



**EMPOWERING LIVES, SHAPING THE FUTURE:**

# A MANIFESTO FOR A UNIFIED APPROACH TO MULTIPLE SCLEROSIS

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EU 2024 ELECTIONS

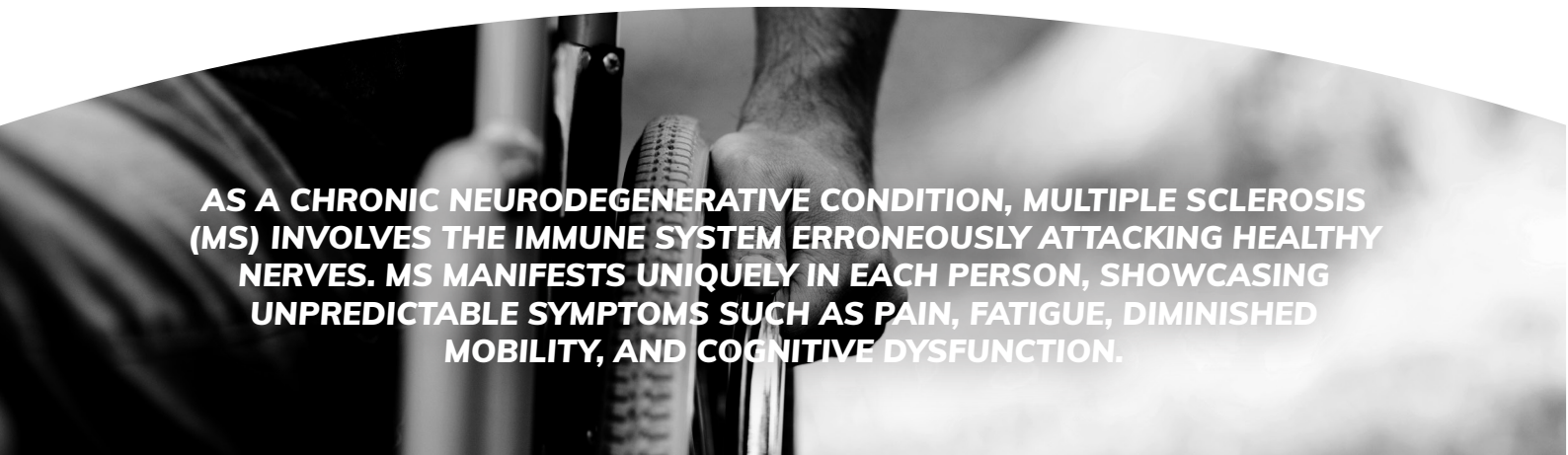
**THIS MANIFESTO IS A RESPONSE TO THE URGENT CALL TO ADDRESS THE UNMET NEEDS FACED BY OVER:**

**1.2 MILLION**  
**INDIVIDUALS**  
LIVING WITH MULTIPLE SCLEROSIS (MS) ACROSS EUROPE

**EVERY 5 MINUTES**

SOMEONE, SOMEWHERE IN THE WORLD IS DIAGNOSED WITH MS

THE PREVALENCE OF MS IS SUBSTANTIAL, WITH  
**37,000 NEW MS DIAGNOSES**  
REPORTED ACROSS 27 COUNTRIES IN EUROPE IN 2020



AS A CHRONIC NEURODEGENERATIVE CONDITION, MULTIPLE SCLEROSIS (MS) INVOLVES THE IMMUNE SYSTEM ERRONEOUSLY ATTACKING HEALTHY NERVES. MS MANIFESTS UNIQUELY IN EACH PERSON, SHOWCASING UNPREDICTABLE SYMPTOMS SUCH AS PAIN, FATIGUE, DIMINISHED MOBILITY, AND COGNITIVE DYSFUNCTION.

# UNMET NEEDS IN THE MANAGEMENT OF MULTIPLE SCLEROSIS

## Inequitable Access to Appropriate and Timely Care

Despite the unpredictable nature of this neurodegenerative disease, timely diagnosis, treatment, and support influence disease progression and enhance the quality of life of those diagnosed with MS. There are significant differences in the availability of treatment and care across Europe, revealing critical systemic issues.

Particularly, **rehabilitation remains overlooked**, with less than half of MS patients accessing required physical rehabilitation, and even fewer benefitting from psychological, cognitive, and occupational rehabilitation.

Despite the presence of neurologists and nurses in multi-disciplinary MS teams, the **shortage of specialists, exacerbated by divided attention and an increasing lack of personnel, leads to inadequate care for MS patients**. This shortage is underscored by alarming ratios from countries like Latvia and Lithuania report having more than one neurologist per 10 people with MS against those like Ireland reporting one neurologist for every 281.

**Inequalities in the availability and reimbursement policies for Disease-Modifying Drugs (DMDs)<sup>1</sup>** among Member States represent yet another barrier for MS patients across Europe to access adequate and timely treatment. DMDs are vital in MS care, minimising relapses and slowing disease progression. Despite this, in 2018, 43% of people with MS in Europe were not receiving DMD treatment, facing barriers such as high co-payments, reluctance from healthcare professionals to approve changes to more expensive therapies, shortages of neurologists to prescribe and oversee treatments, and geographical challenges in accessing treatment.

<sup>1</sup>Approved by the European Medicines Agency (EMA)



To have access to appropriate and timely care, we call on the EU to lead the way by actively supporting the specialisation of healthcare professionals in general education pathways for neurological conditions such as MS, including the development of accredited MS specialist courses for healthcare professionals and driving their widespread adoption across all countries.



## Social Inclusion and Protection

**The unmet needs of individuals with MS extend beyond health; it also impacts social care, employment, and education.**

MS diagnoses often disrupt pivotal life stages like education, career-building, and family planning. For instance, MS is commonly diagnosed at age 20–40 and approximately 75% of patients with MS are women.

Despite this, 21 countries in Europe still lack adequate support for young people with MS to complete their education, and in at least seven countries, legal protection against unfair dismissal from work is absent. In the EU, there are only five countries where at least 50% of people with MS are in employment: Belgium, Czech Republic, Denmark, Finland and Germany.

Additionally, it is crucial to recognise the key role of the family caregivers<sup>2</sup>. Without adequate support, caregivers struggle to provide assistance while maintaining an active professional life and good mental health leading to potential burnout and strained relationships.

<sup>2</sup>Relatives, friends, or neighbours who provide assistance related to an underlying physical or mental disability for at-home care delivery and assist in the activities of daily living (ADLs) who are unpaid and have no formal training to provide those services.

**We call on our policy decision-makers to our policy to ensure the provision of support encompassing social inclusion, financial assistance and accessibility adaptations for people affected by MS and other progressive neurological conditions. These measures would empower individuals affected by MS to continue their education, maintain employment, and contribute actively to society, guided by the principles of human rights, equality, social inclusion, and social protection.**

**To empower young people with disabilities, including those with MS, we call for the expansion of employment and educational support through existing European studies and employment programs. Raising awareness about neurological conditions like MS within the workplace is essential, holding employers accountable for their social responsibility. This involves ensuring the implementation of educational programs provided by civil society organisations and people affected by MS.**

## Economic and Workforce Impact

People affected by MS also count among them dynamic young professionals and individuals in the prime of their careers who with the appropriate support, can contribute to the European workforce. However, data collected in 15 countries across Europe showed that only 48% of people with MS are in full-time or part-time employment.

Addressing these unmet needs will allow the retention and harnessing of talents and skills, while fostering a positive impact on society, reducing the strain on disability and unemployment insurance systems.



# IMPROVING THE QUALITY OF LIFE OF PEOPLE AFFECTED BY MS THROUGH THE CONSOLIDATION OF EXISTING EU ACTIONS

During the past years, the EU has made positive efforts in setting the foundations for the implementation of the rights of people with disabilities and long-term health conditions. However, the persistent challenges in addressing MS requires a tenacious approach. Therefore, we are calling our policy decision-makers to implement changes for healthier and sustainable health and social care systems that truly support those affected by MS and other neurological conditions and further elevate the rights and well-being of people living with MS, building on the following instruments:



A sustained commitment and expanded efforts are still needed to address the unmet needs of those affected by MS across Europe.

# SETTING THE COURSE: PRIORITIES FOR 2024-2029

To tackle such a fragmented political response to MS, a single, comprehensive and cross-sectoral strategy is required. Therefore, we ask:

1

**To make enhanced timely and affordable care delivery and high-quality rehabilitation services a cornerstone of the upcoming work of EU institutions,** including the Framework for Social Services of Excellence for persons with disabilities.

This shall be ensured through the establishment of **specialised EU trainings for social care providers and healthcare professionals.** Such training programmes shall draw inspiration from existing successful EU-funded projects like the Inter-Specialty Cancer Training (INTERACT-EUROPE) initiated under Europe's Beating Cancer Plan.

**Additionally, there is a pressing need to consistently include enhanced education on MS and other neurological conditions in general education programs for healthcare professionals.** This is particularly crucial for general practitioners, often serving as the first point of contact for people with MS.

2

**To empower the European workforce through inclusive employment and education practices and enhanced social support.**

Incentivising the recruitment and retention of people with disabilities in employment and strengthening legal protections against dismissal due to a health condition and aligning with upcoming deliverables in the Disability Employment Package are essential. Promoting an inclusive environment that enables individuals with MS and other chronic conditions to pursue careers and access lifelong learning programs can be accomplished by establishing a harmonised framework for flexible work, offering high-quality e-learning options, expanding ERASMUS+ Virtual Exchange activities for adult learners with limited mobility, and implementing clear criteria for unified protection against dismissal due to health conditions. It is also crucial to encourage the Member States to establish a **dedicated fund to increase financial security for people with MS and other chronic conditions,** who need to reduce work time or quit their jobs. This initiative could be implemented by building on and expanding existing funds, such as the European Social Fund.

3

**To incentivise data collection and research on MS** through existing EU funding programmes and by supporting the development of the infrastructure for the collection and sharing of real-world data through the upcoming European Health Data Space.

This should aim at fostering a collaborative approach to enhance understanding and management of MS on a broader scale and ensure that advancements in research translate into tangible benefits for individuals affected by MS, and finding a cure.

# PLEDGE BY THE CANDIDATE FOR THE EUROPEAN PARLIAMENT 2024-2029

I recognise the urgency to address the persistent unmet needs of over a million people living with MS across Europe, and as a Member of the European Parliament, I pledge to:

- **commit to the empowerment of individuals with MS throughout the upcoming mandate (2024-2029).**
- **champion the principles of human rights, equality, social inclusion, and social protection for the MS community.**
- **actively contribute to creating a more inclusive, supportive, and empowering environment for the MS community in Europe.**



MEP Sirpa Pietikäinen  
Group of the European People's Party (EPP)  
Finland



MEP Stelios Kypourouopoulos  
Group of the European People's Party (EPP)  
Greece



MEP Milan Brglez  
Group of the Progressive Alliance of Socialists and Democrats (S&D)  
Slovenia



MEP Maria da Graça Carvalho  
Group of the European People's Party (EPP)  
Portugal



MEP Adam Jarubas  
Group of the European People's Party (EPP)  
Poland



MEP Tilly Metz  
Group of the Greens/European Free Alliance  
Luxembourg

## ENDORSEMENT

This Manifesto has received the endorsement of:



## ABOUT EMSP

The **European Multiple Sclerosis Platform (EMSP)** is the leading voice of over **1 million people living with multiple sclerosis (MS) throughout Europe. EMSP unites 43 member societies across 37 European countries with a singular mission: to drive critical, state-of-the-art research and advance MS-relevant policies and treatments, and possible cure.** Since its foundation in 1989, EMSP has remained steadfast in its commitment to enhancing the management of MS and the well-being of people affected by MS. Through dedicated advocacy, data collection, support for scientific research, and its pivotal MS Barometer, EMSP endeavours to address disparities in MS care while championing the principles of human rights, equality, social inclusion, and social protection for those affected by MS.



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