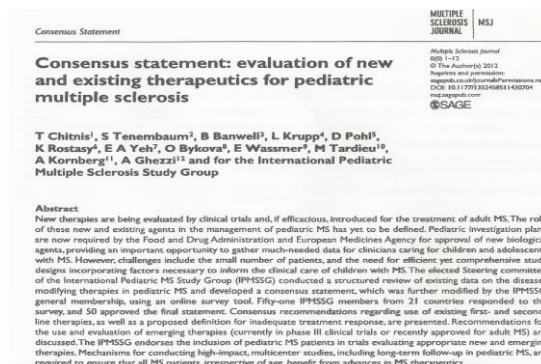
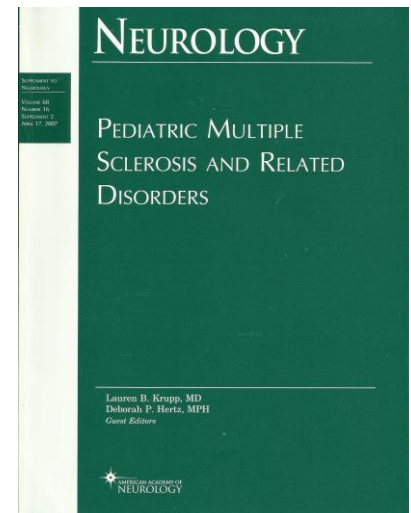
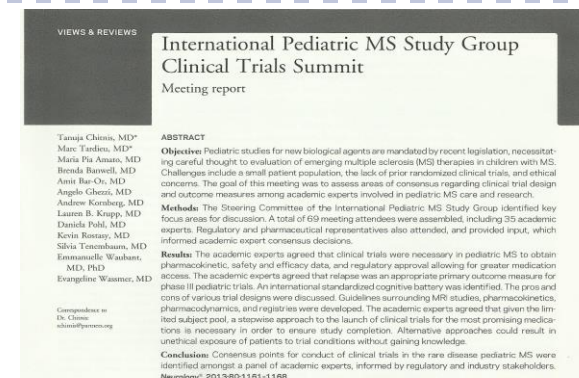
Achieved

Clinical Care

- 2007 Publication of 1st consensus publication – **Neurology** supplement
- 2011 Consensus of treatment
- 2013 Revision of definitions

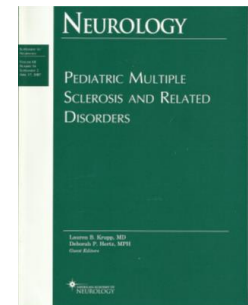
Clinical Trials

- 2012 IPMSSG Therapeutic Summit Workshop with experts, agencies and pharma
- Clinical Trials Task Force
- Engagement with drug companies, FDA, EMA

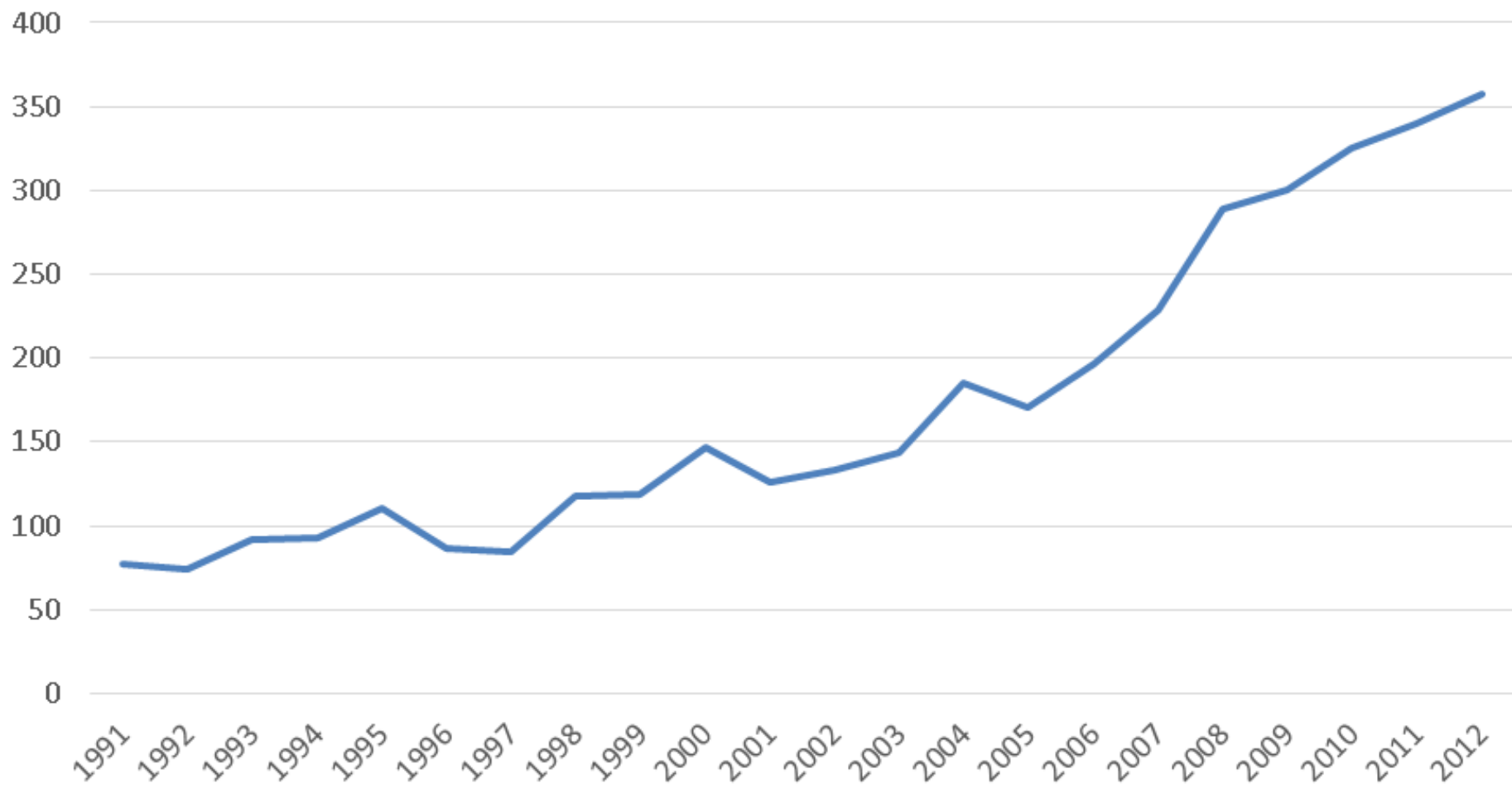


Pediatric multiple sclerosis and pediatric demyelinating disorders: global update and future directions – Neurology supplement 2016

1. Perspectives and concerns from patients and their families.
2. Consensus definitions pediatric multiple sclerosis and other demyelinating disorders.
3. Immunopathophysiology and biomarkers.
4. Environmental and genetic factors in pediatric inflammatory demyelinating diseases.
5. Differential diagnoses.
6. Acute disseminated encephalomyelitis.
7. Transverse myelitis.
8. Optic neuritis.
9. Neuromyelitis optica spectrum.
10. Acquired demyelinating syndrome and multiple sclerosis.
11. Clinical features and outcome.
12. Cognition and mood.
13. MRI-features.
14. First-line treatment and general management.
15. Pediatric multiple sclerosis: Escalation and emerging treatments.
16. Challenges and future



Number of pediatric MS related publications as tracked in PubMed





*Management-care
research*

*Information
training*

*And fun!
+patients voice...*

