

# MS IRELAND ANNUAL REPORT & ACCOUNTS 2014



OUR **MISSION** IS TO ENABLE & EMPOWER PEOPLE AFFECTED BY MS TO LIVE THE LIFE OF THEIR CHOICE TO THEIR FULLEST POTENTIAL.

**EMPOWER** PEOPLE WITH MS TO CONTROL THEIR LIVES & INFLUENCE THEIR ENVIRONMENT // ALLOW PEOPLE WITH MS TO **LIVE WITH DIGNITY** WHILE PARTICIPATING IN THE COMMUNITY // PROVIDE **SUPPORT** FOR THE FAMILIES AND CARERS OF PEOPLE WITH MS // **CO-OPERATE** WITH THE MEDICAL, SCIENTIFIC, SOCIAL & CARING PROFESSIONS // PROMOTE **SCIENTIFIC RESEARCH** INTO THE CAUSES OF MS // **ENCOURAGE** BETTER MANAGEMENT OF MS & ITS SYMPTOMS // **EXCHANGE** & DISSEMINATE **INFORMATION** ON MS // **DEVELOP** AN EFFICIENT, EFFECTIVE AND CARING ORGANISATION TO **SERVE THE NEEDS** OF PEOPLE WITH MS //

WE ARE THE ONLY ORGANISATION PROVIDING COMMUNITY-BASED **SERVICES**, INFORMATION & SUPPORT TO THE ENTIRE MS COMMUNITY ON A NATIONAL, REGIONAL AND LOCAL LEVEL.

THESE INCLUDE: INDIVIDUAL & FAMILY **SUPPORT** // LIVING WITH MS PROGRAMMES, ACTIVITIES & WORKSHOPS // CONFIDENTIAL **MS INFORMATION LINE** 1850 233 233 // **MS CARE CENTRE** FOR RESPITE & THERAPIES // **38 VOLUNTARY BRANCHES** NATIONWIDE // PROFESSIONAL **COUNSELLING** // ADVOCACY AND LOBBYING // **INFORMATION PUBLICATIONS** // WEBSITE: **WWW.MS-SOCIETY.IE** // **MSNEWS** MAGAZINE & E-NEWSLETTER // **RESEARCH & INFORMATION** // NATIONAL **CONFERENCES & GATHERINGS**

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**WORKING  
TOGETHER**

## CHIEF EXECUTIVE & CHAIRMAN WELCOME

Multiple Sclerosis Ireland is the only national organisation solely providing information, support and advocacy services to the MS community. We work with people with MS, their families and carers and a range of key stakeholders including health professionals, students and others interested in or concerned about MS to ensure that we meet our goals. We are committed to the mission of MS Ireland, 'to enable and empower people affected by MS to live the life of their choice to their fullest potential'. We are proud to welcome you to a review of MS Ireland in 2014. Even during these challenging times our staff, volunteers, funders, supporters and people with MS have worked hard to ensure that we continue to work to serve the MS community.

It would be an understatement to suggest that the last few years have been challenging. Like many community and voluntary organisations the reduction in funding support from state sources has certainly been a formidable challenge exacerbated by the impact on our private donations of the recession and where there have been scandals in other charities also. We continue to maintain the highest levels of corporate governance and integrity in everything that we do.

We are successfully negotiating the challenges facing us, on every front, seeking the support of the HSE, the Department of Social Protection, corporates, funders, a dedicated team of staff and volunteers and the Board.

Our MS Information Line, the MS Care Centre and our regional services continue to experience increasing demands. We also continue to work with the University of Limerick and other academic institutions on a number of research projects. People with MS have contributed to numerous surveys throughout the year to help us advocate on issues like medical cards and living with a neurological condition. We were delighted to host the European Multiple Sclerosis Platform Conference in May in Dublin. World MS Day is always a highlight of the calendar year and the theme for 2014 was all about access - access to services, treatments, care or anything else that matters most to you. People in every corner of the country were shouting from the rooftops to raise awareness about MS and the work of MS Ireland.

# CHIEF EXECUTIVE & CHAIRMAN WELCOME

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Our fundraising calendar was very busy and we celebrated 25 years of MS Ireland taking walkers to the Camino. Caroline Morahan, actress, TV presenter and face of Littlewoods was our 2014 Flora's Women's mini marathon ambassador and she ran with several hundred people to raise funds to provide services for people with MS.

The MS & Me Blog team covered topics on fatigue, depression, access to information, accessible holidays and many more topics on living with MS. The MS & Me Blog was shortlisted in the Blog Awards and we are incredibly proud of our team of Bloggers on their success to date. Social media continues to grow, with ever increasing numbers using Facebook and Twitter to communicate with MS Ireland.

We thank all the staff and volunteers in MS Ireland who have an unwavering passion

and commitment and work so hard to change lives every day. Thanks to the Board who give time and expertise freely in support of running the best organisation we can be for people with MS. We would also like to thank all those who support MS Ireland's work on an ongoing basis. Without all this support the environment for people with MS would be much less supportive. So while there is still a lot of work to be done, we remain optimistic that we can continue to garner the support of the community and together we can bring about real change for people with MS.

While this annual report highlights our progress over the past year, it gives only a flavour of the totality of the work done. In the next year and in the years to come, we will continue to challenge ourselves and encourage others to work for a better Ireland for the MS community.

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



**AVA BATTLES**  
**CHIEF EXECUTIVE**



**PADDY STRONGE**  
**CHAIRMAN**

# STRATEGIC GOALS

2014 was the final year of our three year Moving Forward Strategic Plan. The goals in the plan come from our 2011 organisational review which identified the services people with MS most valued from MS Ireland. The results showed a clear mandate for the future:



## SUPPORT & SERVICE PROVISION

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



## RESEARCH

To fund research and disseminate national and international research developments in an accessible format.



## INFORMATION & EDUCATION

To provide timely, accurate, sensitive and accessible information to people who use our services and educational activities for health professionals.



## STRENGTHENING PROFILE & CAPACITY

To continue developing an efficient and effective organisation that supports our services, staff and volunteers within available resources and to deepen the good reputation of MS within the media, allied organisations and those who use our services.



## CAMPAIGNING & ADVOCACY

To represent the views and concerns of people who use our services at a local, national and international level.



## FUNDING THE STRATEGY

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

Log on to our website to read the full strategic plan:  
[www.ms-society.ie](http://www.ms-society.ie)



"I'd describe it as going into a balloon. There's kind of a shield around the care centre. When you go in, all of the concerns you have on the outside of the balloon are gone". John

## ACHIEVING IN SUPPORT & SERVICE PROVISION

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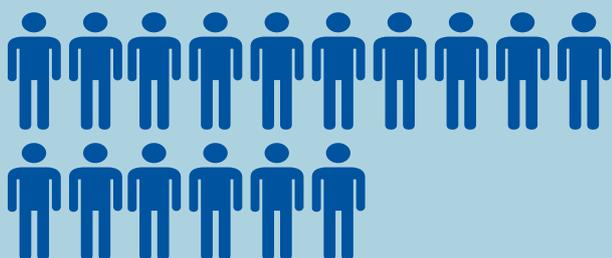
IN 2014, THIS IS WHAT WE ACHIEVED IN SUPPORT & SERVICE PROVISION

# ACHIEVING IN SUPPORT & SERVICE PROVISION

## THE MS CARE CENTRE

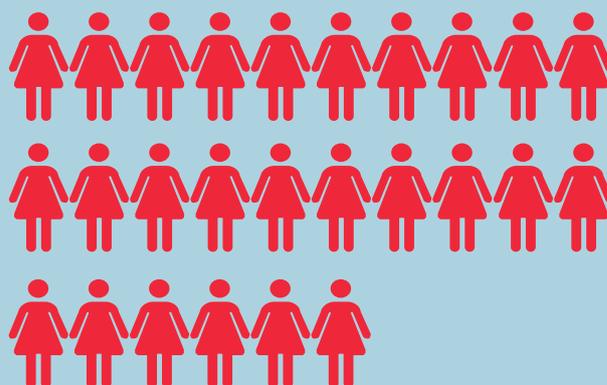
Our MS Care Centre is the only respite and therapy centre for people with MS in Ireland. Providing short-term respite care for people with MS, during a week-long stay a resident can avail of therapeutic services, neurological assessments, access to an MS nurse and a range of social activities to allow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

In 2014 the MS Care Centre provided professional, dedicated care for 412 people. Our highly trained staff and specialised equipment ensures a safe and comfortable stay for residents and peace of mind for family members and carers.

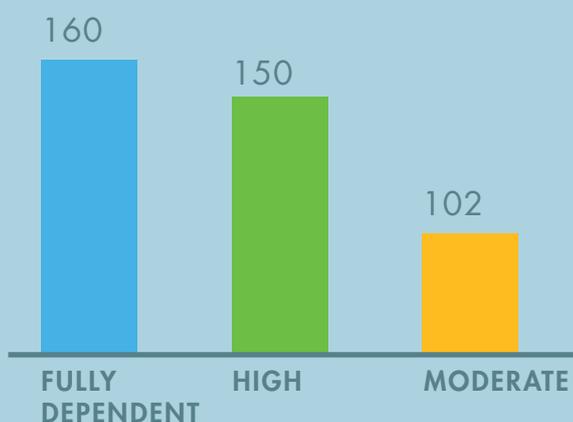


**MALE: 155**

**FEMALE: 257**



## DEPENDENCY



## NEW & RETURNING RESIDENTS



\*SOME RESIDENTS STAYED TWICE OR MORE

## PROFESSIONAL & THERAPEUTIC INTERVENTION



# ACHIEVING IN SUPPORT & SERVICE PROVISION

## IMPROVING THE MS CARE CENTRE

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



**GARDEN MAINTENANCE**



**PAINT WORK**



**NEW FLOORING**



**EQUIPMENT**

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.

The MS Care Centre has had two successful HIQA inspections in 2014 and management at the Centre are very pleased that the outcomes from both visits, confirmed a very high standard of compliance overall. The MS Care Centre expects to officially achieve formal registration as a designated centre for adults with a disability early in 2015.

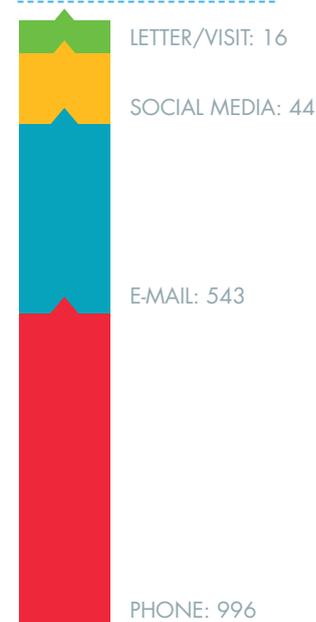


## THE MS INFORMATION LINE

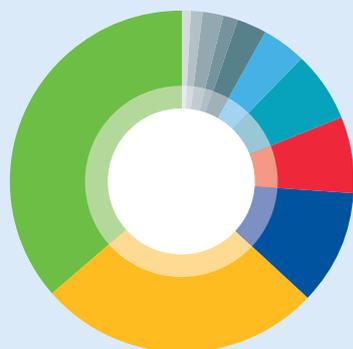
Operating weekdays from 10am-2pm, our dedicated information line provides professional, anonymous and confidential support for people with MS, their families, carers and health professionals.

In 2014,  
**1,599 PEOPLE**  
contacted the  
MS Information  
Line

### HOW PEOPLE MADE CONTACT



### REASON FOR MAKING CONTACT



# ACHIEVING IN SUPPORT & SERVICE PROVISION

## 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.

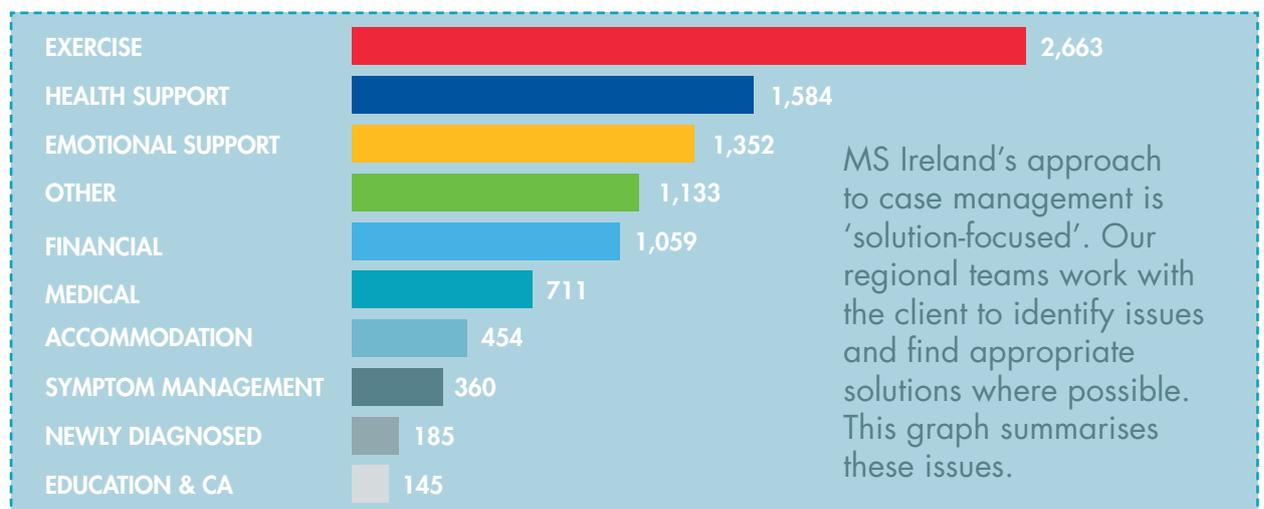
Casework, living with MS programmes and counselling are three of the main services our Regional Offices provide to people and families living with MS. Other services include information to health professionals, service development, public awareness and support to the voluntary Branch structure.

## CASEWORK

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



## TOP 10 ISSUES PRESENTED BY CLIENTS



# ACHIEVING IN SUPPORT & SERVICE PROVISION

## LIVING WITH MS PROGRAMMES

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

These programmes may be one off sessions or a 10 week course, depending on the nature of the programme. The figures below summarises the types of programmes we ran from January 2014 to date:



SYMPTOM MANAGEMENT



PHYSICAL ACTIVITIES



INFORMATION EVENTS



NEWLY DIAGNOSED SEMINARS



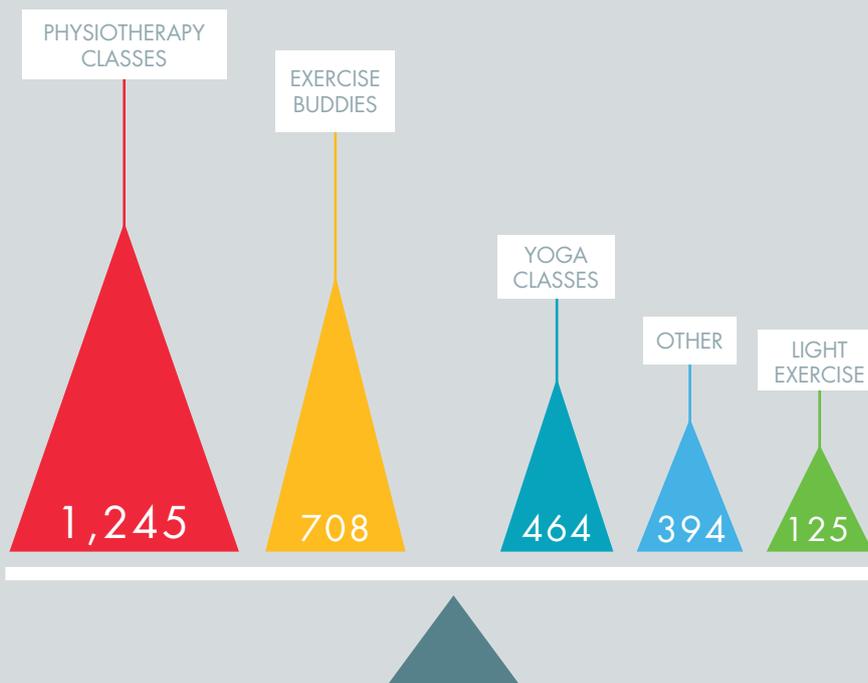
CARERS SUPPORT GROUPS

## 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.

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.

## IN 2014 WE PROVIDED



## COUNSELLING

In 2014, counselling sessions were conducted nationwide for people with MS. The service allows people to explore issues relating to their MS in an individual and confidential manner.



## WORKING TOGETHER: AN INTEGRATED APPROACH

### ACHIEVING IN SUPPORT & SERVICE PROVISION

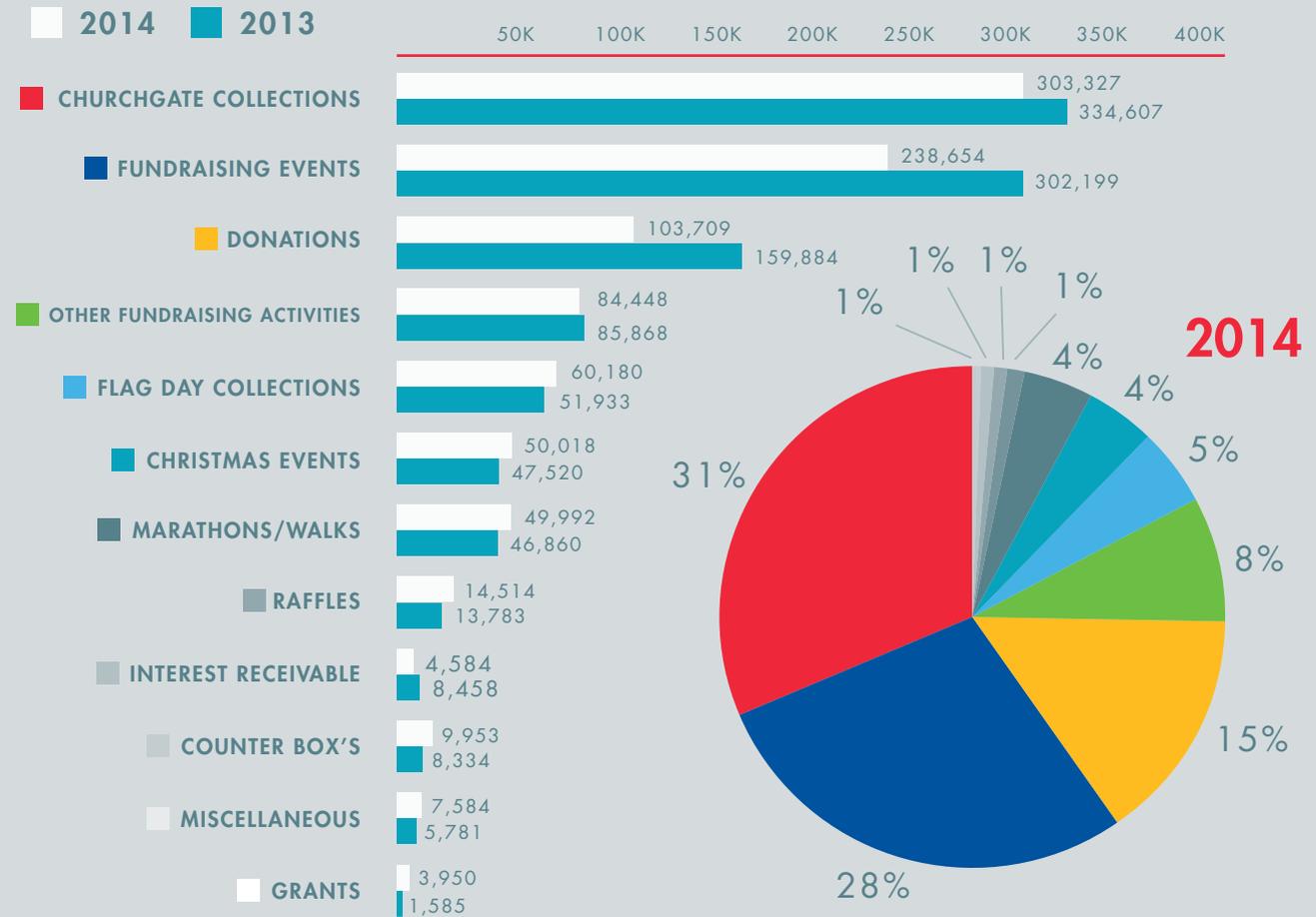
#### VOLUNTARY BRANCH SERVICES WORKING TOGETHER

2014 was the third year of our integrated model of service delivery. Our professional regional staff worked closely with our dedicated teams of volunteers throughout our branch network to best fund, organize and deliver services to the local MS community. This team work has meant that we are able to make the best use of all our resources to best address the needs of people with MS and their families.

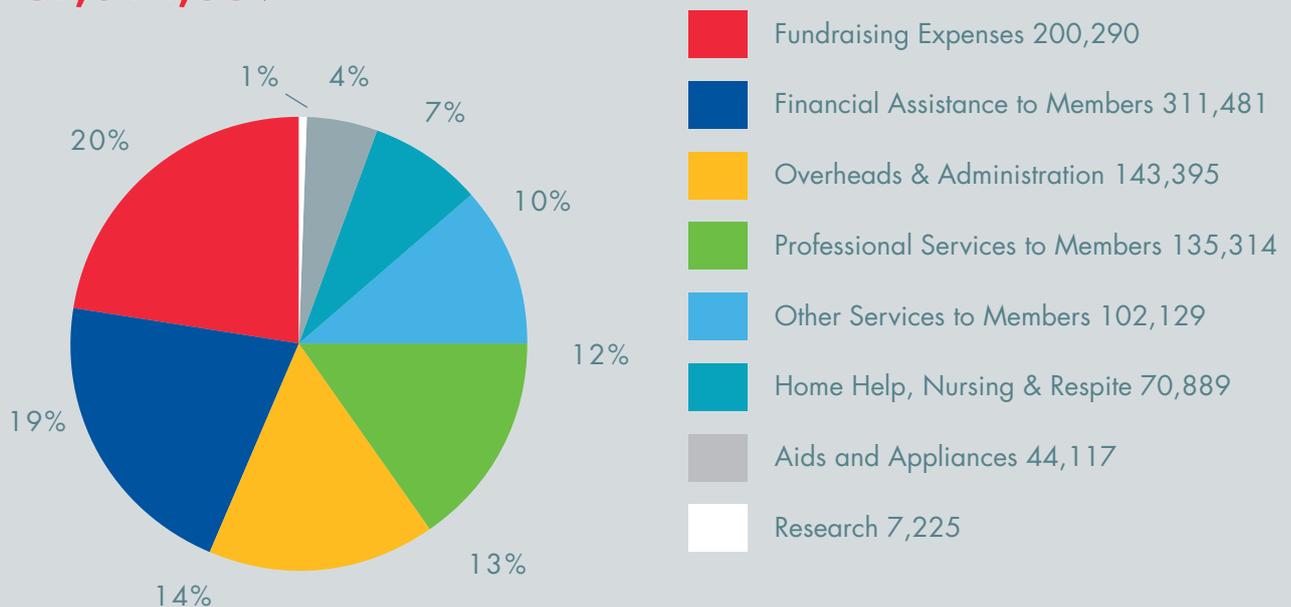


# ACHIEVING IN SUPPORT & SERVICE PROVISION

## BRANCH INCOME 2014: € 930,913



## BRANCH EXPENDITURE 2014: €1,014,839 (DEFICIT 83,926)



# ACHIEVING IN SUPPORT & SERVICE PROVISION

## FIND YOUR LOCAL MS IRELAND

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

### DUBLIN NORTH & FINGAL REGIONAL OFFICE

Providing services in North County Dublin and Dublin City

[na@ms-society.ie](mailto:na@ms-society.ie) | (01) 490 5933

### MIDLANDS REGIONAL OFFICE

Providing services in Laois, Offaly, Longford and Westmeath

[midlands@ms-society.ie](mailto:midlands@ms-society.ie) | (090) 647 1137

### MIDWEST REGIONAL OFFICE

Providing services in Clare, Limerick, Tipperary North

[midwest@ms-society.ie](mailto:midwest@ms-society.ie) | (061) 303 803

### NORTH EAST REGIONAL OFFICE

Providing services in Cavan, Monaghan, Louth, and Meath

[northeast@ms-society.ie](mailto:northeast@ms-society.ie) | (042) 975 4304

### NORTH WEST REGIONAL OFFICE

Providing services in Donegal, Sligo and Leitrim

[northwest@ms-society.ie](mailto:northwest@ms-society.ie) | (074) 912 5017

### SOUTH EAST DUBLIN & WICKLOW REGIONAL OFFICE

Providing services in Wicklow and areas of south Dublin

[eca@ms-society.ie](mailto:eca@ms-society.ie) | (01) 678 1600

### SOUTHERN REGIONAL OFFICE

Providing services in Cork and Kerry

[southern@ms-society.ie](mailto: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](mailto:southeast@ms-society.ie) | (056) 7777 771

### SOUTH WEST DUBLIN & KILDARE REGIONAL OFFICE

Providing services in Kildare and areas of South West Dublin

[swa@ms-society.ie](mailto:swa@ms-society.ie) | (01) 490 5933

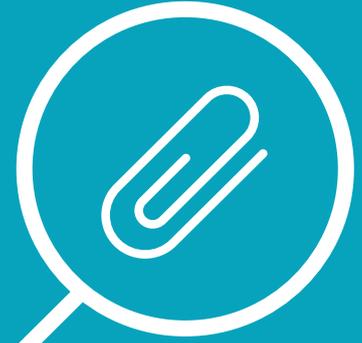
### WESTERN REGIONAL OFFICE

Providing services in Galway, Mayo and Roscommon

[western@ms-society.ie](mailto:western@ms-society.ie) (091) 768 630

## VOLUNTARY BRANCHES

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



# ACHIEVING IN INFORMATION & EDUCATION

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IN 2014, THIS IS WHAT WE ACHIEVED IN  
INFORMATION AND EDUCATION.

# ACHIEVING IN INFORMATION & EDUCATION

## NATIONAL MEETING 2014

### THE DAY'S AGENDA

#### Council Meeting

**Support, Advocate  
and Act for people  
with MS in Europe**  
Emma Rogan Project  
Co-ordinator, EMSP

**Good Governance  
Practise – Willing  
vs Regulatory  
Compliance**  
Sheila Nordon, Irish  
Charities Tax Reform  
(ICTR)

**Discussion on MS  
Ireland's Strategic  
Plan**

The Annual General Meeting (AGM) and a Council meeting took place on 13th September 2014 and three National Annual Awards were presented on the day.

On Saturday the 13th of September MS Ireland invited people with MS, their family and friends to presentations and our Annual General Meeting in the Hilton Hotel, Kilmainham, Dublin.

The presentations on the day covered information on the European MS Platform (EMSP) and also governance, in light of the new Charities Regulator, and what this meant for MS Ireland.

Marcella Flood and Sarah Dempsey were elected to the Board. Dr. Susan Coote and Dr. Kilian Smith were re-elected. Thomas Cronin was elected as the new Council Representative, Sean Murphy was co-opted by the Board. Paddy Stronge was appointed Chairman and Bryan Harty was appointed Deputy Chairman.

Margaret Burke stepped down from the Board and we would like to thank Margaret for her diligent and passionate service to the Board of MS Ireland over the past six years.



All presentations are available to view  
on our website [www.ms-society.ie](http://www.ms-society.ie)

## ACHIEVING IN INFORMATION & EDUCATION

### LIVING WELL WITH MS CONFERENCE



On World MS Day 2014 MS Ireland hosted a one day conference, Living with MS, in Cork. MS and Me blogger Declan Groeger was there to report on the day's sessions.

Dr. Brian Sweeney, Consultant Neurologist Cork University Hospital, kicked off the day by bemoaning the fact that even if 12 more neurologists were appointed by the HSE the ratio would only be 1:100,000 and that would still be shy of what is needed. He spoke on the incidences of MS with Europe standing at 108:100,000 while North America has the unenviable figure of 140:100,000. I'm glad I'm European. He mentioned the signs and symptoms but sadly we are all too aware of those even though we all present differently. Thankfully we don't all have each sign and symptom. The average age at diagnosis is 30; more women than men have MS, there is an hereditary factor, albeit a small one; 97%

of people with MS (PWMS) have no family history.

I have previously blogged on the need for PR training for those giving diagnoses and Dr. Sweeney told us how the use of medical jargon is being discouraged in medical student training. Not quite PR training but it's a start. While commenting on the available treatments he said that MS is a marathon not a sprint. Treatments should be considered with the long-term plan in mind and he urged us not to look for 'instant gratification'. He warned of patients having too high an expectation of any drug but I think that we all know that the treatments currently available are not cures but hopefully are at least stabilisers. Dr. Sweeney noted that the two aspects of MS that cause most concern to PWMS are walking and vision and, with that in mind, he said that Fampyra should be available without the needless worry of cost.

### LIVING WELL WITH MS CONFERENCE

Dr. Eric Downer, Department of Anatomy & Neuroscience, University College Cork, spoke on his Cannabinoids research – he started by noting that he was scientist, not a clinician, who rarely meets patients. Cannabinoids have been used in the treatment of tumours but what has achieved most notice over the last number of years is its use in the alleviation of spasticity and tremors in MS. Over the years cannabis has had bad press with its recognition as a psychoactive drug. Its components are readily absorbed into the system and thus give instant gratification. There are between 80 & 100 active components in cannabis but only two are of real interest, with THC being one. This psychoactive element of cannabis reaches a very high level in the body and stays active for a prolonged period after smoking but when ingested medically its peak is much lower and it remains in the system for a shorter period of time.

Professor Michael Hutchinson, Consultant Neurologist, St. Vincent's University Hospital (Dublin) and MS Ireland Medical Advisor, spoke on Vitamin D and its role in MS. He told us that research is ongoing but much more is needed as there is no universally agreed intake level and its presence, or lack thereof, does not completely explain the prevalence of MS in certain areas. Vitamin D is naturally available through sunlight and fatty fish but both are insufficient in Ireland. Prof Hutchinson recommended a daily supplement especially in the winter months but a discussion with your doctor should take place before starting any supplementation. He told us some very useful Vitamin D facts which are listed here.

#### VITAMIN D FACTS

- Vitamin D deficiency may lead to increased susceptibility to MS
- The incidence of MS is higher in North East France than in South West France
- Immigration prior to the age of 15 causes the immigrant to acquire the MS risk of the recipient country and the converse is also true
- A 22 year study of US armed forces concluded that Vitamin D protects against MS
- MS activity tends to be seasonal, being more active in the spring, after winter, when our Vitamin D levels are depleted and very low activity is often seen in autumn/early winter when levels are raised after the summer sunshine
- High Vitamin D levels reduce the rate of brain atrophy in early MS

**Authors note – take plenty of sun holidays, eat fatty fish and you'll be grand!**

## ACHIEVING IN INFORMATION & EDUCATION

### MS & ME BLOG

Last year MS Ireland launched a community blog as a place for people with MS to Share their experiences of life with MS. In 2014 115 blog posts were authored by people with MS. The blog encourages conversation and debate with the aim of supporting and informing people. We see this as an excellent accompaniment to the formal information available from our website, booklets and other sources.



### MS NEWS MAGAZINE

Two editions of MSnews were published in 2014 and distributed to over 10,000 homes, offices and clinics in Ireland. The spring edition focused on Vitamin D and MS, MS Nurse PROfessional and exercise and MS. The autumn edition focused on relationships and MS, accessible travel and MS READaTHON.





# ACHIEVING IN CAMPAIGNING & ADVOCACY

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IN 2014, THIS IS WHAT WE ACHIEVED IN  
CAMPAIGNING AND ADVOCACY



## CELEBRATING 25 YEARS OF EXCELLENCE

Since 1999 the MS Care Centre has provided professional, specialised and compassionate care for people with MS. As the only dedicated respite and therapy centre for people with MS in Ireland, we were incredibly humbled to celebrate the MS Care Centre's 25th anniversary in 2014.

The centre provides short-term respite care for people with MS and during a week-long stay a resident can avail of therapeutic services, neurological assessments and a range of social activities to allow for complete rest and recuperation. A stay at the centre isn't just a break for a person with MS, it is also an opportunity for family members and carers to recharge.

Time and time again we hear such positive feedback

about staff in the MS Care Centre from past residents and their families as a direct result of the compassion, dedication to professionalism and willingness to go above and beyond for residents. Husband and wife, Janet and Ciarán are fantastic advocates for the MS Care Centre. As Ciarán's primary caregiver Janet knows how important it is to take time off to recharge and the MS Care Centre means she can do just that: "I've come to recognise that it's also a break for me. There's a lot of guilt associated with leaving someone you care for and it is difficult to leave him for a full week but it's now something I have to do to make sure I can provide the best possible care to my husband. That's all I want." With experience of other more generalised respite services Janet insists on continuing to use the MS Care Centre before all

others. Janet says that when Ciarán is there she knows he is safe. The peace of mind she gets from having a history with the centre is something she just doesn't get anywhere else: "I can't stress to you how very important the MS Care Centre is to me. It's essential to my health and wellbeing. It's what keeps me going. I want to keep my husband at home and this allows me to do it."

The MS Care Centre opened its doors on 1st January 1989 as a beacon of hope for people with MS throughout the country. It was the result of unrelenting hard work and perseverance that the centre came into being. The names of people like Mervyn Taylor, Mary Kirk Allen, Tom Connors and Martin Nolan (to name just a few) and their vision of a better future for people living with MS will forever be

# ACHIEVING IN CAMPAIGNING & ADVOCACY

associated with the MS Care Centre and all who pass through the building. From its inception the MS Care Centre was a tightly run ship. The founders knew exactly what they envisaged for the Centre and never wavered far from this.

The Friends of the MS Care Centre was set up to generate funds for the building through landmark events like Carnation Day. Upon finally receiving capital from the Department of Health in 1986, the MS Care Foundation was created to oversee the work of the centre. Mary Kirk Allen, a founder,

recently spoke of how the MS Care Centre in its current form came to light: "While attending an MSIF conference in Australia over 25 years ago now, I visited one of their care centres and saw the incredible facilities they offered. I knew then what we should be aiming for with our own centre." Following the merging of the MS Care Centre with MS Ireland in 1999 a €2 million refurbishment got underway which saw an expansion allowing the centre to accommodate more residents.

New additions included six bedrooms, a physiotherapy

room and most crucially a pathway around the entire building to improve accessibility, particularly in the much loved garden area. The MS Care Centre truly is unique – it was then, and remains, the only place in Ireland where people with MS with high care needs can receive appropriate, around the clock care. 25 years may have passed but we're looking ahead to the next 25!

For more information about the MS Care Centre or to book a stay please see [www.ms-society.ie](http://www.ms-society.ie) or call (01) 490 6234.

## CONGRATULATIONS

During the recent European MS Platform (EMSP) Spring Conference, held in Dublin in May, their Annual General Meeting saw former Chief Executive of MS Ireland and Vice President of EMSP Anne Winslow elected as the new President of EMSP. Anne is deeply committed to promoting equality of life for people with disabilities and to working on the supports and services required to enable people live a full life.

On behalf of the Irish MS community we would like to extend our congratulations to Anne and wish her well in her new role.

Professor Michael Hutchinson, Consultant Neurologist, St. Vincent's University Hospital; Newman Clinical Research Professor, University College Dublin and MS Ireland's Medical Advisor, was awarded the 2014 ABN Medal. Awarded

annually by the Association of British Neurologists, the ABN Medal recognises outstanding contributions by British and Irish neurologists to the science or practice of neurology, or for contributions to the Association. Congratulations to Prof Hutchinson on receiving this prestigious award

# ACHIEVING IN CAMPAIGNING & ADVOCACY

## EMSP CONFERENCE RECAP

Here at MS Ireland we were just thrilled to be involved in the organisation of the European Multiple Sclerosis Platform Spring Conference in May. Welcoming Europe's MS Community to Dublin was definitely a highlight of our year so far. We would like to say thank you all our colleagues at EMSP, the incredible line-up of speakers and all of our wonderful volunteers for making this conference such a success.

**For those of you who were unable to attend, don't worry, read on for a brief update of how the sessions went over the two days.**

- » Kathleen Lynch, Minister of State, Dept. of Health and Dept. of Justice, Equality & Defence, opened the conference with a very moving speech which had the entire room on its feet afterwards. Among other issues she raised about the most vulnerable people in our society being hit time and time again with cuts to services, MS Lynch also revealed that her niece was recently diagnosed with MS.
- » Unsurprisingly one of the most popular sessions of the conference was the Young People's Focus. EMSP Believe & Achieve Project Coordinator Emma Rogan led the workshop while Shana Pezaro from the UK MS Society spoke of how her life changed for the better (eventually) following her MS diagnosis. George Pepper from Shift.mS told the room about his experiences with MS and how his organisation is trying to challenge young people to change their perspective after being diagnosed with MS.
- » MS Ireland's Aidan Larkin and EMSP President Anne Winslow facilitated an in-depth workshop about MS Nurse PROfessional. Using five key modules of online learning, MS Nurse PRO, is the first CME-accredited online platform for MS nurses in Europe.



- » Prof Gavin Giovannoni and Dr. Alexis Willet gave a brief update on the European Code of Good Practice in MS and called on neurologists to get more involved in further training.
- » Anne Winslow launched the Ireland Under Pressure video which featured the moving stories of three Irish people living with MS.

One of the highlights of the conference came from Elisabeth Golding's honest and moving account of being a carer to her husband, former EMSP President John Golding. We wanted to share with you some of her inspiring words:

"I have realised that there are many caregivers and relatives all around the world who feel deep loneliness and have a great need to share their plight, their feelings, and their thoughts with someone.

A marriage partnership is usually drastically changed when one of the partners is diagnosed with MS. It is not always the healthy one who would like to end the relationship. I know of couples who have moved into separate bedrooms the very day of the diagnosis. Personally, I have had to fight hard through the many years of living with an MS person. I have to make sure that his self-worth remains intact and that he realises how important he still is to me, to our children and our friends despite the fact that the disease may progress and deprive him of many possibilities."

## ACHIEVING IN CAMPAIGNING & ADVOCACY



### NATIONAL CARERS WEEK

The aim of the week is to acknowledge the contribution carers make to our communities and families. The week enabled carers to take a day for themselves and participate in events such as pamper days, informative gatherings, live entertainment and local attraction open days. National Carers Week, now in its eighth year, is coordinated by Care Alliance Ireland in partnership with nine other leading Irish charities who support family carers: The Alzheimer Society, The Carers Association, Caring for Carers, The Irish Cancer Society, The Disability Federation, MS Ireland, The Parkinson's Association, Bri, and The Irish Hospice Foundation.

### MEDICAL CARD SUBMISSION

Following the launch of a complete medical card eligibility review, the HSE asked for representative organisations to make a submission around this vital issue. Using the results from a survey (see below) of the MS community conducted by MS Ireland we made

this submission to the HSE regarding medical cards for people with MS. MS Ireland also helped frame the submission made by the Neurological Alliance of Ireland (NAI) on behalf of people with neurological conditions, including MS.

### MEDICAL CARD SURVEY

#### A snapshot of results concluded from our survey:

- 63% thought access to medicines under the medical card were essential
- 71% deemed access to GP services as essential to enable them to remain well
- 64% felt that the medical card was critical in access in therapy services in the community
- 70% said that the medical card was critical in sourcing affordable respite

### LOBBYING

With both local and European Parliament elections taking place in May 2014 we partnered up with Disability Federation of Ireland and Neurological Alliance Ireland to make sure you could get informed before politicians started knocking on your door. Three post cards were available on our, the NAI's, and DFI's website. The campaign was designed so that everyone had the important questions to hand whenever their local candidates came to speak to them.

## ACHIEVING IN CAMPAIGNING & ADVOCACY

### SATIVEX



Sativex is a cannabis based drug, which has been made available in other countries including the UK, to treat the symptom of spasticity (muscle stiffness) in people with MS. In July 2014 the existing legislation concerning the Misuse of Drugs Regulations was amended to allow cannabinoid-based medicines to be prescribed

### FAMPYRA

Fampyra is an oral drug used for the symptomatic treatment of walking impairment in adults with MS. Since July 1st 2014 Fampyra has only been available to patients at a personal cost of between €200 - €400 per month, a cost which is prohibitive to most of those who had been receiving the drug for free on a named patient basis up until that point. Those receiving Fampyra for free up until July 1st found that the drug had a significant impact on their ability to remain

by medical physicians. In the same month, the Health Products Regulatory Authority (formally the Irish Medicines Board) issued a licence for Sativex for the relief of moderate to severe spasticity for people with multiple sclerosis who do not respond to existing medications. However, in October 2014 following a full assessment the National Centre for Pharmacoconomics (NCPE) issued a recommendation that Sativex should not be reimbursed through one of the HSE payment schemes. We are continuing to advocate on this issue.

independent as it has been shown to have clear benefits in improving the mobility of those with MS. Many people have since had to reduce their dosage of Fampyra or cease taking the drug altogether due to the personal cost incurred. In July 2014 Biogen Idec made a new pricing submission to the HSE. Negotiations are still underway regarding Fampyra and a decision about reimbursement has not yet been reached. We are continuing to advocate on this issue.

### TECHFIDERA

The European commission approved the use of Tecfidera (dimethyl fumarate/BG-12) as a first-line oral treatment for people with relapsing remitting Multiple Sclerosis (RRMS) in 2014. In key stages of the studies leading to its approval Tecfidera was shown to reduce the number of relapses by half when compared to the placebo. Ava Battles, MS Ireland Chief Executive, said, "MS Ireland welcomes any new treatments for MS and with the European Commission approval of Tecfidera in Ireland, we are delighted that it offers another treatment option to the thousands of Irish people living with the condition. It's wonderful to see that treatment options in MS are improving all the time and this is having a real impact on improving the quality of life of people with MS."





# ACHIEVING IN RESEARCH

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IN 2014, THIS IS WHAT WE ACHIEVED IN RESEARCH

## ACHIEVING IN RESEARCH

### FALLS IN PEOPLE WITH MS

It is known that more than 50% of people with MS experience a fall within a 6 month period. However, there are currently only a few treatments to prevent or reduce falls for people with MS. Dr. Susan Coote, who leads this research, is part of an International MS Falls Prevention Research network that will develop of a falls prevention programme for people with MS. We want to find out about your MS, your falls and what you would like to be included a falls prevention programme. This will help us to make sure that the programme is based on the needs of the people who will take part in it. This study is ongoing.

### STEP IT UP

Researchers at the University of Limerick (UL) began recruiting people with multiple sclerosis (MS) into the 'Step It Up' exercise and education programme in September 2014. The aim of the 10-week programme was to have a positive impact on many MS symptoms such as reduced muscle strength, reduced walking mobility, fatigue and low mood, while also promoting long-term and sustainable management of the condition. It targeted people with MS who are able to walk independently and who are physically inactive. To see the results of the study please visit our website [www.ms-society.ie](http://www.ms-society.ie)

### NEUROLOGICAL ALLIANCE IRELAND SURVEY

During brain awareness week 2014, MS Ireland joined other organisations at the Mansion House in Dublin to hear the results of a new national survey conducted by the Neurological Alliance of Ireland (NAI), Living with a Neurological Condition in Ireland. The overall findings highlight the challenges facing people with neurological conditions like MS and the significant impact of cuts to health services and changes to benefits and entitlements in the last three years on their day to day lives. The results also showed drastic reductions in access to vital community services for people with neurological conditions and to benefits such as home care packages. The results show that people with neurological services are significantly worse off than after the NAI's 2011 access survey. Also speaking

at the launch were long-time MS Ireland advocate and person with MS Alexis Donnelly, Sinn Fein Health spokesman, Caoimhghin O'Caolain, Independent TD Denis Naughten and Senators Jillian Van Turnhout and Marie Moloney. MS Ireland is joining the NAI in calling on the Government, not just to commit to making no further cuts to community services, or benefits and entitlements, but to look at the human and economic benefits of prioritising investment in community services that can save lives and quality of life on a major scale. In addition to this we are urging the Government to prioritise neurological services, particularly the implementation of the 2008 National Neurorehabilitation Strategy. Read the full report on our website: [www.ms-society.ie](http://www.ms-society.ie)

68% of respondents had been affected by changes to the mobility allowance  
64% were affected by cuts to home care packages  
42% had their medical card withdrawn  
74% found it increasingly difficult to access personal assistance services

## ACHIEVING IN RESEARCH

### MSIF PUBLISH ONLINE SURVEY RESULTS

MSIF have published the results of an online survey taken by 879 people from 65 countries - including Ireland - about information, technology and MS in 2014. The largest age group were people 51-60 (31%) followed by people 41-50 years (26.3%). More than three quarters of respondents were female, with 23% being male. More than half (56.5%) had relapsing-remitting MS, while 18.4% had secondary progressive MS, 11% had primary progressive and 4.5% had progressive-relapsing MS. 10% were unsure.

When asked where they sourced information about MS, The results highlight that the vast majority of people look to the websites of MS organisation, with medical or scientific websites coming second in popularity followed in third place by a doctor or nurse. For a third of respondents, the factor that most increased the reliability of MS information was its scientific or statistical basis. A basis in a medical or professional opinion was ranked highest by 28% of respondents, and personal experience was chosen by 24.5%.

More than half (55.8%) used social media for information on the latest MS research. 46.7% used it for information on MS diagnosis and treatment. More than a third (38.8%) used it to solicit other people's opinions on an MS topic, and to connect with other people with MS (37.8%).

The majority of people taking the survey did not use any apps (75.5%) to manage their MS or assistive technology to access the internet (77%).

More than 232 comments were documented as part of the survey. The most common

responses included people's trust in their MS organisation to only present reliable information on their websites and a tendency to test the reliability of information found online on scientific research databases .

### 2014 NATIONAL INCIDENCE STUDY

Dr. Karen O'Connell, research doctor in MS at St. Vincent's University Hospital, Dublin is conducting a National Irish Incidence study. The aim of this study is to identify all new cases of MS and Clinically Isolated Syndrome (CIS) diagnosed in Ireland over a 12 month period in order to accurately calculate the incidence rate. This would allow us to determine if the incidence is increasing in Ireland. We will update you as soon as the results are released.

### PARTICIPATING IN RESEARCH

Each year we ask the Multiple Sclerosis community to participate in ongoing research. In 2014 we asked you to participate in a number of studies, many of which are ongoing still, to try to help shine a light on symptoms, treatments, and possible causes and cures for MS. Here are some of the studies we asked you to take part in.

- » National Irish Incidence Study
- » Falls prevention
- » Exercise and MS
- » MS and cognition
- » Fatigue and MS
- » Receiving a diagnosis of MS
- » MS treatments and their side-effects
- » Employment and MS



# ACHIEVING IN ORGANISATIONAL CAPACITY & PROFILE

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IN 2014, THIS IS WHAT WE ACHIEVED IN ORGANISATIONAL  
CAPACITY AND PROFILE

## ACHIEVING IN ORGANISATIONAL CAPACITY & PROFILE

### CONTINUING TO WORK WITH PEOPLE AFFECTED BY MS

2014 was the final year of the Strategic Plan 2011 – 2014. Based on review of this plan a decision was taken to conduct an organisational review where over 700 people participated. This was one of the elements that is to guide the new plan moving forward.



RESOURCE ALIGNMENT



INTEGRATED MODEL OF SERVICES



WELFARE REGULATIONS

#### RESOURCE ALIGNMENT

Fundraising and statutory funds continued to diminish in 2014 resulting in sustained or additional reductions in some areas of our work. This was a regrettable situation for the Society but to sustain the organisation into the future tough decisions were made.

- » Staff hours remained curtailed across the organisation.
- » Reduced opening hours at the MS Care Centre remained.
- » Budgets were again reduced and monitored closely. Additional reporting on regional and national level of the costs of service delivery supported efforts.
- » Local Branches were asked to continue their contribution of 15% of net assets the end of year accounts to support local services.

#### INTEGRATED MODEL OF SERVICE

2014 was the second year of the integrated model of working whereby local voluntary Branches and regional staff worked together to plan, organise and fund services for their respective areas. Significant developments occurred this year as more Branches than ever participated in meetings and contributed financially to the provision of Regional services.

In each of our 10 regional areas regional integrated meetings took place at least twice a year and often had a senior manager from National office 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

## ACHIEVING IN ORGANISATIONAL CAPACITY & PROFILE

### FINANCIAL ASSISTANCE

Following consultation with the regional branch members and Regional staff a number of changes were made to the welfare regulations. These changes were to ensure ease of use and to promote uniform approaches to applications. The main changes were:

- » **The application form was edited and reduced in size**
- » **Welfare regulations were changed to Financial Assistance**
- » **As part of the code of good governance Branches were asked to sign a compliance form.**

### WORLD MS DAY



WORLD MS DAY 2014 has been and gone but it's certainly not forgotten!

Across the globe thousands of events were held in almost 70 countries to celebrate the day but closer to home MS Ireland organised a range of activities in every corner of the country. Whether you attended our one day Living with MS Conference in Cork, race night in the West, family days and

coffee mornings in the Mid West, North West and South East, music, coffee and a car wash at the MS Care Centre or bucket collections and information seminars in Dublin and the North East, know that you helped Ireland mark World MS Day.

### RAISE AWARENESS

The 2014 theme was Access, not just physical access, but access to anything to all barriers. Across the world people were asked to share their worlds of encouragement and strength with the MS community by adding their one day wish to the official World MS Day website, 'One Day I wish that we can say "I had MS"'

### RAISE THE ISSUES

We joined with the NAI and our associated organisations to once again campaign for the improvement of neurological services and neurorehabilitation services. Activities included participation in a strategic focus seminar; speaking at a European conference; and encouraging our members to send a red card to the government.

### RAISE FUNDS

MS Ireland works in every county in Ireland providing one-to-one support, programmes and workshops, counselling, social events and therapies. We encouraged people to support their local services by;

- » Organising a Tea Party in their home, community, or workplace
- » Volunteering at a local collection
- » Selling some MSI pins in their work place
- » Or, organising their own event.

## ACHIEVING IN ORGANISATIONAL CAPACITY & PROFILE

### POLICY & BEST PRACTICE

As a legally and socially conscious organisation MS Ireland adopted a key piece of policy this year, the Governance Code. This policy protects the people we work with and makes our work transparent and above reproach.

#### THE GOVERNANCE CODE

The governance code is a national set of principles all community and voluntary organisations are asked to adopt. They set out clear guidelines on how organisations of any size should run, direct and control their activities. Key elements include commitments to abide by legislation, managing risks and consulting with stakeholders. MS Ireland whole-heartedly adopted the Code in 2013 and continued to uphold it throughout 2014.

#### THE GUIDING PRINCIPLES FOR FUNDRAISING

Is a guide to best practice developed by a steering group set up in response to the Charities Act 2009. It exists to improve fundraising practice, promote high levels of accountability and provide clarity and assurances to donors and prospective donors about the organisations they support. MS Ireland whole-heartedly adopted the Principles in 2014.

### 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 2014 four worthy winners were picked from the many wonderful applications. Congratulations to them, their families and the MS communities they work in.



Joint Winner of MS Carer of the Year: Chantel Carroll Nugent with Manfred Huschka, Chairman



Joint Winner of MS Carer of the Year: Joanna Murphy with Patricia Lucey, Regional Community Worker, Elizabeth Hooley, Chair Cork City Branch & Deputy Lord Mayor, Cllr. Fergal Dennehy



MS Person of the Year: Aoife Kirwan and Manfred Huschka, Chairman



MS Volunteer of the Year: Colette Hamilton with Ava Battles, CEO

## ACHIEVING IN ORGANISATIONAL CAPACITY & PROFILE

### 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. And many more volunteers support us at fundraising events, administration work and increasingly through workplace volunteering schemes.

### VOLUNTARY BRANCHES

In 2014 we were delighted to welcome back a voluntary Branch to the MS Ireland family. The re-established South Dublin Branch was formally launched at the 2014 AGM. The Branch will work closely with the national and regional staff and other Branches in the region to support and provide services to people affected by MS in Dublin. We wish the Branch every success in their work.



### 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 2014 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.

### NATIONAL VOLUNTEER WEEK

National Volunteer Week took place between the 12-16th of May 2014. We marked the week by taking the time to thank our volunteers for their wonderful support in the year gone by.

## ACHIEVING IN ORGANISATIONAL CAPACITY & PROFILE

### CORPORATE SERVICES

#### HUMAN RESOURCES

Recruitment during 2014 concentrated on replacing necessary leavers or unfilled posts.

We recruited replacement fundraising staff, a regional community worker and engaged a PR agency to assist our communications department with public relations activities.

##### Employee Relations:

The organisational wide pay freeze continued in 2014 whilst a number of staff continued to work reduced hours. As always we are extremely grateful to all our staff and their representatives for their overall commitment and continued good will and understanding in this regard.

##### Internships and Volunteers

MS Ireland continues to utilise a number of interns and volunteers in National Office. Each brings their own skill set to the society which contributes greatly to our work.

#### INFORMATION & COMMUNICATIONS TECHNOLOGY

In 2014 we invested in our ICT servers and hardware after a number of years of maximizing current equipment. The new servers have improved speed and efficiencies and reduced down time and the need for technical support.

MS Ireland entered a commercial relationship with Enclude IT to further develop and assist with mainstreaming our unified database for the organisation. There were significant developments in

##### Company Pension Scheme

The trustees of the scheme met in July to review scheme performance and to review the trustee annual and administration reports. There were no issues arising.

##### Information and Communications Technology

We have made significant inroads this year in mainstreaming our CRM system, Salesforce, across the organisation.

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

cleansing and streamlining our data as well as migrating many of our legacy databases onto a common platform.

Significant developments occurred in our customer relations management database, Salesforce. The large scale data clean-up continued and the merging of regional data to the more secure, streamlined and accessible platform was a major piece of work in 2014.

## ACHIEVING IN ORGANISATIONAL CAPACITY & PROFILE

### 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 2014.

- » MS Ireland celebrated its 25th year participating in the Camino Trek. The press release received wide media attention and coverage appeared in two national publications the Irish Examiner and Woman's Way.
- » World MS Day received significant on-message media coverage with interview segments with spokespeople included on Ireland AM, TV3; The Last Word with Matt Cooper, Today FM; and Drivetime, Radio na Gaeltachta. Features and diary notifications were included in 5 national publications, the Irish Times, Irish Examiner, Irish Daily Star, Irish Independent, Irish Sun and Woman's Way. Interview segments with local spokespeople were secured on 9 regional radio stations and coverage appeared in 24 regional titles.
- » From July 1st 2014 Fampyra, an oral drug the symptomatic treatment of walking impairment in adults with MS would not be reimbursed by the HSE and people with MS who had been receiving the drug for free on a named patient basis up until then would face a personal cost of between €200 - €400 per month to pay for the treatment. A number of people affected by the decision not to reimburse Fampyra were contacted by MS Ireland and a media spokesperson list was compiled. Fampyra was featured on a special report on Morning Ireland, RTE in July where several of the spokespeople and CE, Ava Battles spoke on the subject and there was a follow-up report included on the show in November. MS Ireland's statement with quotes from Ava was also included several times in national publications the Irish Times and Irish Independent throughout the year.
- » MS READaTHON 2014 was highly successful with popular TV show Moone Boy actors David Rawle and Ian O'Reilly secured as relevant high-profile ambassadors. Due to the strong relationship formed between the actors and MS Ireland during the campaign they have both agreed to be MS READaTHON 2015 campaign ambassadors. There were positive contributions from authors as well as excellent feedback from them on the MS READaTHON. Broadcast coverage for children and adults was secured at the highest level with segments appearing on children's shows News2Day and Elev8, RTÉ and on national radio station Newstalk. There were sustained national print clippings including launch coverage in the Irish Times, Irish Examiner and Irish Independent with features included in the Irish Daily Star and Sunday Independent. There was strong editorial coverage secured across 53 key regional newspapers.

## ACHIEVING IN ORGANISATIONAL CAPACITY & PROFILE

### PUBLIC RELATIONS (CONT'D.)

- » The University of Limerick launched Step It Up, a physiotherapy-led exercise and education programme which aims to impact on MS symptoms such as muscle strength, walking mobility, fatigue, mood and facilitate long-term and sustainable management of the condition. After liaising with project leads Dr. Susan Coote and Dr. Sara Hayes a press release was drafted and sent to all national media and relevant regional media and was subsequently covered by the Irish Times, Irish Independent, Irish Examiner, Limerick Leader and the Limerick Post.

### MEMBERSHIP

At the end of 2014 our membership stood at 4,661. We made concerted efforts this year to clean up information on the membership database and to establish preferences in relation to methods and frequency of communication.

## PARTNERSHIPS & COLLABORATIONS

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

### SIGNIFICANT PARTNERSHIPS IN 2014:

- » The HSE and other state bodies such as The Department of Social Protection and Pobal, regarding funding
- » The University of Limerick (UL), the National University of Ireland, Galway (NUIG), the Medical Research Charities Group (MRCG) and Health Research Board (HRB) regarding research and professional information.
- » The Neurological Alliance of Ireland regarding the campaign for neurological care, neurorehabilitation and Brain Awareness Week.
- » The European Multiple Sclerosis Platform (EMSP) and the Multiple Sclerosis International Federation (MSIF) in the areas of policy, common goal-setting and governance. In 2014 Anne Winslow was made president of EMSP
- » The Disability Federation of Ireland (DFI) in the areas of health sector cuts, governance, rehabilitation and neurological funding.
- » Each of the six pharmaceutical companies; Bayer Healthcare, Biogen Idec, Genzyme, Merck Serono, Novartis, and TEVA regarding funding and educational projects and activities



# ACHIEVING IN FUNDING & GOVERNANCE

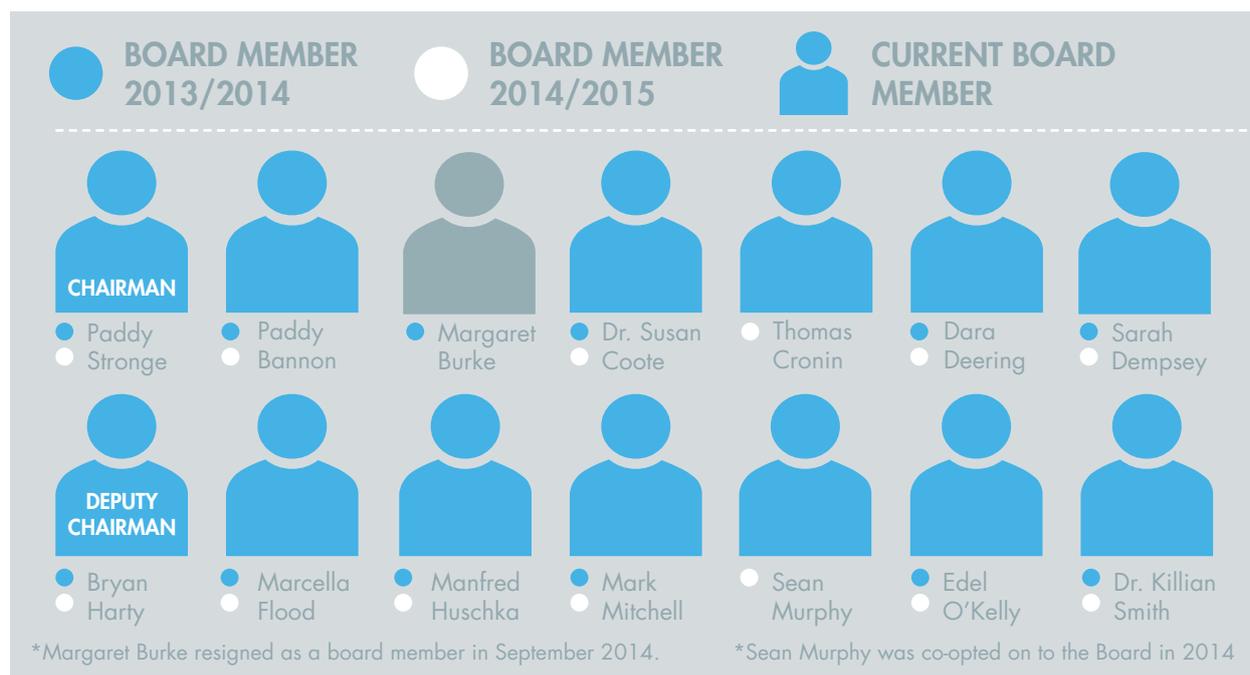
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IN 2014, THIS IS WHAT WE ACHIEVED IN FUNDING AND GOVERNANCE

# ACHIEVING IN FUNDING & GOVERNANCE

## 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 and aims of the Society and charges the Chief Executive to meet these aims through the various departments, services and resources of the Society. In 2014, the Board met five times. Significant work was carried out in the areas of finance and funding, governance and strategy.



## BOARD COMMITTEES

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

**Finance / Research / Nominating / Remuneration / Governance / Sustainability**

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

## BOARD ATTENDANCE 2014

	1 FEB	29 MAR	17 MAY	19 JUL	13 SEP	30 NOV
Paddy Bannon	x	x	✓	✓	✓	✓
Margaret Burke	✓	x	x	✓	n/a	n/a
Susan Coote	✓	✓	x	✓	✓	x
Thomas Cronin	n/a	n/a	n/a	n/a	✓	✓
Dara Deering	✓	x	✓	x	x	✓
Sarah Dempsey	✓	x	x	✓	✓	✓
Marcella Flood	✓	✓	✓	✓	✓	✓
Bryan Harty	✓	✓	x	✓	✓	✓
Manfred Huschka	✓	✓	x	✓	✓	✓
Mark Mitchell	✓	✓	✓	✓	✓	✓
Sean Murphy	n/a	n/a	n/a	n/a	✓	✓
Edel O'Kelly	x	✓	✓	✓	x	✓
Killian Smith	✓	x	✓	✓	✓	✓
Paddy Stronge	✓	✓	✓	✓	x	✓

## ACHIEVING IN FUNDING & GOVERNANCE

### 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.

### 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 2014 the Council met twice nationally. Regionally, local representation improved in 2014 as the integrated model increased the number of meetings between regions and Branches.

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

### VOLUNTARY BRANCHES

At the end of 2014 we had 38 voluntary Branches operating across Ireland. See page 10, 11 and 12 for more information on the wonderful work of our Branches.

### PATRON

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

### MANAGEMENT & STAFF

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

Just under 100 people work for MS Ireland on a permanent basis in a number of locations around Ireland. A further 44 people work with MS Ireland in a number of community employment projects operated by FÁS. MS Ireland's work is supported by committed volunteers around the country.

#### MS. AVA BATTLES, CHIEF EXECUTIVE

**MS. MEMORY  
CHIPERE**

FINANCIAL  
ACCOUNTANT

**MR. DAVID  
ALLEN**

CORPORATE  
SERVICES  
MANAGER

**MS. OLGA  
ESTRIDGE**

SERVICES  
MANAGER

**MR. AIDAN  
LARKIN**

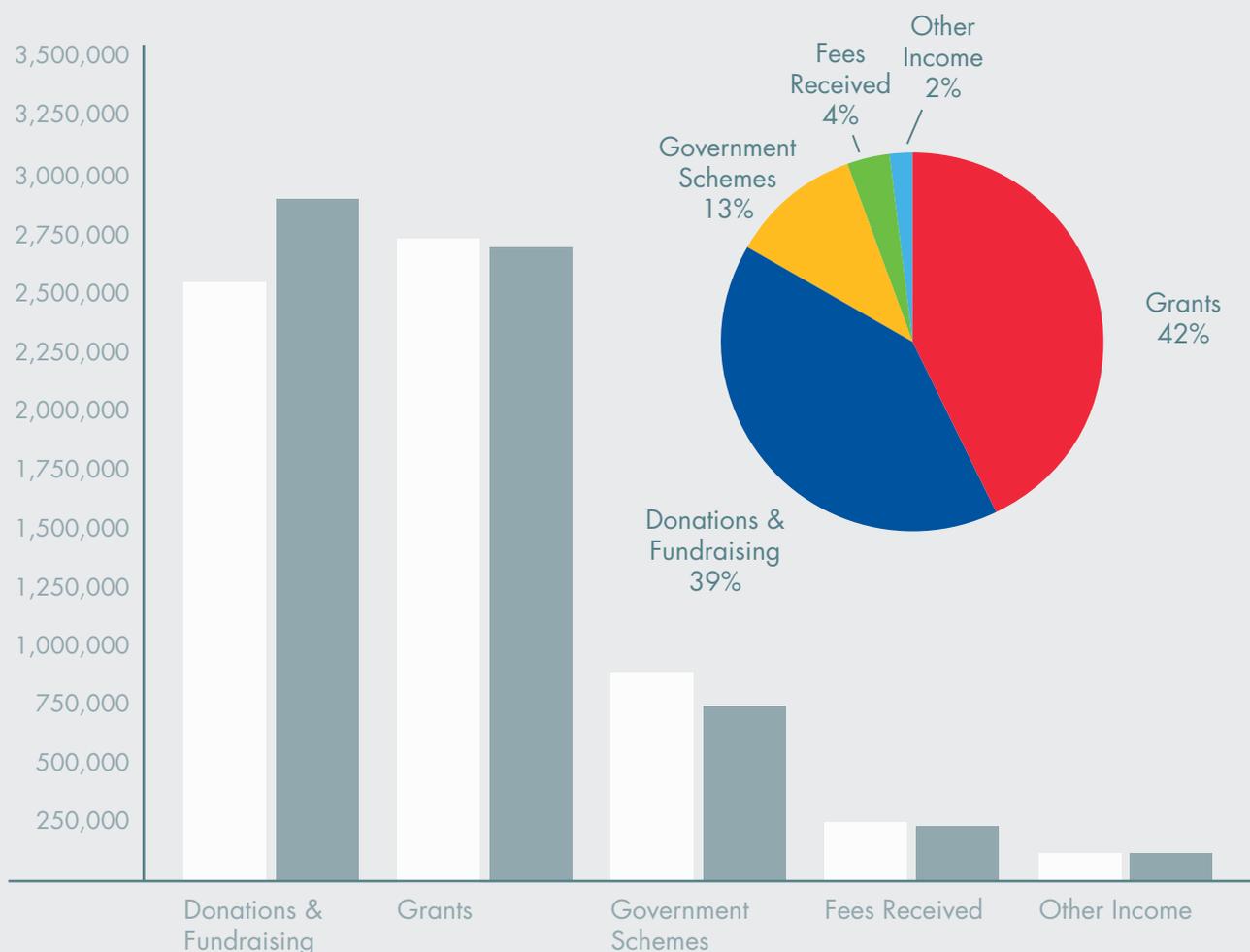
SERVICES  
DEVELOPMENT  
MANAGER

INCOME ANALYSIS 2014:

€6,486,131

	2014	2013
Donations & Fundraising	2,520,469	2,863,432
Grants	2,739,429	2,730,664
Government Schemes	859,593	745,427
Fees Received	228,735	244,351
Other Income	137,905	134,309
<b>TOTAL</b>	<b>6,486,131</b>	<b>6,718,183</b>

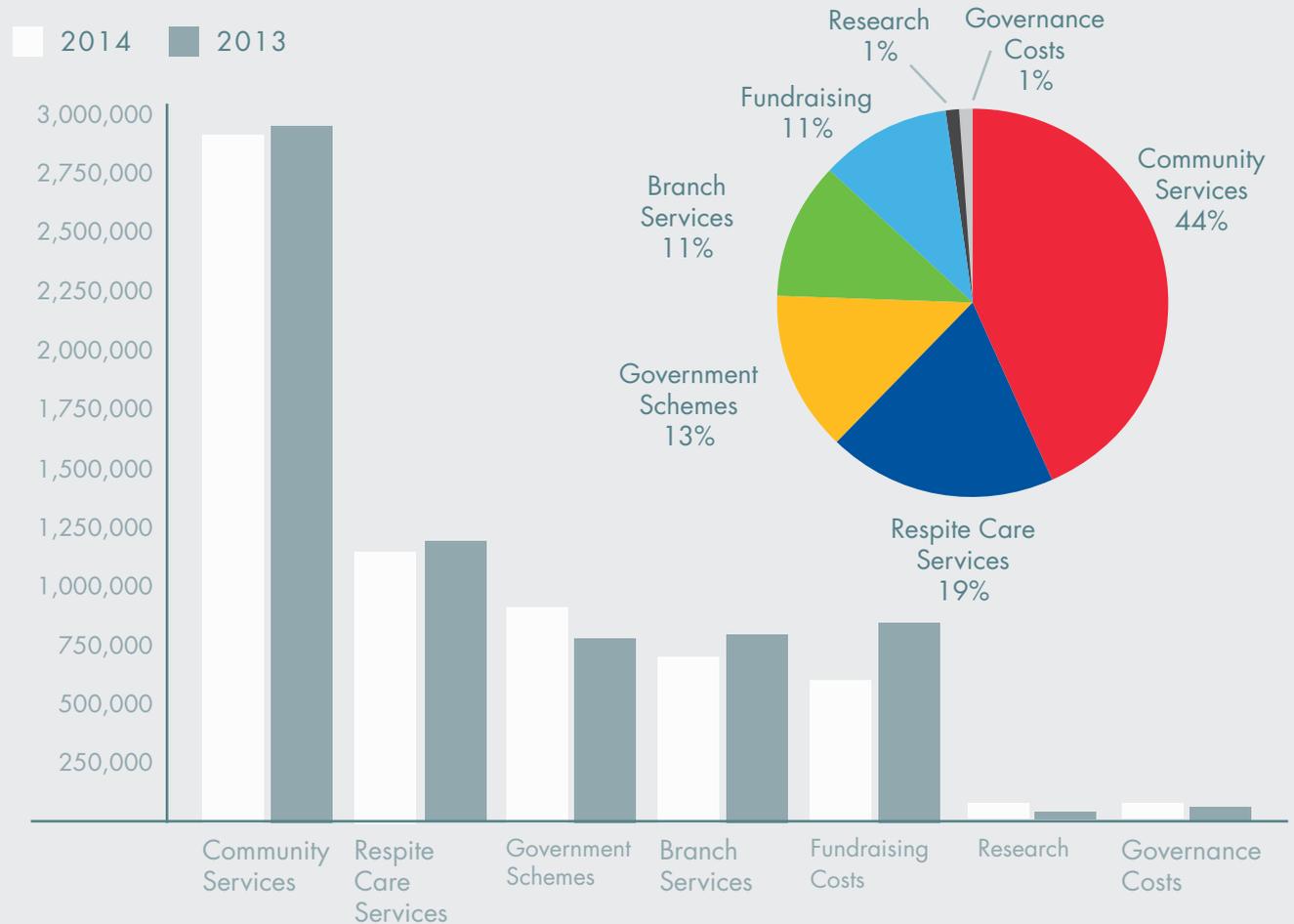
2014 2013



**EXPENDITURE ANALYSIS 2014:**

**€6,469,293**

	<b>2014</b>	<b>2013</b>
Community Services	2,811,531	2,878,908
Respite Care Services	1,218,938	1,243,886
Government Schemes	866,157	752,083
Branch Services	738,072	789,525
Fundraising Costs	706,603	880,490
Research	66,994	38,419
Governance Costs	61,000	59,720
<b>TOTAL</b>	<b>6,469,295</b>	<b>6,643,031</b>



# ACHIEVING IN FUNDING



## MS READATHON

13,500 readers and 443 schools around the country took part in the 2014 MS READaTHON. Over 127,000 books were read in the process – an incredible achievement! We also had nearly 80 school visits given by our wonderful ambassadors. They spoke to schools and classes in their own areas about life with MS. This year we were delighted to have Moone Boy's David Rawle and Ian O'Reilly on board as our ambassadors. The Kirwan family from Kildare were our MS ambassador family this year. 8 year old Adam helped us show people what it's like to have a mom with MS.



## TREKS

The Camino and Turkey were our two spiritual, exciting and rugged destinations for our 2014 treks. 99 wonderful trekkers took up the challenge and raised funds and awareness in their local areas.



## FRIENDS OF THE MS CARE CENTRE

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

## MS IRELAND ANNUAL REPORT & ACCOUNTS 2014

# ACHIEVING IN FUNDING

## SKYDIVE

In 2014 we had 74 adrenalin junkies take to the skies and complete skydives to raise money for local services. Jumping in the Irish Parachute Centre in Offaly, families and friends came along for moral support and to cheer on our brave jumpers.



## FLORA WOMEN'S MINI MARATHON

649 wonderful women took to the streets in June and completed the marathon for MS Ireland.

## DUBLIN CITY MARATHON

In October, 73 people took on the full marathon to support MS Ireland. It was a record breaking year as numbers taking part for us soared.



## 2014 CALENDAR

Our second national image competition ran in 2014 to find 12 beautiful images for our 2015 calendar. Nearly 100 people sent us images from their local community, showcasing the wonderful island we live on.



## WORLD MS DAY

Around the country we had people shaking buckets, selling pins, holding tea parties and up to all sorts to raise money for their local community. Nationally we also ran an awareness campaign My One Day Wish, asking people to share their wishes with the community.



# ACHIEVING IN FUNDING

## CORPORATE LUNCH

Entrepreneur Conor Devine showed us how he's conquering his MS battle, as well as the business world. It's safe to say Conor left everyone in the room a great deal more motivated and inspired than when they first arrived! He spoke of accessing your mind, the importance of exercise and nutrition in managing MS and opening yourself up to new possibilities following an unexpected event like an MS diagnosis. Conor had everyone smiling when he said that maybe one day MS will stand for *Mystery Solved*. We couldn't agree more. Mary O'Rourke re-iterated what Conor had said about the importance of opening up one's mind to new possibilities. She spoke of her past as a student and teacher and of the days she spent learning Latin poetry. One phrase she said always stuck with her and that was *Carpe Diem*, the Latin for "seize the day". Mary said this was a strong belief to have for all people who live with MS as it means seizing the moment and living your life to the fullest. She spoke of the importance of living not in the past or the future but living in the present – advice we could all stand to benefit from.

After lunch was enjoyed, the lively auction took place and was overseen by David Herman of Herman Auctioneers. It was full of fun and laughter and, thanks to generous donations, we had some fantastic items up for grabs. The raffle was next on the agenda which turned into another auction due to the generosity of the recipients of the prizes! Congratulations to all the winners.

We would like to say a sincere thank you to everyone who attended the event and supported our auction and raffle – we were delighted to share this wonderful day with you. Thanks to all the generous businesses and individuals who donated prizes, to the staff at the Four Season's Hotel for the excellent hospitality and to our two guest speakers. A special thank you to the MS Care Centre Lunch Committee for all their hard work, David Herman of Herman Auctioneers for manning the auction and Sean Brosnan from Pixillum Photography for taking the photographs on the day



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## HAPPY CHRISTMAS

There was a lot to get involved in this Christmas as people were able to buy decorations, cards or a star on our Christmas tree. Goodwill spread and many people donated around Christmas or took part in local events.

## AFFILIATES & PARTNERSHIPS

2014 was a wonderful year of support from the business community who showed their commitment to the local community in their areas. Particular mention to RSA Insurance for their RSA Speedo Torpedo, Vantastival for choosing us as their charity partner again following a very successful 2013, and RCSI Student Union for their various events in 2014, in particular their Run-a-Muck adventure race raised over €8,000 for MS Ireland.



## AND SO MUCH MORE.....

- » Our annual Raffle took place in June and was supported by thousands of people around the country.
- » St. Patrick's Day was celebrated in style as supporters ran Shamrockin' events in their offices and homes.

# THANK YOU!

**BIG THANKS** to all our fundraisers, donors and supports for their generosity throughout 2014. We couldn't do it without you!



Find us on:  
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