

## Innovation and Education to Improve the Management of Parkinson's Disease

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Parkinson's disease (PD) was the first neurodegenerative disease in which a neurotransmitter replacement therapy was proven effective. That agent, levodopa, which replaces the deficiency in dopamine, is still the gold standard treatment more than 40 years after its introduction. While management has advanced since the 1960s with the use of alternative symptomatic treatments, adjunctive agents, electric brain stimulation approaches and new methods of drug delivery, no treatment is currently known that is capable of arresting the progressive nature of the disease. As PD progresses, affected patients often experience a multitude of symptoms related to both the motor and non-motor manifestations of the disorder. Successful management of these manifestations requires knowledge of their pathophysiology and skilful application of available treatment modalities. While these developments have helped improve the quality of life (QoL) of people living with PD, many patients still experience disabling symptoms related to the disease itself and/or to complications of chronic administration of anti-parkinsonian drugs. Hence, there is still a need to have a better understanding of the disease processes, the factors that are important to a patient's QoL and to develop new therapeutic approaches. There is also a basic need for better access to the full range of PD treatments. Many patients feel powerless to access the appropriate resources, and those that do gain access often expend a great deal of energy in doing so and require a great deal of knowledge of the disease. Several recent initiatives, however, have sought to improve this situation, such as ParkinsonNet in The Netherlands ([www.parkinsonnet.nl/welcome.aspx](http://www.parkinsonnet.nl/welcome.aspx)), which provides information to patients that allows them to contribute to healthcare decisions, gives access to experts and builds an online network of patients.<sup>1</sup>

The European Parkinson's Disease Association (EPDA: [www.epda.eu.com](http://www.epda.eu.com)) has been an important development in the campaign to improve access to PD treatments. The aim of EPDA is to improve the potential of patients with PD to lead full lives, support the search for a cure and spearhead important initiatives for raising awareness and stimulating better communication.

### The European Parkinson's Disease Association Charter

The EPDA represents 44 national organisations throughout Europe reaching 1.2 million people with PD and their families. The organisation promotes a constructive dialogue between the scientific community,

people with PD and their carers, and society. In 1997, the EPDA published its charter (see *Figure 1*), and on 11 April 2010, the 'Move for Change' initiative was launched to examine how close the community of healthcare providers, patients and carers are to achieving the aims of the charter. Move for Change is an online survey of patients with PD that is open to any patient accessing the EPDA website. The first part of the initiative ran from 12 April 2010 to 29 October 2010, and surveyed patients to assess how well the first two points on the charter (see *Figure 1*) were being met. Subsequent follow-up surveys will assess the other points on the charter (see *Figure 1*) in 2011 and 2012.

The awareness campaign 'Life with Parkinson's' is another initiative from the EPDA, which provides information on the diagnosis, treatment and impact of the disease on people with PD and their families. This is being updated to include further information on:

- the complexity of PD;
- the impact of non-motor symptoms;
- the fact that non-motor symptoms may precede a diagnosis based on motor symptoms; and
- the need to treat PD as soon as it is diagnosed.

These two initiatives, combined with a consensus statement on PD, will be used to raise awareness among decision-makers of the impact of the disease on society and the economy. The idea is that such initiatives will be publicised at international meetings, as they were at the International Forum on Advanced Parkinson's Disease in Athens last year, and that greater awareness of the EPDA's campaigns will ultimately lead to greater equality in the treatment of patients. This forum was an ideal platform for the EPDA to publicise its ideas, as it shares the common goals of stimulating discussions between various groups and providing the audience with the latest findings in the disease area.

### This Supplement

At the fourth International Forum on Advanced Parkinson's Disease in Athens (sponsored by Abbott), over 100 participants gathered, with the aim of discussing the latest issues in clinical care of PD, including:

- recent advances related to the basic science of PD and to development of new rational therapeutic approaches;
- the value of care and novel partnering programmes to enhance

**Figure 1: The European Parkinson's Disease Association Charter for People with Parkinson's Disease**



outcomes (such as the EPDA initiatives discussed in this introduction); and

- how to improve the QoL of those living with the disease.

Interactive case report sessions helped encourage debate on the practical aspects of managing patients with advanced disease – and in particular the evolving role of continuous dopaminergic stimulation (CDS) therapies was discussed. These CDS therapies (which for the purposes of the meeting encompassed subcutaneous apomorphine infusion, intraduodenal levodopa infusion [Duodopa®], rotigotine patch and deep brain stimulation [DBS]) provide opportunities to optimise control of motor and non-motor symptoms in patients with advanced PD, thus improving QoL.

The meeting provided some cutting edge data on the best ways to manage advanced PD and looked to future developments. The forum also encouraged the dialogue between healthcare professionals and patient representatives that EPDA seeks to promote. This supplement provides a summary of the presentations and their conclusions, and the discussions they stimulated. Major conclusions of the talks and of this supplement include the following.

- Non-motor symptoms are as important as, if not more important than, motor symptoms for the deterioration of QoL in PD. K Ray Chaudhuri in his chapter 'Parkinson's disease and quality of life: a clinician's perspective', emphasises the need for a more holistic approach to the management of patients with PD. Whereas treatment for PD is traditionally initiated on the basis of the patient's motor status, it is crucial that both motor and non-motor symptoms are taken into consideration when deciding on treatment options. As many of the non-motor symptoms that may represent key determinants of QoL in PD, relate at least in part to altered dopaminergic mechanisms, the use of optimal dopaminergic treatment is in order. In this regard, different CDS therapies may be useful in reducing non-motor symptoms and this could help guide future treatment decisions.
- Per Odin, Angelo Antonini, Erik Wolters and K Ray Chaudhuri participated in an interactive session on the selection of patients for CDS therapy. While noting that pulsatile dopaminergic stimulation (as

is achieved by the conventional oral antiparkinsonian medications) is key to the development of motor complications and dyskinesias, the authors point out the advantages of using new therapeutic approaches that provide CDS. Specifically, data on the clinical effectiveness of Duodopa, subcutaneous apomorphine infusion and DBS in alleviating non-motor symptoms of PD are presented. Given the potential drawbacks of these methods, patients need to be carefully selected. Patient selection algorithms for CDS therapies have been accordingly developed. In addition, several cases are presented to test issues related to initiation of CDS therapy and determine the CDS approach best suited for the case under consideration. During the meeting, electronic voting was used to gauge the opinion of the whole audience and to compare it with the opinion of this group of experts, and the action that was eventually taken.

- Nir Giladi in his article 'Multidisciplinary team work can improve the care of families with Parkinson's disease' suggests that, because PD is a multidimensional disorder, a holistic approach is needed to provide maximal benefits to patients, their family and carers. He argues that success is best achieved using a rather large team of experts that includes neurologists, gerontologists, psychiatrists, psychotherapists, sexologists, genetic counsellors, physiotherapists, nurses, social workers and others.
- Tom Isaacs, who has been affected by PD since a very young age and has been living with this disorder for over 15 years, presents a patient's perspective for QoL under PD. He believes that the QoL of a person with PD depends heavily on the effectiveness of communication between patient and healthcare provider. He makes a sensible appeal for a successful interaction between clinical expertise and patient experience, together with lifestyle choice, in order to devise and implement optimal management strategies for the disorder. Improved communication between patients, their spouses/partners, carers and the medical community is needed to ensure that all concerned have common goals for improving QoL.
- Mary Baker argues that there are many challenges for people with PD and notes that, due to the aging of the population, brain diseases will overtake cardiovascular diseases and cancer as the biggest burden on human health. More information is needed to accurately estimate the costs of PD and to compare the cost of CDS therapies that are currently available. Partnering programmes not only enhance the outcomes of treatment but may also reduce costs in the longer term.
- Regarding news from the cutting edge, Alexander Storch presents an update on the gene therapy approach to PD, discussing the available viral vectors for delivery of these genes to the brain and current efforts to introduce genes that restore dopamine synthesis, modulate basal ganglia circuitries and stabilise or reverse the progressive neurodegeneration of PD. In addition, cell-based therapy using bone marrow stromal cells, neural stem cells and pluripotent stem cells is discussed. He notes that efforts to use adult adrenal tissue have succeeded in producing functional dopaminergic neurons. He concludes that while cell-based therapies have been proven in principle they require further development. On the other hand, gene therapies have entered clinical trials and may provide a useful new approach to the management of PD.

We hope the papers included here provide a clear and concise review of the issues surrounding advanced PD, and it is our wish that this information will help to stimulate new ideas and initiatives in managing advanced PD. ■

1. Munneke M, Nijkrake MJ, Keus SH, et al., Efficacy of community-based physiotherapy networks for patients with Parkinson's disease: a cluster-randomised trial, *Lancet Neurol*, 2010;9:46–54.