



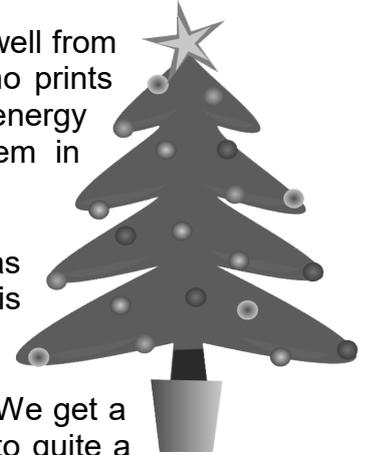
www.mesupportgroup.co.uk

Registered Charity No. 1161356

November 2017 Newsletter

We hope our members are doing as well as can be expected with the shorter days and colder weather, a lot of us struggle at this time of year.

Our usual editor Maxine is healing well from her knee replacement. Angela, who prints and mails the newsletter is low on energy since a virus, so please keep them in your thoughts.



We can't believe it's nearly Christmas time already! It's hard to cope with the noise, lights and crowds this time of year, but we hope you manage to pace and enjoy the festivities. If you shop through Amazon.co.uk, please follow the Amazon picture links on our website and continue to order that way. We get a small commission on the purchase for referring you, which adds up to quite a substantial amount over the year, to help fund the group with minimal effort.

Meeting Dates:

Please be aware that our main meetings in Bolton are now going to be on the **FOURTH** Thursday of the month (except April, August and December), a week later than previously. Same time and place still— The Friend's Meeting House, Silverwell Street, Bolton, BL1 1PP. This will mean a bigger, nearer room, it's quieter and there'll be more car parking spaces available.

Entry is £1, free for carers and under 16's. Refreshments provided. We are in the nearest room and there are disabled toilet facilities opposite. There is a small car park for the building, some on street parking bays and an NHS car park next door to the right of the building that we are permitted to use (the gate will be opened for us).

Thursday Nov 23rd 7:30pm Pre-Xmas Bring and Share Buffet Social.

Please bring food to share and enjoy a social evening with others. There's always plenty for those with dietary requirements.

Thursday December – no meeting.

Thursday January 25th 7:30pm Ann Innes, who visited us in July to talk about benefits, will talk to us in her capacity as a nutritionist and naturopath. She has had M.E herself and works on addressing health issues through food choices, supplementation, natural detoxification techniques and energetics.

Thursday February 22nd 7:30pm Gail Sumner will be talking to us about the NHS study she recently participated in with Dr Perrin, looking at using markers to accurately diagnose patients, and updating us on her clinic work.



Free weekly yoga sessions:

Enjoy nourishing yoga postures, breathing practices & deep relaxation to energise the body, release tension, and calm the mind. Sessions are gentle for people with ME and Fibromyalgia. Mats and equipment provided. You are welcome to bring a carer who can also participate. These classes are FREE for members, thanks to funding from The BIG Bolton Fund, administered by Bolton CVS.

NOTE: There will be no yoga on December 26th.

Every Tuesday, **4:15pm-5:15pm**, Jubilee Centre, Tennyson St, Halliwell, BL1 3DX. Please contact Lisa our yoga tutor with any questions.

Mobile: 07708 036636 or email: lisayogatori1@gmail.com.

New Contact Numbers:

A new landline contact for the group is Maria (meetings secretary) on 01204 575 613. Please leave a message if there's no answer, and she will get back to you. You can also email Maria113@talktalk.net. We welcome any speaker suggestions.

Caroline (chair) can be reached on 07837 077 491 (new number) or caroline@mesupportgroup.co.uk.

Carole (librarian) can be reached on 01942810320 or caroles4@virginmedia.com

Lynda (treasurer) can be reached at: Lynda@mesupportgroup.co.uk

Amazon: The group gets 5% commission when you shop at www.amazon.co.uk, but only if you follow the link from our own website www.mesupportgroup.co.uk.

Think of us when Christmas shopping please! We raise a significant amount each year which helps us run the group.

Mercure Bolton Health Club Discount: The Bolton Mercure branch has a long-standing arrangement with our group and kindly offers our members use of the swimming pool and sauna for only £3.50 per visit, and accompanying carers will pay the same (no charge if they don't use the facilities). The usual price is £8. Just say that you are a member of our group! The best times to use the club are before 4pm weekdays, Saturdays 1-5pm, and all day Sunday (but is busier if it is raining).

Their address is: Mercure Bolton Georgian House Hotel, Manchester Road, Blackrod, BL6 5RU. Tel: 0844 8159029. **If you would like help in approaching your local club for a possible discount for our group, please get in touch!**

Equipment to Borrow: We have a wheelchair and two electric mobility scooters (small enough to fit in car boot for days out or holidays). If you wish to borrow any of these, please phone Pam on 01204 793 846. We also have SmartCrutches to borrow (ergonomic elbow crutches), please contact Caroline for those.

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. Helping write for the newsletter, talking to new members at meetings, applying for funding or fundraising, typing up articles, etc. Please contact Caroline on caroline@mesupportgroup.co.uk or 07837 077 491 for more information. **Several other local groups in Lancashire have had to close over the last couple of years, due to lack of volunteers. Please do not let this happen to us.**

Welfare Rights with Ann Innes:

Since Ann visited us in July to explain applying for PIP and ESA, several members have used her and found her thorough and a great help at filling in the dreaded forms. Our September newsletter had details of her talk in.

If you would like to contact Ann for an appointment or to enquire about her charges, please call her on 07748 473263 or email her at wrafme@gmail.com. She also is a nutritionist and will talk to us in January about that part of her work.

Remember, for benefit form applications/appeals/tribunals, we have excellent guides available for members via post or email (saves us funds). Phone Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk to request them.

September Meeting - Bolton Carers' Support Group Talk:

Following the talk to the group in September by Barry Glasspell of Bolton Carers' Support, here are brief contact details for both Bolton and Bury services. A more detailed account of the talk will follow in a later newsletter.

Bolton: A new 24hr Carers Helpline 01204 363056
Bolton Carers Support, Thicketford Centre, Thicketford Road, Bolton, BL2 2LW.
<http://www.boltoncarers.org.uk/>

Bury Carers Support: 0161 763 4867
Victoria Buildings, 9-13 Silver Street, Bury, BL9 0EU
9am-4.30pm Monday-Friday. Drop in anytime, or phone to make an appointment.
They offer things like art therapy, tai chi classes, complementary therapy and friendly coffee mornings.
<https://www.facebook.com/BuryCarersCentre/>

Report exposes the low level of funding for ME/CFS:

With kind permission from M.E Research U.K. Breakthrough magazine Spring 2017.

We all know that research funding for ME/CFS is abysmally low, but we can now provide some figures thanks to a report commissioned by the ME/CFS Research Collaborative in the UK. It asked the company ÜberResearch to search its database for relevant information on ME/CFS and comparable diseases.

The report found that ME/CFS received less than 1% of all grants given by UK mainstream funding agencies over the past decade. Also, the nature of the support was low-level and patchy, high-lighting the need for increased investment in high-quality studies of biological mechanisms and treatments.

The low level of investment is particularly shocking given the scale and impact of ME/CFS on individuals and society. The illness is at least as disabling as multiple sclerosis and congestive heart failure, and its economic cost is more than £6 billion per year in the UK. Of course, the report does not include research funding by ME/CFS charities. While this can be considerable in relative terms – ME Research UK has committed £1.4 million for more than 40 studies in the UK and overseas, for instance – what charities can provide is small in real terms compared with the larger sums available to institutional funders such as the MRC and the Wellcome Trust in the UK and the NIH in the USA. It is these institutional funders who need to step up to the plate.

As Prof. Stephen Holgate says in the Foreword, “The report presents hard evidence of the chronic lack of research funding for ME/CFS from major funding agencies. I am delighted that the MRC will now review its highlight notice as a result... and hope that other mainstream funders will reassess their attitudes towards ME/CFS and review their funding policies.”

Possible Group Involvement in NICE Guidelines Review:

Many of you will know that NICE are reviewing the guidelines for ME/CFS over the next couple of years. They will collect evidence and views from a range of groups and individuals, including some of the doctors who have pushed the GET/CBT treatment model.

There is a possibility that our group can register as a stakeholder, too: some support groups have done so already. We would need to form a small working group of maybe 3 or 4, including me. This would be quite a big commitment, but I can't give any details of exactly what it would entail at the moment. Perhaps collecting information from members and submitting it to NICE, I imagine.

The trustees will make a decision at our committee meeting at the beginning of December, so would be grateful for any thoughts, opinions, volunteers, by then. You can email (maria113@talktalk.net), phone (01204 575613; please leave a message) or through Facebook Messenger. You can also give your thoughts to the trustees at the November meeting.

Thanks, Maria Sale

Dr Perrin NHS Study Paper Released:

As you many know from previous newsletters, Dr Perrin has been involved in completing a study on using 5 physical markers to accurately diagnose people with M.E quickly, for several years since it's inception. The study took place at Wrightington Hospital in Wigan, and used people from our group and family and friends as controls and chaperones, so many thanks to all who volunteered.

The study paper will be published on the BMJ website (<http://bmjopen.bmj.com/>) on 13th November, titled

Hives, Lucy, Bradley, Alice, Richards, James, Sutton, Chris J, Selfe, James, Basu, Bhaskar, Maguire, Kerry, Sumner, Gail, Gaber, Tarek et al (2017) “*Can physical assessment techniques aid diagnosis in people with chronic fatigue syndrome/myalgic encephalomyelitis? A diagnostic accuracy study.* BMJ Open

Trials of the Heart:

With kind permission from M.E Research U.K. Breakthrough magazine Spring 2017.

A new study from Newcastle looking at measures of cardiac volume and function in patients with ME/CFS. Over the years, a few scientific reports have pointed to the presence of abnormalities of heart (cardiac) function in ME/CFS. These abnormalities include relatively short QT intervals and a reduction in cardiac output or function.

ME Research UK-funded investigations by Prof. Julia Newton and colleagues at Newcastle University have also thrown up some intriguing findings. When the research group looked at the function of the heart using cardiac tagging, they found a dramatic increase in residual torsion in ME/CFS patients compared with control

subjects. Patients had twice as much residual torsion as healthy people, indicating that their heart muscle was taking longer to relax.

The Newcastle researchers have been continuing their investigations, and their most recent report was published in the journal *Open Heart*. In these experiments, cardiac magnetic resonance imaging (MRI) of the heart was performed in 47 patients with ME/CFS (excluding those with depression) who had been ill for 14 years on average, and in 47 matched control subjects. The results were fascinating.

Stroke volume was 23% lower in ME/CFS patients than in healthy controls, while volumes at the end of diastole were 25% lower, volumes at the end of systole were 29% lower, and heart wall masses at the end of diastole were 26% lower. In essence, these findings confirm, in a larger and different group of patients, the reductions in cardiac volume observed previously in pilot studies in Newcastle. The patients' length of illness was not related to any cardiac MRI or volume measurements, suggesting that deconditioning (which would be greater the longer a person was ill) was unlikely to be the cause of these abnormalities.

Also, the total volume of blood (including both plasma and red cells) was 4% lower in the ME/CFS group than in the healthy controls, though this difference was not statistically significant. In 63% of patients, however, the volume of red blood cells was below 95% of the expected levels for healthy people, and there were strong positive correlations between blood volume measurements and the mass of the heart wall at the end of diastole.

The finding that the red blood cell volume was low is intriguing, and it may be that blood volume plays at least a part in the symptoms experienced by ME/CFS patients. One possibility is that low blood volume may be due to problems with the venous circulation, as nearly two-thirds of the blood in the circulation is stored in the venous system, which is controlled by the autonomic nervous system, also affected in ME/CFS.

Overall, these findings using state-of-the-art imaging techniques confirm the presence of cardiac abnormalities in people with ME/CFS. It remains to be seen, however, whether these are caused by the disease and its consequences, or whether (for instance) a pre-existing reduced cardiac volume may make people more vulnerable to the development of illness. As regards low blood volume, there is anecdotal evidence that the symptoms of ME/CFS improve in some patients after treatment with intravenous fluid (although the procedure is not without drawbacks and risks). The team in Newcastle therefore intends to explore interventions to restore fluid volume in ME/CFS patients in further studies.

Unrest:

An acclaimed documentary about life with ME/CFS has been released. Jennifer Brea is an active Harvard PhD student about to marry the love of her life when suddenly her body starts failing her. Hoping to shed light on her strange symptoms, Jennifer grabs a camera and films the darkest moments unfolding before her eyes as she is derailed by M.E.

In this story of love and loss, newlyweds Jennifer and Omar search for answers as they face unexpected obstacles with great heart. Often confined by her illness to

the private space of her bed, Jen is moved to connect with others around the globe. Utilizing Skype and social media, she unlocks a forgotten community with intimate portraits of four other families suffering similarly.

DVDs are available from December. You can purchase it digitally on iTunes, Vimeo, Google Play and Amazon Video as of now. We tried to host a screening of the film, but it was an incredible amount of work and just wasn't possible unfortunately.

Return of Friendship Group:

We used to have a "Link-Up" sub-group for members to contact each other, but it stopped due to lack of volunteers to run it, and the growing use of social media. Emma has kindly volunteered to start this again, so that members can communicate via phone, email, text or letter. Thank you Emma!

Please remember to be respectful of members at all times. As a group we will not tolerate bullying of any kind. Also keep in mind that the person you are contacting might be having a rough day and might not get back to you straight away or need to cut the chat short. If you decide to meet someone in person, do be careful and try to arrange to meet in a public place and let someone know where you are going.

You can send Emma the below information by email at echatwood@ntlworld.com or at one of the meetings or by sending it to: 87 Birchfield Drive, Worsley, Manchester M28 1ND

Name, age* and gender* (*optional):

Phone numbers:

Email:

Address:

Preferences for contact: email/home phone/mobile phone/text/letter

Would you be able to call back members on PAYG mobile: Yes/No

Would you like your address to be included in the contact list: Yes/No

Best times and days to contact you:

Interests:

