

Jenny Writes...



Dear Members,

Well, unbelievably, it's ME Awareness week again! How these years roll by and still we have the need for our support group - more than ever if the rising numbers are anything to go by. Once again we will do our bit to try and promote awareness and to raise some money for biomedical research. It's starting to annoy me beyond bearing that we have been campaigning for so many years and not one single person in authority (those with the power to do something about our plight) seems to have listened to a word we say. Just lately a lot of the avenues where we could voice our views, such as the All Party Parliamentary Group on ME, have been closed to

us, so we thought we would write down a selection of all that we, the sufferers, have said over the years (see page 11) in our ME Awareness newsletter. I will send a copy to all our MPs. I hope they will read it (sometimes it seems they only want to know us at election time... but at least it will make us feel better!) The newsletter is packed full this time - I had a problem knowing what to leave out rather than what to put in! Three pages of research, to make up for last time, which is good. Some very interesting stuff going on there. The State of Knowledge meeting in the US (p. 13) was very encouraging - getting ME researchers together, much like Invest in ME conference does for us here in the UK every year. Lots of national ME news and lots of news from our own group. I am aware that many of you will be facing the next

year with some anxiety- the switch to ESA from Incapacity Benefit is already causing a lot of trouble for people with ME. The cutbacks in welfare & social services are also going to affect us badly. We will do our best to provide as much support and information as we can to try and help us all get through the bad times. And don't forget we are here - see all the ways to contact us below - if you need someone to talk to. On a brighter note, I hope you have all enjoyed the lovely sunshine we had in April. It certainly helps you to feel better after our very long winter, doesn't it? Hope to see as many of you as possible at the coffee morning!

Take care & keep in touch,
Love Jenny
PS Sorry to anyone who has asked me to be a Facebook 'friend' & not heard back, but I have made decision not to get involved on FB other than our group page, otherwise I will never get anything else done as I will be chatting all day - I know me!!!

As always, many thanks to my newsletter working party partner, Gurminder, for all her help and support - Jenny

KEEP IN TOUCH!

For any thoughts, feedback, comments, ideas or just to have a chat you can contact us:

By phone: Jenny 0121 689 0777

Jo: 0121 444 5177 Sun - Fri -12 noon - 7pm

By email: jlgriffin@blueyonder.co.uk

On Facebook: [Solihull and South Birmingham ME Support Group](#)

By textphone: 07785 958 872

By post: 59 Cartland Rd Stirchley B30 2SD

Poetry Corner

It is very fitting in ME Awareness week that our poem comes from "Young Hearts", a book of poems all written by children and young people with ME.

Edited by Jane Colby; Published by TYMES Trust

To order *Young Hearts*, complete the form on the website and send with a cheque for £7.95 and send to: Young Hearts, PO Box 4347, Stock, Ingatestone, CM4 9TE.
<http://www.tymestrust.org/>

Please Don't

by Catie Jenkins

Please don't tell me I look just fine
Please don't say I'll be right in no time
When I can hardly make it through the day
You don't have to live this life
So please don't tell me you know what
it feels like
Or how it really is to be this way

Please don't tell me I'm just a little tired,
Don't shake your head and say I'm not
really trying
When I want to spend some quiet time in bed.
"Come on let's get you out of the house,
We all have our ups and downs".
You haven't heard a single word I've said

Potions, pills and wonder cures -
I don't believe in miracles.
I only wish you understood the truth,
That to watch and wait and pray,
Live in hope from day to day
Is all that either one of us can do.

DON'T FORGET YOUR MEMBERSHIP RENEWAL

For those of you who haven't yet rejoined we have enclosed a spare membership form as a reminder!

CONTACT LIST MEMBERS!

Your contact list update is enclosed with this newsletter

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Round up for ME Awareness Week -
and don't forget our own Coffee Morning on May 9th! (see page 7)

ME Art Exhibition

The Irish Award Winning Poet & Artist Mary Courtney from Earlsdon Coventry was struck down with chronic fatigue syndrome or as it is better known M.E. three years ago. After winning a series of commendations for her poems published by Cambridge and Warwick University & the National Poetry Society she has created an art exhibition combining her love of poetry and painting featuring 8 Haiku's called 'A Story of Energy' which tells the story of her ongoing recovery from M.E. Because the exhibition is all about energy and how it constantly moves, plans are in place for the exhibition to be installed at the **George Elliott Hospitals Chronic Fatigue Unit** to coincide with **National M.E Awareness Day on Thursday May 12th** where Mary's consultant Dr Vinod Patel has show particular interest in Mary's story and Warwick University Medical School before going on a tour. To find out more about Mary you can visit: www.marycourtneypoetry.co.uk

2011 TRIVIA QUIZ - RAISING MONEY FOR M.E. RESEARCH WIN £30!

If you'd like a chance to win and at the same time help raise some much needed funds for ME Research UK & The 25% ME Group, please buy one (or as many as possible!). It's still only **£1** per quiz and the closing date is **Thursday 30th June 2011**. If you have any friends/family who you think might like to buy one, please request more quizzes. To enter, write to: **Jane Hurst, 12 Malten Close, Poringland, Norwich, NR14 7RW** stating how many quizzes you would like and enclose a cheque (£1 per quiz) made payable to Jane Hurst – An S.A.E. would also be appreciated, thanks. If you prefer, you can pay by **Paypal and/or receive a quiz via email** - for details please email: jane@lhurst99.freemove.co.uk. All funds go to the above charity. Oh, and there's organic choc for the runner up!

Thanks for your support.
Jane Hurst & family

SHROPSHIRE ME SUPPORT GROUP ANNUAL CONFERENCE



Jane Colby of the TYMES Trust is speaking on

“Do Treatments For ME/CFS Work?”

At The Bayston Hill Memorial Hall,
Lythwood Road, Bayston Hill,
Shrewsbury,
7th May, 2011 2 - 4 p.m
All welcome - admission free

The 6th Invest in ME International ME/CFS Conference ‘The Way Forward for ME - A Case for Clinical Trials’

Chair - Professor Malcolm Hooper.

Mrs Annette Whittemore, President of the Whittemore-Peterson Institute, will be opening the conference on **MAY 20th 2011**. It is appropriate that an organisation that has its roots in helping patients, and which is furthering the idea of biomedical translational research, should open the conference. The permanent conference slot for the WPI is again filled this year by Research Director **Dr Judy Mikovits** who will be presenting the latest on XMRV research.

One of the world's most experienced, and certainly Europe's most experienced ME researcher is **Professor Kenny De Meirleir** and Professor De Meirleir is back for the third time to an IiME conference.

Dr Kogelnik worked with Dr. Montoya on a placebo controlled double blind antiviral study to test the efficacy of valganciclovir on a subset of ME (CFS) patients (J Clin Virol. 2006 Dec;37). He is the founding director of the Open Medicine Institute, a collaborative, community-based translational research institute dedicated to personalized medicine.

Dr David Bell has enormous experience and a special perspective on ME. He was the paediatrician in the middle of an ME (CFS) outbreak in the rural village of Lyndonville where 214 residents among them 46 children became ill with a mystery disease. Dr Bell has followed his patients ever since still looking for the cause of his patients' ill health.

Professor Olav Mella and Dr Øystein Fluge are cancer researchers from Bergen University in Norway and they have been trialling Rituximab for ME patients with promising results.

Dr John Chia returns to cover the role of enteroviruses in ME. Dr Chia is continuing his enteroviral research looking at the pathogenicity of the viruses he and his team have found. Dr Chia sees and treats a great number of ME patients.

Dr James Baraniuk is currently associate professor at the Department of Medicine at Georgetown university in Washington and will be presenting on cerebrospinal markers in ME.

The University of East Anglia's research park is the focus of IiME's attempt to initiate an examination and research facility for ME and is well equipped to perform state of the art research into ME. They are delighted to welcome **Professors Tom Wileman and Simon Carding** to tell about what could be done to advance UK research into ME.

Dr Wilfried Bieger is a docent of Medicine in private practice in Munich, performing a study in co-operation with a researcher from Heidelberg University to test German ME patients for XMRV. The results of this study will be presented at the Invest in ME conference.

The conference will hopefully help further assist in shifting the momentum toward biomedical research.
<http://www.investinme.org/IiME%20Conference%202011/IiME%202011%20International%20ME%20Conference.htm>

What I'm really thinking: The woman with ME



‘Yes, it's scary to think you could wake up with a cold one day and never be well again’

Twenty years coping with the symptoms of ME is bad enough, but 20 years of coping with people's reactions to it adds insult to injury in the most literal sense. First was the era of "yuppie flu", when people you'd never met before felt entitled to interrogate you as to the validity of your illness and your presumed psychological deficiencies. Nowadays I get either the "you need to pull yourself together" brigade, or the alternative types who ask what my illness means, and are sure I could be well if only I understood what it was trying to tell me. Well, if I haven't figured that out in 20 years, that must mean they think I'm pretty thick. Then there are the ones who say, "But you always look so well." Of course I look well when

I'm out and about; it's because that's a day when I'm well enough to drive. They should see me on the other days.

Of course, this is largely about the rudely healthy being in denial of the reality of illness. Yes, it's scary to think you could wake up with a cold one day and never be well again, and there's little you can do about it. But don't try to force me to collude with you in trying to deny that it happens.

What I mind most, though, are the people who listen to my story with such sympathy, but then take equal time to describe the horrors of their current cold/flu/chilblains. My usual response? "Don't worry too much about feeling ill, it gets easier after the first couple of years." That shuts them up.

<http://www.guardian.co.uk/lifeandstyle/2011/mar/12/what-really-thinking-woman-with-me>

Kay Gilderdale writes about Lynn



Kay Gilderdale has written a book, "One Last Goodbye", about her life with Lynn and the tragic events that led to the death of Lynn and the arrest of Kay for murder.

Following the publication of the book in April, Kay did a series of interviews for the media. During all these interviews Kay conducted herself with great dignity and composure.

She kept her promise to Lynn that she shouldn't die in vain, by raising the aware-

ness of ME and telling just how terrible and severely disabling ME can be.

Kay also told of the devastating consequences of spending a life of pain, illness and isolation without little help or support from the medical establishment.

Kay said: "I had requested May 12 for the launch, to coincide with ME Awareness Day, but there have been complications and the publishers have had to change the date."

(<http://www.meassociation.org.uk/?p=3215>)

On Friday, April 15, Kay was on the ITV 'This Morning' Programme. You can watch the 'This Morning' interview here:

<http://thismorning.itv.com/thismorning/life/i-helped-my-daughter-die>

ME NEWS...ME news...ME news

Atos & Job Centres criticised by their own employees...

'Sick Firm Told us to Catch Out Disabled People'

<http://www.socialistworker.co.uk/art.php?id=24468>

Jean, a former employee of Atos Healthcare in Scotland, ..."I worked for Atos as a 'disability analyst' thinking I would be helping vulnerable people to access their benefits," she said. "I soon discovered that nothing could be further from the truth. The rules laid down by the bosses are designed to catch people out."

Jobcentres 'tricking' people out of benefits to cut costs, says whistleblower (the Guardian)

A whistleblower said staff at his jobcentre were given targets of three people a week to refer for sanctions, where benefits are removed for up to six months. He said it was part of a "culture change" since last summer that had led to competition between advisers, teams and regional offices. See more at: <http://www.meassociation.org.uk/?p=5517>

'84% of British neurologists don't view CFS as a neurological illness'

From the "[Journal of Psychosomatic Research](#), 9 April 2011 Abstract:

"In this month's issue, we report a survey of members of the Association of British Neurologists, which asked if they viewed chronic fatigue syndrome (CFS) as a neurological condition-84% of respondents did not. This is at odds with current classification in ICD-10. We discuss the difficulties of classifying CFS and myalgic encephalomyelitis (ME), including historical and sociological factors, the pitfalls of the physical/psychological dichotomy and why classification matters to doctors and patients."

<http://bit.ly/gggdiP>

NB This paper followed hard on the heels of the original paper from Kings College which looked at how neurologists viewed Background Conversion Disorder. This was co-authored by Simon Wessely ... what a surprise! - Jenny

...group news ...group news

SSB ME Awareness

COFFEE MORNING

at 59 Cartland Road B30 2SD

Monday MAY 9th 2011

1- 3 p.m

All are welcome!

Come along and help raise funds for ME biomedical research - bring your family & friends.

If you are not well enough to come along, join in & support ME research by sending your donation or buying some SSB cards (see page 8)

(Send donations to Jenny - cheques made payable to Solihull & South Birmingham ME Support Group)

MEETING DATES

On Monday...

MAY 9th

ME Awareness Coffee Morning at 59 Cartland Road 1 pm

JUNE 13th

at Shirley Community Centre 7.30 pm

JULY 11th

Short talk by Karen Hunt on Aloe Vera

At 59 Cartland Road 1 pm

N.B NO meeting in August!

SEPTEMBER 12th

At Shirley Community Centre 7.30 pm

...group news ...group news

Meeting News



April Meeting

The April meeting was well attended as we welcomed back some old friends and two new ones, Diane and Yvonne. This was an informal meeting and there was plenty of chat with a focus on young people with ME and their carers and, of course, the current worrying topic of benefit & welfare reforms. We all sympathised with the worries

of caring for young people with ME and how awful it was for young people to have this illness.

Almost everyone in the room was either presently involved in a benefit claim/appeal or anxiously awaiting the switch to ESA. All agreed that the new ESA descriptors did not take account of a fluctuating illness like ME.

The group library was out on display during the meeting and proved very popular.

JANET HARRISON

1943 - 2011

It is with great sadness that we have to tell you that Janet passed away in January.

Janet was one of our longest standing members and joined our group in 1994.

We shall miss her.

We send all our sympathy and love to her daughter, Alison, and to the rest of her family.

*Possible Date for your Diary!

Monday September 12th

meeting at Shirley Community Centre 7.30 pm

We are *hoping* to have a talk from

Professor Derek Pheby & Dr Martin Lee

www.resumecfs.org.uk

Many of you will remember Alistair and Shirley. Well, Alistair is involved in Resume CFS, a recently registered charity, working to improve the research in and understanding of ME. All their Trustees have personal experience of ME themselves or within their family. The Chairman is Professor Derek Pheby, who was on the panel that wrote the Chief Medical Officer's report a few years ago and more recently lead the work on the ME Observatory funded from the Big Lottery Fund. So they have good provenance! RESUME CFS has a new web site where they discuss two of their current projects;

1. The importance of using the best criteria to select a sample base for ME research (a problem we all believe was not properly addressed in the recent PACE study!)
2. The need to develop a better understanding of ME, to empower GPs to make a proper diagnosis.

They hope that our ME Support Group members might be interested in this work and better still wish to help them with these endeavours. As well as a much fuller explanation of these two projects there are links to allow the download of Application forms (for the Disease Register and the Guidelines and Clinical Evaluation Form for GPs). Apart from this, there is a lot of interesting stuff on this web site.

*More in our September newsletter

ME AWARENESS WEEK

Lots of good wishes for ME Awareness Week. We hope you like your postcard posters, enclosed with the newsletter. These are very handy just to put in a local doctors surgery, community centre etc. If you able to do this, or get someone to do it for you, that would be great. If you are not able to do this, could you put it in your window or on your front door or porch - who knows who might see it and it all helps to raise awareness.

In touch...your page...your news

SSB Cards on Sale NOW!

At long last we have some new Solihull & South B'ham **FRIENDSHIP** and **THANKYOU** cards

The profit made from these cards will go towards our fundraising for biomedical ME research.

To order these cards **fill in the ORDER FORM enclosed** or get in touch with Jenny via the usual contacts.

The cards will also be on sale during the **SSB Coffee Morning on May 9th**



Friendship Card 1



Friendship Card 2



Thank you Card 1



Thank you card 2



[Example of our logo on the back of each card]

N.B All cards are blank inside for your own message

All cards £3.99 for a pack of 5 (including envelopes)

Happy Birthday to:

MAY - Jo Draysey; Elaine Samworth; Glenys Thomas; Mary Hopkins

JUNE - Jo Taylor; Wendy Vincent; Judith Jones; Dan Longley; David Slater; Simone Dorsett; Angela Coghlan

JULY - Lin Cook; Mary Donelan; Hugh Jones; David Slater

AUGUST - Mary Denby; Phil Evans; Mark Holland; Rebecca Greenhill; Stephen Moss; Mary Duncan; Sheila Tompkins



In touch...your page...your news



JO'S TRANSPORT

If you would like a lift to a meeting, please phone Jo Taylor on **0121 444 5177**.

We will do our best to arrange this. If you can offer a lift to meetings please phone Jo on **0121 444 5177**

Website:
<http://cfspatientadvocate.blogspot.com/>

Full of current news and opinion. Run by the parent of an ME sufferer in USA - Jenny

DEEPLY RELAXING REVIEW

From: Michelle Bint

I know we are all familiar with those hippy relaxation CDs, the ones with some whales whistling in the background, and porpoises leaping into insipid pastel blue swirls on the cover artwork. I have found a relaxation CD that really works and helps my M.E, It is 'Deep Relaxation' from Andrew Johnson (who is a trained Hypnotherapist).

The CD takes 40 min and It puts you into a deep physical and emotional relaxed state that is not scary, or has any brain washing element (like some of those go-getter life improvement CDs voiced by cheesy DJ types).

It is practical and simple with no expectations required, only positivity, you go at your pace and only implement things that suit you. On the background soundtrack, as you drift into relaxation there is some dude on a guitar and waves swishing about, but it is not intrusive, only integral to the rhythms of the experience. Best of all, no patronising voice, just the gentle Scottish tones of Andrew Johnson taking you deeper and deeper into relaxation.

I bought my version on Amazon as a MP3 download for under a Pound, but it can be also be bought as a CD or download on Andrew Johnson's own website, on 'i-tunes as an audio book' or as a i-phone app. (the i - tunes store seems to be the cheapest)

Thus, digital shopping will save you a trip to the hippy shop, and the experience of parting the air heavy with the scent of patchouli, and choking on joss sticks made by Himalayan monks, as you wend your way to the till!

Many thanks Michelle! - Jenny

FOR SALE

INFRA RED PORTABLE SAUNA

Eve H has an far red infra red portable sauna for sale. Any reasonable offer accepted.

Contact Jenny if you are interested

JOIN OUR FACEBOOK!

- It is FREE to join!
- To get on Facebook, google Facebook and follow the guide for joining - you will need an email address and a password
- If you are new to Facebook there is a link on the Facebook page which will give you easy to follow step by step instructions on making the most out of the website.
- To find the group page type **Solihull and South Birmingham ME Support Group** in the search box.
- When you get to our page, pressing the 'like' button will enable you to be automatically registered as a member of our Facebook group if you are a member of our group.
- On joining the group you will receive a welcome email which will tell you how to go about the site

Why are we still waiting?



Nearly ten years on from the Chief Medical Officer's report on ME/CFS, we take a look at why there has been seemingly little or no progress in the UK over the last five decades - and why many people with ME are saying we are worse off now than we were twenty or thirty years ago.

In the beginning there was just ME. The illness came to prominence in the UK after the 1955 epidemic outbreak at the the Royal Free Hospital in London which struck down 292 nurses and hospital staff, many of whom never recovered and still have ME to this day. The Infectious Diseases consultant at the Royal Free in 1955 was Dr A Melvin Ramsay, who was responsible for the care of these patients. It was due to Dr Ramsay's meticulous observation of this outbreak and his painstaking investigation, in conjunction with Dr Donald Acheson (the then CMO), of other outbreaks at that time and later, that led to his now classic definition of ME. The disease was named benign Myalgic Encephalomyelitis or ME. Dr Ramsay said: "I am in no doubt now that ME is an endemic disease which is subject to periodic outbreaks of an epidemic kind." No one with ME reading Dr Ramsay's work could fail to identify with disease he describes and would find it unbelievable that anyone would even consider this to be a psychological illness. Valuable research into Ramsay defined ME continued throughout the next decade or so.

In 1970 two young psychiatrists, McEvedy and Beard, re-examined the case notes of patients from the Royal Free epidemic of 1955, and suggested that epidemic hysteria was a much more likely explanation of the illness than

an organic disease. Although their papers elicited a huge outcry from experienced ME physicians at the time, the establishment for some strange reason accepted the explanation from two inexperienced doctors without question. The research funding for ME dried up & ME faded from the public perception during the 1970s.

In the 1980s there was a large surge in the numbers of people getting ME - these sufferers were insultingly described as having Yuppie Flu to reflect the fact that a significant proportion of sufferers in the early 80's were young upwardly mobile people working in the booming London city financial services. By the end of the 1980s, however, many people all over the UK and from all walks of life had contracted ME (including many of us in our group). At this time certain psychiatrists and others involved in the medical insurance industry (on both sides of the Atlantic) began their campaign to reclassify the severely incapacitating and discrete neurological disorder known as Myalgic Encephalomyelitis as a psychological or 'personality' disorder, in order to side-step the financial responsibility of so many new claims. The name **Chronic Fatigue Syndrome (CFS)** was adopted in the late 1980s and the psychiatrist Simon Wessely began his rise to prominence in the UK.

Ever since then Wessely has gained dominance in the field of ME in the UK (and increasingly around the world) by producing vast numbers of papers which purport to be about ME. Members of the 'Wessely school' in the UK (which includes Michael Sharpe and Peter White, both in-

involved in the PACE Trial) support a psychosocial approach to 'CFS' and recommend rehabilitation-based approaches such as cognitive behavioural therapy (CBT) and graded exercise therapy (GET) as the most useful interventions for 'CFS' patients.

It suits their purpose to use the terms CFS, chronic fatigue, fatigue and ME interchangeably thus creating confusion, muddying the waters for any serious research on ME, and burying ME under the umbrella term of CFS until it hardly exists as a separate entity in the minds of the media or the public. Conveniently they created their own research criteria, known as the 'Oxford Criteria' (used in the PACE Trial), which probably excludes most patients with ME, and then proceeded to grab all the government funding in the last two decades for their psychosocial research. These psychiatrists, in their lucrative positions as government advisors (e.g to the Dept of Health and the DWP), have also propagated their doctrine to government Ministers and to Members of Parliament, resulting in the withdrawal and erosion of both social and financial support for ME patients. There is no doubt that this doctrine finds favour politically and economically.

Everywhere you look in the structure of ME - NHS services, guidelines, government research, welfare and benefits - you will find a 'Wesselyite' in control. So it is little wonder that many people with ME in the UK are not surprised that, far from moving forwards towards solving the mystery of ME, we have in reality, since the advent of the artificial construct of CFS, moved backwards - leaving ME in the wilderness...



What we said - did anybody listen?

CMO's Report on CFS/ME 2002

Chapter 2 Evidence from patients:

Key messages

Patients' voices are not being listened to and understood. People affected by CFS/ME indicated improvements needed in three main areas:

- Recognition, diagnosis, acceptance, and acknowledgement;
- Healthcare service provision;
- Care of groups with special circumstances.

Patients reported the need for more healthcare professionals who know about and understand CFS/ME. Public awareness campaigns, professional education, and information for patients and carers are accorded high priority.

Experiences of primary care are polarised. Positive experiences are characterised by: "willingness" of clinicians to treat the patient as an equal; supportive attitudes; belief in the patient's experiences; and early recognition and diagnosis.

Experiences of further care are predominantly negative. Needs identified include access to specialists and respite-care services. Those severely affected by CFS/ME (up to 25% of patients) feel "severely overlooked" by services. They experience isolation, lack of understanding, and particular barriers to accessing all forms of care.

2002 - What the patients said (CMO report)

"Dumped in the community - totally invisible."

"Severely ill are severely overlooked - just ignored and invisible."

"GPs could do with more training in how to support people with incurable/untreatable illnesses and in dealing with their own feelings of powerlessness."

2005 - 2009 What the patients said (B'ham NHS CFS clinic feedback)

"When I finally got into the clinic, after waiting weeks for an appointment, I found that they hadn't got my notes from my GP. They said they would make me another appt but I had to wait for 4 months for this. I am still waiting"

"No treatment, very little advice..."

"Difficult to assess - after 19 years with ME, I think I know more than them"

"Very busy, lot of waiting time - diagnosed then discharged as no funding"

"I waited nearly an hour to see the consultant and when I did see him, he just asked me how I was and said he was sending me on a course of therapy. This took 5 minutes. It wasn't worth the ordeal of getting there and the wait. I still haven't heard anything about the therapy course".

2009 - 2011 What the patients said ('We say...' - to SSB ME Support Group)

"Many GPs, DWP assessors, consultants in other fields don't know what ME is. It means we don't get proper treatments from GPs & we get turned down for benefits and passed around the NHS. No one understands."

"I just want health professionals to listen to people who actually have ME. The NHS promotes treatments which few ME sufferers find helpful..."

"Appropriate education for GPs, nurses - any one who has contact with ME sufferers in the early stages..."

"After 8 years of suffering, it was a relief when my GP finally accepted I was suffering with ME. My previous GP refused to accept my illness existed"

Hey Everyone,
I've broken up from university now for a bit, which is a relief as I've been in need of a good rest for a while. People laugh at me when I tell them I've got a month off, but to me it isn't quite long enough.

M.E Awareness week is fast approaching so I've been busy getting our posters ready, hope you all like this years version. I recommend anyone that is able to go, to attend the coffee morning in May as if last years anything to go by, it will be a really nice afternoon. Unfortunately, I won't be

there as afternoons aren't good for me but I'm sending my Nan along to look after you all with some home made scones, that I intend to make for you.

So keep smiling, stay positive and I shall look forward to seeing some of you throughout the year.

Best wishes

George Beech

Georgebeech.designs@live.co.uk



Children & young people with ME - cause for concern

In the last few months some more overt examples of how the pervasive influence of the psychiatric school is filtering down to the care of children & young people with ME, have given us cause for great concern. The RCPCH and GOSH are openly saying that CFS (and by implication, ME) is a psychological illness. Some paediatricians, such as Dr Esther Crawley former Chair of BACME and medical advisor to AYME, have colluded with such a view. If you want to know what around 500 people had to say about AYME's current policy then look at the

petition (*now closed*) on: <http://www.ipetitions.com/petition/ayme/>

Tymes Trust's CEO, Jane Colby's reported at the Forward ME meeting that children are being referred to social services (and in some cases mental health services) because they did not get better quickly enough with CBT & GET [NICE guidelines & PACE Trial recommended treatments for CFS/ME] and therefore could not have CFS/ME. Very worrying implications for young people... We thank Jane for pursuing this further.

From the recent Royal College of Paediatrics and Child Health (RCPCH) submission to the National Institute for Health and Clinical Excellence [NICE] CG53: CFS/ME Guideline Review Consultation -

-quote -
"Regarding the epidemiology of chronic fatigue syndrome as a **psychological illness with physical manifestations ...**"

Thankfully we have just heard that, following letters from Kathleen McCall of Invest in ME & the Countess of Mar, the RCPCH have withdrawn this statement from their NICE review submission. See: <http://www.meassociation.org.uk/?p=5817>

From the Forward ME Group minutes for meeting held on March 1st 2011

Item 6: Child protection and the use of the Mental Capacity Act

Jane Colby [TYMES Trust] thanked the Group for supporting her request for this to be added to the agenda of the APPG on M.E. She advised the Group of a copy of a letter she had from a consultant to the parents of a child with ME/CFS which indicated that, because the child had not responded to any of the treatments recommended in NICE [CBT & GET] they were rescinding the diagnosis of ME/CFS and referring them to social services. Sue Waddle [MERUK] said that she had also encountered such cases.

<http://www.forwardme.org.uk/1st%20march%202011.htm>

[from the Great Ormond Street Hospital website]

1. Feeding & Eating Disorders Service (Dr Nicholls and Dr Bryant-Waugh)

This outpatient service caters for:

- those with early onset eating disorders or at high risk;
- children with behavioural feeding problems in the context of chronic illness/medical problems;
- severe and chronic selective eaters;
- infant feeding problems and failure to thrive;
- emotional eating difficulties (e.g. food phobias) or in the context of **somatic problems such as chronic fatigue syndrome.**

<http://www.gosh.nhs.uk/website/gosh/clinicals/services/DCA>

The 'State of the Knowledge' Workshop on ME/CFS

On April 7th & 8th 2011, the Office of Research on Women's Health in collaboration with the National Institute of Health's ME/CFS Working party held a State of the Knowledge Workshop on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Research in Bethesda, Maryland USA.

This workshop brought together 32 investigators from a wide variety of scientific disciplines to discuss ME/CFS research. The goals were to: 1) document what we currently know about this illness, 2) look for gaps in our knowledge needing more research, and 3) identify outstanding opportunities in science and technology that might advance biomedical research on ME/CFS.

Topics covered included infectious diseases, systems biology, immunology, neurology, exercise physiology/energy metabolism, diagnosis and biomarkers, and treatments. The speakers included Benjamin Natelson, Judy Mikovits, Anthony Komaroff, Leonard Jason, John Chia, Nancy

Klimas and many others. There were also two moving presentations by patient, Mary Schweitzer, and ME campaigner Pat Fero. The entire workshop webcast is now available on the NIH VideoCast Past Events page: <http://videocast.nih.gov/PastEvents.asp>

Note from Jenny: I have watched a bit of this video already and there are some really interesting presentations - and so far (refreshingly) not one mention of CBT! There have been many pleas for some joined up thinking on ME research and it would appear that the American NIH is taking this seriously. For those of you who can't watch videos on the net, a text report of this workshop is in preparation and will be available on the website below when released:

<http://orwh.od.nih.gov/CSF%202011/newsEvents.htm>

We hope to have some extracts from this report, when it is published, in future newsletters.

PS Also see really interesting article from Amy Dockser Martin at:

<http://blogs.wsj.com/health/2011/04/08/at-nih-chronic-fatigue-syndrome-conference-xmrv-debate-heats-up/>

Australian brain MRI study of CFS

A brain MRI study of chronic fatigue syndrome: Evidence of brainstem dysfunction and altered homeostasis

Authors: Leighton R. Barnden, Benjamin Crouch, Richard Kwiatek, Richard Burnet, Anacleto Mernone, Steve Chryssidis, Garry Scroop, Peter Del Fante

http://sacfs.asn.au/news/2011/03/03_01_publication_of_original_adelaide_cfs_mri_study.htm

(Abstract) 'In the midbrain, white matter volume was observed to decrease with increasing fatigue duration. For T1-weighted MR and white matter volume, group x haemodynamic score interactions were detected in the brainstem (strongest in midbrain grey matter), deep prefrontal white matter, the caudal basal pons and hypothalamus.'

A strong correlation in CFS between brainstem grey matter volume and pulse pressure suggested impaired cerebrovascular autoregulation. We argue that at least some of these changes could arise from astrocyte dysfunction. These results are consistent with an insult to the midbrain at fatigue onset that affects multiple feedback control loops to suppress cerebral motor and cognitive activity and disrupt local CNS homeostasis, including resetting of some elements of the autonomic nervous system.'

Chronix Biomedical and Hemispherx Biopharma Jointly File Patent Application for a Blood Test for CFS

"Our technology - based on DNA released into the bloodstream by dying and damaged cells - taps into the dynamic information provided by the genomic alterations unique to each diseased cell. We capture what is happening to the DNA very early in and throughout the disease process, in real time, and patient by patient. That's how our approach differs from other tests that focus on static genomic data or protein biomarkers," said Dr. Urnovitz of Chronix. Use of the Chronix diagnostic technology in CFS will be evaluated in a study being planned by Chronix and Hemispherx, a leader in CFS pharmaceutical research.



Dr. William Carter, Hemispherx CEO, commented: "It is with great enthusiasm that we will be conducting studies aimed at validating the utility of the Chronix technology to identify how different individuals can respond to Hemispherx's experimental drug Ampligen®."

www.hemispherx.net. San Jose, CA 3rd March, 2011

Spinal Fluid Proteins Distinguish ME/CFS from Lyme Disease

Good news of some exciting and encouraging new research - Jenny
‘Distinct Cerebrospinal Fluid Proteomes Differentiate Post-Treatment Lyme Disease from Chronic Fatigue Syndrome’

Steven E. Schutzer, Thomas E. Angel, Tao Liu, Athena A. Schepmoes, Therese R. Clauss, Joshua N. Adkins, David G. Camp II, Bart K. Holland, Jonas Bergquist, Patricia K. Coyle, Richard D. Smith, Brian A. Fallon, Benjamin H. Natelson.

Full paper can be found at:
<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0017287>

From the Herald news services -
<http://www.tri-cityherald.com/>

Pacific Northwest National Laboratory (PNNL) scientist leads research into chronic fatigue syndrome treatment and neurological post treatment Lyme disease patients.

Patients also had proteins unique to each condition, despite their similar symptoms. High-tech protein analysis done in Richland could lead to improvements in diagnosis and treatment of the little-understood chronic fatigue syndrome. The analysis done at the Environmental Molecular Sciences Laboratory on the campus of PNNL identified a subset of proteins in the spinal fluid of pa-

tients with chronic fatigue syndrome that are not present in healthy patients.

The discovery also calls into question the belief of some scientists that chronic fatigue syndrome, with its debilitating fatigue, is an umbrella category that includes other diseases, including Lyme disease, that lingers after treatment.

Research was conducted by a team at the University of Medicine and Dentistry of New Jersey's medical school and a team led by Richard Smith at PNNL. It relied on special protein separation techniques and high-powered mass spectrometry equipment at the Department of Energy's Environmental Molecular Sciences Laboratory. Investigators looked at the spinal fluid of 43 people who had been diagnosed with chronic fatigue syndrome, 25 patients who had failed to completely recover from Lyme disease and 11 healthy people.

"Spinal fluid is like a liquid window to the brain," said Dr. Steven Schutzer of the New Jersey Medical School, in a statement. Researchers found some of the same proteins in chronic fatigue syndrome but patients also had

proteins unique to each condition, despite their similar symptoms.

Because some of the proteins found in the spinal fluid of chronic fatigue syndrome patients also are implicated in Alzheimer's and Parkinson's diseases, the results support the idea that chronic fatigue syndrome has an underlying neurological cause.

"These exciting findings are the tip of our research iceberg," Smith said in a statement. Newer techniques are being developed to allow researchers to learn more about chronic fatigue syndrome, lingering Lyme disease and other neurological diseases," he said.

See also link at:
<http://bit.ly/gggdiP>

PS: Schutzer and his team also analyzed spinal fluid using specialized Polymerase Chain Reaction (PCR) techniques that amplified nucleic acid present in the spinal fluid, and found no evidence of XMRV. Other common viruses also appeared to be absent.

<http://bit.ly/hZnnqp>

‘Assessment of a 44 Gene Classifier for the Evaluation of Chronic Fatigue Syndrome from Peripheral Blood Mononuclear Cell Gene Expression’

Daniel Frampton, Jonathan Kerr, Tim J. Harrison, Paul Kellam
 Published: March 30, 2011 - extract:

Currently there are no laboratory-based diagnostic methods for CFS. However, differences in gene expression profiles between CFS patients and healthy persons have been reported in the literature. Using mRNA relative quantities for 44 previously identified reporter genes taken from a large dataset comprising both CFS patients and healthy volunteers, we derived a gene profile scoring metric to accurately classify CFS and healthy samples. This metric out-performed any of the reporter genes used individually as a classifier of CFS. To determine whether the reporter genes

were robust across populations, we applied this metric to classify a separate blind dataset of mRNA relative quantities from a new population of CFS patients and healthy persons with limited success. Although the metric was able to successfully classify roughly two-thirds of both CFS and healthy samples correctly, the level of misclassification was high. We conclude many of the previously identified reporter genes are study-specific and thus cannot be used as a broad CFS diagnostic. This study was funded by a research grant from the Chronic Fatigue Syndrome Research Foundation (CFSRF)

<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0016872>

(A little bit disappointing news from Dr Kerr's final gene study - Jenny)

MEA Ramsay Research Fund to fund new research into the role of transcription factors in ME/CFS

The ME Association announce that trustees have approved funding for an important new research study that will be investigating the role of what are called transcription factors in ME/CFS.

The research, which has been thoroughly peer reviewed over the past two months, will be carried out by Dr Abhijit Chaudhuri, Professor Peter Behan, Professor John Gow, Professor Chris Hillier, and Simone Hutchinson at Glasgow Caledonian University..

Transcription factors are complicated proteins that act at a cellular level. They are released in a cascade fashion following harmful stimuli such as infections, trauma, exposure to toxins and drugs and form a key part of the body's initial defensive response. They also

help to regulate gene expression – in simple terms they assist in the process of ‘switching on’ genes and the activities they control.

There is already some preliminary evidence suggesting that transcription factor abnormalities are involved in ME/CFS and that interventions aimed at reducing the levels of transcription factors could be of value in reducing key symptoms such as fatigue.

The research will be looking at transcription factors in blood samples obtained from four separate groups.

First are people with well characterised ME/CFS – Professor Behan will be doing the clinical assessments.

Second is a group of healthy controls.

Third are some of the people who were involved in Professor Gow's research into gene expression.

Fourth are blood samples that will be obtained from the CFIDS biobank facility in the United States – because the UK biobank has not yet been set up.

The study is expected to take a year to complete.

If a significant abnormality in transcription factors is confirmed in this study this could well lead onto further research which would look at therapeutic interventions aimed at reducing the activity.

Total Ramsey Research Fund funding is about £42,000

See more at:
<http://www.meassociation.org.uk/?p=5392>

(Fantastic research team! - Jenny)

Excess of activating killer cell immunoglobulin-like receptors and lack of HLA-Bw4 ligands: A two-edged weapon in CFS.

Pasi A, Bozzini S, Carlo-Stella N, Martinetti, M, Bombardieri S, De Silvestri A, Salvaneschi L, Cuccia M.
 HLA Laboratory, Immunohaematology and transfusion Center, Pavia, Italy.

Abstract

Chronic fatigue syndrome (CFS) is an inflammatory disease of unknown aetiology.

Researchers have proposed infectious, neurological and immunological causes of this syndrome. Recently, the xenotropic murine leukemia virus-related virus was detected in 67% of patients with CFS in a US study.

This observation is in agreement with one ascertained aspect of the disease: a decreased efficiency in NK cell lytic activity in CFS patients.

Here, we analyzed the genomic polymorphism of killer cell immunoglobulin-like receptors (KIRs) and their HLA class I cognate ligands in patients with certified CFS.

An excess of KIR3DS1 was found in CFS patients with respect to controls, as well as an increased frequency of the genotype missing KIR2DS5. Forty-four CFS patients and 50 controls also underwent genomic typing for the HLA-ligands. In the patients, a great proportion of KIR3DL1 and KIR3DS1 receptors were found to be missing their HLA-Bw4Ile80 binding motif.

We hypothesize that an excess of KIR3DS1, combined with an excess of ligand-free KIR3DL1 and KIR3DS1 receptors, may hamper the clearance of a pathogen via NK cells, thus favouring the chronicity of the infection.

<http://www.ncbi.nlm.nih.gov/pubmed/21468604>

COMEDY CENTRAL...



Quips and Quotes...

“If it works well, they’ll stop making it”
Jane Otten & Russell Baker

“It is impossible to make anything foolproof because fools are so ingenious”
H.W Robinson

“Exercise is bunk. If you are healthy you don’t need it. If you are sick, you shouldn’t take it”
Henry Ford
(who lived to be 83!)

“To err is human, but to really foul things up requires a computer”
Anon

“Anyone who isn’t confused here doesn’t really understand what’s going on”
Anon

“There are three sides to every argument - my side, your side and the truth”
Anon

“Husbands are like fires - they go out when unattended”
Zsa Zsa Gabor

Extracts from “Am I alone in thinking...?” - Unpublished letters to the ‘Telegraph’ (edited by Ian Hollingsworth; published by Aurum)

SIR -
In the midst of all this doom and gloom I hesitate to offer more disturbing news, but I must warn readers that both Barretts and Tesco have seen fit to remove the all-important sherbert centre from sherbert sweets.
Is there no end to the destruction of those things we hold so dear?
Please do not tell me the EU is to blame. Not that I would be surprised.

G.A.B

SIR -
May I suggest that Lloyds TSB and HBOS be called Bolshy SOBs Ltd?

Roger Brady
Germany

SIR -
Now that Prince Charles is entitled to a free bus pass I do hope that he doesn’t bring too many minders with him when he travels on the 195 from Great Hollands to Bracknell bus station. It sometimes gets rather crowded.

Rev Michael Bentley
Bracknell Berkshire

SIR -
I read yesterday that Katherine Jenkins “wore a deep pink dress and matching hat with giant roses”.

Yesterday I wore a dark blue linen jacket, khaki chinos and a blue and white striped shirt.

F.C

The Group Library

We have recently acquired some new books and CDs for the SSB Library. Along with a second copy of Dr Charles Shepherd’s ‘Living with ME’ and an up to date Disability Handbook (2010-2011) the following new titles are now available:



Chronic Fatigue Syndrome / ME

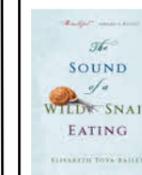
by Elizabeth Turp
This book also provides the families and friends of people with CFS/ME with an accessible introduction to the condition, and explains what can be done to support those who have it.

Osler’s Web - Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic
by Hilary Johnson

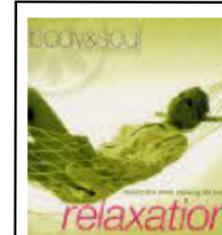


Tenth year anniversary edition with an update by the author "A relentless, meticulous, and highly persuasive exposé by a journalist who spent nine years investigating the medical research establishment's failure to take seriously chronic fatigue syndrome... In a chronology that runs from 1984 to 1994, Johnson crams in fact after telling fact, building up a dismaying picture of a rigid and haughty biomedical research establishment unwilling or unable to respond to the challenge of a multifaceted disease for which a causative agent has yet to be found... A compelling, well-documented account..."
Kirkus Reviews
(Amazon.co.uk)

The Sound of a Wild Snail Eating
by Elisabeth Tovey Bailey
(reviewed in the Christmas newsletter)



Two CDs (available separately or together)
Tranquil Sleep & Ultimate Relaxation
Dr Hilary Jones



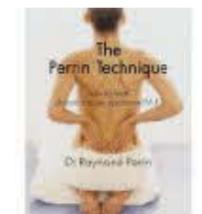
Music CD - relaxation music - various artists

Verity Red’s Diary- a story of surviving ME
by Maria Mann



Filled with mischievously wry wit, this semi autobiographical narrative is an inspiring and hugely enjoyable day-by-day account of a year in the life of a myalgic encephalomyelitis, or CFS sufferer.

The Perrin Technique
by Raymond Perrin
A practical guide to the technique developed for treating ME as a structural disorder with definite diagnosable physical signs.



Also now available from our Library, the DVD of AfME’s London conference:

“Work, welfare benefits and ME - is anyone listening?”

This DVD includes presentations by Dr Pheby & Dr Louis Nacul on the Epidemiology study by the National ME Observatory

To order a book from our library you can:

Fill in a library form and post it to Jenny Griffin
59 Cartland Road Stirchley B30 2SD
[Books/DVDs/Documents will be posted out in jiffy bags with the return postage stamps enclosed]

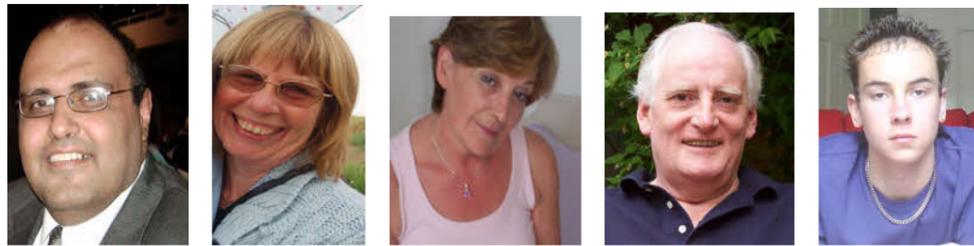
Ring Jenny on 0121 689 077

Text on 07785 958 872

Email jlgriffin@blueyonder.co.uk

Come to a meeting at Cartland Rd

Group News... committee news



Tarsam Jo Jenny Alan George

The committee held the **Annual General Meeting on March 14th.** Your AGM report is enclosed in this newsletter.

Thank you to everyone who attended the AGM. The 'business' bit of the meeting ran through smoothly and we had time to relax and have a nice chat afterwards. We welcomed new contact, Michael, and his mum to the meeting. Michael's Mum, Sheelagh, kindly offered a room at her house in Shirley for the U25s to meet up. George was very grateful for this offer and will try to arrange something in the future when he is well enough (Uni taking its toll on his energy at present). In the meantime, we understand all the U25s are in touch with each other one way or another - so that's good!

We are down to five committee members this year and we would still welcome anyone who wants be a committee member this year. It's never too late! (Look at the cartoon below to see how much we enjoy it!)

As you will see - on p.19 - we have the current results of the survey on our services. Thank you to all those who took part.

The results of our Questionnaire are also completed and are enclosed in this newsletter. Thank you again to all those who took part and we hope you will find the results interesting.

We thank everyone who has helped us in the last year and please keep all those thoughts, comments & suggestions coming in! Our next committee meeting is on May 20th



Group News... committee news

SSB QUALITY ASSURANCE SURVEY RESULTS

(up to April 2011)

(65 returned Membership forms to date - 30 surveys filled in)

	QUESTION	YES	SOME TIMES	NO	Did not answer
1	Do you find it easy to talk to us?	21	2		7
2	Do we respond well to your suggestions/comments?	19	1		10
3	Are you satisfied with our services?				
	a) NEWSLETTER	30			
	b) CONTACT LIST	16	1	1	12
	c) LIBRARY	15			15
	d) MEETINGS	15	4	1	10
	e) INFORMATION LEAFLETS etc	22	1		7
	f) GROUP PHONE, TEXT, EMAILSERVICE AVAILABILITY	15	1		14
	g) WEBSITE	7	2	1	20

[N.B Although 30 people filled in their survey some of those members did not answer every question as they had not had experience of using every service the group offers e.g. for Library - 15 people had not used this service and, therefore, were unable to comment on this service]

Committee Feedback

- First of all we would like to thank everyone who filled in the survey. We were reassured to find that the majority felt that they found it easy to talk to us and that, on the whole, we responded well to your suggestions and comments.
- We were very pleased to see that everyone was satisfied with our Newsletter and all those who had used the Library Service were happy with the service they received.
- We were also encouraged to see that almost everyone who had used the Contact list and the Information leaflet service was satisfied with these and found them helpful.
- Meetings in general were satisfactory, but still remain an area where we can improve. We are not quite sure how to improve things to suit everyone - more suggestions very welcome! - but as you can see we have already made an effort to have speakers at a couple of the remaining meetings this year just to make things a little bit different sometimes. A couple of members suggested meetings on different days of the week and one suggested an all women's meeting. Sadly we do not have the facilities to arrange these at the moment as only one person is available to take the meetings. If these members would like to arrange their own sub-meetings, the Committee would give them all the support we can. Maybe next year we can have some of the Cartland Road and/or Shirley meetings on a different day? (Everything is booked in advance for this year.). One member said that they would feel a bit 'out of it' coming to a meeting as we all seem to know each other beforehand. We can assure you this is not the case and *everyone* is made very welcome at each meeting. We enjoy meeting new people and once in a while all the people who attend are 'new'! It may be that we give this impression in the newsletter, as we tend to refer to everyone by their first name - this is actually because we try & protect members' identities, because the newsletter is also 'published' as a PDF for emailing and could (but not likely) find its way onto the internet. (*Data protection & all that!*)
- We could see that not many of you used our web site, which is probably not surprising as it is mainly used as a contact point for people searching for a local ME group. We are aware that our web site is not as up to date as it could be and have plans to improve it in the coming year.
- The members who answered no to any of these questions have been contacted to try and resolve any issues they have had with these services.

We promise that we will continue to strive to make improvements to all our services and we welcome all your future thoughts & suggestions!