

MS IRELAND
ANNUAL
REPORT &
ACCOUNTS
2016



MISSION, VISION AND AIMS

MISSION

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

VISION

MS Ireland has a vision of Irish society where all people affected by MS live positive and active lives in the community

AIMS

The principal objectives for which MS Ireland exists are:

- » to facilitate people with MS to control their lives and environment, to live with dignity and participate 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 cause of, cure for and management of MS, and the alleviation of medical and social symptoms
- » to exchange and disseminate information relating to MS
- » to provide an identifiable focal point by developing an efficient, effective and caring organisation to serve the needs of people affected by MS

A consultation process with our stakeholders will take place during 2017 to develop MS Ireland's organisational values.

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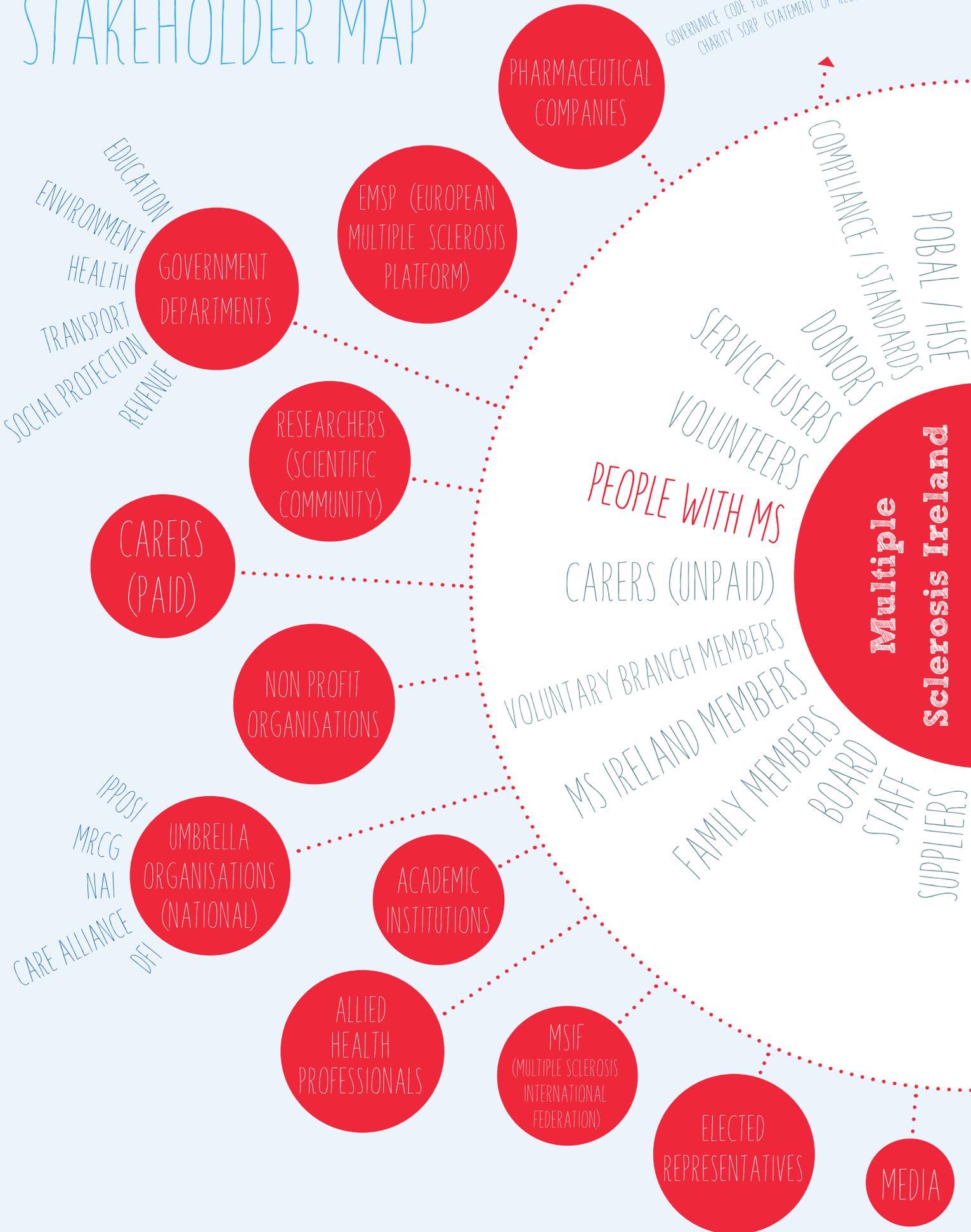
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ACHIEVING IN GOVERNANCE & REGULATION

MS Ireland

STAKEHOLDER MAP

STATEMENT OF GUIDING PRINCIPLES FOR FUNDRAISING
HIQA (HEALTH INFORMATION & QUALITY AUTHORITY)
CRO (COMPANIES REGISTRATION OFFICE)
CHARITIES REGULATORY AUTHORITY
GOVERNANCE CODE FOR THE COMMUNITY AND VOLUNTARY SECTOR
CHARITY SORP (STATEMENT OF RECOMMENDED PRACTICE)



EDUCATION
ENVIRONMENT
HEALTH
TRANSPORT
SOCIAL PROTECTION
REVENUE

GOVERNMENT DEPARTMENTS

EMSP (EUROPEAN MULTIPLE SCLEROSIS PLATFORM)

PHARMACEUTICAL COMPANIES

RESEARCHERS (SCIENTIFIC COMMUNITY)

CARERS (PAID)

NON PROFIT ORGANISATIONS

IPPOSI
MRCG
NAI
CARE ALLIANCE
DFI

UMBRELLA ORGANISATIONS (NATIONAL)

ACADEMIC INSTITUTIONS

ALLIED HEALTH PROFESSIONALS

MSIF (MULTIPLE SCLEROSIS INTERNATIONAL FEDERATION)

ELECTED REPRESENTATIVES

MEDIA

PEOPLE WITH MS
CARERS (UNPAID)
VOLUNTARY BRANCH MEMBERS
MS IRELAND MEMBERS
FAMILY MEMBERS
BOARD
STAFF
SUPPLIERS

SERVICE USERS
VOLUNTEERS
DONORS

COMPLIANCE / STANDARDS
POBAL / HSE

Multiple Sclerosis Ireland



WORKING TOGETHER

CHIEF EXECUTIVE & CHAIRPERSON 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, students 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 2016. 2016 has been a challenging year in many ways, with continued constraints on our funding and resources and several high profile cases of poor governance in charities hitting the news, which has done serious damage to public confidence in the sector. Despite this, MS Ireland's dedicated team of staff and volunteers have continued to work hard on behalf of people affected by MS, and there are many successes and achievements to celebrate.

2016 saw the publication of the 100th issue of MS News, our bi-annual magazine which has been providing a forum for discussion on news and opinions relating to MS since 1980. In June, we launched three key publications relating to employment and MS. The employment resources were launched at a well-attended event at the Mansion House in Dublin, by the Minister for Jobs, Enterprise and Innovation. We have also made some major advances in our advocacy and lobbying work in 2016, with a number of policy submissions made including a Pre-Budget Submission, a submission on Medical Cards and a contribution to a Department of Social Protection

consultation on work and disability. We have collaborated successfully with other organisations on various high profile campaigns including the Neurological Alliance of Ireland's 'We Need Our Heads Examined' campaign for neurorehabilitation services, a campaign calling for investment in home care services and the Disability Federation of Ireland's Disable Inequality campaign. We used the 2016 General Election to highlight issues of importance for people affected by MS, with our 'Make Your Vote Count' leaflet proving very popular and successful.



CHIEF EXECUTIVE & CHAIRPERSON WELCOME

The MS Information Line, MS Care Centre and our regional services continue to be very busy, providing vital support, information and services to the MS community despite very limited resources. World MS Day 2016 was a great success, with our team using the theme of 'independence' to highlight issues such as employment and the importance of exercise. We also launched a new fundraising initiative on World MS Day, '9,000 Steps for MS', with the number 9,000 representing the number of people with MS in Ireland.

We held our second MS Research Explored evening in November, and our annual conference and Healthcare Professionals Day took place in September in Cork. The theme for both the conference and Healthcare

Professionals Day was once again 'Living Well With MS', with a particular focus on brain health. We have made use of live streaming and recording at all our major conferences and events this year, so as to reach as wide an audience as possible.

Research remains central to the organisation and we were delighted to launch a brand new bi-annual research eZine in 2016, as well as the publication of a Research Strategy for 2015-2019. Over 800 people took part in our My MS My Needs survey, a major piece of research which will inform our advocacy work and service development in coming years. We were also delighted to be able to provide funding for a two-year project at NUI Galway investigating mindfulness and MS, thanks to the generosity of an individual donor.

CHIEF EXECUTIVE & CHAIRPERSON WELCOME

Our Fundraising team launched Kiss Goodbye to MS, a major new annual fundraising campaign, in February. This raised a fantastic €53,000 and we hope to build on this success in 2017 and beyond. Other fundraising activities included skydives, treks, the ever-popular Women's Mini Marathon, the Corporate Dinner at Leopardstown Racecourse and of course our biggest annual fundraiser, the MS Readathon, now in its 29th year. We will look forward to marking the 30th year of the Readathon in 2017!

Our MS & Me Blog team covered topics on independence, MS around the world, apps, well-being, research and many other topics of importance to the MS community. The MS & Me Blog is now three years old and we are incredibly proud of our team of Bloggers on their success to date – in 2016, MS & Me was a finalist in the Littlewoods Ireland Blog Awards. In recognition of all their hard work and achievements on behalf of MS Ireland, we were also delighted to award the MS & Me Blog team the Volunteer of the Year award at our 2016 AGM.

None of our achievements in 2016 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 acknowledge and thank all our statutory and corporate funders and also every single individual or group who has donated to us or helped us to raise much needed funds

We anticipate more challenges and uncertainty for the organisation in 2017 but we will never lose sight of our vision, which is of an Irish society where all people affected by MS live positive and active lives in their community of choice. Through our service delivery, information provision, research, advocacy and campaigning, we will continue to strive towards realising this vision in the year ahead. With your support, this is achievable.

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



AVA BATTLES
CHIEF EXECUTIVE



PADDY STRONGE
CHAIRPERSON

STRATEGIC PRIORITIES

2016 was the second year of our 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.



GOVERNANCE & REGULATION

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



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.

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



ACHIEVING IN SERVICES

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

SPECIFIC OBJECTIVES:

- Enable and empower the Care Centre, regions and branches to deliver appropriate supports and services
- Develop a sustainable and quality community service in tandem with relevant stakeholders
- Develop a functional structure that supports branches in delivering services to the local community
- Provision of a quality respite service that is compliant, efficient and sustainable
- Provision of a confidential information line
- Quality, up to date, timely, accessible and accurate information will be available to all in a variety of media appropriate to the needs of the various audiences.
- Information will be shared across strategic alliances to ensure the most up to date information is available

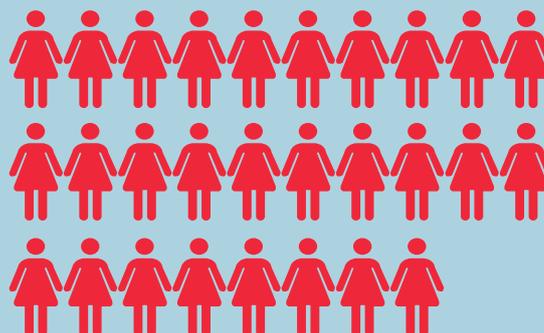
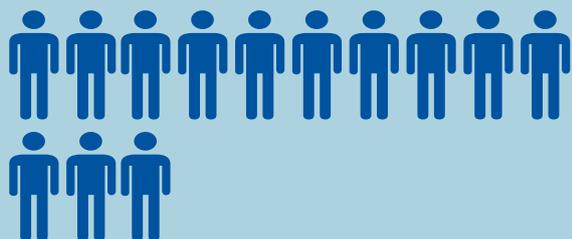
IN 2016, THIS IS WHAT WE ACHIEVED IN SERVICE PROVISION.

ACHIEVING IN SERVICES

THE MS CARE CENTRE

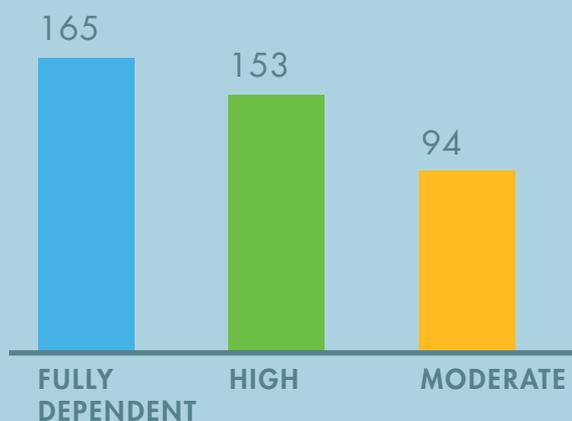
Our MS Care Centre is the only respite and therapy centre for people with MS in Ireland. Providing short-term respite care for people with MS, during a week-long stay a resident can avail of therapeutic services, neurological assessments, access to an MS nurse and a range of social activities to allow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

In 2016 the MS Care Centre provided professional, dedicated care for 412 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.

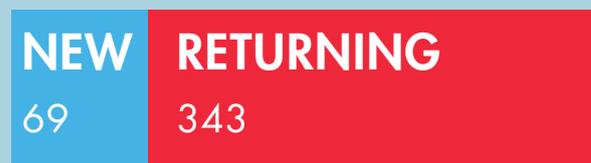


MALE: 128 **FEMALE: 284**

DEPENDENCY



NEW & RETURNING RESIDENTS



*SOME RESIDENTS STAYED TWICE OR MORE

PROFESSIONAL & THERAPEUTIC INTERVENTION



ACHIEVING IN SERVICES

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:



NEW KITCHEN



BUILDING SURVEY



GARDEN MAINTENANCE



PAINTING OF BEDROOMS & CORRIDORS

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.

MS Care Centre staff continue to work very hard to ensure the Centre is fully compliant with HIQA standards, following successful HIQA registration in 2015.

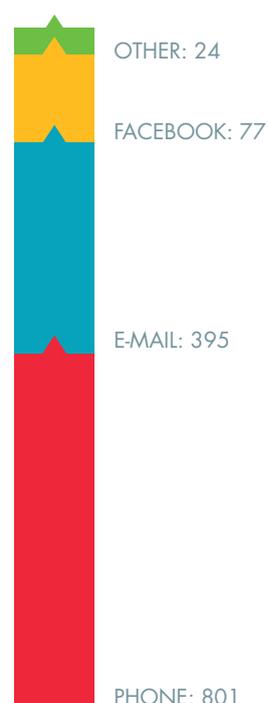


THE MS INFORMATION LINE

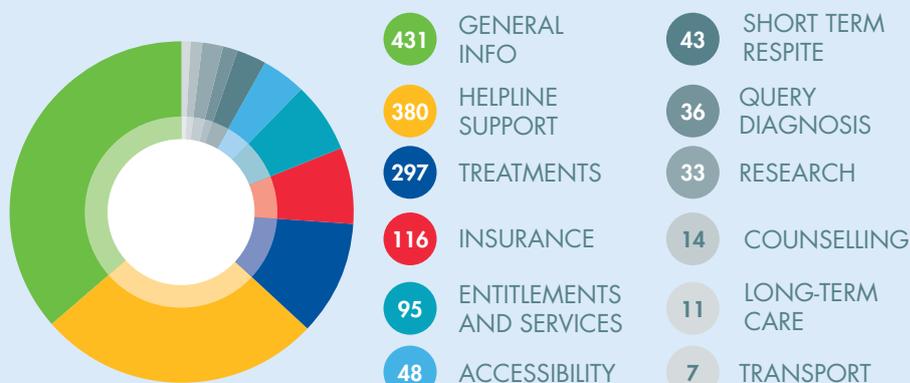
Operating weekdays from 10am-2pm, our dedicated information line provides professional, anonymous and confidential support for people with MS, their families, carers and health professionals.

In 2016, **1,297** people contacted the MS Information Line.

HOW PEOPLE MADE CONTACT



REASON FOR MAKING CONTACT



Please note that due to an IT error, statistics for the MS Information Line are only available from February to December 2016.

ACHIEVING IN SERVICES

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



ACHIEVING IN SERVICES

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.

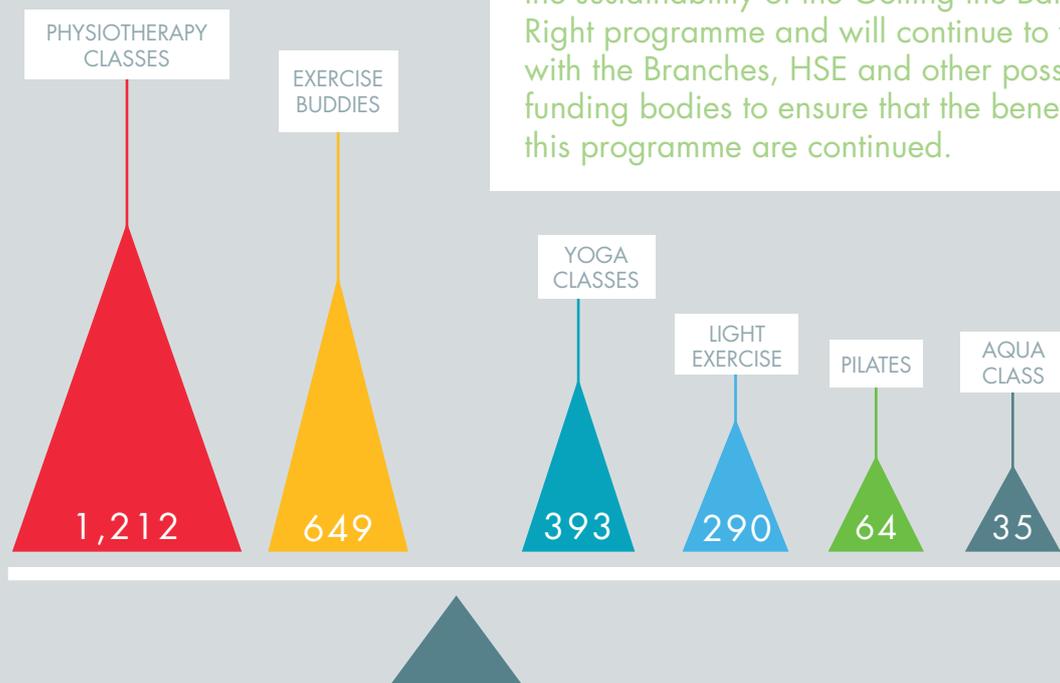
These programmes may be one-off sessions or a ten week course, depending on the nature of the programme. The figures to the right summarise the types of programmes we ran in 2016:

- 82 DIY/MAINTENANCE VISITS
- 76 PEER SUPPORT
- 63 SYMPTOM MANAGEMENT
- 53 COFFEE MORNINGS
- 23 SELF MANAGEMENT PROGRAMMES
- 11 ART CLASSES

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.

IN 2016 WE PROVIDED



MS Ireland continues to be committed to the sustainability of the Getting the Balance Right programme and will continue to work with the Branches, HSE and other possible funding bodies to ensure that the benefits of this programme are continued.



WORKING TOGETHER: AN INTEGRATED APPROACH

ACHIEVING IN SERVICES

VOLUNTARY BRANCH SERVICES WORKING TOGETHER

2016 was the fifth 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. 13 Regional Integrated Meetings took place in 2016.

For a breakdown of the income and expenditure of our branches, see page 61



ACHIEVING IN SERVICES

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

LIVING WELL WITH MS CONFERENCE

PRESENTATIONS ON THE DAY

MS Treatments Current and Emerging

Dr. Brian Sweeney

Strategies for Cognitive Reserve

Prof. Sabina Brennan

Exercise and its Relationship to Brain Health

Trish O'Sullivan,
Snr. Physiotherapist

Better Everyday Brain – Habits, Routines and Roles

Emer Duffy, Specialist
Occupational Therapist

Supporting Clinicians Working in the Area of Progressive Illness

Elaine King, Psychotherapist

Evidence for Cognitive Rehabilitation in MS
Shona Logan-King, RehabCare Galway

MS Brain Health and Time Matters
Professor Gavin Giovannoni

The Living Well with Multiple Sclerosis conference took place on 24 September at the Cork International Hotel. 240 people were in attendance and over 500 people watched via livestream. Afterwards, the videos of the presentations were uploaded to MS Ireland's website and have been viewed by nearly 1,300 people to date.

The first speaker of the day was Professor Gavin Giovannoni from Bart's Hospital, London who spoke about 'MS Healthy Brain: Time Matters'. He highlighted the importance of early diagnosis and treatment in MS and how people with MS can look after their brain health. Then Dr. Brian Sweeney from University College Cork gave an update on 'Current and Emerging Treatments'.

There then followed a series of workshops on cognition, exercise, communication and employment. The day then closed with Professor Sabina Brennan from Trinity College Dublin presenting on 'Strategies for Cognitive Reserve'.

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



ACHIEVING IN SERVICES

AGM 2016

MS Ireland's 2016 Annual General Meeting (AGM) was held on 24 September at the Cork International Hotel. Robin Bradley, Noelle Burke, Ian MacDougald and Anne Restan were elected to the Board. Thomas Cronin was appointed as the new Council Representative on the Board. Paddy Stronge was reappointed Chairperson of the Board.

Manfred Huschka and Sarah Dempsey stepped down from the Board and we would like to thank Manfred and Sarah for their diligent and passionate service to the Board of MS Ireland.



HEALTHCARE PROFESSIONALS INFORMATION DAY

MS Ireland hosted an information day for healthcare professionals on 23 September in Cork. The focus of the day was on multiple sclerosis and brain health, with specific sessions on strategies for cognitive reserve, exercise and brain health and every day strategies for brain health. 104 people attended.



ACHIEVING IN SERVICES

MS RESEARCH EXPLORED EVENT



MS Ireland and Novartis held an MS Research Explored event for people with MS on 17 November in Trinity College Dublin. 200 people attended the event and a further 70 watched via a live stream. The recording of the event was made available on MS Ireland's website afterwards, and a further 300 people watched it.



Dr. Nonnie McNicholas, MS Research Fellow, St Vincent's University Hospital presented 'Cognitive Impairment in Multiple Sclerosis'. Then Professor Eva Havrdova, Consultant Neurologist from Charles University, Prague spoke about the concept of NEDA (No Evidence of Disease Activity) in clinical practice. Finally Conor Kerley from Dublin City University presented on his research into diet and other lifestyle factors that may impact on MS.

Recordings of the presentations are available in the Research section of our website www.ms-society.ie

ACHIEVING IN SERVICES

SOCIAL MEDIA

Our social media channels continued to grow throughout 2016. Our 'Tuesday MS Questions' and 'Friday MS Quotes' on Facebook continue to be 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.

CONNECT WITH US



www.ms-society.ie

EXAMPLES OF TUESDAY MS QUESTIONS ARE:

"What is your biggest MS challenge?"

"Do you find it difficult to ask for help?"

EXAMPLE OF FRIDAY MS QUOTE:

"I am doing the best I can with what I have in this moment. And that is all I can expect of anyone, including me! MS is challenging every moment".



ACHIEVING IN SERVICES

MS NEWS MAGAZINE

Two editions of MS News were published in 2016 and distributed to over 10,000 homes, offices and clinics in Ireland. The spring edition focused on independence, with pieces on employment, physiotherapy and occupational therapy, neurorehabilitation, reporting side effects and advocacy. The autumn edition was our 100th issue, and featured a piece looking back at the 1st, 25th, 50th and 75th issues of MS News and what has changed for both MS Ireland and the general MS landscape since the first issue was published in 1980. The theme of the 100th issue was brain health, and featured articles on mindfulness, cognition and early treatment as well as conference reports and treatment updates.



eNEWS

Our electronic newsletter eNews was sent every month in 2016 to over 4,000 subscribers. eNews provides monthly updates on various aspects of MS research, services, events and developments. This year, eNews also featured a new monthly series on self-management, covering topics such as fatigue, exercise, stress, personal relationships and goal setting.

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 2016 there were 39 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 30 November in Dublin (kindly sponsored by Novartis). The aim of the event was to capture new ideas for 2017. Topics covered in 2016 include choosing an MS medication, partners of MS, parking, research, disclosing, dating, apps and MS Nurses.

We were delighted that MS & Me were finalists in the Littlewoods Ireland Blog Awards 2016 and we were also delighted to present the team with the Volunteer of the Year award at our AGM in September, in recognition of all their hard work.



IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Services in 2016:

ENABLE AND EMPOWER THE CARE CENTRE, REGIONS AND BRANCHES TO DELIVER APPROPRIATE SUPPORTS AND SERVICES

- 412 residents stayed in the MS Care Centre
- 427 individual physiotherapy sessions provided at the MS Care Centre
- 2,422 people engaged in one-to-one casework services

DEVELOP A SUSTAINABLE AND QUALITY COMMUNITY SERVICE IN TANDEM WITH RELEVANT STAKEHOLDERS

- Numerous group Living With MS programmes run including 76 Peer Support programmes, 63 symptom management sessions, 53 coffee mornings and 23 self-management programmes
- 1,212 Physiotherapy classes, 649 Exercise Buddies sessions and 393 Yoga classes provided by community services

DEVELOP A FUNCTIONAL STRUCTURE THAT SUPPORTS BRANCHES IN DELIVERING SERVICES TO THE LOCAL COMMUNITY

- 13 Regional Integrated Meetings carried out between local MSI staff and voluntary Branches

PROVISION OF A QUALITY RESPITE SERVICE THAT IS COMPLIANT, EFFICIENT AND SUSTAINABLE

- Maintenance and improvement works carried out by corporate volunteers at the MS Care Centre including new kitchen,

building survey, garden maintenance and painting of bedrooms and corridors

- Full compliance with HIQA standards at the MS Care Centre

PROVISION OF A CONFIDENTIAL INFORMATION LINE

- 1,297 people contacted the MS Information Line, by phone, email and social media

QUALITY, UP TO DATE, TIMELY, ACCESSIBLE AND ACCURATE INFORMATION WILL BE AVAILABLE TO ALL IN A VARIETY OF MEDIA APPROPRIATE TO THE NEEDS OF THE VARIOUS AUDIENCES

- Two issues of MS News, including special 100th issue
- eNews every month, including new monthly self-management series
- 39 MS & Me Blog posts
- 1,308 new followers on Twitter
- 2,596 new Likes on Facebook
- Living With MS conference with 240 people in attendance and over 500 people watching via livestream

INFORMATION WILL BE SHARED ACROSS STRATEGIC ALLIANCES TO ENSURE MOST UP TO DATE INFORMATION IS AVAILABLE

- Healthcare professionals event held with 204 HCPs in attendance
- MS Research Explored event held, in conjunction with Novartis, attended by 200 people with a further 70 watching via a live stream.



ACHIEVING IN 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.

SPECIFIC OBJECTIVES:

- To liaise and work with umbrella organisations (nationally and internationally) to create a more cohesive and united voice
- Strengthen current advocacy alliances and develop new links to harness the strength of shared visions
- Utilise data sets and service delivery experiences available to MS Ireland to inform our advocacy agenda
- People with MS will have access to effective treatments for their condition, including treatments which can slow, stop or reverse the accumulation of the disability
- To raise MSI's profile as a leading voice and resource for people with MS

**IN 2016, THIS IS WHAT WE ACHIEVED IN
ADVOCACY**

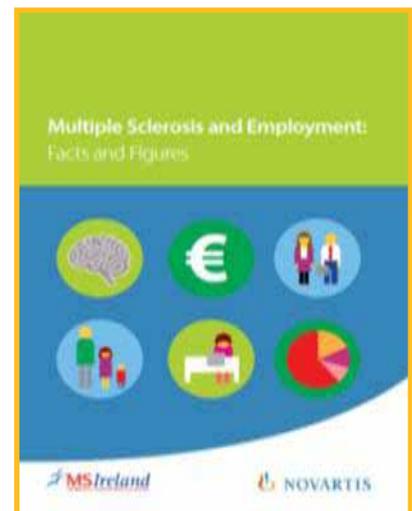
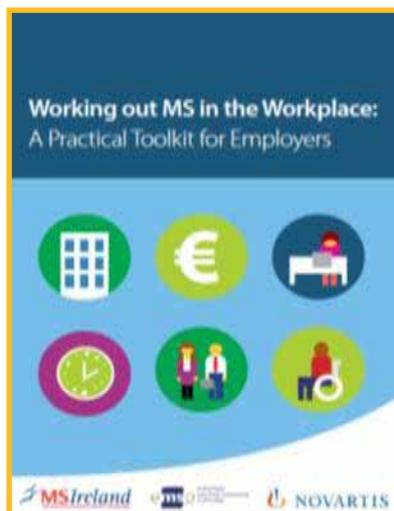
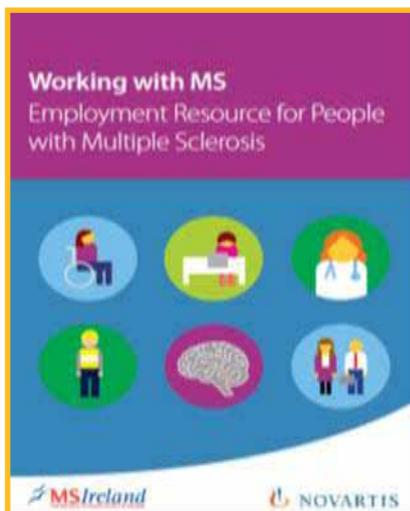


LAUNCH OF EMPLOYMENT RESOURCES

On 2 June, MS Ireland, supported by Novartis and Ibec, launched a set of practical employment resources to support people with MS and their employers. Mary Mitchell O'Connor TD, Minister of Jobs, Enterprise and Innovation, officially launched the resources. The resources, entitled: 'Working with MS: An Employment Resource for People with Multiple Sclerosis' and 'Working out MS in the Workplace: A Practical Toolkit for Employers', follow on from the 'Societal Cost of Multiple Sclerosis' report which was launched last year.

The resources were accompanied by a new report 'Multiple Sclerosis and Employment:

Facts and Figures' which drew on data from the Societal Costs of MS report and international data on MS and employment, and made detailed policy recommendations. The resources provide advice and guidance to people who are living with MS on issues such as whether they will be able to continue to work; discussing their diagnosis with their employer; managing career flexibility and change; and what legal rights they have. The resources also detail various financial supports available to employers to help with adaptations and change. The resources also include case studies from those living and working with MS.



ACHIEVING IN ADVOCACY

FOLLOW-UP ADVOCACY WORK ON EMPLOYMENT

Following the successful launch of the resources, MS Ireland met with the National Disability Authority and the Department of Social Protection to present the findings of the report and our recommendations. We presented on MS and employment retention at the Ibec Diversity Forum, which included companies such as Google and Bank of Ireland, and led a discussion group on employment retention at the Disability Federation of Ireland's Make it Work conference in November. As a result of our advocacy work, we also had the opportunity to make a submission to the Department of Social Protection's consultation on Making Work Pay.



ACCESS TO MEDICINES

FAMPYRA

Following the HSE's decision in late 2015 to reimburse Fampyra to those who satisfy a responder protocol, MS Ireland met with senior managers in the HSE in May to discuss concerns regarding the roll-out and delivery of the reimbursement system. We also produced a Frequently Asked Questions document about the reimbursement process for Fampyra.

SATIVEX

MS Ireland wrote to the Minister for Health twice in 2016 regarding the ongoing lack of availability of Sativex. We also highlighted this issue in the media several times during 2016.

LEMRADA AND TYSABRI

In 2016 MS Ireland continued to advocate regarding the need for a new funding

system for MS medications which are delivered via hospital-only infusion (currently Lemtrada and Tysabri) and therefore funded through individual hospital budgets. We wrote to the Minister for Health and both the Director General and the Chief Financial Officer of the HSE, highlighting the inequities in access that the current funding system causes and calling for the establishment of a centralized funding mechanism for these medications.

MS Ireland also wrote to VHI in March regarding their decision not to reimburse Lemtrada. We then warmly welcomed the decision by VHI in June to include Lemtrada in the specified drug section of the Schedule of Benefits for Private Hospital Service, for admissions on or after 1 June 2016.



ACHIEVING IN ADVOCACY

HOME CARE CAMPAIGN

MS Ireland joined forces with a group of 16 other NGOs in calling on the Government to invest in home care services in Budget 2017. The campaign held an event at Buswells Hotel on 27 September. Person with MS Sinead McArdle spoke at the event and to the media afterwards.

NEUROREHABILITATION

MS Ireland has continued to support the Neurological Alliance of Ireland's (NAI) campaign for development of neurorehabilitation services in 2016. MS Ireland is a member of an NAI working group which developed and launched the 'We Need Our Heads Examined' campaign, calling on the Government to invest in Ireland's critically underdeveloped neurorehabilitation services. The campaign launched officially on 23 June, and this was followed by a series of media, social media and lobbying activities including a meeting with Minister for Health Simon Harris on 3 November.



GENERAL ELECTION 2016

For the General Election in February, MS Ireland produced a leaflet to help people affected by MS to get involved and make the most of the campaign. The leaflet contained six suggested 'doorstep questions' for candidates, and some key statistics about the numbers of people with MS in each region of the country. MS Ireland also participated in the Disability



Federation of Ireland's 'Disable Inequality' campaign in the run-up to the election.

ACHIEVING IN ADVOCACY

POLICY SUBMISSIONS

MS Ireland made the following policy submissions in 2016. All our policy submissions are informed by experiences reported to us by people with MS and their families, and our experiences of delivering services. We have also made extensive use of data from the 'Societal Costs of Multiple Sclerosis in Ireland 2015' report in all our submissions:

Pre-Budget Submission: Our pre-budget submission highlighted deficits in neurology services, neurorehabilitation, employment, home care and Housing Adaptation Grants and called for increased investment in these areas in the 2017 budget.

Medical Cards: In January, we made a submission to the Clinical Advisory Group who have been convened by the HSE to look at the issue of discretionary medical cards, and develop a framework for assessing need where an applicant's income is above the threshold of the means test. Our submission highlighted the additional costs that living with MS can incur for individuals and families.

Neurorehabilitation: MS Ireland made a contribution to the Neurological

Alliance of Ireland's response to the draft implementation plan for the National Neurorehabilitation Strategy.

Making Work Pay: MS Ireland made a detailed submission to the Department of Social Protection consultation on making work pay. Our submission highlighted the barriers that can prevent people from taking up work such as the fear of losing the medical card and the difficulty of moving between work and social welfare payments for people with episodic and unpredictable conditions like MS. This submission made extensive use of data from the 'MS and Employment: Facts and Figures' report.

Physiotherapy: MS Ireland wrote to the Minister for Health in October about the need to protect the job titles of Physiotherapist and Physical Therapist in one professional register.

All our policy submissions can be viewed in the Advocacy section of our website www.ms-society.ie



ACHIEVING IN ADVOCACY

MEETINGS WITH POLITICAL REPRESENTATIVES

MS Ireland had 11 meetings with political representatives in 2016, both individually and in conjunction with the Neurological Alliance of Ireland and their other member organisations. These meetings were used to highlight various issues including neurorehabilitation, lack of home care, access to medicines, medical cards and employment.

HSE NATIONAL PATIENTS FORUM AND COMMUNITY LIVING TASK GROUP

Through our membership of the HSE's National Patient Forum and the Housing Agency's Community Living Task Group we have had an opportunity to feed into HSE policy and practice and influence housing policy relating to people with disabilities. This has included directly contributing to the development of new guidelines for local authorities regarding housing allocations for people with disabilities.

BRIEFING DOCUMENTS AND POSITION PAPERS

MS Ireland has produced a series of Briefing Documents and Position Papers. The aim of these documents is to:

- Provide clear, concise and accurate information on complex and/or controversial issues that are of importance to the MS community
- Where appropriate, provide an organisational position on the topic and suggest realistic solutions to problems

In 2016, we produced Briefing Documents and Position Papers on the following topics. All our Briefing Documents and Position Papers are informed by experiences reported to us by people with MS and their families, and our experiences of delivering services:

- Response to Budget 2017
- Cannabis-based Medicinal Products
- Home Care and Personal Assistance Services
- Neurorehabilitation
- Process for Licensing and Reimbursement of New Medications in Ireland
- Robotic Walking Devices
- Stem Cell Research

All our Briefing Documents and Position Papers can be viewed in the Information Centre section of our website www.ms-society.ie



IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Advocacy in 2016:

TO LIAISE AND WORK WITH UMBRELLA ORGANISATIONS (NATIONALLY AND INTERNATIONALLY) TO CREATE A MORE COHESIVE AND UNITED VOICE

- Participation in Disability Federation of Ireland's Disable Inequality campaign for General Election 2016
- Participation in Neurological Alliance of Ireland's We Need Our Heads Examined campaign for neurorehabilitation services

STRENGTHEN OUR CURRENT ADVOCACY ALLIANCES AND DEVELOP NEW LINKS TO HARNESS THE STRENGTH OF SHARED VISIONS

- New alliance formed with 16 other NGOs to lead a campaign on home care
- Secured membership of HSE National Patients Forum and Housing Agency's Community Living Task Group
- Launch of three employment resources in conjunction with Novartis and Ibec
- 11 meetings held with political representatives, both alone and in conjunction with other organisations

UTILISE DATA SETS AND SERVICE DELIVERY EXPERIENCES AVAILABLE TO MS IRELAND TO INFORM OUR ADVOCACY AGENDA

- Data from report on MS and employment presented to National Disability Authority and Department of Social Protection
- Five policy submissions made, using data from a variety of reports and drawing on MS Ireland's service delivery experience

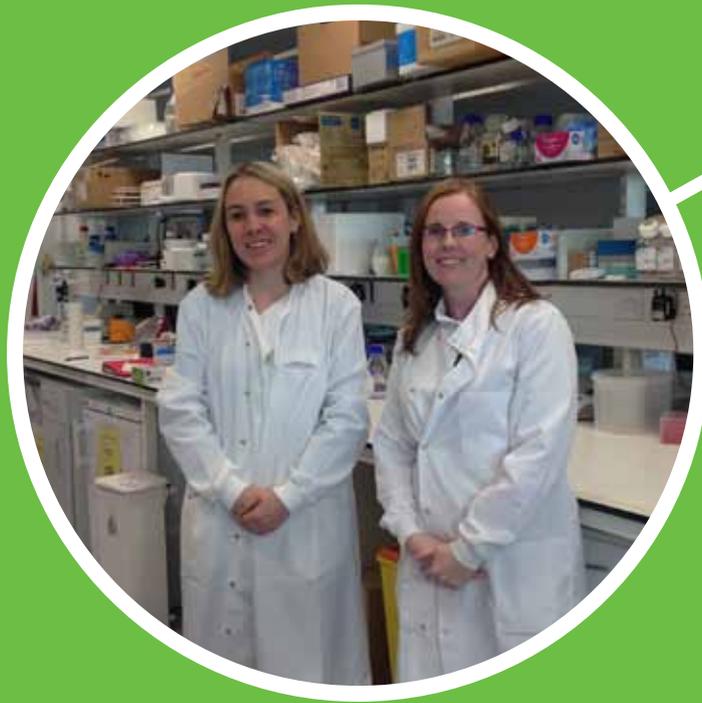
- Seven Briefing Documents and Position Papers produced, using data from a variety of reports and drawing on MS Ireland's service delivery experience

PEOPLE WITH MS HAVE ACCESS TO EFFECTIVE TREATMENTS FOR THEIR CONDITION, INCLUDING TREATMENTS WHICH CAN SLOW, STOP OR REVERSE THE ACCUMULATION OF DISABILITY

- VHI agree to cover Lemtrada
- Letters written to Minister for Health and the Director General and the Chief Financial Officer of the HSE regarding funding arrangements for Lemtrada and Tysabri
- FAQ document produced on Fampyra
- Two submissions to Minister for Health on Sativex

TO RAISE MSI'S PROFILE AS A LEADING VOICE AND RESOURCE FOR PEOPLE WITH MS

- Seven Briefing Documents and Position Papers produced on topics of interest to the MS community
- Presentations made to National Disability Authority, Department of Social Protection and Ibec on MS and employment



ACHIEVING IN 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.

SPECIFIC OBJECTIVES:

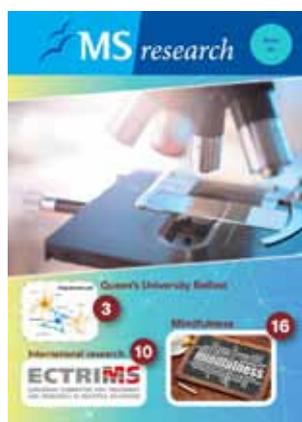
- By 2019 MSI will have developed and implemented a funding strategy to support research appropriate to the requirements of MS Ireland and its members (medical, scientific and quality of life)
- Collaborate with academic institutions on the delivery of research projects
- Support and sponsor a number of research projects aimed at improving the quality of life of people with MS and people affected by MS
- A protocol for researchers who engage with MS Ireland (nationally or regionally)

IN 2016, THIS IS WHAT WE ACHIEVED IN RESEARCH

ACHIEVING IN RESEARCH

LAUNCH OF NEW RESEARCH eZINE

In June, MS Ireland launched a brand new research eZine, MS Research. The purpose of the eZine is to share the latest updates from scientific and social MS research, from here in Ireland and internationally. We produced two issues of MS Research in 2016, which we circulated to everyone on our eNews database as well as healthcare professionals and researchers interested in MS.



Topics covered in the first two issues include:

- » Research into reversing the effects of MS
- » Physiotherapy
- » Updates from the International Progressive MS Alliance and ECTRIMS conference
- » Irish and international research on MS and employment
- » Potential new medication for progressive MS, Ocrelizumab
- » Cognition
- » Bladder function
- » Public Patient Involvement (PPI) in research

RESEARCH STRATEGY AND PROTOCOL FOR RESEARCHERS

In December MS Ireland published a new five year Research Strategy. This document outlines MS Ireland's research priorities for the lifetime of the current Strategic Plan. In addition, the Strategy outlines the activities that will be undertaken to achieve these research priorities.

MS Ireland has also reviewed and updated our Protocol for researchers who wish to engage with the organisation.

NUI GALWAY – MINDFULNESS RESEARCH

In July MS Ireland awarded €50,000 to researchers from the School of Psychology and Centre for Pain Research at NUI Galway, who are evaluating a new internet-delivered, eight week mindfulness programme for people living with MS. The goal is to help people manage their psychological and emotional well-being as they live with MS. The research project will be two years in duration. MS Ireland has been able to fund this research programme thanks to a generous contribution from an individual donor.

ACHIEVING IN RESEARCH

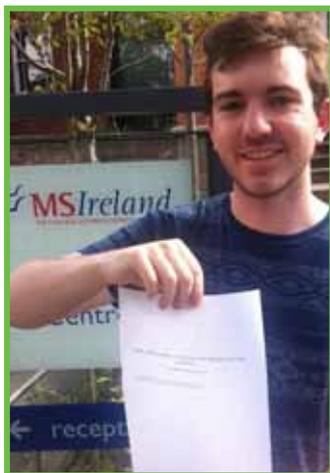
MY MS MY NEEDS SURVEY



In May, MS Ireland conducted a major survey of the needs of people with MS. This was the first such survey of its kind and the intention is to repeat it every two years. The results of the survey will help us to plan our services and will inform our ongoing advocacy work.

We received 826 responses in total to the survey. An infographic showing some of the key results was released at our MS Research Explored event in November and a full report will follow.

STUDENT SUMMER RESEARCH INITIATIVE



In 2016 for the first time MS Ireland hosted an undergraduate medical student as part of UCD's Student Summer Research Initiative.

The student, Matthew McCarthy, carried out a research project on

people with MS's experiences of interacting with medical services. A total of 197 people took part in the study. MS Ireland will use the data from Matthew's study to identify areas of interest for future research projects and advocacy work.

UNIVERSITY OF LIMERICK – PHYSIOTHERAPY RESEARCH

MS Ireland and the University of Limerick marked five years of collaboration on physiotherapy research in May 2016. This was marked with a Research showcase event at the University of Limerick on World MS Day. The MS Research Team from the University of Limerick was joined by Dr. Una Fitzgerald from NUI Galway and Peter Carney, Health Economist from Novartis, to present a series of talks and poster presentations.



FALLS PREVENTION

Work continued in 2016 on ongoing research projects looking at developing a falls prevention intervention for people with MS. Following in-depth surveys of people with MS and clinicians, the researchers are currently working on two research papers which they hope to submit for publication.

ACTIVITY MATTERS

The 'Activity Matters' project aims to change physical activity behaviour in the MS population. Work on the development of web and paper-based resources continued in 2016.

ACHIEVING IN RESEARCH

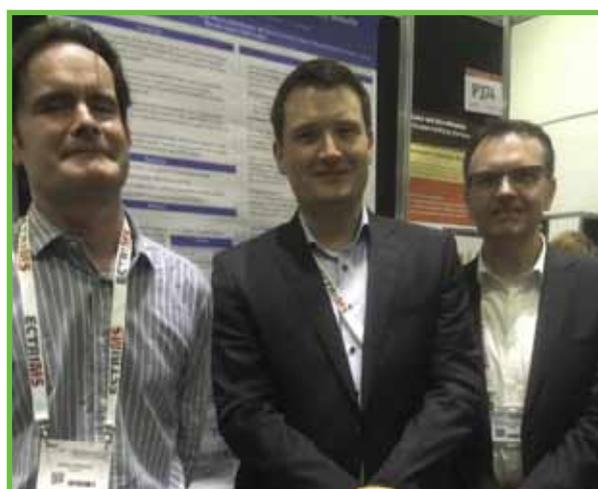
DEAN MEDAL



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 travelled to the Karolinska Institutet in Sweden in Autumn 2016 to further her research into the measurement of cerebrospinal fluid biomarkers indicative of disease progression in people with MS. Dr McNicholas provided a detailed report from her visit for issue 2 of the MS Research eZine and also spoke at the MS Research Explored event in November.



SOCIETAL COSTS OF MS REPORT

Following on from the release of the 'Societal Costs of Multiple Sclerosis in Ireland 2015' report in October 2015, we made extensive use of data from the report throughout 2016 in our lobbying and advocacy work. On 15 September 'The Societal Costs of MS in Ireland' poster was displayed at ECTRIMS, the largest international MS research conference.

MEDICAL RESEARCH CHARITIES GROUP

The Medical Research Charities Group (MRCG) is the national organization of charities active in medical research. MS Ireland actively participated in the

work of the MRCG in 2016, attending board meetings and sitting on their Communications and Advocacy Subgroup. As a result of this MS Ireland were able to secure strong representation for MS researchers at the MRCG annual conference in September.



ACHIEVING IN RESEARCH

INTERNATIONAL PROGRESSIVE MS ALLIANCE

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 2016, MS Ireland branches contributed €7,000 between them to the work of the Progressive MS Alliance.

In February, it was announced that Irish person with MS Alexis Donnelly was selected to sit on the Scientific Steering Committee for the International Progressive MS Alliance. Since his appointment, Alexis has provided valuable feedback and insights from the work of the committee, including two detailed articles for the MS Research eZine.



PARTICIPATING IN RESEARCH

Each year we ask the MS community to participate in ongoing research. In 2016 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:

- » Physical Activity Levels in Multiple Sclerosis
- » Cognition and Occupation
- » My MS My Needs survey
- » Healthcare Experiences of People with MS
- » Falls and MS
- » REAL MS study
- » Cognitive Rehabilitation
- » BT Young Scientist – surveys on hand/arm function and attitudes to medicinal cannabis
- » Patient Opinions on Radiography Services



IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Research in 2016:

BY 2019, MS IRELAND WILL HAVE DEVELOPED AND IMPLEMENTED A FUNDING STRATEGY TO SUPPORT RESEARCH APPROPRIATE TO THE REQUIREMENTS OF MS IRELAND AND ITS MEMBERS

- Research Strategy for 2015-2019 published

COLLABORATE WITH ACADEMIC INSTITUTIONS ON THE DELIVERY OF RESEARCH PROJECTS

- Undergraduate medical student hosted as part of UCD Student Summer Research Initiative
- Five years' of collaboration with University of Limerick on physiotherapy research marked
- Researchers interested in MS invited to contribute articles to new bi-annual research eZine

SUPPORT AND SPONSOR A NUMBER OF RESEARCH PROJECTS AIMED AT IMPROVING THE QUALITY OF LIFE OF PEOPLE WITH MS AND PEOPLE AFFECTED BY MS

- €50,000 awarded over two years to researchers investigating mindfulness and MS at NUI Galway
- €7,000 donated by MS Ireland branches to the International Progressive MS Alliance

- First ever My MS My Needs survey carried out, with 826 responses
- Societal Costs of MS research poster displayed at ECTRIMS
- Researchers supported to recruit participants for projects investigating a variety of topics including cognitive rehabilitation, falls and MS, attitudes to medicinal cannabis and physical activity levels

A PROTOCOL FOR RESEARCHERS WHO ENGAGE WITH MS IRELAND (NATIONALLY AND REGIONALLY)

- Protocol for Researchers reviewed and updated



ACHIEVING IN ORGANISATIONAL CAPACITY

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

SPECIFIC OBJECTIVES:

- To develop more cohesive and coherent information gathering and dissemination processes using ICT as an enabler
- To enable effective communications to take place at all levels within MSI, internally and externally
- To ensure that the human resources available to MSI are most effectively deployed in pursuit of our main strategic priorities
- To ensure MSI remains a viable and sustainable organisation in relation to its funding situation giving specific attention to fundraising; to diversify our funding (particularly fundraising) to avoid an overreliance on one channel of fundraising i.e. Readathon
- To ensure that a functional Branch/ Council structure exists

IN 2016, THIS IS WHAT WE ACHIEVED IN ORGANISATIONAL CAPACITY

ACHIEVING IN ORGANISATIONAL CAPACITY

RESOURCE ALIGNMENT

The situation in relation to statutory and fundraised income remains challenging. The following measures remained in place in 2016:

- » Staff hours remained curtailed across the organisation.
- » Reduced opening hours at the MS Care Centre remained.
- » Budgets were again reduced and monitored closely. Additional reporting on regional and national level of the costs of service delivery supported efforts.
- » 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

2016 was the fifth 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. This year 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 and a Board member 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

13 Regional Integrated Meetings took place in 2016.

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 2016 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.



ACHIEVING IN ORGANISATIONAL CAPACITY

CORPORATE SERVICES

HUMAN RESOURCES

Recruitment during 2016 concentrated on replacing necessary leavers or unfilled posts.

The following posts were recruited in 2016

- » Administrator Southern Region
- » Corporate Fundraising Executive
- » 2 x Part-time Nurses at the Care Centre
- » Administrator North East Region
- » Regional Community Worker Mid West Region (commences Feb 17)

The following posts were advertised but not filled in 2016

- » Marketing Communications Executive
- » Senior Events and Campaign Executive

EMPLOYEE RELATIONS

The organisational wide pay freeze continued in 2016 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.

INFORMATION & COMMUNICATIONS TECHNOLOGY

A review of the use of Salesforce, our CRM system, took place in 2016. A revised list of categories for capturing information and support queries was developed, for roll-out in 2017. This will hopefully support us in our advocacy work by helping us to identify the support needs of people with MS and where gaps and deficiencies exist in services nationally.

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 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.

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 2016.

KISS GOODBYE TO MS 2016

The first Kiss Goodbye to MS campaign in Ireland was a great success. Rosanna Davison was secured as official campaign ambassador, based on her profile and personal experience with MS. A panel of 10 excellent spokespeople, living with MS was central to the campaign. PR activity involved announcing the campaign with great photos, organising feature stories for people living with MS, a Kiss Goodbye to MS survey, media drops of campaign materials, and a final call to media.

The campaign featured on TV3 with Ailse Quinn; Today FM The Last Word with Ava Battles, Rosie McCormack, Maebh Horan-Murphy; Newstalk news bulletins: Featuring Ava Battles; RTÉ Radio na Gaeltachta: Featuring Maebh Horan-Murphy; 98FM news bulletins: Featuring Ava Battles with many more mentions across radio. 15 national newspaper articles appeared across The Irish Daily Star, The Irish Sun, The Herald, Irish Examiner, Irish Daily Mail and consumer magazines as well as The Sunday Independent: Featuring Naomi Donaldson; The Irish Independent: Featuring Katheleen McHugh; Woman's Way: Featuring Sharon Henvey, Rosie

McCormack; and The Irish Examiner: Featuring Laura Lee. More than 30 regional newspapers as well as regional radio and online featured Kiss Goodbye to MS.

WORLD MS DAY 2016 AND 9,000 STEPS FOR MS

MS Ambassador mum of three Olivia Kirwan and her family along with Lorraine Ho, Bootcamp Ireland supported World MS Day and '9,000 Steps for MS' as well as James Tracy, Irish Rugby Player and his sister Sarah Jane who is living with MS. Events at Basecamp in Dublin and UL in Limerick were highlighted as well as activities around the country to mark World MS Day.

RTE Morning Ireland featured a great piece on World MS Day 2016 focusing on the themes of Independence and Employment. RTE presenter Petula Martyn interviewed Naomi Donaldson, Willeke Van Eeckhoutte and Ava Battles.

Newstalk Lunchtime also featured an interview with Naomi Donaldson. World MS Day was also highlighted in TheJournal.ie, The Irish Times Health Supplement Health Board, Woman's Way, The Irish Examiner, Irish Daily Star X 2, Irish Daily Mail, Irish Mirror, Evening Echo. More than 20 regional newspapers covered World MS Day as well as 12 regional radio interviews with 20+ pieces online.

ACHIEVING IN ORGANISATIONAL CAPACITY

PUBLIC RELATIONS



MS READATHON 2016

The PR team was delighted to welcome Deirdre O’Kane along with Moone Boy actor David Rawle to launch the 29th MS Readathon. Great quotes about reading were provided to MS Readathon by author Cecelia Ahern, 2FM presenter Rick O’Shea and top Irish children’s authors. Gerard Murphy who is living with MS and his daughter Lauren supported MS Readathon 2016 with their family’s story. Lauren, a young student at Loreto Balbriggan, took part in the BT Young Scientist and Technology Exhibition inventing, with the aid of a 3D printer, a rehabilitation device for people with MS which aims to counteract hand closure spasm.

RTE News2Day covered the launch of the 29th MS Readathon, visiting a school with MS Ireland featuring as well as covering the awards. Newstalk also featured the MS Readathon with great photos and editorial appearing in The Irish Times and The Irish

Independent. There were also more than 30 regional media articles and more than 10 regional radio interviews.

IRISH INDEPENDENT NEUROLOGY SUPPLEMENT

The PR team ensured strong presence for MS Ireland in the Irish Independent Neurology Supplement 2016 coordinating an interview with Dr Sabina Brennan relating to Brain Health and the MS Ireland conference with Joan Jordan providing an excellent case study.

MEMBERSHIP

At the end of 2016 our membership stood at **4,639**



ACHIEVING IN ORGANISATIONAL CAPACITY

PARTNERSHIPS AND 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 2016

- » 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), University College Dublin (UCD), the Medical Research Charities Group (MRCG), Irish Platform for Patients Organisations, Science and Industry (IPPOSI), the Irish Brain Council and Health Research Board (HRB) regarding research and professional information. MS Ireland’s CEO Ava Battles joined the Board of IPPOSI in 2016 and Information, Advocacy and Research Officer Harriet Doig joined the Communications and Advocacy Subgroup of the MRCG.
- » 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 stood down as Chairperson of NAI in 2016 and was replaced on the Board by Harriet Doig, Information, Advocacy and Research Officer. Harriet is also a member of NAI’s Campaign Working Group for the We Need Our Heads Examined campaign, and attends Policy and Advocacy Forum meetings.
- » Care Alliance for Carers Week, and participating in the Family Carer Research Group.

ACHIEVING IN ORGANISATIONAL CAPACITY

PARTNERSHIPS AND COLLABORATIONS

- The Disability Federation of Ireland (DFI) in the areas of health sector cuts, governance, rehabilitation, neurological funding, employment, assistive technology, Election 2016, housing and accommodation, and disability rights. Services Manager Olga Estridge joined the Board of DFI in 2016.
- 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. MS Ireland sits on MSIF's working group for World MS Day and we presented at their Global Networking Meeting in April. We also attended EMSP's conference in Oslo in May.
- Pharmaceutical companies; in particular Bayer Healthcare, Biogen Idec, Genzyme, Merck Serono, Novartis, Roche, Grünenthal and TEVA regarding funding and educational projects and activities. In particular we would like to note the following collaborations in 2016:
 - » Partnering with Sanofi Genzyme on The World vs.MS, a new international initiative that aims to expose the daily challenges of living with MS and develop ideas to solve them. MS Ireland's Harriet Doig sits on the judging panel for The World vs.MS and we have actively promoted the initiative via our various communications channels
 - » Partnering with Grünenthal Pharma and Chronic Pain Ireland for the My Pain Feels Like campaign. This national campaign aims to raise awareness of different types of pain and how to describe them to healthcare professionals. MS & Me Blogger and MS advocate Willeke van Eeckhoutte participated in the launch of the campaign
 - » Presenting at an Advisory Board organised by Merck Serono in London, on the unmet needs of people with MS in Ireland
 - » Collaborating with Novartis on the production of three new employment resources, and the MS Research Explored event



ACHIEVING IN ORGANISATIONAL CAPACITY

ADVISORY PANEL

In 2016 MS Ireland established an Advisory Panel of leading researchers, academics and practitioners to help with our information, research and advocacy goals. The panel is made up of experts in their respective fields and their expertise will reflect the scope of work carried out by MS Ireland.

THE 2016-2017 ADVISORY PANEL MEMBERS ARE:

 Consultant Neurologist Dr. Lisa Costelloe	 Occupational Therapist Dr. Sinead Hynes	 Dietician Theresa Rennick
 Physiotherapist Prof. Susan Coote	 Palliative care Marie Lynch, Irish Hospice Foundation	 Social Work Dr. Trish Walsh
 Scientist Dr. Una Fitzgerald	 Neuropsychologist Dr Niall Pender	 Law Jennifer White
 Speech and Language Therapist Fiona Hill	 Pharmacist Brendan Quinn	

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 2016 four worthy winners were picked from the many wonderful applications. Congratulations to them, their families and the MS communities they work in. The winners were:



MS Person of the Year: Joan Jordan

Joint Volunteers of the Year: Kass Bielskis & MS & Me Blog Team

Carer of the Year: Curtis Harding



In 2016 across the globe World MS Day (25 May) marked its seventh year under the banner 'Together we're #StrongerThanMS'. The theme was Independence. Thank you to everyone who joined the global movement and helped raise awareness of MS around the world.

ACHIEVING IN ORGANISATIONAL CAPACITY

WORLD MS DAY 2016

This year, MS Ireland challenged everybody to walk 9,000 steps to represent the 9,000 people in Ireland living with MS. Many individuals, groups and companies participated up and down the country. Companies who organised events with their staff included HP, Daft.ie, Icon Gyms, Alkermes Pharma and GLG.

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

DUBLIN: An event was held in Base Camp Outdoor Store with participants completing 9,000 steps on the treadmills in the store.

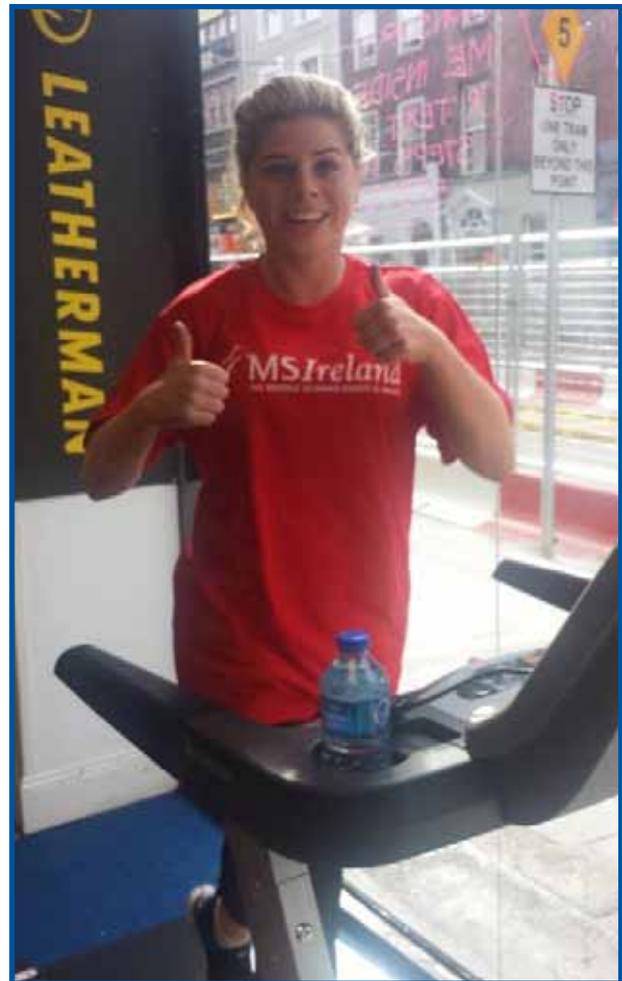
TIPPERARY: The Tipperary South Branch organised an event in the Clonmel Park Hotel. The day coincided with the branches' third birthday. The day involved a coffee morning and a series of talks by local service providers.

DONEGAL: Our Donegal Branch held a coffee morning which raised a total of €1,868.

LIMERICK: Members of the Limerick Branch enjoyed an event in Tara House with MS Ireland Mid West Region staff. A fundraising walk was also held in the University of Limerick.

LOUTH: Our Louth Branch held a vintage care event in the Monasterboice Inn.

WICKLOW: Our East Wicklow Branch hosted an Evening of Short Stories at the Glenview Hotel.



MS CARE CENTRE: Once again the MS Care Centre opened their doors to the public inviting them for a coffee morning with a bonanza raffle, live music and stalls including homemade cakes, plants, artwork, books and flower arrangements. The day was a great success and €4,130 was raised. Many thanks to the team at Software Quality Systems who volunteered their services on the day.

FUNDRAISING 2016

READATHON 2016

10,000 readers and 360 schools took part in Readathon 2016, raising a fantastic €323,000. We were delighted to have Deirdre O’Kane and Moone Boy actor David Rawle on board as our ambassadors. Our ambassador family this year were Gerard Murphy, who is living with MS, and his 17-year-old daughter Lauren.



TREKS

The Portuguese Camino and Everest Base Camp were our exciting and rugged destinations for our 2016 treks. 42 wonderful trekkers took up the challenge and raised funds and awareness in their local areas.



KISS GOODBYE TO MS

In February, MS Ireland launched a major new annual fundraising campaign, Kiss Goodbye to MS. The campaign asked people of all ages to WEAR, DARE OR SHARE to raise vital funds and awareness. Between University ‘red days’, a skydive Dare and exciting partnerships with various companies, the whole country joined together to Kiss Goodbye To MS.

Irish #KissGoodbyeToMS selfies were all over Twitter, Instagram and Facebook. One of the main ways to get involved was for participants to wear their favorite red lipstick, clothes or accessory, share a kiss on social media and text SMOOCH to 50300 to donate €4.

With support from best-selling author Rosanna Davison, whose uncle had MS, and involvement from Ireland’s top bloggers, the campaign drew a huge amount of media attention and raised €53,000.



FUNDRAISING 2016



SKYDIVE

In 2016 we had 36 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. This included our CEO Ava Battles, who rose to the challenge and jumped on 22 October.

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.



WILD ATLANTIC WAY

Alan Ryan and Marie O'Connor both took on the challenge of cycling the Wild Atlantic Way in 2016 to raise funds for MS Ireland.



CHRISTMAS FUNDRAISING

MS Ireland's 2016 Christmas fundraising campaign was Christmas Jumper Day on 16 December.

FUNDRAISING 2016



MARATHONS

Over 200 women ran the mini marathon in Dublin and the Cork City Marathon for Team MS Ireland on June Bank Holiday Monday. A further 36 brave runners took part in the SSE Airtricity Dublin Marathon on 30 October.

WORLD MS DAY

Numerous fundraising events took place up and down the country on World MS Day, including bucket collections, coffee mornings and our new 9,000 Steps for MS campaign.



CORPORATE DINNER

MS Ireland's Corporate Dinner took place on 21 July at Leopardstown Racecourse.



2017 CALENDAR

Our fourth national image competition ran in 2016 to find 12 beautiful images for our 2017 calendar. The 2017 calendar featured 12 stunning images of Ireland, sent in by very talented amateur photographers from all over the country.

FUNDRAISING 2016

DUBLIN'S FITTEST WORKPLACE

13 teams took part in Dublin's Fittest Workplace on 27 February, raising over €7,000 for MS Ireland. The event included both physical and mental challenges curated by the defence forces. Congratulations to first place winners Allianz. The Cavalry Squadron (Defence Forces) were second and Oracle third.



EASTER EGG RAFFLE

David Dunne, with the help of other postmasters in the Dublin area, raised €17,833 in much needed funds for the Care Centre with his annual Easter Egg Raffle.

SUMMER RAFFLE

Our annual raffle was again supported by thousands of people around the country. Women's rugby international Jenny Murphy joined us for the draw at National Office on 8 July.



AFFILIATES & PARTNERSHIPS

2016 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 HPE Galway and Ireland West Airport who made MS Ireland their charity partner for 2016, Dolly Recycling for their continued partnership and Perrigo Ireland who provided extensive support for the Kiss Goodbye to MS campaign and made a very generous donation towards the MS Care Centre and the MS Information Line. Many thanks also to all the other companies who made donations, volunteered staff time for projects and organised fundraising events in 2016.

AND MANY MORE.....

THANK YOU!

Big THANKS to all our fundraisers, donors and supporters for their generosity throughout 2016. We couldn't do it without you!



IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Organisational Capacity in 2016:

TO DEVELOP MORE COHESIVE AND COHERENT INFORMATION GATHERING AND DISSEMINATION PROCESSES USING ICT AS AN ENABLER

- Review of use of Salesforce system carried out, with new categories for capturing information and support queries developed

TO ENABLE EFFECTIVE COMMUNICATIONS TO TAKE PLACE AT ALL LEVELS WITHIN MS IRELAND, INTERNALLY AND EXTERNALLY

- Media coverage secured on a variety of topics including World MS Day, Kiss Goodbye to MS and Irish Independent Neurology Supplement
- Range of events and activities held up and down the country for World MS Day, 25th May

TO ENSURE THAT THE HUMAN RESOURCES AVAILABLE TO MS IRELAND ARE MOST EFFECTIVELY DEPLOYED IN PURSUIT OF OUR MAIN STRATEGIC PRIORITIES

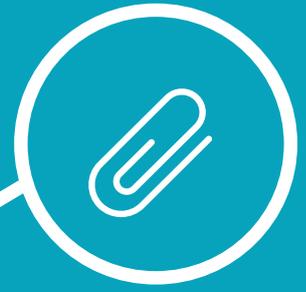
- Six posts recruited, covering necessary leavers and unfilled posts
- New Advisory Panel established of leading researchers, academics and practitioners to help with our information, research and advocacy goals
- Use of corporate volunteers in a number of capacities including administration, gardening and online marketing

TO ENSURE MS IRELAND REMAINS A VIABLE AND SUSTAINABLE ORGANISATION IN RELATION TO ITS FUNDING SITUATION, GIVING SPECIFIC ATTENTION TO FUNDRAISING; TO DIVERSIFY OUR FUNDING (PARTICULARLY FUNDRAISING) TO AVOID AN OVER-RELIANCE ON ONE CHANNEL I.E. READATHON

- Major new annual fundraising initiative Kiss Goodbye to MS established, raising €53,000
- New World MS Day fundraising '9,000 steps' challenge carried out
- MS Readathon raised €323,000
- 13 teams took part in Dublin's Fittest Workplace, raising over €7,000
- Continued cost saving measures in place across the organisation, including reduced staff hours and reduced opening hours at MS Care Centre

TO ENSURE THAT A FUNCTIONAL BRANCH/COUNCIL STRUCTURE EXISTS

- 13 Regional Integrated Meetings took place



ACHIEVING IN GOVERNANCE & REGULATION

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

SPECIFIC OBJECTIVES:

- MS Ireland will continually review its own internal rules and regulations
- Stronger working relationships between National Office/regions/branches to ensure that MS Ireland's governance structure is robust

IN 2016, THIS IS WHAT WE ACHIEVED IN GOVERNANCE AND REGULATION

ACHIEVING IN GOVERNANCE & REGULATION

THE BOARD

MS Ireland is governed by a board of 11 voluntary members. These members have a wide range of experience and skills. Some have MS themselves or have family members with MS. 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 2016, the Board met six times. Significant work was carried out in the areas of finance and funding, governance and strategy.

BOARD MEMBER 2015/2016

BOARD MEMBER 2016/2017

 CHAIRPERSON	 DEPUTY CHAIRPERSON		
● Paddy Stronge	● Marcella Flood	● Paddy Bannon	● Robin Bradley
			 DEPUTY CHAIRPERSON (RESIGNED)
● Noelle Burke	● Tom Cronin	● Sarah Dempsey	● Bryan Harty
			
● Manfred Huschka	● Ian MacDougla	● Rory Mulcahy	● Maurice O'Connor
			
● Edel O'Kelly	● Anne Restan	● Mary Sheahan Lonergan	● Dr. Killian Smith

RESIGNATIONS/RETIREMENTS

Paddy Bannon (Resigned 21st March 2016)

Sarah Dempsey (Retired 24th September 2016)

Bryan Harty (Deputy Chairperson) (Resigned 25th June 2016)

Manfred Huschka (Retired 24th September 2016)

Edel O'Kelly (Resigned 9th November 2016)

APPOINTMENTS

Robin Bradley (Appointed 24th September 2016)

Noelle Burke (Appointed 24th September 2016)

Ian MacDougla (Appointed 24th September 2016)

Anne Restan (Appointed 24th September 2016)

ACHIEVING IN GOVERNANCE & REGULATION

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 who have particular interests, experiences and knowledge. Some non Board members are invited on to the Committees for their experience or expertise. The Board approves all Committees of the Board. 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**

Where staff members attend Committee meetings, they do so in an advisory capacity and do not take part in voting.

BOARD ATTENDANCE 2016

	30 JAN	2 APR	21 MAY	25 JUN	24 SEP (i)	24 SEP (ii)	3 DEC
Paddy Bannon*	✓	n/a	n/a	n/a	n/a	n/a	n/a
Robin Bradley	n/a	n/a	n/a	n/a	n/a	✓	x
Noelle Burke	n/a	n/a	n/a	n/a	n/a	x	✓
Thomas Cronin	✓	✓	✓	✓	✓	✓	x
Sarah Dempsey	✓	x	x	✓	x	n/a	n/a
Marcella Flood	✓	✓	✓	✓	✓	✓	✓
Bryan Harty*	✓	x	x	✓	n/a	n/a	n/a
Manfred Huschka	✓	x	x	✓	x	n/a	n/a
Ian MacDougald	n/a	n/a	n/a	n/a	n/a	✓	✓
Rory Mulcahy	✓	✓	x	✓	x	x	✓
Maurice O'Connor	✓	✓	✓	✓	✓	✓	✓
Edel O'Kelly*	✓	x	✓	✓	x	x	n/a
Anne Restan	n/a	n/a	n/a	n/a	n/a	✓	✓
Mary Sheahan-Lonergan	✓	✓	✓	✓	✓	✓	x
Killian Smith	✓	✓	✓	x	✓	✓	x
Paddy Stronge	✓	✓	x	✓	✓	✓	✓

*Retired mid-year

Martin Nolan, Chairperson of Finance Audit and Risk Committee is a standing invitee

MS IRELAND'S COMMITTEES FOR 2015/2016



Current Board Member



Non-Board Member



Staff Member



Finance, Audit & Risk Committee



Sustainability Committee



Services Monitoring & Evaluation Committee



Research Committee



Remuneration Committee (CEO & Others Reporting Directly to the CEO)



Nominating Committee (for Board membership & National Awards)



Governance Committee



Chairperson



Tom Cronin



Dr. Susan Coote



Sarah Dempsey



Alexis Donnelly



Marcella Flood



Bryan Harty



Manfred Huschka



Aoife Kirwan



Martin J Lynch



Ian Mac-Dougald



Eugene McCarrick



Ann Marie McDaid



Mark Mitchell



Rory Mulcahy



Martin Nolan



Allen O'Connor



Maurice O'Connor



Edel O'Kelly



Mags Rogers



Mary Sheahan Lonergan



Dr. Killian Smith



Paddy Stronge



Louise Wardell



Dr. Trish Walsh



Ava Battles



Memory Chipere



Harriet Doig



Olga Estridge



Aidan Larkin



EMSP Representatives: Anne Winslow is President (Anne was former CEO of MS Ireland)

MSIF International Medical & Scientific Board – Dr Chris McGuigan (MS Ireland's representative)

MSIF – National Contact Person with MS for MS Ireland is Dr Kilian Smith

MSIF – Board Member – Anne Winslow

MSIF – Ava Battles is a member of the CEO Advisory Group

Alexis Donnelly is a member of the Scientific Steering Committee of Progressive MS Alliance (1 of 3 PwMS internationally) – the liaison point for the PwMS Advisory Committee on matters relating to people living with MS. He gets invited to PwMS forums held every two years around the MSIF Council meetings

ACHIEVING IN GOVERNANCE & REGULATION

THE BOARD

RECRUITMENT AND INDUCTION OF BOARD MEMBERS

Notification of vacancies for Board members are advertised in MS News, eNews and on the MS Ireland website. Prospective Board members complete an application form which is considered by the Nominating Committee who then make recommendations to the Board. Once approved by the Board, the chosen candidates stand for election by the members at the AGM. New Board members are given one afternoon's induction training by the CEO. Further training can be made available if required.

LENGTH OF TERMS SERVED BY BOARD MEMBERS

A Board member is elected on to the Board for a period of three years and can serve no more than three terms on the Board, so a maximum of nine years' service as a Board member is permitted.

CONFLICTS OF INTEREST AND LOYALTIES

At every Board meeting, members are asked to state if they have a conflict of interest and/or conflict of loyalty. A register is kept and Board members are asked to complete a form stating their conflict of interest if they have one. MS Ireland also has a Conflict of Interest and Conflict of Loyalty policy. Board members are also asked to sign up to our Code of Practice.

NEW CONSTITUTION

A review of MS Ireland's Memorandum and Articles of Association was carried out during 2016 in order to update these documents to take account of the Companies Act 2014 and best practice. A copy of the new Memorandum and Articles of Association (to be known collectively as the Constitution) were sent to all members of MS Ireland.

The Board approved the New Constitution and it has also been approved by the Revenue Commissioners and the Charities Regulatory Authority. The Constitution was then approved by MS Ireland's members at the AGM in September.

Log on to our website to read the New Constitution: www.ms-society.ie

DECISION MAKING PROCESS

Details of decisions which are reserved for the Board and those delegated to CEO are listed in the organisation's Code of Practice. Schedule of Matters of the Board are detailed in the Code of Practice.

Log on to our website to read the Code of Practice: www.ms-society.ie

RISK MANAGEMENT POLICIES AND PROCESSES

Risks are detailed in a Risk Register which is reviewed by the Board, the Finance, Audit and Risk Committee and the senior management team on a regular basis. MS Ireland has a Risk Management Policy.

ACHIEVING IN GOVERNANCE & REGULATION

ENGAGEMENT WITH STAKEHOLDERS

Ms Ireland communicates with its stakeholders via email, eNews, the website, social media, MS News, council meetings, Regional Integrated Meetings, staff meetings and through correspondence and meetings with third parties.

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 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.

COMPANY SECRETARY

The CE Ava Battles is appointed as Company Secretary. Although this is against best practice required by the Governance Code, MS Ireland has a dedicated Governance Committee of the Board which meets regularly and are satisfied that this ensures governance processes and controls are appropriate and the necessary checks and balances are in place.

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 2016 the Council met four times 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 2016 we had 37 voluntary Branches operating across Ireland. See page 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 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. MS Ireland employs 72 people across national and regional offices and 57 Community Employment participants. MS Ireland's work is supported by committed volunteers around the country.

FINANCE AND AUDIT PROCEDURES

MS Ireland puts its annual audit out to tender on a regular basis. It last went out to tender in 2015 and the contract period was for five years.

MS Ireland holds one credit card. Credit card statements are reviewed by the Chairperson who signs off on them on a bi-monthly basis.

ACHIEVING IN GOVERNANCE & REGULATION

MS. AVA BATTLES, CHIEF EXECUTIVE

MS. MEMORY CHIPERE

FINANCIAL
ACCOUNTANT

*(Maternity Leave Cover
Provided Jan-Jun 2016 By
Ms Jackie Baker)*

MR. DAVID ALLEN

CORPORATE
SERVICES
MANAGER

MS. OLGA ESTRIDGE

SERVICES
MANAGER

MR. AIDAN LARKIN

SERVICES
DEVELOPMENT
MANAGER

REMUNERATION

The number of employees whose emoluments, excluding employer pension contributions, were greater than €70,000 in 2016 is set out below:

1 €70,000 - €80,000

0 €80,000 - €90,000

1 €90,000 - €100,000

The Remuneration Committee, a sub-committee of the Board, is responsible for making decisions regarding remuneration of staff.

CODES OF PRACTICE

MS Ireland operates in accordance with a number of codes applicable to our work. These codes are a combination of best practice guidelines, policies and procedures that protect the people we work with and make our work transparent and above reproach.

On 13th July 2013 the Board signed up to the principles of Good Governance in the Governance Code and has been working on the process of signing up to the Code since then.

THE GOVERNANCE CODE

MS Ireland is fully committed to the standards outlined in the Governance Code.

GUIDING PRINCIPLES FOR FUNDRAISING

The Statement of Guiding Principles for Fundraising is a guide to best practice developed by a steering group set up in response to the Charities Act 2009. MS Ireland is fully committed to achieving the standards contained within the Statement of Guiding Principles for Fundraising.

We commit to:

- » Leading our organisation
- » Exercising control over our organisation
- » Being transparent and accountable
- » Working effectively
- » Behaving with integrity

ACHIEVING IN GOVERNANCE & REGULATION

The Statement exists to:

- » Improve fundraising practice
- » Promote high levels of accountability and transparency by organisations fundraising from the public
- » Provide clarity and assurances to donors and prospective donors about the organisations they support.

BOARDMATCH IRELAND TRANSPARENCY SCALE

MS Ireland complies with the standards contained in Boardmatch Ireland's Transparency Scale 'A' Standard.

NATIONAL FINANCIAL ASSISTANCE REGULATIONS

MS Ireland Branches can offer financial assistance to people with MS to help cover the costs of some expenses associated with the condition. Voluntary Branches raise this money through their fundraising activities.

CODES OF GOOD PRACTICE TO PROTECT CHILDREN

MS Ireland is fully committed to safeguarding the well-being of all the children and young people with whom we work. Our policy on child protection is in accordance with Children First, the national guidelines for the protection and welfare of children.

VULNERABLE ADULT PROTECTION POLICY

MS Ireland is dedicated to implementing and promoting measures to protect the right of all service users to be treated with dignity and respect and is committed to ensuring that the organisation provides a safe environment which is free from all forms of abuse, including discrimination, bullying, harassment or sexual harassment, neglect and mistreatment. In achieving this aim, MS Ireland is committed to ensuring that there are policies, procedures, guidance and training for staff and service users that prevent any infringement of this right.

LOBBYING REGULATIONS

MS Ireland is registered as a lobbying organisation under the Regulation of Lobbying Act 2015 and makes returns three times per year to the Register of Lobbying in accordance with the requirements of the Act. In 2016, MS Ireland published 14 returns to the register on 20 January, 21 May and 15 September.

**Log on to our website for further details of all the Codes of Practice
MS Ireland subscribes to: www.ms-society.ie**

ACHIEVING IN GOVERNANCE & REGULATION

FINANCIAL STATEMENTS

The financial statements are prepared under the historical cost convention, in accordance with the Statement of Recommended Practice (SORP) FRS 102 (Revised 2015) "Accounting and Reporting by Charities (SORP 2015)" applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), effective 1 January 2015; and the Companies Act 2014. Financial reporting in line with SORP is considered best practice for charities in Ireland.

FINANCIAL RESULTS FOR THE YEAR

A surplus of €293,532 was achieved in 2016 mainly due to a once off donation of €130,000 from a trust on its winding down, a Bequest of €92,000 and a surplus from branches of €55,019. Most of our donors are now restricting funds they give to us and this is putting the organisation under pressure to fund the existing day to day operations.

FINANCIAL POSITION AT THE END OF THE FINANCIAL YEAR

The fund balances totalled €8,016,568 (2015: €7,723,036) at the end of the financial year. These funds are comprised of restricted funds of €1,663,403 (2015: €1,753,726) and unrestricted funds of €6,353,165 (2015: €5,969,310)

THESE FUNDS ARE REPRESENTED BY THE FOLLOWING:

	NATIONAL OFFICE & CEP	BRANCHES	TOTAL
	€	€	€
Tangible Fixed Assets	5,853,581	83,635	5,937,216
Net Current Assets (<i>excl. Bank loan</i>)	2,657,814	1,282,359	3,940,173
Bank Term Loan	(1,860,821)	-	(1,860,821)
TOTAL	6,650,574	1,365,994	8,016,568

The tangible fixed assets of the National Office are comprised mainly of the premises at Northumberland Road and Bushy Park Road, Dublin.

Net Current Assets (excluding bank loan) of €2,657,814 are comprised of Restricted Net Current Assets of €696,508 and Unrestricted Net Current Assets of €1,961,306.

RESERVE POLICY

MS Ireland defines its reserves as its total unrestricted funds. In planning and budgeting for its activities, the company considers the level of unrestricted reserves to maintain a balance between the need to safeguard the continuity and development of its services and the need for prudent management of its activities as well as providing for contingencies. The Board aims to maintain its total unrestricted reserves level at three months operating costs.

FINANCIAL STATEMENTS

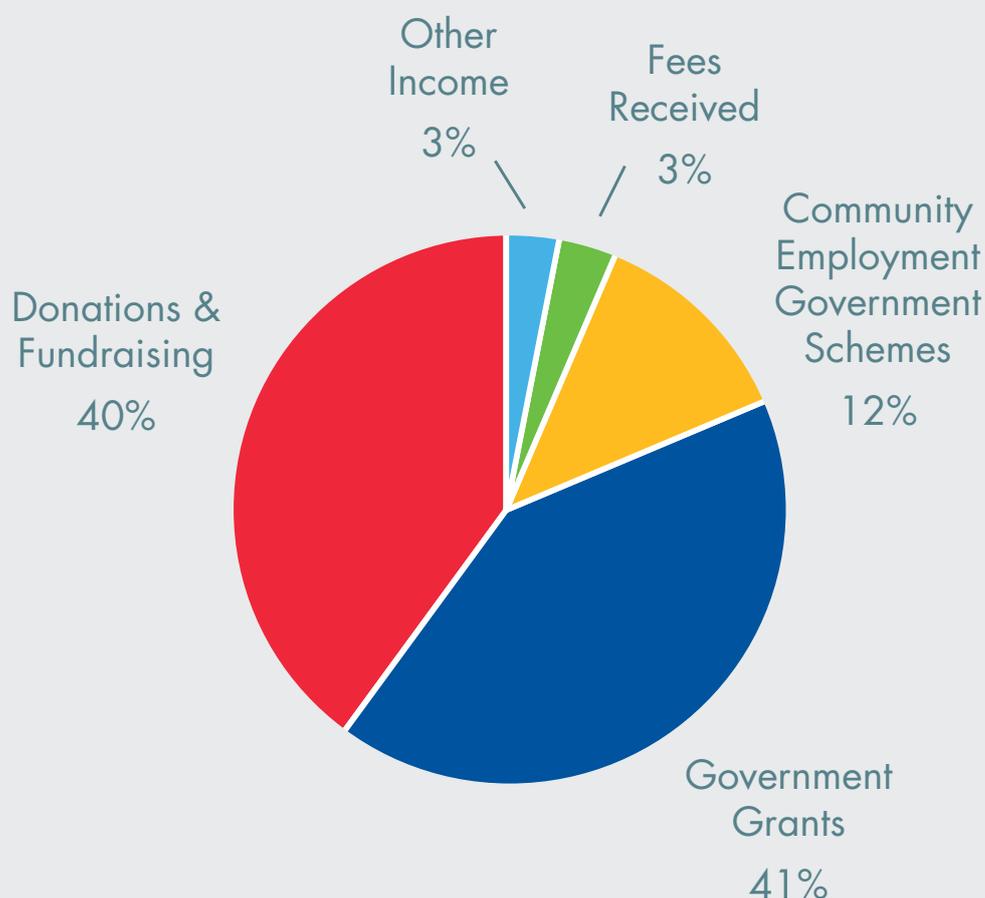
	Unrestricted Funds 2016 €	Restricted Funds 2016 €	Total Funds 2016 €	Total Funds 2015 €
INCOMING RESOURCES				
Income from generated funds				
Voluntary Income				
Donations and fundraising	2,251,646	157,299	2,408,945	2,457,442
Legacies	89,401	3,000	92,401	219,531
Pharmaceutical	58,331	85,395	143,726	119,830
Research	-	6,117	6,117	143,366
Subscriptions	2,840	-	2,840	3,025
Income from charitable activities				
Fees received	220,853	-	220,853	215,041
Grants and other service contract income	-	2,739,964	2,739,964	2,656,718
Government schemes	-	808,161	808,161	874,709
Other income	116,563	100,647	217,210	110,805
Total incoming resources	2,739,634	3,900,583	6,640,217	6,800,467
RESOURCES EXPENDED				
Costs of generating voluntary income				
Fundraising	718,671	35,181	753,852	924,736
Charitable activities				
Community services	323,273	2,319,056	2,642,329	2,789,040
Respite care services	468,989	1,446,979	1,915,968	1,867,049
Research	18,951	112,365	131,316	97,325
Local MS services	764,050	70,595	834,645	841,509
Governance costs	61,845	6,730	68,575	66,958
Total resources expended	2,355,779	3,990,906	6,346,685	6,586,619
Taxation	-	-	-	-
Net income for the year	383,855	(90,323)	293,532	213,848
Reconciliation of Funds				
Total funds brought forward	5,969,310	1,753,726	7,723,036	7,509,188
Total funds carried forward	6,353,165	1,663,403	8,016,568	7,723,036

INCOME ANALYSIS 2016:

€6,640,217

Income of €6,640,217 was received of which 41% was funding from Government Grants, mainly the HSE, 40% was from Donations and Fundraising, 12% was from Community Employment Government Schemes 4% was from fees received from Respite Centre residents and 3% from miscellaneous income.

	2016 (€)	2015 (€)
Donations & Fundraising	2,651,189	2,940,169
Government Grants	2,739,964	2,656,718
Community Employment Government Schemes	808,161	874,709
Fees Received	220,853	215,041
Other Income	220,050	113,830
TOTAL	6,640,217	6,800,467

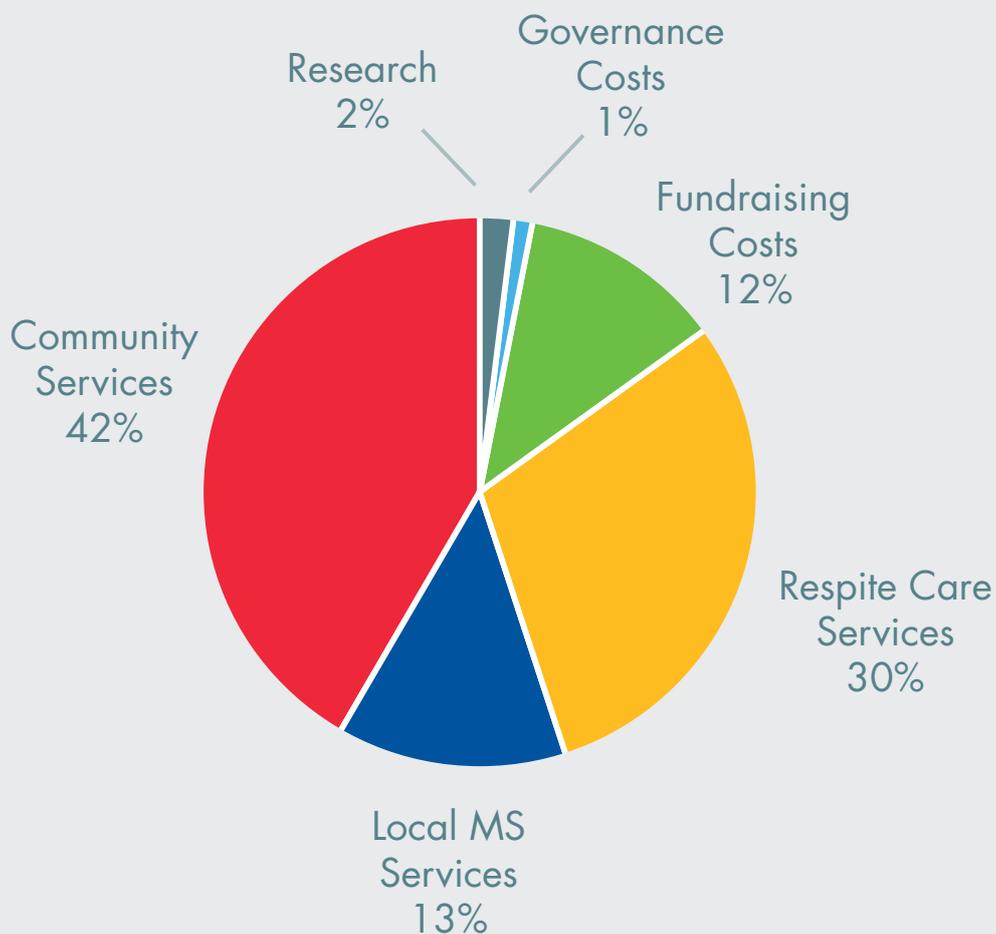


EXPENDITURE ANALYSIS 2016:

€6,346,685

€6,346,685 was spent in 2016 of which 42% was spent on regional Community services, 30% on Care Centre respite services, 12% Fundraising, 13% on Branch local MS services, 2% on research and 1% on Governance costs.

	2016 (€)	2015 (€)
Community Services	2,642,328	2,789,040
Local MS Services	834,646	841,509
Respite Care Services	1,915,968	1,867,049
Fundraising Costs	753,852	924,736
Governance Costs	68,575	66,958
Research	131,316	97,325
TOTAL	6,346,685	6,586,619

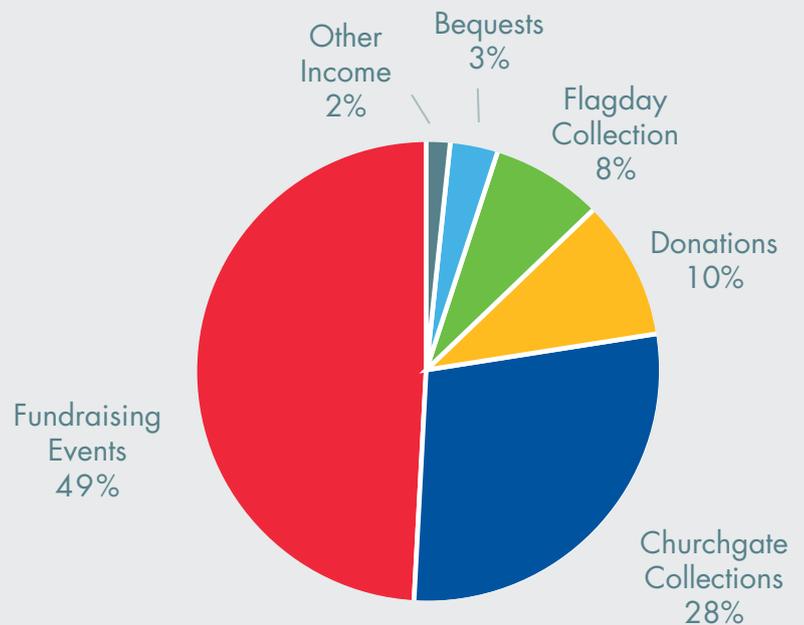


ACHIEVING IN SERVICES

BRANCH INCOME 2016: € 1,003,659

In 2016 38 Branches were in operation. All the funds raised in the Local Branches is spent locally to provide services for people with MS.

Income of €1,003,659 was received of which 49% was raised from fundraising events, 28% from churchgate collections, 10% from Donations, 8% from Flagdays collection, 3% from Bequests and 2% was from other income such as bank interest, christmas party contributions, etc.

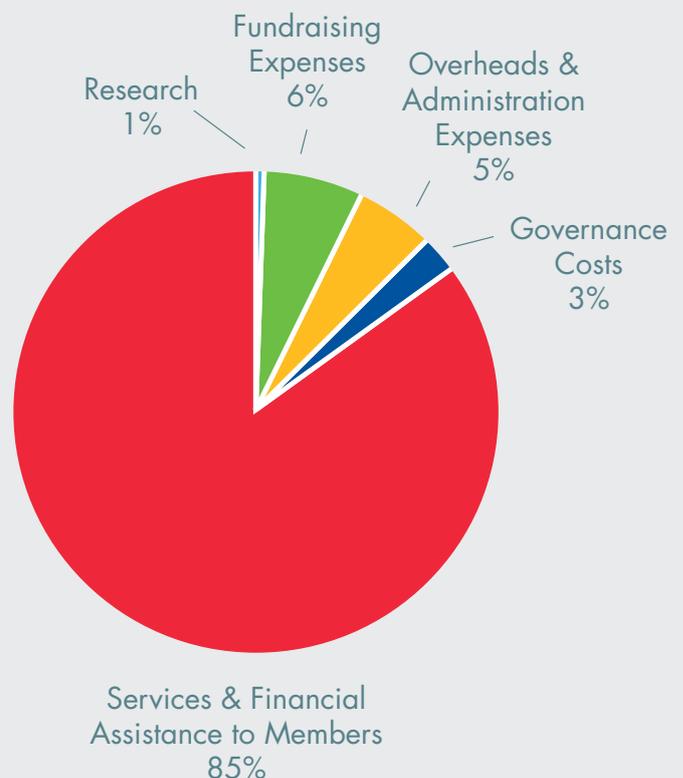


BRANCH EXPENDITURE 2016: €945,854

(SURPLUS 57,085)

€948,640 was spent in 2016 of which 85% was spent on providing services & financial assistance to members, 6% on fundraising expenses, 5% Overheads and Administration expenses, 3% Governance and 1% on Research.

A surplus of €57,805 was achieved by branches. The resources expended figure of €945,854 includes €177,106 which was transferred to National Office to support community services.



ACHIEVING IN GOVERNANCE & REGULATION

PHARMACEUTICAL INCOME

	2016	2015
	€	€
Perrigo Company plc	40,000	45,000
Sanofi	22,395	7,000
Novartis Ireland	20,500	28,730
Merck Serono (Ireland) Ltd	18,000	10,000
Biogen IDEC	15,000	20,000
Roche Pharmholding B.V	10,000	-
Teva Pharmaceutical Ltd	9,030	8,000
Regeneron Pharmaceuticals Plc	5,000	-
Grunenthal Pharma Ltd	2,740	-
Alkermes Pharma Ireland Limited	561	-
Bemis Healthcare	500	-
Allergan Pharmaceutical Ireland	-	600
United Drug	-	500
	143,726	119,830

Projects and services supported by funding from the pharmaceutical industry in 2016 include:

- MS News magazine
- My MS My Needs survey
- Employment resources
- Kiss Goodbye to MS
- MS Care Centre
- MS Research Explored event
- World MS Day activities

Funding received from the pharmaceutical industry in 2016 represents 2.1% of MS Ireland's total income.



IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Governance & Regulation in 2016:

MS IRELAND WILL CONTINUE TO REVIEW ITS OWN INTERNAL RULES AND REGULATIONS

- Significant work carried out by the Board and committees in the areas of finance and funding, governance and strategy
- New Constitution approved
- Compliance with Governance Code, Guiding Principles for Fundraising, Boardmatch Ireland Transparency Scale, National Financial Assistance Regulations, Codes of Good Practice to Protect Children, Vulnerable Adult Protection Policy
- 14 returns made to the Register of Lobbying under the Lobbying Act 2015

STRONGER WORKING RELATIONSHIPS BETWEEN NATIONAL OFFICE/REGIONS/BRANCHES TO ENSURE THAT MS IRELAND'S GOVERNANCE STRUCTURE IS ROBUST

- Four meetings of the Council, the representative body of MS Ireland's Branch network
- 13 Regional Integrated Meetings were held throughout the country



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



pobal

government supporting communities



Find us on:
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twitter 

You 

Multiple Sclerosis Ireland, 80 Northumberland Road, Dublin 4

T: (01) 678 1600 | F: (01) 678 1601 | MS Info Line: 1850 233 233

E: info@ms-society.ie | W: www.ms-society.ie | Charity Number: 05365