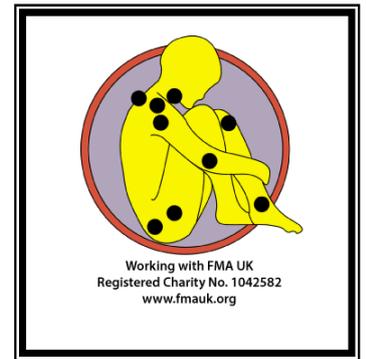




Welcome to the February 2017 Newsletter.

Note from the Editor Maxine: Please fill out the voting slip and send back especially if you can not make the A.G.M. You can email or post it to Carole.



Monthly focus.

NEW MEETING PLACE FOR AGM & RENEWALS

Membership renewal will be due in April, have you thought about setting up a standing order? Or do you prefer to internet banking to pay your membership? We now accept PayPal payments as well. You can also pay by cheque, or pay at the meetings with cash or cheque.

Please note, the membership fee is now £10.

Dates For Your Diary:

Bolton Main Meetings:

Unfortunately we have had to find a new venue due to The Wildlife Trust having a staff shortage and organisational restructure. They have been very helpful, and welcoming and it's a shame to leave such a lovely, peaceful building, with wonderful views of wildlife outside.

The new main meeting venue will be **The Friends Meeting House** (The Quakers), in Silverwell Street, Bolton, **BL1 1PP**. The street is opposite Nelson's Square and has an Italian Restaurant on the end. The venue is all the way to the bottom of this street, on the corner, where all the solicitors are.

There is good provision of car parking between private land and street parking. They have a small car park, for about 11 cars, and next to that, is an NHS car park they are permitted to use, plus street parking bays and double yellow lines for those with blue badges, which will be ample for our meetings.

Blue badge holders can go on yellow lines, all in close proximity to the entrance. It would be helpful if you are on a scooter/powerchair or are able to walk that bit further, to leave the nearer spaces, for others who may need them more please.

The building is warm and welcoming, quiet, a variety of comfy chairs are available, disabled loo, all on ground level etc. We have looked into a lot of venues and this most

meets our needs. The staff are extremely accommodating, so if there is anything you need or have a problem with on the night, they will be happy to try and help.

Meetings remain on the 3rd Thursday.

Bury and Bolton ME/CFS & Fibromyalgia Support Group Meeting Dates

Meetings will be as follows, on the third Thursday of the month at 7:30pm, subject to change:

Thursday March 16th 2017- our A.G.M and raffle (our first meeting in new venue). Please bring unwanted gifts or items for the raffle!

No meeting in April, as usual.

Thursday May 18th 2017 - TBC

Thursday June 15th 2017 – TBC

Thursday July 20th 2017 – our bring and share Summer social

No meeting in August, as usual

Thursday September 21st - TBC

Thursday October 19th - TBC

Thursday November 16th – our pre Christmas bring and share supper Social

No meeting in December, as usual.

Thank you.

Prestwich Socials:

Unfortunately we have decided to cancel the Prestwich socials after the December meeting. The turn out is too low and it is the same few members attending to ensure any new visitors are met. The last few times it's been the same 2-4 people, some travelling from Bolton or Westhoughton to get there.

We may organise the odd one off social now and again.

Members are free to set up any socials they want to arrange themselves if they fancy meeting up with others locally, but please be safe and meet in a public place if you have never met before.

PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANK-YOU.



DISCLAIMER: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Trustees, nor the Bury & Bolton ME/CFS & Fibromyalgia Support Group (Registered Charity Number: 1161356). Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

Reminders:

Membership Renewals:

Renewals are **£10 per year** now, due April 1st, and run till March 31st. There are several ways to pay:

Online Bank Transfer:

Sort Code: 20-10-71

Account No: 00902179

Account Name: Bury and Bolton ME/CFS & Fibromyalgia Support Group.

Standing Order: To same account as above, we can provide you with the form. Please send to your bank, not us.

PayPal Payment: Use the Paypal.com website or phone app to send the £10 membership fee to paypal@mesupportgroup.co.uk and include your name and address in the comments so we know who it's from please.

Cheque: £10 payable to "Bury and Bolton ME/CFS & Fibromyalgia Group". Bring to a meeting, or send to Lynda Marney, Treasurer BBME Group, 10 Osmund Ave, Brightmet, Bolton, BL2 6DR

Online bank transfer, standing order and PayPal are easiest for us to administer. Many thanks for your continued support.

Volunteers: We are looking for volunteers who can help with all activities of running the group, if you think you can contribute, even if a small way,, from home or at meetings, when your energy permits, please contact Caroline. We are just a small number of sufferers, so we need all the help we can get please. Please contact Caroline on caroline@mesupportgroup.co.uk or 07851 647 550 for more information. The group will unfortunately have to gradually cut services as our health declines.

Several other local groups in Lancashire have had to close over the last couple of years, due to lack of volunteers. Most recently, Worcestershire has voted to dissolve the group at their E.G.M. Please do not let this happen to us.

Equipment to Borrow: We have a sparkly new manual wheelchair, and two electric mobility scooters (small enough to fit in car boot for days out or holidays) and two pairs of SmartCrutches (ergonomic elbow crutches). If you wish to borrow any of these, please phone Pam on 01204 793 846. To try the SmartCrutches, call Caroline 07851 647 550.

Newsletter Articles: Please carry on sending us anything you would like to share with the rest of the group; whether it is a whole page, or just a few lines, it all counts! It could be recipes, tips, experiences, book reviews, etc. Deadline for the newsletter is the last day of the month. Please send your contributions to: maxine@mesupportgroup.co.uk. Via email where possible please.

Benefit and Work guides: Remember, for anyone filling in benefit forms or if you have appeals/tribunals, we have excellent guides available via post or email (saves us funds). Phone Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk.

Motability Big Event – Event City, Manchester

EventCity, Phoenix Way, off Barton Dock Road, Urmston, Manchester, M17 8AS (next to the Trafford Centre). FREE ENTRY.

- **Friday 5 May 2016** Doors open 9am, event closes 4pm
- **Saturday 6 May 2016** Doors open 9am, event closes 4pm

If your current car is no longer suitable for your needs, but you are not sure what sort of car would be best, need adaptations, or are interested in the Motability scheme, this event would be worthwhile attending.

The Big Event is Motability's biggest event of the year. Entry is free. Held entirely indoors over two days at EventCity, Manchester, it's your chance to see the largest ever display of Motability vehicles in the UK. This would be a great chance to see and try a large range of cars, and see if they are suitable for you, and can fit your scooter or wheelchair in them. The adaptation specialists will also be there, so you can get advice off them, even if you don't have a Motability car.

The event will host the UK's largest display of vehicles available through the Motability Scheme, including:

- Over 100 cars from 27 different manufacturers
- Over 40 scooters and powered wheelchairs
- Adaptations from a wide range of adaptation companies
- Over 25 Wheelchair Accessible Vehicles

You can also:

- Test drive adapted and non adapted cars
- Chat to our Motability advisors who are on hand to answer your questions
- Meet Scheme Partners - Kwik Fit, RAC and RSA Motability
- Get advice from The Forum of Mobility Centres and Disabled Motoring UK

Plus, there's:

- A free hot or cold drink for every visitor (food available to purchase).
- Children's entertainment including face painting and balloons.
- A chance to win an iPad mini in our free prize draw

There will be a floor plan print out provided on the day.

Only **assistance dogs** are permitted at the events. Please do not leave dogs in your car while you attend the event.

They have a limited number of scooters and manual wheelchairs available to borrow free of charge, bookable in advance.

You can test drive adapted and non-adapted cars, both as a driver or passenger to see which vehicles best suit your needs. The adapted cars are fitted with a wide range of different adaptations including hand controls, steering wheel balls, electronic brakes and left foot accelerators.

They have professional driving instructors that will accompany you on your test drive to help make you feel as safe as possible. Unfortunately, it is not possible to test drive Wheelchair Accessible Vehicles (WAVs).

For more information, please contact Motability on 0800 953 7000, or visit www.motability.co.uk/thebigevent.

*Information provided by Motability.

PACE Trial latest | MEA to pay for open access to independent reanalysis paper | 12 February 2017

Story by Tony Britton, thanks to The ME Association

The ME Association believe that a recent independent re-analysis of the PACE Trial data is such an important document that we have paid the publisher, Taylor & Francis, to open the full paper for all to read.

At the moment, the full text is hidden behind a paywall and the most that people can read without paying a hefty subscription is a 213-word abstract.

When the unpublished PACE trial data was re-analysed by Wilshire et al (2017), the authors found that – when recovery was defined according to the original trial protocol – recovery rates in the CBT and GET groups were low and not significantly higher than in the control group (4%, 7% and 3% respectively).

The authors concluded: “The claim that patients can recover as a result of CBT and GET is not justified by the data, and is highly misleading to clinicians and patients considering these treatments.”

The paper was published in *Fatigue: Biomedicine, Health & Behavior*, an American publication regarded as the house journal of the International Association of CFS/ME. This organisation holds big biannual conferences in the States.

But, as the publisher only allows free public access to an abstract, the whole paper can only be read for a fee.

MEA medical adviser Dr Charles Shepherd commented: “The MEA believes that this is such an important item of research that we have paid for the whole paper to be made open access.

“This will mean that everyone, health professionals in particular, will now be able to read the very important findings from the re-analysis of the PACE trial recovery data.

“As soon as our contractual arrangement with the publisher is finalised, the full paper will be available to view on the MEA website”.

The MEA has negotiated a reduced fee of US\$2,000 with Taylor & Francis.

THE PUBLIC ACCOUNTS COMMITTEE DECLINE AN IMMEDIATE INVESTIGATION

In a separate development, the influential Public Accounts Committee of the House of Commons have declined to launch an immediate investigation into whether taxpayers got value for money out of the £5m put into the PACE Trial.

The chairman, Meg Hillier MP, has told the Countess of Mar, who called for the inquiry, that she will take no action until after NICE has completed their next review of their guidance on ME/CFS, expected in the summer of next year.

There has been lengthy correspondence between Meg Hillier's office and the Countess, some of which was released at the beginning of February. It shows that Meg Hillier has called in the National Audit Office for advice.

The latest letter from Meg Hillier can be read in full here: www.meassociation.org.uk/wp-content/uploads/public-accounts-committee.pdf

Benefit and Work Guides:

*new guides. Others have been updated. Page numbers indicated in ().

Please don't forget about the Benefit and Work guides that we pay for so that you don't need to pay individual subscription fees to access them. They are invaluable and incredibly helpful and successful for members. This is a valuable resource we have, please utilise it. Available via email (will save us paper & postage), but we also can provide printed copies for only the cost of postage.

To request the guides, please call Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk.

Please do not distribute or pass on to non-members, copy pages or upload to the internet, as this violates our licence agreement with the company.

Claiming Personal Independence Payments (PIP) (70)
Example PIP Diary Extracts for CFS (3), FM (2), arthritis (3), mobility (3), anxiety & depression (2), blank template (2)
*PIP GP Notes for your GP or health professional to fill out
PIP Mandatory Reconsideration and Appeal Submissions (33)
*Sample PIP appeal submissions
Ways to Challenge a PIP Medical Report: (24)
I've Been Awarded PIP, What Else Can I Claim? (12)

DLA claims for adults physical grounds (61) / mental health grounds (53)
DLA adult renewal claims on physical (58) and/or mental health grounds (50)
Changes of circumstances for people claiming DLA (8)

Transferring from Incapacity Benefit to ESA (22)
ESA and Universal Credit claims for mental health difficulties (86)
ESA and UC claims on physical health grounds (84)
ESA and UC mandatory reconsideration and appeals (39)
*Ways to prevent and overturn ESA Sanctions (30)

Caution, may not count as voluntary work (6)
If I do any work can I continue to claim? (4)

Work and benefits for people with long term health conditions (7)
Getting better treatment from the DWP (12)
Getting help with your benefits (12)
Am I covered by the Disability Discrimination Act? (9)
Reasonable adjustments: Employers and Jobseekers (9)
Bedroom Tax Case-Law Round-Up (7)

Bolton and Bury ME/CFS & Fibromyalgia Support Group **AGM Minutes - 17th March 2016**

Present Pamela & Roy Turner, Jeff Glasser, Mandy & Dave Gore, Lynda Marney, A.M Barker, C Higson, Maria Sale, Carole Senior, Helen Green, Louise & Soph Day, Margaret Barlow, Sue Courtney, Maria McCluskey, Mr & Mrs Bevan, Jennifer Coupe.

Apologies

Rosalind Smith, Maxine Fairhurst, Jean Higson, Steve Higson, Claire Hindle, Angela Cassidy, The Frymans, The Gillibrands.

1. Minutes of last AGM held on 19th March 2015- Pam Turner proposed that these be accepted as correct and Jeff Glasser seconded the proposal. Members voted unanimously to accept.
2. Matters Arising. No matters arising.
3. Secretary's Report and Committee Report - Members were able to read copies available at the meeting. Mandy Gore proposed and Maria Sale seconded that the reports be accepted. All present voted in support.
4. Treasurer's Report - Lynda Marney gave a brief outline of her report, copies of which were available at the meeting. Jenny Coupe proposed and Sophie Day seconded that the accounts be accepted as correct. All present voted in favour.
5. Trustees' Report – Michael Barker proposed and Pam Turner seconded that the accounts be accepted as correct. All present voted in favour.
6. Resolution to vote on increasing membership fee to £10 from April 2017. Caroline explained the reasons behind the proposed increase. Sue Courtney proposed it be accepted. Mandy Gore seconded the proposal. All members voted in support.
7. Election of Committee. It was proposed by Louise Day and seconded by Mandy Gore that the five candidates be accepted. The vote was passed unanimously. Elected members of the committee are: Jeff Glasser; Caroline Higson; Lynda Marney; Maria Sale; Carole Senior.
8. Appointment of Honorary Auditor - it was proposed by Maria Sale and seconded by Margaret Barlow that David Whittall should be adopted as auditor for the coming year. This was agreed unanimously.
9. Any Other Business. No other business.
10. Date and time of next AGM - to be held on the 16th March 2017 at 7:30pm.

The AGM closed at 7:55 , followed by a raffle and social evening.

Agenda for A.G.M

Thursday 16th March 2017, 7:30pm

Venue: Friend’s Meeting House, 50 Silverwell street, Bolton, BL1 1PP. We have the use of their own car park, and the NHS car park next door. On street bay parking also available and blue badge holders can also utilise the double yellow lines outside. Disabled toilet facilities available and on the ground floor.

- Apologies
- Minutes of last AGM
- Matters Arising
- The Secretary’s Report
- The Treasurer’s Report
- The Committee Report
- Nominations for the Committee
- Appointment of honorary Auditor for next year
- Any other Business
- Date and Time of next AGM
- Raffle

If you are unable to attend but would still like to cast your vote for the trustees, please tick the names on the list below and return to: Carole Senior, 182 Church Street, Westhoughton, BOLTON, BL5 3SX by the **12th March**. Please can you label the envelope with the words Ballot Paper on the left-hand side of the envelope?

Alternatively you can send an email to **caroles4@virginmedia.com**, stating AGM Ballot in the heading and copying/typing all of the names that you want to vote for. PLEASE STATE YOUR NAME. It is important that you are able to place your vote, as we have to show that are members are getting a say in who represents them each year. Thank You.

Raffle prizes welcome, please bring to the AGM on the night, or you can arrange to drop off at Caroline’s if nearby. Thank you!

✂.....

Please tick next to which trustees you are voting for:

- [] Carole Senior [] Caroline Higson [] Jeff Glasser [] Lynda Marney
 [] Maria Sale

Your name:

Date:

Please return to: AGM Ballot, Carole Senior, 182 Church Street, Westhoughton, BOLTON, BL5 3SX or email to **caroles4@virginmedia.com**, stating AGM Ballot in the heading