

ANNUAL REPORT



January – December 2015

ME SUPPORT NI

Annual Report January-December 2015

Chairs report

This is my third 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 2015.

Charity registration no: NIC104006

Registered office:

12d Curran House
155 Northumberland Street
Belfast, BT13 2JF

Phone: 07526252055

Chair person

Antoinette Christie

Committee Members

Jeanette Marley, Secretary
David Christie, Young persons support
Anne Smyth, Client Support
Catherine Burrell
Frankie Hall (stepped down)
Aine Heffernon (stepped down)

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 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.

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Patient Client Council update

As you know we have been part of an ME/Fibromyalgia Steering Group working alongside the Patient Client Council over the past year. This has involved lengthy monthly meetings with the PCC. This culminated in a ME/Fibromyalgia symposium, which was well supported, but unfortunately not by the professionals we had hoped for. It did highlight however with the PCC how difficult it is to get professionals within the health service interested in ME.

The ME and Fibromyalgia workshop has now been divided into 2 separate groups to avoid competing interests.

ME/Fibromyalgia Symposium 23/2/15

The ME/Fibromyalgia Symposium was held on 23/2/15. It was felt that feedback was very positive overall about the symposium. However this should be put into context, as it transpires that the audience had large number of patients in attendance (which was not supposed to be the case), necessitating the PCC having to open another room to accommodate the audience. They are unsure why so many patients attended, given there was a restriction on the number actually allowed to attend as per instructions to support groups.

It was deeply disappointing that chief decision makers, from both Trusts and Boards (HSCB and DOH) left early before the question/answer session.

PCC stated that several different professions were represented i.e: physio, occupational therapist, social worker, doctors. Despite registration they were unable to confirm numbers.

PCC accept that they were probably naive in thinking that the symposium would have been supported by professionals, as that had been their experience with previous symposiums for other diseases. They believe this highlights the need for more work in regards to encouraging interest from professionals.

The symposium did highlight that ME is not high up the agenda and exposed lack of interest in ME

Joanne McKissock said that a broad brush event won't work, that it needs to be more targeted should we focus on certain departments i.e. Neurology, Rheumatology. It was pointed out that neurologist won't take on ME, despite it being recognised as a neurological illness.

Anne Smyth felt that more direct approach might work i.e. taking training directly to the professionals. She has had discussions with several professionals who were very receptive.

International ME Awareness day 12th May 2015

To mark International ME Awareness day we took the time to show everyone our new office accommodation in Twin Spires. We also managed to hold a mini fundraiser in Aid of ME Research UK in our new premises "A Cuppa tea for ME.

With coffee, tea and lovely cakes and buns and a ballot or two sold, we managed to raise: £250

Thanks to Caroline Marley for donating a crocheted throw as one of our ballots.

Thanks especially Amanda Mann and Sarah Duff for sorting out catering and selling ballots on the night.

Thanks also to Bernie Carson, for making/supplying sandwiches on the night.

Shine a light

This year we also managed to have the following buildings lit blue to mark International ME Awareness Day:

1. Mossley Mill, Newtownabbey
2. Antrim Civic Centre
3. Victoria Square, Dome, Belfast
4. Derry City Council Offices
5. Smiley Building, Larne Borough Council
6. St Patricks Visitors Centre, Downpatrick

Unfortunately the Belfast City Council were unable to facilitate our request this year to light the Belfast City Hall, due to changes in their policy for lighting of the building.

HSCB Meeting

We met with the Health Service Commissioning Board on 28/5/15 to receive an update on any progress that had been made for service development since our last meeting.

Iain Deboys, Health Service Commissioning Board, explained the Regional Commissioning Plan, which took into consideration a workshop from 3 years ago/talks to HSCB/ Lothian, Scotland/Northern Trust.

Discussion about NICE guidelines implementation in the health service:

Paediatric physiotherapists question graded exercise program, as they harm children more than it helps. There is a general lack of knowledge about the illness among health care professionals. Training for GPs & other health care professionals is lacking. GPs are supposed to handle ME patients but they have no support by consultants, as there is no consultant available. Therefore Health Care professionals have no support and patients are left on their own as well.

New model: Specialist support to GPs

However, it should not end up with having a good management of GPs but not having a real expert/consultant available who knows about this particular illness and has enough experience through client contacts.

Discussion about collective agreement about the way forward:

Addressing the points people are asking about, for example, ME groups expressed that the commissioning plan did not take into account what people asked for

Key issue: specialist service

There is a difference of understanding how the Board views a specialist service and the expectations that patients & carers of CFS/ME have of a specialist service.

Board: Management Program/Support GPs/diagnosis according to NICE guidelines/ give GP access to a consultant

ME groups: want a specialist service headed by a consultant which is accessible to the ME patients and gives individual advice.

Furthermore the interpretation of NICE guidelines differ between Board and ME groups, as ME is a defined disease, patients have the right to a consultant. However, Ian seemed to indicate that the Board does not see it this way.

Ian said: a specialist consultant for ME patients is not sustainable/they will offer a proactive management and symptom management/they also can't implement everything the ME groups are asking for - specialist treatment will be based on NICE guidelines (specialist GP) - there is no plan for supporting further research into CFS/ME. In addition, funds are not approved yet.

Despite these differences, how do ME groups have an ongoing role in this problem? How do we get a system that we can influence?

We need to stay involved in that. Commitment to hear, to listen and to respond.

Iain: The management programme is the first stage to deal with that. It is meant as a service to get people better lives. HSCB is keen to work with people and engage constructively with them, discuss how to improve the service, give advice what to do to get confirmation of diagnosis. An ongoing conversation is necessary, as it will take years to find a satisfactory solution. We need the feedback of the groups, however, patients need to be registered through their GPs, as funds are only available who are known by GPs.

The post HSCB is suggesting for a consultant: main task is medical lead to support GPs and training them; it will be a consultant lead post and not a consultant provided post; part-time post.

Issues discussed referring to the post:

- Stigma attached to CFS/ME in the medical world. Consultants who are interested in this area are few.
- ME groups want a consultant provided post, but this post will be consultant lead with a small element of primary care.
- ME groups very much in favour to offer this post first to consultants

Result: Iain agreed to offer this post first among consultants

Every 6 months the steering group and HSCB will meet for discussion and evaluation of the situation.

Pain Summit, 18 November 2015

The Pain Summit consisted of a morning and afternoon session. The morning session consisted of talking about pain issues through various conditions, but mostly seemed to concentrate on Fibromyalgia.

Chronic pain should not be passed off as either:-

1. Age related

or

2. Wear & tear etc.

There was a talk on self management which went along with pain management programme. Self management is very difficult when an individual suffers along with ME/CFS.

For the afternoon session we were divided into groups to participate in various workshop sessions.

Anne Smyth and Amanda Mann got the opportunity to speak about ME, and Amanda gave a personal account about living with this illness. Anne spoke on helping with the disability side and the assistance she gives in support of ME sufferers.

In general it was agreed that there was a need for an improved understanding among GP's and more provision for carers. In fact there is a lack of support and information for sufferers and carers.

In general Quality of Care and Quality of Life.

At the pain summit, Antoinette spoke with Dean Sullivan, Director of Commissioning, Health & Social Care Board. She raised particular concerns about the lack of services for patients with ME.

MAKING CONNECTIONS

New Patron

In May we were pleased to announce that Dr Nigel Speight, Consultant Paediatrician (retired), had agreed to be our first ever Patron for our group. We were greatly honoured that he accepted our invitation, given the amazing work he does for severely affected ME Sufferers.

Meeting with Lady Sylvia Hermon, MP

Annie Owens approached Lady Sylvia Hermon with a view to raising awareness of ME and the possibility of a meeting with herself.

Veronica, Lorna Bryson, Annie Owens and Catherine Burrell, met with Lady Hermon.

At the meeting we talked at length about the lack of facilities for people with ME. We explained that there is not any specialist in NI with an interest in ME.

We give personal accounts of living with ME to Sylvia. She was very shocked to hear that people were receiving no support. She appeared to be very sympathetic and was sure she could help.

She said she would speak to the Health Minister and would meet with us again.

Lady Hermon wrote to the Health Minister 16/7/15 and received a response from Mr Hamilton's office on 16/9/15. Lady Hermon felt that the response from the Health Ministers office was disappointing, a view which we share. We will continue to follow up with Lady Hermon.

Tymes Trust

Our Group became a Young ME Sufferers Trust Partner Group. Tymes Trust will support our Group in the following ways:

- Provide advice/information in connection with children and young people
- Send us a copy of Tymes Trust campaigning posters and other publications
- Permit us to reprint items from Tymes Trust publications without seeking permission provided full credit is given and that no changes are made.
- Send us Jane Colby's news Alert emails; permission to reprint
- Have our Group's questions answered by the Trust's professional advisers
- Send extra leaflets and posters for our own use when required (within reason)

AYME

As part of their recent BBC Children in Need project, AYME were trying to reach out to as many young people and their families as possible. To kick start their "Spotlight" tour, Sheila Carruthers, National Support Worker, AYME contacted our group. She came to Belfast on 16th November and met with the committee and also with group members the following day to discuss how to make services more accessible to young people and their families on a one to one basis. She also wanted to see if she could offer assistance to try to help the current situation/challenges and to explain the services that AYME can offer and what they could assist with.

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Meeting with Neurology Care Coordinator for NI

Joanne Westwood, Neurological Care Coordinator for Northern Ireland, Belfast HSCT based in the Royal Victoria Hospital, Belfast contacted our office.

In her role as Neurological Care Coordinator, she will be leading a team of care advisors who will provide a regional point of contact for information for patients and their families who have been affected by neurological conditions.

She wanted to discuss the service of ME Support NI provide and how she could best establish the link between our services.

In her initial phone call to Joanne, Antoinette mentioned research and in particular the recent PACE study which has rightly caused such controversy. On following up, Joanne had taken the time to read through of some of the articles regarding the Lancet study and the concerns raised re how the study was undertaken/results interpreted/issues on how results are interrupted etc. Her comments were as follows: "It certainly made for very interesting reading! It highlights the importance of clear, correct information being given to the public. Will certainly keep an eye out on for more information on this story!

Joanne also suggested that we might like to become members of NINCA, Northern Ireland Neurological Charities Alliance. They said, they feel it's good to have strength in numbers with some commonality for the people we represent.

We have discussed the benefits of this with the committee and have decided it would be worthwhile joining NINCA as a member. We have subsequently been invited to a Long Gallery Event they are holding in Stormont on 14th March 2016.

Joanne Westwood has sent out a draft of their new Neuro Care Advice leaflet, and although we were disappointed not to see ME Listed in the neurological illnesses we feel that the connection we have made with Joanne and her advisors will be very beneficial to sufferers.

Meeting with Lord Mayor Arder Carson, 19th November 2015

Following several unsuccessful attempts by Lord Mayor Arder Carson to join us at one of our support group meetings, the Lord Mayors Office issued an invite to our group to meet with him in the Lord Mayors Parlour.

This was a lovely afternoon, and we were very thankful for the warm reception we received from the Lord Mayor.

As well as listening to our stories of our journey with the illness, and how it affects our lives and the lack of support services here. He was very interested and promised to get involved in raising awareness of the condition. He gave some suggestions about how he could help. We will be following up on this in the coming weeks.

We took it as a positive sign when we left the City Hall, to find that it had been lit blue!

We would like to thank Mags, David & Danny Maloney, Chloe Steward, Claire Prideaux, Josephine & Desmond Maguire, Carol Patrick & Noel & David Christie

Raising awareness

1. NVTV (6/1/15), contacted Me Support NI to see if they could interview some people with regards to ME. They attended our Support Group Meeting in January and interviewed Dr Pamela Bell, Pain Alliance, Antoinette Christie, Chair, ME Support NI, and some of our members including Lorna Bryson, David Maloney, Amanda Mann.
2. Belfast telegraph (10/11/15) contacted ME Support NI looking to interview some people for their paper with ME. They were particularly interested in speaking to someone between the age of 30-40 years old to get a feel for how ME affects the lives of people in this age group. Two of our members Amanda Mann (and her family) and Jim Wilson bravely stepped forward to be interviewed and a two page article made it to the paper. Fabulous coverage.
3. Radio Ulster, 29/10/15 - Antoinette took part in an interview with Radio Ulster. Also one of our younger members Lorna Bryson also participated in the programme. This awareness came on the back of the recent Oxford University Study by Michael Sharpe.

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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 year's Christmas Dinner such a success. Firstly 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.

We would also like to thank Mags and David Maloney, who did were our two elves this year, threading all of our Christmas decorations and bagging them for each member. They also once again supplied a hamper which we were able to ballot on the night, raising much needed funds for the group.

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.

Guest Speakers throughout the year

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

January Dr Pamela Bell

September Karen Hall, Disability Action - Benefits Advice/Welfare Reform

DONATIONS RECIEVED:

£200 received from Bronagh (nee Smyth) & Ronan McKeown who raised money through their Wedding Party Favours.

DONATIONS GIVEN

£250 donation to ME Research UK

£1000 donation to Ian Lipkin - **Lipkin ME/CFS/Microbiome study**

Web: www.meresearch.org.uk
 E-mail: meruk@glaxo.org.uk
 Telephone: 01738 451234

ME Research UK, The Gateway,
 North Methven Street,
 Perth PH1 5PR, UK

Mrs A Christie
 Chair Person
 ME Support Northern Ireland

21 September 2015

Dear Antoinette,

On behalf of the Trustees of ME Research UK, I would like to thank ME Support Northern Ireland for the Group's Donation of £250 which was received today. The continued support of the Group is most appreciated.

As before, I have allocated the donation to our Research Fund – 100% of which is dedicated to biomedical research.

As you will be aware from our Facebook page, the work of Prof Newton (for whom's project ME Support Northern Ireland's last donation was applied) is continuing and, indeed, those severely affected by ME are now being contacted to allow this aspect of the study to be progressed.

Since the beginning of this year, we have funded 3 new studies which arose from our world-wide call for applications. Full details have now been announced on-line. The first is in Australia (brain imaging of young people with ME/CFS), one is in Canada (gene expression following exercise), and the other in Belgium (genetic determinants of pain). These contrast with the UK based studies which we announced most recently at the Universities of Leicester, Newcastle and Dundee.

Without support from active supporters, such as ME Support Northern Ireland, we could not invest in such important items of research and it is unlikely that they would ever be carried out.

Once again, I would like to thank you all for your support; every penny helps us in our quest to make the breakthrough that people with ME/CFS deserve.

Best wishes

Stewart Walker
Development Director

Patron: The Countess of Mar
 Co-founder & Patron: Roger Johnson CBE DL

Chairman: Dr Vance Spence
 Secretary & Treasurer: Dr Robert Miller

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ME Support Northern Ireland
 Wellington Park Business Centre
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 Belfast BT9 6DJ
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Columbia gratefully acknowledges your gift.

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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 approximately fifty M.E sufferers and their families.

Read what Anne has achieved over the last year (in her own words):

“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 multidisciplinaries 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.”

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M.E. Support Northern Ireland (MESNI) Jan 2015 - Dec 2015

Details of Income & Expenditure

<u>Income</u>	<u>2015</u>	<u>2014</u>	<u>Expenditure</u>	<u>2015</u>	<u>2014</u>
DVD's Books & Pens		£161.00	Bank Charges	£49.40	£62.75
Membership of MESNI	£75.00	£130.00	Insurance	£206.70	£401.24
Donations	£1,513.34	£1,233.00	Membership Fees		£32.00
Just Giving		£5,709.34	Promoting ME		£1,426.19
Ballet		£100.00	Petrol Expenses		£38.33
Ballynab Choir		£1,000.00	Stationery/Signs	£1,062.80	£597.48
Club Oxygen		£290.00	Office Equip &Phone	£546.07	£221.62
Bank Interest	£6.18	£4.61	Tea/Cof &Xmas Dinner	£1,174.94	£1,151.95
CFNI	£1,000.00	£1,200.00	Conferences& Exhibitions		£180.00
Christmas Dinner		£180.00	Just Giving Fee		£126.00
Cheques not cashed		£26.49	ME Research UK	£300.05	£1,000.00
NI Electricity	£500.00		Office	£2,462.96	£420.00
LBF Grants	£2,880.00		Refund of Cheque		£10.00
LATM	£690.00		Xmas Gifts	£126.00	£71.62
			Petty Cash balance	£14.77	
			Donation Ian Lipton	£1,000.00	
			Donations	£28.00	
			Expenses	£61.65	
Balance Carried Fwd					
Income for Year					
Expenditure for Year					
Balance at Bank	£6,664.52	£10,034.44		£7,033.34	£5,739.18

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