

## Welcome to Our April 2014 Newsletter

Note from the Editor Maxine: Thank you to Caroline for doing this month's newsletter whilst I'm recuperating. Thank you for the gift.

Note from Caroline: Thank you to all who have sent in their renewal forms for membership so far. Please send yours in ASAP if you haven't already. Membership is £8 please.

From May onwards, we will be moving across the road to the main church building for our Harwood meetings. The venue of our Prestwich socials has also changed.



READ MY LIPS. DOCOTR - EXERCISE ONLY MAKES HER EXHAUSTION EVEN MORE OVERWHELMING.

With thanks to Invest in ME ([www.investinme.org](http://www.investinme.org)) for their kind permission to reprint this cartoon from the calendar available to download from their website.

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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**

**Longsight, Harwood Meetings:** Our main meetings, often with guest speakers, are held at Longsight Methodist Church (the big stone building with an elongated wheelchair ramp outside, not the smaller church hall opposite), Longsight Lane, Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). There is a car park and blue badge parking on the street and the building is wheelchair accessible. Entrance is £1. Tea, decaf coffee, water, biscuits, 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).

### **No Harwood Meeting in April.**

**Thursday 15<sup>th</sup> May 7:30pm: Dr Raymond Perrin:** Dr Raymond Perrin will be coming to talk about his latest research

**Thursday 19<sup>th</sup> June 7:30pm Tracy Hughes, Holistic Therapist:** She does reiki and massage and has been recommended by members. She is based in Tottington.

**Thursday 17<sup>th</sup> July 7:30pm Bring and Share Supper Summer Social:** Our second annual bring and share summer supper, where we all bring food to share. There are always plenty of leftovers and lots of gluten/egg/dairy free, etc.

**Neuro Support Groups:** These groups, run by Greater Manchester Neurological Alliance, provide information, advice and support for people with any type of neurological condition and/or their carers. Call 0161 743 3701 or visit [www.gmneuro.org.uk](http://www.gmneuro.org.uk) for information about meeting times and locations.

**Yoga Classes:** Are 3:30pm-4:30pm on Tuesdays at the Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX. Please arrive around 3:20pm. 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.**

**Radcliffe Socials:** The Sparking Clog is set to reopen after refurbishment at the end of April, so all being well, our next Radcliffe socials will be on the first Wednesdays of the month again- **Wednesday 7<sup>th</sup> May, and Wednesday 4<sup>th</sup> June at 2pm.** The Sparking Clog has ample parking and is wheelchair accessible. We will put our newsletter on the table, so you can recognise us. The address is Moor Road, Radcliffe, Bury, M26 3WY.

**Prestwich Socials:** Attendance has picked up in recent months at the Prestwich socials. Maybe because there are no Sparking Clog socials in Radcliffe whilst they undergo their refurbishment, or the danger of them stopping has increased attendance. Now the Clog socials will be starting again, we will see how attendance at Prestwich continues. **Please note change of venue to The Church Inn, 40 Church Lane, Prestwich, M25 1AJ. This has level access and free parking outside.**

May's meeting is provisionally set for the usual second Wednesday of the month- **Wednesday 14<sup>th</sup> May 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.**



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### **Reminders:**

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

**Radar keys:** We have Radar disabled toilet keys available at cost (£2.35, plus 50p if posted, or you can pick up at our Harwood meetings). Small headed or large headed (for those with dexterity problems). Contact Caroline on 01204 525 955 or email [caroline@mesupportgroup.co.uk](mailto:caroline@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).

**Helpful GP's:** Don't forget, we have a list of helpful GP's! There are only 13 on it at the moment, but 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).

**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.

**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).

**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. Please send your contributions to: [maxine@mesupportgroup.co.uk](mailto:maxine@mesupportgroup.co.uk), or if you are unable to email, post to Maxine Fairhurst, 33 Heath Avenue, Summerseat, Bury, BL0 9UN

**March A.G.M meeting and raffle:** Thanks to all who attended our Annual General Meeting in March. Business was conducted in a record 11 minutes! This left lots of time for the raffle and a chat. We had far more prizes than people! We raised £66 from the raffle, thank you. Caroline would like to pass on the raffle prize collecting baton to someone else, are there any volunteers please? Please get in touch on 01204 525 955.

**Yoga Class Changes:** We're sorry to report that Olivia has decided to move on from leading our yoga classes, which she has been teaching for 9 years now. Members say they are very good for relieving stress, maintaining flexibility, and getting rid of aches and pains. The class presented her with a card and plant as a farewell gift. We wish her all the best for the future. We welcome her replacement, Julia Silver-Wren.

The room we are in, and time of the yoga has also changed. It is now in a carpeted, quieter room and the lights can be turned off. Since we have moved rooms, the times have changed slightly, to **3:30pm-4:30pm, they are still every Tuesday.** Please arrive around 3:20pm to get settled. Yoga mats and blocks are provided, please wear loose comfortable clothes. If you haven't been to a class yet, why not come along and give it a go? The exercises are very gentle and you don't have to do anything you don't want to. They are at the Jubilee Centre, Bolton. Reception staff can direct you to the room. We have received funding to provide the classes for free. **Our yoga classes are currently being funded by Comic Relief and The Co-operative Membership Community Fund.**

**Longsight, Harwood meetings moved:** As mentioned above, our meetings at Harwood, have now moved (but not very far!). We have been in the Methodist Church Hall since 1991 when our group was officially formed. Longsight Church have built a lovely community hall in the main church, in the building opposite, and we will now be meeting in there from now on.

We can still use the same car park as we have done till now, which is next to the Church Hall. There are also double yellow lines outside the front, and to the side of the church, so you can park on there if you show a valid blue badge and time disc. There is a long wheelchair ramp up the front entrance. There is normal parking on the road further down Longsight (the main road) and Longsight Lane.

The Church's address is Longsight Church Hall, Longsight, Harwood, BL2 3HX. The Church does not have a number itself, but is next to house number 120 Longsight, so the best Sat Nav instructions to use are 120 Longsight, BL2 3HX. Longsight Church is a large stone building on the main road. It is on the 507 bus route.

Please come and join us for our meetings, you are welcome to bring a friend, relative, etc.

**CFS/ME Service changes:** We are sorry to tell you Helen Davin, senior neurological physiotherapist and team leader left the CFS/ME Service on 20 March 2014. She has been an integral part of the Service since it started in 2005. We will greatly miss her commitment and passion to help and support ME patients and their carers. Her professionalism in maintaining the profile of CFS/ME has been exceptional and she has always kept her knowledge of developing research and strategies up to date.

We wish her well in her new career at Physio Worx, Carrington Lane, Sale, Manchester M33 5NL, where she will be available to see ME patients privately. Her telephone number is 07563770796 or [helendavin@physioworx.co.uk](mailto:helendavin@physioworx.co.uk).

Helen's position in the CFS/ME Service is being advertised shortly and we look forward to welcoming her replacement.

On behalf of the Support Group I gave Helen a basket of flowers and card to thank her for all the love and support she has shown to us over the years.

Also Janet Priest, the manager of the CFS/ME Service took early retirement on 28 February. Janet has been an important part of the Service since its inception in 2005 and worked very hard to ensure the Service developed to what we have now. She has always worked very closely with Dr Gaber to meet the needs of CFS/ME patients. Michelle Wardle, who has worked alongside Janet for several years, will take over the day to day management of the Service and Simon Crozier will be the Principle Service Lead.

On behalf of the support Group I gave Janet a basket of flowers and card to thank her for all the love and support she has shown to us over the years. We wish her well in her retirement. Yvonne Leech



### **Chaperones Required for NHS Research Project:**

**30 Volunteers required to be chaperones for a new NHS research project at Wrightington Hospital, Wigan starting in July. Please ask your friends, family, carers, if they could participate for this important research.**

**Examining the accuracy of a physical diagnostic technique For Chronic Fatigue Syndrome/Myalgic Encephalomyelitis**

**Aim:** The aim of this study is to explore if there is validity in the use of specific physical signs as an aid to diagnosing CFS/ME

**Recruitment** :100 participants, 50 CFS/ME sufferers and 50 healthy controls, will take part in the study, which will consist of CFS/ME patients and participants who do not have CFS/ME as controls who have seen the advert for the research and have voluntarily contacted the research assistant.

**Health professionals involved the study:** Two practitioners will separately carry out the examination of the participant using the Perrin Technique.. The third practitioner involved in examining the participant will be a physician who will not have had any experience regarding the physical aspects of the Perrin technique.

**Examination of Participants:** The participant will see all three practitioners on the same day at Wrightington Hospital. This will take place no later than 1 month after consenting to the study.

The examination of the participant by both the physiotherapist and osteopath will follow the same format based on the physical signs being tested

The NHS physician will examine the participant using a standard clinical neurological and rheumatological examinations. As with the other two practitioners, no clinical history will be taken and the physician will only perform neurological and musculoskeletal screening tests on the upper and lower extremity.

**The Role of The Chaperone:** A chaperone will be present while the physical examination is carried out primarily to listen, observe and verify what is discussed and carried out. They must ensure that no conversation is carried out between the practitioner and participant with the exception of asking if there is any pain or tenderness on palpation of certain regions. The chaperone will also be there to safeguard both the practitioner and participant to identify any unusual or unprofessional behaviour. They will also witness the diagnosis and conclusion of the practitioner and validate the documentation by signature.

For the success of this project we need chaperones to volunteer for five hours on at least one Sunday from July 2014 to June 2015. We need three chaperones per day and there will be 10 Sundays during the research project that we will be seeing participants in Wrightington. So we need 30 volunteers in total (NB if you want to do more than one day...Great!) Please contact Dr Perrin at [drperrin@theperrinclinic.com](mailto:drperrin@theperrinclinic.com) if you want further details and are interested in volunteering. Thank you.

**Thinking of Buying a Scooter? By Jeff Glasser:** I thought it may help people who are considering buying a new or used scooter or electric wheelchair to provide some points to consider before proceeding with your purchase.

Where are you going to store it? This is a biggy because if you have nowhere to keep it you have problems. If you store it in the house, is there a step or door-ledge you'll need to get it over? Are you strong enough to lift it over? Consider an Occupational Therapy assessment off the council who may be able to provide ramps, etc. You could also get ones made out of wood. Is there an accessible garage or shed where it can be kept? If not, will there be problems trying to find a suitable place in the house without causing an obstruction (also think of fire safety if it blocks an exit, this is an issue in sheltered housing)? What about an electrical supply to charge the battery? Is it safe to keep in your car boot overnight?

Have you ever driven a scooter or electric wheelchair before? If not why not join one of the Shopmobility schemes if you meet their membership conditions. Try using different types for a while to see which suits you best if at all. Do any of your friends have one you can try

out? You could also contact organisations such as Disability Living Service to see if they can advise on suitable vehicles for your needs

Are you more comfortable with either a 3 or 4 wheel scooter, or if an electric wheelchair is better, can you operate it yourself or do you need someone else to operate the controls? There are smaller 3 wheel ones which have better manoeuvrability for going around shops, and are lighter for getting in cars. The 4 wheel ones are bigger, but more stable and can go further distances and are usually faster.

What do you want to use it for? If you want to get to the local shops are there sufficient dropped kerbs, how dangerous are the roads to cross? Why not try it in a manual chair with someone pushing you to feel the severity of the kerbs, or if you are able, try walking & see if you would be safe, what obstacles are there to negotiate?

What about trips out to towns & cities? It matters how you are going to reach your destination. Not all public transport is accessible, (or easily accessible)! To take scooters on the tram, you need a permit and the scooters need to meet certain conditions (they were previously banned up until this month, they are trialling allowing them back on). Luggie brand scooters are allowed on without a permit, as they can be encased, but these can be expensive.

If travelling in your own or a family car how will the vehicle fit in, will it need taking apart? If so because of the size & weight (average foldable scooters are about 38kg, but they separate into several components) is there someone with the ability, hand dexterity and strength to dismantle, lift it in the car, then reassemble it at the other end (if the car is big enough)? Can you have a hoist fitted? These can be quite costly though, but are more reasonable when added on when ordering a new Motability car, if you are eligible for one if on certain benefits.

Where are you going to buy it from? Beware of companies that are only interested in making a sale at a great profit, make sure you check out various providers & check the different prices. Internet companies are usually cheaper, but customer service can vary widely. Ask friends where they bought theirs, were they happy with after sales service? Ask on our group's Facebook page, many members can offer advice. Again some people say buy off EBay.co.uk (you can get good deals of barely used scooters if you search for auctions local to you), others tell of disasters particularly if cheap, the batteries often need replacing which can be costly, members have told us.

How are you going to pay for it? Bearing in mind that they can cost thousands of pounds for a good new one and depreciate quite quickly in value. You can get electric scooters on the Motability scheme, but consider if it is worth handing over £55 a week for 2/3 years for a scooter which you could buy much cheaper in the shops, or second hand. Grants and benevolent funds exist for those on low incomes or in former professions to purchase aids and equipment (Try <http://www.disability-grants.org>).

What about insurance in case it breaks down, is stolen, if you damage other people's property, or injure somebody? How will you pay for this? After a couple of years, the policy may not cover the full value to purchase a new scooter, only what it is worth at the time. There are several insurance companies that offer scooter/wheelchair insurance. Your house contents insurance may cover it if it was stolen/damaged in your house, but not if kept in your car on the driveway.

I hope the above has been helpful I am not trying to put you off obtaining a scooter or wheelchair only trying to help you to consider the options avoiding some or all of the pitfalls in owning your own.

**The Mobility Trust:** If you are in desperate need of a powered wheelchair or scooter and cannot obtain one through statutory (NHS) sources or afford to purchase such equipment yourself, you can apply to The Mobility Trust.

Please write a letter explaining why you need this equipment, giving details of any disabilities you have. Address your letter to: Mrs Anne Munn, Mobility Trust, 17b Reading Road, Pangbourne, Berkshire, RG8 7LR. See <http://mobilitytrust.org.uk/>

**Hydrotherapy sessions:** Preston and Chorley Fibromyalgia and Chronic Pain Support Group have kindly offered to let our group attend their hydrotherapy sessions on a trial basis for 3 months. If successful, we can consider carrying it on long-term.

Hydrotherapy (aquatic therapy) is physiotherapy treatment in water, instead of on dry land. Water provides buoyancy, which relieves the stress on weight bearing joints and allows movement without the impact of gravity. The resistance can also be used to challenge muscles. Hydrotherapy can help ME/CFS by aiding in pain relief, easing muscle/joint stiffness, strengthening muscles, and also improve relaxation, well-being and quality of life.

The sessions are 12pm-1pm on the first Friday of the month, at the Jubilee Centre, Bolton. It is £3 per person and carers are free.

The sessions will be on: **2<sup>nd</sup> May, 6<sup>th</sup> June, 4<sup>th</sup> July from 12-1pm.**

Their group private hire the pool and changing rooms, so it is a lot quieter than when the pool have sessions open to the public. 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.

It would be good if you had physiotherapy exercises to do in the water, or just paced up and down a few times. Also, take a drink for afterwards and have a bit of a rest before you go home if you need it. At first, perhaps limit yourself to 20-30 minutes in the water to see how you go on and your symptoms are afterwards. I know from experience that it is quite difficult to get a hydrotherapy referral, so this is an excellent opportunity to try it out.

Thank you to group leader Natalie for the generous offer to our members. If you have any questions or are interested and want more information, please contact Caroline on 01204 525 955.

### **Non De Plume:**

I have always been interested in transformation, especially the kind that delivers instant gratification. Tempering Chocolate satisfies such an itch, but can appear challenging and therefore better suited to a lab than domestic kitchen. But there are ways and means around such intimidation, were one does not have to compromise on flavour or succumb to spending too much time in the kitchen.

As well as having a fascination with chocolate's physical form, I have an equal interest in its flavour. It has the ability to absorb other ingredients and in so doing, becomes more complex. The ability to draw from and into other flavours means chocolate is as well suited to savoury as sweet dishes. I admire this flexibility greatly and it may explain why it has become part of my arsenal.

But there is much more to the power of Chocolate than this. Contained within its core is the ability to soothe, unite and repair the very tired and deficient amongst us, which is the most proficient talent of all. May you all have a happy and restful Easter.

### Not cheese cake

#### Ingredients

120g of dairy free margarine  
300g of wheat and dairy free biscuits  
2 large organic free range eggs  
300g of Lindt (90% dark chocolate)  
2 tablespoons of tahini (room temperature)  
1/5 teaspoon of smoked salt  
5 drops of orange essence  
The zest of an organic orange

- Lightly grease a 15cm spring form tin.
- On a moderate heat, slowly melt the margarine
- Using a food processor, grind the biscuits into a medium crumb texture. Combine the two ingredients thoroughly. Firmly pat the mix into the base of the tin.
- Zest an orange, and sprinkle it over the biscuit base. Refrigerate until hard, preferably overnight.
- Separate the egg whites from their yolks. Using a kitchen-aid, whip the whites until very firm and fluffy.
- Bring a small pan of water to the boil while breaking the chocolate up into small pieces. Remove the pan from heat, immediately placing a bowl containing broken shards of the chocolate, on top of the saucepan, to the melt chocolate. Leave till completely melted.
- Should the chocolate need a little more heat, repeat the process, taking care not to burn it. Remove the bowl of chocolate from the pan. Add to it the tahini, salt and essence.
- Stir to combine and infuse the chocolate with their flavours.
  
- Add the egg yolks into the chocolate mix, which will change its texture.
- Allow the heat from the chocolate to cook the yolks for several minutes.
- With a spatula, spoon all the chocolate sauce into the egg white.
- Whip until completely combined and at the consistency of single cream.
  
- Remove the tin containing the biscuit base from the fridge.
- Pour the sauce onto the base, returning it to the fridge as soon as possible.
- Leave overnight to set into a firm mouse.
- Remove the cake from tin and decorate it with fresh fruit or additional orange zest.
- Serve with coconut or almond cream.

**Diseases can stigmatize:** Leonard A. Jason is a professor of clinical and community psychology at DePaul University, director of the Centre for Community Research, and the author of Principles of Social Change. This article originally appeared on the OUPblog, (a US website) reprinted with kind permission:

<http://blog.oup.com/2014/01/diseases-can-stigmatize-chronic-fatigue-syndrome/>

Names of diseases have never required scientific accuracy (e.g. malaria means bad air, lyme is a town, and ebola is a river). But some disease names are offensive, victim-blaming, and stigmatizing. Multiple sclerosis was once called hysterical paralysis when people believed that this disease was caused by stress linked with oedipal fixations. AIDS was initially called "Gay Men's disease" when it was considered a disease only affecting white gay men. Fortunately, when these disease names were changed, those afflicted with Multiple Sclerosis and AIDS experienced less stigma. Inspired patient activists from around the world are currently engaged in another major effort to rename chronic fatigue syndrome (CFS). It is a political struggle to alleviate some of the stigma caused by the language of scientists at the CDC 25 years ago.

Chronic fatigue syndrome is an illness as debilitating as Type II diabetes mellitus, congestive heart failure, multiple sclerosis, and end-stage renal disease. Yet 95% of individuals seeking medical treatment for CFS reported feelings of estrangement; 85% of clinicians view CFS as a wholly or partially psychiatric disorder; and hundreds of thousands of patients cannot find a single knowledgeable and sympathetic physician to take care of them. Patients believe that the name CFS has contributed to health care providers as well as the general public having negative attitudes towards them. They feel that the word "fatigue" trivialises their illness, as fatigue is generally regarded as a common symptom experienced by many otherwise healthy individuals. Activists add, that if bronchitis or emphysema were called chronic cough syndrome, the results would be a trivialization of those illnesses.

Powerful vested forces have opposed changes. In the late 1990s and early 2000s, when I mentioned over the years that patients were stigmatized by the term chronic fatigue syndrome, I was explicitly told it was reckless and irresponsible to change the name. This was despite the fact that patients wanted more medical-sounding name, and our research group had found that a more medical-sounding term like myalgic encephalopathy (ME) was more likely to influence participants to attribute a physiological cause to the illness. Over the last decade, patient demands for change have grown louder. New names have occurred for several patient organizations (e.g. the Patient Alliance for Neuroendocrine-immune Disorders Organization for Research and Advocacy and the Myalgic Encephalomyelitis Society of America) and research/clinical settings (Whittemore/Peterson Institute for Neuro-Immune Disease). Even the federal government has begun to use the term ME/CFS, and the organization of researchers changed their name to the International Association of CFS/ME. Ultimately, many activist groups want the term myalgic encephalomyelitis to replace CFS. Bringing about a name change is a complicated endeavor, and small variations of language can have significant consequences among the stakeholders.

In addition to this effort to rename chronic fatigue syndrome, there is considerable patient activism to change the case definition, which was arrived at by consensus at the CDC rather than through empirical methods. Patients report and surveys confirm that core symptoms of the illness include post-exertional malaise, memory/concentration problems, or unrefreshing sleep. Yet these fundamental symptoms are not required within the current case definition. Patients want the current case definition to be replaced with one that requires these types of fundamental symptoms. If laboratories in different settings identify samples that are not homogenous, then consistent biological markers will not be found, and then many will continue to believe the illness is one of a psychogenic nature, just as once occurred for multiple sclerosis.

Clearly, issues concerning reliability of clinical diagnosis are complex and have important research and practical implications. In order to progress the search for biological markers

and effective treatments, essential features of this illness need to be empirically identified to increase the probability that individuals included in samples have the same underlying illness.

If progress is to be made on both the name change and an empirical case definition, key gatekeepers including the patients, scientists, clinicians, and government officials will need to work collaboratively and in a transparent way to build a consensus for change. Considerable activity is currently ongoing at the federal level on these critical issues, but only through open communications and the building of trust will there be the possibility of overcoming the past 25 years, which have been marked by feelings of anger and hostility due to being excluded from the decision-making process.

### **Child Protection Issues:** (with thanks to Tymes Trust)

Once again, I return to this whole issue of inappropriate child protection investigations of families whose children have ME.

Paediatrician Dr Nigel Speight is a member of the Trust's Professionals Referral Service. I have worked with Nigel since the early 1990s, including on the Chief Medical Officer's Working Group and compiling the subsequent report. This report, which made important statements about child protection, was never issued to doctors but it was published by the Department of Health: read our booklet 'Revisiting the 2002 Department of Health Report on CFS/ME here: <http://www.tymestrust.org/pdfs/revisitcmreport.pdf>

Dr Speight has recorded interviews and in one of these he describes some of the cases he has dealt with or helped the Trust with. We are now up to our 115th such case and I do urge you to call our Advice Line if anything like this is likely to affect you (0845 003 9002). It is important to seek advice early; we advise families to see their child's medical and school records to find out what may be written there. It is your right to see these. Dr Speight's interviews are at <http://wp.me/s3Txzy-18527>

### **Free prescriptions for people with physical disabilities who need assistance outside:** (Thanks to Chorley & Preston Fibromyalgia & Chronic Pain group.)

Medical exemptions for free prescriptions are available for people if they have:  
A continuing physical disability which means the person cannot go out without the help of another person. Temporary disabilities do not count even if they last for several months.

There are also other conditions which meet medical exemptions, but this you can use if you need assistance outside and cannot go out unaided (e.g. need to be pushed in a wheelchair, or need to be driven and get someone to get your scooter out, etc). M.E is a recognised disability. Remember, we have a letter from Earl Howe stating this, please contact Caroline if you need it for this, blue badge applications, benefits, etc.

To apply for a Medical exemption certificate ask your doctor for an FP92A form. Your GP, hospital or service doctor will sign the form to confirm that your statement is correct. At your GP's discretion, a member of the practice who has access to your medical records can also sign the form.

<http://www.nhs.uk/nhsengland/Healthcosts/pages/Prescriptioncosts.aspx>

## Late edition – March 2014

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

K-PAX Pharmaceuticals believes it may have developed an effective treatment for the disease. They conducted a 12-week pilot study with 15 patients using Ritalin. Dr Jon Kaiser said. "One woman had been out of work for six years due to her symptoms, and went back to work six weeks after starting this treatment." More trials are planned to see how effective the drug is. San Jose Mercury News – [Bay Area pharmaceutical company develops treatment for chronic fatigue syndrome](#) – March 24

Recent research may have proved the theory that Epstein-Barr virus (EBV) is a possible cause of some cases of CFS/ME. In the study however, scientists found evidence that the virus fighting B- and T-cells of many CFS/ME patients were unable to remember EBV, meaning a reactivated virus would be better able to gain a foothold and cause symptoms. Researchers found this "impaired cellular memory" in 76% of the 400+ study participants. Source: [EBV Reactivation: New Evidence for Role in Chronic Fatigue Syndrome](#) – About.com – March 5

This is a long article about mitochondria and CFS/ME. Mitochondria are present in every cell and they provide us with energy. There is strong evidence that they don't function properly in CFS/ME patients. One important section covers the "energy envelope", where patients are asked to recognise the amount of energy they have each day. So, any patient needs to make regular and constant judgments about doing activities that use energy but within their energy envelope. Source: [Mitochondrial Dysfunction, Post-Exertional Malaise and CFS/ME](#) – ProHealth – March 31

A brief article by Action for ME which recognises mums who have CFS/ME and how difficult it could be on a day like Mothers Day. Source: [Chronic ME affects lives of many of our mums](#) – Derby Telegraph – March 26

A US based biotech company, Innovative Med Concepts, has finished phase two testing of a drug that could help Fibromyalgia patients. It started 15 years ago in an effort to find ways to relieve the pain of people suffering from irritable bowel syndrome. Dr William Pridgen has a theory that Fibromyalgia and other gastrointestinal disorders may all be caused by the same virus that causes cold sores. The research is on track towards finding a cure although more tests need to be conducted. Source: [Fibromyalgia drug being researched in Tuscaloosa](#) (Alabama) – CBS42 – March 30

Less than half of patients treated for pain or Fibromyalgia say they are very or extremely satisfied with their prescription medication, according to new findings from Kantar Health, a leading global healthcare consulting firm. The study covered patients across the world and results were divided by country. Satisfaction in the UK was very low at 35%. Kantar's spokesperson said, "Cultural attitudes may come into play with self-reporting and treating pain; patients in Asia, for example, may not experience pain less frequently but may be less willing to admit to their condition than patients in the West," Source: [Pain and Fibromyalgia Sufferers Are Dissatisfied with Treatments, Kantar Health Says](#) – PR Web – March 25

### **Vacant Positions within the group:**

Bury Medical Sub-Group Representative: Vacant

Carers' Contact: Vacant

Parent's Contact: Vacant

Fundraising Ideas: Vacant

Publicity & Awareness: Vacant

Writing the speaker reports at meetings: Vacant