

Achievements in the field of MS in Europe – ...and why we cannot sit back and relax (yet)

MS Barometer 2013 - overall results

Multiple Sclerosis can be defeated: let's join forces!
Lunch debate in the European Parliament on Nov. 10, 2015
Contribution by Christoph Thalheim, Director External Affairs



Practical uses of the Barometer

At European level

- Obtaining an accurate picture of the situation for people with MS across Europe and providing comparable data
 - Monitoring implementation of the European Code of Good Practice
- ➔ Identification of **Best Practice** between countries with **similar socio-economic situations**.

At national level: High-level National Roundtables (Greece, Poland, Russia)

- Identification of aspects of the condition which are well-managed and areas where administrations need to improve their policies and practices

What is EMSP's mission?

A world without MS

ADVOCACY

- Ensure the voice and influence of people with MS is recognised
- Campaign for equitable access to high quality treatment, services and employment across Europe

KNOWLEDGE and EXPERTISE

- Share and promote evidence-based best practice
- Foster effective cooperation between people affected by MS, health professionals, policy decision-makers and researchers

RESEARCH

- Encourage and support high quality MS research and international MS research collaboration
- Support the collection, pooling and interrogation of essential MS data across Europe

Improving the quality of life of more than 700,000 people with MS across Europe

EMSP has 41 members from 36 European countries

European Code of Good Practice in MS:
Defeating MS Together

Current situation

MS Facts

- 700,000 people in Europe have MS

- 70% diagnosed during prime working years

- 9 million people with neuro-degenerative diseases

- € 800 billion = cost of brain conditions in Europe

€ 1,5 million per minute*

are being spent on brain conditions in Europe



* European Brain Council, *Cost of Brain Diseases in Europe*, 2010

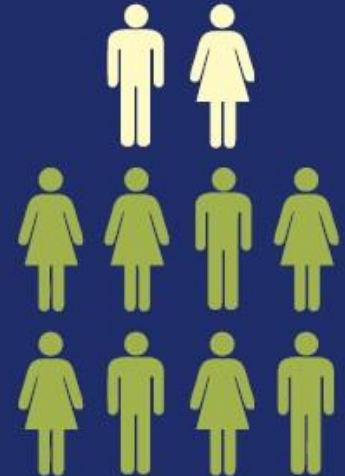
65% of the 1300 respondents to our young people with MS survey said they are currently employed or doing voluntary work ...

... but 80% usually stop working within 15 years of the onset of the disease



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Activity in the workplace for young people with MS



8 out of 10 stop working*

* Work Foundation, *Ready to Work?*, 2011

Three major achievements related to the COLLOQUIUM's CALLs for ACTION (2014)

Call 1:

Increase awareness & understanding about the burden of MS

- MS Barometer
- Believe & Achieve
- Under Pressure

Call 4:

Educate and develop new tools to better capture the total clinical (+PRO) burden of MS

- EUREMS
- European Network of MS Registries

Call 9:

Support people with MS remaining at work

- Believe & Achieve

Achievement example 1: Better awareness through UNDER PRESSURE Exhibitions



Example 2: From EUREMS to the European Network of MS Registries (proof of concept!)

- Collaborative and geographically representative **Network of MS data providers in Europe, capturing real-world evidence**;
- Inspiration for creation of **new national registries** already in Poland, Czech Republic, Switzerland and the UK;
- **Validated procedures** and methodology for temporary MS data merging;
- **IT infrastructure for pooling and analysis** of (pooled) MS data at Medical University Göttingen (UMG);
- **Ethical and legal framework** for central MS data analysis on the base of temporary cross border data pooling.

Example 3:

Disability management according to WHO:

A proactive process that minimizes the impact of an impairment

Paving the Path to Participation

This project aims to promote policy change that will support maximum participation of people with MS in the labour market in Europe.

Pact

PPP relies on a multi-stakeholder network in its efforts to promote a **European Employment Pact**. People with MS, employers, health-care providers and policy-makers are all taking part.

Action

- **Implement Pact** in employment policy and best practice.
- **Support businesses** to create solutions for people to stay in or return to work.
- **Persuade policy-makers** and national authorities to adapt policies for flexible working.

Breaking down the barriers
**Access to employment and the
economics of brain health**

An event
hosted by
Rosa Estaras

To register, please contact Andreea Antonovici,
andreea.antonovici@emsp.org

Tuesday, March 24, 2015 | 09:00 - 11:00

European Parliament, Brussels

The event is organised in partnership with the European Multiple Sclerosis Platform

Patients do have a say about their treatments! (...national example)

Polish authorities
Say “Yes” to reimbursement of first-line DMDs, BUT:
limited to 3 years for eligible MS Patients !!!

Polish People with MS raise their voice –
DMDs are reimbursed for 5 years for eligible MS Patients!!

Building up a strong coalition via EMSP
using evidence based on MS Barometer

Polish authorities say “Yes” to reimbursement of first-line DMDs for eligible MS Patients with no time limit -
as long as prescribed by neurologist

One major achievement NOT related to the COLLOQUIUM's CALL for ACTION

2,721 total registered users across **30** different countries

	Spain 1,672		South America 17		Austria 26		Romania 3
	Italy 331		Greece 9		Denmark 4		India 6
	UK 244		Hungary 7		Norway 5		Saudi Arabia 5
	Ireland 120		Switzerland 22		Australia 6		Poland 3
	Czech Rep 54		Netherlands 6		Portugal 4		Turkey /Israel 4
	Germany 120		Belgium 12		France 5		Finland/ Sweden 3
	USA/ Mexico/ Canada 19		& Philippine s		South Africa 5		Slovakia 2

855 users have completed the course

What's next: European Network of disease specific registries – supportive tool for certain European regulatory tasks?

If yes – which tasks ?

- Request for MA for a new centrally approved product (CAP)
- Post Authorization Safety Studies (PASS)?
- Monitoring and optimizing risk minimization measures
- Right treatment, right patient, right time?
- Labeling changes?
-

If no – why not?

Our second proposal for joint action: European Network of MS registries acting as nucleus for

”SINGLE EUROPEAN PLATFORM FOR PATIENT CENTERED OUTCOMES”

- US government funded NGO called PCOR (Patient Centered Outcomes Research Institute) currently invites patient registries for potential collaborative opportunities worldwide on comparative effectiveness research on MS treatments
- BUT:
- Though there are a number of PRO (patient reported and patient relevant outcomes) registries in MS at local, regional and national levels in Europe (e.g. Sweden, UK, Germany) and in the US (NARCOMS),

no global or even European standard for PCO in Multiple Sclerosis exists today, neither for the choice of validated scales, nor for a commonly agreed core dataset, which would cover the relevant sets of clinical and PRO data.

"BD4BO - Big data for better outcomes"

Goal: Support the evolution towards outcomes-focused and sustainable healthcare systems, exploiting the opportunities offered by big and deep data sources

Goal

1

Design sets of standard outcomes and demonstrate value

2

Increase access to high quality outcomes data

3

Use data to improve value of HC delivery

4

Increase patient engagement through digital solutions

Themes / Enablers



ROADS: ALZHEIMER'S DISEASE



HEMATOLOGIC MALIGNANCIES



MULTIPLE SCLEROSIS



CARDIOVASCULAR



EUROPEAN DISTRIBUTED DATA NETWORK

Topic Proposals

Coordination and Support Action (CSA)

Operating structure

Data Center

www.emsp.org

Thank you!

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