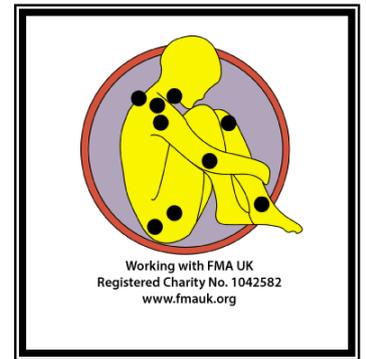




Welcome to Our June 2016 Newsletter.

Note from the Editor Maxine, thank you all who turned up for the AGM. Subscriptions are over due. If you have paid thank you and you will continue to receive the newsletters.



Monthly focus.

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? Are you a cheque sender? The group would prefer the first two as it saves the group energy and time having to go to the bank to cash the cheques. The Standing Order form can be obtained on our website.

Update: We can now accept Paypal payments. Please send to paypal@mesupportgroup.co.uk with your details in the payment. They send a receipt.

Volunteers: We are looking for volunteers who can help with all activities of running the group, if you think you can contribute, or are up for a certain task, please contact Caroline. **We are really struggling to keep the group going;** 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 01204 525 955 for more information.

Dates For Your Diary:

Bolton Main Meetings at Wildlife Trust Centre, Bury Rd:

Our main meetings, often with guest speakers, are now held at The Wildlife Trust Centre, 499-511 Bury Rd, Bolton, BL2 6DH.

They occur on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). The building is past Morrisons/Home Bargains/Brightmet Health Centre on the right hand side as you go into town, very near the junction before you turn onto Crompton Way from Bury Rd.

Entrance is £1, carers are free. Tea, decaf coffee, water, biscuits, orange squash, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email caroline@mesupportgroup.co.uk.

Parking: If you come to our Bolton main meets at the wildlife centre, you might have had to double park when the small car park is full.

We mentioned that blue badge holders can park on the main road at that time when displaying their badge correctly.

Issue: 118 Registered Charity number 1161356

June 2016

Looking at it again, we see that people without a badge would also be able to park on the main road at that time, as the restrictions end at 6:30pm, and our meeting is 7:30pm with people arriving from 7pm. **Bolton Council parking services have verified this is correct.**

Obviously, this is a main road, so do be careful if you choose to park here, badge or no. This option may not obviously be suitable for some, but an option if places are full and you can't walk from the other side street parking available elsewhere.

If you happen to be parked behind someone who is blocking you in due to lack of spaces, please ring the door buzzer for reception and ask the staff member on duty upstairs to pass on the message (with car details) to us, and the car owner can come down. This means you don't have to trek up and down twice.

Thanks, hope you can join us.

16th June: Dr Tarek Gaber, the consultant of the Bury and Bolton ME/CFS clinic, will be talking about a research paper he contributed to, about the overlap in symptoms between MS and ME/CFS.

21st July: our Summer Bring and Share Supper. Sara plans to bring her lovely home made jewellery.

No Meeting in August

Yoga Classes: Are 3:15pm-4:15pm on Tuesdays at the Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX. Designed to cater for the average ME& FM sufferer, classes are free and yoga mats are provided. **Carers/friends etc welcome**, also free of charge. Please wear loose, comfortable clothing. Please contact our instructor Lisa. Mobile: 0770 803 66 36 Email: lisayogatori1@gmail.com. **Our yoga classes are currently being funded by The BIG Bolton Fund, administered by Bolton CVS.**

Prestwich Socials: The Woodthorpe, Bury Old Road, Prestwich, M25 0EG. This is a very roomy pub, with ramp access, a disabled toilet, a variety of comfortable seating and free parking outside. It also serves a range of full meals and snacks if anyone is hungry. We meet on the **second Wednesday** of the month at 2pm, so the next meeting is **Wednesday 8th June and Wednesday 13th July 2016**. Numbers have been low lately, so we may have to rethink or cancel this social.

Please try not to turn up too late, because if numbers are low and those attending are not feeling very well on the day, it would be a shame if you missed us.

If you are thinking of attending any of our socials, whether you are a new member or a member who hasn't been able to attend for a while, please remember that you can bring along your carer or a friend. We don't bite, but we understand that meeting new people or if you have been house bound for a while, it can be quite daunting going out by yourself and we look forward to seeing you.

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.

Annual Subs Due Please

The yearly subscriptions are now due, the renewal letters were sent out last month. Thanks to those who have already renewed. Membership is £8, and you get the monthly newsletter, access to our comprehensive library, benefits and work guides, weekly yoga class and more.

To pay via Online Banking:

Please send a payment to the following account details:

Sort Code: 20-10-71

Account No: 00902179

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

Then email lynda@mesupportgroup.co.uk with your payee reference, so we know who it's from.

NEW To pay via Paypal: Please sent payment to paypal@mesupportgroup.co.uk with your details in the notes section of the payment screen. Paypal automatically send a receipt. Paypal do charge us a small fee, but this has been requested for a while.

To pay by cheque, please make it payable to:

Bury & Bolton ME/CFS and Fibromyalgia Support Group and post to: Lynda Marney, BBME Group, 10 Osmund Ave, Bolton, BL2 6DR.

Please note: Lynda is having to step away from the group for a while, so it may take a while to pay in cheques or get back to your emails. Please be patient.

May 2016 BBME & FM Meeting

We had a very well-attended meeting, where people brought along finished craft projects, work in progress, or ideas for pastimes. We saw a wide range of ideas, including origami, watercolour painting, knitting, cross-stitch, card-making, jewellery-making, Chinese brush painting, drawing, sewing, paper cut-out thingies (the technical term!), etc.

As so many of us spend a lot of time at home, it's good to get ideas. Thanks to everyone who brought something along, donated to the group, and to those who. Simply came along to chat. We raised £34 towards group funds.

TRUSTEES REPORT AGM - MARCH 2016

This year has thankfully been quieter than last year, which had a lot of upheaval and extra work for us. As always, huge thanks to all our volunteers and supporters who keep the group going.

We must emphasise that all of the people who help run the group have ME/CFS and/or FM, along with other conditions which makes it extremely difficult to get things done. We try our best. We continue to help, despite our health as we do not want to see 175+ members (plus unspecified numbers of non members who also benefit from our work), to go without. We would welcome any help.

Maxine continues to edit and sent our monthly newsletter by email. She has great ideas and is a valued helper. Thanks Maxine.

Ruth is still co-ordinating distribution of the Benefit and Work Guides, by email and post. These are essential reading for anyone with a benefits claim and are invaluable resources. Thank you Ruth.

Sara, our admin of all things stepped down last year after taking care of printing and sending the newsletter, welcome packs and leaflets for over a year. We are grateful for her stepping in to fill the role.

Angela has very kindly taken over the admin responsibility from Sara. The Super Member prints, assembles and sends out paper copies of the monthly newsletter, makes up the welcome packs to new members and more. She has got it down to a fine art, getting the famiy to form a production line. We are really grateful for all your hard work, Angela and family.

Angela's mum Sue, manager of the One-Stop store in Farnworth is also a great supporter of the group. She has done a bake-sale for us at the shop and they kindly nominated us as the charity beneficiary of the 5p bag charge at the shop. They also have a "keep the change" tin, which is donated to us. This is a great boost to our funds, thank you Sue!

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

After our door-person Susan stepped down last year, thanks to all who fill the role. Sorry we never have enough pens to sign in, it the brain fog. Louise and her daughter Sophie continue to expertly manage our stall at the main meetings, selling ME and FM merchandise and positive disability items. They recently held a book stall and donated the proceeds to us which was very kind. Big thanks to both of you.

Lisa is now our yoga tutor and popular with members. Many thanks to the two donators who enabled us to buy small yoga balls for the sessions. Our yoga group remains well-attended with a core group of regulars. This remains free due to funding from the Big Lottery Fund, obtained by Caroline. From May, the funding will be provided by BIG Bolton Fund, administered by Bolton CVS. Lynda, our Treasurer, still keeps very good care of our finances. This is an important job, and very hectic around this time when renewals are due. Thanks to Lynda for all her much appreciated work.

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 when supporting members on our facebook page. This year she has attended a lot of meetings on our behalf, like ETAG, the ME/CFS Clinic Steering Group and multiple DevoManc meetings. 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. He is a regular attendee of the Bolton and Prestwich socials and a valuable contributor to our Facebook group. Thank you Jeff.

Caroline fills many roles as group leader. She maintains the membership database, manages our website, applies for the grants that keep us functioning, writes newsletter articles, attends meetings, is group contact for enquiries and does various bits and bobs behind the scenes. Thanks Caroline.

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 friendly hosts for our main monthly meetings. They set up the room for us, clear away afterwards, and have organised cupboard space.

Caroline wishes to thank all those involved in her 30th birthday celebrations at the January meeting, and those who sent their best wishes. It was a lovely evening and she was very touched by the effort and thought put into it. Grateful thanks to all our sponsors, whose grants allow our group to function: Festival Medical Services, The Big Lottery Fund, Bolton Council/The Big Bolton Fund, administered by Bolton CVS.

Last but not least, to all our members, apologies if your help has not been acknowledged individually. Together we are more able to help each other, and break the isolation these conditions bring. Thank you all. 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.

SECRETARY'S REPORT – AGM 2016

Finally, after a prolonged period of change for the group, the past year has been much more settled.

We are now happily established at the Lancashire Wildlife Trust, where Sandra and her colleagues have been welcoming and supportive and we have the bonus of beautiful views from the windows in spring and summer months.

We have also been granted charitable status which, while involving a great deal of paperwork during the application (mostly handled by Caroline, for which we thank her), has made very little change to the ongoing running of the group. Accounts will need to be submitted annually but, since Lynda already does this very efficiently for the AGM and we are audited, it is business as usual.

Your committee remains at 5 members - officially Trustees now - so the help and support of volunteers is essential. The group would not function without them and we all owe them our thanks.

The last year has seen our usual 9 meetings - this time they were all at the same venue! - with a mix of guest speakers and socials.

In May, Jennifer Gilmour stepped in at short notice. Jennifer oversees a variety of craft and activity groups in Brightmet, which she told us about and showed examples, before setting us some drawing exercises. Some of us found these quite challenging! but it was enjoyed by all.

At our June meeting, James Hall of the Wildlife Trust spoke to us about their work followed by a short walk outside for those who were able. It was fascinating to see the diversity of life to be found in this small area and to hear the plans of the Trust.

July saw our usual summer social, with the customary spread of delicious food.

Marie Oxtoby of Bolton Neurovoices spoke to us in September, with an update on the hydrotherapy sessions which some members have found both enjoyable and beneficial.

Our speaker in October was to have been the Engagement Officer for Bolton CCG. However she cancelled at very short notice - and has yet to respond to requests for an alternative date - so members present took the opportunity to share experiences and swap advice.

We held our traditional bring-and-share supper in November; as ever there was a generous and delicious array of food to enjoy and chat over.

January brought Caroline's 30th birthday, which was celebrated at a social

Late edition - May 2016

Here's a brief roundup of some of the recent articles covering CFS/ME and Fibromyalgia during May.

A recent study in Australia aimed to describe a wide variety of characteristics of Australian CFS/ME patients. The study will help their authorities to identify potential risk factors and predictors associated with CFS/ME, and will help their decisions about health care provision, diagnosis and management.

Briefly the study revealed: The average age of all 535 patients was 46.4 years, and 79% were female, Caucasian, and highly educated. 15% reported chronic fatigue but did not meet criteria for CFS/ME and 23% were considered non-cases due to exclusionary conditions. For those with CFS/ME, the most common events before the illness were cold/flu, gastrointestinal illness and periods of undue stress.

Of the 60 symptoms surveyed, fatigue, cognitive, short-term memory symptoms, headaches, muscle and joint pain, unrefreshed sleep, sensory disturbances, muscle weakness, and intolerance to extremes of temperature were the most commonly occurring symptoms (reported by more than two-thirds of patients). – [Epidemiological characteristics of chronic fatigue syndrome/myalgic encephalomyelitis in Australian patients](#) – ProHealth – May 27

The Millions Missing campaign happened on May 25th. In London a “sea” of empty shoes were placed outside the Dept of Health in Whitehall. The tagline, and the empty footwear, illustrates the millions of people who are missing from their careers, schools, social lives and families across the globe due to the debilitating effects disease. Ollie Cornes, who was unable to attend the event due to his condition, but sent a pair of shoes, said: “We're just patients fed up waiting for research funding to get anywhere close to reflecting the levels of disability caused.” The campaign also went global through social media and other events in Norway, Canada and Australia.

In the US, CFS/ME patients, care givers and advocates protested at the U.S. Dept. of Health and Human Services headquarters, as well as their regional offices. They demanded the US government make a serious commitment to urgently address the disease, including increased funding of \$250m per year for research and promoting appropriate clinical care for CFS/ME patients. – #MillionsMissing: Sea of empty shoes left outside Department of Health in global ME protest – Market Wired – May 25

Having endured more than 20 operations for breast cancer and gynaecological issues, Tisha Bratt was ready to put her health problems behind her. However, the high-flying financial director wasn't expecting a severe bout of CFS/ME which, at its worst, would render her unable to do basic sums or even write her own name. It also left her bed bound for months at a time and still be affecting her 22 years later, aged 60. In the article, Trisha explains her journey with good and bad GPs, a caring husband, giving up work at 42 and the constant loneliness. Despite all this though, she maintains a positive outlook and tries to manage her condition the best she can. Trish says, “If I were a pessimist, it would be hell, but I am always optimistic. Lots of conversations start with me saying ‘when I'm well...’.” – High-flying director Tisha Bratt tells of 'exhausting' struggle with chronic fatigue syndrome – The Daily Echo – May 31

A teaching assistant struck down by a debilitating illness with no known cure is set to finish a year-long challenge. CFS/ME sufferer Alison Woodland made a pledge to walk 250,000 steps in 12 months, one for every person in the UK with the condition. Ms Woodland, 27, from Worthing, was diagnosed in 2009, 11 months after falling ill with a flu-like virus. So far she has raised £550 for the ME Association. – ME sufferer coming to the end of her step-by-step charity challenge – The Argus – May 31

This story features 2 men, both who contracted CFS/ME and both who were eventually seen by Lancashire Care Foundation Trust's CFS/ME service. They benefitted from the treatments and therapies and also made significant improvements to their lifestyles. Irene Lewis, specialist occupational therapist for the CFS/ME Service at the trust, says, “...people with the condition are diagnosed rather late. However, there is a lot that can be done to help people manage the condition and the CFS/ME specialist service is at hand to empower people with the condition to live as normal lives as possible.” For more information, contact the CFS/ME team on: 01772 777022 or visit: www.lancashirecare.nhs.uk/CFS-ME. – 'My illness felt like someone was beating me with a baseball bat...' – Lancashire Evening Post – May 19

This will be the last Late Edition, as the contributor is unable to continue in the role. Many thanks to them for the time and effort into the monthly contributions which I'm sure you find you useful.

If you would like to continue this on, or contribute to the newsletter in other ways, please contact Maxine or Caroline.