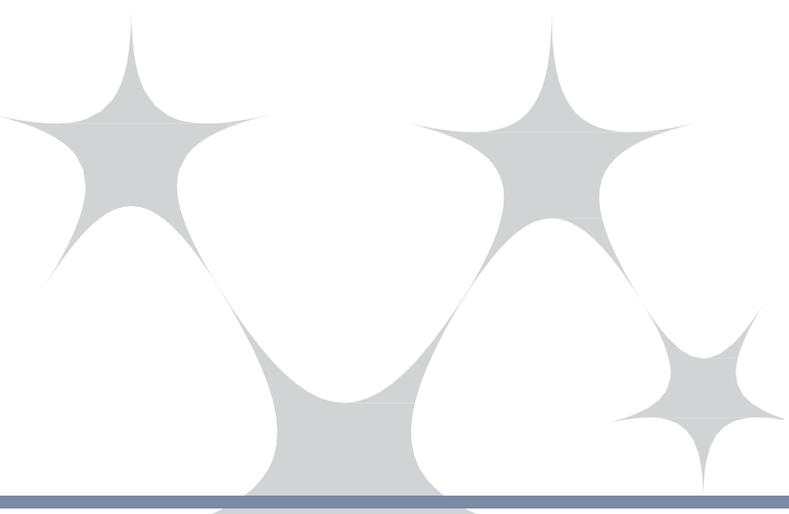


# Take Home Messages



# Conference theme

## Crossing the Interface to Explore new Possibilities

- Beyond Europe
- Integrated Care
- Technical Opportunities
- The Sociological Perspective
- Lessons from the Laboratory

# Opening lecture: Cognition and Consequences for Learning, Rehabilitation and Social Participation – *Prof. DeLuca*

- Cognitive dysfunction occurs in up to 70% of persons with MS and should be assessed regularly
- Cognitive dysfunction can have a significant impact on the everyday life of patients and loved ones
- Cognitive dysfunction should be treated and can be done effectively using behavioral techniques

# KEY NOTE I: Shift MS – *Mr. Pepper*

- MS alongside emotional development
- Key need for MSers to play an active role in their health
- Shift.ms' role in patient activation

# Participation has to Change: from Self-Sufficiency to Sense of Belonging – *Dr Schippers*

Beyond binary thinking: celebrate diversity

- Society (so: all of us) has a responsibility to provide for all;  
-> beyond the 'normal-abnormal' dichotomy towards 'equal aspects of human diversity'

*(Brown et al, in press)*

-> beyond competency of the patient towards valorisation in society

# EBC MS Value of Treatment and Policy Narrative – Mrs. Merkel

- Across Europe it is clear that rehabilitation is underutilised and access to specialised and personalised rehabilitation is highly variable both within and between countries. Rehabilitation programmes are often not fully integrated or initiated early enough into MS management programmes.
- Providing integrated and coordinated MS care is organisationally challenging. Across Europe, there is typically a lack of communication between the neurology, rehabilitation and social care systems. As a result many people do not receive the care and support that they need. We need to ensure that all neurologists and specialist clinics are able to signpost people with MS to suitable options for rehabilitation, patient education and support groups.
- There is a lack of political prioritisation of rehabilitation – many policymakers and decisionmakers are unclear about what rehabilitation entails and how it is beneficial to people with MS and their families and society as a whole. This needs to be better communicated from all involved stakeholders.

# Epidural Spinal Cord Stimulation to enable Locomotion: Historical Approaches in MS and Current Studies in Spinal Cord Injury – *Dr Minassian*

- Early applications of epidural spinal cord stimulation in multiple sclerosis patients produced fast and profound improvements of lost motor function surpassing the effects produced by any other method of that time – but these studies seem to have been forgotten in history
- Currently, there is a re-emergence of spinal cord stimulation in spinal cord injury. Independent studies have demonstrated enabled intentional control of movement of previously paralyzed extremities and walking
- Improved understanding of the target spinal circuits for locomotion together with advancements in stimulation technology and the success in spinal cord injury justify new clinical studies bringing this intervention back to multiple sclerosis patients

# Effects of Exercise in EAE Animal Models – *Prof. Centonze*

- Voluntary exercise may protect central synapses from excitotoxic neurodegeneration
- Voluntary exercise potentiates the endocannabinoid signal, reducing spasticity and pain and enhancing cognition and mood.
- Voluntary exercise interferes with the process of central demyelination

# KEY NOTE II: Rehabilitation in and Beyond Europe – Prof. Feys

- The world health organisation has launched an ambitious Rehabilitation Action Plan 2030 with the aim to include rehabilitation in the health systems worldwide. The program includes a focus on evidence-based rehabilitation interventions and current status of governmental policies on rehabilitation.
- International organisations in MS are increasingly adopting the concepts of functioning, especially at body function and activity level. Also patient reported outcome measures are gaining credibility in order to also measure invisible symptoms and real life experiences.
- International organisations in MS, outside of Europe, United States and Canada, are showing increasing understanding and interest in the concept of rehabilitation. Assisting eager health care professionals from these countries is a moral duty in order to achieve universal access to high-quality services.

# KEY NOTE III: Let's Talk about Pelvic Problems

## – Prof. Vodusek

- Pelvic problems (*lower urinary tract, anorectal and sexual dysfunction*) are prevalent in MS patients, and need to be **identified**, diagnosed and treated.
- Effective **communication** is essential for delivering quality patient care in pelvic problems.
- Pelvic floor muscles have a specific neural control, but can be trained. Such training may have a positive influence on pelvic organ function in patients with MS.
- There is need for more research on rehabilitative approaches to pelvic organ dysfunction in patients with MS.

# Economic Analysis of Chronic Care Model

## - *Dr Desmedt*

- Crucial key factor of integrated care are: shared vision, efficient communication, financial incentives and education, shared organizational processes, defined roles and responsibilities, clinical pathways and patient empowerment
- Overall, integrated care models have a positive economic impact
- Nevertheless, there is still a need for more economic evaluations of integrated care models (including cost-effectiveness)

# Co-design for Implementing Patient Participation in Hospital Services – *Prof. Sermeus*

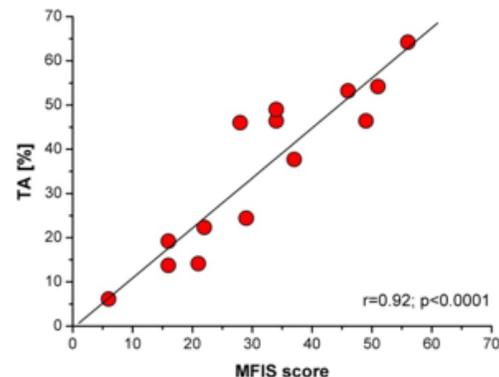
- Why we need to involve patients?
- What is the difference between patient participation, patient centeredness and patient empowerment?
- What are different methods for patient participation?
- How to organize co-design for patient participation?
- What are the results of involvement of experts-by-experience on experiences of patients and health professionals ?

# Wearable, Portable and Low-cost Devices for Monitoring, Assessment and Rehabilitation of People with MS in the Internet of Things Era – *Prof. Pau*

- Within few years, most clinically relevant data will be collected outside the clinical settings
- In the Internet of Things era, patients will gradually assume a leading role in the management of their diseases and in the development of future diagnostic and treatment procedures by sharing data and adopting new technologies as life companions.
- Patient-generated data (particularly those coming from wearables devices) has the potential to reduce costs and improve outcomes, assisting clinicians in more effectively tailoring treatments
- Clinicians should not become engineers. We need to organize multidisciplinary teams (establishing a minimal common ground to optimize communication) to make “technical” data clinically useful and meaningful

# Brains in Action: Cortical Hemodynamic Activity during Movement – Prof. Bove

- Be careful with PwMS pushing always toward higher level performance during motor rehabilitation and in other daily tasks. They can be at risk of subjective fatigue.
- Don't fall in love with technology!
- Working hypothesis, please!
- Trade-off between motor performance and functional brain investigation accuracy



## Managing fatigue

Because fatigue can also be caused by treatable medical conditions such as depression, thyroid disease or anemia, may occur as a side effect of various medications or be the result of inactivity, persons with MS should consult a physician if fatigue becomes a problem. A comprehensive evaluation can help identify the factors contributing to fatigue and make it possible to develop an approach suited to the individual's needs. Options for dealing with fatigue include:

- › Occupational therapy to simplify tasks at work and home.
- › Physical therapy to learn energy-saving ways of walking (with or without assistive devices) and performing other daily tasks, and to develop a regular exercise program.
- › Sleep regulation, which might involve treating other MS symptoms that interfere with sleep (e.g., spasticity, urinary problems) and using sleep medications on a short-term basis.
- › Psychological interventions, such as stress management, relaxation training, membership in a support group, or psychotherapy.
- › Heat management — strategies to avoid overheating and to cool down.
- › Medications — amantadine hydrochloride (Symmetrel®) and modafinil (Provigil®) — are the most commonly prescribed. While neither is approved specifically by the U.S Food and Drug Administration (FDA) for the treatment of MS-related fatigue, each has demonstrated some benefit in clinical trials. The most recent trial of modafinil, however, reported no difference between modafinil and placebo in relieving fatigue.