Multiple Sclerosis Society of Ireland
Annual Review 2005

To enable and empower people with MS to live the life of their choice to their fullest potential.

MSIreland

THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

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THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

letter from the chairman

It has been another exciting year for the Society with many developments in our services directly having an impact on the lives of people with MS, their families and carers. We have held two extremely successful conferences and continue to develop MS Ireland as a professional organisation.

2005 has been a period of review for the Society. We have conducted research into the needs of people with MS, undertaken a review of the Society's structures and carried out both internal and external audits of the Care Centre. The results of this research will empower the Society to develop and ensure we continue to meet the needs of the MS community.

We are now in a time of reflection. The implementation of our Strategic Plan, based on the results of our research and the international publication 'Principles to promote the Quality of Life of people with MS', will provide all stakeholders with a clear vision of the future focus of MS Ireland.

With a strong management team in place, committed staff, the support of our many volunteers and fundraisers and the goodwill of all involved, everything can be achieved.

We are aware that there is a lot to be done, but we continue to strengthen our efforts to make a real difference to the lives of people with MS.

Louise Wardell

Louise Wardell
Chairman

MS is one of the most prevalent diseases of the central nervous system and directly affects an estimated 2.5 million people worldwide. It is the most common disabling neurological disorder amongst young people but it can occur at any age. It is neither infectious nor hereditary.

Myelin, one of the fatty substances that sheathe, insulate and protect nerve fibres, aids the transmission of nerve signals throughout the body. MS attacks this myelin, disrupting the ability of the nerves to transmit signals to and from the brain. The sites where myelin is lost appear as hardened, scarred areas on the nerves. Indeed, the term multiple sclerosis literally means 'many scars'.

MS is a very variable condition and the symptoms depend on which areas of the central nervous system are affected and how severe the attack is.

There is no set pattern to MS and everyone affected by it has a different set of symptoms that vary from time to time and can change in severity and duration. In many cases MS causes gradual disability. The symptoms of MS commonly include:

- Visual disturbances including blurring of vision, double vision and (in rare cases) complete loss of sight
- Co-ordination problems including unstable walking, lack of co-ordination, vertigo and loss of balance
- Slowing of speech and slurring of words
- Loss of concentration, judgement and short term memory
- Numbness, 'pins and needles' and pain
- Unpredictable general fatigue
- Bladder and bowel dysfunction

These long-term disabling symptoms result in a high socio-economic cost to individuals, families, employers and society as a whole. People with MS, like others with a lifelong chronic illness, experience lower income levels than the general community whilst unpaid caregivers remain the culturally accepted mode of care for people with MS worldwide. The resulting loss of productive capacity and the replacement valuation of informal community care are the two largest cost components of the economic cost of MS.

We do not know why people get MS and, although researchers throughout the world are slowly getting closer to an answer, there is no known cure. We do know that women develop the disease more frequently than men, Caucasians develop MS more frequently than non-Caucasians, and people living further from the equator are more likely to develop the disease than those closer to it. At present there are only partially effective treatments and medications providing relief for the symptoms, but in many countries even these are too expensive or unavailable.

Alan Thompson
Chairman of the International Medical
and Scientific Board of MSIF

Approximately 7000 people in Ireland have MS.

MS Ireland

This year the MS Society celebrates 45 years of service to people with MS and those who share their lives. The Society has continued to grow and develop by basing its resources and services on an overriding mission and key aims.

Our Mission

> **" To enable and empower people with MS to live the life of their choice to their fullest potential"**

Our Care Centre, based in Rathgar Dublin, offers respite for people with MS

Our Aims

- to empower PwMS to control their lives and influence their environment
- to allow PwMS to live with dignity while participating in the community
- to provide support for the families and carers of PwMS
- to co-operate with the medical, scientific, social and caring professions
- to promote scientific research into the causes of MS
- to encourage the better management of MS and its symptoms
- to exchange and disseminate information on MS
- to develop an efficient, effective and caringorganisation to serve the needs of PwMS

Our Structures

- National Office
- Regional Offices
- The Care Centre
- Branches

National Office

Located at 80 Northumberland Road, Dublin 4 the National Office houses the central business functions of the Society such as Finance, Human Resources, ICT and Fundraising. Membership and the Helpline are also centred here and national conferences and conventions organised. Two conferences were held in 2005; one in Cork and one in Donegal.

Regional offices

Offer professional services to people with MS and their families. With 11 Regional Offices located nationwide and a team of 30 Community Workers, Case Worker and Administration / Resource Workers, services are localised and accessible.

Branches

40 nationwide, run by volunteers providing local support, working in tandem with the regional workers, befriending, socialising, organising physiotherapy and various programmes financed locally by local fundraising.

Care Centre

The MS Care Centre provides short-term respite care and therapy services for people with MS and other neurological conditions. The Care Centre allows the carer to take a break while the person with MS can relax and avail of services. 24 hour care staff are able to meet the various physical and emotional needs of clients.

Tánaiste and Minister for Health, Mary Harney, officially opened the National Office. Also pictured is Dr. Orla Hardiman Consultant Neurologist with Beaumont Hospital Hospital and Allen O'Connor past Chairman of the Society

6129 – **Members**

40 – **Voluntary Branches**

12 – **Respite beds**

11 – **Regional Offices**

> **"MS Ireland information Helpline is there for support and guidance"**
> **MARY McKEON – lives with MS**

Primary core service is the provision of support to people with MS, their families and carers and intervention to secure all their entitlements.

Casework

Casework is a professional one-to-service offered to individuals or families living with MS. This service is run through the regional offices and is often the first point of contact a person has with someone from the MS Society. This meeting gives the client an opportunity to discuss their concerns and ask questions. It also allows the Case Worker to assess the needs of the client and to pass on information about the condition

The most common issue presented during casework focused on the emotional side of living with MS such as counselling and personal assistance. This was closely followed by respite / accommodation and health/well-being issues.

Programmes

Health and Well-being Programmes
Give participants an opportunity to discover ways of living successfully with MS: may include yoga sessions, support groups for carers and newly diagnosed weekends. New programmes in 2005 included aqua aerobics, minding relationships, well being days, confidence building and symptom management.

Education Programmes
Concentrate on the skills of the person with MS or the awareness of a certain group about MS. Many are run for various health professionals to ensure they have the most up-to-date information on MS. Others provide information on varied topics or offer participants a chance to learn new skills.

Activity programmes
Offer an opportunity for participants to get away from their everyday lives and explore some facet of living with MS in an interactive and informal way. Residential weekends or day/overnight breaks for the newly diagnosed, carers and children are typical types of programmes. 2005 saw a significant increase in the range of activity programmes for children and young adults.

Many of the programmes run by the Society are run in conjunction with other voluntary and community agencies. Funding, facilities and facilitators are often provided by organisations with similar interests as MS Ireland. This cooperation with similar agencies and members ensures the success and development of programmes in all regions.

MS Helpline

A direct and confidential service run by a team of trained professionals who are on hand to talk, or more importantly listen to anyone concerned about or with MS. The helpline offers immediate advice and assistance and is a gateway to all other services of the Society.

Over 2000 people called the Helpline in 2005.

Welfare Grants

Local Welfare
Most assistance is provided by the branches and covers a range of needs, leading to an enhancement of the quality of life of people with MS.

National Welfare
A fund is available to assist primarily in major home adaptions, which would otherwise put a large strain on branch resources.

MS Care Centre

The Care Centre can accommodate 12 clients at any time an in 2005 over 500 people used the Centre for respite. The first of its kind in Ireland, the Centre was established to:

Enable people with Multiple Sclerosis and other disabilities to continue living in the community by providing short-term care when families and carers are temporarily unable to provide care or are in need of a break.

Prevent people with disabilities from being unnecessarily placed in long-term care in institutions and hospitals which is often the result of crisis brought on by continuous unaided care in the home.

Assist people in dealing with physical and emotional difficulties which can accompany a diagnosis of Multiple Sclerosis or any form of long term disability.

In 2005 the Centre provided care for nearly 500 people, 117 of which were new clients staying for the first time. Additional services on offer while there are occupational therapy, physiotherapy, various massages, internet café, shopping outings and entertainment.

The future:
Increasing emphasis on high dependency clients and a change of entry day to Tuesdays to facilitate a better break for carers.

Advocacy

Increased emphasis on advocacy for individuals at local level and on major issues at National level.

Disability Bill 2004
The Society focused on one particular issue: the potential exclusion of people with MS in the Bill's definition of disability. The final outcome was people with MS were included in the definition.

Neurological Services
There are only 16 neurologists in Ireland. The recommended target is 39. MS Ireland will continue and increase its lobbying for more neurologists as well as for the necessary MS Clinics throughout the country.

Individual Advocacy
Plays an important part in the acquisition of services. Housing, respite and personal security concerns were addressed through advocacy with the major issues being the pursuit of independent living and the provision of personal assistants.

Ireland: 17 Neurologists for a population of 4 Million

Northern Ireland: 30 Neurologists for a population of 1.5 Million

Over 500 people stayed in the Care Centre in 2005

research

Research falls into 2 categories:

- Medical and Scientific
- Social

Medical and Scientific Research

The Research Committee considers applications for funding and selects those with merits for external evaluation.

€72,000 was allocated to Medical and Scientific Research in 2005.

International Research
While not presently funding research at an international level directly, the Society by its association with the International Multiple Sclerosis Federation may feed funds into and is party to research carried out throughout the world.

Social Research

Two important pieces of research were commissioned in 2005.

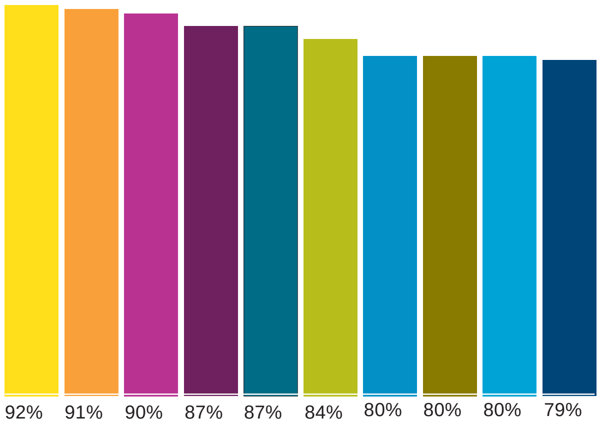
Structural Review
Carried out by Dr Gemma Donnelly Cox, the Academic Director of Centre for Non-profit Management, based in Trinity College.

This research was carried out to look at the organisational structure of MS Ireland.

Service Provision
Lansdowne Market Research conducted a survey to assess our current services and current needs of people with MS.

Most important services ranked by MS members

🟨	Information/Advice about MS	92%
🟧	Home help & personal assistance	91%
🟪	Physiotherapy	90%
🟪	Occupational therapy	87%
🟦	Respite services	87%
🟩	Welfare services	84%
🟦	Direct individual/family support	80%
🟫	MS news publication	80%
🟦	Holidays for people with MS/carers	80%
🟦	Referrals to other agencies	79%



> **“MS Ireland has been brilliant at helping the whole family to understand.”**
> **ELIZABETH – mother has MS**

international links & communications

International links

MS Ireland is a member of both the Multiple Sclerosis International Federation (MSIF) and the European Multiple Sclerosis Platform (EMSP). Ireland is represented on both organisations with Allen O'Connor sitting on the Board of IMSF and a member of its finance committee.

The new Chief Executive of the Polish Society, Goshia Poreba, visited the Society for an information-gathering week, as part of a new initiative from MSIF. The initiative links established MS organisations with developing MS organisations. Our Society has offered to assist the Polish Society develop their business and services. Specifically MSI will aid the Polish Society in seeking finance, internal organisational structures, advocacy/political awareness and also establishing a branch network.

Communications

The dissemination of information is a key service of the Society and often identified as the most important service required by people with MS.

The Society offers a whole range of publications and resources covering many areas of MS. Our selection of booklets, Information Sheets and brochures explore MS as a condition and MS Ireland as an organisation.

MS News
Issued quarterly, recently updated and modernised it provides a key communication tool.

Website
Constantly developing and improving. t is a focal point for members, health professionals and all those interested in MS .

Public Relations
MS Ireland's presence in the media greatly increased throughout 2005. Contributing on such topics as Tysabri and stem cell therapy in addition to personal stories.

The Future
The establishment of a members email database and the launch of a periodic electronic newsletter.

MSnews magazine

Website 984 visitors a day

I Get By With A Little Help From My Friends… The work of MS Ireland, in providing support and assistance for people with MS is only made possible by the valuable support and assistance from a wide range of volunteers and supporters.

Local branch fundraising

In our 40 branches throughout the country the local work of the society is supported by a wide range of Fundraisng activities such as church gate collections, raffles, sponsored cycle rides, plant sales and sporting events.

MS National Fundraising

MS READaTHON
Specsavers Opticians sponsored the annual MS READaTHON with additional support provided by Puffin Book Club, the Den, O'Brien Press. In 2005 a record 703 schools and over 33,000 young people took part raising €1.5 million.

Walks
Over 150 volunteers took up the walking challenge. Destinations included in June, the 15th Annual walk along The Camino de Santiago, in northern Spain. In September the 4th Annual walk along the Inca trail in Peru. As well as in October the real Africa walk in Tanzania visiting Mount Kilimanjaro and the incredible Ngorongoro Crater.

Mini Marathon
On a sunny June Bank Holiday there were 382 registrations for the Society in the Womens' Mini Marathon, supported by Pigsback.com.

MS Corporate Stars
At Christmas, the first Corporate Stars campaign ran in partnership with Blanchardstown Shopping Centre and 19 companies agreeing to make a donation to MS Ireland. Companies that supported the initiative included McCann Fitzgerald & Co, Sanofi-Aventis, Yamanouchi / Estellas, Michael McNamara and Co, Schering, Bristol Myers Squibb and Biogen.

MS Christmas Stars
MS Ireland Christmas Stars were sold at €2 each through local MS Ireland branches and participating businesses.

Swimathon
In May, 100 people took part in the annual Swimathon at Marion College Swimming Pool, Dublin.

Charity Shop
The Charity shop in Bray continues to provide valuable funds for the Society with support from local people visiting the shop and donating good quality goods.

At the MS READaTHON Awards for 2005: Irish rugby international Gordon D'Arcy and RTÉ presenter Laura Woods with John Jay Mooney aged eight from Drogheda and Thea Curran aged eight from Sandycove

MS READaTHON

Irelands 2nd largest charity fundraiser

fundraising

Individual Donations

The general public continues to offer ongoing support through the 40 local branches fundraising activities. In addition, individual donations were made at a national level by cheque, credit card and via our website other areas of significant support came from monthly committed gifts and individuals remembering MS Ireland in their wills.

JP McManus Fund

Greatest input attributed to an individual. Funds donated have been used towards the 'Tara' project in Limerick, which is to be the Mid-West Regional Office and drop in centre.

***MS Walks** – The Peru Group arrive at Machu Picchu*

Irish Rugby player Shane Horgan, poses with UCD med students and MS volunteers at the launch of their one day fundraising blitz in September 2005

How Can You Support?

MS Ireland continues to need your support and you can help through a wide range of ways including:

HERE'S 10 WAYS YOU CAN HELP:

- **01 Committed monthly donation**
- **02 Remembering our work in your will**
- **03 Taking part in one of our sponsored events such as a walk**
- **04 Sponsor a young person to take part in the READaTHON**
- **05 Buy and wear a Christmas Star**
- **06 Donate good quality goods to our shop**
- **07 Volunteer with one of our 40 local branches**
- **08 Buy a long life bag in a Tesco Ireland store**
- **09 Run in the Mini Marathon**
- **10 Recycle your inkjet cartridges and old mobile phones.**

NB – If you are a taxpayer and have made an annual donation of over €250, MS Ireland can reclaim the tax paid.

2006...

2006 promises to be another great year with MS Ireland being selected as Charity of the Year for Tesco Ireland with nearly 100 stores throughout the country fundraising towards the provision of a range of new services including minibuses, computers and physiotherapy sessions for people with MS.

In addition, a wide range of fundraising activities including three overseas walks, MS READaTHON, MS Stars, Womens' Mini Marathon, Golf Classic and the Swimathon will also take place.

60% of the cost of our services are funded by all our fundraising activities.

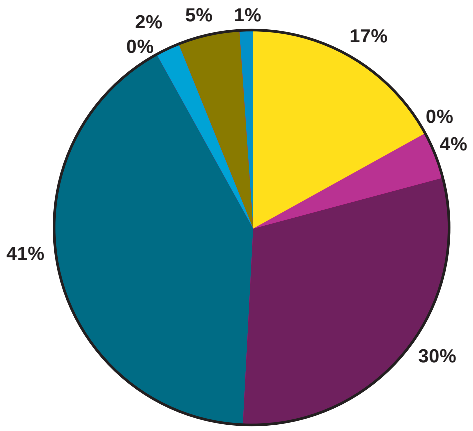
finance

Voluntary organisations are not bankers; money that comes in gets spent. However, it is important to keep the books balanced and yet again the Society has produced healthy results with a credit balance.

total income

■ Branches	1,382,781	17%
■ Research	3,108	0%
■ Donations	324,650	4%
■ Fundraising	2,415,949	30%
■ Grants	3,287,619	41%
■ Interest	5,240	0%
■ Other	192,494	2%
■ Residents Fees	398,719	5%
■ Trading	66,152	1%

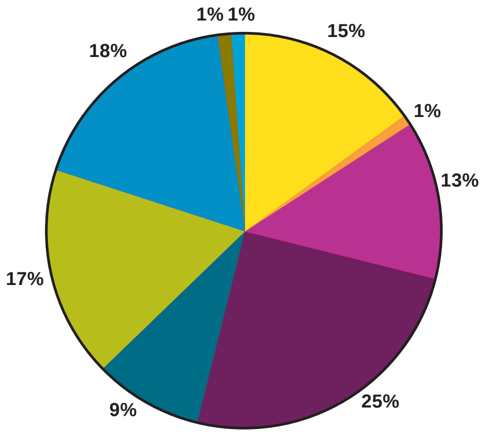
Total Income
€8,076,712



expenditure

■ Branches	1,232,019	15%
■ Research	57,041	1%
■ Fundraising	1,040,844	13%
■ Services to Members	1,996,228	25%
■ CEP Schemes	721,745	9%
■ Administration	1,398,786	17%
■ Residents Care Centre	1,450,071	18%
■ Trading	53,483	1%
■ Other	104,675	1%

Total Expenditure
€8,054,892



future

Continuing to meet the needs of the MS Community. Broadly our main objectives going forward are:

- The approval and the implementation of a new **strategic plan**, 2007 – 2010
- Lobbying for more **neurologists** and dedicated MS clinics throughout the country.
- Endeavouring to ensure that all present and future **drug treatments** for MS will be funded, as they already are by the State.
- Providing more support for **carers**. It is envisaged that daycare, more short term respite and longterm care facilities specifically for PwMS will be researched and developed over a period of time.

More specifically, it is envisaged that:

- The **Care Centre** will focus on higher dependency people with MS, and that everyone staying will benefit from the existing and new practices and procedures put on place.
- At a regional level, that there will be a re-focussing **on core services** leading to a uniformity and regularisation of services throughout the country, whilst maintaining elective services which allow for particular expertise at local level.
- We will continue to rely on **branches** for all important befriending, welfare, fundraising and awareness

The Board of the Society could not function without the support of the **staff at National Office** providing the back-up and co-ordination for all its services.

These services will continue to be streamlined and regularly assessed, to provide the most professional service possible. Senior management has acquired a boost with the recruitment of Olga Estridge as dedicated Services Manager, Aoife Kelly as HR Manager and the more recent appointment of Paul Collins as Fundraising Manager. The finance department functions extremely well under the control of Paul Flood.

When the team is fully in place with the appointment of a new Chief Executive, the Society will be well positioned for the future and well capable of implementing the policies and plans of the Board.

Without our thousands of fundraisers and supports MS Ireland would not be able to deliver services to the MS Community

> **"Not only does MS Ireland help my wife live with her MS, they also support the whole family"**
>
> **MARTIN TREACY – wife has MS**

board members & supporters

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Allen O'Connor

Board members:
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Ms. Louise Wardell
Deputy Chair:
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Mr Paul Flood
Mr Allen O'Connor
Mr. Paddy Power
Ms. Louise Wardell

Senior Management Team:
Acting Chief Executive:
Mr. Paul Flood
Financial Controller:
Mr. Paul Flood
Services Manager:
Ms. Olga Estridge
Human Resource Manager:
Ms. Aoife Kelly
Fundraising Manager:
Mr. Paul Collins

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Specsavers Opticans
Sunday Business Post
Supercare 2000 Ltd
The Access Directory
The Den
TML Mobility Solutions
Virgin Megastores
Woodside Engineering/Cable Plan
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Cork North West
Donegal
Dublin North
Dublin South
Dublin West
Dungarvan/Sth Tipp
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Galway
Kerry North
Kerry South
Kildare
Kilkenny
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Meath
Monaghan
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