

European Parkinson's Disease Association (EPDA)

– *Life with Parkinson's* campaign –

What is the EPDA?

The EPDA is a European body that aims to ease the lives of people with Parkinson's disease and their families and carers by promoting a constructive dialogue between science and society, and by encouraging and supporting the development of national Parkinson's organisations.

Its specific objectives are to:

- Promote international understanding of Parkinson's disease
- Enable patients and carers to draw on best caring practice worldwide
- Provide access to the latest medical and surgical advice
- Exchange knowledge and understanding of the care of Parkinson's to help patient and carers make informed choices to achieve the best quality of life possible
- Develop knowledge and awareness of the medical, social and personal needs of people living with Parkinson's and overcome barriers to good communication with patients, their families and between professionals

The EPDA is a non-religious, non-political, and non-profit making organisation. It was founded in June 1992, in Munich, with a membership of nine European Parkinson's patient organisations; the EPDA currently has a membership of forty-one organisations across Europe. Further information is available at www.epda.eu.com.

What is *Life with Parkinson's*?

Life with Parkinson's is an educational campaign which will help to raise awareness about the impact that Parkinson's has on daily life and improve the understanding and knowledge relevant for all stages of the disease.

It hopes to:

- Highlight the challenges experienced by people with Parkinson's
- Raise awareness, especially its consequences
- Influence decision makers
- Raise funds for resources, management and research projects.

The campaign booklet focuses on the challenges of living with Parkinson's. It highlights the importance of early diagnosis and treatment to delay the progression of the disease and to prolong a good quality of life. It also illustrates the economic and social burden in the late stages

where the impact is at its greatest on people with Parkinson's, their families, carers and society as a whole. The need for such a campaign has been highlighted by the results of a recent survey that show levels of awareness of Parkinson's among the general public in Europe (see enclosed survey executive summary).

Multiple language versions of ***Life with Parkinson's*** will be launched at the International Congress of Parkinson's Disease and Movement Disorders in Paris on the 8th June 2009. Versions of the booklet in English will be distributed at the congress

The focus of the ***Life with Parkinson's*** campaign is a booklet that includes comprehensive information on all aspects of living with this difficult condition:

- *What is Parkinson's disease?* This section covers subjects such as the cause and symptoms of Parkinson's as well as coping strategies and information for families
- *Prevalence across Europe*
- *Diagnosis and treatment of Parkinson's.* This new section includes details of symptoms that may be seen in the early stages of Parkinson's to help people present for early diagnosis and treatment
- *Indications and contraindications for advanced Parkinson's disease therapies*
- *Case studies* where people with Parkinson's share their experiences
- *Questions on Parkinson's disease* providing answers to frequently asked questions.

The copy has been written by the EPDA and by medical professionals, Professor F Stocchi, (Rome, Italy) and Professor P. Odin (Bremerhaven) as well as a number of people with Parkinson's who tell their own stories.

The ***Life with Parkinson's*** booklet will be distributed:

- At the Movement Disorder Society in Paris on the 8th June 2009
- On the EPDA website www.parkinsonsawareness.eu.com.
- Through EPDA member organisations

What languages is *Life with Parkinson's* available in?

The information is available in the following languages through support from H. Lundbeck A/S and Teva Pharmaceutical Industries Limited; English, French, German, Italian, Spanish and Turkish. The EPDA and its member associations are also supporting translation to Swedish, Norwegian, Romanian and Greek.

How has the campaign been funded?

The EPDA would like to extend special thanks to all the people who have contributed by providing their personal stories.

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