

# European Multiple Sclerosis Platform

## EMSP 2015- Key Achievements

**Maggie Alexander**  
*CEO*

# Well functioning Health Care Systems require strong Patient Organisations



# EMSP

The **European Multiple Sclerosis Platform (EMSP)** is the umbrella organisation of the main national MS Societies in 35 European countries\* and represents more than 700.000 people with MS and 1.5 million people daily affected by MS (such as family and other care givers).



\* Austria, Belarus, Belgium, Bosnia-Herzegovina, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, **Moldavia**, Netherlands, Norway, Poland, Portugal, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, **Turkey**, Switzerland, UK.

# What did we work on in 2015?

1. Believe and Achieve
2. Paving the Path to Participation – Employment Pact
3. European MS Barometer
4. Pan-European Patients survey
5. EUREMS
6. MS Nurse Pro
7. Under Pressure

# Improving access to employment

Addressing all stakeholders:

- **Believe & Achieve** training programme for young people
- **Paving the Path to participation** project (co-funded by the European Commission): development of a European Employers' Charter and a toolkit for the employers
- **Ready to work** project – in collaboration with the Work Foundation and Novartis

# Believe and Achieve (B & A)

- B&A programme started: January 2015
- Internships completed in Spain, Greece, Portugal, Italy)

*What is next?*

EFPIA and the European Parliament have agreed on joining the B & A programme

# What do we want to achieve?

## Believe & Achieve

This project aims to provide young people with MS with opportunities to work in supportive environments, through partnerships with businesses across Europe.

### Action

- Support young people with MS to gain professional experience.
- Promote healthier and more inclusive workplaces.

### Employees

- Have their abilities and resilience properly recognised and rewarded.
- Receive support to fulfil their potential while becoming full contributors to society.

### Employers

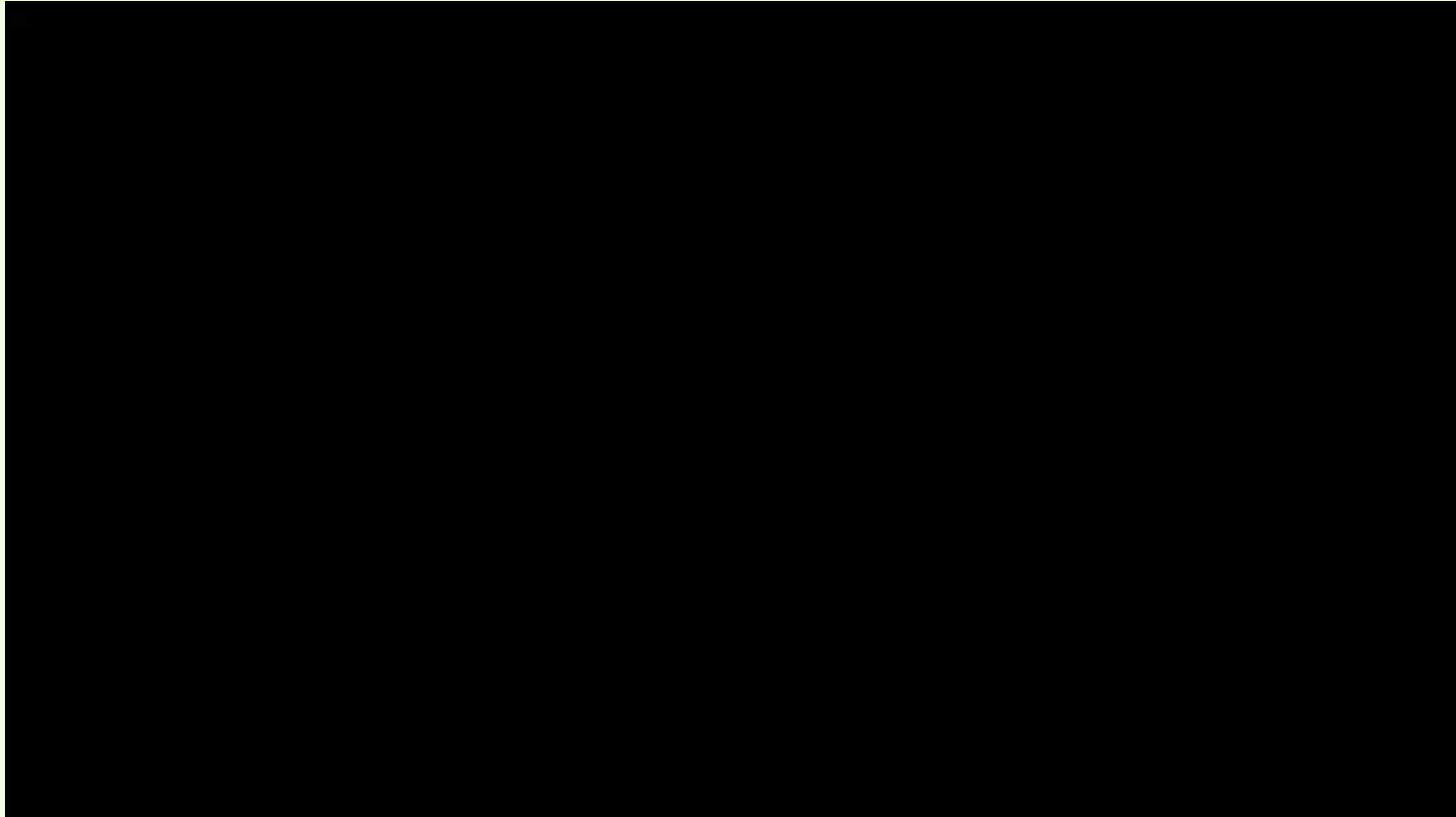
- Become better adapted to the changing needs of the workforce by supporting greater diversity and inclusion.
- Demonstrate good business practice while being able to tap into a new talent pool.



*A Believe and Achieve intern – Anna from Italy – shares her first impressions of the project:*

<https://youtu.be/mqVESoW6nIc>

# Video (Anna)





# Employment Pact for People with MS

- ✓ **Launch event, 24 March, European Parliament, Brussels.**
- ✓ **Call to Action on Access to Employment for People with MS, World MS Day, 26 May, European Parliament, Brussels.** Event hosted by MEP Adam Kosa, Co-Chair of the Disability Intergroup

*Supporters:* more than 60 Members of the EP Parliament

*What is next?*

Debate on access to employment for people with NDDs, EP

# MS Barometer

## *A benchmarking tool*

**Objective:** to obtain an accurate picture of the situation for people with MS across Europe (via responses from clinicians and patient organisations) to key questions about obstacles and barriers faced by people with MS

**7 Areas:** access to treatment and care; research, education, employment and job retention; involvement and empowerment of people with MS; reimbursement of costs related to MS; data collection at national level; medicines coming to the market

***EMSP launched the questionnaire in 2015 and will publish the results of the 5th edition in 2016.***

# European Register for Multiple Sclerosis II (EUREMS)

*EUREMS 2 is supported from 1st July 2015 throughout 30 June 2016 by a competitive investigator initiated research (IIR) grant received by EMSP from Biogen.*

## **Main activities June - December 2015:**

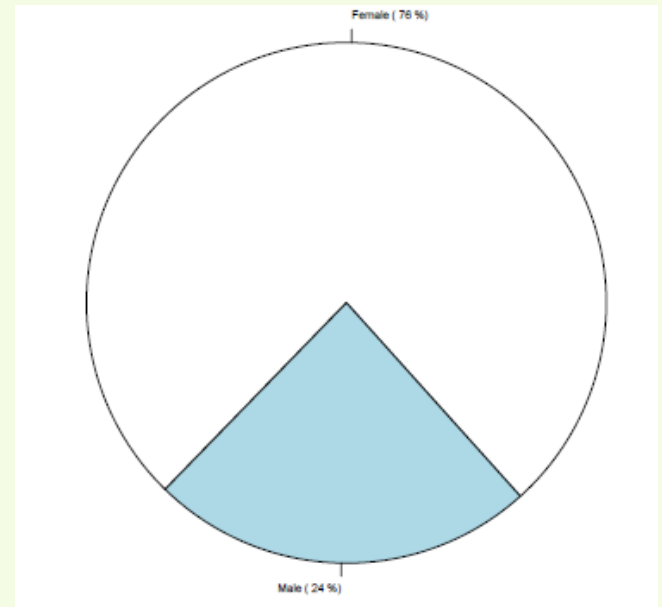
- ✓ **Contractual issues** : prepared draft contracts with Biogen UM Gottingen for subcontracting and EUREMS data handling.
- ✓ **Organisational issues**: Set up the project structure and the EUREMS Working Groups EPI2, DMD2 and PRO2
- ✓ Midterm reports of the EUREMS WGs and their planning for 2016 prepared on December 15, 2015
- ✓ The work on the EUREMS studies is on-going at a different speed; for details, see the attached reports of the WGs.

# Pan – European Patient Survey

*A total of **2743 MS patients** participated in the survey*

- ✓ 33 countries
- ✓ 76% of the respondents were women

EMSP will publish the results during the 1st quarter of 2016



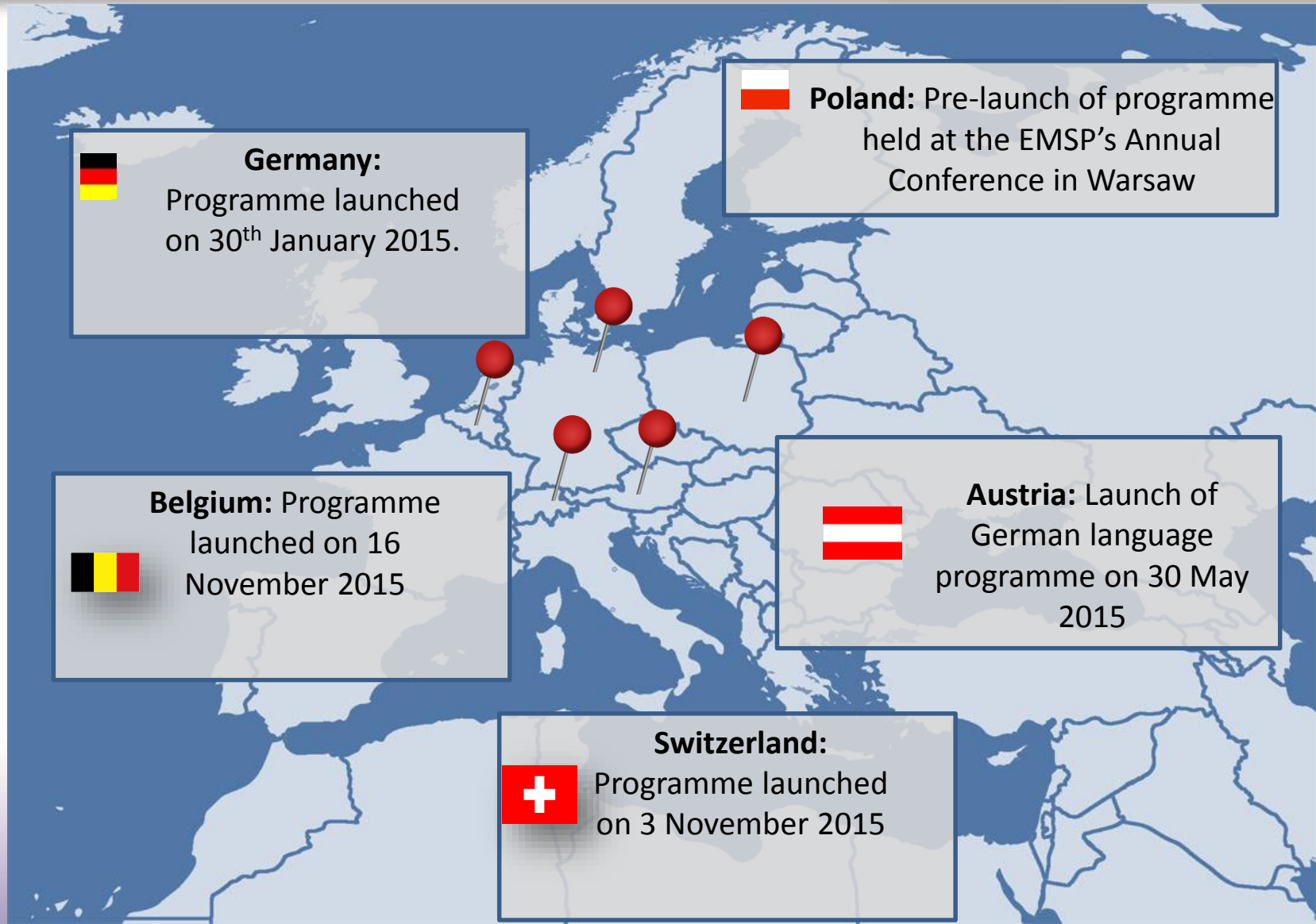
# **MS Nurse PROfessional**

**First and Only European CME-Accredited MS Nurse Online Training Curriculum**

**2015 launches**

- ✓ **5 launches in 2015, making the programme available now in 10 countries in 8 languages**

# 2015 Launches



# MS Nurse PROfessional

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



For the period March 2013 – November 2015

# 855 users have completed the course

	<b>Spain</b> 667		<b>Argentina</b> 5		<b>India</b> 1
	<b>Czech Rep</b> 23		<b>Germany</b> 9		<b>Switzerland</b> 10
	<b>UK</b> 25		<b>Hungary</b> 3		<b>Belgium</b> 1
	<b>Italy</b> 93		<b>Finland</b> 1		<b>Greece</b> 1
	<b>Ireland</b> 14		<b>Norway</b> 1		<b>Austria</b> 1



# What events did we host in 2015?

- **3 March: EMSP Annual Networking event**

*Where?* The Dominican Hotel, Brussels

- **24 March: launched the Employment Pact for People with MS**

*Where?* European Parliament, Brussels

- **14 – 16 May: EMSP Annual General Meeting and Spring Conference**
- **15 May: launched the EMSP Young People with MS Network**

*Where?* Polonia Palace Hotel, Warsaw

# What events did we host in 2015?

- **26 May: launched the Call to Action on Access to Employment for People with MS**

*Where?* European Parliament, Brussels

- **6-10 October: EMSP participated in ECTRIMS as speaker & session co-chair (with Prof. M. Clanet)**

*Where?* Barcelona

- **18 October: MS Nurse Pro Steering Committee**

*Where?* London

# Outreach and communication activities I

In 2015, EMSP's team members covered **17 countries** to present at various events and speak with one voice on behalf of / to support our members.

## *Where did we go?*

Belgium, Czech Republic, Germany, Greece, Finland, France, Italy, Latvia, Malta, Norway, Poland, Portugal, Romania, Spain, Switzerland, UK and the US.

# Outreach and communication activities II

← → ↺ | ncbi.nlm.nih.gov/pubmed/26611275

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Neurodegener Dis Manag. 2015 Dec;5(6 Suppl):55-8. doi: 10.2217/nmt.15.65.

**Pooling real-world multiple sclerosis patient data on a European level: a true story of success.**

Thalheim C<sup>1</sup>. Rectangular Snip

 **Author information**

**Abstract**

Patient-based evidence is becoming increasingly important in budget-restricted healthcare systems as the information can help influence the direction of funds towards interventions that provide the most relevant outcomes for people living with a chronic disease. The European Multiple Sclerosis Platform (EMSP) is an umbrella organization for national multiple sclerosis (MS) patients' associations in Europe which represents the interests of >700,000 MS patients, their families and caregivers. EMSP aims to ensure the delivery of high-quality equitable treatment for persons with MS across Europe. EMSP is involved in numerous projects and activities that encompass its vision and mission. The European Network of MS Registries project has provided proof of concept that high quality MS data from previously unconnected sources can be integrated to inform research and improve patient outcomes.

**KEYWORDS:** European Multiple Sclerosis Platform; European Network of MS Registries; multiple sclerosis

# Outreach and communication activities III

- European Neurological Review, June 2015: Report on the Employment Pact for People with MS
- MS Nurse PRO Thunderclap, ECTRIMS, October 2015
- WorkOutMS Tweet Chat, October 2015
- MS Brain Health: Time Matters in MS, October 2015: Christoph Thalheim, EMSP External Affairs Director as contributor

# Sustainable Health Care requires constant feedback by strong Patient Organisations

**2015:** Working Group initiated by EMSP & EPF on EU funding & general sustainability of patient orgs (PO)

**2016:** Mapping exercise on major contributions by PO to sustainable health care on national & EU level + search of allies

**2017:** Multi-angle campaign led by EPF on PO value for society and the vital need for sustainable funding of PO work

# Partnerships and collaborations

- EMSP Director External Affairs, Christoph Thalheim, is member of **two EMA bodies:**

The Patient  
and  
Consumer  
Working  
Party



The Cross  
Committee  
Task Force  
on Patient  
Registries

# Partnerships and collaborations

EMSP CEO, Maggie Alexander, is board member of



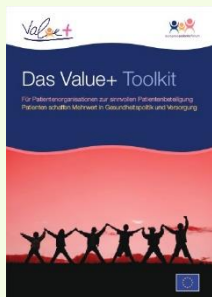
- ✓ EFNA General Assembly and Board meeting: June 2015, Berlin
- ✓ EBC General Assembly: September 2015, Brussels
- ✓ EFNA Advocacy Awards: October 2015, Brussels
- ✓ EFNA MEP Brain, Mind and Pain meetings



# Partnerships and collaborations



EMSP = Founding Member of EPF



**www.emsp.org**

**Thank you for your great support  
of our work for people with MS in  
Europe!**

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