

# RIMS/2011 CONFERENCE

**A LIFELONG PERSPECTIVE:  
REHABILITATION FOR MS PATIENTS WITH COMPLEX NEEDS**  
MAY 13–14 TURKU / FINLAND



# RIMS 20 year's celebration

Dr. Pierre Ketelaer

# 1° R.I.M.S. Meeting

## Preliminary meeting in Trento, July 12-13, 1990

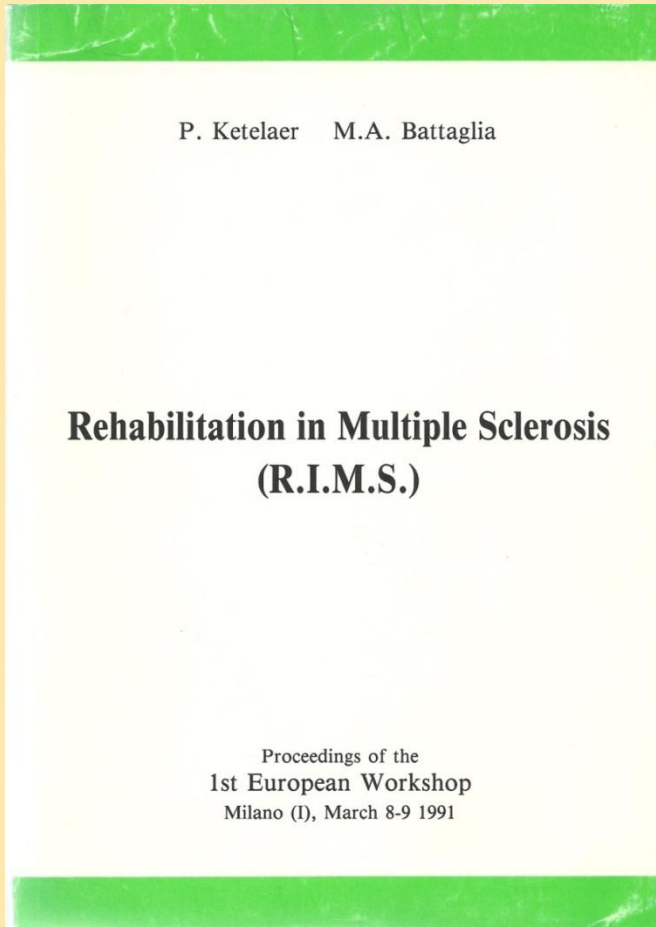
Participants : Drs. Battaglia, Crimi, Gasco, Ketelaer & Millet.  
Objective : Network of European MS Centres.

## Topics of the first RIMS meeting, March 8-9, 1991 :

Introductory speech by Otto Hommes : C.A. in MS Research in Europe (1990-1991).

EDMUS, MRI, T-Cell autoimmunity, SUDIMS, ECTRIMS, GAMES, Myelin Destruction & remyelination, Standards on CSF in MS.

- Overview of European M.S. facilities for rehabilitation (B, CH, D, DK, F, I, Ir, S, SP)
- Need of Inventory of MS Facilities in Europe
- Need of exchange of team members, material, information.
- Need of assessment and outcome measurement
- First steering committee : M. Battaglia, P. Ketelaer, M-F Millet, J.Mertin, J.Kesselring, + GB and Scand. Candidate.
- Publication of the proceedings of workshops.

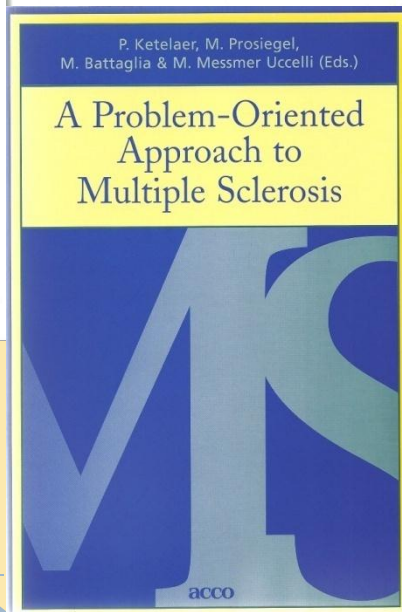
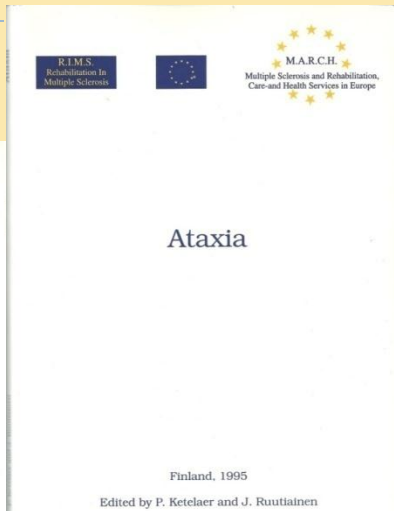


# MARCH meeting, Tenerife December 1994



# M.A.R.C.H. Biomed & Health Research

BMH1-CT-93-1453



## C.A. with 5 taskgroups :

- Evaluation of Need (Dr. Alan Thompson)
- Assessment of Disability, Handicap & Q.O.L. (Dr. Prosiegel)
- Health Care Systems & Services (Prof. Mario Battaglia)
- Optimal rehabilitation programs (Dr. M-F Millet)  
Bowel, bladder & sexual disorders, Psychology & neuropsychology, Ataxia, Spasticity, Communication
- Cost of MS (Prof. Jef Pacolet)

## Extension with PECO program : Estonia and Slovenia





# REHABILITATION IN MULTIPLE SCLEROSIS

# RIMS

## *Network of European MS Centres*

▶ 1991 :

- ▶ Milano (Italy), First meeting of the Consortium of European MS Centres, March 8-9, 1991.

▶ 1992

- ▶ May 29-30 : Brussels (Belgium), "Assessment of disability and handicap".

▶ 1993 :

- ▶ September 24-25 : Brussels (Belgium), "Assessing the Quality of Life of MS patients"

▶ 1994 :

- ▶ May 13-14 : Dublin (Ireland), "Optimising Rehabilitation Programmes in Multiple Sclerosis", Joint meeting with the European Platform of MS Societies (EPMSS)
- ▶ December 2-4 : Tenerife, Canary Islands (Spain) Symposium on Bladder, bowel and sexual disorders in Multiple Sclerosis

▶ 1995 :

- ▶ May 19-21 : Stockholm (Sweden), "Psychology and Neuropsychology in Multiple Sclerosis",
- ▶ November 30-December 2 : Masku (Finland), "Ataxia in Multiple Sclerosis"

▶ 1996 :

- ▶ February 22-24 : Siena (Italy), "Spasticity in Multiple Sclerosis"

▶ 1996 cont.

- ▶ May 10-12 : Paris (France), "Communication and Swallowing Disorders in Multiple Sclerosis",

▶ 1997 :

- ▶ May 9-11 : Bad Windsheim (Germany), "Advances in Clinical Rehabilitation and the Role of Nursing"

▶ 1998 :

- ▶ May 7-10 : Helsinki (Finland), " The Management of Early MS across Europe"

▶ 1999 :

- ▶ September 14-16 : Basel (Switzerland), First International MS Week, ECTRIMS, CMSC , RIMS "Measurement in Rehabilitation and Models of Care".

▶ 2000 :

- ▶ April 13-16; Venice, Italy Annual Conference, The Future of Rehabilitation in MS

▶ 2001 :

- ▶ May 17-19 : Copenhagen, Denmark. Science in Rehabilitation.

▶ 2002 :

- ▶ June 5-9 : Chicago Illinois Second International MS Week Multiple Sclerosis : A World View



# REHABILITATION IN MULTIPLE SCLEROSIS

# RIMS

## *Network of European MS Centres*

### ▶ **Mission statement**

- ▶ RIMS aims to link the European MS Centres in order to encourage all professionals interested in Multiple Sclerosis to exchange knowledge of clinical, scientific, social, economical and educational matters about MS.

### ▶ **Administration**

- ▶ RIMS is a non-profit organization of MS Centres in Europe, bringing together all health care professionals involved in care of persons with MS.
- ▶ RIMS is affiliated with the Consortium of MS Centres (CMSC), ECTRIMS, the European Platform of MS Societies and the I.F.M.S.S.
- ▶ The Executive Board of 8 members shall reflect the interdisciplinary team approach : at least half of the positions will be reserved for psychologists, nurses, physiotherapists, occupational therapists, social workers and therapists of other disciplines.

### ▶ **Benefits of membership**

- ▶ Collaboration in multicentre studies
- ▶ Enhancement of interdisciplinary teamwork
- ▶ Access to networking

### ▶ **The Clinical Care Committees**

- ▶ These committees have to promote research and improve the management of Persons with MS and their caregivers.
- ▶ Different Committees have been created :
  - ▶ Committee on Mobility
  - ▶ Committee on Bladder, bowel and sexual disorders
  - ▶ Committee on Communication and swallowing
  - ▶ Committee on Psychology and neuropsychology
  - ▶ Committee on Occupation
  - ▶ Committee on Integration and participation
  - ▶ Committee on Nursing

### ▶ **"Network"**

- ▶ is the official newsletter of RIMS, published twice a year

### ▶ **RIMS website**

- ▶ <http://www.rims.be>

### ▶ **RIMS Awards**

- ▶ at the annual meeting the RIMS awards are delivered for the best platform and best poster presentation



# REHABILITATION IN MULTIPLE SCLEROSIS

# RIMS

## *Network of European MS Centres*

- ▶ 2003 :
  - ▶ May 22-25 : **Montana** (Switzerland), RIMS Annual Meeting.
- ▶ 2004
  - ▶ October 6-9 : **Vienna** (Austria): Joint Meeting RIMS-ECTRIMS
- ▶ 2005 :
  - ▶ May 19-22 : **Tallinn** (Estonia): RIMS Annual Meeting.
- ▶ 2006 :
  - ▶ May 10-12 : **Barcelona** (Spain) : RIMS Annual Meeting - XVIII Techn. Workshop Guttmann.
- ▶ 2007 :
  - ▶ October 11-14 : **Prague** (Czech. Rep.) : Joint Meeting RIMS-ECTRIMS
- ▶ 2008 :
  - ▶ May : **Leuven** (Belgium), RIMS Annual Meeting.
- ▶ 2009 :
  - ▶ April 23-25 : **Genoa** (Italy): RIMS Annual Meeting. Research challenges in MS Rehabilitation
- ▶ 2010 :
  - ▶ October 13-16 : **Göteborg** (Sweden): Joint Meeting RIMS-ECTRIMS. Behavioral interventions in MS.
- ▶ 2011 :
  - ▶ May 12-16 : **Turku** (Finland) : RIMS Annual Meeting  
Lifelong perspective : Rehabilitation for MS patients with complex needs.

### ▶ **RIMS Presidents**



- ▶ Mario Battaglia M.D. 1991 - 1996
- ▶ Alan Thompson M.D. 1996 - 1999
- ▶ Claude Vaney M.D. 1999 - 2005
- ▶ Eija Luoto R.N. 2005 - 2011

# Special Interest Groups (SIG)

## Goals, strategies, meetings

- ▶ Mobility (1994)
- ▶ Bladder Bowel & Sexual disorders (1995)
- ▶ Psychology & Neuropsychology (1995)
- ▶ Communication & Swallowing (1996)
- ▶ Integration & participation (1996)
- ▶ Occupation (1995)
- ▶ Patient Education (2009)



# More recent RIMS initiatives

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## ▶ Publications :

- ▶ Psychology & neuropsychology
  - ▶ Neuropsychological guidelines
  - ▶ Personality, behaviour and MS, 2006.
  - ▶ Emotional reactions in MS, 2006.
- ▶ Communication & swallowing
  - ▶ Talking about communication in MS, 2007.
- ▶ Recommendations on Rehabilitation Services for PwMS in Europe, 2004.

- ▶ RIMS Multi-centre rehabilitation studies organised by SIG Mobility

## ▶ RIMS Fellowship

- ▶ Since 2008
- ▶ Multidisciplinary approach
- ▶ Training young European professionals



# MS diagnosis, treatment & rehabilitation

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**Before**

**1990 -2011**  
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- ▶ The disease is recognized by its clinical features
- ▶ Cause is unknown, no known means of combating the disease. Treatment of intercurrent infections and avoidance of overfatigue are indicated.
- ▶ Massage and exercises, if not too vigorously prosecuted, are comforting to severely incapacitated individuals

*(Elliott, Clinical Neurology, 1964)*

- ▶ Diagnosis : Early nineties : MRI, 1991 : Rao Battery, 1999 : MSFC (Cutter) 2001: C.I.S. and Mac Donald criteria, 2005 : Revised Mc Donald criteria, 2010 : Revised Mc Donald criteria
- ▶ Treatment efficacy: Interferons , Glatiramer acetate : Copaxone : 30%  
IV: Mitoxantrone, Natalizumab : 50%  
IV: Monoclonal AB & Oral treatm. 60%
- ▶ Rehabilitation :
  - ▶ Aerobic exercises,
  - ▶ Sports
  - ▶ Motor imagery
  - ▶ Mindfulness :MBSR
  - ▶ Starting vocational training at diagnosis



# RIMS Milestone Publications

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## **Efficacy of MS Rehabilitation**

25 years of experience in adaptation training in MS (Ruutiainen J. 1996)

Improvement in physical endurance, work and mood after 5-8 weeks inpatient rehabilitation (Jønsson A. 1996)

CRT The impact of inpatient rehabilitation on progressive MS (Freeman J.A., Langdon D, Hobart J.C & Thompson A.J. 1997)

CRT Physical rehabilitation has a positive effect of disability in multiple sclerosis patients (Solari, A. 1999)

Inpatient rehabilitation in multiple sclerosis : do the benefits carry over into the community? (Freeman J.A. et al 1999)

Rehabilitation in MS is effective (Kesselring J. 2001)

CRT of the effects of physiotherapy on mobility in chronic MS (Wiles 2001, Mostert 2002)

## **Multicentre research :**

- Intention tremor rated according to different finger-to-nose test protocols: a survey (Feys P. & coll) from Melsbroek, Bristol and Masku, 2003).

- Emerging evidence-based physical rehabilitation for multiple sclerosis - towards an inventory of current content across Europe. (Rasova K, Feys P, Henze T, van Tongeren H, Cattaneo D, Jonsdottir, Herbehova A. 2010).

## **Research on symptomatic treatment & management by the S.I.G's**

### **Quality management**

Integrated care pathways: disease-specific or process-specific? (Edwards SG, Thompson AJ, Playford ED. 2004)

# Quality Management



## Grateful for fruitful collaboration

- ▶ ECTRIMS
  - ▶ Joint meeting every three year with education symposia and exhibition
- ▶ Consortium of MS Centers (CMSC)
  - ▶ Joint meetings in Basel 1999 & Chicago 2002.  
Inspiration & support
- ▶ National MS Societies -Italian MS Society
  - ▶ RIMS 1° European workshop, Milano 8-9/03/1991
  - ▶ supporting the annual RIMS meetings.
  - ▶ European MS Platform

International Organisation for Standardisation :  
Documented statement of quality,  
Policy & objectives by effective planning,  
operation and control of its processes

Clinical pathways  
Multidisciplinary goal setting

Fluctuat nec mergitur