

Nov 2014,

Issue 25

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



### Monday 1<sup>st</sup> December

2 - 4.30pm

### Bethel Church

Llangrannog Road, Llanishen, Cardiff, CF14 5BL

All welcome, members, friends, family, carers, partners. Please contact us to let us know you are coming or if you need a lift.

Email: mesigwales@gmail.com

Tel: 029 20762 347 Text: 07825 641 970

**Bran Tub** \*Please bring a gift up to £5 wrapped which goes in a box and we exchange gifts.

There will be food provided.

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# MESiG on Cardiff Radio



6th May 2014

It was the request that one either dreads or embraces:

"Miriam, would you do an interview on the radio about M.E.?"

The immediate question was, "Why me?" But I suppose it was obvious, as I have the ominous title:

Political Liaison Officer.

But no! It was the result of a slip-up by the Station about the day and date that Radio Cardiff had offered us to speak about M.E. Week. Fortunately it was recognised in the nick of time by Christalla but meant that she'd be out of town on the day of the programme and unable to do it herself. Another brave person was needed!

I was very happy when Dee agreed to come to the studio with me. I'd never visited Radio Cardiff before and their location is well hidden. Despite experience in radio and TV, I was fearful of addressing the subject, lest the interviewer ask for difficult medical or technical information. I also knew that I couldn't get through without having to pronounce Myalgic Encephalomyelitis at least once! It's quite a mouthful under pressure but Dee was happy to say it for me. Thank you Dee!



The interview went really well and I expect some of you heard Dee and I live, or listened to the recording. The two friendly interviewers put us at ease. The four of us enjoyed a relaxed chat that covered many aspects of M.E. including possible causes, various symptoms, the lack of understanding of the illness, caring for those with the condition, no Specialist help, the isolation and frustration of people with M.E. and their Carers. We were able to advertise the showing of the M.E. film, 'Voices from the Shadows' at Penarth Pier and the Awareness Day at the Heath Hospital during M.E. week.

It seemed that it was a well balanced presentation. We only came off the rails once, when we were suddenly asked about an event during M.E. Week, of which we were unaware. Both Dee and I were confused but bluffed our way through by talking about a presentation that Dee had made in a Cardiff M.E. event at City Temple. It was only after the interview that I found the website that the interviewer had presumably read and a National event by an M.E. organisation to which he was referring!

Overall, it was a good experience and we discovered that the people at Radio Cardiff are well aware of M.E. and that one of the people who works there has the condition. This seems to be fairly common to most of us, doesn't it? When the subject is raised someone will say,

"Yes, I know how difficult M.E. is because..." and they then proceed to tell the story of a family member, friend, neighbour or work colleague who has the condition, often for many years.

MESiG have been on Cardiff Radio for two years running and would like to thank Cardiff Radio for having us on the show.

#### **Review by Miriam Wood**

# The Hummingbirds' Foundation for M.E

### What is known about Myalgic Encephalomyelitis so far?



There is an abundance of research which shows that M.E. is an organic illness which can have profound effects on many bodily systems. These are well-documented, scientifically sound explanations for why patients are bedridden, profoundly intellectually impaired, unable to maintain an upright posture and so on. More than a thousand good articles now support the basic premises of M.E. Autopsies have also confirmed such reports of bodily damage and infection (Hooper & Williams 2005a).

## Many different organic abnormalities have been found in M.E. patients (in peer reviewed research). Patient advocates Margaret Williams and Eileen Marshall explain that:

- ♦ There is evidence of disrupted biology at cell membrane level
- ♦ There is evidence of abnormal brain metabolism
- ♦ There is evidence of widespread cerebral hypoperfusion
- ♦ There is evidence of central nervous system immune dysfunction
- ♦ There is evidence of central nervous system inflammation and demyelination
- There is evidence of hypomyelination
- ♦ There is evidence that Myalgic Encephalomyelitis is a complex, serious multi-system autoimmune disorder (in Belgium, the disorder has now been placed between multiple sclerosis and Lupus)
- ♦ There is evidence of significant neutrophil apoptosis
- ♦ There is evidence that the immune system is chronically activated (eg. the CD4:CD8 ratio may be grossly elevated)
- ♦ There is evidence that natural killer (NK) cell activity is impaired (ie. diminished)
- ♦ There is evidence that the vascular biology is abnormal, with disrupted endothelial function
- ♦ There is novel evidence of significantly elevated levels of isoprostanes
- There is evidence of cardiac insufficiency and that patients are in a form of cardiac failure (which is exacerbated by even trivial levels of physical activity, cognitive activity and orthostatic stress)
- There is evidence of autonomic dysfunction (especially thermodysregulation; frequency of micturition with nocturia; labile blood pressure; pooling of blood in the lower limbs; reduced blood volume (with orthostatic tachycardia and orthostatic hypotension. Findings of a circulating blood volume of only 75% of expected are common, and in some patients the level is only 50% of expected.)
- ♦ There is evidence of respiratory dysfunction, with reduced lung function in all parameters tested
- ♦ There is evidence of neuroendocrine dysfunction (notably HPA axis dysfunction)

- ♦ There is evidence of recovery rates for oxygen saturation that are 60% lower than those in normal controls
- ♦ There is evidence of delayed recovery of muscles after exercise. (Affecting all muscles including the heart.)
- ♦ There is evidence of a sensitive marker of muscle inflammation
- ♦ There is evidence that the size of the adrenal glands is reduced by 50%, with reduced cortisol levels
- ♦ There is evidence of at least 35 abnormal genes, (these are acquired genetic changes, not hereditary), specifically those that are important in metabolism;
- ♦ There are more abnormal genes in Myalgic Encephalomyelitis than there are in cancer
- ♦ There is evidence of serious cognitive impairment. (Worse than occurs in AIDS dementia)
- ♦ There is evidence of adverse reactions to medicinal drugs, especially those acting on the CNS
- ♦ There is evidence that symptoms fluctuate markedly from day to day and even from hour to hour (2006, [Online])

(Note that this is only a sample of some of the research available, not an exhaustive list.)

#### It is known that Myalgic Encephalomyelitis is:

- 1. An acute onset (biphasic) epidemic or endemic infectious disease process
- 2. An autoimmune disease (with similarities to Lupus)
- 3. An infectious neurological disease, affecting adults and children
- 4. A disease which involves significant (and at times profound) cognitive impairment/ dysfunction
- 5. A persistent viral infection (most likely due to an enterovirus; the same type of virus which causes poliomyelitis and post-polio syndrome)
- 6. A diffuse and measurable injury to the vascular system of the central nervous system (the brain)
- 7. A central nervous system (CNS) disease (with similarities to MS)
- 8. A variable (but always, serious) diffuse (acquired) brain injury
- 9. A systemic illness (associated with organ pathology; particularly cardiac)
- 10. A vascular disease
- 11. A cardiovascular disease
- 12. A type of cardiac insufficiency
- 13. A mitochondrial disease

- 14. A metabolic disorder
- 15. A musculo-skeletal disorder
- 16. A neuroendocrine disease
- 17. A seizure disorder
- 18. A sleep disorder
- 19. A gastrointestinal disorder
- 20. A respiratory disorder
- 21. An allergic disorder
- 22. A pain disorder
- 23. A life-altering disease
- 24. A chronic or lifelong disease associated with a high level of disability
- 25. An unstable disease; from one hour/day/ week or month to the next
- 26. A potentially progressive or fatal disease (Hyde 2007, [Online]) (Hooper et al. 2001, [Online]) (Cheney 2007, [video recording]) (Ramsay 1986, [Online])

Myalgic Encephalomyelitis affects every cell in the body



## <u>Is there a legitimate scientific debate about</u> whether or not M.E. is a 'real' medical condition?

Despite popular opinion, there simply is no legitimate scientifically motivated debate about whether or not M.E. is a 'real' illness or not or has a biological basis. The psychological or behavioural theories of M.E. are no more scientifically viable than are the theories of a 'flat earth.' They are pure fiction.

#### Similar Medical Conditions?

There are a number of post-viral fatigue states or syndromes which may follow common infections such as mononucleosis/glandular fever, hepatitis, Q fever, Ross river virus and so on. M.E. is an entirely different condition to these self-limiting fatigue syndromes however (and is not caused by the Epstein Barr virus or any of the herpes or hepatitis viruses). People suffering with any of these post-viral fatigue syndromes do not have M.E.

More information can be found on http://www.hfme.org

# MESiG raising awareness at Heath Hospital Concourse

### Tuesday 13th May 2014

Urban myths are rudely infamous and their notoriety knows no bounds. For instance, one such myth claims that if you stand underneath the statue of Eros in London's Piccadilly Circus for long enough, eventually some body you know will walk by. Such logic escapes me - how long do you have to wait? But proving (or disproving) these myths are best left to experts. That not withstanding, I recently ventured forth into that busy crossroads of humanity, also known as the Concourse at the University Hospital Wales. Given its vast volume of daily visitors, I wondered if any one known to me would ultimately walk past.



For anyone who has never visited this medical hub, or has not done so recently, I can confirm that nothing has adversely influenced with its primary function since the discovery of penicillin. Paradoxically, it's more than an information and focal point. People arrive, loiter and eventually leave; some stay longer, some are clearly ill and some are clearly joyful at leaving the area. People struggling hopelessly with crutches (along with the odd eye patch) lead you to believe that they would fit easily into a film set of 'Pirates of the Caribbean'. People in the 'state of the art' wheelchairs, people clutching helium filled "New Baby" balloons whilst some people are silently wrapped in their faraway thoughts. Limbs encased in pastel hues of plaster of Paris glide and shuffle by whilst the 'magazines under arm' brigade quickly climb stairs to where loved ones await. Whatever their reason, it's a noise filled caldron offering an opportunity for grabbing their attention away from their normal environment and routine.

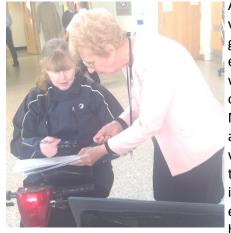
Receptionists' cheerfully relate information; bottle green ambulance personnel scuttle to and fro offering reassurance and guidance and efficiently barking official acknowledgements to colleagues into the bargain. Cash tills in the coffee and newspaper shops constantly announce that this is more than a cavern for receiving and distributing patients and visitors. Amongst other reasons, it's a meeting place where superfluous time waiting for you appointment is anxiously frittered away.

It serves as a rendezvous point where pyjama clad patients eagerly seize the opportunity of slipping away from the routine of hospital ward life to discuss the progress of the escape tunnel under the nurse's quarters. Call me old fashioned, but dressed in one's pyjamas in public is not natural and the thought of it leaves me feeling vulnerable and exposed to the stares and comments of those suitably attired for the occasion. Having said that, I understand that supermarket shopping in one's pyjamas is perfectly acceptable, indeed it's as normal as serving your Friday night dinner guests kippers topped with lashings of custard.



My mission, should I accept it, was to gather as many signatures to the MESiG petition as possible, but without any hint of coercion or favour. Biro pens poised, I tried to look intelligent and casual in equal measure. To the untrained eye, this look may have proved disconcerting. With a purposeful manner I launched myself at the unsuspecting gathering and thrust under their noses the clipboard on which the MESiG petition lay.

If I had any doubts relating to the collection of signatures for this worthy cause, they were quickly dispelled. Maybe it was the venue, or the impressive MESiG display boards, but either way, people were willing to sign without hesitation and freely enter into conversation relating to ME. Once the first batch of signatures were under our belts, we embarked on a campaign of visiting the refreshment tables confidently armed with the petition and Biro pens. This manoeuvre proved fruitful. However, such was our enthusiasm we did once or twice approach the same people!



At this point, I was hoping that my experiences would translate into a veritable catalogue of interesting people I had met during this signature gathering exercise. But sadly no, these people were just like us. They had everyday problems- usually associated with a medical malfunction or other, which is not surprising given the venue. Friends neighbours, family, friends of friends or work colleagues, most could relate to the issues surrounding ME. I did meet a couple who engaged in a lengthy conversation. I threw in an item which was broadcast on the television recently. This couple, who were probably in their mid to late 60's, looked at me and confessed that they did not own a television set. Now, it's not every day that you come into contact with someone who is not interested in watching that piece of ever evolving electronic gadgetry sitting in the corner of the room. I mean, how are they going to keep track of the English football team as they try to

make an impression on the World Cup in Brazil? Perhaps they knew all along that it could be a lost cause and why elongate and compound the misery?

Eventually my stint at name collecting came to a close. I handed over the baton to one of the MESiG committee members with a message of encouragement. As I walked away from the UHW Concourse I looked once more on the scene. I visualised it as an old varnished dance floor in its heyday. An era when girls sported stiletto heels and waist nipping skirts with masses of petticoats which proved more than a challenge when sitting down. Continental travel greatly influenced men's fashions in the late 1960's, but prior to this it was tweeds, white shirts, leather soled shoes and drab coloured ties. A time when people actually looked as though they were enjoying themselves, waltzing and weaving around but not wishing to enter into another's personal space. This day, coffee drinkers sat out the dances together with crossword solvers and fading wallflowers. Wheelchair pilots negotiated around guests and parked in the tiniest of spaces with everyone joining in and moving around and around in an unscripted formation dancing routine. All that was missing was a big band.

I squinted as I searched for someone I knew. Would you believe it, not one person was found. Perhaps a scale model of Eros could be erected in the UHW Concourse and by doing so, this urban myth could be put to bed, for once and for all.

#### **Review by Robert Goodman**

# Llanishen Fun Day

### 21st June 2014

Dee saw a notice that the Llanishen Police were to hold a "Fun Day" at the Llanishen Leisure Centre, and booked a couple of tables for us in the car park.

It started at mid-day with Chris and Ken in control, and lasted until about 3:30 pm. The weather, being fine and warm, contributed to the success of the day.

We had a very good Raffle, led by Daniel and Kath, name the bear (Cuddles) and a Lucky dip, run by Mary, which was very popular with the children. Dee's partner, Peter, with the help of a neighbour, Collin, made a base for the "stocks", which were borrowed from Llanishen Primary School (who knows what they are normally used for).





Dee also managed to buy a second hand Candy Floss machine, which was operated by Annette and Shade with Rob's help, and was a huge success, despite the loss of power for several minutes. The ladies found, at the end, that their clothes were stiff from the sugar strands.

Dennis and I were pleased to be able to persuade many people, all willingly, to sign the petition, which was on display. We found many of them knew of friends or family who were, or are, sufferers.

Thanks go out to all those concerned, who made the day a great success, raising £230 for MESIG

**Review by Mary Jones** 

## Candy Floss Machine available for Hire

Available to hire for Birthdays, Weddings, School Fetes, Halloween, Christmas

DAILY HIRE PRICE LIST:

£50 (Schools or Organisations)

£25 (House Parties, Celebrations

Pick up from Radyr, Cardiff. Please return as collected.

Please contact
Dee Penny on
07713752074



## The Gorilla In Your House

#### Published Thurs, April 10th, 2008

Acquiring a disability is a bit like getting home to find there's a gorilla in your house. You contact the approved and official channels to get rid of infestations of wild animals (in this case, the NHS) and they umm and aah and suck air in through their teeth before saying something roughly equivalent to "what you've got 'ere, mate, is a gorilla, and there ain't really a lot what we can do about them, see..." before sending you back home to the gorilla's waiting arms.

The gorilla in your house will cause problems in every part of your life. Your spouse may decide that (s)he can't deal with the gorilla, and leave. Your boss may get upset that you've brought the gorilla to work with you and it's disrupting your colleagues, who don't know how to deal with gorillas. You're arriving for work wearing a suit the gorilla has slept on. Some days you don't turn up at all because at the last minute, the gorilla has decided to barricade you into the bathroom or sit on you so you can't get out of bed. Your friends will get cheesed off because when you see them - which isn't often, because they don't want to come to your house for fear of the gorilla and the gorilla won't always let you out - your only topic of conversation is this darn gorilla and the devastation it is causing.

#### There are three major approaches to the gorilla in your house.

**One** is to ignore it and hope it goes away. This is unlikely to work. A 300-lb gorilla will sleep where he likes, and if that's on top of you, it *will* have an effect on you.

Another is to try and force the gorilla out, wrestling constantly with it, spending all your time fighting it. This is often a losing battle. Some choose to give all their money to people who will come and wave crystals at the gorilla, from a safe distance of course. This also tends to be a losing battle. However, every so often, one in a hundred gorillas will get bored and wander off. The crystal-wavers and gorilla-wrestlers will claim victory, and tell the media that it's a massive breakthrough in gorilla-control, and that the 99 other gorilla-wrestlers just aren't doing it right due to sloppy thinking or lack of commitment. The 99 other gorilla-wrestlers won't have the time or energy to argue.

I have known people spend the best years of their life and tens of thousands of pounds trying to force their gorillas to go away. The tragedy is that even if it does wander off for a while, they won't get their pre-gorilla lives back. They'll be older, skint, exhausted, and constantly afraid that the gorilla may well come back.

The third way to deal with the gorilla in your house is to accept it, tame it, and make it part of your life. Figure out a way to calm your gorilla down. Teach it how to sit still until you are able to take it places with you without it making a scene. Find out how to equip your home with gorilla-friendly furnishings and appliances.

Negotiate with your boss about ways to accommodate, or even make use of, your gorilla. Meet other people who live with gorillas and enjoy having something in common, and share gorilla-taming tips.

People get really upset about this and throw around accusations of "giving up" and "not even trying". They even suggest that you enjoy having a gorilla around because of the attention it gets you (while ignoring the massive pile of steaming gorilla-turds in your bedroom every morning and night, not to mention your weekly bill for bananas). The best way to deal with these people is to smile and remind yourself that one day, they too will have a gorilla in their house.

For more details visit http://batsgirl.blogspot.co.uk/2008/04/gorilla-in-your-house.html

# Tea In The Park

*10th August 2014* 





It is pleasing to say that this year the weather was fine and sunny, in total contrast to last year.

Eighteen members with family and friends were there, which included one new member.

It was rewarding to see four members, who have been unable to join us for some time due to poor health.

There was a lot of chatter and some useful tips that may be of help to some people.



I do not know how much tea was drunk but, together with coffee, cakes and wraps, it all went down a treat.

We thank all those who came and look forward to meeting everyone again next year.

**Review by Mary Jones** 

# MESiG Teleconference with Action For M.E

On 7<sup>th</sup> May 2014 Chris from MESiG spoke to Clare Ogden and Sonya Chowdhury from Action For ME by way of teleconference. Clare is Head of Communications and Policy and Sonya is the Chief Executive Officer.

The aim was to unite in moving forward to help people with M.E.

Action For ME have discussed the idea of a round table meeting with MESiG and Healthcare professionals in Wales. This is already in process in Scotland, Ireland etc.



MESiG will keep you updated.

#### **Review by Christalla Bailey**

# Book: A New ME

### **By Barry John Evans**

This book mainly focuses on my personal struggle with the illness M.E. so far. It focuses a lot on what my first year has been like since being diagnosed, the lead up to my diagnosis and my plans/thoughts for the future.

The aim of writing this book was first and foremost to raise more awareness for this terrible illness. It's also helped me personally to share my experiences and I genuinely hope that anyone who reads this can take something positive away from it.

#### Here's a brief overview of what's happened so far:

"I was born Barry John Evans on the 8th April 1991 making me aged 23 at the time of writing this book".

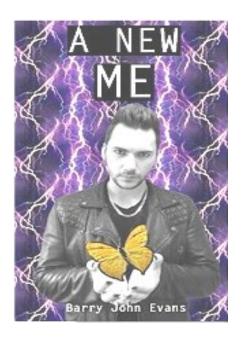
"I was born and raised in a little seaside town in the North West of England called Southport".

"I was diagnosed with Asperger Syndrome aged nine".

"I graduated from university in 2012 and also from a Personal Training academy".

"I was diagnosed with Myalgic Encephalomyelitis on the 10th January 2013".

"I have gone from mild to moderate in a short space of time and have since had to adapt my life to accommodate this".



This book takes you through my entire journey from when I was young right up to this present day sharing my personal struggles along the way. My experiences have made me into a stronger person today despite suffering with a chronic illness. "This is a new chapter in my life and "A New ME".

If you would like to order a copy, the book is available in all countries in paperback and also on kindle.

It can be purchased through Amazon.

Thank you for reading, keep on fighting!

One review says "It's a book for people with M.E but also a must read for people who aren't familiar with the illness"

"10% of sales made online from this book will be going to the charity Invest in ME"

https://www.youtube.com/watch?v=TIvc\_1SCKhI



# Temporo- Mandibular Joint Dysfunction and Atlas asymmetry



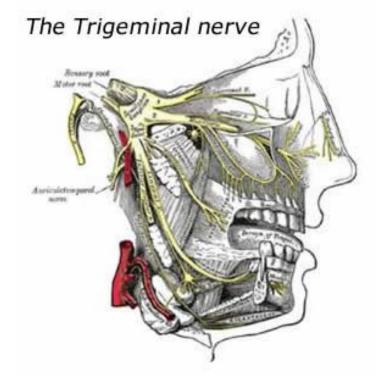
Are these the cause of many chronic illnesses?

While searching the internet recently, I came across an interesting article by a London **Dental Surgeon**, who specializes in medical problems eminating from **TMJ/Atlas** (misaligned Jaw and Atlas), including **ME/CFS.** Having spoken to two people who had suffered from M E who have recovered with this treatment, I decided to include it here.

Article written by:- Dr M Amir BDS MSc(U of London) LDS RCS (England) :-

"The reader must realize that patients are categorized into ME/CFS only after they have been completely debilitated. I feel that the whole concept has gone astray and a number of factors have conspired to create this new western illness. The illness has as much to do with the negligent treatment of the earliest symptoms symptomatically, either with drugs or Cognitive Behaviour Therapy (CBT), both of which suppress the underlying symptoms as the patient's health continues to deteriorate behind the scenes culminating in what is now called ME?CFS. My experience place the patients firmly in the realm of Temporo Mandibular Joint Dysfunction. A perfect smile if synonymous with good health. However, this is not always so. The slightest departure from ideal symmetry in the Cranio-facial complex can lead to severe health problems. This is a vast subject and cannot be adequately explained here. Suffice to say that if the patient's symptoms include tooth grinding, jaw clenching, neck and lower back pain it is imperative that the patient be examined for jaw asymmetries. Many Alternative practitioners do that by palpating the muscles around the lower jaw, mainly the pterygo-palatine muscle, which will always be very painful in ME/CFS patients.

Treatment involves the wearing of various dental appliances and the recovery can be very rapid if the patients are seen at the early stage of the illness. It is slower in cases where the lack of proper timely treatment has made the condition more chronic. I would like to add that it should become mandatory for all doctors, ME/CFS Associations and anyone involved in the care of the supposed ME/CFS/ FMS and MS scenario to be required to refer the patient for a differential diagnosis to a dental surgeon who is well versed in the treatment of such patients. This must be done at the outset and not when the patient has been mistreated for a number of years before doing so. We might then see fewer becoming bedridden patients housebound.'



#### **Testimonial**

David Sherman writes:- After 10 years of increasing suffering and endless search to the answer to why I felt so ill and exhausted, all I had to show for it was a long list of ineffective treatments and a huge hole in my bank account, after my GP had eventually diagnosed ME/CFS. He sent me to a specialist who recommended a 'CFS Profile'. Expensive blood tests to allegedly pinpoint what was causing my symptoms. Then a costly treatment to make me feel normal again. Instead I spent 2010 bed-bound or housebound. After 8 months of 'rebalancing my mitochondria with vitamins etc', I became more disabled, isolated and desperate!

In November 2010 I was given Dr. Amir's phone number. He came highly recommended, but pessimism led me to sequester his number in the kitchen drawer. However by Spring 2011, my emotional and physical state led me to phone Dr. Amir and he assured me, in very positive terms that he could help me, before even seeing me, and during the following appointment demonstrated what was wrong with me and the correlation between my symptoms and the physical asymmetry of my teeth, jaw and skeletal structure. He was very clear, detailed and emphatic about what I could expect following his course of treatment. After speaking to some of his success stories on the phone and reading the Testimonials of others, I was back in the chair two days later, and being fitted with a Dental Appliance designed to deal with my specific issues. The' fog' began to lift and I felt brighter and stronger very soon after, just as Dr Amir had predicted. Three months since my first treatment, I am off all medication, including sleeping pills, anti-depressants, pain-killers, blood-pressure medicine, and hormones, and I have lost 18 pounds in weight that was much needed.

#### **Review by Dee Penny**

More information and testimonials can be found on the website: dramir.com and dramir ME/CFS



Food intolerance friendly!

We source our foods from all over the place, looking for organic products, product that avoid allergens, products as close to raw as possible, from this we created a list that changes from week to week depending on feedback and whim. All are delicious, all are Paleo Approved, we are gluten free, wheat free, grain free, dairy free, we do not use refined sugars, everything we make and bake is as close to the earth as we can possibly get it so that you don't get any nasty surprises.

We bake and make our products in a gluten free environment and we love what we do and we hope that you will also love us.

We live and bake in Penarth, we deliver throughout the UK.

Tel. 07565541857

Email. jinandmatt@jinspaleotreats.co.uk

Website. www.jinspaleotreats.co.uk



# Presentation of Petition to Welsh Assembly

Llywodraeth Cynulliad Cymru Welsh Assembly Government

## Tuesday 16th September

This year have been we wonderfully deprived of that perennial (and somewhat pleasurable) British pastime of having a gripe about the lack of warm, dry, weather during the months. summer What enviable summer we had in 2014

and the balmy days during September were an added bonus.

16<sup>th</sup> Tuesday lt is September, and we enjoy another temperate day as we gather and loiter on the plum hued slate steps leading to the Welsh Assembly Government's seat of governance, neatly settled amongst the hustle, bustle and commerce of Cardiff Bay.

A gentle breeze carries the sound of lanyards slapping against the masts of sailing craft as they bob and sway in the cold, steel grey waters of The Bay. These colourful yachts passively while away the time of day, whilst their owners enthusiastically do little or nothing to interrupt this tranquil scene.

The Senedd's next door elderly statesman, the timeless and majestic Pier Head Building with its scrubbed, rich, terracotta façade, stands in defiant contrast to the modern architecture of the Welsh Assembly building.

Both structures play silent witness as they lazily reflect the afternoon heat in the direction of rambling pedestrians and lunch time loafers alike. A cloudless azure blue sky forms the perfect back drop and for a moment the thoughts of dark, cold, winter

Im Here.....

2 3hrs
A DAY

nights take a back seat. The imposing large black iron minute hand on the Pier Head's china white clock face slowly climbs towards the vertical. It's almost 1 o'clock signalling that our allocated time for officially handing over the MESiG petition is almost nigh and we shuffle our feet and exchange nervous chit chat in anticipation.

Prior to this somewhat apprehensive ceremony, we had discussed as to what method we should employ so that maximum publicity could be achieved. From this meeting of minds, there came the notion of taking a bed

(yes a bed!) to this seat of power. For a brief moment, the notion of undertaking such a radical gesture ran (hesitantly) through our thoughts. After a lively debate, it was agreed that a fold down (or is that a fold up?) type bed would take up

> temporary residence on the slate steps of The Senedd (the English translation is Senate), complete with occupant, as a visual aid to advertise our presence.

> With the bed in situ, (complete with 'stand in' patient) and the electronic petition (along with a paper adaptation of the MESiG petition) in readiness, all that was

required were the officials from the Assembly to receive from us the MESiG petition(s).

The statistics surrounding the number of MESiG petition signatures achieved runs well past the thousand mark. A petition is a vehicle which is employed to reflect and convey public opinion and although the amount of signatures may have an influence on its initial impact, the fact that it has been produced and received should be the main driving force. But it does not end there, a point taken up towards the end of this article.

Lights! Cameras! Action! For those not accustomed to 'petition handing over' duties it appears that The Senedd is well versed in this practice and is the preferred venue of choice. Along with our small band, there is a symphony orchestra protestors demanding one thing or another and we expectantly for this colourful wait demonstration to subside whilst busy our selves with

unfurling banners and slipping into MESiG logo tee shirts and of course, preparing the bed! The poster which announces that a bed is their "Home for 23 hours per day" does catch the attention of more than the odd passer by. We take up our positions and, as we rapidly gain in confidence, we

present ourselves to the WAG reception team and are received in a friendly, welcoming and accommodating manner. Kathryn Thomas representing the Assembly takes the lead and with appropriate clip board to hand, escorts us to where we had set up base camp.

Just before the official hand over, Chris is interviewed by Steve George and a video clip is taken by the WAG official, presumably for their records. Chris had prepared a speech outlining the aims of MESiG and of the problems associated with ME, including past attempts at initiating action from the Welsh With Government. **Bethan** Jenkins from The Welsh Assembly close by, Chris delivers the oration with compassion and vigour. Irene proficiently reads

out just a few of the many е mails we moving in received. which people expressed their experiences of life with ME. Belatedly we are joined on the steps by William the chair of Powell, the committee responsible receiving and discussing public petitions. He asked to excused for the delay immediately appearing and engages in an impromptu



question and answer session.

The Assembly members listened intently and asked questions whilst offering ideas that had been explored or suggested previously. Listening without appearing patronising is more of an art than a science and we were treated with interest and respect in equal measure. We were informed of the protocol and procedures once the petition had been received and this included information relating to the next committee meeting which was due shortly.

All in all, we are content that the purpose of producing the petitions has reached the attention of those who are in the position of affecting its aim. However, it does not finish here, and it will take more lobbying and persuasion in the quest to gel the necessary WAG officials and their associates into bringing our ambitions, desires and aspirations into being. It's a case of finding out the correct approach and language which will assist us in achieving the aims of MESiG when dealing with the representatives of The Welsh Assembly government.

With banners folded, tee shirts boxed and bed in transit, we reflected on the afternoon's events as we slowly disperse. We had begun our journey in the Concourse of The University Hospital Wales some while ago. Dennis Jones took the helm and steered through the electronic version of the petition via the WAG website. We talked with

many strangers during the paper petition exercise and although the internet has much to offer, it's the personal touch that successfully engages with those who are suffers or know someone who has suffered with ME. We trust that we have seen the beginnings of the quest to raise awareness the and recognition of this much misunderstood condition and of practical steps to confront and overcome this wretched illness.

#### **Review by Robert Goodman**



# Speech used at Presentation to Welsh Assembly by MESiG

## Tuesday 16th September

#### **WHO WE ARE**

MESIG( ME Support In Glamorgan). A support group for people with M.E. We have been established since 1988. Each member of the committee have been personally affected by M.E. in one way or another. We are not many but we represent many. A voice for the voiceless. We represent those who are unable to physically be here, those who are bedbound/ housebound. Those who are struggling to tackle each day, those who are in such pain, with no relief. Those who have been let down by the system.

Only yesterday I spoke to a lady from away for the first time. She had been suffering with M.E for many years but hadn't told anyone. Said I was the first. Why? You may ask yourself. I met another lady who battled M.E for 10 years, was healed and didn't tell anyone she was healed. When I asked her why, she said no one believed she was sick in the first place. I, myself battled M.E for 23 years, it took 5 years to get a diagnosis. That's 5 years of ceasing to function normally on every level until the point of collapse and complete shutdown. I went from a successful business woman, independent from the age of 10, to someone who needed help to get to a toilet. This has an impact on oneself but more so is NOT BEING BELIEVED. Feeling ashamed to be ill because of the stigma attached to the label M.E. to the point where people pretend not to have it. I would know straight away which doctor, medical person was M.E friendly or not before they even spoke. That's what 23 years experience gives you. We don't say this to point fingers or blame, we love doctors and thank God for them. But it does highlight a need. A need for education, a need for research, a need for services, a need for change.

#### **QUOTES FROM SOME MEMBERS UNABLE TO ATTEND**

"My thoughts are that we need more support - professionally and medically. For me I feel there is not enough being done and I am being left to cope on my own. I feel that when I go to the Doctors, they send me for bloods or up my meds or tell me there is nothing they can do.

There needs to be some provision for us. There needs to be an acknowledgement of this syndrome. There needs to be awareness.

More needs to be done."

"We're Fed-Up of people in power Shutting their eyes & ears & PRETENDING we're Alright - WHEN WE'RE NOT!!!!"

"Wish I could come but sorry just can't. I've been flattened by this illness for 15 years. The first 7 spent entirely in my bedroom, recent years I've been a lot better but unable to get out much and never on my own. Probably now up to 35%-40% of how I was 15 years ago, then I was a busy working mum of two, productive, and felt a valued member of society. now though only valued by my family and friends.

There are many similarities to MS plus we have the complete exhaustion that is Indescribable and yet ME is so underfunded in comparison. We need specialists we need a clinic We need help."

#### **WE HAVE BEEN HERE BEFORE**

In 2006 a previous petition was launched. A 7,000-signature petition handed to the then Welsh health minister Dr Brian Gibbons in 2006 – was started by the late Christine Llewellyn, shortly after she stepped down as MEA chairman. Christine died heart problem 2007 unexpected. Her daughter had ME.

#### Nearly a decade later we are still here asking for help!! Nothing has changed.

MESIG (ME Support In Glamorgan), know that early diagnosis delays harm. We have been running since 1988, that's a lot of people and experiences we have come across. We have seen people come on board very unwell but in early stages, they take advice and some recover, some only enough to work part time but have better quality of life. Symptoms not so severe etc. The point is that the lack of services for people and the delay in diagnosis costs the government in the long run. With benefits, tests, long term illness, care etc. We are not saying all sufferers can be cured but all would benefit from appropriate care and especially from being believed. A clinic would save the Government money.

There is a clinic in Kent called Burrswood. They have a team who understand M.E and have had some success with bedbound patients. It is critical to have this understanding as pushing sufferers beyond their capacity can cause death.

#### **WHAT IS M.E.?**

Myalgic Encephalomyelitis (M.E.) is a chronic, fluctuating illness affecting an estimated 250,000 people in the UK. It may be diagnosed as Chronic Fatigue Syndrome (CFS) or Post Viral Fatigue Syndrome (PVFS). For continuity and clarity we refer to the condition throughout this report as M.E./CFS.

The World Health Organisation classifies M.E./CFS as a neurological condition. The National Institute for Health and Clinical Excellence (NICE) emphasises that this is a real illness and that the physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis and other chronic conditions.

M.E./CFS involves a complex range of symptoms which includes fatigue, malaise, headaches, sleep disturbance, difficulties with concentration and muscle pain. The pattern and intensity of symptoms vary between people, and during the course of each person's illness.

People often have symptoms for many years before M.E./CFS is diagnosed. Some patients recover fully and most improve to a varying degree over time. However, a significant minority remains very ill and do not respond to the therapies available.

M.E./CFS is a major cause of long term school absence in children with potentially devastating impact on their social and educational development.

Up to 25 per cent of patients are so severely affected that they are unable to leave their homes or their beds for prolonged periods which for some can last for years. In addition to their medical symptoms, the large majority of M.E./CFS patients experience significant degradation in the quality of their life. Most of those in employment are unable to remain in their jobs and experience extreme financial hardship.

They also endure a significant degree of social isolation, skepticism and even disbelief, because the illness has yet to throw off the wholly undeserved stigma that prevails in some quarters due largely to our scientific ignorance about its biology. (Taken from Action For ME)

Health minister Mark Drakeford this May 2014 launched a plan to help people with neurological conditions. M.E is a neurological condition.

#### KEY POINTS TAKEN FROM MARK DRAKEFORDS NEUROLOGICAL DELIVERY PLAN.

Health Minister launches Neurological Conditions Delivery Plan

Health Minister Mark Drakeford has launched a plan setting out new commitments to help people with neurological conditions. Dated Thursday 8<sup>th</sup> May 2014. Welsh Government.

Neurological conditions affect approximately 500,000 people in Wales. The Neurological Conditions Delivery Plan provides a framework for action by health boards and their partners. It sets out the Welsh Government's expectations for the planning and delivery of high-quality person-centred care for anyone affected by a neurological condition. It focuses on meeting population need, tackling variation in access to services and reducing inequalities across seven themes:

- Delivery theme one: Raising awareness of neurological conditions
- Delivery theme two: Timely diagnosis of neurological conditions
- Delivery theme three: Fast and effective care
- Delivery theme four: Living with a neurological condition
- Delivery theme five: Children and young people
- Delivery theme six: Improving information
- ♦ Delivery theme seven: Targeting research

#### **QUESTIONS TO MARK DRAKEFORD**

This report shows acknowledgement of a need. How is this going to be achieved for those with the neurological condition M.E when doctors currently don't recognise, rarely diagnose and are even taught that M.E does not exist??

How are people with M.E going to be catered for when M.E is not recognised as a neurological condition??

Thank you Welsh Assembly for allowing us to present this petition to you asking for a dedicated consultant/clinic and medical support team for people with M.E.

We also have an added 1000 signatures on a paper petition.

We have spoken to many Health Ministers over the years Jane Hutt, Edwina Hart, Brian Gibbons, Lesley Griffiths, now Mark Drakeford. It's good to talk but seriously, we need some action. Please end this ignorance.

This is a golden opportunity for Wales to be paramount in the fight to recognise and treat this terrible illness which effectively robs those of everyday life who fall foul of this vindictive ailment.

We commend this petition to you.



Llywodraeth Cynulliad Cymru Welsh Assembly Government

#### **Speech by Christalla Bailey**

# Award winning documentary film about M.E. shown at Penarth Pier Pavilion



Voices In The Shadows shown in Penarth Pavilion. All tickets (and a few more) were sold out! So after a short introduction by Chris Bailey, the film was shown to a packed house.

The new Town Mayor, Martin Baker came to support us and we were honoured to find that it was his first official engagement. We were also very pleased to welcome Julie Morgan AM who is a staunch supporter of MESIG and our important quest for a desperately needed ME clinic in Wales. There were a number of carers and friends in the audience, as well as a number of doctors and medical staff. One GP who attended said that it really opened her eyes to the reality of M E and the problems, and there was general shock and a great sense of sympathy amongst people in the audience, when they realised the severity of the illness and what patients had to endure. When the film was concluded, the Mayor gave a very sympathetic speech and wished us well in our endeavour. Julie Morgan also gave a supportive speech, before Chris concluded with a little of her own long experience of the

illness and her wonderful recovery.

This important event was brought about by Noelle, whose daughter has ME, Her hard work, dedication and planning brought a very innovative occasion to make people aware of everything that sufferers have to go through, often with little help from the medical profession. On contrary, they are deprived of the usual support that other illnesses receive and often vilified for being ill at all? Sometimes not believed, diagnosis is a long time coming, and often the wrong advice and given. Patients are treatment advised to exercise which is entirely wrong, most are sent to a psychiatrist, and sometimes even put into psychiatric wards where they can only deteriorate.

Although the World Health Organisation and the B M A accepts ME/Fibromyalgia as a physical Illness, the psychiatric adopted fraternity have wrongly, preventing the much needed research into the true cause of ME and so delaying much needed positive treatment. It is a neurological illness which causes severe, unnatural exhaustion, pain in all the muscles, terrible physical difficulty and much more. Everyone who came to the film was kind enough to sign our Petition for a Clinic here and the necessary specialist medical staff



to treat the illness. We were very happy that so many people came to support. It is only the start of what we hope to achieve for patients in Wales.

A big thank you to Noelle for her inspired thinking in bringing about this film show. What an achievement! And thank you to everyone involved. Chris and Ken and the photographers, Noelle's husband Gareth and Judith and John Fraser, who also arranged for Martin to come. Last but not least. thank you to lovely Julie Morgan who is a constant support to us.

On a light note, a number of us went for coffee and cake in the new cafeteria downstairs with a beautiful view of the water and the North Devon coast. We had a very warm feeling inside (beside the coffee) that something wonderful had been achieved that day. Very Well done Noelle. The proceeds, after expenses went to M E Research.

Special thanks to Voices In The Shadow and Penarth Pier.

#### **Review by Dee Penny**





# Woman takes first steps in NINE YEARS after being struck down by debilitating ME

Published Thurs, July 31st, 2014



Jessica Taylor was struck down by a deadly virus when she was just 14, which attacked her immune system and left her with Myalgic encephalomyelitis (ME).

ME leaves sufferers with long-term disabling tiredness as well as muscular, joint pains, poor concentration and headaches.

Ms Taylor, now 23, spent nine years building up her strength – and her hard work finally paid off at the end of June.

She said: "I had been pushing for this moment for nine years.

"I have spent almost a decade in bed, there have been times when I couldn't move and have been fed through a tube.

"Walking was just a dream but now it's a reality.

"As I stood up I realised I was I had grown by four inches too."

Although she only managed three steps, Ms Taylor, from Rochester, Kent, is continuing to improve.

"Walking was just a dream but now it's a reality"

Jessica Taylor

She added: "I've missed out on all my teenage years, that's the hardest part of having this condition.

"Shopping with friends and clubbing until the early morning is something I could only dream of doing."

"But with my latest development, I'm hopeful that one day I'll lead a normal life."

Before she was struck down, Ms Taylor enjoyed a life like every other teenager and loved socialising with her friends.

But she was left so weak that she was unable to even lift her head, meaning she had to be fed through a tube.

She said: "Since that moment my life has been an emotional rollercoaster for me and my family.

"It was a shock for everyone, I had gone from being an outgoing person to not being able to get out of bed.

"Everything changed, now the slightest infection can leave me fighting for my life."

But Ms Taylor, who lives with her mother, Kate, 50, father, Colin, 52, and sister, Ruby, 19, is determined to continue with her progress.

She said: "I heard of many miracle stories whereby people walk again but I never thought it would happen it me. "I'm so proud of myself and all the hard work I put in to make my dream a reality."

Ms Taylor spent 16 weeks staying at the Burrswood Centre in Kent, which specialises in helping those with ME, where she underwent physiotherapy and hydrotherapy.

She said: "It was exhausting trying to build my muscles back up.

"It was all so worthwhile when I saw the look on my parents faces when I stood up and was able to take those few steps. They were so happy.

"Now I've managed to get out of bed the key is to keep on building up my muscles so I can walk for longer."

She is now back home and making good progress.

Despite her condition, brave Ms Taylor even set up a website, called **Share a Star**, to help sick children and adults.

She said: I set up the charity from my bed to help those in a similar position to myself. "I wanted to help others feel special, it also gave me something positive to focus on."

She has been praised by the ME Association for her work.

Spokesman Tony Britton said: "This is a lovely story and we wish Jessica Taylor all the best in her recovery.

"But M.E. affects about 250,000 children and adults in the UK - many of whom can only hope and pray that they too will one day be able to receive the same kind of attention that she received through her stay at this private hospital.

"For vast numbers of severe sufferers, though, the reality is that they languish disbelieved and untreated because the NHS doesn't provide the care and understanding that people with this illness need to overcome its worst effects. They remain isolated and cut off from the rest of society because they are often too ill to leave their homes, they become bed bound and - in the worst cases - need to be fed by tube.

"Researchers are beginning get to grips with the causes of M.E., which can affect all bodily systems. The day when there are widely available treatments and perhaps even a cure can't come too soon."

I never thought it would happen

For more details visit http://www.express.co.uk/news/uk/494068/ME-woman-walk-for-first-time-in-nine-years#782373937079683



# The Muscle-Brain Connection in ME/CFS Revealed

#### Published Tues, July 22nd, 2014

People with Chronic Fatigue
Syndrome have weakened
muscles and, let's face it,
weakened brains as well. They
can't exercise and their ability to
focus, to process information
quickly and to retain it, is shall
we say, blunted. One would
think those two problems are
not related, but a recent Belgium
study suggests they are
intimately related.

We recently saw Dr. Bateman incorporate a bunch of different findings into a 'big picture' view of ME/CFS. This studies findings suggest that was a good thing to do.

#### **The Study**

Can recovery of peripheral muscle function predict cognitive task performance in chronic fatigue syndrome with and without fibromyalgia? Ickmans K, Meeus M, De Kooning M, Lambrecht L, Pattyn N, Nijs J. Phys Ther. 2014 Apr;94 (4):511-22. doi: 10.2522/ ptj.20130367. Epub 2013 Dec 20. Studies have shown that muscle recovery in Chronic Fatigue Syndrome takes longer than expected and the cognition problems (slowed information processing, reduced short term memory,

difficulty concentrating) are evident.

These Belgium researchers wanted to know whether ME/CFS patients with longer muscle recovery times also did more poorly on the cognition tests.
They gave cognition tests to ME/CFS and ME/CFS plus
Fibromyalgia patients one day and then did a muscle challenge test using a handgrip tool the next.

#### Results

They found that ME/CFS patients with or without Fibromyalgia who recovered their strength less quickly also did worse on the cognition tests; ie. poor muscle recovery is associated with reduced brain power. That's probably not surprising to people with ME/CFS who get hit both physically and mentally after exerting themselves too much, but now it has to be explained.

The ME/CFS patients with Fibromyalgia (Wolfe criteria) also did worse on the cognition tests and took longer to recover from the muscle test than ME/CFS patients without FM. Since the more comobid conditions a

person has, the worse off they tend to be, this makes sense.

#### The Muscle Brain Connection

The authors suggested that reduced blood vessel formation could, among other things, be responsible for their findings. The Ickman's group tied the muscle recovery/cognition results to a study by De Lange showing that reduced grey matter in the brains of ME/CFS patients was associated with reduced physical activity. In that vein they suggested that reduced angiogenesis - blood vessel formation - and neurogenesis – nerve formation - associated with reduced physical activity might be responsible.

Indeed, it's possible all things considered, that the more fit a person with ME/CFS is the better they do cognitively.

They also pointed to central sensitization as a probable factor; the more central sensitization present – the worsened muscle recovery and the poorer cognition you exhibit. Increased pain can dampen both muscle functioning and cognition, and the fact that the CFS patients with Fibromyalgia

had substantially worse cognition than the ME/CFS patients without FM fit this idea.

They noted that other possibilities are present and we're going to take a look at one.

#### **Autonomic Nervous System**

"Our findings add to the growing body of evidence linking autonomic dysfunction to the symptomatology in this poorly understood disease" Beaumont et. al. Other factors, however, have been associated with poor cognition. Two consequences of autonomic dysregulation; low heart rate variability (HRV) and the presence of orthostatic symptoms, have been associated with reduced cognition in ME/ CFS. Australian study authors argued that vagus nerve withdrawal was best associated with cognitive problems. (Interestingly, they also found reduced heart rate 'recovery periods' during cognitive testing. In a big picture attempt they proposed that pre-frontal cortex damage results in loss of autonomic nervous control, reduced vagal tone and poor cognition) Could autonomic issues and reduced blood flows also play a role? Newton's finding that poor pH handling by the muscles in ME/ CFS patients is associated with low heart rate variability

effectively tied the autonomic nervous system problems in ME/CFS to muscle recovery issues. Her ability to further tie reduced pH handling in the muscles to reduced blood flows to the brain directly linked muscle, brain and ANS issues together.

Newton's studies in other disorders back up her focus. Autonomic nervous system symptoms were highly correlated with cognitive issues in a immune thrombocytopenia study. Newton proposed that impaired 'cerebrovascular autoregulation' (impaired blood flows to the brain) were causing cognitive declines in primary biliary cirrhosis (PBC), another severely fatiguing disease, In 2008 Newton found that brain lesions and autonomic issues were associated with cognitive declines in PBC.

All this is to say that reduced grey volume and angiogenesis may very well be associated with both reduced cognition and muscle recovery in ME/CFS as the authors suggest, but an increasing body of work suggests autonomic dysregulation may play a key role.

With the low blood volume and

with the low blood volume and autonomic nervous system issues present in ME/CFS it's not hard to envision systemically reduced blood flows causing problems with both muscle recovery and the cognition. We do, after all,

have two aerobically active areas of the body (muscles, brain) with problems. Perhaps it's not so difficult to connect the two after all; simply follow the blood. Time will tell. For now it's great to see a connection made between these two critical problems in ME/CFS. At some point they and all the other seemingly disaparate findings in ME/CFS need to be explained.

#### **Conclusion**

It's big picture time; what could be causing issues in two seemingly different systems? Longer muscle recovery times are associated with cognitive declines in Chronic Fatigue Syndrome (ME/CFS). Explaining this strange muscle-brain connection works will likely require showing how similar issues affect both system. The authors propose that reduced grey matter in the brain and central sensitization may play a role. The major controller of blood flows to both - the autonomic nervous system – is another possibility. This study was intriguing because it connected too seemingly separate systems; the muscles and the brain. Explaining the results will require stitching together two systems that are not ordinarily stitched together - a good exercise in a disease that affects

so many systems of the body.



# Fibromyalgia Mystery Finally Solved!

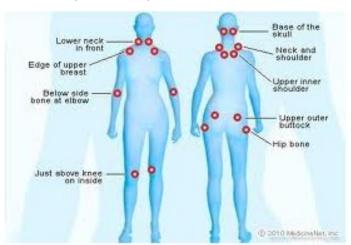
## Researchers Find Main Source of Pain in Blood Vessels

#### Added by Rebecca Savastio on Thurs, June 20th, 2013

Researchers have found the main source of pain in Fibromyalgia patients, and contrary to what many believe, it does not stem from the brain. The findings mark the end of a decades-old mystery about the disease, which many doctors believed was conjured in patients' imaginations. The mystery of Fibromyalgia has left millions of sufferers searching for hope in pain medications. Up until recently, many physicians thought that the disease was "imaginary" or psychological, but scientists have now revealed that the main source of pain stems from a most unlikely place- excess blood vessels in the hand.

The discovery may lead to new treatments and perhaps even a total cure in the future, bringing relief to as many as 5 million Americans thought to have the disease. To solve the Fibromyalgia mystery, researchers zeroed in on the skin from the hand of one patient who had a lack of the sensory nerve fibers, causing a reduced reaction to pain. They then took skin samples from the hands of Fibromyalgia patients and were surprised to find an extremely excessive amount of a particular type of nerve fiber called arteriole-venule (AV) shunts.

Up until this point scientists had thought that these fibers were only responsible for regulating blood flow, and did not play any role in pain sensation, but now they've discovered that there is a direct link between these nerves and the widespread body pain that Fibromyalgia sufferers feel.



The breakthrough also could solve the lingering question of why many sufferers have extremely painful hands as well as other "tender points" throughout the body, and why cold weather seems to aggravate the symptoms. In addition to feeling widespread deep tissue pain, many Fibromyalgia patients also suffer from debilitating fatigue.

Neuroscientist Dr. Frank L. Rice explained: "We previously thought that these nerve endings were only involved in regulating blood flow at a subconscious level, yet here we had evidences that the blood vessel endings could also contribute to our conscious sense of touch... and also pain," Rice said. "This mismanaged blood flow could be the source of muscular pain and achiness, and the sense of fatigue which are thought to be due to a build-up of lactic acid and low levels of inflammation fibromyalgia patients. This, in turn, could contribute to the hyperactivity in the brain."

Current treatments for the disease have not brought complete relief to the millions of sufferers. Therapies include narcotic pain medicines; anti-seizure drugs, anti-depressants and even simple advice such as "get more sleep and exercise regularly." Now that the cause of Fibromyalgia has been pinpointed, patients are looking forward to an eventual cure. Other expressed frustration about how much they had suffered already:

"When are they ever going to figure out that things are never "all in your head?" said one commenter. "Whenever something doesn't fit in their tiny little understanding, they belittle the patient and tell them they are crazy. People have suffered through this since they were invented.



Prescribing SSRIs for everything is not the answer any more than a lobotomy or hysterectomy was."

The announcement has the potential to unlock better future treatments and undoubtedly has patients all over the world rejoicing that the mystery of Fibromyalgia has finally been solved.

Read more at http://guardianlv.com/2013/06/fibromyalgia-mystery-finally-solved/#rzv1wkAHvi5TTAyE.99

## Your Newsletter

Hi, as your newsletter editor I encourage you to send in any tips, ideas, poems, stories etc for the newsletter.

We have also had some interest from an ME person who would like to meet in central Cardiff. If this is something you would like, please let us know.

Another lady has asked if there are young people with ME in the Penarth area who could visit her daughter, (in 30's).



MESiG hope to see you on 1<sup>st</sup> December for our Christmas get together celebrations.

Jan from WAMES is hoping to attend our support group meeting in January.

We are hoping to book Liz Babbs for M.E awareness week in May next year. Liz has recovered from ME, written books and is a woman of many talents including performing. Will keep you posted.

Wishing you all well.

Irene and Chris

**MESIG** 

## Survival of the Fittest

### 28th September 2014





On 28<sup>th</sup> September Nick Tatham ran in the 'Survival of the Fittest' race to raise as much money as possible for MESiG. This is when it is especially useful to have a Facebook page with lots of friends who want to sponsor you! The race has become very popular and it is mainly to raise awareness for Men's Health, but Nick was running for us & so we kitted him out with the MESiG tee-shirt.



We also managed to get our huge MESiG banner right by the start line. The atmosphere in Cardiff Bay was full of energy with entrees preparing to start their 12k run which included 10 obstacles along the way. The first one being a huge Hay Bale Wall to climb over before heading out towards the white water rafting area where more challenges awaited them.





So we (the supporters plus a dog) also headed off - but only a hundred yards to a café, to enjoy our well earned rest in the sunshine. We incidentally nearly missed Nick's return, I wonder why! But did in the end spot him amongst the others, scaling the final MH Wall of Fame. He managed the run in good time and felt really spurred on by us supporting him.

Although the amount raised hasn't yet been finalised it is heading towards £1200. So we want to thank all those who sponsored Nick and a special thanks to Nick for choosing MESiG and we know the money will be put to very good use for the forthcoming year. We also want to thank Poppy (the dog) for wearing her tee shirt and looking so cute.

For more details visit http://www.mhsurvival.co.uk/cardiff-2/



## JOIN US

If you suffer with ME/ Chronic fatigue syndrome (CFS), Fibromyalgia, you are very welcome to come and join us for a chat and coffee in the following venue:

Llanishen Community Shop City Temple North Llangranog Rd Llanishen CFI4 5BL

Every first Monday of the month, (except August, second Monday if first Monday is bank holiday)

11.00am - 12.30pm

## BENEFITS INCLUDE...

- monthly meetings with occasional speakers
- · friendship and support
- · regular newsletters
- · raising awareness

We would love to hear from you, even if you are too unwell to come, or are housebound.

Email. mesigwales@gmail.com

Tel. 02920 762 347

Web. mesupportinglamorgan.co.uk

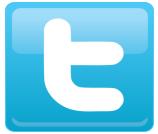
# MESiG on Social Media





Please 'Like' our Facebook page:

ME Support in Glamorgan M.E.S.I.G





Follow us on Twitter:

@MesigWales



Send us a message:

Mesigwales@gmail.com



Visit our Website:

www.mesupportinglamorgan.co.uk

## **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

25% ME Group

21 Church Street

Troon

Ayrshire KA10 6HT

Tel: Office 01292 318611

Advocacy line: 01292 312369

Website: www.25megroup.org

**ME Connect** 

**Helpline** 08445765326

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

STIFF (UK)

PO Box 1484

Newcastle-under-Lyme

Staffordshire, ST5 7UZ *Tel:* 01782 562366

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

Brame

30 Wimmer Avenue

Winterton-on-sea

Great Yarmouth

Norfolk

**NR29 4BA** 

UK Tel/Fax: 01493393717

Email: 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

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)

## Contact and Support continued

#### Fibromyalgia Association

PO Box 206

Stourbridge

West Midlands

DY98YL

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

Ingatestone

**CM4 9TE** 

Tel: 0845 003 9002

(best between 11 -1 and 5-7pm week-

days)

Website: www.tymestrust.org

#### **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

## Contact and Support continued

#### **Travel**

National Rail Enquiries

**Tel:** 0845 748 4950

Disabled assistance

Advance notice is required by the train op-

erator.

**Bus and Coach:** 

National Express

Tel: 0870 580 8080

**Travel Line** 

Tel: 0870 608 2608

<u>VEST</u>: for help with local lifts and transport for the disabled - *Ring* 029 20490325 and

ask for an information pack.

#### 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.

#### 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

### **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

## M.E.S.I.G Committee Members

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

or email

Irenedavies01@hotmail.com



M.E.S.I.G

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