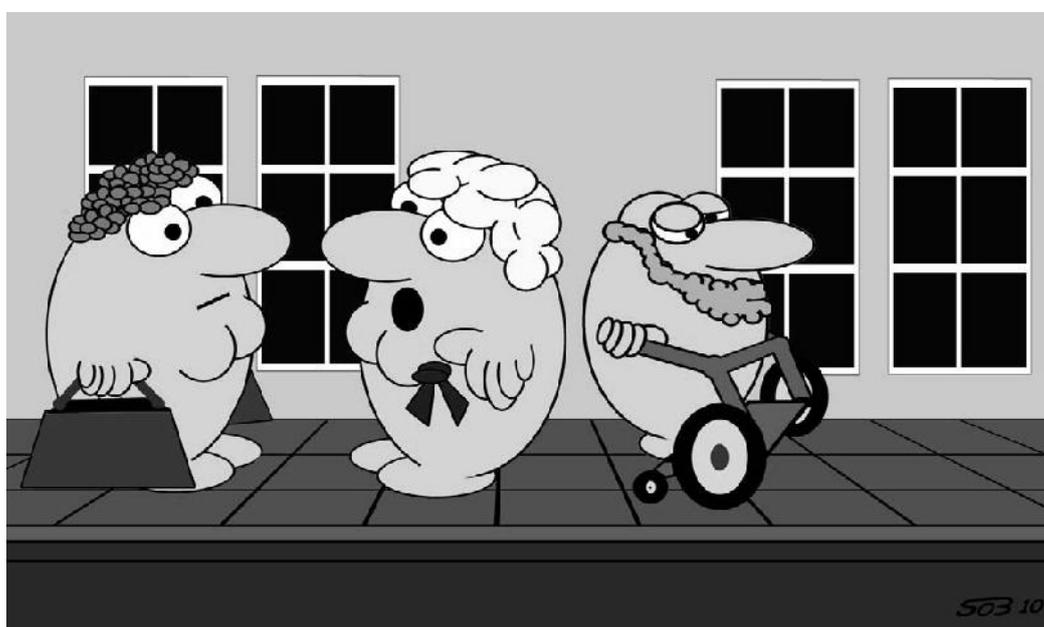


Welcome to Our August 2011 Newsletter



I HAD A GOOD DAY YESTERDAY, I EVEN MANAGED TO KEEP UP ALONGSIDE GRANDDAD ON A SHORT WALK.
 With thanks to Invest in ME (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.

Bury/Bolton ME/CFS Support Group & Sponsors

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.

Support Group Posts & Contact Information:

Group Contact / Welfare & Benefits Advice:	Pam Turner	
Treasurer & Parents' Contact:	Kim Finney	01204 882826
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:	David Gore	07919 234256 Dave@ mesupportgroup.co.uk
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Librarian:	Carole Senior	01942 810320 carole.senior@tiscali.co.uk
Door at Meetings:	Sue Forshaw	01204 883506
Roving Reporter:	Andrew Levy	0161 798 6183 andmk1@googlemail.co.uk

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.

Please note there will be no meeting in August.

Thursday 15th September – Don Stenhouse, curator of natural history at Bolton Museum. He will tell us some amusing and interesting stories about the objects and will bring some objects with him. These might include fossils, seashells, butterflies, etc.

Thursday 20th October – Sara Grimshaw (Kirkman), Occupational therapist with our clinic, will talk about ways of making life easier.

Thursday 20th November – Pre-Xmas Social.

Please note there will be no meeting in December.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 5th September 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. **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: These are continuing on the first Thursday of every month, the next will be **Thursday 8th September, 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 07746 197511, 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.

Important Notice!!

There will be no yoga classes on the 2nd & 9th of August.

Bury/Bolton ME/CFS Support Group Meeting

July 2011

Our July meeting was essentially a social meeting and as such no speaker had been arranged.

However Pam took the opportunity once again to ask for help with the running of the group if it is to be able to continue in its present format in the future.

We have a committee as well as several members who do a lot of the large jobs necessary, although they are not on the committee officially. This arrangement runs very well, however the main task that needs a volunteer is that of being responsible for opening the hall for meetings.

Pam explained that her health has been declining over the past two years, added to the fact that she will be 68 this year. It is inevitable that in the not too distant future she will not be able to continue to do so much for the group. She would be very sad if it does not continue as so many people have been helped in the past and there is still a great need for the group to continue the good work. She said that of course she will continue to be part of the committee and help organise things, but feels the need of support for this job in particular.

Ideally anyone wishing to help with this would need to have a carer willing to come as well in order to put out the tables and chairs and the library, and to put them away and close up the hall.

Pam will still come to as many meetings as she is able and I'm sure that the committee can arrange to take it in turns to introduce the speaker so that the job is not too onerous.

If you value your group please give this request some serious thought and if possible offer your help.

Thank you.

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. 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_CFS_Support_Group/

METRIC ME: **Education, Training & Resources In Primary Care**

By Yvonne Leech

NIHR National Institute for Health Research for Patient Benefit (RfPB) Programme. Chronic Fatigue Syndrome (CFS/ME) interventions within the primary care setting: Developing resources for support and self-management in primary care.

Management Group Meeting 25 May 2011

We attended the 2nd meeting held at the University of Manchester where there are 10 members including Pam and myself. The study is scheduled to take 3 years. Prof Carolyn Chew-Graham, who is also a GP in Manchester, gave us an overview of the study plan. We were then updated on their progress since the last meeting. 2 Patient Involvement Groups of ME patients and carers have been set up in Bolton and Preston with up to 8 people in each group. Their first meetings were to be held 25th and 26th May. These meetings will continue to be held on a regular basis to review the proposals being put forward by the Management Group.

To date 3 GPs have been interviewed about their current diagnosis and management views and concerns. Arrangements are in place to interview practice nurses on a similar basis. 2 housebound patients and 1 carer have been interviewed in their own homes to gather their views about their current CFS/ME experience and how it could be improved. A full literature review around CFS/ME is being undertaken together with establishing the current links with existing support resources including those from the third sector.

A discussion then took place around what should be included in the training of GPs, Practice Nurses and other members of the practice. A lot of ideas came up which are being used around the country and further information is being obtained. All this will be considered further together with patient materials at our next full day Training and Resource Development meeting on 29th June.

Yvonne Leech and Pam Turner.

The Patient Involvement Group is keen to recruit patients and carers from the Black and Minority Ethnic Community in the area as it is very important their views about CFS/ME are obtained. If YOU feel you can help please contact Pam on or myself on 0161 764 7822 or at ryleech@talktalk.net.

Inaugural Meeting of The CFS/ME (Patient) **Stakeholder Group.** **By Gill Mesce**

During a rainy May afternoon in Bolton I along with five other ME sufferers attended the inaugural meeting of the CFS/ME (patient) stakeholder group.

The aim of this and future CFS/ME patient meetings led by Dr Lisa Riste from the University of Manchester is to find out how primary health care services could be improved. A variety of resources for GPs etc. will then be designed and developed in the hope that CFS/ME sufferers will receive a better service.

Sharing past positive and negative experiences of our treatment by GPs and others responsible for our Primary Care became a good starting point. Many issues were raised such as some GPs

disbelief of CFS/ME symptoms, not listening, a need to be aware of both the physical, psychological and cognitive symptoms and a need by GPs and their staff to accept that CFS/ME exists and to be aware of the huge range of symptoms that patients can present.

Our discussion then focused upon how the GPs service could be improved. A variety of ideas were raised such as signposting to specialist care, for GPs to be honest about their understanding of the illness, asking patients to keep diaries or check sheets to record and monitor the affects of CFS/ME and to be provided with information packs that includes details of self help measures and contact details of support agencies such as local groups, Action for ME and the ME association.

A future meeting is planned for September.

Has the link between XMRV and CFS/ME been finally put to bed? By Andrew Levy

New evidence has emerged casting doubt on XMRV as a cause of CFS/ME. Since 2009 scientists have been trying to repeat a study by the Whittemore Peterson Institute to prove they were correct. Since then many studies have been unable to find XMRV in their samples of CFS patients. The XMRV link was originally published in the journal Science, a respected scientific journal, and generated worldwide headlines. It also generated incredible hope for CFS/ME patients around the world. However, the journal now wants the publishers to withdraw their findings, because so much doubt has been raised by so many studies. Science's editor in chief, Bruce Alberts, said at least 10 studies had since failed to reproduce those results.

One recent study which hammered another nail in the original research's coffin was undertaken by Tobias Paprotka's team at the US National Cancer Institute. They found that the XMRV allegedly found in the blood of patients with CFS/ME was not actually there at all, but due to laboratory contamination in the animal cells, or reagents, used to test their blood. Another recent study came from the Wisconsin Virus Research Group who attempted to repeat the 2009 study. Dr. Konstance Knox examined blood samples from 61 CFS/ME patients finding no evidence of XMRV in any of the samples.

The Whittemore Peterson Institute continue to defend their original study and findings. Their President, Annette Whittemore, said, "We are extremely disappointed that the editor of Science has published an 'editorial expression of concern'". All along they have argued that subsequent studies have not used the same methods as theirs. Annette also said, "Much of the work on this new retrovirus has yet to be performed, and we look forward to new studies which will support the results and findings described by these accomplished scientists."

The XMRV issue has still not been concluded, and the Whittemore Peterson Institute is continuing to defend its corner. Evidence against is amassing all the time, and until they concede defeat, the debate about XMRV will stay alive.

Equipment Hire: 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.

Incapacity Benefit to ESA Migration

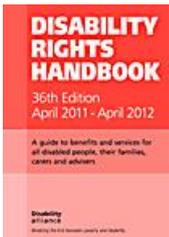
Benefits and Work have produced a new guide entitled: “Being transferred from Incapacity Benefit to Employment Support Allowance”. It is 22 pages long and gives information on how the process takes place, including how you will be contacted and important differences from the old IB assessment.

This new guide is not a replacement for the other guides on how to apply for ESA, and anyone in that situation should read those also, however it does provide some answers for anyone currently on IB who is wondering what is going to happen.

If you would like a copy of the new guide you can pick one up from one of our meetings, or if you contact dave@mesupportgroup.co.uk it can be emailed to you. If you need a copy to be sent to you by post please ring Dave on 07919 234256.

There is no charge for copies sent by email or collected in person, however for postal copies we would ask if you are able to make a donation of £2 towards expenses.

Disability Rights Handbook (36th edition) April 2011 - April 2012



The latest version of the Disability Rights Handbook is now out. At nearly 300 pages long, it is essential reading for anyone who is on, or needing to apply for, welfare benefits. This latest version includes a segment on the migration of Incapacity Benefit and Severe Disablement Allowance to Employment Support Allowance.

Although our group has access to the fantastic Benefit & Work Guides, there is a lot of very valuable extra information in this book – however conversely, the B&W Guides have a lot of essential detail that is not in this book.

The Disability Rights Handbook covers all of the benefits you will encounter, whereas the Benefits & Work Guides cover only IB, ESA, DLA and AA (albeit in considerably more detail). Ideally it is beneficial to consult both.

The Disability Rights Handbook is published by the Disability Alliance and available from their website www.disabilityalliance.org or by phoning them on 020 7247 8776. Normal price is £28.50, but for anyone receiving benefits it costs only £14.

Benefits and Work (who produce the excellent information on benefits) now have their own **Facebook** page, so if you have access you might like to follow them there for useful updates.

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). For example it costs us £1.50 to send 20 pages to you, £2.50 for 40 pages, £3.50 for 60 pages and £5.50 for 100 pages etc.

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

DLA & AA

Being transferred from Incapacity Benefit to Employment Support Allowance (22)

- 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 (42)
- ESA claims for mental health and learning difficulties (75)
- ESA claims on physical health grounds (70)
- 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)