



December 2013, no. 5

me voice

The WAMES Magazine

WAMES
Welsh Association of ME and CFS Support

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me voice

me voice is published 5 times a year. You can subscribe to the paper copy for £10 p.a., or receive it free by email, or read and/or download it from our website www.wames.org.uk

Contact tony@wames.org.uk

WAMES Subscriptions
The Coach House Frongôg
Aberystwyth SY23 3HN

the wames enformation exchange

offers a number of ways to share news and views which interest and entertain people with ME who live in Wales (and carers and family):

- newsblog on website
- magazine
- facebook
- twitter
- e-group

We welcome news items, articles, cartoons, jokes, poems, suggestions etc. We will include them whenever it is appropriate.

Send them to:
admin@wames.org.uk

or to the WAMES Subscriptions address in the previous column.

Making the web links in *me voice* work in your Browser

Internet Explorer - when you click the *me voice* link, this opens your default pdf reader. The hyperlinks and the email addresses all work.

Google Chrome, Opera, Torch - hyperlinks and email addresses work correctly.

Mozilla Firefox - If 'This pdf might not be displayed correctly' appears top left under the bookmarks toolbar, click on the box to the right 'Open with a different viewer'. Choose your favourite pdf reader and tick the box 'do this automatically for files like this in future'. The hyperlinks and email addresses will now work correctly.

Read the magazine full screen:

In Foxit Reader click F11 to increase and decrease size of page. In Adobe Acrobat press "control" and "L" together.

Copy dates for the magazine:

27 Jan. & 24 March 2014

wames news

Let's talk ME! campaign

Join in our online polls and help WAMES represent you!

Which symptom would you most want health professionals in Wales to help you with?

- Fluctuating Energy
- Stomach, Bowel, Nausea
- Sleep
- Pain
- Cognitive
- Balance
- Psychological (depression, anxiety, low mood etc.)
- Allergies & Sensitivities
- Other

The Poll closes end December.

<http://tiny.cc/bo5v7w>

Which term best describes the key ME symptom ?

- fatigue
- exhaustion
- post-exertional malaise (PEM)
- ill and weak
- low / fluctuating energy
- Post- Exertional Neuroimmune Exhaustion (PENE)
- other

This Poll closes end January 2014

<http://tiny.cc/aa0v7w>



news from wales

ME Group events round Wales

Clwyd ME Support Group

Next meeting 15 March, 12 noon.
For more about meetings contact Margaret Dyas on 01952 271430 and leave a message.

Carmarthenshire ME Group

Meets on 15 Feb, 12th April at Caemaen Day Centre, Coleshill Terrace, Llanelli SA15 3BT. Please ring John James [pm] for further details.

North Ceredigion Group Get-togethers

There will be no more get-togethers on specific dates. But if you would like to come out for a cup of tea/coffee and a chat, please ring Derryan on 01970 828896 or email derryanpaul@gmail.com

North Ceredigion Yoga Class

The class in Penrhyncoch will continue and meets at 11 Nant Seilo, Penrhyncoch on Thursdays 2.30-4.00pm. Contact Derryan [above] for more information. Or Cathy on 01570 421144 or 07748 031614 or cathycrick@hotmail.co.uk

If you are interested in yoga classes in South Ceredigion or

North Carmarthenshire, please contact Cathy (details as above).

ME Support in Glamorgan (MESiG)

6th January, 3rd February, at Llanishen Community Shop, Llangranog road (off Templeton Ave), Llanishen CF14 5BL.

Contact Christalla 0292976 2347
christallaconstantinou@talktalk.net
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS/FM Group

Telephone Mike or Karen on 0796 9665419 [between 2-4 only please] or email karen@kandm46.plus.com for details of meetings.

West Wales ME Group

4th Monday in month - 11am until 1pm at 65, Tudor Gardens, Merlin's Bridge, Haverfordwest, Pembrokeshire SA61 1LB.

Next meetings: 27th January, 24th February. Transport can be arranged from the bus or train stations. Parking is available.

Contact Tina tretiul@talktalk.net or phone 01437 454359.

Meetings are informal, for anyone with ME/CFS or FM and their carers.

news from wales

Haverfordwest Carers meetings

Open to all Parent Carers of all conditions, not just ME, and all ages of 'child'. Meets on last Wednesday of month, 11am – 1 and again 7 – 9pm as many carers work. Next meetings: January 29th, Feb 26th

ME & CFS Task & Finish Group

The Government's Task & Finish Group meets in Cardiff on 13th December. Each Health Board has been asked to send a representative and will meet with government officials and patient & carer representatives from WAMES..

WAMES has already met with the officials to discuss problems with service provision so the aim of the first T&F Group meeting will be to hear from each Health Board about the problems they face in improving services and plan what can be done to help them implement service development.

The group will meet a few times in the first half of 2014.

Restless Legs Syndrome / Willis Ekblom Disease

Do you have RLS and would like to be part of a support network?

Does your GP understand this condition?

Are you frustrated at the lack of information or research into this condition?

A group is looking at developing a patient care pathway including support and services for people diagnosed with RLS.

Working from the current NICE guidelines, clinical knowledge summaries they will be looking to work with the ABMU Health Board pathway team to develop a pilot pathway. Once developed, they aim to roll this out to the other Health Boards across Wales.

Simultaneously, they will be setting up a support network by establishing a patient organisation to represent patients who have the condition in Wales, which will have strong links to the UK patient group, RLS UK.

An important role of the pathway is to identify research opportunities for patients to become involved with studies to enhance understanding of the condition and to develop potential new treatments. A stakeholder group in Wales will take this forward and will include clinicians, researchers, patients, organisations.

For further information and to be part of the network please contact Carol at carol_ross09@sky.com 07845 007304
<http://www.rls-uk.org>

Choose pharmacy for common ailments

A new scheme has begun which encourages patients in north Wales and the Rhondda Valleys to consult a participating community pharmacy, rather than their GP for common ailments.

Patients using Choose Pharmacy will be offered consultations with approved pharmacists. Unlike other minor ailment services Choose Pharmacy has been developed so that all advice and treatment will be provided by a pharmacist. 32 pharmacies are available in Cwm Taf and Betsi Cadwaladr Health Boards.
<http://www.wales.nhs.uk/news/29095>

Consultations

Blue badge consultation

This consultation outlines proposals to include people who are unable to travel safely because of sensory and cognitive impairments.

Find out more:

blue.badge@wales.gsi.gov.uk
Blue Badge Team, Integrated Transport Unit, Welsh Government, Cathays Park, Cardiff, CF10 3NQ

<http://tiny.cc/rg3r7w>

Closing date 8 Jan 2014

Neurological Conditions Delivery Plan

The Welsh Government recently published its draft Delivery Plan for Neurological Conditions – a document that will shape the treatment and care of all neurological conditions, although it is unclear whether they consider ME to be a neurological condition.

The plan outlines initiatives for raising awareness, timely diagnosis, fast and effective care, living with a neurological condition, improving Information, targeting research and the public is invited to comment. The plan and response form can be found at <http://tiny.cc/qk3r7w>

majorhealthconditionspolicyteam@gsi.gov.uk

Major Health Conditions Policy,
Health Quality Division, Welsh
Government, Cathays Park, Cardiff
CF10 3NQ

Closing date 31 January 2014

The Wales Neurological Alliance (WNA) wants to hear your views of the Plan so they can include a wide range of views in their response. They invite you to complete their short survey online.
<http://tiny.cc/4n3r7w>

An e-file is also available from Jan. Please respond by 10th January 2014 to give them time to collate all the responses.

Transport Charter

What are the most common / important access barriers faced by disabled people when travelling on all modes of transport?

Disability Wales plan to compile a passenger's charter; setting out common issues that affect disabled travellers when using public transport. They will use the charter to inform transport providers and others of the barriers faced by a range of passengers with disabilities.

Brief Survey Monkey questionnaire:
<http://tiny.cc/dq3r7w>

More info: 029 2088 7325
www.disabilitywales.org



In Memoriam

Anne Faulkner, Honorary Director of the CFS Research Foundation passed away peacefully in hospital after a short illness on 7th November. She co-founded the Foundation then known as the Persistent Virus Disease Research Foundation with her late husband Hugh in order to provide good quality research into ME, looking for better treatments and eventually a cure.

Dr Gordon Skinner, a tireless campaigner for changing the way thyroid patients are diagnosed and treated in the UK, died on 26th November from a stroke. His clinic in Birmingham will remain open for three months and then it will then be wound down.

Tom Hennessy, creator of International Awareness Day died on Sep 9th aged 59 in the USA. He was known as a fervent patient advocate. He founded the website RESCIND and campaigned for the name CFS to be changed.

Gabapentin / pregabalin

Des Spence GP from Glasgow is uneasy about prescribing them, although approved by the authorities, because of the harm they can do.

“Bad medicine: gabapentin and pregabalin”
<http://tinyurl.com/na2e7ee>

Canary in a coal mine

American people with ME launched a campaign on 25th October to make an international film about ME/CFS. The film is to be called “Canary in a Coal Mine - an ME documentary.” The trailer is at <http://kck.st/1bbLKru> and they have been successful in achieving their funding.

What to expect from your doctor

The General Medical Council (GMC) has launched a guide which sets out what patients can expect from their doctor.

The guide underlines the importance of dignity, mutual respect and partnership between patients and their doctor. It sets out the duties of the doctor and that all doctors need to be honest and open if things go wrong, and to make the care of patients their first concern.

This guide complements Good medical practice, the GMC's core guidance which sets out the standards expected of every doctor on their register.

You can download it, along with an easyread version and translations in Welsh and other languages.
<http://tiny.cc/s2hv7w>

For more information email patientsguide@gmc-uk.org
Or call 0161 923 6602

wales regional news

NORTH WALES

South Gwynedd Long Term Health Conditions Alliance

Next meeting: Monday Feb 3rd at the Glan Wnion Leisure Centre, Dolgellau at 10:00 am.

If you would like to represent WAMES and ME on this alliance please contact Jan for more info. www.southgwyneddlta.org.uk

MID WALES

Hywel Dda services for ME & CFS

The 2nd meeting of the Hywel Dda Health Board ME Group met in November to discuss developing a care pathway for the 3 counties. Patients, carers and professionals discussed the type of services that are needed.

If you know of services or professionals in health, social care or the 3rd sector who are interested in understanding ME and providing services to patients, please pass this information on to Jan.

The next meeting will take place in February to discuss the draft pathway.

The Neuro Voice Project Powys

Some people with ME have already contacted the Project Coordinator to discuss the problems they have experienced accessing services of all kinds in Powys. She would like to hear from more people and will seek to help with specific problems.

Her normal working days are Thursday and Friday but she is happy to meet or phone you at any other time. Contact Gayle at

gayle@mangomontgomeryshire.org.uk
07918 077 721. She is based



at PAVO Plas Dolerw in Newtown, so you can also write to her there or leave a message for her at 01597 822191.

MANGO

The next meeting of the Montgomeryshire Alliance of Neurological Groups and Organisations will be on the 31st January at Plas Dolerw in Newtown when they hope to formally launch the Neuro Voice Project. Contact Jan for more information.

www.mangomontgomeryshire.org.uk

Need for psychological support

A new report states the case for psychological support for people living with neurological conditions in West Wales. A range of cognitive dysfunction and mental health issues are outlined, many of which are shared by a number of conditions. It was noticed however that hypersensitivity to light, noise, busyness, chemicals, odours and touch was more commonly found in ME than other conditions.

Cognitive problems that can result from neurological conditions are often downplayed by medical professionals in importance compared to physical impairment but can severely affect daily life.

Recommendations include extending the neuropsychology service, possibly with a clinical psychologist who has an interest in neuropsychology based in Hywel Dda HB, who works under the governance of the neuropsychologist in Morriston hospital, and clear information provision on how to access primary care counseling support and mental health services.

The report was published in November and presented at a Neurological Cross party group meeting in Carmarthen. Neurologists, neuropsychologists and Health Board staff attended and supported the call for better service provision.

The report can be downloaded from the WAMES website www.wames.org.uk

West Wales Neurological Alliance

The next meeting of the WWNA will be in February, probably in Carmarthen, when it is hope to have speakers from the Health Board.

The WWNA is joining forces with the Community Health Council to do a follow up survey to see if there has been any improvements to patients' experiences of services following surveys of a few years ago. Contact Jan for more information.

Wellbeing Group & Centre Llandoverly

A newly forming wellbeing group in Llandoverly is seeking Expressions of Interest from people in the district who would like to play a part in setting up the group and a Centre in the town.

The aim is provide a diverse range of affordable complementary therapies, outreach courses, workshops and other tools for achieving optimum health, wellbeing and transformation and a book/craft shop.

The premises will be available in the Spring of 2014. The Wellbeing Group and Centre shall be run in a way that does not exploit people, animals or the Environment.

What is needed:

- Experienced, self-employed therapists and practitioners
- Artists and artisans to run courses and/or to display and sell their handmade goods
- Other compatible businesses to rent shelf space/floor space
- People with skills in the healing arts, business, retail, social enterprise, volunteer organisation & management etc. to volunteer to set the venture up and oversee the business management side of things
- Local volunteers to run the enterprise



- Pledges of donations (seed fund capital) and other gifts to set the project up.

Please write (include an SAE if you would like a reply) to:
The Wellbeing Centre Project, c/o Cwm Cottage, Cwmyrnys, Cilycwm, Llandoverly, Carmarthenshire, SA20 0EU.

llandoverlywellbeingcentre@yahoo.co.uk

Mark the letter or email either: [Artisan/business], [Help offered], [Join group], [Seed fund pledge], [Therapist], [Volunteer] or [Other]. Thank you.

Sandra Ozolins and friends of The Wellbeing Group [Sandra has ME and is keen that the Centre is helpful to others with ME].

wales regional news

SOUTH WEST WALES

Neurological Alliance

SWWNA (the South West Wales Neurological Alliance) will meet on Wednesday 15th January 2014 - 2pm - 4pm at Ysbrid Y Mor, Tir Morfa Road, Port Talbot. SA12 7PB (along the Aberavon Beach front).

Contact Jan if you would like to find out more about how working with other organisations in the Swansea, Bridgend and Neath Port Talbot areas can improve all types of services for people with ME. www.swwna.com

SOUTH WALES

Mel's Handy People

Mel's Handypeople is a community service in SE Wales that is backed by Melin Homes. They can put up a fence or shed, lay some patio slabs, cut your lawn or even paint one of your rooms. Sometimes you might just need a spare pair of hands to help you. They offer good quality work that's affordable and will give you a quote for any work

you want done.
<http://www.melinhomes.co.uk/melshandypeople> 01495 745925

Ability Project Torfaen

Do you have a Work Limiting Health Condition or a Disability and want to learn, work or volunteer?

You can get help such as one to one support, a variety of workshops, qualifications and assisted job search. Topics include:

- Communication in the Work Place
- Confidence Building
- IT
- Problem Solving Skills
- Job Shadowing
- Exploring Entrepreneurship
- Enterprise Skills
- Customer Service Skills
- Equal Opportunities
- Advice on benefits and grants

Visit the Work Clubs for help with CVs, applications and job search. Pop in for more information at Croesyceiliog CEC any Thursday between 1:30pm - 3:30pm. Travel voucher scheme available!

To speak to an advisor call 01633 647743 or email ability@torfaen.gov.uk

technology to improve your health

MECFS diary app

This app for Android aims to be a versatile tool to help manage activity, exhaustion and other symptoms. Using touch screen technology you can enter your activities and experience of symptoms in your phone or tablet, taking only a few minutes a day.

Graphs and charts display your information and remind you to enter your data and pace and switch activities to conserve energy. Once you have worked out your baseline (when your symptoms trouble you least) you can choose whether or not to increase your activity.

Another feature is the ability to generate a measurable report in the form of an email that can be reviewed and discussed with health and medical professionals.

WAMES is trying out this app and will be discussing it with health professionals. **We would like to hear from you, whether or not you find it helpful.**

Cost: £4.99. Versions to use with an iPhone or on the website are under development.
<http://www.mecfsdiary.com>

ActiveME app

This has been developed by the Northern CFS/ME Clinical Network for the iPhone and is used to help patients and practitioners as part of a graded activity programme.

<http://apps.nhs.uk/app/activeme/>

Choose well app

NHS Wales has produced an app with details about how and when patients should contact health services. This includes contact information, opening hours, GPS location and digitally mapped directions to services. Available for iPhone/iPad and Android.

<http://tiny.cc/9v4r7w>

Website for health apps

www.myhealthapps.net is a new international website helping patients and public find the best health apps to suit their individual needs.

Add to your life

A free NHS Wales health check is available online to 'help you live longer, feel better, and stay healthy and active into the future'. If you register online you can save your information, or come back later to check your progress.

<https://addtoyourlife.wales.nhs.uk>

My local health service

This new Website is designed to share more information about NHS Wales and currently includes:

- bilingual access to info on how well the NHS is performing
- the option to view information as a table or chart
- direct links to useful websites for further information
- a frequently asked questions tab

The aim is to increase the range of information to include info about the performance of individual services within a hospital or General Practice.

<http://mylocalhealthservice.wales.gov.uk>

Symptom checker

Common health problem?
Get advice online.

NHS Wales has launched more symptom checkers including colds, flu, vomiting. Find out about the most suitable treatment and where to find it on the NHS Direct website. There are also self-examination videos (cancer) and a skin rashes slideshow.

<http://tiny.cc/9lfs7w>



Choosing assistive technologies

The Everyday-Life website helps you to assess your needs in the comfort of your own home, care home, or your GP's surgery.

The assessment tool has been developed in conjunction with the College of Occupational Therapists. Simply answer the questions and get free impartial guidance on a range of assisted living products and services that can help and support independence and manage health at home. The whole assessment should take no more than five minutes or so and answering all of the questions will give you the most suitable solutions.

<http://everyday-life.co.uk>

Last minute Christmas tips

If you run out of time, don't let it stress you!

- Warn someone if a gift will arrive late, a late gift just extends the festivities, but adults will understand this better than children!
- If you need a gift very quickly, consider shopping online and printing out the details e.g. a store or restaurant gift voucher or charity 'present aid' donation, or magazine subscription. If you think that is too impersonal, add it to something small you know they will like, such as a book, mug, chocolates, wine etc. Or look for unusual food, drink, toiletries, candles, calendars, games etc at your local supermarket or deli.
- If absolutely necessary, regift. Just be careful you don't return a gift to the person who gave it to you!
- Consider having Christmas dinner on Christmas Eve so you have more energy to spend with family or friends on Christmas Day.
- Subscribe to an online card firm such as www.jacquielawson.com



to send your animated cards and greetings.

- Spread the card sending by sending New year cards or letters to those who are less excited about Christmas.
- If you forget to send a card to someone special, give them a ring at a quiet moment after Christmas.
- Restaurants are often booked up over the festive season. If you run out of energy to cook, take-aways or good quality ready made meals can be just as much fun for a change. Check to see if your local supermarket will deliver.
- Most of all, take regular rests and enjoy!

What do you call people who are afraid of Santa Claus?

Claustrophobic!

living with me

Housebound but enjoy reading?

If you are finding it difficult to get out of the house, or to visit a library, you can get the mobile library to visit your home each month with a selection of reading materials for you. This is a handy, friendly and free service.

A selection of books, audio books on CD and large print books – in Welsh and English – are usually available. To get more information about this service for either yourself or another person, contact your local library.

Coping with Christmas blog

<http://tiny.cc/x6zv7w>

Neater Solutions' Arm Support

The powered Mobile Arm Support helps people with muscle weakness to use their arms, enabling them to manage all sorts of everyday activities independently, such as feeding themselves, drinking, using the phone, applying make-up - even those trivial things (until you can't manage them) like scratching your head, wiping your nose, etc.

The arm support can position the user's arms for working with a keyboard, and can also be used for exercise.

More information:
<http://www.neater.co.uk>
01298 23882



carers

Carers allowance

In October the Carers Allowance was whisked away from those who work 16 hours a week for minimum wage, as the modest increase in this hourly amount to £6.31, takes them over the £100 weekly earnings limit for receiving the benefit.

Carers allowance can now be claimed online, as can JSA and Universal Credit. To maximise benefit, claims should be made as soon as possible. This is to secure a date of claim. Benefit rules vary but generally benefit is paid from this date. Often a client is advised online to make sure they have a checklist of information before they claim. As the ability to claim online rises, it's important that clients are advised of the urgency to claim quickly and not to delay.

Childcare vouchers

If you are a parent caring for a disabled child and you pay for childcare, you could access a special government scheme, called "childcare vouchers", which is operated through employers. The scheme enables parents to pay for child care out of your pre tax and national insurance income.

Childcare vouchers can potentially save parents with children aged up to 15 over £1000 on childcare. The Family Information Service describe how the scheme works:

You need to find out from your employer whether they run a childcare voucher / salary sacrifice scheme. If so, you can choose to take part of your salary (up to £55 per week or £243 per month) in childcare vouchers which is tax and National Insurance free. It's up to you how you spend them.

Each working parent can take part in a scheme offered by their employer. So if both parents work for an employer who has a scheme, they can both save up to £100 per month.

If your employer doesn't run a scheme, please let us know and we can provide them with some useful information, as it's very easy to set up a scheme.

Childcare Vouchers can be used to pay for the care of children up to the age of 15 including out of school clubs (breakfast clubs, after school clubs, holiday clubs).

For more Information
<http://tiny.cc/z0ot7w>



Cerebra's Sleep Service

Sleep disturbance is often a problem for families who have children with a neurological condition or brain injury. Cerebra's sleep team can support parents and carers and help with a wide range of sleep issues including:

- Bedwetting
- Good sleep hygiene
- Nightmares
- Night terrors
- Anxiety at night
- Night-waking
- Sleeping alone
- Rhythmic movement disorder
- Biology of sleep
- Melatonin

They can give advice by telephone, post or e-mail and in certain areas they have sleep counsellors who can make home visits.

Contact them at sleep@cerebra.org.uk or call them on their Freephone helpline 0800 328 1159
www.cerebra.org.uk.

Cerebra have also produced a Disabled Children Parents' Guide: Parent/Carers, available at:
<http://tiny.cc/r6xt7w>

www.hmrc.gov.uk/calcs/ccin.htm
HMRC (here you can also do an online calculation to see whether you are better off claiming childcare vouchers or tax credits)

The National Association of Family Information Services (NAFIS)
<http://www.daycaretrust.org.uk/nafis>

Your local Family Information Service (FIS) provides a range of information on all services available to parents, to help you support your children up to their 20th birthday, or 25th birthday if your child has a disability. FIS also hold up-to-date details of local childcare and early years provision in your area.

Powys Carers Strategy

Powys County Council is developing a new Commissioning Strategy for Carers Services which will be implemented next year. The Council and the Health Board currently spends over £1 million a year on services for Carers and they are now reviewing what they spend and deciding how it can be most effectively used.

Powys Carers sent out a questionnaire on behalf of the council asking Carers what they see as being the highest priority for them from the following list. 230 Carers responded and marked the themes as follows:

Information & Advice 107
Easier Access to Services 103
Breaks from Caring 93
Access to employment, training and leisure opportunities 83
Early Identification and Recognition of Caring role 83
Transport 81
Assessments (how to get service) 56
Engagement and involvement - having a voice 49
Education 37
Housing 31

Of course Carers have different priorities at different times so any of the above might be important at specific points in a Carer's 'caring

pathway'. Powys County Council will be taking this response from Carers into account when completing the commissioning strategy. If you have any comments to make Powys Carers would be delighted to hear from you!
www.powyscarers.org.uk
info@powyscarers.org.uk or call 01597 823800

[There are Carers services throughout Wales – get in touch with your local one to influence service provision or access help.]

Protecting your pension

The amount of State Pension you get is based on the National Insurance contributions you have paid and any that have been credited to you. If you care for someone you may be entitled to National Insurance credits for carers.

These credits are usually given automatically if you get Income Support. If you can't get Carer's Allowance but care for at least one person for 20 hours or more a week, you may apply for a weekly Carer's Credit towards your pension.

Find out more at www.gov.uk/carers-credit or phone 0845 608 4321

First Aid basics

Carers sometimes have to deal with unexpected situations. The St John's Ambulance Service gives advice on how to cope with falls, seizures etc. by starting with a quick assessment which they call the Primary Survey or DRAB

DRAB

Danger – look around for any dangers to you, to others, and the casualty. If possible remove the danger, and do not proceed until it is safe to do so.

Response – check to see if the casualty is responsive. Call the casualty, "Hello, can you hear me?"

If there's no response, try again but louder. Ask them to respond to a question like "Can you open your eyes?", they may not be able to respond verbally but can respond physically. If there is no response, gently shake their shoulders.

Airways – You need to open the casualty's airways. Remove any blockage such as food. Tilt their head back and open their mouth.

Breathing – place your ear by their mouth, facing their chest. Look for chest movements, listen for & feel breaths for no more than 10 secs.

If the casualty is unconscious and breathing, you should place them in the recovery position. If the casu-

ality is not breathing you should dial 999/112 for the emergency services and start CPR.

First aid tips – convulsions & seizures

A small percentage of people with ME experience seizures of one kind or another. To help them:

1. Make the casualty safe. Remove any objects that could cause them harm. Place a blanket/pillow under their head to prevent injury. Loosen clothing around their neck.
2. DO NOT restrain the casualty – this could cause harm to them and you
3. After the seizure, place the casualty on their side and tilt their head up to open airways, check for breathing. Note the duration of the seizure.
4. Call 999 if:
 - the casualty is unconscious for more than 10 minutes
 - the seizure continues for more than 5 minutes
 - this is the casualty's first seizure or is having repeating seizures
 - the casualty is not aware of a reason for the seizure

[Thanks to Kayleigh Jones]
More info: <http://tiny.cc/xfyt7w>
The St Johns Ambulance runs First Aid courses in most areas. Find details online or in the phone book.

young people

Lightning process research

The Bath & Bristol Paediatric CFS/ME service, led by Esther Crawley has carried out a pilot study to see if it is possible to test the Lightning Process's effect on young people.

56 teenagers were given

- i) medical care or
- ii) medical care plus the lightning process, so the results could be compared. This process is called a Randomized Control Trial (RCT).

The aim of the study, called the SMILE study, was to find out the best way to test the Lightning process. The researchers decided that, with some alterations to the ways they recruited teenagers and parents, and measured the treatments' effectiveness, it will be possible to go ahead with a larger study.

The 2 treatments they want to compare are:

1. Specialist medical care for CFS/ME, which follows the NICE guideline recommendations of CBT (the psychological therapy Cognitive Behavioural Therapy) and GAT (Graded Activity Therapy)

2. The Phil Parker Lightning Process® (LP) was developed from osteopathy, life coaching and neurolinguistic programming. LP trains individuals to recognise when they are stimulating or triggering unhelpful physiological responses and to avoid these, using a set of standardised questions, new language patterns and physical movements with the aim of improving a more appropriate response to situations (www.lightningprocess.com).

LP is a controversial technique which is expensive, costing around £620 a course, and is reported to use exercise techniques that do not acknowledge the abnormal response to exercise that is characteristic of ME.

The LP is a psychological training programme, not a medical treatment or a cure. The Advertising Standards Authority ruled in August 2012 that the Phil Parker website should cease from advertising the LP programme as a treatment or cure for medical conditions as it was misleading. <http://tiny.cc/ocnt7w>

The Tymes Trust and ME Association believe this study is unethical.

Their reasons include:

- The Medical Research Council (MRC) guidelines for research states: 'Research involving children should only be carried out if it cannot feasibly be carried out on adults.' No adult trials have been conducted into the LP.
- The scientific basis of the programme is unproven i.e. the prolonged nature of ME/CFS is caused by 'the adrenaline, nor-adrenaline and cortisol loop'
- the outcome measure of school attendance after 6 months is inappropriate.

Children have a legal right to 'suitable education' for their particular needs, which may or may not include school attendance. [Following the trial the researchers decided that school attendance was not an appropriate measure for 16-17 yr olds]



<http://tiny.cc/bgnt7w>

More information:
<http://tiny.cc/fhnt7w>

What is a Randomized Control Trial [RCT]?

- Considered by many to be the gold standard for a clinical trial.
- It is a study in which a number of similar people are randomly assigned to two (or more) groups to test a specific drug or treatment.
- One group (the experimental group) receives the treatment being tested, the other (the comparison or control group) receives an alternative treatment, a dummy treatment (placebo) or no treatment at all.
- The groups are followed up to see how effective the experimental treatment was.
- Outcomes are measured at specific times and any difference in response between the groups is assessed statistically. This method is also used to reduce bias.

[From NICE website]

Can we trust CFS research?

WAMES recommends that no research results be accepted at face value. Unfortunately we need to ask questions to find out if the results might be of help to people with neurological ME:

- **Who took part in the study?** If the participants were selected using broad criteria or if they only suffered from fatigue or were only mildly affected, then the results might not be helpful for the severely affected or those experiencing a wide range of symptoms.
- **How was improvement measured?** Some studies use scales and measures that are not accurate enough so people can appear to be much improved, when they are still considerably disabled.
- **How were the statistics calculated?** Studies like the £5 million PACE trial have been criticised by statisticians because the methods they use alter the results.
- **Did they change the rules part way through?** When researchers experience problems they sometimes change the 'protocol' so they

can finish their research. This might not appear to affect the results to those with little knowledge of ME, so is allowed. ME experts don't always agree.

- **Did they follow up later?** To see if an improvement or harm continued week, months and years later. Some 'treatments' work under controlled circumstances but cannot be sustained in normal life or through a relapse. Also delayed reactions to exercise mean that changes in the body might become apparent until days later.

Some research studies, like the £5 million PACE trial, have been criticised on all the above counts!



'That flying reindeer stuff is just a silly myth.'

The Room – the NHS explained

The Room is an NHS website where children and young people can get information about the Welsh Ambulance Service. It also provides information about first aid and emergencies with quizzes and videos.

A new feature is a *Bug blaster* game, based on the 80s space invaders theme, the aim of Bug blaster is to shoot the bugs using the soap dispenser at the bottom of the screen before they get you. The more levels you complete, the harder and faster the game becomes.

In the winter washing your hands to avoid spreading bacteria and cold bugs is especially important so download the fun poster where 'Jack tells you' when and how to wash your hands.

www.ambulance.wales.nhs.uk/theroom

Poster:
<http://tiny.cc/z0ot7w>



Best read aloud

There was once a great tsar in Russia named Rudolph the Red. He stood looking out the windows of his palace one day while his wife, the Tsarina Katerina, sat nearby knitting. He turned to her and said, "Look, my dear, it has begun to rain!"

Without even looking up from her knitting she replied, "It's too cold to rain. It must be sleeting."

The Tsar shook his head and said, "I am the Tsar of all the Russias, and Rudolph the Red knows rain, dear!"

young people's christmas fun page!



Pantomime characters crossword

Some Musical Christmas Advice

Make out your Chopin Liszt early before Debussy season, when you have time to check out Verdi good bargains are, can still get gifts Faure good price, not have to Handel large crowds and have time to give Bach things you decide you don't want.

Reindeer jokes

What do reindeer say before telling you a joke ?

This one will sleigh you !

Why do reindeer wear fur coats ?

Because they would look silly in plastic macs!

How do you make a slow reindeer fast ?

Don't feed it !

How long should a reindeer's legs be ?

Just long enough to reach the ground !

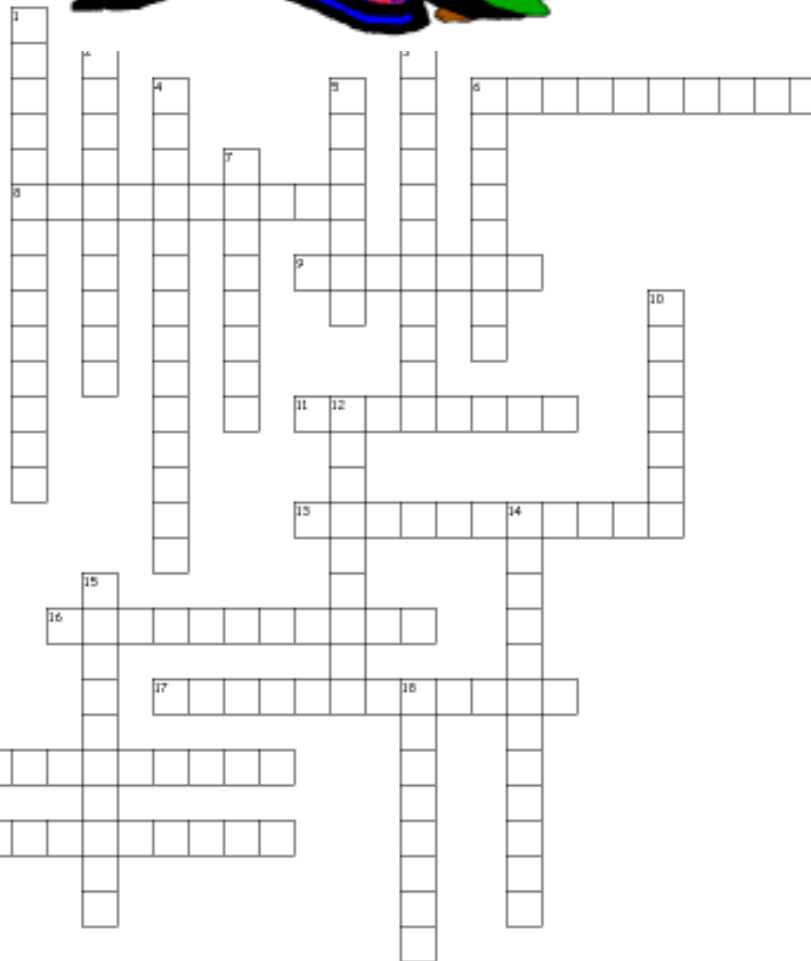
What do reindeer have that no other animals have ?

Baby reindeer !

Where do you find reindeer ?

It depends on where you leave them !

AhHa Jokes



Across

6. Famous fairy
8. Your parents mother and another name for a hat
9. A royal rodent
11. Jill's lazy brother
13. They sang Hi Ho as they went to work
16. Peter Pan's enemy
17. The old washer woman
19. Robin Hood's friend who is a monk
20. Cinderella's relatives

Down

1. She waves her magic wand and grants wishes
2. He tried to eat the 3 little pigs
3. Female parent and an alternative Christmas bird
4. Queen's son who is very pleasant
5. He has a magic carpet
6. Jack climbed the beanstalk to slay him
7. She gave Sleeping Beauty a poison apple to eat
10. Fasteners for clothes
12. A female sir and a horse's pace
14. She laundered the clothes
15. Robin Hood's beau
18. He has 40 thieves

Answers on page 17

Family Crisis grants

Buttle UK's Small Grants programme provides a fast response to families living in crisis, when there is no one else that can help. By paying for basic items such as a cooker, fridge or bed, the grants offer relief from a critical situation. Grants are distributed through the BBC Children In Need Emergency Essentials Programme.

They work with over 400 voluntary sector or local authority partners in Wales, which enables them to provide far-reaching support for those most in need. These agencies make applications for children and young people experiencing a wide range of issues such as illness, disabilities, behavioural and psychological problems. Other social issues surrounding their family life may include abuse, neglect, domestic violence, homelessness, drug and alcohol dependency and living in severe poverty.

Most grants are awarded within ten days of receipt of on-line application and often far faster:

<http://tiny.cc/nejv7w>

If you are eligible for the new **Discretionary Assistance Fund (DAF)** which replaced Social Fund Community Care Grants and Social Fund loans apply there first - as you are likely to receive much more

help with several items where we can only offer one item. We work in partnership with this Fund and help where they cannot help or add to very small grant awards. The turnaround time for DAF applications is far faster than the older system and is run from Wrexham. The best chance of success is to apply by telephone on the Freephone number so you can speak to an advisor direct. Please follow the link below for more information about the DAF.

<http://tiny.cc/bhjv7w>

Sally Ward, Casework Manager for Wales, Buttle UK
PO Box 224, Caerphilly CF83 9EE
01633 440052 www.buttleuk.org
wales@buttleuk.org

Benefits tips

One person with ME won her bid to be put into the support group because her consultant rightly specified that the stress of applying for jobs and attending interviews in the Jobseekers group was likely to cause a relapse.

In the case of DWP Customer Compliance visits to check on people in the ESA Support Group and receiving DLA, bear the following in mind:

- have some form of ID handy and be prepared to show bank statements.

- remember the ME policy about contact with the DWP: don't tell them unless they ask you, record all visits and have someone present as a witness
[from Shropshire ME n/l]

WOW petition

The campaign by and for sick and disabled people and carers to fight the War On Welfare - reached its target of 100,000 signatures in the last few days, thus obliging the government to at least consider giving time to a Parliamentary debate. The next step is getting as many MPs as possible from all parties to engage in the democratic process of achieving a Cumulative Impact Assessment of the disproportionate effect of welfare reforms on sick and disabled individuals.
<http://wowpetition.com>

Jack's petition

Jack's petition to force the government to debate the causes of UK hunger reaches over 130,000 signatures as doctors and academics warn that hunger in Britain has reached the level of a "public health emergency".

Petition <http://tiny.cc/wojv7w>
Independent article
<http://tiny.cc/5piv7w>

welfare

Scavenging for free food

Disabled people are being taught how to scavenge for free food in supermarket skips and dustbins because they can't afford to feed themselves, as a result of the government's cuts and welfare reforms.

The workshops are being run in south Wales by members of the Disabled Activists Network Wales (DAN Cymru). They have been building up a database of information about when particular supermarkets put out food that has passed its sell-by date.

[From disabilitynewsservice.com]

Back to work support survey

Mind has collaborated with the Centre for Welfare Reform and sick and disabled people to produce a survey of your experiences of the back-to-work support you receive as a condition of getting ESA, either via the Work Programme or Jobcentre Plus.

The survey asks about the quality of help you're offered and how you feel about the "work-related activity" you are told to do. It asks about

welfare

what things help or get in the way when you are on one of these government programmes.

Please complete the survey if this affects you. Your evidence will help build a case to make ESA fairer and more effective for people with illnesses and disabilities
<http://www.surveymonkey.com/s/esaworksupport>

Guide to benefits for young disabled people 16+

For parents of a disabled child: Personal independence payment and other benefits at 16
<http://tiny.cc/ktjv7w>

ILF

The Court of Appeal ruled on 6 November that the Government's decision to close the Independent Living Fund [ILF] in 2015 was unlawful
<http://tiny.cc/gwjv7w>

Older People and Benefits

AgeUK and Age Cymru estimate that about £5.5 billion in means-

tested benefits for older people goes unclaimed every year. As they say "State benefits are an entitlement – they are not a hand-out from the government, neither are they charity".

Age Cymru and their local partners can help people to

- Find out what they are entitled to
- Claim what they are entitled to

Contact them on 0800 169 65 65 to find out where you can get a benefit health check.

They can also help with money management and budgeting. Call your local branch, listed in the Business Section of the telephone directory under Age Cymru or Age Concern (their old name) or visit www.ageuk.org.uk/cymru

Housing Benefit and Universal Credit

New regulations have been issued regarding exemptions to the size criteria in the social rented sector (the bedroom tax) for both HB and UC from 4th December.

The main parts introduced for Universal Credit are where the size restriction won't apply:

- an overnight carer provides regular overnight care (the renter needs to both be the in receipt of the care component of disability living allowance at the middle or highest rate or attendance allowance or the daily living component of PIP and A foster parent (for up to 12 months if they don't actually have a child with them) or an adopter who has a child placed with them for adoption.
- A child - where they are entitled to the care component of Disability Living Allowance at the higher or middle rate, and they are not reasonably able to share a bedroom with another child by reason of their disability.
- A non dependent who is son or daughter of the renter and is in the armed forces and away on operations.

Universal Credit delays

Ian Duncan Smith has attempted to defend his welfare reform: Universal Credit before the Work and Pensions Committee of MPs. The £300 million IT system has experienced problems and it is unclear how much of that will have to be written off. Now we hear that 700,000 people on ESA won't be transferred onto the Credit until after 2017.
<http://tiny.cc/x9jv7w>

Benefits changes

Disabled people denied ESA have had their right to appeal reduced

On 28 October the DWP introduced change affecting people who are too ill to work. If a claimant wishes to appeal against a decision that they are not entitled to ESA, they must now ask the DWP to reconsider the decision before lodging an official appeal – and receive no money in the meantime.

Long-term sick people are having their benefits sanctioned ... for being sick

Nearly 600,000 have had adverse benefit sanctions taken against them. 45,000 sanction decisions have been made against sick and disabled people. 11,000 sick and disabled people had their ESA penalized in just seven months – either for not participating in work related activity or missing a meeting with the Job Centre. 120 disabled people receiving JSA have had their benefits stopped for three years.

50,000 disabled people are being cut out of work

But as DLA is phased out and replaced by Personal Independence Payments (PIP) – and half a million people lose their support –

it's been projected 50,000 disabled people will no longer be able to hold onto their jobs. One in five disabled people who receive the now scrapped DLA are in work and use the benefit to cover the additional costs that come with that – be it help showering in the morning or a motability vehicle to get to the office.

Eviction letters are now including veiled threats to remove people's children

Housing association tenants who fall behind in their rent this year due to the bedroom tax can be evicted. Some housing associations are sending out letters that include the threat that eviction proceedings may lead to the tenant's children being taken into care, although legally councils should provide alternative accommodation.

From 2011 there has been a one-year limit on sickness benefit

700,000 people with long-term sickness or disability have had their benefit taken as a result. The means test is only £7,500 for this change, leaving someone earning barely £8,000 per year having to support themselves and their ill partner.

From *New Statesman* article <http://tiny.cc/rikv7w>



Answers to Panto Crossword

- Across
6. Tinkerbell
 8. Granny Hood
 9. King Rat
 11. Idle Jack
 13. Seven Dwarfs
 16. Captain Hook
 17. Widow Twankey
 19. Friar Tuck
 20. The Ugly Sisters
- Down
1. The Fairy Godmother
 2. Big Bad Wolf
 3. Mother Goose
 4. Prince Charming
 5. Aladdin
 6. The Giant
 7. The Queen
 10. Buttons
 12. Dame Trot
 14. Wishee Washee
 15. Maid Marian
 18. Abanazer

Research: (Irregular noun) That which I do for the benefit of humanity, you do for the money, he does to hog all the glory.

“Research is the process of going up alleys to see if they are blind.”

Marston Bates

PACE Trial paper

Another paper has been published about the PACE trial, this time promoting the Statistical Analysis Plan used. <http://tiny.cc/sulv7w>

Tom Kindlon of the Irish ME Group questioned the effect on the validity of the published results of “improvement” when the criteria were changed after the results were in. He has also shown that they do not show an improvement at all. His article “Simply giving a reason why

research

an outcome measure was changed is not necessarily sufficient” at <http://tinyurl.com/oe6fmap> was published and Prof White wrote trying to justify the official findings. This has led to further letters from several others who challenge the published results.

AfME & research

Action for ME have published the first stage of their research strategy <http://tiny.cc/5ylv7w> which includes promises to fund medical and biomedical pilot studies, to heed the patient voice and to work collaboratively.

Speakers at AfME’s research conference on 18 Nov included Prof Stephen Holgate chair of the UK CFS/M.E. Research Collaborative (CRMC), Prof Derek Pheby, (M.E./CFS Disease Register), Dr Luis Nacul: (M.E./CFS biobank), Prof Julia Newton, (understanding muscle dysfunction), Dr Jason Ellis (the role of sleep), Prof Annalena Venneri (cognitive dysfunction).

Watch the films on AfME’s Youtube channel <http://tiny.cc/g1lv7w>

research

Mt Sinai ME/CFS Conference

was held on 20th Nov in the US organised Dr Enlander. A long summary is available at <http://tinyurl.com/p3vjs73>. Speakers were Dr Schadt, Dr Mikovits, Dr Peterson, Dr Enlander, Dr Klimas.

ME Research UK news

the Autumn 2013 issue of "Break-through" magazine can be downloaded at <http://tinyurl.com/o6pzns8>

Chemical and electro-sensitivities survey

Adults in the UK who have disabling chemical and electro-sensitivities are being invited to take part in an online survey which is attempting to find out how successful they are at sourcing safe housing materials and plants for their homes and gardens. Run by MCS Aware as part of the Safe As Houses Project for low-emission, low-allergen housing.

Take part here <http://tiny.cc/77lv7w>

Or get paper copy from MCS-Aware, 56 Gaping Lane, Hitchin, Herts.SG5 2JE.
<http://tiny.cc/29lv7w>

Survey on long-term use of prescription medicines

The Medway School of Pharmacy is attempting to find out how long-term medication affects the lives and outlook on life of people with long-term illnesses. Take the survey (should only take 10 to 15 minutes) <http://tiny.cc/mbmv7w>

AfME follow-up survey

Action for M.E. is following-up its 2008 report by looking, five years on, at health, welfare, employment and education for people with M.E. in the UK. Take part online <http://tiny.cc/gemv7w> or request a paper copy from:

Action for M.E., PO Box 2778, Bristol BS1 9DJ
Tel: 0845 123 2380 (lo-call) or 0117 927 9551 (Mon to Fri 9am to 5pm)

Closing date 14 Feb 2014



New Australian research centre

The National Centre for Neuroimmunology and Emerging Diseases (NCNED) has opened on the Gold Coast in Queensland and is dedicated to research on the interaction between the nervous system and the immune system. It is led by CFS/ME expert Prof Sonya Marshall-Gradisnik. In February 2014 they hope to open a specialised CFS Clinic. The integrated facility will provide treatment to anybody living with the condition and will build on the research being conducted with

participants which has shown a strong association between the condition and a dysfunctional immune system.

Subgroup in ME/CFS have POTS

Prof Julia Newton and her team at the University of Newcastle found that 13% of 179 patients had POTS. They were younger (average age 29), less fatigued, less depressed, and reported less daytime sleepiness than the 155 (87%) without POTS [Postural orthostatic tachycardia]. Crucially, they also had greater orthostatic symptoms and autonomic dysfunction.

POTS is defined as symptoms of orthostatic intolerance (problems with standing), and it is easily diagnosed by observing the increase in heart rate on moving from lying to standing (a person with POTS has an abnormally large increase).

The results support the view of ME/CFS as a central nervous system disorder. Clearly, it is important that POTS be recognised and managed, since treatment can improve functional impairment and quality of life. <http://tiny.cc/7jmv7w>

Dysfunction found in eye movements

Dr Claire Hutchinson and Dr Steve Badham of the University of Leicester have identified the following vision problems in ME:

Heightened visual awareness: hypersensitivity to light; difficulty suppressing visual information or directing visual attention

Eye-movement and tracking problems: Difficulty focusing on images; slow eye movements; difficulty tracking object movement

Reading difficulties: Confused or distracted by irrelevant print; difficulty tracking lines of print.

Future research will attempt to understand the reasons for these problems.

<http://tiny.cc/eqmv7w>
<http://tiny.cc/9qmv7w>

Research round-up

Acupuncture is moderately helpful in CFS

<http://tiny.cc/btmv7w>

Probiotic can reduce pro-inflammatory cytokines in ME/CFS

<http://tiny.cc/dumv7w>

Valganciclovir is potential treatment for CFS subset

<http://tiny.cc/fvmv7w>

Self management can improve fatigue

Fred Friedberg
<http://tiny.cc/3xmv7w>

No evidence that cervical cancer vaccine causes CFS
<http://tiny.cc/qzmv7w>

The supplement French oak wood extract (Robuvit®) shows promise in treating oxidative stress in ME

<http://tiny.cc/30mv7w>

South Asian cultural attitudes lead to lack of diagnosis of CFS/ME

<http://tiny.cc/91mv7w>

Probiotics with lactic acid bacteria strains are useful treatment for IBS

<http://tiny.cc/e3mv7w>

Younger CFS patients should be screened for heart rate variability to identify POTS

<http://tiny.cc/g4mv7w>

Memory of CFS symptoms becomes inaccurate after 6 months for majority of

symptoms and 1 month for joint pain

<http://tiny.cc/v5mv7w>

Information processing time is prolonged in CFS for most complex tasks.

<http://tiny.cc/d7mv7w>

Future research

Osteopath Raymond Perrin wants to find out if there is validity in the use of specific physical signs as an aid to diagnosing CFS/ME. He has raised £40,000 of the £60,000 cost. More info & ways to donate at: <http://tiny.cc/ygpv7w>

ME Research UK has asked a team in Leeds to explore the major common immunological mechanisms that might be responsible for the catalogue of symptoms shared by people with cancer or ME/CFS. <http://tiny.cc/eipv7w>

The Open Medicine Institute, the US research institute has received \$612,000 towards an in-depth study of 20 ME/CFS patients, which will include whole genome sequencing, protein profiles, cell analysis, mitochondrial and related biochemical pathways, brain/ cognitive data gathering. Leading

this research effort will be Dr Andreas Kogelnik.
www.openmedicinefoundation.org

ME/CFS/FM/Lyme trial

The Gottfries Clinic in Gothenburg, Sweden, along with several U.S. ME/CFS/FM/Lyme experts have observed significant reduction in fatigue and cognitive symptoms in 20%-50% of their patients that have a MTHFR mutation in response to alternative formulations of Vitamin B12 and Folate supplementation. Preliminary data has shown that these mutations are commonly found in ME/CFS/FM/Lyme patients

The Open Medicine Institute is launching a multi-site, multi-country, double-blinded, placebo-controlled clinical trial to confirm these findings. The goal is to fund this by Feb 14, 2014, start it in March, and have results by end of the year. The 100-patient, multi-centre trial will cost \$275,000. They are asking for \$12 (or multiples of twelve) to reach the necessary target.

Donate at <http://tiny.cc/9kpv7wlf> you need help submitting your donation or would like to donate by phone call 011-650-352-0310 or email to info@openmedicinefoundation.org

ME Groups

WAMES would be pleased to hear from anyone who runs a small group, no matter how informal, or from anyone who would like assistance in setting up local meetings

Anglesey & Gwynedd Fibromyalgia / ME Group
Contact: Rhian Medi (secretary)
01248 722184
fmsmemonagwy@yahoo.com

Brecon area contact
Richard Jones
richardj5@virginmedia.com
01874 622310

Carmarthenshire ME Group
Meets Caemaen Day Centre, Coleshill Terrace, Llanelli SA15 3BT. Please ring John James pm 01267 233793 for further details.

Clwyd ME group
clwydme@googlemail.com
01745 822953
www.clwydme.net

ME Support in Glamorgan (MESiG)
Monthly meetings are held on the first Monday of the month, 11am - 12.30pm at The Community Shop, Llangranog Road, Llanishen, Cardiff CF14 5BL
Contact: Christalla Bailey,
029 2076 2347



christallaconstantinou@talktalk.net
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS FM Group
Please telephone Mike or Karen on 0796 9665419 (between 2-4pm only please) or email karen@kandm46.plus.com for more information and the date of the next get-together.

North Ceredigion Group meets in Penrhyncoch, Aberystwyth. Contact Dr Derryan Paul on 01970 828896 edpaul@phoncoop.coop

North Ceredigion Yoga Class 11
Nant Seilo, Penrhyncoch on Thursdays 2-30-4.00pm. Contact Derryan above for more information.

Pembrokeshire Get together at 65, Tudor Gardens, Merlin's Bridge, Haverfordwest SA 61 1LB. Tina, 01437 454359, tretiul@talktalk.net

Live near the border? An English group may meet closer to you:

Shropshire
www.shropshiremegroup.org.uk
Maralyn Hepworth 07516 401097

Chester
www.chestermesh.org.uk
Joan Crawford 01244 370988

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