



# ME & You

The Newsletter of the  
Mid & West Wales ME Group

## Have you paid your subscription yet?

Registered Charity No. 1085348

The Mid & West Wales ME Group is a member of  
**WAMES**  
Welsh Association of ME & CFS Support

### MEETINGS

**North Ceredigion:** Wed. May 11<sup>th</sup> at 2 pm at The Coach House, Frongôg. Ring Derryan on 01970 828896 for directions or a lift.

Wed. July 13<sup>th</sup> at 2 pm at Gary and Marion's house at Swyddfynnon. Ring 01974 831697 for directions. Ring Derryan for a lift.

**South Carmarthenshire:** Sat. June 11<sup>th</sup> and Sat. Aug. 13<sup>th</sup> at 2 pm at Gwendraeth Day Centre, Pontiets. Contact John James on 01267 233793 for details.

**Cardigan & N. Pems:** Sat. May 21<sup>st</sup> in Cardigan. Ring 01239 613246 for details/directions.

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So far 104 members have kindly paid subs for 2005, for which, many thanks. 67 of you have not yet done so, although I am sure that it is top of your list! Please let me have your sub by the end of May (or contact me to arrange a concession), or you will slip onto the non-subscribing membership list, which means you will not receive any more newsletters! Wailing and gnashing of teeth!

108 members are already in the non-subscribing category as they haven't been in touch for 2 or more years, which means that they get the full support of the Group, but do not receive a newsletter.

So if you have not yet paid, please try to make that special effort. Fill in the form, blow the dust off your cheque book, find an envelope (it does not have to be a new one!), stick on a stamp (that does have to be a new one unless you have been lucky enough to have received an unfranked one recently), and send your £4 cheque (made out to Mid Wales ME Group) to me, Tony Thompson, at Membership, MWMEG, The Coach House Frongôg, Aberystwyth SY23 3HN.

Done it? Thank you! Now take an extra long rest!

### Wear Your Blue Ribbon

BROME (Blue Ribbon for the Awareness of ME) is an organisation that aims to promote understanding of ME through the wearing of ribbons. [www.brame.org](http://www.brame.org)

Your blue ribbon is enclosed with this newsletter.

### Group Fundraising

The Group will be collecting at the Co-op in Aberystwyth on Friday, May 27<sup>th</sup>.

If you can help for an hour or two, please contact Sharonrose. (Contact details on the back page).

### Early Diagnosis Campaign

ME Awareness Week

9-13 May 2005

Read [how you can get involved on page 6.](#)

### This is YOUR Newsletter!

If you have something to say or a contribution you'd like to see in print, please get in touch. We are always on the lookout for interesting material.

We are happy to publish letters, articles, announcements, poems and even cartoons where space permits.

Get more from your newsletter by contacting the Editor today!



### Welcome To New Members

Nicola Dean  
Neil Platt  
Lynne Harland  
Shireen Linton  
Carolyn Auldhouse

No. 58  
April 2005



# Group News

## National ME Week

North Ceredigion Meeting

The BBC are coming to film at the meeting and to do interviews in Welsh. They may also be doing interviews in English.

**If you speak Welsh and are willing to come and be interviewed, please contact Derryan.**

(Contact details on the back page).

Meeting is at 2 pm at Frongôg (see front page).

## Low Energy Fundraising !!!

The following ideas, for low energy fundraising, are offered by Action for ME. Try them (if you can) for Mid & West Wales ME Group, for WAMES or for one of the UK charities.

- ◆ Hold a sponsored silence for a day, asking friends and family to sponsor you.
- ◆ Keep a swear box by your bed for a day – or for the whole week! You can contribute yourself, and ask any visitors to do so too.
- ◆ Have a sponsored shave or a haircut.



## Pennies

Pennies, pennies, pennies – please save as many as possible. I know it is a large target (£10,000) but it can be done.

Ask all your family and friends to help. You can keep the monies until your subscription is due next year or send us a cheque at any time.

## Greetings from Japan

It has been already 5 months since I left Aberystwyth. My journey back home went smoothly apart from Heathrow airport which I found very confusing.

Immediately after the journey I was so exhausted and got worse as I expected but fortunately it was a temporary dip. I still have to rest a lot to survive each day and am housebound, but I feel a little stronger. At least I sleep better and my digestion is better.

Last week I received your newsletter which my neighbour redirected for me. It is really nice to have a local group. I cannot find one back home. Although there are a few websites to share the info on ME.

At the moment I just stick to 'rest and pace'. I am hoping to translate books/articles on ME when I get a bit better so that I can contribute to the other people.

Many thanks for your help when life was the hardest. Please take care and keep in touch.

Love, Keiko

from MWWMEG member Keiko Nakamura

## Postal Library Additions

**Clwyd Group ME newsletter**, Still Winter 2005 [includes: Psychology & illness; Stress annihilation, by Dr Bruno; Explaining ME; Setting goals with a chronic illness; Efexor/venlafaxine]

**Interaction** no. 51, Feb 2005 [includes: Prof Pinching on English clinics; Recovery stories; Altered gene expression in CFS/ME patients; Cochrane review of exercise therapy; Skewed – book review; Operations & ME patients]

**ME Essential**: the magazine of the ME Association, no. 92 Oct 2004 [includes: PACE trial; Pain by Dr Shepherd; Flu vaccinations; View of the English Clinical Champions; Nimodipine; Regional neuro Alliances; homeopathy]

**ME Essential**: the magazine of the ME Association, no. 93 Feb 2005 [includes: Scottish services; Sleep disturbance, Dr Shepherd; Permanent Health Insurance problems; Piped oxygen for sleep ap-

noea; comment on RCPCH guidelines]

**NI MEA newsletter**: Spring 2005 [includes: Prof Pinching on ME; ME is not medically unexplained; Patients, doctors & Sickness benefit; Help for nausea; Nut allergies; Insomnia tips; Aromatherapy]

**Shropshire & Wrekin ME Support newsletter** no. 74, Jan/Feb 05 [includes: Recent research & management of ME/CFS, by Dr A McIntyre; Biomedical aspects of ME/CFS; Report on Canadian guidelines; ME Outbreak at the Royal Free Hospital; Health effects of fish; Pleconaril – new drug for enteroviral infections]

**Shropshire & Wrekin ME Support newsletter** no. 75, Mar 05 [includes: Alternative treatments for pain; Homeopathy in CFS/ME]



# Other News

## Department of Work and Pensions Highlights ME

The DWP has recently taken out full-page advertisements containing guidelines and advice to small businesses on their responsibilities under the Disability Discrimination Act.

They give ME as an example of an invisible illness. They point out that people with ME suffer from debility and intense tiredness, muscle and joint pains, brain fog and inability to remember things. BUT you wouldn't realise this just by looking at them.

At the end of the advert, under the heading 'Do the little things' they explain that keeping background noise low can help people with ME and also people with hearing problems.

**REMEMBER!** If anyone tries to tell you that ME doesn't exist, ask why the DWP uses it as an example of an invisible illness.

Derryan Paul

## Pembrokeshire Coalition: Opportunities for Disabled People

Pembrokeshire Coalition is launching a new scheme to empower and support Disabled People to become involved in social, leisure, educational and work-related activities, including voluntary opportunities, within their local community.

The scheme is for all disabled people over the age of 18 living in Pembrokeshire. **It is not a befriending service**, but their volunteers can help people to develop their own social networks.

For more information contact:  
**The Coalition Development Officer at Pembrokeshire Association of Voluntary Services on 01437 769422**  
or e-mail: rachel.gibby@pavs.org.uk

## Pembrokeshire Carers Week

Pembrokeshire Carers Week 2005 is taking place from 13<sup>th</sup> to 21<sup>st</sup> June.

A Carers Day, including a Carers Forum, will be held at Clynyfw on Friday, 17<sup>th</sup> June. The theme this year is 'Work, Rest and Play'.

Contact Pembrokeshire Association of Voluntary Services on 01437 769422 for more information.

## Cardigan & North Pembrokeshire Meeting

Five members met on 19<sup>th</sup> of March in Cardigan for a chat and a cup of tea.

**Speaker** The speaker at the next meeting in Cardigan will be Peter Evans, who is a faith healer. The meeting will be on May 21<sup>st</sup>. (Contact details on the front page.) All are welcome.

## Powys Carers Service

(incorporating

Powys Young Carers)

The service provides information and advice on local and regional support from both the statutory and the voluntary sector.

They have contacts with a wide range of local, regional and national organisations. Ring them on **01579 823800** or e-mail carers@powys.org.uk

## Your Campaigns

If there is a campaign in your area which you would like *ME & You* to highlight, please contact the Editor Chris Shaftoe (details on the back page).

## Deep Thoughts

Never raise your hands to your kids. It leaves your groin unprotected.

## Powys Community Transport

Dial a Ride Schemes are available in Newtown and Rhayader and there is a taxi card scheme in Crickhowell. New community car schemes are due to start in Machynlleth and Hay-on-Wye.

Contact:  
PAVO Helpdesk  
Tel: 0845 009 32288  
or e-mail: info@pavo.org.uk

Their address is Powys Association of Voluntary Organisations, Marlow, South Crescent, Llandrindod Wells, Powys LD1 5DH

## 2005 Trivia Quiz Win £25!

I've put together a trivia quiz to raise money for MERGE – It only costs £1 to enter and the winner receives £25.

If you'd like to enter, please 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 MERGE – An S.A.E. would also be appreciated.

If you have any friends/family who you think might like to buy one, please request more quizzes. The closing date is 30th June 2005.

All funds go to MERGE. MERGE is a national UK charity funding biomedical research into ME/CFS. Their principal aim is to commission and fund high-quality scientific (biomedical) investigation into the causes, consequences and treatment of ME.

www.mereseach.org.uk

Thanks for your support  
Jane Hurst



# ME Diagnosis: Delay Harms Health

This is the title of a new report written by Dr Charles Shepherd and due to be launched in ME awareness week. The consensus of opinion is that ME can and should be diagnosed within 6 months for adults and 3 months for children. Most people have to wait many months longer and sometimes years.

A MWWMEG survey in 2000 found that 70% of members waited longer than a year for a diagnosis, the longest wait being 48 years! We know from your comments that many still have to wait years. One lady in West Wales was diagnosed last year after being told for 15 years that all that was wrong with her was depression.

Please return the enclosed survey form so we can tell whether or not the situation is improving and we will use the statistics to challenge the NHS and the Assembly Government to improve healthcare for ME patients.

## What harm can occur?

Without appropriate medical advice in the crucial early stages of the illness many will lapse into severe and prolonged health. Some attempt to exercise their way back to health and end up more severely affected. Worrying about all the awful things that could be wrong with them or the effect on their family life, work or education and the difficulties in getting benefits without a diagnosis, can exacerbate symptoms in others or lead to depression.

When people are advised to rest in the early stages, then taught pacing techniques, learn how to manage energy, avoid infections, eat properly, treat pain, change their diet etc, their recovery can speed up dramatically.

## Alternative diagnoses

Many doctors still know little about

ME and are unable to diagnose accurately, so there is also a need for training, so that the correct diagnosis can be made. An increasing number of our members are being re-diagnosed, often after many years of thinking they had ME. This is worrying because there is an effective treatment for some conditions which could have dramatically reduced the length of time they were ill.

The following are a few of the more recent alternative diagnoses given to MWWMEG members:



## Sleep Apnoea

Symptoms:

- Loud Snoring
- Morning Headaches
- Un-refreshing Sleep
- Dry mouth upon awakening
- Overweight
- Change in Personality
- Depression
- Excessive Perspiring during sleep
- Heartburn
- Reduced libido
- Insomnia
- Frequent nocturnal urination
- Restless sleep

Obstructive sleep apnoea (OSA) is a condition in which you repeatedly stop breathing during the night, because the pharynx (throat) repeatedly collapses during sleep. This blocks the pipe that carries air into the lungs intermittently. In OSA, the person fights to breathe against a blocked airway, resulting in decreased oxygen levels in the blood.

Eventually, the sense of suffocation wakes the person, the throat muscles contract, the airway opens, and air rushes in under

high pressure. When the airway is opened, the rushing air allows the patient to once again drift back into sleep, but creates a loud gasping sound.

People with OSA are generally not aware that this is happening, although their partners often have severely disrupted sleep from the snoring and gasping.

This cycle repeats itself many times throughout the night, and this constant waking from deep sleep, as well as the loss of oxygen in the blood, can cause next-day sleepiness, brain fog, poor concentration, and mood changes. Another side effect of OSA is high blood pressure and patients with ME or CFS are more likely to have low blood pressure.

The main reason for OSA is being overweight, and having a neck circumference of 17 inches or more also predisposes one to OSA. Because we inherit certain physical characteristics of the throat, there also appears to be a genetic predisposition to sleep apnoea. There are several treatments for sleep apnoea and they fall into three main treatment categories: behavioural (weight management, avoiding sleep medication etc), mechanical (masks or dental appliances) and surgical.

More information:

Welsh Sleep Apnoea Society  
Roger Paterson [Secretary]  
Tel: 01633 774087  
[www.welshsas.org](http://www.welshsas.org)

The Sleep Apnoea Trust  
12a Bakers Piece, Kingston Blount  
Oxon, OX39 4SW  
Tel: 0845 6060 685  
[www.sleep-apnoea-trust.org](http://www.sleep-apnoea-trust.org)

## Sjogrens Syndrome

Symptoms can include:

- Dry mouth
- Mouth ulcers
- Dry eyes - light sensitivity

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Dry nose  
 Dry & itchy skin  
 Dry throat - difficulty swallowing  
 Fatigue  
 Aches & pains  
 Bowel problems  
 Headaches  
 Neural weakness & numbness

**Sjögren's Syndrome (SS)** is a systemic autoimmune disease, which is associated with inflammation of the salivary and lacrimal glands. This usually causes clinical symptoms of dryness, particularly in the eyes and mouth. Treatment aims to manage the symptoms and to avoid or limit organ damage.

More information:  
 The Arthritis Research Campaign  
 (arc)  
 PO Box 177, Chesterfield  
 Derbyshire S41 7TQ  
 Tel: 0870 850 5000  
[www.arc.org.uk](http://www.arc.org.uk)

BSSA (British Sjögren's Syndrome Association)  
 PO Box 10867 Birmingham  
 B16 0ZW

Tel: 0121 455 6532  
[www.bssa.uk.net](http://www.bssa.uk.net)  
[www.dry.org](http://www.dry.org)

### CREST Syndrome

CREST syndrome is a limited form of scleroderma. Scleroderma is an autoimmune connective tissue disease affecting blood vessels and collagen production. It is more common in women than men. The cause is still largely unknown and although there is no cure, there are many treatments to slow down or halt disease progression.

## Real Airline Announcements

After a real crusher of a landing in Phoenix, the attendant came on the horn, "Ladies and Gentlemen, please remain in your seats until Capt. Crash and the Crew have brought the aircraft to a screech-

The word scleroderma, which means "hard skin", is the generic term describing a group of related diseases in which the skin becomes hardened and sclerotic.



There are two kinds of scleroderma: systemic sclerosis, which affects the internal organs as well as the skin, and localised scleroderma, which affects a specific area of skin but not the organs.

Symptoms can affect:  
 Skin, joints, circulation, mouth, eyes, gut, fatigue, sexual function, psychological health.

However the term *scleroderma* covers a wide spectrum of conditions and the disease is different for each person. In other words different people will experience different symptoms at different stages.

**CREST**...stands for:  
**C**alcinosis, refers to the formation of tiny deposits of calcium in the skin.

**R**aynaud's phenomenon refers to the spasm of the tiny artery vessels supplying blood to the fingers, toes, nose, tongue, or ears. These areas turn blue, white, then red after exposure to extremes of cold, or even sometimes with extremes of heat or emotional upset.

**E**sophagus disease in scleroderma is characterized by a poorly functioning muscle of the lower 2/3 of the esophagus. Heartburn, inflammation, difficulty and scarring can result.

**S**clerodactyly refers to the localized thickening and tightness of the skin of the fingers or toes, giving them a "shiny" and slightly puffy appearance. The tightness can cause severe limitation of motion of the fingers and toes.

**T**elangiectasias are tiny red areas, frequently on the face, hands and in the mouth behind the lips. These areas blanch when they are pressed upon and represent dilated capillaries.

Patients can have variations of **CREST**, i.e. **CRST**, **REST**, **ST**, etc. or even "overlap" illness with features of both CREST and the diffuse form of scleroderma.

More information:  
 Raynaud's & Scleroderma Association  
 112 Crewe Road, Alsager  
 Cheshire ST7 2JA

Tel: 01270 872776)  
[info@raynauds.org.uk](mailto:info@raynauds.org.uk)  
[www.scleroderma.org.uk](http://www.scleroderma.org.uk)

The Scleroderma Society  
 3 Caple Rd, London, NW10 8AB

Tel: 020 8961 4912  
[info@sclerodermasociety.co.uk](mailto:info@sclerodermasociety.co.uk)  
[www.sclerodermasociety.co.uk](http://www.sclerodermasociety.co.uk)



ing halt against the gate. And, once the tire smoke has cleared and the warning bells are silenced, we'll open the door and you can picak your way through the wreckage to the terminal."

# Welsh News

## WAG CFS Forums Cancelled

The Welsh Assembly Government have cancelled the planned CFS Forums for health professionals for the Mid/West and North Wales regions, due to 'lack of interest'. WAMES are in discussions with WAG officials to see how they can keep the development process moving and they are due to meet the new Health Minister, Dr Brian Gibbons, on May 12<sup>th</sup> (ME Awareness Day).

They are also planning an intensive awareness campaign aimed at health professionals to make up for the cancellation of the Forums.

## Awareness Week May 9-14 2005 Early Diagnosis Campaign

WAMES is pleased to announce that we will be joining the ME Alliance (a group of UK ME charities) and other ME groups during Awareness Week in May 2005 in their Early Diagnosis Campaign.

The Alliance will be publishing a report (written by Dr Charles Shepherd of the ME Association) on the importance of early diagnosis and we hope to use that in our campaign in Wales, as it will reinforce our own long running campaign to persuade the WAG and health professionals of the importance of a speedy and accurate diagnosis.

The Campaign and press activity will focus on:

- ◆ Alerting **health professionals** in Wales to the importance of a speedy and accurate diagnosis
- ◆ Informing the **public** that viral infections, like glandular fever or ordinary flu-like infections, can cause ME
- ◆ Pressing the **UK government** to provide funds for research into diagnosis
- ◆ Urging the **Medical Research Council** to proactively commis-

sion research into the diagnosis of ME

## WAMES will use the report on diagnosis when:

- ◆ Targeting the national press and media
- ◆ Sending information about diagnosis to every GP surgery in Wales
- ◆ Pressing the new Health Minister, Brian Gibbons, to develop a national policy for ME and CFS

## How you can get involved

◆ Please take part in the survey by completing the enclosed short **questionnaire**. The statistics will be used in local, national and UK press releases. Please return it to Jan and she will share the info with AfME, who are coordinating the UK statistics.

◆ Can you be a **media case study** (in Welsh or English) and share your story about diagnosis? This doesn't have to involve a recorded interview or be on the national news or newspapers. We also need short stories for local newspapers.

◆ Can you suggest an **awareness raising event**?

◆ Can you give us the **name of a doctor** or therapist who would appreciate more information about ME?

◆ **Write to your Local Health Board** asking what plans they have made to improve services for patients with ME/CFS. MWWMEG will also be contacting them but your letters, emails or phone calls will help to apply pressure on them. Write to the Chief Executive and they will pass it on to the relevant person.

◆ **Meet the BBC** at the MWWMEG meeting near Aberyswtyth on Wednesday May

11<sup>th</sup>. They will want to speak primarily to Welsh speakers, but we are hoping they will also record interviews in English for *Wales Today*.

## LHB Contact details

**Bridgend** North Court, David Street, Bridgend Industrial Estate, Bridgend. CF31 3TP  
Tel: 01656 754400  
[www.bridgendlhb.wales.nhs.uk](http://www.bridgendlhb.wales.nhs.uk)

**Cardiff** Trenewydd, Fairwater Road, Llandaff, Cardiff, CF5 2LD  
Tel: 029 2055 2212  
[www.cardiffhlhb.wales.nhs.uk](http://www.cardiffhlhb.wales.nhs.uk)

**Carmarthenshire** Unit 5, Parc Dafen, Heol Cropin, Llanelli, SA14 8QW  
Tel: 01554 744400  
[www.camarthenlhb.wales.nhs.uk](http://www.camarthenlhb.wales.nhs.uk)

**Ceredigion** The Bryn, North Road, Lampeter, Ceredigion, SA48 7HA  
Tel: 01570 424100  
[www.ceredigionlhb.wales.nhs.uk](http://www.ceredigionlhb.wales.nhs.uk)

**Gwynedd** Eryldon, Campbell Road, Caernarfon, Gwynedd LL55 1HU  
Tel: 01286 672451  
[www.gwyneddlhb.wales.nhs.uk](http://www.gwyneddlhb.wales.nhs.uk)

**Neath Port Talbot** Suite C, Britannic House, Llandarcy, Neath, SA10 6JQ  
Tel: 01792 326500  
[www.neathporttalbotlhb.wales.nhs.uk](http://www.neathporttalbotlhb.wales.nhs.uk)

**Pembrokeshire** Unit 5, Merlin's Court, Winch Lane, Haverfordwest, Pembrokeshire SA61 1SB  
Tel: 01437 771220  
[www.pembrokeshirelhb.wales.nhs.uk](http://www.pembrokeshirelhb.wales.nhs.uk)

**Powys** Mansion House, Bronllys, Brecon, Powys LD3 0LS  
Tel: 01874 711661  
[www.powyslhb.wales.nhs.uk/](http://www.powyslhb.wales.nhs.uk/)

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**Swansea** Kidwelly House,  
Charter Court, Phoenix Way,  
Swansea Enterprise Park,  
Swansea SA7 9FS  
Tel: 01792 784800  
www.swansealhb.wales.nhs.uk

## WAMES AGM Report

This took place on April 9<sup>th</sup> near Brecon.

### Election of Officers

*Chairman:*

Ian McDonald (MWWMEG)

*Secretary:*

Jan Russell (MWWMEG)

enquiries@wames.org.uk

Tel: 01970 636515

*Treasurer:* Liz Chandler

*Minutes Secretary:*

Richard Jones (MWWMEG)

*Co-secretary:*

Sylvia Penny (Glamorgan)

*Young People's Contact:*

Michelle Penny (Glamorgan)

*Neurological Sciences & Research*

*Officer:* Karl Krysko (NWWMEG)

*Publications Advisor:*

Tony Thompson (MWWMEG)

### Finances

A donation of £1,500 received from the Swansea & West Wales Insurance Institute, on top of the donations from NWWMEG and MWWMEG rescues WAMES from a precarious financial position, and enables us to carry out intensive campaigning throughout 2005. The young people's support fund remains healthy. WAMES recorded a grateful vote of thanks to MWWMEG for making a regular financial commitment of 50p per paid up member, to WAMES.

### Constitutional matters

The following policies were updated and endorsed in an attempt to maintain high standards of practice:

◆ Volunteering; Equal Opportunities; Confidentiality & Data protection; Child protection & vulnerable

adults; People with criminal records.

◆ 3 members of the committee have now been passed a criminal records check which WAMES requires of anyone working with children or vulnerable adults.

◆ No Annual report has been published over the last few years but one for 2002-2004 will soon be available from WAMES or from the website.

### Political & Awareness Campaigns

The main priorities will be to meet with the new Health Minister on May 12<sup>th</sup> and find out how he is prepared to proceed with the service development process; and to raise awareness / provide information for health professionals, decision making bodies and trainers. For years we have been emphasising the priority need of a speedy and accurate diagnosis and have been asking for the training of GPs. The ME Alliance *Early Diagnosis* campaign ties in nicely with this and WAMES will adapt it for use in Wales. We will also be sending info about ME to all GP surgeries, LHBs, CHCs etc in Wales. HTV and Real Radio have abandoned their charity broadcasts so we will be looking for other ways to raise public awareness.

### Young People's Support Service

A *Young People's Officer* joined the team for a couple of months but had to resign for health reasons. While looking for a replacement the committee will continue to maintain the production of a national bilingual newsletter (hopefully quarterly) and develop some info sheets for distribution along with the posters to schools and colleges. We took part in 2 consultations: The *Welsh National Services Framework for Children* (not yet published) and the *Royal*

*College of Paediatrics & Child Health guidelines for CFS/ME*. A Report is due to be published soon, based on surveys carried out by Sylvia Penny in 2004 & 2005 on the difficulties house-bound students face in accessing education.

### Wales Neurological Alliance

The WNA has received a grant for £5,000 and will be using this to campaign on behalf of neurological illnesses. WAMES has been involved with them in the Assembly Government's Review of Neurological Services, which is progressing very slowly and frustratingly. More info about the Alliance on the WAMES website.

### Publications

Current publications are mostly in English and the intention is translate into Welsh as well:

*Introduction to WAMES*

*ME factsheet*

*Info sheet for health professionals*

*Teacher's information on ME*

2 Welsh & English young people's posters

2 Welsh & English national / local posters

*Report on ME & CFS* to the WAG, Feb 2004

*Report on young people and ME* to the WAG, May 2004

*Pacing*, by Dr Ellen Goudsmit

Planned:

***Carers' tips***

Leaflets on education & ME

***Report on education for house-bound students in Wales***

News sheets for doctors

### Website

WAMES are very grateful to MWWMEG member Hedd Gwynfor for establishing and maintaining the website over the last few years. Tony Thompson and Julia Jenkins are now learning web skills with a view to helping to develop it further.

## Shrewsbury ME Conference: The Way Ahead

Hosted by Shropshire & Wrekin ME Support  
ME Awareness Day - Thursday 12<sup>th</sup> May 2005

To launch the new CFS/ME Local Multidisciplinary Team Service  
for Shropshire, Telford & Wrekin  
at the LORD HILL HOTEL Abbey Foregate, Shrewsbury.

Afternoon 2.00 - 5.00 p.m.

Conference for Health workers, teachers Social services, etc.  
Open Evening 7.00-9.00 p.m. For ME sufferers, carers, etc.

### SPEAKERS

Dr Betty Dowsett - Group Patron/ medical advisor  
Dr Nigel Speight - Paediatrician/ medical advisor to MEA + AfME  
Dr Stella Townsend - Lead clinician Shropshire Enablement Team  
Dr John Hegarty - Head of Psychology Keele University

Admission FREE – but Donations welcome towards Group Funds.

## CFS Clinic Job Advert Furore

Recent job adverts for posts of psychologists in the new CFS clinics in Liverpool and the Epsom & St Helier Trust, caused great offence in the ME world. The adverts advised job applicants that:

'Psychological treatment [aims] to change perpetuating illness behaviour and ... modify predisposing personality style.'

'For some clients there can be significant barriers to accepting the changes needed in behaviour'

'As some clients with CFS may be resistant to working in a psychological framework there may be exposure to verbal aggression.'

'Patients referred to the service often present with complex medical and psychological problems, are highly distressed and may have difficulty accepting and be hostile to the rationale for adopting a cognitive-behavioural approach to the management of their fatigue.'

'In addition, patients using this service may have problems of

an intimate nature eg sexual difficulties, history of trauma or abuse, which are not suitable for treatment in a group setting.'

In addition to this picture of difficult patients with psychological problems who don't want to get better, one advert also mentioned that 'Individual treatment sessions are up to 2 hours long, twice weekly group sessions are 3 hours in length, and frequent counselling phone call sessions are up to one hour long!'

These adverts have confirmed the fears of English ME patients that many of the new CFS clinics are unlikely to be suitable or helpful to patients with strict ME.

The ME Alliance, representing 5 major UK charities, complained to the offending advertisers. Dr Fred Nye from Liverpool issued an apology and said the advert would be redrafted.

[via IMEGA]

## In Memoriam

Professor Mina Behan died at her home in Glasgow on Saturday evening, March 19<sup>th</sup> 2005.

As a pathologist at the Western Infirmary in Glasgow, Mina made a major contribution to the role of understanding muscle pathology in ME/CFS.

She had also been carrying out research into the role of the blood-brain-barrier in the onset of ME/CFS. Unfortunately, it seems unlikely that anyone else of her stature here in the UK will now be able or willing to pursue this type of research.

Dr Charles Shepherd  
via IMEGA

## AfME on the move

*Action for ME* will be in new offices from 14<sup>th</sup> May.

3rd Floor, Canningford House,  
38 Victoria Street, Bristol, BS1 6BY

## Cheap Phone Calls

Pay a 2p connection charge and then your phone calls are free day or night .  
[www.call18866.co.uk/](http://www.call18866.co.uk/)

You can also make cheap international calls to some countries. You must have an email address and a credit card to apply.

Install Skype on your computer and talk to friends for no additional cost over the internet. You can also send instant messages or make cheap calls to landlines overseas. You need a microphone and someone to chat to! [www.skype.com](http://www.skype.com)

Doone Cooper via Interaction

## Points To Ponder

A wise schoolteacher sends this note to all parents on the first day of school:

"If you promise not to believe everything your child says happens at school, I'll promise not to believe everything he says happens at home."

Cartoons reprinted with kind permission from *Interaction*, AfME, PO Box 1302, Wells, Somerset BA5 1YE, tel. 01749 670799



## Parents with ME: a few thoughts

At last, thanks to the Mid and West Wales ME Group for bringing to the forefront this very serious subject and, one that I have personally thought about on a day to day basis. I have worried about the effects of my ME on my daughter so much so last year that I contacted Marjorie our 'listening ear' at the time. Marjorie put me in touch with a parent who was a carer for her 16 year old daughter with ME. We did chat for a while and I began to understand what it would be like if 'the shoe was on the other foot'. It made me appreciate the fact that my daughter wasn't suffering physically from the condition.

I have a friend with the condition, also a single parent without support, trying to cope with a very active and intelligent three year old. Again listening to her problems, I appreciate my circumstances now that my daughter is older and more independent, making my life easier to cope with ME.

Last year was a particularly bad year for me with the condition, but I was not able to get any care or help from my daughter and felt completely isolated because we did live on our own. I tried every-

thing to make her understand the situation but through either not appreciating what was happening to me, being so used to my lethargic state that it had become the norm, or blocking it out completely, meant that I suffered depression too and our relationship practically broke down.

Guilt is a common feeling for every parent regardless of illness but for parents with ME the guilt must be endless. I look at my daughter and sometimes wonder how my condition will affect her 'decision making' and how she will view the world in future.

A good example of this is that I found out that in the past that my daughter doesn't come to me with her problems knowing the worry will make me bed ridden for a few days, as I was and still am, for the most part, unable to deal with stressful situations.

Over the years I wonder how the lack of conversation due to lack of energy has affected her, having to prepare her own food sometimes (she has known how to make a roast using prepared frozen food since she was nine) or having a home that isn't cleaned properly all

the time. How will this lack of parental nurturing affect her self esteem and confidence?

My friend has felt extremely guilty for falling asleep while her three year has played in front of her which could obviously be dangerous. But I doubt that any single mother with ME would contact social services for fear of losing her child. Yet really they should be made aware otherwise nothing will ever be done to help. This conjures up a saying concerning the devil and the deep blue sea!! I certainly would not have written my thoughts and sent them to the newsletter, had my daughter been a few years younger.

Maybe it is for the best that nobody fully appreciates the condition of ME unless they have had it themselves as it means that the 'At Risk' register for children is devoid of those with ME suffering parents.

One thing is for sure, our children may develop, seeing life differently, but the survival instinct, I feel, will have clarity in abundance.

from Lorraine  
a MWWMEG member

### Websites

**Yoga for ME/CFS** [www.gentleyoga.co.uk](http://www.gentleyoga.co.uk)

**Christians with ME** [www.cwme.co.uk](http://www.cwme.co.uk)

**Dorothy Hillbeck's road to recovery** [www.wordsandme.org](http://www.wordsandme.org)

**William Collinge's book** Recovering from CFS free to download  
[www.healthy.net/collinge/cfs.htm](http://www.healthy.net/collinge/cfs.htm)

**Overton Studios Trust** new URL  
[www.ostrust.co.uk](http://www.ostrust.co.uk)

**RiME** the site of campaigning group *Research into Myalgic Encephalomyelitis* includes their newsletters.  
[www.erythos.com/RiME](http://www.erythos.com/RiME).

**Igenus** – research showing health benefits of fatty acids (EPA) [www.igenus.com](http://www.igenus.com)



**Actual newspaper  
Headlines for 1997:**  
Enfields Couple Slain;  
Police Suspect Homicide

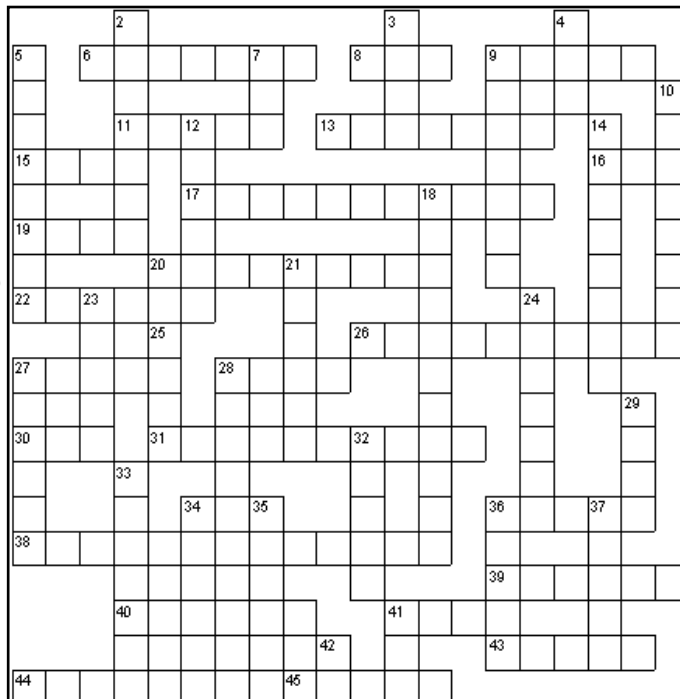
## Quick Crossword No. 39

### ACROSS

6. Canadian city (7)
8. Weapon (3)
9. The Doctor's foe (5)
11. Often needs a kick (5)
13. Hamlet it's not...(7)
15. Force (4)
16. Assist (3)
17. Alien director (6, 5)
19. Finishes (4)
20. Puzzling noise-maker? (9)
22. A segment of film production (4)
26. Paul O'Grady's alter ego (4, 6)
27. Straight to the point (5)
28. Hurt (4)
30. Electrical measurement (3)
31. Periodic inspection (10)
36. Sometimes just for starters (5)
38. Ruthlessly overwhelmed (13)
39. Atmospheric vibrations (6)
40. Bird (6)
41. She's a bit plain they say (4)
43. Fermenting agent (5)
44. Mountain (7)
45. He's a dazzler! (5)

### DOWN

2. Swimming group (7)
3. Add to the fire (4)
4. It's bitter for some (3)
5. Edifice (8)
7. Pretend to do something? (3)
9. Video by numbers? (7)
10. Unveil with ceremony (8)
12. Russian dog breed (6)
14. Likes to have people for dinner? (8)
18. Not so easy, is it? (11)
21. Beginner (6)
23. German arms manufacturers (7)
24. Christen (7)
25. Boil slowly (4)
27. Finds the culprit (6)
28. Is elected religiously after death (4)
29. The first garden? (4)
32. It's bite is worse than it's bark (5)
33. Taste (7)
34. Reaches for (6)
35. Rest (5)
36. Filthy lucre (5)
37. Group in need of refreshment? (5)
41. Earth moving equipment (3)
42. Don't stop! (2)



### Answers in June's issue

#### February's Crossword Solution

**ACROSS:** 1. Strobe; 8. Diversion; 9. Arm; 11. Them; 12. Overtime; 13. Room; 15. Denzel; 16. Conflict; 19. Memory; 21. Timid; 23. Cometh; 24. Cub; 25. Wembley; 26. Crew; 28. Diary; 30. Angola; 31. Trident; 33. Vest; 35. Solid; 36. March; 43. Elm; 44. Noticed; 46. Kelp; 47. Sudden; 48. Offer; 49. Pottery.

**DOWN:** 1. School; 2. Rum; 3. Brave; 4. Victorian; 5. Team; 6. Dislodge; 7. Underneath; 10. Ribald; 14. Micron; 17. Tricycle; 18. Refund; 20. Imitate; 22. Dew; 26. Celtic; 27. Bait; 29. Orbit; 32. Farming; 34. Yoke; 37. Alps; 38. Heads; 39. Golf; 40. Time; 41. Spit; 42. Deny; 45. Dip.

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### Mid & West Wales ME Group Activities

- ◆ **Meetings** at regular intervals in different venues. Details on front page. Everyone is welcome.
- ◆ **advice and an understanding ear** from Sharonrose.
- ◆ this **Newsletter**, published every two months.
- ◆ **Postal Library** of books, audio and video tapes about ME. Lists available from the Librarian, Jan Russell, or the Secretary, Ms Derryan Paul.
- ◆ **Annual Subscription 2005** Please send £4 to the Subscription Officer, Tony Thompson. This helps towards the cost of the Newsletter, postage and telephone calls. Money can be sent in stamps if preferred.
- ◆ the Group also has 4 wheelchairs, a commode and bedside table (hospital variety - ideal for taking meals etc.) for members to borrow. A small donation is requested for their upkeep.

The Mid & West Wales ME Group does not endorse any treatment mentioned herein. Such articles are for information only.

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We are happy for articles and news items to be quoted or copied, provided the intended meaning is preserved and the author/source and *ME & You* is properly acknowledged.

Next Issue June 2005. Contributions to Chris Shaftoe by 1<sup>st</sup> June 2005