



ANNUAL REPORT

January-December 2018

MARCH 1, 2019
M.E SUPPORT NORTHERN IRELAND
Conway Mill, Belfast

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Annual Report January-December 2018

Chairs report

This is my sixth year as Chair of ME Support Northern Ireland, having been elected at the last AGM. Firstly, I would like to thank all the Committee Members and volunteers 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.

We continue to work in partnership with the Patient Client Council re services for patients. Further work will take place in the coming years to move things forward once the Consultant Physician for M.E takes up post.

Antoinette Christie

Chair person

Date:

Report of the committee.

The committee presents its report and financial statements for the year ended 31st December 2018.

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 Vice-Chairperson
Anne Smyth, Patient Support
Uli Speers
Amanda Mann
Bruce Bingham
Emma Shaw
Annie Owens

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 8 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 have family members who are affected by ME.

Objectives

M.E Support Northern Ireland's main objectives are to provide information, support and practical advice for people (including children), families and carers affected by M.E (Myalgic Encephalomyelitis). Our aim is to improve the lives and experiences of those children, young people and adults affected by this devastating neurological illness. We will do this by lobbying for services which are underpinned by expert knowledge and an understanding of M.E.

Patient Client Council Update

Over the past 2 years, members of our committee have been working as part of the ME Steering Group set up by the Patient Client Council. We have together been working towards improving services for ME Patients in Northern Ireland.

We are therefore pleased to say that after 2 years of sometimes exhausting work, that funding has been agreed and the post for Consultant Physician for ME has now been filled. The details have not been officially released by the Health Service Commissioning Board, as the post holders base has not yet been finalised. We have been reassured by the Patient Client Council that we will be informed prior to the HSCB issuing a statement.

Projects

Awareness campaign – throughout the year we have distributed 40,000 flyers and leaflets to every post primary school, 250 primary schools, all 337 GP surgeries and 500 pharmacies across Northern Ireland.

We designed flyers and leaflets for different professions (teachers, GP's, etc.)

These flyers and leaflets were paid for in part with grants from;

“This project has been supported by the Community Foundation for Northern Ireland through the Wesleyan Small Grants Fund”

Events

Unrest at Stormont

As part of our May 12th activities, ME Support NI presented the documentary Unrest in the Long Gallery, Parliament Buildings, Stormont, hosted by Paula Bradshaw MLA. Including an exclusive intro by Jen Brea, 20 minute film screening and guest Dr Nigel Speight, Dr Charles Shepherd and Professor Malcom Hooper and also support by Dr Pamela Bell.



Despite some technical difficulties, the evening went well, with 75 guests in attendance including GP's, Occupational Therapists, MLA's, Councilors, teachers, representatives from disability action, advice NI, reports, Christine McMaster.



M.E Awareness Day- May 12th

On M.E Awareness Day we held a Missing Millions Event at Belfast City Hall attended by the Deputy Mayor of Belfast, Sonia Copeland, UUP.

The event involved the displays of shoes to represent the missing millions, on the grounds of Belfast City Hall and a distribution of flyers to raise awareness of M.E. It was well attended by our members and by some young volunteers, who helped distribute leaflets.

Special thank you to Debbie Deboo for her photography skills on the day.



Fundraisers in Aid of M.E Support Northern Ireland

North Channel Swim



Jeff Gallagher was sent our way by Micky McDaid, whose brother John has severe M.E. Jeff and 8 other men and 1 woman took on the challenge of swimming across the North Channel, one of the world's toughest open water swims, managed fewer than 20 times before by other relay teams.

The event date had to be postponed several times due to the weather conditions, finally taking place 7J July 2018. Jeff reports a very eventful, meeting a lot of very friendly Jelly Fish along the way.

We wish to thank the following individuals: John Coyle, George Meenan, Gerard Curran, Jolene Linehan-Harkin, Darren Bradley, James Jackson, Marc Power, Paddy Bradley, Daniel Meehan, Jeffrey Gallagher.



Belfast City Marathon

A member Chloe Stewart's partner John Creighton completed the full 26 miles of the Belfast City Marathon on 1st May 2018. We wish to thank all of those who sponsored John and encouraged him to complete the marathon.

Comber Rifle Club

Our member, Lynn Wade, and her slimming world group held a fundraiser at Comber Rifle Club on 25th January 2019. Lynn's son James has had M.E for many years.



We wish to thank Lynn and her Slimming World Group for organising this event and to Amazon Hair Salon, Gibson's Butchers, Black Knights, The Pharaoh, Davidsons Bar, The Man Barbers of Ballygowan, Lenny Hutchinson, The Sugarcane of Comber, Li Li's Of Bangor And Dessie Welshpool, Garage of Ballygowan.

Donations

McCracken memorial Presbyterian Church Choir

In memory of the late Crawford McKelvey – the monies received shall be used towards the development of M.E Support Northern Ireland's website.

In memory of the late Adrian Moorhead. M.E Support Northern Ireland sends its condolences to his partner Miss Girlie Nuguid and his loved ones.

Grants awarded to M.E Support Northern Ireland

Our committee member, made numerous grant applications throughout the course of the year, this involved filling out many forms, compiling cost information and following up with grant agencies via telephone, email and in person.

Awards for all

Amount: £1,973

Date awarded: June/July

Purpose: Exhibition costs including display table and promotional material and merchandise.

Status: Completed



Halifax foundation

Amount: £2203

Date awarded: June

Purpose: Promotional costs, flyers, postage, presentation folders

Status: Completed



Enklon

Amount: £500

Date awarded: July

Purpose: Office rent and cost of support group meeting hall

Status:



Micro Grants

Amount: £795.99

Dates awarded: August

Purpose: Towards “a series of small interventions to reduce isolation for M.E Sufferers” – postcards, phone calls, visits etc

Status: Completed

Wesleyan Small grants

Amount: £1,904.91

Dates awarded: July

Purpose: “towards the design, production and distribution of information packages to primary and secondary schools across Belfast”

Status: “This project has been supported by the Community Foundation for Northern Ireland through the Wesleyan Small Grants Fund”

WESLEYAN
we are all about you

Foyle foundation

Amount: £1,500

Date awarded: November

Purpose: “to produce a booklet, providing information and advice to people with M.E and others”

Status: This project is currently in the planning stages and will take place in May



The Honourable Irish society

Amount: £800

Date awarded: October

Purpose: Towards “costs associated with promotional material and equipment”

Status: This project is currently in the planning stages and will take place in May for M.E awareness month



Ulster bank Community Staff Charity Funds

Amount: £250

Date awarded: October

Purpose: Towards the cost of developing a Website



James tutor foundation

Amount: £2,000

Date awarded: October

Purpose: Towards “the cost of the production and distribution of the M.E information packs”

Status: This project is currently in the planning stages and will take place in May



Black Santa Appeal

We were very pleased to receive a donation from this year's appeal of £750. Which has been offset against our office expenses.

Special Note:

This year, there has been a substantial increase in the number of grants applied for and that we have been successful in obtaining.

Support Group

This year we held 10 support group meetings. The group meetings continue to be well attended with several dozen new members attending as well as over 100 attendances of old members.

Speakers at the group



Advice NI – Gavin Ferris – very popular among our members with requested for more presentations by Gavin in the future - May and November?

Anne Smyth – hosted a benefits advice evening – how M.E Support Northern Ireland helps its members regarding social and welfare support - November?

Gerry Carroll MLA attended to speak about how welfare reform effects his constituency and learn about M.E from our members – October?



Thoughts from members

“When [M.E Support Northern Ireland] helped me with benefits it was the first time someone knew more about M.E than me. I don’t have to explain to [M.E Support Northern Ireland] how much of a challenge living with M.E was” - Anonymous

“After working all my life, I needed help [M.E Support Northern Ireland] guided me through the benefits process” – Anonymous, aged 35, worked in finance for 13 years

“No one wants to have to live of benefits but we didn’t have a choice, [M.E Support Northern Ireland] made sure I was getting the support I was entitled to after paying tax for 20 years” - Anonymous, age 56, primary school teacher

“I hated having to fill out benefit forms alone but [M.E Support Northern Ireland] understood my illness and made the process much easier to get through” - Anonymous

Christmas dinner

Our Christmas dinner was held in the Beechlawns hotel with 43 members and guests attending. We were really pleased that Jeff Gallagher and his wife were able to join us and meet our members.

In lieu of gifts from M.E Support Northern Ireland our members, even those who could not attend each donated to local food banks – as a charity we feel it is important to support other local charities within the community

Social care and 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.

Some of our committee arrange to meet up with members, who live outside of the Belfast area and who are unable to attend support group meetings.

We also have in the past year, sent out >100 cards, Birthday Cards, Christmas cards, information about upcoming events etc.

We are also continuing to engage with members who are unable to attend the support group meetings due to their health.

Social Media

We once again are very grateful to Mags Maloney for her management of our Facebook page. Mags is always there to welcome new members.

Final word by the Chair

Special thank you to our committee members, particularly those who are stepping down this year. Your support and help has been invaluable over the past year.

We hope that the new committee will get much accomplished in the forthcoming year.

A huge thank you to all of our members for their continuing commitment to the group and their help in supporting each other throughout the year.

Email: info@mesupportni.com

Facebook: <https://www.facebook.com/groups/365117956886428/>

Scientific Advisor: Dr Vance Spence, ME Research UK

Patron Dr Nigel Speight Consultant Paediatrician MA MB Chir, FRCP FRCPCH
DCH

Charity No: NIC104006