



## Welcome to Our May 2012

### Newsletter

**A Note from Alex:** Well I'm in shock that we're already in May, I'm sure it was New Year only the other day! In this month's newsletter we have started a new feature called 'Late Edition' in it we hope to be able to bring to you a review of some of the articles on ME/CFS during the previous month, and bring you a more in depth report if anything more transpires in a later newsletter.

Please can you also make sure that you have paid your membership fee as this will be the last newsletter that you will receive if you fail to do so. If you want to pay your membership over the internet you will find the instructions on how to do this on page 8.



**This is a short list of my main symptoms in the last week....**

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.

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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, Alex Wootton, Carole Senior, Maria Sale, Lynda Marney & Phil Seddon

## **Support Group Posts & Contact Information:**

Welfare & Benefits Advice:	Pam Turner
Treasurer	Lynda Marney <b>lynda@mesupportgroup.co.uk</b>
Parents' Contact:	Kim Finney            01204 882826
Minutes Secretary:	Carole Senior        01942 810320
Bolton CVS Contact:	Ann Richards        01204 521769
Meetings Secretary:	Maria Sale            01204 575613
Medical Sub-Group, Group Rep & Carers' Contact:	Yvonne Leech        0161 7647822
Web Master:	Caroline Higson     01204 525955 <b>caroline@mesupportgroup.co.uk</b>
Membership Secretary:	Phil Seddon           01204301713 <b>phil@mesupportgroup.co.uk</b>
Newsletters & Distribution:	Alex Wootton        01617615493 <b>alex@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 7986183 <b>andmk1@googlemail.co.uk</b>

**Supported by:**  
**Health for Bolton and the  
Big Bolton Fund 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 17<sup>th</sup> May – Debbie McIntosh**, who is a nutritionist. She will explain why good nutrition is so important in this disease, and for everyone

**Thursday 21<sup>st</sup> June – Philippa O’Callaghan**, from the Red Cross. she will explain their equipment loan service and their carers' care scheme (the latter runs in Bury only at the moment).

**Radcliffe Socials:** We meet informally on the first Monday of each month, our next will be on **Monday 14<sup>th</sup> May 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.

**Yoga Classes:** Are **2:45pm-4:00pm 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](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.

IF YOU ARE THINKING OF ATTENDING ANY OF OUR SOCIALS, WHETHER YOU ARE A NEW MEMBER OR A MEMBER WHO HASN’T BEEN ABLE TO ATTEND FOR A WHILE, PLEASE REMEMBER THAT YOU CAN BRING ALONG YOUR CARER OR A FRIEND. WE DON’T BITE, BUT WE UNDERSTAND THAT MEETING NEW PEOPLE OR IF YOU HAVE BEEN HOUSE BOUND FOR A WHILE, IT CAN BE QUITE DAUNTING GOING OUT BY YOURSELF AND WE’LL LOOK FORWARD TO SEEING YOU.

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

**Please note that the next two (May & June) Radcliffe Socials at the Sparking Clog are to be held on the 2nd Monday of the month due to the usual Monday’s being Bank Holidays.**

It is with great sadness that I announce that one of our members has died. Gilly Gehrke has been a member of the group for many years and has attended the yoga sessions regularly, despite suffering constant pain she was always cheerful and ready to have a joke. A very kind and thoughtful lady, she will be sadly missed by all who knew her. Our sincere condolences go to her family at this sad time.

# Dr. Myhill's Views on Fatigue, The Immune System's Energy Demands, and Rituximab

by Andrew Levy

*Dr. Myhill is a UK-based physician with a special interest in nutrition and fatigue. Information in this article is the opinion of Dr Myhill, and hasn't been reviewed by her peer group. This information is not intended as a recommendation, and you must get professional medical advice before deciding on any treatment.*

Each one of us has a limited amount of energy which we use over each day. The energy is spent in merely staying alive, as well as being used in mental, physical and emotional tasks. Fatigue enters the fray because it acts to prevent us from overspending the energy. A person with CFS/ME probably has a smaller amount of energy to live normally, and this could be made worse by wasting energy on things we don't really need to be doing or thinking about.

Pacing helps sufferers spend that energy in a more measured way. For example, most of us know the consequences of spending too much emotional energy. However it is also possible that wasted energy can be caused by the immune system.

Immune system aside, the energy used to stay alive each day can be broken like this:

- Liver 27%,
- Brain 19%,
- Heart 7%,
- Kidneys 10%,
- Skeletal muscle 18%,
- Other organs 19%.

## **Source: Basal metabolic rate entry in Wikipedia**

It's astonishing that the liver consumes more energy than the heart and brain combined! Much of this has to do with assimilating and detoxing food from the gut. The immune system is similar to the brain. It demands lots of energy and the effects can be seen for example when a healthy person gets the flu. i.e. they become bedbound for a week.

We also know that when animals put on weight the first place that fat is deposited is around the immune system, the lymph nodes. Bone marrow, of course, is very fatty, so this suggests the immune system does not just ask for any type of energy, but something more intensive i.e., fats and oils.

If the immune system is working well, it uses energy to fight infection. However a broken immune system may end up fighting the body itself. It could also lead to an allergy where it fights substances which don't actually cause harm. With CFS/ME Dr Myhill suspects there is another waste of energy caused by a possible allergy to microbes.

Many cases of CFS/ME come after a viral infection and/or a vaccination where the immune system starts to fight the offending microbe. This is all good when it works well. However, when it works against our bodies it becomes an allergy. We also know that vaccinations can trigger allergies, and that some ME patients recover after taking antivirals.

So what does this really mean? Firstly there may be no outward sign of infection. The microbes involved could be present at low levels which wouldn't usually harm the body. Despite this, the immune system continues to fight it, using up lots of our daily energy store.

Whilst the immune system is in overdrive, our brains are also telling us what is happening. This information can be different to what's really going on as the brain can get it wrong. Imagine that the brain has a map of the body which is not quite right, and needs correcting. This could explain why some therapies, e.g. Bowen therapy, Reiki and Kinesiology, work because they improve the way the brain processes the information by re-drawing the map.

Similarly the immune system could use its own map to look out for infections. It's possible that many different types of immune therapies are also geared to redraw the immune system's map. It is possible that the mapping takes place in B lymphocytes who decide on either attack or tolerance; think of it as "war" or "peace". So people with CFS/ME may have B lymphocytes which are constantly at war.

If this is correct, and B lymphocytes can either be re-educated or killed. Dr Myhill has had many years of experience with Enzyme Potentiated Desensitisation (EPD), and has found it to produce results after a few months. Some patients also need "topping up" to maintain the positive effect.

## **Dr. Myhill's Views on Fatigue, The Immune System's Energy Demands, and Rituximab cont...**

Alternatively Rituximab could be used to kill the B lymphocytes. Originally developed as a cancer drug, it had surprising results after a patient who also had CFS/ME reported her fatigue symptoms disappeared. Subsequent studies have shown the drug to have a "highly significant beneficial effect." Again there is a delay in the positive effects, and although some were cured others relapsed. Finally, we could try to remove the levels of microbes so that the immune system stops thinking there is an infection to fight. It may be that this approach explains the success of Dr. Martin Lerner's work with antivirals, treatments with antibiotics for Lyme disease, and with antifungals for chronic yeast problems.

In conclusion there are a lot more questions than answers, but at least the right questions are being asked.

### **Time For Action - A Reminder by Tracy Morris.**

Just to remind you that Action For ME (AFME) need your help in recording an ambitious 10,000 online votes before ME Awareness Day (Sat May 12<sup>th</sup>) with their "Time For Action" campaign. They aim to raise awareness of the ignorance, injustice and neglect of ME and to commit the Govt. to tackling the problem. Remember that the campaign is open to anyone wishing to register their opinion, so please remind friends, family, neighbours etc that their votes are important and could make a big difference. In mid-April the online total stands at approximately 4,500 votes.

Register online at: [www.actionforme.org.uk/time-for-action](http://www.actionforme.org.uk/time-for-action) (Twitter and Facebook options available) or use the postcards supplied with our last newsletter. Extra postcards are available from Action For ME on 0845 123 2380 or 0117 927 9551. Photocopies are also allowed but would be best sent in an envelope as they are not as strong as the originals (plus you can get many photocopies in an envelope for the cost of only one stamp!).

The campaign continues beyond ME Awareness Day and we will have further photocopies available at the meeting in May. We will also collect any postcards brought in that evening and post them en-masse. All contributions gratefully received.

AFME seem to have stepped up their campaigning recently (possibly because the NICE guidelines are due for review next year). These guidelines form the basis of PCT provision and are generally only reviewed every 3 years. At the last review in 2010 hopes were high that the PACE trial results would convince NICE to re-assess their position. Unfortunately the results proved inconclusive and the guidelines were not changed.

The All Party Parliamentary Group (APPG) have been informed of the campaign and some MPs have already raised issues individually in Parliament. Obviously the more pressure that can be generated the better. Annette Brooke, Chair of the APPG, has tabled an Early Day Motion (EDM 2977) to highlight the Time For Action campaign. This does not necessarily mean that the issue will be debated but the more MPs that sign up in agreement the better.

Mr. D Crausby MP is aware of the campaign as he has been in discussion with the local PCT over the last 12 months. You can find out who your MP is by going to [www.parliament.uk/MPs](http://www.parliament.uk/MPs) Lords and offices/MPs/Find Your MP. Is your MP aware of the petition? Would they sign this EDM?

AFME also offer a template letter for writing to your MP or for meeting your MP if any individual wishes to do so. [www.actionforme.org.uk/Get involved/Campaign For Change/How To Get Involved In Our Political Campaigns/Guide](http://www.actionforme.org.uk/Get%20involved/Campaign%20For%20Change/How%20To%20Get%20Involved%20In%20Our%20Political%20Campaigns/Guide).

Other MPs have written questions to the Secretary of State for Health. Ian Paisley asked how much had been spent on research, treatment and care of those with ME in the last five years. Andrew Lansley replied that expenditure on research/ research units etc was:

2006-7 £0.1 million. 2007-8 £0.0 million. 2008-9 £0.1 million. 2009-10 £0.2 million. 2010-11 £0.3 million.

If there are 250,000 people with ME in the UK then (if my maths is correct) this means that it was only in the final year that each person had more than £1 spent on them with regards to ME research.

He admitted that information on healthcare expenditure for ME was not collected centrally ie. he has no idea how much has been spent on treatment.

MP George Howarth has also sent five questions to the Health Secretary re ME. He asks if Mr. Lansley will: 1) publish the research evidence papers on ME for the last 20 years, 2) how he intends to raise medical awareness about ME, 3) whether his department classify ME as a neurological condition, 4) how many people were diagnosed or died from ME since 2005, 5) whether they consider the Perrin Technique to be a useful treatment for ME and is it available as an NHS treatment? Reply yet to be received.

If you hear of surveys or campaigns that other ME organisations are running do please let the committee know so that we can give other group members the chance to comment.

## **Dr Raymond Perrin Next Phase in His Research into ME. by Pam Turner**

Osteopath Dr. Raymond Perrin is about to start a new and exciting phase in his research into ME. The aim of this research will be to prove once and for all that ME is a physiological illness that can be accurately diagnosed. It will involve Dr. Perrin examining patients without knowing anything about their background or medical history to prove that the physical signs that he finds are an accurate diagnostic test of ME.

Dr. Perrin will not receive any payment for his part in the research but the money is vital to pay for the necessary research assistants. Although sixty thousand pounds seems a huge amount, in research terms it is very small. If anyone feels that they can contribute, even a small amount would be very helpful.

The consequences of this piece of research are potentially enormous. There would be an accurate diagnostic test, this in turn could save hundreds of thousands of pounds and endless frustration as most of the blood tests done at present would no longer be necessary. More importantly the attitude of people towards ME sufferers would begin to change for the better.

Please help if you can, cheques should be made payable to FORME and if you send them via Pam Turner, 7 Burghley Drive, Radcliffe, Manchester, M26 3XY.

## **Bolton Healthcare Open Day by Alex Wootton**



Bolton Healthcare in association with Millercare Mobility Specialists and Gordons Ford are holding an open day on Thursday 17<sup>th</sup> May 2012 10.30am – 3pm at the Bolton Indian Sports Centre, Hacken Lane, Bolton, BL3 1SD. You will find one of their

invitations in with your newsletter for postal members and in an extra email for our email members. I went in to the Bolton Millercare Mobility Specialist shop on Bury Road, Bolton, BL2 6HR, to find out more about them and their open day, and you couldn't meet nicer people. They are very understanding to the needs of disabled people, have a good knowledge on their products and will spend as much time with you as you need to find the right products for you, they do not get commission for any other their sales (which I think is important as I don't like pushy sales men), they also know what it's like to use the scooters they sell (one of the team told me that when they were new to the company they were taken in to the town centre and left with a scooter and had to get back to the shop), so they do know what it feels like going around in a scooter.

They told me that this was their 3<sup>rd</sup> year in having an open day (it's also their 60<sup>th</sup> anniversary year along with the Queen's Jubilee and have brought out a celebratory range of scooters), where people can come along and get to look at the products they sell, to make life easier, give people their independence and hopefully a better quality of life.

Gordons Ford will also be able to help you and answer any questions you may have about the Motability scheme along with a display of Ford cars.

They use the Bolton Indian Sports Centre for the ease of access, as its all on ground level, with plenty of free parking, disabled facilities and plenty of room in the hall they use. Oh and there will be a free buffet on the day.

## **Book Review: by Tracy Morris**

**Improve Your Digestion: The drug-free Guide to Achieving a Healthy Digestive System, by Patrick Holford Published in 1999.**

I recently found this book and would recommend it to anyone struggling with digestive problems. It includes the best explanation of how the digestive system is supposed to work that I have ever seen, what the body needs in order for it to function correctly, and the most common reasons why things go wrong. The book is detailed and yet simply written, covering a complicated subject in a very readable way. The chapters are relatively short with bullet points to summarise which I found helpful.

The author explains how digestive difficulties can lead to absorption problems and how this then becomes a vicious circle by weakening the body further, leading to increased fatigue and greater digestive or whole-body problems. As the digestive tract is also important for neurotransmitter, hormone activity, and immune-system function it is a great centre of communication for the body and of vital importance. He is the first person to confirm my suspicion that digestive problems can be a major factor for some people in developing ME.

As the digestive system has such a vital role to play in good health the cells in the gut reproduce far quicker than in any other part of the body. This means that any changes made to improve the situation can give results quite quickly.

Some of the topics he covers include: digestive enzymes and stomach acid, food combining, absorption, fibre, healthy intestinal flora, allergies and intolerances, digestive irritants, Candida, leaky gut, liver and detoxification problems, Irritable Bowel Syndrome, Crohns / Colitis and Diverticulitis, wind, bloating, constipation, haemorrhoids, digestive cancers, and stress and peristalsis.

Having explained how these problems occur he then gives general suggestions to improve the situation which he believes should relieve or cure many of the simpler problems, and goes on to examine the more complicated conditions in more detail. At the back of the book is a guide to the dose of various vitamins/ minerals and supplements he would recommend for gut healing. I have needed to adapt some of these slightly and one of the recommended supplements is no longer available but using the guidance in the book I was able to find an alternative approach.

Despite many expensive tests and consultations with various nutritionists I have never been able to make much headway in improving my digestive problems. By following his guidelines cautiously I have been able to introduce small amounts of certain foods that I have been unable to tolerate for years. I still have a long way to go and he does suggest that for more complicated problems a visit to a nutritionist would be recommended, but my plan is to do as much as possible for myself before consulting someone when I can make no further improvement. Much of what he suggests also form part of the recommendations from Alex Howard and his Optimum Health Clinic.

At the time our newsletters publication you can purchase this book priced at £6.49 from Amazon

Other books by the same author include:

**The Optimum Nutrition Bible:** which includes general information and advice on vitamins, minerals and diet.

**The Optimum Nutrition Cookbook:** I was a little disappointed in this book as the recipes seemed to need a lot of ingredients and some appeared unnecessarily complicated (unhelpful when being made with little energy).

**The Holford 9 Day Liver Detox.**

**The 10 Secrets Of 100% Healthy People.**

## **Paying Your Membership Fees Online**

You will need to have an online banking account to pay your membership fees online. Please also make sure that you have good Anti-Virus software on your computer before you start. Natwest give you an extra Anti-Virus called 'Repport' and HSBC have 'Macaffee' as an example so go to your own bank to find out what extra free security they can offer you.

The Bury & Bolton ME/CFS Support Group Account details you will need to make the transaction are as follows: Sort Code: 20-10-71 Account No: 00902179 Account Name: Bury & Bolton ME/CFS Support Group.

If you do pay your membership fees this way it is important that you email Lynda Marney our Treasure [lynda@mesupportgroup.co.uk](mailto:lynda@mesupportgroup.co.uk) with the date and the reference (Lynda suggests that you use your name or a pseudonym) you have used so she can identify your payment. Once she has received the bank statement and identified your payment she will then send you a receipt via email.

## **ESA Appeal Tips by Alex Wootton**

Some of you already know that in the middle of April I was transferred from Incapacity & Income Support benefits to ESA Work Related Activity Group, where you only receive this benefit for the maximum of 365 days. Below are a few tips that I have learnt for myself in putting in my appeal.

Make sure that you get in your appeal letter in within the given deadline (I found that writing a letter was better than the appeal form GL24 as it really didn't help with ESA appeals). Get a copy of your medical records and a supporting letter from your GP if your GP is supportive of you. You will probably have to pay a fee for your medical records and GP letter, but I think it's worth it. If you haven't already got copies of your medical records make sure that you send your appeal in without them stating that you will be sending more evidence to back up your appeal at a later date. Once you have your medical records contact your local Job Centre Plus and ask for an appointment to have your medical records verified. I had already made my own copies to be verified but don't do this, the Job Centre will copy and verify them for you all in one go. They did offer to send the copies on for me but I refused this as I didn't fancy the chance that they could get lost as some of our members told me that they'd lost their records. So I sent my appeal letter and then my medical records via Special Delivery, this does cost more than the usual postage but I wanted my documents to be tracked and have the knowledge that they did receive them. Lastly make sure your National Insurance Number is on all the correspondence you send to them. I hope you find this useful and will update you with any other useful info as my appeal goes on.

## **Late Edition**

### **ESA survey by Action for ME via Keep Me Uptodate email on 2nd May 2012:**

If you have applied for Employment and Support Allowance (ESA) in the past 12 months, please complete our survey [http://www.actionforme.org.uk/get-informed/news/our-news/applied-for-esa-please-complete-our-survey?dm\\_i=1HO,SF6N,1SU6NE,2B73V,1](http://www.actionforme.org.uk/get-informed/news/our-news/applied-for-esa-please-complete-our-survey?dm_i=1HO,SF6N,1SU6NE,2B73V,1) More than 200 people with M.E. participated in a similar survey in 2010. Results showed that the Work Capability Assessment (WCA), the face-to-face assessment for ESA, was not suitable for testing fluctuating conditions such as M.E. Paper copies of the survey are available from Policy Officer Tristana Rodrigues at [tristan@actionforme.org.uk](mailto:tristan@actionforme.org.uk)

### **ME Association Quick Survey**

Taken off the ME Association Website Monday 7<sup>th</sup> May 2012.

*Question:* Overall, what best describes the attitude of your immediate family towards your illness?

*Answers:*

- Very understanding (19%, 69 Votes)
- Understanding (12%, 42 Votes)
- Mixed (understanding in some ways but not in others) (43%, 158 Votes)
- Lacking in understanding (18%, 64 Votes)
- Not interested (6%, 22 Votes)
- No immediate family (2%, 9 Votes)
- Total Voters: 364