

Annual Report 2007





### **Mission Statement**

'To enable and empower people affected by Multiple Sclerosis to live the life of their choice to their fullest potential'.

#### Aims

- to empower people with MS to control their lives and influence their environment
- to allow people with MS to live with dignity while participating in the community
- to provide support for the families and carers of people with MS
- 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 caring organisation to serve the needs of people with MS

### Services

The Society provides a wide range of services and programmes designed specifically to meet the needs of the MS community and to ensure that the fundamental objectives of the Society are achieved. Our key services are:

- 10 professionally-staffed Regional Offices
- Living with MS programmes, activities and workshops
- Confidential helpline 1850 233 233
- Respite Care Centre
- 41 voluntary branches nationwide
- Professional counselling
- Advocacy and lobbying
- Publications and fact sheets
- MS News magazine and e-newsletter
- Website www.ms-society.ie
- Information and research
- National conferences

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## **Chairman's letter**

In this review of the organisation's activities in 2007, you will see the further development of the Society under the leadership of our Chief Executive, Anne Winslow.

Your Board finalised its strategic plan to take the Society to 2012. It is an ambitious undertaking, but realisable if all strands of the organisation work together towards its implementation. Many of the items are already being addressed. The principal activity which required the most attention in the year was the setting up of the 'Getting the Balance Right' programme. This exercise-based, health promotion and research programme for people with MS is the first such national undertaking by the Society. It has been made possible by Tesco Ireland Charity of the Year programme funding, with the



support of a grant from the Dormant Accounts Fund and backing from the HSE. There has been in-depth preparation to ensure that an efficient, equitable service will be provided. I will trespass for one moment into the territory of 2008, as I would like to share with you the fact that, as we go to print, there have been over 1,500 expressions of interest made to the Society in response to our call – a strong confirmation of the need for such a service.

Work on the accreditation of the Care Centre got under way. Thanks to much-needed funding, refurbishment of some areas was undertaken, among which was the redecoration of the dining-room, which now looks very swish indeed.

The management structure was tightened, with clear lines of authority put in place to enable a more efficient service.

The Society was represented at all European and International MS meetings, having input at some, with benefits accruing to us.

Thank you for your support throughout the year; we could not have achieved so much without you.

Yours sincerely,

This Warel

Louise Wardell Chairman



Multiple Sclerosis is a progressive, neurological disease of the Central Nervous System where the myelin surrounding the nerves becomes damaged and distorts the flow of messages.

## **Chief Executive's letter**

In 2007 we showed leadership on many fronts:

Our MSLiving Convention in the RDS, Dublin attended by 1,200 people, was the largest gathering of people affected by MS in Ireland. The event addressed people's expressed need and interest in being enabled to access information, support, and up-to-date research on managing the condition and coping strategies for living with MS.

As the voice of people affected by MS, our concern about existing services not meeting needs was exacerbated when the HSE pulled back on resource commitments and introduced budget constraints in frontline services in September.



Our 2007 campaign on areas for development of services also became one of advocating for the retention of existing services. The campaign included making representations directly to the HSE, meeting the ministers and officials and creating public awareness in the media, including participating on RTE's Prime Time.

Similar to previous years, we welcomed the appointment of neurologists to Sligo, Waterford and Limerick. This is progress but remains a long way from achieving the recommended number of 39 neurologists with supporting multi-disciplinary teams.

We designed and planned for MSI's first national programme, 'Getting The Balance Right', for delivery in every county simultaneously. 'Getting the Balance Right' will give people with MS opportunities to participate in guided exercise programmes. It will promote healthy living and will provide a profile of the physical needs of people with MS. It will enable learning about the impact of exercise on people with MS at various stages of the MS process.

Our first Regional Resource Centre was opened in October.

As over the years, in 2007 many people and organisations, national and international, worked with us. I believe that this collaborative working greatly assists progress to making a difference. That, allied to persistent and clearly defined goals, actions and measurable outcomes, enables us to deliver on our plans. In 2007 we commenced work on our strategic direction for 2008–2012 with the completion of our strategic plan 'Making It Happen'.

Work on future strengthening of our organisation has begun, with appropriate structures, systems and resources to deliver on the plan coming into place. The recognition and support of the State for our work remains critical, as does the need for fundraising.

Our staff and volunteers are the face of MS Ireland, their work towards enhancing lives and providing hope to people affected by MS continues to be vital, and together we will work to fulfil our responsibilities with commitment, energy, innovation and integrity.

Finally a special thank you to people affected by MS, members, supporters, staff, volunteers, sister community organisations, the HSE and other state bodies for working with us.

Yours sincerely,

Ane Wiglow

Anne Winslow Chief Executive



MS affects each person differently. While there are 4 types of MS the presence, severity and duration of symptoms varies from person to person. However, common symptoms include fatigue, visual problems, mobility and muscle strength.

## **Regional Services**

MS Ireland has 10 Regional Offices around the country, providing professional services to the MS community. Our team of over 40 staff provides information and support to individuals, families and groups of people living with MS or working with people with MS.

In 2007 much work was done on defining the work of the regions and consolidating our core services. While there will always be services and resources particular to each region, the core services of all regions are:

#### 1. Information service

Information is provided on a number of topics including entitlements, life events and in particular MS as a condition and how it may affect the person or family.

#### 2. Casework

Regional Community Workers provide one-to-one support to the person or family living with MS. This allows the person or family to ask questions or talk about their concerns and allows the Regional Community Worker to inform, support and refer.

#### 3. Living with MS programmes, workshops and activities

A wide range of group support is available through programmes, workshops and activities covering such areas as health promotion, coping strategies, caring, personal development and support groups.

#### 4. Referrals and advocacy

Individuals and families living with MS continue to experience difficulties accessing local and community services such as housing, respite, personal assistants and neurology services, which have been further affected by HSE budget constraints. Regional Community Workers advocate on these and other issues on behalf of their clients and make referrals to other MS Ireland services, where necessary.

#### 5. Links with external services and resources

Regional Community Workers operate in close collaboration with many other local community services and organisations. Joint programmes and events, referrals to services and case conferences are a feature of collaborative regional work.

#### 6. Counselling

In order to meet the emotional and psychological challenges often experienced by people with MS, a confidential counselling service is available for the person or family members. The Regional Community Workers are responsible for referring people to the service and are sometimes called upon by the counsellors to follow up on certain issues arising from the counselling.

## National statistics 2007

Number of people in contact with regional offices	4143
Number of newly diagnosed first contacts	210
Number of non-newly diagnosed first contacts	239
Number of counselling sessions conducted	401

## North West Regional Office – covering Donegal, Sligo and Leitrim

#### Services and activities included:

- Residential breaks for carers, newly diagnosed and couples, run in conjunction with the TACTICS project, a cross-border initiative run with the support of MS Society Northern Ireland and Co-operation Ireland, funded by the Peace III programme.
- New courses, such as computer classes and a yoga programme, for people with MS,
- An information day in Letterkenny Hospital and a joint health professionals' day in Sligo with the Western Regional Office of MS Ireland and the Neurological Alliance of Ireland,
- MS Ireland's national conference, held in Bundoran in November, with over 250 people in attendance,
- MS Ireland staff were supported by Community Employment Participants (FÁS) who provided a befriending and support service to clients.

### Western Regional Office – covering Galway, Mayo and Roscommon

### Services and activities included:

- 'Soulfeast' a residential weekend exploring ways to live a balanced, healthy and fulfilled lifestyle,
- A young person's support programme and self-care programme for carers,
- 'Photovoyage', a photo-based counselling tool, was run for the first time,
- A joint health professionals' day in Sligo with the North West Regional Office of MS Ireland and the Neurological Alliance of Ireland,
- MS Ireland staff were supported by CEP (FÁS) participants who provided a befriending and support services to clients.

### Southern Regional Office – covering Cork and Kerry

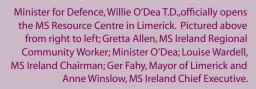
### Services and activities included:

- A well-being weekend and fatigue/symptom management programmes,
- A 'newly diagnosed' day, computer classes and a number of support groups,
- A new yoga programme was established in 2007,
- A number of educational sessions among students in nursing, physiotherapy, occupational therapy and speech and language therapy.

## South East Regional Office – covering Wexford, Waterford, Carlow, Kilkenny and South Tipperary

### Services and activities included:

- A number of land and water-based exercise programmes,
- Two family days out,
- A new well-being and MS Support programme was run in a number of locations in the South East,
- A nine-week professional advice and information course was run for health professionals,
- A number of information days and presentations were run for a variety of professionals and officials.





### Mid-West Regional Office – covering Limerick, Clare and North Tipperary

#### Services and activities included:

- The launch of the Tara Resource Centre by Minister of Defence Willie O'Dea TD. The centre is a services hub for the MS community in the Mid-West offering support and therapy sessions for people and families living with MS. The centre is also a base for the community work team. The centre was financially supported the JP McManus Trust,
- A new stress management programme and a 'newly diagnosed' seminar,
- Computer training, peer counselling, chiropody,
- A Motomed machine for exercise and health promotion.

### Midlands Regional Office – covering Longford, Laois, Offaly and Westmeath

Services and activities included:

- A 40% increase in participation on the National Physical and Sensory Disability database,
- A number of information days,
- Concentration on casework function.

### North East Regional Office – covering Cavan, Monaghan, Meath and Louth

Services and activities included:

- Programmes for newly diagnosed, teenagers and couples,
- The continuation of the 'Optimise and Empower' physiotherapy programme,
- The Independent Advocacy Service.

### Eastern Region – South West Area – covering South West Dublin and Kildare

Services and activities included:

- Exercise programmes such as yoga, Tai Chi and physiotherapy,
- A 'newly diagnosed' information day and a new self-management programme,
- A number of educational sessions for health professionals and clients throughout the year.

### Eastern Region – East Coast Area – covering Dublin East Coast and Wicklow

Services and activities included:

- Yoga programmes, carers' information and support programme and a number of activity days for teenagers and young people,
- An information day for people newly diagnosed,
- Spring Feast a residential weekend that helped to explore ways to live a balanced, healthy and fulfilled lifestyle,
- A series of professional advice and information sessions for people with MS and family members,
- A number of educational sessions for health professionals and clients throughout the year.

### Eastern Region – Northern Area – covering North Dublin City and County

#### Services and activities included:

- Two respite and wellness weekends, with one designed for people with significant disability,
- A series of yoga and exercise classes and events/activities for teenagers and young people,
- A coffee evening for young people was introduced and a series of events and training was run for the first time for carers. This included safe lifting training, a wellness day and an information day,
- A number of educational sessions for health professionals and clients throughout the year, including a number of health professional talks.

## Priority Concerns for people with MS in 2007

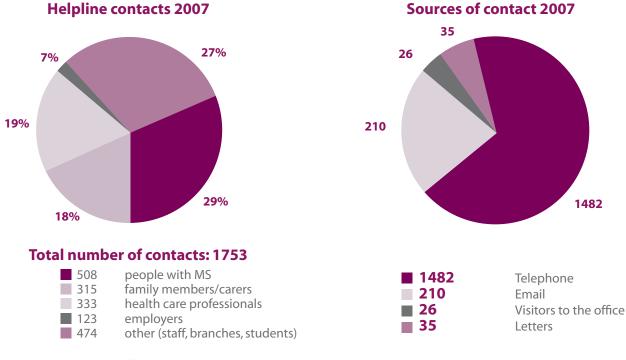
- Housing and accommodation
- Home care, personal assistants, home help
- Access to social services and entitlements
  - Neurology and associated health services

## **Helpline and Welfare**

### Helpline

The MS Helpline provides information and support on all aspects of living with the condition to people with Multiple Sclerosis, their families, friends and colleagues. The helpline is staffed by a team of trained professionals who are on hand to talk or, more importantly, listen to anyone concerned about MS.

In 2007, 1,753 people used the services of the helpline. During the year developments were made to the email services and an increase in the number of people emailing queries has grown from last year.



The helpline is a service offering both emotional support and practical information. Of the calls received in 2007, the following were the most common issues and concerns:

- **1.** MS as a condition and its treatments
- **2.** The Society's other services
- **3.** How to access and use health services
- 4. How to access social and family services
- 5. How to access transport options

#### Welfare

MS Ireland offers financial support to families who require assistance in meeting the extra costs sometimes borne by those living with a disability. In principle the state should provide assistance to these individuals and families, but this is often not sufficient. To fill this gap, MS Ireland's welfare service can help to alleviate some of the financial burdens.

#### **Branch Welfare Fund**

All branches of MS Ireland operate a welfare fund for individuals and families in the locality. In 2007, branches spent €294,112 on welfare.

#### **National Welfare Committee**

The National Welfare Committee accepts applications from clients who are unable to obtain funding from other sources (including the Branch Welfare Service) or who need money to fill the shortfall between existing funding and cost. In 2007, a total of €70,709 was allocated to 12 families across the country. Applications concentrated on bathroom and vehicle adaptations.

## The MS Care Centre

The MS Care Centre provides short-term respite care and therapy services for people living with MS and other neurological conditions. The centre allows the person with MS to relax and avail of services while the carer or family can take a break.

In 2007, 448 clients stayed in the Care Centre for one or two week visits. 60% of those that stayed had high dependency levels and required significant care, ably provided by the staff at the Centre. Themed weeks, including a young person's week and various county weeks, were a feature of 2007.

MS Ireland is committed to providing the best care and services possible to all our clients. In 2007, MS Ireland undertook an accreditation process in order to review and improve services. 'Committed to Excellence' is an accreditation programme governed by Excellence Ireland Quality Association (EIQA). With the commitment and hard work of staff and management, the Care Centre completed the programme in 2007 and was approved for accreditation in 2008. The Care Centre dining room received a makeover in 2007 when celebrity chef Kevin Dundon danced his way to the upper ranks of RTE's 'Celebrity Jigs and Reels'. Kevin, his dance partner Rachel and all those who voted, managed to raise a fantastic €16,000 for the MS Care Centre. The money was used to refurbish the Care Centre dining room. Features include a new self-service tea station, a serving counter, new accessible furniture and a slip-proof floor.





The dining room in the Care Centre received a makeover in 2007 from the funds raised through RTE's Celebrity Jigs and Reels series.

'The Care Centre is a wonderful place to stay. I get to rest, be looked after by great staff and try out therapies and services I wouldn't usually get at home. I think its also good that my husband can take a break; he really deserves it." Mary, person with MS.



## **Advocacy and Campaigning**

One of the primary concerns for MS Ireland is the adequate provision of state services, resources and entitlements for people and families living with MS. It is MS Ireland's belief that the State and its structures and organisations should sufficiently address the needs and rights of people affected by MS. Where services, resources and entitlements are unavailable or inaccessible, MS Ireland aims to highlight the deficiency.

MS Ireland represents people on two levels; individually and collectively. MS Ireland's team of Regional Community Workers assists individual clients to access services, resources and entitlements in their own locality, while the Board, the Chief Executive and her team represent at a national and international level.

2007 was another active year for MS Ireland in representing the collective needs and concerns of the MS community. Based on our eight campaign issues, many local and national representations and submissions were made throughout the year to various bodies and officials. This continuous reinforcement of our message is essential to keep the issues present in the minds of the decision makers and policy setters.

### Notable activities in 2007 include:

#### 'Quiz an Election Candidate' – General Election Campaign

Based on our eight collective issues, MS Ireland asked all members, staff and branches to quiz their local election candidates on the doorstep or to send them a letter. A pull-out section was included in MS News and a standard letter was available from the website. MS Ireland also contacted all political parties to highlight the issues. Additional media work brought the concerns of the MS community to the public.

### **European Multiple Sclerosis Platform (EMSP) Conference**

At an EMSP conference in May, figures were released comparing MS services across Europe. Ireland was ranked bottom of the list when it came to the ratio of people with MS to neurologists. MS Ireland used the conference as an opportunity to highlight their concerns for neurology services in Ireland and to call on the Government to invest heavily in nationwide services for the MS community. A significant amount of publicity was generated with a significant piece broadcast on RTE News.



MS Ireland represents the concerns of the Irish MS community at European level through the European Multiple Sclerosis Platform (EMSP). MS Ireland members took part in an EMSP conference in Prague in October 2007. From left; Allen O'Connor, June O'Connor, Austin Dempsey, Aine Smyth, Mary Lonergan and William Lonergan

The adequate provision of neurology services and associated multi-disciplinary teams is top of MS Ireland's lobbying agenda.

#### **HSE Neurology Review**

The 'Strategic Review of Neurology Services' was undertaken by the HSE to identify the current level of service provision and future requirements for neurology and neuro-physiology services in Ireland. MS Ireland contributed through the Neurological Alliance of Ireland, focusing on the role of voluntary agencies and neurorehabilitation in the community.

The report is due to be launched in the summer of 2008.

#### Other highlights include:

- Meetings with Dr Jimmy Devins, Minister of State with responsibility for Disability and Mental Health at the Department of Health and Children, to discuss our eight campaign issues and the 'Getting the Balance Right' programme.
- HSE cutbacks in the autumn of 2007 impacted on the provision of services to many people living with MS. MS Ireland highlighted the issue of care packages to the HSE and raised public awareness through RTE's Prime Time show and other media outlets.
- MS Ireland supported the UN Convention For People With Disabilities, which aims 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and 'To promote, protect and ensure respect for their inherent dignity.' Ireland signed up to the convention in March but Irish legislation will need to be passed for the Convention to become binding in Ireland.

### **Campaign Issues in 2007**

For the last two years, MS Ireland has worked on a number of collective issues it feels that if addressed adequately would yield the greatest impact for families living with MS. In 2007, MS Ireland continued to campaign on these issues.

Multiple Sclerosis Ireland Calls on the Government to:

Invest in services and supports for people with Multiple Sclerosis and their families and carers by providing additional resources to address the lack of adequate, timely services for people with Multiple Sclerosis. Progress must be made to deliver critical and essential services.

#### Specifically MS Ireland is seeking:

An increase in the number of neurologists and associated multi-disciplinary teams to be brought to the minimum recommended EU level of 39, within a three year timeframe commencing in 2007;

The provision of the required staff and facilities for the delivery of approved treatments on an equitable basis throughout the country;

The introduction of a Cost of Disability payment of €40 per week for all people with MS;

A significant increase in the Disabled Person's Housing Grant and to ensure equity of access to grants throughout the country;

The issuing of a medical card to every person diagnosed with MS;

The assurance that the necessary physiotherapy services are made available to people with MS on an equitable basis throughout the country;

A review of the current criteria for drivers' tax concessions, so that anyone diagnosed with Multiple Sclerosis automatically becomes eligible for these rebates; and

Additional personal assistants who can enable people with MS and their families to participate in the community.

## **Branches and Membership**

### Membership

The membership of the Society at the end of 2007 stood at 5633, an increase from the previous year. MS Ireland continues to encourage people with MS, their families, health professionals and supporters to join the Society.

#### **Benefits of membership**

	Access to services, information and resources
•	Support from professional staff and voluntary Branches
•	Influence the government through lobbying and campaigning
•	Vote on the aims and priorities for MS Ireland
•	Receive complimentary copies of MS News
•	Sense of ownership

### **Branch network**

Many of our members are linked to the Branch network as volunteers. The Branch network is one of the most vibrant and important sections of the Society, offering services, interaction and financial assistance to members in their local communities.

In 2007, 41 Branches operated in every county throughout Ireland. Over €1,714,928 was raised by the Branches, with the majority of this spent on financial assistance, social events and support/exercise groups directly benefiting families affected by MS.



## **Branch Highlights 2007 Include:**

### **Cork City Branch 40th Anniversary**

In September 2007, the Cork City Branch celebrated 40 years of caring and supporting the local community. A gala dinner was held for members, volunteers, fundraisers and friends of the Branch.

#### **Limerick Supports Carers**

The Carers' Support group in the Limerick Branch further developed, offering practical advice and emotional support to members. The group is run by members for members.

As part of Cork City's 40th Anniversary, the Branch hosted the 2007 National Conference. The weekend was held in the Silver Springs Moran hotel in March. Pictured at the event were MS Ireland Chief Executive Anne Winslow; Dr Amanda Stroud, Consultant Neuropsychologist at Leeds Training Hospital, UK; and Dr John Buckley, Consultant Radiologist at Cork University Hospital. Both doctors presented at the conference.



The Donegal Branch fundraised heavily in 2007, building and maintaining contacts with the local business community. This resulted in some good local media publicity.



Members of the Kildare Branch receive a cheque from proceeds of book co-authored by member Byran Sammon.

#### **Kildare's Literary Present**

'Clane: The Village We Knew' was written by Kildare Branch member Bryan Sammon and local history enthusiasts Paddy Behan and Liam Burke. Proceeds of over €10,000 were donated to the Kildare Branch.

#### **Leitrim's Minibus**

After an extensive fundraising campaign the Leitrim Branch launched its new minibus in June. It is used to bring members to and from appointments and social events.

#### **Exercise and Support in Meath**

The Meath Branch supports direct therapy and home help hours for members in their own home. The Branch continues to provide funds for a physiotherapist based in the Trim Resource Centre.

#### Donegal's active fundraising plan

The Donegal Branch had a most active year in raising funds to support their services. Many local business and individuals donated money to the Branch. Funding and publicity improved as a result.



## **Information and Communication**

The Communications Department of MS Ireland is charged with overseeing the information capacity and media relations of MS Ireland. It does this through a number of established communications tools and resources and helps to inform people with MS, their families, health professionals, staff and supporters.

### **Communications highlights in 2007:**

- Two editions of MS News, our 44 page glossy magazine, circulated to 5000 people
- Eight editions of eNews, our electronic newsletter, transmitted to 1000 people
- Launch of internal intranet and Info Bulletin to improve staff communication
- Our website continued to keep visitors up-to-date with developments in MS and MS Ireland with an average of 1,110 people visiting every day

## **MSLiving: A National Convention for People Affected by MS**

Multiple Sclerosis Ireland was delighted to host the biggest and most successful information sharing event ever held in Ireland for people with MS. Just under 1,200 people attended the RDS, Dublin 4 on Saturday 5th May. The day was a fabulous success and feedback proved it was a thoroughly beneficial day for people living with MS.

## **Exhibition and Venue**

There were 62 stands showcasing products and services for people and families living with MS. These included:

- Mobility companies, medical equipment, travel/leisure and services/resources from sister organisations
- Pharmaceutical companies
- 'Meet the Scientists' stand where people could talk to some of the researchers and scientists who are currently involved in MS research
- 'Therapy Taster' area where people could try out therapies such as reflexology, meditation, massage and reiki
- 'Action Zones' where people were encouraged to take part in MS Ireland activities. Zones included:
  - o Becoming a member
  - o Becoming a spokesperson
  - o Involvement in our general election campaign 'Quiz An Election Candidate'
  - o Log onto the website
  - o Get involved in fundraising activities
- MS Ireland services and resources



Above, 62 individuals stands showcased products and services such as mobility solutions. Right, author and presenter Kevin Myers hosted the big debate in the afternoon were professionals and families living with MS discussed a variety of topics.





The morning presentations were delivered by UK Professors, specialists in their field. Pictured from left, Dr Stanley Hawkins, Consultant Neurologist, in the Royal Victoria Hospital, Belfast. Dr Hawkins is an MS Ireland Board member and chaired the morning session; Professor Alistair Compston, Consultant Neurologist at Cardiff University and University of Wales; Anne Winslow, CE of MS Ireland; Professor Neil Scolding, Director of the Institute of Neurosciences at Frenchay Hospital and Bristol University.

## **Talks and Debate**

There were three sessions during the day – two presentations and an afternoon debate.

The first talk of the day was by Professor Compston, Consultant Neurologist at Cardiff University and University of Wales. His talk 'Genetics: Why Me?' looked at the genetic factors relating to MS. Professor Scolding, Director of the Institute of Neurosciences at Frenchay Hospital and Bristol University, was the second speaker of the day. His talk looked at the role of stem cells in the treatment of MS.

The afternoon debate, hosted by journalist Kevin Myers, looked at the various issues affecting people with MS and allowed health professionals and those living with MS to share experiences and opinions. The five topics covered were quality of life; emotional impact of MS; treatments; carers; and services available. The panellists were Nancy Law, Vice president of Client Services, National MS Society USA; John Golding, Vice President, EMSP; Prof. Michael Hutchinson, Consultant Neurologist, St. Vincent's Hospital Dublin; James O'Grady, HSE National Disability Manager; and Anne Winslow, CE of MS Ireland.

Extensive audio-visual equipment ensured all attendees were able to hear and see the talks as they happened. Copies of all the talks are available on CD and DVD from the National Office. Full set costs €15.)

Celebrity Chef and 'Jigs and Reels' contestant Kevin Dundon, his dance partner Rachel and her dance troupe entertained delegates with their Irish dancing skills.

## **Gala Awards Dinner**

The convention culminated in a Gala Dinner in the Berkeley Court Hotel. At the dinner, MS Ireland presented its annual awards to Breda O'Gorman, MS Carer of the Year; Michael Classon, MS Volunteer of the Year; and Michael Crowley, MS Person of the Year. The Annual Awards are an opportunity for MS Ireland to acknowledge the courage and contribution people make in the lives of their families, communities and MS Ireland.



The Chief Executive of the Multiple Sclerosis International Federation (MSIF), Peer Baneke, presented the annual awards. Left, Michael Classon receives his award for Volunteer of the Year; Centre, Breda O'Gorman receives her award for Carers of the Year; Right, Michael Crowley receives his award for MS Person of the Year.

Research is an important component of the work of MS Ireland. Finding a cure for MS is the ultimate goal for researchers but this can only be achieved with more understanding of MS as a complex neurological condition. Although medical and scientific research is the mainstay, social research plays a significant role in understanding the quality of life implications MS has on a person, family, community and society.

In 2007 MS Ireland funded a number of research projects, the most significant of which is the research element of the 'Getting the Balance Right' programme, an exercise-based, health promotion research programme for people with MS. This project is supported by funds raised through Tesco Ireland Charity of the Year campaign and the Dormant Accounts Fund.

### **Research Funded 2007**

Project name:	'Getting the Balance Right' programme. This research aims to profile the physiotherapy needs of people with MS and ascertain the benefits of a variety of interventions.	Project name:	Treatment of demyelinating disease by transient gene therapy using cytokine expressing Semliki Forest virus vectors.
Researchers:	MS Ireland and Physiotherapy Department of the University of Limerick	Researchers:	Prof. G. Atkins and Prof. B. Sheehan, Trinity College and UCD
Project name:	Further studies on the molecular and cellular basis of blood-brain barrier injury in multiple sclerosis; (i) the grey matter and (ii) primary progressive MS.	Project name:	Multiple Sclerosis in Ireland: A prevalence study in Dublin, Wexford and Donegal looking at differences in clinical needs and vitamin D status.
Researchers:	Drs Kirk, McQuaid, McDonnell, Queens University Belfast	Researchers:	Drs Tubridy, Hutchinson, McKenna, Lonergan, St Vincent's Hospital, Dublin

MS Ireland improved its communications regarding research developments and findings, with more information available through the website, MS News, eNews and through the MSLiving convention, where people heard of the developments in research with two excellent talks from Dr Scolding and Dr Compston from the UK.

The Research Committee was re-established in October 2007 and is charged with evaluating incoming applications to the research fund in the coming years. As per the strategic plan, MS Ireland aims to provide funding of €100,000 per year for research.

"Finding a cure for MS is the ultimate goal but developing other drugs and ways to help my symptoms and improve my quality of life today, is incredibly important too" Stephen, person with MS.

## **Collaboration and Partnership**

MS Ireland relies on the support of many different organisations in the provision of services to the MS community and the development of MS Ireland as an organisation. It is through these partnerships and mutual cooperation that services are provided in a way that meets the needs of clients while being financially viable and adequately resourced.

### Partnership and Support Highlight – 'Getting the Balance Right'

The most significant MS Ireland partnerships in 2007 were with Tesco Ireland, Pobal and the Physiotherapy Department of the University of Limerick. Each of these organisations played a vital part in the creation of the 'Getting the Balance Right' programme, a nation-wide exercise-based, health promotion and research programme for people with Multiple Sclerosis.

In the spring of 2007, MS Ireland was presented with a cheque for €1Million from the proceeds of the 2006 Tesco Ireland Charity of the Year campaign. An application for matching funding was made to the Dormant Accounts Fund, administered by Pobal. In late spring, MS Ireland succeeded with its application and plans got underway to devise a comprehensive physiotherapy and physical therapy programme. Expert help was enlisted from the Physiotherapy Department of the University of Limerick.

The 'Getting the Balance Right' programme will be rolled out nationwide in 2008 and 2009. It is expected that over 1,500 people will take part in the programme.

The 'Getting the Balance Right' programme is first and foremost an opportunity for people with MS to participate in a monitored and guided exercise programme with greater frequency. It will enable all participants to be assessed by a trained physiotherapist and allocated to an exercise/physiotherapy programme most suited to their needs.

Research is a vital component of the programme. It is an opportunity for MS Ireland to profile the physical needs of its members and learn more about the impact of exercise in a variety of settings on people with MS at the various stages of the MS process. It will both inform the MS Society in terms of service delivery in the area of physiotherapy and exercise and provide us with much needed evidence to influence government policy in relation to the direction and development of exercise-based therapeutic interventions for people with MS.



The fundraising partnership between MS Ireland and Tesco Ireland culminated in the official cheque presentation, which took place in the Conrad Hotel in Dublin on 28 February. From left: Paul Collins, Fundraising Manager, MS Ireland, Patricia Harte, **Corporate Responsibility** Manager, Tesco Ireland; Tony Keohane, Chief Executive, Tesco Ireland; Anne Winslow, Chief Executive, MS Ireland; and Louise Cahill, Corporate Responsibility Executive, Tesco Ireland.



The Tesco Ireland Charity of the Year programme is the largest corporate fundraising programme in Ireland. MS Ireland was the designated charity of the year in 2006.

### NATIONAL

#### **Health Services Executive**

MS Ireland works with the HSE to ensure the provision and development of appropriate services for people and families living with MS. In 2007, in access of 40% of our funding came from the state (HSE and other state bodies) which financed some of our regional and national services.

#### Pobal

The North East region benefited from funding from Pobal with the continuation of the 'Optimise and Empower' programme, an exercise programme for people with MS in Monaghan, Meath, Cavan and Louth.

#### **Peace II Programme**

MS Ireland received funds from the programme to continue the cross-border initiative, MS TACTICS, in collaboration with MS Society Northern Ireland.

#### FÁS

MS Ireland, with the support of FÁS, employs staff via the Community Employment Schemes to supplement existing work. In 2007, five Community Employment Schemes ran in four Regional Offices and in our Care Centre.

#### **Neurological Alliance of Ireland (NAI)**

MS Ireland is a member of NAI, an umbrella body for all neurology organisations. In 2007, MS Ireland inputted into raising awareness of the lack of funding for neurology, the HSE neurology review and Brain Awareness Week 2007. Anne Winslow, MS Ireland's Chief Executive, is the Treasurer of NAI.

#### **Disability Federation of Ireland (DFI)**

DFI is an umbrella organisation for all disability agencies. MS Ireland worked with DFI on a number of issues including the service level agreements, funding, regional coordinating committees and various legislative issues. MS Ireland's Chief Executive is a Board member of DFI.

#### **INTERNATIONAL**

#### **MS Society UK**

The UK Society has assisted MS Ireland in providing information on models of service and best practice in a range of areas. At the end of 2007, the UK Society made available the content of its range of information sheets, which will be adapted to the Irish context in 2008.

#### European Multiple Sclerosis Platform (EMSP)

EMSP works with MS organisations in Europe in three key areas; lobbying and awareness, facilitating projects and providing information. MS Ireland attended and collaborated in many projects with EMSP in 2007, including the MS-ID project (a comprehensive database of Europe-wide statistics on MS currently being developed) and the promotion of the 'Code of Good Practice in Multiple Sclerosis'.

#### **Multiple Sclerosis International Federation (MSIF)**

The Multiple Sclerosis International Federation (MSIF) is an international body linking the activities of national MS societies around the world. In 2007, MS Ireland was active in the activities and developments of MSIF, including a presentation at the Prague conference, work on the World Atlas of MS, promotion of MSIF's 'Principle to Promote the Quality of Life for People with MS' and inputting into MSIF's strategy for the next few years.

MS Ireland works with a variety of different organisations and agencies in the provision of services and resources at a regional, national and international level.

#### The services and resources of MS Ireland are supported by staff working in the business side of the organisation.

#### Human Resources

The HR Department of MS Ireland is responsible for all staff-related issues such as recruitment, training, entitlements, performance management and employee relations.

In 2007 the primary focus of the HR Department was:

- The introduction and restructuring of key positions within the regions, including the posts of responsibility (Regional Coordinators) and the National Coordinator for the 'Getting the Balance Right' programme.
- The development of policies and procedures which provide clear and concise guidance to employees on a range of employment related issues e.g. bullying and harassment.
- A number of training opportunities were provided including helpline skills training for regional administration and resource workers and helpline staff. An educational grant was made available to staff to part-fund various qualifications.

#### Information Communication Technology

The ICT systems of the Society support the work of MS Ireland through the configuration of a number of servers, networks and systems. This allows the work of MS Ireland to be more accurate and efficient.

In 2007, the National Office, the Care Centre and all Regional Offices were, for the first time, working off one integrated, secure system. This allowed the synchronisation of applications and resources, granted access to staff from any location and generally improved the security, speed and reliability of systems and the information stored on them.

#### Finance

The Finance Department supports all other departments and services by providing accurate and efficient financial information. The department is responsible for the day-to-day accounts as well as the publication of reports and statements as required by departments, managers, the Chief Executive and the Board.

In 2007 the Finance Department initiated a protocol overview, based on the advice of Deloitte and Touche, the Society's auditors. These protocols addressed issues such as fundraising, credit limits, staff signatories, sign-off limits and purchasing procedures.

Ahead of the introduction of the Charities Act, a number of policy and practical changes were implemented to fundraising arrangements of branches. This was coordinated by the Finance Department.

#### Administration

The administrative function of the Society is far-reaching and supports a number of projects, departments and people.

In 2007, administrative support centred on:

- Secretarial support to the senior management team
- Organisation of the AGM and associated elements
- Support to the Convention Team 2007
- Information to staff and allied organisations

## Fundraising

The work of MS Ireland, in providing support and assistance for people with Multiple Sclerosis, is only made possible by the valuable support and assistance from a wide range of supporters and fundraisers. In 2007 approximately 55% of our income came from our range of fundraising activities, events and charity shop.

### Fundraising Highlight – Celebrity Jigs and Reels

Celebrity Chef Kevin Dundon danced for MS Ireland in RTE's Celebrity Jigs and Reels. Making it down to the last four, Kevin and his professional dance partner Rachel O'Regan not only raised a great deal of money for MS Ireland but they also raised the profile of the Society and its work in the community.

Celebrity Chef Kevin Dundon and dance partner Rachel O'Regan came along to the MSLiving convention and entertained the crowd. They are pictured here with Anne Winslow, MS Ireland Chief Executive.



### **National Campaigns - MS READaTHON**

MS READaTHON is a sponsored read carried out annually through national and secondary schools in Ireland.

In 2007:

- 33,000 children read 50,000 books and raised €1.4 million for MS Ireland
- MS READaTHON celebrated its 20th birthday
- Special supporters included authors Oisín McCann, Cecilia Ahern, presenters Laura Woods and Aidan Power and rugby star Gordon D'Arcy



MS READaTHON celebrated it's 20th birthday in March 2007. Author and friend of the MS READaTHON Cecelia Ahern came along to the party. Pictured with Cecilia are students from 2nd Class in St. Mary's NS, Donnybrook, Anne Winslow, MS Ireland Chief Executive and Cheryl Gunning, MS READaTHON Manager.

### **Christmas Stars**

MS Ireland Christmas Stars were sold at €2 each through local MS Ireland Branches and participating businesses. Volunteers also sold stars on the street and in shopping centres.

Now in its fourth year, the corporate stars campaign was the biggest success to date. €106,000 was raised by a number of companies, led by McCann Fitzgerald Solicitors. Thirty different companies each sponsored a star, which were placed on the MS Ireland Christmas Tree in the Blanchardstown Centre. Their company logo/listing also appeared in the Irish Times and Business Plus magazine.

### **MS Walks**

#### Three walks took place in 2007:

- In June, 60 people took part in our annual Camino de Santiago walk
- In September, 45 trekkers ventured on our sixth trek in Peru
- In November, 58 walkers took the inaugural trip to Nepal

Our team of Walkers raised €764,778 in 2007

### NEW CAMPAIGN – MS Care Centre Raffle

MS Ireland welcomed a new campaign to its cache of fundraisers in November – the MS Care Centre Raffle. A successful telephone campaign and distribution through MSnews and Branches which helped to bring in an astounding €122,000 in its first year.

### **Flora Mini Marathon**

An amazing 400 women and skirt-wearing men took part in the Flora Mini Marathon on the June bank holiday. Runners brought in a fantastic €143,000 for MS Ireland.

#### **MS Swim**

The annual MS Swim took place in Marian College swimming pool in March 2007. 250 swimmers raised €9,000 for MS Ireland.

### **Corporate Donations**

A wide range of companies continued to support our work through once-off

donations, planned giving and corporate events.

The pharmaceutical companies Sanofi Aventis, Serono, Bayer Schering, Biogen Idec and Elan also donated generous amounts of money in support of our community workers' meetings, our convention and other support services.

### **MS Charity Shop**

The shop in Bray, Co. Wicklow is run by a team of 25 volunteers. The shop continues to raise funds and act as point of information on MS and MS Ireland.

## **Branch Fundraising**

To fund local services, our 41 branches organise a range of events and activities. Church gate collections, sponsored walks, raffles and flag days are some of the ways branches raise their own funds. In 2007, over €1.7 million was raised by our branches.

# Individual Donations and Bequests

Private contributions through once-off donations, direct debits or legacies provide significant essential resources.

In 2007, approximately 55% of our income came from our range of fundraising activities and events. The provision of services and supports for the MS community relies heavily on this income. If you would like to donate or fundraise for MS Ireland, call us on 1850 650 950 or email fundraising@ms-society.ie







### **10 WAYS YOU CAN HELP US**

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

•	Committed monthly donation
•	Remembering our work in your will
•	Taking part in one of our sponsored events such as a walk
•	Sponsor a young person to take part in the MS READaTHON
•	Buy and wear a Christmas star
•	Donate good quality goods to our shop
٠	Volunteer with one of our 41 local branches
•	Set up payroll giving in your work
•	Run in the Mini Marathon

Become a life member

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

In 2007, MS Ireland was privileged to welcome as patron of the Society Mary McAleese, President of Ireland. President McAleese has greatly supported the disability and community sector and has always been an advocate for inclusion and equality. President McAleese opened our first Convention in 2003, where many of our members met and spoke to the president.



President of Ireland Mary McAleese with past MS Ireland Chairman Allen O'Connor at the 2003 MSUncovered convention.

## Governance

MS Ireland is the only national organisation working for people and families living with Multiple Sclerosis. It is a limited company with charitable status. It is governed by a Board of Directors which is accountable for the financial dealings and overall execution of the Society's vision. MS Ireland's structure enables it to develop as an organisation that continually meets the needs of the MS Community in a professional and accountable manner.

#### The Board

MS Ireland is governed by a Board of 17 voluntary members. These members have a wide range of experience and skills. Some have MS themselves or have family members with MS. Others have long careers in business, social services and other areas. The Board promotes the vision and aims of the Society and charges the Chief Executive to meet these aims through the various departments, services and resources of the Society. In 2007, the Board met nine times. It concluded the strategic planning process and agreed MS Ireland's strategy for 2008-2012.

#### **The Council**

MS Ireland's Council is a representative body of the voluntary branch network. It encourages communication on a range of issues and enhances cooperation between all structures of the Society. In 2007 the council met six times. All branches are entitled to be represented on the Council. Three Council members are elected to sit on the Board of Directors.

#### **Management and Staff**

The management and staff carry out the day-to-day activities of the Society through various services, departments and facilities. These are directed by the Senior Management Team, headed by the Chief Executive.

#### Senior Management Team:

Chief Executive: Financial Controller: Services Manager: Human Resource Manager: Fundraising Manager: Ms. Anne Winslow Mr. Paul Flood Ms. Olga Estridge Ms. Aoife Kelly (until October 2007) Mr. Paul Collins Just over 100 people work for MS Ireland on a permanent basis in a number of locations around Ireland.

A further 48 people work with MS Ireland in a number of Community Employment Projects. MS Ireland's work is supported by committed volunteers around the country.

### 2007/2008 Board members:

Ms Louise Wardell, Chairman Mr Oliver Durkin, Deputy Chairman Mr Joe Cahill Dr Art Cosgrove Ms Jean Croucher Ms Deirdre Dollv Dr Gemma Donnelly-Cox Mr Kevin Doyle Ms Chris Fahy **Mr Brian Farrell** Ms Maureen Feenev **Dr Stanley Hawkins** Mr Paul Hogan Ms Mary Keane Mr William Lonergan Mr Sean Murphy Mr Paddy Power

### **Board Committees**

A number of committees inform and complement the work of the Board. Each committee is made up of Board members with particular interest, experience or knowledge. A number of staff and external professionals sit on some of the committees.

- Finance and Risk Management
- Strategy, Policy and Development
- Nominating
- Medical Advisory and Research
- Remuneration

- National Welfare
- Carers
- Care Centre Advisory
- Fundraising Task Force
- Membership

	_
Athlone	Fermoy
Ballina	Galway
Ballinasloe	Kerry North
Bandon/Kinsale	Kerry South
Bray	Kildare
Carlow	Kilkenny
Cavan	Laois
Clare	Leitrim
Cork City	Limerick
Cork North West	Limerick West
Donegal	Louth
Dublin North	Longford
Dublin South	Mayo South
Dublin West	Meath
Dungarvan/South Tipp	Monaghan

Mullingar Offaly Roscommon Skibbereen/Bantry Sligo Tipperary Tralee Tuam Waterford Wexford North Wexford South

**Branches in 2007** 

## **Strategic Planning Process – Building for the Future**

One of the main areas of work for MS Ireland throughout 2007 was the development of a Strategic Plan outlining actions for 2008-2012. This was initiated by the Board and further developed with the Chief Executive and her team. Our Strategic Plan 'Making It Happen' is the culmination of research, consultation and deliberation. A comprehensive schedule of consultation and research was conducted among staff, members, allied disability/support agencies and international MS societies and umbrella organisations. It was particularly important that people and families affected by MS were consulted, as it is their direct needs that MS Ireland aims to address.

'Making It Happen' is a five year plan, beginning in 2008, and will be supported by annual business plans and resourcing strategies required for its effective rollout. The International Multiple Sclerosis Federation's publication 'Principles to Promote the Quality of Life' and the European Multiple Sclerosis Platform 'Code Of Good Practice On The Rights and Quality Of Life Of People Affected By MS' will be actively used as tools to achieve goals. Building partnerships with State and Government agencies, the disability sector, voluntary sector, community service groups and most importantly with people affected by MS, will also underpin the success of the plan.



## Goal 1 - Support and service provision

To provide appropriate quality nationwide services based on individual and family needs.

## **Goal 2 – Campaigning and advocacy**

To effect change in policy and services with respect to people affected by MS and to ensure equitable access to services and programmes throughout Ireland.

## Goal 3 – Research

To support, promote and advocate for all aspects of research beneficial to people living with MS and to disseminate research findings.

## **Goal 4 – Strengthening MS Ireland's organisational capacity**

To enable MS Ireland to be at the forefront of good organisational practice and governance and to maximise its capacity to deliver on organisational objectives and value to its stakeholders.

## **Goal 5 – Funding**

To increase levels of funding to deliver on the organisation's objectives.

To read more about the Strategic Plan you can log onto our website and download a copy or contact our National Office for a hard copy.



## The Multiple Sclerosis Society Of Ireland

Consolidated Statement Of Financial Activities For The Year Ended 31 December 2007

	Total Funds 2007 €
INCOMING RESOURCES	e
Incoming resources from generated Funds:	
Voluntary Income	
- Donations and fundraising	5,100,070
- Research	11,480
- Subscriptions	7,010
Activities for generating funds	.,
- Trading	86,333
Incoming resources from charitable activities	00,000
- Fees received	386,257
- Grants and other service contract income	3,209,345
- Government Schemes	711,692
- Other income	218,426
	,
Total incoming resources	9,730,613
RESOURCES EXPENDED	
Costs of generating funds	
Costs of generating voluntary income	
- Fundraising	1,162,373
Charitable activities	, - ,
- Community Services	3,236,505
- Respite Care Services	1,567,417
- Research	14,375
- Government Schemes	831,904
- Local MS Services	2,507,973
Other resources expended	2,007,070
- Trading	58,505
Governance costs	89,857
Total resources expended	9,468,909
Net Incoming resources	261,704
Total funds brought forward	
at 1 January 2007	7,855,812
Total funds carried forward	
at 31 December 2007	8,117,516

Total Funds 2007

All gains and losses arose from continuing activities.

The financial statements were approved by the Board of Directors on 17 May 2008 and signed on its behalf by:

**DIRECTORS** Louise Wardell Oliver Durkin

## The Multiple Sclerosis Society Of Ireland

Consolidated Balance Sheet As At 31 December 2007

	2007 €
FIXED ASSETS	
Tangible fixed assets	7,661,936
CURRENT ASSETS	
Stocks	20,245
Debtors	630,465
Investments	70,664
Cash at bank and in hand	3,032,252
	3,753,626
CREDITORS:	
(Amounts falling due within one year)	(1,153,583)
NET CURRENT ASSETS	2,600,043
TOTAL ASSETS LESS CURRENT LIABILITIES	10,261,979
CREDITORS:	
(Amounts falling due after more than one year)	(2,144,463)
NET ASSETS	8,117,516
FUNDED BY:	
Restricted funds	2,170,975
Unrestricted funds	5,946,541
FUNDS	8,117,516

The financial statements were approved by the Board of Directors on 17 May 2008 and signed on its behalf by:

**DIRECTORS** Louise Wardell Oliver Durkin

### **National Office**

80 Northumberland Road, Dublin 4		
Tel:	01 678 1600	
Fax:	01 678 1601	
Web:	www.ms-society.ie	
Email:	info@ms-society.ie	
Helpline:	1850 233 233	

## **MS Shop**

56 Main Street, Bray, Co. Wicklow Tel: 01 286 1913

## **MS Care Centre**

65 Bushy Park Road, Rathgar, Dublin 6 Tel: 01 490 6234 Fax: 01 490 6724 Email: mscare@ms-society.ie

## Regions

## Eastern Region, East Coast Area

Unit 10a, The Egan Centre, Dargle Road, Bray, Co. Wicklow Tel: 01 286 6800 Fax: 01 272 4110 Email: eca@ms-society.ie

## Eastern Region, South Western Area

65 Bushy Park Road, Rathgar, Dublin 6 Tel: 01 256 9585 Fax: 01 490 6724 Email: eca@ms-society.ie

## Eastern Region, Northern Area

65 Bushy Park Road, Rathgar, Dublin 6 Tel: 01 256 9585 Fax: 01 490 6724 Email: na@ms-society.ie

## **South Eastern Region**

Nuncio Road, off Waterford Rd, Kilkenny Tel: 056 77 51522 Fax: 056 77 71011 Email: southeast@ms-society.je

## **Southern Region – Cork**

North Quay House, Pope's Quay, Cork Tel: 021 430 0001 Fax: 021 430 0533 Email: southern@ms-society.ie

### **Southern Region – Kerry**

The Courtyard House, Fairhill, Killarney, Co. Kerry Tel: 064 30851 Fax: 064 38927 Email: siobhanl@ms-society.ie

## **Midlands Region**

Newtown Terrace, Athlone, Co Westmeath Tel: 090 647 6353 Fax: 090 647 7466 Email: midlands@ms-society.ie

## **Mid Western Region**

'Tara', St Nessan's Road, Ballykeefe, Limerick Tel: 061 335 565 Fax: 061 303 802 Email: midwest@ms-society.ie

## **North Eastern Region**

1 Church Street, Carrickmacross, Co. Monaghan Tel: 042 966 4410 Fax: 042 969 2812 Email: northeast@ms-society.ie

### **Western Region**

Roxboro House, Raleigh Road, Galway Tel: 091 862 478 Fax: 091 862 511 Email: western@ms-society.ie

## **North Western Region**

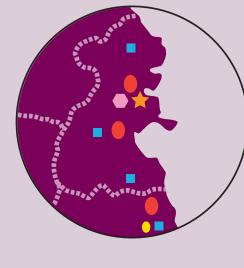
Unit 6, Rossview Business Park, Port Road, Letterkenny, Co. Donegal Tel: 074 912 5017 Fax: 074 912 3044 Email: northwest@ms-society.ie

## Legal and Administrative Information

Charity Number:	5365
Company Registration Number:	296 573
Company's Registered Office:	80 Northumberland Road, Dublin 4
Company Secretary:	Paul Flood
Company Auditors:	Deloitte and Touche
Company Bankers:	Bank of Ireland
Company Insurers:	Mullarkey Hooper Dolan

MS Regional Office MS National Office MS Voluntary Branches MS Care Centre

MS Shop



To make contact: Call: 01 678 1600 Helpline: 1850 233 233 Email: info@ms. society

Email: info@ms-society.ie Web: www.ms-society.ie

