

# PARKINSON'S DISEASE SOCIETY OF THE UNITED KINGDOM

## ANNUAL REVIEW, REPORT & ACCOUNTS 2003



120,000 people in the UK have Parkinson's disease, a progressive and currently incurable neurological condition. Up to seven million people are touched by Parkinson's, either personally or as a family member or friend. The Society aims to be one of the leading neurological charities in the UK – serving all people with Parkinson's. The PDS is a registered charity and has 30,000 members. It is the only UK charity dedicated to helping people affected by Parkinson's. It is funded almost entirely by voluntary donations. Its work includes:

- a helpline [freephone 0808 800 0303, textphone (Minicom) 020 7963 9380, open Monday-Friday, 9.30am-5.30pm] staffed by nurses offering advice and support to anyone affected by Parkinson's;
- research into the cause, cure and prevention of Parkinson's, better treatments, and research into improving the quality of life of people affected by Parkinson's, as well as support of best practice for the management of Parkinson's in the UK's health and social care systems;
- the PDS Tissue Bank at Imperial College London – which gathers tissue for its own research, as well as to share with other Parkinson's researchers in the UK and internationally;
- information on all aspects of Parkinson's including drugs, surgery, therapies, social and health care rights, benefits, insurance, employment, driving, holidays, respite care etc;
- a wide range of information sheets, booklets, audio tapes and videos for people with Parkinson's, families and carers, as well as people working in Parkinson's;
- a quarterly colour membership magazine about living with the condition, *The Parkinson*;
- a website full of news, information and advice: [www.parkinsons.org.uk](http://www.parkinsons.org.uk);
- a comprehensive programme of continuing and professional education for people working in all areas of Parkinson's, as well as for those living with the condition;
- 300+ local branches, support groups and special interest groups throughout the UK. Run by volunteers, often people with Parkinson's and their families, they offer mutual support, information, social activities and practical help at a local level;
- community support workers working locally with branches and support groups, who can provide emotional and practical support;
- as well as offices in London, Scotland, Wales and Northern Ireland, we have a national network of staff working with people affected by Parkinson's, branches, support groups and local organisations, furthering the aims of the PDS;
- an outreach service for black & minority ethnic communities in Birmingham – providing culturally appropriate information, advice and support, including some bilingual support; as well as resources available national in key community languages;
- promoting the development and support of Parkinson's Disease Nurse Specialists, nurses specially trained in Parkinson's management;
- special interest groups: YAPP&RS for younger people (of working age) and their families, and SPRING for those with a special interest in medical research.

## **Parkinson's Disease Society of the United Kingdom**

Registered Charity No. 258197

A company limited by guarantee. Registered No. 948776 (London)

Registered Office: 215 Vauxhall Bridge Road, London SW1V 1EJ

215 Vauxhall Bridge Road, London SW1V 1EJ **Tel** 020 7931 8080 **Fax** 020 7233 9908

**Helpline** telephone (free) 0808 800 0303; textphone (Minicom) 020 7963 9380 (Monday-Friday, 9.30-5.30)

**E-mail** [enquiries@parkinsons.org.uk](mailto:enquiries@parkinsons.org.uk)

**Website** [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

There are local PDS branches and support groups throughout the UK – please call 020 7932 1306 for details.

120,000 people in the UK have Parkinson's disease, a progressive and currently incurable neurological condition. Up to seven million people are touched by Parkinson's, either personally, or as a family member or friend.

The Parkinson's Disease Society's mission is the conquest of Parkinson's disease and the alleviation of the distress it causes, through effective research, education, care and communication.

The Society is increasingly a force for change through its campaigning and influencing activities. Our 29,000 members, over 300 branches and support groups and 18,000 other regular supporters, are a powerful constituency.

# CHAIRMAN'S MESSAGE

LUCIANNE SAWYER CBE



I am delighted to introduce the Parkinson's Disease Society's *Annual Review, Report and Accounts* for 2003 and to report on another year in which we have developed our influence, and increased awareness of the impact of Parkinson's disease and the importance of the Society's work.

I will concentrate my comments here on the development of the PDS but I am sure you will also be interested and impressed by the achievements summarised in the following pages. There are some marvellous snapshots of our many activities across the UK as we all work to make a real difference to the lives of those living with Parkinson's disease.

I believe the Society is gaining in strength and recognition, not least because we are

genuinely working together as one Society reaching out to all people with Parkinson's. We are also doing better at involving people, listening to their views before we move forward and we are committed to continuing consultation. I am also pleased that we are increasingly diverse as an organisation and we will build on this as we reach out to members of all communities.

The geographical network of support for people with Parkinson's, with a new structure in place, has been greatly strengthened during 2003. This embraces our branches and support group network, local health and social care professionals including the invaluable Parkinson's Disease Nurse Specialists and our Community Services teams. We will now be looking at areas which are still not well served and considering what we can best do to ensure that the Society's presence and support is more evenly spread throughout the UK.

In the vital area of research the Society welcomes the contribution of all those who help to unravel the puzzle of Parkinson's, including more effective treatments and support, as well as the scientific questions

which may lead to cause and cure. Our Research Advisory Panel brings together the expertise both of members of the Society living with Parkinson's and also skilled researchers and clinicians.

The Society is increasingly a force for change through its campaigning and influencing activities. Our 29,000 members, over 300 branches and support groups and 18,000 other regular supporters, are a powerful constituency. The new network of Area Advisory Groups, including both people with Parkinson's and carers and professionals with a special interest in Parkinson's, will increase our ability to influence local service provision.

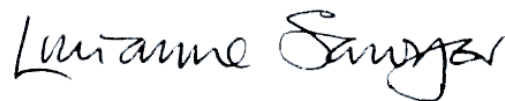
As local champions for Parkinson's they have already helped in developing the Parkinson's Disease Nurse Specialist network, and we are delighted to report a further 26 PDNSs in post during 2003.

The Society was also very active in professional education and development in 2003. Education remains very much at the heart of our work and we are delighted that health and social care professionals who provide treatment, support and services for people with Parkinson's are keen to increase their knowledge and understanding.

Finally, I want to express my warm appreciation to all those who have contributed to the success of the Society in 2003. This will be my final Chairman's Report as my term of office comes to an end in September 2004. I particularly want to emphasise how much I have appreciated the warm welcome I have received from the branches I have been able to visit, the pleasure I have gained from meeting so many of you who are committed to helping the PDS, and the sense of pride I take in the Society's achievements.

There are many people who have helped us in so many ways and I must thank you all. I think the Society's trustees have carried out their responsibilities superbly and have also given me valuable support as your Chairman. The Society is indeed fortunate to have Richard Briers as our President; we are very grateful to Richard for finding so much time despite his professional commitments to support us and promote awareness of Parkinson's. The branches, support groups and our volunteers across the country have carried out excellent work and I must also thank Linda Kelly, Chief Executive, and her staff for their hard work and commitment.

It has been an honour to have undertaken the role of Chairman of the Society and I will now seek to make my contribution to the PDS as a continuing trustee and as a volunteer. We still have much to do as we seek to defeat this devastating condition but I am very confident the Society will grow from strength to strength in the years ahead.



**Lucianne Sawyer CBE**  
Chairman, Parkinson's Disease Society  
of the United Kingdom

Building links with locally based statutory health and social care services has become an increasing focus of our work. During the year we developed our advisory groups across the UK, involving our supporters, volunteers and external professionals. We also strengthened and expanded our Parkinson's Disease Nurse Specialist network.

# SUPPORTING



*When I started the job I didn't really know anything about Parkinson's, but now I have to be an expert!*

*I really like working with people affected by Parkinson's – more than any client group I've worked with in my career. I get great job satisfaction.*

*Any help I can give really seems to make a big difference to people's lives.*

Norma Elliot  
PDS Community  
Support Worker

In 2002 the PDS held a major review of its field services. This resulted in 14 PDS areas being established across the UK with an increased focus on helping people achieve better access to and better quality health and social care services locally. This is especially important, given that three-quarters of NHS spending is now controlled by local primary care trusts (PCTs) and health boards.

The review also led, during 2003 to the setting up of advisory groups in each of the 14 areas, to assist in the planning of PDS work locally. These groups include people with Parkinson's and their carers, PDS staff, and representatives from local health and social care agencies, such as consultants and practitioners from PCTs and social services departments.

The advisory groups are an opportunity for the Society, its supporters and volunteers to share expertise and experience and drive changes forward to improve services for people living with Parkinson's locally. They also help the PDS to develop relationships with key professionals in health and social care services. A whole range of work took place to improve services, including:

- In the PDS Eastern England area, PDS representatives met with Chief Executives and Chief Nursing Officers at several PCTs to discuss the potential role of PDNSs and other partnership arrangements between the Society and the statutory sector. This was a highly successful venture, the model being rolled out across the UK in 2004.
- The PDS in Scotland was actively involved in major reviews of neurological services in the Scottish Borders and Shetland.
- In Wales there was very positive pilot trial of a partnership with Age Concern to provide benefits information, advice and support to people living with Parkinson's.
- We also engaged in partnership working with a local borough, Rhondda Cynon Taff, in a project to increase awareness and improve understanding of Parkinson's. This model is likely to be developed to enhance services in areas in which there is not yet a Community Support Worker (CSW).

The Society also continued to expand its network of Parkinson's Disease Nurse Specialists (PDNSs) over the year. These nurses work within the community and from hospitals to help those living with Parkinson's improve their quality of life. They assist by helping people better manage their Parkinson's,

linking them to appropriate care services, liaising with doctors and other health professionals and promoting understanding of Parkinson's in the NHS.

The nurse specialist posts are funded by the Society and other partners for the first one to two years, after which funding is taken on by the NHS.

Like 2002, 2003 was another successful year in our PDNS campaign, and we were delighted to secure the creation of a further 26 PDNS posts (the current total, in July 2004, is 200). Our immediate aim is to establish 240 nurse specialists in the NHS, right across the UK by the end of 2006.

We saw particular development of the nurse network in the West Midlands, where six new nurse posts were created, followed by four in the South West and three in the North West. New posts included:

- Bexley, after several years of negotiating and fundraising by the Branch.
- Cheltenham, following a three-way partnership between the branch, the PDS and the local PCT.
- Bristol, where a PDNS was appointed to help develop services in the community.
- The first appointment of the first PDNS nurse consultant, in Cornwall. The Society hopes to develop more nurse consultant posts in future.

Our plans to extend the PDNS network were boosted during the year by a study at Glan Clwyd Hospital in North Wales:

- The study found that, by introducing a PDNS, the hospital saved more than £50,000 in consultant clinical time in a six-month period (£100,000 savings on an annual basis). The study looked at the cost savings of PDNS interventions for patients who would otherwise have attended a specialist outpatient

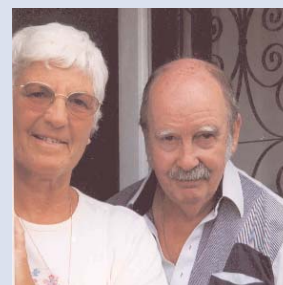
clinic. The hospital also calculated that there were additional savings arising from education, health promotion, research and development and home visits.

We also secured the appointment of 10 new Community Support Workers (CSWs) posts (formerly known as welfare visitors) during the year, right across the country including Aberdeen, Bradford and Minehead. CSWs give information, emotional and practical support in local areas to people with Parkinson's, their families and carers.

## IN 2003, WE HELPED PEOPLE WITH PARKINSON'S AND THEIR CARERS CLAIM £1.6 MILLION WORTH OF BENEFITS

We estimate that in 2003 PDS staff helped people with Parkinson's and their carers claim £1.6 million worth of benefits, such as disability living allowance and attendance allowance.

Over the year the Society continued to make grants to benefit people with Parkinson's and their carers. This included 42 grants from our Small Grant Fund. These payments included the funding of housing repairs, respite and holiday requests and help with equipment and mobility aids.



Our volunteer-led network of branches and support groups continued to grow, with their crucial role in influencing local health and care service expanding in 2003. Branches also continued to provide a wide range of information, activities and vital social support, as well as an extremely active programme of fundraising work.

# CARING

Photo: David Matthews



*Guildford Branch was formed in 1982 and we now have over 500 members – one of the largest PDS branches.*

*Among our many activities we have regular meetings in several venues in the area, plus a regular evening pub meeting for our working-age members.*

*Other events include: Christmas parties, a lunch in Guildford Cathedral Refectory during PAW, trips (e.g. to Denbies winery, Basingstoke Canal), and a summer picnic lunch with cream tea. We support five physiotherapy classes too.*

*We're also lucky in having had the same great CSW, Mary Brown, for 10 years now as our anchor.*

*There's a great deal for the committee to organise but they enjoy it – mostly!*

**Mike Leahy, Chairman  
Guildford Branch**

Branches and support groups are the lifeblood of the Society involving in 2003, more than 3,500 volunteers right across the UK.

During 2003 our network expanded, with eight new branches and 25 new support groups being started, from Skegness to Greenwich and Fraserburgh to Southampton.

Branches and support groups provide much needed advice, information and support, as well as social activities and friendship. In addition to this, branches have become increasingly involved in influencing local services, working with staff and other statutory bodies locally. Involvement has included work with social services, influencing primary care trusts (PCTs) and involvement in patient-public initiatives with local health authorities.

As ever, branches worked incredibly hard to promote awareness of Parkinson's, and the PDS, and to fundraise for the work of the Society.

- During Parkinson's Awareness Week, all the North West branches came together to host a variety of events at Manchester town hall. These included an

information day, a fundraising abseiling event, a Black and Minority Ethnic information day and a volunteer recruitment day. The event was concluded with a branches day at the town hall, where members of branches and support groups across the region had a chance to meet and share ideas and experiences.

- In Northern Ireland, Causeway Coast Branch organised a cycle event that raised over £8,000 and gained wide publicity. The branch also held an information and therapy weekend, reaching more than 30 people with Parkinson's and their carers from across the province and forging links with people from the Republic of Ireland.
- During Parkinson's Awareness Week the Jersey Branch promoted the PDS Tissue Bank, publicising two branch members who had decided to bequeath their brain tissue. They received excellent media coverage, with interviews on BBC radio and TV. Following the publicity several new people agreed to donate their brain tissue for research.

A pilot befriending scheme was launched in the north-east of England during Parkinson's Awareness Week. The scheme was supported by the Abbey National Charitable Trust and will offer support to people with

## CAUSEWAY COAST'S INFORMATION & THERAPY WEEKEND REACHED PEOPLE FROM ACROSS THE PROVINCE – AND FORGED LINKS WITH PEOPLE FROM THE REPUBLIC OF IRELAND

1,650 calls from branch volunteers. 68% of these callers received a full response within one hour with 83% having the enquiries successfully closed by the end of the next day.

- The monthly *Branch Update* became a bi-monthly production and branches have made positive contributions to share examples of local events and good practice projects.

Parkinson's, their families and carers through volunteer befrienders. It was co-ordinated by locally based PDS staff, working in partnership with volunteer agencies. An initial evaluation of the pilot scheme is very promising and could lead to the scheme's development in other areas.

Support in the forms of classes and workshops provided by branches also developed over the year. Many branches were able to take advantage of the CREATE IT Awards (see next page). Others were very successful in securing funding from other sources:

- The Doncaster and Huddersfield Branches were successful in being awarded grants from the Lottery's Community Fund to fund community support workers in Yorkshire.
- The Reading Branch raised £16,000 over three years from the PCT to run therapy sessions.

To help our branches volunteers in their work, a Branch Support Unit was set up during the year. Its aim is to provide all branches and support groups with quicker, easier and more direct access to information and advice.

- The freephone Branch Support Unit telephone line received



Not everyone is aware of or able to access services. However the PDS exists to help *all* people living with Parkinson's and we are particularly keen to reach out to carers, younger people and those from black and minority ethnic communities. We made significant advances with these groups in 2003.

# REACHING



*I found the PDS Younger Persons' event in Cardiff a very rewarding experience.*

*It was great meeting other people in the same position as me, and was interesting to be updated on the latest developments in treatment and research.*

*A common theme was how important the support network for people with Parkinson's and their carers is, and how vital it is to have a dedicated Parkinson's nurse.*

Hywel Griffiths, (right), participant at the Cardiff Young People's Event, who was diagnosed aged 33

This year we continued our efforts to build links with carers and younger people, through consultation events aimed at helping us shape the future development of PDS services and support. Views from user-group events with carers and younger people have been very important in influencing plans for work with these groups in 2004. Their opinions and experiences have also greatly helped guide the Society in its campaign aims.

There were a wide range of events and initiatives working with younger people and their families, from local workshops to national conferences, including:

- two major national events, in Cardiff and Nottinghamshire, which gave younger people the chance to meet up and share experiences, as well as influence PDS plans for 2004. These events also provided opportunities for this group to find out about specific support services and get an update on the latest developments in treatment and research.

A similar programme of activities took place for carers, including information days, workshops, and three national carers events which took place in June and July, in collaboration with the

Princess Royal Trust for Carers and local care organisations. Held in Kent, County Durham and Suffolk, these events allowed carers to give their views on the developments in services and support they wanted to see.

Key findings from these days included a desire for more information about Parkinson's, especially medication, side-effects and mental health issues.

The Society was pleased to further its links with carers organisation during the year, including closer involvement with Carers Week in June, and partnership with charity Carers UK at the national party political conferences in the autumn.

The Society also continued to improve its reach to people from black and minority ethnic (BME) communities.

- The Society led a one-day national workshop, in partnership with several other neurological organisations, called Reaching out to Diverse Communities. This aimed to discuss best practice in improving support for people from BME communities. The event resulted in a practical guide, which was published in 2004.

- The Society hosted an outreach event in Leicester for people from minority ethnic communities with neurological conditions. Service providers from NHS organisations and charities such as the Stroke Association and Alzheimer's Society attended. The event included awareness raising, information and a selection of multi-cultural entertainment. More than 400 people attended and a directory of organisations supporting BME groups locally was produced as a result.
- In Birmingham the social services department and local PCT doubled their grant for the Society's work with carers from BME communities, bringing it to £20,000. This allowed us to make significantly more financial awards to help individual carers in the area. The Birmingham BME carers group continues to grow and has organised numerous activities and outings as a result of the increased grant.

The CREATE IT Awards, funded by the Millennium Commission in 2001, came to a close at the end of 2003. CREATE IT was a hugely important project in which Awards were made to people with Parkinson's to set up projects which would benefit their local community.

During the year the awards supported 105 projects nationally, taking the total number of awards since 2001

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to 132. The kinds of activities funded in 2003 ranged from the Alexander Technique and Tai Chi classes to weekly art groups and community choirs. Many people commented how much the projects had benefited not only themselves, but improved understanding of Parkinson's, and disability generally, in their community

The PDS award launched by the family of author Mervyn Peake in 2002, to celebrate the art, poetry and photography of people with Parkinson's, took place very successfully again in 2003. It was won by Bridgit Morton of Hertfordshire, for her poem, *Spring Clean*.

Young, Alert, Parkinson's Partners & Relatives (YAPP&Rs), the PDS's group for younger people affected by Parkinson's had a busy and productive year. Highlights included: a busy AGM in Rugby; and four editions of the popular *YAPmag*.



Publications, the PDS website, our helpline and special events – these are just some of the ways we provide information on Parkinson's to a cross-section of audiences.

# INFORMING



*I often say that Parkinson's was not the end for me, but rather the beginning of a new life. I have met some great people and become friends with many through my involvement with the PDS.*

*It is such a help to be able to pick up the phone when I am struggling and talk to someone else who understands what I am going through.*

*I am now secretary of the local branch. Being involved with the Society helps me a lot – I feel that I am giving back something to others.*

Gerry McCann, focus of the PDS BTA Schools Study Card on Parkinson's 2003

During the year information days were held at a wide range of venues, from Alton to Blackpool and Croydon to Cumbria. Over 80 information days allowed us to reach more than 3,000 people, a significant number of whom were new to the Society and its services. As well as information days, a host of other information events took place, including:

- A 'roadshow', organised by six Parkinson's Disease Nurse Specialists from the West Midlands, hosting information events throughout the region.
- A conference held in East Anglia to showcase examples of good practice in relation to Parkinson's services. The conference, which had input from the education and campaigns team, was jointly organised and supported by a local consultant.
- 'Touring' information from the Society's Mobile Resource Unit on travels to some of the more remote areas of the UK to spread awareness of Parkinson's.

It was a busy year for the Society's Welfare and Employment Rights Service, with 3,132 people contacted the service, generating 8,658 enquiries. Employment information days were held in Birmingham, Manchester and London.

Our range of resources and information on Parkinson's continued to grow.

- There were eight new information sheets, covering topics including anaesthesia, fatigue, James Parkinson, keeping moving, fluctuations and tips for talking to your doctor. All information sheets are now on the PDS website. We also achieved improved coverage of the Society's work on the Association of British Neurologists and the NHS Direct websites.
- Circulation was substantially increased for *Parkinson's News*, the quarterly awareness bulletin for health and social care professionals, following its raised profile on the PDS website. Four editions of the popular *The Parkinson* magazine were produced (plus audio tape versions), with 30,000 copies circulated of each edition.
- *Keeping Moving*, a new exercise programme for people with Parkinson's was launched in April. Provided as a booklet and video, the programme aims to encourage people with Parkinson's to exercise, whatever their abilities, and show them how beneficial activity can be. The initial run of 500 videos sold out by the end of 2003.
- Readers gave PDS booklets an average 6.5 out of 7 quality rating in their evaluation response forms.

Our helpline continued to be an extremely valuable resource for people with Parkinson's, their families and carers.

- The helpline handled 9,668 enquiries during the year, an average of 805 calls per month compared with 645 in 2002.
- We established a text phone service within the helpline, allowing the PDS to reach people with hearing difficulties.

2003 saw a number of exciting developments in the Society's web programme (visit [www.parkinsons.org.uk](http://www.parkinsons.org.uk))

- The role of Web Manager was created to coordinate a comprehensive programme of enhancements over the year. This has led to a substantially redeveloped website, launched in July 2004, with initiatives including on-line donations, notice board and professional forum. 35 new branches and support groups have pledged to join the 45 that have already created subsites.

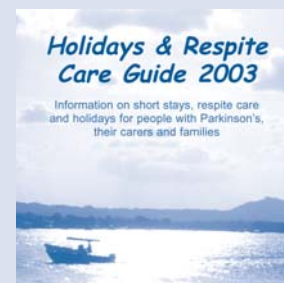
Education is key to our work. 2003 saw an increase in our courses for professionals, many offering accredited professional learning. A wide range of professionals attended PDS courses, including nurses, social workers and GPs. With the changing legislation on care standards, 2003 also saw a dramatic uptake from domiciliary and home care providers.

- We ran 219 education courses, attended by almost 5,000 professionals.
- There were also courses facilitated by branches, such as specific carers' seminars and 'understanding Parkinson's' sessions.
- In addition to direct education, we produced a variety of journal articles, to enhance the continuing professional development of pharmacists, nurses, allied health professionals and care staff.
- New programmes for half and full-day seminars for health and social care professionals were developed and produced, on

issues such as working safely with vulnerable people and on dementia and cognitive challenges in Parkinson's.

- We continued to promote and accredit the Quality in Care certification scheme for support staff working in residential, nursing or domiciliary settings.
- The Society also worked closely with the National Care Standards Commission (now the Commission for Social Care Inspection), producing a resource pack to educate all its 1,500 care home inspectors about Parkinson's and the particular needs of people with the condition.
- 300 community pharmacists qualified for the *Understanding Parkinson's* certificate, following a training CD-Rom launched by the PDS in 2002. The new education programme outlines details about the disease, side effects of medication and recent advances that have been made, as well as an evaluation of the role of supplements and vitamins.
- Following a successful first year project in 2002, we again worked with BTA Publications to produce a Schools Card on Parkinson's. Focusing on a young family affected by Parkinson's, the Card was part of a pack used by all UK schools, studied in science classes by children aged 7-16.

## NEARLY 300 COMMUNITY PHARMACISTS QUALIFIED FOR A CERTIFICATE IN UNDERSTANDING PARKINSON'S, AFTER THE LAUNCH OF OUR TRAINING CD-ROM



Promoting and funding research into the causes, treatment and cure of Parkinson's remains a key activity for the Society. This year saw the widening of our database of scientists for external peer review, and the creation of our research advisory panel – which includes PDS members, supported by a Network of people affected by Parkinson's, to ensure members' concerns truly influence PDS research.

# RESEARCHING



*It was a great compliment and surprise to be picked to represent carers on the newly formed Research Advisory Panel.*

*I found it all fascinating as we proposed and rejected applications. To be an Essex housewife sitting around this great table on equal terms with some of the very best brains in the Parkinson's research world was quite awesome.*

*By including lay members, people with a real understanding of living with Parkinson's, I believe research will become better focused on things people with Parkinson's really need, not just what scientists think we need. The PDS is doing a remarkable job on our behalf.*

**Ann Lunn, Research Advisory Panel Member**

Following the 2002 merger of our medical advisory panel and welfare research committee, we created a new unified research advisory panel (RAP) and standardised the assessment process. In 2003 the RAP met three times, the first was combined with the annual parliamentary dinner, the second in April to review grant applications and the third in October to discuss general research matters.

To ensure members' concerns help drive research, RAP includes three PDS lay members. They are backed by the Support Group Network, 42 people with Parkinson's or carers, who study and advise the three lay members on each proposed grant.

Key research work during the year included:

- continuing to build on the existing database of scientists for external peer review. This is important because we need a large pool of scientists who are familiar with Parkinson's and who are willing to give independent views that can supplement the opinions of our research advisory panel. We now have 70 professionals willing to undertake reviews of grants.
- an updating of the project grant application form, encouraging researchers to include more detailed descriptions of their science in lay language. The Society also

developed a joint project with the British Library and SPRING (the PDS's Special Research Interest Group) called *Science in Progress*. This aims to provide research information in clear lay language, and work was begun on the papers *An Overview of Parkinson's Research* and *Clinical Trials*, both published in 2004.

The Society funds basic and applied science, and health and social care research projects. In 2003 we awarded the following seven grants:

- *modulation of metabotropic glutamate receptors as a novel neuroprotective strategy.*
- *development of a better mouse model of Parkinson's (suitable for drug screening or testing gene therapy/stem cells) by crossing the existing mouse with mice that express a mutant form of the human protein  $\alpha$ -synuclein, which accumulates in the dopamine cells of people with Parkinson's.*
- *an investigation of how priming for dyskinesia is produced by making use of the best experimental model available.*
- *using positron emission tomography (PET) to look at the striatal toxicity of MDMA as a possible cause of Parkinsonism.*
- *MT DNA Complex 1 Polymorphisms in Parkinson's – assessing how common these gene changes are in Parkinson's and general populations.*

- *The ability of xenografted neural stem cells to target damage and effect repair in animal models.*
- *Choice reaction time in rats: effects of alternative cell repair therapies on deficits induced by dopamine cell loss.*

The following three fellowships were awarded:

- *Deep brain stimulation: an analysis of mechanism of action and neurophysiologic markers of clinical efficacy.*
- *Chromatin-based analysis of the generation of neural progenitors from embryonic stem cells.*
- *New tools for directed neural differentiation of embryonic stem cells.*
- There was also a studentship into genetic programmes governing maintenance of midbrain dopamine neurons, regulated by homeobox gene Pitx3.

An analysis of all research funded by the PDS from 2001 to 2003, showed we have a broad research portfolio. It revealed that genetics accounted for 33% of PDS research, cellular studies 24%, stem cells 18%, developing therapies 16%, symptoms 5%, surgical 2% and social policy 2%.

2003 research events included:

- Three open days: the PDS Tissue Bank in March, Dundee's Nine-wells Hospital in October and the MRC Cyclotron Unit in November.
- The SPRING 2003 Research Forum '*Curing Parkinson's: From Molecules to Man*'.
- The Society's Research Conference, held prior to the PDS AGM, in Coventry.
- An MRC Stem Cell Conference, in September.

2003's research equipment 'shopping list' was again a very successful scheme with PDS branches, with nearly all the requested items purchased. The scheme will run again in 2004.

The PDS was involved in the following care research in 2003:

- The Advanced Care Project into the needs of people with complex Parkinson's, entitled *Just Invisible*.

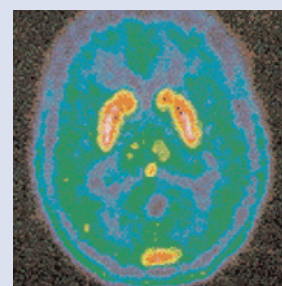
## PDS RAP LAY MEMBERS ARE BACKED BY THE SUPPORT GROUP NETWORK – 42 PEOPLE WITH PARKINSON'S OR CARERS

- An Economic and Social Research Council-funded project, in partnership with Sheffield University, looking at '*Being a Woman with a Long-Term Condition*'.
- A patient-centred study, the first of its kind, assessing the impact of Parkinson's on an individual's physical, social and psychological wellbeing. The study is led by the UK PD LIFE Group and is taking place over five years.

The PDS was encouraged by the results of a PDS-funded pilot study, published in the peer-review journal *Nature*. This looked at the safety and clinical efficacy of direct brain infusion of 'glial cell line-derived neurotrophic factor' (GDNF) into the brains of people with Parkinson's. The results showed significant improvements in all five patients' symptoms.

The Society also announced interim findings from a study into employment and Parkinson's. Eighty percent of respondents said their symptoms had made work difficult and less than a third were actually in work at the time of the study. Just over half had retired due to Parkinson's and the average age of retirement was 49.6. Less than a third of respondents said their employer had been supportive.

The PDS special interest group for research, SPRING, enjoyed a successful year. SPRING's activities include campaigning, a website, *SPRING Times*, talks to branches, sponsorship of a PhD student, biannual members' forums and the biennial research forum.



Promoting the Society's work to legislators, public bodies and the general public is vitally important. This year we put particular efforts into parliamentary campaigns and into helping prevent a European ban in stem cell research.

# INFLUENCING



*The photo shoot was a really fun day. It was a little awkward at first because they were very close-up shots, but we all got into the swing of it; and by the end we were all good friends!*

*I think posters are really important for raising awareness of Parkinson's. We've got posters at our branch, obviously, but they've got them in the clinic at our local hospital too. I particularly remember seeing the PDS poster "laughing at the same joke", which I liked because it was so positive. I'm all for getting the word out about Parkinson's as much as possible.*

Denise Webster, PAW poster campaign model

Campaigning and influencing is a key part of the Society's work. As well as driving forward our work influencing services locally, this year our priorities also included strengthening our links with decision makers in Westminster, the Scottish Parliament, the National Assembly for Wales and in Northern Ireland. We were also strongly involved in the coalition to oppose a ban on stem cell research in Europe and in the commissioning of market research that revealed seven out of 10 Britons supported the use of embryos for medical research.

Our campaigning and lobbying work included:

- a manifesto for the elections taking place to the Scottish Parliament in May. This called on candidates to look at practical ways of implementing better services for people with Parkinson's disease, their carers and families.
- A manifesto for elections to the National Assembly of Wales, which called on candidates to commit to a review of services for people with Parkinson's and other neurological services early in the new Assembly term.
- Urging members of the European Parliament to reject amendments to the European Commission's

draft *Human Tissues and Cells Directive*. The amendments, which were subsequently defeated, would have held back vital medical research that could lead to new treatments and possibly a cure for Parkinson's disease. In March 2003 the Society welcomed the positive ruling in the House of Lords on 'therapeutic' cloning, which allows healthy cells from patients to be copied for use in replacing or repairing damaged or diseased tissues or organs.

- Membership of a coalition of organisations that commissioned research into the views of the British public on the use of embryos for medical research. The poll, conducted by MORI, found that around 70% of the public supported such research to find treatments for serious diseases and for fertility research.
- Developing a campaign involving other voluntary organisations to abolish prescription charges for people with conditions such as Parkinson's.
- Membership of a coalition of charities, called Mobilise, to campaign against age discrimination in the provision of Disability Living Allowance.
- Developing our work on the National Institute for Clinical Excellence's Parkinson's guideline.

- Participation in the NHS's National Service Framework (NSF) for Long-Term Conditions.
- Membership of the Neurological Alliance.
- Working with the NHS Modernisation Agency to promote service developments and improve access to health care for people with Parkinson's
- Participation in expert panels such as the 'Choice, Responsiveness and Equity' initiative launched by the Department of Health which aims to give people more choice in accessing health care and reducing delays.
- Under the theme *Time to Care*, many of the 300 PDS branches throughout the UK organised awareness-raising and fundraising events.
- The parliamentary launch of Parkinson's Awareness Week was supported by Carers UK and sponsored by Pharmacia. Conservative MP Angela Browning hosted the event and speakers included Labour MP Liz Blackman and Liberal Democrat MP Dr Evan Harris. Nearly 100 guests attended, including more than 30 parliamentarians and representatives from the Department of Health and a number of campaigning charities.

## TIME TO CARE HIGHLIGHTED THAT CARING FOR SOMEONE WITH PARKINSON'S CAN BE DEMANDING SOCIALLY, PSYCHOLOGICALLY AND PHYSICALLY

- Ensured that the Society's concerns were raised in briefings for Parliamentarians – we focused on support for vital research, improving access to health care, the importance of specialist nurses and improved support for people with Parkinson's in employment.
- Establish cross-directorate partnerships to create more effective working by linking work locally to influence PCTs and social services with our Parliamentary campaigning and media work – developing the impact of the Society as a campaigning organisation.

Parkinson's Awareness Week was again a prime opportunity to reach the wider public with information about the disease and this year's programme was filled with imaginative events.

- A Time to Care for Carers document was launched, highlighting the fact that carers need support and that caring for someone with Parkinson's can be demanding socially, psychologically and physically.

Promoting the needs of younger people with Parkinson's has become an important part of our work. After all, one person in 20 diagnosed with Parkinson's is under 40. We were very happy, therefore, to work with the BBC medical drama *Holby City* in an innovative awareness-raising exercise.

The Society worked with BBC researchers to develop a storyline involving a younger person with Parkinson's. This was particularly valuable because many people still associate Parkinson's with older people. In the series a young surgeon, Dr Alex James (played by Jeremy Sheffield), was diagnosed with Parkinson's. Each week the PDS website carried messages of support and advice for people who had been affected by the issues raised in the episodes. Jeremy Sheffield also took part in an interview for *The Parkinson* magazine in which he talked about his role.



We value hugely the fundraising contribution of thousands of individuals and the support of many organisations. Our current income of over £13 million is a testament to the fantastic support of individuals and groups up and down the country. We need to raise more, however, to help everyone affected by Parkinson's.

# INVOLVING



*A group of us were walking in Snowdonia when we thought of doing the Three Peaks Challenge. One of the police officers on our team has Parkinson's, so we thought we'd do it for the PDS as a show of support for Dave.*

*So in July, 11 Murder Squad officers and one support staff completed the Challenge – climbing the highest mountains in Scotland, England and Wales – and we did it in less than 48 hours.*

*It was fantastic achievement for our group. We collected over £16,000 for the PDS and raised awareness not only within the police but the local papers also took a keen interest.*

Shaun McLeary,  
PDS fundraiser

Everything you have read about in these pages has been made possible by people or organisations raising or giving money to make a difference to people affected by Parkinson's. Here is just a snapshot of how you helped the Society in 2003.

- Legacies left to the Society contributed a record £7.1 million in 2003 – over half of our total income. These gifts come in all shapes and sizes, often from people who have benefited personally from the Society's work, or whose friends or relatives have done so. If you would like to know more about leaving a gift in your Will to the Society, please contact Donor Services on 020 7932 1303.
- People giving donations in memory of friends and family were again an important part of our fundraising and in 2003 close to £806,000 was received from In Memoriam gifts.
- This year we invested further in our direct marketing programme and recruited over 6,000 new supporters for the Society. We start 2004 with over 13,000 donors and will continue to build this successful area.
- Our appeal programme went from strength to strength in 2003 raising over £350,000. Many thanks to all of you who supported these appeals.
- People giving to the Society through standing orders and direct debits donated just over £150,000 in 2003, providing us with a regular predictable income with which to plan ahead.
- More and more people signed up to Gift Aid this year. Signing a Gift Aid declaration form means that for every pound donated by an individual who pays income or capital gains tax, the Society gets an extra 28 pence from the Inland Revenue, helping your donation to go further. This means that £10 can be turned into £12.80 at no extra cost to you. To find out more, please contact Donor Services on 020 7932 1303.
- The Society continued to receive significant support from Charitable Trusts and companies across the UK, with over £500,000 being donated in 2003 including a wonderful £50,000 from the Gwyneth Forrester Charitable Trust. We were thrilled to be chosen as one of Dixons' charities for their 2003/2004 Action4Disability campaign, which aims to raise £100,000 for the Society. The year also saw continued cooperation with the pharmaceutical industry, which resulted in support for a variety of Society activities from the PDNS programme to information provision and sponsorship of fundraising events.

## WE SAW AN EXPANSION IN "ADRENALINE" EVENTS – OVER 100 PEOPLE TOOK PART IN PARACHUTE JUMPS, RAISING £35,000

Fundraising by the Society's branches continued to play a crucial role in supporting local and national services and research. Activities in 2003 were as imaginative as ever. These included:

- a 'Stars In Their Eyes' concert in Scotland which included 'Elvis', 'Elton John', 'Madonna', 'Robbie Williams' and many more.
- a balloon race in the South West.
- car boot sales in Wales.
- quiz evenings in the East Midlands.
- a 400 km cycle ride in Northern Ireland

The year saw continued growth in the number of people undertaking fundraising events and we are enormously grateful for their hard work in raising close to £600,000 for the Society as well as helping to publicise our work to countless friends, family members and work colleagues.

- The Society's running team continued to go from strength to strength and is acknowledged as one of the most successful in the sector. The year started with a record London Marathon team of 170, who raised a spectacular £230,000 for the Society.
- The London Marathon also marked the end of Tom Isaacs' year-long *Coastin'* venture. Tom, 36, has Parkinson's, and walked Britain's entire coastline, generating great awareness, as well as raising a superb £335,000.

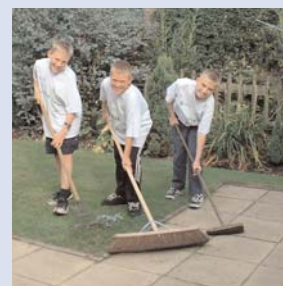
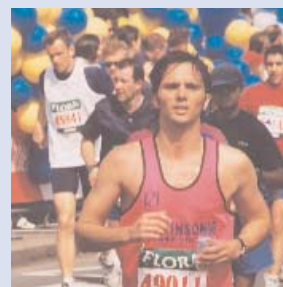
- The PDS's second year of involvement with the Flora Light Challenge for Women saw 200 runners wearing our distinctive team running vests. This, together with a record number of runners in the Great North Run, saw a further £45,000 raised.
- The year also saw an expansion in the Society's 'adrenaline' events, including parachuting. Over 100 adventurous individuals took part in parachute jumps raising £35,000 in the process and we already have 30 signed up for 2004.

The number and variety of fundraising events organised by supporters this year was again tremendous. Highlights included the East London Homicide Squad's Three Peaks Challenge, the Vintage Motorcycle Club's Lands End to John O'Groats ride and 11-year-old Angela Grain's walk in Derbyshire that raised £700.

To find out about more about taking part in or organising a fundraising event, please contact the Events Team on 020 7932 1313/1342.

Throughout 2003 the Society was fortunate to have support from a number of celebrities and particularly from our President, Richard Briers, whose dedication to the Society's work and to all those affected by Parkinson's has been unstinting since he first became involved with the Society 10 years ago.

We look forward to continuing to work with the Society's celebrity supporters in 2004 and thank them for their ongoing support.



# THANK YOU

We would like to thank everyone for their support and donations in 2003. In particular we would like to thank the following who gave £1,000 or more:

## Charities, Trusts & Foundations

The 1989 Willan Charitable Trust  
Abbey National Charitable Trust  
Henry & Grete Abrahams Charitable Foundation  
Albright Charitable Trust  
The HB Allen Charitable Trust  
The Avenue Charitable Trust  
The Harry Bacon Foundation  
The Barbour Trust  
Phillip Barker Charity Trust  
The Dorothy Bayles Trust  
The John Beckwith Charitable Trust  
The Bothwell Charitable Trust  
C Brewer & Son Ltd Trust  
Chamberlain Foundation  
The Chapman Charitable Trust  
The Martin Connell Charitable Trust  
CS Charitable Foundation  
The D'Oyly Carte Charitable Trust  
The DLM Charitable Trust  
Mr & Mrs William Donald's Charitable Trust  
The Thomas Farr Charitable Trust  
Fishermens Wives Benevolent Association  
The Donald Forrester Trust  
The Gwyneth Forrester Trust  
Mrs Jean M F Fraser Charitable Trust  
Gannett Foundation  
Gatwick Airport Community Trust  
The Sir Robert Gooch Charitable Trust  
Gough Ritchie Charitable Trust  
The Irene Hammerton Charitable Trust  
The W A Handley Charitable Trust  
The Hartley Charitable Trust  
The Hawthorne Charitable Trust  
The Haymills Charitable Trust  
The Percy Hedley 1990 Charitable Trust  
Herts Community Foundation  
Alison Hillman Charitable Trust  
Lady Hind Trust  
The Edith Jamieson Charitable Trust  
The Kinsurdy Charitable Trust  
The Kirby Laing Foundation  
Lasletts Charities  
The Lambert Charitable Trust

The Enid Linder Foundation  
Lloyds TSB Foundation  
Lord & Lady Lurgan Trust  
Ian Mactaggart Trust  
The Orr Mackintosh Foundation  
The P F Charitable Trust  
The Gerald Palmer Eling Trust  
Col W W Pilkington Will Trust  
The Märit & Hans Rausing Charitable Foundation  
The Florence Reiss Trust For Old People  
Reuters Foundation  
The Robertson Trust  
Rockley Abbey Lodge  
The Salters' Charities  
The David Saunders Charitable Trust  
John D Scott Charitable Trust  
The Scouloudi Foundation  
The N Smith Charitable Trust  
The Sovereign Health Care Trust  
The Spear Charitable Trust  
The Spurrell Charitable Trust  
St Jude's Trust  
The Stone-Mallabar Charitable Foundation  
The Sunrise (Sidmouth) Trust  
The Tanner Trust  
The Three Oaks Trust  
The Ursula Keyes Trust  
Mrs Waterhouse Charitable Trust  
Mrs M E J Webber Charitable Trust  
The James Weir Foundation  
Felicity Wilde Charitable Trust  
Woking Crematorium Charitable Trust  
The Elizabeth & Prince Zaiger Trust  
Westminster Healthcare Foundation

The PDS looks forward to working further with its celebrity supporters during 2004 and thanks them for their help and dedication during 2003:

Richard Briers CBE  
Angela Down  
Kate Ford  
Elizabeth Hurley  
Gary Lineker  
Jenni Murray OBE  
Bill Neeley  
Michael Palin CBE  
Denise Robertson  
Harriet Scott  
Barbara Thompson MBE  
Anthea Turner

## Companies & Other Supporters

Amersham plc  
Bank of England  
Barclays Plc  
Barratt North London  
BP Exploration  
Bramshill Police Training College  
Britannia Holidays  
Britannia Pharmaceuticals Ltd  
Burford Ladies Golf Club  
Castle Cement Ltd  
Chipping Sodbury Golf Club  
Dresdner Kleinwort Wasserstein  
Elan Pharma Ltd  
A. Ferraris Ltd  
FIBI Bank Plc  
GlaxoSmithKline UK Ltd  
Hamptons International  
Heron & Brearley Ltd  
HSBC Trust Company (UK) Ltd  
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Kleinwort Benson Private Bank Ltd  
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Moor Park Golf Club  
N M Rothschild & Sons Ltd  
Norgine  
Orion Pharma (UK) Ltd  
Pfizer Ltd  
Pharmacia Ltd  
Probus Club of Goring  
Probus Club of Wombwell  
Radlyn Court Flats Ltd  
Roche Products Ltd  
Rotary Club of Dudley  
Rotary Club of Langley & Iver  
Rotary Club of Glasgow  
Royal Bank of Scotland  
St Francis De Sales Church  
Shire Pharmaceuticals  
Six Continents plc  
Soroptomists International  
Suffolk Golf Union  
Sun Capital Partners  
Swiss Reinsurance Company UK Ltd  
Tesco plc  
Three Pigeons  
Windsor Yacht Club  
Eastern District Young Farmers Club  
ZRH Ltd  
Zurich Staff Charity Fund

We thank too our many individual supporters, all those who gave gifts in memoriam, and of course our many legators.



**Parkinson's**  
Disease Society

# **PARKINSON'S DISEASE SOCIETY OF THE UNITED KINGDOM**

## **ANNUAL REPORT & ACCOUNTS 2003**

## Legal and administrative information

### Registered Office:

215 Vauxhall Bridge Road,  
London, SW1V 1EJ

### Patron

HRH The Duchess of  
Gloucester, GCVO

### President

Richard Briers, OBE

### Vice Presidents

Dr Anthony Blowers, CBE,  
JP, PhD

John Bowis, OBE, MEP  
Professor Leslie Findley,  
TD, MD, FRCP, DCH

Baroness Susan  
Greenfield

Keith Levett, BSc(Hons),  
Mphil, Cphys, Dip Ed Mgt

Jenni Murray

Dr Brian Pentland

Baroness Jill Pitkeathley

Janet Sanders

Margery Taylor, OBE, MA

Lady Gillian Howard de  
Walden

### The Board of Trustees

# Lucianne Sawyer, CBE,  
SRN, Dip Soc. Admin,  
MSc, (Chairman) (EC)

# James Berlis  
(from 13.9.2003)

# Jeremy Browne  
(to 13.9.2003)

§ John Creed, BA, FCA

§ Michael Cutler, FCA,  
(Hon Treasurer) (EC)

§ Mark Dumas (EC)

§ Dr Oliver Foster, MA,  
PhD, FRCP

# Donald Hardicre  
(to 13.9.2003)

# Ronald Harvey  
(Trustee from Wales) (EC)

§ Susann Hill  
(from 8.7 2003)

# Charles Holme, BA,  
FCIPD (Hon Secretary) (EC)

# Carole Ions (from  
13.9.2003)

# Patrick Mark (Trustee  
from Scotland) (EC)

# Ethna Watterson  
(Trustee from Northern  
Ireland) (EC)

(EC) = Member of  
Executive Committee

# Elected § Appointed

### Audit Committee

Colin Price, BSc (Econ),  
PhD, FCCA (Chairman)

Cephas Chitambara, FCMA,  
AMCT, MA, MSc, BAcc

John Creed, BA, FCA

Michael Cutler, FCA

### Nominations Panel

Janet Sanders (from  
13.9.2003) (Chairman)

Beryl Bradshaw

Michael Cutler

Donald Hardicre

Lucianne Sawyer

Margery Taylor  
(to 13.9.2003)

### Subsidiary Bodies

#### Research Advisory Panel

Professor Dame Ingrid  
Allen (Chairman)

#### YAPP&Rs

Dave Kirby BSc (Hons)  
(Chairman)

#### SPRING

Charles Holme, BA,  
FCIPD (Chairman)  
(to 2.6.2003)

Charles Frederick  
(Chairman) (from 2.6.2003)

#### Scottish Council

Ronald Partington  
(Chairman)

#### Northern Ireland Council

Eileen McMahon  
(Chairman)

#### Wales Council

Ronald Harvey (Chairman)

### Professional Advisors

#### Auditors

Deloitte & Touche LLP  
1, Little New Street,  
London EC4A 3TR

#### Bankers

Royal Bank of Scotland  
97 New Bond Street,  
London W1Y 0EU

#### Investment Managers

Newton Investment  
Management Limited  
160 Queen Victoria Street,  
London EC4V 4LA

#### Solicitors

Denton Wilde Sapte  
1 Fleet Place,  
London EC4 7WS

Farrer & Co  
66 Lincoln's Inn Fields,  
London WC2A 3LH

#### Staff Principal Contacts

##### Chief Executive

Linda Kelly, BPharm,  
MRPS, FRSA

##### Director of Community Services

Simon Antrobus, BSc

##### Director of Finance & Administration

Lester Corp, BSc (Econ),  
FCA

##### Director of Policy, Research & Information

Robert Meadowcroft,  
BEd (Hons), MA

##### Director of Fundraising

Hugo Middlemas, MA  
(Hons), MInstF

##### Company Secretary

Diana Pert (Solicitor)

## Report of the trustees for the year ended 31 December 2003

The trustees, who are also the directors of the charity for the purposes of the Companies Act 1985, submit their annual report and the audited financial statements for the year ended 31 December 2003.

The Society is both a charity, Registered Charity No. 258197, and a company limited by guarantee, Registered No. 948776 (London). It is governed by its Memorandum and Articles of Association. The Articles of Association were last amended at the Society's Annual General Meeting held on 13 September 2003.

The Society's mission is the conquest of Parkinson's disease and the alleviation of the distress it causes through research, education, welfare and communication. It is the only national organisation working exclusively to help people with Parkinson's, their families and carers.

The Statement of Financial Activities for the year is set out on page 28. A summary of the financial results and the work of the Society is set out below.

## Review of activities and future developments

### Highlights of 2003 include:

- Seven research Project Grants, three Fellowships and PDS/SPRING Studentship awards.
- Successful Annual Parkinson's Awareness Week, focused on Carers.
- A great many Information Days, Workshops and Talks held across the UK, benefiting several thousand participants.
- 11 new Community Support Workers (CSWs) appointed; bringing total to 71. CSWs and the Welfare & Employment Rights staff team raised over £1.6m in benefits for people with Parkinson's and their carers during the year.
- Society's Millennium Commission Award CREATE IT Scheme which made 105 grants.
- Three national consultation events for carers and two for younger people.
- The placing of 26 new Parkinson's Disease Nurse Specialists, together with two Clerical Supporters.
- Branch Support Unit which was launched with free-phone line providing quick and easy access to national office – 1,650 enquiries were received in 2003.
- Distribution of 12,715 Factsheets on benefits and employment rights.
- Production of eight new Information Sheets, including on: Anaesthesia, Fatigue, Motor Fluctuations, Stem Cells and Tips for Talking to Your Doctor. Six Information Sheets were translated into community languages.
- New Video and Booklet with an exercise programme for people with Parkinson's – *Keeping Moving* (initial run of 500 videos sold out by the end of 2003).
- Science information project with British Library '*Science in Progress*', which resulted in new web-based articles, in lay language, on Parkinson's.
- 4,771 people participating in 219 education courses, involving over 648.5 hours of direct education.
- 9,668 enquiries handled by the Helpline (an average of 805 calls per month, up from 645 in 2002).
- Campaigning with other charities to oppose European ban on stem cell research; fighting age discrimination in Disabled Living Allowance; and opposing prescription charges for people with Parkinson's.
- Work on NICE guidelines for Parkinson's and participation in the NSF for long-term conditions.
- Joining with Carers UK to hold highly successful fringe events at all the major Party Conferences.
- Production of the Society's first *Campaign Guide*.
- A co-ordinated tie-in with TV drama *Holby City* to boost public awareness.
- Issue of a Society Style Guide for all printed material.
- Update of Human Resources Policies and Procedures and issuing of a *Handbook* to staff.

### **Plans for 2004 include:**

- Increasing the number of Community Support Workers by a further 15.
- Aiming to place a further 25 new Parkinson's Disease Nurse Specialists in post in the NHS and developing further the Society's Training Programme.
- Conducting a full review of volunteers and identifying the needs for volunteering in the Society.
- Fully implementing and actively promoting the agreed Research Strategy throughout the scientific community.
- Developing the Society's profile and income generating capacity through a range of events in collaboration with and supporting all sections of the Society.
- Improving administrative support and financial information systems, including introduction of a new website which will allow for donations on-line.

### **Income generation**

Incoming resources increased to £13.4 million, an increase of 13%. The pie chart at the end of this report shows the main sources of the Society's income.

Legacies left to the Society and In Memoriam donations, at a record £7.9m (including a single bequest of £1m), grew by 22%.

Donations decreased by 10% to £2.3m, from the exceptionally high level achieved in 2002, which included a large single donation of £250,000. 6,000 new donor supporters were recruited through a direct marketing programme.

Grants increased by 63% to £0.9m. Income from Events remained steady. We received a record £230,000 from the Flora London Marathon team.

Included in total income are amounts raised by branches of £2.1m. (See note 4.)

### **Investment policy and returns**

The main points of the investment policy which has been adopted by the Board of Trustees are:

- invested funds are to be preserved and, to the extent possible, enhanced;
- a balance is to be maintained between growth and income through a diversified portfolio;
- speculative forms of investment are to be avoided.

The required level of reserves for cash flow needs in the immediate future is invested in cash or short term investments. Remaining funds are held in medium or long term investments within an investment portfolio.

The investment managers have discretion to manage the portfolio within these objectives and their performance is measured against a composite index, weighted in accordance with a new, agreed benchmark allocation. After allowing for additions to the portfolio, the market value at 31 December 2003 has increased by 10% in the year.

### **Resources expended**

The cost of generating funds increased by 6% to £1.4 m. The cost of generating funds as a percentage of total resources expended is 13%.

The cost of charitable activities increased by 15% to £8.9m

£1.7m was committed in the year for Research, an increase of 19% on the previous year.

£4.4m was spent on Care and Service Provision, of which £3.9 was Community based. As a result of the reorganisation of community services in 2002 to reflect the NHS changes at local level, the headings of Welfare and Field Services have been replaced by one heading of Care and Service Provision.

£0.6m, an increase of 43%, was committed for the placement of 26 new Parkinson's Disease Nurse Specialists and two Clerical Supporters and associated administrative costs.

£1.7m was spent on information and education services that disseminate the comprehensive range of knowledge and experience the Society has accumulated, to patients, professionals and policy makers.

Management and administration amounted to 4% (2002-5%) of total resources expended.

## Grant making policy

Grant applications for research are scrutinised by expert panels and undergo peer review before successful applications are presented to the Board for its approval. Grants awarded and paid during the year are shown in note 7.

## P.D.S. (Sales) Limited

The company is the trading arm of the Society. It sells pamphlets and brochures, audio and video tapes, Christmas cards, stationery and general gift items. The company donates its profits to the Society (see note 3).

## Reserves

The Society's policy is to maintain reserves at (and not significantly above) a level which ensures that the Society's core strategic activities are able to continue in the immediate future (at least one year).

As restricted expenditure and branch activities depend on the existence of related reserves, their corresponding reserve requirements are generally satisfied.

As regards the remainder of the Society's activities, the reserve policy takes into account the following factors:

- planned budget deficits
- budgeted capital commitments
- the risks associated with the Society's different income streams
- the risks and effects of any proposed new strategic objectives
- the risks and effects of any known external factors or contingencies

In accordance with this policy, the trustees have calculated that the minimum level of reserves required at 31 December 2003, excluding restricted funds and branches, amounts to £4m. At that date this was covered by unrestricted reserves amounting to £8.8m, comprising total unrestricted funds of £15.4m less the designated fixed assets fund of £3m and unrestricted branch funds of £3.6m. This reserves level and opportunities to utilise any surplus are under continuous strategic review.

The Society's general, designated and restricted funds are detailed in note 15 in the financial statements.

## Changes in tangible fixed assets

The movements in tangible fixed assets during the year are set out in note 9 to the financial statements.

## Governance

The Board of Trustees is the governing body of the whole Society. Its principal duties are:

- to establish the policies and strategies of the Society;
- to ensure the effective and efficient use of the Society's resources in the furtherance of the Society's primary objectives;
- to exercise general control of the administration of the Society, and to ensure, by supervising the work of the Chief Executive and through her the staff, that the Society is run efficiently and accountably; and
- to ensure that all statutory obligations relating to the Society and to its business are fully complied with.

The members of the Board of Trustees are listed on page 20 of this report and were in office throughout the year except where shown. Following a recommendation from the Nominations Panel Ms Susann Hill was appointed a trustee by the Board of Trustees at their meeting on 8 July 2003. At the AGM held on 13 September 2003 two trustees from England retired by rotation and Mrs Carole Ions and Mr James Berlis were duly elected to the Board to fill the vacancies. At the Board meeting held on 13 September 2003 after the AGM Dr Oliver Foster was re-appointed a trustee. Elected and appointed trustees currently serve fixed terms of between three and four years.

During the year 2003 the trustees held seven Board meetings and attended a Board 'Away Day' to discuss issues of governance. The Executive Committee which has power to act on behalf of the Board on urgent matters met once. The Audit Committee met four times and the Nominations Panel met four times. A number of subsidiary bodies continue to provide specialist advice to the Board.

No trustee received any remuneration for his or her services but some members of the Board were reimbursed their reasonable travelling, hotel and other expenses properly incurred by them in connection with their attendance at meetings or otherwise in connection with the discharge of their duties.

## Responsibility for the financial statements

Company and charity law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Society and of the surplus or deficit of the Society for that period. In preparing those financial statements the trustees are required to have:

- selected suitable accounting policies and then applied them consistently;
- made judgements and estimates that are reasonable and prudent;
- stated whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepared the financial statements on a going concern basis.

The trustees have overall responsibility for ensuring the Society has appropriate systems of control, both financial and otherwise. They are also responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the Society and enable them to ensure that the financial statements comply with the Companies Act 1985. They are also responsible for safeguarding the assets of the Society and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities and to provide reasonable assurance that:

- the Society is operating efficiently and effectively;
- its assets are safeguarded against unauthorised use or disposition;
- proper records are maintained and financial information used within the Society or for publication is reliable;
- the charity complies with relevant laws and regulations.

## Internal control and risk management

The systems of internal control are designed to provide reasonable assurance against material financial misstatement or loss to the Society.

At the same time the trustees and management are engaged in identifying the types of risk the Society faces, and considering the likelihood of their occurrence and their potential impact. This process involves:

- a remit to senior management and to the audit and other sub-committees to consider risk in their work
- receiving regular financial management reports and comparison with agreed budgets
- developing a reserves policy which takes account of the risks of streams of income and expenditure
- reviewing and if necessary updating branch rules
- engaging internal and external auditors who use a risk based approach.

In addition as part of the development of strategy the trustees and the chief executive will consider risks, map these against strategic aims and set up performance measures to monitor progress.

The trustees are pleased to report that the charity's internal financial controls conform to guidelines issued by the Charity Commission.

## Volunteers

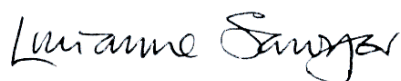
Volunteers are at the heart of the Society and play a vital role in our work supporting all people with Parkinson's, their families and carers. We would like to acknowledge the outstanding contribution of these 3,500 volunteers and thank them for their continuing support.

We were delighted to recognise the particularly outstanding work of the following volunteers, granting them Honorary Life Membership of the Society in 2003: Lynne Allard; Reg Bailey OBE; Jean Ballantyne; Sidney Brewer; Kirsty Brewer; Audrey Bromley; Betty Caddick; Diana Alexandra Collister; Bea Cook; Jean Couper; Yvonne Fortey; Maureen Frith; A V Goold; John Gregory; Marion Grimwood; Mary Hansford; Freda Harrod; Freddie Hicks; Robert Hinwood; Valentine Hurrell; William Ibbot; Ruby Ibbot; Richard Jenkins; Paula Justham; Paul Lewin; Dorothy Lynam; Cicely Mair; Dorothy Phillips; Vi Pownall; Phyllis Pring; Mabel Procter; Margeret Purkis; Elizabeth Roberts; Wyn Smith; Anthea Stutchbury; Edith Trueman; and Susan Wilson.

## Auditors

A resolution proposing that Deloitte & Touche LLP be re-appointed as auditors of the charity will be put to the Annual General Meeting in September 2004.

This report was approved by the Board on 13 July 2004.

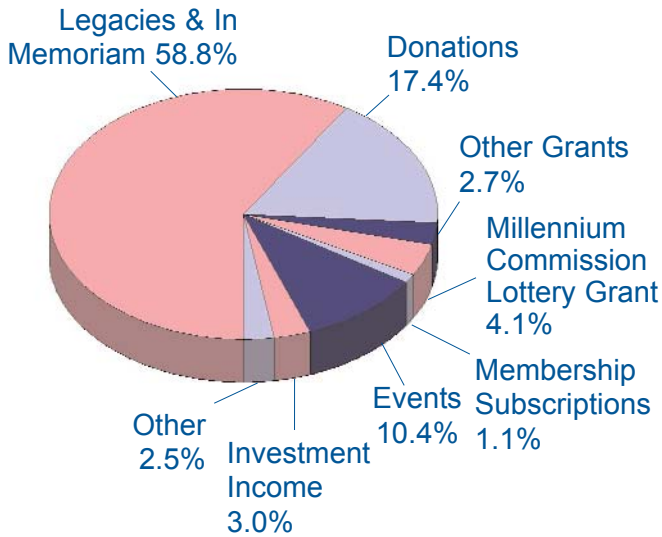


### **Lucianne Sawyer CBE**

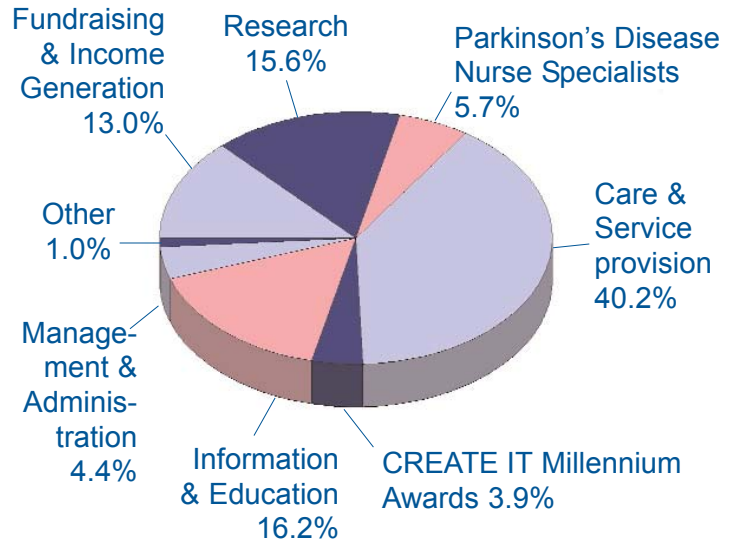
Chairman, Parkinson's Disease Society of the United Kingdom

## TOTAL SOCIETY

### INCOMING RESOURCES IN 2003: £13.4m

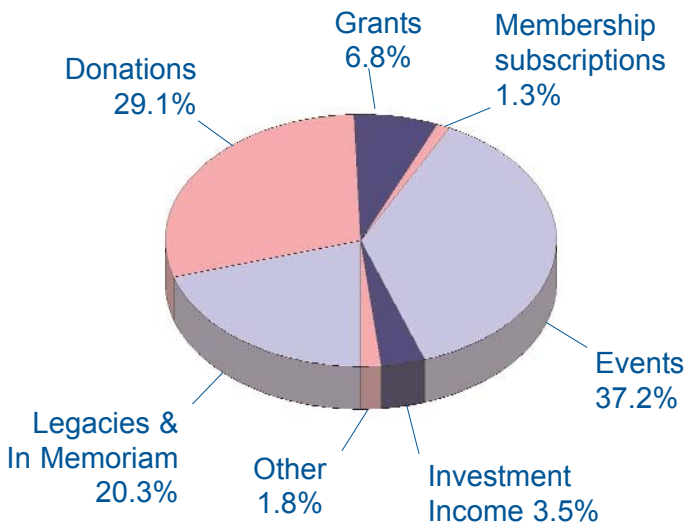


### RESOURCES EXPENDED IN 2003: £10.8m

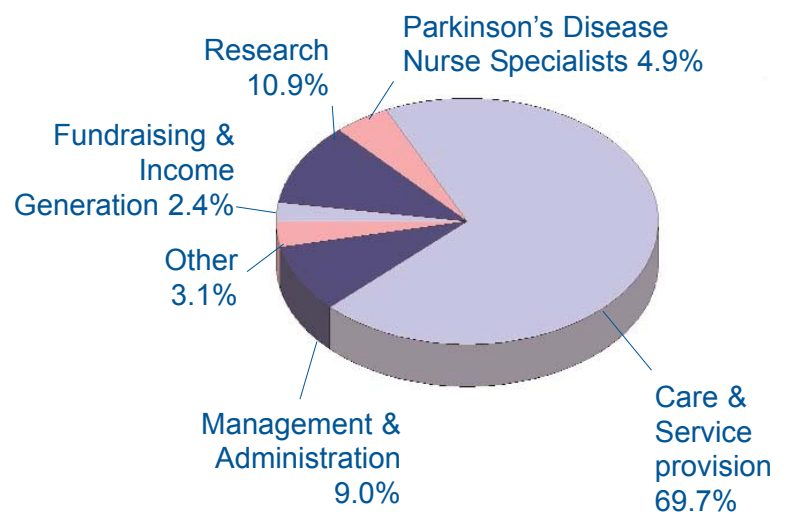


## BRANCHES AND SUPPORT GROUPS

### INCOMING RESOURCES IN 2003: £2.1m



### RESOURCES EXPENDED IN 2003: £1.8m



## Independent Auditors' Report

### To the Members of the Parkinson's Disease Society of the United Kingdom

We have audited the financial statements of the Parkinson's Disease Society of the United Kingdom for the year ended 31 December 2003 which comprise the Consolidated Statement of Financial Activities, the Consolidated and Society Balance Sheets, the Consolidated Cashflow Statement, including the cash flow related notes, and the related notes numbered 1 to 18. These financial statements have been prepared under the accounting policies set out therein.

This report is made solely to the Society's members, as a body, in accordance with section 235 of the Companies Act 1985. Our audit work has been undertaken so that we might state to the Society's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company and the Society's members as a body, for our audit work, for this report, or for the opinions we have formed.

### Respective responsibilities of the Board of Trustees and auditors

As described on page 24, the Society's trustees are responsible for the preparation of the financial statements in accordance with applicable United Kingdom law and accounting standards. Our responsibility is to audit the financial statements in accordance with relevant United Kingdom legal and regulatory requirements and auditing standards.

We report to you our opinion as to whether the financial statements give a true and fair view and are properly prepared in accordance with the Companies Act 1985. We also report if, in our opinion, the Report of the Trustees is not consistent with the financial statements, if the Society has not kept proper accounting records, if we have not received all the information and explanations we require for our audit, or if information specified by law regarding trustees' remuneration and transactions with the Society is not disclosed.

We read the Report of the Trustees, including the Legal and Administrative information, for the year and consider the implications for our report if we become aware of any apparent misstatements.

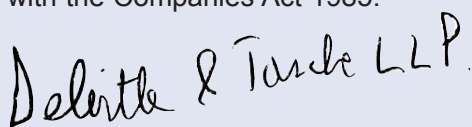
### Basis of opinion

We conducted our audit in accordance with United Kingdom auditing standards issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the directors in the preparation of the financial statements and of whether the accounting policies are appropriate to the Society's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion, we also evaluated the overall adequacy of the presentation of information in the financial statements.

### Opinion

In our opinion the financial statements give a true and fair view of the state of the affairs of the Group and the Society as at 31 December 2003 and of the incoming resources and application of resources of the Group, including its income and expenditure, for the year then ended and have been properly prepared in accordance with the Companies Act 1985.



### Deloitte & Touche LLP

Chartered Accountants and Registered Auditors, London  
13 July 2004

**CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)**

For the year ended 31 December 2003

	Notes	Unrestricted Funds £'000	Restricted Funds £'000	2003 Total £'000	2002 Total £'000
<b>Incoming Resources</b>					
Legacies and In Memoriam	12	6,970	892	7,862	6,454
Donations		1,798	523	2,321	2,570
Activities in furtherance of the charity's objects:					
Grants, excluding Millennium					
Commission Lottery Grant	18	81	285	366	459
Millennium Commission Lottery Grant		0	546	546	102
Membership subscriptions		142	0	142	136
Activities for generating funds:					
Events		1,153	237	1,390	1,396
Trading activities	3	178	0	178	190
Investment income	2	280	127	407	388
Other incoming resources		103	52	155	99
<b>Total Incoming Resources</b>		<b>10,705</b>	<b>2,662</b>	<b>13,367</b>	<b>11,794</b>
<b>Resources Expended</b>					
<b>Costs of generating funds</b>					
Fundraising and income generation		1,212	18	1,230	1,172
Trading activities	3	171	0	171	148
	6	1,383	18	1,401	1,320
<b>Net Incoming Resources available for Charitable Application</b>		<b>9,322</b>	<b>2,644</b>	<b>11,966</b>	<b>10,474</b>
<b>Charitable Expenditure</b>					
Costs of activities in furtherance of the charity's objects:					
Research		550	1,139	1,689	1,419
Parkinson's Disease Nurse Specialists		149	470	619	433
Care and Service provision		3,799	542	4,341	4,095
CREATE IT Millennium Awards		0	426	426	56
Membership administration		107	0	107	114
Information and Education		1,661	86	1,747	1,634
Management and administration		469	1	470	453
	6	6,735	2,664	9,399	8,204
<b>Total Resources Expended</b>	6	<b>8,118</b>	<b>2,682</b>	<b>10,800</b>	<b>9,524</b>
<b>Net Incoming Resources for the year</b>	5	<b>2,587</b>	<b>(20)</b>	<b>2,567</b>	<b>2,270</b>
<b>Recognised Gains &amp; Losses</b>					
Net gains/(losses) on investments	10	931	0	931	(1,834)
<b>Net Movement in Funds</b>		<b>3,518</b>	<b>(20)</b>	<b>3,498</b>	<b>436</b>
Fund balances brought forward at 1 January	15	11,827	4,550	16,377	15,941
<b>Fund balances carried forward at 31 December</b>	15	<b>15,345</b>	<b>4,530</b>	<b>19,875</b>	<b>16,377</b>

All the above results derive from the continuing activities of the Society. There are no other gains or losses other than those shown above.

The net incoming resources for the financial year dealt with in the accounts of the parent company was £1,555,733 (2002: £2,226,951).

As permitted by Section 230 of the Companies Act 1985, no separate income and expenditure account is presented in respect of the parent company.

The accompanying notes form an integral part of these financial statements.

**CONSOLIDATED AND SOCIETY BALANCE SHEETS**

as at 31 December 2003

	Notes	2003 Group £'000	2002 Group £'000	2003 Society £'000	2002 Society £'000
<b>Fixed Assets</b>					
Tangible assets	9	2,984	3,336	2,984	3,336
Investments	10	13,767	11,604	13,792	11,629
		<b>16,751</b>	14,940	<b>16,776</b>	14,965
<b>Current Assets</b>					
Stock		35	37	0	0
Debtors	11	4,432	2,016	4,350	1,934
Short term deposits		305	399	305	399
Bank and cash balances		4,795	5,838	4,750	5,831
		<b>9,567</b>	8,290	<b>9,405</b>	8,164
<b>Creditors</b>					
Amounts falling due within one year	13	(3,723)	(4,625)	(3,586)	(4,524)
<b>Net Current Assets</b>		<b>5,844</b>	3,665	<b>5,819</b>	3,640
<b>Total assets less current liabilities</b>					
		<b>22,595</b>	18,605	<b>22,595</b>	18,605
<b>Creditors</b>					
Amounts falling due after more than one year	14	(2,720)	(2,228)	(2,720)	(2,228)
<b>Net Assets</b>		<b>19,875</b>	16,377	<b>19,875</b>	16,377
<b>Funds</b>					
Unrestricted funds:					
General funds		7,558	7,024	7,558	7,024
Designated funds		7,787	4,803	7,787	4,803
Non charitable trading funds		0	0	0	0
Restricted funds		4,530	4,550	4,530	4,550
<b>Total Funds</b>	15	<b>19,875</b>	16,377	<b>19,875</b>	16,377

The financial statements were approved by the Board of Trustees and signed on its behalf by:



Lucianne Sawyer



Michael Cutler

13 July 2004

The accompanying notes form an integral part of these financial statements.

**CONSOLIDATED CASHFLOW STATEMENT**

for the year ended 31 December 2003

	Notes below	2003 £'000	2002 £'000
Net cash (outflow)/inflow from operating activities (a)		(183)	1,736
Returns on investments and servicing of finance (b)		405	383
Capital expenditure and financial investments (c)		(1,283)	(542)
Management of liquid resources (d)		94	0
Financing (e)		(76)	(83)
<b>(Decrease)/Increase in cash the year</b>		<b>(1,043)</b>	<b>1,494</b>

**Notes to the Cashflow Statement****(a) Reconciliation of net incoming/(outgoing) resources to net cash inflow from operating activities**

Net incoming resources		2,567	2,270
Investment income		(407)	(388)
Depreciation		416	411
Loss on sale of tangible fixed assets		1	0
Interest element of finance lease rentals		2	5
Decrease in stock		2	0
(Increase)/Decrease in debtors		(2,416)	193
(Decrease) in creditors, representing mainly accrued grants		(348)	(755)
<b>Net cash (outflow)/inflow from operating activities</b>		<b>(183)</b>	<b>1,736</b>

**(b) Returns on investments and servicing of finance**

Investment income		407	388
Interest element of finance lease rentals		(2)	(5)
		<b>405</b>	<b>383</b>

**(c) Capital expenditure and financial investments**

Purchase of tangible fixed assets		(52)	(167)
Proceeds from sale of tangible fixed assets		1	0
Funds transferred (into) investment portfolio		(1,000)	(101)
Other net (increase) of funds within investment portfolio		(232)	(274)
		<b>(1,283)</b>	<b>(542)</b>

**(d) Management of liquid resources**

Decrease in short term deposits		94	0
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**(e) Financing**

Principal payments under finance leases		(76)	(83)
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**CONSOLIDATED CASHFLOW STATEMENT**

for the year ended 31 December 2003 – continued

	2003 £'000	2002 £'000
<b>(f) Reconciliation of net cash inflow to movement in net cash funds</b>		
(Decrease)/Increase in cash	(1,043)	1,494
(Decrease)/Increase in short term deposits	(94)	0
Increase in lease financing	76	83
Changes resulting from cash flows	(1,061)	1,577
New finance leases	(14)	(41)
Movement in year	(1,075)	1,536
Net cash funds at 1 January	6,079	4,543
<b>Net cash funds at 31 December</b>	<b>5,004</b>	<b>6,079</b>

**(g) Analysis of changes in net cash funds**

	At 1 January 2003 £'000	Cash flows £'000	Other changes £'000	At 31 December 2003 £'000
Cash at bank and in hand	5,838	(1,043)	0	4,795
Short term deposits	399	(94)	0	305
Finance leases	(158)	76	(14)	(96)
<b>Total</b>	<b>6,079</b>	<b>(1,061)</b>	<b>(14)</b>	<b>5,004</b>

The accompanying notes form an integral part of these financial statements.

## NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS

for the year ended 31 December 2003

### 1. Accounting policies

#### Basis of accounting

The financial statements have been prepared under the historical cost convention, with the exception of investments which are carried at market value.

The financial statements comply with applicable UK accounting standards and the Statement of Recommended Practice (SORP 2000), 'Accounting and Reporting by Charities', except that the Society has not separately identified grants awarded on the face of the Statement of Financial Activities. This is because all expenditure is shown by aggregating all costs in pursuit of a specific activity and grants are treated in the same way. The total amount of grants awarded is shown in note 7.

#### Basis of consolidation

The group financial statements consolidate the financial statements of the Society, its branches and support groups ("branches") and its trading subsidiary, P.D.S. (Sales) Limited. No Statement of Financial Activities of the Society has been presented as permitted by Section 230 of the Companies Act 1985 and paragraph 304 of SORP 2000.

#### Funds

Unrestricted funds are funds which are expendable at the discretion of the trustees in furtherance of the Society's objectives. General funds represent the Society's minimum reserve requirement, plus the amount of the Society's unrestricted net assets held at branches. Any remaining unrestricted funds are treated as Designated funds, to be set aside by the trustees for specific purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the Society for particular purposes. The aim and use of each designated and restricted fund is set out in note 15.

#### Incoming resources

All incoming resources are included in the Statement of Financial Activities when the Society is legally entitled to the income. Legacies are included in the Statement of Financial Activities when probate has been granted, it is reasonably certain the legacy will be received and the amount can be quantified with reasonable accuracy.

#### Resources expended

Expenditure has been classified by reference to specific activity and not by type of expense, so that all costs relating to a specific activity have been aggregated. Certain overheads and support costs have been allocated to reflect expenditure incurred by each specific activity. The basis of allocation is reviewed regularly.

Grants to third parties for specific activities are charged in the accounts when an award is made, although disbursement of the funds may be made in subsequent accounting periods.

Operating lease rentals are charged to the Statement of Financial Activities over the period of the lease, as incurred.

Assets held under finance leases are capitalised as fixed assets. Obligations under such agreements are included in creditors. The difference between the capitalised cost and the total obligation under the lease represents the finance charges. Finance charges are written off to the Statement of Financial Activities over the period of the lease.

#### Website development costs

The costs of developing the design and content of the website are charged to the Statement of Financial Activities as incurred.

#### Tangible fixed assets

Tangible fixed assets are stated at cost, net of depreciation and any provision for impairment.

Depreciation is provided to write off the cost of tangible fixed assets over their useful economic lives on a straight line basis at the following annual rates:

Freehold buildings	2.0%
Freehold improvements	15.0%
Motor vehicles	33.3%
Office equipment and fixtures	15.0%
Computer equipment	33.3%
Restricted assets – MRU, medical and other equipment	33.3%

**Investments**

Listed investments are included in the balance sheet at market value. Realised and unrealised gains and losses in the year are included in the Statement of Financial Activities.

**Stock**

Stock comprises goods for resale and is valued at the lower of cost and net realisable value.

**Taxation**

The Society is a registered charity and no tax is payable on its charitable income.

The Society is not registered for VAT and expenditure is shown inclusive of VAT.

P.D.S. (Sales) Ltd is registered for VAT.

**2. Investment income**

	2003 £'000	2002 £'000
Interest on deposits held by		
– head office	44	24
– branches	76	68
Income from Investments		
– interest	148	206
– dividends	139	90
	<b>407</b>	<b>388</b>

**3. Trading activities of subsidiary**

The Society holds the entire issued share capital of 25,000 £1 Ordinary Shares in P.D.S. (Sales) Limited, a company incorporated in England and Wales. P.D.S. (Sales) Limited sells pamphlets and brochures, audio and video tapes, Christmas cards, stationery and general gift items. P.D.S. (Sales) Limited covenants its taxable profits to the Society.

The Financial Statements of P.D.S. (Sales) Limited, before consolidation, were:

**PROFIT AND LOSS ACCOUNT**

	2003 £'000	2002 £'000
Turnover	178	190
Cost of sales	(136)	(102)
Gross profit	42	88
Interest receivable	0	1
	42	89
Distribution and administration – external	(32)	(46)
– Society	(8)	(16)
Interest payable	(2)	(3)
Profit for the year before Covenant to Society	0	24
Covenant to the Society	0	(24)
	0	0
Tax	0	0
<b>Net income transferred to reserves</b>	<b>0</b>	<b>0</b>

**BALANCE SHEET**

Tangible fixed assets	0	0
Current assets	263	185
Creditors: amounts falling due within one year	(238)	(160)
Net current assets	25	25
<b>Net assets</b>	<b>25</b>	<b>25</b>
Share capital	25	25
Profit and loss account	0	0
	<b>25</b>	<b>25</b>

#### 4. Financial Returns of the branches and support groups ("branches")

The Society carries out a number of its charitable activities through a network of branches. The branches raise income sufficient to fund their activities and the majority also send funds to National Office to assist with the funding of nationally based services.

The Financial Statements of the Society's branches incorporate independently examined accounts or branch returns. 20 branches did not submit returns. For these, the last reported balances were included.

Income and Expenditure relating to branches was:

<b>INCOME AND EXPENDITURE</b>	Notes below	<b>2003</b> £'000	2002 £'000
Total Incoming Resources	(a)	<b>2,107</b>	2,172
Total Resources Expended	(b)	<b>(1,200)</b>	(1,137)
Net gains/(losses) on investments		<b>36</b>	(10)
<b>Net Movement in Funds</b>		<b>943</b>	1,025

Application of net funds raised by branches:

Transfers (to)/from National Office for:

Research	<b>(183)</b>	(112)
Parkinson's Disease Nurse Specialists	<b>(91)</b>	(103)
Community Support Workers	<b>(332)</b>	(279)
Other	<b>(60)</b>	(87)
Legacies received	<b>64</b>	34
<b>Total net resources transferred</b>	<b>(602)</b>	(547)

<b>Net Movement in Funds retained by branches after transfers</b>	<b>341</b>	478
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Branches fund balances brought forward at 1 January	<b>4,091</b>	3,613
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<b>Branches fund balances carries forward at 31 December</b>	<b>4,432</b>	4,091
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#### BALANCE SHEET

Investments	<b>150</b>	144
Debtors	<b>12</b>	45
Short term deposits	<b>303</b>	395
Bank and cash balances	<b>3,976</b>	3,510
	<b>4,291</b>	3,950
Creditors due within one year	<b>(9)</b>	(3)
<b>Net Assets</b>	<b>4,432</b>	4,091

#### NOTES:

(a) Incoming Resources

Legacies and In Memoriam	<b>378</b>	330
Donations	<b>632</b>	659
Activities in furtherance of the charity's objects:		
Grants	<b>148</b>	246
Membership subscriptions	<b>29</b>	30
Activities for generating funds:		
Events	<b>808</b>	779
Investment income	<b>76</b>	75
Other incoming resources	<b>36</b>	53
<b>Total Incoming Resources</b>	<b>2,107</b>	2,172

(b) Resources Expended

Costs of generating funds		
Fundraising and income generation	<b>45</b>	44

Charitable Expenditure

Costs of activities in furtherance of the charity's objects:

Research	<b>20</b>	20
Care and Service provision	<b>968</b>	897
Management and administration	<b>167</b>	176
	<b>1,155</b>	1,093
<b>Total Resources Expended</b>	<b>1,200</b>	1,137

**5. Net Incoming Resources is stated after charging:**

	2003 £'000	2002 £'000
Auditors' remuneration		
– audit fee	35	34
– other services	0	0
Depreciation	416	411
Operating lease rentals	70	93
Finance lease interest	2	5
Loss on sale of tangible fixed assets	1	0

**6. Total Resources Expended**

	Direct & allocated Grants £'000	staff costs £'000	Other direct costs £'000	Other allocated costs £'000	Total 2003 £'000	Total 2002 £'000
<b>Costs of generating funds</b>						
Fundraising and income generation	0	575	504	151	1,230	1,172
Trading activities	0	0	171	0	171	148
	0	575	675	151	1,401	1,320
<b>Charitable Expenditure</b>						
Costs of activities in furtherance of the charity's objects:						
Research	1,303	171	138	77	1,689	1,419
Parkinson's Disease Nurse Specialists	468	72	48	31	619	433
Care and Service provision	0	2,092	1,692	557	4,341	4,095
CREATE IT Millennium Awards	0	43	383	0	426	56
Membership	0	73	21	13	107	114
Information and Education	0	512	1,186	49	1,747	1,634
Management and administration	0	86	350	34	470	453
	1,771	3,049	3,818	761	9,399	8,204
<b>Total Resources Expended</b>	1,771	3,624	4,493	912	10,800	9,524

As a result of the reorganisation of Community Services staff, the headings of Welfare and Field Services have been replaced by one heading of Care and Service provision.

**7. Amounts committed for grants**

	Research £'000	PDS Tissue Bank £'000	PD Nurse Specialists £'000	Group and Society Total 2003 £'000	Group and Society Total 2002 £'000
Balance at 1 January	3,704	1,028	1,378	6,110	6,650
Awarded (note 6)	1,303	0	468	1,771	1,226
Payments	(1,424)	(218)	(566)	(2,208)	(1,766)
<b>Balance at 31 December</b>	3,583	810	1,280	5,673	6,110
Estimated to be disbursed:					
Within one year (note 13)	1,965	313	729	3,007	3,980
After more than one year (note 14)	1,618	497	551	2,666	2,130
	3,583	810	1,280	5,673	6,110

Details of awards made are available on request from the Society.

**8. Employees and Trustees**

	2003 £'000	2002 £'000
a) Total Costs:		
Salaries	3,110	2,781
National Insurance contributions	297	257
Pension contributions	217	252
	<b>3,624</b>	<b>3,290</b>
b) Average number of staff during year:	2003	2002
Chief Executive	2.0	2.0
Community Services	69.0	57.5
Policy, Research and Information	17.0	15.5
Fundraising and Communications	15.5	13.5
Finance and Administration	26.5	24.5
	<b>130.0</b>	<b>113.0</b>

The number of employees shown represents full time equivalents.

The number of employees whose emoluments (including remuneration and benefits in kind and excluding pension contributions) amounted to more than £50,000 was:

	2003	2002
Band £50,001 to £60,000	2	3
Band £60,001 to £70,000	1	0
Band £80,001 to £90,000	1	1

## c) Pensions:

The Society matches, on a two to one basis, employee contributions of up to 5% of salary into employees' personal pension plans.

## d) Trustees:

No trustees received remuneration for their services in either 2003 or 2002.

Expenses of attending meetings amounting to £23,883 were reimbursed to 14 trustees (2002: £19,883 to 14 trustees).

**9. Tangible Fixed Assets**

Group and Society	Freehold	Freehold	Motor	Office	Computer	Restricted	Total
	land & building	improvements	vehicles	equipment & fixtures	equipment	assets – MRU & medical equipment	
	£'000	£'000	£'000	£'000	£'000	£'000	£'000
<b>Cost</b>							
At 1 January	2,700	610	341	283	674	86	4,694
Additions	0	0	14	1	47	4	66
Disposals	0	0	(14)	0	0	0	(14)
At 31 December	<b>2,700</b>	<b>610</b>	<b>341</b>	<b>284</b>	<b>721</b>	<b>90</b>	<b>4,746</b>
<b>Accumulated Depreciation</b>							
At 1 January	180	294	206	213	404	61	1,358
Charge for the year	42	91	89	13	167	14	416
Disposals	0	0	(12)	0	0	0	(12)
At 31 December	<b>222</b>	<b>385</b>	<b>283</b>	<b>226</b>	<b>571</b>	<b>75</b>	<b>1,762</b>
<b>Net Book Values</b>							
At 31 December 2003	<b>2,478</b>	<b>225</b>	<b>58</b>	<b>58</b>	<b>150</b>	<b>15</b>	<b>2,984</b>
At 31 December 2002	2,520	316	135	70	270	25	3,336

Motor vehicles with a net book value of £58,080 are held under finance leases (2002 £135,011)

**10. Investments**

	<b>Group &amp; Society 2003 £'000</b>	Group & Society 2002 £'000
<b>Marketable Securities</b>		
Market Value at 1 January	10,314	12,673
Acquisitions	2,311	2,264
Proceeds of sale	(2,078)	(2,789)
Net gains/(losses) on investments	931	(1,834)
	<b>11,478</b>	<b>10,314</b>
Transfer from bank and cash balances	1,000	0
Market value at 31 December	<b>12,478</b>	<b>10,314</b>
<b>Cash funds held within managed portfolio</b>		
Cash on deposit at 31 December	1,289	1,290
<b>Total at 31 December – Group</b>	<b>13,767</b>	<b>11,604</b>
Investment in subsidiary company	25	25
<b>Total at 31 December – Society</b>	<b>13,792</b>	<b>11,629</b>

The cash funds incorporate reinvested dividends and interest received, the proceeds of sales and the funds used for acquisitions.

**Investments are represented by:**

Fixed interest securities	7,498	6,195
Equity shares	4,980	4,120
Cash funds held within managed portfolio	1,289	1,289
Investments in subsidiary company	25	25
	<b>13,792</b>	<b>11,629</b>

**Analysed between:**

UK investments	7,122	7,107
Overseas investments		
– Managed Institutional Sterling cash fund, based in Ireland	4,796	3,641
– Other Countries	1,874	881
	<b>13,792</b>	<b>11,629</b>

The historical cost of marketable securities at 31 December 2003 was: **11,913** 10,737

**11. Debtors**

	<b>Group 2003 £'000</b>	2002 £'000	<b>Society 2003 £'000</b>	2002 £'000
Legacies (note 12)	3,895	1,726	3,895	1,726
Amounts owed by P.D.S. (Sales) Limited	0	0	100	59
Tax recoverable on donations and other incoming resources	29	45	29	45
Other debtors	34	67	34	67
Prepayments and accrued income	474	178	292	37
	<b>4,432</b>	<b>2,016</b>	<b>4,350</b>	<b>1,934</b>

**12. Amounts accrued for legacies**

	<b>Group &amp; Society 2003 £'000</b>	<b>Group &amp; Society 2002 £'000</b>
Balance at 1 January	1,726	1,861
Entitlement	7,041	6,053
Receipts	<b>(4,872)</b>	<b>(6,188)</b>
<b>Balance at 31 December (note 11)</b>	<b>3,895</b>	<b>1,726</b>

**13. Creditors – amounts falling due within one year**

	<b>Group 2003 £'000</b>	2002 £'000	<b>Society 2003 £'000</b>	2002 £'000
Amounts committed to grants (note 7)	3,007	3,980	3,007	3,980
Obligations under finance leases	43	61	43	61
Tax and social security	91	78	91	78
Other accruals	582	506	445	405
	<b>3,723</b>	<b>4,625</b>	<b>3,586</b>	<b>4,524</b>

**14. Creditors – amounts falling due after more than one year**

	<b>Group 2003 £'000</b>	2002 £'000	<b>Society 2003 £'000</b>	2002 £'000
Amounts committed to grants (note 7)	2,666	2,130	2,666	2,130
Obligations under finance leases falling due between two and five years	54	98	54	98
	<b>2,720</b>	<b>2,228</b>	<b>2,720</b>	<b>2,228</b>

## 15. Statement of funds

	Balance at 1 January 2003 £'000	Total Incoming Resources £'000	Total Resources Expended £'000	Transfers £'000	Net gains on Investments £'000	Balance at 31 December 2003 £'000
<b>Unrestricted funds</b>						
<b>General funds</b>						
– National Office	3,598	9,304	(6,424)	(3,384)	895	3,989
– Branches	3,426	1,223	(1,116)	0	36	3,569
	<b>7,024</b>	<b>10,527</b>	<b>(7,540)</b>	<b>(3,384)</b>	<b>931</b>	<b>7,558</b>
<b>Designated funds</b>						
Research	800	0	(400)	1,200	0	1,600
PDS Tissue Bank	100	0	0	0	0	100
Parkinson's Disease Nurse Specialists	0	0	0	500	0	500
Care and Service Provision	300	0	0	1,000	0	1,300
IT and communications	0	0	0	250	0	250
Freehold improvements	0	0	0	70	0	70
Contingency	267	0	0	686	0	953
Fixed assets	3,336	0	0	(352)	0	2,984
<b>Total designated funds</b>	<b>4,803</b>	<b>0</b>	<b>(400)</b>	<b>3,384</b>	<b>0</b>	<b>7,787</b>
<b>Non charitable trading funds</b>	<b>0</b>	<b>178</b>	<b>(178)</b>	<b>0</b>	<b>0</b>	<b>0</b>
<b>Total unrestricted funds</b>	<b>11,827</b>	<b>10,705</b>	<b>(8,118)</b>	<b>0</b>	<b>931</b>	<b>15,345</b>
<b>Restricted funds</b>						
Research	1,173	936	(1,139)	0	0	970
Parkinson's Disease Nurse Specialists	625	196	(470)	0	0	351
Care and Service Provision	1,996	1,218	(910)	0	0	2,304
Information and Education	91	30	(79)	0	0	42
Branches	665	282	(84)	0	0	863
<b>Total restricted funds</b>	<b>4,550</b>	<b>2,662</b>	<b>(2,682)</b>	<b>0</b>	<b>0</b>	<b>4,530</b>
<b>Total funds</b>	<b>16,377</b>	<b>13,367</b>	<b>(10,800)</b>	<b>0</b>	<b>931</b>	<b>19,875</b>

**Restricted Funds**

The Research funds represent income received to be used to meet direct costs of the research programme.

The Parkinson's Disease Nurse Specialist fund is for making grants to fund posts and associated training in the NHS around the UK.

Care and services provision funds are to meet costs of activities in furtherance of the Society's objectives throughout the UK or in specified areas therein.

The Information and Education fund is a fund to be used on information and education activities of the Society.

Branches funds are all held at Branches for purposes similar to those mentioned above.

**Analysis of net assets between funds:**

	Unrestricted Funds £'000	Restricted Funds £'000	Total Funds £'000
Tangible fixed assets	2,984	0	2,984
Investments	10,100	3,667	13,767
Current assets	8,704	863	9,567
Liabilities	(6,443)	0	(6,443)
<b>Net assets</b>	<b>15,345</b>	<b>4,530</b>	<b>19,875</b>

## 16. Related and Connected Party Transactions

In accordance with Financial Reporting Standard 8 the Society discloses the following related party transactions.

During 2003 the Research Advisory Panel awarded the following grants to organisations to which its members are connected:

Member	Organisation	£'000
Dr R Barker	Cambridge Brain Repair Centre	124
Professor S Dunnett	Cardiff University	48

The above individuals did not participate in the decision to award grants to organisations to which they are connected.

## 17. Operating Lease Commitments

As at 31 December 2003 the Society had annual operating lease commitments as set out below:

	2003 Land & Buildings £'000	2003 Other £'000	2002 Land & Buildings £'000	2002 Other £'000
Operating leases which expire:				
within one year	20	26	17	26
in two to five years	49	49	30	58
after five years	2	0	0	0
	<b>71</b>	<b>75</b>	<b>47</b>	<b>84</b>

## 18. Grants Received

In accordance with agreements entered into with government departments and the Millennium Commission the Society acknowledges the receipt of the following grants included within the total grant income of £912,000 in the Statement of Financial Activities.

	£'000
Department of Health	25
Department of Health	17
Department of Health	34
Scottish Executive, Health Department	18
Scottish Executive, Health Department	4
Millennium Commission	546

The PDS wishes to thank all those featured and pictured in this *Annual Review, Report and Accounts*.

**To get involved or for more information, please complete the form below and return it to the PDS, 215 Vauxhall Bridge Rd, London SW1V 1EJ**

- I enclose a donation of £ .....
- Please send me a direct debit form
- Please send me the PDS Christmas Card Catalogue
- Please send me information on making a Will and leaving a legacy
- Please send a fundraising pack
- Please send me the PDS introductory pack (includes booklet, membership form and resource list/order form)
- Please send me details of YAPP&Rs, the PDS group for people of working age
- Please send me details of SPRING, the PDS research special interest group

**For enquiries, or to make a credit card donation, please call 020 7932 1303.**

**Cheques/postal orders should be made payable to Parkinson's Disease Society.**

**Name (Mr / Mrs / Miss / Ms)**

.....  
.....

**Address** .....

.....  
.....

**Postcode** .....

**Tel** .....

**E-mail** .....

**THANK YOU**

R-2410 ANNRPT



**Parkinson's**  
Disease Society

**Parkinson's Disease Society**

215 Vauxhall Bridge Road, London SW1V 1EJ

Tel 020 7931 8080 Fax 020 7233 9908

**PDS Helpline:** telephone (free) 0808 800 0303;  
textphone (Minicom) 020 7963 9380  
(open Monday-Friday, 9.30-5.30)

**E-mail** enquiries@parkinsons.org.uk

**Website** [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

*There are local PDS branches across the UK;  
please call 020 7932 1306 for details.*

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