



Annual Report 09





Mission Statement

To enable and empower people affected by MS 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 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, programmes and activities, designed specifically to meet the needs of the MS community and to ensure that the fundamental objectives of the Society are achieved.

These include:

- Individual and family support;
- Living with MS programmes, activities and workshops;
- Confidential information line, 1850 233 233;
- Respite Care Centre;
- 41 Voluntary Branches, nationwide;
- Professional counselling;
- Advocacy and lobbying;
- Publications and website www.ms-society.ie;
- MSnews magazine and e-newsletter;
- Research funding and information;
- National Conferences.

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Message from the Chairman and Chief Executive



2009 WAS ONE of the most financially difficult years MS Ireland has experienced in recent times. However, as an organisation, we have met those challenges and continued to grow and develop our services and interventions to people affected by MS.

MS Ireland operated with approximately €803,807 less income than 2009. HSE cuts and reductions in fundraised income necessitated many cost-saving measures and new and innovative approaches to the way we carry out our work. We believe our timely and creative solutions have been effective and have reduced the impact on our direct services to people affected by MS.

The voluntary Branch network has greatly supported our deficit this year by contributing from the balance of its funds at the end of 2008. This joined-up approach within the organisation, with staff and volunteers always working to achieve our objectives, is enriching at this time.

How we organise ourselves in difficult times is vital. We need to always use the best skills, resources, expertise and talents available to us. We are committed to joined-up approaches between Branch, regional and national services. The critical pathway for a person affected by MS seeking our support needs to be seamless. Our services need to always cater appropriately to the needs of the people we work for.

Our services always aim to improve the quality of life of the person and family living with MS. In 2009 we achieved this in a number of ways. Our casework service, which was reviewed this year, provides individuals and families with opportunities to explore issues concerning them in a private and supportive manner. Our range of 'Living with MS' programmes help participants explore coping mechanisms and skills to living with MS in positive and practical ways. Our voluntary Branch network continues to support people locally, and we were particularly delighted to welcome the newly extended East Wicklow Branch (formerly Bray) into the family.

The services we provide are complemented and supplemented by a range of other activities. Research is a key component in improving the health and quality of life for all people with MS. In 2009 our research programme provided funding for two projects. The results of our physiotherapy and exercise programme, Getting the Balance Right, were also announced. These projects will add to our knowledge of MS and contribute globally to the need to improve the quality of life for people with MS but also to find the cure.

Representation is a significant part of our work as we

convey the views and concerns of the MS community to a number of stakeholders. In an effort to limit the cuts imposed by the HSE we met a number of representatives to outline the needs of our clients and the importance of our work. In 2009 we also contributed significantly to the neurorehabilitation strategy and made a number of submissions in areas such as palliative care, positive ageing and home care packages.

We continue to be active at a European and international level with the European Multiple Sclerosis Platform (EMSP) and the Multiple Sclerosis International Federation (MSIF). Our involvement with both organisations in 2009 ensures that we are at the cutting edge of research, policy, governance and other developments. In 2009, we were delighted to take part in the first ever World MS Day, the brain child of MSIF.

Now is the time to develop new and innovative long-term strategies rather than just focus on short-term approaches. This involves greater collaborative work between us and the HSE and with other agencies, which have a similar vision for supporting people with progressive neurological conditions. It involves challenging the health services to adopt innovative and proven methods of working across all regions, and also to really recognise the huge resource and added value that MS Ireland and other non-governmental agencies bring to services in Ireland. At last, the time has come to realise a partnership approach.

Responding and being relevant to people affected by MS needs constant monitoring and review. In 2009, we facilitated meetings of younger people with MS just to hear what they wanted. A number of young people are, and want to become, more active in organising social and peer group events, networking on the web and speaking out to raise the profile.

We want to sincerely thank people with MS and their families, the Board of Directors, donors, fundraisers, volunteers and staff, who all give generously of their time and expertise to the Society. You are making a difference.

Anne Winslow, Chief Executive

Allen O'Connor, Chairman



Support and Service Provision

Our Support and Services Goal: To provide appropriate quality nationwide services based on individual and family needs. How we moved forward in Support and Services in 2009:

National Services

MS Care Centre

In 2009, our Centre provided just under 4,000 bed nights for people with MS and other neurological conditions.

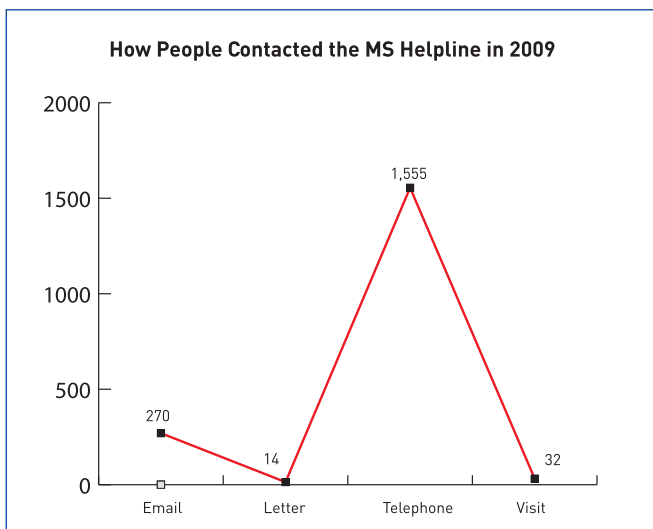
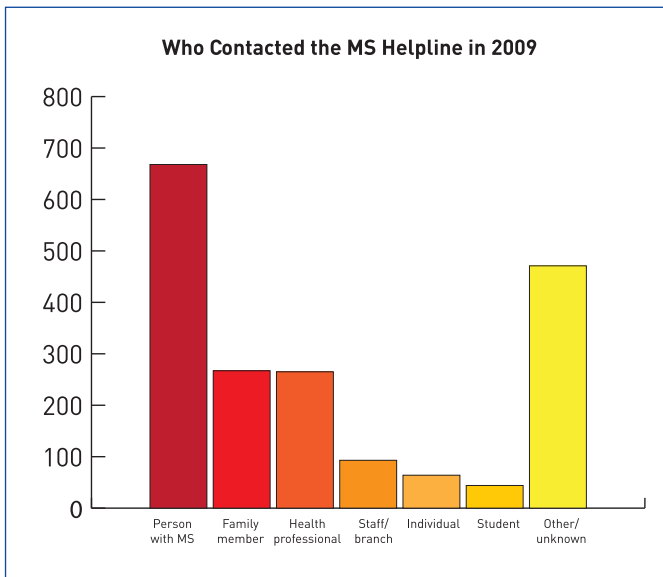
2009 Highlights:

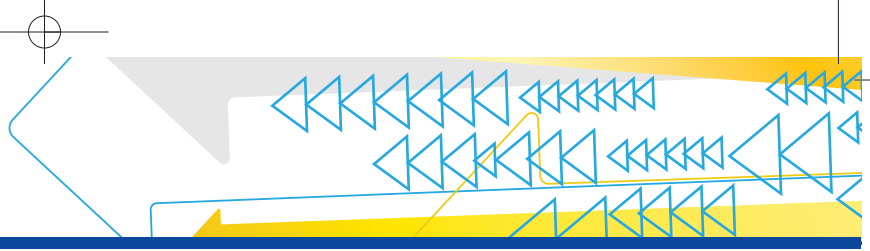
- In 2008, the Centre achieved the 'Committed to Excellence' award from the Excellence Ireland Quality Association. As a follow-on from this and to further develop quality standards to meet patient care, the Centre began work on the CHKS accreditation, an Irish and UK recognised accreditation for medical and care organisations. Work will be completed in 2010.
- The FÁS Project rolled over successfully. Due to the excellent training opportunities provided to participants, the Centre has a very high progressive rate of employment. FÁS has confirmed that the MS Community Employment Project has one of the highest progression rates in the South Dublin area.
- The Centre refined and reviewed the neurological assessment programme, which is carried out by the Clinical Nurse Specialist. Feedback for this programme has been very positive. The Centre has been in a position through this programme to review a range of issues for people with MS, which have directly affected their quality of life
- A number of care staff successfully completed FETAC Level 5 and were awarded their certificates. Modules included care skills, work practices and health and safety.
- The Centre commenced part of the planned refurbishment programme just before Christmas with painting of the bedrooms and corridors.

MS Helpline

The MS Helpline provides information and support on all aspects of living with the condition to people with MS, 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 2009, 1,872 people used the services of the helpline, 196 of which were newly diagnosed.

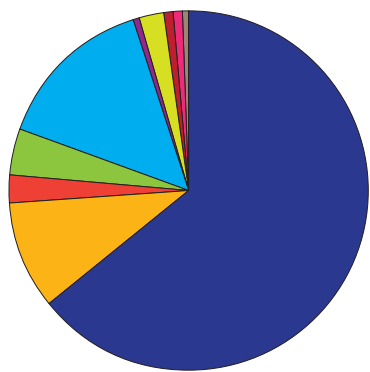




Regional Services

Our regions provide a range of services to individuals, families and healthcare professionals in their area. These services are aimed at providing support and information, assisting the person and family to learn about MS and to discover coping mechanisms to improve their quality of life. The graph below illustrates the activity level of our regional services.

Overall Regional Activity 2009



- 39,567. Telephone calls to and from the Regional office
- 5,995. Home visits to people with MS
- 1,694. New cases referred or self referred
- 2,420. Ongoing complex case work
- 8,976. Cases closed (i.e. presenting issue resolved)
- 297. Newly diagnosed referrals
- 1,419. Referrals to statutory and non-statutory agencies
- 460*. Symptom management programmes
- 608**. Getting the Balance Right (Physio and exercise)
- 210. Annual Neurological Information Days (HSE and private Allied Health Care Professionals)

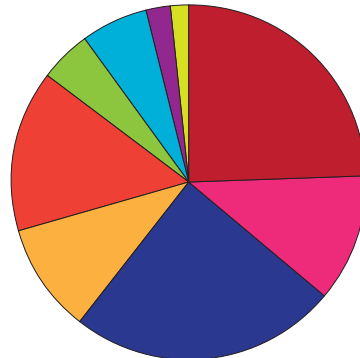
**Symptom management programmes are group-based and can have anywhere from 10 participants in an eight-week fatigue management programme up to 50 participants for a symptom management day*

***The Getting the Balance Right programme is delivered collaboratively with many HSE physiotherapy departments. Sessions are usually run in cycles of between six and 10 weeks.*

Casework

Our casework service revolves around home visits, contact with clients, issue exploration/ resolution and referrals to other agencies. This is a hugely important service to those newly diagnosed or struggling with the impact their MS is having on a part of their life. Casework allows the person or family to discuss issues and receive information, support and guidance from our trained and professional staff who work with all clients to empower them to make decisions about their life with MS. In 2009, a number of presenting issues were explored or resolved by staff, in consultation with the client.

Overall Issues Presenting 2009



- 1,710. Counselling, emotional support, personal development and bereavement
- 789. Advocacy in relation to PA, home help and health related services
- 1,703. Symptom management, complementary therapies and aids and appliance
- 686. Respite and accommodation
- 1,025. Financial and welfare entitlements
- 326. Insurance/assurance related issues
- 326. Insurance/assurance related issues
- 167. Education, training and employment
- 98. Legal/equality issues

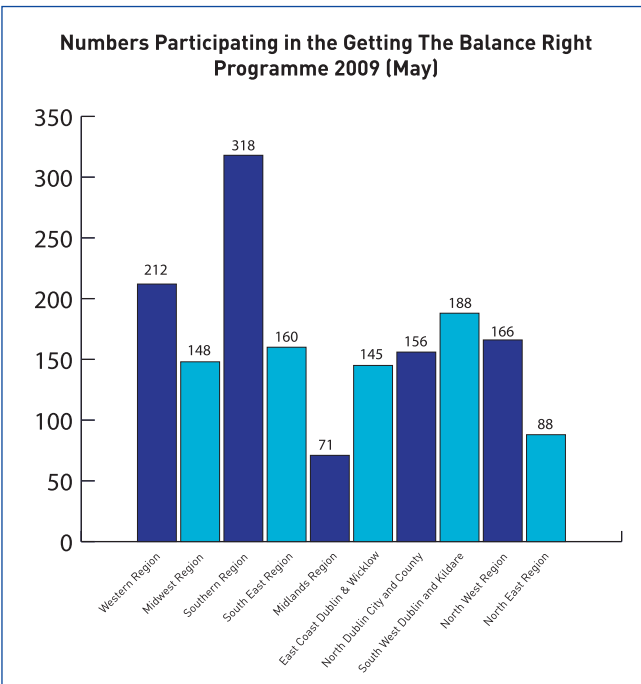
In 2009, we evaluated our casework service in line with our aim to continuously improve the services we offer. The evaluation has indicated a need to develop the casework we offer to make it more solution focused. In 2010, a development plan will be initiated.

Living with MS Programmes

Our regional services provide a wide range of group support through programmes, workshops and activities covering such areas as health promotion, coping strategies, caring, personal development and support groups. Types of programmes include newly diagnosed seminars, fatigue management, carers support groups, information mornings, yoga and symptom management.

Getting the Balance Right, our nationwide exercise, health promotion and research programme for people with MS continued to be an enormous success in 2009. The programme offered a range of opportunities for people with MS to maintain and improve a full range of motion, which may have been impacted on as a result of the MS disease process. The programme was delivered across the country in a variety of venues, with interventions ranging from physiotherapy-led group programmes, physiotherapy 1:1, yoga, gym-based programmes, hydrotherapy and tai chi.





In 2009 we launched the results of the research arm of the programme. See page 11 for details. We also published a number of resources:

- 'Everybody Stretch' and 'MS and Fitness' are two booklets aimed to help people understand and use various types of exercise and physiotherapy techniques
- Physiotherapy Toolkits were published to help Physiotherapists devise programmes specifically for people with MS.

Please visit our website to download these resources. We are continually indebted to Dr Susan Coote and her team in The Physiotherapy Department of the University of Limerick, for all their work and advice on the programme.'

Counselling

In 2009, 377 counselling sessions were conducted nationwide for people with MS and their family members. The service allows people to explore issues relating to their MS in an individual and confidential manner.

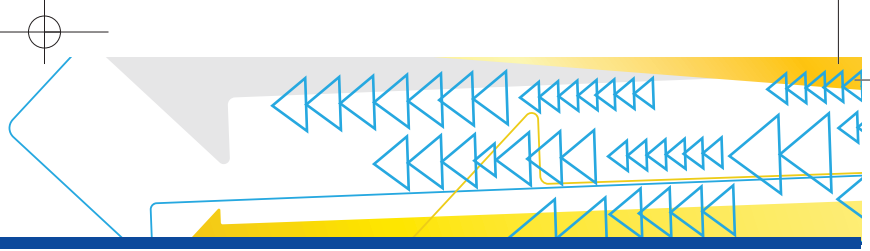


Pictured at the launch of the Getting The Balance Right results were, Olga Estridge, MS Ireland's Services Manager, Allen O' Connor, MS Ireland's Chairman, Dr. Susan Coote, University College Limerick, Minister Eamonn O'Cuiv, Minister for Community, Rural and Gaeltacht Affairs, Anne Winslow MS Ireland's Chief Executive and Aidan Larkin, MS Ireland's National programme Coordinator

Regional Highlights, 2009

Casework, living with MS programmes and counselling form the majority of our regional services. However, in 2009 a number of other services and activities took place. (See the panel for more details).

- **The South West Dublin and Kildare Region** continued the ever popular coffee morning sessions and ran a very successful 'Therapy Taster' day for people to try out various alternative and complementary therapies.
- **The Mid-West Region** ran a number of successful training and group sessions in the Tara Resource Centre, including a newly diagnosed seminar, group counselling and art, Spanish and computer classes.
- **The Southern Region** held the Cork Convention in May to tie in with World MS Day. Over 300 people attended the day, which included information stands, a seminar by Drs Sweeney and Coles and opportunities to socialise and meet people with MS. A successful Young People's Forum was also held in the year.
- **The North East Region** ran a newly diagnosed seminar in March and organised quarterly coffee morning or support groups in each county.
- **East Coast Dublin and Wicklow Region** organised a very success Wellness Day for clients and introduced them to a new programme called Brain Gym, which promotes wellness through movement.
- **North Dublin City and County Region** ran a training course around safe physical assistance for carers, and introduced a Mindfulness programme for people with MS and for carers and family members. Separate sessions allowed each group to explore common issues in a confidential and safe environment.
- **The North West Region** ran a three-day carers break and a three-day newly diagnosed break. Both explored issues relevant to those who provide care and who have been recently diagnosed with MS.
- **The South East Region** ran a successful newly diagnosed seminar and participated in a pilot scheme for the National Physical and Sensory Disability Database.
- **The Midlands Region** ran workshops on cognition and stress for both people with MS and their carers. Cognition training was also delivered to health professionals.
- **The Western Region** hosted the 2009 National Conference and distributed a Pobal grant of over €54,000 towards aids and appliances in the region.



Local Services

MS Ireland provides local services to all affected by MS through a network of 41 Branches. Run by volunteers, these Branches provide services, social opportunities, fundraising activities and a welfare system for those in need.

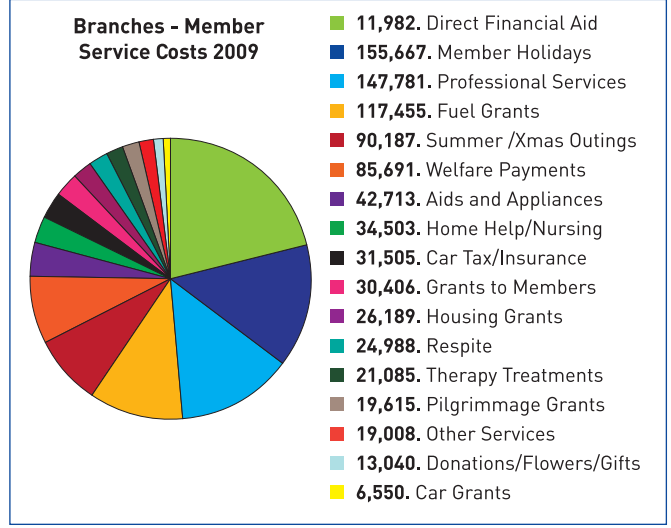
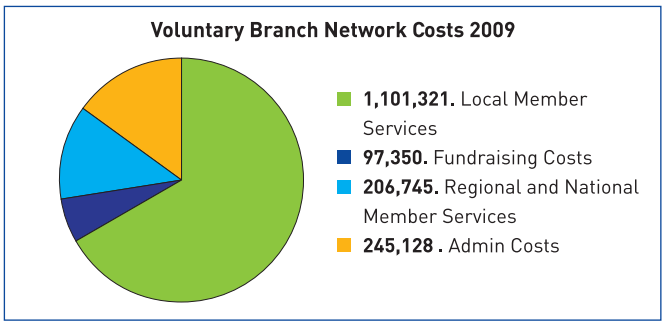
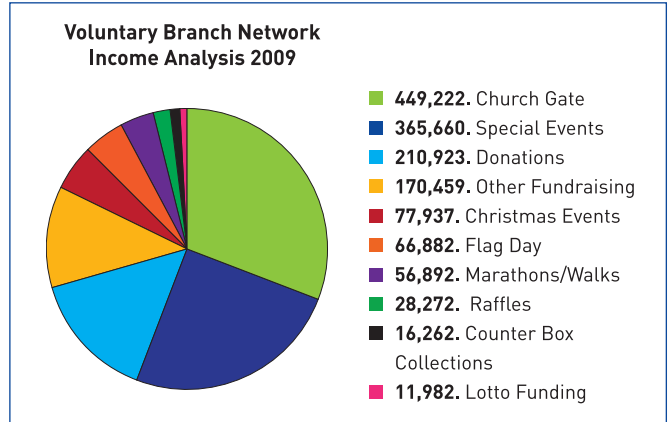
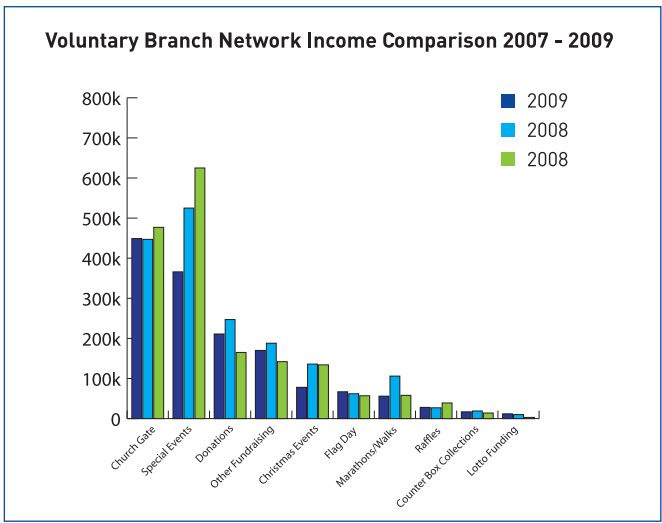
Some Branch Highlights of 2009:

- **The East Wicklow Branch** was established, taking in the Bray Branch and expanding its work into east Wicklow;
- **The Galway Branch** received funds from Paddy Rafter of The Three Tenors fame, who invited MS Ireland to be recipients of the musical debut night of his family's new music group;
- **The North Kerry Branch** received funds from the Rally of the Lakes;
- **The Tipperary Branch** received proceeds from Irish Rail on foot of the Thurles walk, which it had organised on behalf of the Branch;
- **The Monaghan Branch** received funds from a special performance of three Monaghan choirs.



See our Branch pages on the website for more details of the work and achievements of our voluntary Branch network.

Branch Income and Expenditure:





Our Campaigning and Advocacy Goal:

To effect change in policy and service with respect to people affected by MS and to ensure equitable access to services and programmes throughout Ireland. How we moved forward on Campaigning and Advocacy in 2009:

MS Ireland advocates on behalf of all people affected by MS, individually and collectively.

Individual Advocacy

Individual advocacy centres on the individual issues and concerns of the person or family living with MS. With the support of our professional staff, the person or family is assisted to address these issues. Individual advocacy is practised by our regional staff. See page xx for more information on issues presenting.

In 2009 the very successful North East Advocate programme continued as per additional funding from the Citizens Information Board. The Advocate assists people with MS (and other neurological conditions) to address issues relating to entitlements, respite, accommodation and other issues affecting the health and welfare of people with MS. In 2009, issues centred around those in residential care regarding services available, entitlements, choice and treatment/care issues.

Campaigning and Representation (Collective Advocacy)

MS Ireland collectively campaigns on issues and represents the concerns of the MS population. Our aim is to find ways to address those issues that lack adequate policy, structural or service provisions. In 2008, MS Ireland worked in a key number of areas and in consultation with a variety of agencies and organisations.

Key Representative Work

MS Ireland receives nearly 50% of its funding from the state, mainly through the HSE. The economic downturn threatens MS Ireland's ability to deliver on the services it provides to people with MS. As individuals become affected by the downturn in employment and the cuts in services and welfare payments, the services and supports MS Ireland provide become more important. To protect the funding we receive we met with a number of funding stakeholders to outline the need and importance of our services, the concerns of the MS community and to request that funding cuts do not affect our services and people affected by MS. Meetings were held with:

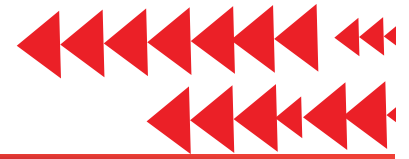
- Senators Timmy Dooley and Mark Daly
- Ms Patricia Ryan, Special Advisor to Minister Mary Harney
- Mr Ger Reaney, Interim National Care Group Lead, Disability Services for the HSE
- Mr Brian Murphy, National Director of Community Care, HSE

We also worked with our colleagues from the disability sector through our membership of the Disability Federation of Ireland (DFI) and the Neurological Alliance of Ireland (NAI).

We continue to work with the European Multiple Sclerosis Platform (EMSP) and the Multiple Sclerosis International Federation (MSIF). We represent the needs and concerns of Irish people with MS and ensures that we are at the cutting edge of research, policy, governance and other developments.

Significant Campaign Work

- MS Ireland was involved in the HSE's drafting of a **neurorehabilitation strategy**. We provided input around the needs of people with MS and other neurological conditions, the services required, the policy needed and the resources necessary to deliver appropriate and adequate neurorehabilitation in Ireland. Input was provided by person with MS, Alexis Donnelly, Getting the Balance Right National Co-ordinator, Aidan Larkin, and Chief Executive, Anne Winslow.
- MS Ireland made a submission to the HSE's **Positive Ageing Strategy**, outlining the difficulties people with MS over the age of 65 experience. Of particular concern was: access to appropriate accommodation if MS related disability becomes an issue; the provision of care for older people with MS who experience MS related disability in later years; and the costs of living with MS with reduced income, as MS often increases medical, transport and care costs.
- MS Ireland made a submission to the Irish Hospice Foundation regarding their **Forum on End of Life** in Ireland. The submission outlined the incidence of various debilitating symptoms and the need for appropriate palliative care for people with MS
- **Access to treatments** became an issue in 2009 as people



with MS were given limited access to Tysabri, a new disease modifying therapy (DMT) for those with highly active forms of MS. Unlike other DMTs, Tysabri is funded through individual hospitals, which have received no extra subvention to fund the cost of the drug. Therefore, hospitals limited the number of people receiving Tysabri. MS Ireland sat on a committee with a number of neurologists and the HSE to explore ways to fund the drug and to improve access to and use of DMTs in general.

- MS Ireland made a submission to the HSE's review of the **Home Care Package** Scheme. See the panel for more details.

Home Care Package – Submission Overview

The provision of care can be an important part of life for those living with progressed MS. Maintaining quality of life, participating in society and the health and wellbeing of the person with MS and their family carer(s) are the primary objectives of adequate, appropriate and professional care services. MS Ireland identified the following issues associated with current care provision:

- Access to homecare packages was limited and varied between community care areas;
- The co-ordination and responsibility of care services were unclear particularly if more than one agency was providing care to one person;
- The quality of care differed, both between agencies and individual carers;
- Communication between the agencies, the family and the carer could be improved to enhance any care provided.

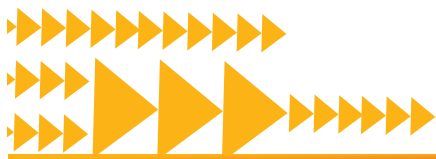
MS Ireland put forward the following recommendations to improve the provision of homecare packages:

- The National Disability Authority's document 'Person Centred Planning for People in Ireland who have Disabilities' should be adopted as a model as it places the person at the centre of their support structure;
- People with MS should be given the opportunity to purchase their own care, reducing administration costs and increasing the person and family's ability to choose the most appropriate care;
- The Home Care Support Scheme should be standardised throughout the country, addressing the model of care and taking in the training supervision and other issues relating to the provision of quality care;
- The Home Care Support Scheme can only be operated with funding that ensures the development of the scheme meets the needs of those needing care.



Dr Geoffrey Dean, RIP

In September 2009, MS Ireland was saddened to hear of the death of Dr Geoffrey Dean a world renowned researcher who had been based in Ireland for over 40 years. To honour his life and work, MS Ireland will introduce a Dean Medal in 2010 aiming to assist young researchers in developing their knowledge of MS. Dr Dean is pictured above with Dr Hugh Brady, president of UCD, at the presentation of Dr Dean's Honorary Doctorate in recognition of his commitment to MS research.



Our Research Goal:

To support, promote and advocate for all aspects of research beneficial to people living with MS and to disseminate research findings. How we moved forward in Research in 2009:

Research is a key component in improving the health and quality of life for all people with MS. Investigations to improve the understanding of the condition, translational research into how this knowledge can be useful and practical, what interventions can be beneficial and how service delivery can positively impact, are all considerations driving the research agenda.

MS Ireland's Research Programme provides opportunities for Irish researchers to contribute to MS research. Overseen by a committee of neurologists, scientists, social/policy advisors and a person with MS, projects are chosen on their scientific merit and contribution to the global research.

MS Ireland's Research Fund

The 2008/2009 programme

At the end of 2009 current recipients of funding produced their interim reports on how their projects are progressing.

PROJECT 1:

In-vitro assessment of the efficacy of the nootropic nefiracetam to enhance plasticity after experimental demyelination.

Dr Mark Pickering, Conway Institute, University College Dublin (UCD)

Difficulties with memory and cognition are problems experienced by many people with MS, and there is no specific treatment at present. It is most likely that these problems occur when the loss of myelin affects a part of the brain known as the hippocampus.

In Dr Pickering's project a tissue culture model of the hippocampus will be treated to cause a loss of myelin. The tissue will then be treated with nefiracetam, a drug previously shown to protect memory, to investigate if this alleviates the effects of demyelination.

Interim results have been very exciting with the researchers discovering an interesting piece of information. Using rat cultures, the researchers simulated demyelination using a known agent. This resulted in the loss of myelin-based proteins and the loss of molecules associated with learning

and memory. The cultures were then treated with nefiracetam, a known drug already used in other conditions to treat memory loss. This resulted in the reversal of loss in both the myelin proteins and the learning/memory molecules. While the researchers were aiming to study the effects of nefiracetam on memory, this discovery will refocus their project to study the effects of remyelination.

PROJECT 2:

Endoplasmic Reticulum as a component of neurodegeneration in MS grey matter lesions.

Dr Una Fitzgerald, National University of Ireland, Galway.

This project is examining the pathology of lesions occurring in the grey matter of people with MS i.e. lesions in the outermost layers of the brain. This area of the brain is increasingly under the spotlight as it is known that lesions develop all over the grey matter and these may be responsible for chronic neurodegeneration occurring in the later stages of MS.

Dr Fitzgerald is particularly interested in finding out if a set of molecules linked to the occurrence of a form of cellular 'stress' called 'endoplasmic reticulum stress' is occurring in these lesions. The hypothesis is that these molecules could be causing brain damage.

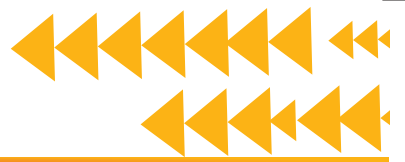
Seventeen MS tissue samples and 11 control tissue samples are being stained to show the presence of the following processes/activities:

- Grey matter lesions;
- Oxygen supply and endoplasmic reticulum stress response;
- Neuronal damage and loss.

The first two tests have been completed and the tissues have been classified according to their type of grey matter and the grade of oxygen supply and endoplasmic reticulum stress response. Work is continuing on the analysis of the neuronal damage and loss.

The 2009/2010 Programme

In our 2009 call for submissions to the research programme, eight applications were received and three were deemed appropriate for external, expert review. Based on these results



one application was selected and was successful in being awarded funding by the Board of MS Ireland.

TITLE:

Endoplasmic Reticulum as a component of neurodegeneration in MS grey matter lesions.

Research Lead: Dr Marion Butler

Institution: National University of Ireland, Maynooth

Duration: 1 year

To learn more about Dr Butler's project log onto www.ms-society.ie

Getting the Balance Right

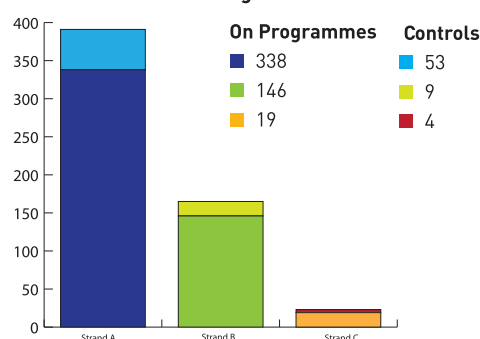
At the 2009 Annual Conference MS Ireland launched preliminary details of the research arm of our nationwide physiotherapy and exercise programme.

The Getting the Balance Right research programme was a stratified, single blind, randomised, controlled trial co-ordinated by the Physiotherapy Department of the University of Limerick. Ethical approval was obtained from 11 ethics committees nationally. All participants received an assessment by a Chartered Physiotherapist to ensure safety and suitability.

Some 503 people took part in the research element through the various physiotherapy and exercise programmes. They were grouped according to their mobility, and randomised to various programmes e.g. one-to-one physiotherapy, group physiotherapy, yoga and fitness instructor-led gym sessions. Each person was assessed before and after their normal 10 week programme and again 10 weeks after the programme finished.

Another 76 people took part in the research as controls and did not alter their usual activity. Once they finished their control period, participants were offered the physiotherapy or exercise-based programme of their choice.

Number Of People Taking Part In The Research Arm Of Getting The Balance Right'



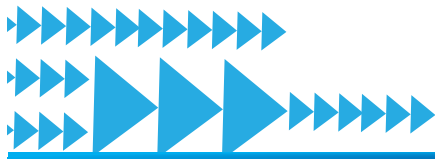
Some key findings:

- Over one fifth, 23%, of the total number of people who at most use a stick improved their level of fatigue to the extent that they moved from a clinical measurement of 'fatigued' to 'non-fatigued'. This was reported in 27% of those on physiotherapy programmes, 18% of those on yoga programmes and 23% of those on instructor-led gym programmes. (Other studies have shown that up to 93% of people with MS report fatigue as a limitation.)
- Five per cent of the controls in the group who at most use a stick experienced a relapse, while only 1% of those on physiotherapy-led programmes experienced a relapse.
- Those in the group physiotherapy programme for people who at most use a stick experienced a 19% reduction in the level of fatigue. Participants noted improvements in energy, ability to recall information and reduced time needed to complete tasks.
- Those in the physiotherapy-led programmes for people who at most use a stick experienced a 15% reduction in the psychological impact of MS. Participants noted improvements in their general attitude and happiness.
- One quarter of participants in the group physiotherapy programme, who use a rollator or two sticks, moved from a high to a low risk of falling. (Other studies have shown that 64% of people with MS report at least two falls per year, affecting confidence in walking and social participation.)
- Those who use a rollator or two sticks and participated in one-to-one physiotherapy programmes experienced a 16% reduction in the level of fatigue.
- Those who use a rollator or two sticks and participated in group physiotherapy experienced a 20% improvement in their balance.
- Those who use a rollator or two sticks in the yoga programmes experienced a 20% increase in their walking ability, improving the distance they were able to walk in six minutes.
- Wheelchair users receiving a standard physiotherapy programme experienced improvement in the impact of MS. Carer burden was also reduced for this group
- The University of Limerick' with the Medical Charities Research Group

Collaboration and Communication

With the assistance of funds from MS Ireland, the Neurology Department of St Vincent's University Hospital conducted its prevalence, vitamin D and quality of life study in Dublin, Wexford and Donegal. Results are due to be published in 2010.

We continue to inform and update people affected by MS on the various research developments worldwide. Our MSnews, eNews and website are used extensively.



Our Strengthening of MS Ireland's Organisational Capacity Goal:

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. How we moved forward in Organisational Capacity in 2009:

Human Resources and ICT

- The inaugural meeting of the Trustees of the MS Ireland pension scheme was conducted in January. Their function is to oversee the administration of the scheme on behalf of its members. Trustees will meet twice yearly. We are grateful and indeed honoured to have Mr David Kingston, formerly of Irish Life, as Chair of the Pension Scheme Trustees.
- The quality of care at our care centre continues to be enhanced by the participation of our care staff on the DFI-sponsored Skills Project. Successful completion of this programme provides participants with a FETAC Level 5 qualification, which is internationally recognised. This year saw eight team members continue their training under this programme.
- We were all saddened by the sudden passing of Sheila Farrell, the administration resource worker at our Cork office. Sheila worked with the Society for nearly eight years and was a very important, loyal and dedicated member of the MS Ireland team in Cork. She was highly regarded by all her colleagues locally and nationally and in particular people with MS in the Cork region.
- MS Ireland introduced a customer relationship management programme – Salesforce – to help manage the various databases and lists of members, donors and fundraisers. The system will reduce duplication and aid communication with our valuable supporters.

Organisational Structure and Development

- There has been continued development of the Regional Co-ordinator structure. Eight meetings were held in 2009 which focused on the development of regional services, budget cuts and casework review.
- MS Ireland ran a pilot study with the Health Research Board regarding its National Physical and Sensory Disability Database. It is used by the HSE to collect, analyse and report on a range of issues relating to the status of people with disabilities e.g. their primary diagnosis, service

needs and quality of life issues. MS Ireland was given direct access to the database in the pilot scheme. We will now evaluate how continued access could enhance our work.

Collaboration and Partnerships

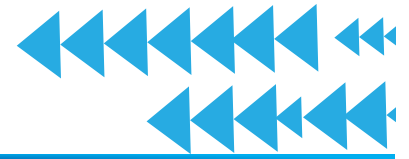
MS Ireland continues to form partnerships and work collaboratively with a number of allied organisations, umbrella agencies and specialised interest groups. Significant partnerships and collaborative work included:

- The Health Services Executive and other state bodies such as Pobal, FAS etc
- The European Multiple Sclerosis Platform (EMSP) and the Multiple Sclerosis International Federation (MSIF) in the areas of policy, common goal-setting and governance;
- The DFI and the NAI in the areas of health sector cuts, governance, rehabilitation and neurological funding. In particular MS Ireland was involved in NAI's Brain Awareness Week, which in 2009 focused on innovation in the health sector;
- The Medical Charities Research Group.

In light of reduced income we also met with a number of organisations to identify and discuss common vision and actions particularly in the areas of services and research. Our meetings with Cheshire Ireland, Muscular Dystrophy Ireland and the MS Society in Northern Ireland are helping us to forge links, which may help to reduce costs, develop services and streamline operations. These discussions will continue into 2010.



Dr Tim Lynch of the Mater Hospital, Dublin, gave a seminar on MS treatments during Brain Awareness Week.



Communications

- In 2009, MS Ireland participated in first ever World MS Day. Joining with other MS societies worldwide we raised awareness and funds for those living with MS.
- Our website continues to be our most widely-used communication tool, with over 800 people a day visiting the site for various pieces of information.
- Two editions of MSnews and 24 editions of eNews (electronic newsletter) were delivered in 2009.
- There were significant media achievements throughout the year including a number of national pieces on World MS Day.



For World MS Day we hosted the Pringle Lecture in Cork. Dr Sweeney from Cork University Hospital, Cork and Dr Alasdair Coles from Cambridge University, delivered the seminar on current and emerging MS treatments.

Membership

At the end of 2009 our membership stood at 5472.

The MS community is a strong, vibrant gathering of different people and groups affected by or interested in MS. Some of our members are actively involved in the Society and attend programmes, volunteer and speak publicly about their MS. Others prefer to maintain their privacy and wish only to receive information. However much, or little, you want to get involved, becoming a member will benefit you and us in many ways.

MS Ireland is delighted to offer membership to any person interested in the work of the Society. Our members include people with MS, family members, carers, health professionals, employers and donors.

Why Become a Member?

- 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 MSnews
- Sense of ownership

Information and support services are available regardless of membership but membership will help us to develop services and make them more accessible.

In 2009 MS Ireland's Annual Awards were given to three very special ladies, who all make a wonderful contribution to the lives of their family, community and the Society.



Carer of the Year Florrie Gibbons



MS Person of the Year Katherine Flynn



Volunteer of the Year Yvonne Corrigan



Our Funding Goal:

To increase levels of funding to deliver on the organisation's objectives.
How We Moved Forward In Funding in 2009:

2009 was a difficult year for MS Ireland financially, we reduced our actual budgeted income significantly. We managed to stay within our budget by renegotiating many financial arrangements, reducing our expenditure in many areas including our fundraising campaigns; creatively using the resources at our disposal and streamlining services and operations. This work has also led us to begin formulating a more dynamic Funding Strategy for 2010 onwards, to ensure financial difficulties do not limit or reduce the positive impact MS Ireland has on the lives of people affected by MS.

In 2009 we were especially indebted to our voluntary Branch network, which helped to shore up our funds for the year. Some 90% of our Branches contributed 12.5% of their cash in the bank. This money was invaluable throughout the year.

Fundraising Highlights of 2009: World MS Day

Wednesday, 27th May 2009 was the very first global World MS Day. The day aimed to raise awareness of MS and mobilise the MS community. In Ireland, we held a number of local and national events, including a national bucket collection; a radio ad campaign; and a seminar in Cork where Cambridge Neurologist and Researcher, Dr Alasdair Coles, joined Irish Neurologist, Dr Brian Sweeney, to outline the development in MS treatments.

Our staff, Branches, supporters and celebrity ambassadors all pulled together to make the day a great success. In addition to raising awareness across the county we also raised over €20,000 to fund our services.



MS READaTHON

Some 25,000 students, 633 schools, 2,600 teachers and librarians participated in the 2009 MS READaTHON.

Celebrity endorsements by Laura Woods, Síle Seoige, Ross O'Carroll-Kelly and authors Marita Conlon-McKenna, Judi Curtin and Sarah Webb helped to raise the profile and ensure the success of the campaign.



MS Walks and Adventures

2009 was the 21st year of our overseas charity treks and we had groups travelling to four different destinations: The Camino de Santiago; Peru; Nepal, and a

new destination, Cuba. Some 135 people took part in the walks with the largest number (58) travelling to Cuba. Among the participants in Cuba were two RTÉ personalities Evelyn Cusack and Joe Mulholland.

The number of people who participated in the Flora Women's Mini Marathon 2009 was up on the previous year by almost 100 people with 662 participants. We also had almost 80 people participate in the Dublin City marathon. Many volunteers also participated in various sports events around the country, including the Gael Force West Challenge, iron man challenges, sky diving, golf events and individual sporting events.





MS Ireland Raffles

The Spring raffle was once again a huge success with Emily Martin taking home the first prize of a trip to New York. Due to the success of the Spring raffle a second raffle was introduced for Christmas 2009. This was another great fundraising event with Mr G McCaffrey taking first prize. Congratulations to our winners and thank you to all who took part.



B&Q

MS Ireland was delighted to be chosen as one of B&Q's charities in its Charity of the Year campaign. MS Ireland was given a two-year commitment by B&Q allowing for collections to be held outside its 10 stores on allocated days. This has proved to be a fantastic opportunity for MS Ireland and we look forward to continued successes in 2010.

MS Swim

Swimmers of all levels took part individually or as a team. This event has proved to be a great way to build team spirit, to encourage healthy competition between friends and colleagues and to promote wellness, all while raising much needed funds for MS Ireland.

Christmas 2009

- The MS 'Reach for a Star' corporate Christmas campaign saw 50 corporates sponsoring a star on the MS Christmas Tree in Blanchardstown, in lieu of sending cards out to their clients. The total raised was €72,000 with two corporates sharing the Gold Star worth €7,500 each – Research and Markets and Combilift.
- A wonderful selection of Christmas cards was produced for members of the public to buy online, through the regional offices and from a number of our voluntary Branches.



Individual and Corporate contributions

We are delighted that once again MS Ireland received amazing support from people through direct debits, donations and legacies. Direct debits are a continuous source of long-term funding, which allows for projections of future income to be more accurately achieved.

Many individuals and organisations took the initiative to fundraise on behalf of MS Ireland. Fundraising came from a range of initiatives including table quizzes, non-uniform days, wedding favours, funeral collections, coffee mornings and many sporting activities.

Join the MS Team

MS Ireland's year is jam packed with activities and events you can participate in to support our work and raise funds. Here are 10 ways you can get involved:

1. Make a donation or set up a direct debit
2. Take part in some of our walks, sports or adventures
3. Sponsor a young person to take part in the MS READaTHON
4. Donate good quality goods to our charity shop
5. Volunteer with one of our 41 local Branches
6. Set up payroll giving in your work
7. Become a life member
8. Include MS Ireland in your will
9. Buy or sell raffle tickets

Or if our planned events and activities don't suit you....

10. Organise your own event and send the proceeds to MS Ireland. How about a barbecue, a casino night, a coffee morning, a golf classic, a jumble sale, a non-uniform day, a sports day, a teddy bears' picnic, a quiz night etc?

Our fundraising department can provide you with promotional materials like t-shirts, balloons and posters. It is also available for help, support and encouragement when organising your event.

Get into action and contact our Fundraising department today on 01 678 1600 or email fundraising@ms-society.ie

We are continuously indebted to those walkers, readers, donors, fundraisers and volunteers who give their time and money to support the work of the Society. Thank you for your generosity and good will.

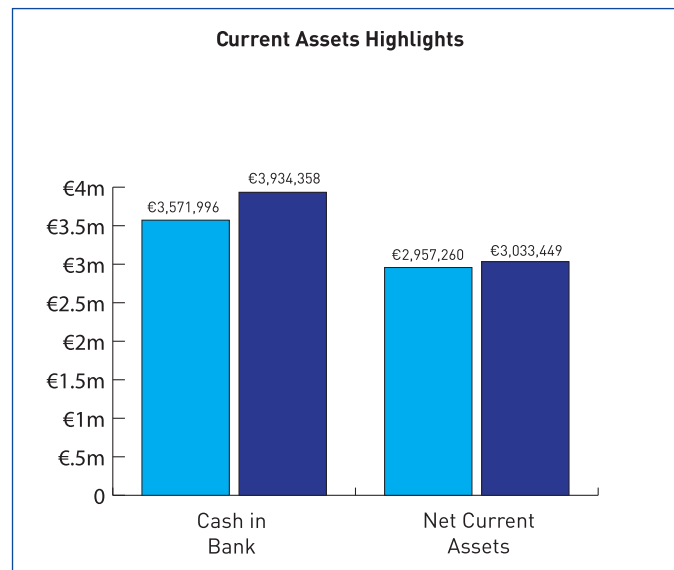
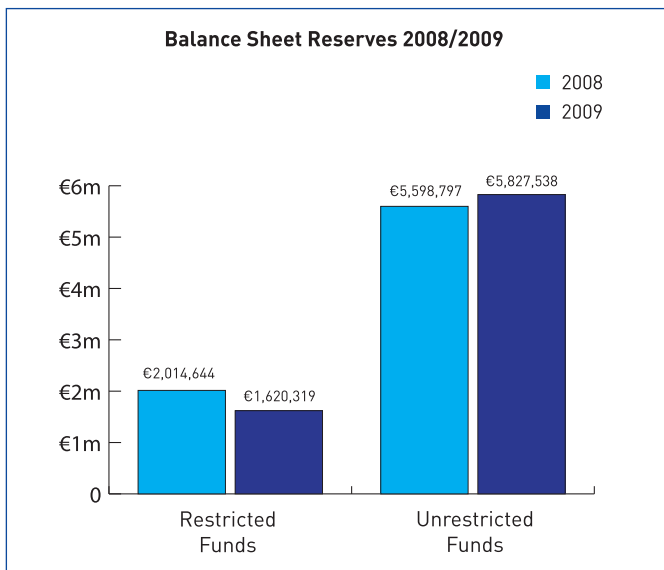
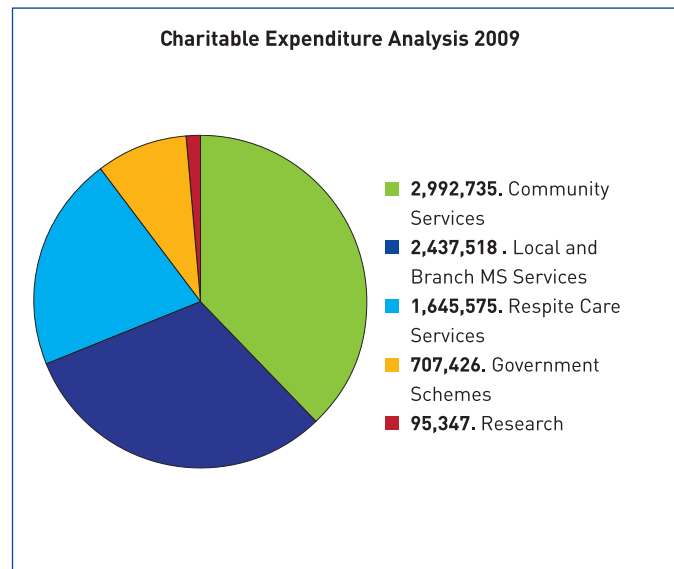
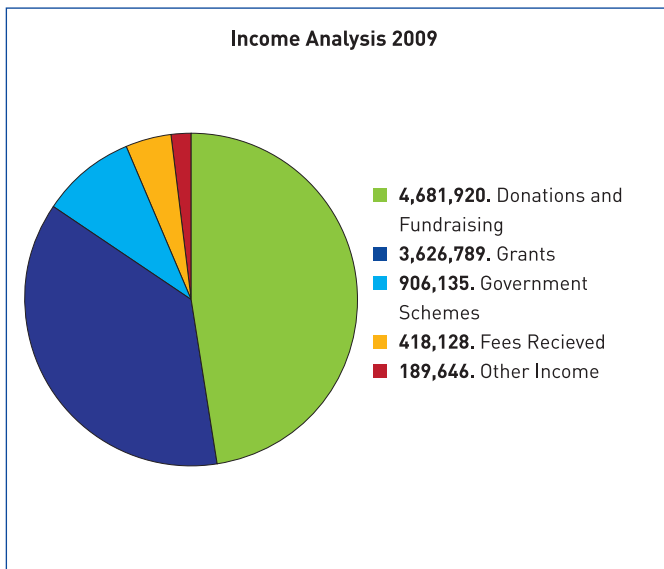
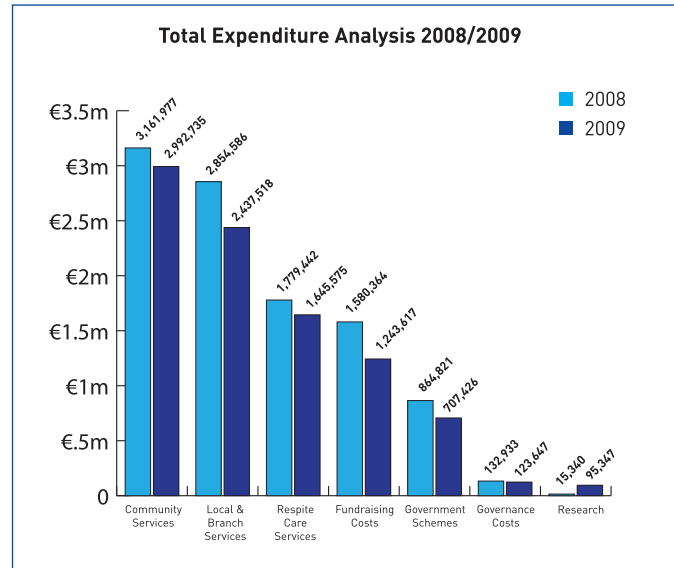
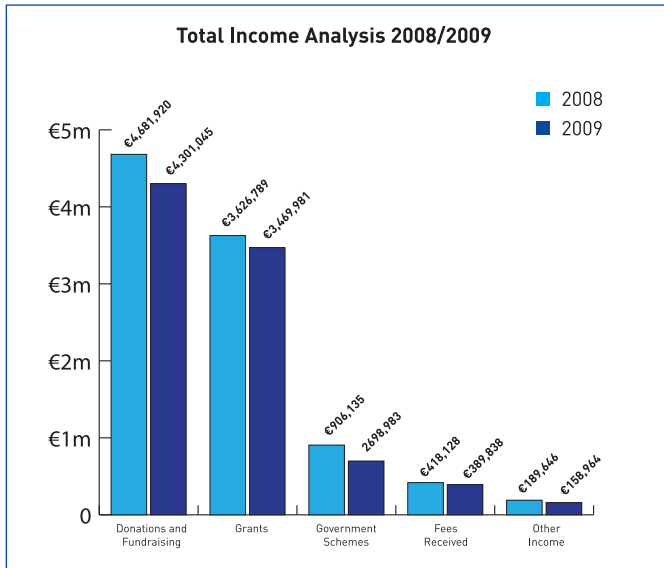
SUMMARY CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES

FOR THE YEAR ENDED 31 DECEMBER 2009

Income & Expenditure Account	Unrestricted Funds 2009 €	Restricted Funds 2009 €	Total Funds 2009 €	Total Funds 2008 €
INCOMING RESOURCES	4,846,652	4,172,159	9,018,811	9,822,618
RESOURCES EXPENDED	4,617,911	4,566,484	9,184,395	10,326,693
Net outgoing resources	228,741	(394,325)	(165,584)	(504,075)
Total funds brought forward at 1 January 2009	5,598,797	2,014,644	7,613,441	8,117,516
Total funds carried forward at 31 December 2009	5,827,538	1,620,319	7,447,857	7,613,441

Consolidated Balance Sheet

	2009 €	2008 €
FIXED ASSETS		
Tangible fixed assets	7,256,592	7,430,716
CURRENT ASSETS		
Stocks	6,297	12,688
Debtors	322,874	739,930
Investments	21,138	70,664
Cash at bank and in hand	3,934,358	3,571,996
	4,284,667	4,395,278
CREDITORS: (Amounts falling due within one year)	-1,251,218	-1,438,018
NET CURRENT ASSETS	3,033,449	2,957,260
TOTAL ASSETS LESS CURRENT LIABILITIES	10,290,041	10,387,976
CREDITORS: (Amounts falling due after more than one year)	-2,842,184	-2,774,535
NET ASSETS	7,447,857	7,613,441
FUNDED BY:		
Restricted funds	1,620,319	2,014,644
Unrestricted funds	5,827,538	5,598,797
FUNDS	7,447,857	7,613,441





Governance

MS Ireland is the only national organisation working for people and families living with MS. 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 continuously 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 2009, the Board met nine times. Significant work was carried out in the areas of finance and funding, governance and strategy. At the end of the year the Board decided to undertake a governance health check with a view to acquiring governance accreditation.

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 co-operation between all structures of the Society. In 2009 the Council met four times.

All Branches are represented in the Council. Three Council members are elected and 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	Ms Anne Winslow
Financial Accountant	Ms Memory Chiperie
Services Manager	Ms Olga Estridge
Human Resource Manager	Mr David Allen
Fundraising Manager (Acting)	Mr David Allen
Communications Executive	Ms Taragh Donohoe

Just under 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.

MS Ireland is delighted to have Mary McAleese, President of Ireland, as sole patron.

2008/2009 Board members:

Mr Allen O'Connor, Chairman	Mr Kevin Doyle
Mr Brian Farrell, Deputy Chairman	Ms Maureen Feeney
Mr Brian Barrett	Mr Manfred Huschka
Ms Margaret Burke	Prof Michael Hutchinson
Mr Joe Cahill	Ms Lorna Mitchell
Mr Barney Cunningham	Mr Gerry Murphy
Dr Gemma Donnelly-Cox	Mr Sean Murphy
	Mr Paddy Power
	Mr Paddy Stronge

Board Committees

A number of Board committees inform and complement the work of the Board. Each committee is made up of Board members who have particular interests, experiences and knowledge.

- Finance
- Strategy and Policy
- Structural
- Nominating
- Medical Advisory and Research
- Remuneration

As the need arises a number of staff and external professionals will be asked to sit on these committees.

Branches in 2009

Athlone	East Wicklow	Monaghan
Ballina	Fermoy	Mullingar
Ballinasloe	Galway	Offaly
Bandon/Kinsale	Kerry North	Roscommon
Carlow	Kerry South	Skibbereen/
Cavan	Kildare	Bantry
Clare	Kilkenny	Sligo
Cork City	Laois	Tipperary
Cork North West	Leitrim	Tralee
Donegal	Limerick	Tuam
Dublin North	Limerick West	Waterford
Dublin South	Louth	Wexford North
Dublin West	Longford	Wexford South
Dungarvan/South	Mayo South	
Tipperary	Meath	



Service Reminder and Contact Details

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

MS information Line: The MS Information Line provides people with Multiple Sclerosis, their families, friends and colleagues information and support on all aspects of living with the condition. The service is staffed by a team of trained professionals who are on hand to talk, or more importantly, listen to anyone concerned about MS. The Information Line is open Monday to Friday from 10am - 2pm.



LoCall: 1850 233 233 Email: info@ms-society.ie

Regions: Our Regional Offices provide individual and family support, living with MS programmes and events, counselling and other services to the MS community in their area.

REGIONAL OFFICE	COUNTIES/AREAS COVERED	CONTACT DETAILS
South West Dublin and Kildare	Kildare South West Dublin (including Terenure, Tallaght, Clondalkin, Chapelizod, Lucan, Rathcoole)	01 490 5933 swa@ms-society.ie
East Coast Dublin and Wicklow	Wicklow East Coast Dublin (including Ballinteer, Kiltarnan, Monkstown, Killiney, Shankhill)	01 287 1704 eca@ms-society.ie
North County Dublin and City	North Dublin city and county (including Fairview, Cabra, Coolock, Malahide, Finglas, Lusk, Balbriggan, Naul)	01 490 5933 na@ms-society.ie
South East Region	Wexford, Waterford, Carlow, Kilkenny and South Tipperary	056 777 7771 southeast@ms-society.ie
Southern Region	Cork and Kerry	021 430 0001 southern@ms-society.ie
Mid-West Region	Limerick, Clare and North Tipperary	061 303 802 midwest@ms-society.ie
Midlands Region	Laois, Offaly, Longford, Westmeath	090 647 1137 midlands@ms-society.ie
North East Region	Cavan, Monaghan, Meath, Louth	042 966 4410 northeast@ms-society.ie
Western Region	Galway, Roscommon and Mayo	091 768 630 western@ms-society.ie
North West Region	Donegal, Sligo and Leitrim	074 912 5017 northwest@ms-society.ie

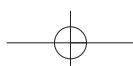
MS Care Centre: The MS Care Centre offers respite and therapeutic services to people with MS and other neurological conditions. In addition it also runs a MS Specialist Nurse Programme, which gives residents the opportunity to receive an assessment by one of the centre's new MS Specialist nurses. The specially trained nurses can talk through any issues the person may be having with treatments, symptoms, access to services or any other issue that is impacting on the person's health or quality of life.

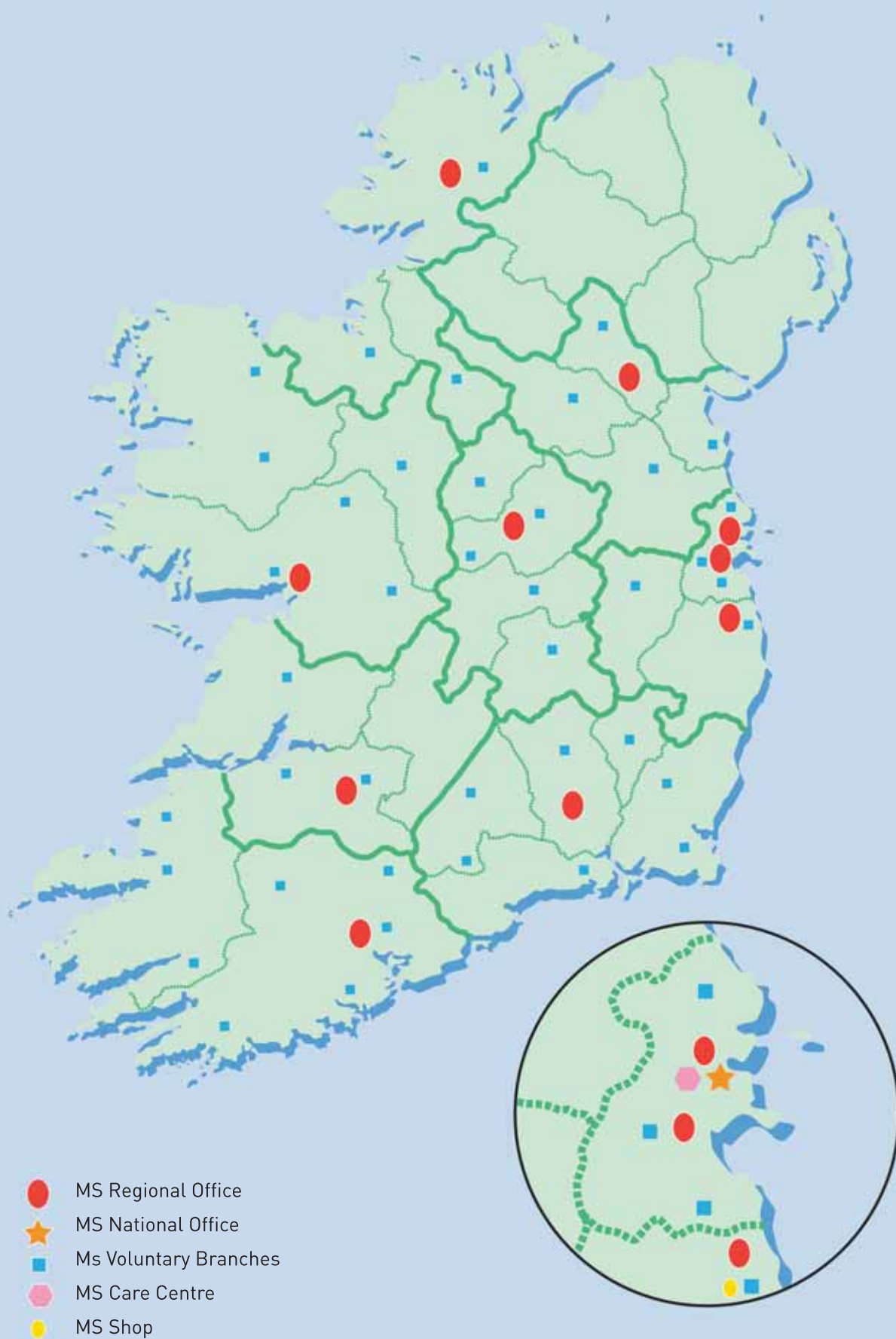
MS Care Centre: 65 Bushy Park Road, Rathgar, Dublin 6, t: 01 490 6234, f: 01 490 6724, e: m scare@ms-society.ie

Voluntary Branch Network: Our 41 Branches provide local support to the MS community. Run by people affected by MS for people affected by MS, they provide opportunities for people to come together to socialise and share experiences. Many fund therapy services and offer welfare to people with MS in the locality. Call 01 678 1600 to make contact with your local Branch.

MS Charity Shop: Our charity shop sells an array of good-quality second-hand items such as clothes, jewellery, books and ornaments.

MS Charity Shop: 56 Main St., Bray, Co. Wicklow. Tel: 01 286 1913. msshop@ms-society.ie





To make contact: Call: 01 678 1600
Information Line: 1850 233 233
Email: info@ms-society.ie
www.ms-society.ie

