

Notice of Annual General Meeting 2011

Bury/Bolton ME/CFS Support Group AGM will be held on:

Thursday 17th March, 7.30pm

At:

Longsight Methodist Church Hall, Longsight, Harwood, BL2 3HX.

Agenda

1. Apologies
2. Minutes of last AGM
3. Matters Arising
4. The Secretary's Report
5. The Treasurer's Report
6. The Group Leader's Report
7. Nominations for the Committee
8. Appointment of Honorary Auditor for next year
9. Any Other Business
10. Date and Time of next AGM

We would sincerely beg as many people as possible to attend the AGM, in order to show support for the Committee and to tell us your views and ideas. We will keep the business part of the evening as short as possible so that we can have time to socialise and try out the cakes and biscuits (wheat/dairy free catered for!) The AGM usually lasts about an hour.

As you can see, our committee is getting smaller, please consider carefully if you feel you could be a committee member, or to volunteer to help in any small way. If you think you can join us, please let Pam know by 1st March 2011

For any one unable to attend but who would like to vote for committee members, please tick the names on the list and return to Pam Turner, 7 Burghley Drive, Radcliffe, Manchester, M26 3XY by the 10th March 2011.

Pam Turner

Kim Finney

Sheila Myerscough

Margaret Benn

Maria Sale

Ann Richards

Bolton & Bury ME/CFS Group Annual General Meeting 18th March 2010

Present: Pam Turner, Sue Forshaw, Philip Hayworth, Sue Courtney, Carole Senior, Maria Sale, Angela Cassidy, A Gore, Sarah Bainbridge, Margaret Benn, Caroline Higson, Viv Makin, R Barlow.

Apologies:

Yvonne Leech, Russell Leech, Kim Finney, Angela & Neil Glendinning, Mrs B Kitchen, Mrs Alice Doyle, Kathleen Thornton, Rosalind and Mark Smith, Ann Richards, Christine Farrington, Tom & Lois Nicholson, Olga Carey, Karen Scully, Sue and Paula Stephenson.

Several people had returned ballot papers but did not sign them.

1. Minutes of last AGM held on 19th March 2009

The minutes of the previous AGM were accepted as being correct.

2. Matters Arising

There were no matters arising.

3. Secretary's Report and Group Leader's Report

A copy of both the Secretary's report and the Group Leader's report was given to all attending for them to read.

4. Financial Report

Pam read out The Treasurer's report. It was proposed by Maria Sale and seconded by Sue Forshaw that the report be accepted as correct. All voted in favour of the proposal.

5. Election of Committee

There were no further nominations for membership to the committee. The present committee are willing to stand again. It was proposed by Sarah Bainbridge and seconded by Caroline Higson that the remaining six members of the committee continue to serve the group.

All voted in favour.

6. Appointment of Honorary Auditor

It was proposed by Maria Sale and seconded by Sue Forshaw that our Honorary Auditor Lisa Fletcher be appointed again for next year. All voted in favour.

7. Increase in subscriptions

The committee had requested that the group consider an increase in subscriptions to £8 from April 2011.

Caroline Higson proposed that there should be an increase in subscriptions and Sarah Bainbridge seconded the proposal.

All voted in favour.

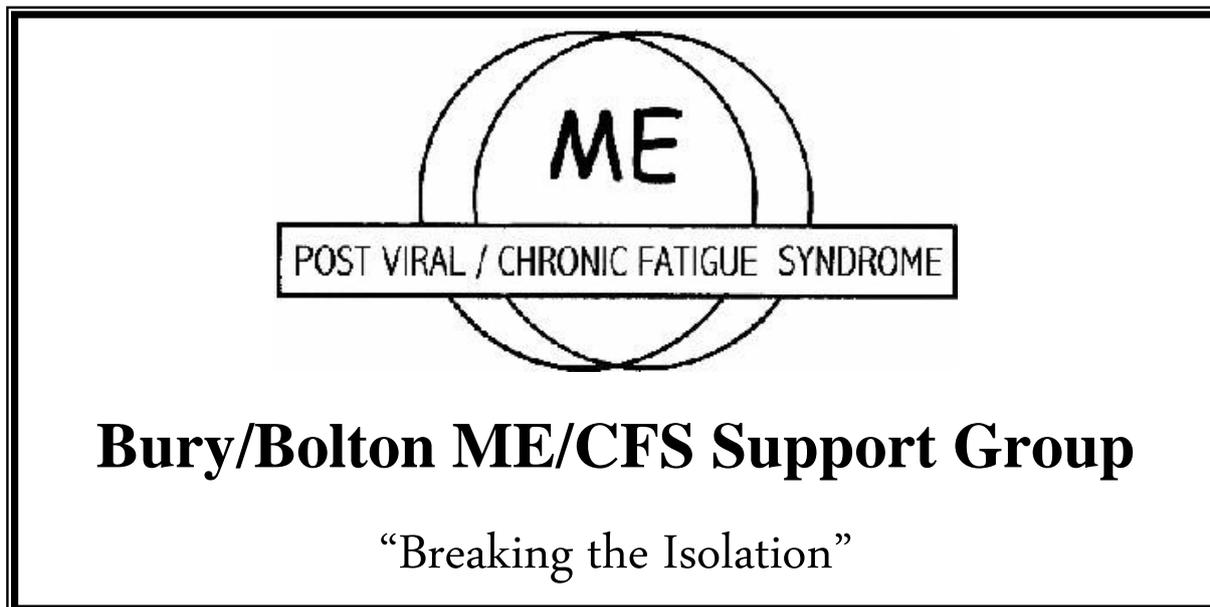
8. Any Other Business

There was no other business.

9. Date and Time of Next Meeting

The next AGM will be held at 7.30pm on Thursday 17th March 2011.

The meeting closed at 7.50pm.



Issue: 57

February 2011

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	01204 793846
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, Newsletters & Distribution:	David Gore	07919 234256 Dave@ mesupportgroup.co.uk
Librarian:	Carole Senior	01942 810320 carole.senior@tiscali.co.uk
Door at Meetings:	Sue Forshaw	01204 883506
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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.

17th February 2011, 7:30pm – Emma King, a holistic therapist who offers aromatherapy, holistic massage, and workshops for relaxation and stress management.

17th March 2011, 7:30pm – AGM. For more information, please see the separate notice enclosed with this newsletter.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 7th March 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 3rd March, 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.

Dr Charles Shepherd (Medical Adviser to The ME Association) will be speaking at the Stockport ME Group on **Friday 8th April.** Doors open **10:30am** for an 11am start, at The Toby Carvery, 271 Wellington Road, Heaton Chapel, SK4 5BP.

Bolton/Bury ME Support Group Meeting January 2011: **Alistair Mirfin from Bury Carers Service**

On a very cold and foggy night, seventeen brave souls ventured out and were treated to a very informative evening.

Our speaker was Alastair Mirfin, who is the Carers Development Worker for Bury Metro Adult Services. Alastair is very enthusiastic about his job of ensuring that carers are given as much help as possible, and he also wanted to learn from us about the difficulties faced by ME carers. He came to give us a brief overview of the services they provide and added that he thought that Bolton would have the same kind of service. The whole point being that they provide the help that carers need to enable them to care for the person they care for.

He started by clarifying what a carer is: it is someone of any age who looks after a relative, friend or neighbour who has an illness, disability, frailty or addiction. The help that they provide is not paid for as part of their employment and the care may be personal, emotional or supervisory. They may or may not live with the person they care for.

Alastair said he didn't know much about ME and acknowledged that it is a very misunderstood condition that isn't given the same high profile as other conditions such as stroke, which has an active campaign.

He then went on to say that his service works with all ages of carers, including some very young carers, and told us that carers save the country around £50 billion each year. They not only save money by not having to use NHS resources, but also give a continuity of care.

Bury Carers Service have developed a strategy so that:

1. It is easy to access support. There is a carers centre where there are drop in sessions and carers can get advice on any subject including benefits.
2. Ensures the health of the carer by offering regular health checks, for example with the cardiac team to help reduce stress and breakdown of the carers health.
3. They also provide breaks for carers. At present there is a voucher scheme. When the carer has an assessment of need they are awarded vouchers, maximum of 3 hours per week. These vouchers can be exchanged, for example for Crossroads to provide an hour or two or three, and you give them a voucher which the council then pay for the time given. In March the voucher scheme will be changed to a personal budget to be spent on whatever helps the carers best – this will however be a means tested system.

Alastair's job involves trying to find those carers who are not supported. He said that, from the last census, it is estimated that there are 19,000 carers in Bury but that they only have 4,000 on their register. Many people do not see themselves as carers, for example a parent looking after a disabled child or looking after a family member, but any person who looks after someone is a carer.

Some people may be concerned that having a carers assessment is some kind of test to see if you are doing it properly. In reality it is a wonderful opportunity to talk about whatever

problems you are encountering and to get help to make them easier. The Carers Services Team aims to give carers a voice and now we know who Alastair is we can contact him.

Every GP in Bury has a notice Board at the practice with information for carers and also has a list to be able to refer people to the service. Alastair also told us that North Manchester General Hospital has a carers centre at the front of the hospital.

When Alastair told us that everyone has a right to a carers assessment, the question was asked if that is the case even if the cared for person doesn't have a diagnosis and he said yes that is so, it is the fact that you are caring that is important.

Bury Carers Service can send you a pack which included a comprehensive Carers Guide which lists every caring service. It also includes a benefit guide and there is an expert available to discuss things with you, usually Wednesday mornings. They also try to get information specific to your circumstances. There is information about a device called Care Link, which the sufferer wears around their neck so that they can press a button if they need help, which gives the carer a little more peace of mind if they have to go out.

Also British Red Cross have a carers emergency card which you keep on you, like a credit card, and if you have an accident the emergency services will know from your card that you are a carer and there is someone at home in need of care.

A tip from one of our members is that if you carry a mobile phone you should put a phone number you would like to be called in case of emergency and list it under ICE. The emergency services are trained to look for this on your phone in case of accident or medical emergency.

Alastair also told us about discount cards that are available to carers, e.g. for pamper sessions at Bury College, for hair beauty and nail therapy.

Bury Carers have a drop in coffee morning on Fridays 10am-12noon at their premises on Silver Street, telephone 0161 763 4867. or see www.carers.org/local-centre/bury.

Bury Metro Adult Services Carers Service Team, Alastair Mirfin can be contacted on tel 0161 253 6110, or email carersservices@bury.gov.uk.

Yvonne gave us information that if anyone has a small job that needs a handyman, Sixtown Housing offers a service of up to 2 hours of work for £15, contact 0161 686 8368. There is a Handyman Service in Bolton for the over 60s, which is free for 3 hours those on benefits, otherwise £10 per hour, phone 01204 335679. Also Age Concern will offer a similar service for older people. Otherwise contact your local social services to ask about similar schemes to help disabled people in your area.

For carers in the Bolton area, contact details for Bolton Carers Support are: 01204 363 056 or visit their website www.boltoncarersupport.org.uk.

It is better to be registered as a carer and have a plan of action before a crisis arises, so that all the information is easily available and help can be offered before the carer is in crisis.

A most enjoyable evening with plenty of discussion and good information. Thank you Alastair.

New study on XMRV and CFS/ME makes the issue clear as mud!

A new study by a number of different organizations has continued the controversy over whether XMRV virus is a cause of CFS/ME. The researchers, who included University College London, Wellcome Trust Sanger Institute and Oxford University, looked at the potential for human and cancer cells to become infected with the XMRV virus. They found that in many cases the cells were contaminated with the virus, and that some cancer cells contained a mix of viruses which were mistaken for XMRV. As a result, they cast doubt on the previous studies who said that CFS/ME was caused by the XMRV virus. They also went further, suggesting that the XMRV virus was not a human pathogen. This means it is not an agent of disease and therefore not a cause of chronic fatigue.

The researchers used their own methods to make these conclusions, but did not have any way of analyzing the samples from previous studies to support their claims. The Whittemore Peterson Institute, who first made the link between XMRV and CFS/ME are actively justifying their position, which remains the same.

It seems as if the scientists are dividing into two different camps, with two directly opposing views. Then methods and their science are at stake, and each new study seems to confuse the issue even further. Organizations such as Invest in ME are trying to rise above the controversy, and guide the different research groups to a unified position. This will be difficult to achieve, although they hope to make progress at their conference in May this year.

Some commentators have recognized the difficulty involved when two groups of scientists disagree. They point out it is difficult to get a resolution, on the only way to produce a real breakthrough is for someone to work “out of the box”. In this case for example, this could mean test groups trying antiretrovirals to see what the effects are.

Can you spare any time to help the group?

We are looking for someone who lives in the Heywood/Rochdale/Middleton area who can spare half an hour twice a year. In January and July we send out leaflets to all of the libraries in the Bury, Bolton, Salford and Rochdale areas, but this isn't as difficult as it sounds, all we have to do is drop a bundle of envelopes into one library in each area and they do the rest for us – don't worry, the envelopes will already be stuffed, labelled and ready for you, so all you would have to do is drop them off at the library desk (having picked them up from us at one of our meetings, socials or yoga classes).

We also always welcome anyone else who can volunteer to help us in any way, large or small. If there is anything you think you could assist with, please do let us know. Even if it is a role that is already being covered, don't worry our existing volunteers will always appreciate extra help, since many of the tasks required for our group to function are covered by a relatively small number of people.

Please have a think about what you might be able to offer and contact either Pam or Dave.

Whittemore Peterson Institute responds to Retrovirology article

21 December 2010

XMRV results stand, says WP Institute

Researchers at the Whittemore Peterson Institute in America have responded to the recent article in *Retrovirology* which suggested that their studies, linking murine leukaemia virus-related virus (XMRV) with chronic fatigue syndrome, were due to contaminated samples.

In response to the claims the Institute - which published its initial results on XMRV and CFS in 2009 - has placed the following statement about the article on its website:

www.wpinstitute.org/

Statement from Whittemore Peterson Institute

The Lombardi et al. and Lo et al. studies were done using four different methods of detection. They were not simply PCR experiments, as were the studies by McClure et al. and others who have recently reported their difficulties with contamination.

Experienced researchers such as Mikovits, Lombardi, Lo and their collaborators understand the limitations of PCR technology, especially the possibility of sample contamination. As a result, we and Lo et al. conducted rigorous studies to prevent and rule out any possibility that the results reported were from contamination.

In addition to the use of PCR methodology, the Lombardi team used two other scientific techniques to determine whether, in fact, we had found new retroviruses in human blood samples.

We identified a human antibody response to a gamma retroviral infection and we demonstrated that live gamma retrovirus isolated from human blood could infect human cells in culture.

These scientific findings cannot be explained by contamination with mouse cells, mouse DNA or XMRV-related virus-contaminated human tumor cells. No mouse cell lines and none of the human cell lines reported today by Hue et al. to contain XMRV were ever cultured in the WPI lab where our PCR experiments were performed.

Humans cannot make antibodies to viruses related to murine leukemia viruses unless they have been exposed to virus proteins. Therefore, recent publications regarding PCR contamination do not change the conclusions of the Lombardi et al. and Lo et al. studies that concluded that patients with ME/CFS are infected with human gammaretroviruses.

We have never claimed that CFS was caused by XMRV, only that CFS patients possess antibodies to XMRV related proteins and harbor infectious XMRV, which integrates into human chromosomes and thus is a human infection of as yet unknown pathogenic potential.

"The coauthors stand by the conclusions of Lombardi et al. Nothing that has been published to date refutes our data." Judy A. Mikovits

With thanks to Action For ME (www.afmeorg.uk)

NICE defers review decision

04 January 2011

Changes to guideline depend on PACE trial findings

The National Institute for Health and Clinical Excellence (NICE) has deferred its decision on whether or not it will update its guideline on CFS/M.E.

NICE posted the following notice on its website, 23 December:

“During the public consultation on NICE’s review proposal for clinical guideline 53 on the diagnosis and management of CFS/ME, a number of stakeholders advised that the results of the PACE trial are due to be published in 2011.

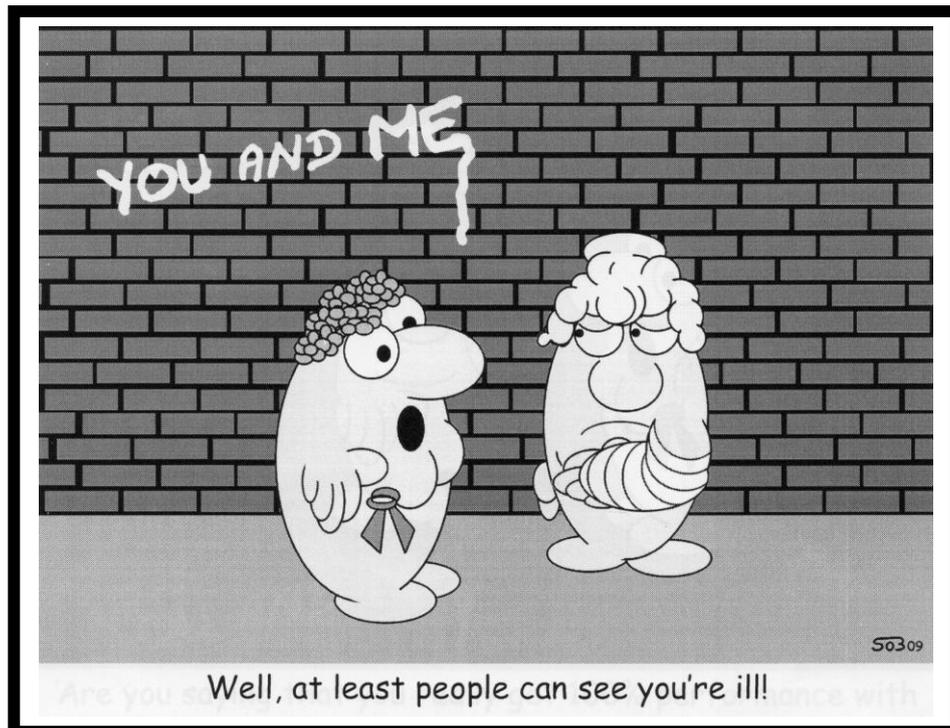
“As this significant trial may affect NICE’s final decision regarding whether its existing guideline warrants an update, NICE is deferring its announcement until further information is available.

“This is so that the conclusions made by NICE are as accurate and informed as possible.

“In the interests of high quality patient care, it is important that health professionals continue to adhere to the existing recommendations as they represent best clinical practice for the NHS.”

Action for M.E.’s response to the review consultation was published 15 November 2010. (*Please see last month’s newsletter*)

With thanks to Action For ME (www.afmeorg.uk)



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.

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

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)