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www.mesupportgroup.co.uk

The Bury/Bolton ME/CFS Support Group was founded in September 1990
and is managed by a committee of six members:

Pam Turner, Margaret Benn, Ann Richards, Maria Sale, Sheila Myerscough & Kim Finney.

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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.

Supported by:
Health for Bolton, via Bolton CVS



Dates For Your Diary

Longsight Meetings: Our main meetings, often with guest speakers, are held at Longsight Methodist Church, Longsight Lane. Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). Entrance is £1, tea, coffee, water, biscuits, etc provided.

Thursday 21st October 2010 – Dr Carolyn Routledge will talk about the Egyptian collection at Bolton art gallery and museum, show slides of excavations in Egypt and bring some objects from the collection.

Thursday 18th November 2010 – The pre-Christmas social with “Bring & Share” buffet supper.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 1st November at 4pm**, at **The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY**. It has plenty of parking, good accessibility, comfortable seating, is relatively quiet and serves very tempting chips that we just can't resist. For anyone who does fancy a snack, these start at just £1.50, with main courses from £3.50. For more information please phone 07919 234256 or email dave@mesupportgroup.co.uk.

Bury Socials: These are continuing on the first Thursday of every month, the next will be **Thursday 4th November, 3pm** at **The Automatic, next to the Met theatre** (it is across the street from Yates, not the Met Café next to Yates), **Derby Hall, Market Street, Bury, BL9 0BW**. http://themet.biz/location/find_the_met.pdf.

If you need any more information, please phone Sheila on 0161 7970026 after 12noon.

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. Contact Olivia on 01706 829488, or olivia@oliviayoga.co.uk for more information.

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 for information about meeting times and locations.

PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANKYOU.

New Scooter

Thanks to Yvonne and family, who requested no flowers but donations to our group, on the sad occasion of Russell's funeral, we have been able to buy a new scooter. It is to be a permanent reminder of a true gentleman who was a founder member of our group. Many, many thanks to Yvonne and her family from all of us.

The Next Carers Outings

Don't forget to return your form and let Pam know as soon as possible which date you want to come.

Bolton/Bury ME Support Group Meeting September 2010: **Petra Barlow Holistic Therapist**

Petra told us her story and began by saying originally she trained as a hairdresser but very soon decided that it was not for her. Whilst at college she had done work experience in a health farm in Northampton and eventually got a permanent job there and so left home to live in that area.

She had a wonderful time working there and met some very interesting people such as George Best and Jimmy Saville. Whilst she was there she married and divorced and then came back home to Manchester and through one of her clients she went on a blind date and met the person she felt was “the one” and she got married again. They ran a garden centre together and then she became pregnant but during her pregnancy they had many difficulties, they had financial problems when Barton Grange opened and the business had to close, her husband had a nervous breakdown and later was diagnosed with cancer. He had operations and went into remission but it was like living with a time bomb. They were told he had 6 to 18 months to live and he died at 18 months when their son was still a baby.

Petra then returned to her therapies and has done many courses including counselling training.

Her son became ill and never really recovered and after having a d&v bug he became much worse, losing 11/2 stone, this put Petra in a panic and as a mum she would rather have the illness herself.

Petra believes stress plays a major part in any illness and feels that all the stress she had whilst she was pregnant was transferred to her baby whilst he was growing inside her and this resulted in his illness.

Petra praised Gail Sumner's work and said that she has helped Dominic and she went on to tell us about the healing power of touch and massage. She also feels that self affirmation is a strong tool towards improving for example each morning Petra says to herself “every day I am getting better”. The Touch research Institute has shown that it has a calming effect and helps with many illnesses because it decreases the level of stress hormones.

Petra then did a meditation with us to relax our tension and we visualised the colours of the rainbow in turn to help reenergise the various centres in our bodies.

Petra offers Aromatherapy, Reiki, Indian Head Massage, Metamorphic Technique and Hopi Ear Candling. She has kindly offered her services at half price to members and carers and can be contacted on 01204 453121.

Our Anniversary Meal, 12th September 2010

What a wonderful occasion our 20th anniversary turned out to be. Thanks to a grant provided by Greater Manchester Foundation we were able to celebrate in style at the beautifully refurbished Red Hall Hotel at Walmersley, Bury. We were very happy to have our ME Clinic staff and Dr Raymond Perrin and Elaine join us for an absolutely wonderful meal in sumptuous surroundings. A fantastic afternoon which was enjoyed by everyone.

MAGICAL MEDICINE: HOWTO MAKE A DISEASE DISAPPEAR

By Professor Malcolm Hooper & Margaret Williams

The Medical Research Council's PACE Trial of behavioural interventions for Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) attracted considerable opposition from the outset and the Principal Investigators had difficulty in recruiting a sufficient number of participants. PACE is the acronym for **P**acing, **A**ctivity, and **C**ognitive behavioural therapy, a randomised **E**valuation, interventions that, according to one of the Principal Investigators, are without theoretical foundation.

The MRC's PACE Trial seemingly inhabits a unique and unenviable position in the history of medicine. It is believed to be the first and only clinical trial that patients and the charities that support them have tried to stop before a single patient could be recruited and is the only clinical trial that the Department for Work and Pensions (DWP) has ever funded.

Since 1993, the giant US permanent health insurance company UNUMProvident has been advising the UK DWP about the most effective ways of curtailing sickness benefit payments. The PACE Trial is run by psychiatrists of the Wessely School, most of whom work for the medical and permanent health insurance industry, including UNUMProvident. These psychiatrists insist – in defiance of both the World Health Organisation and the significant biomedical evidence about the nature of it -- that “CFS/ME” is a behavioural disorder, into which they have subsumed ME, a classified neurological disorder whose separate existence they deny. Their beliefs have been repudiated in writing by the World Health Organisation.

In 1992, the Wessely School gave directions that in ME/CFS, the first duty of the doctor is to avoid legitimisation of symptoms; in 1994, ME was described as merely “a belief”; in 1996 recommendations were made that no investigations should be performed to confirm the diagnosis and in 1999 patients with ME/CFS were referred to as “the undeserving sick”. There are legitimate concerns about the MRC PACE Trial that are centred on apparent coercion, exploitation of patients, contempt in which patients are held, manipulation, pretension, misrepresentation, flawed studies yielding meaningless results and lack of scientific rigour; the unusual personal financial interest of the Chief Investigator; the vested interests of the Principal Investigators; high rates of Severe Adverse Events (SAEs) and in particular, the underlying non-clinical purpose of the trial, which seems to have the politically generated aim of removing patients from benefits (ie. the use of motivational behaviour therapy to achieve the intended result of the cessation of benefits for patients with “CFS/ME”). The Manuals used in the Trial seem to show that the authors either ignore medical science or they do not understand medical science.

There is rightful objection to the denial of appropriate investigations and to the nationwide implementation of behavioural modification as the sole management strategy for the nosological disorder ME/CFS. That strategy is believed to be based on (i) the commercial interests of the medical and permanent health insurance industry for which many members of the Wessely School work and (ii) the dissemination of misinformation about ME/CFS by the Wessely School, whose members also act as advisors to UK Government agencies including the DWP, which it is understood has specifically targeted “CFS/ME” as a disorder for which certain State benefits should not be available.

The Wessely School rejects the significant body of biomedical evidence demonstrating that chronic “fatigue” or “tiredness” is not the same as the physiological exhaustion seen in

ME/CFS and persists in believing that they have the right to demand a level of “evidence-based” definitive proof that ME/CFS is not an “*aberrant belief*” as they assert, when their biopsychosocial model of “CFS/ME” that perpetuates their own aberrant belief about the nature of ME/CFS has been exposed by other psychiatrists as being nothing but a myth.

There are some extremely disquieting issues surrounding the MRC PACE Trial and documents obtained under the Freedom of Information Act allow the full story to be told for the first time.

The above is the opening summary of an utterly fascinating 400 page document. If you are interest in reading the rest, we have a copy of it in our library, available at our meetings. Alternatively, it can be downloaded from www.meactionuk.org.uk/magical-medicine.pdf.

XMRV research and update on the link between chronic fatigue and XMRV

Another study has recently confirmed the link between XMRV and chronic fatigue syndrome. This study reinforces the findings of last year’s research by the Whittemore Peterson Institute. In this latest research, 37 out of 41 people with CFS also had XMRV (xenotropic murine leukaemia virus). The same study found only 3 instances of XMRV in a sample of 44 healthy patients. However, this study identified a range of viruses as opposed to a single type. Whilst this is encouraging news, the researchers said, “Further studies are needed to determine whether the same strong association with MLV-related viruses is found in other groups of patients with CFS, whether these viruses play a causative role in the development of CFS, and whether they represent a threat to the blood supply.”

In order to progress this, the 1st International Workshop on XMRV was held in Maryland in early September. In order to resolve disagreements between different laboratories, Anthony Fauci, head of the National Institute of Allergy and Infectious Diseases, will direct a multi-centre study of CFS patients. The new study will involve new blood samples from 100 chronic fatigue patients and 100 healthy people. The samples will come from around the USA, so that there’s no concentration of patients in one area. The samples will then be sent to 3 different labs, and if all 3 find XMRV, the result will be valid and accepted. When the results come in, we’ll cover what the researchers found.

PS: Some scientists, such as Andrew L. Mason, Associate Professor of medicine at University of Alberta, are calling for research into antiretroviral drugs used on chronic fatigue patients. Again, will keep you up-to-date on any new developments.

Ban on M.E. blood donations

From 1 November, the Department of Health will ban blood donations from people who have had M.E./CFS.

In an email to the ME Association, Clara Swinson (Director of Health Protection) wrote: “**This change is being made on the grounds of donor safety, as ME/CFS is a relapsing condition. It brings** practice for ME/CFS into line with other relapsing conditions or neurological conditions of unknown origin.”

The change follows a recommendation by the UK Blood Services Standing Advisory Committee on the Care and Selection of Donors, and Joint Professional Advisory Committee (JPAC).

With thanks to Action For ME

LIGHTNING PROCESS STUDY IN CHILDREN UNETHICAL

Joint Statement from The Tymes Trust and The ME Association

The ME Association and The Young ME Sufferers Trust are issuing this joint statement due to widespread public concern, together with our own serious reservations, about a forthcoming study of the psychologically-based Lightning Process on children.

The pilot study, scheduled to start in September, will look at the feasibility of recruiting children aged eight to 18 with ME/CFS into a randomised controlled trial (RCT) comparing the Lightning Process with specialist medical care. It is planned that over 90 children aged between eight and eighteen and their families will be involved in the study.

The Medical Research Council (MRC) produces specific guidelines for research involving vulnerable patient groups. The document 'MRC Medical Research Involving Children' is quite clear on this issue. It poses the question: 'Does the research need to be carried out with children?' In answer, the MRC states: 'Research involving children should only be carried out if it cannot feasibly be carried out on adults.' The ME Association and The Young ME Sufferers Trust do not believe that it is ethically right to use children in trialling an unproven and controversial process such as the Lightning Process.

A survey of 4,217 people carried out by the ME Association on the management of ME/CFS found that over a fifth of those who had tried the Lightning Process were made worse (7.9% slightly worse, 12.9% much worse).

If any trial is to be held, it should first be on adults, who can give informed consent. No rigorous RCTs into the application of the Lightning Process have ever been undertaken.

Despite many years of scientific research there is still no single diagnostic test for ME/CFS, nor is there a curative treatment. The theory upon which the Lightning Process is based, together with its claim that the prolonged nature of the illness is caused by 'the adrenaline, nor-adrenaline and cortisol loop' is not scientifically proven. Moreover, the Advertising Standards Authority recently ruled that an advertisement in an internet sponsored link containing claims of its effectiveness by a Lightning Process practitioner should be removed. We understand that the practitioner will be involved in this study and we find this concerning.

The Trading Standards departments of two local authorities have also taken action over therapeutic claims by Lightning Process practitioners following referrals by Dr. Charles Shepherd of the ME Association. The Lightning Process calls itself a training programme, not a medical treatment, combining concepts from Neuro-Linguistic Programming, Life Coaching and Osteopathy. It claims to be effective for ME/CFS and psychological problems such as anxiety, stress, depression, guilt, low self esteem. Any evidence for this effectiveness on ME/CFS is purely anecdotal. ME has long been classified by the World Health Organisation as a neurological illness, not a psychological condition.

We cannot approve of a study involving children as young as eight when no rigorous trials have first been undertaken into the safety, acceptability, long and short-term effects of the application of this controversial and unregulated 'process' with adults.

Furthermore, we have serious concerns about the primary outcome measure, which is school attendance after six months. Children have a legal right to 'suitable education' for their particular needs, which may or may not include school attendance.

The statutory guidance 'Access to Education for Children and Young People with Medical Needs' explains that whilst it is desirable for children to be educated in school, other forms of education must be provided for those who need it.

The Chief Medical Officer's Working Group Report on CFS/ME (DOH 2002) stated that most children with ME will need education in their homes at some time, potentially for a considerable period. In 2009 the Education White Paper 'Back on Track: A strategy for modernising alternative provision for young people' included virtual education. Chapter 7, 'Learning from the best and supporting innovation', spoke of 'e-learning and virtual provision, particularly for pupils who cannot attend school due to health needs.' Accessible education is also provided for in disability discrimination law.

If school attendance is the primary outcome measure of this study, families involved may then feel pressurised into avoiding alternative forms of education which would benefit their children and to which they are legally entitled.

For all these reasons, it is our considered opinion that this study of the Lightning Process in children is unethical and should be abandoned.

With thanks to www.tymestrust.org

Neuro Rehab Conference 9 September 2010

For some unexplainable reason Maria and Pam were able to attend a study conference of professionals involved in all aspects of neurological rehabilitation.

At present there is a review of neuro rehabilitation services being undertaken and the conference was "The challenge of neuro rehabilitation: exploring the potential of patients and clinicians." They didn't attend the morning session as it was presentations of some of the services now available. They felt their input would be better in the exchange of ideas sessions in the afternoon. The professionals at their table were all very keen to listen to the viewpoint of patients and gave them a warm welcome and really took notice of their views and input on your behalf.

New Study reveals more about Children with CFS/ME

A recent study at the University of Dundee found abnormalities in the blood samples of children suffering from CFS. The study used a sample of 25 children with CFS/ME, and 23 without. When they compared the results of the 2 groups they found the following:

- The children with CFS/ME had increased oxidative stress - Oxidative stress is linked to free radicals, which interact with other molecules within cells. The presence of free radicals can lead to oxidative damage to proteins, membranes and genes.
- They also had an increased rate of white blood cell apoptosis - This means the white blood cells were dying probably in much greater levels due to some type of infection.

The team also observed that their results matched adult who had CFS. The exception was when they tested for stiffening of the arteries, which did not match the adults. Professor Jill Belch, who led the research, said, "What we've found are blood changes that suggest chronic inflammation. This is important because it's showing an abnormality that we might be able to devise a treatment for." She also added, "It's also important because some people do suggest that ME is a disease of the mind and here we are showing that it is a disease of the body".

Benefits & Work Guides

The guides are created by a welfare rights expert and a barrister, drawing on their own in-depth knowledge, plus use of the Freedom of Information Act. They are essential reading for anyone filling in a benefits application or renewal form, attending a medical, or faced with an appeal.

The group's subscription allows us to make these guides available to our own members for FREE.

If you can get to our meetings, socials or yoga classes, you will be able to pick the guides up in person. Alternatively we can email them to you - if you do not have internet access yourself, perhaps a friend or relative could help out.

Please note that we will only ask you for a donation if we need to post the guides out to you (this is because some of the guides are rather lengthy (number of pages in brackets below)).

Please look through the list below and if you need anything phone Dave on 07919 234256 or email dave@mesupportroup.co.uk.

DLA & AA

The best possible Attendance Allowance claims on physical health grounds (44)
The best possible Disability Living Allowance claims for adults on physical health grounds (61)
The best possible Disability Living Allowance claims for adults on mental health grounds (53)
The best possible Disability Living Allowance claims for children on physical health grounds (65)
The best possible Disability Living Allowance claims for children on mental health grounds (58)
70 questions you are likely to be asked at your DLA medical (5)
The best possible way to challenge a DLA or AA medical report (28)
The best possible support for clients with DLA and AA appeals (41)
Appealing against a DLA decision (16)
Giving persuasive information about how far you can walk (13)
Challenging the claim a bottle or commode will replace the need for help (8)
DLA renewal claims (6)
Changes of circumstances for people claiming DLA (8)
Letter claimant to decision maker requesting reconsideration because of additional evidence (3)

Incapacity for Work

The best possible incapacity for work claims on mental health grounds (43)
The best possible incapacity for work claims on physical health grounds (48)
Exempt but sent a questionnaire (7)
60 questions you're likely to be asked at your incapacity medical (3)

ESA

Understanding Employment and Support Allowance (43)
ESA claims for mental health and learning difficulties (88)
ESA claims on physical health grounds (65)
ESA appeals (35)

Permitted Work (6)

Knowing Your Rights at Pathways to Work Interviews (12)
Work Capability Assessment Score Sheet (12)

Other

If I do any work can I continue to claim my...? (4)
Caution, it may not count as voluntary work (5)
Am I covered by the Disability Discrimination Act? (9)
Which benefits can I claim? (9)
Reasonable adjustments: Employers and Jobseekers (8)
Work and benefits for people with long term health conditions (7)