

**Issue: 54**

**November 2010**

**[www.mesupportgroup.co.uk](http://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 <b>caroline@mesupportgroup.co.uk</b>
Membership Secretary, Newsletters & Distribution:	David Gore	07919 234256 <b>Dave@ mesupportgroup.co.uk</b>
Librarian:	Carole Senior	01942 810320 <b>carole.senior@tiscali.co.uk</b>
Door at Meetings:	Sue Forshaw	01204 883506
Roving Reporter:	Andrew Levy	0161 798 6183 <b>andmk1@googlemail.co.uk</b>

**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 18<sup>th</sup> November 2010** – The pre-Christmas social with “Bring & Share” buffet supper.

**DON'T FORGET THERE IS NO MEETING IN DECEMBER, OUR NEXT WILL BE:**

**20th January 2011** - Alistair Mirfin, Bury Carers' development worker, will talk about his work, and the outreach service.

**Radcliffe Socials:** Please note that our next social on **Monday 6<sup>th</sup> December** at **4pm**, at **The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY** is for those who have already booked to come to the carers meal on this date (please see note about this later in the newsletter).

**Bury Socials:** These are continuing on the first Thursday of every month, the next will be **Thursday 2<sup>ND</sup> December, 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](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](mailto: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](http://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.

**Carers Outings:** Please note that the lists for the December 6th meal and for the February 6th meal are now full. There are still a few places for the February 20th meal so please let Pam know as soon as possible if you want to join us.

**Don't \Forget:** The group gets 5% back from Amazon for every purchase you make from them – but for this to work, instead of going to the Amazon site directly, you need to follow the link on our own website instead (at the bottom of the left hand menu on our home page [www.mesupportgroup.co.uk](http://www.mesupportgroup.co.uk)). It doesn't cost you any extra, but is a great way for our group to make some money.

## The Canadian Consensus Document – An Overview

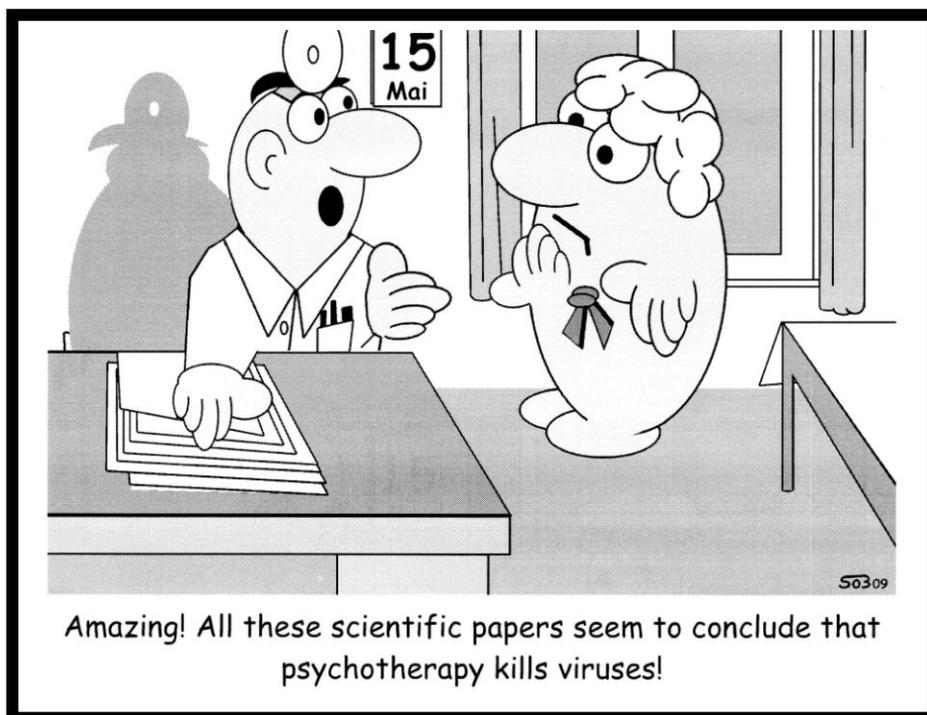
We are very pleased to tell you that we have bought enough copies of the ME/CFS Clinical Case Definition and Guidelines for Medical Practitioners, to be able to give one to each member of the group.

This document is an absolutely brilliant piece of work which has been put together by consensus of a large group of very knowledgeable and highly respected doctors and scientists, mainly from Canada and America. It was produced in response to the increasing numbers of patients asking for a doctor who was knowledgeable in ME. The consensus group sent out a questionnaire to ask doctors what would be most helpful to assist them with their ME patients. The answer came back loud and clear, they needed a clinical definition as well as a diagnostic and treatment protocols. From there a group of very knowledgeable ME doctors got together to produce a comprehensive view of ME under the guidance of Health Canada.

Health Canada selected an Expert Consensus Panel consisting of eleven members who were chosen from more than 40 nominations. The Consensus Group represented clinicians, university medical faculty and researchers in ME. Together the panel had diagnosed and treated over 20,000 ME patients.

The overview document is very comprehensive but easy to read and to understand. Professor Malcolm Hooper has praised it as a VITAL DOCUMENT which offers HOPE, CLARITY, DIRECTION and UNDERSTANDING.

We hope that you will find it useful and we will do our best to see that it reaches as many professionals as possible. Your copy is included with this newsletter, or you can find it online at: [http://www.mefmaction.net/documents/ME\\_Overview.pdf](http://www.mefmaction.net/documents/ME_Overview.pdf).



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.

## **Bolton/Bury ME Support Group Meeting October 2010:**

### **Dr Carolyn Routledge on the Egyptian collection at Bolton art gallery and museum**

We were very fortunate that Dr Carolyn Routledge, from Bolton Museum, came to tell us about her excavating experiences when working on a dig site in Abydas.

Dr Carolyn is Canadian but working temporarily at Bolton Museum and will be going back to the site to continue the excavation next year. She has been working for the past three seasons on a dig led by Dr Josef Wagner and his wife Jennifer. They also take along their son Alexander who has been going to Egypt since he was a baby.

Abydas is in mid Egypt and the excavation is in South Abydas, a middle kingdom and they were working in a Royal Tomb complex. It is one of the largest sites in Egypt and is a cemetery dedicated to the god Khentyamentiu. Carolyn then showed us a picture of a small lion made of ivory which dates back to the first kings of Egypt. This area with the tombs of the first kings is very important as it gives much information of what Egypt is about and their belief system. She showed us a picture of some large hill/cliff type mounds which had a cleft or valley through them. The people believe this is the entrance to the land of the dead. There were lots of smaller hills made up of broken pots, these are from people over thousands of years bringing offerings to the gods and then breaking the pots.

There is a lot of material from the tombs of the first king such as pots which have the name of the king in hieroglyphs, which would have contained things like perfume. These hieroglyphs date back over 5,000 years and are the first writing in the world. The pots also may have contained turquoise and gold but much of it has been stolen. Carolyn showed us a strange looking piece of what looked like sticky dirt about 6" x 4" but was in fact a piece of ancient ointment. Carolyn said that this was a favourite piece for her. It was found on an excavation to that place in the early 1920's by a man called Petrie. When he cut into the ointment he could still smell the perfume.

She then showed us pictures of several small rocks which had names on them, these were tombstones of the servants. A picture of a grave showed how the body was placed and Carolyn explained that when the king died the servants were sacrificed and all died with him and all the tombs were closed at the same time.

A map of Ta Djoser, which means holy land, showed a giant fort which was another monument to the dead king. From the fort to the tomb was a processional route and there would have been enacted a ritual battle between good and bad; of course good always won.

A picture of Seti's Temple showed the Osirian which is a burial site for the god Osiris. Seti was a very important king who reigned after Tutankhamum and before Rameses 11. Then a picture of Senwasret who reigned from 1878-1841BC, another important king. This picture showed a very sad, careworn face and there was also a picture of a piece of his wife's jewellery.

Carolyn then explained the excavation site where she and Dr Wagner's team were working had first been excavated by Petrie. This team found what they called "a great devil's punch

bowl”, which was a tomb in very hot, very harsh conditions. In Petrie’s time it was so hot in the tomb that the men would work naked but of course not in a modern dig.

Carolyn first went with the Wagner team in 2004 and on that expedition they went to find the tomb. She lived in a dig house, which she described as being very comfortable and quite pleasant. They kept cats to keep away the snakes and scorpions. While the men were out with the workers trying to find the tomb Carolyn worked cataloguing small finds, drawing pictures of them and copying writing from seals.

They did not get down as far as the tomb on this expedition but went back again in 2006 to try to find the entrance. This time she was sorting out pottery which was very difficult as in order to get a whole pot together she had to sort through many baskets containing hundreds of fragments. She showed us a picture of a large pot she had completed but there were many small pots which would hold lights or perfume. This time they found the entrance to the tomb.

In 2008 they went back again and this time they cleared the entrance and got into the tomb. It is not just a case of clearing a small doorway, a massive long area has to be cleared, otherwise sand would keep filling the passage way (known as the chimney). It is built in this way in order to deter robbers. Carolyn showed us a diagram of the complex arrangement of the tomb which was previously opened by Correlli whose expedition went in and mapped the tomb, but the new expedition is trying to do more clearing and to find more artefacts. As she is claustrophobic it was a great challenge to Carolyn to go down into the tomb, but after working for three seasons she is obviously going to go down.

She showed us a picture of herself near to the sarcophagus, which was in the burial chamber. There were no jewels there, just a few old bones. They did however find a Canopic chest which would have contained jars which held the internal organs from the mummification process.

The area beyond the burial chamber was not safe because some of the stones had shifted so Carolyn did not go further, she did have a picture of where Correlli had written his name in the rock.

Carolyn said that it will be very difficult to get further as it will cost a lot of money to get an engineer and equipment but they are hopeful that they may get more funding.

She showed us a picture of what she described as the highest quality alabaster which is probably from a canopic jar and this is very important because it shows that some one of high status is buried there. The tomb has been seriously robbed, probably in Roman times because lots of the pottery fragments are from that era.

Carolyn then passed around some interesting objects for us to see including a lovely bracelet of beads.

In answer to a question Carolyn said that at all times there is an official present from Egypt and everything belongs to them. The teams are not even allowed to take away a soil sample.

A very unusual and interesting evening.

## **Action for ME**

# **National ME Observatory: Report of the first three years**

Yvonne, Pam & Sonia attended a presentation by Action for ME in Sheffield on 28th September.

Action for ME with funding from the Big Lottery Fund has sponsored the National ME Observatory to undertake groundbreaking research into important and previously neglected aspects of ME. The Observatory is an academic research collaboration which includes Action for ME, University of East Anglia (UEA), London School of Hygiene and Tropical Medicine (LSHTM) and the University of Hull.

In this first stage of research the Observatory looked at:

1. Epidemiology: distribution and causes of disease, vital to show the scale of the illness and in identification of risk factors for disease, which may lead to a better understanding of the pathology (effects) of the illness.
2. Qualitative and Social research:- helps them to show scientifically exactly what it is like to have ME and the impact it has on the lives of all those affected by it.

While sufferers and carers know this, it is only by formal publication in scientific journals that government, service providers, health care and other professionals will be able to understand the nature of the illness and the needs of those affected.

The first phase has addressed 5 main barriers to health and well being for people with ME.

1. For understanding of what it's like to live with ME and social exclusions (isolation)
2. Lack of information on the sources of support for people with ME
3. Lack of epidemiological information about the distribution of the disease and its impact on the quality of life of patients and carers
4. Health inequalities affecting people with ME
5. Research knowledge mainly restricted to the academic community because it is often done without active involvement of people with ME and therefore fails to address their real needs.

The Observatory has done six interrelated studies looking at these, 4 short term and completed within this first 3 years and 2 longer term studies to be part of the developing research and service infrastructure which is necessary for real progress to be made combating ME.

In qualitative social research the 2 completed studies assessed how ME impacted on the lives of a range of sufferers and their carers. It included looking at both health and social care provision and the interaction between patient and professional in order to see what makes for a good, successful and effective relationship. The long term project involves setting up a services directory which will be available via AFME website. This will help to identify national gaps so that service providers can be informed. It will be important that this is kept up to date.

In epidemiology they have completed projects to study occurrences and distribution of ME in East Anglia, East Yorkshire and London and wish to extend this to the rest of the country. They hope to be following on groups of sufferers to see how the illness progresses and what is the outcome. Their study has included the severely affected which has not usually been done previously.

Over the whole 3 years they have made great efforts to involve the ME community as full members of the project. They acknowledge the invaluable feedback from sufferers and carers and now have various ideas as to the type of research which is now needed.

Two of the researchers involved gave fuller details of what the studies had found and what were their future plans.

Following on from the epidemiology study and the need to have a proper disease register they would like to expand from just having a diagnostic definition into developing a tissue sample bank and a post mortem tissue bank which would help greatly in the future development and understanding of ME.

Louis Nacul LHSTM said that at present there is no common consensus to say how prevalent is the illness and there is need for a good diagnostic test. Their studies have included patients who were diagnosed clinically and who met the Canadian Consensus Criteria.

They found that there are 9 to 10 thousand new cases per year and that in total there are around 2 cases per thousand of the population. So for a town the size of Bolton, 26,000 people, you would expect 520 people with ME. When looking at the severity of the illness he said it causes a substantial reduction in activity and went on to say that disability is defined as any restriction or lack of ability to perform an act.

When looking at quality of life using a question based comparison tool based on 2 components a) physical b) mental, for ME sufferers both scales are below that of healthy people. However the graph curve shows a lower physical line and an upward mental line, this is totally opposite to sufferers of depression who have a higher physical line but a lower mental line.

Louis stressed that the fluctuating symptoms affect people's ability to be in control over social and work relationships. He said that there is a need for control over symptoms of the illness and a need for economic support. He also said that ME sufferers must not be expected to use their limited energy having to justify themselves and explain their problems constantly to professionals.

Louis did differentiate between ME and CFS and at question time was asked to clarify his statement. He said that ME & Fibromyalgia overlap greatly and appear to be part of the neurological condition as we understand it. However CFS or just chronic fatigue can be caused by many other illnesses or other factors. The problem being that many doctors now use the two terms to mean the same condition but they do not. This is why it is vital to have an accurate diagnostic tool/criteria.

After a short break we were asked to discuss our views and make suggestions for the areas where research should continue in the future.

The need for accurate diagnosis, good information and education of doctors and of course the hope of finding the cause headed the lists, as well as concerns about financial support for the many unable to work.

Although it was a long and tiring day, with many thanks to Yvonne for driving, I feel it was well worthwhile to find we have such excellent people doing valuable research to enable us to understand ME much better.

**More information will be available on Action for ME website: [www.actionforme.org.uk](http://www.actionforme.org.uk)**

## **SOME CONTACTS YOU MAY FIND USEFUL**

**Benefits Agency Information Officer:** Bolton - 01204 367000 Bury - 0161 762 2000  
**Bolton Primary Care Trust:** 01204 907724  
**Bury Primary Care Trust:** 0161 762 3100  
**Citizen's Advice Bureau:** Bury - 0161 761 5355 Bolton - 01204 900200 (/213 Housebound)  
**Disabled Living:** 0161 832 3678  
**DIAL** Disability Information and Advice Line: equipment/gadgets and where to get them: 0161 703 8887  
**Bolton Community Voluntary Services:** 01204 546010 **Carers Support (Bolton):** 01204 363056  
**Bury Council for Voluntary Services:** 0161 764 2161  
**Social Services:** Bolton 01204 337841  
Bury (town hall) – 0161 253 5000 (ask for adult social care team)  
**Bury Carer Services:** : 0161 763 4867 and **Bury Carer Assessment:** 0161 253 7190.  
**Basic Neurocare Centre (inc Assisted Gym):** 554 Eccles New Road, Salford, M5 2AL: 0161 707 6441  
**Ring & Ride:** Bolton - 01204 388500 Bury - 0161 764 1999  
**Welfare Rights Advice Line:** 01204 380460  
**Benefits Helpline:** 0800 882200. **Completing Forms:** 0800 44 11 44  
**Equality Human Rights Commission (was Disability Rights Commission):** 0845 604 6610  
**JOB CENTRE PLUS:** [http://www.jobcentreplus.gov.uk/JCP/Customers/Disabled\\_People\\_and\\_Carers/index.html](http://www.jobcentreplus.gov.uk/JCP/Customers/Disabled_People_and_Carers/index.html)  
**ACCESS to WORK:** [http://www.jobcentreplus.gov.uk/JCP/Employers/advisoryservices/diversity/Dev\\_015798.xml.html](http://www.jobcentreplus.gov.uk/JCP/Employers/advisoryservices/diversity/Dev_015798.xml.html)  
**General government guidance on entitlements:** <http://www.direct.gov.uk/DisabledPeople>  
**SHOPMOBILITY:** Bolton – 01204 392946 Bury – 0161 7649966  
Manchester Arndale - 0161 839 4060 Trafford Centre: 0161 749 1728  
Bolton Market Place - Wheelchair Service: 01204 361100  
**ACTION FOR ME:** 3rd floor, Canningford House, 38 Victoria Street, Bristol. BS1 6BY.  
Tel: 0845 1232380 (or 0117 9279551), e-mail [admin@afme.org.uk](mailto:admin@afme.org.uk) for general enquiries  
Welfare Rights Helpline – 0845 1228648 - Mon 9-5, Tues 9:30-12:30 & 3:15-6:45, Wed 1:30-4:30, Thurs 9:30-1:00  
Telephone support - 0845 1232314 (11am to 1pm Mon to Fri) - advice and information for anyone affected by ME (including non-members). [www.afme.org.uk](http://www.afme.org.uk) or for young people with ME [www.a4me.org.uk](http://www.a4me.org.uk)  
**ME ASSOCIATION,** 7 Apollo Office Court, Radclive Road, Gawcott, Bucks., MK18 4DF. 01280 818968.  
Information Line: 0870 444 1836 (10am to 12noon, 2pm-4pm & 7pm to 9pm – every day) [www.meassociation.org.uk/](http://www.meassociation.org.uk/)  
**BRAME:** (Blue Ribbon for the Awareness of ME) 30, Winner Avenue, Winterton on Sea, Great Yarmouth, Norfolk. NR29 4BA. Tel/Fax - 01493 393717. The BRAME campaign was launched to create a greater awareness and understanding that ME is a very real and debilitating illness. [www.brame.org](http://www.brame.org)  
**CHRONIC FATIGUE SYNDROME RESEARCH FOUNDATION:**  
2 The Briars, Sarrat, Rickmansworth, Herts. WD3 6AU. 01923 268641. [www.cfsrf.com](http://www.cfsrf.com)  
**M.E. Research UK:** The Gateway, North Methven Street, Perth, PH1 5PP. 01738 451234 [www.meresearch.org.uk/](http://www.meresearch.org.uk/)  
**NATIONAL ME SUPPORT CENTRE:** Disabled Services Centre, Harold Wood Hospital, Romford, RM3 9AR.  
01708 378050 <http://www.nmec.org.uk>  
**The 25% ME GROUP:** Simon Lawrence, 4, Douglas Court, Beach Road, Barassie, Troon, Ayrshire, KA10 6SQ ME Group for the Severely Affected ME sufferer. [www.25megroup.org](http://www.25megroup.org)  
**CHROME:** (Case History Research on ME), 3 Britannia Road, London SW6 2HJ. 020 7736 3511 This charity was set up to identify as many severely affected ME sufferers as possible in the UK and monitor the course of their illness over 10 years. The study will supplement medical research into the condition.  
**TYMES TRUST** (The Young ME Sufferers Trust): P.O. Box 4347, Stock, Ingatestone, CM4 9TE, Advice line 0845 003 9002 (Mon-Fri 11-1 or 5pm-7pm). [www.tymestrust.org](http://www.tymestrust.org)  
**AYME:** Association for Young People with ME, Box 605, Milton Keynes MK2 2X. 08451 232389. [www.ayme.org.uk](http://www.ayme.org.uk)  
**INDEPENDENT COMPLAINTS ADVOCACY SERVICE (ICAS):** help with NHS complaints: 0845 120 3735  
**COMMUNITY LEGAL ADVICE:** 0845 3454345 [www.communitylegaladvice.org.uk](http://www.communitylegaladvice.org.uk)  
[www.writetothem.com](http://www.writetothem.com) - type in your postcode to find out who is your MP/MEP/councillor & how to contact them.  
**The Pensions Advisory Service (TPAS):** 0845 6012923 [www.pensionsadvisoryservice.org.uk](http://www.pensionsadvisoryservice.org.uk)  
**The Pensions Ombudsman:** 020 7630 2200 [www.pensions-ombudsman.org.uk/](http://www.pensions-ombudsman.org.uk/)