



Serving ME/CFS patients, carers and interested parties in Glamorgan

MESIG COMMITTEE CHANGES

It is with regret that I have to inform you that three of our valuable committee members have had to step down from the committee, for personal reasons. Although they will remain cherished members of the group Linda Taylor, our former Treasurer; Gareth Price and Gina Fisher will no longer be involved with the general day to day running and organisation of MESIG.

We are pleased to report that Gareth and Linda in particular have made tremendous progress and now feel able to re-build on other areas of their lives, for which they understandably need all of their energy to focus on. We wish them every success with this and will offer support in any way that we can. We would like to take this opportunity to thank all of them for their commitment and hard work.

In light of the resignations the remaining committee members made the choice to reorganise themselves to best serve our members. Ken Bailey stepped down as Chair into the Vice Chair position as he felt unable to commit as much time to the group as he'd like to but wanted to remain on the committee in a less demanding role. Gemma Phillips stepped down as Secretary after being proposed as Chair, which she accepted. Dee Penny was proposed Treasurer, which she also gladly accepted. Chris Davies remains our valid membership secretary.

We are also pleased to announce that a potential new member has joined the committee. Rebecca Thomas will hopefully be taking over our General Secretary post very soon. We'd like to take this opportunity to welcome her to the group.

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Fundraising event – the Cardiff 10K run.

The Team here at MESIG would like to congratulate and say a massive thank you to 3 amazing individuals from HSJ accountants for successfully completing the Cardiff 10k Run on Sunday September 11. It was a fantastic event and they managed to raise an impressive amount of funds for the organisation. **HSJ Accountants** love to support events outside of business such as local charities whenever they can and this year MESIG was fortunate enough to be supported by them.

After training for several months, Kim Jackson, Nick Sakkas and Rachael Yelland took part in the Cardiff 10km Race which started and finished on Cardiff's iconic King Edward VII Avenue at the heart of the City Hall. After a very successful race, they managed to raise the targeted **£1000!**

Kim and the team are not only delighted with the amount raised but also by achieving goals and breaking personal best targets they set themselves. With over 3000 runners this year we are proud to say they did really well. Nick came in and finished at **0:56:20**, followed by Kim who finished at **00:58:00** and Rachael who despite her pre training injuries pushed through with her "never give up spirit" and admirably finished the race at **1:18:52**. This is indeed an outstanding achievement and we simply cannot thank them enough for their contribution.



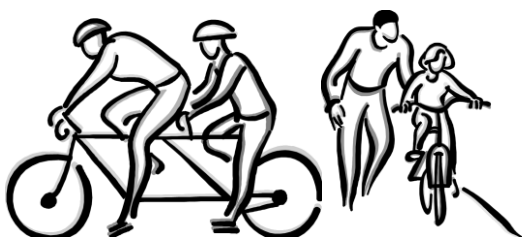
Information sources from <http://www.hsjaaccountants.co.uk/blog-post/cardiff-10km-charity-run>

Services for the disabled!

Intandem

Supporting opportunities for all to experience a bike ride. Come and join us at Sandfields education Centre. Seaway Parade, Port Talbot, SA12 7BL.

If you would like to enjoy the experience of a bike ride call 07913 047116. All disabilities are catered for.



Cardiff Christian Healing Time

Woodville Christian Centre, Crwys Road on Thursdays 1.00pm - 3.00pm. This is a relaxing quiet time spent lying down or sitting in a chair with music and prayer if requested.

The following dates have been organised:
2011: 3rd& 17thNovember, 1stDecember
2012: 5th& 19thJanuary, 2nd& 23rd February, 8th& 22ndMarch, 19thApril, 10th& 24thMay, 14th&28thJune, 12thJuly

For further information check out www.cardiffchristianhealing.org.uk



And She's Off.....

Grandmother Gwyn's off has ventured on the Walk Of Her Life. The day after her 60th birthday Gwyn Hopkins did not put her feet up and enjoy a cup of tea whilst contemplating a knitting pattern, settling into the stereotypical role of grandmother. Instead she' packed a 14 kilo rucksack and set off on a 150 mile trek across the width of Wales.

Grandmother Gwyn walked from Monmouth to St.Non's chapel near St David's over the course of 10 days, using footpaths and bridleways and spending nights in her one woman tent. But the challenge represented far more than a 60 year olds determination not to take the onset of retirement sitting down. Every mile emphasised the dramatic transformation in the life of a woman who once seemed destined to spend the rest of her days in a wheelchair.

Thirteen years ago Gwyn was struck down with the mystery condition M.E. After weeks in hospital she became bedbound in her own home and faced a future in which mobility meant being pushed in a reclining wheelchair.



Her walk across Wales was aimed at demonstrating to the tens of thousands of ME sufferers in Britain that a full recovery is possible. Also she wanted to raise funds for

'M.E. Research UK', a charity funding biomedical research into Myalgic Encephalomyelitis. Prior to her walk gwyn stated "I want to do it simply because - now - I can; it is such a joy to be out in the countryside again after spending years in bed, unable to walk more than a few paces. If I can help or inspire M.E. sufferers at the same time then that's great. The victims of this condition can be forgotten people often living within their own four walls with very little help or understanding. I was told I had very little hope of making a complete recovery and I want others to realise they should never give up."

Gwyn, a former Monmouth care support worker who now lives in Somerset, says she made her against-the-odds recovery with great family support and by adopting Complementary Therapies. It took her 5 years. She set out from Monmouth School Sports Club on a highly personal route which linked many of the places that have been important in her life over the past six decades.

The first night she stayed in a camp site on the edge of Abergavenny, overlooked by the Black Mountains where she worked for years as a Pony Trek Leader. Then she headed west on the Brecon canal past Brecon and then on towards Pembrokeshire where her parents were born and bred and she spent wonderful summer holidays by the coast with her granddad.

"In recent years I've walked over 600 miles for charity" says Gwyn "but this is special. Not just because of my age but because this is my very own 'Tracks of My Years' route full of memories and nostalgia".

Gwyn is happy to talk to M.E. sufferers or their carers and can be contacted through her website www.gwynhopkins.co.uk or phone 07596115021.

Anyone wishing to donate money to her charity can do so on www.justgiving.com/gwynhopkins

News from Action for ME!

Action for M.E. has joined forces with the ME Association, ME Research UK and a private donor to fund the next stage of the UK's first biobank of human blood samples for research into the causes of M.E./CFS. Initially, principal researchers Dr Eliana Lacerda and Dr Luis Nacul, London School of Hygiene and Tropical Medicine, asked patients from a dedicated disease register to submit blood specimens. It is hoped that further donors will be recruited at the end of next year.

Media attacks have been launched on M.E. campaigners and Charities including Action for M.E. ME Research UK and the MEA have been working hard, countering press articles which focus on a small number of M.E. activists who issue threats to researchers.

Researchers and clinicians from around the world joined forces to propose the development of International Consensus Criteria to help "help clarify the unique signature of M.E." in a paper published online on 20 July. The news came days after a BMJ editorial said the Canadian criteria "may be reasonable, but is probably not practicable."

Sir Peter Spencer, is among those invited to attend a seminar to discuss the independent review of the Work Capability Assessment (WCA) which Professor Malcolm Harrington is leading. The event took place on 17 August in London. The WCA, Atos Healthcare and media coverage of welfare benefits were criticised by MPs in July, perhaps contributing to the Government's decision to postpone the second reading of the Welfare Reform Bill until 13 September.

The minutes of the last meeting of the All Party Parliamentary Group (APPG) on M.E, held on 22 June, are now available to review. For regular updates on all policy matters, including structural reform, consultations on council tax benefit, supported housing and much more, check out 'Action for ME' policy and campaigns news stream. Not to mention their Daily Press Summary, Research, Scottish Hub, Our news, Your news...

Action for M.E. has also developed a new booklet, M.E. and work, for people with M.E. who are in work or well enough to be thinking about a return to work. The new publication is the latest in a series which includes an Employer's guide to M.E. an M.E. in the workplace leaflet and a video featuring Occupational Therapist, Nikie Catchpool talking about work and M.E. Action for M.E. also held a workshop for large-scale employers, in London, on 27 September.

A new friendship forum, M.E. friends online, is now available the Action for Me website for people who want to meet others, make friends and support each other. Registration is free and easy. Why not give it a try? NLP or advice for relapses: they want to hear from you. Have you used NLP to manage your symptoms? Have you any advice or tips for dealing with relapse? They would like to hear your experience, good or bad, for articles in forthcoming issues of InterAction, their quarterly members' magazine.

Action for ME can be found on social networks such as Facebook and Twitter! Or log onto their website at www.actionforme.org.uk



Information sourced from <http://www.actionforme.org.uk/get-informed/news/email-newsletters>

The hobby hideout

Sometimes, nothing can be more beneficial for people with chronic illnesses than taking part in hobby activities. Hobbies can distract us from feelings of depression, insecurity and associated hopelessness we all experience at some point or another. They are a great way to rebuild self-confidence, encourage creativity and interaction and help us to discover a new way a life by showing us that there are other things we can do that we would never have considered before. The hobby hideout is a new initiative to encourage members to try new things. Each edition we will suggest a few new hobbies/activities for you to attempt, so go on give them a try. You never know, you may discover a hidden talent!



Card crafting.

A very simple hobby to try, one which allows complete creativity and freedom of expression and can save you a few pennies when it comes to buying those Christmas and birthday cards every year! Anyone can do it. You can purchase pre-packed card designs and follow instructions to create universal designs or purchase various individual items and create original and unique works of art. The sky's the limit and the best thing about this hobby is that it is fairly inexpensive, doesn't require too much effort and the finished product can be presented to individuals as a gift. Nothing says I care about you like a personal handmade card!



Support Group Meetings

Meetings are held every first Monday of the month from **2.30pm-4pm** at the **Ararat Centre for the Community, Plas Treoda, Whitchurch, CF141PT** (unless this falls on a bank holiday, in which case the meeting will be held the second week of that particular month). Please note: no meeting in AUGUST.



Painting and sketching

Remember those carefree days as a child when colour was so fascinating and you noticed everything around you in detail; often asking your parents why and how. Why is the sky blue? Why does the sun appear round, well now is the time to start exploring such questions again, only now ask yourself how do I feel, why do I feel this way and then paint a representation of this. You don't have to be Picasso, anything can be considered art these days. It's fun; it's a great and inexpensive way to express yourself and it's recommended by many therapists as a great tool. We are currently trying to arrange an art class demonstration for our members to participate in.

Art workshop with Sian Williams

March 5th, 2.30-4pm, Ararat Centre.

Come play with colour. No experience needed just the desire to have some fun in a hands on way.

Sian is a local Welsh artist who likes to work through a variety of media including drawing and painting, collage, photography and sculpture. She particularly likes combining colour and texture on flat or 3-D surfaces and working with discarded materials including different types of packaging from old envelopes to empty, used teabags! .She has a studio in Canton and tutors art classes and workshops in the South Wales area. For further info: visit her website, marged-sian-artist.com or e-mail her on mail@marged-sian-artist.com .



MESIG's AGM & Awareness event

Just after midday on the 14th May 2011, I arrived at Chris's home in Llanishen to find a 'hive of industry'. Ken, Chris and Liz; Chris's friend and carer were in the kitchen preparing food, including a couple of delicious big bowls of salad, crisps and snacks; whilst Irene, Chris's daughter was sat cross legged on the floor in the sitting room, with a mound of buttered sliced bread on the table in front of her. I joined Irene for the next hour and we got cracking on the sandwiches. They were quickly put onto large platters and covered in film and then everything was loaded into the army of cars waiting outside to transport us to the Ararat Centre in Whitchurch, where the event was to take place.

When we arrived at the hall there was a pleasant buzz of activity. Our willing helpers Irene, Gemma's sister-in-law, Rachel, together with Ken, Liz and later Peter and of course Gemma, Chris and Myself worked quickly to prepare the hall for the soon to arrive members and guests. The food and goods for the many different stalls were brought in and many table set up to accommodate them including: a stall which proudly displayed all our modern and up to date M.E information; Steve's wonderful wooden carvings - the portraits so lifelike. He really is talented! Teresa's beautiful jewellery in a rainbow of colours. Her necklaces, earrings, bracelets and broaches were arranged to catch the eye - so professional! Peter arrived with my various plants, planted baskets and books. Denise also arrived with a few of her own plants to sell, and after a sneak preview I bought a couple that I didn't have. She also contributed a beautiful hand knitted baby blanket, the proceeds of which she donated to the charity. Dave brought his 'balancers' in the form of pendants that users would wear to counteract any adverse effects from mobile phones and PC's and Gemma brought a selection of her beautiful handmade greetings cards.

After the majority of items were set up we just had time before starting for a brief chat with a few people, including Kyle Davies who had been invited to give a talk about Mickel Therapy. Then the AGM commenced.

Everyone took their seats and after official matters were completed, such as the election and reinstatement of committee members and then there was a presentation of certificates, which had been created and designed by our talented young secretary, Gemma; who incidentally has also designed and set up our wonderful website.

Certificates were presented to Linda Shakespeare in recognition of all her hard work and loyalty in running the ME group at Keppoch Street for many years. There was one for Chris Davies in recognition of all her hard, inspirational work for the group and leading the committee, very often against the odds. A certificate was put aside for Athena, who sadly was unable to attend the event and finally, we presented a colourful bouquet of flowers to Gemma to thank her for all her inspirational work of late, despite

difficult times for her. The AGM was then closed and the way was made clear for Kyle Davies to commence his talk on Mickel Therapy.

We all listened to Kyle with great interest as he explained the process to us and when he had finished we listened again in wonder as Alison Lenihan gave an account of her recovery from ME, achieved from participating in Mickel Therapy with Kyle. There was quite a lot of interest after and many questions followed. There were a couple of other people who had recovered their health aided by the therapy at the event who also shared their experiences, including Helena; who wrote her marvellous recovery story that was printed in the May edition of the MESIG newsletter (issue 18).

Everyone then tucked into the buffet, raffle tickets were sold as everyone chatted and the room was a buzz with joy laughter. The energy -giving Biomat, which was kindly loaned by Grace and Linus, was tried and tested and found to be very beneficial, especially by Chris and Gemma, who then had the energy to carry on at the function. Then it was time for the exciting raffle draws and there were several prizes to be won. The prizes for the first raffle draw were a set of 3 sessions of Mickel Therapy with Kyle. For the second raffle, prizes included vouchers for reflexology treatment, music lessons, a fruit hamper, wine and chocolates and a Wittards tea pot set.

The event then drew to a close and finally it was time to clear up and Liz did a great job in handing out the leftovers giving everyone strict instructions to take them home and enjoy!

Chairs and tables were returned to their original positions, cups washed, rubbish cleared and goods taken back to the cars ready for the journey home. Reluctant goodbyes were exchanged and the end had come to a happy and highly successful day.

We would like to take this opportunity to extend our thanks to all our committed and willing helpers who made the event possible.



Written by Dee Penny.

Disability Wales AGM event

Our new chair Gemma Phillips has been working with Disabilities Wales over the last few months to reinforce to the government the issues concerning the new ESA system and other benefit processes and the effect they are having on the disabled community. As part of this initiative Gemma participated in an ITV news interview on 5th July and has been filmed for a video link that has been released on YouTube (<http://bit.ly/GEMMAstory>).

In recognition of her work Gemma was invited to attend the Disabilities Wales annual AGM event to represent MESIG, which this year focused on ESA and other disability benefits. Attending the event were various political representatives directly related to the implementation of the schemes under scrutiny, including Huw Brodie (Head of Strategic Planning, Finance and Performance for the Welsh Government), Simon Dawson (Director for ESA and disability benefits) and Adrian Masters (Political Editor, ITV Wales). The panel were faced with a very hostile audience and answered questions for over two hours with regards to the current issues. It was clear to them from the level of passion and grief displayed by all, that the system currently is unacceptable and simply doesn't work. It's fair to say a lot of the feedback they received was a surprise to them. They genuinely seemed shocked with regards to all feedback relating to ATOS but as Simon Dawson then stated 'unfortunately there's not a lot that can be done about that at present because they have a contract'. He did however, assure everyone that he would be taking comments back with him to other significant parties to consider.

A great deal of beneficial information came out of the day. Gemma had the fortune to meet representatives of various other organisation and form new alliances, uniting MESIG with many great allies. She was very honoured to receive the invitation and looks forward to next years' event.

THE PERFECT AFTERNOON TEA!



This year's annual tea in the park was an extremely successful event. A great number of members made the effort to attend and a great time was had by all, even though for the majority of the day the weather was fit for ducks!

The conversation flowed as many enjoyed the delights the lake side café had to offer. When the weather brightened up a little, a few of us ventured outside to the sheltered

seating area to enjoy the fresh air and when it was eventually time to go the disappointment was clear on everyone's face, despite the exhaustion felt by all. Fingers crossed all future events will turn members out in such numbers.

On a personal note Chris would like to take this opportunity to apologise if she appeared antisocial. Chris has been severely challenged by chemicals which have been affecting her heart and causing fainting. This was her first trip out for some time and she had to stay outside away from enclosed area in case she reacted to perfumes.

Thank you to all who made the effort that day.



Mitochondria not hypochondria

We thought members should be made aware of this review published in January of this year. There has been much dispute about this but we leave members to draw their own conclusions.....

Mitochondria, not hypochondria

Thursday, January 06, 2011

University of Hull Professor of Psychology Rhona Johnston argues against the widespread belief that ME/chronic fatigue is a psychological condition...

ME/chronic fatigue syndrome (ME/CFS) is a chronic state of profound exhaustion, often accompanied by pain, sleep problems and cognitive dysfunction, and it is made worse by exercise. In my local health authority area, individuals with a long-term fatigue problem used to be sent to the immunology department at the regional hospital for diagnosis and treatment, but now they are referred to a psychiatrist. This is a growing trend throughout the UK. These days, getting a diagnosis of chronic fatigue is tantamount to getting a psychiatric diagnosis. This is good for creating work for psychiatrists, but is it good for the individuals concerned? If their condition is a physical illness, they will not receive suitable treatment and so will not make a full recovery.

The psychiatric view of what they term 'chronic fatigue syndrome' (the term 'fatigue' clearly trivialises the severity of this illness) has gained considerable ground in the UK in recent years, aided by the supposed lack of evidence of physical causes of the condition. What evidence can psychiatrists adduce to support their assertion that ME/CFS is a

purely psychological illness, that is, a form of hypochondria?

Psychiatrists argue that individuals with medically unexplained symptoms have 'functional somatic syndromes' – that is, although their symptoms appear to be physical, they are psychological in origin. It has been argued, on the basis of an analysis of the literature, that having the belief that ME/CFS is a physical illness leads to a poorer prognosis, and that these faulty attributions perpetuate the illness. Thus the fact that these individuals believe that they have a physical illness is seen as a further manifestation of their psychological problems. However, if those who assert that they have a physical illness do indeed have one, the prognosis for recovery without suitable treatment is clearly going to be poor.

One of the main treatments on offer for the condition is cognitive behavioural therapy (CBT), which has been shown to lead to a significant reduction in fatigue symptoms. This finding might be taken as support for the idea that ME/CFS has a psychological cause. However, there is a higher incidence of depression in those with chronic physical illnesses than in the general population, although in the case of ME/CFS this has been found to be no higher than in, for example, rheumatoid arthritis. Thus CBT may, for a subset of individuals, ameliorate some of the tiredness resulting from a concomitant depression, while not addressing the underlying fatiguing disorder. It is unclear, however, if this is indeed the case, as the authors of these studies use ME/CFS classification criteria that take fatigue as the main symptom. The exclusion of physical symptoms allows the inclusion of individuals who do

primarily have a psychiatric disorder. Thus the statistical reduction in fatigue found with CBT may be largely due to the fact that individuals suffering purely from depression are included in these studies. It should also be noted that there is a lack of evidence of long-term benefits of CBT for individuals with an ME/CFS diagnosis. The higher proportion of women suffering from ME/CFS is also thought to be evidence that the illness is psychosomatic. It is unclear why this should indicate a psychological illness; after all, women are more prone to gallstones as well. It is noteworthy that when a doctor made a study of viral illnesses in his patients over a 40 year period, of those who subsequently experienced central nervous system pathology, 67.8% were women (of whom a third also experienced ME/CFS) and 32.2% were men (of whom a third also had ME/CFS). Thus there was a clear physical basis for the disproportionate number of females suffering from ME/CFS in this study.

It has also been asserted that ME/CFS is a psychiatric illness because patients have often experienced abuse in childhood. However, stressors like abuse are known to cause physical ailments. For example, it has been found that child abuse is associated with an increased incidence of ischemic heart disease. It has also been shown that individuals having severe chronic stressors in the 12 months prior to being deliberately exposed to a virus were significantly more likely to become ill than those with acute stressors or a low number of stressful life events.

A mitochondrial problem?

It is clear that there is little evidence in favour of a psychological explanation of ME/CFS. We therefore need to consider the biomedical evidence for a physical disorder, of which there is a considerable amount. To aid simplicity, the approach taken here is to consider the possibility that individuals with ME/CFS may in the majority of cases have a similar physical problem, but that it may have diverse causes. A recent study has found that 70 out of 71 individuals suffering from chronic fatigue had abnormally low mitochondrial function.

Mitochondria are organelles within cells and are the main producers of cellular energy. Mitochondria have to have an intact inner membrane to produce energy via a process called the electron transport chain. There is evidence that a wide range of chemicals impair mitochondrial function, including pesticides, herbicides, PCBs, solvents, toxic metals (such as dental amalgam), plastics, and fluoride. Impairments can also be caused by drugs such as antibiotics, non-steroidal anti-inflammatories and anti-parasite drugs.

There are also infections that cause mitochondrial problems, such as mycoplasma. This is a micro-organism that lacks a cell nucleus and a cell wall; it damages the inner membrane of mitochondria, depleting the nutrients in the cells, disrupting the electron transport chain, and causing chromosomal aberrations in the host cell. Studies by Dr Garth Nicolson have shown that individuals with ME/CFS have many bacterial and viral infections; however, a high percentage of them have mycoplasma infections. Thus, over a number of studies,

Nicolson and his group have found that between 51% and 68.9% of individuals with a chronic fatigue diagnosis have a mycoplasma infection. Most of these studies were carried out in the United States, but the higher figure comes from a Belgian study, in which only 5.6% of controls showed signs of the infection. Nicolson's group has also shown that using a supplement that restores the mitochondrial membrane leads to both a reduction in fatigue and an increase in mitochondrial function in individuals with chronic fatigue. Clearly, the infection scenario is a complicated one; susceptibility to mycoplasma and other infections may arise from having an immune system weakened by viruses, and viruses themselves might damage mitochondria. However, getting rid of a mycoplasma infection in those affected will be very beneficial for energy levels, and so reduce stress on the body. Chronic exposure to stress can in itself damage mitochondria and also impair the functioning of the adrenal glands. Adrenal insufficiency could be a primary cause of ME/CFS in some individuals, as the symptoms are similar to those of Addison's disease. Less extreme debilitating adrenal problems also occur. It has been shown that overworking the stress system leads to problems in keeping a balance between the functioning of the hypothalamic-pituitary-adrenal (HPA) axis and the immune system. If there is an immune challenge, this produces inflammation, and the actions of the HPA axis reduce it by damping down the inflammation. However, if the body has to do this often it becomes overstressed and cannot maintain the balance – this is

likely to happen if the body is dealing with a long-term infection like mycoplasma.

Treatment

What can the NHS do to help individuals with ME/CFS? At the moment, many individuals are offered expensive but harmless CBT. This technique is now widely used for so many illnesses, including cancer, that it can even be purchased online. They are also offered potentially damaging graded exercise regimes. Exercise can be very beneficial, but not if misinformed practitioners believe their patients to be depressed and persuade them to exercise beyond their reserves of cellular energy. Pacing is excellent and can cost nothing – here, individuals make sure that they keep their activity level within their energy envelope, and so avoid bouts of disabling exhaustion.

In order to help at least some people recover, it would seem a good use of resources for the NHS to screen ME/CFS patients for low mitochondrial function, adrenal problems (not just testing cortisol levels at midday) and mycoplasma infections. The latter can be treated by antibiotics, which if administered early on could mean that these individuals would avoid having to suffer this debilitating disease for decades, with the consequent weakening of their adrenal glands. Removing this infection is unlikely to lead to an immediate cure for long-term sufferers because of collateral damage to other bodily systems, but there must be a chance that a proportion of individuals will regain their health and lead happier and more productive lives.

Sourced from: www.publicservices.co.uk

LAUGHTER CORNER

Prospective husband: Do you have a book called 'Man, The Master of Women'?

Salesgirl: The fiction department is on the other side, sir.

How do you make a group of lawyers to smile for a photo? - Just say, "Fees."

Q: What's the difference between a teabag and England?

A: The teabag stays in the cup longer!

If you've got any joke to share send them in to Chris or Gemma and we'll publish as many of them as we can in our next edition



Riddle me this...

We thought we'd try something new and give our readers something to really think about and give your brain a quick work out, so we decided to include a few riddles in this edition. See if you can solve them and above all enjoy!

The more I am the less you see....strange result, what can I be?

Ans: I am _ _ _ _ _

I can only be kept if I'm given first.

Ans: I am a _ _ _ _ _

I'm neither here nor there, an in-between place...bend backwards under bars, I'm a dance with pace.

Ans: _ _ _ _ _

The answers to these riddles can be found on page 22

Leger-M.E

When people have M.E. the way forward may not be obvious, things may seem out of proportion and remote. Members will be thrilled to know that Leger-M.E are there to help.

We are all aware that yet there is money trouble ahead.

In the recent budget, the government announced that VAT would rise from 17½% to 20% from January. The cuts in public spending may cause a second dip recession as many civil servants are likely to lose their jobs, with reduced jobs, the benefits load is increased and disposable income reduced.



Nearer home, welfare benefits are to be targeted for austerity savings. The most vulnerable are those still receiving Incapacity Benefit. The Government's intention is to move them to JobSeekers Allowance rather than Employment and Support Allowance, thereby cutting the basic state benefit rate from £91 per week to £65 per week.

There have been rumblings about the fitness for purpose of the system which the DWP will use. Being refused a benefit causes much stress, and it is certain that this causes more harm to people with ME/CFS by delaying recovery. Evidence is being sought about the harm this causes. There is also a similar situation with Disability Living Allowance. How this could happen with ESA was covered in the last Pathways 24.

We have been fortunate enough to discover the Leger-M.E website and urge members to view it for themselves. Leger-M.E offers advice on a number of benefit related issues and keeps readers up to date with all the recent information and procedures. If you are struggling with the recent changes to benefits, why not contact them for assistance. The website address is www.leger.me.uk.

Article sourced from www.leger.me.uk

Hardest Hit campaign 22.10.11

The Hardest Hit campaign brings together disabled people / carers and organisations and groups who represent them to send a message to Government - you are hitting disabled people and their families the hardest: stop these cuts.

Disabled and ill people and their families are being hit hard by cuts to the benefits and services they rely on.

The Government's plans to cut billions from support for disabled people and their families. Their proposals include:

- Cutting 20% from the budget for disability living allowance (DLA). Disability Alliance estimates that over 700,000 disabled people could see their benefits reduced or removed. DLA helps disabled people with the extra costs of disability and without it more disabled people would be pushed into poverty. The cuts could have a knock-on impact on Carer's Allowance, leaving thousands of families even worse off.
- Taking mobility payments away from disabled people living in residential care and children going to residential schools. Cutting these payments would trap many in their own homes.
- Cutting off payments of contributory employment and support allowance after a year to people struggling to get back into work due to disability or serious illness.

Hardest Hit Day of Action

On 22 Oct disabled people, their families and friends took to the streets in cities across the UK protesting against Government cuts to disability benefits and services. Protests took place in cities including Edinburgh, Cardiff, Leeds, Nottingham, Brighton, Manchester, Newcastle and Bristol.

ALMOST 1,000 campaigners descended on Cardiff city centre to oppose cuts to the Disability Living Allowance.

For 45 minutes, the Welsh capital came to a standstill as the crowds marched through the streets as part of the Hardest Hit campaign.

The coalition Government is planning reforms to introduce a new Personal Independence Payment to "ensure people get the right levels of support", according to the Department for Work and Pensions. But campaigners say they fear the changes will mean "a life sentence" for the disabled people of Wales, who are already struggling financially.

The Welsh rally was taken to the doorstep of Cardiff City Hall before passing through the city.

Members of ME Support In Glamorgan turned up in support of the Hardest Hit Campaign and to represent ME sufferers, our Chris did get interviewed by ITV Wales though has yet to be aired. Thank you to those who managed to get there, those who intended to and those who got part way. All efforts greatly appreciated.



Lets Party!

It's that time of year once again to trim the tree, wrap the presents and really let our hair down and what better way to start than with our annual MESIG Christmas party. This year we'll be holding at the Ararat Centre for the Community in Whitchurch, commencing at 2.30pm on Monday 5th December 2011. As usual there will be a selection of goodies to munch on, the ever popular bran tub and a warm and friendly welcome to all. So come along, exchange cards and have a good old natter to one and all.

Could anyone wishing to attend please let Chris or Gemma know by 1st December 2011, so that we can account for numbers and prepare enough food for everyone to enjoy. Could each participant also bring a wrapped gift to add to the bran tub up to the value of £5.

We look forward to seeing you all there. Let's hope this years will be just as successful as the previous!



Septembers' Speaker

Septembers' monthly meeting saw one of our largest turn outs this year, with members new and old joining us to welcome our guest speaker, Paul Swann from Disabilities Wales; who generously donated his time offer us advice with regards to the current benefits system and inform us of the positive work his organisation are doing in relation to this. Member enthusiastically joined in the conversation offering advice to others based on their personal experience and entered into a healthy debate with Paul in relation to some of the facts stated and ideas put forward.

It was a wonderful afternoon, which appeared to be enjoyed by all. It was great to see so many people passionately involved in debate. In view of this we are keen to invite guest speakers to meetings on a more regular basis to offer their advice and affirm our alliances. If anyone has a suggestion in relation to guest speakers please contact Chris, who will make every effort to arrange a presentation. For more details of the services offered by Disability Wales call 02920 887325, email info@disabilitywales.org or check out their website at <http://www.disabilitywales.org>

MESIG GROUP EMAIL

For the benefit of our members we are pleased to announce that we now have a group email. Chris Davies will be sending out regular updates to all members on the list in relation to upcoming events, breakthrough treatments and any other relevant ME News. Get the News as it happens!

If you'd like to be included in the group email, please forward your email address directly to Chris for inclusion.



POSITIVE CHANGE FOR M.E./CFS



We've been asked to make all our members aware of this and encourage you to your story forward.

This is a national (international) campaign to create real political, social and legal change towards the treatment of people with M.E./CFS.

The more people act, the more powerful and positive it will be.

If you have stories of how you have been treated unfairly or neglected by medical or care professions, please write to the: -

1. General Medical Council
2. (sending a copy to Prince Charles,
- 3 and another copy to the Health Secretary).

This is to create positive change, so please include dates, names and facts. DO NOT include any malice or aggression, as this is a peaceful protest.

Here's a step by step guide on how to do this:

PART ONE General Medical Council www.gmc-uk.org

FILL IN AN ONLINE COMPLAINT FORM (OR PRINT ONE AND POST)

www.gmcuk.org/concerns/making_a_complaint/a_patients_guide.asp

They want to know

1. **THE DOCTOR(S) NAME AND ADDRESS**
2. **THE COMPLAINT**
3. **SUPPORTING DOCUMENTS/EVIDENCE**
4. **WITNESSES, NAMES** e.g. PALS, family or friends present, nurses
5. **HAVE YOU COMPLAINED TO ANYONE ELSE, IF SO WHO?**

The Health Ombudsman for England, 13th Floor, Millbank Tower, Millbank, London, SW1P 4QP.

Please include facts, dates and people.

This is not malicious or an attack – it is just factual evidence to create positive change for the treatment, support and attitudes towards patients with M.E./CFS

PART TWO You can send a copy of the GMC complaint form to: -

Prince Charles (Princes William and Prince Harry)

POSITIVE CHANGE FOR M.E./CFS

Clarence House

London

England

SW1A 1BA

PART THREE You can also send another copy of the GMC complaint form to: -

Andrew Lansley CBE MP

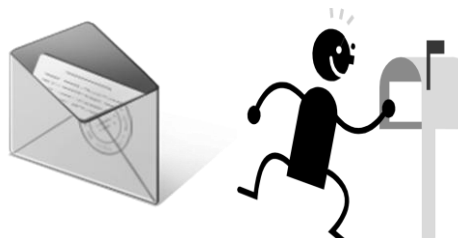
POSITIVE CHANGE FOR M.E./CFS

Department of Health

Richmond House

79 Whitehall

London SW12 2NS



The Amethyst Biomat

There is a revolutionary new healing device on the market that is making a big impact and being described by the professional as 'an electronic healing device, centuries ahead of its time'. The Amethyst Biomat. And for the benefit of our members Mesig has purchased this amazing device! The purchase was possible as a result of money raised by fundraising events and money donated from Arlene's son's funeral. A plaque has been made in memory of Huw, which will be attached to Biomat.

It is considered to be the perfect blend of nature and technology, a state-of-the-art light reverses degenerative disease cycles and speeds cellular renewal. This allows post traumatic and surgical healing processes to occur 57% faster. It is a 17 layer medical device that gives long lasting healing effects. Ideal to use for Holistic Therapists/Reiki Practitioners/Crystal Healers for added healing as well as ideal to use at home for your own well-being.

This is not just another 'New Age' fad. It is approved by the FDA, and incorporates negative ions and far infra red rays with the health benefits of amethyst to produce a "heating pad" for amazing benefits. Patients are thought to benefit greatly if they use the device with their eyes closed whilst listening to soothing sounds, Binaural Beats/ Isochronic brainwave entertainment.

It's a combination of three therapies in one:

FAR INFRARED: Though it is invisible to the human eye approximately 80% of the sun's rays fall into the far infrared range. It is simply a form of energy that is directly transmitted into objects because of its specific wavelength. First discovered by NASA, scientists propose it is the most beneficial electromagnetic energy available for the human body, directly affecting all metabolic and cellular functions.

NEGATIVE ION: The key players in creating the electric energy within our body are structures called ions. Cells create electrical energy as ions move from the solutions inside the cells of our body to the solutions outside the cells. This becomes the energy source that initiates body functions ranging from muscle contraction to creative thought.

AMETHYST CRYSTAL: It has been deemed "nature's tranquilizer" by many healers because of its effectiveness in relaxing not only the mind but also the nervous system. It is described as the crystal that works for clearing the energy blockages to provide the proper alignment of the Chakras and free flow of energy through them.

What are the benefits of these Therapies?

FIR Therapy has been shown to:

- Reduce pain, stiffness, swelling and inflammation
- Improving lymph flow and the endocrine system.
- Increase blood circulation and strengthens the cardiovascular system.
- Activate healthy molecular vibration with long-lasting, life-sustaining activity by initiating enzyme activity.
- Found to penetrate deeply into the innermost parts of the body, stimulating healing and regenerating of cells, nerves and meridians hidden beneath surface, adipose (fat) and muscle tissue layers.
- Balance pH by decreasing acidity.
- Help remove toxins and detoxifying the body.
- Improve the Immune System
- Reduce Stress and Fatigue
- Improve Skin and Muscle Tone
- Help control Weight & Burns Calories
- Reduce Cholesterol
- To attain a Deep Delta State of Relaxation
- As the molecules of your cells are illuminated with far infrared light rays of the same "frequency" it actually boosts your cellular metabolism and microcirculation
- It can also promote the elimination of poisons, carcinogenic heavy metals and other toxic substances that the body encapsulates in water molecules and stores in the subcutaneous fat cells.

Negative Ions are considered to be "Nature's Battery Charger". Negative Ions are a major natural element that provides energy to the human body and have been shown to:

- Deliver a molecular level massage that accelerates and deepens all healing and cleansing processes.
- Be the "Master Power Switch", which activates the body's entire cellular communication system and makes every single body function work better. (Nobel Prize in Medicine 1991 - Reviving the Cell - When the amount of Negative Ions in the blood increases, the function of the cell is activated. Thus increasing nutrient absorption, waste elimination, metabolism and cell function.) The reverse holds true if there is a lack of negative Ions, and too
- many positive Ions within a cell. Then, absorption of nutrition and elimination of waste material cannot be done effectively. As a result diseases happen.

- Alleviate allergies, migraines, and sinus problems.
- Purification of our Blood - Through research done by Dr. Tanaka in Japan, it was discovered that when Negative Ionization is introduced, the Ions in calcium and natruim (salt) in the blood increases, and the blood is purified by increasing blood alkalinity.
- Increase the flow of oxygen to the brain; resulting in higher alertness, decreased drowsiness, and more mental energy, (Pierce J. Howard, PhD, author of "The Owners Manual for the Brain: Everyday Applications from Mind Brain Research" and director of research at the Center for Applied Cognitive Sciences in Charlotte, N.C.)
- To produce biochemical reactions that decreases levels of the mood chemical serotonin, helping to alleviate depression, relieve stress, and boost our daytime energy.

Amethyst Quartz is "Natures Super Conductor".

Scientifically found to offer the steadiest and most powerful delivery of beneficial far infrared light waves and highest vibrational frequencies into the human body. Amethyst also aids inner alignment, balances inner body energies and clears energy blocks. Has been shown to:

- Aid with sleep
- Improve mood and depression
- Help with swelling and inflammation
- Detoxify the body
- Enhance relaxation
- Balance and stabilize energies located within certain areas of the body
- Induces Delta State
- Restorative theories of sleep describe sleep as a dynamic time of healing and growth for organisms. For example, during stages 3 and 4, or slow-wave sleep (delta), growth hormone levels increase, and changes in immune function occur
- Negative ions applied to the body via the Bio-Mat have been shown to induce a delta wave state within several minutes of usage. This greatly facilitates deep relaxation, reduction of stress, and improved sleep function. Those who have a history of poor sleep or insomnia may find the Bio-Mat very helpful
- Hypothalamic dysfunction (a major player in CFS/FM) affects sleep, as well as blood pressure, hormonal systems, and temperature regulation. In animal studies done at the University of Tennessee by Carol Everson, Ph.D., sleep deprivation resulted in immune suppression, resulting in multiple infections (including yeast overgrowth in the gut). Many other abnormalities also occurred based on the sleep disorder. These same processes seem to occur in people with CFS/FM. (Chronic Fatigue)

How it Works

BioMat™ Amethyst Pro. contains more than 28 lbs of amethyst crystals which naturally produce and are superconductors of Far Infrared Rays

- When the Bio Mat™ mx Amethyst is turned on pulses of energy ((DC- Current) radiate through the layers containing the Japanese Kurare Carbon Ceramic Super Fiber Material generating Long wave Far Infrared Rays (8-12 micron) that the human body can easily absorb.
- The superconductor properties of the amethyst crystals amplify these Bio Natural rays so they can penetrate the body up to six inches unlike most other far infrared technologies which only penetrate 1 to 1.5 inches.
- Bio Mat™ mx Amethyst also has a special feature of direct conduction of negative potential that transforms positive Ions to negative Ions inside the human body. This process changes the acidic condition of the body to alkaline which is its natural healthy state.

The mat has been tried a tested by various members of the committee, all of whom have found it very beneficial, especially when used on a regular basis. If any of our members would like to use the biomat they can do so on a fixed term basis for 3 weeks. To arrange to borrow the mat or if you would like anymore advice about it please contact Chris or Gemma.

Information sourced from <http://www.crystalhealinglondon.co.uk/bio-mat.html>



P.A.T.C.H

Don't despair, there is help available out there! If you need support to develop skills and get back in to work PATCH can help.

The Rhondda Cynon Taff PATCH (Positive Action Towards Change) Project, funded by the Wales Council for Voluntary Action and delivered by Bryncynon Strategy, offers a range of activities and educational projects for people with physical health conditions in various centres throughout the borough.

You will have the opportunity to learn new skills in a supported environment through exciting and creative activities. Some of the activities on offer include:

Independent Living Skills



Courses are run on a weekly basis throughout RCT to help encourage independent living. Courses include but are not limited to:

- Accessing Support
- Cookery
- Healthy Eating
- Health & Wellbeing
- Money Advice
- Keeping Active

Recreational courses



The PATCH Project will also involve a wide selection of 'just for fun' activities which include:

- Photography
- Life Drawing
- Arts & Crafts
- Scrap-booking

Adult learning courses



You will also have the chance to gain a recognised qualification by attending adult learning courses which include:

- Basic Skills
- Computers
- Food Hygiene
- First Aid
- Sign Language

We can also offer a wide range of introductory courses including hair and beauty, nail care, aromatherapy and various construction skills.

Who can take part? You must be 16 and over, living in Rhondda Cynon Taff, have a physical health condition which is holding you back and be unemployed (or working less than 16 hours per week). Transport may be available if you need it.

Help getting into work

The PATCH Project can also provide help and support in finding work or additional.

For further information, or if you or anyone you know would be interested in joining the programme, please contact:

PATCH Co-ordinator
The Feel Good Factory, Abercynon Road,
Matthewstown, Mountain Ash, CF45 4XZ

T: 01443 479018

F: 01443 478503

patch@bryncynonstrategy.org.uk can support you with job-search, CV writing, form filling and interview techniques. We can also help you to improve your confidence and show you how to achieve your job goals. Whatever your employment status.



Cardiff Foodbank was officially brought into being on 29th April 2009 as a franchise of the Trussell Trust, and is part of the National Foodbank Network. It is a project to help and support those suffering financial hardship and who are facing the reality of being unable to feed themselves or their families.

Nationwide the Network helped over 60,000 people UK wide (41,000 in 09/10)

- 20-30% increase in clients due to recession
- Benefit delay affects 35-45% of our clients

A Christian Initiative enabling the whole community to fight hidden hunger in Cardiff, where upwards of 50,000 are deemed 'deprived' and in some areas 78.5% of children live in benefit reliant families.

How it works

Food is donated by individuals, schools, businesses and churches and is sorted and stored for future use in the Warehouse in Ely.

Front line professional care workers such as health visitors, charities, church pastoral workers social services, etc issue clients vouchers.

Clients can exchange vouchers for 3 days of nutritionally balanced emergency food.

Clients collect food from our distribution centres across the City where they find a safe place to chat over a hot drink and snack and receive signposting to a range of support services.

M.E.S.I.G as a charity organisation have applied for vouchers, due to our members experiencing difficulties with finances and benefit cuts.

If you are experiencing difficulties with purchasing basic food please get in touch with Chris or Ken.

Fibromyalgia support group – Don't go it alone!

For our members who suffer from fibromyalgia it may interest you to know there is an independent support group available who focus on supporting patients specifically with Fibromyalgia.



Support groups meet in Neath Port Talbot on the 2nd Tuesday of every month at St Mary's Church Centre, Port Talbot, between 12.30pm and 2.30pm
Contact Yvonne for details on 01633 681468 or email: singletonyvonne@gmail.com

Alternatively there is a second support group who hold meetings in Swansea the 1st Tuesday of each month. The meeting are held at Swansea Resource Centre, Llansamlet, between 4.00pm and 6.00pm.
Contact Pam or John for details on 01792 862171 or email: jandp2010@hotmail.co.uk

HELPING OTHERS TO ABUNDANT LIVING!

The Guild of Health's ruling Council of Trustees, on Wednesday 27 May 2010, agreed to make a substantial grant to Burrswood Christian Hospital to enable people with Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME) to receive treatment at Burrswood and to get some qualitative research under way at the same time.

NHS sources say CFS/ME affects about 250,000 people in Britain today and Burrswood frequently has a waiting list for people referred for admission with this condition.

Dr Paul Worthley explained how limited the evidence base is to guide best practice in this disabling condition.

The grant of £91,000 will contribute towards the cost of treatment and care at Burrswood Hospital for one patient each month over a two year period. These patients will be given a 'Guild of Health' bursary.

The funding will also support qualitative research into the outcomes achieved. This work will be overseen by the University of Kent. The information obtained will further inform clinicians on helpful therapeutic approaches for many people with this condition.

Burrswood has a long track record in caring for people with CFS/ME and has frequently seen people returned to health again. One young woman, a former solicitor, told her story of being brought back to a near normal life after years of a "twilight existence". She is convinced that Burrswood's approach through Christian ministry, medical treatment, experienced nursing, empowering physiotherapy and emotional support will offer hope and healing to many. Her written account is a work in progress.

For more information tel 01892 863637. www.burrswood.org.uk Burrswood Hospital, Groombridge, Tunbridge Wells, Kent, TN29PY.

Gone but not forgotten

Enid Brewer was born, Enid Mair Haskins in April 1936 at Gelli. She went to Tonypany Grammar School where she gained five 'O' Levels, and also at this time she met her future husband Bryan. She had a couple of jobs before finding her niche with Rhondda Further Education Office in Pentre. After she and Bryan married, they had three children, Phillip, Jeanette and Tony. Enid went back to work at the Rhondda Teachers Centre after each one had started school. She worked there until she retired from the job she loved in 1989 through ill health.

Enid was a devoted Wife to Bryan (as he proved to be to her) She was always full of praise for the way he supported her. She was a loving Mother and Grandmother, ever proud of her offspring.

A very warm, caring person - a words person was Enid . Always writing little verses on Birthdays and anniversaries etc. She would always be thinking of ways to bring comfort and encouragement to others, despite her illness and all the times she spent in hospital. Enid would never miss a birthday or a celebration, and Bryan would be sent to get the card with the best verse!

Enid suffered with M E and other illness for a good many years, but it never stopped her interest and concern for others, and it was always a joy to chat to her -

You always felt better afterwards.

Sadly, Enid contracted cancer for the third time in May this year, and died at home on 24th July 2011, at Mill Street, Ystrad, where she had lived for fifty years. She was one of the loveliest people I have ever known, and she will be sadly missed by us all.

Bryan very generously collected donations from his family and friends, for our M E Group, and to date he has sent us £320 for which we warmly thank him.

Sandville Self Help Centre



Sandville self help centre is open to all people suffering difficulties. We offer help in a very relaxed and happy atmosphere. Sandville Offers You a People Centered Service

There is no advanced booking system. Therapies are organised on the day according to availability. Therapies include Reflexology, Reiki, Bowen to name a few. There is no charge, just donations.

- Social and Psychological
- Care for Patients and Families

- Overnight Facilities Available on Request
- Therapies
- Social Activities
- Information and Support
- Continuing education e.g. Seminars and Workshops
- Placements for Schools, Collages and Nursing

One of the therapists Margaret, will be attending MESIG support group meeting on 6th February in Ararat Centre for the community 2.30-4pm. Margaret is a Bowen practitioner among many other strings to her bow.

For as long as she can remember Margaret has favoured natural health where at all possible and fortunately was lucky enough to have forward thinking doctors who understood her logic.

When in 2004 she sought Holistic therapies for the relief of pain and low energy she tried The Bowen Technique and was so impressed she took a domestic course in the treatment of others. In the

production of her case study results she was so hooked that she immediately enrolled for the professional course where she qualified with the European College of Bowen Studies in 2005 and the following year qualified in Anatomy and Physiology.

To date she has qualified in twelve remedial treatments that work on both the physical and emotional levels including becoming an Usui /Tibetan Reiki Master Teacher and taking a teaching qualification to teach a selection of her therapies.

Margarets work includes charity work with Sandville Self Help Centre in Porthcawl where she provides Bowen every other week, and work in Bosnia for two weeks every year to treat rape and war victims, and to treat our own returning service men.

**Sandville Court, Ton Kenfig,
Bridgend, CF33 4PU
Tel.01656743344
www.sandville.org.k**

The Wonders of Bowen

The Bowen Technique is not massage, acupressure or chiropractic. There is no manipulation, adjustment or force used. The practitioner uses thumbs and fingers to gently move muscles and tissues. In between each set of moves, the practitioner will break off for short periods. These pauses and the gentleness of the treatment are what makes Bowen unique.

Bowen Therapy stimulates circulation of energy and clears energetic blocks. Coincidentally, several of the moves are located along acupuncture meridians or on specific acupuncture points which are known to stimulate and balance the body's energy. It offers rapid, lasting relief from pain and discomfort, and most conditions respond within two or three treatments.

I first heard about the Bowen Technique from a friend. I had bumped into Sue in the supermarket and when I complained about the arthritis in my joints to the point where it was painful to walk, she proceeded to explain that Bowen kept her on her feet. It helped with the pain and discomfort and also the flexibility in the joints, and she made me promise to contact her Bowen Therapist.

I did, and had an appointment for the following week. The treatment was so gentle that I wondered how effective it was going to be. But indeed, after three sessions, I was walking quite normally, and out of pain. It was wonderful!

On another occasion I had strong pain in my left shoulder and could not lift my arm. There were so many things I couldn't do. Housework or dressing myself, and I couldn't do my hair. So I rang for an appointment with my Bowen Lady and after one session I was able to lift my arm right above my head without restriction or pain. Magic!

Article by Dee Penny

The Art of A poet.

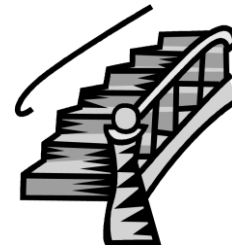
We are delighted to share news of one of our members' latest achievements.

Jill Berrett recently took part in an event called 'a 100,000 poets for change' which took place simultaneously in 95 countries. The Welsh event was held in 'Shot in the Dark' where she read her own work of a monologue and poem. The theme was 'Doors of Perception'. All performers were streamed live on the internet. One of the poems she read was called 'Borders' and was written during and about an M.E relapse and Jill introduced it from this point of view. She had a good response from people talking about M.E.. Jill also took part in an interview on Saturday 22nd October with a woman from Creative Cardiff the content of which focused on having M.E and writing, as part of 'Room to Read'; an event during the Made in Roath Arts Festival. This interview has been detailed on the Creative Cardiff website and features the poem 'Borders'. We are delighted to be able to share that work with you.

Borders

*Cocooned in soft welsh wool I lie.
Sore muscles soothed
This bed a home
My velux delineated view
a slideshow of fluffy clouds
moving past, moving past
And in front glistening on the mirrored glass
a parade of powder, perfume, purple beads,
the accoutrements for going out
But beyond the door
a flight of stairs
my personal everest
my territorial border
my lawful constraint
And I think of the man from Darfur*

*I heard his voice this morning beside my bed
Could hear his spitting fire
he sat beside, on the edge of Europe
minus 5 degrees and the police ready
to extinguish, freeze out hope.
And all he wants is England
England to die for.
England where I was born
not knowing that I could lose along the way
the power to climb upstairs to bed
run after the wayward 45 bus
play ball on Whitesands beach
And still have everything.
Cry, cry for the pain in all our hearts*



Congratulations Jill and thank you for sharing this with us!

Dates for your Diary's



DEC 5TH- Christmas Party

JAN 9TH - Ben from speakeasy advice centre will be attending our meeting to give a 10 minute talk about help with fuel costs. (Especially important for British Gas customers struggling financially).

Energy Advice Project:T: 07896959422

Speakeasy Advice Centre, 166 Richmond Road, Cardiff, CF24 3BX

FEB 6TH- Guest speaker Margaret, Bowen Therapy

MARCH 5TH- Art Workshop (Will involve colour therapy and be hands on).

Confirmation of Date of attendance from Julie Morgan, Assembly member to follow.

M.E.S.I.G 2012 Calendars



In an effort to raise awareness of M.E we are hoping to publish a calendar for 2012 and as a contribution we are again asking members to forward any photo's or images they have that they feel depict what it's like to live with M.E. You may also like to include a little anecdote, caption or phrase to go with it. The best ones will be selected for inclusion in the calendar and there will be £10 high street voucher for winner of January entry chosen. Please submit all entries by 10th December by email or post to either Chris or Gemma.

M.E Survey

We encourage members to log onto www.cfs-survey.net and complete a survey about living with ME to aid research. Dr Hugo Van Woerden aims to develop blood test for ME and needs our help!

How to beat chronic fatigue... by learning to hold your breath

22nd October 2011 in Mail

When your health deteriorates for no obvious reason it can be a very nerve-racking business. This is what happened to me, 18 months ago, quite unexpectedly.

It started with one of those random viruses that knocks you sideways for a day. But recovery never came.

Where once I was swimming, running, working out or playing tennis every day, now I couldn't summon up the energy to play-fight my daughter after school.

My strength and stamina had gone. I had a persistent cough and worried it was heart trouble or cancer. After a year, and countless tests and scans, no cause was apparent. Possibly it was chronic fatigue syndrome (ME), but my GP couldn't say. There was nothing he could do for me, unless I fancied anti-depressants. I'm not going to bore you with details of everything I tried that didn't work (including antibiotics, homeopathy, and diets), just about the one that did – Buteyko.

It sounds like a Japanese martial art but it's a special breathing technique named after the man who invented it in the Soviet Union in the 1950s, a Ukrainian doctor called Konstantin Buteyko.

Medical students have long known that carbon dioxide (CO₂) plays a vital part in releasing oxygen from the blood to cells and tissue – the Bohr effect. Buteyko took this further by postulating that most of the chronic medical conditions of our modern age – from asthma to lupus and Crohn's disease – are the result of a deficiency in our body of CO₂, caused by not breathing correctly, in a panicky way, so you take in too much oxygen.

On the face of it, this sounds a barking idea. All I can say with certainty is that his method worked in the Soviet Union (where it was popular with the elite of cosmonauts, KGB officers and athletes) and, since it came to the West, it has acquired a very loyal following here too.

In the early stages, you need intensive hands-on help of this kind, first to give you the will to keep going, and to explain all the ghastly side-effects. You feel as if you're developing flu; you feel feverish, depressed; you get headaches,

nausea, violent mood swings and once I found a blister on the roof of my mouth that vanished as mysteriously as it had arrived.

It is also by far the most gruellingly horrible health therapy I have ever tried. The exercises are easy enough to master. Take a normal breath in, then out, hold your nose and time on a stopwatch how long it takes before you need to take another breath. That's your Control Pause. Then wait three minutes and do it again, only this time keep holding your breath for as long as you can. That's your Maximum Pause. Try it now and see how well you do. If you're in good shape your Control Pause should be at least 30 seconds, though the average is just 17 seconds.

The Buteyko method aims to get you up to a Control Pause of around 60 seconds and a Maximum Pause of around two minutes, which is nearly where I am now. But boy was it hard work getting there.

It's essential to have a good Buteyko teacher, like the inspirational Christopher Drake, who trained me (mainly on Skype from his home in Bangkok).

Read more: <http://www.dailymail.co.uk/health/article-2052234/Buteyko-breathing-technique-I-beat-chronic-fatigue-learning-hold-breath.html#ixzz1c0OSaRYp>

Chris of MESIG would be interested to hear from anyone who has tried the Buteyko method. Chris recently looked into this for herself as due to symptoms of fainting and heart racing attacks, she went to Breakspear in Hemel Hempstead. Here a test determined that her co2 levels were dropping on any exertion and as a reaction to chemicals and allergens. Any information or experience with Buteyko, Breakspear hospital, heart racing issues or ways around chemical sensitivities would be appreciated. Chris did find a woman called Martha who has recovered from ME with the Buteyko method and is now a practitioner. This did take Martha 10 months and wasn't cheap. Martha can be contacted on 02072911733, www.learnbuteyko.co.uk.

Please note MESIG are not recommending these methods but just keeping you informed.

Action For ME AGM and Conference 22.10.11 in London

- Peter Spencer was told by Prof Harrington who is reviewing the Work Capability Assessment that 2013 is the earliest time that it will be changed to allow for fluctuating conditions.
- Sue Owen a very senior official in DWP (Director General, Welfare and Wellbeing), emphasised that the Atos professional who interviews applicants for ESA does not make the final decision. The DWP Decision-maker assigned the case is the person who does that after phoning the claimant. This phone call is the claimant's opportunity to present evidence from GP, consultant etc
- Sue Owen said that Harrington's 2nd review is due end November and will report on fluctuating conditions and the WCA (but see 1st bullet point above)
- Dr Charles Shepherd gave his opinion that Decision-makers should find evidence themselves - the onus to do so should not be on the ME sufferer. Peter Spencer said that Harrington is looking at this as GPs can charge to provide evidence for DWP, which is an unfair burden for the claimant.
- A member said that people with chronic conditions for which they receive medical treatment may well be able to be helped back into work, but as there is no medical treatment for ME, that should be taken into consideration. Sue Owen said that Harrington is aware of this cause for concern and is looking at it.
- Sue Owen said that Universal Credit will allow very short hours of work without penalty. If a fluctuating condition makes someone drop in and out of work and pay, Universal Credit will kick in on the months of non-work.
- Sue Owen: DLA will be replaced by Personal Independence Payment from 2013 until everyone is migrated to PIP by 2015-6. PIP will consider someone's ability to carry out everyday activities, rather than their health condition or impairment. It will remain non-taxable, not means-tested, for those in employment too.
- Dr Shepherd said that Postmortem Tissue Bank is more or less on hold due to lack of resources (time etc) to do the necessary complicated planning.
- Biobank for blood samples is going well - may be a call for donors in the future, not yet as have identified donors for the start up phase already.

I asked a question during the Q&A for Esther Crawley's talk on the National Outcomes Database. My question was about Wales and asking all those present - especially the researchers giving presentations - not to forget us as my impression from the conference was that we are being left behind. I told conference that we have no ME services, which means that we are outside their data sets - we don't get counted or put forward for research etc. Esther Crawley said that as a doctor based in Bristol she has challenged the Welsh Government on their lack of ME services and been told that Wales DOES have ME services. She is hoping to do the National Outcomes Database and then go back to the WG and convince them that it IS cost-effective to provide a ME service (she mentioned she had offered to provide children's clinics in South Wales, but WG turned the offer down). My understanding from a contact who worked in WG is that WG sees ME people as adequately catered for in the Expert Patient programme. The residential course at Bronllys to do with learning how to manage chronic pain is similar to or allied to that programme.

60 people had signed up to attend the AGM, but far fewer actually attended. Maybe 80 people came to the conference, plenty of whom asked questions. It was a very well-organised event and very interesting. I think AfME is working very hard to help us all.

Members of MESIG committee were unable to attend this year despite booking 2 places but a member very kindly wrote the above report for us as they had attended. MESIG are extremely grateful, it is wonderful that individuals are coming forward and offering their support. Many thanks Sue.

Further information about the conference plus agenda can be found on www.actionforme.org.uk

So what are the answers?

Here are the answer to the puzzles and riddles identified on pages 4 and 5. Did you get the answers correct?

Page 4

The more I am the less you see....strange result, what can I be?

Ans: I am **darkness**

I can only be kept if I'm given first.

Ans: I am a **promise**

I'm neither here nor there, an in-between place...bend backwards under bars, I'm a dance with pace.

Ans: **Limbo**



Vacant Committee Positions

Should you wish to offer your services as part of the MESIG committee then please contact Chris or Gemma for further information. All applications are welcome and you can be sure of a warm and friendly reception.

We currently have 2 vacant posts as well as general committee positions available. These include, Political Liaison Officer and Newsletter Editor, a position which is currently being shared by Chris and Gemma. The post descriptions are detailed below.

Political Liaison Officer

The Political Liaison Officer is responsible for all general political communication with other organisations, health authorities and the government. The duties in relation to this are as follows:

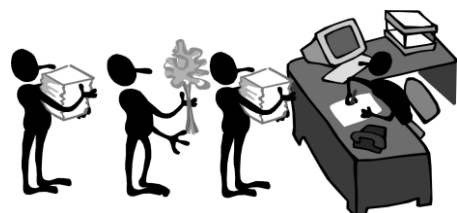
- Discuss any correspondence received with the Chair and other committee members if necessary
- Draft all political correspondence for committee approval and forward it to the necessary recipient
- The organisation, design and presentation of PowerPoint presentation
- Establish supportive parties and Liaise with them on a regular basis
- To endeavour to keep up to date with the latest progress for services and legislation for ME sufferers.
- To be pro active in requesting these services and highlighting lack of services/support/understanding.
- To be looking at ways to engage media to improve services and raise awareness through newspapers/radio/tv.
- To seek to arrange meetings with all who will listen in order to educate in a friendly informative and non-threatening way.
- To liaise with other ME organisations and form contacts in order to make more noise in numbers, striving for unity where possible.



Newsletter Editor

The newsletter editor is solely responsible for the production and distribution of the twice annual newsletter and under this category becomes responsible for:

- Providing a copy of the newsletter for all members in May and November
- Liaising with the Membership Secretary, Secretary and Chair concerning the articles that are to be printed to ensure all relevant information is included
- Ensuring the Newsletter is produced in accordance with all policies and procedures
- To manage the Newsletter subgroup and delegate work fairly
- To provide support for all members of the subgroup
- To source facts and information
- To get involved with advertising, design and merchandising in regard to other projects between the inactive months of newsletter production



ME/CFS Information

How does ME/CFS start?

ME/CFS is often reported as having started with a virus or other infection, commonly involving the chest or stomach. However, it can also develop after an accident, operation, vaccination, exposure to crop sprays or sheep dip, or other shock to the system. Alternatively, it may creep on very gradually. The causes of ME/CFS are still unknown.

What distinguishes ME/CFS from other chronic illnesses?

By far the most widely reported characteristics of the illness, which distinguishes it from other chronic conditions, is exhaustion and malaise following physical or mental activity, the full extent of which becomes apparent only 24 to 48 hours after activity. Recovery from this flare-up of symptoms may be prolonged—days, weeks or even months. Rapid fluctuation of symptoms is a second key indicator.

What are the other main symptoms?

Abnormal muscle fatigue following activity. Muscle pain and muscle twitching. Sometimes with eyelid tic or twitch. Failures in attention span, short term memory and concentration.

Other cognitive problems such as tendency to lose track of conversation in the middle of sentences, along with difficulty thinking of the correct word when speaking or writing and difficulty putting ideas into order.

Constantly feeling unwell, with 'flu-like' symptoms (e.g. sore throat, enlarged glands, joint pains) and problems with temperature control and night sweats.

Other symptoms may include:

Sleep disturbance, especially waking unrefreshed. The disturbance can include sleeping for long periods, perhaps 12 to 18 hours at a stretch, inability to get to sleep, sleeping during the day while staying awake at night, dreams (sometimes nightmares) particularly memorable by their vivid colour.

Pain in one or more joints, but with no signs of swelling, redness or joint deformity.

Feelings of unsteadiness, when walking or standing. Some people report feeling as though they are 'walking on rubber'.

Sudden, unexplained mood swings.

Headaches of a new type, pattern or severity.

Sensations of tingling or numbness, loss of sense of touch.

Over-sensitivity to noise and/or light.

Alcohol intolerance, particularly in the early stages of the illness, and onset of food intolerances.

Is there a diagnostic test or a cure for ME/CFS?

No, to both. The diagnosis has to be made from the typical pattern of symptoms, with the exclusion of other possible causes. Anyone suspected of having ME/CFS should have a number of routine blood tests to identify other possible illnesses, and have more specialized investigations if the diagnosis remains in doubt.

What are the chances of recovery?

People with ME tend to fall into one of three groups:

People who manage to return completely to normal health, but this may take considerable time. The percentage of people falling into this category is fairly small. The majority, tend to follow a fluctuating pattern with both good and bad periods of health. Relapses or flare-ups are often triggered by infections, operations, temperature extremes or stressful events.

A significant minority remain severely affected and will require a great deal of practical and social support. Continued deterioration is unusual. When this occurs, a detailed medical assessment is advised to exclude other conditions.

How can recovery be helped?

It is important to remain positive about the prospect of recovery. The period of illness varies from person to person and improvements in health can occur, even in people who have been ill for a long time.

Anecdotal reports suggest two things which improve prospects for recovery. They are:

Taking control early on in the illness (in particular not trying to ignore the symptoms in the hope they'll go away).

Youth-younger people seem to make a better recovery than adults.

Sudden improvement and sustained recovery

Fluctuation in symptoms may lull you into a false sense of security, so do not be tempted to do too much if you suddenly feel better for a short while. Sustained recovery is preferable to a roller-coaster ride of inappropriate activity and relapse.

If recovery slows or stops

Experience suggests a large proportion of people make a degree of recovery but then reach a point where the rate slows dramatically, becomes sporadic or even stops. We do not know the reason for this. Some doctors suggest this happens because the person develops an incorrect understanding of the illness and so rehabilitation therapy is offered.

Relapses

Relapses are a feature of ME/CFS and may occur through a variety of circumstances: exposure to other illness, sustained physical or mental activity unsuited to a person's capacity at the time, incompatible treatments and therapies, emotional stress, vaccinations, anaesthetics etc. So it may make sense to limit exposure to these situations, except where the consequences of doing so could make matters worse.



Contact and Support

ME Association

7 Apollo Office Court,
Radclive Road,
Gawcott,
Buckinghamshire
MK18 4DF

Tel: 01280 827070 10am - 3.30pm

Email: meconnect@meassociation.org.uk

Website : www.meassociation.org.uk

ME Connect

Helpline 08445765326

10am-12pm, 2pm-4pm, 7pm-9pm weekdays



25% ME Group

21 Church Street
Troon
Ayrshire
KA10 6HT

Tel: Office 01292 318611

Advocacy line: 01292 312369

Website: www.25megroup.org

MCS Matters

(Multiple Chemical Sensitivity)

Gordon D McHenry
UK Co-ordinator

Global Campaign for recognition of MCS

Tel Helpline: 01446 794 700

Tues & Thurs 2 –4 and 6 –7pm (manned when able)

STIFF (UK)

PO Box 1484
Newcastle-under-Lyme
Staffordshire
ST5 7UZ

Tel: 01782 562366

BRAME

30 Winner Avenue
Winterton-on-Sea
Great Yarmouth
Norfolk
NR29 4BA
UK

Tel/Fax: 01493 393717 **E-Mail:** info@brame.org

Action for M.E.

PO Box 2778
Bristol
BS1 9DJ

Membership/general: 0845 123 2380 / 0117 9279551

Mon - Fri: 9.30am - 5pm

Telephone support: 0845 123 2314

Mon - Fri: 11am - 3pm

Welfare rights helpline: 0845 122

8648 (Membership only service)

Monday: 1pm - 5pm

Tuesday: 9.30am - 12.30pm & 3.15pm - 6.45pm

Wednesday: 1.30pm - 4.30pm

Thursday: 9.30am - 1pm

Friday: Closed

Email: admin@afme.org.uk **Website:**

www.afme.org.uk



National ME Centre

Disablement Services Centre.
Harold Wood Hospital
Gubbins Lane
Harold Wood
Romford
Essex
RM3 0BE

Tel: 01708 378050 **Website :** www.nmec.org.uk

Contact and Support continued

Fibromyalgia Association

PO Box 206
Stourbridge
West Midlands
DY9 8YL

Helpline:

Tel: 0844 887 2444 (10am - 4pm Mon - Fri)

Email: fmauk@hotmail.com



Welsh Association of ME & CFS Support (WAMES)

Tel: 029 20515061

Email: enquiries@wames.org.uk

Website: www.wames.org.uk

C.L.I.P.-

Coping and Living in Pain, support group.

Tel: Richard Goss, 01443 757378

Gloria Edmunds, 029 20530593

Steve Sweetman, 02920214339

Email: pain.help@ntlworld.com

Association of Young People With ME (AYME)

10 Vermont Place
Tongwell
Milton Keynes
MK15 8JA

Email: info@ayme.org.uk

Tel: 08451 23 23 89

10am-2pm Mon-Fri

Website: www.ayme.org.uk

The Young ME Sufferers Trust

PO Box 4347

Stock

Ingatstone

CM4 9TE

Tel: 0845 003 9002

(best between 11 –1 and 5—7pm weekdays)

Website: www.tymestrust.org

A 4 ME

Third Floor

Canningford House

38 Victoria Street

Bristol

BS1 6BY

Tel: Lo-call 0845 123 2380 or 0117 927 9551

Fax: 0117 9279552

Email: admin@afme.org.uk

Website: <http://www.a4me.org.uk>

Welsh Association of ME & CFS Support (WAMES Young People)

Michelle Penny

Tel: 029 20515061

Email: michelle@wames.org.uk

Website: www.wames.org.uk

(Carers—same as above but contact Sylvia Penny—same tel no.

Email: Sylvia@wames.org.uk)



Contact and Support continued

Travel

National Rail Enquiries

Tel: 0845 748 4950

Disabled assistance

Advance notice is required by the train operator.

Bus and Coach:

National Express

Tel: 0870 580 8080

Travel Line

Tel : 0870 608 2608

VEST: for help with local lifts and transport for the disabled - Ring 029 20490325 and ask for an information pack.

Carers Line

Tel: 0808 808 7777

The Samaritans

24 hour confidential and emotional support helpline and email service for anyone in crisis.

Tel: 0845 90 90 90

Email: Jo@samaritans.org

Useful Websites

www.mererearch.org.uk

www.butyoudontlooksick.com/the-spoon-theory

www.nice.org.uk

www.entitled.co.uk

www.benefitsandwork.co.uk

Benefits advice and Support

If you are having problems with your benefits, need some advice or your benefit entitlement checked, you might like to get in touch with one of the three listed below.

The Law Centre

41-42 Clifton Street

Adamsdown

Cardiff

TEL: 029 20498117

Drop in: Monday, Wednesday, Friday
10-12.30

Tuesday, Thursday 2-4.30

Phone advice: Monday and Thursday

Speakeasy Advice Centre

166 Richmond Road

Cardiff, CF24 3BX

TEL: 029 20453111

Riverside Advice

41a Lower Cathedral Road.

Cardiff

TEL: 029 20341577

Useful Telephone Numbers

A range of useful information leaflets can be obtained from any of the groups.

Benefits:

Citizens Advice Bureau

Tel: See telephone directory for nearest office

Website: www.citizensadvice.org.uk

Dial UK (Disability Information and Advice Line services)

Tel: 01302 310 123

Website: www.dialuk.info/index.asp

Benefits Helpline

Tel: 0800 88 22 00

Social Care:

Assessment Centre

Will help with occupational therapy and evaluations

Tel: 029 2052 0984

Occupational Therapy:

Tel: 029 2076 7404

M.E.S.I.G Committee Members

Gemma Phillips

(Chair, Newsletter Co-editor and Website Facilitator)

Tel: 07542 526831

Email: gemmaphillips47@yahoo.co.uk

(Please only telephone me between 2pm and 4pm on Mondays and Wednesdays. Email welcome anytime)

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Ken Bailey

(Vice Chair)

Tel: 07825702171

Email: kenbailey@talktalk.net

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Chris Davies

(Membership secretary and Newsletter Co-Editor)

75 Llanon Road

Llanishen

Cardiff

CF14 5AH

Tel: 029 20762347

Email: christallaconstantinou@talktalk.net

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Dee Penny

(Treasurer)

Tel: 02920842499

Email: deirdrepenny@yahoo.co.uk

Please send us anything you wish us to submit in next newsletter: poem, recipe, personal story, question etc.

or email

christallaconstantinou@talktalk.net

gemmaphillips47@yahoo.co.uk



M.E.S.I.G (M.E. Support In Glamorgan)

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www.mesupportinglamorgan.co.uk

Disclaimer: The views expressed in this newsletter are not necessarily those of the editor or The Glamorgan Group. Individuals may express opinions—We do not recommend any particular treatments.