

## **Welcome to Our November 2014 Newsletter.**

Note from the Editor Maxine: Hope you all have a safe bonfire and not too many trick or treaters. Please coordinate with Caroline about the bring and share supper. Please note we are trying a shorter newsletter to save on pennies. Would people mind if I removed the contents page to make room for more articles? Please get in touch with either Caroline or myself with your views.

### **Monthly focus.**

**Please think about going paperless and having your newsletter sent by email. See full article below.**

**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. To trial the SmartCRUTCH's, call Caroline on 01204 525 955.

## **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). It is not far from Brightmet Health Centre. The building is on Bury Rd, between Morrisons/Home Bargains and the junction to turn onto Crompton Way, on the way into Bolton town centre.

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](mailto:caroline@mesupportgroup.co.uk).

There are steps up to the venue from the car park, but a ramp at the front of the building. Once inside there is stairs and a lift to the second floor, where our meeting will be. The lift can take 3 people, or 2 and wheelchair or small/average scooter. The lift needs to be operated by hand (a small lever needs to be pushed down by hand, but I used my elbow!). There will be a member of the Wildlife Trust on hand for the evening, but if you need assistance to operate it, please ask. Unfortunately the larger type scooters cannot fit in, but they can be left at the bottom of the lift if you can walk from the lift to the room upstairs.

**Thursday 20th November-** Pre-Xmas Bring and Share Supper Social, please bring an item of sweet or savoury food to share and enjoy for our buffet. Gluten/dairy free are usually very well catered for and we always go home with leftovers. People who do not have dietary intolerances/allergies are more than welcome to have the “free from” food as well, as there is more than enough for everyone!

**No meeting in December.**

**Yoga Classes:** There will be no yoga sessions on the 2<sup>nd</sup>, 9<sup>th</sup> and 30<sup>th</sup> December.

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 sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. **Our yoga classes are currently being funded by Comic Relief and The Co-operative Membership Community Fund.**

**Bolton Socials:** Are now at Pizza Me ([www.wannapizzame.com](http://www.wannapizzame.com)), which is on Brightmet Fold Lane, BL2 6PP, just next to Brightmet health centre. We meet the first Wednesday of the month at 2pm, so the next will be on 3<sup>rd</sup> December 2014. There will put a newsletter on the table so that you can recognise us.

**Prestwich Socials:** Our Prestwich socials are now at The Church Inn, 40 Church Lane, Prestwich, M25 1AJ. This has level access and free parking outside. Wednesday 10<sup>th</sup> December 2014 at 2pm. **Please check on Facebook first to check it is still going ahead, as that’s the quickest and easiest way, or call Maria on 07867 862 341 if you are not on Facebook.** Apologies to those not online, but it is either this, or stop them altogether.

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, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANK-YOU.**



## **Reminders:**

**Volunteers:** We are looking for volunteers who can help with all activities of running the group, if you have a particular skill (or just a pair of hands!) 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](mailto:caroline@mesupportgroup.co.uk) or 01204 525 955 for more information.

**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. To trial the SmartCRUTCH's, call Caroline on 01204 525 955.

**Social Media:** Please follow us on twitter on: @BBMECFS

Also our Facebook page just for members is [www.facebook.com/groups/buryboltonmecfs/](http://www.facebook.com/groups/buryboltonmecfs/)

And our new open page

<https://www.facebook.com/bbmecfsopen>

Don't forget our own web page <http://www.mesupportgroup.co.uk/>

**Recommended GP's:** Don't forget, we have a list of recommended GP's! If you have a sympathetic or helpful GP, please let us know, as people ask us for one in their area all the time. 01204 525 955, [caroline@mesupportgroup.co.uk](mailto:caroline@mesupportgroup.co.uk).

**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](mailto: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](mailto:ruth@mesupportgroup.co.uk).

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

## **Hydrotherapy sessions: now cancelled**

### **Appeal to go paperless:**

A large portion of outgoings is photocopying costs – awareness leaflets, welcome packs, monthly newsletters and several lengthy BenefitsAndWork.co.uk guides. It would help cut printing and postage costs (as well as our volunteer's energy, electricity and time) if you would get the email versions of the benefit guides and newsletters if you are able to please. (If you do not have access to email/a printer, does a friend or relative?) Could you also return the guides where possible so we can pass them onto other members to re-use, and also save some trees). Only around 40% of our newsletters go out by email. Of course we know not everyone has email, but if you can get the newsletter this way, please would you consider it to save us funds. A huge, unseen amount of work by people with ME/CFS/FM goes into them, producing these and getting them to you. Please contact [caroline@mesupportgroup.co.uk](mailto:caroline@mesupportgroup.co.uk) / 01204 525 955 to switch to email newsletters. Thank you.

## **Fundraising Update.**

### **Waitrose:**

Many thanks to Waitrose and their customers, as they raised £105 for us in September, via their Community Matters Scheme. Our box was one of three chosen as a local good cause after Caroline wrote in to the Manchester Spinningfields branch.

**Asda:** We were also one of three local good causes for the month of September and October in the Burnden Park branch, after Caroline sent in a nomination. Many thanks to Asda and everyone who chose us for a token.

### **Chico & Jeff:**



Well, thank you very much to everyone who has donated to Chico and Jeff's fundraising efforts so far. We are delighted that they are at the half-way point of their fund-raising target now. Now a word from Chico....:

"I've been out and about with Jeff as usual this month. I met up with group members at the Prestwich social at The Church Inn. We also went to Leamington Spa, but Jeff kept getting lost (not sure how he will fare on our round the world trip?) and people kept sitting on me.

However, we have been continuing to raise awareness of M.E, especially with my nice blue ribbon. Jeff's main problem at the minute is packing all my lovely clothes in the suitcase."

If you would like to see updates of Chico, please "friend" him on Facebook, by searching for "Gulliver

Chico Glasser", or joining our private closed group page where the updates will also be shared. We will share some in the upcoming newsletters too.

To securely donate to Chico and Jeff's efforts, the GoFundMe page is here:  
[www.gofundme.com/gulliver](http://www.gofundme.com/gulliver).

If you can't donate on internet, or through friends or family, you can send us a cheque for Jeff and Chico's efforts to 53 Denstone Crescent, Bolton, BL2 5DE, payable to "Bury/Bolton ME/CFS Support Group", or donate at meetings. Thank you.

## **Bury Bolton ME/CFS October 2014 Meeting**

This was a doubly stressful meeting for the committee and volunteers, as it was the first one in our new venue, the Environmental Resource Centre, a Wildlife Trust Building on Bury Rd. Bolton. It also happened that our DWP P.I.P speaker cancelled on us a couple of days before.

We informed people that the meeting would not be going ahead as scheduled via our private Facebook group and sent out an email to everyone we held an email address for. We also put a notice on the website, Twitter, and the group's open Facebook page. Hopefully we got through to most of you, but please ensure we hold your most up to date email (if you have one) for times like these where you may be making a special trip.

Alternatively, please check the website before you travel, or ask a fellow member you are friends with, or someone who has internet access, to avoid disappointment.

Instead, we did a very informal talk about the things you should mention on the form to increase your chances of success. Jeff and Maria were the only committee members holding the fort and Jeff kindly stepped up and gave personal advice based on experience, and a couple of others chipped in with their own advice too. We were pleased to welcome some members we had not seen in a while, and some new members.

Earlier in the day, The Wildlife Trust posted on Facebook that a swarm of ladybirds had descended on the building (attracted by the heat of the bricks) and posted pictures of them all, so I was wondering if we were going to have to battle our way past a wall and carpet of ladybirds, in addition to dragging along the balloons and all the other assorted bits and bobs we always bring to meetings? Luckily they had dispersed by that time in the evening!

The venue seemed to be well received by most and is accessible via ramp/lift. It was our first time in there and we did not know what to expect, or how things would quite work out, so please excuse any frazzled flailing about or if we seemed pre-occupied, as we were very short on people too.

We are all volunteers with M.E/C.F.S/F.M just like you. If you experienced any problems with the venue or the meeting that need bringing to our attention, please let Caroline know, so we can see what we can do about them.

### **New Measures To Speed Up PIP Claims Process**

From the DWP's own newsletter, 'Touchbase'. (found via M.E Association Facebook page who found it).

“DWP has improved all parts of the Personal Independence Payment (PIP) claims process to make sure that claimants who are entitled to the benefit are paid as quickly as possible.

The two PIP assessment providers, Atos Healthcare and Capita Health and Wellbeing, have taken on more health professionals and administrative staff and have opened new assessment centres so they can increase the number of assessments they do.

DWP has also introduced new guidance for assessment providers to support them to increase the proportion of cases that are assessed from paper evidence, reduce the length of assessments and ensure that DWP's decision makers are given quality advice.

The PIP IT systems have also been improved. These changes are already having an effect. Both providers have more than doubled the number of assessment reports they are returning to DWP each month and this is expected to continue to increase over coming months.

DWP's decision-makers have also more than doubled their output since April 2014. Extra resources have been put into this area to clear the growing number of assessment reports that providers are returning.

By the end of the year it is anticipated that no one will be waiting longer than 16 weeks for a PIP assessment.

The first experimental official statistics on PIP were published by DWP in June 2014 and a subsequent release was published in September 2014. Both documents are available at Personal Independence Payment statistics - [GOV.UK](http://gov.uk)."

## **Volunteer driving schemes**

Volunteer drivers work through some local councils so they can drive people in need to appointments, shopping etc. They are a great way provide freedom to people who might be housebound, or when it's too difficult for them to use public transport or a taxi.

Drivers are checked and will have a fully maintained and insured vehicle together with a full UK driving licence. Some councils may also be able to offer a vehicle which can take a wheelchair, but you'll need to check before you book. Also councils are likely to have different rules for their services, so you'll need to check to see if you qualify. For example, could they take you to the supermarket and wait whilst you shop?

Details of the services in the local area are as follows:

- Bury Council - Do not run a standalone driver service, but trips may be included as part of an adult social care package. Bury Council also has [a range of transport options](#) such as Ring and Ride (tel: 0845 688 3989) or the [British Red Cross Transport Service](#) for a door to door service (tel: 01204 369620). For the Red Cross option, you only pay for petrol and if you can't afford it you won't be refused.
- Rochdale Borough Volunteer Drivers Scheme can be contacted on 0800 032 0868, although the council offers many [types of transport alternatives](#).
- Bolton Council also [have a range of services](#) such as Local Link, a door-to-door bus service for people in one of 4 specific areas of Bolton. Use Traveline and TfGM (see below) when organising your travel from Bolton.

If in doubt, you can plan any journey using [Traveline's website](#), or contact them on 0871 200 2233. General Information about accessible transport can be found on the [Transport for Greater Manchester \(TfGM\) website](#).

Finally for people reading this on a paper copy, or who don't have access to the internet, please call Andrew Levy on 07922 922375 and he will point you in the right direction.

## **EmergencySMS**

Over 32,000 phones have been registered with the EmergencySMS service so far. The emergencySMS service lets deaf, hard of hearing and speech-impaired people in the UK send an SMS text message to the UK 999 service where it will be passed to the police, ambulance, fire rescue, or coastguard. Simply by sending an SMS message to 999 you can call for help and the emergency services will be able to reply to you.

The EmergencySMS service is an add on to the existing 999 and 18000 text relay services that are available in the UK.

You will need to register your mobile phone before using the emergencySMS service, and re-register if you change your number. You should only use this SMS method if you have no other option (as it will take longer than other methods such as 999). You must only use this service in an emergency!

Send a message stating which emergency service you require, what the problem is and where it is, so they can respond as quickly as possible without asking more questions. Do not assume your message has been received until you get a message back from the EmergencySMS service (which can take up to 2 minutes).

For more information or to register, visit <http://www.emergencysms.org.uk/> which has more information, Q&A's and BSL videos.

## **Culinary Corner.**

Please can people send me their recipes to [maxine@mesupportgroup.co.uk](mailto:maxine@mesupportgroup.co.uk)

**Quorn Chilli** recipe for the slow cooker. Adjust times for oven. Serves 2 Adults and 2 children.

### Ingredients

250g Quorn mince (frozen)

Handful of chopped onion (frozen, or half a fresh white onion)

2 tins chopped tomatoes

1 tin of kidney beans

1 tin of baked beans (optional)

1 teaspoon of chilli powder

1/2 tablespoon of ground coriander

1/2 tablespoon of ground cumin

1/2 teaspoon of ground cinnamon

1 tablespoon of tomato puree

Splish of soy sauce

One veg stock cube

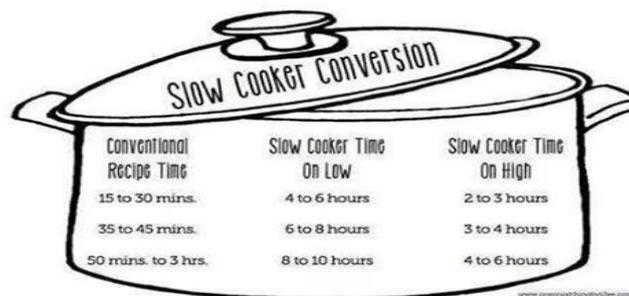
Put everything apart from the kidney beans (and baked beans if using them) into the slow cooker and give it a good stir.

Cook on low for 6-8 hours, or high for 3-4 hours.

Stir kidney beans and baked beans into the mixture about 30 minutes (low) or 15 mins (high) before serving.

Add cheese to the top in the last 5 mins

serve with rice or Jacket potatoes or nachos, or for a bit of a change add pasta for the last hour to make a chilli pasta bake



## **Late edition - October 2014.**

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

A recent study published in Radiology compared the brain images of 15 CFS patients with those from 14 volunteers with no history of fatigue or fatigue related conditions. The differences centred on areas devoted to carrying signals and the brain's data processing areas. At this stage, the team are not clear on what this means, but they are encouraged that it could be a "biomarker" which could be used to diagnose the illness. It's also possible the results might show CFS/ME has affected the central nervous system. - [Some headway on chronic fatigue syndrome: Brain abnormalities pinpointed](#) – Scope blog by Stanford Medicine - October 12

Julie Rehemeyer is a journalist who has CFS/ME. She writes about the controversies caused by a loose definition which hampers research, treatment and diagnosis. She writes from her own experience and describes how she was treated by Nancy Klimas, an immunologist and CFS expert. Although she had many treatments from Dr Klimas, the key to unlock her disease was avoiding mold. Julie finishes off her assessment by saying, "Yes, we need a sound accepted definition, but we also need so much more. It's time to treat patients with respect, to move beyond political squabbling and to make an investment in researching this illness that is in proportion to the devastation it causes." What is chronic fatigue syndrome, and why aren't we doing more to treat the illness? – Washington Post - October 13

The Open Medicine Foundation (OMF) has announced a project called End ME/CFS. They are raising money for an annual budget of \$5m. The team is led by Ron Davis PhD who describes this initiative as a "total attack on the problem." So far they have recruited many eminent CFS/ME researchers as well as 2 Nobel Laureates and specialists from other fields for alternative opinions. – "End ME/CFS" Mega Chronic Fatigue Syndrome Project Begins – Health Rising Blog - October 15

Cytokines are important in health and disease, specifically in responses to infection, immune responses, inflammation and other conditions. In this study the researchers compared people with moderate and severe CFS/ME and found differences in cytokines between the 2 groups. The study supports the idea that different categories of CFS/ME should be created when conducting research and for treatment. - Serum cytokines in patients with moderate and severe Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) - Source - October 12

ME Cures trading as Smile Qigong, based in Sutton Colefield, recently had an online advert banned by the Advertising Standards Authority (ASA) following a complaint by the ME Association (MEA). A page headed 'Smile Qigong' on the website [www.mecures.co.uk](http://www.mecures.co.uk) included a graphic with text referring to the suitability and benefits of 'Smile Qigong' for people suffering from ME and stated "Benefits of Smile Qigong include raised energy levels, improved focus". MEA challenged whether the efficacy claims for the treatment could be substantiated and complained that the advertisement breached the Committee of Advertising Practice code by offering treatment for conditions for which medical supervision should be sought.- Sutton Coldfield medical company has advertisement banned after claiming to treat M.E. – Royal Sutton Colefield Observer - October 10

A draft document issued by the US National Institutes of Health (NIH) in advance of a December workshop on CFS/ME has provoked strong opposition from the patient advocate community and some experts. They say the document, "Diagnosis and Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)," does not reflect the reality of the illness. "It's hard to identify research needs if you haven't articulated the current situation. I don't think they have done that." said Kenneth J. Friedman, PhD. Others were also concerned about how the Evidence Review was conducted, the diagnostics and the subgroup. Concerns were also raised about treatment conclusions and the risk of undue harm the report may create for patients.- Chronic Fatigue: NIH Literature Review Faulted - Medscape - October 17

**DISCLAIMER:** Anything expressed within this newsletter may not necessarily represent the views of the editor, the Committee, nor the Bury/Bolton ME/CFS Support Group. Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.