MS IRELAND
ANNUAL REPORT & ACCOUNTS
2017

MSIreland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

MISSION, VISION, AIMS & VALUES

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

VALUES

Supportive

"We support individuals whether they are People with Multiple Sclerosis (PwMS), staff or volunteers so that we can work together to fulfil our mission"

Transparent

"Being open and honest in everything that we do"

Informative

"Communicate reliable, accurate and useful information"

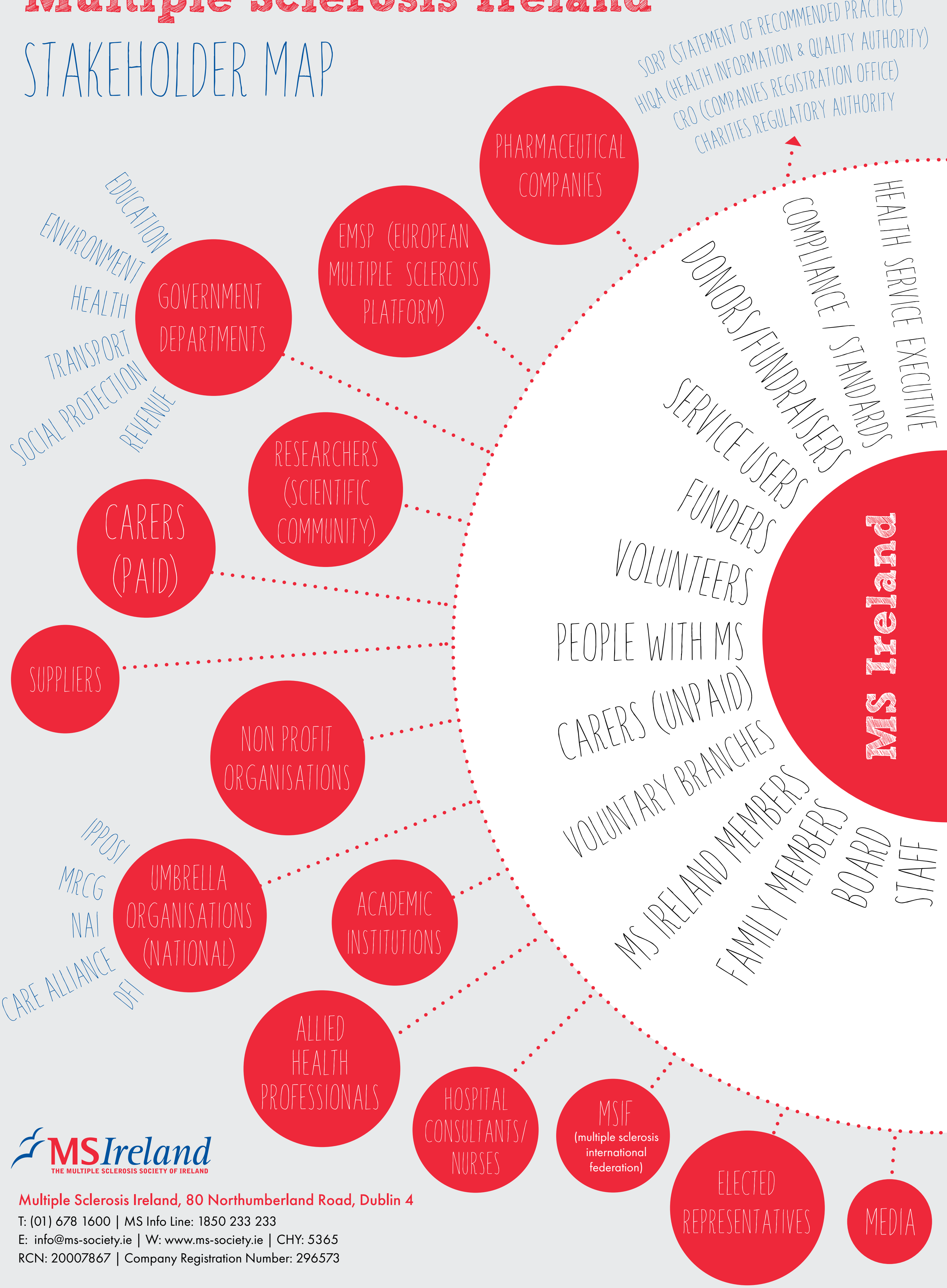
Empowering

"Through the provision of information, advocacy and support services we enable people to make informed choices"

CONTENTS

Multiple Sclerosis Ireland

STAKEHOLDER MAP



SORP (STATEMENT OF RECOMMENDED PRACTICE)
HIQA (HEALTH INFORMATION & QUALITY AUTHORITY)
CRO (COMPANIES REGISTRATION OFFICE)
CHARITIES REGULATORY AUTHORITY

PHARMACEUTICAL COMPANIES

EMSP (EUROPEAN MULTIPLE SCLEROSIS PLATFORM)

GOVERNMENT DEPARTMENTS
- EDUCATION
- ENVIRONMENT
- HEALTH
- TRANSPORT
- SOCIAL PROTECTION
- REVENUE

RESEARCHERS (SCIENTIFIC COMMUNITY)

CARERS (PAID)

SUPPLIERS

NON PROFIT ORGANISATIONS

UMBRELLA ORGANISATIONS (NATIONAL)
- IPPOSI
- MRCG
- NAI
- CARE ALLIANCE
- DFI

ACADEMIC INSTITUTIONS

ALLIED HEALTH PROFESSIONALS

HOSPITAL CONSULTANTS/ NURSES

MSIF (multiple sclerosis international federation)

ELECTED REPRESENTATIVES

MEDIA

HEALTH SERVICE EXECUTIVE
COMPLIANCE / STANDARDS
DONORS/FUNDRAISERS
SERVICE USERS
FUNDERS
VOLUNTEERS
PEOPLE WITH MS
CARERS (UNPAID)
VOLUNTARY BRANCHES
MS IRELAND MEMBERS
FAMILY MEMBERS
BOARD
STAFF

MS Ireland

MSIreland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

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RCN: 20007867 | Company Registration Number: 296573

CHIEF EXECUTIVE & CHAIRPERSON WELCOME

The Multiple Sclerosis Society of 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 2017. It has been a challenging year in many ways, with continued constraints on our own funding and resources alongside several high-profile cases of poor governance in which seriously damaged 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.

In 2017 we have collaborated successfully with other organisations on various high-profile campaigns. We continued our work with the Neurological Alliance of Ireland on the 'We Need Our Heads Examined' campaign for neurorehabilitation services. MS Ireland also continued to work with a group of more than 20 plus organisations throughout 2017 on the need to improve home care services. Furthermore in 2017, MS Ireland began working with a group of organisations on the issue of bin charges. The group have written to and met with the Department of Environment, Community, and Local Government a number of times in 2017 to advocate on behalf of people affected by incontinence issues to ensure they are not negatively impacted by changes to bin charges.

We conducted a Research Priorities Survey to establish what areas of research the MS community in Ireland consider the most important. This will help inform future decisions around funding .We have made some major advances in our advocacy and lobbying work in 2017, in total we made five submissions in response to Government consultations, using data from a number of MS Ireland reports and drawing on MS Ireland's service delivery experiences. Further submissions were made to Government departments and TDs on a variety of topics including Sativex, physiotherapy and the need to invest in neurology services.

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 2017 was a great success, with our team using the theme of 'life with MS' to highlight issues of quality of life with MS. We also launched a new report, highlighting issues faced for people living with MS called the 'Quality of Life report'. This report was launched at Leinster house on world MS Day which was attended by several TDs and political representatives

We held our third MS Research Explored evening in November in the excellent facilities at Trinity College, and our annual conference and Healthcare Professionals Day took place in September in Sligo. The theme for both the conference and Healthcare Professionals Day was on 'Quality of Life', with specific sessions on strategies for cognitive reserve, exercise and brain health and every day strategies for brain health. Over 80 health care professionals attended. 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.

Our Fundraising team celebrated the 30th year of our flagship fundraiser the MS Readathon. It was a huge honour to welcome Felicity Dahl to Ireland to launch the 30th MS Readathon, marking a milestone for the reading initiative as the first ever MS Readathon which was supported by her late husband Roald Dahl in 1988. The Readathon in 2017 was sponsored by Heinz and over 9,000 readers and 327 schools took part raising a grand total of €325,779. Other fundraising activities included skydives, treks, the ever-popular Women's Mini Marathon and for the first time fundraisers abseiled down from the roof in Croke park in aid of MS Ireland.

CHIEF EXECUTIVE & CHAIRPERSON WELCOME

2017 was a year of change and new beginnings for our very successful MS and ME blog team. The blog has been running for the last 5 years and this year we decided it was time to grow and diversify the team by recruiting some new writers whilst some of the original cohort decided to remain. We put a call out for new bloggers across our social media channels and through internal email looking for potential writers from different backgrounds. We were delighted with the response and now have a new blog team of 18 who will be taking the MS and ME blog forward throughout 2018 and beyond.

You are all more than aware that MS Ireland has faced difficult decisions in relation to ensuring that the Organisation is sustainable and delivering services to People with MS into the future. You will be aware that these difficulties have been with us for some years and even though we have tried to stem the tide with non-replacement of staff who have left or retired, reduction in staff hours and non-payment of increments we had to take further actions in 2017. These actions have resulted in a restructuring programme which has meant changes throughout the organisation:

In National Office there have been three voluntary redundancies and one compulsory redundancy and role changes as a result. In the Regions there has been one voluntary redundancy and restructuring of administration functions and lines of reporting. At this time there have been no further changes in the Care Centre which continues to operate on reduced hours.

None of our achievements in 2017 would be possible without the dedication of the staff and volunteers who work so hard to make a difference to the lives of people affected by MS in Ireland, including our Board who give their time and expertise for free to support the running of the organisation. We would like to thank everybody who has supported our work in any way, by making donations, engaging in fundraising activities, and raising awareness about who we are and what we do.

We anticipate more challenges and uncertainty for the organisation in 2018 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

AVA BATTLES
CHIEF EXECUTIVE

Marcella Ó Flood

MARCELLA FLOOD
CHAIRPERSON

STRATEGIC PRIORITIES

2017 was the third 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.

ADVOCACY

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

RESEARCH

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

ORGANISATIONAL CAPACITY

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

GOVERNANCE & REGULATION

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

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 most up to date information is available.

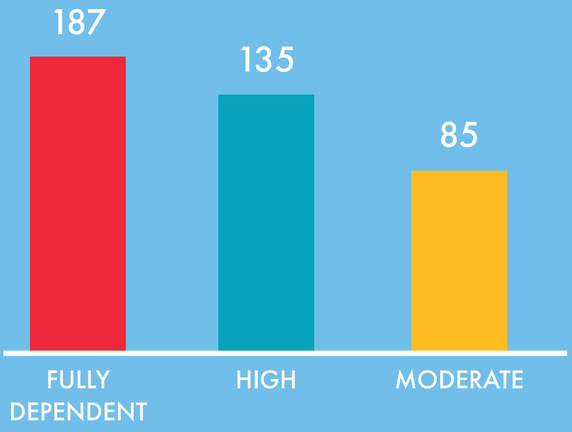
IN 2017, THIS IS WHAT WE ACHIEVED IN SERVICES

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 5, 7 or 12 night 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 2017 the MS Care Centre provided professional, dedicated care for 407 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.

DEPENDENCY



NEW & RETURNING RESIDENTS

*SOME RESIDENTS STAYED TWICE OR MORE

PROFESSIONAL & THERAPEUTIC INTERVENTION

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:

- ALL GARDEN PATHS UNGRADED TO COMPLY WITH HIQA STANDARDS AND TO AFFORD BETTER ACCESS FOR PEOPLE WHO USE A WHEELCHAIR
- COFFEE DOCK REFURBISHED
- NEW BOILER INSTALLED
- CONTINUED WORK ON THE GARDEN.
- NEW MORE APPROPRIATE DINING CHAIRS

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.

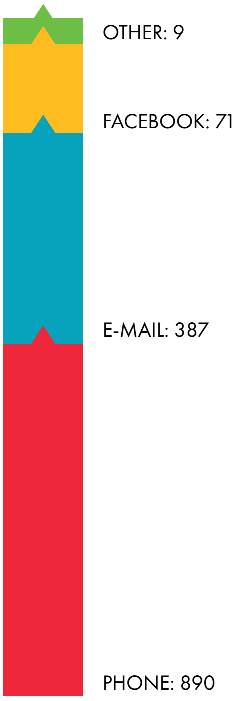
MS Care Centre staff continues to work very hard to ensure the Centre is fully compliant with HIQA standards, following successful HIQA registration in 2015. We were re-registered again in 2018.

THE MS INFORMATION LINE

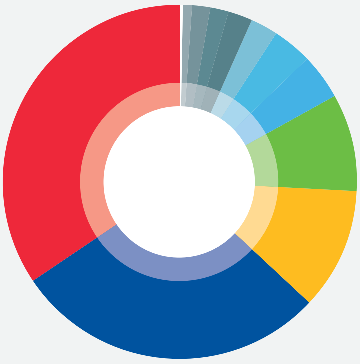
Operating weekdays from 10am-2pm, our dedicated information line provides professional, anonymous and confidential support for people with MS, their families, carers and health professionals.

In 2017, **1,357** people contacted the MS Information Line

HOW PEOPLE MADE CONTACT



REASON FOR MAKING CONTACT



410	HELPLINE SUPPORT
342	GENERAL INFO
134	INSURANCE
107	ENTITLEMENTS AND SERVICES
48	ACCESSIBILITY
43	RESEARCH
32	SHORT TERM RESPITE
27	QUERY DIAGNOSIS
19	TREATMENTS
19	TRANSPORT
10	LONG-TERM CARE
4	COUNSELLING
2	HEALTH CARE PROFESSINAL

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.

2,073

PEOPLE ENGAGED IN ONE-TO-ONE SERVICES

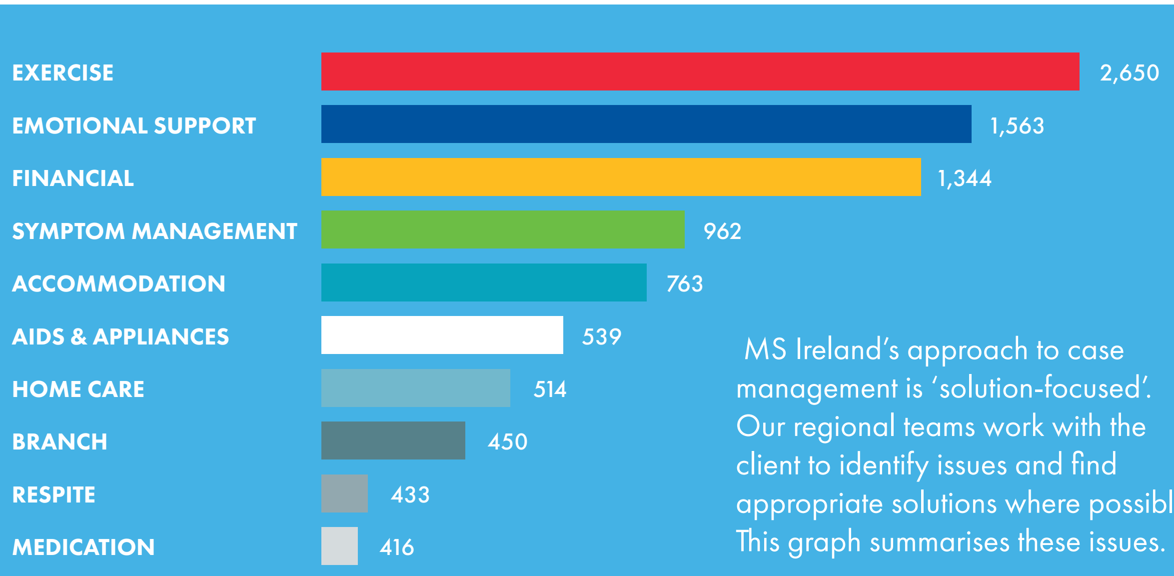
8,956

CASE NOTES RECORDED OF ENGAGEMENT WITH CLIENTS

103

NEWLY DIAGNOSED CONTACTS

TOP 10 ISSUES PRESENTED BY CLIENTS

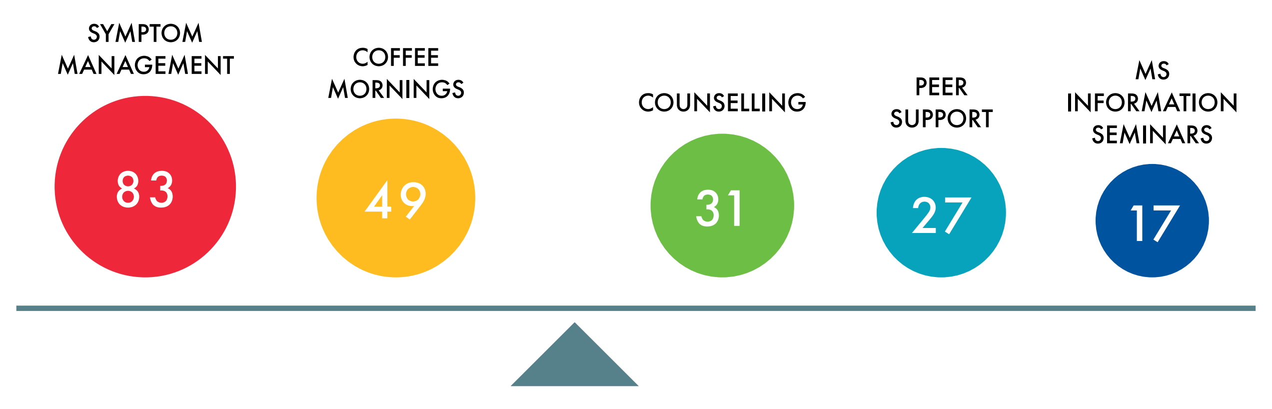


MS Ireland's approach to case management is 'solution-focused'. Our regional teams work with the client to identify issues and find appropriate solutions where possible. This graph summarises these issues.

LIVING WITH MS PROGRAMMES

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

These programmes may be one-off sessions or a ten week course, depending on the nature of the programme. The figures below summarises the types of programmes we ran in 2017:

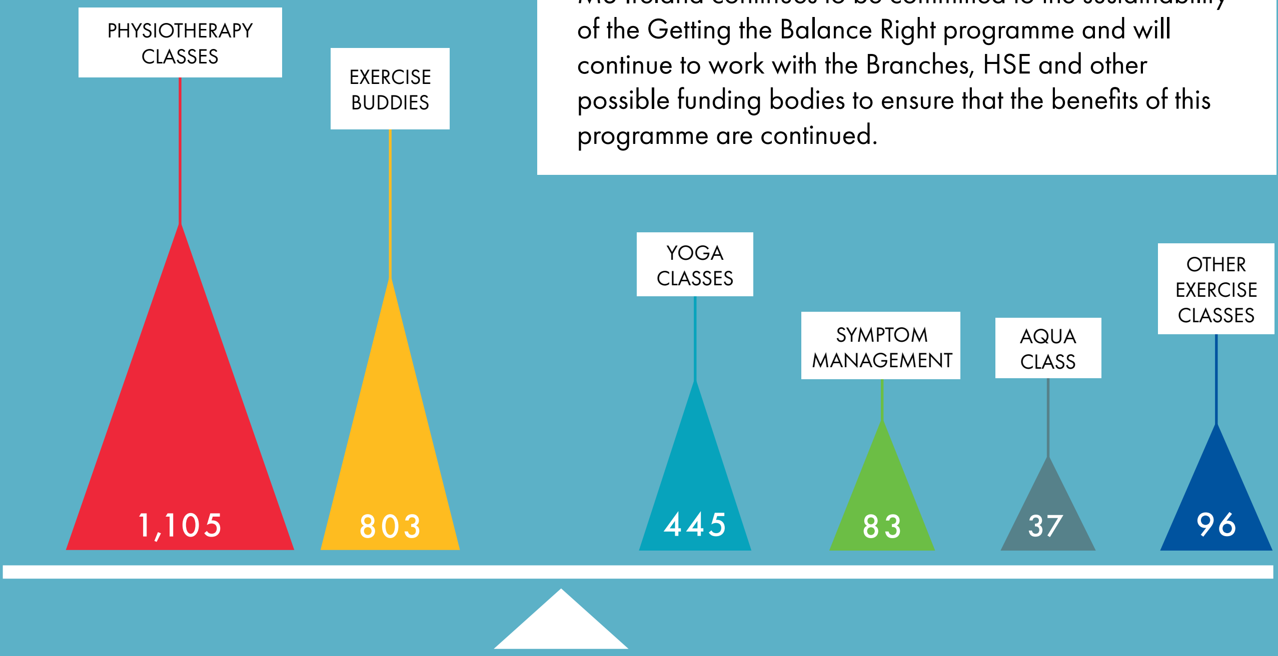


GETTING THE BALANCE RIGHT

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 2017 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.



QUOTES FROM THE MS CARE CENTRE

"I know from the moment I go inside that door, I am cared for instantly, my worries go away from the moment I go in that door, they take my bags, make sure I am ok, provide me with food and tea, it's a safe place to go, you feel happy knowing that everyone there is looking after you"

"If we are lucky enough to receive two weeks respite for my husband per year it enables me to continue to care for him at home as his care takes an enormous physical and emotional toll on me. I know that he will receive excellent nursing and holistic care in the MS Care Centre. He is included in all activities and treated with great dignity and respect."

"They are like your second family in a way"

"I go there to meet up with other people, I don't get out very mulch and gives my wife a break, its great for rest- I enjoy the activities and the music they have at night."

VOLUNTARY BRANCH SERVICES WORKING TOGETHER

WORKING TOGETHER: AN INTEGRATED APPROACH

Over the last number of years the way in which the regional offices staff communicates with the Branches has changed. At the centre of this change has been the development of the Regional Integrated Meeting process. The purpose of these meetings is to improve communication between the regional offices and branches. These meetings provide the opportunity for the regional office staff and the local branches to jointly plan and review their calendar of events for a given year. While this is still the focus of the meetings they have developed in such a positive manner that they are also an excellent forum for the national organisation to give information on a range of policy, financial and strategic developments. These meetings are also a forum for the branches to meet with other branches to exchange information. In 2017 the number of regional meetings held was 15.

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

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

LIVING WELL WITH MS CONFERENCE

The Living Well with Multiple Sclerosis conference took place on 23rd of September at the Radisson Blu Hotel Sligo. The theme of the conference was 'Quality of Life'. Over 180 people were in attendance and over 350 people watched via livestream. Afterwards, the videos of the presentations were uploaded to MS Ireland's website.

AGM 2017

MS Ireland's 2017 Annual General Meeting (AGM) was held on 23 September in Sligo at the Radisson Blu Hotel. Eugene Kearney, Jacinta Kelly and Martin Power were elected to the Board. Marcella Flood was appointed Chairperson of the Board.

Killian Smith stepped down from the Board and we would like to thank him for his diligent and passionate service to the Board of MS Ireland.

HEALTHCARE PROFESSIONALS INFORMATION DAY

MS Ireland hosted an information day for healthcare professionals on 22nd of September at the Radisson Blu Hotel Sligo. The focus of the day was on Quality of Life, with specific sessions on strategies for cognitive reserve, exercise and brain health and every day strategies for brain health. Over 80 health care professional attended.

LIVING WELL WITH MS CONFERENCE

PRESENTATIONS ON THE DAY

Dr. Orla Gray
Neurologist, Queen's Hospital, Belfast

Dr. Sinead Hynes
Occupational Therapist, NUIG

Dr. Marcin Uszynski
Snr. Neuro Physiotherapist, MS Ireland

Aideen Melanaphy
Snr Neuro Physiotherapist, North West MS Therapy Centre, Sligo

Dr Deirdre Corby (DCU)
Evidence to Support Assistive Technology

Dympna Mc Namee
Social Worker

Mary Ananda Shakti
Laughter Yoga

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

MS RESEARCH EXPLORED EVENT

MS Ireland and Novartis held an MS Research Explored event for people with MS on the 30th November in Trinity College Dublin. Over 100 people attended the event and a further 150 watched via a live stream. The recording of the event was made available on MS Ireland's website afterwards, and a further 60 people viewed the event.

Professor Susan Coote, University of Limerick, spoke on Balance and falls in MS. Then Dr Downer, from Trinity College Dublin spoke about exploring the therapeutic avenues in MS from exercise to cannabis. The day ended with a question and answer session with speakers and patient advocates

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

SOCIAL MEDIA

Our social media channels continued to grow throughout 2017. 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. We have also introduced more video to our social media content, an example of which being the 'Life Hack' video and our MS Ireland abseil shoot which received 35,000 and 10,000 views respectively.

Instagram
multiple_sclerosis_ireland
1,278 Followers

Facebook
MultipleSclerosisIreland
14,926 Likes

YouTube
MSSocietyIRELAND
28,887 Views

Twitter
@MSIRELAND
7,668 Followers

E-News
Sign up on our website
4,204 Subscribers

Website
www.ms-society.ie
156,891 Website Visitors

EXAMPLE OF A TUESDAY MS QUESTIONS ON FACEBOOK IS:

"MS support comes in all shapes and sizes and even from the most unexpected sources. Have you ever received support from someone you really didn't expect? "

EXAMPLE OF FRIDAY MS QUOTE ON FACEBOOK:

"Dear Multiple Sclerosis, I get it , every time I am doing well you are going to knock me down, but Know this, every time I will get back up ".

MS NEWS MAGAZINE

2017 saw the publication of two editions of MS News. The theme of the spring/summer edition was 'Quality of Life'. It featured pieces such as understanding relapse, medicines adherence and personal stories. Information and services were showcased to inform our readers of some of the supports available to them. The second issue focused on MS and Money. Information on tax, insurance, and travel with MS and financial support for students were featured. Both the spring/summer and autumn/winter editions highlighted regional services and news from the branches as well as updates on advocacy and conference reports.

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 2017 there were 49 MS & Me blog posts. The blog encourages conversation and debate with the aim of supporting and informing people. In 2017 we decided to extend and diversify of our current blog and recruited some new writers. We put a call out for new bloggers across our social media channels and through internal email looking for potential writers from all different backgrounds. We were delighted with the response and now have a blog team of 18 who will be taking the MS and ME blog forward throughout 2018 and beyond.

eNEWS

Our electronic newsletter eNews was sent every month in 2017 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.

IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Services in 2017:

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

- 407 residents stayed in the MS Care Centre.
- 436 individual physiotherapy sessions provided at the MS Care Centre.
- 2,073 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 17 Peer Support programmes, 18 symptom management sessions, 34 coffee mornings and 35 MS information seminars.
- 1,105 Physiotherapy classes, 803 Exercise Buddies sessions and 445 Yoga classes provided by community services.

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

- 15 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

- 1,357 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.
- eNews every month.
- 49 MS & Me Blog posts.
- 884 new followers on Twitter.
- 1,879 new Likes on Facebook.
- Living With MS conference with 180 people in attendance and almost 350 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 over 80 HCPs in attendance.
- MS Research Explored event held, in conjunction with Novartis, attended by over 100 people with a further 150 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 2017, THIS IS WHAT WE ACHIEVED IN ADVOCACY

WORLD MS DAY – AV ROOM BRIEFING IN LEINSTER HOUSE

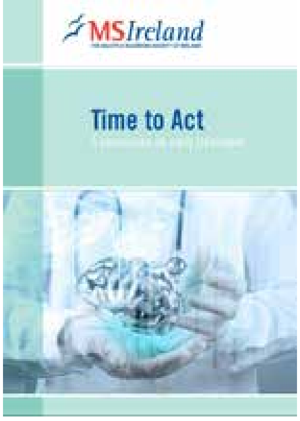
On World MS Day, 31 May, MS Ireland and Novartis launched a new report on MS and quality of life. The report was launched at a very successful briefing in the AV Room at Leinster House, organised with the kind support of Senator Jerry Buttimer. Over 50 political representatives and their staff attended to hear our message. Firstly, Ava Battles, CEO of MS Ireland welcomed everybody and gave a brief introduction to MS and MS Ireland. Then Peter Carney, Health Economist with Novartis, talked through some of the key findings from the report. Then Aoife Kirwan, Information, Advocacy and Research Assistant with MS Ireland and person with MS, gave an incredibly powerful personal account of her life with MS and her hopes and fears for the future. Finally Harriet Doig, Information, Advocacy and Research Officer with MS Ireland finished off the event by outlining the policy recommendations in the report.

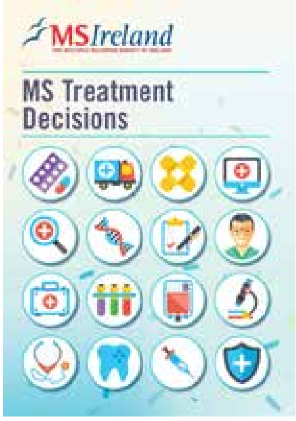
LAUNCH OF TIME TO ACT REPORT AND MS TREATMENT DECISIONS

In Brain Awareness Week in March, MS Ireland launched two major new publications, ‘Time to Act – A consensus on early treatment’ and ‘MS Treatment Decisions’. ‘Time to Act – A consensus on early treatment’ is a consensus statement on early diagnosis and treatment of MS. Based on a paper published by the UK MS Society in September 2015, this document outlines and reviews the latest research evidence regarding the importance of starting treatment with a disease modifying therapy (DMT) as soon as possible after diagnosis. In adapting this paper for the Irish context, MS Ireland consulted with a group of Irish neurologists - Professor Michael Hutchinson, Dr Lisa Costelloe, Professor Tim Lynch and Dr Brian Sweeney. ‘Time to Act’ contains detailed recommendations for policy makers and clinicians, and MS Ireland envisages that this will be a valuable tool in helping us to advocate for greater investment in neurology services in Ireland and better access to treatment and care for people with MS. ‘MS Treatment Decisions’ is for people with MS or suspected MS. It aims to empower and equip people with MS or suspected MS to engage in shared decision-making with their clinicians about their treatment options.

ADVOCACY STRATEGY

In April, MS Ireland published a detailed Advocacy Strategy stating our advocacy priorities for the lifetime of our current strategic plan and detailing actions that will be undertaken to achieve these. The strategy was developed based on results of MS Ireland research and informed by our experiences of delivering services to people with MS and their families/carers.





ACCESS TO MEDICINES

SATIVEX

MS Ireland made a detailed submission to the HSE Corporate Pharmaceutical Unit on Sativex in February and we have continued to liaise with the pharmaceutical company that markets Sativex and the HSE to try and encourage re-opening of negotiations on price.

LEMTRADA AND TYSABRI

In February, MS Ireland warmly welcomed the announcement that a new centrally managed funding system for MS medications delivered via hospital-only infusions (currently Tysabri and Lemtrada) has now been established. These medications will now be reimbursed by the National Drugs Management Scheme (NDMS) rather than by individual hospitals. Under the previous funding system, many people were unable to access the treatment that had been prescribed for them because the hospital they attended did not have the money in the budget. The establishment of the NDMS should address these inequities and help to ensure fair access based on clinical need, not funding availability. MS Ireland also worked with the HSE to develop a set of FAQs for people with MS on the new funding system.

OCRELIZUMAB

Ocrelizumab is the first DMT ever to be indicated for primary progressive MS. In December, MS Ireland wrote to the Minister for Health requesting that a new reimbursement system be piloted whereby people with MS are given access to the treatment while negotiations are ongoing between the pharmaceutical company and the HSE on price.

CLADRIBINE

In October, MS Ireland made a Patient Group Submission to the National Centre for Pharmaco-economics on potential new DMT Cladribine, as part of the assessment process to determine if it will be reimbursed by the HSE. This is the first time MS Ireland has made such a submission, and the content was informed by a survey we conducted in September on the experiences of people with MS of being prescribed and using DMTs.

MEDICINAL CANNABIS

In February it was announced that the Government will be establishing an access programme for medicinal cannabis products for a number of named conditions including MS. MS Ireland cautiously welcomed this announcement whilst still expressing concern that the quality, efficacy and safety of such products cannot be guaranteed. MS Ireland made a submission to a consultation on the development of draft clinical guidance for this proposed scheme.

COLLABORATIVE WORK ON ACCESS TO MEDICINES

MS Ireland has joined a working group looking at issues around medications access and reimbursement. Organized by the Irish Platform for Patients Organisations, Science and Industry (IPPOSI) and the Medical Research Charities Group (MRCG), the group met twice in 2017. As well as patient organisations, industry representatives have also participated. A report, 'Steering a course to avoid the drugs iceberg' was launched in August, to which MS Ireland contributed case studies.

IPHA COPNFERENCE

In November, MS Ireland's CEO Ava Battles presented on the importance of timely access to medications at the annual conference of the Irish Pharmaceutical Healthcare Association (IPHA).

NEUROREHABILITATION

MS Ireland has continued to support the Neurological Alliance of Ireland's (NAI) campaign for development of neurorehabilitation services in 2017. 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 group has continued to meet regularly in 2017 and has met with the Minister for Health twice. Political representatives supportive of the campaign also brought forward a Private Members Motion on neurorehabilitation in December, which gained the support of all parties.

HOME CARE CAMPAIGN

MS Ireland has continued to work with a group of 20+ organisations throughout 2017 on the need to improve home care services. This campaign has included a number of meetings with political representatives and ongoing media coverage of the issue. In September, MS Ireland made a detailed submission to a Government consultation on establishing a statutory home care scheme.

EMPLOYMENT

In April, the Government launched the Make Work Pay report on employment and disability. MS Ireland made a submission to the consultation for this report in 2016 and several of the recommendations we made were reflected in the final report. In June, MS Ireland participated in another consultation event in the implementation of the Comprehensive Employment Strategy for People with Disabilities, and also made a written submission to the National Disability Authority. Via membership of a Disability Federation of Ireland working group on employment retention, we also had the opportunity to contribute to a submission to the National Action Plan for Jobs. We were also approached by the National Disability Authority to provide feedback on plans to develop specialist vocational rehabilitation services.

MS Ireland has also convened a working group of occupational therapists with a specialist interest in MS and employment, with a view to developing a professional resource that can be used by OTs in practice, when advising and supporting clients with MS on employment issues.

LOBBYING AND POLICY SUBMISSIONS

MS Ireland made the following policy submissions in 2017. 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, the 'Time to Act' report, the 'Quality of Life of People with MS in Ireland' report, the 'My MS My Needs' report and the 'Multiple Sclerosis and Employment' report in our submissions:

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

Time to Act: The Time to Act report, with detailed recommendations on the need to invest in neurology services and implement the National Clinical Programme for Neurology Model of Care, was sent to the Minister for Health and all members of the Joint Oireachtas Committee on Health.

Home care: MS Ireland made a detailed submission to a Government consultation on home care.

Personalised Budgets: MS Ireland made a detailed submission to a consultation on the proposed introduction of personalised budgets.

Employment: Submission made to National Disability Authority consultation on employment, as part of the implementation of the Comprehensive Employment Strategy for People with Disabilities.

Health Information Bill: MS Ireland made a detailed submission to a consultation on the Draft Health Information Policy Framework.

Sativex: MS Ireland made a detailed submission to the HSE Corporate Pharmaceutical Unit on Sativex.

Cladribine: MS Ireland made a Patient Group Submission to the National Centre for Pharmaco-economics on new DMT Cladribine.

Physiotherapy: MS Ireland wrote to the Minister for Health about the need to protect the job titles of Physiotherapist and Physical Therapist in one professional register, at the request of the Irish Society for Chartered Physiotherapists.

Medicinal cannabis: MS Ireland made a contribution to a consultation on development of draft clinical guidance for a proposed new access programme for medicinal cannabis products.

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

CARERS' WEEK

MS Ireland was once again a partner in National Carer's Week, from 12-18 June. As part of Carers' Week MS Ireland re-launched a revised and updated version of our 60-page online resource for caregivers of people with MS.

PAY-BY-WEIGHT BIN CHARGES

Ms Ireland has begun working with a group of organisations on the issue of bin charges. The group have written to and met with the Department of Environment, Community and Local Government a number of times in 2017 to try and advocate on behalf of people affected by incontinence issues to ensure they are not negatively impacted by changes to bin charges.

COMMUNITY LIVING TASK GROUP

MS Ireland has continued to participate in the Housing Agency's Community Living Task Group in 2017. Work of the group has included developing guidelines for building accessible properties. Also as a result of membership of the group MS Ireland had the opportunity to take part in a meeting with the Department of Environment, Community and Local Government on a review of the Housing Adaptation Grant scheme.

IPPOSI ADVOCACY AND RESEARCH NETWORK

MS Ireland has joined a new Advocacy and Research Network organised by IPPOSI, to discuss advocacy and research topics of common interest such as access to medicines, development of patient registries and eHealth, and plan advocacy actions on these issues. Other organisations in the network include Irish Cancer Society, Alzheimer's Society, Muscular Dystrophy Ireland and Fighting Blindness.

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 2017, 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:

- Treatment and Care Decisions in Advanced MS.
- MS Patient Registries.

We also revised and updated our briefing document on Cannabis-Based Medicinal Products.

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 2017:

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

- Participation in Neurological Alliance of Ireland's We Need Our Heads Examined campaign for neurorehabilitation services.
- Ongoing collaboration with 20+ organisations on the need to improve home care services.
- Participation in IPPOSI and MRCG working group on access to medications and contribution of case studies to the 'Drug Iceberg' report.
- Participation in Disability Federation of Ireland working group on employment retention and making submissions to consultations on employment via membership of this group.

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

- New alliance formed with a group of organisations on the issue of proposed changes to bin charges.
- Formation of a working group of occupational therapists with a specialist interest in employment and MS, to develop a professional resource for OTs.

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

- Publication of a detailed Advocacy Strategy for 2015-2019, informed by MS Ireland research and our service delivery experiences.
- Five submissions made in response to Government consultations, using data from a variety of MS Ireland reports and drawing on MS Ireland's service delivery experiences.
- Additional submissions made to Government departments and TDs on a variety of topics including Sativex, physiotherapy and the need to invest in neurology services, drawing on data from a variety of reports and MS Ireland's service delivery experiences.

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

- Detailed submission made to the HSE Corporate Pharmaceutical Unit on Sativex.
- First ever Patient Group Submission made to the National Centre for Pharmaco-economics on Cladribine.
- New centralised funding mechanism established for Lemtrada and Tysabri.
- Contribution of case studies to 'Steering a Course to Avoid the Drug Iceberg' report, produced by IPPOSI and MRCG.
- Presentation by MS Ireland CEO at Irish Pharmaceutical Healthcare Association conference on medications access.

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

- Submissions made to five Government consultations on home care, Personalised Budgets, health information, employment and medicinal cannabis.
- MS Ireland were approached to provide feedback on the development of new vocational rehabilitation services and to speak at the IPHA conference on access to medicines.
- Participation in a number of high-profile collaborative advocacy campaigns and projects including the We Need Our Heads Examined campaign for neurorehabilitation services, the Invest in Home Care campaign and the IPPOSI/MRCG working group on access to medicines.

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 2017, THIS IS WHAT WE ACHIEVED IN RESEARCH

RESEARCH PRIORITIES SURVEY

Between June and October, members of the MS community in Ireland were asked to complete a Research Prioritisation Survey. It is hoped that as and when MS Ireland has funding available for research in the future, the results of this survey will help guide us as to how best to utilize them so that we are funding research that is most in line with the views and needs of the MS community here in Ireland. The survey will also help us to identify and prioritise potential new research partnerships and collaborations, both nationally and internationally, and guide us as to what type of content people would most like to see disseminated in future research eZines. A total of 451 people completed the survey. A report of the results was published in the December issue of our research eZine, and a summary was presented to a group of MS researchers at our networking event in November.

NETWORKING EVENT FOR MS RESEARCHERS

On 30 November, MS Ireland and Novartis hosted a networking event for Irish researchers interested in MS, in Trinity College Dublin. The purpose of the event was to encourage MS researchers to connect with each other, and to have a discussion on what needs to change to make Ireland a better place to do MS research, and how MS Ireland can support this. In total, 19 researchers attended from all around Ireland, including Northern Ireland. There was a broad range of research disciplines represented, including bench scientists (lab-based researchers, sometimes also known as 'basic' research), geneticists, physiotherapists and occupational therapists. People with MS were also in attendance. There were presentations from Harriet Doig, Information, Advocacy and Research Officer with MS Ireland, Claire McCoy from Royal College of Surgeons and Kate O'Brien from Genomics Medicine Ireland. There was also a facilitated round-table discussion, chaired by Professor Susan Coote, Chairperson of MS Ireland's Research Committee.

Lots of great ideas were shared including:

- Facilitation of researchers to contact each other when they need samples, or have samples they are willing/able to share with others
- Creation of an internet platform where researchers can contact each other and share information – Facebook Workplace was suggested as one platform which could be used for this
- Establishment of a Public Patient Involvement (PPI) Network of people with MS, who researchers can contact for assistance with designing studies and grant applications
- Moving towards the standardisation of patient data that is currently recorded at neurology centres, to support the eventual establishment of a registry

RESEARCH NEWS

MS Ireland published two more editions of our research eZine, MS Research, in 2017. Topics covered in the eZine included:

- Re-myelination research
- The potential of cannabinoids as treatments for MS
- Potential new progressive MS treatment Biotin
- Causes of MS
- Physiotherapy
- Genomics research
- Incidence of MS in Ireland
- Fatigue
- Why does clinical research take so long?
- Reports from ECTRIMS conference (European Congress of Treatment and Research in Multiple Sclerosis

Ms Ireland have also created a new section on our website called 'Reliable sources of MS research', to help people with MS to stay up to date with accurate and reliable reports on MS research.

Please visit the Research section of our website www.ms-society.ie for further information.

NUI GALWAY - MINDFULNESS RESEARCH

In 2016 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. Work continued on this project throughout 2017, with focus groups taking place with people with progressive MS to establish what the programme would need to contain, and a pilot programme being designed.

MY MS MY NEEDS SURVEY

In May 2016, 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. The full report of the findings was published in September. Data and recommendations from the report have already been used in a number of policy submissions including MS Ireland's responses to the Government consultations on home care and Personalised Budgets

UNIVERSITY OF LIMERICK - PHYSIOTHERAPY RESEARCH

The collaboration between MS Ireland and the University of Limerick on physiotherapy research has now been ongoing for six years. Work on a number of different research projects took place in 2017:

FALLS PREVENTION

Work continued in 2017 on ongoing research projects looking at falls prevention for people with MS. A survey was conducted with 140 people with MS who had recently experienced falls and the findings were submitted for publication in a leading journal. A trial Falls Prevention intervention has also been developed. A systematic review and meta-analysis to quantify balance problems in people with MS in comparison to people without MS to help to inform future Falls Prevention interventions was also conducted and submitted to a leading journal for review.

PILATES

A new project looking at the effect of Pilates on mood in people with MS was begun in 2017.

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 2017, attending Board meetings and sitting on their Communications and Advocacy Subgroup. Harriet Doig, Information, Advocacy and Research Officer, joined the Board of the MRCG in September. MRCG have also established a new Shared Learning Group on the topic of public patient involvement (PPI) in research, which MS Ireland have been participating in.

INTERNATIONAL PROGRESSIVE MS ALLIANCE

A number of MS Ireland branches made donations to the work of the International Progressive MS Alliance in 2017, to support research into developing treatments for progressive forms of MS.

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 third Dean Medal Travel Bursary in 2017. The successful applicant was Sravanthi Bandla from NUI Galway, who plans to travel to the University of Glasgow to deepen her knowledge in relation to discovering the therapeutic activity of ER chaperones in the context of multiple sclerosis.

ACHIEVING IN RESEARCH

IRISH BRAIN COUNCIL

MS Ireland was part of the steering group of the Irish Brain Council in 2017 and were involved in organising their conference in March, on the theme of "Brain Research in Ireland: Investing in all our Futures". MS researchers were also well represented among the poster displays at the conference.

PPI IGNITE COLLABORATION

MS Ireland were approached by the University of Limerick and asked to be collaborators on a new PPI Ignite programme. PPI Ignite is a scheme funded by the Health Research Board to encourage universities to involve patients and the general public in the design and delivery of research programmes. UL were successful in their application to the Health Research Board and MS Ireland will be a partner, along with a number of other patient organisations.

MS IRELAND RESEARCH CONFERENCE PRESENTATIONS

MS Ireland were invited to speak at the Irish Association of Rehabilitation Medicine conference in June, on the topic of using internet platforms to engage people with MS in research. We also spoke at a conference in the Royal College of Surgeons in June on the subject of public patient involvement (PPI) in research.

PARTICIPATING IN RESEARCH

Each year we ask the MS community to participate in ongoing research. In 2017 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. All researchers who request MS Ireland's support in recruiting participants are asked to comply with MS Ireland's Protocol for Researchers, which was revised and updated in 2016. Here are some of the studies we asked you to take part in:

- Exploring parents' experiences of a diagnosis of MS in their young adult sons/daughters
- The psychological impact of living with MS
- The effect of Pilates on mood among people with MS
- The effect of gender identity on help-seeking and social support in male carers of people with MS
- MS brain health video resources
- Validation of speech pathology questionnaire
- Research priorities of the MS community in Ireland
- Exploring social isolation, loneliness, and social asymmetry as predictors of complex post-traumatic stress disorder in MS
- Impact of health literacy on emotional health in people living with MS
- Experiences of disease modifying therapies (DMTs)
- Trial for online pain self-management programme
- Better Balance falls prevention programme
- Genomics of MS

IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Research in 2017:

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 Priorities Survey conducted to establish what areas of research the MS community in Ireland consider the most important, to inform decisions around funding when funds are available in the future.

COLLABORATE WITH ACADEMIC INSTITUTIONS ON THE DELIVERY OF RESEARCH PROJECTS

- Research networking event held to strengthen relationships between MS Ireland and researchers.
- MS Ireland selected as a collaborator for new PPI Ignite project at the University of Limerick.

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

- Ongoing funding and practical support provided to researchers investigating mindfulness and MS at NUI Galway.
- Third Dean Medal Travel Bursary awarded.
- Donations made by a number of MS Ireland branches to the International Progressive MS Alliance.
- My MS My Needs survey report published and data utilised in policy submissions.
- Researchers supported to recruit participants for projects investigating a variety of topics including Pilates, the psychological impact of living with MS, the genomics of MS, falls prevention and post-traumatic stress disorder in MS.

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

- All researchers who request support in recruiting participants for studies are required to comply with MS Ireland's Protocol for Researchers.

ACHIEVING IN ORGANISATIONAL CAPACITY

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

SPECIFIC OBJECTIVES:

- 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 2017, THIS IS WHAT WE ACHIEVED IN ORGANISATIONAL CAPACITY

RESOURCE ALIGNMENT

The situation in relation to statutory and fundraised income remains challenging.

» In August 2017 after long negotiations with staff and their unions, members of staff were made redundant. These redundancies were part of a wider resource alignment for 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 their year end net assets to support local services.

INTEGRATED MODEL OF SERVICE

2017 was the sixth 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

15 Regional Integrated Meetings took place in 2017.

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 a number of different 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 2017 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.

HUMAN RESOURCES

Recruitment during 2017 concentrated on replacing necessary leavers or unfilled posts.

Angela Minogue, Administrator in the Mid-West & Frank Kiely, Community Worker in the Dublin, South West Area retired.

The following posts were recruited in 2017:

- Thomas McCarthy, Marketing and Communications.
- Aideen Connolly, Community worker in the Southern region.
- Mary McCusker Community worker in the Midwest region.
- Paul Halpin, Senior Corporate fundraising executive.
- Sally Spearman , Campaigns and Fundraising executive.
- Melanie Cunningham, Senior fundraising executive.

EMPLOYEE RELATIONS

MS Ireland has faced difficult decisions in relation to ensuring that the Organisation is sustainable and delivering services to People with MS into the future. You will be aware that these difficulties have been with us for some years and even though we have tried to stem the tide with non-replacement of staff who have left or retired, reduction in staff hours and non-payment of increments we had to take further actions in 2017. These actions have resulted in a restructuring programme which has meant changes throughout the organisation:
In National Office there have been three voluntary redundancies and one compulsory redundancy and role changes as a result. In the Regions there has been one voluntary redundancy and restructuring of administration functions and lines of reporting. The Care Centre which continues to operate on reduced hours.

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 the 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 2017.

KISS GOODBYE TO MS 2017

Kiss Goodbye to MS 2017, the second year of the campaign in Ireland, brought great support for the research and vital services initiative.

The 2017 campaign was supported by actor Aoibhinn McGinnity, Sara Jane and James Tracy and panels of 10 excellent spokespeople, living with MS. MS ambassadors were the highlight of this campaign with features on TV3's Ireland AM (Sara-Jane Tracy and Dr Sabina Brennan, TCD), TV3's Sunday AM (James Tracy), Newstalk, Irish Country Living front cover, Irish Mail on Sunday and top women's publications. Aoibhinn was featured in The Irish Times, Irish Independent, and Woman's Way. Regional media relations resulted in strong photo coverage and campaign focused articles.

Media relations activity continued from the launch in January 2017 through to February 14th until the end of February.

PR activity involved announcing the campaign with great photos, organization feature stories for people living with MS, a Kiss Goodbye to MS survey, media drops of campaign materials, and a final call to media.

PUBLIC RELATIONS

WORLD MS DAY 2017

World MS Day 2017 took place on Wednesday May 31st with the theme of Life with MS, raising awareness of Multiple Sclerosis for thousands of people in Ireland and their families. MS Ireland, represented by Aoife Kirwan from Kildare and Maggs O'Riordan Wall from Limerick, both living with MS, highlighting the challenges of life with MS and the crucial need for increased neuro rehabilitation services. Events around the country to mark World MS Day were also communicated including new research from UL highlighting the benefits of exercise for people living with MS. Maggs O'Riordan Wall featured on TV3's Ireland AM with MS Nurse Jane Roche as well as being interviewed for a feature piece in The Sunday Independent.

Sara-Jane Tracy and Maggs O'Riordan Wall were interviewed by Matt Cooper on The Last Word, Today FM. Newstalk did a piece on Paul and Karen McGovern who completed the Wild Atlantic relay during the summer.

TheJournal.ie featured Aoife Kirwan.
World MS Day was also covered in The Irish Times, The Irish Examiner, The Irish Independent, The Evening Echo, regional newspapers and radio.

MEMBERSHIP

At the end of 2017 our membership stood at 4,624

PUBLIC RELATIONS

MS READATHON 2017

It was an honour to welcome Felicity Dahl, the wife of the late Roald Dahl, to Ireland to launch the 30th MS Readathon, marking a milestone for the reading initiative and the first ever MS Readathon which was supported by her late husband Roald Dahl in 1988.

Michelle Hanley who is living with MS and her children Abbey and Alex, from Cork represented the MS community as an ambassador, telling her story and promoting the 30th MS Readathon.

The official launch took place in Hodges Figgis bookshop with Felicity Dahl, Michelle Hanley and her family as well as top children's authors, Children's Books Ireland (CBI), Penguin and MS Readathon sponsor Heinz.

Teacher Leanne Tracy, sister of MS Ireland ambassador Sara Jane Tracy and Irish rugby international and MS ambassador James Tracy brought along two 4th classes from St Fintan's NS, Dublin, 50 children in all to create great excitement.

RTE News2Day recorded the launch event interviewing ambassadors, teachers and children. They followed their report in September with the MS Readathon prizes announcement.

The Ryan Tubridy Show featured an interview with Felicity Dahl on the day of the launch event. Penguin / Roald Dahl foundation supplied 50 Roald Dahl books for attending school children. Publisher MacMillan donated 30 children's books by Irish authors for prizes.

The 30th MS Readathon was also shared via Rick O'Shea Book Club, Newstalk with articles in The Irish Independent, The Irish Times, Irish Examiner, Evening Echo, TheJournal.ie, Irish Mirror, MyKidsTime, EUmom and Mummypages. Thank you and launch press releases tailored to each County in Ireland resulted in great coverage across the regional press.

IRISH AUTHORS

Ireland's best authors provided enthusiastic quotes about kids reading. Cecelia Ahern, Rick O'Shea, Sarah Webb, Alan Early, Nicola Pierce gave their testimonials about the MS Readathon. Alan Early brought the pens he won doing the MS Readathon 20 years ago!

IRISH INDEPENDENT NEUROLOGY SUPPLEMENT

The PR team ensured strong presence for MS Ireland in the Irish Independent Neurology Supplement 2017.

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 2017

- 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 is on the Board of IPPOSI and Information, Advocacy and Research Officer Harriet Doig is on the Communications and Advocacy Sub-group of the MRCG and also joined the Board of the MRCG in 2017. Harriet also joined the Irish Health Research Forum (organised and run by MRCG).

- The Neurological Alliance of Ireland regarding the campaign for increased investment in neurological services, neurorehabilitation and Brain Awareness Week. Harriet Doig represents MS Ireland on the Board of NAI. Harriet is also a member of NAI's Campaign Working Group for the We Need Our Heads Examined campaign.
- Care Alliance for Carers Week, and participating in the Family Carer Research Group.
- The Disability Federation of Ireland (DFI) in the areas of health sector cuts, governance, rehabilitation, neurological funding, employment, assistive technology, housing and accommodation, and disability rights. Services Manager Olga Estridge is on the Board of DFI.
- 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 CEO meeting in September. We also attended EMSP's conference in Athens in May.
- Pharmaceutical companies; in particular Biogen Idec, Genzyme, Merck Serono, Novartis, and Roche regarding funding and educational projects and activities. In particular we would like to note the following collaborations in 2017:
    * Working with Merck Serono to support the development of a patient support programme for a new disease modifying therapy.
    * Attending the International Patient Organisation Information Exchange and Global MS Patient Group Summit, organised by Roche.
    * Collaborating with Novartis on the production of the MS and Quality of Life report.

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 2017 three worthy winners were picked from the many wonderful applications. Congratulations to them, their families and the MS communities they work in. The winners were:

VOLUNTEERS OF THE YEAR:
Marie Cronin-O'Donoghue & Paddy O'Donoghue.

MS PERSON OF THE YEAR:
Paul McGovern

WORLD MS DAY 2017

In 2017 across the globe World MS day took place on the 31st of May and this marked the 8th year of the campaign. The theme of this year's campaign was #lifewithMS. Thank you to everyone who joined the global movement and helped raise awareness of MS around the world.

On World MS day, we hosted an event in the A.V room of Leinster House. The event was in conjunction with Novartis who produced a new report on the quality of life with MS.

The event was attended by over 40 TDs and senators where the lack of support available in areas such as neurorehabilitation services and home care was highlighted.

The highlight of the event was Aoife Kirwan's personal and inspiring speech on her #lifewithMS

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:

DONEGAL: In Donegal there was an awareness/ information day held in the Abbey Hotel.

LIMERICK: In the Limerick office a coffee morning took place, where Pauline O'Brien a psychotherapist held a seminar on Mindfulness skills for Living. Also in Limerick, UL launched their findings from their research in to the area of Exercise and MS led by professor Susan Coote.

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

CORPORATE

Although this year's Worlds MS day was primarily an awareness day, shining a light on #LifewithMS, fundraising events still took place throughout the country.

One of our charity partners, SAP held a raffle of two signed Irish Rugby Jerseys which took place on World MS day.

The staff at Irish life held a "Red Walk" on their lunchtime to mark the day and also raised funds.

Transfermate held a 5k run, while Gecas in Shannon held a 9,000 steps event. A big thank you to all.

MS CARE CENTRE:

On World MS day the care centre in Rathgar held its annual Coffee morning to celebrate World MS day. At the Event there was a tombola raffle, garden plants flower arrangements, a book stall, greeting cards, fiver Friday, old style sweet shop, photography live music and lots more. The event was attended by friends, family and volunteers and was a great success. We had volunteers from SAP Ireland who assisted on the day while carrying out bucket collections in nearby Rathgar.

FUNDRAISING 2017

MS READATHON 2017

2017 marked a milestone year for the MS Readathon, it was our 30th anniversary. 9,000 Readers and 327 schools took part raising a grand total of €325,779. We were honoured to have Felicity Dahl at our launch in Hodges Figgis Bookshop, whose late husband Roald Dahl helped launch our first ever MS Readathon all those years ago. Michelle Hanley and her two children Alex & Abbey were this year's family ambassadors.

BOWL-A-THON

In November we held our first ever Bowl-a-thon with all funds raised going to the Care Centre. The event took place in Leisureplex Stillorgan with eleven teams battling it out for the top spot. Katie Finnegan and her team were the ultimate victors after a competitive knock out round. Along with a raffle on the night, the event was a great success and raised over €6,000.

CHRISTMAS JUMPER DAY

So many companies from across Ireland got in the Christmas spirit to help out MS Ireland on our Christmas Jumper Day appeal. Some of the costumes were very 'unique', but everyone had a great time and raised over €10,000 for MS Ireland. A huge thanks to all those who took part – we are already looking forward to the 2018 pictures!

2018 CALENDAR

We ran our fifth annual image competition in 2017 to find thirteen stunning images for our 2018 calendar. We had hundreds of entries from lots of very talented amateur photographers from around the country, each with their own interpretation of the theme, which was Reflections of Ireland. The production f the calendar was very kindly sponsored by Novartis as well as 12 individual monthly sponsors.

FUNDRAISING 2017

KISS GOODBYE TO MS

This was the second year of the campaign where we asked people of all ages to WEAR, DARE or SHARE. Along with the Red Lab Coat day, a Skydive dare and a partnership with Costa Coffee, the whole country joined together to KISS Goodbye to MS.

The hashtag #KissGoodbyetoMS was all over Twitter, Instagram and Facebook. People were asked to take a selfie wearing their favourite lippy or an item of red clothing, upload the picture to social media and donate €4.00 by texting SMOOCH to 50300.

With support from Ireland and Leinster rugby player James Tracy and his sister Sara-Jane, along with a raft of bloggers and influencers the campaign drew lots of media attention.

TREKS

In September we took on the challenge of trekking through Croatia. We travelled up the Dalmatian Coast to Podgora and started the trek in the Biokovo Mountains, followed by a day in the Dana Mountains before Trekking on 3 of the islands and finishing up in Dubrovnik. This was a successful trek with 40 participants.

AD HOC SPORTS

We had a variety of people participating in a huge number of events and challenges; most notable was Finlay Ray who planned to climb Mont Blanc. When he got there he was advised by his guide that the weather was not in his favour so he changed his challenge to 7 (very high) peaks during his challenge the weather cleared so he decided to climb Mont Blanc and the 7 peaks! Not content with this he also raised over €4,000.

FUNDRAISING 2017

MINI MARATHON

The 2017 mini marathon had over 230 participants who raised over €36,000 for MS Ireland. We had great support from both individuals and groups. We started off with photos at the beginning of the race and ended up with a thank you event which is very much appreciated by the ladies after their run.

DUBLIN CITY MARATHON

We had over 30 runners in the Marathon in 2017 that brought in over €22,000. A big thank you to all who took part.

ABSEIL

Last November we have had lots of fundraisers check one off the bucket list by scaling the heights of Croke Park, taking in the beautiful panoramic views of Dublin City, and then abseiling down to the hallowed turf below! Whether they were someone living with MS, taking part for a friend or family member, or simply overcoming their fear of heights, the Abseil has proved to be a very popular event.

WILD ATLANTIC RELAY

In 2017 Paul and Karen McGovern completed their epic walk from Mizen to Malin Head, raising vital funds for MS Ireland's regional services. In total they raised a whopping amount of over €40,000.

A huge thanks to everyone who walked, crawled, sang, attended a fundraiser, provided some physio, made tea, cut sandwiches, helped out with the driving, and generally kept spirits high.

The Cork City, Cork North West, Kerry South, Tralee/West Kerry, Kerry North, Clare, Galway, Mayo South, Ballina, and Donegal branches all rolled up their sleeves to lend a massive hand and help Paul & Karen. The McGovern's literally could not have completed this daunting challenge without all of the fantastic support they received along the way.

Paul & Karen are now relaxing in their home in Dunleer, but plans are afoot for their next challenge. Watch this space!

FUNDRAISING 2017

IRISH LIFE CHARITY PARTNERSHIP

A massive THANK YOU to our charity partner for 2017 Irish Life who presented us with a cheque for a phenomenal €170,000! There was an incredible effort from everyone at Irish Life throughout the year and we were all absolutely blown away by their commitment, engagement, and enthusiasm. From Abseiling off the roof of the Irish Life Building to getting out their green fingers in the garden of the Care Centre, we are truly appreciative of all their efforts. This will have a huge impact on our services in 2018.

DAA PARTNERSHIP

Thank you to all the staff at Dublin Airport and to everyone who travelled through Dublin Airport for their overwhelming generosity and support in raising €100,000 for MS Ireland in 2017. As well as raising vital funds for our services, this partnership gave us the opportunity to create an awareness of Multiple Sclerosis and the work that we do here at MS Ireland. This will have such a positive impact on our local support services nationwide, as well as our respite Care Centre, ensuring that we can continue to make a difference to the MS community in 2018 and beyond.

PWC PARTNERSHIP

A huge THANK YOU to all the staff in PWC for their fantastic support throughout 2017 and their amazing donation of €13,131.75! Thank you for all the hard work in organising various fundraising events throughout the year. PwC employees also volunteered on various different projects around Ireland for the MS Community, pats on the back all round! These funds will have a massive impact on our services nationwide and make a huge difference to our work.

AND MANY MORE.....

PERRIGO PARTNERSHIP

Our fantastic supporters Perrigo Company plc donated €40,000 for the refurbishment of our bedrooms in the MS Care Centre in 2017. These works are now complete, and are already having a hugely positive impact for our residents and staff there. Brian O'Broin, Ciara Cassidy & Dr. Grainne Quinn joined Olga Estridge our MS Ireland Services Manager for a cheque presentation last October. We are extremely grateful for the amazing generosity and continued committed support of Perrigo, the lasting impact that they have had on our MS Care Centre residents is second to none.

THANK YOU!

Big **THANKS** to all our fundraisers, donors and supporters for their generosity throughout 2017. 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 2017:

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, 31st May.

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

- Use of corporate volunteers in a number of capacities including administration, gardening and online marketing.
- Six new posts were filled throughout the country in the areas of fundraising, community work and Marketing and communicaitons.

TO ENSURE MS IRELAND REMAINS A VIALBLE 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

- New World MS Day event at Leinster house attended by several TDs and political representatives.
- MS Readathon raised €325,779.
- €100,000 raised as a result of our partnership with the Dublin Airport Authority.
- Irish Life Raised €170,000.
- PWC raised €13,131.75.
- Perrigo Raised €40,000.
- Inaugural MS Ireland abseil took place in croke park in November.
- 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

- 15 Regional Integrated Meetings took place.

ACHIEVING 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 2017, THIS IS WHAT WE ACHIEVED IN GOVERNANCE & REGULATION

WHO WE ARE

MS Ireland is the only national organisation providing information, vital services and support to the MS community. We provide a wide range of specialised services and resources on a national, regional and local level. Services include: Regional Community Worker programmes for one-to-one support; physiotherapy; symptom management courses; newly diagnosed sessions and the MS Information Line, one of the first services used in the time leading up to or following a diagnosis. We also provide the only national respite and therapy centre for people with MS in Ireland.

More than two-thirds of the 9,000 people living with MS in Ireland access these resources. All those affected by the condition rely on MS Ireland to advocate on their behalf on any issues which will impact their quality of life.

PATRON

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

ORGANISATION DETAILS

AUDITOR

Deloiite
Chartered Accountants and Statutory Audit Firm
Deloitte & Touche House
Earlsofrt Terrace
Dublin 2

PRINCPAL BANKERS

Bank of Ireland
College Green
Dublin 2

SOLICITORS

Joynt & Crawford
8 Angelsea Street
Dublin 2

REGISTERED OFFICE

80 Northuimberland Road
Dublin 4

CHARITY NUMBER

CHY 5365

CHARITY REGULATORY NUMBER

20007867

COMPANY NUMBER

296573

DATE OF INCORPORATION

19th November 1998

YEAR MS IRELAND WAS FOUNDED

1961

THE BOARD

MS Ireland is governed by a board of 13 voluntary members. These members have a wide range of experience and skills. Some have MS themselves or have family members with MS. Others have long careers in business, social services and other areas. The Board promotes the vision, aims and values of the Society and charges the Chief Executive to meet these aims through the various departments, services and resources of the Society. In 2017, the Board met six times. Significant work was carried out in the areas of finance and funding, governance and strategy.

🔵 BOARD MEMBER 2016/2017

🟢 BOARD MEMBER 2017/2018

		🔵 BOARD MEMBER 2016/2017	🟢 BOARD MEMBER 2017/2018
CHAIRPERSON	Marcella Flood	🔵	🟢
VICE CHAIRPERSON	Maurice O'Connor	🔵	🟢
	Robin Bradley	🔵	🟢
	Noelle Burke	🔵	🟢
	Tom Cronin	🔵	🟢
	Eugene Kearney		🟢
	Jacinta Kelly		🟢
	Rory Mulcahy	🔵	🟢
	Ian MacDougald	🔵	🟢
	Edel O'Kelly	🔵	
	Martin Power		🟢
	Anne Restan	🔵	🟢
	Mary Sheahan Lonergan	🔵	🟢
	Killian Smith	🔵	
	Paddy Stronge	🔵	🟢

RESIGNATIONS/CHANGES

Edel O'Kelly (Resigned 9th November 2016)

Killian Smith (Resigned 30th March 2017)

Patrick Stronge (Chairperson until 23/9/2017)

APPOINTMENTS

Eugene Kearney (Appointed 23 September 2017)

Jacinta Kelly (Appointed 23 September 2017)

Martin Power (Appointed 23 September 2017)

THE BOARD

BOARD COMMITTEES

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

- Finance, Audit and Risk Committee
- Governance Committee
- Nominating Committee
- Remuneration Committee
- Research Committee
- Services Monitoring & Evaluation Committee
- Strategic Planning and Fundraising Committee

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

BOARD ATTENDANCE 2017

	25 JAN	1 APR	27 MAY	24 JUN	23 SEP (i)	23 SEP (ii)	3 DEC	TOTAL
Robin Bradley	✓	✓	✓	×	✓	×	✓	5/7
Noelle Burke	×	✓	×	✓	×	×	✓	3/7
Thomas Cronin	✓	✓	✓	✓	✓	✓	✓	7/7
Marcella Flood	✓	✓	✓	✓	✓	×	✓	6/7
Eugene Kearney	n/a	n/a	n/a	n/a	n/a	✓	✓	2/2
Jacinta Kelly	n/a	n/a	n/a	n/a	n/a	✓	✓	2/2
Ian MacDougald	✓	✓	✓	✓	✓	✓	×	6/7
Rory Mulcahy	✓	✓	✓	✓	✓	×	✓	6/7
Maurice O’Connor	✓	✓	✓	✓	✓	✓	✓	7/7
Martin Power	n/a	n/a	n/a	n/a	n/a	✓	✓	2/2
Anne Restan	✓	×	✓	✓	✓	✓	✓	6/7
Mary Sheahan-Lonergan	✓	✓	✓	×	✓	✓	×	5/7
Paddy Stronge	✓	✓	✓	×	✓	✓	✓	6/7

THE BOARD

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.

RECRUITMENT AND INDUCTION OF BOARD MEMBERS

Three of our thirteen Board Members vacancies are filled on a rotational basis from the council branch representatives. Notification of the remaining vacancies for Board members is 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. In 2017 one Board member was elected under Article 56 of the Constitution who, with the support of fifteen members, was elected by going directly to the AGM rather than via the Nominating Committee election process.

New Board members are given one afternoon's induction training by the CEO to familiarise them with their duties as Board members, their legal obligations, the governance of the organisation and policies and procedures. Further training can be made available if required.

BOARDMATCH IRELAND TRANSPARENCY SCALE

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

SKILLS AND EXPERIENCE

Annually the Nominating Committee with the CEO determine the skills required on the Board. When the Nominating Committee recommend candidates to the Board, they ensure that the skills gap is filled. Candidates are required to be committed to MS Ireland's development, share in its values and be problem solving in their approach as well as having proven professional skills. MS Ireland's Board members have expertise in a wide range of areas including accounting, legal, banking, HR and strategic marketing. For full board profiles log on to our website, www.ms-society.ie

LENGTH OF TERMS SERVED BY THE BOARD

A Board member is elected on to the Board for a period of three years. The Board member can opt to stand for re-election for a further three years. Each board member can serve no more than three terms of three years on the Board so a maximum of nine years' service as a Board member is permitted.

DECISION MAKING PROCESSES

Decisions reserved for the board and those delegate to CEO are listed in the organisations Code of Conduct. Schedule of Matters of the Board are detailed in the Code of Conduct. Log on to our website to read the Code of Conduct: 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.

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 CEO Ava Battles is appointed as Company Secretary. Although this is not in line with 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 2017 the Council met three 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

We have 34 voluntary Branches operating across Ireland. See page 14, 15 and 37 for more information on the wonderful work of our Branches.

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 68 people across national and regional offices and 53 Community Employment participants. MS Ireland's work is supported by committed volunteers around the country.

MS. AVA BATTLES, CHIEF EXECUTIVE

MS. MEMORY CHIPERE	MR. DAVID ALLEN	MS. OLGA ESTRIDGE	MR. AIDAN LARKIN
FINANCIAL ACCOUNTANT	CORPORATE SERVICES MANAGER (Redundant Sept. 2017)	SERVICES MANAGER	SERVICES DEVELOPMENT MANAGER

REMUNERATION

The number of employees whose emoluments, excluding employer pension contributions, were greater than €70,000 in 2017 is set out below:

1	€70,000 - €80,000
0	€80,000 - €90,000
1	€90,000 - €100,000 (CEO)

The Remuneration Committee, a sub-committee of the Board, is responsible for making decisions regarding remuneration of the senior management team and those who report directly to the Chief Executive.

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 ensure that our work transparent and above reproach.

THE GOVERNANCE CODE

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

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

On 13th July 2013 the Board signed up to the principles of Good Governance in the Governance Code. On 28 Jan 2017 the board certified its compliance with the governance Code with 2 exceptions

2.1(b) The CEO is appointed as Company Secretary. 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.

2.2(e) MS Ireland does not have an internal audit function. Given the size of the organisation, we have sufficient controls in place and oversight of the controls. All branches are required to have an annual independent audit of their accounts.

In 2017 MS Ireland became a member of the Charities Institute of Ireland Triple Locked Standard – Best Practice in Transparency and Accountability.

ACHIEVING IN GOVERNANCE & REGULATION

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.

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.

NATIONAL FINANCIAL ASSISTANCE REGULATIONS

MS Ireland 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.

Log on to our website for further details of all the Codes of Practice MS Ireland subscribes to:

www.ms-society.ie

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

There was a net incoming resource before exceptional items of €397,448 for the year (2016: €293,532). There was a deficit of €655,109 for 2017 after exceptional items. The exceptional items totalled €1,052,557 and are comprised of a property impairment charge of €854,400 and a Redundancy charge of €198,157 arising from an organisatioanl restructuring review. Income for the year includes significant Legacies/Donations totalling €113,368 (2016: €222,401) and a surplus from branches of €80,205 (including Legacies). 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 €7,361,459 (2016: €8,016,568) at the end of the the financial year. They are are comprised of restricted funds of €1,575,967 (2016: €1,663,403) and unrestricted funds of €5,785,492 (2016: €6,353,165)

THESE FUNDS ARE REPRESENTED BY THE FOLLOWING:

	NATIONAL OFFICE & CEP	BRANCHES	TOTAL
	€	€	€
Tangible Fixed Assets	4,831,564	70,504	4,902,068
Net Current Assets (excl. Bank loan)	2,749,171	1,368,018	4,117,189
Bank Term Loan	(1,657,798)	-	(1,657,798)
TOTAL	**5,922,937**	**1,438,522**	**7,361,459**

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 €2,749,171 are comprised of Restricted Net Current Assets of €727,238 and Unrestricted Net Current Assets of €2,021,933.

RESERVES 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.

EXTRACT FROM AUDITED FINANCIAL STATEMENTS

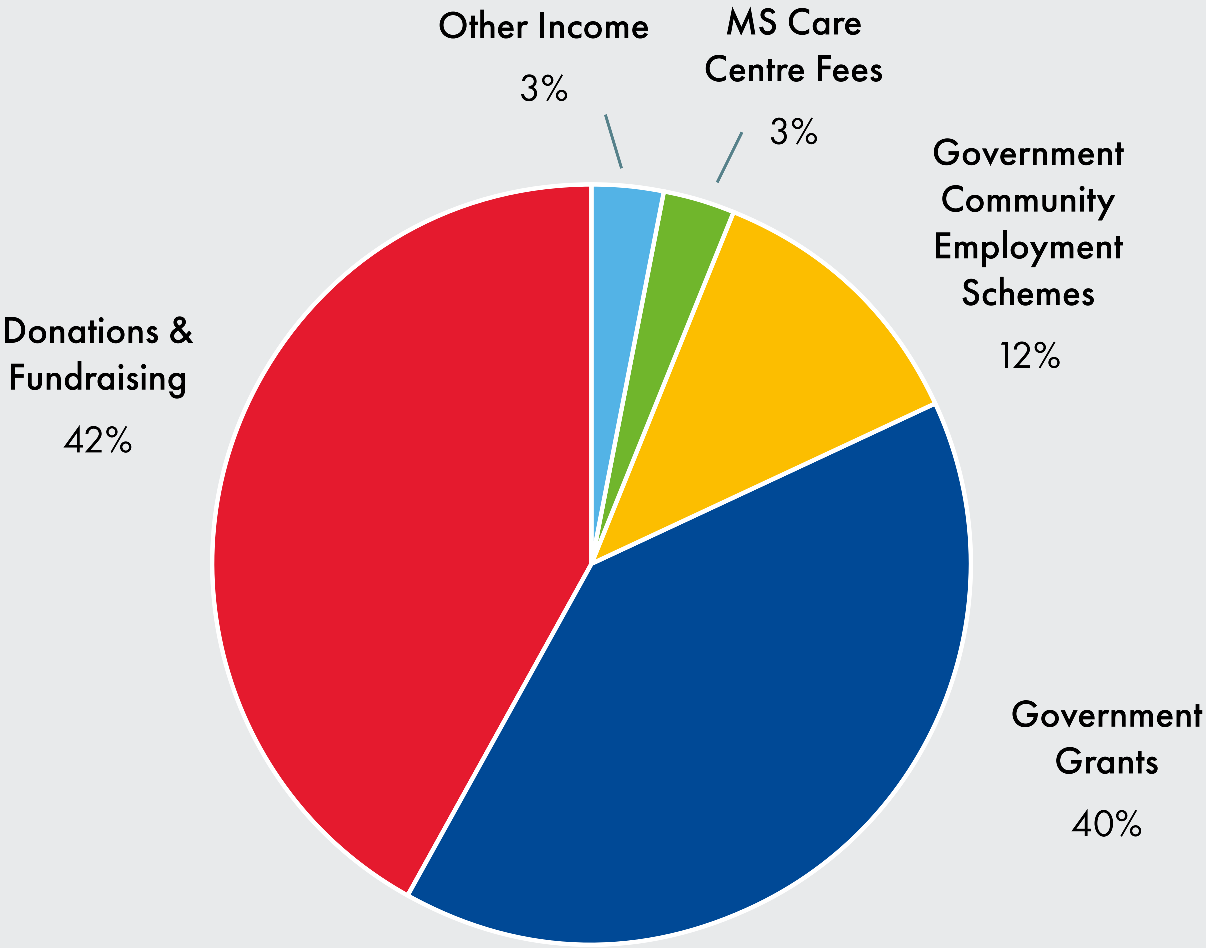
	Unrestricted Funds 2017 €	Restricted Funds 2017 €	Total Funds 2017 €	Total Funds 2016 €
INCOMING RESOURCES				
Income from generated funds				
Voluntary Income				
Donations and fundraising	2,414,840	166,454	2,581,294	2,552,671
Legacies	113,368	62,013	175,381	92,401
Research	-	47,930	47,930	6,117
Subscriptions	3,280	-	3,280	2,840
Income from charitable activites				
Fees received	213,553	-	213,553	220,853
Grants and other service contract income	-	2,695,672	2,695,672	2,739,964
Government schemes	-	796,662	796,662	808,161
Other income	112,744	93,948	206,692	217,210
Total incoming resources	2,857,786	3,862,679	6,720,464	6,640,217
RESOURCES EXPENDED				
Costs of generating voluntary income				
Fundraising	727,430	44,927	772,357	753,852
Charitable activities				
Community services	235,333	2,332,776	2,568,109	2,642,328
Respite care sercices	551,813	1,410,012	1,961,825	1,915,968
Research	5,056	99,620	104,676	97,325
Local MS services	792,110	55,049	847,159	834,646
Governance costs	61,159	7,731	68,891	68,575
Total resources expended	2,372,901	3,950,115	6,323,016	6,346,685
Taxation	-	-	-	-
Net income for the year	484,884	(87,436)	397,448	293,532
Exceptional items	(1,052,557)	-	(1,052,557)	-
Reconciliation of Funds:				
Total funds brought forward	6,353,165	1,663,403	8,016,568	7,723,036
Total funds carried forward	5,785,492	1,575,967	7,361,459	8,016,568

INCOME ANALYSIS 2017

€6,720,464

Income of €6,720,464 was received of which 40% was funding from Government Grants mainly HSE, 42% was Donations and Fundraising, 12% was from 3 Department of Social Protection schemes we have in Donegal, Galway and Dublin, 3% was from fees received from Respite Centre residents and 3% from miscellaneous income.

		2017 (€)	2016 (€)
🟥	Donations & Fundraising	2,804,605	2,651,189
🟦	Government Grants	2,695,672	2,739,964
🟨	Government Community Employment Schemes	796,662	808,161
🟩	MS Care Centre Fees	213,553	220,853
🟦	Other Income	209,972	220,050
	TOTAL	6,720,464	6,640,217



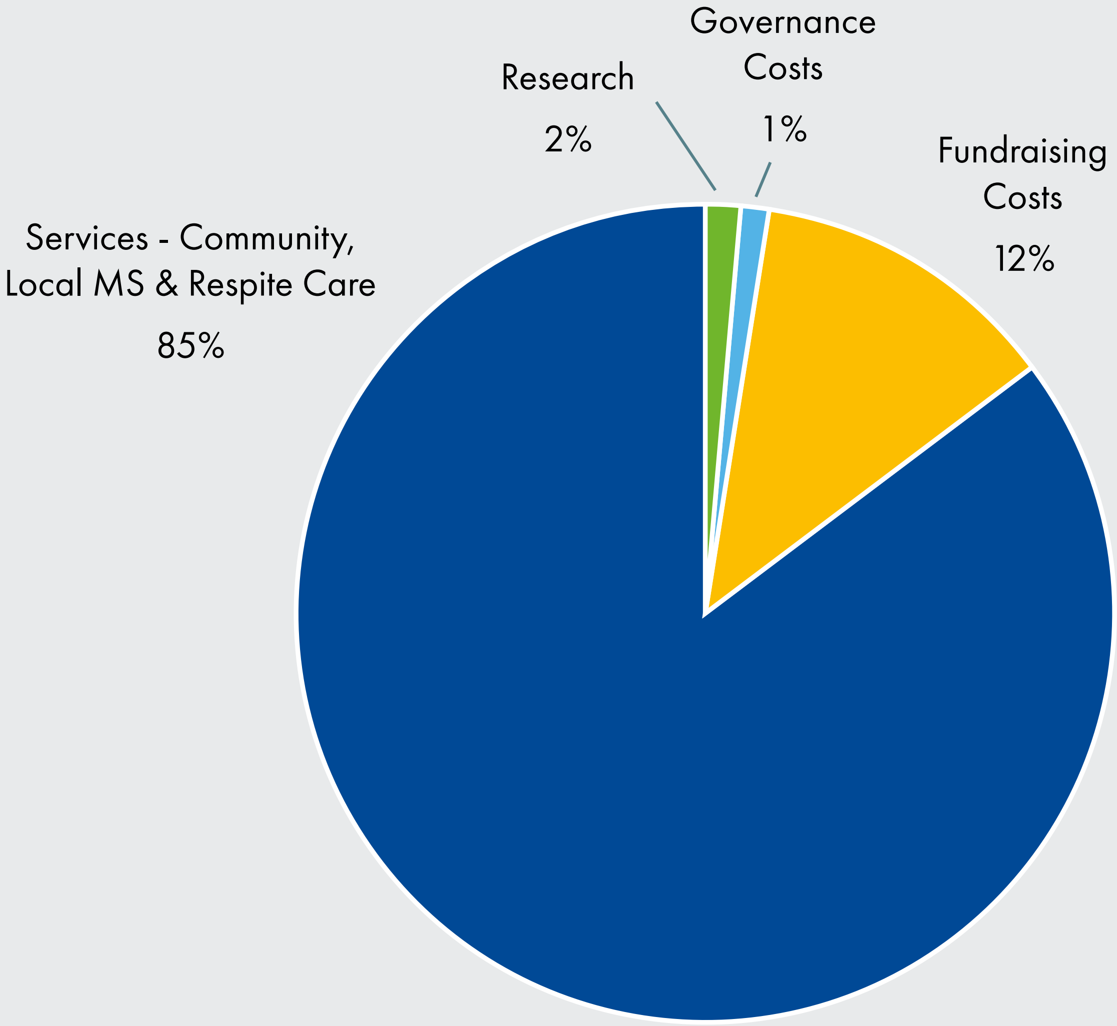
OPERATIONAL EXPENDITURE ANALYSIS 2017

(excluding exceptional items)

€6,323,016

€6,323,016 was spent in 2017 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.

		2017 (€)	2016 (€)
🟦	Services - Community, Local MS & Respite Care	5,350,452	5,426,933
🟨	Fundraising Costs	772,357	753,852
🟦	Governance Costs	68,891	68,575
🟩	Research	131,316	97,325
	TOTAL	**6,323,016**	**6,346,685**



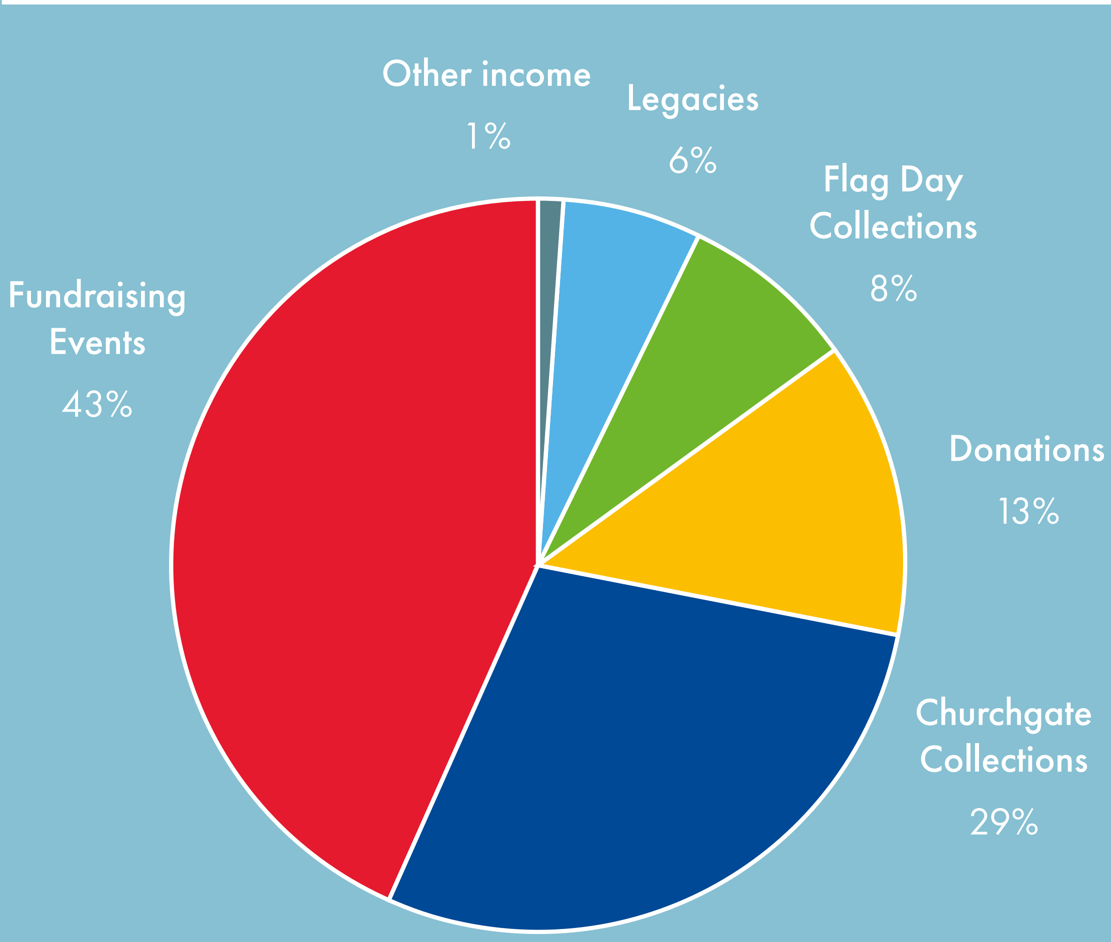
BRANCH INCOME ANALYSIS 2017

€1,005,906

There were 34 Branches in operation during the year. During the year 3 branches ceased activities. All the funds raised in the Local Branches is spent locally to provide services for people with MS.

Income of €1,005,906 was received of which 43% was raised from fundraising events, 29% from churchgate collections,13% from Donations, 8% from Flagdays collection, 6% from Bequests and 1% was from other income such as bank interest, christmas party contributions, etc

		2017 (€)	2016 (€)
🟥	Fundraising Events	434,291	491,590
🟦	Churchgate Collections	288,510	285,306
🟨	Donations	129,637	96,365
🟩	Flag Day Collections	78,904	77,697
🟦	Legacies	62,013	35,887
⬛	Other income	12,551	16,814
	TOTAL	**1,005,906**	**1,003,658**

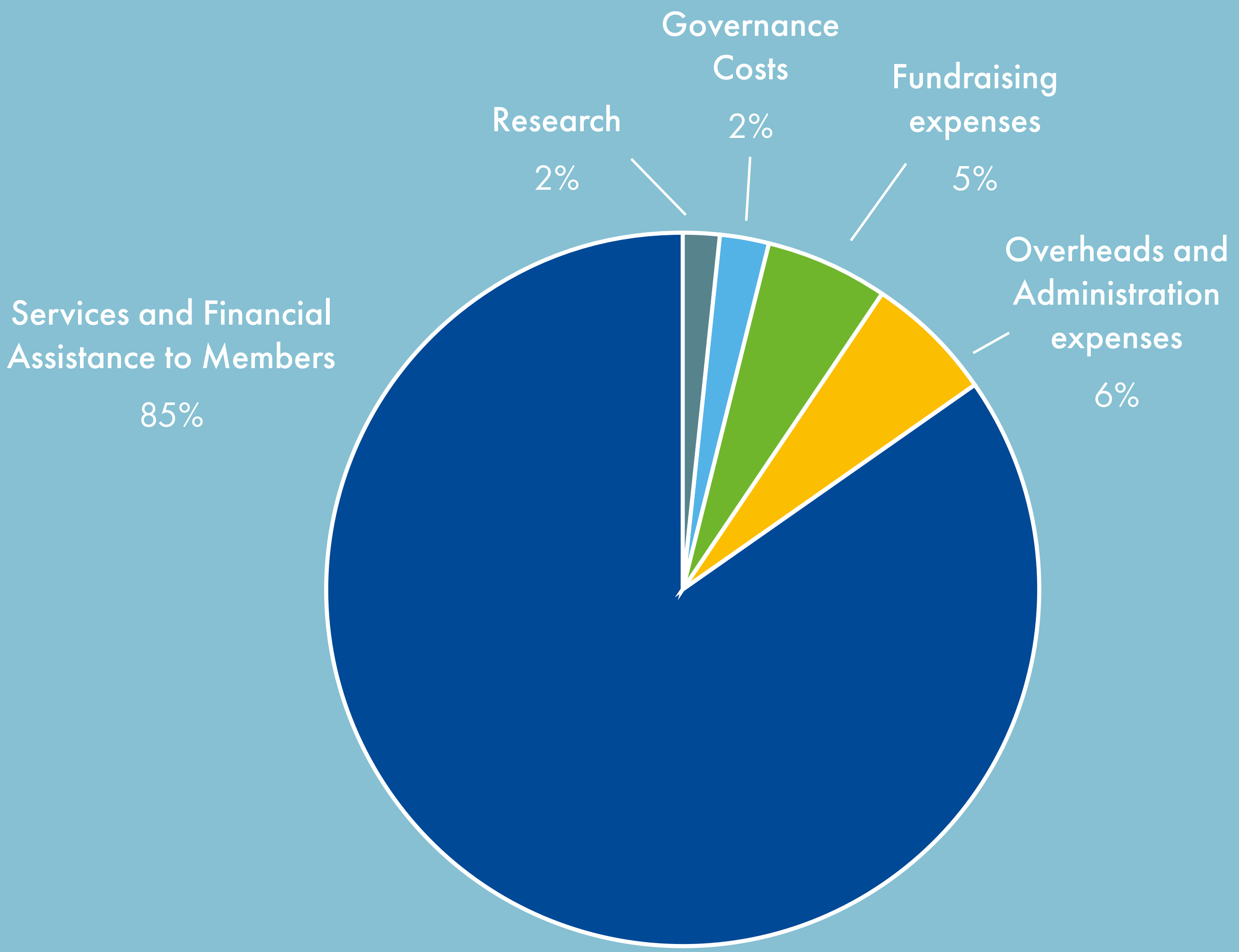


BRANCH EXPENDITURE ANALYSIS 2017

€925,702

€925,702 was spent in 2017 of which 85% was spent on providing services & Financial assistance to members, 5% on fundraising expenses, 6% Overheads and Administration expenses, 2% Governance and 2% on Research.

		2017 (€)	2016 (€)
🟦	Services and Financial Assistance to Members	782,436	802,774
🟨	Overheads and Administration expenses	54,460	48,936
🟩	Fundraising expenses	50,351	62,145
🟦	Governance Costs (Audit Fees Only)	22,748	24,499
⬛	Research	15,707	7,500
	TOTAL	**925,702**	**945,854**



IN SUMMARY

Here is a summary of how we have achieved our stated objectives in Governance & Regulation in 2017:

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

- Significant work was carried out by the Board and sub-committees in the areas of:
  - Finance and funding,
  - Governance and strategy,
  - 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.

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, were held in 2017.

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

pobal
government supporting communities

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