

Parkinson's Association of Ireland



ANNUAL REVIEW 2009

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INTRODUCTION

Chairperson's Report

The Board of PAI has been tasked with delivering significant change to the organisational culture and structure of PAI through a series of changes required for the better management of the organisation and delivery of service from 2009 to 2010. Towards the end of 2009 and beginning of 2010 the employment of new staff members was key to our continued success and provision of forward planning into the future.

With that as the context, the plan of work for the year took shape around a number of core areas. Firstly, we were aware of the need to protect and advance the roll out of informational services to members and their families. This saw a number of meetings taking place around provision of these services in areas that were least best served during the year.

Secondly, significant progress was made in developing a range of information leaflets that were necessary for our members and their families. These were important developments for PAI, and areas that we worked on continually throughout the year and will continue refine throughout 2010.

Thirdly, PAI continued to work on delivery of contact services with our members. In the first instance this required the continuous training of our Helpline Manager, Pauline Mahady, and the extension of our Helpline hours.

All of the above were supported by the current Board in the knowledge that the Board itself required strengthening at all levels. The Board continued to give attention to the development of Board Governance, which was progressed during the year through the introduction of a Strategic Plan which was launched in early 2010. In parallel with this, the Board decided to bring the introduction of a new CEO to the forefront of any new plans, which provided additional governance and support in the early part of 2010. The CEO's appointment was supported by the Board, and two members of the Board participated in the interview process on behalf of Board members. Furthermore the Board, having made a decision to introduce a new CEO, have also embarked on a process of recruitment and strengthening of the Board itself. An organisational health check at Board level should be undertaken at the end of 2010 possibly in conjunction with an external consultant, as a preliminary action.

Throughout this Annual Review you will identify progress made across distinct areas, namely, providing enhanced services and supports to members, primarily through

developments to information services such as first contact services and information road shows that deliver required informational services directly into the communities that members live in. The leadership and coherence of delivering meetings in the local community embraces the needs of people with Parkinson's to have services brought to them in a safe environment that fully addresses their needs in dealing with their condition at this very difficult time.

These are all examples of the Board systematically responding to its governance responsibilities in tandem with delivery of vital services to our members and their families. From the start of the year the Board gave a strong lead, as set out above, in determining the shape and orientation of the organisation.

This has been a year where more demands were made on the Board in relation to planning and governance issues. I wish to acknowledge, and to state my appreciation for, the work and support of all members of the Board. It is important to be aware that Board members have to operate from the perspective of PAI's vision and mission, having regard to the membership, while, at the same time, carrying the responsibilities and issues of their own home lives on a day to day basis.

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 reported to our AGM in 2009, participated in Information Days, Management Team meetings and meetings with medical professionals on behalf of PAI. As Directors of PAI we are all conscious of our obligation to have regard for the well being of the Association and to carefully mind its interests on behalf of you, the members of the company. PAI is also well served by many people from our membership and beyond, who actively engage in work to support the objectives of the Association.

I also wish to acknowledge and thank Pauline Mahady for what was a very challenging year for her during which both the Board and membership were, and continue to be, more reliant on Pauline than ever before. We depend on the professionalism and dedication of our staff and volunteers to support the Board and our members to progress the work of the organisation. We now look forward to the leadership and support that will be delivered by our new CEO, Joe Lynch, to members and branches of this organisation, to enable us to maximise the quality and quantum of services that we can provide together to people with Parkinson's.

Una Anderson Ryan
Chairperson

Chief Executive Officer's Remarks

Activity and progress across many areas of the organisational structure of PAI must be a priority. Firstly, in relation to our corporate capacity we must be focused on tightly managing our income and seek 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 PAI. Our vision for 2010 is to copper fasten our continued governance progression, complete our Board revamp, increase our fundraising activity, achieve some progress in relation to HSE funding, enhance our services and deliver tangible change to our member's lives.

During 2009, for the most part, there was only one paid employee, Pauline Mahady, who is part time. This is a situation that is unsustainable for a modern organisation with the ambitions and needs that have been ably set out by our Chairperson. It is necessary, therefore, to ratchet up service provision, lobbying for change within the services currently being provided by the HSE and employment of key personnel within PAI. During the coming year an Annual Plan and Work Plan will be agreed with the Board of Directors. New personnel will be engaged, as needed, once we have secured enough additional funds for such people.

Lobbying will be the watch word for the coming year and this will need to be both co-ordinated and cohesive in its message. The Board and staff cannot be distracted from the task in hand and there needs to be a systematic approach developed to implementing the changes that are necessary within PAI to ensure that we maximise our fullest potential during 2010 and onwards for the years to come.

The co-operation and support of branches and members will be crucial to the success of PAI in the coming year and I look forward to working closely with everyone concerned.

Joe Lynch
Chief Executive Officer

THE YEAR IN REVIEW

Introduction

PAI is a national organisation with a growing branch network throughout the country. Our main aim is to make contact with as many people with Parkinson's as possible and ensure that they are receiving the best possible outcomes for their condition. Part of this process was setting in place an educational program that addresses the main informational deficits being experienced by people with Parkinson's and their families, carers and other service providers. Key to our ongoing strategy to ensure that points of contact are varied and ample is that access to information is made as easy as possible. The help and assistance of our volunteers throughout our branch network was necessary and very much appreciated by the national office. Without the sterling work of these individuals very little could have been achieved.

The overarching elements of this work were identified early in the year:

- **Delivery of high quality information through the production of good quality, well researched leaflets dealing with the many aspects of living with Parkinson's**
- **Consistently reviewing and revising the material to ensure that it meets the needs of our members and that there are sufficient quantities available**
- **Extending the range and number of information days to a wider geographical area so delivering the provision of a range of timely and practical projects and services to assist members and branches directly in their communities**
- **Continuing to engage with pharmaceutical companies and health professionals to ensure that information days deal with the immediate difficulties being encountered by people with Parkinson's**
- **Extending the opening times for our National Helpline service**
- **Engagement with Medical Professionals**
- **Adoption of a Three Year Strategic Plan**
- **Fundraising**
- **Upgrading of our Web Site**

- **Supporting research into Parkinson's**
- **Appointment of staff**
- **Production of a Parkinson's Alert Card**

These continued to be at the core of activity for the year across all aspects of our work and have grown to represent a huge body of ongoing work throughout 2009 and will continue to be a feature of our work plan for 2010.

Information

Information Leaflets

In response to the many queries received on the PAI Helpline and through contacts from branches and feedback from information days a range of informational leaflets have been developed, with the grateful assistance of many health professionals. The range and topics covered through the information leaflets is very varied:

- **Finding the inner peace – for carers and families**
- **Tips for carers**
- **Anti freeze – suggestions to combat freezing**
- **Avoid falling, get walking**
- **Adjustment, adaptation and coping – strategies for helping with the process of coping**
- **Practical physiotherapy pointers**
- **Wearing off. What's that?**
- **Drug management of Parkinson's**
- **Coping with Parkinson's**
- **Exercise program for people with Parkinson's**
- **Dry mouth**
- **Depression in Parkinson's**
- **Physiotherapy in Parkinson's**

- **Communication and swallowing issues**
- **Falling and walking tips**

Information Booklets/Charts/Cards

In addition to the extensive range of leaflets produced by the association PAI also developed more in-depth charts, booklets and cards during 2009 dealing with an array of important concerns for people with Parkinson's:

- **Flexibility exercise chart**
- **Simple handbook for healthy eating with Parkinson's**
- **Cognitive aspects of Parkinson's and what we know about dementia**
- **Parkinson's Disease and nurses handbook**
- **Tips and tricks booklet – living with Parkinson's**
- **Parkinson's Alert Card**

Flexibility Exercise Chart

During 2008 PAI in conjunction with Lundbeck (Ireland) Ltd. developed an exercise chart with gracious assistance from Gráinne McKeown, Dublin Physiotherapy Clinic and PDNS Brian Magennis, Mater Hospital Dublin as well as PAI members, David Magennis and Helen Stapleton. During 2009 this exercise chart was updated with information on the management of Parkinson's Disease through a multidisciplinary approach. The chart continues to be one of the most requested items from contacts with members and is well received by those who availed of it.

Simple Handbook for Healthy Eating With Parkinson's

One of the major causes of concern among people with Parkinson's and their physicians is correct diet especially when considered in relation to certain Parkinson's medications. This was identified as requiring some thought and actions and in early 2009. The Chairperson, Una Anderson Ryan made contact with Megan O'Riordan, Lundbeck (Ireland) Ltd., with a view to sponsorship of a Nutrition Handbook and Jennifer Allen, Naturopathic Consultant, Limerick, for assistance in assembling a healthy dietary guide for members. Following on from this initial work Hugh Cormack, PAI, made contact with award winning chef, Neven Maguire, McNear House and Restaurant, Cavan, who designed simple and healthy dietary information and recipes in

conjunction with Jennifer and again this has been of huge benefit to people with Parkinson's. Over one thousand five hundred books were distributed to members and other interested parties during 2009 and the book is also available in downloadable format from the Parkinson's Association web site.

Cognitive Aspects of Parkinson's And What We Know About Dementia

Dementia describes a group of symptoms caused by the degeneration of brain cells leading to impaired operation that can interfere with social functioning. Parkinson's is one of the most common neurological disorders affecting people between the ages of forty and seventy years. Even so, it only occurs in about 1% of people over sixty five. There is a higher risk of developing dementia in people with a confirmed diagnosis of Parkinson's. Professor Brian Lawlor, St. Patrick's Hospital, Dublin has developed a very useful booklet for PAI, which continues to be used for a small minority of members.

Parkinson's Disease A Nurses Handbook

During 2009 it became apparent that the Association needed to develop a dedicated Nurses Handbook. The handbook was developed and distributed in conjunction with Orion Pharma and was written by PDNS Brian Magennis, Mater Hospital, Dublin and PDNS Mags Richardson, Limerick Regional Hospital. It deals with:

- **Parkinson's Disease – General Information**
- **Medication Management**
- **Surgery**
- **The Multidisciplinary Team**
- **Nursing Care**
- **Parkinson's Support Groups**
- **About the Authors**
- **Glossary of Terms**

The handbook was widely distributed to nursing homes and GPs and is freely available from the PAI headquarters and through our Freephone Helpline, 1800 – 359 359. Many family members have also requested the booklets for their loved ones in regard to provision of care within nursing homes.

Tips and Tricks Booklet – Living With Parkinson’s

This booklet was produced as a common sense guide to living with Parkinson’s. It was developed in collaboration with Lundbeck (Ireland) Ltd. and provides tried and tested tips and tricks to help people with Parkinson’s save time and energy and, together with medical care and appropriate medication, helps to improve and maintain a good quality of life.

Production of Parkinson’s Alert Card

Parkinson’s Association of Ireland has produced an alert card in association with Glaxo Smith Kline and these are freely available to people with Parkinson’s. The card alerts people to some of the symptoms that may be present with Parkinson’s and asks for time and understanding when dealing with people with Parkinson’s.

Reaching Members

Information Days & Social Weekend

PAI has long been committed to the delivery of information directly to people with Parkinson’s. This has, to a large extent, been predicated in the knowledge that the information resources of the state have been deficient in relation to people with Parkinson’s. As set out above our aim has been, and will continue to be, the delivery of quality assured information. To this end, during 2009, we have delivered information meetings in Wexford, Sligo and Limerick. Each meeting was well attended with an average turn out of over hundred and thirty people with Parkinson’s and their families. The Information Days have been hugely constructive in delivering quality information from health professionals directly to people with Parkinson’s. Each session allowed for questions and answers from the floor and proved invaluable for all concerned.

Our grateful thanks is extended to Dr. Kevin Murphy, Sligo General Hospital, Dr. Ken Mulpeter, Letterkenny General Hospital, Dr. John Doherty, Sligo General Hospital, Dr. Michael Reardon, Wexford General Hospital, PDNS Brian Magennis, Mater Hospital, Dublin, Marian Deely, Chairperson, East Midlands Branch, PAI, Anne Roche Clinical Nurse Manager, Wexford Day Hospital, Dr. Helena Moore, Bon Secours, Tralee, Dr. Peter Boers, Limerick Regional Hospital, Dr. Paul Reynolds, Limerick Regional Hospital, Ann Keilthy, PAI, and Frances Shinkins, SLT. Each of the many participants has contributed to our knowledge and understanding of Parkinson’s and its symptoms. Our special thanks are also extended to Mr. Ronnie Gardner who is an American Jazz musician, and who entertained and educated members in his Rhythm and Music Method during our social weekend in Sligo, which fulfilled both a social and informational role for us this year.

National Help Line

Effective communication with people with Parkinson's and their families is seen as a key element of our ongoing strategy. The Helpline has become the single most important contact PAI has with its members. Our Helpline Manager, Pauline Mahady, deals with a wide range of calls:

- **First Diagnosis**
- **Spouses and Families Enquiring About the Disease**
- **Calls for Assistance with Coping**
- **Sign Post for Other Services**
- **Onward Transmission of Calls to PDNS**
- **Calls Reflecting Helplessness and Loss**
- **Information Requests**

During 2009, our helpline hours were extended to cover a twelve hour day, 9am – 9pm. Although the main body of calls were dealt with during office hours a significant number fell outside these hours. It is hoped to implement a database in 2010 to log calls and register assistance given. The Board also feel that during 2010 it would be an important measure to have the Helpline manned over the weekend period, funds dependent.

Engaging with the Medical Profession

Engagement with Medical Professionals

At the heart of many difficulties experienced by people with Parkinson's is the apparent lack of knowledge that exists within the medical profession around Parkinson's and its symptoms. A strategic objective during 2009 was engagement with these professionals at an early stage. Lectures were given by PAI members from a patient's perspective to students of the University of Limerick, University College Cork and the Royal College of Surgeons of Ireland, Dublin. These sessions introduce students, at an early stage, to the complexity of the Parkinson's condition. It is critically important to our work that these types of contacts are maintained and enhanced. Mainstreaming of Parkinson's will continue to be a challenge and our aim through 2010 will be to increase these interactions. In addition PAI continues to provide support for the Limerick based PDNS, Mags Richardson, through the provision of a part-time paid secretary.

Development of Structures

Adoption of PAI Three-Year Strategic Plan

PAI is acutely aware of the need for its continued progression within the community and voluntary pillar. We have also been aware of the deficiencies within the organisational structure which have arisen over the past few years and the decision to address these issues was taken towards the end of 2008. In early 2009, Mr. Stephen O'Rourke was engaged to look at the structural deficits within PAI and map out a way forward for the organisation. It was clear from the beginning that the organisation needed to deliver major change within its own structures before seeking service level agreements with the HSE. This change has commenced with the appointment of Special Projects Director, Ed Rice at the end of 2009. Mr. Rice has been engaged to raise funds for PAI as well as raising our profile and overseeing the revamp our web site.

This position will be closely followed by the appointment of a professional CEO, Joe Lynch in January 2010. Two Board members were appointed to ensure that the correct person was selected for the job of CEO and these were Una Anderson Ryan and Hugh Cormack. The organisation also engaged Adare HRM, to assist with the selection and interview process for the CEO position. This work would not, in itself, rectify the deficits within PAI and must be matched with a commitment to enhance the Board's strength and depth. To this end PAI has engaged with Board Match Ireland and set in place a process of meeting and selecting suitable candidates to augment the current Board of Directors. This work is hoped to be completed in the first quarter of 2010.

The three year plan, developed by Mr. O'Rourke, will not formally be implemented until our CEO has taken up his position although it has been adopted with minor amendments at our AGM in March 2009. One of the major pillars within the plan relates to HSE funding for the expansion of services. It is envisaged that PAI should seek an initial service level agreement in the amount of €250,000. This will, of course, need to be matched by a similar commitment from PAI itself to raise an equal amount of funds on an annualised basis. Change will not be easy for some of the people within the organisation though most agree it is wholly necessary.

Financing PAI

Fundraising

Fundraising is a perennial problem for all charities. That said many charities have some form of state agency funding through the HSE and Pobal, to name just two state agencies. Access to regularised funding is essential to PAI's success. During 2009 **NO**

state funding was secured. The charity organised many events to raise badly needed funds:

- **Flora Ladies Mini Marathon**
- **Gala Variety Night**
- **Books, Cards & Candles Sales**
- **Skydiving**
- **Slow Bike Ride**
- **Donations in Lieu of Presents**
- **Raffles**
- **Donations from Private Individuals and Companies**
- **Membership Fees**

All of which have been fantastic in raising funds for PAI and our grateful appreciation is extended to everyone who participated and who donated their time and money to our cause. The main difficulty that has been highlighted is that PAI does not receive regular funding and as such the work being carried out is constantly under threat. Branches have consistently been to the forefront in raising funds and this has been the life blood of PAI. Regular funding is necessary to ensure the continuance and enhancement of our vital services.

In addition many pharmaceutical companies contributed much needed funding towards vital projects during the year.

Communications

Quarterly Magazine

Throughout 2009 four editions of our quarterly magazine were published with an extensive collection of articles dealing with the day-to-day aspects of living with Parkinson's as well as updates on the organisations functions and medication for Parkinson's. The magazine had many contributors throughout the year and we wish to acknowledge the work carried out by the editorial team of Ann Keilthy, Una Anderson Ryan, Ricky Mahon (RIP), Pauline Mahady and Ed Rice. In addition the magazine dealt with many queries from people with Parkinson's and their families and carers through the 'Ask the Expert' section and our grateful appreciation is extended to our ever willing experts, Dr. Tim Counihan, Galway University Hospital, PDNS Paddy Browne, Galway

University Hospital, Dr. Michael Riordan, Wexford General Hospital and Dr. Richard Cahill, Cavan General Hospital. Each magazine would not be complete if it were not for the 'Tips and Tricks' section, which is ably and willingly supplied by PDNS Mags Richardson, Limerick Regional Hospital. The magazine is distributed to all members and is also distributed to Neurologists, Parkinson's Nurse Specialists, Pharmaceutical Companies, Doctors Surgeries, Dublin Neurological Institute, Information Meetings and an ever growing list of other donors who appreciate the work of the PAI.

Upgrading of PAI Web Site

Web sites have become critically important in the provision of information and as part of the communications gambit of every organisation. PAI recognises the extensive role that Ann Keilthy, PAI, has played in this particular communication tool. In the current climate improvement of an already good service is important. Web sites have become the first port of call for people with Parkinson's and others who are interested in the disease and this is recognised by PAI. Our Special Projects Director, Ed Rice, who joined us towards the end of 2009, began work on the web site on taking up his appointment and we will have the new site ready for operation in mid 2010. The site already has a suite of information available and throughout 2010 this will be enhanced with newer software that will enhance the delivery capacity of the site.

Parkinson's Research

Supporting Research into Parkinson's

In the face of extraordinary advances in the prevention, diagnosis, and treatment of human diseases, devastating illnesses of the nervous system, such as Parkinson's Disease, continue to deprive people of health, independence, and well-being. Research in human developmental biology has led to the discovery of human stem cells (precursor cells that can give rise to multiple tissue types), including embryonic stem (ES) cells, embryonic germ (EG) cells, and adult stem cells.

PAI recognises that there are varied social, political, ethical, and religious viewpoints to be considered in discussions about the scientific use of tissue from human embryos and fetuses. Trinity College senior lecturer and researcher, Dr. Gavin Davey, is using a technique developed by Dr. Shinya Yamanaka's team at Kyoto University. The reverse programming procedure produces induced pluripotent stem cells from Parkinson's patients own tissue. This research overcomes some of the ethical hurdles encountered by embryonic research and still addresses the central issues around Parkinson's research. Dr. Davey is particularly interested in examining the link between mitochondria cells and their relationship to Parkinson's. During 2009, PAI made a substantial donation of €50,000 towards Dr. Davey's research. This donation was made

possible through a bequest to PAI. It is hoped to further enhance PAI's research funding during 2010.

Staffing

Appointment of Staff

There was one staff appointment during 2009, Mr. Ed Rice, who has taken on the role of Special Projects Director and is responsible, for fundraising and promotion of PAI on a contractual basis. In addition our Helpline Manager, Pauline Mahady, had her hours increased for our helpline.

Conclusion

The period under review posed significant challenges for PAI in both human and financial resources. PAI has been active in progressing advocacy on behalf of our members and has worked with like minded organisations with which it has established an understanding and in some cases, membership. PAI has looked in an in depth way at the structures and mechanisms within our organisation, and it has been consistent in driving the twin areas of protecting the rights and services of people with Parkinson's while simultaneously working to strengthen the capacity of our organisation.

PAI is will be actively pursuing Government and HSE for funding opportunities throughout 2010 and into the future. Our part in the community and Voluntary Pillar and membership of national and international organisations will continue to provide us with access to cogent opinions for advanced research into the causes and, hopefully, a cure for Parkinson's. There is a sense within PAI that organisations in general are becoming more interested in working with others across key policy or the practical areas of service delivery or organisational support. PAI can take some heart in the fact that we have taken on the hard task of looking inward before looking to Government and Non-Governmental agencies for funding. The major issue facing the organisation in 2010, and forward for the years ahead, will be maintaining and improving services to members and their families with an extremely limited budget. The key issue through 2010 will be securing a service level agreement with the HSE and ensuring core funding.

It is plain to see that the levels of assistance rendered to our members are extraordinary given the lack of funding in place for PAI. This is a testament to the incalculable hours that have been given up willingly by countless volunteers at branch and national level and who, to a large degree, go unrecognised. It is also true that this level of commitment cannot be expected to continue indefinitely. Funding must be sought and delivered if PAI is to continue to provide to type and level of service now in place.

Board of Directors

Board 2009

Una Anderson Ryan (Chairperson)
(Mid West Branch)

Ann Keilthy (Secretary)
(PALS Branch)

Patrick Rellis (Member)
(Mid West Branch)

Hugh Cormack (Ex-Officio)
(Cavan Monaghan Branch)

Staff

Pauline Mahady (Helpline Manager)
1 800 359359

Ed Rice (Special Projects Director)
01 8722234

APPENDIX I

Financial Statements

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