The International Pediatric MS Study Group - IPMSSG

EMSP Oslo - May 2016

Rogier Hintzen
neurologist
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**

- **Forming 2004-2007**
  - Inaugural meeting
  - Consensus publications
  - Decision to formalize international collaboration

- **Growing 2007-2009**
  - International Pediatric MS Research Meeting
  - Pilot project
  - Outreach

- **Initiating 2009-2011**
  - Charter with guiding principles for collaboration
  - 100+ members
Key Activities

Guiding 2011-2013
- IPMSSG Clinical Trials Summit
- Research Writing Group

Evolving 2013-2015
- Implementing the strategic plan
- Establishing the new infrastructure
- Protocol reviews
- Charter revision
- Boston 2014

2015 +
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
MOTIVATION TO FOCUS ON

PEDIATRIC MS

Focus on aggressive variants/BMT

Question form 3P (parents, patients, professionals)

International attention

Scientific: unique window into MS risk factors, genetics and immunology

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
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.
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.
16. Challenges and future
Number of pediatric MS related publications as tracked in PubMed
And fun!
+patients voice...

Management-care
research
Information
training