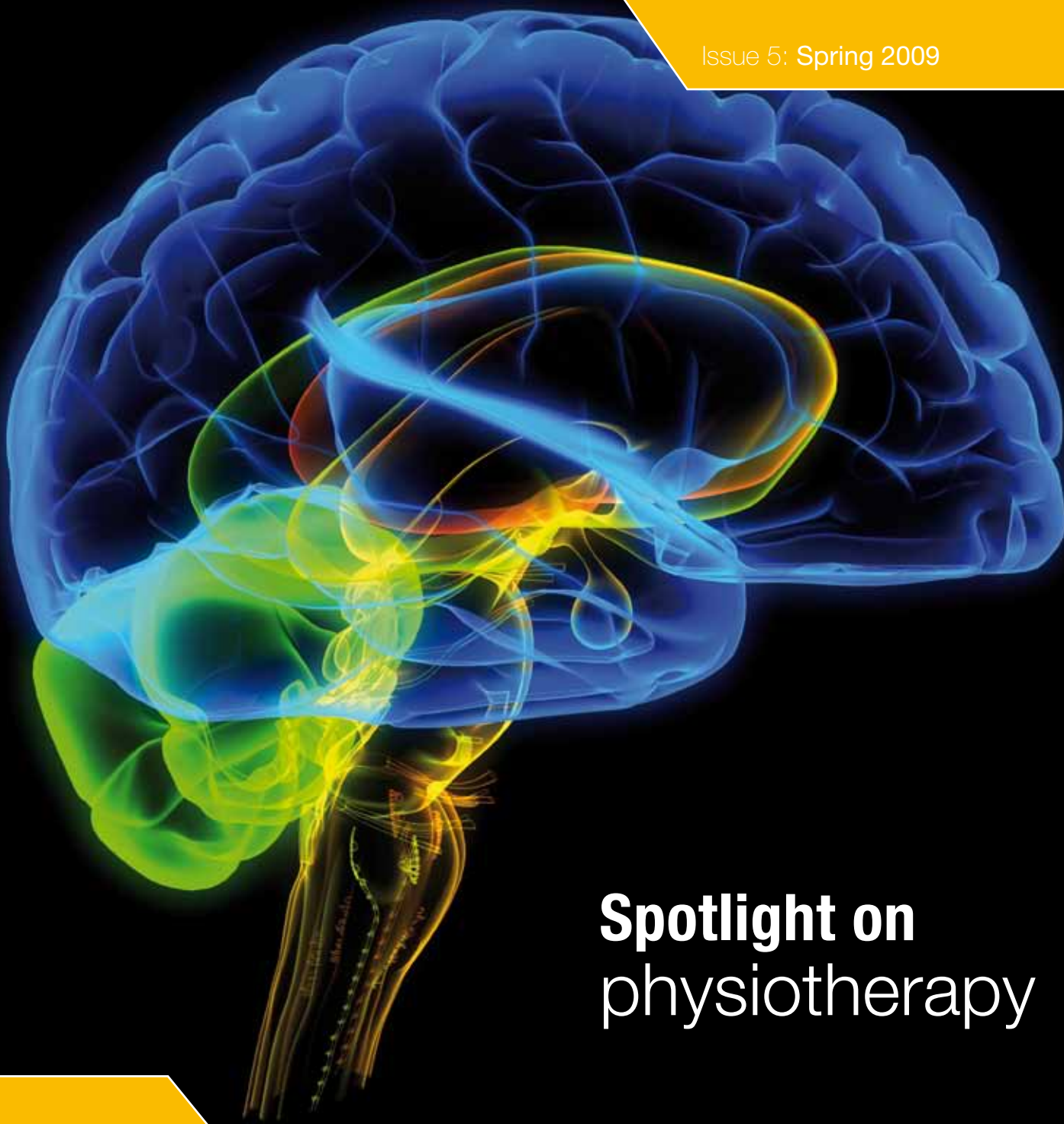


The research magazine of the Parkinson's Disease Society

PROGRESS

Issue 5: Spring 2009



Spotlight on physiotherapy

Combating sleep problems

A step closer to identifying the causes of Parkinson's

Can physical activity stop Parkinson's from getting worse?

What the Members' Survey revealed



**Parkinson's
Disease Society**

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Welcome

I am delighted to welcome you to the Spring edition of *Progress*, the Parkinson's Disease Society's research magazine. Inside is a glimpse of the most current and innovative research that we are funding across the UK's best universities and hospitals. Our research priorities are clear and focussed - to develop better treatments and find a cure for people living with Parkinson's.



This year is our 40th anniversary and I am particularly proud of looking back at the achievements that have come from research supported by the Society. Our new anniversary brochure *Four Decades of Discovery* highlights how our accomplishments have improved the care and treatment of people with Parkinson's (**page 5**). We are completely dependent on voluntary donations, so without your generous support we would have not taken such great strides in research.

During April's Parkinson's Awareness Week, the Society launched our Brain Donor Appeal to encourage more people – with and without Parkinson's - to join the Parkinson's Brain Donor Register. Research using human brain tissue is one of the most promising routes to finding a cure. We have been thrilled at the public's interest but we still need more people to pledge to donate their brains for Parkinson's research (**page 21**).

Looking forward, we are continuing to work hard to speed up the delivery of research discoveries to help people with Parkinson's. I have been building strong links with major organisations like the Michael J Fox Foundation who fund Parkinson's research both in the UK and overseas. This perspective makes sure the Society is at the forefront of the international research and spends its money carefully. Be part of our challenge, support research and help to find the ultimate breakthrough – a cure for Parkinson's.

A handwritten signature in black ink that reads "Kieran".

Dr Kieran Breen

Director of Research & Development

Spotlight on... the benefits of physiotherapy for people with Parkinson's

What is the problem?

People with Parkinson's experience a variety of physical problems related to their condition. Current drug treatments, such as levodopa and dopamine agonists, are aimed at treating the symptoms of Parkinson's, such as tremor. However, they may not provide any assistance with some of the everyday problems faced by people with Parkinson's, such as difficulties with washing, dressing and eating. This is stressful to both the person with Parkinson's and their carer, and has a substantial impact on their quality of life. In particular, Parkinson's causes problems with muscle stiffness, which can lead to an increase in falls and, potentially, broken bones.



Physiotherapy running exercises

Samuel Ashfield/Science Photo Library

What are the benefits of physiotherapy?

Physiotherapy uses physical means, usually exercise or movement strategies, to improve aspects of mobility necessary for walking, balance and flexibility. This covers a range of techniques, although it focuses mainly on exercise and the improvement of mobility, with the aim of improving quality of life and reducing secondary complications such as falls.

In its 2006 Guideline for Parkinson's, the National Institute for Health and Clinical Excellence (NICE – **see Fact box 1**) recommended that physiotherapy should be available to people with Parkinson's, with particular consideration given to aspects such as improvement of:

- balance, muscle flexibility, and strength
- the ability of people with Parkinson's to start moving
- mobility and performing everyday tasks
- the provision of advice regarding safety in the home.



Fact box 1: What is NICE?

The National Institute for Health and Clinical Excellence (NICE) is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

However, NICE did also state that more research into the effects of physiotherapy for people with Parkinson's was needed. While many people with Parkinson's feel a benefit from physiotherapy, very few clinical trials (termed randomised controlled trials (see Fact box 2) have been carried out to support this claim.

The lack of research to prove that physiotherapy helps people with Parkinson's means that they are often not referred to a therapist early enough so that therapy may be of benefit (see Fact box 3). Therefore, we need more research to be carried out to ensure that we understand better who will gain most from it and that people are referred for physiotherapy when it will be of most benefit to them.

What studies are the PDS supporting?

The Parkinson's Disease Society (PDS) recognises the importance of physiotherapy and is supporting two key studies – at the University of Birmingham and the University of Southampton – in this area.

One project will assess the usefulness and cost-effectiveness of physiotherapy as a treatment for Parkinson's. This research is part of the Society's Themed research grant scheme (read more about this scheme on pages 12 – 13). Natalie Ives from the University of Birmingham said:

“We will undertake a review of randomised controlled trials which compared people who received physiotherapy with those

who did not use physiotherapy. The reviews combine the results of all the trials that have been carried out to date in order to obtain an overall assessment of how well the treatment works. This provides a more reliable assessment of the evidence than would be obtained by considering the trials individually, and will provide doctors with more objective information upon which to base a decision about whether to refer a person with Parkinson's for physiotherapy.

“It will also provide NICE with a better evidence base upon which to base its recommendations. In addition, if the review shows physiotherapy to be effective in the treatment of Parkinson's by, say, reducing the burden on carers and reducing the likelihood of falls and fractures, then the provision of physiotherapy for people with Parkinson's within the NHS will need to be increased. This review may also provide the impetus for a full-scale randomised trial to assess the cost-effectiveness of physiotherapy in Parkinson's.”

Fact box 2: What is a randomised controlled trial (RCT)?

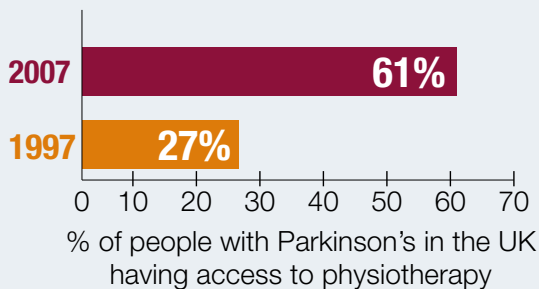
An RCT is a commonly used type of clinical trial that aims to test a specific treatment. This may be a drug or some other form of treatment, such as physiotherapy.

RCTs seek to measure and compare the outcomes after the participants receive the treatments.

The trial usually involves people with similar symptoms who are randomly put into a group who receive a specific form of treatment. The person's doctor is often not told about which treatment the person is receiving so that they can objectively assess whether the treatment is working.

Fact box 3: What the Members' Survey showed

According to the PDS Members' Survey, the number of people having access to physiotherapy has increased since 1997. Read more about the Members' Survey on pages 27 – 28.



The second project is investigating the difficulty that some people experience standing up from sitting, as this is common in Parkinson's. These problems may also increase the likelihood of falling. Dr Emma Stack from the University of Southampton says:

“Over 18 months, we will evaluate a physiotherapy programme based on exercise, problem solving for complex movements and cueing techniques to make movement easier. This will be delivered at home three times a week for four weeks. 60 participants will be recruited via two local consultants: half will receive the programme we are testing and half will act as controls, who will be visited but will not receive physiotherapy.

“We believe our specific programme will help people to be able to stand up without any help and it will benefit walking, balance and, generally, a person's ability to carry out everyday tasks. We will assess participants before and after the programme and over the following two months to identify whether any improvements last after the programme stops.

“The results, plus the opinions of the participants and their carers, will help us to measure the effectiveness of the therapy and whether any improvements need to be made. These will be used in a subsequent study involving a larger number of people.”

Real life benefits of physiotherapy



Bhanu Ramaswamy, Consultant Physiotherapist in Chesterfield, Derbyshire, gives an account of how physiotherapy has helped Mrs G (name has been withdrawn to protect her identity), a 58 year old lady who has had Parkinson's for seven years.

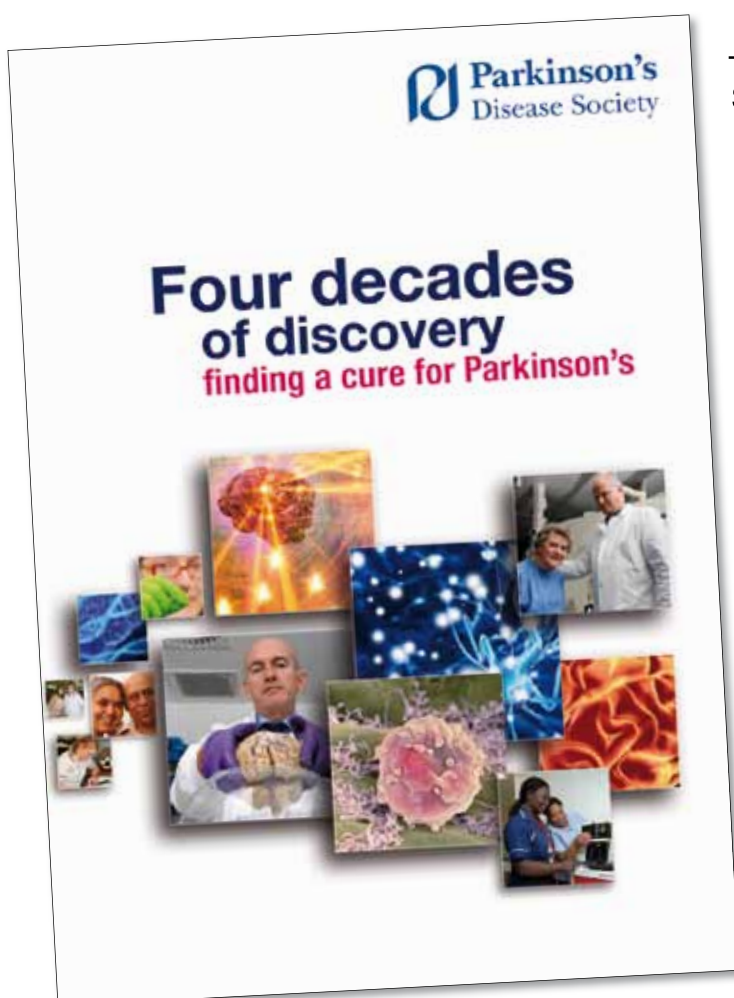
“As the years have progressed, Mrs G has become dyskinetic, experiencing random movements due to the effects of her medication. Plus she has been experiencing increasing ‘off’ periods and is therefore more prone to falling. Her husband was also finding it more difficult to cope due to being woken at night to see her safely to the bathroom or to help ease painful night cramps. She developed a bladder infection resulting in a further decrease in mobility in addition to hallucinations. She subsequently required hospitalisation as Mr G was unable to cope with the additional need to assist her.

“Mrs G's medical consultant felt it would be a good opportunity to review her medication regime, while she received more therapy input, so she was transferred from hospital into a rehabilitation unit. She was an anxious lady and the whole change had made her lose confidence in her ability to cope. Her family had concerns that she would not be able to manage at home if she were to be discharged straight from hospital.

“Mrs G received daily physiotherapy over the first week after being discharged to practise balance and leg strengthening exercises, walked on the treadmill to regain her endurance, and was taught stretching exercises to maintain her flexibility.

“In her second week, she began to walk outdoors with the therapists, which allowed her to regain the confidence to return home. She now only requires help from her family for shopping and outings.”

Parkinson's Disease Society celebrates its 40th year



Parkinson's Awareness Week 2009 (which ran from 20 to 26 April) saw the launch of the Brain Donor Register Appeal.

It also saw the publication of the *Four Decades of Discovery* brochure that highlights the role that PDS-funded research achievement and the role that it has played in improving the lives of people with Parkinson's over the last 40 years. Due to our investment in research

– we have spent over £40million since the Society was founded – major breakthroughs have been made in our understanding of Parkinson's, paving the way for new treatments that strike at the root cause of the condition. Our research has also driven changes in medical practice, improving diagnosis, developing the role of Parkinson's Disease Nurse Specialists and raising awareness of the non-motor aspects (such as sleep problems) of the condition.

The PDS is committed to funding research that helps us to understand better the causes of Parkinson's, potentially identify new improved treatments and ultimately develop a cure for the condition. We are confident that PDS-supported research will continue to build upon the research findings already obtained from key studies funded by the PDS.

If you would like a copy of *Four Decades of Discovery* please contact a member of the research team on:

Tel: **020 7931 8080**

Email: **research@parkinsons.org.uk**

Website: **www.parkinsons.org.uk/research**

New research projects

The PDS is currently funding 90 projects costing over £14million. These include all areas of Parkinson's research from understanding the causes of Parkinson's, searching for new and better treatments and improving the quality of life of people with Parkinson's, but ultimately we aim to find a cure for the condition. In 2008 alone, we invested £4.2million on 34 new research projects. Here are details of some of these studies.

Understanding the causes of Parkinson's

Why do nerve cells die in Parkinson's?

Lead researcher: **Dr Kurt De Vos**, King's College London

Cost: **£109,907 over 24 months**



The nerve cells that produce the chemical dopamine are primarily affected in Parkinson's, although we still do not understand fully how or why this happens. However, changes known as mutations in a number of genes play a role in the inherited

form of Parkinson's, but it is still unclear how these changes cause the nerve cells to die (see Fact box 4). Only a small number of cases of Parkinson's are directly inherited (up to 5%), but understanding the role of the genes which cause this form of the condition may help us to understand the process of cell death.

Fact box 4: Nerve cell death

Parkinson's is due to the death of nerve cells that produce the chemical dopamine in a specific region of the brain called the substantia nigra. The cause of nerve cell death is unknown.

It is likely that multiple factors are involved and that there is a combination of genetic and environmental factors. Therefore, some people may be more susceptible to developing the condition, but external factors are required to spark off the death of the nerve cells.

This project aims to study an important aspect of the working of the nerve cell called axonal transport. This is vital for the correct functioning and survival of nerve cells. Importantly, several of the genes associated with the inherited form of Parkinson's are linked to this process inside the cells.

Work already carried out by Dr De Vos's group and other researchers has shown that problems in axonal transport are important

in other conditions that are due to the death of nerve cells, such as Alzheimer's disease and motor neurone disease. Although there is evidence that problems with axonal transport might play a role in Parkinson's, very little research has been carried out.

Dr De Vos said:

"Understanding the changes in axonal transport in nerve cells will increase our understanding of some of the mechanisms that may cause nerve cells to die in Parkinson's and may identify new ways in which to overcome this."

Genes that may influence the age at which people develop Parkinson's

Lead researcher: **Dr John Powell, King's College London**

Cost: **£61,409 over 12 months**



The age at which people with Parkinson's begin to exhibit the symptoms of the condition (the age of onset) is very variable. Studies of families where more than one person has Parkinson's suggest that certain genes may influence the age of

onset, and that differences in age of onset between different people is likely to be a combination of these genes in addition to the effects of external factors.

The aim of this project is to try to identify those genes which influence age of onset of Parkinson's in addition to similar conditions.



Chromosomes consist of proteins and DNA. DNA contains the genetic instructions required for the development and functioning of living organisms

Dr Powell said:

"The identification of genes that may influence the age at which a person develops Parkinson's will help us to understand better what happens in nerve cells that leads to the development of the condition. It also may suggest new treatments that could ultimately delay, halt or reverse the progression of Parkinson's. Parkinson's is only one of several conditions caused by the death of nerve cells that develops later in life. It is possible, therefore, that those genes which influence the age at which a person gets Parkinson's may also influence other conditions that occur when nerve cells in the brain die."

Searching for better treatments

Developing new treatments with fewer side effects

Lead researcher: **Dr Stephanie Cragg**, University of Oxford

Cost: **£164,250 over 36 months**



One type of drug known as the antimuscarinics (such as orphenadrine hydrochloride or Biorphen) can be used to treat Parkinson's. However, this drug class, like many used to treat the condition, has considerable side effects owing to the

fact that it acts on many different parts of the brain and not only those affected by Parkinson's. A way to overcome this problem would be to develop drugs that work in a similar way but only work in the specific area of the brain where nerve cell death occurs in Parkinson's. The advantage of this would be that you could still get the benefits with fewer side effects.

Dr Cragg said:

"If we can understand how this type of drug affects the production of dopamine by nerve cells, it may be possible to create drugs that will only have an effect in specific parts of the brain. These drugs would have fewer side effects and may be useful for the treatment of Parkinson's in some people."

How does deep brain stimulation work?

Lead researcher: **Professor Peter Brown**, University College London

Cost: **£56,005 over 12 months**



Deep brain stimulation (DBS) is a type of surgery that can be used to help some people with Parkinson's. It is generally only used to treat people who have had Parkinson's for some time and whose symptoms are not controlled effectively

by medication. It may also be used for people who are experiencing severe involuntary movements (dyskinesia) that are associated with drugs such as levodopa.

The procedure involves the implantation of a thin wire, termed an electrode, into a specific part of the brain (**Figure 1**). The wire is then connected to a small unit – like a pacemaker – that is implanted under the skin in the chest. The battery, which is called a stimulator, generates electrical signals to stimulate specific nerve cells. The stimulator can be switched on and off by the person with Parkinson's using a hand held programmer. When the stimulator is switched on, electrical signals are sent to the brain and these help to stop or reduce the Parkinson's symptoms. When the stimulator is switched off, the symptoms return.

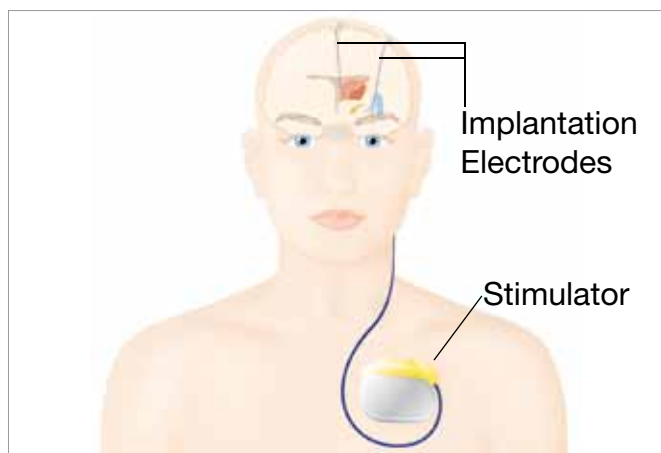


Figure 1 Diagrammatic representation of implantation of electrodes in DBS

Although this form of surgery has been in use for nearly 20 years to treat some people with Parkinson's, we are still unsure as to how it works. As a result, it has proven difficult to further improve this therapy. The researchers think that in Parkinson's, the nerves in a specific part of the brain are not producing the correct electrical signals and that by giving a small electric current from the battery, the nerve cells will be 'shocked' into working normally – like a pacemaker that helps the heart beat regularly.

Immediately following the operation, the researchers plan to record electrical signals from the DBS electrodes in people with Parkinson's for the first few days before the electrode is connected to the battery in the chest and switched on. In this way, they can try to find out what the problems are in the electrical signalling in the brain of the person with Parkinson's.

Professor Brown commented:

“Once we know what is going wrong in specific nerve cells in the brain, it should be possible to set the pattern of electrical pulses from the battery so that they overcome the abnormal electrical signals in the brain that are associated with the Parkinson's. This should make DBS more effective and less likely to give rise to side effects. It will also allow the operation to be

more specific because the electric current from the battery will be designed specifically to overcome the problems in the person who has undergone surgery. Finally, this tailored approach would be more efficient so that the stimulator batteries would also last longer.”

For more information about surgery, you can obtain a copy of our *Surgery and Parkinson's Disease* booklet by downloading it from www.parkinsons.org.uk or by obtaining a copy, free of charge, from

Sharward Services Ltd
Westerfield Business Centre
Main Road
Westerfield
Ipswich
Suffolk IP6 9AB

Tel: 01473 212 115

Fax: 01473 212 114

Email: pds@sharward.co.uk

Combating faulty brain signalling in Parkinson's

Lead researcher: **Dr Peter Magill,**
University of Oxford

Cost: **£178,000 over 36 months**



In Parkinson's, a decrease in the amount of the chemical dopamine is one of the key factors that gives rise to the movement problems that are characteristic of the condition. This also alters the electrical activity of certain brain

cells and how efficiently they communicate with each other (**Figure 2**).

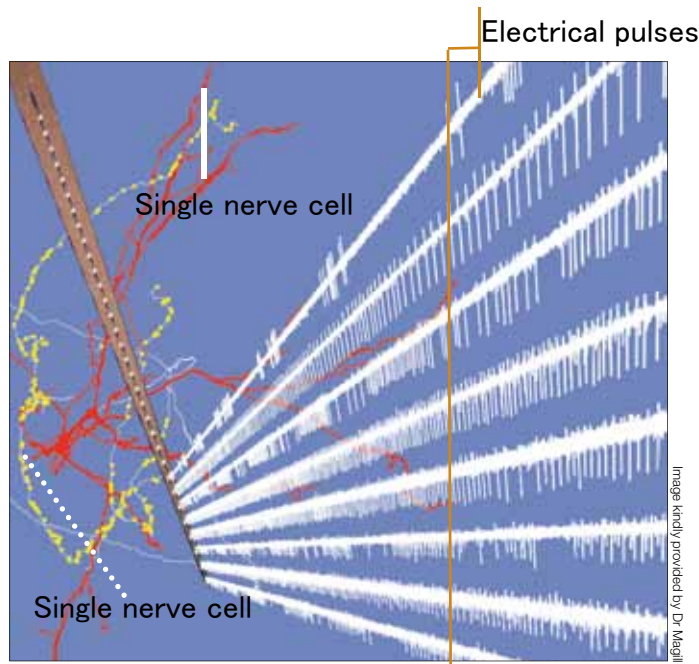


Figure 2 One nerve cell (coloured in red) communicates with another nerve cell (coloured in yellow) using electrical pulses. The radiating white lines are a diagrammatic representation of the recorded pulses that occur during cell communication

One common change in people with Parkinson's is that cells in two different brain areas generate abnormal electrical signals or rhythms, which may interfere with people's abilities to start or carry out physical activities such as walking.

The problem is that we do not know exactly where, how and when these abnormal signals appear in the brain. If researchers can predict how best to disrupt these rhythms, they may be able to combat some of the movement problems associated with Parkinson's.

Dr Magill said:

"This research will provide important new information about how these brain cells communicate with each other to control movement. Importantly, if indeed these abnormal electrical signals do cause motor problems, we will have an indication of how we may develop new surgical or drug therapies."

Improving the quality of life of people with Parkinson's

The role of dopamine in thinking and problem solving in Parkinson's

Lead researcher: [Dr Roger Barker, University of Cambridge](#)

Cost: [£96,323 over 36 months](#)



In Parkinson's, there is a loss of dopamine-producing nerve cells in the region of the brain that controls movement. The chemical dopamine allows people to perform smooth co-ordinated movements. The symptoms of Parkinson's usually develop when over 70% of these cells die.

As a consequence, drugs which replace dopamine in the brain are usually used to treat Parkinson's, but these drugs are known, in some cases, to give rise to difficulties in certain types of thinking and solving problems, such as those which involve planning. This may be due to too much dopamine being released in other parts of the brain that control our ability to solve problems. Therefore, this shows how important it is to have the correct balance of dopamine in different parts of the brain to allow them to work properly.

Recently, the researchers have shown that different forms of a specific gene, influence people's abilities to solve certain tasks.

People with specific forms of the gene may not be as good at balancing the levels of dopamine in their brain and this is why there are side effects when they take drugs that increase the levels of dopamine that treat their Parkinson's symptoms. This project will look at this in more detail using brain scans to examine changes in dopamine levels in specific parts of the brain.

Dr Barker said:

"This work is important because it will help us understand better the role of dopamine in thinking and problem solving in people with Parkinson's. It will also help us decide what are the best drugs to use in people with Parkinson's who have different forms of this gene."

How do people with Parkinson's deal with day-to-day problems?

Lead researcher: [Professor Richard Brown, King's College London](#)

Cost: [£70,171 over 18 months](#)



Everyone experiences unexpected problems on a daily basis – people with Parkinson's perhaps more than most. Some of these problems are easily dealt with, but others can be much more difficult to resolve. How we go about solving day-to-day

problems that arise in work, social or household settings may be important for how

much stress we feel and for our mood and wellbeing. At present, we know very little about how people with Parkinson's deal with day-to-day problems, and what may influence this.

In this study, the researchers will measure how well a group of people with Parkinson's can solve problems that they would come across every day, particularly problems that involve other people. These may include dealing with embarrassing situations with friends or having to handle a noisy neighbour. They will also measure what sorts of things affect their ability to deal with problems – including their ability to think clearly, how they deal with other people and how they are feeling at the time. It is expected that the research will result in simple, practical approaches to help people with Parkinson's deal more effectively with day-to-day situations that may occur and reduce the amount of stress and worry that they feel.

This research is part of the larger study entitled Prospective Study of Mood in People with Parkinson's Disease (PROMS-PD) which is also funded by the Parkinson's Disease Society. This project is studying all aspects of mood in Parkinson's, including those factors that can contribute to problems and the effects that problems have more widely.

Professor Brown said:

"People with Parkinson's have a lot of challenges to deal with on a daily basis. While many cope with these fantastically well, some struggle and this can lead to stress, worry and low mood. We want to examine what makes some people better real-life problem solvers than others. If we can do this we will be in a better position to identify those people that may need extra support and to potentially develop some simple self-help strategies for people to deal more effectively with real-life problems."

Themed research

Combating the sleep problems facing people with Parkinson's

The PDS Themed research grant scheme is primarily based on the members' research priorities that were published in the Research Agenda during 2005. There are currently six projects being funded under this scheme, totalling over £3million. Other areas of research include compulsive behaviours associated with specific drugs (reported in the summer edition of *Progress*) and determining the benefits of physiotherapy for people with Parkinson's (read more about this on pages 2 – 4). Just last year an important study looking at sleep problems in Parkinson's was given the go-ahead.

What are we looking into?

People with Parkinson's often report problems with sleep, including difficulty in getting to sleep and waking during the night. The lack of a good night's sleep can affect their ability to carry out everyday activities and places additional stress on carers and families. Some researchers believe that the development of sleep problems can be an early sign of Parkinson's in some people. Despite these sleep disturbances being common and complex, little research has been done in this area.



Suzanne's account on how sleep problems are impacting on her life

As a 47-year-old mother of busy teenagers, and dealing with the stress and excitement of supervising the

building of my first house, you could say that sleep is vitally important to me.

The first real sign of what was later diagnosed as Parkinson's began in February over six years ago, when I noticed that I was having problems stopping my fork from shaking in my left hand.

I had got used to living with erratic sleep patterns during the years of working as a stewardess on long haul flights with British Airways. Then, I would get up whenever my body clock told me to wake up, wherever I happened to be in the world, not wanting to miss out on the day ahead.

Now, with Parkinson's, I seemed to be reverting back to those sleepless times, unable to sleep through the night. The lack of sleep affects every aspect of my life, I find it hard to concentrate and my organisational and decision making skills are affected by being so tired all the time.

Another side effect of sleep deprivation is that I can be very irritable with family and friends, blowing tiny things out of all proportion.

Living with sleep problems seems to be something I am just having to accept as part of having Parkinson's. I just hope that the PDS-funded research into this area may hold some clues for the future.

Why is the study so important?

Research is needed in order to find out how common the problem is, and whether it occurs more commonly in certain types of Parkinson's which are associated with specific symptoms. Understanding the cause of the problem will then allow us to decide what is the best treatment to overcome it.

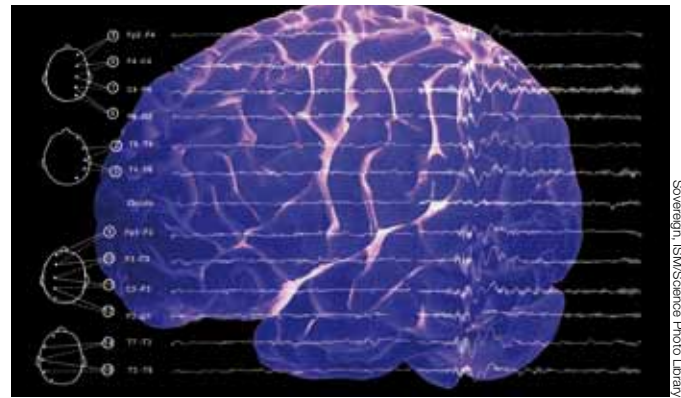
PDS funding the research gap



The Parkinson's Disease Society awarded Dr Roger Barker, a neurologist from the University of Cambridge, a grant of £436,239 to carry out research into sleep problems that are encountered by people with Parkinson's. This research was made possible through generous sponsorship by the Big Lottery Fund and will be carried out in partnership with Oxford and the Papworth Hospital NHS Trust.

How is the research being done?

The researchers aim to study about 200 people newly diagnosed with Parkinson's from the Cambridge area. Importantly, they will also study around the same number of 'controls' in the study. These are individuals who do not have Parkinson's and will thus enable us to identify the sleep problems that are specific to Parkinson's.



Brain waves during sleeping

Dr Barker and his team will carry out the following four key studies:

- Determine how common sleep problems are in people with Parkinson's right from the time they are first diagnosed with Parkinson's or even before. This will enable them to see how sleep problems change over time as the condition progresses.
- Visit people newly diagnosed with Parkinson's in their own homes to assess their quality and quantity of sleep. This will be followed by a more in-depth assessment at a local sleep laboratory. They will be asked to wear a watch-like device on their leg which will monitor their movements and disturbances during the night due to problems with their sleep.
- Investigate the relationship between sleep disturbance, changes to the body clock and the levels of key hormones.
- Determine whether particular genes involved in the regulation of the normal 24 hour body clock are altered in Parkinson's. This part of the project will use brain tissue donated from people at different stages of the condition to the Parkinson's Disease Society Brain Bank (read more about this on pages 21 – 24), and also 'control' tissue (from people without Parkinson's).

If you are experiencing sleep problems, the PDS advises that you to talk to your doctor or Parkinson's Disease Nurse Specialist.

Site visit

A step closer to identifying the causes of Parkinson's

What the research is all about?

Although the cause(s) of Parkinson's remains to be discovered, it is likely to be caused by a combination of both genetic and environmental or external factors (such as exposure to pesticides; see the Frequently asked question section on pages 25 – 26). However, in a small number of cases of Parkinson's (up to 5%) the condition is believed to be directly inherited. In addition, there may be genetic factors that make people more susceptible to the non-inherited form of the condition.

We know that several genes, such as alpha-synuclein, parkin and PINK1, have been linked to the development of the directly inherited form of Parkinson's. In order to help understand how these genes are involved in the development of the condition, the PDS awarded Professor David Latchman two grants; one project studied alpha-synuclein alone (this study finished towards the end of 2008) and the other combined research into parkin and PINK1 (this study is due to finish in 2009).

Members of the Research Network, SPRING (Special Parkinson's Research Interest Group) and PDS staff visited Professor Latchman and his team at the Institute of Child Health, University College London, to learn more about both projects. During the visit, Professor Latchman gave a presentation on the results so far, followed by a tour of the research laboratories to see where the research was being carried out. Throughout the visit, there was opportunity to ask questions.



Professor Latchman gives an account of the projects so far

“Changes or mutations in any one of these three genes results in the production of an abnormal protein which then leads to

the development of the condition. In the vast majority of cases of Parkinson's, these genes are entirely normal and produce a normal protein.

“However, our hypothesis is that specific stimuli acting on these genes could encourage them to produce an incorrect amount of the normal protein. This increase or decrease in the amount of the normal protein would produce a similar effect to having the abnormal protein and would therefore produce the condition.

The point of our study

“Based on this hypothesis, we have examined the effects of the toxic chemical MPTP on the function of genes such as alpha-synuclein, parkin or PINK1.

Results so far

“Interestingly, what we found was that these stimuli do indeed induce increased levels of the Parkinson’s-associated proteins.

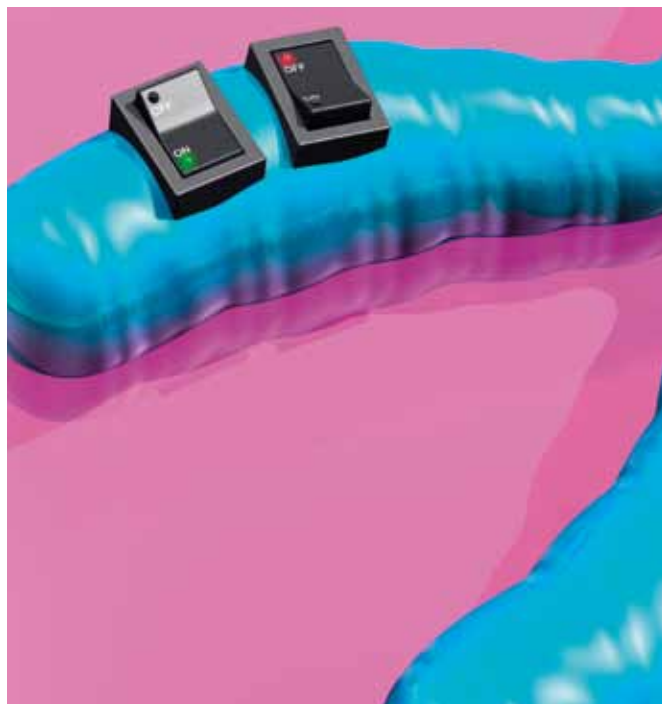


Figure 3 Genes need to be switched on so that they are able to function

“We have shown that this effect is caused by MPTP being able to turn on the alpha-synuclein and parkin gene so that they can function (Figure 3). We also looked at how this happens and found a factor that binds to the region of the alpha-synuclein gene that controls how this gene functions. However, this was only observed after dopamine treatment.

What happens next...

“This work has helped us to understand how Parkinson’s-associated genes work. Further research into the factors responsible for this will help us to understand why nerve cells die and subsequently cause Parkinson’s and may lead to improved therapies based on these findings.

How this helps people with Parkinson’s

“The genes involved in Parkinson’s provide us with valuable clues about how the condition occurs. Understanding how we may be able to control these genes could provide novel targets for therapy of the condition.”

Who went and what they said

These site visits have proven to be a valuable way for Society members to learn about the science surrounding Parkinson’s. Likewise, researchers report of how invigorating it is to meet people living with Parkinson’s. In some instances, the site visit has been their first opportunity to meet people living with Parkinson’s.

Mike, member of SPRING and the Research Network, said:

“I am impressed with the excellent and high standard of research being carried out. This research will hopefully lead to the better treatment of Parkinson’s.”

Looking to the future

Professor Latchman’s research and other studies we are supporting will help us to unravel the mysteries surrounding the development of Parkinson’s with the ultimate aim of improving the treatments available for Parkinson’s and finding a cure for the condition. To find out more about how PDS-supported research has made a difference to the lives of people with Parkinson’s since the Society was founded, 40 years ago, read our research achievements brochure *Four Decades of Discovery*. Details on how you can get hold of a copy are found on page 5.

Completed Research

Understanding the genes involved in Parkinson's

Lead researcher: **Dr David Nicholl**,
Queen Elizabeth Hospital, Birmingham
Cost: **£123,391 over 36 months**

What it's all about



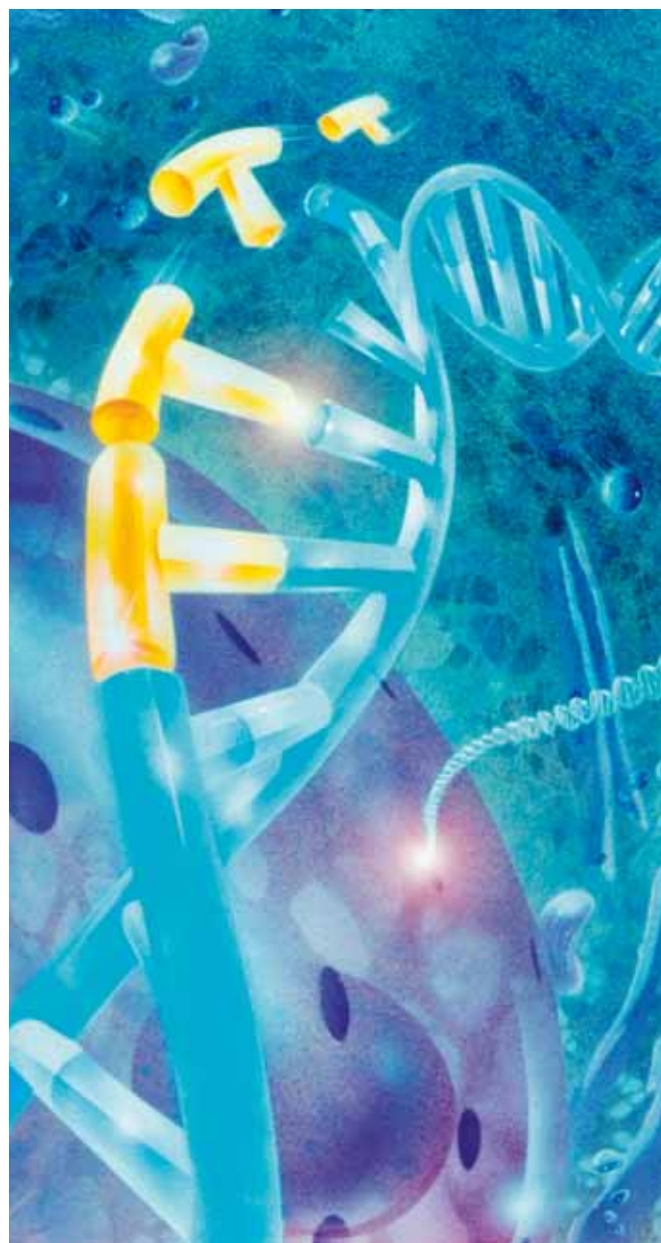
Although the cause(s) of Parkinson's remain unknown, a lot of research done in the last ten years has shown that environmental or external factors play an important role in its development. Also, a number of genes have been directly linked

to the development of the inherited form of Parkinson's in a small number (up to 5%) of people, but their function remains to be determined.

The point of our study

Back in 2004, we identified one of the key genes involved in Parkinson's, namely LRRK2, at the same time as another team.

The purpose of this project was to determine how common changes in the LRRK2 gene, termed mutations, are in people with Parkinson's in the UK.



Jim Dowdalis/Science Photo Library

What we did

We approached 190 families from across the UK who were said to have a history of Parkinson's in three or more family members. These were recruited either as self-referrals from patients or the relatives of families already recruited to the Queen Square Parkinson's Brain Bank, of these, 46 families were included in the study. People with Parkinson's with no family history of the disorder (so-called sporadic cases) were recruited from the largest drug trial yet performed in Parkinson's, the PD MED trial (see Fact box 5). This made it the largest and most comprehensive study of LRRK2 in the UK.

Fact box 5: What is PD MED?

PD MED is a large, clinical trial that aims to determine much more reliably which class of drugs provides the most effective control, with the fewest side effects, for both early and later Parkinson's. For more details of this trial, visit www.pdmed.bham.ac.uk

What we discovered

Interestingly, it would appear that LRRK2 is not only the commonest cause of familial Parkinson's where there is a family history of the condition (9% of the 46 families recruited across the UK), but is also responsible for the cause of about 1% of Parkinson's where there is no family history of the condition.

In some of the families, the mutations in the LRRK2 gene resulted in too little LRRK2 protein being produced by cells. This is the first time this has been reported and highlights the importance of understanding LRRK2's function more fully.

What happens next...

The collection of information on Parkinson's families, stored in a database, will be an

important resource for future research. This research emphasises that much more needs to be done to understand what are the effects of mutations in the LRRK2.

How this helps people with Parkinson's

The more we study Parkinson's, the more we realise that it is like a massive jigsaw puzzle with a number of different pieces that need to be joined together. Understanding the LRRK2 part of this 'Parkinson's puzzle' will be vital in developing better treatments based on our understanding of this gene and the role that it plays in the death of nerve cells in Parkinson's.

Can physical activity stop Parkinson's from getting worse?

Lead researcher: **Dr Lucy Annett**,
University of Hertfordshire

Cost: **£92,586 over 36 months**

What it's all about



Parkinson's is caused by the death of dopamine-producing nerve cells in a specific region of the brain. Previous research has suggested that physical activity, such as running on a treadmill, may slow down the rate at which the nerve cells die and

therefore prevent the Parkinson's symptoms from getting worse.

The point of the study

We investigated this theory further using an animal model of Parkinson's. Our aim was ultimately be able to relate it to people with the condition.

What we did

In the laboratory, the team first of all created an animal model by giving rats a toxic chemical that caused Parkinson's-like symptoms. We then used a variety of physical activity tasks that altered their behaviour, such as picking up food pieces placed on one side of their body in addition to drug treatments such as levodopa to encourage physical activity in these rats.

What we discovered

The results were encouraging – they showed that physical activity can protect against the death of the nerve cells but, disappointingly, protection is not guaranteed and may not be sufficient to overcome the death of a large number of cells that would be found in the more advanced stages of Parkinson's.

What happens next...

More experiments are needed to look in further detail at whether the initial extent of the nerve cell damage (i.e. number of missing dead cells) determines the success of physical therapies as a possible neuroprotective treatment for Parkinson's.

How this helps people with Parkinson's

For people with Parkinson's, the results suggest that physical activity during the early stages of the condition may be beneficial, but less so at later stages when substantial numbers of nerve cells have been lost.

The prospect that exercise may not only be good for general health but may also slow the progression of Parkinson's is of great interest and is supported by a number of pieces of evidence. Previous studies have shown that forced exercise of a limb or running on a treadmill can protect nerve cells from damage in animal models of Parkinson's. Our present studies found that energetic exercise may not be essential to prevent cell death; a simple task such as working to retrieve food from the side of the body affected by Parkinson's-like symptoms may be sufficient. However, the extent of the damage within the brain may also be important and this factor has not previously been considered. More research is needed to establish both the type and amount of exercise needed for neuroprotection and at which stage it is most likely to best effect.

SPRING research conference

Members of the Parkinson's Disease Society's Special Parkinson's Research Interest Group (SPRING) are hosting a research conference on Parkinson's and exercise in September 2009. The aim of this conference is to bring international researchers together, identify gaps in knowledge and develop new research collaborations.

Meet...

Dr Dileas Sweetenham

Chair of the Parkinson's Disease Society Bath Branch and a Patient and Public Involvement representative within Dementias & Neurodegenerative Diseases Research Network (DeNDRoN)



Background

Dr Sweetenham is a former GP living in Bath with her husband Walter. They have two sons and five grandsons. She was diagnosed with Parkinson's at the age of 69 and became a member of PDS shortly afterwards.

What is DeNDRoN?

DeNDRoN supports NHS clinical research into a range of conditions including Parkinson's. As part of the National Institute for Health Research, DeNDRoN co-ordinates research activities and aims to make clinical trials in the NHS more successful, more relevant and more rapid. It works with organisations, such as the PDS, to ensure research resources and expertise are shared, and that the research carried out is relevant to people living with Parkinson's.

DeNDRoN has seven Local Research Networks in England. These employ dedicated research nurses and similar staff to help run large-scale multi-centre clinical trials and local/pilot studies, working with hospitals, GPs, care homes, the pharmaceutical industry, existing local research teams, and patient groups, including local PDS branches.

Getting to know you

What is your favourite food?

My favourite food is salmon, cooked simply to retain its natural flavour.

If you could be reincarnated – who or what would you like to come back as?

If reincarnated I would choose to come back as myself without Parkinson's.

If you were stranded on a desert island with someone famous who would this person ideally be?

On my Desert Island I would like to be with Princess Anne. She is a practical lady with much common sense and a sense of humour.

What do we mean by Patient and Public Involvement?

By 'Patient and Public Involvement' (PPI) we mean involving patients, carers and other members of the public in DeNDRoN's local committees and activities and in national study development. The goal of this PPI is for NHS clinical research to be truly relevant to people affected by conditions such as Parkinson's.

Dr Sweetenham gives us an insight into her involvement in the South West DeNDRoN Steering Group, and in DeNDRoN nationally.

What is your involvement?

“I was first invited to become a Patient Representative on DeNDRoN by Professor Roy Jones who is Lead Clinician for DeNDRoN in the South West early in March 2007. I have known him as a colleague since the 1980s when he provided GPs with sessions for our post-graduate education.

“I sit on the Steering Committee of DeNDRoN South West. We meet twice a year in Bristol; my role really is to keep meetings understandable for us and all present, by avoiding for example undefined abbreviations.”

What satisfaction do you get from being part of PPI?

“Satisfaction comes from being active in medicine after retirement and to feel that I am making a difference to the future of Parkinson’s research.”

What is the value of the PPI in your opinion?

“PPI in DeNDRoN helps to keep meetings focused on essentials, practical and relevant to patients’ needs and to make sure that what is written is understandable. Primarily people with Parkinson’s want their symptoms relieved, although longer term research should look towards prevention and a cure for neurodegenerative conditions. Ultimately, their aim is similar to that of the PDS to, provide support for all with good treatment tailored to the individual.

“I recently attended a Forum on Recruitment of Patients. At this meeting, researchers discussed the difficulties in contacting eligible people to take part in research; yet I meet people who are keen to offer themselves for research. Hopefully, having organisations like DeNDRoN will help bridge this gap.”

Terry McGrath, the PPI Co-ordinator at DeNDRoN says:

“Dileas contributes fully to discussions about studies DeNDRoN supports, including the Parkinson’s studies on the portfolio, and about how to communicate research to people with Parkinson’s, explain terms such as placebos, work with GPs and boost interest.

“At a national level, Dileas was part of a recent conference group thrashing out recommendations on how to convince new hospitals and clinics to join in studies, and how DeNDRoN can improve recruitment of patients to studies. This included specific practical ideas for how DeNDRoN can enhance relationships with PDS groups, and Parkinson’s Disease Nurse Specialists. Dileas doesn’t just help with ideas for Parkinson’s research, but also looks at other DeNDRoN work areas. She took part in a focus group in Bath which came up with ways to improve recruitment to an important dementia study.”

Can others become involved?

The DeNDRoN website (www.dendron.org.uk) invites interested people to register to join the Network and become PPI Representatives.

Or contact **Terry McGrath:**

Tel: **020 7905 2995**

Email: **info@dendron.org.uk**

Supporting the Brain Donor Appeal



Jane Asher, President of the PDS, has signed up to the Brain Donor Register

The Parkinson's Disease Society has launched a nationwide Brain Donor Appeal to raise awareness and encourage more people – with and without Parkinson's – to pledge to donate their brains, alongside celebrities such as BBC's *Newsnight* presenter Jeremy Paxman and actress Jane Asher. The Brain Donor Appeal aims to get another 1,000 people to sign up to the Brain Donor Register at the Parkinson's Brain Bank which is currently based at Imperial College, London.

Fact box 6: Research achievements using donated human tissue

In 1988, research supported by the PDS developed a test called the UK PDS Brain Bank Criteria.

The NICE Guideline for Parkinson's (**see Fact box 1 on page three**), recommends using of the UK PDS Brain Bank Criteria for diagnosis.

In 1986, PDS-funded research discovered that certain nerve cells in the brains of people with Parkinson's are damaged by oxidative stress.

Oxidative stress is a biochemical process that leads to toxic chemicals building up inside nerve cells. These toxins damage cells and they eventually die.

In 1990, research supported by the PDS discovered that nerve cells in people with Parkinson's have problems with tiny energy-producing batteries called mitochondria.

Mitochondria are present in every cell in our bodies. They produce the energy that keeps us alive. If the mitochondria in nerve cells do not work properly, the cells get sick and die.

Taking the decision to donate your brain is one of the most valuable contributions to Parkinson's research you can make. The PDS has funded the Parkinson's Brain Bank since the 1980s. It has proved an extremely valuable resource for researchers in the UK and overseas to study what causes Parkinson's and search for a cure and better treatments. Indeed, the medical criteria that are usually used for the diagnosis of Parkinson's were established by the Parkinson's Brain Bank. Importantly, if we didn't have donated human tissue, some of our research achievements may not have been possible (see **Fact box 6**).

To date, over 250 donated brains have been collected and more than one thousand people have currently joined the Parkinson's Brain Donor Register. However, there is a desperate shortage of 'control brains' from healthy donors. These are used by researchers who need to be able to compare what happens when nerve cells die in a Parkinson's brain with one without the condition.



Cutting the brain into blocks

Dr Kirstin Goldring, Parkinson's Brain Bank Manager, explains:

“Examining tissue is the only way to be able to understand the full extent of what happens in a brain with Parkinson's. Only when you look at the brain post mortem can you actually confirm the diagnosis of Parkinson's or, in some cases, a related disorder, and by doing this we can gain a greater understanding of the condition and potentially develop new treatments.

“We hope to increase the number of people with Parkinson's and other neurological disorders joining the Brain Bank Donor Register, but we also need healthy brain tissue samples, in order to compare these with brain samples from people with Parkinson's.”

Over the last seven years, donated brain tissue has supported over 80 research projects in the UK and across the world, helping scientists and researchers look into all aspects of Parkinson's and related disorders, and investigating what happens in the brain as Parkinson's develops.

Deciding to become a brain donor

Joan Grycuk, who had Parkinson's, donated her brain after her death to the Parkinson's Brain Bank in 2005. Joan's son, Michael, speaks about his mother's decision:

“My mother always made it clear that when she died, if medical people wanted to use parts of her body for research then she was happy for this to happen. She had decided she wanted to donate parts of her body to help others.”

Mrs Grycuk was 81 when she died, and Michael described her as being very fit up to that point, apart from the problems with Parkinson's.

“She was a very independent and resourceful woman. She walked everywhere and had travelled the world. She never asked for help from anyone, so developing Parkinson’s was very difficult for her.”



The family was initially unsure of whether to go ahead with the brain donation when Joan died, but Michael felt it was important to fulfil his mother’s wishes.

“On the day she died, I said to the family that mum had wanted to donate. The family was not sure whether to bother, as she had said it some time ago. I told them that is the point: you say it so people know, and can do something about it when the time comes, as you may not be able to tell them again.”

Michael didn’t immediately know what to do to in order to fulfil his mother’s request. The process of the actual donation was described by Michael as very quick with little fuss or trouble.

“Seeing her afterwards did not distress the family at all. They were hardly aware anything had happened.”

Michael also spoke of the importance of people becoming donors, like his mother.

“If you don’t do research into diseases or illnesses, then you will never find a cure, and progress stops.

“Often it’s the relatives who become distressed at the idea of their loved one becoming a donor, but it was my mother’s expressed wish to help someone else, and I didn’t hesitate to do so.”

How valuable is it for researchers to have access to brain tissue?

Genes and Parkinson’s

Dr Roger Barker is based at the Cambridge Centre for Brain Repair. His group has been using tissue from the Parkinson’s Brain Bank for a number of years as part of his work into the role of genetics in Parkinson’s and the development of the non-motor symptoms of the condition.

In 2006, Dr Barker requested brain tissue from the Parkinson’s Brain Bank for a study to compare the genetic make-up in people with Parkinson’s with those who do not have the condition (control donors). This research group had previously found a difference in the structure of a specific gene that could potentially increase the risk of Parkinson’s developing, and he wanted to use Parkinson’s Brain Bank donated material to find out how common this difference was and what effect it would have on nerve cells.

They believed that the different form of the gene they had identified may result in changes in how it functions. In order to test this, they needed to compare how efficiently the gene works in individuals carrying the genetic change who had a higher risk of developing Parkinson’s with levels in individuals with the normal form of the gene. This involved finding out two pieces of information from each sample. Firstly, whether they had the altered form of the gene and, secondly, how active the gene was in the brain tissue.

From the first 15 samples that the Parkinson’s Brain Bank initially provided, he only found one case that had the genetic change that he was investigating. Work on this project is continuing using additional samples.

This research highlights the importance of increasing the number of donations to the Parkinson's Brain Bank. Only with more samples can he find enough potential cases with the altered form of the gene, to enable him to determine whether there is a relationship between the altered form of the gene and how efficiently it works. Read more about Dr Barker's ongoing research in this area on pages 10 – 11.

Sleep and Parkinson's

A further supply of brain tissue from the Parkinson's Brain Bank will also be required for another PDS-funded project investigating sleep disturbances, which is also being carried out by Dr Barker. You can read more about this study on pages 12 – 13.

Non-motor symptoms and Parkinson's

Dr Michail E Kalaitzakis, a Research Fellow based at Imperial College London and Hammersmith Hospitals Trust, has a special interest in Parkinson's. He works closely with Dr Ronald Pearce, a Consultant Neurologist who is currently on the Brain Bank management board.

Michail gives an account of how important it is to have brain tissue available:

“Up until very recently, most research in Parkinson's has focused entirely on the movement aspects of the condition, but our research aims to understand and define the causes of some of the most common non-motor symptoms, such as dementia, hallucinations, anxiety and sleep disturbances. We hope this will lead to better treatments that can help manage these problems.

“When I first started my research on Parkinson's I thought that the changes in the brain were mostly confined to the substantia nigra (an area of the brain that controls

movement), but from looking at the post-mortem brain it's clear that many other areas are also affected. For instance, in my studies I have found that changes in the amygdala (an area of the brain responsible for memory and emotion) are common in people who experienced visual hallucinations.

“Using high quality human brain tissue is crucial and I consider myself lucky to use tissue from the Parkinson's Brain Bank. The Bank also provides a very comprehensive clinical history for all the brain tissue they provide which is vital for my work and means I can match up any changes in the brain with the clinical symptoms very accurately.

“We have recently studied 100 post-mortem brains from the Parkinson's Brain Bank in order to assess the accuracy of clinical diagnosis and found that 98% of people with Parkinson's were correctly diagnosed. This is very encouraging and suggests that despite limitations of available diagnostic criteria and a lack of a totally accurate diagnostic test in routine clinical practice, it is possible for clinicians to diagnose accurately the vast majority of people with Parkinson's.”

Dr Goldring acknowledges:

“While the thought of donating the brain of a recently deceased loved one, or your own brain, for medical research may shock some people, we always treat potential donations with utmost sensitivity and minimal personal intrusion.

“Without brain tissue to study we are simply not going to be able to develop new and more effective treatments. For example, it would not have been possible to develop the use of levodopa for Parkinson's.”

To sign up to the Parkinson's Brain Donor Register:

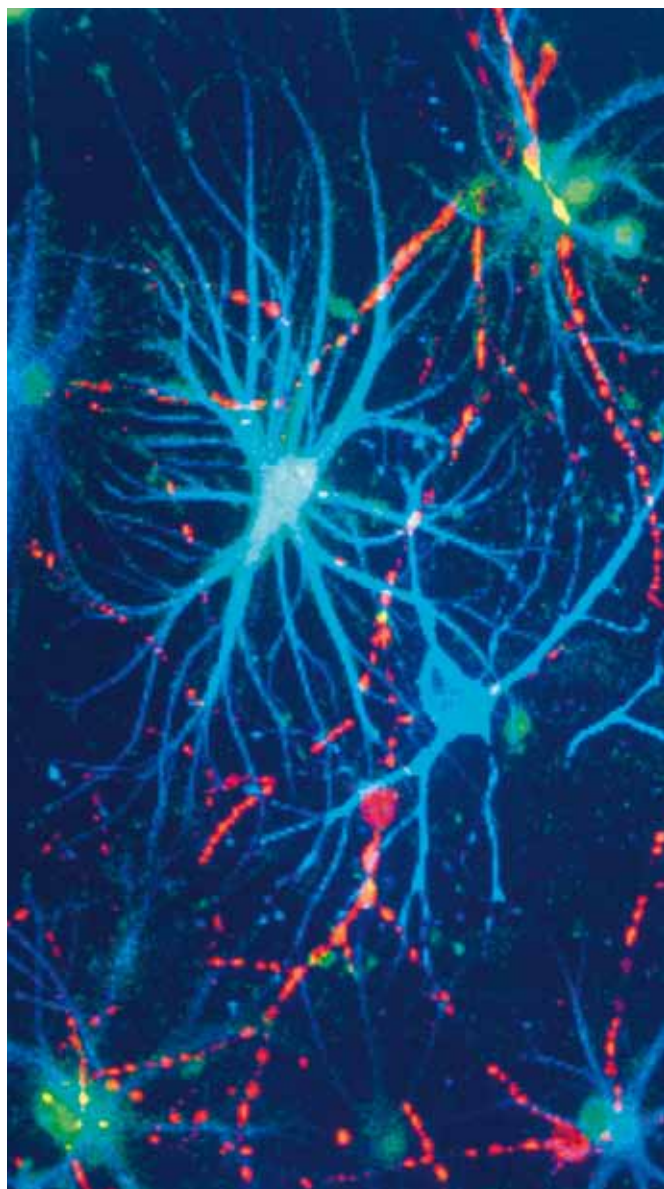
Visit: www.parkinsons.org.uk/brainbank

Email: pdbank@imperial.ac.uk

Tel: 020 7594 9732

Frequently asked questions

I have heard about stem cell therapy being available in Germany – is it safe?



Phillipe Prally/Eurelios/Science Photo Library

The PDS is concerned about reports of stem cell treatments being available in Germany, the Netherlands and China. There is no evidence whatsoever that these work and, indeed, they may be particularly harmful for people with the potential for irreversible side effects.

Stem cells are cells in the body that have the capability to being transformed into a number of specialised cells, such as nerve cells. These cells are usually found in the embryo, but are also present in small amounts in adults, and particularly in bone marrow. The PDS firmly supports stem cell research, provided it is carried out within the UK's strict ethical and legal regulatory framework.

An exciting new type of stem cell, termed induced pluripotent stem cells, or iPS, has the potential of turning into any type of cell without using human embryos. Researchers have recently successfully used reprogrammed skin cells to form nerve cells that ease the symptoms of rats with a Parkinson's-like condition.

Initial studies on reprogramming skin cells involved the introduction of new genes into cells using viruses, and unfortunately this has the potential to switch on cancer genes. Indeed, there were recent reports about the first documented case of tumours resulting from stem cells transplant into a patient's spine in Moscow.

A new safer technique would allow the transformation of skin cells into stem cells without the need for a virus. These cells could be transformed into nerve cells and then transplanted into the brain to replace the cells that die in Parkinson's.

Because this research is still at a very early stage, no appropriate clinical trials of the use of stem cells to treat Parkinson's have been carried out within the strict regulatory framework for the development of new treatments. The European Medicines Agency have also stressed that we need to have a greater understanding of the progression of Parkinson's before we can determine if a treatment such as this is effective.

The summer 2008 edition of *Progress* features a comprehensive overview of the status of stem cell research and Parkinson's, which you may find useful. Contact the Research team for your free copy or down it from our website:

Visit: www.parkinsons.org.uk

Is there a link between pesticides and Parkinson's disease?

We still do not know exactly what causes Parkinson's. It's most likely to be a combination of genetic susceptibility and environmental factors.

The potential link between Parkinson's and pesticides has been recognised for some time. The results of a study published last year point to a strong connection between pesticides and people with the non-inherited form of Parkinson's, adding to the evidence linking pesticides and Parkinson's.

Fact box 7: What the Members' Survey showed

The PDS has recently carried out a survey of more than ten thousand people with Parkinson's and only 9% of them told us that they had ever had long term exposure (of more than one year) to pesticides or herbicides. Of the 3,000 carers surveyed (most of whom were family members) less than 2% had had similar exposure.

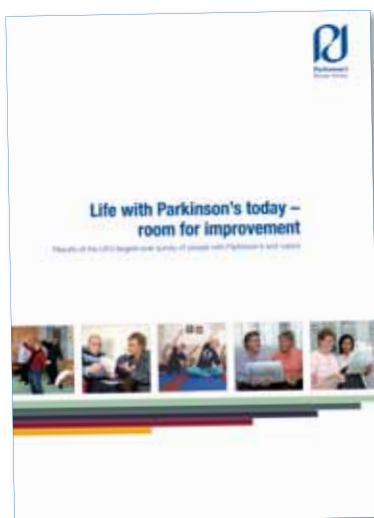
This demonstrates that pesticides may be contributing to nerve cell death in some people with Parkinson's, but is unlikely to be the only cause. Read more about the Members' Survey on page 27.

The researchers compared people with Parkinson's to family members without the condition and found that those with Parkinson's had a greater exposure to pesticides and that these were mainly in the form of insecticides and herbicides. Interestingly, the investigators did not find a link between Parkinson's and living or working on a farm, or drinking water from wells. To learn more about what the Members' Survey showed see Fact box 7.



Richard R. Hansen/Science Photo Library

What the Members' Survey revealed about research



In 2007, a questionnaire was sent to almost all members of the PDS (nearly 28,000 people). The aim of the survey was to increase our understanding of the needs of people living with Parkinson's and help the PDS plan for the future so that it remains as the leading organisation of people

with Parkinson's in the UK. Approximately 50% of the questionnaires were returned with respondents' identity remaining anonymous. A previous survey has been conducted by the PDS in 1997, with nearly 1,700 returned, making the current one much more comprehensive.

Some interesting findings are reported below:

- The main role of the PDS for the future was seen to be promotion of research, the dissemination or provision of support, and work to ensure high quality services for people with Parkinson's and carers.
- Medical research into causes, improved treatments and the development of cures were seen as most pertinent.

The Society is active in all of these areas of research and one of our priorities this year will be to identify key research themes that are likely to result ultimately in a cure. To learn

more about the PDS's achievements in these areas of research over the past 40 years read our publication *Four Decades of Discovery*. Details of how you can obtain a copy of this can be found on page 5.

- Most members had been diagnosed between the ages of 55 and 74 years, and were likely to have had the condition for at least five years.

The age of onset of Parkinson's is variable and a study, funded by the PDS, is looking at what influences this (**see page 7**).

- The initial symptoms most commonly experienced by people were a slowing down of movement or tremor. Also, in terms of living with Parkinson's, nearly all of the respondents noticed variation in their symptoms. Fine motor tasks such as writing or doing up buttons were most commonly proving difficult as well as more fundamental motor co-ordination such as standing up or starting to walk.

People with Parkinson's are faced with a number of problems related to their condition, some of which (including tremors) can be controlled by drugs treatments (such as levodopa) but other everyday problems (such as writing) may need rehabilitation such as physiotherapy to help improve the persons ability to perform everyday tasks. To learn more about the studies the PDS is supporting in the area of physiotherapy read pages 2 – 4.

The PDS is also funding a study that ultimately aims to help stop people with Parkinson's falling. This is a great problem experienced by people with Parkinson's and may be caused by muscle stiffness (this study was reported on page 17 of the summer 2008 edition of *Progress*).

- A small number (2%) of respondents had undergone surgery, called deep brain stimulation to treat their condition. Surgical treatment seems to have been quite successful in improving movement but in some people it tended to have an impact on their memory and concentration.

The PDS is supporting a number of studies in this area including understanding how deep brain stimulation works, (which is highlighted on page 8) and how it can cause depression in some people with Parkinson's (reported on page 12 of the Summer 2008 edition of *Progress*).

- Half of the carers felt their health had deteriorated since becoming a carer, most commonly suffering from stress, fatigue or sleep problems. Other problems, such as arthritis, heart or circulation problems, were in evidence for more than half the people.

The PDS recognises the impact that caring for people with Parkinson's can have on carers and is supporting a study that is developing therapy aimed at reducing the carers level of stress and burden (this was reported on page 18 of the Summer 2008 edition of *Progress*).

The PDS has produced a booklet *The Carer's Guide* which is downloadable from the website or available, free of charge, from Sharward Services Ltd (see page 9 for contact details).

People with Parkinson's also experience non-motor symptoms that are unrelated to the movement aspects of the condition, such as sleep disturbances and hallucinations. The Society, as part of the Themed Research scheme, is funding a major study into sleep disorders that is looking at understanding the cause of the problem in order that it can be treated better (read more about this study on pages 12 – 13).

More information about the Survey can be obtained by either downloading a copy of the report *Life with Parkinson's today – room for improvement* from our website at:

www.parkinsons.org.uk

or contacting a member of the media team on:

Email: pr@parkinsons.org.uk or

Tel: 020 7963 9370

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How interesting did you find this issue? (tick the appropriate box: 1 = not very interesting, 5 = very interesting)

	1	2	3	4	5
Spotlight on benefits of physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Meet... Dr Dileas Sweetenham	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supporting the Brain Donor Appeal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Frequently asked questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What the Members' Survey revealed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Which article did you like most and why? _____

Which article did you like least and why? _____

Which research topics would you like to hear more about? _____

Is there a research-related question you would like to ask us? _____



Progress is produced by the PDS Research & Development team in collaboration with the Information Resources and Communications team

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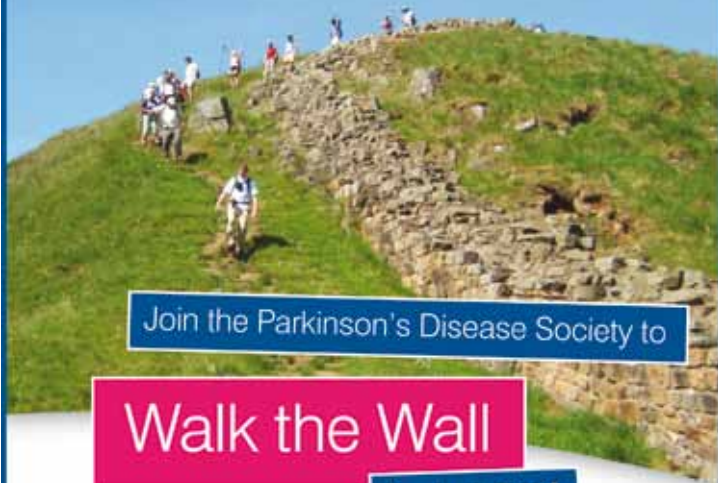
Email research@parkinsons.org.uk

Visit www.parkinsons.org.uk/research

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215 Vauxhall Bridge Road, London SW1V 1EJ

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7-9 August 2009



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www.parkinsons.org.uk

Parkinson's
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 Parkinson's
Disease Society

40 years of progress

2009

"The Parkinson's Disease Society supports people like me and gives us all hope for a cure in the future."

Mike Godfrey
Sutton, Kingston and Epsom Branch

2004

Two genes associated with inherited Parkinson's are discovered, giving us a better understanding of the causes of Parkinson's.

1989

The first Parkinson's Disease Nurse Specialist is appointed, providing specialised local care for people with Parkinson's.

1984

The Parkinson's Brain Bank is established, enabling crucial research into the condition.

1969

Levodopa becomes the first major breakthrough in drug treatment for Parkinson's, revolutionising how symptoms are controlled.

Call our free and confidential Helpline on **0800 800 0303**

Visit www.parkinsons.org.uk

The time is now to get involved.



Parkinson's
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Helpline

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Monday–Friday, 9.30am–9pm Saturday, 9.30am–5.30pm (except Bank Holidays)

email: enquiries@parkinsons.org.uk

The Parkinson's Disease Society (PDS) works with people with Parkinson's, their carers, families and friends, and health and social care professionals to provide support, information and advice. We are committed to investing in research, education and campaigning to improve the lives of people affected by the condition. The PDS has over 29,000 members, and more than 330 branches, support groups and special interest groups throughout the UK.

How you can help us

We are totally dependent on voluntary donations so if you would like to make a contribution, it will be gratefully received and help us support people affected by Parkinson's through information, care and research.

To make a donation, please call **020 7931 0303**

To discuss supporting a specific project please call **020 7932 1309**

visit www.parkinsons.org.uk/donate

write to **Parkinson's Disease Society, 215 Vauxhall Bridge Road, London SW1V 1EJ**. Thank you.

Parkinson's Disease Society of the United Kingdom

215 Vauxhall Bridge Road

London SW1V 1EJ

Tel: **020 7931 8080** Fax: **020 7233 9908**

Free Phone Helpline: **0808 800 0303**

(available Monday–Friday, 9.30am–9pm, Saturday, 9.30am–5.30pm)

Email: enquiries@parkinsons.org.uk

There are local PDS branches throughout the UK.

Please call **0808 800 0303** for details.

www.parkinsons.org.uk

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