

# Parkinson's Disease Society

## Policy and Campaigns Briefing

Spring 2008

The Parkinson's Disease Society (PDS) is campaigning to ensure that people with Parkinson's benefit from high-quality treatment, care and research.

This quarterly briefing provides an update on our recent policy and campaign activity across the UK.

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## New All Party Parliamentary Group to press for improved Parkinson's services

A cross-party group of Parliamentarians is coming together to set up an All Party Parliamentary Group (APPG) for Parkinson's disease. The inaugural meeting will take place on **3 June at 5 pm** in **Committee Room G, House of Lords**. The PDS has been invited to provide the Secretariat to the Group.

Despite the existence of the Parkinson's disease NICE Guideline and the Department of Health's National Service Framework for Long-term Conditions, there is great variation in the services and treatments available to people with Parkinson's and their carers in different parts of the country. Key health and social

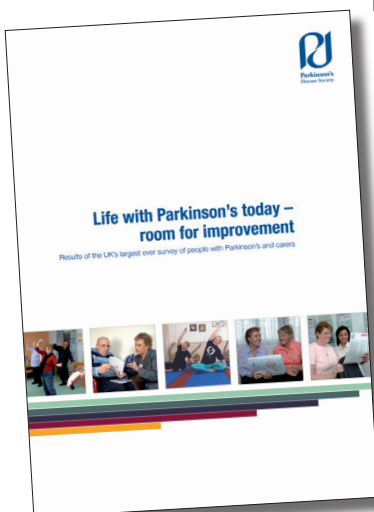
services that people with Parkinson's require include timely diagnosis by a specialist, access

to a specialist nurse, regular reviews by a specialist, appropriate social services care packages, access to allied healthcare professionals and effective support for carers. As a degenerative, incurable condition, it is vital that promising avenues of clinical research remain open within the UK's strict ethical and regulatory framework.

The Group will aim to raise awareness of these issues amongst parliamentarians as well as campaigning to ensure these issues are adequately addressed at national and local levels.

At the meeting, the PDS will be launching a new report, *Life with Parkinson's today – room for improvement*, which details the findings of our recent membership survey, alongside country-specific reports for Wales, Scotland, England and Northern Ireland. The PDS received over 13,000 responses to the survey, which provides a detailed insight into the lives of people with Parkinson's and their carers, and the quality and accessibility of services and support.

If you are a parliamentarian and are interested in joining the new Parkinson's disease APPG, please contact [campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk) or call Anjuli Veall on 020 7932 1323.



## How you can help

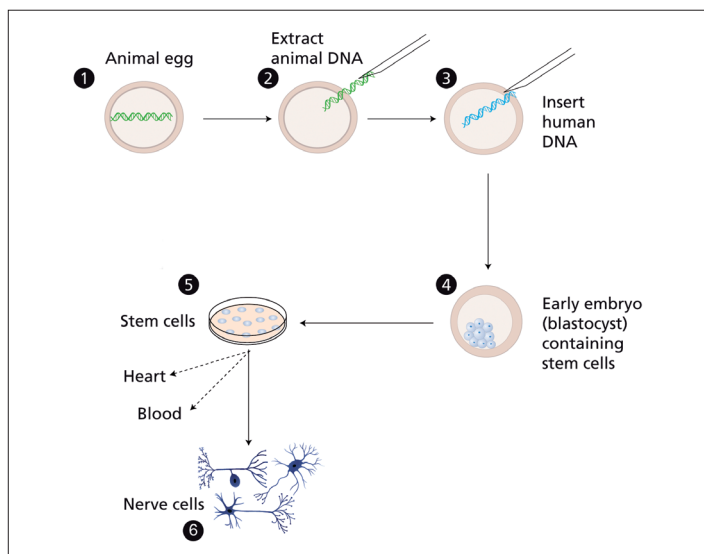
- Come to the inaugural meeting of the Parkinson's APPG on 3 June 2008, 5pm
- Join the Parkinson's APPG and help to champion the needs of people with Parkinson's disease, their family and carers

## Human Fertilisation and Embryology Bill

The Human Fertilisation and Embryology Bill is due to be debated in the House of Commons following its passage through the House of Lords earlier this year. The PDS is urging MPs to support the provisions set out in the Bill to permit the creation of human admixed embryos, such as cytoplasmic hybrid embryos, for research purposes. These offer great potential to further our understanding of devastating and, currently, incurable conditions, such as Parkinson's, and could lead to improved treatments and even potential cures.

The Bill is designed to ensure that this area of research is subject to strict regulation by the Human Fertilisation and Embryology Authority, and research projects involving the creation of human admixed embryos would only be permitted under licence by the regulator.

Cytoplasmic hybrid embryos – created by fusing human DNA taken from a mature adult cell, such as a skin cell, with an animal egg that has had most of its DNA removed – offers an alternative method of producing stem cells without the need for human embryos to be used. See the below diagram.



How Cytoplasmic cells are created

The cells produced using this technology would be genetically more than 99% human, and could potentially be used to inform our understanding of the process by which dopamine-producing nerve cells die in the brains of people with Parkinson's, and how we may be able to prevent, halt or reverse this using therapeutic or other approaches. However, these cells would never themselves be used therapeutically. Regulation requires Cytoplasmic hybrid embryos to be destroyed at a maximum of 14 days of development and so they would never be implanted into a human or any other animal.

The PDS has sent MPs a briefing on this issue in advance of Second Reading in the Commons. Please contact Helen Kirrane for a copy of this briefing, or if you would like any further information on this issue.

## What we want

The PDS want all avenues of research to remain open, subject to strict regulation and controls, because it is not known which route will ultimately lead to the development of more effective therapies and cures for conditions such as Parkinson's.

## How you can help

- Please support the provisions in the Bill to permit the creation of human admixed embryos for research purposes in any votes on this issue

## Prescription charges

A recent MORI survey revealed that approximately 800,000 people were going without vital medication because they could not afford to pay for their prescriptions. This echoes many calls to our Helpline from younger people with Parkinson's who, forced into early retirement because of their condition and with young families to support, have forgone their medication at times to make ends meet.

Although sustained and consistent daily medication is essential for people with Parkinson's to be able to manage the complex symptoms of their condition, Parkinson's is not automatically exempt from charges. And while under the current system, all prescriptions are free for those aged 60 and over, one in 20 people with Parkinson's will be diagnosed before they reach 40, and, therefore, face paying charges for 20 years or more.

Last July, the Government announced that there would be a public consultation on proposals to reform the prescription charges system in England, following an internal Department of Health review. However, although the consultation was originally scheduled for last autumn, it has still not been launched.

## What we want

The PDS is calling for all people with long-term conditions, such as Parkinson's, to be exempt from these charges.

## How you can help

- Please sign EDM 1264, which calls on the Government to bring forward this consultation without any further delay

### EDM 1264: REVIEW OF PRESCRIPTION CHARGES

That this House welcomes the commitment in a Written Statement on 22 July 2007 to launch a public consultation on the review of prescription charges in England; notes that this consultation, initially expected in autumn 2007, has not yet been published; is concerned that recent MORI research found that an estimated 800,000 people are going without vital medication because they cannot afford to pay for their prescriptions; and supports Arthritis Care, Association for Spina Bifida and Hydrocephalus, Asthma UK, Breast Cancer Care, Citizens Advice, Disability Alliance, Macmillan Cancer Support, Mind, MS Society, Parkinson's Disease Society and the Terrence Higgins Trust in urging the Government to launch its consultation as soon as possible.

## Support for carers

The Government will shortly be announcing its New Deal for Carers, the revised National Carers Strategy. It is imperative that the new Strategy results in a genuine improvement in the support provided to carers.

The results of the recent PDS Members Survey show that the 1999 Strategy has not led to any significant improvement in carer's lives. The survey report is being formally launched at the Parkinson's APPG meeting on 3 June. Issues highlighted by the survey include:

- Carers are providing more care than in our 1997 survey – 79% of respondents provide care for 20 hours or more per week (up from 60%) and 63% are caring for 50 hours or more per week

- The number of carers receiving support from social services has actually fallen since our 1997 survey, from 16% to just 11%
- The vast majority (71%) of carers are still unaware of their rights to an assessment of their own needs
- 28% of carers reported that they were worse off since becoming a carer and 45% of those under 65

In order to explore these problems in more detail, during 2007 and 2008 the PDS has held a series of focus groups across the UK with carers of people with Parkinson's, to find out about the support they needed and the support they actually received. The findings echoed the problems raised by the Members Survey:

- **Awareness of carer's assessments remains low**, even amongst long-term carers. Some carers had requested an assessment but not yet received one and others had not received any services as a result of their assessment.
- **The needs of carers were often overlooked by service providers.** One carer had to cancel her own operation three times because social services didn't put a package of care in place. Another was unable to get the overnight help that would enable her to visit relatives. Long waits for aids and adaptations also meant that carers had to manage without support, in one case forcing them to leave work.
- **Many carers faced health problems themselves**, brought on by the stress of living with the condition, but these were also largely overlooked. Just a handful of carers were registered as a carer with their GP. Carers were particularly worried about what would happen in an emergency, but only one carer had an emergency plan in place.
- **Lack of information** about benefits, carer's assessments and other support available was a major problem at all five meetings. Almost none of the carers had received information through 'official' sources, people found out through friends or PDS services such as branches, Helpline, newsletter, website and staff.
- Carers also raised **financial concerns** – in particular the low level of Carer's Allowance and losing entitlement to Carer's Allowance when you receive your pension.

There were some positive stories, including some examples of carers using direct payments to purchase the services they need. Some services were singled out for praise, including those provided by Crossroads and the Red Cross, and there were also good examples of GPs giving regular health checks and signposting carers to support.

## What carers want

It is essential that the New Deal for Carers and subsequent parliamentary action genuinely addresses the needs of carers as a priority. In particular:

- Sufficient resources to be allocated to, and spent on, meeting the needs of carers
- All carers to be able to access appropriate respite breaks
- NHS targeted support for carers, including increasing the number of carers registered with their GP, receiving health checks and getting flu jabs
- Every carer to have the opportunity to establish an emergency plan
- Better information and advice about support available, resulting in an increase in the number of carers being offered an assessment

## How you can help

- Join the APPG for Parkinson's Disease and help to champion the needs of people with Parkinson's disease and their carers
- Support Carers Week 2008 (week beginning 9 June) for details of parliamentary activity and events near you visit [www.carersweek.org](http://www.carersweek.org)

## Parkinson's Disease Society

The Parkinson's Disease Society (PDS) is the UK's leading Parkinson's charity, with around 30,000 members and over 330 branches and support groups across the UK. The Society provides support, advice and information to people with Parkinson's, their carers, families and friends, and information and professional development opportunities to health and social services professionals involved in their management and care.

## How you can help

- Meet with your local Parkinson's Disease Society branch to discuss the needs of people in your area and raise their concerns with commissioners and providers

## Further information

If you would like more information about any of these issues or a briefing on your local area please email the Policy and Campaigns team on:

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