



Welcome to the April/May 2017 Newsletter.

Thanks to all who came out to the A.G.M in our new venue last month.

You can park in the venue's small car park, the NHS car park next door (the gate will be open & unlocked), in the on-street parking bays and on the regular yellow lines where blue badge holders are permitted to park.

Monthly focus.

RENEWALS

Membership renewals re now due, thanks to those who have sent them in already. 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.

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

Unfortunately we have had to find a new venue due to The Wildlife Trust having a staff shortage and organisational restructure. Our new main meeting venue is **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. The NHS car park, to the right of the building, will have the gate unlocked and open before the meeting.

Blue badge holders can go on the regular 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.

Thursday 18th May 7:30pm: Hannah Carrington, engagement officer at Bolton CCG, will give a short presentation on Patient Care Records. These are the online records that have been rolled out across the country for the last couple of years. There has been quite a lot of discussion as to the pros and cons, and issues of privacy, and so on.

Thursday 15th June 7:30pm: TBC. Please check the website and Facebook pages for updates, or email/call/text Caroline on 07851 647 550.

Thursday 20th July 7:30pm: Summer Social Bring and Share. We have access to a lovely courtyard now, lets hope for nice weather!

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.

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 now due, with a minimum donation of now **£10 per year please**, 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 (deep breath!) "Bury and Bolton ME/CFS & Fibromyalgia Support 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, but please let us know if you are having problems. 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 in a small way. Please contact Caroline on caroline@mesupportgroup.co.uk or 07851 647 550 for more information. The group will unfortunately 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). We pay a considerable sum to make these available to members, but **we believe they are essential reading!** Please don't forget them when you are applying/renewing. Phone Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk.

Open letter to the editors of Psychological Medicine:

The trustees have decided to add the group to the signatories of an open letter, asking the editors of this journal to retract an uncritical article on the PACE trial, following an exchange of correspondence. The has been signed by dozens of respected doctors and scientists, including: Prof. Jonathan , Ian Gibson PhD (former MP and author of the Gibson report). Prof. Malcolm Hooper, . Lenny Jason, Prof. Jose Montoya, and Dr Myhill.

Many ME charities and support groups have also signed. Removing these articles is important, because future researchers doing an initial search of the literature will cite these wholly misleading articles and perpetuate the myth that GET and CBT lead to recovery.

<http://www.virology.ws/2017/03/23/an-open-letter-to-psychological-medicine-again/>

PIP Assessments

As we will all eventually have to change over from DLA to PIP, I bought 2 tape recorders for my own f2f (face to face). I am willing to lend them to any member. You would have to buy two normal sized cassettes: one for yourself and one to give to the assessor. The online help groups recommend recording your assessments, to avoid the worst of the untruths, and for PIP you have to provide the equipment yourself.

Inform them you will be recording (preferably on the form), tell them again when you receive an appointment (and email if possible to PIP-customerservice@atos.net) and again when you arrive for your appointment.

You may still find the assessor refuses (their right) or hasn't been informed. At that point you may decide to go ahead, or cancel the appointment and wait for another. Remember, this is for PIP only.

You may record ESA assessments, but they provide the equipment. I know, confusing. Please note: these recorders are my property, NOT the group's. I would prefer contact by email at maria113@talktalk.net to save my energy, but if that's not possible, then phone contact at 01204 575613: not before 10am, please! Please leave a message. Good luck, everyone.

Thank you Marie for your kind offer. Maxine

Sponsored Walk

As part of ME Awareness Week, Salford and Trafford ME Group is organising a sponsored “walk” in aid of Invest in ME (a very good research charity) . It will take place on 13th May at 11am at Chorlton Water Park, Maitland Avenue, Manchester, M21 7WH. This is off Barlow Moor Road, opposite Southern Cemetery.

The course is 1 mile and suitable for motor scooters. Of course, you might persuade family and friends to complete the walk. If the weather is favourable there will be an opportunity to socialise, too. Other ME and fibro groups have also been invited. There is a possibility of running the event in future years nearer to us.

Medical Abuse In ME Sufferers (MAIMES)

Dr Myhill has formed the MAIMES campaign - Medical Abuse in ME Sufferers - and the preliminary but very important stage in this campaign is detailed below. Please only offer your help if you can complete it. No one should become more ill from it. Maybe ask if friends and family could act on your behalf.

Campaign MAIMES is a drive for a Government Public Inquiry aimed at:

- Achieving proper recognition that this is a physical illness so that patients can properly access benefits and appropriate treatments. The abuses of PWME must be reversed.
- Rewriting NICE Guidelines using evidence based medicine that is logical, biologically plausible and with a proper scientific evidence base.
- Establishing that PWME should be treated by practitioners with specialised training in the physical causes of ME. These practitioners should include doctors, nutritional therapists and experienced patients.

Please note that once an MP has been adopted then no one else can adopt that same MP.

Campaign OVERVIEW

- This is a campaign to get MPs to sign slips that will be used to demand a Public Inquiry into the abuse of ME sufferers over the last few decades. This campaign is called MAIMES. [the slip calls for a Public Inquiry]
- The first goal is to sign up as many MPs as possible to the aims of MAIMES. Once we have sufficient MPs on side we will approach the Secretary of Health to demand a Public Inquiry
- We need “adopters” who are physically able to attend their MPs’ surgery and also who feel that they can explain the issues as detailed below in as convincing a manner as possible!
- If you can be such an “adopter” please email your details and the MP’s name and constituency details to Gail (gail@doctormyhill.co.uk) .
- Gail will then send the adopter (you) a free copy of Dr Myhill’s new book second edition: “CFS/ME – it’s mitochondria not hypochondria”
- Attend your local MPs surgery, give him/her the copy of the book, show them Chapter 1 and try convince them to sign the slip! If you are successful, please scan the slip and return it to Gail (gail@doctormyhill.co.uk)

- If you cannot convince your MP to sign the slip, please leave them with the more detailed 'MAIMES letter' - see below for link to detailed MAIMES letter
- Further on in the campaign will be an opportunity for EVERYONE to help .
- For more information visit <http://www.drmyhill.co.uk>

W.H.O Classification of M.E & CFS

The World Health Organisation (WHO) is reviewing its International Classification of Disease (ICD) for its upcoming 11th edition (ICD-11). There has been lots of discussion about what was going to happen to how ME & CFS are classified.

Campaigners recommend that the disease be listed as Myalgic Encephalomyelitis and Chronic Fatigue Syndrome for the "concept titles" for the disease. (previously indexed as "Benign Myalgic Encephalomyelitis" and "Postviral Fatigue Syndrome." They wish to change those titles since the disease is not benign, and not all cases are postviral. Postviral Fatigue Syndrome will be listed as a synonym of the disease.)

It's also being recommended that ME and CFS be retained under Chapter 08: "Diseases of the nervous system" and "Other disorders of the nervous system.". These definitions will last for a long time, so need to be accurate. We are still using the definitions from ICD-10 in 1994. They urgently need comments on the ICD site to support their proposed classification.

For more information and how to comment on the document, go to ww.meaction.net/2017/04/04/global-call-to-action-help-secure-the-world-health-organisations-classification-of-me-cfs/

Annual General Meeting 2017

After a couple of months break due to a change of venue being required, our meetings resumed with March's Annual General Meeting, our first opportunity to try out our new home of The Friends' Meeting House, Bolton. There were many donations for the raffle, so thank you for your support. We also welcomed some new members. We try to get business finished as soon as possible, as it's not that interesting, we admit. Sadly, we didn't match the 11 minutes we achieved last year, but 25 minutes is still reasonably quick and painless. Many thanks for all who attended and sent in votes.

The group would like to give a huge thank you to Neil Turner and Dunscur Golf Club for a very generous £500 donation from their fundraising activities this year. Neil (former group leader Pam's son), was elected as Captain of Dunscur Golf Club last year, and we were honoured to be chosen as a charity to benefit from their fundraising. Neil attended our AGM to present the cheque. We are very grateful to be chosen, as it is a very energy heavy process to apply for all the grants we need, and we cannot do many forms of fundraising due to volunteers having the conditions themselves. Thank you Neil, and well done on your term as Captain!

AGM Minutes - 16th March 2017

Present: Pam Turner, Maria Sale, Michael Barker, A & N Glendinning, J Foy, Caroline Higson, Jeff Glasser, M & D Gore, K & L Marney, Margaret Barlow, Sara Drage, Carole Senior, S Singh, R Jones, Diane Knowles, E & J Chatwood, Sue Birkenshaw

Apologies: Carol Hobson, Claire Bond, A Cassidy, Y Leech, A Wooton Maria McCluskey, S & J Higson, L& S Day

Minutes of last AGM held on 17th March 2016:- Maria Sale proposed that these be accepted as correct and Pam Turner seconded the proposal. Members voted unanimously to accept.

Matters Arising. No matters arising.

Secretary's Report and Committee Report - Members were able to read copies available at the meeting. Jeff Glasser proposed and A. Gore seconded that the reports be accepted. All present voted in support.

Treasurer's Report - Lynda Marney gave a brief outline of her report, copies of which were available at the meeting. 60% of donations/memberships are now done direct to our bank account, which helps Lynda a great deal and reduces trips to the bank and paperwork involved. Membership fees have now gone up from £8 to £10 this year, as agreed and voted for by members at last year's AGM. Some Standing Orders that people currently have will therefore need to be increased.

Lynda asked that we could agree on an amount to gift our honorary auditor in exchange for their time. The amount of £25 was agreed on. Maria attends many meetings on our behalf, Lynda asked if we could agree on a set amount to cover her petrol, wear and tear, etc as she does not currently claim this back. The amount of £50 was agreed on. D. Gore proposed and Carole Senior seconded that the accounts be accepted as correct. All present voted in favour.

Trustees' Report – M. Gore proposed and Maria Sale seconded that the report be accepted as correct. All present voted in favour.

Election of Trustees. It was proposed by Joyce Foy and seconded by D. Gore that the five existing candidates be accepted. There were no new nominations. The vote was passed unanimously. Elected trustees are: Jeff Glasser (advisor); Caroline Higson (chair); Lynda Marney (treasurer); Maria Sale (meetings secretary); Carole Senior (librarian).

Appointment of Honorary Auditor – It was proposed by Maria Sale and seconded by Jeff Glasser that David Whittall should be adopted again as auditor for the coming year. This was agreed unanimously.

Any Other Business. A member explained that since the newsletter had been decreased to bi-monthly, and that Caroline no longer had a land-line number, only a mobile, they did not feel as supported by the group.

Caroline explained that due to switching providers, to keep a landline would be prohibitively expensive for her and the group could not be asked to pay when there was an alternative. Caroline is happy to call anyone back on her mobile so they don't incur a charge, as she has always done for those calling from mobiles themselves. You could also leave a voicemail, text her or email her to ask her to call you. She does attempt to call missed calls back, so you can let it ring a couple of times then hang up so your number will appear to her. She does not claim the costs of calls from the group.

Due to a shortage of volunteers, and very ill existing ones, we had to take the decision to cut the newsletter to bi-monthly, as the three of us involved in it were very poorly and the frequency wasn't sustainable. New members may not be aware, but several years ago, our newsletters were quarterly and there was no Facebook or Yahoo group to keep in contact or remind members of meetings. We ask regularly for any volunteers, jobs that can

be done, that they can be shared, etc. We have said that if no one comes forward, we would have to cut services, and unfortunately reducing the newsletter was a result of that, as we could not continue making ourselves more unwell.

For those not on Facebook/online, a member suggested bringing back the scheme we operated years ago whereby members who wished to talk to others via phone/email/letter, could supply their details and interests, and a list of participating names would be circulated quarterly with the newsletter. This gradually subsided once Facebook gained popularity, and it also relied on a volunteer to update and maintain the list. Emma has kindly volunteered to oversee the new list.

Caroline explained, as we have previously, we are run solely by a small number of people with the conditions. The five trustees are all ill, and four of the five have no partner/carer to help them. The other has a husband who suffers from M.E as well. There are a handful of other volunteers who mainly help from home, who are also ill. Many of us are on the moderate to severe end of the scale and have additional medical conditions. Please bear with us if we take a while to get back to you, or forget something, and be aware that our energy is a finite resource like yours.

Following the AGM, a few members came forward to ask about volunteering.

Date and time of next AGM - to be held on the 15th March 2018 at 7:30pm.

The AGM closed at 8:00pm, followed social evening and a raffle, which raised £24.

Secretary's Report: A.G.M. March 2017

So, just when we thought we were settled in a comfortable venue, we've been on the move again! Sadly, due to their restructuring and staffing problems, the Wildlife Trust's building is no longer available for evening meetings and we were given notice, though Sandra, the manager who has been a real ally to us, was as sorry to see us go as we were to move.

After lots of discussion, suggestions and checking out potential new venues, it was agreed that the most suitable would be the Friends' Meeting House on Silverwell Street in Bolton which met our needs in several ways:

- it's reasonably central, neither too far towards Bury or too far west of Bolton
- there is parking available - a small car park at the venue, further spaces at an NHS facility nearby and on-street.
- we can have the room for our established day and time
- the room is a good size with easy access (the whole building is on one level with no steps)
- tables and chairs will be set out for us in a format of our choosing
- the kitchen is in the adjoining room with storage for our tea, coffee etc as well as the use of crockery and a dishwasher - so no-one gets left with the washing up!
- AV equipment, including projector and screen, plus flip charts and stands will be available should any of our guest speakers need them

Fingers crossed that everyone finds it comfortable and we are able to stay for a long time.

We began the year since the last AGM with our usual mix of speakers and socials at our monthly meetings:

- May saw us holding a craft evening, where members brought samples of their work and kit both to show and sell. There were a variety of activities and some very impres-

sive skills on display, including jewellery, knitting, dressmaking and paper craft. It was definitely something we would happily repeat.

- In June, Dr Gaber spoke to us about his recently published paper on the overlap of symptoms in ME and MS. The meeting was very well attended and the subject matter interesting.
- We had our usual summer social in July, when we had the opportunity to share food, chat and catch up on news.
- In September Gail Sumner was to have been our speaker but was unable to attend so we used the evening as an extra social.
- Gail joined us in October to tell us about the recent trial into the efficacy of Perrin Technique as a diagnostic tool for ME. As ever, Gail had lots of information for us and stayed on to discuss various matters with members.
- November's meeting was our traditional bring-and-share supper - lots of food, lots of chat.

At this point we were faced with moving from the Wildlife Trust and finding a new home (again!) and, given the time of year and the limited time available, a temporary venue wasn't really a practical proposition. We decided to cancel the January and February meetings - which are often poorly attended due to adverse weather and winter generally - and restart with the AGM in March.

We still hope to have staff from the Fibromyalgia Clinic speak to us and we would like to have Dr Perrin visit us again; Maria is negotiating on our behalf.

Yoga sessions, which are still free to members, continue to be well attended and some members are also involved in hydrotherapy sessions. However the Prestwich socials have been discontinued as they were being attended only by the volunteer greeters, who were travelling considerable distances to be there. Despite the situation being flagged up in newsletters, there was no increased interest.

We now have a new wheelchair, available for loan, which was bought with the residue of the donation received from the family of the late Christopher Hampson.

Our association with the ME/CFS Clinic in Brightmet continues, while discussions go on across Greater Manchester to establish future provision. Maria in particular has been attending meetings and working hard to maintain our profile and address our interests.
Carole

Trustees Report A.G.M 2017

This year has been a relatively stable year for the group, apart from the panic and work involved in finding a new meeting venue at the end of the year.

Our numbers of members remains fairly consistent, but we don't seem to have as many new members joining as last year, which is somewhat of a blessing as there's a lot of admin, time and resources needed to make up the membership packs that people receive upon joining. Whether we have 50 or 150 members, the workload is more or less the same for most tasks.

As always, huge thanks to all our volunteers and supporters who keep the group going. Together we are more able to help each other, and break the isolation these conditions bring. If a few of us can share a task together, that saves one person relapsing from one huge workload.

All the people who help run the group have ME/CFS and/or FM, along with other conditions, so it's really hard to achieve many of our goals, as we simply don't have the

people-power. We often have the money to achieve something, just not the volunteer to do it. So we focus on the main "essentials" (meetings, newsletter, yoga, grants for these), and other things have to wait for now (like carer meals out or leaflet drops to all libraries), re-writing some group materials, etc. The newsletter was cut from monthly to bi-monthly, as the three of us involved were just exhausted from writing, editing and preparing it each month. From what I gather, quite a few don't seem to read it, which is a shame, as there is such useful information in them and we work so hard on it.

Our yoga is still continuing (perhaps in the 10th year now?). Lisa is our yoga tutor and popular with members. Our yoga group remains well-attended with a core group of regulars. This remains free until August 2017 due to funding from The BIG Bolton Fund, administered by Bolton CVS, obtained by Caroline. Further funding applications will be made before then so the sessions can continue. However, it is getting harder to obtain grants as the number of providers are getting smaller, and they are limiting the amounts they donate and number of times you can apply.

We couldn't run this group without our small but faithful army of volunteers.

Ruth distributes the Benefit and Work Guides, by email and post. These are essential reading for anyone applying for benefits like PIP or ESA. Thank you Ruth, we know these are very popular and valued by members.

Angela is our admin star, and with the help of her family, assembles and sends out paper copies of the monthly newsletter, makes up the welcome packs to new members and more. She's had a stressful year with a house move, but we are hugely grateful for all their contributions and dedications.

Angela's mum Sue, manager of the One-Stop store in Farnworth is also a kind supporter of the group. She has done a bake-sales and donated items in the past and we also benefit from the 5p bag charge and a change tin at the store. This is a great easy way boost to our funds and we really appreciate it, thank you Sue!

Carole is our librarian, a service much valued to members to help them learn more, explore and self-manage their condition. Her house is over-flowing with books. If you have any requests, please pass them on to Carole. She also writes the minutes at our trustee meetings and the secretary report for the AGM.

Maxine is our newsletter editor and distributes it bi-monthly by email. She has not been in the best of health this year, so we really appreciate her valued contribution to the group.

Louise and her daughter Sophie continue to manage our stall at the meetings, selling ME and FM merchandise and positive disability items. Many thanks.

Lynda, our Treasurer, still keeps a good eye on our pennies, and is meticulous in her record keeping. This is probably the most important job in the group, and is very busy this time of year with renewals due. She makes the loveliest pie charts too. We are very grateful for all you do Lynda.

Our Meetings Secretary, Maria, is responsible for finding and booking the speakers for our monthly meetings and has also typed up reports for the newsletter. She is also a valued contributor our Facebook group. She attends a lot of meetings on our behalf, like ETAG with the local CCG, the ME/CFS Clinic Steering Group and multiple DevoManc meetings, to make sure that our group and conditions are represented, and our views and needs are considered before change is implemented. Thank you for all you do Maria.

Jeff continues to offer support and advice to fellow trustees and members, drawing on his many years of knowledge and experience. Thank you Jeff.

Caroline has a few duties as chair of the group, but most of it is behind the scenes. She maintains the membership database, manages our website and facebook group, applies for the grants that keep us functioning, writes newsletter articles, attends some meetings, takes enquiries etc. You can't see what I'm doing, but I'm patting myself on the back.

Thanks to all those who donated raffle prizes for our AGM, and those who bought raffle tickets.

Thank you to Sandra and colleagues, at the Lancashire Wildlife Trust, our hosts for our main meetings until last December when they had staffing problems and restructured. We will miss the nice, peaceful venue and helpful staff, but we look forward to working with our new hosts at The Friends' Meeting House, Bolton, who seem very accommodating in a venue that ticks almost all of our numerous boxes!

We are extremely thankful to all our donators, without which, we could not exist: The Big Lottery Fund, Bolton Council, The Big Bolton Fund, (administered by Bolton CVS). Thank you to all those who help at meetings, by helping set up, tidy away, carry my bags to my car and so forth. It really does help on a night we have a million things to remember, bring with us, do, pass on to someone, etc.

I apologise if I've perhaps not got back to you quickly, or forgot something I was going to do, but most of the volunteers including myself are severely affected and we are running on fumes, with other conditions, and most things result in relapses. We force ourselves to attend meetings or do tasks even when we shouldn't, because we want to help people.

Last but not least, to all our members, apologies if your help hasn't been acknowledged individually.

Please remember to send us feedback on anything we do, like yoga or the newsletter. Feedback/testimonials are always needed to show grant providers that our services are needed, and helps us improve.

After having read the new CDC's CFS toolkit she developed a new kind of fundamental resistance against analytic psychotherapy. Any idea, Dr. Simon?

