Parkinson’s Association of Ireland

STRATEGIC PLAN

2010-2013
Foreword

Dear Friends,

The Parkinson’s Association of Ireland has come to the brink of new beginnings. It is important for the Association to move forward in a professional way and for that reason we hired Mr. Stephen Rourke to compile a strategic plan. He was asked to consider our strengths and weaknesses and then to guide us in the right direction to ensure a positive future. Stephen produced this plan in a thorough and sensitive way. He worked for over eighteen months and presented it to our members at our Annual General Meeting in 2009. Subject to a few amendments, which were included in the final draft, it was accepted by all the members.

We would like to thank Stephen for his excellent approach and the final presentation of this plan.

Any plan such as this is only as good as the follow through and so we have appointed a Chief Executive Officer, Mr Joe Lynch, to draw up a work plan and to guide the Association into the future.

I now ask all concerned to assist our CEO in every way possible for the successful outcome of this plan. This will be for the future of our Association and for people with Parkinson’s disease. They deserve the very best to support them and their carers while living with their condition.

Una Anderson Ryan
Chairperson

VISION STATEMENT

The vision of the PAI is that the quality of life for people with Parkinson’s and their families will be improved and enhanced and that all people with Parkinson’s and their families will be presented with opportunities to link into a wider range of relevant services and supports.

MISSION STATEMENT

That the PAI will become a strong and effective organisation on behalf of people with Parkinson’s and their families in Ireland and that it will deliver a broad range of services to a significantly increased number of people with Parkinson’s in Ireland. The PAI has a particular focus on the provision of healthcare supports, advocacy, information and advice to people with Parkinson’s and to their carers.

The Parkinson’s Association of Ireland:
A company limited by guarantee, having no share capital,
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“Parkinson’s is a progressive neurological condition which directly impacts upon about 8,000 people who have Parkinson’s in the Republic of Ireland”
INTRODUCTION

1.1 BACKGROUND

The Parkinson’s Association of Ireland (PAI) was established in 1987. The PAI provides services and supports to people affected by Parkinson’s disease in Ireland. Parkinson’s is a progressive neurological condition which directly impacts upon about 8,000 people who have Parkinson’s in the Republic of Ireland. Parkinson’s is primarily caused by the degeneration of nerve cells (or ‘neurones’) in a part of the brain that controls movement, called the substantia nigra. Normally, these nerve cells produce dopamine – a chemical messenger or ‘neurotransmitter’ - which is used by the brain to control movement. In Parkinson’s, the production of dopamine is reduced and muscle tension and movement are affected. The main physical symptoms of Parkinson’s are tremor, muscular rigidity and slowness of movement.

PAI agreed that it was important to produce a three year Strategic Plan which would help to guide and direct the work of PAI over the next few years. 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 PAI 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 PAI operates. Key factors in this external environment for the period from 2010 to 2013 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 to expand existing services).

1.2 OBJECTIVES AND PURPOSE OF STRATEGIC PLAN

The production of the three year Strategic Plan for PAI aims to achieve the following objectives:

- To identify and agree the main strategic priorities and objectives for PAI in the period from 2010 to 2013
- To consider the most appropriate roles for PAI in relation to policy development and influencing the policies and programmes of relevant statutory agencies
- To identify the gaps in services and supports for people with Parkinson’s in Ireland and to clarify the most appropriate role for PAI in responding to these gaps
- To consider the organisational structures within PAI and the ways in which PAI manages and organises its affairs; and, if necessary, to put in place organisational changes and improvements which will enhance the capacity of PAI to achieve more practical and positive outcomes for people with Parkinson’s
• To analyse the funding environment in which PAI operates and to put together a strategy for significantly increasing the funding which PAI currently receives

• To set up evaluation and monitoring mechanisms which will enable PAI to assess, on an ongoing basis, the impact of its work vis-à-vis the various strategic objectives and action points which will be contained within the three year Strategic Plan

1.3 METHODOLOGY FOR PRODUCTION OF STRATEGIC PLAN

The production of the three year Strategic Plan for PAI has involved the following actions:

• Meetings with Management Team and National Executive Committee of PAI

• Meetings with PAI members

• Meetings with the Development Manager of PAI

• Analysis of documents produced by PAI

• Analysis of documents produced in relation to the needs and circumstances of people with Parkinson’s

• Analysis of planning documents produced by Parkinson’s support and advocacy organisations which have been set up in other countries

• Literature review of documents produced concerning the symptoms and consequences/effects of Parkinson’s

1.4 STRUCTURE OF STRATEGIC PLAN

This introductory section of the Strategic Plan will be followed by a brief description of the causes and consequences of Parkinson’s (Section 2). Section 3 of the document will describe the work and activities of the PAI. Section 4 will consider the needs of people with Parkinson’s and Section 5 will detail the main challenges for the PAI. Section 6 will outline the guiding principles and mission/vision statements for the PAI and Section 7 will set out the main strategic objectives for the PAI between 2010 and 2013. Section 8 of the document will address issues relating to the governance and organisation of the PAI.
2.1 INTRODUCTION

Parkinson’s Disease is named after James Parkinson who lived between 1755 and 1824. In 1817 he published a small book entitled ‘Essay on the Shaking Palsy’ in which he described his own observations on six patients who had involuntary shaking of the arms, legs and body. James Parkinson recognised that the features of all these six patients were very similar and differed from other medical causes of shaking that had been known up to that time. He called the new disease paralysis agitans (shaking palsy) but a French neurologist, Charcot, later suggested that the disease be named Parkinson’s Disease in honour of the man who first recognised it and this term has remained ever since.

This section of the Strategic Plan will provide some basis information about a number of key issues relating to Parkinson’s. These issues are as follows:

2.2 Causes of Parkinson’s
2.3 Symptoms of Parkinson’s
2.4 Prevalence of Parkinson’s
2.5 Treatment of Parkinson’s
2.6 Individuality of Parkinson’s

2.2 CAUSES OF PARKINSON’S

Parkinson’s is a progressive neurological condition which occurs as a result of a loss of nerve cells in the part of the brain known as the substantia nigra. These lost cells are those that produce dopamine, a chemical messenger that enables people to perform smooth, co-ordinated movements by transmitting messages between nerve cells and muscles. When a high percentage of the dopamine is lost (i.e. between 70% and 80%), the symptoms of Parkinson’s appear and the level of dopamine will continue to fall slowly over many years.

The reason why people with Parkinson’s lose the dopamine-producing cells is currently unknown. Most researchers believe it is likely that many factors play a role in causing Parkinson’s. Areas of research into the cause include genetics and the role of environmental factors.

2.3 SYMPTOMS OF PARKINSON’S

Parkinson’s has three main physical symptoms:

Tremor – This may begin in one hand or arm and is more likely to occur when the affected part of the body is at rest. Tremor will usually decrease or disappear when the affected part is being used and often becomes more noticeable when a person with Parkinson’s is anxious or excited. About 70 percent of people with Parkinson’s have a tremor and it is slightly less common in younger people with Parkinson’s.

Muscular rigidity or stiffness – This is a common early sign in people with Parkinson’s. People may experience problems turning round, getting up from a chair, turning over in bed or making fine finger movements, such as fastening a button, because of rigidity. Some people find their posture becomes stooped, or that their face becomes stiff, making facial expressions more difficult. Stiffness can affect many everyday tasks and can sometimes be quite painful.
Slowness of movement – People with Parkinson’s often find that initiating movements becomes more difficult or that it takes them longer to perform movements. Lack of co-ordination when making movements can also be a problem.

As well as these three main symptoms, people with Parkinson’s may experience a range of other symptoms, such as tiredness, depression, balance issues, constipation, and difficulties with handwriting and other forms of communication, such as speech and facial expression.

2.4 PREVALENCE OF PARKINSON’S

On the basis of international incidence studies, it is estimated that Parkinson’s affects 1 in every 500 people. This would indicate that there are approximately 120,000 with Parkinson’s in the United Kingdom and 8,000 people with Parkinson’s in the Republic of Ireland. There has been no significant epidemiological study of Parkinson’s within the Republic of Ireland, and given some of the difficulties in precisely diagnosing Parkinson’s (it is often misdiagnosed or its symptoms are often considered part of the ageing process) it is evident that there is a lack of precision in relation to the number of people in the Republic of Ireland who have Parkinson’s. Throughout an entire lifetime people have a 1 in 40 chance of developing Parkinson’s (Sagar, 2002). Men are slightly more likely to develop Parkinson’s than women.

The Global Declaration for Parkinson’s Disease produced in 2004 estimated that there are 6.3 million people in the world with Parkinson’s. Most people develop Parkinson’s between the ages of 50 and 80. It affects about 1 person in every 60 between the ages of 70 and 80. Interestingly it is less common after the age of 80. About 1 in 20 people with Parkinson’s will be aged less than 40 at the time of diagnosis – diagnosis at this early stage in life is known as young-onset Parkinson’s. If Parkinson’s is diagnosed before the age of 18 it is known as juvenile Parkinson’s – juvenile Parkinson’s is, however, extremely rare.

Famous people with Parkinson’s include the following: Muhammad Ali, Michael J. Fox, Billy Graham, Janet Reno, Sir John Betjeman, Salvador Dali, Francisco Franco, Adolf Hitler, Pope John Paul II, and Mao Zedong.

2.5 TREATMENT OF PARKINSON’S

Everyone with Parkinson’s is different and will have a different range of symptoms and responses to treatment. The nature and severity of symptoms, and the rate at which the condition progresses, will also be individual. Symptoms may take years to progress to a point where they cause major problems, and when they do, many symptoms can be treated.

Drugs are the main treatment to help control the symptoms of Parkinson’s. Surgery may be very rarely appropriate in the later stages of Parkinson’s if drug treatments stop working. Physiotherapy, speech and language therapy, and occupational therapy can play an important role in the day-to-day management of Parkinson’s. Leading a healthy lifestyle and remaining as active as possible can also help.

2.6 INDIVIDUALITY OF PARKINSON’S

The symptoms of Parkinson’s usually begin slowly, develop gradually and in no particular order. It is important to remember that everyone with Parkinson’s is very different and may have a different collection of symptoms and responses to treatment. The nature and severity of symptoms and the rate at which the condition progresses will also be individual. The symptoms may take years to progress to a point where they cause major problems and when they do, many of these symptoms can be treated.

There have been advances in treatments that can offer a better quality of life to people with Parkinson’s than was possible a few years ago. This trend is likely to continue. At present there is no cure for Parkinson’s but researchers and scientists are steadily making advances in understanding the condition, its causes and the most effective ways of treating it.
Section Three

PARKINSON’S ASSOCIATION OF IRELAND

3.1 HISTORY AND EVOLUTION

The PAI was founded in 1987 to meet a growing need of people with Parkinson’s. Over the years the group has expanded from its original Dublin base to having 12 member branches throughout the country with a membership base of 1,100 people. It has successfully campaigned for the recruitment of five Parkinson’s Disease Nurse Specialists within the country. Until recently it has been an almost wholly voluntary organisation. It has recruited a Chief Executive Officer as part of the process of supporting, professionalising and expanding the range of services that it offers to its members and the wider community.

Over the years, changes have included a significant overhaul of the organisation, an increase in the number of branches and the participation of these branches in the association’s national structures. Each branch sends two representatives to sit on the National Executive Committee, with a core group of officers responsible for organisational development and financing.

The focus of the PAI has broadened over the years from being there to support patients to educating the general public as well as the people with Parkinson’s and carers and also the health professionals, many of whom have reported they knew little about Parkinson’s except for what they had read while studying. The association has worked with several of the pharmaceutical companies to bring information to people with Parkinson’s, families, other carers, health professionals and the general public.

3.2 MAIN WORK AND ACTIVITIES

LEAFLETS

The PAI produces information leaflets on many aspects of Parkinson’s, including the drug treatment, physiotherapy, alternative treatments, relationships, and coping for carers.

HELPLINE

The PAI operates a helpline, Freephone 1 800 359 359, which provides a gentle and sympathetic introduction for many newly diagnosed people or their concerned spouses or families. It also provides information to people who have lived with Parkinson’s for a number of years.
INFORMATION DAYS

The PAI run information days throughout Ireland in an effort to ensure that access to support and information is available. Notices appear locally, or people can phone 1 800 359 359 for details on the next one, or to suggest different venues.

BOOKLETS

The PAI produce booklets in association with a sponsor, usually a pharmaceutical company. Recent ones include: “More than Meets the Eye” infopack which was distributed to every pharmacy in Ireland for every patient in the country and which won a pharmaceutical industry award. Other successful publications were a booklet on cognitive aspects of Parkinson’s, a detailed handbook on Parkinson’s for nurses, a flexibility exercise chart, and a book of tips and tricks in relation to Parkinson’s.

RESEARCH

PAI members have, co-ordinated by PAI, assisted on numerous projects, including the TRIL (Technology Research for Independent Living) at St. James’ Hospital in Dublin and several physiotherapy-related research projects at the same hospital. PAI members also participated in the recent GSK Quality of Life Survey, as part of a European research project.

BRANCH NETWORK

PAI has branches throughout the country - a local base upon which members rely, a source of friendship and support. Young Onset Parkinson’s (for those diagnosed before the age of 55) is also catered for within the local branches and by PALS Support Group, the nationwide branch for the younger members.

QUARTERLY MAGAZINE

PAI’s recently revamped and expanded magazine is sent to all members and to health professionals. Subscription is included in the annual membership fee, but separate subscription is also available – phone 1 800 359 359 for more information.

The PAI website www.parkinsons.ie has a lot of literature, news, branch details and events, and an ‘Ask the Expert’ section. The PAI works on expanding the range of information on an ongoing basis.

AFFILIATIONS

PAI is a member of the European Parkinson’s Disease Association and has participated actively, hosting the EuroYapmeet (YOPD) in 2005 and participating at General Assembly level and in their campaigns to raise awareness of Parkinson’s. PAI is also a member of the World Parkinson’s Disease Association and the Neurological Alliance of Ireland.
NEEDS OF PEOPLE WITH PARKINSON’S IN IRELAND

4.1 INTRODUCTION

In the course of the consultations which took place during the process of producing the 2010 – 2013 Strategic Plan for the PAI and through analysing research which has been carried out in relation to Parkinson’s, it is clear that people with Parkinson’s have a variety of different needs. It is also clear that these needs will differ from person to person and that the symptoms and treatments will vary quite dramatically from one Parkinson’s person to another Parkinson’s person. Therefore whilst it is not possible or sensible to be prescriptive about the precise needs of all people with Parkinson’s it is possible to outline the main issues which are most concern to people with Parkinson’s in Ireland. These issues are as follows:

- The need for accurate and up-to-date information
- The need for individual and personalised advice and support
- Education of healthcare professionals
- Loss of independence and mobility
- Lack of socialisation opportunities

4.2 THE NEED FOR ACCURATE AND UP-TO-DATE INFORMATION

Parkinson’s is a complicated and complex neurological condition. It can be difficult to diagnose and it can be difficult to determine with any degree of precision the appropriate remedies and treatments for people with Parkinson’s.

The problems experienced by different people with Parkinson’s vary quite considerably and the drugs used for these various problems differ correspondingly. In addition some people develop side effects on drugs that do not affect others. Thus, treatment that is suitable for one person may be quite unsuitable for another person.

(Sagar, 2002)

Therefore, it is evident that access to information is of significant importance to many people with Parkinson’s – information about the condition, information about treatment and medication, information about issues relating to diet and exercise. In a major survey of 13,000 people with Parkinson’s produced by the Parkinson’s Disease Society (UK) in 2008, 47% of respondents said that they needed more information about Parkinson’s. This survey also revealed that 3 out of 10 people diagnosed with Parkinson’s in 2007 felt that they were not given clear information about the condition and medication at the time of diagnosis and 86% of members joined the Parkinson’s Disease Society to receive advice and information about Parkinson’s.
The provision of knowledge is vitally important – knowledge about what Parkinson’s is, knowledge of how to cope with it and to minimise difficulties and knowledge of what help is available.

(Sagar, 2002)

Good information about symptoms, treatment options and what is available to people living with the condition is vital to help them to make informed choices and better manage the condition for themselves.

(Parkinson’s Disease Society survey, 2008)

4.3 THE NEED FOR INDIVIDUAL AND PERSONALISED ADVICE AND SUPPORT

In addition to the need for information there is also a need for individual advice and support to be provided to people with Parkinson’s. Whilst general information – provided through newsletters, information notes, websites etc. – can be of benefit, there is also a clear desire from people with Parkinson’s to be provided with 1-to-1 assistance and support in relation to how they might most effectively deal with Parkinson’s. Feedback from the consultations which took place during the process of producing the Strategic Plan for the PAI would indicate that people with Parkinson’s in Ireland would really appreciate the opportunity to receive ongoing advice and support on a regular basis from specialists in Parkinson’s.

Unfortunately there are only a limited number of Parkinson’s specialists in the Republic of Ireland. There are only 22 neurologists in a country of slightly over 4 million people (compared to over 600 specialists in Belgium which has a population of approximately 10 million). There are only 3 Parkinson’s Disease Nurse Specialists in the Republic of Ireland (compared to 240 Parkinson’s Disease Nurse Specialists in Britain and 5 in Northern Ireland). There is a clear need to improve the number and range of specialist services which are available to people with Parkinson’s.

Parkinson’s is a complex neurological condition. People living with Parkinson’s require regular inputs from specialists in the condition from diagnosis onwards so as to ensure that their symptoms are managed effectively and their quality of life is maintained. People should be diagnosed initially by a specialist and have access to a Parkinson’s Disease Nurse Specialist and therapies when they need them throughout the course of the condition.

(Parkinson’s Disease Society survey, 2008)

15% of people with Parkinson’s have never been seen by a hospital doctor with specialist knowledge of the condition. This is extremely worrying as Parkinson’s is a complex condition requiring specialist input.

(Parkinson’s Disease Society survey, 2008)

Although access to therapies such as physiotherapy, occupational therapy and speech language therapy is improving, the majority of people with Parkinson’s are still not being assessed for or receiving therapies to help them manage their condition.

(Parkinson’s Disease Society survey, 2008)

In relation to the provision of specialist advice and support to people with Parkinson’s there is an evident need to substantially increase the number of Parkinson’s Disease Nurse Specialists in Ireland. Consultations
which have taken place during the production of the 2010-2013 Strategic Plan and the outcomes from research in other countries clearly demonstrate the need/demand for more Parkinson’s Disease Nurse Specialists. For example, access to these Nurse Specialists is the top campaign priority for people with Parkinson’s and their carers living in the United Kingdom. However over a quarter of people in the United Kingdom have never talked to a Parkinson’s Disease Nurse Specialist. This figure is likely to be considerably higher in Ireland.

The particular roles and functions which are performed by Parkinson’s Disease Nurse Specialists include the following:

- Assessing the person with Parkinson’s and identifying their needs – they often act as key workers linking their patients to professionals and services that can help them
- Developing care plans
- Helping with drug management
- Providing information and education on the condition to people with Parkinson’s, carers and healthcare professionals
- Providing emotional and lifestyle support
- Providing support when the person with Parkinson’s is admitted to hospital

4.4 EDUCATION OF HEALTHCARE PROFESSIONALS

The relatively low numbers of neurologists and Parkinson’s Disease Nurse Specialists in Ireland demonstrates the importance of trying to ensure that other workers within the health service in Ireland have a good understanding of Parkinson’s – of its causes, its symptoms, its treatments and remedies. There is concern that healthcare professionals such as general practitioners and nurses might have an insufficient knowledge and understanding of Parkinson’s and that a key challenge for the PAI over the next three years is to increase understanding and awareness about Parkinson’s amongst healthcare professionals in Ireland. This might help to ensure that diagnoses and treatments for people with Parkinson’s might be improved.

- One in five people with Parkinson’s diagnosed in the last year was diagnosed by their General Practitioner.
  
  (Parkinson’s Disease Society survey, 2008)

- Parkinson’s is a complex, individual and fluctuating condition and a large number of health and social care professionals are involved in helping people manage their condition. A solid understanding of the nature and complexity of Parkinson’s is key to these professionals making effective health or social care interventions.

  (Parkinson’s Disease Society survey, 2008)

- Nearly 3 in 10 (27%) of those who had been a hospital patient in the last 5 years felt that doctors, nurses and other staff did not understand Parkinson’s and how it affected them at all.

  (Parkinson’s Disease Society survey, 2008)
These outcomes clearly indicate that there is a significant piece of work which needs to be carried out in relation to increasing levels of awareness and understanding amongst healthcare professionals about the causes and consequences of Parkinson’s and about the needs and requirements of people with Parkinson’s. There is a sense that there is an inadequate understanding of Parkinson’s amongst healthcare professionals and that this inadequate understanding mitigates against appropriate treatments and remedies being provided for people with Parkinson’s in Ireland.

- It is unlikely that General Practitioners will understand the full nature of Parkinson’s if they only have a handful of patients with Parkinson’s or see the condition rarely. In fact, in a survey of 203 General Practitioners conducted by the Parkinson’s Disease Society in November 2005 over 9 out of 10 of them stated that they had no specialist knowledge of Parkinson’s.

  (Parkinson’s Disease Society survey, 2008)

- More than one third of people with Parkinson’s are admitted into hospital each year. Being cared for by staff who understand the complex nature of Parkinson’s and the importance of the timing of Parkinson’s drugs is crucial to a patient’s well being in hospital. If people with Parkinson’s do not get their Parkinson’s medication at the time that works for them during their hospital stay their symptoms can get worse and the length of time they have to stay in hospital can be extended.

  (Parkinson’s Disease Society survey, 2008)

It is evident that the provision of accurate and well-informed advice from healthcare professionals is of significant importance to improving the quality of life for people with Parkinson’s in Ireland. It is also evident that many people with Parkinson’s do not know what type of supports are available and that many healthcare professionals do not have the knowledge required to deal most effectively with people who have Parkinson’s. There is a clear need for the PAI to have a stronger focus on increasing awareness and understanding of Parkinson’s amongst healthcare professionals in Ireland.

- As Parkinson’s is a progressive condition, having regular clinical reviews and medication adjustments are vital to people’s ability to manage the condition.

  (Parkinson’s Disease Society survey, 2008)

- People with Parkinson’s have a right to high quality information when and where they need it. Being given clear information at the time of diagnosis is important to how people manage their condition.

  (Parkinson’s Disease Society survey, 2008)

### 4.5 LOSS OF INDEPENDENCE AND MOBILITY

It is evident that the loss of independence and mobility is one of the most difficult and distressing aspects of Parkinson’s, especially as the condition becomes more progressive and more severe. People with Parkinson’s who were consulted during the process of producing the 2010-2013 Strategic Plan talked of their frustration and their anger at not being able to do fairly basic things which they were able to do without any difficulty or problems earlier in their lives. They talked of difficulties in dressing themselves, in writing, in remembering
things. There was a sense that people with Parkinson’s are more dependent on other people to do things for them and this has an obvious impact on one’s own self-esteem and ability to lead an independent life.

This loss of independence and reliance on others is particularly stressful for people who are diagnosed with Parkinson’s at a relatively young age. For some of these people it is necessary to give up paid work – in the 2008 survey carried out by the Parkinson’s Disease Society 17% of the 13,000 respondents had to give up work on account of the fact that they had Parkinson’s. For younger people who are likely to have more financial pressures than older people aged 60 and over the financial implications of Parkinson’s is more severe – the 2008 Parkinson’s Disease Society study concluded that there were significant negative financial implications for a large majority of younger people with Parkinson’s. Less mobility and more limited independence also have consequences for younger people with Parkinson’s who are raising young families.

In consulting with people who have Parkinson’s it is clear that one of the single most stressful aspects of the condition relates to those people who can no longer drive a car. This seriously impacts upon the quality of life for many people with Parkinson’s and inhibits their capacity to participate in a wide variety of different activities – activities which might have therapeutic and social benefits. To have to stop driving after having driven for perhaps 40 or 50 years is a heart-wrenching decision for many people with Parkinson’s, especially for people living in areas not well served by any form of public transport.

- Accessibility to transport is crucial to allow people with Parkinson’s to stay active, enjoy a number of social relationships, maintain hobbies and access training or employment: these are all vital elements of a healthy and independent lifestyle.

(Parkinson’s Disease Society survey, 2008)

4.6 LACK OF SOCIALISATION OPPORTUNITIES

The need for the development of more opportunities to socialise and to meet with other Parkinson’s people was mentioned on a regular basis by people who were consulted during the process of producing the Strategic Plan. In the absence of these socialisation opportunities there is a real concern that many people with Parkinson’s may become more reclusive and depressed and may have very little contact with any other people on any kind of regular basis. In addition to meeting with other people, the organisation of activities for people with Parkinson’s also present opportunities to learn new skills and pick up new information which would be of benefit to people with Parkinson’s.

- Nearly half of people with Parkinson’s wanted to do activities outside of their home such as socialising, visiting relatives or pursuing hobbies, but could not in the three months before being surveyed. Common reasons why not were feeling too unwell, feeling too tired, lack of public toilets, problems getting around the streets, difficulties with transport, problems with access to buildings.

(Parkinson’s Disease Society survey, 2008)

In considering the situation in Ireland it is clear that there are only limited opportunities for people with Parkinson’s to participate in social activities which would be both enjoyable and therapeutic. There are many parts of Ireland where there is no branch of the PAI and in other areas the local branches are quite weak and are not able to organise social events and activities for people with Parkinson’s within their area. A clear challenge for the PAI and for other service providers is to set up more social activities for people with Parkinson’s and to overcome the obstacles or barriers which might be preventing people with Parkinson’s participating in activities which are already taking place (e.g. barriers around transport or around having the confidence to participate in social activities).
“It is also clear that, at present, the PAI does not have the resources to provide a comprehensive, countrywide service.”
Section Five

KEY CHANGES FOR PARKINSON’S ASSOCIATION OF IRELAND

5.1 INTRODUCTION

The PAI should aim to provide a broader and more comprehensive range of supports and services to people with Parkinson’s within the Republic of Ireland. It is evident that a significant majority of these people (estimated at approximately 8,000 people) have no existing contact with the PAI and are not receiving the services and supports which they require or which they desire. It is also clear that, at present, the PAI does not have the resources to provide a comprehensive countrywide service - it only employs 1½ staff and it does not receive any ongoing statutory funding from the HSE.

In considering the main challenges for the PAI over the next three years (i.e. for the lifespan of the 2010-2013 Strategic Plan) it is apparent that the following represent the primary challenges:

- Increase awareness of Parkinson’s and of the PAI
- Develop organisational and branch structures within the PAI
- Increase the resources available to the PAI
- Become more relevant to people with Parkinson’s in Ireland
- Influence public policy and increase knowledge/understanding of Parkinson’s amongst healthcare professionals

5.2 INCREASE AWARENESS OF PARKINSON’S AND OF THE PAI

There is a need to increase public awareness and understanding about Parkinson’s – about its causes, its symptoms, its treatment and its impact upon people with Parkinson’s and their carers. This need to raise awareness and understanding is important for a number of reasons. It will make potential funders more aware of the fact that there are approximately 8,000 people in the Republic of Ireland with Parkinson’s (with many other family members and carers affected by Parkinson’s), it will make potential volunteers more aware of Parkinson’s, it will increase understanding amongst healthcare professionals who are in contact with Parkinson’s patients.

One person who was interviewed during the process of producing the Strategic Plan said that Parkinson’s was:

‘an invisible condition which most people have not heard about, which very few people can describe and which receives very little media coverage or public attention’.

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This statement is reflected, for example, in coverage of the report of the strategic review group on neurology. The Irish Times articles of 13th January 2009 on this report referred to conditions such as dementia, epilepsy, multiple sclerosis and acquired brain injury. There was no reference whatsoever to Parkinson’s.

In addition to raising public awareness about the needs and circumstances of people with Parkinson’s there is also a need to raise the profile of PAI. Heretofore the PAI has been a low-profile organisation which provides some useful services to people with Parkinson’s in Ireland – services around the provision of information and the creation of opportunities to meet and to socialise. PAI would not have a similar type of profile or public image as some of the better known charities in Ireland.

It is recognised that there is a direct link between resources, services and profile, i.e. the better resourced organisations are able to deliver more services and are able to build up a higher profile. In this context it is anticipated that a significant increase in resources will lead to a significant increase in the services being provided by the PAI and that this, in turn, will lead to an enhanced profile and greater public awareness of the work and activities of PAI.

5.3 DEVELOP ORGANISATIONAL AND BRANCH STRUCTURES WITHIN PAI

The organisational structures and decision making structures within PAI are unwieldy and confusing. There is a need for more clarity about the role of Directors of PAI, the role of the Management Team within PAI, the role of the National Executive within PAI, the role of the staff employed by PAI. Issues relating to roles, functions and responsibilities will be considered in more detail in Section 8 of this Strategic Plan. However, at this stage, it is important to recognise that a key challenge is to create a more streamlined and efficient organisation within which people are clear about the respective roles and responsibilities of different structures/groups within the overall organisation.

It is also important that every member of PAI subscribes to the guiding principles, mission statement, vision statement and strategic objectives/goals which will be included in the 2010-2013 Strategic Plan of PAI. At present, PAI is the only national voluntary organisation providing services and supports to people with Parkinson’s in the Republic of Ireland. It is important to retain this role and to ensure that there is a unity of purpose and vision within all parts of the PAI i.e. the national structures, the individual members, the geographical branches, the group supporting people with early-onset Parkinson’s.

In order to develop this unity of purpose and vision there should be a clear identity for the PAI, an identity which should permeate across all parts of the organisation. This common identity would be reflected in a single logo, in a single website and in Memorandum of Understanding between the national structure and the local branches. This unity of purpose and vision would also be reflected in an updated Memorandum and Articles of Association and in high levels of participation from branches in the national structures of PAI.

In addition to providing services at the local level it is also important that branches recognise the fact that they are vital parts of a national organisation which will hopefully be providing increased and more comprehensive services both to people with Parkinson’s and to existing/emerging PAI branches. In order to become a truly national organisation it will be necessary for PAI to work towards a national branch structure within which there will be a vibrant branch in every region within the Republic of Ireland.
5.4 INCREASE THE RESOURCES AVAILABLE TO PAI

PAI relies financially on contributions from pharmaceutical companies, on one-off grants, legacies, subscriptions from members and on donations from branches. Unlike many other organisations and groups in the voluntary healthcare and disability sector, PAI does not receive any core funding from the HSE. This is most disappointing and unfortunate. It is also surprising given the number of people with Parkinson’s in Ireland (circa 8,000 people), the severe ways in which Parkinson’s can impact upon many sufferers and the specific individual needs of people with Parkinson’s (within which the symptoms and the treatments differ from person to person).

In this type of context, one would assume that PAI would be a well-resourced and well-funded organisation which would be providing a range of direct supports to people with Parkinson’s and building up the local branch structures across the Republic of Ireland. In reality PAI is not a well-resourced and well-funded organisation and there is only a small amount that PAI can do with an annual turnover of approximately €150,000 and a staff complement of 1½ paid workers. It is clear that PAI could be doing a lot more for people with Parkinson’s and for local branches if it had more money and more paid workers.

In analysing the 2007 Annual Report and Accounts of the HSE, it is evident that 608 voluntary organisations in the Republic of Ireland received over €100,000 from the HSE in 2007 and that the HSE made 3,836 grants of under €100,000 to voluntary organisations. It is considered useful and instructive to list below some of the HSE allocations in 2007 (especially to organisations dealing with specific medical conditions and disorders).

<table>
<thead>
<tr>
<th>NAME OF ORGANISATION</th>
<th>CORE GRANT FROM HSE IN 2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer Society of Ireland</td>
<td>€8,332,00</td>
</tr>
<tr>
<td>Asperger Syndrome Association of Ireland</td>
<td>€326,000</td>
</tr>
<tr>
<td>Bodywhys – Eating Disorders Association of Ireland</td>
<td>€294,000</td>
</tr>
<tr>
<td>Brainwave – Irish Epilepsy Association</td>
<td>€882,000</td>
</tr>
<tr>
<td>Headway – National Association for Acquired Brain Injury</td>
<td>€2,861,00</td>
</tr>
<tr>
<td>Irish Association for Spina Bifida &amp; Hydrocephalus</td>
<td>€1,063,00</td>
</tr>
<tr>
<td>Irish Motor Neurone Disease Association</td>
<td>€265,000</td>
</tr>
<tr>
<td>Migraine Association of Ireland</td>
<td>€193,000</td>
</tr>
<tr>
<td>MS Ireland – Multiple Sclerosis Society of Ireland</td>
<td>€2,965,00</td>
</tr>
<tr>
<td>Muscular Dystrophy Ireland</td>
<td>€1,263,00</td>
</tr>
<tr>
<td>Post Polio Support Group</td>
<td>€436,000</td>
</tr>
</tbody>
</table>

In considering these figures it is clear that PAI should be receiving reasonable levels of annual statutory funding – at least €250,000 each year. There are roughly the same number of people with multiple sclerosis in Ireland as there are people with Parkinson’s – yet the MS Society receives core funding of nearly €3 million each year from the HSE whilst PAI receives no core funding at all. There is a clear need to link into ongoing statutory funding which would enable PAI to employ Parkinson’s Disease Nurse Specialists and Regional Support Workers. These staff would, in turn, significantly improve the services and supports being provided to people with Parkinson’s and to the local branches of PAI.

5.5 BECOME MORE RELEVANT TO MORE PEOPLE WITH PARKINSON’S

There are approximately 8,000 people with Parkinson’s in Ireland. The membership of PAI is around 1,100 – this includes a combination of people with Parkinson’s and the family members and carers of people with Parkinson’s. If one assumes that people with Parkinson’s represent two thirds of the total membership of
1,100, this leaves a figure of around 750 people. This figure of 750 represents less than 10% of people with Parkinson’s in the Republic of Ireland. In relation to the figure of 750, it is estimated that only around 250 regularly participate in events and activities organised by PAI and by PAI branches.

It is clear that PAI needs to make itself more relevant to the life circumstances of people with Parkinson’s in Ireland. PAI can play an important and vital role in improving the quality of life for people with Parkinson’s. This can be achieved through providing information about medication, about exercise, about diet and about other treatments; through directly providing advice on physiotherapy, speech therapy and other therapies which will be of benefit to people with Parkinson’s; through organising opportunities for people with Parkinson’s to socialise and to meet with each other; through the employment of Parkinson’s Disease Nurse Specialists and people to develop local branches of PAI.

These are all practical ways in which PAI can contribute to improvements in the quality of life for people with Parkinson’s. In relation to younger people with early-onset Parkinson’s it is considered that there are other ways in which PAI might assist people with advice about issues concerning work/employment, loss of income, relationships, raising of young children etc. These are all very important issues which could benefit through information, advice and support provided through PAI. It is also recognised, however, that the provision of this information, advice and support will be dependent on the employment of workers and that the employment of workers will be dependent on core funding being successfully negotiated with the HSE.

5.6 INFLUENCE PUBLIC POLICY AND INCREASE UNDERSTANDING OF PARKINSON’S AMONGST HEALTHCARE PROFESSIONALS

PAI should play a more prominent role in influencing public policy, and the priorities and budgets of the HSE in relation to the needs of people with Parkinson’s. It is evident that a key role of the Parkinson’s Disease Society in the United Kingdom relates to influencing public policy for the national government at Westminster and for the regional assemblies in Edinburgh, Cardiff and Belfast. This policy development work helps to ensure that the needs of people with Parkinson’s are taken into account when developing policies, drawing up budgets and determining healthcare priorities.

It is evident that PAI does not have the resources and staff to influence public policy in Ireland. As a comparator, the Parkinson’s Disease Society in the United Kingdom produced nearly 20 policy statements and policy papers in a two month period towards the end of 2008. PAI in Ireland simply do not have the resources to generate this type of policy output. However, PAI should aim to influence public policy and spending decisions in a more effective manner both through its membership of campaigning organisations such as the Disability Federation of Ireland and perhaps through the employment of its own Policy Development Worker/Officer.

PAI should also strive to increase understanding and awareness amongst healthcare professionals about issues relating to Parkinson’s and the needs of people with Parkinson’s. Earlier references have been made in this document to the ways in which many General Practitioners, nurses, social workers and other healthcare professionals are ill-informed and misinformed about the causes, symptoms and consequences of Parkinson’s (e.g. in the United Kingdom one in five people with Parkinson’s were diagnosed by their own General Practitioner). There is a clear need for PAI to develop strategies which would increase awareness amongst healthcare professionals about Parkinson’s, about how to diagnose Parkinson’s and about how to treat Parkinson’s.
Section Six

PRINCIPLES & STATEMENTS

6.1 GUIDING PRINCIPLES

The 2010 – 2013 Strategic Plan of the PAI will be informed by the following guiding principles:

- The PAI believes in the rights of everyone with Parkinson’s to be treated with dignity and respect
- The PAI will aim to ensure that all people with Parkinson’s are provided with opportunities to link into services and supports which are appropriate to their needs and circumstances
- The PAI will aim to provide countrywide coverage to people affected by Parkinson’s
- The PAI believes that early diagnosis is a key factor in the development of effective treatment programmes for people with Parkinson’s
- The PAI recognises the fact that Parkinson’s effects people in different ways and that people with Parkinson’s will each require different remedies, medication and treatment
- The PAI believes that there is a low level of understanding and awareness about Parkinson’s both amongst the general public and amongst healthcare workers/professionals
- The PAI recognises the need for increased resources and services to be provided for people with Parkinson’s in Ireland
- The PAI believes that the number of neurologists and Parkinson’s Disease Nurse Specialists is far too low and needs to be increased as a matter of urgency
- The PAI feels that the highest possible levels of services and supports should be provided to people with Parkinson’s in Ireland and that people with Parkinson’s should be made aware of these services
- The PAI believes that it is possible to improve the quality of life for people with Parkinson’s through a fair and reasonable level of investment in key services and supports which are required by people with Parkinson’s
- The PAI will aim to ensure that the objectives and goals established for the PAI are attainable and realistic. Whilst it is recognised that people with Parkinson’s in Ireland have a variety of different needs, it is also recognised that the PAI can only respond to some of these needs.

6.2 VISION STATEMENT

The vision of the PAI is that the quality of life for people with Parkinson’s and their families will be improved and enhanced and that all people with Parkinson’s and their families will be presented with opportunities to link into a wider range of relevant services and supports.

6.3 MISSION STATEMENT

That the PAI will become a strong and effective organisation on behalf of people with Parkinson’s and their families in Ireland and that it will deliver a broad range of services to a significantly increased number of people with Parkinson’s in Ireland. The PAI has a particular focus on the provision of healthcare supports, advocacy, information and advice to people with Parkinson’s and to their carers.
“The PAI will aim to ensure that all people with Parkinson’s are provided with opportunities to link into services and supports which are appropriate to their needs and circumstances.”
Section Seven

STRATEGIC OBJECTIVES

7.1 OVERVIEW

The strategic objectives for the PAI in the period from 2010 to 2013 will be as follows:

- To provide services and supports to people with Parkinson’s
- To develop appropriate organisational structures and decision making structures for the PAI
- To increase public awareness and understanding of Parkinson’s and of the work and activities of the PAI
- To lobby for additional services and resources in relation to people with Parkinson’s
- To secure the resources which will be required to enable the PAI to provide a comprehensive range of services to people with Parkinson’s and to represent the interests of people with Parkinson’s
- To support research which will be carried out on issues relating to the needs and circumstances of people with Parkinson’s in Ireland
Strategic Objective No. 1

To Provide Services and Supports to People with Parkinson’s

<table>
<thead>
<tr>
<th>STRATEGIC GOALS</th>
<th>ACTIONS</th>
</tr>
</thead>
</table>
| To provide information on issues which are of interest to people with Parkinson’s | • Produce information leaflets and booklets on relevant topics (perhaps through linking into materials produced by other Parkinson’s Associations)  
• Produce magazine four times each year  
• Organise information meetings for people with Parkinson’s and their carers  
• Develop comprehensive website for PAI  
• Provide information about equipment and appliances for people with Parkinson’s  
• Produce medication cards (to include information about drugs you are taking, your doctor’s name and other emergency details)  
• Produce alert cards (to include messages to help people with Parkinson’s who may have communications difficulties when they are out and about) |
| To offer support to people with Parkinson’s | • Maintain the helpline and increase the times when it is operational  
• Increase the number of Parkinson’s Disease Nurse Specialists from three people to six people within the Republic of Ireland  
• Equip more Public Health/Community Nurses with specialised training in Parkinson’s |
| To provide opportunities for people with Parkinson’s to socialise and to meet with other people who have Parkinson’s | • Organisation of social activities and events at the national level and at the local level  
• Production of guidelines and information about the most effective ways of organising social activities and events |
| To develop a long-term plan for the optimal management of people with Parkinson’s | • Development of plan in conjunction with Dublin Neurological Institute, the HSE and other relevant institutes and agencies  
• Development of regional centres of excellence which provide access to services of relevance to people with Parkinson’s  
• Establishment of best practice treatment in line with current international treatment guidelines  
• Monitoring of treatment of patients via a treatment cohort (to provide information on management of patients receiving multiple therapies that is not currently available from clinical trials) |
Strategic Objective No. 2

To develop appropriate organisational structures and decision making structures for the PAI

<table>
<thead>
<tr>
<th>STRATEGIC GOALS</th>
<th>ACTIONS</th>
</tr>
</thead>
</table>
| To strengthen organisational structures within the PAI |  • Review, amend and update existing Memorandum and Articles of Association  
  • Make necessary changes to Memorandum and Articles of Association  
  • Streamline committee structures within the PAI so as to establish strong operational Board of Directors and an advisory National Council  
  • Recruit people onto the Board of the PAI with a view to developing an 8-10-person Board of Directors  
  • Clarify the roles of PALS within the overall PAI structure |
| To build up branch structures within the PAI       |  • Develop recruitment drive for new people to join branches of the PAI  
  • Increase the number of branches so as to ensure national coverage for PAI branches within Republic of Ireland  
  • Organise training and education courses for branch leaders  
  • Clarify relationship, expectations and responsibilities between national office and local branches (perhaps through Memorandum of Understanding between national office and local branches)  
  • Employ two Regional Support Workers to work specifically on building up the capacity of existing branches within the PAI and on setting up new branches of the PAI |
| To increase staffing levels within the PAI         |  • Employment of two Regional Support Workers to support development of branches across Republic of Ireland  
  • Employment of Information and Media Worker to provide information for people with Parkinson’s, for carers, for professionals working with people with Parkinson’s and for the media  
  • Employment of Policy Development Worker to carry out research, and to develop policies and recommendations to be submitted to statutory agencies and political parties  
  • Consider possibility of hiring a Welfare Officer to facilitate access to existing benefits and services for people with Parkinson’s and their carers  
  • Employment of fundraiser |
### Strategic Objective No. 3
To increase public awareness and understanding of Parkinson’s and of the work and activities of the PAI

<table>
<thead>
<tr>
<th>STRATEGIC GOALS</th>
<th>ACTIONS</th>
</tr>
</thead>
</table>
| To develop public awareness of Parkinson’s                                    | • Design and implement national public awareness programme in relation to Parkinson’s  
• Encourage prominent public figures with Parkinson’s to share their experiences of living with Parkinson’s                                     |
| To develop understanding of Parkinson’s amongst healthcare professionals     | • Produce booklet on Parkinson’s for health professionals  
• Ensure that there are modules on Parkinson’s Disease within training programmes provided for General Practitioners, nurses and other healthcare professionals |
| To increase understanding of the work of the PAI                              | • Production of annual reports by the PAI  
• Production of leaflets detailing the work and activities of the PAI                                                                                                                                   |

### Strategic Objective No. 4
To lobby for additional services and resources in relation to people with Parkinson’s

<table>
<thead>
<tr>
<th>STRATEGIC GOALS</th>
<th>ACTIONS</th>
</tr>
</thead>
</table>
| To secure employment of more neurologists and Parkinson’s Disease Nurse Specialists | • Campaign for increase in the number of neurologists in the Republic of Ireland together with other relevant organisations  
• Campaign for increase in number of Parkinson’s Disease Nurse Specialists together with other relevant organisations |
| To network with other campaigning and lobbying organisations                  | • Develop and maintain involvement with Disability Federation of Ireland  
• Develop and maintain involvement in Neurological Alliance of Ireland  
• Develop and maintain involvement with European Parkinson’s Disease Association  
• Maintain involvement with World Parkinson’s Association                      |
Strategic Objective No. 5

To secure the resources which will be required to enable the PAI to provide a comprehensive range of services to people with Parkinson’s and to represent the interests of people with Parkinson’s

<table>
<thead>
<tr>
<th>STRATEGIC GOALS</th>
<th>ACTIONS</th>
</tr>
</thead>
</table>
| To significantly improve the financial situation of the PAI | • Increase income to a minimum level of €500,000 per year  
• Negotiate Service Level Agreement with HSE in order to secure minimum financial commitment of €250,000 per year  
• Raise a minimum of €250,000 per year from corporate/business contributions and from fundraising events |
| To acquire suitable premises for the PAI | • Explore possibilities of collaborating with other organisations to purchase premises or sharing services within rented/leased building  
• Secure sponsors/donors who will contribute to costs of purchasing premises/building for PAI |

Strategic Objective No. 6

To support research which will be carried out on issues relating to the needs and circumstances of people with Parkinson’s in Ireland

<table>
<thead>
<tr>
<th>STRATEGIC GOALS</th>
<th>ACTIONS</th>
</tr>
</thead>
</table>
| To initiate research projects on issues and topics which are of interest and relevance to people with Parkinson’s in Ireland (e.g. issues around the cause, care and prevention of Parkinson’s Disease, and around improving treatments for Parkinson’s Disease) | • Carry out primary person-centred research on the circumstances and needs of people with Parkinson’s in Ireland (along the lines of the 2008 study carried out by the Parkinson’s Disease Society in the United Kingdom)  
• Identify issues/topics which are considered most important by people with Parkinson’s  
• Develop research prospectuses in relation to these issues/topics  
• Secure funding for research to be carried out  
• Identify the organisations, institutes and/or agencies which have the competencies to carry out research in relation to Parkinson’s and neurological conditions |
| To contribute to research being carried out in relation to Parkinson’s and neurological issues | • Partner with other organisations in relation to research which has the potential to improve the quality of life for people with Parkinson’s  
• Facilitate and support research which requires the active participation of people with Parkinson’s  
• Support research on related neurological conditions |
“To secure the resources which will be required to enable the PAI to provide a comprehensive range of services to people with Parkinson’s...”
Section Eight

GOVERNANCE AND
MANAGEMENT OF PAI

8.1 INTRODUCTION

In order to provide a high quality and comprehensive service to people with Parkinson’s in Ireland, it is imperative that PAI has the appropriate governance and management structures in place. These structures will be essential to provide confidence and reassurance to members of PAI, to branches of PAI and to funders of PAI. Governance arrangements for PAI will need to take into account the following issues:

- Organisational structures for PAI
- Relationships between national structures and local branches
- Maximisation of talents and abilities within PAI

8.2 ORGANISATIONAL STRUCTURES FOR PAI

The organisational structures within PAI need to be revamped and streamlined. At present there is a lack of clarity about the respective roles of the Directors of PAI, of the Management Team within PAI and of the National Executive Committee within PAI. It is suggested that the main decision-making forum within PAI should be the Board of Directors who would hold Board meetings 8-10 times each year. The Board of Directors would be elected at the Annual General Meeting each year and would effectively assume the roles currently being undertaken by the PAI Management Team. A number of places (perhaps 4) would be reserved on the Board for representatives of branches. In the proposed new organisational structure, the Management Team would become obsolete (to be replaced by a strong Board of Directors).

It is also proposed that the existing National Executive Committee should become a National Council of PAI. This National Council should comprise representatives from each of the branches as well as the membership of the Board of Directors for PAI. The National Council would primarily be an advisory group. It would advise the Board and staff of PAI on issues relating to the ongoing development of PAI and would be a forum for sharing information between PAI branches. These proposals in relation to the roles of the PAI Board and PAI National Council will need to be reflected in amendments to the existing Memorandum and Articles of Association for the PAI company.

8.3 RELATIONSHIPS BETWEEN NATIONAL STRUCTURES AND LOCAL BRANCHES

There is a need for more clarity between the national structures of PAI (i.e. Board of PAI, National Council of PAI, national office of PAI) and PAI branches – there are currently 12 geographical branches of PAI and the national PALS branch which is focused on people with Parkinson’s who have been diagnosed with Parkinson’s
before the age of 55. For the future, it is proposed that branches of PAI should be geographical branches, that PAI should aim to have a presence in each region in Ireland (through the existence of branches and support groups) and that there should be an assessment of the most appropriate roles for PALS (whether as a branch or as a support group). It is suggested that PALS should carry out this assessment of its future roles, responsibilities and relationships with national structures.

There is also a need to be clearer about the relationship between the national structures and local branches and about the expectations which should be put in place in relation to the respective roles of national structures and local branches. Local branches should expect support and the development of resources and information materials from national structures (especially the national office) whilst national structures should expect some level of funding and some level of accountability (e.g. annual accounts, annual reports) from local branches.

It is suggested that the respective roles and responsibilities of national structures and local branches should be set out in Memoranda of Understanding between PAI and local branches. The national structures and local branches would be expected to abide by the contents of these Memoranda of Understanding (in relation to issues like financing of PAI, participation of branches at National Council meetings and submission of annual reports and annual accounts). If local branches do not comply with the terms set out in the Memoranda of Understanding some sanctions will need to be applied (which might ultimately result in local branches not being allowed to use the PAI identity/brand-name, logo etc.)

8.4 MAXIMISATION OF TALENT AND ABILITIES WITHIN PAI

It is evident that PAI needs to recruit more people at every level within the organisation. It needs more people to serve on its Management Team/Board, it needs people who will join sub-committees which might be set up (around issues like research, fundraising, branch development etc.), it needs people to join the local branch committees of PAI (some of these branches are very weak and are often dependent on a small number of people who at times suffer bouts of ill-health and are unable to carry out work on behalf of the branch).

PAI needs to recruit more volunteers and there is no clear reason why PAI should not be successful in recruiting more volunteers if it was to launch a comprehensive and effective volunteer recruitment campaign. This campaign could be launched in tandem with the production of the 2010-2013 Strategic Plan and hopefully with a significant improvement in the levels of public understanding about Parkinson’s and about the work and activities of PAI. Local branches also need to be supported in their development and evolution and it is anticipated that the proposed Regional Support Workers will play a significant role in supporting existing branches and in helping to set up new branches.

PAI should also link into the skills and talents of its members. At present PAI has approximately 1,100 members and there are a whole range of skills and talents within this membership base. PAI should develop a strategy to identify which skills and competencies do exist within the existing membership and to ascertain whether members with specific skills (e.g. project management skills, legal skills, financial management skills, public relations and media skills) would be willing to contribute these skills to PAI. This process might involve a skills audit or a survey of members. It is considered that the skills of existing members are not being fully utilised and that the development of a skills bank by PAI would help to identify new volunteers to support the ongoing development of PAI.
Section Nine

CONCLUSIONS

9.1 CONCLUSIONS

1. People with Parkinson’s in Ireland and their families have a variety of different needs and requirements – the ways in which Parkinson’s impacts upon people differs significantly from person to person. However, on the basis of the consultations and the research which have taken place in relation to the production of this Strategic Plan for the PAI it is evident that there are a number of needs which are common to many people with Parkinson’s in Ireland. These needs include the need for information, the needs for personalised advice and support, the need for socialisation and opportunities to meet with other people with Parkinson’s.

2. It is clear that many of these needs are currently unmet both by statutory organisations such as the HSE and voluntary organisations such as the PAI. In relation to the PAI there are significant constraints on what it is able to do on account of the shortage of resources. It is only able to employ one and a half workers to cover the whole country and this situation compares unfavourably to the United Kingdom and to Northern Ireland (where there is virtually one paid worker for each of the six counties).

3. In order for the PAI to provide a broader range of services to people with Parkinson’s it is imperative that the PAI employ more workers to provide the types of services and supports which are clearly required by people with Parkinson’s in Ireland. It is also important that the PAI recruit more volunteers to participate in the national structures and branch/local structures within the organisation. It is hoped that this Strategic Plan will enable the PAI to secure more resources (paid staff and volunteers). Without acquiring these resources the PAI will not be in a position to provide the types of services which are so urgently needed by many people living with Parkinson’s in Ireland.

Into the future

Dear Friends,

As I take up the role of CEO for the Parkinson’s Association of Ireland, I believe that, based on the blueprint of this strategic plan, we can develop services and supports that meet the needs of our members. Our annual plan will outline the effective measures that we can take, as an Association of like minded people, to deliver the necessary changes both internally in the PAI and externally with the HSE over the coming year.

We can look forward to tough challenges in the knowledge that PAI has excellent people who are both dedicated and ambitious about the services and supports required for our members. Our work will show dividends if we act together in a cohesive manner and if we apply our minds and honest efforts in a concerted manner to deliver on the promise of this plan. I look forward to these challenges, along with my colleagues on the Board of Directors, Branch Officers and the ever hardworking staff of the PAI.

Joe Lynch
Chief Executive Officer
The leaves of the aspen tree shake
Even on a still day,
But its trunk and its branches
Are strong and enduring.

The aspen leaf is our logo.