



ANNUAL REPORT

January – December 2017

MARCH 1, 2018
M.E SUPPORT NORTHERN IRELAND
Conway Mill, Belfast



Annual Report January-December 2017

Chairs report

This is my fifth year as Chair of ME Support NI, 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.

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

Antoinette Christie
Chair person

Date:

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



REPORT OF THE COMMITTEE

The committee presents its report and financial statements for the year ended 31st December 2017.

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 person's support
Anne Smyth, Patient Support
Uli Speers
Amanda Mann
Bruce Bingham
Emma Shaw

Principal Bankers

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

Independent Accountant Review

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

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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 effected by 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 continue to dip in and out as they are able.

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Patient Client Council update

Still ongoing. Awaiting update.

Belfast City Marathon – 1st May 2017

This year we again had a relay team representing us at the Belfast City Marathon. Terri and Steven Simpson undertook the full 26 miles and Catherine Mullan, Deborah Sullivan, Ann Marie Sullivan and Michelle Monaghan undertook the relay race.

Exciting day was had by all. With awareness raised for ME Support NI.

Welfare Reform- 2 May 2017

Terry Smyth, Disability Action and Gavin Ferris, Advice NI give an update about Welfare Reform in NI and were able to answer and give advice to members.

Sadly, Terry has now been made redundant from his job with Disability Action due to recent cuts. This is a huge loss, as Terry has always been very supportive.

ME Awareness Day – 12 May 2017

We held an awareness evening in our new premises at Conway Mill. We incorporated a display for Missing Millions with shoes on display representing all the missing ME people.

A presentation was also on display throughout the evening giving the history of ME, information about our group and how we started and how far we have come.

We also launched our new logo and released balloons on the night, with the help of our Deputy Mayor, Mary Ellen Campbell (SF).

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Aware Defeat Depression 6 June 2017

Siobhan Doherty spoke at our group meeting. As Chief Executive of Aware Defeat Depression, she reiterated the importance of looking after your mental health. Siobhan shared her own experiences and the work that Aware Defeat Depression does, offering courses etc to combat depression and improving mental health.

Causeway Challenge – Half Marathon – 5/8/201

Seamus Cradden ran the Causeway Challenge Half Marathon on August 5th 2017 and raised a further £840 for our Charity.

MESNI would like to thank all involved.

Fun day, open day and Coffee Morning – 12 August 2018-03-04

The Victoria Evangelical Hall was the venue for a fun day, open day and coffee morning. They were very kind to donate proceeds from the day to ME Support Northern Ireland.

We would like to thank David & Avril Dale who organised this event.

Antoinette attended alongside Amanda Mann, Joseph Marley, Sarah Duff and Leah Duff.

It was an absolutely fabulous day and raised both awareness and funds for ME.

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Unrest Documentary – Queens Film Theatre – 11th & 12th November 2018

Antoinette had been in touch with QFT and the Unrest team with a view to supporting the film herein Belfast. Antoinette introduced the film at QFT on the opening night of the film. It was very well attended, with all tickets sold, necessitating committee members from ME Support NI to have to give up their own seats to accommodate people who had come from further afield.

We also held an information stand at QFT for the 2 days that the film was shown.

Synopsis

Jennifer Brea's Sundance award-winning documentary, *Unrest*, is a personal journey from patient to advocate to storyteller. Jennifer is twenty-eight years-old, working on her PhD at Harvard, and months away from marrying the love of her life when a mysterious fever leaves her bedridden. When doctors tell her it's "all in her head," she picks up her camera as an act of defiance and brings us into a hidden world of millions that medicine abandoned.

In this story of love and loss, newlyweds Jennifer and Omar search for answers as they face unexpected obstacles with great heart. Often confined by her illness to the private space of her bed, Jennifer connects with others around the globe. Like a modern-day Odysseus, she travels by Skype into a forgotten community, crafting intimate portraits of four other families suffering similarly. Jennifer Brea's wonderfully honest and humane portrayal asks us to rethink the stigma around an illness that affects millions. *Unrest* is a vulnerable and eloquent personal documentary that is sure to hit closer to home than many could imagine.

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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 was a great help to the committee in organising this event.

A special thanks as always to all those who donated hampers for the day.

Fundraising this year

Belfast City Marathon - £672
ME Awareness Day – £1,000 (approximately)
Translink - £1,000
Fun day, open day and Coffee Morning –£800
Football card sale - £420
Seamus Cradden - £840

Donations

11/7/17 - ME Support NI donated £1000 to ME Research UK.

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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

Aware Defeat Depression – Siobhan McFadden
Disability Action – Terry Smyth, Welfare reform
Advice NI – Gavin Ferris

Promotional material & information leaflets

This year we designed our very own trolley coin and pin to raise the public awareness of M.E Support. This has also allowed us to provide small tokens of thanks to those who support our charity.

We have also continued to improve our existing information leaflets, for school. Doctors and other medical professionals and continue to work to distribute information as effectively as possible. Additionally, we were encouraged by professionals within the education sector to translate our school leaflets into Irish. We would like to thank Jim Donnelly who offered to take on the substantial task of translation free of charge. Jim also provided advice on the best ways to distribute our leaflets within the Irish school community.

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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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Additional Contributions

Amanda Mann, has this year taken on the task of reaching out to our more isolated members who are unable to attend the support group meetings.

Home visits

We have continued to do frequent home visits to our 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 person's advocate

David Christie engages regularly with many of our members via email as well as home visits and personal meetings. Additionally, he has facilitated meetings between our members who live in more isolated parts of the country.

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Upcoming events

Talk Lorraine Henry, OT
May 12th Awareness Event
Relay Swim across the North Channel June 2018

Final word by Antoinette Christie

Lastly, I would like to thank some people who I feel do not get enough credit for the work they do for all of us. Veronica Bryson volunteers as our treasurer whose' work is vital to the administration of our charity. As well as Jeanette Marley who acts as our sectary and without who I couldn't act as the chair for M.E Support. As well as Anna Smyth, Amanda Mann and David Christie who provided great support to our members and myself. As well as Uil Speers, Bruce Bingham and Emma Shaw for taking the time to contribute to M.E support.

Additionally, thank you to Dr Lisa Bradley and new husband Dr Bradley for raising money for M.E Support on their wedding day. I want to credit Micky McDaid for his continued support as well as NI Technology for attending all of our technology needs.

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