



ME SUPPORT NI

Annual Report January-December 2013

Chairs Report

This is my first 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 one of our members Uli Speers for the wonderful work she undertook in conjunction with ourselves to complete a dissertation "It's about you, not ME". I believe this is the first piece of research commissioned in NI which looked specifically at the needs of carers.

I would also like to extend my thanks to Dr Nigel Speight, for agreeing to come to NI to speak at the ME/Fibromyalgia Conference. Dr Speight is someone I have greatly respected for all of the work he does for people with ME, particularly those severely affected.

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

We have attempted 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 contacted the HSCB and DOH with regards to an update on their plans for future service delivery for ME patients. Having been informed the Belfast City Hospital CFS Clinic was affectively closed due to the retirement of the lead consultant, we spoke in person to Jim Wells, Health Committee raising our concerns, and wrote to the DOH asking for information in relation to the closure of this service.

Finally and most importantly I would like to extend my thanks to Bronagh O'Toole and her family without the financial support donated to us from their Feile Joe Fundraising event each year, we would be greatly restricted in what we are able to achieve year on end.

Antoinette Christie
Chair person

Date:



REPORT OF THE COMMITTEE

The committee presents its report and financial statements for the year ended 31st December 2013.

Charity registration no: N100262

Registered office:

c/o 61 Orchardville Avenue
Belfast
BT10 0JH

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
Angela Mulholland, Health and Client Support
Ian McIlroy (resigned 29 December 2013)

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 **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 (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

On 18 February 2013, ME Support NI arranged to have the film Voices from the Shadows premiered in the Long Gallery at Stormont. The event attendees including Sue Ramsey, Chair of the Health Committee, MLA's, the Right Honourable Lord May or Lisburn, William Leathem, the Social Care Commissioning Lead - Children and Families, HSCB, Barnardos, Suicide Awareness, members of support groups etc. Several hundred people attended. There was music provided by Beccy Henderson and Rosy Barr. A reception was held after the event.

A major achievement for ME Support NI this year was having the opportunity to participate in a medical conference, with our colleagues in Fibromyalgia NI, on 10 August 2013.. We were able to obtain the services of Dr Nigel Speight, MA, MB, BChir, FRCP, FRCPC, DCH. Dr Speight is the most knowledgeable and experienced ME Consultant Paediatrician in the UK. His talk titled "Paediatric ME/CFS" give an



overview of his work with Paediatric patients with ME and the difficulties encountered. He spoke about Supportive Management:

- Treat symptoms (Pain, insomnia etc)
- Nutritional support (Tube feeding often necessary)
- Avoidance of contractures, venous thrombosis, pressure sores (by gentle physiotherapy)
- Maintain morale (e.g. special nurse assigned, maximal tender loving care)
- Beware of involving too many others

He concluded that:

- ME/CFS is primarily a genuine ORGANIC clinical entity, which can effect patients that are at least initially psychologically normal
- For too long this area has been hi-jacked by psychiatry, mainly because no medical speciality has been willing to accept responsibility for the condition

One of our committee members Darren Magee, **Reg MBACP NCS (Acc), Sentient counselling** also spoke about “Counselling and Chronic illness”. This was followed by a question and answer session, in which both our Chairperson Antoinette Christie and Darren Magee, also participated in. The conference was a huge success, with high attendance.

A lot of hard work went in to organising the event, with numerous meetings with Fibromyalgia NI, convincing Dr Speight to come to Belfast, organising flights, hotel, and transport to and from event and airport and evening meal with Dr Speight after the event.

JORDANSTOWN UNIVERSITY

Jordanstown University contacted us to see if we could support one of their students Uli Speers in completing her dissertation. “It’s about you, not ME - counseling needs of and provisions for carers of ME patients in Northern Ireland”.

Uli attended the group and met with members and their carers, who completed a questionnaire and semi structured interviews. This mixed method design demonstrated a clear need for psycho therapeutic intervention among carers of ME patients and identified carer emotional needs.



Objectives:

- To identify the emotional needs of the carers of ME patients.
- To determine counseling up-take of carers of ME patients.
- To determine counseling provisions for carers of ME patients.
- To establish which types of counseling approach are beneficial for carers of ME patients.
- To determine recommendations for counseling provision for carers of ME patients in Northern Ireland.

Future research

Future research could examine why existing counselling provisions are not better used by carers of ME patients and how to make counselling more accessible to them. In addition, research could investigate whether negative carer experience of psychological intervention for patients leads to an aversion and reluctance to use psychological interventions for themselves. Also, additional research is needed into which counselling approaches would be beneficial to carers.

The results of her dissertation can be obtained from the group.

WEBSITE

Daniel McDowell, a student from Jordanstown kindly agreed to design/create a website for ME Support NI as part of his degree. The website requires updating before it can become live.

SUPPORT GROUP

This year we held 11 support group meetings, the December meeting was cancelled as we held our Christmas dinner in lieu of this.

MEMBERSHIP

40 Members of which 25 are full members – 15 are non paying

Attendances this year at Support Group: 110



FUNDRAISING

This year we once again participated in the Belfast Marathon in aid of ME Support NI.

We attended Feile Joe, Armagh - a fundraising event organised by Bronagh O'Toole and her family, who sadly lost her husband Joe in sad circumstances. Bronagh and her family have been hugely supportive of our group and with the money donated by them in 2012 we were able to hold a showing of Voices from the Shadows. This year they give a substantial amount to us which was partly used to fund the medical conference held in Stormont.

The Ballymacnab Choir approached us with a view to creating a CD to sell in Aid of ME Support NI. The launch of the CD was held in the Tomas O'Fiach Library, Armagh. Sales of the CD are still ongoing.

Dougie Hutchinson, Milltown Bowling Club, Armagh also contacted us to present us with a cheque. Each year the bowling club hold a bowling competition and give the proceeds to 2 charities. Happily this year they chose to donate £500 to ME Support NI.

COLLECTION TINS:

We have received donations from collection tins at the Falls Leisure Centre and Mr John Colgan Greengrocer Crossgar.

DONATIONS:

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

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 provided 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. has dealt with fifty referrals since joining ME Support NI, some are ongoing. These included providing help on both practical and emotional levels, assessment of needs, referral agent to multidisciplinary professionals re care plan and support young sufferers re education needs. We are very grateful for her constant support.

SYNOPSIS OF EVENTS (not withstanding support group meetings)

On the 6th May 2013, ME Support NI participated in the Belfast City Marathon

On 4th June 2013, ME Support NI organised a guest speaker at their support group meeting - Paul Wright, Acupuncturist – gave a presentation about the benefits for acupuncture for people with chronic illness/pain. He also gave a short demonstration on acupuncture.

On 3rd September 2013, ME Support NI organised a guest speaker at their support group - Sinead McKinley from North Belfast Partnership give a presentation on the changes to the Benefits System.

On the 20th September 2014, ME Support NI participated in a Health and Wellbeing Event in Victoria College. This took the form of an awareness day, giving students and staff information on ME and contact details where students can turn to for help

On 7th December 2013, ME Support NI funded and held a Christmas dinner for the members, in the Devenish, Finaghy Road North, Belfast. It was once again well attended and a few members from Newry & Mourne Support Group were our guests.

FUTURE PLANS & PROSPECTS

We have organised further speakers for the group:

May 2014 – Defeat Depression

June 2014 – Transcendental Meditation

August 2014 – Uli Speers, presenting her dissertation – “To investigate the counseling needs of and provisions for carers of ME patients in Northern Ireland”.



12 May 2014, we have arranged to have the Belfast City Hall lit Blue to raise awareness of ME on what will be ME Awareness Day.

30 & 31 May, ME Support NI has arranged to participate in a Disability Exhibition in Kings Hall Pavilion.

We have also booked to attend a seminar on Charity Regulation and Good Governance on 10/4/14 2-4.30pm, NICVA, 61 Duncairn Gardens, Belfast, BT15 2GB

OTHER WORK

We are planning to take forward the following in the next year:

Introduction of an information pack for schools

Introduction of an information pack for medical professionals, possibly to be piloted with GPs.

GP Survey on their views of ME

Newsletter for the group

Flyers for the group



FINANCE

M.E. Support Northern Ireland (MESNI) Jan 2013 - Dec 2013

Details of Income & Expenditure

Income

Milltown Bowling	£500.00
Belfast Marathon	£203.00
Fundraising	£807.13
Feili Joe	£1,800.00
DVD's and Books	£87.00
Membership of MENSİ	£115.00
Donations	£623.41
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	£4,135.54

Expenditure

Bank Charges	£76.07
Insurance	£389.55
T Shirts	£122.50
DVD's	£48.00
NICVA Membership	£107.10
Fees to enter Belfast Marathon	£82.50
Promoting ME	£20.00
Petrol Expenses	£94.81
Stationery/Signs	£670.00
Plaque	£15.00
Christmas Gifts & post	£30.55
N&M Feili Joe Donation	£2,100.00
Tea/Cof & Xmas Di Group	£452.40
Talks & Conferences	£904.07
Redrafting Constitution	£50.00
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	£5,162.55

Balance Carried Fwd	£3,749.71
Income for Year	£4,135.54
Expenditure for Year	£5,162.55
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Balance at Bank	£2,722.70