





PRESS RELEASE

Keeping people with neurodegenerative diseases in work: Pledge for action at EU level

Brussels, Belgium (July 9, 2013) – Member of the European Parliament Angelika Werthmann brought a fresh perspective towards improving the quality of life of over 9 million people living with neurodegenerative diseases (NDDs) in Europe. Following a panel discussion on the challenges of NDDs in the workplace, MEP Werthmann offered to launch and sign a 'Written Declaration' of EU parliamentarians, in order "to give people with neurodegenerative diseases better opportunities within Europe".

Neurodegenerative conditions such as Parkinson's disease, Alzheimer's disease and multiple sclerosis affect people at different stages of their professional lives. Contrary to common belief, one in ten people with Parkinson's gets diagnosed at working age and Alzheimer's disease can affect people well before retirement. As for multiple sclerosis, the diagnosis hits fairly early, with the average age being 29. What all three diseases have in common is that the people affected tend to leave the workplace far earlier than necessitated by their condition. For example, half of those with MS stop working three years after diagnosis and, according to a recent UK survey, 60 per cent of people with Parkinson's are reported to retire from work early.

Representatives from the <u>European Multiple Sclerosis Platform</u> (EMSP), <u>Alzheimer Europe</u> and the <u>European Parkinson's Disease Association</u> (EPDA) - co-organisers of the event - highlighted what could be done to help people stay in work:

- Raising awareness improving understanding and fighting stigma, for instance through education and training of employers and colleagues;
- Adapting social legislation offering better protection for people with NDDs and their carers through social legislation, such as improved pension rights;
- Work place adaptations allowing people to work with their remaining competencies. For instance, fatigue is a common feature for some NDDs. Many people could continue working if adjustments such as parking spaces, flexible schedules and special resting areas were provided;
- **Early intervention** early access to diagnosis and treatment allows people to remain professionally active.

The commitment of EU parliamentarians should help people with neurodegenerative diseases achieve recognition for the contribution they can make to companies and to the wider culture of the EU. "We are the politicians, we are the stakeholders and we will be asked urgently to take the appropriate steps. I do not think I'm being too optimistic if I aim to have the Written Declaration ready by September-October", Mrs Werthmann pledged.







Appropriate measures also require financial commitment. Two recent developments offer positive perspectives leading up to 2020: the European Commission, Parliament and Council of the European Union agreed in principle to increase the budget for brain research and European leaders promised special funding to boost employment for young people across the EU.

As Shana Pezaro, a young person with MS, underlined in her speech from the panel discussion on neurodegenerative diseases in the workplace, "we're not asking for charity, we're asking for our talent to be put to good use".

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