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.
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.
Our Expertise

30 years of advocacy for people with MS across Europe.

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 & Expertise
Share and promote evidence-based best practice. Foster effective cooperation between people affected with MS, health care 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.
Empowering MS societies and MSers

Strive for better access to healthcare, treatments and therapies

Progress our flagship projects

Strengthening partnerships

Secretariat capacity building
Empowering People with MS

#EMSP2018
Clinical trials workshop
Baltic states meeting

Young people’s network
Comms network
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**
Access to Better treatment and care

MS Nurse PRO

MS Barometer

Cost-of illness study

N2B-patch

EMA
Advocacy and Campaigning
Access to Employment

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
MS Data Alliance

**MSDA Academy**

**Objective 1: community engagement & awareness raising**
WP2: Community engagement strategy
Dissemination & communication - PR strategy - Nurse PRO training module

WP3: Stakeholder engagement meetings
Meeting 1: Inform stakeholders on MSDA strategy and discuss challenges and opportunities
Meeting 2: MSDA evaluation + future steps

**Objective 3: Implementation strategies & standard operating procedures**
WP7: MSDA academy workshops
Testimonials - Informed consents - GDPR – minimal data set including MRI outcome - PRO - Quality and interoperability

**MS Data Alliance**
Better data for better decision making
EMA approved minimal data set and quality standards
Data sharing challenges: towards a federated IT independent data ecosystem

**MSDA Toolbox**

**Objective 2: Tools for data discovery & sharing**

WP4: MSDA CATALOGUE
- FIND YOUR COHORT - web-based application that integrates MS data registries and cohorts, allowing end-users to browse meta-data

WP5: SWITCHBOX - TransForMS
- DATA HARMONIZATION - harmonizing an EMA minimal data set (incl. PRO and MRI data);

WP6: MSDA COHORT EXPLORER
- REQUEST & ANALYZE YOUR DATA - Enables searching aggregated data, allows requests for data and provides a platform to analyze this data securely.
EMSP Joining Forces
Meet Our Team

Pedro Carrascal
President

Elisabeth Kasilingam
Managing Director

Christoph Thalheim
Director External Affairs

Nora Kriausaitė
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
Wishing you a lovely evening!

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