

Welcome to Our October 2014 Newsletter

Note from the Editor Maxine: Welcome to this month's newsletter. Please note the changes of venues that are in place. I missed my pat on the back last month as I've been editing the news letter for twelve months now.

Once again I have included the Halloween posters. One of yes please and the no thank you as the trick and treaters will be out and about.

Monthly focus.

Writing the speaker reports at meetings. We still need a regular person to write up the meetings. The Meetings are recorded therefore even if you can't make the meetings then you could still help the group.

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. Please can we all remember to use the link with Christmas around the corner.

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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.

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.

The venue has its own car park. Committee members who are usually the first to arrive and last to leave will park to the left of the car park, so it is fine to park behind them if need be. Blue badge holders can park on the main road if displaying their badge and time disc (which may actually get you closer to the door and leave more room in the car park for those who do not have a badge). Caroline has verified with parking services at the council that it is ok to park on the main road with a blue badge at that time.

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 (we are working on a solution to this).

Thursday 16th October- Oliver Mawdsley, DWP Relations Officer, will be coming to talk to us about Personal Independence Allowance (PIP), formerly Disability Living Allowance, and about the changes surrounding it. If you have any questions, please send them to us in advance. He was recommended to us by another support group, who said he was very nice and informative. **THIS IS OUR FIRST MEETING IN THE WILDLIFE TRUST BUILDING ON BURY RD.**

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.

No meeting in December.

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 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), 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 5th November 2014.** Pizza Me has ample parking, with a very short distance to walk to the front door, where there is level access with no steps. The toilets are located to the left of the door as you go in, or there is a disabled toilet in the entrance way. Although this is a restaurant, they are happy for us just to have drinks, but there is a range of food available for anyone who is hungry, including small snacks. We will be sat to the right of the bar (in the comfier seating) and 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.

September's meeting is provisionally set for the usual second Wednesday of the month- **Wednesday 8th October 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 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/
And our new open page

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

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.

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.

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.

Mercure Bolton Health Club Discount: The Bolton Mercure branch has kindly agreed that our members can use 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 the group, please get in touch!

Hydrotherapy sessions: Preston and Chorley Fibromyalgia and Chronic Pain Support Group have kindly offered to let our group attend their private hire hydrotherapy sessions. There is no instructor, you can do your own exercises, or swim a few lengths.

The sessions are 12pm - 1pm on the first Friday of the month.

They are at the Jubilee Pool, Tennyson St, Bolton, BL1 3HW. It is £3 per person and carers may attend for free. The sessions will be on:

Friday 7th November 12-1pm

Friday 5th December 12-1pm

Friday 2nd January 12-1pm

The pool is 34.9 degrees and air temp is 38.9 degrees so it is lovely and warm. They supply pool noodles, hoists and they have a stair case to get into the pool. They are a very friendly bunch.

Please text or phone Natalie on 07855 777636 if you are planning to attend, so they know possible numbers. Thank you to the P&C group for the generous offer to our members.

September E.G.M & Book Swap Social

Many thanks to those who sent in postal/email ballots, and those who attended the meeting in person. The EGM was very quick and the documents which will help enable us to become a registered charity were voted in without problems (unless you count an

exhausted Caroline struggling to remember the names of people she has known for many years a problem)?

This was one of the last steps in a very lengthy preparation process that Caroline has struggled to get her head around for months. The next and final step is to submit our application, so hopefully if there are no problems, it will not be long before we are officially a registered charity!

After the voting, books were swapped and a small amount of funds raised for the group. We have started to sell a small amount of ME and FM awareness items and Stickman Communications products (a disabled cartoonist who promotes a positive disability image and has made lots of practical items). These are sold at reduced cost to you, and also save you postage. They also help make a small amount of money for the group and raise awareness of our condition. Thank you to all our volunteers on the night for helping out.

This was our last meeting in Longsight Church, Harwood. We will be meeting in the Wildlife Trust, Bury Rd, Bolton, for October's meeting onwards, which is only a few minutes away.

Smartcrutch competition

The winner of the Smartcrutches is Maria McC! Well done Maria and we hope they are helpful. Grumpy cat is delighted for you.



M.E/C.F.S Clinic Team Meeting

We will be meeting with the M.E/CFS Clinic team at the beginning of November. If you have any questions you want us to ask them or any feedback you wish us to pass on about any aspect of the service or (anonymously), please let Caroline know on 01204 525 955 or caroline@mesupportgroup.co.uk.

Where Fibromyalgia and Chronic Fatigue Syndrome Part Ways (and Where They Don't)

Reprinted with the kind permission of Cort Johnson and Health Rising.

Lately we've seen what appears to be a great deal of similarity in muscle issues in Chronic Fatigue Syndrome and Fibromyalgia. We know that Dr. Bateman and others believe ME/CFS and Fibromyalgia occur on a fatigue-pain continuum – that they are similar disorders that differ in the amount of fatigue and pain present. They both predominantly

affect women, and similar medications are used in both.

Both Dr. Natelson and the Lights, however, have found differences in ME/CFS + FM vs ME/CFS patients alone, and Natelson argues that they're quite different disorders. Now a recent study demonstrates an important way that this is so.

Reduced levels of BDNF – described as a **nerve repair agent** – were recently found in Chronic Fatigue Syndrome and multiple sclerosis. The levels found – less 25% of normal – were stunningly low, and this suggested that neuron functioning was taking a real hit in both these disorders. Given the nerve damage found in MS, that result was expected for MS – but not in ME/CFS.

A recent Fibromyalgia BDNF study seems to portray a very different disorder. It examined BDNF and a marker of central sensitization (S100B) in the blood of fifty-six FM patients and then determined if this correlated with pain pressure thresholds (the threshold at which pressure starts producing pain). The lower the pain threshold, the more pain a person is in. The study did not involve healthy controls and thus did not, strictly speaking, determine if BDNF levels were higher or lower than normal in FM.

Microglia Activation and Central Sensitization

Before we get to the findings, let's look at S100B. S100B is such an intriguing factor that it's surprising it hasn't been studied before in FM or in any other pain disorders. S100B upregulates two key cytokines, IL-1b and TNF-a, both of which may be involved in FM and ME/CFS. It also activates the nuclear transcription factor which Maes proposes underlies the inflammatory milieu in ME/CFS and depression. It is also considered a surrogate for microglial activation.

Study Findings

This study found that increased BDNF and S100B levels were associated with increased pain sensitivity in FM. Other studies have found increased BDNF levels in FM as well. These FM findings contrast sharply with the decreased BDNF levels found in ME/CFS. With regards to BDNF, ME/CFS looks more like multiple sclerosis than it does Fibromyalgia.

High Levels of Excitation vs Low Levels of Nerve Repair?

While high levels of BDNF in FM look like they're enhancing the activity of excitatory pain pathways in FM, low levels of BDNF in ME/CFS look like they may be impeding neuron repair and slowing down nerve transmission. Could FM be a disorder of brain excitation while ME/CFS is a disorder of brain loss and slowed functioning? Could it be that simple?

A quick look at the research findings in ME/CFS and Fibromyalgia indicate more overlaps than dissimilarities. Both are characterized by sympathetic nervous system activation, reduced aerobic capacity, increased lactate levels (in one place or another), reduced brain blood flow, decreased cortisol, and decreased grey matter in the brainstem.

Similarities between the ME/CFS and Fibromyalgia

- Reduced heart rate variability – sympathetic nervous system activation in FM and ME/CFS
- Reduced aerobic capacity in FM / Reduced aerobic capacity in ME/CFS

- Increased lactate – muscles in FM / Problems with lactate metabolism in FM / Increased lactate brain in ME/CFS
- Homocysteine increased in spinal fluid in both disorders
- Reduced brain blood flow in FM / Reduced brain blood flow in ME/CFS
- Neuropeptide Y increased in FM / Neuropeptide Y increased in ME/CFS
- COMT Polymorphism Implicated in FM / COMT Polymorphism in ME/CFS
- Reduced salivary awakening response cortisol in ME/CFS / Reduced salivary awakening response cortisol in FM
- IL-6 increased in FM / IL-6 increased in ME/CFS
- Decreased grey matter – brainstem in FM / Decreased brain matter – brainstem in ME/CFS

Differences between the ME/CFS and Fibromyalgia

- Substance P increased in FM / Reduced in ME/CFS
- BDNF increased in FM / Reduced in ME/CFS
- IL-8 increased in FM / IL-8 decreased in ME/CFS
- Leptin reduced – FM / Leptin increased – ME/CFS

Central Sensitization – the Key?

It's intriguing that the two major differences between the two disorders, increased substance P and BDNF in FM, are associated with central nervous system activation.

Given the high amount of pain and problems with stimulus overload, we've assumed ME/CFS is also a central sensitization disorder. Yet two markers associated with central sensitization that are elevated in FM, BDNF and substance P, are not elevated—or are actually lowered—in ME/CFS.

The excitatory neurotransmitter glutamate is also clearly increased in some parts of FM patients' brains, but a CDC gene expression study suggested decreased glutamate uptake may be present in ME/CFS. At the Stanford Symposium Dr. Zinn described an ME/CFS brain characterized by substantial 'slowing'. It was a brain that seemed to be more asleep than awake.

On the other hand, Jason has proposed that limbic kindling produces a kind of 'seizure activity' in parts of the brain in ME/CFS, and high levels of neuropeptide Y and reduced heart rate variability indicate the sympathetic nervous system is activated in both disorders. Klonopin (clonazepam), a nervous system inhibitor, is used in treating both disorders.

In the end it may be that, like the immune system in ME/CFS, parts of the brain are over- and under-activated in both disorders.

Conclusion

Increased levels of BDNF and S100B levels are associated with increased pain sensitivity in Fibromyalgia. They join a variety of other markers of central sensitization markers found in FM.

Differing levels of BDNF and substance P in Chronic Fatigue Syndrome and Fibromyalgia suggest that the two disorders differ in important ways. However, the two disorders share many more commonalities than differences. The central nervous system could be, however, where the two disorders diverge.

Pain is common in ME/CFS, but it appears that the pain is, at least in part, being produced in different ways than it is in Fibromyalgia.

About the Author: Cort Johnson has had ME/CFS for over 30 years. The founder of Phoenix Rising and Health Rising, Cort has contributed hundreds of blogs on chronic fatigue syndrome, fibromyalgia and their allied disorders over the past 10 years. Find more of Cort's and other bloggers' work at Health Rising.

Healthy Eating in Wigan

Maybe if you're in the area or want to go out for lunch, maybe try these places? Caroline.

Food Positive Ltd is a social enterprise dedicated to addressing food poverty by delivering food based skills and knowledge training. They work with individuals and community groups teaching people to cook from scratch, helping them make healthier choices and increasing their knowledge and enjoyment of food.

They also do food based activities for children in the school holidays and have a cook and craft club. From 8:30 to 5:30, 5 days a week, all staff are DBS checked. They also offer children's parties (cupcake, pizza or chocolate! 10% off if you quote "leaflet" source). They offer day services of small groups to learn how to cook and bake, then do crafts in the afternoon.

Services/Classes: Cooking/baking classes, Pre school lunch club, cooking on budget, after school lunch club, nutrition consults, family mealtime conflict support, skills for life sessions, cooking for fun sessions, over 55 cooking club, basic food hygiene, children's parties, kitchen hire. These are at their base in Upper Dicconson St. Tel: 01942 581042

They serve healthy hot and cold food and drinks in their café in Platt Bridge Community Zone, 81 Ribble Rd, Wigan. Open from Mon-Fri 10-2:30pm. www.foodpositive.co.uk.

Nooch has become a favourite of mine. A vegetarian/vegan and gluten-free speciality food shop on Hallgate. They sell groceries, beauty stuff, fridge/freezer stuff, vintage clothing and handmade local stuff. Bookcycle are also there and she sells absolutely lovely hand-painted stones and little "fairy-doors" and decorated stones from McFairies. Nooch is open 6 days a week (closed Wednesdays). The owners are friendly and really happy to help.

I've bought delicious ice-cream, cakes, chocolate bars (these don't last very long!), lovely bag charms (they kindly agreed to make me some custom ones) and basic groceries like gravy and rice, all gluten free and vegan.

I've got some good health and nutrition books from the bookcycle bookcase, which is run by a charity. You give a donation for the books you choose. You can also donate any health/vegan/gluten-free ones you no longer want..

The Gingerbread Bunny (Sarah), a textile artist specialising in crochet and felt making, has recently moved into a space in Nooch and makes some lovely items. She also teaches workshops there so if you are interested in beginning how to crochet, perhaps get in touch.

If you cannot make it to Wigan, or up the stairs, she can come to your home to teach you privately for a tuition fee. thegingerbreadbunny@hotmail.co.uk, www.facebook.com/gingerbreadbunny

Access wise, Nooch is up a flight of stairs, but they plan to put all the stuff on their website soon, so you can pick what you want and they can bring it down if you are unable to manage stairs. You can park outside on the road with a blue badge (no parking restrictions on Sunday on Hallgate), or there is a pay and display bay just outside the street.

Nooch, 21 Hallgate, Wigan, WN1 1NS. 01942 243789.
<https://www.facebook.com/NoochSpecialistFood>

Just down the street is a vegetarian café called **The Coven**. They do lots of vegan options (dairy and egg free) and wheat/gluten free options too. They also host the occasional acoustic music night and pudding club! I recommend the Fentiman's drinks and their cakes! They have a lovely outdoor area too. **The Coven: 43 Halgate, Wigan. 01942 237801.** <https://www.facebook.com/TheCovenWigan> <http://thecoven.moonfruit.com/>

NHS Choices – What Are Your Rights?

Reprinted with kind permission from Arthritis UK. This was printed in Fragile Links, an Ehlers Danlos Syndrome charity magazine and references EDS, though the content can apply to anyone with a long term or rare condition. We have kept in the references to EDS as they appear in the original article. By Dr Tom Margham.

The NHS Constitution, published in March 2013 “*establishes the principles and values of the NHS in England. It sets out rights to which patients, public and staff are entitled, and pledges which the NHS is committed to achieve, together with responsibilities, which the public, patients and staff owe to one another to ensure that the NHS operates fairly and effectively.*”

This seems like a good place to start a conversation about both your rights as a patient and also how to get the best out of an encounter with a healthcare professional in the NHS. The core principles guiding the NHS - the right to receive comprehensive care, available to all; irrespective of race, gender, age, disability, sexual orientation or belief; with access based on clinical need, not on the ability to pay, make it unique amongst health systems around the world.

Healthcare works most effectively when patients and healthcare practitioners – whether GPs, nurses, physiotherapists or pharmacists work together to the benefit of the patient, and it is important to emphasise that good healthcare is a collaborative effort. Most patients want to be active partners in their care: healthcare ‘done with me’ rather than ‘done to me’.

That said, sometimes this can seem like it is not the case. Many patients report that they do not have this relationship with their GP, feel that they are not taken seriously, or that their GP may not have the skills and knowledge to manage rarer conditions like EDS.

It may be useful to dig a little deeper into why this may be the case and consider things that can be done to improve a situation that may not seem ideal. But I feel it is important to state this point - having had the good fortune of working with many GP colleagues over the course of my career, the overwhelming sense I get is of people dedicated to trying to help the patients they serve. You don't go in to general practice if you don't want to help people. But we are all human. We have good days and bad days (and good and bad bits of days) and as individuals there are areas where our knowledge and expertise is greater than in

other areas. Though one thing is for absolute certain – you cannot know everything about everything.

During the course of an average day your GP will be directly consulting either face-to-face, on the phone or email, with anything up to 60 patients, making time the most valuable commodity we have. So it can really help to have a plan of the things that you would like to cover during your consultation to get the most out of the time available with your GP, whether it's writing down a list of things you would like to discuss, bringing along a friend or family member or checking what's been covered so you leave the consultation fully understanding what the plan and next steps are. The RCGP have produced a useful patient guide to GP services that has other useful tips to getting the most out of both your consultation and the GP practice itself.

(http://www.nhs.uk/choiceintheNHS/Yourchoices/GPchoice/Documents/rcgp_iyp_full_booklet_web_version.pdf)

When considering rarer conditions such as EDS it's probably fair to say that many GPs won't have a great deal of experience and knowledge of patients with the condition, but it can certainly be worth asking around at your practice – you just might be surprised. GPs, like all other healthcare professionals, learn the most important lessons from the patients we see, and being involved in the care of someone with a rarer condition is a steep learning curve, but that experience is carried with us throughout our careers. Remember also, that whilst healthcare professionals can be experts on particular disease areas or parts of the body, you are the 'expert in you' and how a health condition may be affecting your body and mind. So if you have access to useful sources information or can highlight good areas of practice, please let your GP know.

Good relations and communication between you and your GP are essential. You should be happy with your GP on a professional and personal level, which will require thought, consideration and patience from both of you. If you feel that the relationship you have with your GP is simply not working, for whatever reason, I would urge you to exercise your right to choose another GP, either within the same practice or at another practice. Although for most people this choice is currently limited to a practice near where they live, there are almost ten thousand GP practices in the UK with around sixty thousand practicing GPs, so hopefully you should be able to find someone that you can develop a working relationship with.

The NHS choices website (www.nhs.uk) will help you find a local GP practice and has a really useful page on choosing a GP. There is also the opportunity to leave feedback (anonymous or otherwise) about the service you have received, both good and bad. Good practices take this feedback very seriously and will try to respond constructively to negative feedback, but also find positive feedback really rewarding and motivating. You could also consider joining the patient participation group at your GP practice to really help shape the services that are provided. Other forums are available such as www.patientopinion.org.uk that facilitates dialogue between patient and health service providers to improve services.

Within the NHS constitution there are other important legal rights – that of choice and of complaint and redress. Choice of healthcare practitioner, choice of treatment, choice of location of care and the right to say no to treatment if you wish. You have the right to have any complaint you make about NHS services acknowledged within three working days and to have it properly investigated. And the right to be kept informed of progress and to know the outcome of any investigation into your complaint, including an explanation of the

conclusions and confirmation that any action needed in consequence of the complaint has been taken or is proposed to be taken.

What about seeing a specialist? In the NHS you are entitled to ask for a referral for specialist treatment on the NHS and to do this you will need to see a GP at your registered practice. This is because all your medical records are held by your GP and even if you are referred to see a specialist your GP remains responsible for your overall care. However, the decision whether or not a referral takes place will depend on what your GP feels is clinically necessary in your case and also who might be the most appropriate specialist to see. If you feel that you are being unnecessarily prevented from seeing a specialist when it is necessary, then it's important to bring this up with your GP or one of their colleagues at the practice to understand the reasons behind the decision and agree a way forwards. If you do need to be referred to a specialist, you can choose to be seen at any hospital in the country as long as it is offering a suitable treatment that meets NHS standards and cost.

You can ask your GP or another healthcare professional for a second or further opinion (an opinion about your health condition from a different doctor).

Although you do not have a legal right to a second opinion, a healthcare professional will rarely refuse to refer you for one. What is vitally important when you are seen by a specialist is good communication between all parties – you, your GP and the specialist, so that everyone involved in your care is fully informed of what's happening to you.

So, to conclude, good healthcare is a team effort with patients and healthcare practitioners working together to get the best possible outcomes. In the NHS patients and the public and staff have rights and responsibilities, and above all choice, to get the best care possible.

Dr Tom Margham is a GP in Tower Hamlets, East London and Lead for Primary Care at Arthritis Research UK. You may also find the following links useful:

Living with long term pain:

<http://www.arthritisresearchuk.org/arthritisinformation/arthritis-and-daily-life/pain-and-arthritis/pain-report.aspx>

Second opinions:

<http://www.nhs.uk/chq/Pages/910.aspx?CategoryID=68&SubCategoryID=156>

Complaints:

<http://www.nhs.uk/choiceintheNHS/Yourchoices/GPchoice/Pages/GPcomplaints.aspx>

Choice in the NHS:

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Yourrightstochoice.aspx>

Chico and Jeff's Fundraising Trip

Hi everyone, Chico here! I've been a very busy monkey this month, as I've been to Manchester and Blackpool a couple of times, and Ireland too! I was very kind and let my friend Jeff tag along for the ride (I needed someone to carry my bags).

If you become my friend on Facebook (search for my full name "Gulliver Chico Glasser") you'll be able to see all that I get up to on my travels, with lots of pictures too. Make sure you do it in time for my big



trip at the start of November, because I hope to raise money for the group as well as having lots of fun.

Jeff had a good idea of taking pictures of him and I (but mostly me!) while we are on our big round the world trip. We will be stopping off in places like Singapore and Australia and will be away for a month.

We have heard that there are Build-a-Bear workshops (where Jeff found me) all over the world, so it's wonderful opportunity to expand my wardrobe and get some great pictures for you all to enjoy.

I will also be wearing a blue ribbon on my clothes. A blue ribbon is the symbol for M.E awareness, so I hope to spread the word about M.E while I am out and about.

Don't worry if you don't have internet access, we will try and post as many as we can with updates in the newsletter for you.

If you like Jeff's (and Chico's) idea and enjoy their photos and updates, please consider donating to the group. His GoFundMe page is here:

www.gofundme.com/gulliver where you can donate securely by credit card.

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. Thank you.

Culinary Corner

Please join in with sending in your favourite recipes sweet or savoury.
maxine@mesupportgroup.co.uk.

This month we have **Bacon Hot pot**

This can go into a slow cooker

Also replace the bacon with cheese for cheese and onion version.

Ingredients

serves 4

700 g (1 1/2 lb) potatoes, peeled and sliced

8 oz (225 g) bacon

1 large onion, chopped

Salt and pepper to taste

3 tbsp (25 g) flour

2/3 cup (150 ml) 1/4 pt meat stock

Method

1. Boil the potato slices in lightly salted water for 5 minutes, then drain well.

2. Cut off the rind and chop the bacon.

3. Layer in a greased casserole dish the potatoes, bacon and onion.

4. Sprinkle with salt and pepper.

5. Blend together the flour and stock until smooth, then pour over the casserole ingredients.

6. Cook in the oven Gas mark 4, 350°F (180°C) for 45 minutes.

Late edition – September 2014

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

Some GPs can be reluctant to make a CFS/ME diagnosis and might be unsure how to manage someone with the illness. So a UK research team looked at 21 studies to find out how other health professionals overcame the issues. They found GPs who made a diagnosis tended to have a broader outlook of the condition and more positive attitudes towards CFS/ME. The same GPs worked with the patients and agreed on how they would care for themselves and manage the symptoms. The team recommended more appropriate training is given to make sure the patients receive the necessary care and treatments. Overcoming the barriers to the diagnosis and management of chronic fatigue syndrome/ME in primary care: a meta synthesis of qualitative studies – Prohealth – Sept 6

Up to 40 families have been investigated by child protection officers after disagreeing with GPs about their diagnosis and treatments for their children who they say have CFS/ME. The issue was raised by Dr Nigel Speight, a paediatrician and adviser to the Tymes Trust (The Young ME Sufferers Trust). If a GP does not diagnose CFS/ME and the family complains, then the child can be referred to social services and even taken away from their parents. Dr Speight is asking for GPs to diagnose according to the guidelines so that families do not have to face suspicion, doubt and possible break up. 40 families reported to social services after GP disputes - The Sunday Times – September 27

A patient of Dr Paul Cheney, in the USA, recently wrote about the treatments offered to him. He calls it the Cheney protocol because the doctor has developed a number of specialised treatments that have helped people with CFS/ME. Some of the prescriptions include EDTA, Argentyn 23 and Vasoactive Intestinal Peptide. They also include lifestyle changes such as drinking only bottled water, diet changes and saying “no” to avoid a relapse. He also recommends Hydroxocobalamin to address toxins, Klonopin to help with energy and Magnesium for better sleep. The writer accepts the treatments may need some adjustments because the dosages will not be “right” for everyone. He also recognises the expense involved which could be too high for some. - The Cheney Protocol for Chronic Fatigue Syndrome – Prohealth – September 17

In a separate article Dr Richard Powell, also based in the USA, discusses his preferred treatments. They include Low Dose Naltrexone, antiviral drugs and AHCC to improve the immune system. He also moves onto anti-inflammatory treatments such as Low Dose Naltrexone and Doxycycline. He also mentions rituximab, but points out it is toxic and is not currently used in his surgery. He also tests patients for MTHFR folic acid mutation, low coenzyme Q, low carnitine, magnesium, zinc and other nutritional metabolic factors. - Ask the Doctor: What Are Your Favourite Treatments for ME/CFS? – Prohealth– September 30

In December The ME Association will be launching a £100,000 appeal to raise money to fund the ME/CFS Biobank. The “bank” contains blood samples of people with the disease and is used by researchers in the UK, and around the world, to help with a wide range of research projects. In advance of the campaign, they launched a 3 min film where leading researchers impress on how important the Biobank will be and how it will ultimately benefit patients. - New live film for our ME/CFS Biobank Appeal – could you become a sponsor today? – September 25

Do you take, or have you taken LDN?

This lady has contacted me about Low Dose Naltrexone. Please can you contact her email at the bottom if you can help. (edit- this is what LDN is, you can;t get it on nhs and even

very hard on private prescription): <http://phoenixrising.me/.../antiviral.../ldn-low-dose-naltrexone>

Do you take or have you taken LDN for ME/CFS? Can you help me? Please read on!

You may have heard of people taking LDN for ME/CFS. Are you one of those people? Has it worked well for you – well enough that you'd want others to know about it? Can you think of the one group of people that don't know about LDN? - doctors! Why? Because there's very little written about LDN in the medical journals. There are very few clinical trials of LDN in any disease and there isn't a single case report in a medical journal of someone with ME/CFS improving when they take LDN! (Anecdotal reports on the web don't count as far as doctors are concerned.) And until that changes, those of us on LDN will have real difficulties getting prescriptions for it from our doctors.

I have just started a Masters in Research degree at Manchester University, England, with the sole purpose of learning how to organize a clinical trial of LDN in ME/CFS. It will take me several years. But before I could set up a clinical trial, I have to convince the local Medical Ethics Committee that LDN is safe to use in ME/CFS, otherwise they won't allow me to do the trial. So I must be able to show them some published work in a medical journal about LDN in people with ME/CFS. The first stage is to get some case reports published – that's just an account of what happened to some people when they started LDN – how they improved, any side effects, what dose they now take etc.

I'm an ex-doctor and I'm one of the lucky people who has responded well to LDN. I was mainly house bound before I started LDN and I now have a full life – not quite 100% but not far off. I'm wanting to write my story up as a case report, but I need others to join me. The more people I write up in one go, the more likely it is to be accepted for publication. So, would you consider volunteering? If so, please get in touch. I particularly want to hear from you if your health has improved a lot on LDN. That may not be you, but someone you know who is back at work or has found a new hobby and not likely to read this – please ask them. Also, if you were on LDN and have now stopped it for any reason, I'd like to know how you are now compared to when you were on LDN.

Please remember, I am no longer a doctor, and can't give advice about LDN, or suggest at this stage that anyone starts taking it – we need the clinical trials to show whether it works, and how effective it is.

But please – if you think you could help me – get in touch!

Thanks

Monica Bolton

mjbtd8@phonecoop.coop

Hi everyone.

I'm looking to include some CFS/ME related stories for the newsletter which are about your experiences. They could be related to your GP, visits to the hospital, life at home or at work. Whatever it is, I'm hoping it will make the newsletter more relevant as people can identify with what others have gone through. If you'd like to take part please email me first and I'll get in touch. You can also remain anonymous to protect your identity. Andrew
Contact: andmk1@gmail.com.

Sorry

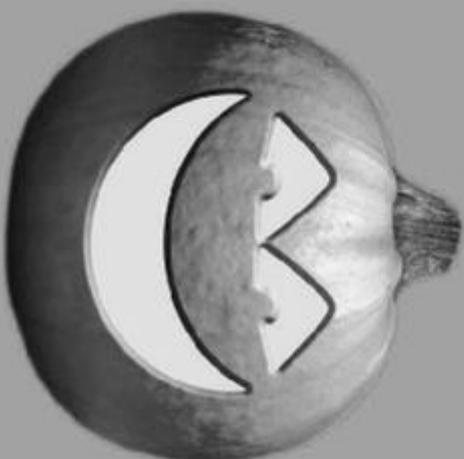
No Trick or Treaters Please



*There are no treats here.
Please be polite on Halloween night.*

Hello

Trick or Treaters Welcome



*There are treats here, but remember
be polite on Halloween night.*

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