

ANNUAL REPORT



January – December 2016

ME SUPPORT NI

Annual Report January-December 2016

Chairs report

This is my fourth 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.

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 2016.

Charity registration no: NIC104006

Registered office:

Conway Mill
5-7 Conway Street
Belfast
BT13 2DE

Phone: 07526252055

Chair person

Antoinette Christie

Committee Members

Jeanette Marley, Secretary
David Christie, Young persons support
Anne Smyth, Client Support
Catherine Burrell
Uli Speers
Amanda Mann

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

STRUCTURE, GOVERNANCE AND MANAGEMENT

ME Support NI is a registered charity number **NIC104006**

The committee consists of 6 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 (Myalgic 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

This year we have been encouraging members to be become more involved in the Charity, especially now that we have our own premises. Even in small ways people can have a huge impact on what we can achieve. Some people may not want to commit to a large project but if tasks can be broken down then it is possible for individual members to help out, remember “more hands make light work”.

This year we have had quite a few members coming forward to offer to help out with the group and group activities. We hope members will feel free to continue to dip in and out as they are able.

We are especially grateful to Mags Maloney for all of her positive quotes on our facebook page every morning.

Also big thank you to Joan Burnison, who continues to create beautiful cards which we sell to raise funds for the group.

Conway Mill, 5-7 Conway Street, Belfast, BT13 2DE Phone: 07526252055

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

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Patient Client Council update

As you know we are continuing our very positive work with the Patient Client Council. An action paper has been drawn up with regards to ME and we have now got funding for a Medical Lead for ME in NI. At a previous meeting we were told that an Expression of Interest for a Medical Lead had been sent to Doctors within the Trusts. Unfortunately whilst this is a step forward for us, there hasn't been the interest from professionals that we had hoped for. This post will initially be for 1 ½ days per week, but could be expanded in the future. It's a small step and we still need to get someone in place who will have the right skills and knowledge to lead this forward.

It has been agreed that we would revise the expression of interest sent out, with a view to encouraging someone with the appropriate skills and knowledge to take on this new and innovative post.

It is hoped that the Medical Lead will be responsible not only for seeing and treating patients but also to provide training and advice to other professionals, in keeping with the most up to date research. It is hopeful the post will be eventually advertised in the BMJ. Although we are looking for professionals from specific disciplines to apply.

Whilst only a part time post at present, there may be scope in the future as the service develops to expand on this.

Other areas discussed where:

Condition Management Programmes and their reliance on graded exercise therapy, which is felt to be harmful to patients.

1. Support for children
2. Support for severely effected sufferers, including domiciliary visits
3. Community nursing support
4. ELearning training for staff

Black Santa Appeal, St Annes Cathedral – 7/2/16

The Black Santa Appeal by the Dean of St. Anne's Cathedral supports a broad range of charitable causes including: medical research; children and young people; older people; the improvement of employment opportunities for young people and a host of small charities which cannot afford to employ paid fundraisers.

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This year ME Support NI were recipients of this appeal and Antoinette and Jeanette attended the presentation in St Annes Cathedral. Antoinette and Jeanette were presented with the cheque by Jimmy Cricket for £800.

Rare Diseases Day Conference – 29/2/16

The Conference was a unique opportunity to hear from Dr Michael McBride, our Chief Medical Officer and from a range of patients, carers, and professionals about what is already happening; and to engage in developing what more could be done to make a difference to the lives of those affected by rare disease.

Rare disease day was attended by Antoinette and Clare, Kerry and Emma alongside Researchers, medical professionals, carers, healthcare employees and institutions

Northern Ireland Neurological Charities Alliance (niNCA)- 14/3/16

niNCA is an alliance of charities working to improve care, raising awareness and working together to deliver a cohesive approach to lobbying government and health and social care providers

As a member of niNCA, members of ME Support NI attended the niNCA presentation at Stormont. Annie Owens, Uli Speers, Amanda Mann & Antoinette Christie attended.

An Introduction was given by Fearghal McKinney MLA

There are 34,000 suffering from long-term neurological conditions.

Another speaker was Patricia Gordon Director MS Society NI

There are 11 member groups and the focus of the organisation is to ensure that all conditions are given priority at all levels of service.

Many causes of neurological conditions are unknown and some do not begin until adulthood. Many cause life-long disabilities often not understood.

Many face stigma and unhelpful attitudes from the all services and general.

We need multi-disciplinary support and care.

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The aims of the Charity:-

- IMPROVE CARE
- RAISE AWARENESS
- WORK TOGETHER

Maeve McLaughlin MLA

Maeve initially agreed with Patricia Gordan that the care is not given by multi-disciplinary teams for the conditions.

She stated

- * overview of lack of information and support for sufferers
- * allocating need is not done sufficiently
- * lack of understanding of conditions and people become depressed and are written off by the Health Service.

What have the Assembly been doing to help?

- * Waiting times is a major issue so they have been addressing this
- * 36 per cent wait longer for consultant referral than a year and this is a challenge for everyone and is contrary to Department of Health guidelines.
- * Launched an enquiry into the system but has not been implemented
- * £40million used to tackle waiting lists plus another £30 million which is to include Neurology,

Noted

Social care needs an overhaul as it is not sustainable with too many boards competing for money. i.e. nobody knows what everybody else is doing!

We need a proper Public Health Model

Maeve said that we can see her anytime if any problems and she is very supportive of the Organisation.

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Patricia replied to Maeve and stated that money spent on waiting lists, although admirable, did not free up funds for us as we need consistency of care.

Dr John McConville Belfast and South Eastern District HSCT

John gave a powerpoint presentation on Adult Inherited Neurological Diseases and stated that there is inadequate specialist services for the number of sufferers and that most care is given by General Practice Doctors.

He gave statistics on funding compared to other disorders within the spectrum, i.e. brain tumours vs other neurological disorders and the difference was large.

He believes that we can never sort out waiting lists as the numbers are just not there to cope with the myriad of diseases and access scans etc.

He highlighted Whole System Services

Illustrated the life of Baroness Campbell who is a vocal advocate for neurological conditions.

There was a Short Video presentation made by a family member of a local man suffering from a Neurological disorder.

Relaxation Pain & Fatigue management workshop – 27/4/16

The above workshop was held at our offices. Lene McFarlane was the speaker at this event.

Some of the proposed topics at the Workshop were:

Fatigue management PPP. Plan, Pace and Prioritise

Building on resources - what do I know to do and not doing

Anchors - resourceful state

Pain relief and management - oils, nutrition and supplements

Self care - time out

Meditations

Mindful breathing techniques

Welfare Reform- 3/5/16

Benefit talk was given by Karen Hall and Terry Smyth in Balmoral hotel. Terry also give one to one advice for members on the night.

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Disability Action Exhibition – Eikon Centre- 4/6/16

ME Support NI again held a stall at the Disability Action Exhibition. This was manned on the day by several of our members: Antoinette, David, Jeanette, Jim Wilson, Amanda Mann and Albert.

Family & Friends fundraiser – 2nd August

We held a family and friends fundraiser in our offices. This was well supported by many of our members and their families. With tea/coffee and cakes and buns etc served. A raffle was also held and we raised: £410 on the night.

Thanks to Amanda Mann and her family for all their help on the day.

Care Plan information session – 24/8/16

Anne Smyth held an information session on care plans for people with ME. She was able to give advice to members who attended and also provided care plans for 2 of them.

What is a care plan?

A care plan sets out how your care and support needs will be met. You should be fully involved in the preparation of your care plan and should have a written copy of this. The care plan must set out the needs identified by the assessment.

Your care plan should be individual to you, and you should be allowed to have as much involvement in the development of your plan as you wish.

Care and support should help you to live independently, have as much control over your life as possible, participate in society on an equal level, with access to employment and a family life, have the best quality of life and keep as much dignity and respect as possible

What about ME- 21/9/16

This was a one off session for people to come together and talk about their experiences and journey with ME.

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Christmas dinner

We would like to especially thank you to all our members for all of their support this year helping to make this year's Christmas Dinner such a success. Special thanks to Diana Moody 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.

A special thanks also to Terry Smyth, who provided us with some entertainment on the day of the Christmas Dinner by having his legs waxed to raise funds for our group. Our thanks also to Chloe Stewart, who assisted in the leg waxing and Terry's stepson who seemed to take a wee bit too much delight in pulling of the wax strips.

Fundraising this year

8 March 2016 a fundraiser was held following our AGM and raised £468 through sales of bracelets, food and raffle.

Friday 2nd December, Falls Leisure Centre keepfit group took part in the Toasty Tour in Belfast to raise funds for ME Support NI, £225 was raised

Sunday 4th December, Terry Smyth had his legs waxed to raise funds ME Support NI £261 was raised. Thank you also to Chloe Stewart for doing the waxing.

Donations

Banbridge Slimming world £100, Cecilia (Alana Gallaghers ME Sufferer's mum)

Jim Wilson Beer Fest £150

Black Santa Appeal, St Annes Cathedral, £800

Joan Burnison for her continued contribution to the group by handmaking cards to help raise funds for the group

Frances Webster, donation given through coin collection.

Anne Smyth collection tin, £131.25

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SUPPORT GROUP

This year we held 11 support group meetings. In December we held our Christmas dinner in lieu of the group meeting. The group meetings continue to be well attended.

Speakers at the group

Open University- Maggie Bates
Disability Action – Karen Hall and Terry Smyth, Welfare reform

ONE TO ONE SUPPORT

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 ME sufferers and their families.

As a physical Disability Social Worker Anne provides support and advice on both practical and emotional levels. Whatever difficulty an ME sufferer/ family finds itself in due to devastating nature of this illness, even just coping on a daily basis, financially, educationally, or socially Anne will provide a listening ear service. Due to her vast knowledge and expertise of this illness she will be able to make a full and comprehensive assessment of both needs of sufferer and those of carers involved. If appropriate and if requested she can refer sufferer to community physical disability team to ensure that a care package is put in place to further meet needs of person referred. This helps to alleviate stresses involved in trying to manage this complex multifaceted illness. With regards financial assistance she can advise people with regards to filling in various benefit forms. She can provide written reports as part of advocacy service. As a fellow sufferer of M.E and being a social worker she can help sufferers navigate the health and benefit system in a competent and confident manner and during this process help to educate various health care workers who have often minimal experience of M.E. This can lead to collaboration with child care social workers who through lack of understanding complex nature of this illness become embroiled in inappropriate child care proceedings. She works alongside all of the many health care professionals in an effort to meet all the needs of the sufferer, similar to that of being a social worker with any other physical disability trying to gain equal status and treatment. Finally over the years working for M.E.SUPPORT N.IRELAND She has now established a core caseload of people who require ongoing continuous social work support. Unfortunately but understandably the number of people feeling suicidal due to devastating nature and ignorance surrounding this illness is increasing all the time highlighting urgency to establish well coordinated medical and social support network similar to what other physical disabilities have and need to ensure appropriate management of illness.

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Home visits

Late last year we have started to do some home visits to some of our house bound members, who have been unable to attend the group due to ill health. This has been well received by members and we are hoping to try to do more of these over the coming year, as we recognise how isolating it must be for sufferers when they are unable to get out and about.

Young persons advocate

David continues to keep in regular contact with many of our young people in the group via email. He has also managed to meet up with quite a few of them for coffee, drinks and dinners, when he has been well enough.

New Office

In December 2016, we once again moved to new premises in Conway Mill, which will save the charity some money as the rental is a lot cheaper than our previous offices.