

# EVENT REPORT



## **CALL TO ACTION**

### **Access to Employment for People with Multiple Sclerosis**

**An event  
hosted by  
Ádám KÓSA**

**May 26, 2015  
European Parliament, Brussels**

**Organised in partnership with the European Multiple Sclerosis Platform**

# SUMMARY:

## SUPPORTING PEOPLE WITH MS IN EMPLOYMENT



*"We need to work together. But not only institutions with EU member states, we also need civil society and NGOs. You are the ones who keep us connected to reality."*

Maria Luisa Cabral, European Commission

The European Multiple Sclerosis Platform (**EMSP**) is asking fellow patient organisations, national and European decision-makers and European employers to support a recently launched **Employment Pact** for people with multiple sclerosis (MS) and other neurodegenerative diseases (NDDs).

There are over 9 million people living with NDDs in Europe.

Among them, 700,000 have MS.

The Employment Pact aims to persuade European businesses and other relevant stakeholders that people with MS are able and willing to work,



and that they can be integrated into the workplace with only minor adaptations.



The Call to Action was launched on 26 May in the European Parliament (EP) in Brussels and chaired by MEP Adam Kosa (**video above**), Co-President of the EP Disability Intergroup.

The Employment Pact was introduced at the same venue on 24 March, at an event co-chaired by MEPs Rosa Estaras-Ferragut (**video below**) and Jeroen Lenaers.



EMSP will work with all Pact supporters to ensure a fair and indiscriminate access to jobs for people with MS and other NDDs.

# EU'S FIRST DEAF MEP: WE MUST FIND REAL SOLUTIONS



Member of the European Parliament Ádám Kósa is Europe's first deaf MEP. His own experience with disability is an important reason for his support of EMSP's Employment Pact.

Another factor is Mr Kósa's awareness of the challenges facing people with multiple sclerosis (MS):

*"We are seeing people between the ages of 20 and 40 years diagnosed with MS. This is in the prime of their lives and it puts them at a great disadvantage".*

*"I know what it is like to be a person with a disability trying to find work. I see the need to address this issue and I know we must find real solutions."*

MEP Ádám Kósa

Now in his second mandate as a Member of the European Parliament, Mr Kósa was among the authors of a successful 2012 Written Declaration on tackling multiple sclerosis ([linked image below](#)).



As Mr Kósa ([pictured above](#)) mentions, over 60 percent of MEPs, in real numbers more than 400, signed the Written Declaration three years ago.

Although non-binding in nature, this Written Declaration acknowledged

the barriers in access to employment, treatment and care for people with multiple sclerosis.

*"My advice to people with MS: don't give up!"*  
MEP Ádám Kósa

# WORKING TOGETHER: EU INSTITUTIONS AND PATIENT ORGANISATIONS



The European Multiple Sclerosis Platform's Chief Executive Maggie Alexander (**picture above**) took the opportunity of EMSP's Call to Action event to send a signal that the Employment Pact represents a change for all interested stakeholders to act with urgency.

Ms Alexander (**video below**) also conveyed a message to employers:

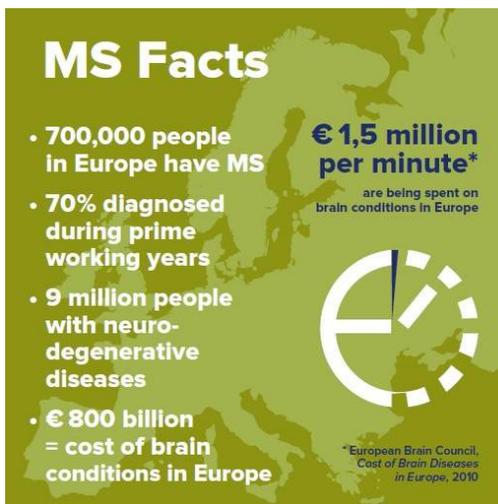
*"If you're a good employer of somebody with MS, you're a good employer per se because you will have the right kind of work policies, conditions and awareness within your organisation."*



The European Commission was represented at the event by Maria Luisa Cabral (**picture above**), Head of Unit, Directorate-General for Employment, Social Affairs and Inclusion.

*"The European Commission has a clear agenda for creating jobs and growth, promoting a Europe where discrimination has no place",* said Ms Cabral.

She also mentioned the United Nations Convention on the Rights of People with Disabilities (UNCRPD), which brings certain obligations for the EU (**below**).



*"We are asking our member societies, partner NGOs and members of the European Parliament to endorse this Pact. To spread the word and demonstrate good practice."*

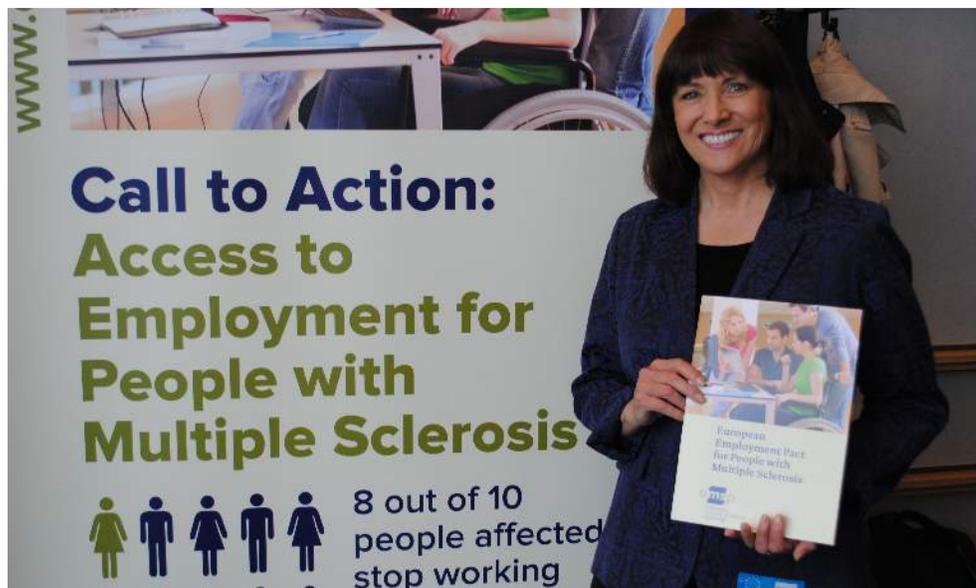
EMSP's Chief Executive Maggie Alexander

## United Nations Convention on the Rights of Persons with Disabilities

### ARTICLE 27

State Parties recognise the right of a person with disabilities to work on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.

# CONQUERING MS: SCALING MOUNT EVEREST



EMSP's Ambassador for the Call to Action event on the Employment Pact was MS advocate Lori Schneider (**picture above**), the first person with multiple sclerosis (MS) to scale Mount Everest and the Seven Summits.

Having lived with MS for almost 20 years, Ms Schneider made a passionate address urging employers to give people with similar conditions a chance:

*"We each have our own disabilities. But don't think that it is impossible for a person with a neurological disease to hold down a job, because it is not. Most people like me go months or years without even having symptoms. It is a matter of a few adaptations."*

## BIO

US-based Lori Schneider is an international speaker, a mountain climber, an advocate for people living with MS and other neurological conditions, a life-long learner and teacher. She was diagnosed with multiple sclerosis in 1999, aged 34.

This shock also helped her accelerate her love of travel and mountains, and set out to climb the highest peak on each continent. In 2009, Ms Schneider became the first person with MS to summit Mount Everest.

Find out more at <http://www.empowermentthroughadventure.com> and <http://www.lorischneider.net>

*"We all have different symptoms with MS, but we also all have different dreams. My dream was to climb mountains. I had to believe in myself in order to give myself permission to try. There's no summit in our careers and in our life. We can all believe and we can all achieve more than we ever thought possible."*

MS advocate Lori Schneider  
(video above)

# PANEL DISCUSSION

## A COLLABORATIVE APPROACH: MS AND EMPLOYMENT

### PATIENT PERSPECTIVE - GEORGE PEPPER, Founder of social network shift.ms

George Pepper was diagnosed with MS in 2005, aged 22.

He mentioned he was 'lucky' because his employer at the time allowed him a flexible working schedule.

Mr Pepper said that, generally, employers are unaware of how to implement basic adaptations for people with symptoms such as fatigue or blurred vision.

A few examples of basic adaptations:

- Having flexibility to work from home
- Commuting outside rush hour
- Finding a suitable desk location, preferably close to toilets
- The need for regular and open communication with employers

*"Early retirement and loss of employment is the biggest economic burden for people with MS in Europe."*

MS advocate George Pepper



George Pepper (**right**) talking to the moderator of the panel, healthcare specialist Dee O'Sullivan, Founder of the PatientView network

### EMPLOYER PERSPECTIVE - ANTONELLA CARDONE, Executive Director of Fit for Work EU

Antonella Cardone said that "employers need to really consider MS in a specific way because of the unpredictable and fluctuating nature of the condition".

She added that businesses should look at people's capacity, not incapacity. Her concrete recommendations:

- Communication between employees, line managers, and healthcare professionals
- Raising awareness within teams
- Listening to individuals and addressing individual needs
- Identifying and sharing good practice in the workplace



*"Work opens doors for people. And can provide income, a sense of purpose, dignity and social connectivity."*

Antonella Cardone, Fit for Work EU (**picture above**)



**POLICY-MAKER PERSPECTIVE - SIMONA GIRRATANO,  
European Disability Forum (EDF)**

Simona Gerratano (picture below) mentioned that in tackling employment issues the European Union, albeit not directly responsible, can use a number of instruments at its disposal.

She referred especially to the Employment Equality Directive which, according to Ms Gerratano, has limited effectiveness:

*"I'm talking about the provision for **reasonable accommodation** in particular. In this case, there is a lack of information and awareness on all sides, chiefly among employers."*



What can reasonable accommodation entail? Among others:

- Flexible working hours
- Guidance of implementation at national level
- Accessible transport, social security, health services

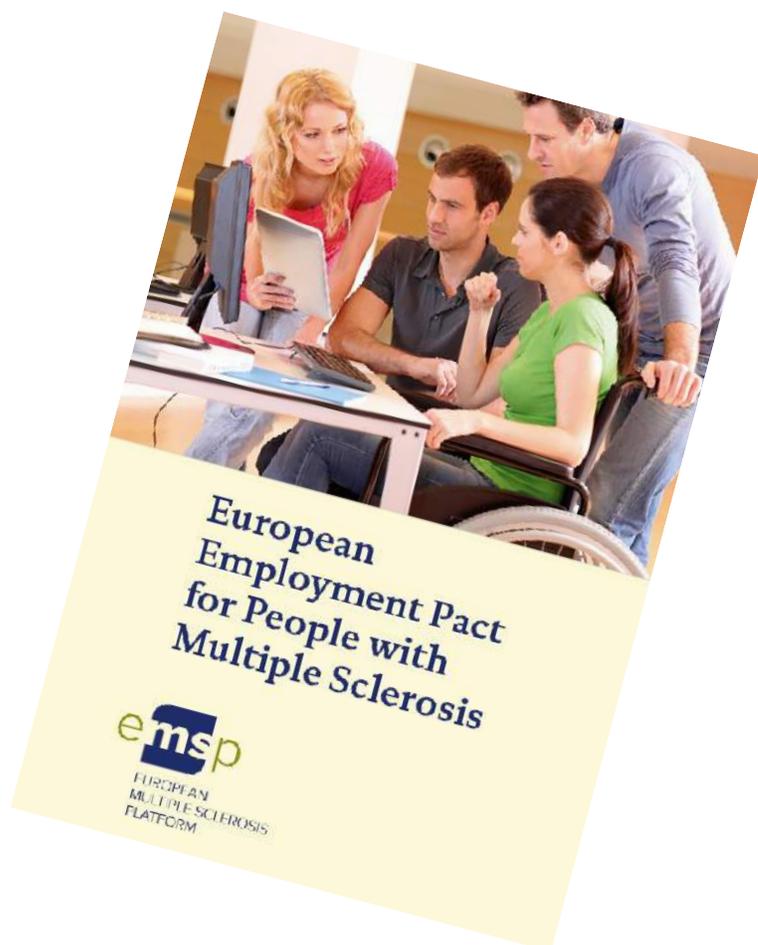
Simona Gerratano, EDF:

The overall employment objective of the EU is to reach 75% and more employment rate across the EU. For persons with disabilities, this rate is currently at 47%



*"What has been interesting from the three presentations is that there is clearly a need for more awareness and education regarding the situation of people with MS on the labour market."*

Dee O'Sullivan, PatientView



## What is MS?

Multiple sclerosis is one of the most common long-term conditions affecting the central nervous system (brain and spinal cord) and the main cause of non-traumatic disability in young adults.

MS is a neurodegenerative disease, a group of conditions that includes, amongst others, Parkinson's, Alzheimer's and Huntington's disease.

**MS is mainly diagnosed between the ages of 20 and 40.**



EUROPEAN  
MULTIPLE SCLEROSIS  
PLATFORM

700,000 PEOPLE

# BACKGROUND NOTES



## EMSP

The European Multiple Sclerosis Platform is an umbrella organisation of 41 national MS societies in 36 European countries. EMSP works at the crossroads of healthcare policy, patient advocacy and research in MS and its main goal is to raise the voice of people living with multiple sclerosis in Europe.

More information on EMSP and multiple sclerosis at [www.emsp.org](http://www.emsp.org).

## EDF

European Disability Forum is an independent NGO which aims to influence policy-makers on behalf of 80 million people living with disabilities in Europe. EDF is the only European platform run by persons with disabilities and their families.

More information on <http://www.edf-feph.org>.

## FIT FOR WORK

Fit for Work Europe is a multi-stakeholder coalition driving policy and practice change across the work and health agendas. Its aim is to deliver more investment in sustainable healthcare by promoting and implementing early intervention practices. Fit for Work Europe is a project led by The Work Foundation.

More information on <http://www.fitforworkeurope.eu>.

## SHIFT.MS

Shift.ms is a social network for people with multiple sclerosis. Its aim is to create a positive, enabling community which empowers people with MS to acknowledge their condition, rethink how to achieve their ambitions and get on with their lives.

More information on <http://shift.ms>.

## PATIENT VIEW

Network offering "patient views for better patient care".

More information on <http://www.patient-view.com>