

Issue: 51

August 2010

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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Minutes Secretary:	Margaret Benn	0161 761 2723
Bolton CVS Contact:	Ann Richards	01204 521769
Meetings Secretary:	Maria Sale	01204 575613
Medical Sub-Group, Group Rep & Carers' Contact:	Yvonne Leech	0161 764 7822
Bury Socials:	Sheila Myerscough	0161 7970026 (after 12noon)
Web Master:	Caroline Higson	01204 525955 caroline@mesupportgroup.co.uk
Membership Secretary, Newsletters & Distribution:	David Gore	07919 234256 Dave@ mesupportgroup.co.uk
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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.

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Dates For Your Diary

Longsight Meetings: ***PLEASE NOTE, THERE IS NO MEETING IN AUGUST.***

The next meeting will be Thursday 16th September, details to be confirmed.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 6th September at 4pm**, at **The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY**. Don't worry about getting to the venue and not being able to find us – just phone 07919 234256 when you get there and we will find you!

Bury Socials: ***PLEASE NOTE, THERE IS NO BURY SOCIAL IN SEPTEMBER*** These resume as normal in October.

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.

*****PLEASE NOTE, THERE WILL BE NO YOGA ON 17TH OR 24TH AUGUST***
CLASSES RESUME AS NORMAL THE FOLLOWING WEEK.**

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. There will be no meetings in August, when they recommence in September the Bury group will expand to include Rochdale and Oldham, the Salford group will expand to include Trafford and Manchester. Call 0161 743 3701 or visit www.gmneuro.org.uk for information about either group.

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

Yoga Classes: Olivia, our yoga therapist, is starting up a new yoga session to be held on Thursday mornings at the St John's Ambulance premises, just off the roundabout at Radcliffe. The cost will be £5 if it is a one hour session or £6 if it is one and a half hours. If you are interested please contact Olivia on 01706 829488 or email: olivia@oliviayoga.co.uk

Anniversary Meal

This is your last opportunity to tell Pam if you and your guest would like to come to our anniversary meal on Sunday 12th September at 3.00pm at the Red Hall Hotel, Manchester Road, Walmersley, Bury. We are looking forward to having a lovely afternoon please join us if you can.

VERY IMPORTANT If you book a meal but cannot attend you must let Pam know by Tuesday 7th September if at all possible so that we do not pay for meals that are not required.

Email Chat Group: Our Yahoo! Chat group is another great way of keeping in touch with other members between meetings. Unlike a conventional chat room, contact is made by email and/or message board, so you don't miss out if you are not online when a message is sent and can catch up at any time that suits you. Also, on our Yahoo Group home page we have also built a large database of links to information and services that we have found to be useful. To join, email dave@mesupportgroup.co.uk or visit: http://health.groups.yahoo.com/group/Bury_Bolton_ME_CF_S_Support_Group/

Dave's contact number:

Please note that although this is a mobile number, it is not his personal mobile and he does not always have it with him. If you are unable to get through, please do be patient and try again later. Also, it has no voicemail & he may not always notice any missed calls, so please keep trying.

Library Update

We've recently added several books and CDs to our library:

- The Big Wheat and Gluten-free Cookbook - Jody Vassollo

The next 4 books have been given to us by Irene Firth:

- Your Thyroid and How to Keep it Healthy - Dr. Barry Durrant-Peatfield
- An Introduction to the Lightning Process - Phil Parker
- Chronic Fatigue Syndrome - Professor Basant K. Puri
- Adrenal Fatigue: The 21st Century Stress Syndrome - James L. Wilson

We also have 20 relaxation CDs, donated to us by Jeanette Holland. These include:

- 7 Sounds of Nature and Music
- 5 Wellbeing Relaxation series
- 4 Oriental themes
- 2 sleep related
- 1 anti-stress
- 1 Relaxation Collection

Finally, donated by Sue Forshaw: Dr David Servan-Schreiber - Anti Cancer: A Way of Life

Many thanks to Irene, Jeanette and Sue for their generosity.

This month your newsletter is a couple of pages shorter than usual, this is because it is being sent to you with an additional 5 page supplement. This includes a full list of the library contents and other information, which we hope you will find useful.

In addition, Pam has secured us a grant to buy new stock for the library so we'd like to know what *you* think we should include. If you have any ideas, for specific titles or just a subject area, please contact Carole on 01942 810320 or carole.senior@tiscali.co.uk.

Bolton/Bury ME Support Group Meeting May 2010: Hugh Templeton's Watercolour Workshop

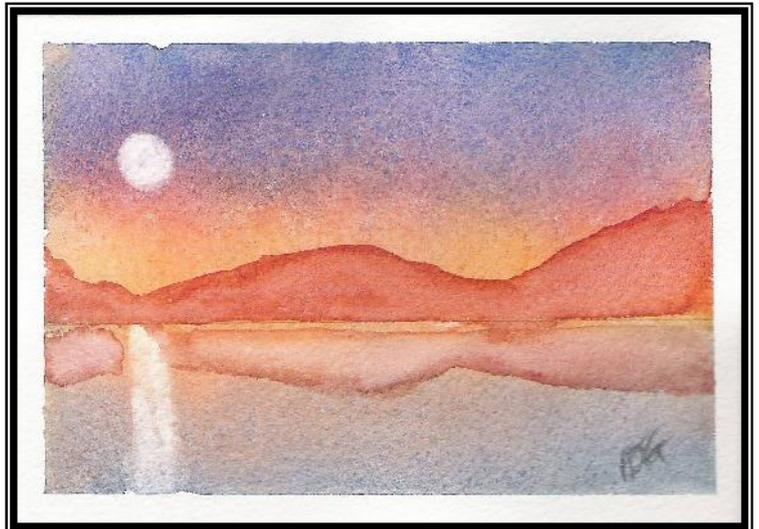
For our July meeting we were very happy that our friend Hugh Templeton could once again come along and teach us to paint lovely pictures.

Hugh wanted to dedicate the evening to the memory of Russell Leech as Russell had always enjoyed the painting sessions he attended.

Hugh is an excellent teacher and because he demonstrates what to do in small and simple stages, it gives people the confidence to have a try for themselves.

As Hugh explained to us painting is a way of switching on the right brain, which is the side of the brain which is relaxed and happy and non critical. There is no wrong in painting it is purely for your pleasure and enjoyment and the key is to paint what you see, not what you think should be there. Hugh also said that during the evening, at some point, all of us would experience, even if for only a few moments, a complete switch off from the cares and worries that usually beset us, and this was correct as we all became engrossed in mixing paint and painting.

This time we learned how to paint a sunset and everyone came away with a lovely picture. It is amazing that even though we all painted with the same few colours and essentially the same view, the pictures were all beautifully individual. Thank you Hugh for another lovely evening.



An update on the link between XMRV and CFS/ME

In October last year, the Whittemore Peterson Institute (WPI) showed that out of a sample of over 200 CFS/ME patients, 95 % had the XMRV virus. The WPI's findings caused worldwide interest and excitement within the scientific, medical and patient communities. Their results suggested that for the first time, there may be a cause for CFS/ME. Announcing the link was only the beginning, and since then other groups of scientists have been looking to verify the results with their own research. In addition, the WPI stated that their sample was very small and that large groups of patients would have to be tested in order to draw, in their words, "significant conclusions".

XMRV is a human retrovirus and is similar to the HIV virus. It is a blood borne virus and is transmitted through bodily fluids such as blood, semen, breast milk etc. The WPI believe that the XMRV virus causes "chronic inflammation and immune deficiency". The consequences of this are that the body cannot mount an effective defence against certain types of infection.

Since October 2009, a number of studies have been undertaken, which did not immediately verify WPI's findings. For example, a study of 186 patients in the UK found no evidence of XMRV. This was also backed up by a study in the Netherlands of 76 Dutch patients and another UK study sampling 170. However, in June 2010 a new study appeared in which 2 independent research groups, again from the Netherlands, proved that the virus did occur in CFS patients. In their study they claimed that, "The association with CFS is very strong, but causality not proved".

As the methods and results from each of the studies are not uniform, many people are suggesting ways in which each study fell short or did not address important and related issues. In the WPI study for example, Cathie Sudlow, from the University of Edinburgh, observed that some of the sample were drawn from areas where there were CFS/ME outbreaks. She suggested that in these areas the patients could be more susceptible to viral outbreaks (i.e. XMRV). In addition, she also posed a number of scientific questions, which if answered, would make the WPI findings more robust. The main example is did the study looked at reverse causality? In other words, the study did not look into whether CFS/ME patients might have contracted the XMRV virus as a result of their reduced level of immunity to infection?

The testing and overall methods used when testing for XMRV have also been questioned. In the UK studies for example, Dr. Suzanne Vernon of the CFIDS Association of America, suggested that their testing techniques may not have been as good at detecting the virus. To address this issue, the WPI has licensed their XMRV testing technology so that uniform tests can be undertaken by other research teams. Finally, the 76 patients in the Dutch study were selected based on an outdated definition of CFS/ME called the Oxford criteria. This means that this group may not have the same characteristics as other samples, so results could not be directly compared.

What we do know is that further research will be undertaken before the scientific community agree about the role of XMRV. Before that happens however, consistent scientific research methods need to be undertaken so that results can be properly compared and matched. In order to progress the research, there will be an international workshop in September 2010 to, "evaluate the state of our knowledge, address controversies, and develop an understanding between experts that will help direct future research". In the meantime, patients will have to watch and wait to see if a causal link can be proved. This could take some time.

Amazon Reminder: We get 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

Equipment Hire: Don't forget, we have a wheelchair, an electric mobility scooter (small enough to fit in car boot for days out or holidays) and a light box. If you wish to borrow any of these, please phone Pam on 01204 793 846.

Superfit mum left devastated by ME - May 15, 2010

The first signs that all wasn't well came when Susan Mulkeen started suffering from agonising pain in her feet, fingers, spine and legs.

Soon afterwards the 37-year-old from Norden was devastated to be told that she had a severe form of ME - a condition that she had never heard of before.

ME, which has no known cure, has caused inflammation in the brain and it has attacked her central nervous system.

As well as pain in her joints and limbs Susan is prone to fainting and shaking, her immune system is shattered, leaving her susceptible to infections, and she is also losing feeling in her legs.

She says the diagnosis came as a massive shock because she had always been such an active person. Susan had worked as a personal trainer and fitness instructor at various gyms, including and Hopwood Hall College, but was forced give up when the illness struck.

She was also a member of an indoor rowing team that came third in the British Northern Rowing Champions and came fourth in an individual section of the same contest in 2001.

By speaking out about her ordeal to coincide with ME Awareness Week Susan is hoping to raise awareness about the condition.

"It came as such a shock to be diagnosed because I was always such a fit person," said Susan.

"I used to be in a rowing team but now I am left with a very sad illness.

"The muscles waste, it goes to the kidneys and other organs and eventually leaves you bedbound or in a wheelchair."

Symptoms also include severe fatigue with difficulties such as poor concentration and difficulty in finding the right words to say, dizziness, nausea and palpitations.

Susan, who has three sons - Lewis, 14, Harry, three and Matthew, two - believes that having two caesarean sections triggered her illness.

She began to feel ill shortly after giving birth to Matthew.

The single mum now has a personal assistant provided by social services, who helps her to prepare meals, get the children dressed and general tasks around the home for three and half afternoons a week.

"My magnesium levels are very low and I'm not producing enough red blood cells so I don't have enough energy to last the full day," she added.

"ME has been called yuppie flu but if it was just a case of flu I would be the happiest woman around.

"People do recover from it but the worse thing is that there is no cure, it is just about having the best care and rest for a body that's deteriorating.

"Doctors have said that if you don't have children you could recover a lot quicker because all my energy is put to looking after the boys.

"I am a member of the ME Association of Bury and Bolton and I have met some fantastic people who have recovered from ME or who have it.

"I want to put across the message that this could happen to anybody, people who are educated with physically demanding jobs.

"It can be caused by stress and pushing the body to the extreme.

"One thing I have realised is the most important thing is your health, without that you lose everything.

"This is true in my case, except for the boys."

To get more information about the condition visit the Bury/Boltons ME/CFS Support Group's website www.mesupportgroup.co.uk.

Thanks to The Rochdale Observer, for permission to reprint this article about one of our members

Charles Tully, who talked to us about the Alexander Technique in May, is offering half price introductory sessions to our members until September 15th (priced at £17.50 daytime, or £20 after 5pm). Contact him on 0161 947 9184 or charlestully@ntlworld.com, or see www.charlestully.co.uk.

Group Membership Survey: Thank you to all of you who have completed our questionnaire. Some of you may have wondered why we asked a question about ethnicity, as you know everyone is always welcome to join our group and all are treated equally. However when we apply for grants we are asked the ethnicity of our members and we like to reply as accurately as possible. Thank you all for your cooperation.

From “Ask the Doctor” – 7th June 2010

Dr Scurr says: “By the way... at last I’ve been convinced that ME is real”

I admit it, I was wrong. For many years, I - like many of my medical colleagues - have blamed ME on psychological or behavioural causes.

Then, last month, I attended the 5th World Conference on ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome).

There I spoke to a number of experts who were emphatic that the evidence shows the condition really does have a viral origin.

This has never previously been clear - before, there had been only hazy circumstantial evidence. There have been two problems really; first, identifying the cases - who does and who does not have ME/CFS?

The second, how to tell if any identified bacteria or virus is actually the cause of a disease, or merely there by chance (and not actually involved in the disease process).

When it comes to diagnosing ME, it's always been difficult distinguishing it from another common but hard-to-prove condition, depressive illness. Both involve the major symptom of fatigue - a gross tiredness unlike any other, such is its overwhelming severity.

Both are associated with sleep disturbance, impairment of memory and concentration, emotional symptoms - indeed, there are many in the medical profession who have long considered that those who believe they have ME/CFS have a form of depression and are in denial.

But there is one challenging difference: those with ME/CFS have a flare of their malaise lasting at least 24 hours after physical exertion, whereas people with depression - if they can manage exercise - tend to be briefly a bit better.

At the conference, a number of plausible ideas were advanced for the condition, including one from Professor Brigitte Huber, an immunologist from Boston. She explained that 8 per cent of all the DNA in our bodies is basically a form of infection - it's become incorporated into the genetic code of our cells.

This infection 'gene' gets switched on whenever you catch a common viral illness - such as glandular fever or herpes simplex (the type that gives you cold sores). This triggers the immune system to pour out vast quantities of chemicals which cause widespread effects such as muscle pain and exhaustion.

In most patients, this reaction stops after a week or two as they recover - the immune system puts the infection gene back to bed.

But in a small number of people this doesn't happen, so the immune cells continue to be activated, causing grief, and the illness becomes ME/CFS.

Knowing why this happens still needs to be explored. But it is an exciting time and some solace to those who have this awful illness and have never been believed.

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Obituary

It is with very great sadness that we have to inform you of the death of one of our founder members, Russell Leach.

Russell was a real gentleman and a genuinely lovely person. He had suffered for very many years with ME but was also recently diagnosed with carcinoma. He died peacefully at home surrounded by his loving family.

Russell will be greatly missed and our sincere condolences go to Yvonne and family.