

The European Parkinson's Disease Association (EPDA) welcomes the opportunity to contribute to:
the European Commission's Consultation on the Green Paper on a Common Strategic Framework for future EU Research and Innovation Funding.

EPDA is a not-for-profit organisation and is the only European umbrella organisation for Parkinson's disease. Parkinson's is a serious chronic neurodegenerative condition with no cure, which affects all aspects of daily living. Parkinson's is the most common neurodegenerative condition after Alzheimer's affecting an estimated 1.2 million¹ people in Europe alone. Incidence of Parkinson's is forecast to double by 2050 primarily as a result of the ageing population. Studies in the US² have shown prevalence increases rapidly over the age of 60 years, with only 4% of the cases being under the age of 50 years.

Treatment and management is available for a number of aspects of the disease but not yet accessible to all. On-going research has resulted in significant improvements but more is needed to delay, stop or even reverse Parkinson's. EPDA's vision is to enable a full life with Parkinson's whilst supporting the search for a cure.

The EPDA is a partner in the REPLACES programme (www.replaces-pd.org/) which has received funding under the 7th Framework Programme. Greater administrative simplification of projects would be welcomed by patient organisations such as EPDA as our staff capacity is small. EPDA would also welcome a greater patient involvement in EU health research to integrate researchers' theoretical expertise with patients' real-world knowledge and experience.

EPDA agrees with the Green Paper that EU funding programmes must address societal challenges and radically simplify access, reducing time to market and strengthening excellence. Certainly Europe needs innovative solutions to assist the challenge of our ageing population. The EU Active and Healthy Ageing Innovation Partnership has set a target of two years increased life expectancy and quality of life. We would however note that although Europeans are living longer not all years of a person's life are typically lived in perfect health. Chronic diseases, such as Parkinson's disease, become more prevalent with an ageing population.

We hope "innovation" will be broadly interpreted; innovation does not need to be expensive, and should be valued for its potential to improve quality of services, quality of care, equity in access, and the quality of life. Projects that aim to empower patients and citizens, and improve health literacy in the EU are very valuable sources of innovation. As an example of a user-friendly patient tool we would cite Parkinson's Decision Aid³.

¹Andlin-Sobocki 2005

²<http://aje.oxfordjournals.org/content/157/11/1015.full>

³www.parkinsonsdecisionaid.eu.com

As you are aware under the existing funding programme over 6 billion euro has been allocated to health. From this budget there are currently 34 EU financed projects for neurodegenerative diseases (NDD) with funding totalling EUR 159 million⁴. EPDA anticipates the next research programme will maintain or even increase the overall health budget. EPDA also trusts sufficient resources will be allocated to NDDs in order to reflect the impact of NDD to European society.

EPDA would welcome research into the prevention of Parkinson's Disease. EPDA endorses the recommendation in the European Parliament resolution of 19 January 2011 of the need to include projects in the fields of non-drug, behavioural and cognitive therapies as currently they are insufficiently explored.

We present our points in summary below and thank you for your consideration.

- EPDA hopes the next research programme **will maintain or even increase the overall health budget;**
- EPDA trusts sufficient **resources will be allocated to neurodegenerative diseases, including Parkinson's disease, in order to more accurately reflect the impact of these chronic conditions on European society;**
- EPDA considers that **research into prevention of Parkinson's Disease** is highly desirable;
- EPDA endorses the recommendation in the European Parliament resolution of 19 January 2011 of the need to **include projects in the fields of non-drug, behavioural and cognitive therapies** as currently they are insufficiently explored;
- **Greater administrative simplification would be welcomed** by EPDA;
- EPDA would also welcome a **greater patient involvement in EU health research;**

⁴ European Parliament resolution of 19 January 2011 (2010/2084(INI))