

ANNUAL REPORT



January – December 2014

ME SUPPORT NI

Annual Report January-December 2014

Chairs report

This is my second year as Chair of ME Support NI, having been elected at the last AGM. Firstly I would like to thank all the Committee Members for their ongoing support, I also like to pay tribute to all the M.E. sufferers and carers who attend our support group as I know how difficult it is to muster the energy to attend and give support to each other.

I would like to pay tribute to a young man who contacted us this year volunteering to run the Derry Walled City Marathon to help us raise funds. Michael McDaid whose brother John has severe ME, raised a huge amount of money for ourselves this year, and this will allow us to continue our work.

As you can see in this report, ME Support NI continues to work hard to identify and provide support to people (including children) with ME, their families and carers.

We have continued to focus on several areas this year, including supporting one to one needs of members, raising awareness of ME, fundraising, and lobbying for better services for people with ME within the health service.

This year we have participated in discussions with the Patient Client Council re services for patients and are now part of an ME/Fibromyalgia Steering Group who meet on a monthly basis.

Antoinette Christie
Chair person

Date:





REPORT OF THE COMMITTEE

The committee presents its report and financial statements for the year ended 31st December 2014.

Charity registration no: N100262

Registered office:

Wellington Park Business Centre
3 Wellington Park
Belfast
BT9 6DJ

Chair person

Antoinette Christie

Committee Members

Jeanette Marley, Secretary
Veronica Bryson, Treasurer
David Christie, Young persons support
Darren Magee, Counselling Support
Anne Smyth, Client Support
Maria McCooey

Principal Bankers

Bank of Ireland 202 Andersonstown Road, Belfast, BT11 9EB

Independent Accountant Review

John Beacom FCA, Muir & Addy Chartered Accountants, Muir Building, 427
Holywood Road, Belfast, BT4 2LT

Wellington Park Business Centre, 3 Wellington Park, Belfast, BT9 6DJ Northern Ireland Phone: 07526252055

Email: info@mesupportni.com Facebook: <https://www.facebook.com/groups/365117956886428/>

Scientific Advisor: Dr Vance Spence

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STRUCTURE, GOVERNANCE AND MANAGEMENT

ME Support NI is a registered charity number **N100262**

The committee consists of 7 members who meet at least twice per year and are responsible for the strategic direction and policy of the charity.

All members of the committee are elected from and by the membership and hold office until the close of the next Annual General Meeting, where they can be re-elected. The Chair is chosen from within the Committee and remains in office for not more than three consecutive years, unless 2 thirds of the full committee vote in favour of the person being re-elected as Chairperson. All Committee members are volunteers who have either got ME or are affected by people with ME.

OBJECTIVES

ME Support NI provide information, support and practical advice for people (including children), families and carers affected by M.E (Myelagic Encephalomyelitis). We aim to improve the lived experience of those children, young people and adults affected by this devastating neurological illness by lobbying for services which are underpinned by expert knowledge and an understanding of M.E.

ACHIEVEMENTS AND PERFORMANCE

Newsletter for the group

This year we published our first ever Newsletter, which we were able to get professionally printed and sent out to all group members. This incorporated some information about how the group started, achievements in the past and information about the group activities through the year. This could never have been achieved without the grant we received from ORTUS.

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SYNOPSIS OF EVENTS (not withstanding support group meetings)

4/2/14	Attended Medical Conference in Stormont	
28/2/14	Rare disease Partnership Conference	
27/3/14	Genetic conference Queens	
14/5/14	Meeting with Claire Mulrone, Jordanstown University – Antoinette & Paul Christie	
5/7/14	Joint Meeting with Newry & Mourne ME/FMS Support Group Chairperson and Co- ordinator	Antoinette Christie Jeanette Marley Darren Magee Joan McParland Martina Marks
9/7/14	Meeting with Fearghal McKinney, SDLP	Antoinette Christie
19/9/14	Health & Wellbeing Day, Stormont	
	Literature for staff in relation to ME	

Medical Conference Stormont

Members of ME Support NI attended a medical conference on ME in Stormont in February. At this conference, presentations were given by Dr Weir, Vance Spence, ME Research UK, Dr Mark Van Ness, Pacific fatigue Lab, Horace Reid, Expert Patient and Jim Wells, also spoke.

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NI Rare Disease Partnership Conference

Antoinette attended the NI Rare Disease Partnership

Genetic Conference Queens

Antoinette and Jeanette attended the Rare Disease Partnership Conference in February. At this event were stalls for various rare diseases. We were pleased to have our own stall to raise awareness of ME, with medical students and other health professionals. Dr Fiona Stewart, Clinical Geneticist.

May 12th International ME Awareness Day

This year to mark ME Awareness Day we took part in an international effort to get many of our buildings lit blue on May 12th. Our Shine a Light on ME campaign was well supported and we managed to get 11 buildings in Northern Ireland lit blue to mark the day including:

1. Belfast City Hall
2. Great Hall, Stormont
3. Derry City Council Offices
4. Antrim Borough Council
5. North Down Borough Council
6. Lisburn Council Offices
7. Newry City Hall
8. Sean Hollywood Arts Centre
9. Bessbrook Town Hall
10. Craigavon Civic Centre
11. St Patricks Centre, Downpatrick

Costa, went one better and allowed us to display our banners and leaflets at their premises in Kennedy Centre, Andersonstown, Belfast and Boucher Road Belfast. They also took some of our collection tins to raise funds.

As a result of the above Aine Hefferon, one of our newest members took part in a radio interview on U105, which was very well received.

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We also managed to get an article in the Belfast Telegraph, Andersonstown News and the Derry Journal to highlight the day.

Mickey McDaid had his photo taken with the Martin Reilly, Mayor of Derry.

A group photo was taken with Steven Corr, now newly elected councillor and our members outside the Belfast City Hall.

A further photo was taken in the great Hall of Stormont with Health Committee Chair Michelle Gildernew and Mickey Brady, Member of Health Committee.

Veronica and Lorna Bryson also managed to have their photo taken with the Mayor of North Down Borough Council.

Disability Action Exhibition

On 30 & 31 May, ME Support NI participated in a Disability Exhibition in Kings Hall Pavilion. We had an information stall at the exhibition and managed to man this for the 2 days of the exhibition.

Health & Wellbeing Day, Stormont

In September 2014, we were asked to be a part of a Health And Wellbeing day, for staff working in Stormont. Literature and information about ME and about our group was given and shared with staff at Stormont at the health and wellbeing day. Uli Speers, very kindly took all of the literature to Stormont for us.

The feedback received from Stormont on 8/10/14 was that “The health and wellbeing event went well, it had a good turnout”.

We were also advised that training courses were available to inform people about how the assembly works. They have added ME Support NI to their database and will advise of any courses coming up in the future.

SUPPORT GROUP

This year we held 10 support group meetings. The August meeting was cancelled due to holidays. In December we held our Christmas dinner in lieu of the group Meeting.

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Christmas Dinner

We would like to especially thank 3 of our members for all of their support this year helping to make this years Christmas Dinner such as success. Firstly Paula Graffin (new member) who compiled a list of all the people attending the Christmas dinner and their dietary requirements. This was a great help to the committee and we were able to supply the Hotel with numbers and meal choices prior to the event.

We would also like to especially thank Mags and David Maloney, who supplied a hamper which we were able to ballot on the night, raising much needed funds for the group. David also arranged for Santa to give out gifts to members at the dinner and each member had their photograph taken sitting on Santa's knee, reminding them all of when they were much younger. Great fun was had by all and no one is allowed to ask who Santa was, were Santa came from or more importantly where he disappeared too.

New Premises

In order to fulfil the terms for Charity Status, we obtained new premises in Wellington Park Business Centre. This means that the group can now be contacted on a landline, as well at a mobile number. All calls to the landline will be answered and messages redirected to the Chairperson. Mail can also be delivered to this address. This would not have been achievable without the significant donation we were given by Mickey McDaid.

On 3rd November we relocated our support group meetings to the Richmond Suite, Balmoral Hotel, Dunmurry. We hope that the premises will be more suitable for the group needs and give us a more permanent base. This could not have been achieved without the support of a grant from The Community Foundation for NI.

Guest Speakers throughout the year

This year we arranged to have several guest speakers at our support group meetings including:

- | | |
|-----------|---|
| May 2014 | Siobhan Doherty, Aware defeat depression |
| June 2014 | Andrea Gribben, Transcendental Meditation |

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October 2014 Sarah Trimble, Nutritionist
Fearghal McKinney, MLA, SDLP

November 2014 Disability Action
Scott Duncan from Rejuveo
Noreen McClelland, SDLP

MEMBERSHIP

52 Members of which are full members – are non paying

Attendances this year at Support Group:

FUNDRAISING

This year Michael McDaid, ran the Derry Walled City Marathon, raising a massive £5,623.61 for ME Support NI. This is an outstanding achievement for one individual to have raised and will allow us to continue our work. A special bequest was made by Michael's brother to donate some of the funds to Biomedical Research. To date we have made a donation of £1000 to ME Research UK.

COLLECTION TINS:

We have received donations from collection tins at the Falls Leisure Centre and Colin Harbinson, The Meat Joint. We are very grateful for this continuing support throughout the year.

DONATIONS RECIEVED:

We have received several donations from individuals which we are extremely grateful for as every penny is needed to continue the support.

One of our members Joan Burnison, undertook a fundraising initiative herself this year, by knitting some children's handbags to sell to raise funds for the group. We cannot commend her enough for this, especially as we realise the impact this work will have had on her health.

This year we also received a donation from Ballymacnab Choir, Armagh, who raised some funds for us by selling CD's they had created.

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ONE TO ONE SUPPORT

We were also able to assist member with advice regarding disability and employment.

We assisted members with drafting letters for different issues.

On top of this we were able to provide emotional support to other individuals who lived outside the Greater Belfast area, and were able to put them in touch with each other so that they could provide support to each other closer to their home.

Our committee member Anne, who is a qualified social worker and fellow sufferer of M.E. continues to provide practical emotional and social care support to approximately fifty M.E sufferers and their families. My previous experience as a social worker in physical disability continues to provide me with a strong and informed base to work from. The nature of new referrals remains the same requiring information and support. Also majority of people are requesting referral to social services and various multi disciplinaries to ensure that appropriate care package is put in place. Finally most of M.E sufferers are asking for advice with regards different benefits especially DLA and ESA. Over the past year I have built up a core group of twenty M.E sufferers and their carers who are looking and needing constant and ongoing support. There has been a steady increase in number of suicidal sufferers needing ongoing support. Also there has been noticeable increase in number of people asking for help and advice with regards appeals system. This all reflects growing needs of M.E sufferers and carers and difficulties they are facing in attempting to get the help that they need and are entitled to in trying to manage their illness.

Steering group for ME/Fibromyalgia

In November we were approached by the Patient Client Council to form a Steering group for ME/Fibromyalgia. Antoinette, Darren and Anne (committee members) have attended monthly meetings and are working towards organising and participating in Workshops for Professionals on ME/Fibromyalgia in February 2014.

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FUTURE PLANS & PROSPECTS

1. Steering Group ME/Fibromyalgia

We will continue to work in partnership with the Patient Client Council. We will participate in Invisible ME, a workshop for professionals planned February 2015. We will continue holding monthly meeting with the Patient Client Council in the coming year.

2. Media planned in January 2015

Television programme with NVTV including Chairperson of ME Support NI and 3 of our members, David Maloney, a carer, Lorna Bryson, a young person with ME and Dr Pamela Bell, Pain Alliance.

3. Shine a light campaign for ME

As last years campaign was so successful, we will continue to see how many buildings we can get lit blue for ME Awareness Day, May 12th 2015. We will also try to improve media coverage for this campaign.



M.E. Support Northern Ireland (MESNI) Jan 2014 - Dec 2014

Details of Income & Expenditure

<u>Income</u>	<u>2014</u>	<u>2013</u>	<u>Expenditure</u>	<u>2014</u>	<u>2013</u>
Milltown Bowling		£500.00	Bank Charges	£62.75	£76.07
Belfast Marathon		£203.00	Insurance	£401.24	£389.55
Fundraising		£807.13	T Shirts		£122.50
Feili Joe		£1,800.00	DVD's		£48.00
DVD's Books & Pens	£161.00	£87.00	Membership Fees	£32.00	£107.10
Membership of ME					
Support NI	£130.00	£115.00	Fees Belfast Marathon		£82.50
Donations	£1,233.00	£623.41	Promoting ME	£1,426.19	£20.00
Just Giving	£5,709.34		Petrol Expenses	£38.33	£94.81
Ballet	£100.00		Stationery/Signs	£597.48	£670.00
Ballynab Choir	£1,000.00		Plaque		£15.00
Club Oxygen	£290.00		XmasGifts, Phone&post	£221.62	£30.55
Bank Interest	£4.61		N&M Feili Joe Donation		£2,100.00
CFNI	£1,200.00		Tea/Cof & Xmas Dinner	£1,151.95	£452.40
			Conferences&		
Christmas Dinner	£180.00		Exhibitions	£180.00	£904.07
Cheques not cashed	£26.49		Redrafting Constitution		£50.00
			Just Giving Fee	£126.00	
			ME Research UK	£1,000.00	
			Virtual Office	£420.00	
			Refund of Cheque	£10.00	
	£10,034.44	£4,135.54		£5,667.56	£5,162.55
Balance Carried Fwd	£2,739.70	£3,766.71			
Income for Year	£10,034.44	£4,135.54			
Expenditure for Year	£5,667.56	£5,162.55			
Balance at Bank	£7,106.58	£2,739.70			

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