European Multiple Sclerosis Platform

Elisabeth Kasilingam, Managing Director

Brussels, 25th February 2019

About **EMSP**

WHO WE ARE

- Pan-European NGO engaged in advocacy and awareness-raising activities

- Offering knowledge and expertise in the field of multiple sclerosis (MS).

- Aiming to improve quality of life as well as access to treatment, care and employment.

WHAT WE DO

■ **Campaigning through advocacy & awareness raising;**

■ **Collecting and sharing knowledge and expertise;**

■ **Encouraging research and data collection;**

OUR NETWORK

- 41 national MS member societies

- 36 European countries

We work together to ensure that people with MS have a real voice in determining their own priorities.

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Our **Vision & Mission**

Vision

A world without Multiple Sclerosis.

Mission

Improve quality of life of people with MS

Core Values

Equity and solidarity

WE REPRESENT MORE THAN 770,000 PEOPLE LIVING WITH MS IN EUROPE.

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Our **Expertise**

30 years of advocacy for people with MS across Europe.

Knowledge & Expertise

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

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.

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.

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Priorities 2018/2019

Empowering MS societies and MSers

Strive for better access to healthcare, treatments and therapies

Progress our flagship projects

Strengthening partnerships

Secretariat capacity building

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Empowering **People with MS**

#EMSP2018

Clinical trials workshop

Baltic states meeting

Young people's network

Comms network

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Empowering People with MS 2019

- **Annual Conference 10-11th May,** in Vilnius, Lithuania on Digital health in MS management

- Continued series of **workshop on Clinical trials** and collaboration with the European Centre for Clinical research training

- **Focus on the Balkan region** to support the MS societies to address better the challenges faced by the people with MS

- Implementation of the **Young People's Network 2.0**

Transform!

Impact!

Live the change!

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Access to **Better treatment and care**

MS Nurse PRO

MS Barometer

Cost-of illness study
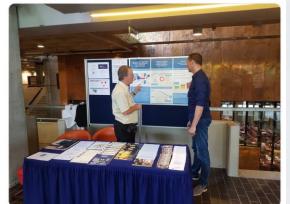

N2B-patch

EMA

Advocacy and **Campaigning**

European MS Platform @eumsplatform · 7 Jun 2018
Policy Coordinator @AAntonovici presents on the EMSP MS Barometer. We ask our members for their priorities at EU level and national level, to work out together and present to the rest of the attendees. Where is leadership at European level & support at local level. #EMSP2018

Christoph Thalheim @stefanschnur · 2 Jun 2018
Great RIMS congress in Amsterdam indeed - Christoph Thalheim explaining EMSP-supported "Burden of Disease Study" with 17.000 PwMS from 16 countries - the biggest study of its kind ever being done...

Access to **Employment**

MSatWork.LIFE

This platform of information, tools, events and networking on MSatWork.LIFE provides people with MS, employers, healthcare professionals and decision-makers with the instruments to overcome the challenges. And we'll keep adding Really Useful Information as the site develops.

Work and employment have been part of EMSP's work for the past 20 years. In particular, we've looked at ways to break down barriers by showing the real-life issues that people have to deal with. We've been ahead of the curve, working closely with the people who know the issues first hand- people with MS and employers.

MS affects people differently, but there are commonalities. Many people experience a range of symptoms. They include mobility issues, loss of senses (sight, feeling, touch sensitivity) chronic pain, fatigue and cognitive issues to name some of the common types. Allowing for symptom management, people with MS want to stay in work and continue with their careers.

Data for Better decisions

Big Data for Better Outcomes

A PRACTICAL TOOLKIT

FOR THE IDENTIFICATION, SELECTION AND MEASUREMENT OF OUTCOMES INCLUDING IN REAL-WORLD SETTINGS

IMI DO→IT DELIVERABLE 2.2

MS Data Alliance

Better data for better care for people with MS

Mission & Objectives
- Increase data quality through a

MSDA academy:
community engagement and awareness raising + support implementation strategies

- Decrease efforts to find, access and re-use data with a

MSDA toolbox:
tools for data discovery and re-use, a federated ecosystem

Principles
The MSDA tools can only be used for assessing the feasibility of a study and for conducting research by bona fide research organisations as well as for the objective of discovering new knowledge intended for the public good and to be made publicly accessible (i.e. published)

Data sources
- will always have autonomy over which data are made accessible and for which types of research
- will always determine ethical acceptability and scientific validity
- must be transparent about their data

Data users
- must adhere to the ethical rules and privacy protection policies of each data source
- may only use the data for the specific agreed research purposes
- must acknowledge the sources of the data they have used, and MSDA

People with MS/ patient societies
Increase *awareness for the relevance* of real-world evidence studies for a better care of people with MS
Increase data quality to support *patient-centered* decision making by regulators
Promote *personalized – precision level* management and care through large, quality-assured datasets

Market Authorisation holders/Applicants
Increase data quality (EMA approved) to support drug safety and effectiveness research
Reduce costs and time necessary for post-authorisation studies by using existing, quality-assured data

Registry custodians
• *Support* implementation strategies of (EMA) guidelines for standardised, quality-assured (minimal) datasets
• Facilitate contact with *data science experts* and provide *help desk* services to tackle legal, ethical and technical challenges
• Promote and enable *collaborations* between registries

Health Technology Assessment bodies
• *Reduce time and costs* to incorporate data from clinical practice in drug development processes
• *Increase data quality* (EMA approved) to support drug assessment
• Increase *awareness* to include functional- and patient relevant outcome measures when assessing health technologies

Clinicians
• Promote development of *decision support systems* for diagnosis, prognosis and treatment
• Offer education and training in and access to real-world evidence data

Researchers
Push *innovation* in data science
Find, access and analyze big datasets for research purposes
Enable *collaboration* between researchers leading to publications, project applications, ...
Increase data quality to support development of decision support systems for diagnosis, prognosis and treatment

The MS Data Alliance is an joint initiative lead by Hasselt University and the European Multiple Sclerosis Platform

The MSDA project initialisation group:
EMSP, the Universities of Hasselt and Swansea, the University Medical Center Göttingen, the German MS Registry plus Biogen and Celgene as industry voice

Want more information?
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MS Data Alliance

EMSP **Joining Forces**

New Executive Committee

Meet Our Team

Pedro Carrascal

President

Elisabeth Kasilingam

Managing Director

Christoph Thalheim

Director External Affairs

Nora Kriauzaite

Programme Coordinator

Emma Rogan

Project Coordinator

Máté László Tagaj

Communications and Membership Officer

Žilvinas Gavėnas

ICT Coordinator

Krystalenia Ampreou

Administrative Assistant

Industry Partners

Key **Milestones**

MS Barometer 2008

John Golding

esident, European MS

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Wishing you **a lovely evening!**

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