



Annual Report 2010

CONTENTS

Introduction	Page
Chairman's Report	5
Chief Executive Officers' Report	6
Support & Services	
Freephone Helpline	7
Call Analysis	8
Call Categories	9
Calls by Type	9
Call by Gender	9
Types of Calls and Membership Status	10
Calls by Time and Membership Status	10
Patient Information Meetings	11
Information Leaflets	12
Magazine	12
Web Site	13
Annual Social Weekend	13
Branch Activities	14
2nd World Parkinson's Congress	15
Campaigning & Advocacy	
HSE Meetings	16
Meetings with Ministers	16
Membership of Other Voluntary Bodies	17
Research	
Collaborative Research on Carers	18
Parkinson's Research	18

Organisational capacity

CEO Appointment	19
Board Co-Options	19
Increased Office Capacity	19
Strategic Plan	19
Meetings with Branches	20
Communications	20

Funding

Core Funding	21
MyCharity.ie	21
Bequests	21
Membership	21
Sponsorship (Corporate & Social Responsibility)	21

Financial

Financial Statements	22
Summary	23

Governance

Board Members	24
AGM	25
EGM – Consolidated Accounts	25
EGM – New Articles of Association	25

Contacts

National Office – Helpline, CEO, Nurse Specialist	26
Branches & Officers	26

Chairman's Report



As we start a new year it is important that, as a service led organisation, we review our performance throughout the previous year. 2010 will be marked by many of us as a very difficult year both professionally and personally. The difficulties felt by almost everyone from a shrinking economy, reduction in services from state agencies and cutbacks in the HSE, being the prime concerns for people with Parkinson's. For the Association it was a very much a year of change.

With that as the context, our commitment to people with Parkinson's has not diminished and, as you will see from this report, our delivery of services has been maintained and in some areas enhanced. In April we successfully launched a very ambitious three year Strategic Plan. The plan outlines our starting point and a road map of where we wish to go in regard to our membership, services for people with Parkinson's and awareness of Parkinson's disease under six key objectives. As can be seen from this report, some objectives have been progressed well and others need more attention in the coming year.

Contact with our members and people with Parkinson's who have not yet joined our Association, is critically important to us and throughout 2010 we endeavoured to ensure that this continued very strongly. In the first instance this required the continued excellent service provided by our Helpline Manager, Pauline Mahady.

During the year we continued with the process of strengthening our Board Governance with the co-option of ten new Board members, including myself, to augment the existing three member Board, in May of 2010. In parallel with this the introduction of our CEO, Joe Lynch, has helped to ensure the roll out of our new policies developed from our Strategic Plan. It would be remiss of me not to mention the former Chairperson, Una Anderson Ryan, who remains on the Board as our Vice Chairperson. Una has been an inspiration for the Association and has been a guiding light for me in taking up the position of Chairman, in December 2010. It is also important that I acknowledge the hard work and dedication of the other two existing Board members, Ann Keilthy and Patrick (Sid) Rellis, who have been active Board members and contributors to the Association cause for many years now.

Throughout this Annual Report you will identify progress made across many distinct areas, primary among these are heightening awareness and provision of enhanced services and supports to members. Our commitment to Branches and Branch activity is paramount. Our highly successful Leaders Conference, where all of our Branch leaders were invited, was a key marker in a very demanding year.

Before I conclude, I want to thank my fellow Directors and particularly to acknowledge the support that they have provided. Apart from preparation for, and attendance at meetings, the Directors have also participated in informal day-to-day matters and important Association events. As Directors of the Parkinson's Association of Ireland we are all conscious of our obligation to have regard for the financial well being of the association and to carefully attend to its interests on behalf of you, the members of the Association. Our Association is tremendously well served by many people from our staff and membership and beyond, who actively engage with the necessary work and objectives of the Association. Key among these are our overworked and under resourced Branch officials to whom we owe a debt of gratitude.

I also wish to acknowledge and thank our CEO, Joe Lynch, and Pauline Mahady for their dedication and hard work on behalf of the members and branches of this organisation.



Pat O'Rourke
Chairman

Chief Executive Officer's Report



I was delighted to have been appointed as Chief Executive of the Parkinson's Association of Ireland in January 2010. To date I have been given a very warm welcome and I have strived to meet as many people with Parkinson's, their families and friends, during the year and to assist them in any way that I can. Our first priority within the Association is to provide effective services to our members. We can do this by enhancing our corporate capacity by focusing on tightly managing our income and expenditure and seeking greater efficiencies through renegotiating a range of our non-pay costs, along with commencing a review of our financial systems. We upgraded our computer software and

hardware in the early part of 2010 as part of our improving information management systems, and we also addressed a range of health and safety issues.

I am committed to delivering more and better services to our members and their families. We cannot do this without the co-operation and support of our members and our branch network. Each and every branch has a role to play in the continued success of the Association. Our vision for 2011 is to copper fasten our continued governance progression, complete our Board revamp, increase our fundraising activity, achieve some progress in relation to HSE/state funding, enhance our services and deliver tangible change to our member's lives.

The Parkinson's Association of Ireland's vision and mission has been safe guarded during 2010 and will continue to be to the forefront of the Boards thinking in 2011 and beyond. I should also note that the Association's membership grew by 10% during the year, demonstrating the real impact and connection that our association has had with people with Parkinson's. As part of our growing services to members, the Board took the decision in November last year, to employ a part time Parkinson's Disease Nurse. This new service will become live in February 2011. During the year, new books of account were introduced for Branches to assist them in keeping their accounts and it is expected that all Branches will utilise the books for the forthcoming year.

I have to thank the Branch Officers and members for their support and cooperation and my fellow Board colleagues for their continued professionalism and dedication to the Association. It would be remiss of me not to take this opportunity to thank our extremely hardworking and committed helpline Manager, Pauline Mahady, who guided me through a very chaotic year that would have been impossible without her steady hand of guidance. The co-operation and support of branches and members will be crucial to the success of the Association in the coming year and I look forward to working closely with everyone concerned.

A handwritten signature in blue ink that reads "Joe Lynch". The signature is written in a cursive, flowing style.

Joe Lynch
Chief Executive Officer

SUPPORT & SERVICES

Freephone Helpline

The freephone helpline service operates from 9am to 9pm, Monday to Friday and is also operated on an ad hoc basis over weekends where Parkinson's is anticipated to be highlighted in the media. This service has proved more popular than ever during 2010. Just fewer than one thousand phone calls were received throughout the year with calls coming through from all counties in the Republic of Ireland. The freephone helpline remains our most important link to people with Parkinson's throughout Ireland. The most frequent requests relate to basic information about Parkinson's disease and living with its affects. A strategic decision was taken in early 2010 to capture the relevant information from the helpline and a database was established.

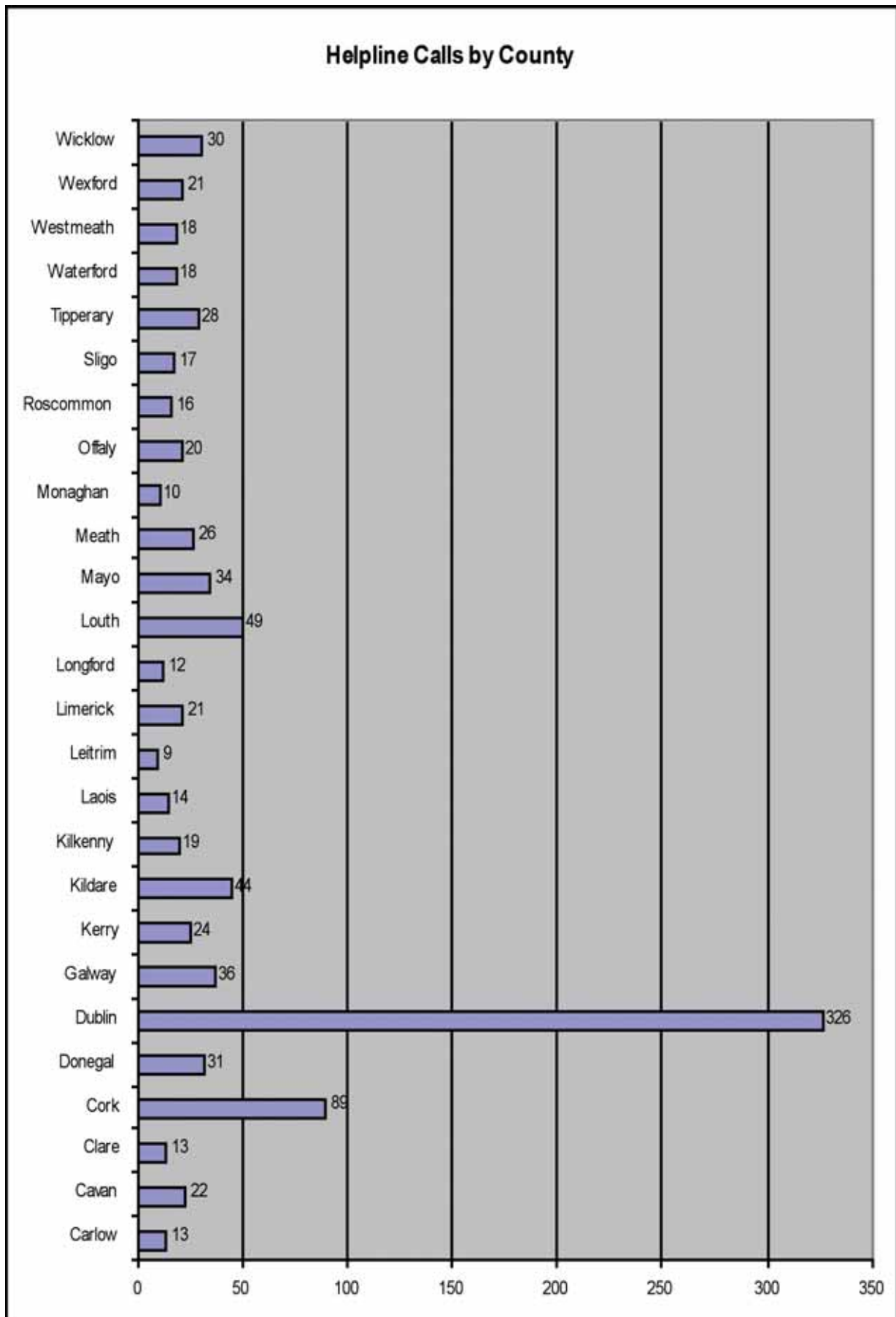


All too often analysis of our helpline database shows that people recently diagnosed with Parkinson's, or their families, have received scant information about the disease, its affects and progression. Our helpline manager, Pauline Mahady, continues to be an effective information source for people with Parkinson's and their families, offering sound advice as well as a listening ear. The service also provides a clear route of access for the Parkinson's Association to engage with our customer base; people with Parkinson's and their families.

“ analysis of our helpline database shows that people recently diagnosed with Parkinson's, or their families, have received scant information about the disease, its affects and progression. ”

Dublin still remains the area that has most contact with our helpline service with Cork presenting as the next highest amount of call traffic. An analysis of the helpline calls shows the level and frequency of calls increased throughout the year and interestingly all counties now access this service. Through our analysis of the data collected some interesting statistics are apparent including the severe lack of access to either a neurologist or a Parkinson's disease nurse specialist. However the most frequent calls to the service related to the progression of the disease following diagnosis and fears around the affects on the family of the patient. Over forty five percent of calls were from a friend or relative who were trying to gain a better understanding of the disease and how to respond to it. Over eighty percent of calls resulted in an information pack being forwarded to the individual and a further twenty percent of calls needed a follow up call. Ten percent of calls resulted in 'drop ins' where face to face interaction was required. It is anticipated that with the employment of a Nurse Specialist in 2011 calls will increase again.

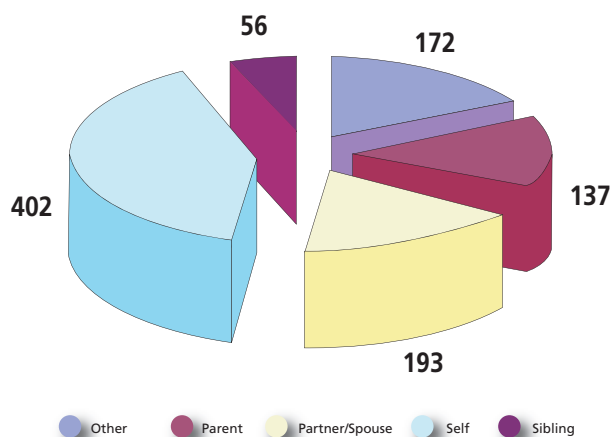
Call Analysis



Call Categories

An analysis of the calls received on our freephone service shows that of the 960 calls received 42% related to people calling about their own condition with a further 20% in relation to a spouse or partner. Over 14% of calls related to a parent and just fewer than 6% were about a sibling. Interestingly almost 11% of calls received were from health and social care professionals seeking information about Parkinson's and Parkinson's care. Over 80% of calls resulted in our association supplying an information pack to the caller or the person they were calling on behalf of.

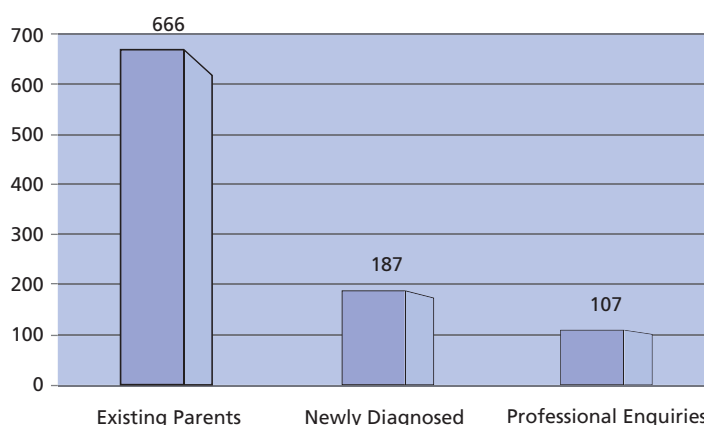
Calls by Category



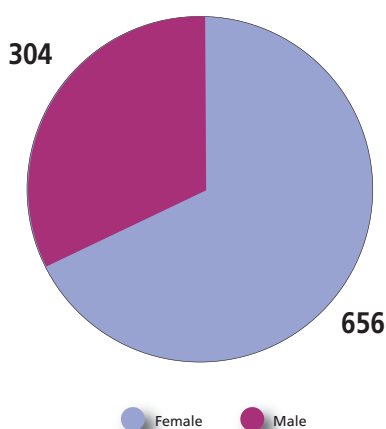
Calls by Type

Gender still plays an important part in the types of calls received by the association. The majority of calls received were from female callers. Just fewer than 32% of calls came from male callers with the remaining 68% emanating from female callers. These calls were further analysed in relation to whether the calls related to; Existing Patient; Newly Diagnosed; or Professional Enquiries. Almost 70% of calls were from existing patients and demonstrates that there is still a large demand for more information; even from people who have been diagnosed

Calls by Type



Calls by Gender

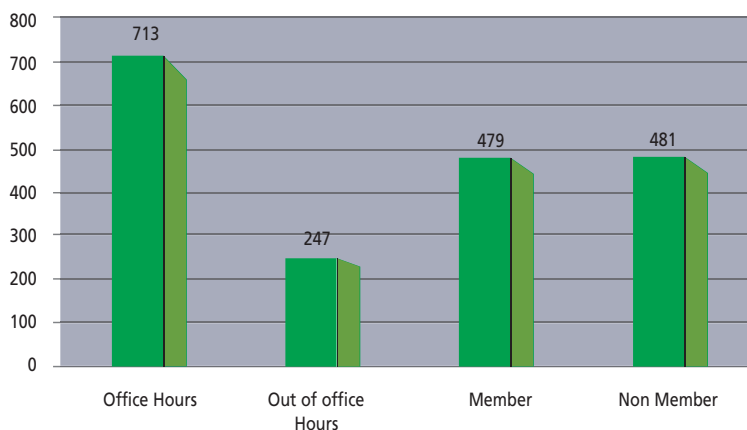


for some time and who still rely on the support offered through our helpline service. Just under 20% of calls were in relation to a new diagnosis. Often people were tremendously unsure of what Parkinson's is and how it would affect their lives on an ongoing basis. There is undoubted scope for the association to help address the information deficit experienced by newly diagnosed patients through increased interaction with neurologists and geriatricians throughout Ireland. There is often an increased demand on the Freephone helpline service following some exposure in the print media or on television. Professional enquiries have reached around 11% of our enquiries this year. These calls were from a range of health professionals such as doctors, nurses, speech and language therapists, nutritionists, physiotherapists and occupational therapists. This indicates a knowledge deficit for these health professionals.

Time of Calls and Membership Status

Not unsurprisingly, just under three quarters of calls received were during office hours. However a significant amount of calls to the helpline were out of office hours (later than 5pm each evening). Keeping the helpline manned from 5pm to 9pm has proven very effective in aiding people who might otherwise not have made contact with the association. While there was no distinguishable pattern to the type of calls that were received out of office hours the volume of calls received in 2010 does support the decision taken in 2009 to extend the helpline hours. Of the 960 calls received there was a pretty even split of almost 50/50 between members and non members. This is an area that has been utilised by the association to increase its membership through the inclusion of membership forms with all written responses to calls.

Calls by Time & Membership Status



Our helpline continues to be a rich source of information for the association and helps to inform the direction of talks given at our patient information meetings as well as valuable input for Board meetings. Two areas have consistently been highlighted from the helpline:

1. Provision or access to a Parkinson's Nurse Specialist.
2. Provision of home help or respite services by the association.

There is a huge level of surprise that we are not in a position to provide such services and our lack of state funding is cited as the main bar. In June 2010 one of our members, Mr. Eddie O'Brien, provided the association with funds that he had raised previously so that a Parkinson's Nurse could be employed. The Board has started the process of recruiting a Parkinson's Nurse and it is hoped to have this process completed by early 2011. There is an undoubted need for respite care and home help services and this should be a priority should core funding become available in the coming years.

Patient Information Meetings

During 2010 our association held four very successful Patient Information meetings throughout Ireland in the following locations; Galway, Louth, Kildare and Cork. These meetings could not have taken place had it not been for the kind support of Orion Pharma.

In total over three hundred and fifty people attended the events with various speakers from hospitals based closest to the seminar venues who all gave their time and knowledge freely and with great generosity of spirit. Our support team is small but very dedicated and our thanks go to our former Chairperson, Una Anderson Ryan, Joe Lynch our CEO, Pauline Mahady our Helpline Manager and Board member, Ann Keilthy, all of whom contributed to the success of the meetings and to the enjoyment of the people who attended.



*Dr. Tim Counihan
Speaking in Galway*

The Galway meeting was hosted by the Galway Branch and great credit is due to all of the Branch Officers for their assistance on the day. Neurologist, Dr. Tim Counihan opened his session on drug management of Parkinson's before handing over to Parkinson's Nurse Specialist, Patrick Browne and Physiotherapist Anne Marie O'Rourke. Psychiatrist Donna O'Donoghue provided sound practical advice on coping with depression, and Speech and Language Therapist, Fiona Rogers, gave a fantastic talk on the difficulties some people have with this aspect of the disease and the questions and answers session was handled expertly by the Session Chair, Audrey Kinahan.

Our Louth meeting took place in the Crowne Plaza Hotel, Dundalk with the theme 'Compulsive Behaviour in Parkinson's'. Over one hundred people attended the meeting with a great cross section of people with Parkinson's, carers and medical professionals attending. Neurologist Dr. Ronan Walsh spoke about drug management while Parkinson's Disease Nurse Specialist, Brian Magennis, dealt with Wearing Off. Specialist Registrar in Neurology, Dr. Étain Quin, addressed the meeting on Dopamine Dysregulation Syndrome and Community Physiotherapist, Caroline Purcell, informed the meeting about the role of the physiotherapist. The session chairman, Dr. Afolabi Abayomi also contributed some thoughts that complemented the information from the speakers.



Dr. Ronan Walsh Speaking in Louth



*(L-R) Ann Keilthy, Johanne Murphy,
Dr. Graham Hughes, Anne Heavey,
Una Anderson Ryan*

The Kildare meeting took place in October and we held this information meeting in the Keadeen Hotel, Newbridge where over sixty five people with Parkinson's and their families, attended. Talks included topics such as 'Wearing Off', presented by Dr. David Bradley, Specialist Registrar in Neurology, Tallaght Hospital and the role of the physiotherapist by Johanne Murphy, Physiotherapist. The question and answer session was very lively and the interaction between the audience and Health Professionals, was excellent. Geriatrician, Dr. Graham Hughes talk was informative with some good humour thrown in and Nicola Kavanagh, Parkinson's Nurse, Tallaght Hospital, gave some very sound practical advice on managing

Parkinson's. The day was rounded off with a complete yoga body work out by Patricia O'Connor, Yoga instructor, who guided everyone through this energising and enjoyable session. The day was a fantastic success due in the main to the terrific work of the Kildare/East Midlands Branch.

The Cork patient meeting took place in the Rochestown Park Hotel in November of 2010 and provided our final venue for year. While the weather played a part in reducing the numbers in attendance we were very surprised to see over eighty people make such a huge effort on the day. Dr. Aisling Ryan spoke to our members about drug management while Dr. Eugene Cassidy discussed mental health issues that are associated with the disease. There were also input from Liz O'Sullivan on physiotherapy and non motor symptoms were dealt with by Ethna Mitten NNS. Dr. Suzanne Timmons identified wearing off and drug management in Parkinson's. Dr. Timmons also introduced the new Movement Disorder Clinic that was opening in St. Finbarr's Hospital in Cork.

Information Leaflets

Leaflets remain the primary source of written information from the Parkinson's Association and with this in mind a process began in December 2010 to overhaul the current leaflets and examine whether they met the needs of patients and carers. Following this review a small sub-committee met and decided that the format that best suited our needs was A4 and that they would be uniform and colour coded. It is expected that this work will be completed in 2011. Special thanks go to the committee members, Ann Keilthy, Joe Lynch, Dr. Richard Lynn, Riona Horton, Pauline Mahady and John O'Mahony.

Magazine

Parkinson's Ireland is the association's magazine and is published quarterly. It provides the association with its most critical regular interaction with our members. During 2010 the format of the magazine changed and the make up of the editorial team also changed with the addition of our CEO. Our quarterly Branch reports are also extremely important to the ongoing interaction with our Branch network.



The topics covered this year included:

- ▲ New CEO
- ▲ World Parkinson Congress in Glasgow
- ▲ The World Parkinson's Pledge
- ▲ Dental Issues
- ▲ Alternative Therapies
- ▲ Non Motor Symptoms
- ▲ Meetings with the HSE
- ▲ Ask the Expert
- ▲ Professional Profiles
- ▲ Impulsive and Compulsive Behaviours in Parkinson's
- ▲ Fundraising
- ▲ Newbridge Silverware Partnership

During the year the production and distribution of the magazine was streamlined and this has resulted in time and cost savings for the association. It is important that for future publications our articles should be more focused on issues around Parkinson's, living with the disease and the science and scientific advances.

Website

At the December meeting of the Board of Directors it was decided to progress with the redesign of our website, www.parkinsons.ie. A budget has been set and this work will be completed in advance of the Parkinson's Awareness Week in April 2011.

Annual Social Weekend

A very valuable part of our annual calendar is our Parkinson's Association of Ireland Social Weekend that is organised for our members to actively participate in meetings, social activities and events that are organised with their needs in mind. This is the one opportunity each year where people with Parkinson's, their partners/carers and friends can gather together with like minded people to discuss their condition and unwind in a safe environment.



In February 2010 we travelled to the Radisson Blu Hotel, Athlone where almost two hundred members were in attendance and many expressed their wish to see this annual event continue into 2011 and beyond.

The information portion of the weekend was sponsored by Orion Pharma, to whom we are very grateful. Dr. Dan Healy, consultant neurologist with Beaumont Hospital, spoke to our members on the progression of Parkinson's disease and he gave some very interesting insights into the current research that is taking place both in Ireland and in other countries. Dr. Healy was also on hand for questions from the audience, which was well received.

Branch Activities

One of the many functions and supports that our Branch network provides for members is through activities such as yoga, exercise classes, Branch meetings and outings.

East Midlands Branch

AGM

4 Social Events:

- Yoga Class for four week in April
- Summer outing to Powerscourt House and waterfall.
- Four weeks of yoga in October.
- Christmas Party in December.

3 Educational Events:

- Information day in Keadeen Hotel.
- World Parkinson's Congress
- November meeting with guest speaker Margaret Mullarney

1 Fundraising Event

- Annual Golf Classic in October in Abbeylix Golf Club

New treasurer Martina Sinnott appointed.

Mid West Branch

10 Monthly meetings

4 Educational Events:

- 10 weeks of physical therapy classes
- Two 10 week periods of voice club for 15/20 people
- Transition year students from Crescent Comprehensive College provided 14 sessions for Silver Surfers
- Sid Rellis and Eddie Butler addressed the Second Year Medical Students at UCC.

5 Fundraising events:

- Bridge Morning
- Golf Classic
- Sponsored cycle around the Ring of Kerry
- Corn Milling event
- Limerick Women's Mini Marathon

1 Social Event:

- Barry McGuigan visited the Glor Theatre in Ennis.

Tipperary Branch

AGM

7 Educational Events:

- Talk from Mags Richardson in Nenagh
- Meeting at Civic Offices as part of Awareness Week.
- Talk from Catherine Maher on Physiotherapy in PD at Thurles Community Hospital
- Talk from Ann O Farrell on continence advice.
- World Conference
- Talk from Mags Richardson.
- Talk from Evelyn Norton on speech and language therapy in PD.

2 Social Events:

- Annual Mass followed by music and refreshments.
- Mid Summers Night sing a long with refreshments.

Dublin Branch

AGM

- Margaret Mullarney spoke after the meeting "Outside the Box"

4 Committee Meetings Held

2 Educational Events:

- Summer Meeting - Mary Jones gave a talk and demonstration on Yoga
- Autumn Meeting - Neurologist Raymond Murphy gave a talk

1 Social Event:

- Christmas Lunch- postponed until Easter '11 due to the bad weather.

2 Fund raising events:

- July
- November.

Appointment of Nicola Kavanagh PNS Sponsored by the Dublin Branch and Pals.
Exercise classes continue in Clontarf and Donnybrook weekly.

PALS

AGM

2 Committee meetings:

- Held in the the Glenview hotel Wicklow

4 Social Events:

- Horse Racing in Kilkenny
- Annual PALS walk in Marley Park
- Christmas Lunch in the Goat Grill
- Concert in Maynooth College

2 Fundraising Events:

- Tablequiz
- Christmas Concert in St. Patrick's College, Dublin in aid of the National Office

North Kerry

1 Educational event:

- Information evening with guest speaker Mags Richardson. Refreshments afterwards.

2nd World Parkinson Congress, Glasgow 2010

The 2nd World Parkinson Congress took place in Glasgow from the 28th of September to the 1st of October this year. The World Parkinson Congress provides an international forum for the latest scientific discoveries, medical practices and caregiver initiatives related to Parkinson's disease. By bringing physicians, scientists, allied health professionals, caregivers and people with Parkinson's disease together, the organisers hope to create a worldwide dialogue that will help facilitate the discovery of a cure and best treatment practices for Parkinson's disease.

Registrants from 70 countries represented 550 people with Parkinson's & care partners; 1,690 clinicians & researchers; 626 rehab specialists and advocates; and 159 press and accompanying persons. The Congress was an outstanding success with over 3,025 registrants and the Association was well represented with the National Office and Branches and Branch members well represented. The Association also took the opportunity to research training given to Nurse Specialists from the UK, America and Australia, which will be useful in our drive to encourage more training of general nursing in the area of Parkinson's. The next Congress will take place in Canada in 2013.

CAMPAIGNING & ADVOCACY

HSE Meetings

2010 marked a new departure for our association with meetings taking place with the HSE around core funding (more in our funding section) and with management around nurse training and primary care teams. In June we met with the disability manager of the HSE to submit our strategic plan and service provision and spending targets for the forthcoming year. It was important for us to make this initial contact to accentuate the positives of our organisation and to set in motion our application for state support for 2010 and beyond.

Parkinson's Association of Ireland also took the opportunity to engage with managers in the Primary Care Teams (PCT) of the HSE in conjunction with the Disability Federation Ireland (DFI) and Neurological Alliance of Ireland (NAI). The project centres on training and information issues for PCTs and their desire to gain more knowledge on neurological issues while at the same time being realistic about the number of charities representing conditions, that they can actively interact with. A 'One Stop Shop' web site is being pursued that gives up to date information on each condition and that can be accessed by the PCTs. There are also ongoing discussions about access to PCTs and in particular where different diseases and conditions have similar symptoms there may well be commonality for the care teams. It is hoped to conclude this work in late 2011.

Finally in 2010, through the grateful assistance of Glaxo Smith Kline (GSK), a consultant was hired to enable us to engage with senior nurse educators and management to start a discussion on nurse training for all nurses. Mr. Bernard Faughey enabled and focused the discussions on nurse training within the undergraduate model and continuing professional development (CPD) for qualified nurses. There was some reluctance from the HSE to engage fully in relation to undergraduate training as there was no perceived need for such training emanating from requests from nurses throughout the HSE. Through negotiations it has been agreed that our association will assist the HSE in delivering training to nurses on a modular basis in their places of work with the HSE facilitating this initiative. Ongoing discussions are set to conclude during the latter part of 2011 with role out during 2012.

Meetings with Ministers

Our ongoing campaign for recognition of Parkinson's disease as a critically important neurological condition is ongoing. During June, and October meetings took place with the Minister for Disabilities, John Moloney TD and the Minister for Older People, Moira Hootor TD, to emphasise the importance of proper treatment of Parkinson's disease. There were three main issues:



1. Lack of neurologists and specialist nurses within the HSE and the long waiting periods as a result,
2. the dire need for a Deep Brain Stimulation (DBS) unit in Ireland,
and
3. lack of core funding for our association.

All of our meetings were well received, however to date there has been no movement in regard to core funding for our association and we wait to see if the findings of the committee to review neurosurgical services will be implemented. This review is focusing in particular on issues of capacity and geographic configuration in the context of delivering high quality and safe services.

Membership of Other Voluntary Bodies

During 2010 the association continued to be a member of the following lobby and support groups:



Disability Federation Ireland (our CEO, Joe Lynch is a member of DFI's Board)



Neurological Alliance of Ireland (Board member, Ann Keilthy is a member of NAI's Board)



Medical Research Charities Group (MRCG)



European Parkinson's Disease Association (Board member, Ann Keilthy is a member of EPDA's Board)



World Parkinson Congress (Parkinson's Association of Ireland is a partner with the WPC)



Care Alliance Ireland (CAI)



The Irish Platform for Patients' Organisations, Science and Industry (IPPOSI)

“ Our ongoing campaign for recognition of Parkinson's disease as a critically important neurological condition is ongoing. During June, and October meetings took place with the Minister for Disabilities, John Moloney TD and the Minister for Older People, Moira Hoctor TD, to emphasise the importance of proper treatment of Parkinson's disease. ”

RESEARCH

Collaborative Research on Carers

The contribution made by Family Carers is crucial in enabling sick, disabled and older people to remain in the home. However, many Carers are forced to provide care to family members while being inadequately supported in their role. This research sought to develop a greater understanding of the health status of Family Carers in Ireland. A random sample of 20 Family Carers of people with Parkinson's disease participated in a series of qualitative semi-structured interviews.



It was found that the role of the Family Carer was both physically and emotionally demanding, particularly as the person's condition deteriorated and the caring needs intensified. Providing care had powerful physical impacts with significant changes to daily routines noted. High blood pressure, tiredness, lack of physical energy, back problems and arthritis were seen as consequences of caring. As a result of the physical demands of caring, feelings of loneliness, anxiety and depression were all expressed. Providing care also resulted in significant limitations to personal interests and hobbies.

Current periods of respite and state provided home care support were viewed as inadequate by many. Experiences of support from healthcare professionals differed greatly. Family members' support had an important social inclusion aspect. Current levels of financial assistance were seen as insufficient in meeting the needs of Family Carers. Support received by various non-government organisations (NGOs) was seen as highly beneficial. However, joint support meetings for both the Family Carer and care recipient were also problematic. A training programme for Family Carers was singled out as a crucial intervention that would assist Family Carers in building up the necessary physical and emotional skills for providing care to a person with Parkinson's disease, thus impacting positively on their health status.

Our thanks for this important collaborative research is extended to the Care Alliance and especially their Executive Director, Liam O'Sullivan and of course the report's author, Ann Stokes. It would also be remiss of us not to acknowledge the twenty families who also took part in the interviews that make up the report. Credit is due to Ann Keilthy, who supplied Parkinson's information to Ann Stokes and who also verified, proof read and assisted in ensuring correct medical provenance of the material used. This report was part funded by the Citizens Information Board.

Parkinson's Research

There are many research programmes currently underway throughout the world. Clinical and laboratory based research and trials are taking place. The concentration is on trying to identify and locate the genes (or combination of genes) that lead to Parkinson's Disease. To date mutations have been found in five genes that are associated with Parkinson's Disease. The five genes are: alpha-synuclein, parkin, ubiquitin carboxyl terminal hydrolase, SCA2 and DJ-1. These mutations have been found to have a role in abnormal protein processing in cells. Researchers have found that these mutations lead to cell death. This cell death extends to neurons that release dopamine. Parkinson's Disease research has improved our knowledge and ability to use gene therapy to alleviate symptoms. Glial-derived neurotrophic factor (GDNF) has been found to protect dopamine releasing neurons. Trials in humans have been limited, but trials in primates showed that GDNF stimulates the body to produce GDNF naturally. Researchers have also been working with introducing vectors that carry the GDNF gene in monkeys. They have found substantia nigra (dopamine producing) cell death decreases. In other research, gene therapy, using stem cells, was found to reduce some cardinal Parkinson's Disease symptoms, mainly, dyskinesias (the abnormal involuntary movements).

Our association is currently part funding Dr. Gavin Davey, Senior Lecturer in Neuroscience, Trinity College Dublin. Dr. Davey's research interests are molecular and cellular mechanisms that underlie neurodegeneration in the brain are the main focus of his research, in particular, the role that energy metabolism and bioenergetics play in controlling neuronal function and dysfunction. Cell reprogramming technologies are used to generate induced pluripotent stem (iPS) cell lines from mouse and human dermal fibroblasts. These cell lines are then differentiated into neurons that are used to study the biochemical mechanisms that control neurodegeneration.

ORGANISATIONAL CAPACITY

New CEO



In January our new CEO, Joe Lynch, joined the team. Joe has vast experience in differing environments and most recently worked as a business development manager with the Irish Concrete Federation. Joe also had previous experience in the Irish Defence Forces, the Disability Federation and as a former CEO of the ex-servicemen and women's organisation, ONET. During the year there were many changes to the work practice of the organisation and upgrading of capacity.

New Board Members



All our Board members with Mr. Brian Crowley, MEP

With the completion of our strategic plan it was apparent that the Board needed to be strengthened and the process started in early January of this year. The Board increased from three to thirteen members and the knowledge and skills available to the Board has increased dramatically. The recruitment process, guided by the Chairperson, Una Anderson Ryan, led to the recruitment of nine new Board members from January to May and a further one member in June bringing the

total Board size up to thirteen. The first meeting of the new Board took place in May. The Board also took the decision at their May meeting to select the CEO as the Company Secretary.

Increased Office Capacity

From January new computers were installed with greater capacity and networking capabilities. The helpline information is now being gathered for analysis through the introduction of an in-house database that enables proper interrogation of the data collected. The efficient collection and collation of this information enables the organisation to formulate cogent arguments based on actual data.

Strategic Plan

During 2008 the management team of the association took a decision to examine the workings of



Joe Lynch, CEO, Una Anderson Ryan, Chairperson & Senator James Carroll

the organisation and the interaction it had with its members and wider health community and general public. It was agreed that it was important to produce a three year Strategic Plan which would help to guide and direct the work of the association between 2010 - 2013. It was anticipated that the Strategic Plan would have a significant focus on both the effectiveness of the organisation (i.e. the impact which it has on members, on the general public, on relevant statutory agencies and other voluntary organisations)

and the efficiency of the organisation (i.e. the ways in which the association organises and structures itself to ensure that it meets the objectives and targets which it establishes for itself).

The three year Strategic Plan would also need to take account of the external environment in which the association operates. Key factors in this external environment for the period from 2009 to 2012

are likely to include the implementation of the Charities Regulation Bill; a stronger focus from the Department of Health and the Health Service Executive on collaboration and inter-agency co-operation between voluntary organisations; and a tightening up of public finances (which will result in many voluntary organisations finding it difficult to maintain or expand existing services).

The plan was, in essence, a health check document and took into account the current situation within the association and the desired outcomes which it wanted. A special word of thanks must go to the author of the plan, Stephen Rourke and the sterling work he carried out over the course of the compilation of the report.

There are six strategic objectives contained within the report:

1. To provide services and supports to people with Parkinson's
2. Increase public awareness and understanding of Parkinson's and the work and activities of the association
3. Develop appropriate organisational structures and decision making structures for the association
4. To develop appropriate organisational structures and decision making structures for the association
5. To lobby for additional services and resources in relation to people with Parkinson's
6. To secure the resources which will be required to enable the Parkinson's Association of Ireland to provide a comprehensive range of services to people with Parkinson's and to represent the interests of people with Parkinson's

The Plan was successfully launched in the Mansion House, Dublin by Senator James Carroll in April 2010.

Meetings with Branches

The association's Branch network is of critical importance to the ongoing success of the association and it was recognised that a meeting with our Branch leaders was necessary to ensure that the association was meeting the needs of Branches and also to bring Branches up to speed on the recent changes in the organisation. The meeting also served a very useful purpose in a social context with many Branch leaders meeting each other and Board members for the first time.

Also during 2010 the CEO took the opportunity to visit 8 Branches to meet committee members and Branch members.

Communications

Throughout the year regular press releases were issued with limited success. Our strategic plan launch was by far the most successful news item on a national basis with coverage in the Irish Times and on RTE's Six One news and RTE 1's one o'clock news bulletin. The value of regular coverage cannot be overestimated. Local media also covered launches including our Newbridge Silverware launch in October and all four of our patient information days. There is no doubt that we have significant room for improvement in this area.



FUNDING

All charities rely heavily on regular funding. The perennial difficulty of fundraising and funding applications is not unique to our association. In 2010 we commenced the process of seeking core funding from the HSE. This process is still ongoing and while we hope to have completed the application process in mid 2011 there are obvious problems in relation to public finances. However, it's heartening to know that over twenty new charities received some funding in 2010 from the HSE.

In 2010 the association relied heavily on funds from reserves, the flora women's mini marathon, once off donations, membership fees, our national raffle, Christmas concert, donations from Branches and ad hoc fundraising efforts largely organised by members and non members alike. The Flora women's mini marathon deserves a special mention as it has now become one of our major events each year. The publicity gained, and the funds raised, ensure that this particular annual event has a special place in our calendar of events. Special thanks to Pauline Mahady our helpline manager as she has developed this funding stream over the last four years.

MyCharity.ie

MyCharity.ie was a new venture for the association and marked a step forward into online donations. Some charities are large enough to be in a position to collect donations directly from the public. However a strategic decision was taken by the Board to opt for a third party collection method. MyCharity.ie operates on behalf of a large number of charities and enables people to be able to contribute once off donations or regular donations through their credit or debit cards online. Web space also enables fundraisers to be able to set up their own pages and raise funds for the association for their individual events. With the launch of our new web site in 2011 this method of fundraising should become even more critical to our success.

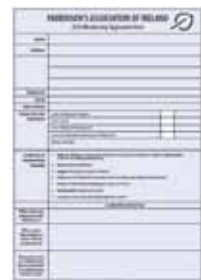


Bequests

Donations through bequests have enabled the organisation to build up some reserves and while this is a difficult area to promote it should none the less be a part of our fundraising activities.

Membership

Our membership fee remains at €25 per annum and raises small amounts of money in the context of the running costs of the organisation. However these fees are very important to the charity and its work. Often annual membership fees are accompanied by a small additional donation which is always very welcome.



Sponsorship – Corporate & Social Responsibilities

Big business often receives very little recognition for the work it carries out through Corporate Social Responsibility (CSR) schemes. Many of the activities that took place during 2010 would not have been viable had we not been in receipt of sponsorship from the following pharmaceutical companies:



Orion Pharma



Lundbeck



Clonmel Healthcare



Boehringer Ingelheim



Glaxo Smith Kline



UCB Pharma

Each of these pharmaceutical companies provided funding for various activities such as our patient information days and our magazine, with most also provided material, such as information leaflets, and/or staff support. Each of these companies has contributed to the success of the association in 2010 through their expertise and close co-operation with us, for which we are very grateful.

Parkinson's Association of Ireland
(A Company Limited by Guarantee and not having a Share Capital)

Income and Expenditure Statement
for the ended 31 December 2010

	2010	restated 2009
	€	€
Income		
Membership	22,499	17,874
Marathons	47,232	21,730
Donations	90,827	75,870
Telephone Raffle	-	3,286
Sales of Goods	25,621	11,410
Fundraising	87,945	90,813
Sponsorship	22,500	-
Bequests	-	29,070
Seminar Income	32,531	41,095
Sundry Income	-	11,246
Dormant account introduced	13,656	-
Bank deposit interest	18,713	32,821
Investment Income	150	-
	361,674	335,215
Expenses		
Cost of sales	10,433	14,081
Wages and salaries	101,292	79,582
Staff pension costs	2,743	-
Courses and training	330	295
Rent and rates	4,292	-
Insurance	820	720
Administration expenses	1,470	7,229
Hotel, seminar & meeting expenses	70,304	97,814
Social events	27,095	-
Postage	14,541	-
Printing, postage & stationery	30,871	36,059
Advertising	5,997	6,588
Telephone	9,650	4,584
Membership fees	2,660	1,480
Travelling and subsistence	61,761	33,871
Nursing, therapy & classes	32,536	12,115
Consultancy	-	51,962
Audit & Accountancy	14,275	11,705
Fundraising	33,794	1,620
Bank charges	1,842	1,460
Donations & gifts	6,070	84,756
Staff welfare	-	8,262
General expenses	7,078	2,911
Depreciation on FF & Equipment	2,124	261
	441,978	457,355
Deficit for year	(80,304)	(122,140)

Parkinson's Association of Ireland
(A Company Limited by Guarantee and not having a Share Capital)

Balance sheet
as at 31 December 2010

	Notes	2010		2009 restated	
		€	€	€	€
Fixed assets					
Tangible assets	7		8,896		3,666
Financial assets	8		26,635		30,635
			35,531		34,301
Current assets					
Stocks		10,465		357	
Debtors	9	10,862		19,824	
Cash at bank and in hand		3,338,448		3,365,281	
		3,359,775		3,385,462	
Creditors: amounts falling due within one year	10	(2,341,701)		(2,285,854)	
Net current assets			1,018,074		1,099,608
Net assets			1,053,605		1,133,909
Capital and reserves					
Income and expenditure account			1,053,605		1,133,909
Total funds	11		1,053,605		1,133,909

On behalf of the board



Patrick O'Rourke
Director



Hugh Cormack
Director

GOVERNANCE

Our Board of Directors

With the advent of a larger Board of Directors and with the majority being new members it was prudent to adopt new procedures including an increase in Board meetings, induction process for new Board members, establishment of committees with relevant expertise, a new Board attendance procedure, circulation of Board information in advance of meetings and training available as required. In addition the Board decided that the maximum number of Board members should be thirteen.

During 2010 the Board met on seven occasions and following is a list of meetings attended by each Board member:

Name	Position	Number of Meetings Attended	co-option Date
Pat O'Rourke	Chairman	7	May 2010
Una Anderson Ryan	Vice Chairperson	6	Existing
Hugh Cormack	Director of Finance	6	May 2010
Mary Reynolds	Board Member	6	May 2010
Ann Keilthy	Board Member	6	Existing
Elaine Quinlan	Board Member	6	May 2010
Seamus Funge	Board Member	7	May 2010
Patrick Rellis	Board Member	6	Existing
John O'Mahony	Board Member	6	May 2010
Bernadette Coleman	Board Member	7	May 2010
William Rice	Board Member	7	May 2010
Noel Lappin	Board Member	5	May 2010
Colm Dennehy	Board Member	3	September 2010
Joe Lynch	CEO/ Company Secretary	7	Appointed in May 2010



(L-R) Dr. Richard Lynn, Parkinson's CEO Joe Lynch and Riona Horton

Our AGM, which took place in March in the Green Hills Hotel, Limerick, was reasonably well attended with over fifty people in the room. The members heard about the association's activities for the previous year as well as a breakdown of the national accounts. Following the AGM Dr. Gavin Davey neuroscientist at Trinity College Dublin, gave a very informative talk to our members on the advances currently being undertaken in stem cell research.

EGM June

This EGM was necessary to adopt the consolidated accounts for the association for 2009. While there was a small turn out for the meeting the quorum was maintained.

EGM November

This EGM was necessary to adopt articles of association for our organisation. The articles of association are the guidelines that explain the internal organisation of the company. They are filed along with the memorandum of association when registering a company and the Board felt that as a result of implementing the new strategic plan it would be wise to adopt new articles that better reflect the organisation. While there was a small turn out for the meeting the quorum was maintained.



CONTACTS - National

National Office

Joe Lynch, CEO	01 - 8722234	joe.lynch@parkinsons.ie
Pauline Mahady, Helpline Manager	1800 - 359359	info@parkinsons.ie
Alison Cashell, Nurse Specialist	01 - 8722234	nurse@parkinsons.ie
Lauren Webb Office Administration	01 - 8722234	office@parkinsons.ie

Carmichael House, North Brunswick Street, Dublin 7

CONTACTS - Branch

CORK

Chairperson	Pat Walsh	087-2460853	littlepaddy@eircom.net
Secretary	Ted Horgan	087-2375558	tedhorgan@ireland.com
Treasurer	John Curtin	086-1731773	john.curtin@iol.ie

DONEGAL/NORTH WEST BRANCH

Chairperson	Anthony O'Malley Daly	086-8444744	
Secretary	Kathleen	087-2418152	cranford@ireland.com
Assistant Secretary	Ann Foxe	086-1605847	
Treasurer	Patricia O'Gara	071-91 83853	patriciamaryogara@hotmail.co.uk

SLIGO SUPPORT GROUP/SUB COMMITTEE OF DONEGAL BRANCH

Chairperson	Maureen Giblin	071-9130666	
--------------------	----------------	-------------	--

DUBLIN BRANCH

Chairperson	Ann Davis	087-7424026	
Secretary	Isabel Somerville	01-4909646	
Treasurer	Michael Long	087-2701143	mblong@indigo.ie

CAVAN/MONAGHAN BRANCH

Chairperson	Paddy Conaty	087-2798811	
Secretary	Eileen McGearty	049-4332401	
Treasurer	Seamus Minogue	049-9522148	

GALWAY BRANCH

Chairperson	Marie Cahill	087-7783825	mcahill92@hotmail.com
Secretary	Caroline Rushe	086-2566655	carolinerushe@gmail.com

KILDARE/EAST MIDLANDS BRANCH

Chairperson	Marian Deely	087-0638264	mariandeely@vodafone.ie
Secretary	Moira Barry	086-3429324	barrymoira@gmail.com
Treasurer	Martina Sinnott	087-6550176	martinasinnott@gmail.com

LOUTH/MEATH BRANCH

Chairperson	Maurice O'Connell	087-7512608	mauriceocon@hotmail.com
Secretary	Anne Matthews	086-1779697	
Treasurer	Kathleen Molloy	042-9321444	

MAYO BRANCH

Chairperson	Vincent McDonnell	086-8305907	
Secretary/Treasurer	Mary Nolan	094-9022085	

MIDWEST/LIMERICK BRANCH

Chairperson	Billy Rice	087-6410406	wrice.email@gmail.com
Secretary	Ann Butler	061-342971	ejbutler@tinet.ie
Treasurer	Eddie Butler	087-6776446	ejbutler@tinet.ie

NORTH KERRY BRANCH

Chairperson	Liam Walsh	086-3771844	
Assistant Chairman	Jerry Hurley	087-9785438	jerryhurley@eircom.net
Secretary	Mary Thornton	087-2935787	marygte@hotmai.com
Treasurer	Michael Collins	087-9829853	

PALS BRANCH

Chairperson	Ann Keilthy	087-2853117	parkingconsultant@eircom.net
Vice Chairperson	Tim Kelly		
Secretary	Rebecca Kelly		
Treasurer	Cathy Pollard	01-2982621	pollard.cathy@gmail.com

SOUTH KERRY BRANCH

Chairperson	Michael Moynihan	065-7758308	
Treasurer	Teddy Cronin	066-9762335	
President	Grace McCrea	064-7758837	

TIPPERARY

Chairperson	Michael Burke	087-2864798	
Secretary	Mary Carey	086-3916726	mcareyoo@eircom.net
Treasurer	John Carey	0504-54335	

WATERFORD/SOUTH EAST BRANCH

Chairperson	Mary Myler	057-355764	
Vice Chairperson	Teresa Peacock	086-3585738	teresa.peacock@hotmail.com
Secretary	Nicola Clarke	087-9542927	nclarke@nmh.ie

Carmichael Centre
North Brunswick Street
Dublin 7
Ireland

FREEPHONE HELPLINE 1800 359 359

Tel: 01 - 872 2234

Fax: 01 - 872 5540

Email: info@parkinsons.ie

Web: www.parkinsons.ie

Parkinson's Association of Ireland is a registered charity with limited liability

Company Registration No. 123532

Charity Reg. No. 10816