MS IRELAND





OUR MISSION IS TO ENABLE & EMPOWER PEOPLE AFFECTED BY MS TO LIVE THE LIFE OF THEIR CHOICE TO THEIR FULLEST POTENTIAL. **EMPOWER** PEOPLE WITH MS TO CONTROL THEIR LIVES & INFLUENCE THEIR ENVIRONMENT // ALLOW PEOPLE WITH MS TO LIVE WITH DIGNITY WHILE PARTICIPATING IN THE COMMUNITY // **PROVIDE SUPPORT FOR THE FAMILIES AND CARERS** OF PEOPLE WITH MS // CO-OPERATE WITH THE MEDICAL, SCIENTIFIC, SOCIAL & CARING **PROFESSIONS // PROMOTE SCIENTIFIC RESEARCH** INTO THE CAUSES OF MS // ENCOURAGE BETTER MANAGEMENT OF MS & ITS SYMPTOMS // **EXCHANGE & DISSEMINATE INFORMATION ON** MS // DEVELOP AN EFFICIENT, EFFECTIVE AND **CARING ORGANISATION TO SERVE THE NEEDS OF PEOPLE WITH MS //** WE ARE THE ONLY ORGANISATION PROVIDING **COMMUNITY-BASED SERVICES, INFORMATION & SUPPORT TO THE ENTIRE MS COMMUNITY ON** A NATIONAL, REGIONAL AND LOCAL LEVEL. **INDIVIDUAL & FAMILY SUPPORT // LIVING WITH MS PROGRAMMES, ACTIVITIES & WORKSHOPS** // CONFIDENTIAL MS INFO LINE 1850 233 233 // MS CARE CENTRE FOR RESPITE & THERAPIES // 38 VOLUNTARY BRANCHES NATIONWIDE // **PROFESSIONAL COUNSELLING // ADVOCACY** AND LOBBYING // PUBLICATIONS // WEBSITE: WWW.MS-SOCIETY.IE // MSNEWS MAGAZINE & E-NEWSLETTER // RESEARCH & INFORMATION // **NATIONAL CONFERENCES & GATHERINGS**

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CHIEF EXECUTIVE & CHAIRMAN WELCOME

Multiple Sclerosis Ireland is the only national organisation solely providing information, support and advocacy services to the MS community. We work with people with MS, their families and carers and a range of key stakeholders including health professionals, researchers and others interested in or concerned about MS to ensure that we meet our goals. We are delighted to welcome you to a review of MS Ireland's activities and services in 2015. Despite many ongoing challenges in the economic and political climate, MS Ireland's staff and volunteers continued to work hard throughout 2015 to serve the MS community and to fulfil our mission statement, which is "to enable and empower people affected by MS to live the life of their choice to their fullest potential".

2015 saw the release of two key publications, the 'Access to Medicines' Campaign Handbook and the 'Societal Cost of Multiple Sclerosis in Ireland 2015' report. The Access to Medicines handbook represents an important milestone in our ongoing advocacy work for fair and equitable access to MS treatments. The Societal Costs report is a major piece of research that highlights the need for access to interventions that reduce relapses and slow disability progression, and support working and living independently. It also highlights the need for improved employment opportunities and adoption of flexible work practices, as well as acknowledgement of the unpaid work carried out by carers. We have already made extensive use of data from the report in our advocacy and lobbying work.

The MS Information Line, MS Care Centre and our regional services were all in high demand throughout 2015. Resources for all these services remain stretched, but our staff and volunteers continue to do all they can to provide high quality services and supports to people affected by MS. We once again participated in World MS Day, the theme for which this year was "Stronger than MS". A range of events and activities were held up and down the country, spreading awareness and raising issues and funds.

We held several successful conferences and events in 2015. The theme for our annual conference, which took place in September, was "Living Well with MS" and we also held a well-attended Information Day for healthcare professionals which featured presentations from key experts in the fields of MS treatments and care. In November, we held an MS Research Explored event which was attended by over 100 people with a further 162 watching via live stream.

CHIEF EXECUTIVE & CHAIRMAN WELCOME



Research remains high on MS Ireland's agenda, despite extremely limited financial resources to invest in research. Our partnership with the University of Limerick has continued to grow and develop with further exciting research into exercise and MS, including the 'Step It Up' project which finished recruiting in May 2015. We have assisted researchers investigating cognition and bladder dysfunction by helping with the recruitment of participants and we were also delighted to award a second Dean Medal Travel Bursary in 2015.

Our Fundraising team have once again had a busy and successful year. 15,000 readers took part in the 2015 Readathon, raising an amazing €500,000. Other fundraising activities included skydives, treks, the everpopular Women's Mini Marathon and the Galway's Fittest Workplace challenge. Our website saw an increase of over 14,000 visitors on 2014 and our eNews subscriptions and social media presence also grew. Our MS & Me Blog team covered topics on parenting, education, politics, holidays, medication and many other topics of importance to the MS community. The MS & Me Blog is now two years old and we are incredibly proud of our team of Bloggers on their success to date – in 2015, the blog won the silver medal in the Health and Wellbeing Category at the Blog Ireland awards.

None of our achievements in 2015 would be possible without the dedication of the staff and volunteers who work so hard to make a difference to the lives of people affected by MS in Ireland, including our Board who give their time and expertise for free to support the running of the organisation. We would like to thank everybody who has supported our work in any way, through making donations, engaging in fundraising activities, and raising awareness about who we are and what we do.

Whilst we have achieved a lot, there is much work still to be done to try and make Ireland a better place for people affected by MS. There will no doubt be many challenges ahead and with the continued support of the MS community we are confident we will meet them head-on.

We hope you enjoyed reading this report and we look forward to working with you in the coming year.



AVA BATTLES CHIEF EXECUTIVE



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PADDY STRONGE CHAIRMAN

STRATEGIC PRIORITIES

2015 was the first year of our new five-year Strategic Plan for the period of 2015 - 2019. This plan builds on the achievements of the previous Strategic Plan (2013 - 2014), and is based on those guiding principles which are fundamental to the work we do: enabling and empowering people with MS to live the life of their choice to their fullest potential. In preparing the Strategic Plan, we have consulted with our stakeholders.

The Strategic Priorities in our 2015-2019 Strategic Plan are:



SERVICES

To provide quality services nationally to ensure everyone with multiple sclerosis and their families have full access to services and supports when needed.



ORGANISATIONAL CAPACITY

Build and strengthen MS Ireland's organisational capacity, to ensure delivery of our Strategic Plan.



ADVOCACY

MS Ireland will be the voice for people with MS, driving an advocacy agenda that includes areas of greatest concern to people with MS.



RESEARCH

MS Ireland will develop a research strategy that will focus on supporting and participating in research that is in line with member expectations on local, national and international stages.

GOVERNANCE & REGULATION

To source, fundraise and effectively manage our financial resources to fund the services and activities of the organisation.

Log on to our website to read the full strategic plan: www.ms-society.ie



To provide quality services nationally to ensure everyone with multiple sclerosis and their families have full access to services and supports when needed.

ACHIEVING IN SERVICES

IN 2015, THIS IS WHAT WE ACHIEVED IN SERVICE PROVISION.

THE MS CARE CENTRE

Our MS Care Centre is the only respite and therapy centre for people with MS in Ireland. Providing short-term respite care for people with MS, during a stay a resident can avail of therapeutic services, neurological assessments, access to an MS nurse and a range of social activities to allow for complete rest and recuperation.

In 2015 the MS Care Centre provided professional, dedicated care for 390 people. Our highly trained staff and specialised equipment ensures a safe and comfortable stay for residents and peace of mind for family members and carers.

Image: Second second

***SOME RESIDENTS STAYED TWICE OR MORE**

PROFESSIONAL & THERAPEUTIC INTERVENTION

MODERATE

FULLY

DEPENDENT

HIGH



1 2 3 4 5 **6** 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34

IMPROVING THE MS CARE CENTRE

Thanks to ongoing fundraising efforts, and donations and volunteers from our generous corporate supporters, we were able to complete a number of improvements to ensure the continued safety, comfort and enjoyment of the Centre, including:









GARDEN & BUILDING MAINTENANCE



A special **THANK YOU** to the residents and their families who made a donation to the MS Care Centre on foot of their stay. We deeply appreciate their generosity which helps us keep this wonderful and essential service operating.

We were advised that the MS Care Centre had successfully completed the HIQA registration process on 20th March 2015.



LETTER/VISIT: 5

HOW PEOPLE MADE CONTACT

THE MS INFORMATION LINE

Operating weekdays from 10am - 2pm, our dedicated information line provides professional, anonymous and confidential support for people with MS, their families, carers and health professionals. From January to October 2015, **1,319** people contacted the MS Information Line.



Please note that due to an IT error, statistics for the MS Information Line are only available from January to October 2015.

PHONE: 833

REGIONAL SERVICES

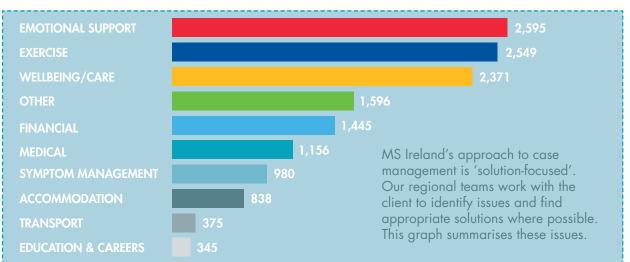
Our regions provide a range of services to individuals, families and health care professionals in their area. These services are aimed at providing support and information, assisting the person and family to learn about MS and to discover coping mechanisms to improve their quality of life. Casework and living with MS programmes are two of the main services delivered through our Regional Offices to people and families living with MS. Other services include information to health professionals, service development, public awareness and support to the voluntary Branch structure.

CASEWORK

Our casework service revolves around one-to-one meetings, 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 to empower them to make decisions about their life with MS.



TOP 10 ISSUES PRESENTED BY CLIENTS



LIVING WITH MS PROGRAMMES

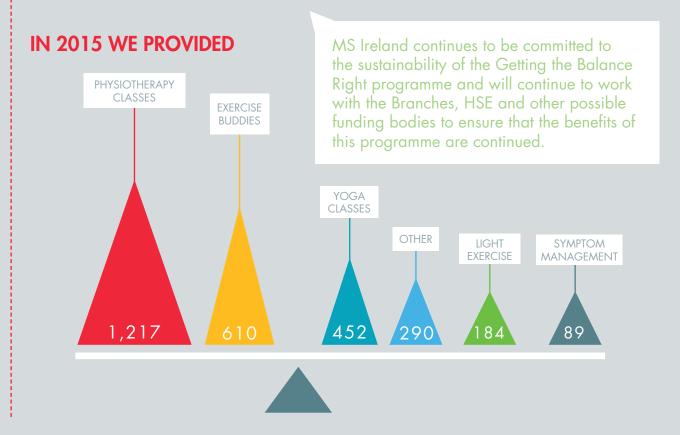
Our regional services provide a wide range of group support through programmes, workshops and activities. Types of programmes include newly diagnosed seminars, symptom management, carers support groups, information mornings and yoga sessions.

These programmes may be one-off sessions or a ten week course, depending on the nature of the programme. The figures below summarises the types of programmes we ran in 2015:



GETTING THE BALANCE RIGHT

Getting the Balance Right, our nationwide exercise, health promotion and research programme for people with MS, continues to be an enormous success. The programme offers 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. Interventions range from physiotherapy-led group programmes, physiotherapy 1:1, yoga, gym-based programmes, hydrotherapy and tai chi.



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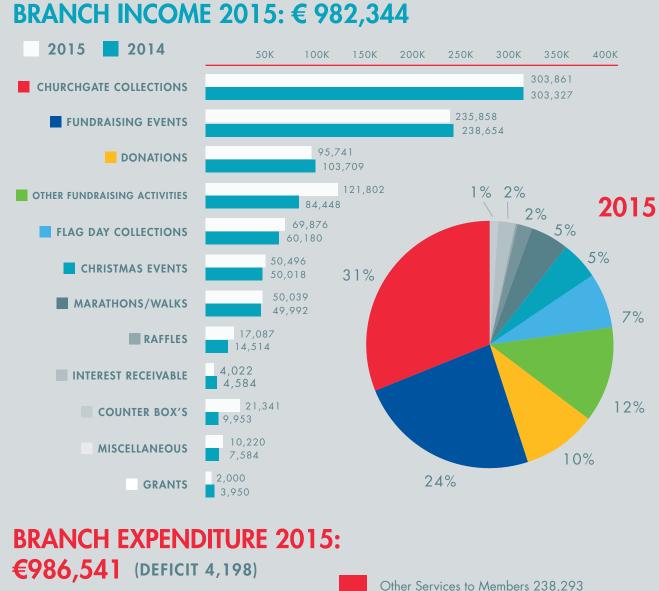
WORKING TOGETHER: AN INTEGRATED APPROACH

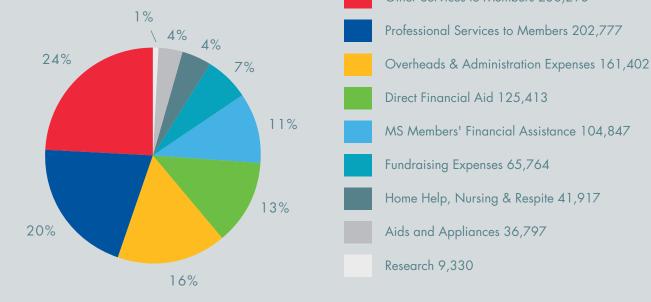
ACHIEVING IN SERVICES VOLUNTARY BRANCH SERVICES WORKING TOGETHER

2015 was the fourth year of our integrated model of service delivery. Our professional regional staff worked closely with our dedicated teams of volunteers throughout our Branch network to best fund, organize and deliver services to the local MS community. This team work has meant that we are able to make the best use of all our resources to best address the needs of people with MS and their families. 15 Regional Integrated Meetings took place in 2015.









FIND YOUR LOCAL MS IRELAND

To learn more about services available in your area, contact your local Regional Office. All voluntary Branches can be contacted through their associated regional office.

DUBLIN NORTH & FINGAL REGIONAL OFFICE

Providing services in North County Dublin and City

na@ms-society.ie | (01) 490 5933

MIDLANDS REGIONAL OFFICE Providing services in Laois, Offaly, Longford and Westmeath

midlands@ms-society.ie | (090) 647 1137

MIDWEST REGIONAL OFFICE Providing services in Clare, Limerick and **Tipperary North**

midwest@ms-society.ie | (061) 303 802

NORTH EAST REGIONAL OFFICE

Providing services in Cavan, Monaghan, Louth, and Meath

northeast@ms-society.ie | (042) 975 4304

NORTH WEST REGIONAL OFFICE

Providing services in Donegal, Sligo and Leitrim

northwest@ms-society.ie | (074) 918 9027

SOUTH EAST DUBLIN & WICKLOW **REGIONAL OFFICE**

Providing services in Wicklow and areas of South Dublin

eca@ms-society.ie | (01) 678 1600

SOUTHERN REGIONAL OFFICE

Providing services in Cork and Kerry

southern@ms-society.ie | (021) 430 0001

SOUTH EAST REGIONAL OFFICE Providing services in Kilkenny, Wexford, Carlow, Waterford and South Tipperary

southeast@ms-society.ie | (056) 7777 771

SOUTH WEST DUBLIN & KILDARE **REGIONAL OFFICE**

Providing services in Kildare and areas of South West Dublin

swa@ms-society.ie | (01) 490 5933

WESTERN REGIONAL OFFICE Providing services in Galway, Mayo and Roscommon

western@ms-society.ie (091) 768 630

VOLUNTARY BRANCHES

Athlone Ballina Carlow Cavan Clare Cork City Cork North West Fermoy Cork West

Donegal Dublin North Dublin South Dublin West Dungarvan East Wicklow Galway

Kerry North Kerry South Kildare Kilkenny Laois Leitrim Limerick Limerick West

Louth Longford Mayo South Meath Monaghan Mullingar Offalv Roscommon

Tipperary Tipperary South Tralee/West Kerry Tuam Waterford Wexford South

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ANNUAL GENERAL MEETING (AGM) 2015

PRESENTATIONS ON THE DAY

MS Treatments Current and Emerging, Focus on Progressive MS Prof. Alan Thompson

Challenges for Integrated Care Packages in Multiple Sclerosis

Dr. Jenny Freeman

RehabCare: Cognitive Rehabilitation in MS Shona Logan-King

The Importance of Educational Access for MS Nurses - Integrating Knowledge & Skills MS Nurse Professional

Vicki Matthews, RIMS Specialist Nurse Advisor

Challenges of End of Life Care in a Progressive Neurological Population

Deirdre Shanagher & Sarah Cronin



MS Ireland's 2015 Annual General Meeting (AGM) was held on Saturday, 26th September 2015 at the Red Cow Moran Hotel, Dublin. Maurice O'Connor and Rory Mulcahy were elected to the board. Mary Sheahan Lonergan was elected as the new Council Representative on the Board. Paddy Stronge was reappointed Chairman of the Board and Bryan Harty was reappointed Deputy Chairman.

Dara Deering and Mark Mitchell stepped down from the Board and we would like to thank Dara and Mark for their diligent and passionate service to the Board of MS Ireland over the past three years.

HEALTHCARE PROFESSIONALS INFORMATION DAY

MS Ireland hosted an information day for healthcare professionals on Friday, 25th September 2015 in Dublin. The focus of the day was on multiple sclerosis, its treatment and management with specific sessions on challenges in cognition, end of life care and exploring online learning to support allied healthcare professionals in the management of MS.

All presentations are available to view on our website www.ms-society.ie

LIVING WELL WITH MS CONFERENCE



The Living Well with Multiple Sclerosis conference took place on Saturday, 26th September at the Red Cow Hotel in Dublin. 225 people were in attendance. The first speaker of the day was Professor Alan Thompson, Consultant Neurologist from University College London who presented on 'New and Emerging Treatments and Developments in Multiple Sclerosis'. He spoke about the need for improved education about ways to selfmanage MS and recent developments in the field of disease modifying therapies (DMTs). Next was Professor Michael Hutchinson, Consultant Neurologist from St Vincent's Hospital, who gave an update on their research into vitamin D and MS.

There then followed a series of workshops on exercise, diet and nutrition and everyday brain health. There were also sessions lead by Shift.MS, a UK based forum for young people living with multiple sclerosis.





MS RESEARCH EXPLORED EVENT



MS Ireland and Novartis held an MS Research Explored event for people with MS on Thursday, 19th November in Trinity College Dublin. 100 people attended the event and a further 162 watched via a live stream, from eight different countries. Professor Gavin Giovannoni from Barts Hospital in London presented 'Treating MS in 2025'. Professor Giovannoni's presentation looked at future developments in MS treatment and prevention. Dr Susan Coote from the University of Limerick presented on 'Exercise for people with MS'. She outlined some of the evidence that supports the benefits of exercise for people with MS, and some of the reasons why people with MS struggle to keep active. Dr Chris McGuigan, Consultant Neurologist from St Vincent's Hospital, presented the findings of the 'Societal Costs of Multiple Sclerosis in Ireland 2015' report and also outlined the reasons why this research needed to be carried out. Feedback from the event was broadly very positive, with the majority saying they found all the talks interesting, clear and relevant.

MS & ME BLOG

In 2013 MS Ireland launched a community blog as a place for people with MS to share their experiences of life with MS. In 2015 there were 46 MS & Me blog posts. The blog encourages conversation and debate with the aim of supporting and informing people. A meet-up for the MS & Me team was held on 9th December in Dublin (kindly sponsored by Novartis). The aim of the event was to capture new ideas for 2016. We continue to work closely with the team producing topics, creating monthly blog schedules, sourcing images, reviewing/editing content and promoting on our website, social media and eNews.

We were delighted that MS & Me won the silver medal in the Health and Wellbeing category at the Blog Awards Ireland in 2015.

SOCIAL MEDIA

Our social media channels continued to grow throughout 2015. Our 'Tuesday MS Questions' and 'Friday MS Quotes' on Facebook have proved very popular and are great for stimulating discussions. We have done a lot of live Tweeting from events, and both Facebook and Twitter have become increasingly popular as ways of contacting us with information and support queries.

facebook. twitter

eNEWS

Our electronic newsletter eNews was sent every month in 2015 except August, to over 4,000 subscribers. eNews provides monthly updates on various aspects of MS research, services, events and developments.

MS NEWS MAGAZINE

Two editions of MS News were published in 2015 and distributed to over 10,000 homes, offices and clinics in Ireland. The Spring edition focused on the national neurorehabilitation strategy, understanding relapses, falls and MS and vitamin D studies. The Autumn edition focused on the Access to Medicines campaign, stem cell research, the Believe and Achieve programme and cognition and MS.

MS news







I.

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MS Ireland will be the voice for people with MS, driving an advocacy agenda that includes areas of greatest concern to people with MS

ACHIEVING IN ADVOCACY

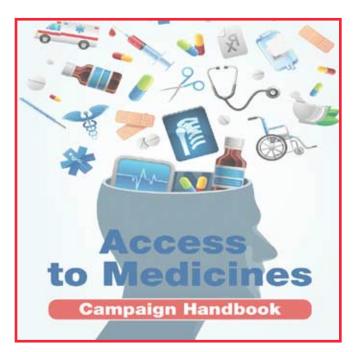
IN 2015, THIS IS WHAT WE ACHIEVED IN ADVOCACY



MS Ireland believes that people with MS should have access to the right treatment for them at the right time. Unfortunately, this does not always happen. Indeed there have been cases where people with MS have been denied access to clinically indicated treatments altogether. With this in mind, one of MS Ireland's greatest achievements in 2015 was the development and launch of our 'Access to Medicines' Campaign Handbook.

The handbook was developed with the following aims in mind:

- » To help people with MS to understand what their treatment options and rights are
- » To give practical advice on how to engage with the health system
- » To ensure people with MS have access to the medicines that are right for them
- » To give people enough information about how medicines are approved, funded and made available so they can make their own case based on the facts



On 24th August, the Access to Medicines Campaign Handbook was launched by Minister for Health Leo Varadkar. Minister Varadkar commented, "In Ireland over 8,000 people are living with MS, the launch of this handbook today will empower those 8,000 people and their families to access the medicines needed. This handbook is a fantastic publication and one that I know will prove extremely useful and beneficial to those who will use it."

ACHIEVING IN ADVOCACY

FAMPYRA

MS Ireland wrote to the Minister for Health on the issue of Fampyra in February. Our submission highlighted the enormously beneficial impact that Fampyra can have for some people with MS on their mobility and quality of life, and how having to pay for the drug privately was imposing a financial burden of between €300 and €500 a month on people who struggled to manage without it.

In October, MS Ireland warmly welcomed the decision by the HSE to reimburse

Fampyra for people with MS who satisfied a responder protocol. This represented a significant win in our ongoing Access to Medicines advocacy campaign.

NATIONAL CARERS WEEK



MS Ireland was once again a partner in National Carers Week, now in its ninth year. The aim of the week is to acknowledge the contribution that carers make to our communities and families. In 2015 the week took place from 8th-14th June. MS Ireland once again used the week as an opportunity to highlight the 60 page Caregivers Resource on our website.

HSE NATIONAL PATIENTS FORUM

MS Ireland became a member of the HSE National Patients Forum in December. It is envisaged that this Forum will become the first point of reference for HSE divisions and clinical care programmes when seeking an input from patients/service users in the planning, design and delivery of services and will act as a sounding board for implementation of new and existing national programmes. The plan for 2016 is to invite various senior executives in the HSE and representatives from the Department of Health to meet with the Forum, so this should be a good platform to raise issues relating to HSE policy that affect people with MS.

NURSING HOME RESEARCH ADVISORY GROUP AND COMMUNITY LIVING TASK GROUP

In late 2015 we identified two opportunities to feed into policy relating to housing and community living. One is a research project being led by the Disability Federation of Ireland looking at the reasons why people under the age of 65 are having to resort to nursing home care, with the aim of developing policy recommendations to address this.

The second is the Community Living Task Group which is a sub-group of the implementation plan for the National Housing Strategy for People with Disabilities. We look forward to working with these two groups into 2016.

NEUROREHABILITATION

MS Ireland has continued to support the Neurological Alliance of Ireland's (NAI) campaign for development of neurorehabilitation services, including participating in a campaign working group of NAI member organisations. MS Ireland supporter and advocate Alexis Donnelly also had a letter on neurorehabilitation published in the Irish Times in January



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MS Ireland will develop a research strategy that will focus on supporting and participating in research that is in line with member expectations on local, national and international stages.

ACHIEVING IN RESEARCH

IN 2015, THIS IS WHAT WE ACHIEVED IN RESEARCH

SOCIETAL COSTS OF MULTIPLE SCLEROSIS IN IRELAND 2015



On 21st October, MS Ireland, with Novartis and UCD, launched a report on the costs of multiple sclerosis to Irish society. Based on a representative sample of 595 people with MS, the report is entitled 'Societal Costs of Multiple Sclerosis in Ireland 2015' and key findings include:

- » 9,000 people and their families live with MS throughout Ireland
- » Average societal cost per person with MS amounts to €47,600
- » The total cost of MS to Irish society is more than €429 million each year
- » Total cost of relapses amounts to €16.9 million
- » People with MS report on average a 32% lower quality of life than the general population
- » Reducing costly disease activity and disability progression is possible

This report shows that the direct healthcare cost of MS is €159 million, which includes spending on medical treatments and scans, doctors and hospital visits. According to the research, treating MS requires approximately 54,000 GP visits per year, more than 16,000 nights in hospital and more than 1,500 emergency department visits annually.

Some 84% of respondents visit their GP six times each year, while it was also revealed that people with MS account for around 21,800 neurology visits every year. When it came to hospital resources, over one fifth (or 21%) spent up to nine nights in acute hospital care.

Overall, each person with MS received nearly 1,000 hours of care per year, most of which are informally provided and unpaid. A quarter said their carers took time off work to provide care. Within this group of carers, one fifth (20%) had to give up work completely to provide care. Just 14% receive formal care, which is supplied privately. The majority, 63%, receive informal care from family and friends.

MS IRELAND ANNUAL REPORT & ACCOUNTS 2015



A huge burden is placed on the spouse and partner; 60% report that their spouse or partner is the main caregiver.

The report also discovered that MS has a huge impact on a person's mental

health and wellbeing. A striking one in three people with MS had been diagnosed or treated for depression since their onset of MS and some 27% had been diagnosed or treated for anxiety, while the overwhelming majority (92%) reported having fatigue due to their MS.

The results also underscored the burden of MS on families and children. Of respondents, 61% said they felt they were not able to financially provide for their children as much as they would like to; one third (33%) reported that their MS impinged on their children and 73% felt their children worry excessively about their parents' health.

Of the 595 respondents surveyed, 41% reported having a relapse in the previous year, with 1.83 relapses reported in the past 12 months on average. As a result of their most recent relapse, 47% of respondents said they rang or visited their GP and of these, 18% were admitted to hospital. The report discovered the indirect costs of a relapse are on average €1,101. The report notes that reducing relapses among those who live with MS would result in saved resources.

The report revealed that MS is associated with high costs, many of which are outside

the healthcare system. Indirect costs include time lost from work, care needs, and transport amounted to an average of $\in 23,754$ per person with MS each year. Intangible costs – an economic value of the lost quality of life per year – amount to, $\notin 9,039$.

The research highlights the need for access to interventions that reduce relapses, disability progression, and support working and living independently. It also highlights the need for improved employment opportunities and adoption of flexible work practices, as well as acknowledgement of the unpaid work carried out by carers. The analysis examined different ways of reducing the impact of MS and showed how reducing the number of relapses experienced by those with MS could save upwards of €10 million each year.

When it comes to indirect costs, MS greatly affects employment. Employment is lower in the MS population than in the general population at just 43% and is lower for men than women. One third of people with MS reduced their working hours due to their condition, while another 25% have retired on medical grounds.

The report was launched at an event in the National Gallery in Dublin. Ava Battles, CEO of MS Ireland, opened the event and the findings of the report were presented by neurologists Dr Chris McGuigan and Dr Killian O'Rourke. Joan Jordan, MS & Me blogger and EUPATI trainee also read out one of her blogs.

Data from the report will inform our advocacy and lobbying work in 2016 and beyond.

MS IRELAND ANNUAL REPORT & ACCOUNTS 2015

UNIVERSITY OF LIMERICK – PHYSIOTHERAPY RESEARCH

Our collaboration with the University of Limerick continued to progress and develop in 2015. Projects carried out in 2015 are:

FALLS PREVENTION

A systematic review and meta-analysis is being undertaken relating to the difference in gait variables between people with MS and healthy control subjects. Data collection/extraction was completed in 2015.

75 people participated in a phone-based survey of people with MS who have experienced a recent fall, regarding the context of their most recent fall alongside what they would like to see included as part of a future falls prevention intervention in order to inform development. Preliminary results from this study were presented in Portland Oregon at a conference relating specifically to gait and balance disorders in people with MS. Simultaneously semistructured interviews were conducted with physiotherapy clinicians with varying experience in treatment for people with MS. Five interviews were carried out in 2015.

The Smartphone study, involving a questionnaire and a timed walk assessment and filling out falls diaries for a period of three months, was run throughout 2015. Initial analysis shows that 46% of the group were fallers and that the timed gait test (TUG) alone is not sufficient to differentiate between fallers and non-fallers, but further analyses looking at all items on the questionnaire and the instrumented data will be used to develop a fall risk algorithm that can reliably predict those at risk of falling.

ACTIVITY MATTERS

The 'Activity Matters' project aims to change physical activity behaviour in the MS population through the medium of a web and paper based resource. Qualitative interviewing was conducted with a range of people with MS with a range of mobility and activity levels, and a pilot website has been developed. An international collaboration with a Canadian university was established after attending a meeting in Boston in adjunct to presenting the 'Activity Matters' research in a conference in Indianapolis in May 2015. This collaboration aims to conduct a systematic review of the literature to establish the key factors that influence physical activity behaviour in people with MS.

STEP IT UP

The Step it Up project is funded by the Health Research Board and is a collaboration between the MS team at the University of Limerick and Prof Rob Motl, a well-known exercise researcher from the University of Illinois at Urbana Champaign. Researchers at UL began recruiting people with MS into the Step it Up exercise and education programme in September 2014 and recruitment continued until May 2015.

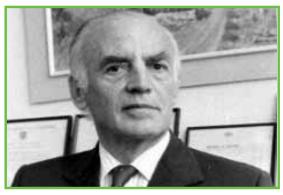


DEAN MEDAL

MS Ireland established the Dean Medal in 2011 to honour the life and work of Dr Geoffrey Dean, a renowned MS scholar. The aim of the award is to enable new MS researchers to travel to centres of excellence to enhance their understanding and knowledge of MS.

MS Ireland was delighted to award the second Dean Medal Travel Bursary in 2015. The successful applicant was Dr Nonnie McNicholas from St Vincent's Hospital who is planning to travel to the Karolinska Instituet in Sweden to further her research into the measurement of cerebrospinal fluid biomarkers indicative of disease progression in people with MS.





INTERNATIONAL PROGRESSIVE MS ALLIANCE

PROGRESSIVE MS ALLIANCE

CONNECT TO END PROGRESSIVE MS

The International Progressive MS Alliance is an international alliance working to advance research on progressive MS, both primary and secondary, and to improve the lives of people with progressive MS. In 2015, two MS Ireland branches contributed €7,000 between them to the work of the Progressive MS Alliance.

PARTICIPATING IN RESEARCH

Each year we ask the MS community to participate in ongoing research. In 2015 we asked you to participate in a number of studies, many of which are ongoing still, to try to help shine a light on symptoms, treatments and possible causes and cures for MS. Here are some of the studies we asked you to take part in.

- » National Irish Incidence Study
- » Global MS employment survey
- » Maternity Care survey
- » Understanding Fatigue in Paediatric MS
- » Managing Bladder Dysfunction
- » Study investigating the impact of exercise on the immune system and cognition
- » Cognitive Rehabilitation study



Build and strengthen MS Ireland's organisational capacity to ensure delivery of our strategic plan.

ACHIEVING IN ORGANISATIONAL CAPACITY

IN 2015, THIS IS WHAT WE ACHIEVED IN ORGANISATIONAL CAPACITY

ACHIEVING IN ORGANISATIONAL CAPACITY

NEW STRATEGIC PLAN 2015-2019

An external consultant facilitated a workshop with regional staff, a workshop with the Senior Management Team and a workshop with the Board on the strategic direction of the organisation. A SWOT analysis was completed. We identified the Strategic Priorities for 2015-2019 and produced an Operational Plan for 2015 and 2016.

RESOURCE ALIGNMENT

The situation in relation to statutory and fundraised income remains challenging. In 2015 the Senior Management Team prepared a sustainable model for service delivery for the Board. In addition, the following measures remained in place:

- » Staff hours remained curtailed across the organisation.
- » Reduced opening hours at the MS Care Centre remained.
- » Budgets were again reduced and monitored closely.
- » Local Branches were asked to continue their contribution of 15% of net assets at the end of year accounts to support local services.

INTEGRATED MODEL OF SERVICE

2015 was the fourth year of the integrated model of working whereby local voluntary Branches and regional staff worked together to plan, organise and fund services for their respective areas. Significant developments occurred this year as more Branches than ever participated in meetings and contributed financially to the provision of Regional services. In each of our 10 regional areas regional integrated meetings took place at least twice a year and often had a senior manager from National Office in attendance. These meetings led to a number of outcomes:

- » Better use of monies available as resources are pooled
- » More targeted services as service users are more involved in planning
- » Improved planning as skills, materials and equipment are pooled
- » Improvement in communications

15 Regional Integrated Meetings took place in 2015

ACHIEVING IN ORGANISATIONAL CAPACITY

VOLUNTEERING



MS Ireland would not exist without the invaluable support of volunteers around the country. The majority of our volunteers work within our voluntary Branch Network, directly supporting people affected by MS. Many more volunteers support us at fundraising events, administration work and increasingly through workplace volunteering schemes.

VOLUNTARY BRANCHES

Our voluntary Branches are a support network for people and families living with MS in local communities. They provide a welfare service, access to various therapies and organise various social gatherings.

CORPORATE VOLUNTEERS

The growth in corporate volunteering has had a wonderful impact as many organisations actively support their employees volunteering work time to MS Ireland and other charities. In 2015 we benefited from the time and talents of many employees from a number of big and small workplaces throughout the country. From administration to gardening to online marketing, we are indebted to the generosity of employers and employees alike.



MS IRELAND ANNUAL REPORT & ACCOUNTS 2015

CORPORATE SERVICES

HUMAN RESOURCES

Recruitment during 2015 concentrated on replacing necessary leavers or unfilled posts. The following posts were recruited in 2015:

Head of Fundraising, Corporate Fundraiser, Accounts Payable Officer, Admin Support Worker (contracted to the HSE), Information, Advocacy & Research Officer

Employee Relations: The organisational wide pay freeze continued in 2015 whilst a number of staff continued to work reduced hours. As always we are extremely grateful to all our staff and their representatives for their overall commitment and continued good will and understanding in this regard.

Internships and Volunteers: MS Ireland continues to utilise a number of interns and volunteers in National Office. Each brings their own skill set to the society which contributes greatly to our work. **Company Pension Scheme:** The trustees of the scheme met in July to review scheme performance and to review the trustee annual and administration reports. There were no issues arising.

Staff training: In March, a one-day training programme was delivered in the Care Centre covering solution focused training and stress management among other issues. In September, service staff attended the information day for healthcare professionals. Ongoing FETAC Level 5 training in Health Skills related areas was carried out in the three Community Employment schemes operated by MS Ireland. Time was also given to staff to complete self-funded training, in line with company policies.

INFORMATION & COMMUNICATIONS TECHNOLOGY

A review of the use of Salesforce, our CRM system, took place in 2015. Training was facilitated for regional administrators on Salesforce use. The Care Centre was added to Salesforce for the first time in 2015.

Along with assisting us in the management of our key relationships with donors and service users, Salesforce provides us with valuable user profiling information which in time will contribute to more relevant client led engagements and in particular improvements in our service planning.



ACHIEVING IN ORGANISATIONAL CAPACITY

PUBLIC RELATIONS

Raising awareness of multiple sclerosis and MS Ireland's services and campaigns amongst the public is an important part of our work to support the MS community in Ireland. Included below are the PR campaign and media highlights from 2015.

'TOGETHER WE'RE STRONGER THAN MS' TO LAUNCH WORLD MS DAY 2015

World MS Day 2015 launched under the banner 'Together we're stronger than MS'. Ireland's women's rugby stars Ailis Egan, Hannah Tyrrell and Jenny Murphy pledged their support to World MS Day, with the team players championing the #strongerthanMS campaign. The campaign generated strong national coverage in The Irish Times, Irish Star, TheJournal.ie, UTV Ireland X 2 with World MS Day radio interviews across 16 stations including Dublin, Galway, Clare, Kildare, Tipperary, South East region, Louth and Meath. There were 34 World MS Day articles with photographs in regional newspapers, giving a combined reach of 1,834,862.

VHI WOMEN'S MINI MARATHON

MS Ireland's campaign for the Women's Mini Marathon was picked up by two national publications (RTÉ Guide, Irish Sun), six regional publications (Evening Echo, Nationalist and Munster Advertiser, Tipperary Star, Meath Chronicle, Limerick Post, Southern Star) and one online (lifeandfitnessmag.ie).



'ACCESS TO MEDICINES' CAMPAIGN HANDBOOK

In August 2015, then Minister for Health, Leo Varadkar announced the launch of the 'Access to Medicines' Campaign Handbook produced by Multiple Sclerosis Ireland. The launch generated strong media coverage with an Irish Times interview and two articles as well as The Sunday Independent, Irish Daily Mirror, Irish Examiner, Evening Echo, Irish Medical Times, Life and Fitness Magazine and a number of regional publications.

MS IRELAND ANNUAL REPORT & ACCOUNTS 2015

PUBLIC RELATIONS

FOUR QUINN BROTHERS RUN NYC MARATHON FOR MS IRELAND

Four brothers, Sean, Brian, Frank and Michael Quinn, from Tyrone, announced their return to New York 35 years on, to participate in the New York City Marathon on 1st November 2015, after running it together in 1980. The Quinn brothers, now in their sixties, took part in the marathon to raise funds for MS Ireland. The Quinns were the first set of four brothers in the world to run a marathon together when they ran the NYC Marathon in 1980. At the time their story received widespread media attention with the New York Times, New York Daily News and news networks ABC, CBS and NBC featuring it in the lead-up to the race.

The Quinns appeared on the Late Late Show and their fundraising for MS Ireland attracted widespread national and local media coverage.



MS READATHON 2015

For the second year running popular TV Show Moone Boy actors David Rawle and Ian O'Reilly agreed to be MS Readathon ambassadors. There was support as always from Irish authors who provided great content on reading and books. Highlights included an Irish Times feature on MS ambassador family Lucina Russell and her twins Mya and Leon and on reading, with teacher and author interviews as well as Newstalk radio, RTE News2Day Swipe TV and strong national and regional media coverage across print and online.

NEUROLOGY SUPPLEMENT IN THE IRISH INDEPENDENT

MS Ireland worked closely with organisers of a neurology supplement in the Irish Independent, which published in November 2015, to set up key neurologist interviews, supply up to date information and raise awareness of MS and core issues.

KISS GOODBYE TO MS

December 2015 saw preparations begin for a new campaign in 2016, Kiss Goodbye to MS.

MEMBERSHIP

At the end of 2015 our membership stood at **4,613**

MS IRELAND ANNUAL REPORT & ACCOUNTS 2015

ACHIEVING IN ORGANISATIONAL CAPACITY

PARTNERSHIPS & COLLABORATIONS

Working in partnership with those who share a common interest is an essential part of MS Ireland's work. To provide, change and develop services and practices we are proud to collaborate with the following organisations to achieve what we do for people with MS.

SIGNIFICANT PARTNERSHIPS IN 2015

- » The HSE and other state bodies such as The Department of Social Protection and Pobal, regarding funding.
- » The University of Limerick (UL), the National University of Ireland, Galway (NUIG), the Medical Research Charities Group (MRCG), Irish Platform for Patients Organisations, Science and Industry (IPPOSI) and Health Research Board (HRB) regarding research and professional information.
- » The Neurological Alliance of Ireland regarding the campaign for increased investment in neurological services, neurorehabilitation and Brain Awareness Week. MS Ireland's CEO Ava Battles also became Chair of NAI in 2015.
- » Care Alliance for Carers Week.
- » The Disability Federation of Ireland (DFI) in the areas of health sector cuts, governance, rehabilitation, neurological funding, preparation for Election 2016, housing and accommodation and disability rights.
- » The European Multiple Sclerosis Platform (EMSP), the Multiple Sclerosis International Federation (MSIF) and the International Progressive MS Alliance in the areas of policy, common goalsetting, research and governance.
- » Each of the six pharmaceutical companies; Bayer Healthcare, Biogen Idec, Genzyme, Merck Serono, Novartis, and TEVA regarding funding and educational projects and activities.

ANNUAL AWARDS

Our national awards are a way of recognising the contribution the MS community makes in towns and villages across Ireland. Each year volunteers and staff nominate those who make a difference in their own lives and the lives of others. In 2015 three worthy winners were picked from the many wonderful applications. Congratulations to them, their families and the MS communities they work in.



MS Person of the Year Maura Maye (centre)



Carer of the Year Janet Lambe (right)



Volunteer of the Year Irene Barry (right)

WORLD MS DAY

deck, coffee and freshly-baked cakes for all who came along.

banner 'Together we're #StrongerThanMS'. The theme was Access – access to medicines, to information, to tools, services and facilities. Thank you to everyone who joined the global movement and helped raise awareness of MS around the world.

In 2015 across the globe World MS Day

(27th May) marked its sixth year under the

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A range of events and activities were held up and down the country, spreading awareness, raising issues, funds and lots of smiles. Here is a snapshot of what happened on the day!

DUBLIN: We kicked off World MS Day with an early silent disco at Grand Canal square! Our North Dublin Regional Office held a bucket collection in the Pavilions Shopping Centre in Swords.

CORK: Our Southern Regional Office organised a rock 'n' roll bingo afternoon and the Cork Physio Group held a Celebrity Dress up night.

DONEGAL: Coffee mornings held throughout the county.

LIMERICK: Our Midwest Regional Office held an Open Day at Tara with a BBQ on the **LOUTH:** Our Louth Branch hosted a coffee morning and everyone attending had the opportunity to take a 'selfie' on the day.

GALWAY: Our Western Regional Office hosted an information evening and seminar with a fantastic line-up of speakers.

KILKENNY: Our South East Regional Office organised a pop up shop on the day, spreading the World MS Day message to everyone in Kilkenny.

MAYO: Meet up and a cuppa in Café Clay.

WICKLOW: Our East Wicklow Branch hosted an evening of short story readings by the St. Killian's Writers.

MS CARE CENTRE: held their annual fun day in Bushy Park Road. Coffee, home-baked cakes and live entertainment meant a great day out for all!

COFFEE MORNINGS: Coffee mornings were the order of the day for many areas around the country and what better way to get people together and have a cuppa and a chat than on World MS Day.

MS IRELAND ANNUAL REPORT & ACCOUNTS 2015





READATHON 2015

15,000 readers and 460 schools took part in Readathon 2015, raising a fantastic €500,000. We were delighted to once again have Moone Boy's David Rawle and Ian O'Reilly on board as ambassadors. Our ambassador family this year were Lucina Russell and her children Leon and Mya.

FRIENDS OF THE MS CARE CENTRE

Support for our respite and therapy centre grew this year with so many wonderful corporate partners coming on board. In addition to donations and fundraising events we had lots of volunteers this year helping out in all sorts of areas, from music to painting and gardening.



TREKS

Mount Kilimanjaro and Morocco were our exciting and rugged destinations for our 2015 treks. 47 wonderful trekkers took up the challenge and raised funds and awareness in their local areas.

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VHI WOMEN'S MINI MARATHON

Over 500 women ran the mini marathon for Team MS Ireland in June.



Image: Image:

WORLD MS DAY

Numerous fundraising events took place up and down the country on World MS Day, including bucket collections and coffee mornings.

SKYDIVE

In 2015 we had 39 adrenalin junkies take to the skies and complete skydives to raise money for local services. Jumping in the Irish Parachute Centre in Offaly, families and friends came along for moral support and to cheer on our brave jumpers.



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GALWAY'S FITTEST WORKPLACE

A total of 30 businesses from across Galway took part in the inaugural "Galway's Fittest Workplace" competition. Each business entered a team of four employees and subsequently raised funds for MS Ireland as their "entry fee". In total approximately €22,000 was raised.

The teams were professionally trained twice a week, for six weeks in a Kingfisher Club in Galway and then tested in competition against all others in a live final. The Kingfisher Group donated their time and services to MS Ireland free of charge in support of the event. The live final was held in February in the Sports Complex in NUIG

This event has the making of being a successful annual fundraiser for MS Ireland.





CORPORATE DINNER

MS Ireland's Corporate Dinner took place on 23rd July at Leopardstown Racecourse.

FESTIFY

MS Ireland's Christmas fundraising campaign was Festify, encouraging supporters to festify their desks, their pets, their home or themselves and post a picture on social media with a text donation.





MARATHONS

Brothers Sean, Brian, Frank and Michael Quinn ran the New York Marathon for MS Ireland in 2015, raising an incredible €40,000.

2015 CALENDAR

Our third national image competition ran in 2015 to find 12 beautiful images for our 2016 calendar. The 2016 calendar featured 12 stunning images of birds, sent in by very talented amateur photographers from all over the country.

EASTER EGG RAFFLE

David Dunne, with the help of other postmasters in the Dublin area, raised €18,000 in much needed funds for the Care Centre with his annual Easter Egg Raffle.

SUMMER RAFFLE

Our annual raffle took place in June and was supported by thousands of people around the country.

AFFILIATES & PARTNERSHIPS

YOU!

2015 was a wonderful year of support from the business community who showed their commitment to the local community in their areas. Particular mention goes to the Airtricity Dublin Marathon who made MS Ireland their charity partner for 2015. Many thanks also to all the other companies who made donations, volunteered staff time for projects and organised fundraising events in 2015.

AND MANY MORE.....

THANK Big THANKS to all our fundraisers, donors and supporters for their generosity throughout 2015. We couldn't do it without you!

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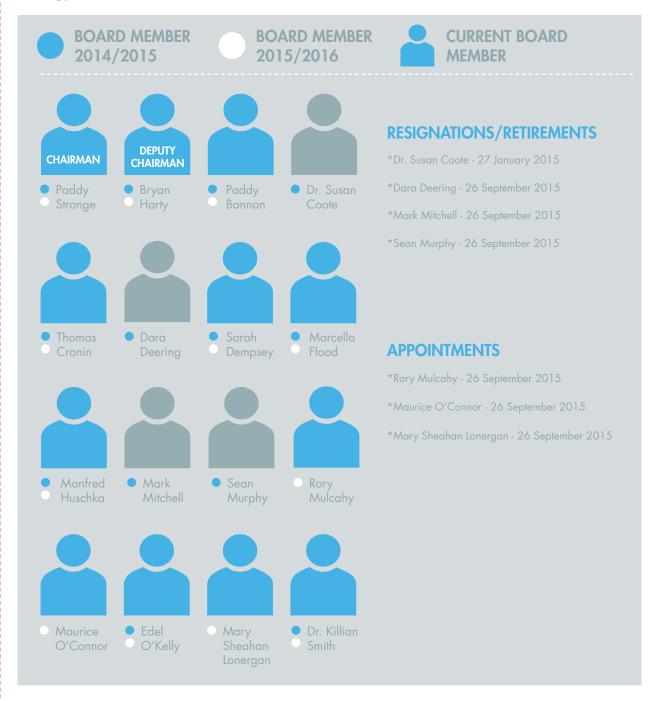
Continue to strengthen the governance and regulation of MS Ireland, ensuring compliance with relevant regulatory bodies.

ACHIEVING IN GOVERNANCE & REGULATION

IN 2015, THIS IS WHAT WE ACHIEVED IN GOVERNANCE AND REGULATION.

THE BOARD

MS Ireland is governed by a board of 12 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, legal 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 2015, the Board met six times. Significant work was carried out in the areas of finance, funding, governance and strategy.



MS IRELAND ANNUAL REPORT & ACCOUNTS 2015

THE BOARD

BOARD COMMITTEES

A number of Board committees inform and complement the work of the Board. Each committee is made up of board members and others who have particular interests, experiences and knowledge. The Board Committees include the following:

- » Finance, Audit and Risk Committee
- » Governance Committee
- » Nominating Committee
- » Remuneration Committee
- » Research Committee
- » Services Monitoring & Evaluation Committee
- » Sustainability Committee

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

BOARD ATTENDANCE 2015

*Technical fault unable to connect via conference call

	31 JAN	28 MAR	23 MAY	18 JUL	26 SEP (i)	26 SEP (ii)	28 NOV
Paddy Bannon	\checkmark	\checkmark	\checkmark	\checkmark	×	×	*
Susan Coote	n/a						
Thomas Cronin	\checkmark						
Dara Deering	\checkmark	\checkmark	\checkmark	×	\checkmark	n/a	n/a
Sarah Dempsey	\checkmark	×	\checkmark	×	\checkmark	×	\checkmark
Marcella Flood	\checkmark	×	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
Bryan Harty	\checkmark	\checkmark	×	\checkmark	\checkmark	\checkmark	\checkmark
Manfred Huschka	\checkmark	\checkmark	\checkmark	×	\checkmark	\checkmark	x
Mark Mitchell	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	n/a	n/a
Rory Mulcahy	n/a	n/a	n/a	n/a	n/a	\checkmark	\checkmark
Sean Murphy	\checkmark	\checkmark	×	×	\checkmark	\checkmark	n/a
Maurice O'Connor	n/a	n/a	n/a	n/a	n/a	\checkmark	\checkmark
Edel O'Kelly	\checkmark	\checkmark	×	×	\checkmark	\checkmark	\checkmark
Mary Sheahan-Lonergan	n/a	n/a	n/a	n/a	n/a	\checkmark	\checkmark
Killian Smith	\checkmark	×	\checkmark	×	\checkmark	\checkmark	x
Paddy Stronge	\checkmark						

Martin Nolan, Chairman of Finance Audit and Risk Committee, is a standing invitee of the Board and attends Board meetings

MS IRELAND ANNUAL REPORT & ACCOUNTS 2015

GOVERNANCE/ ADMINISTRATIVE DETAILS

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 overall execution of the Society's vision and financial dealings. 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.

In 2015 we submitted the required information on MS Ireland to the Charities Regulatory Authority. Our Charity Regulatory Authority number is: 20007867; Our Charity Number is: CHY 5365; Company Registration Number is: 296573.

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 2015 the Council met twice nationally. All Branches are represented on the Council. Three Council members are elected by Council representatives and sit on the Board of Directors.

VOLUNTARY BRANCHES

At the end of 2015 we had 38 voluntary Branches operating across Ireland. See pages 10 & 11 for more information on the wonderful work of our Branches.

PATRON

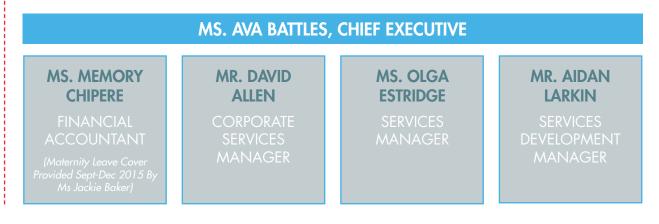
MS Ireland is delighted to have Micheal D. Higgins, President of Ireland, as sole patron.

MANAGEMENT & 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. 72 people work for MS Ireland on a permanent basis in a number of locations around Ireland. A further57 people work with MS Ireland on a number of community employment projects operated by Solas. MS Ireland's work is supported by committed volunteers around the country.

LOBBYING REGULATIONS

In September, MS Ireland registered as a lobbying organisation in accordance with The Regulation of Lobbying Act 2015. This means we will now complete quarterly returns on all our lobbying activities.

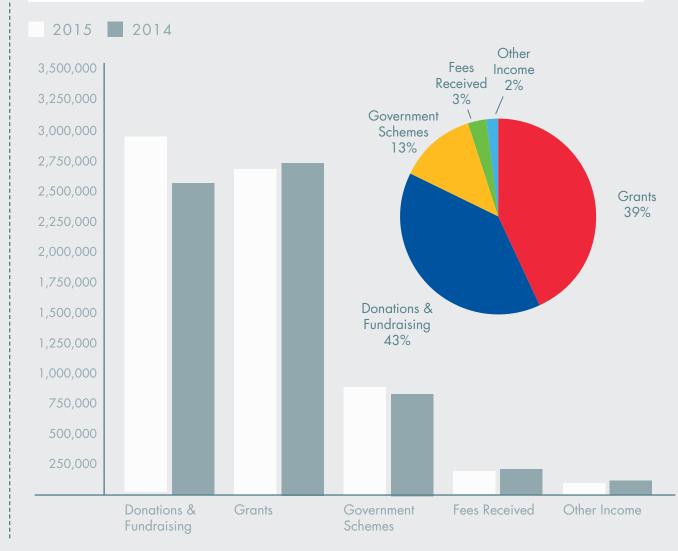


MS IRELAND ANNUAL REPORT & ACCOUNTS 2015

ACHIEVING IN GOVERNANCE & REGULATION

INCOME ANALYSIS 2015: €6,800,467

	2015	2014
Donations & Fundraising	2,940,169	2,520,469
Grants	2,656,718	2,739,429
Government Schemes	874,709	859,593
Fees Received	215,041	228,735
Other Income	113,830	137,905
TOTAL	6,800,467	6,486,131

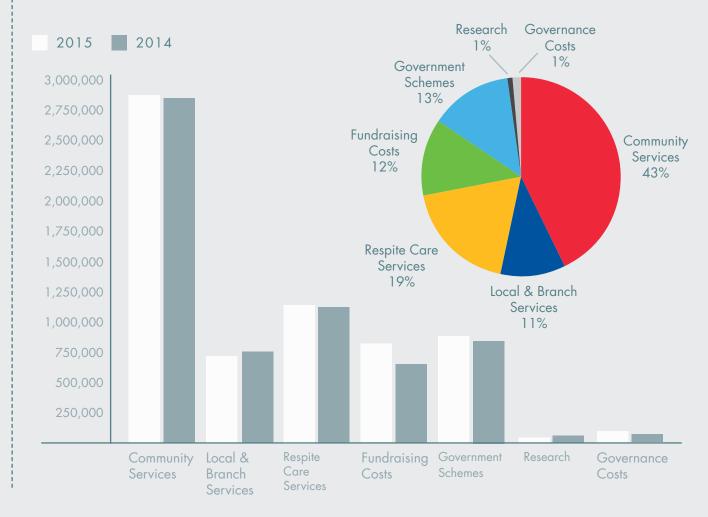


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ACHIEVING IN GOVERNANCE & REGULATION

EXPENDITURE ANALYSIS 2015: €6,586,619

	2015	2014
Community Services	2,823,095	2,811,531
Respite Care Services	1,229,041	1,218,938
Government Schemes	878,570	866,157
Fundraising Costs	809,448	706,603
Local & Branch Services	704,011	738,072
Research	83,843	66,994
Governance Costs	58,611	61,000
TOTAL	6,586,619	6,469,295



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An Roinn Tithíochta, Pleanála, Pobail agus Rialtais Áitiúil Department of Housing, Planning, Community and Local Government



Find us on: facebook. twittery You Tube

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