



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. Mar. 9<sup>th</sup> at 2 pm at John & Marjorie's house in Ysbyty Ystwyth.

Wed. May 11<sup>th</sup> at 2.00 pm at The Coach House, Frongôg, Llanbadarn Fawr.

Ring Derryan on 01970 828896 for directions or a lift.

#### South Carmarthenshire:

Sat. Sat. Apr. 9<sup>th</sup> & Sat. June 11<sup>th</sup> at Gwendraeth Day Centre, Pontiets at 2 pm. Ring John James on 01267 233793 for details.

**Cardigan:** Sat. Mar. 19<sup>th</sup> at Huldah George's house in Cardigan.

Ring 01239 613246 for directions. 2-4 pm.

**Llanybydder/Lampeter:** No details available.

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# ME & You

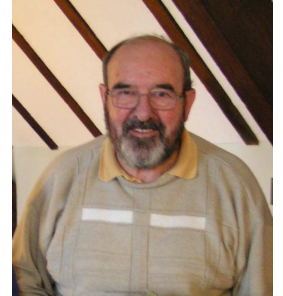
The Newsletter of the  
 Mid & West Wales ME Group

## Group Chairman Retires

John Crispin, founder and long-serving Chairman of the Mid & West Wales ME Group has retired.

A sufferer of ME for many years, John has decided that his declining health means he can no longer shoulder the responsibilities the position entails.

See page 7



## Ceredigion One-Day Conference Transport Issues For People With Disabilities

Transport and travel is always a major problem for people with disabilities - particularly in rural areas where public transport is hard to provide on a frequent, accessible basis - and where the long distances involved make the cost of running a car (or accessible vehicle of one's own) very expensive.

A variety of initiatives have been launched in Mid Wales in recent years, but the problems are still apparent.

It may well be that - while the statutory agencies and voluntary bodies are keen to try and help, they perhaps do not always discuss the issues with those people who are most keenly aware of the problems - disabled people themselves, and their full-time car-

ers, who have to live with the experience of disability 24 hours a day, 365 days a year.

**Disability Rights Services** - a local voluntary organisation set up and run by disabled people - has organised a major conference to look at the problems of transport for people with disabilities - particularly in our area.

This is being run in conjunction with the **Disabled Drivers Motor Club**, a national charity, and has the support of Ceredigion Association of Voluntary Organisations and of Ceredigion Chamber of Commerce. We are extremely grateful to Awards for All Wales, who have provided the bulk of the funding for this conference.

Continued on page 8...

Welcome  
 to  
 New Member  
 Delyth  
 Morris-Jones

### Subscriptions are now due!

Please return the enclosed membership form and subs before you forget!

### Your Campaigns

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

### Who Are You?

You wrote to Tony Thompson in mid-November 2004 because you had been re-diagnosed and wished to discontinue your membership.

Please contact Tony again with your name & address so he can remove you from the database!

No. 57

February 2005

# Group News - At The AGM

## AGM

The Group's Annual General Meeting was held at the Coach House, Frongôg, Llanbadarn Fawr on Wednesday, 26<sup>th</sup> January 2005 at 2.00 pm.

Ten members were present and eight sent apologies.

### Elections 2005

Group Officers  
and Committee Members

John Crispin stood down as chairman after nearly 16 years and Tony Thompson was elected as Acting Chairman in his place. The other officers and committee members were re-elected. They are:

Treasurer - Chris Shaftoe

Secretary - Derryan Paul

Publicity - Sharonrose Ellis

Librarian, Campaigns Co-ordinator -

Jan Russell

Committee Members - John Crispin,

Marjorie Crispin, L. Mair Jones,

### WAMES Reps

Jan Russell and Richard Jones were re-elected to represent the Group on WAMES' Committee.



## 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.

Marjorie Crispin

## Treasurer's Report

The Treasurer reported that the Group had a balance of just over £1,200 in its account at the end of December 2004, as compared with just over £1,800 the previous year. The drop is largely due to the fact that the grant to cover the cost of the newsletter for one year has expired.

Expenditure was just under £2000. The main item of expenditure is printing and posting the newsletter, which accounts for about one third of the total.

Other substantial items are the servicing and maintenance of the photocopier, used mainly for the newsletter and publicity material; the healthcare campaign; and publicity throughout a large catchment area. Administrative costs (postage and telephone bills) accounted for just under £50.

### Subscriptions

The Committee made the following recommendations, which were endorsed by the meeting.

- ◆ That the subscription should remain at £4 for 2005 and go up to £5 for 2006
- ◆ That from 2005 members who have not paid a subscription for the current year should be sent final reminders in October and given the option of becoming non-subscribing members, in which case they would not receive the newsletter
- ◆ That members who are already more than a year in arrears should be asked to pay a subscription for 2005 if they wish to continue receiving the newsletter
- ◆ That the Group should pay an annual levy of 50p per paid-up member to WAMES to support their campaign for better health care for people with ME in Wales, and that this should be topped up from fund-raising activities as far as possible.

## BBC Broadcasts

The Secretary reported that the BBC had broadcast an item about ME in Wales on *Newyddion* on December 27<sup>th</sup> 2004. This included two clips from an interview with Patrick Owen, a young ME sufferer from North Wales and short clips from interviews with her and Dr. Hefin Jones from Merthyr Tydfil.

She also reported that the BBC will be coming to the North Ceredigion meeting in May and will possibly send Siân Lloyd their Health Correspondent from Cardiff. The meeting will be on Wednesday, May 11<sup>th</sup> at the Coach House, Frongôg, Llanbadarn Fawr at 2.00pm.

It was agreed that all Group members would be most welcome to join this occasion.

## Publicity

The Secretary reported on behalf of Sharonrose Ellis that leaflets and posters had gone to all doctors' and dentists' surgeries in the Group's catchment area and to libraries, council offices and Co-op stores in several of the counties.

She will be completing circulation to these as soon as possible, and will then circulate publicity to hospitals and will look at the possibility of links to websites.

## Presentation to John and Marjorie Crispin

At the end of the AGM a presentation was made to John and Marjorie Crispin who founded the Group in 1989 to thank them for all the hard work and dedication they have shown in their roles as chairman, secretary, membership secretary and listening ear.

...At The AGM continued

## Medical Campaigns

### Mid and West Wales ME Group

Jan Russell, the Group's Campaign Co-ordinator presented the following report:

"Each county has now completed their *Health, Social Care and Well-being Strategy* and they will be formally adopted in April. The final reports were quite general except for singling out a few key health issues such as heart disease and obesity. Over the next couple of months I will be assessing each report and using them (yet again) to present our case for ME health-care to the Local Health Boards.

I will also be using the forthcoming Welsh Assembly Government Forums as a way of stimulating discussion about ME. They should take place before Easter and I will be writing to each Local Health Board and Trust drawing attention to the Welsh Assembly Government's intention of developing a service, and asking them to send a rep and get involved both nationally and locally."

## Group Meetings

The Secretary reported that, at the moment, the Group has meetings in North Ceredigion, Cardigan, Llanybydder and Pontiets. During the past year each of these groups has met once every two months.

At present supermarket collections are held in Aberystwyth by members from the North Ceredigion and Llanybydder meetings, their friends and relatives.

It was suggested that other meetings might consider arranging fund-raising events, like half-day supermarket collection or coffee mornings, when they felt able to do so.

## WAMES Online Message Board

Ask questions and share experiences with other adult ME patients and carers living in Wales. <http://health.groups.yahoo.com/group/WAMES>

## WAMES

Jan Russell, who is WAMES' Secretary and one of our Group reps reported the following developments.

The previous Health Minister, Jane Hutt, appeared to be sympathetic to ME sufferers but was not prepared to make services an NHS priority. WAMES now has to get to know the new Minister Dr Brian Gibbons, who has so far not responded to WAMES' communications or shown interest in the plight of ME sufferers.

WAMES spoke at the Welsh Assembly Government's Forum on ME & CFS in south Wales and will be speaking at the Forums to be arranged for mid and south Wales.

WAMES will soon be appointing a Young People's Officer to spearhead the support service for young people throughout Wales, who are currently not being fully catered for by the local support groups.



## Supermarket Collections

In 2004 the Group collected £399.81 at the Co-op in Aberystwyth.

The Secretary reported that the Committee had decided to make donations of £40 to the following five organisations:

- ◆ Action for ME,
- ◆ the Beacon of Hope,
- ◆ CFS Research Fund,
- ◆ WAMES
- ◆ Young ME Sufferers Trust (formerly Tymes Trust).

## ME Awareness Week:

### North Ceredigion

### Meeting

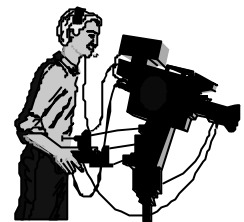
The BBC will be coming to the North Ceredigion meeting on Wednesday, May 11<sup>th</sup> to film and to do interviews in Welsh for an item on the 7.30 news bulletin *Newyddion*.

When more detailed arrangements are made, it is possible that they will also be doing interviews in English.

If you speak Welsh, if you have ME or if you are a carer and are willing to do an interview, please contact Derryan (details on the back page).

If you are taking part, the BBC will phone you beforehand to find out a little about you and about how the illness affects you, so that they can plan the item.

**All members of the Group are most welcome to come to this meeting.**



## General Election

In the past the Group has written to all candidates before the election, but the response has been poor.

It was therefore agreed that the Group should write to those elected after the election, but should ask members to lobby local candidates.

(see page 5 of this newsletter)



# Bits & Pieces

## Meetings Extra

### CARMARTHENSHIRE Group Meetings for 2005

Meetings will be at the Gwendraeth Day Centre in Pontiets on the following Saturdays at 2 pm: 12<sup>th</sup> Feb, 9<sup>th</sup> Apr, 11<sup>th</sup> June, 13<sup>th</sup> Aug, 8<sup>th</sup> Oct., and 3<sup>rd</sup> Dec.

### CEREDIGION Group Meetings for 2005

Llanybydder. There will be no meeting for the rest of the winter.

It is hoped to arrange meetings again in the summer and to invite speakers.

## Ceredigion Carers' Emergency Card Support Scheme: Update

This scheme has recently been introduced by the Red Cross. The Carers emergency Card is a credit sized card that the carer always carries. It is used as a source of identification in case of accident and sudden illness.

The Red Cross hold a registration number and details where help can then be co-ordinated to assist the carer and the cared for in an emergency.

On receipt of a telephone call the Red Cross will respond by carrying out the instructions on the enrolment form.

The service is available when the carer is delayed returning home as the result of sudden illness or accident. The service is NORMALLY not available for general delays that may arise in the course of being away from home.

**Contact Name:** Bob Salmon  
**Tel:** Red Cross 01686 626663; Carers Development Officer 01970 615941.

## Powys

**Disability Montgomeryshire** now has an administrative officer.

Her name is Jackie Crossley and her telephone number is 01686 629487

## Brecknock Access

Their current telephone number is 01874 611401.

## Employment/Training Opportunities

**Jobability.com** is a site for disabled people set up in response to the Disability Rights Commission's "Actions Speak Louder than Words" initiative.

The project is run as a three-way partnership between Microsoft, Leonard Cheshire and total-jobs.com.

The website has an advice section designed to help make essential career decisions. A jobsearch section gives details of jobs throughout the UK, a useful links page and detailed information about workability, an organisation which provides disabled people with skills and support needed to gain access to training and employment, and also provides disabled adults with computer equipment in their own homes.

(Disability Powys, *Newsletter*, Summer 2004)

## The WAMES AGM..

...will be held on a Saturday in April, probably somewhere in mid-Wales.

All local support group members are welcome to attend. Contact Jan if you would like to be informed of the details once they are finalised.

janmrussell@btinternet.com  
Tel: 01970 636515

## Disabled Workers Co-operative

The co-operative promotes the skills and services offered by local disabled workers on a searchable database.

Any disabled individual, sheltered workshop, company or organisation employing a significant number of disabled people can register FREE on their database. It is also free to use.

For more information, to register or search:

[www.disabledworkers.org.uk](http://www.disabledworkers.org.uk)

E-mail:

[admin@disabledworkers.org.uk](mailto:admin@disabledworkers.org.uk)

Address: Alma House, 3 High Street, Llandovery, SA20 0PU.

## Free Home Insulation

SWALEC is offering free cavity wall insulation and/or free loft insulation to people drawing the following benefits:

- ◆ Council tax benefit
- ◆ War disablement pension
- ◆ Housing benefit
- ◆ Child tax credit
- ◆ Income support
- ◆ Working tax credit
- ◆ Disability living allowance
- ◆ Pension credit
- ◆ Income based jobseeker's allowance
- ◆ Disablement pension benefit (which must include constant attendance allowance)

SWALEC has sent the Group a small supply of leaflets and application forms. Contact Derryan (details on back page) OR for forms and more information ring SWALEC on 0845 777 6633.

Closing date for application: 31 December 2005

You must own the property where the work is to be carried out, but you do not have to be a SWALEC customer to take up this offer.

# News

## Carers Go Free to the Cinema

If you need someone to accompany you to the cinema you can apply for a CEA (Cinemamatograph Exhibitors' Association) Carer's card which will allow your Carer to be admitted free of charge. The new card has been adopted by all CEA members and the Disability Rights Commission.

To apply for the card, which is valid for 3 years, and will cost £5 for a processing fee, you will need to meet one or more of the following criteria:

- ◆ be in receipt of Disabled Living Allowance
- ◆ be a registered blind person
- ◆ be a holder of a disabled person's rail card.



Information on participating cinemas and application forms (very brief and easy to fill out but you will need to attach a passport sized photo) can be obtained from any participating cinema, downloaded from:

[www.ceacard.co.uk](http://www.ceacard.co.uk)

or from:

The Card Network  
The Technology Centre  
Rossmore Business Park  
Ellesmere Port  
Cheshire. CH65 3EN

Tel: 0151 348 8020

Fax: 0151 348 8021

Minicom / Text phone:

0151 356 7113

email: [info@ceacard.co.uk](mailto:info@ceacard.co.uk)

[Thanks to Lynne Kersh & IMEGA]

## General Election

The General Election seems likely to take place in May, in which case local campaigning could start before the April newsletter reaches you. Please lobby your local candidates if you can.

Here are some guidelines.

**The Westminster Government** is still responsible for:

- \* Funding for medical research
- \* Running and monitoring the benefits system.

**Action for ME** is running campaigns for more research funding and for a fairer deal from the benefits system for people with ME.

Action for ME can be contacted on their website: [www.afme.org.uk](http://www.afme.org.uk).

Their telephone numbers are:

**General enquiries and information service** 01749 670799 or low-cost 0845 123 2380 from 9.30am to 5pm Monday to Friday.

There is an All-Party Parliamentary Group on ME at Westminster,

which all MPs are able to join. Does your present MP belong to it? Find out at:

[www.publications.parliament.uk/pa/cm/cmparty/041217/memi304.htm](http://www.publications.parliament.uk/pa/cm/cmparty/041217/memi304.htm).

Will candidates join this Group if they are elected? Read the minutes in the campaigning section of [www.afme.org.uk](http://www.afme.org.uk)

The provision of health services by hospitals and GPs is the responsibility of the Welsh Assembly Government. BUT candidates for Westminster and AMs belong to the same political parties, so you can express disappointment that services in Wales are lagging behind those in England. £8.3 million pounds has already been committed in England.

Nothing has been committed in Wales. Ask candidates to raise this concern with AMs.



## Need an eye test in your own home?

The *Outside Clinic* is a domiciliary optician service that operates in mainland Britain and is paid for by the Welsh Assembly Government, Dept of Health & Scottish Executive.

Who is eligible?

All those who cannot visit an optician unattended, regardless of age.

Who is entitled to a sight test?

- ◆ anyone who has eye problems

- ◆ anyone over 70 who has not had a test for 1 year
- ◆ anyone under 70 who has not had a test for 2 years
- ◆ anyone who has been advised to have more frequent eye exams and is now due.

More info:

Free phone: 0500 295 245

The Outside Clinic

Freepost SN479

Swindon, Wilts, SN1 4SY

[thanks to 25% Group]

## 2004 Olympics ~ NBC Sports Comments

Softball announcer: "If history repeats itself, I should think we can expect the same thing again."

Basketball Analyst: "He dribbles a lot and the opposition doesn't like it. In fact you can see it all over their faces."

# Young People's News

## Online Education

The Nisai virtual classroom is a tool that allows users to join a live online classroom to interact and collaborate with the tutor and other learners in real time.

Jane Colby of the Young ME Sufferers Trust says:

"I recommend e-learning for the great majority of children with ME. It combines flexibly timed and live virtual classrooms, involving interaction with a teacher rather than just a PC screen, with other self-paced work that can be done whenever the pupil is well enough."

There are very few young people in Wales who are currently engaged in e-learning. Gwynedd and Powys are registered with Nisai, but only Gwynedd currently has any students using this method. One student in Glamorgan has successfully received funding from an ELWA supplementary fund to take part.

It is expensive for an Education Authority to register and they are unlikely to willingly offer it as an option, so the more families who request it, the more pressure the LEA will be under to consider providing it.

[www.supportit-uk.com/pressrelease/tymes.htm](http://www.supportit-uk.com/pressrelease/tymes.htm)  
[www.nisai.com/education](http://www.nisai.com/education)

The Healthy House has just launched its new forum for people to discuss allergy issues. For people who suffer from many of the debilitating, life altering, or even just annoying, allergies there has until now been very few places where they can discuss these issues with other people who understand and are interested in the topic.

The Healthy House was originally set up 14 years ago by Maxima and Don Skelton, who had per-

## New Study Into Children with ME

Merge, the Young ME Sufferers Trust (Tymes Trust) and Search ME is undertaking a study on children looking for the biochemical markers in the blood of children with ME and hoping to find out if ME could be caused by a continuing challenge to the immune system, such as a persistent virus.

Results are expected by the Autumn of 2006.

## New Healthcare Guidelines

The Royal College of Paediatrics and Child Health has published guidelines for doctors caring for children and young people with ME/CFS.

WAMES and other charities were involved in the consultation process. An eight page leaflet for young people has also been produced in conjunction with AYME.

There are many good things in the two documents but WAMES and The Young Sufferers Trust have some concerns and is unable to wholeheartedly recommend them.

Online at:  
[www.rcpch.ac.uk/publications/recent\\_publications.html](http://www.rcpch.ac.uk/publications/recent_publications.html)

## Let's Talk Allergies

sonal experience of allergies and chemical sensitivity, both themselves and in their children, and needed to find solutions. Their website not only offers products, but is also a good place to find out about allergies, read recent news articles relating to the topic and now chat to others who have similar problems.

Within the first few hours of the forum being posted on The Healthy House website many people had logged on to offer advice

## Young hearts

A collection of inspirational poetry by children and young people with ME is now available from the Young ME Sufferers Trust. Foreword by Terry Waite CBE. All profits will be used for the Trust's services.

£7.95 by cheque or credit card.

Young Hearts  
PO Box 4347, Stock,  
Ingatstone, CM4 9TE  
Tel: 01245 401080

[www.tymestrust.org](http://www.tymestrust.org)

## The Young ME Sufferers Trust...

..has re-launched their magazine for children, now called *Vision*, which also includes information for parents and older readers.

*Vision* (and back issues of the Tymes magazine) can be found on their website:

[www.tymestrust.org/tymes-magazine.htm](http://www.tymestrust.org/tymes-magazine.htm)



to other sufferers on a variety of topics from formaldehyde and chemicals in the home to ways to tackle dampness and mildew. This proves that this is a function that people have been wanting for some time.

The forum is easy to use just log onto the website [www.healthy-house.co.uk](http://www.healthy-house.co.uk). You can also add your own question and see who replies.

[via IMEGA]

# John Crispin Retires

**A**s announced in the last issue, John Crispin has officially stepped down as Chairman of the Mid & West Wales ME Group.

John and his wife Marjorie founded the group in 1989. Since then John's tireless dedication and diligence has moulded the group into one of the largest and most influential in the UK.

Although an ME sufferer himself, John steered the fledgling self-help group of sufferers and carers into a respected organisation with full charity status.

For over sixteen years John and Marjorie gave their time, their sympathy and even their home over to the needs of ME sufferers from all walks of life, spending hours on the phone as 'Listening Ears' and ceaselessly campaigning on our behalf; indeed, the first ever ME/CFS Symposium was organised thanks to John's forward thinking.

Sadly, John's health has taken a turn for the worse and he has handed over the post of Chairman to Tony Thompson, who, in a short speech, echoed the sentiments of the committee by praising both John and Marjorie for all their hard work over the years.

Gifts of flowers and Amazon vouchers were presented by Tony on behalf of the group at the AGM, along with all our wishes for a long and happy retirement.

## From Marjorie - an open letter...

Cae Newydd  
Tuesday, 1<sup>st</sup> February

Dear Friends

John and I were quite overwhelmed by the kind words said about us at the A.G.M. We have done our best over the years to help as many sufferers as possible and together with the excellent help from all members of the committee we know we have achieved a great deal.

Thank you so much for our lovely gifts. I am looking after the flowers well, and we are having great fun looking through Amazon's long list of items trying to decide what to buy.

Lastly, we know that we are leaving the group in good hands, so let's hope there will soon be a better service for all ME/CFS sufferers here in Wales.

Thanking you once again

Marjorie and John



Tony Thompson presents gifts to John & Marjorie from the Group at the AGM.

## John Announces His Decision

After sixteen years as Chairman of our ME Support Group I have decided to stand down. Advancing years and increasing poor health (other things as well as ME) have led to this decision.

Over the years I have made many good friends amongst you all, given lots of advice and helped in many ways to fight our cause.

I hand over to Tony Thompson who will be your caretaker Chairman for a while - I feel certain he will carry on the good fight.

I would like to thank all the Committee Members (present and past) for all their support and hard work in the day to day running of the Group, often on days when their ME wanted to take control.

Thank you so much for your support over the years.

Keep up the fight - we will win in the end.

John Crispin

## ME Awareness Day 12th May 2005

Can you or your family and friends help?

Interviewees are needed for TV, radio and the press (both local and national) in both languages

People are needed for supermarket collections  
(1 hour stints)

Do you know where we can display posters  
& leaflets? Any other ideas?

Contact: Derryan or Jan (details on back page).



...continued from front page

The Conference will take place on **Friday, 8th April 2005** at the **Llety Parc Lodge, Parc-y-Llyn, Llanbadarn Fawr, Aberystwyth** - at the 'Safeways' roundabout, from 10.00 to 4.00.

The venue is fully accessible for disabled people. There is no charge for attending. There will be a number of speakers, including those professionals involved in transport, who will set the scene and set out some of the schemes and the problems associated with transport for disabled people.

The main purpose of the conference is to allow disabled people themselves, and in particular those specialised organisation in the voluntary sector which are run by disabled people, to talk about their problems and to tell the professionals what they really want

and need in the way of transport services - both as regards public transport and in terms of private transport.

**You are invited** to come along to the Llety Parc Lodge on the day and take part in this. As we expect a considerable number of people to attend, we would ask you to let us know in advance.

Booking will be done on a first come, first served basis, and all those interested in the issues are welcome, but we will give preference to people who are themselves disabled and to their carers.

There will be a limited amount of bursaries to cover the travel costs of those from around Ceredigion who wish to attend, and we hope to be able to organise transport for

those people who do not have access to vehicles.

Lunch will be provided, and there will be simultaneous translation for people who prefer to make their contribution in Welsh, as well as help for people with impairments of hearing and sight.

To book your place, please contact **Disability Rights Services** by writing to us at:

Tanparcau, Llanrhytud,  
Ceredigion, SY23 5AL  
or  
telephone 01974-202783  
or email:  
tanparcau@btinternet.com.

Please respond as soon as possible, but in any event not later than 25th March 2005.

## Disabled Parking Bays

### Baywatch Survey: Results for 2004

Over 1 in 5 disabled parking bays are being abused by non-disabled drivers, despite efforts to stop it happening.

The survey carried out in January 2004 in 800 supermarket car parks round the UK, shows that the number of bays being abused rose from 18.5% to 21%. This meant that disabled shoppers were unable to park in an allocated bay at 37% of stores.

The Baywatch campaign has launched a competition to find the best and worst supermarkets in relation to disabled parking. Nominations forms for the competition can be found at :

www.baywatchcampaign.org  
and at Supermarkets.

(Disability Powys, Newsletter,  
Summer 2004)

### Blue Badge Crackdown

Disabled motorists are to get some protection for their parking spaces. The Government has added an amendment to the Traffic Management Bill, due to come into force in Spring 2005.



It will give police officers, traffic wardens, parking attendants and new civil enforcement authorities the power to inspect blue badges. If a badge is being used by someone not entitled to it, they could be fined £1000.

An organisation that campaigns vigorously to protect the rights of legitimate Blue Badge users is at: [www.bluebadgenetwork.org](http://www.bluebadgenetwork.org)  
Tel: 01384 257001.

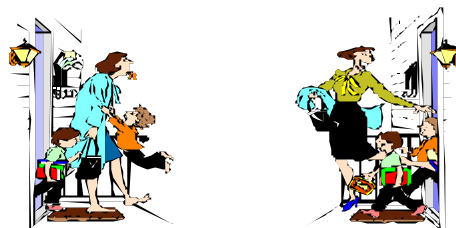
(Disability Powys, Newsletter,  
Autumn 2004)

## Kids & ME

Do you have ME/CFS?  
Do you have children/young people in your care?

We'd like to hear from you if you are a sufferer or care for children who are sufferers. Send us your story outlining your experiences or just ring. You can even e-mail us.

Contact details for the Editor on the back page.



## Help Request

I am CFS affected. Can anyone please recommend a CFS friendly GP in BOTH the Talybont and Newtown area?

Tel: Joanna on 01545 580773 (answerphone in use, please leave message if necessary)

or email: [joandmal@onetel.com](mailto:joandmal@onetel.com)

## POSTAL LIBRARY ADDITIONS

**CFS Research Foundation newsletter**, no. 10, 2004 [report of gene expression study]

**Clwyd Group ME newsletter**, Twelfth Birthday issue 2004 [includes: articles by Simon Wesley; Intuitive Life Guidance Therapy; Keeping a diary; Sleep]

**Clwyd Group ME newsletter**, Christmas 2004 [includes: Gary Frankum's TV interview; DLA tribunal report; Getting a good night's sleep; personal account of attending the NW Wales CFS clinic; Returning to work, by Margery Morgan]

**Energise**: the Red Apple Clinic newsletter, no. 23 2004 [includes: MEA candida trial; Chi Gung, reflexology & acupuncture]

**Energise**: the Red Apple Clinic newsletter, no. 24 2004 [includes: Trial results; What are 'natural' products?]

**Energise**: the Red Apple Clinic newsletter, no. 25 2004 [includes: adrenal glands; using supplements; why we use saliva tests]

**Herefordshire CFS/ME/FMS Group Newsletter**, Dec 2004 [includes: Acupuncture]

**Hermes**: Health & Education regarding ME in Stockport, no. 42 Dec 04 [includes: Fighting the spirouchetes; Manchester East Multi Disciplinary Team; Herbs & Bach Flower remedies]

**Interaction** no. 50, Nov 2004 [includes: Expert Patients Pro-

gramme; short story; Anxiety in ME; male perspective on ME; Muscles in ME, by Dr Vance Spence; Herbal medicine; Chronic infection & ME; improving relationship with parents for ME young people; Parenting with ME]

**MEtro news**, Dec 2004 (Glamorgan ME Group) [includes: checklist of ME/CFS symptoms]



**ME North Devon & ME Support Group Mid Devon newsletter**, Summer 2004 [includes report of the Exeter conference & talks by Prof Pinching]

**NIMEA newsletter**: Autumn 2004 [includes: Memory & concentration, Frankie Campling; Antidepressants; GET; Pacing; Essential oils]

**NIMEA newsletter**: Winter 2004/05 [includes: Education, learning and schooling; CFS (ME) when exercise makes you worse; Immune system balance research; Beating the sugar blues; Taking a nap, by Dr R. Bruno; Cutting running costs in the home]

**Open ME**: newsletter of the NMEC no.11 2004 [includes: coping with winter; Herbal treatment]

**Paul McKenna's deep relaxation**. Daily Mail, 2003 [CD of guided deep relaxation techniques]

**The Quarterly**: newsletter of the 25% Group, Dec 2004 [includes: The changing face of community care; Samento; Gene research news; update for carers; Pleconaril & enteroviruses by Dr Dowsett]

**Shropshire & Wrekin ME Support newsletter** no. 71, Oct 04 [includes: Gulf War Syndrome research; ME Alliance statement]

**Shropshire & Wrekin ME Support newsletter** no. 73, Dec 04 [includes: FMS & CFS/ME, by Prof Pinching; ME-itis or ME-opathy; Gulf War Syndrome inquiry; Energy management and sleep; CFS & Pensions; Neurotoxins]

SPENCE, Dr Vance & STEWART, Prof Julian

**Standing up for ME** in Biologist 2004, 51(2): 65-70 [6p article about orthostatic intolerance in CFS/ME]

**Vision**: the Young ME Sufferers Trust magazine Nov/Dec 2004 [includes: poems, jokes & experiences; Are injections safe for children with ME/CFS?; new research project into biochemical markers]

**Succeeding with ME**: virtual education for children and young people with ME CFS. Young ME Sufferers Trust, 2004 [26 p A4 booklet about online education & the Nisai Education service]

### Water Helps Low Blood Pressure

Researchers from Imperial College London found drinking two glasses of water (480ml) can raise blood pressure. This research is of interest to the many people with ME who suffer with low blood pressure and feel faint when standing.

<http://news.bbc.co.uk/1/hi/health/4063049.stm>



### Supermarket Collection 2005

The Group will be collecting at the Co-op in Aberystwyth on Friday, 27<sup>th</sup> May. If you are able to help, please contact Sharonrose (details on the back page).

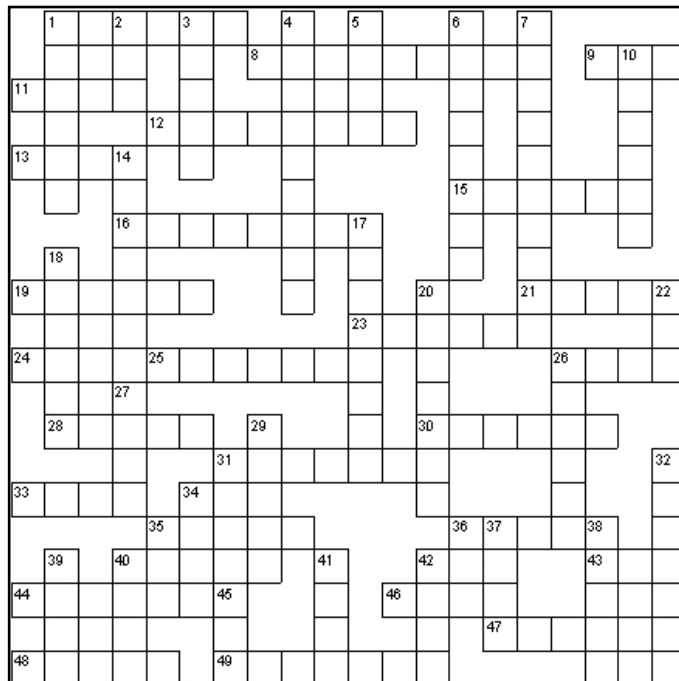
## Quick Crossword No. 38

### ACROSS

1. Flashing light (6)
8. Off the beaten track? (9)
9. Use a limb to prepare a weapon (3)
11. Several it seems (4)
12. Longer period pays more (8)
13. Perhaps with a view (4)
15. Washington DC without the 'C' (6)
16. Battle (8)
19. Recollection (6)
21. Shy (5)
23. Completes the iceman warning (6)
24. Scouts around for the youngster (3)
25. Home of the hallowed turf (7)
26. Motley 2 down drinkers (4)
28. Journal (5)
30. West African country (6)
31. Neptune's missile system? (7)
33. Almost suited to Steve (4)
35. Well-built (5)
36. Walk out of winter? (5)
43. Tree (3)
44. Spotted (7)
46. Seaweed (4)
47. Without warning (6)
48. Propose (5)
49. Clay workshop (7)

### DOWN

1. Place of learning (6)
2. Drink (3)
3. Courageous (5)
4. Of a certain age (9)
5. Group of like-minded people (4)
6. Move (8)
7. Not on top of things (10)
10. Kind of funny (6)
14. A small measure (6)
17. Go around 3 times perhaps (8)
18. Talk about getting money back (6)
20. Copy (7)
22. Morning moisture (3)
26. Knot the seafaring kind (6)
27. Tempt with a bite? (4)
29. World class merry-go-round? (5)
32. Using the land (7)
34. Couple (4)
37. Pals make for the high road (4)
38. Better than two tails (5)
39. Flog with a stick perhaps (4)
40. Some of 12 across (4)
41. Often used with polish (4)
42. Refuse (4)
45. A quick plunge? (3)



### Answers in April's issue

#### December's Crossword Solution

**ACROSS:** 1, Emboss; 4, Add-Up; 8, Museum; 9, Charlie Chan; 10, Biscuit; 12, Stake; 13, Gin; 14, Reek; 15, Creep; 17, Aunt; 18, Charles; 19, Snowdon; 20, Ant; 21, Parsnip; 22, Flutter; 25, Naff; 27, Floozy; 28, Net; 30, Pre; 31, Public; 34, Hoover; 35, Ted; 36, Border; 39, Note; 41, Ibrox; 42, Collapse; 43, Rich; 44, Tricycle.

**DOWN:** 2, Boris Karloff; 3, Speak-Easy; 5, Draughts; 6, Amos; 7, Feline; 9, Correction; 11, Insider; 15, Con; 16, Pitch; 20, Asprin; 21, Polish; 23, Trebor; 24, Equine; 26, Freed; 29, Event; 30, Patriot; 32, Bother; 33, Wrench; 36, Box; 37, Drome; 38, Waif; 40, Elf.

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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 April 2005. Contributions to Chris Shaftoe by 1<sup>st</sup> April 2005**