



*Supporting those who suffer Myalgic Encephalomyelitis,
Chronic Fatigue Syndrome, Fibromyalgia and Lyme disease.*

AGM With Guest Speaker

Saturday 7th July 2018

2pm-5pm

Bethel Community Church
Llangranog Rd
Llanishen
Cardiff
CF14 5BJ



2-3pm AGM

3-3.50pm Guest Speaker: Jill Shelton
Community Health Council

3.50-4pm Q&A

4-5pm Tea and Cakes, Raffle

If you are subscribed to MESiG, we need you for our Annual General Meeting, to vote in your committee.

If you want to be put forward for a role please contact us.

All are welcome to this event, bring friends, family, carers, anyone with an interest.

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Comings and goings.

Introducing MESiG Chair



Dear members,

Most of you may know by now that last Autumn I stepped into the shoes of Christalla, as Chair for MESiG. Chris devoted so much time, energy and soul to MESiG over many years and left big shoes to fill. However since the Autumn, with a wonderful committee of longstanding, loyal volunteers at the core of MESiG, along with some fresh new additions, we've come together for a new chapter.

I'd like to introduce Andrew (Vice Chair), Emma and Emma-Jayne (Committee Members). MESiG is close to all of our hearts. The committee are predominantly a group of sufferers or carers, doing our best in our own lives and doing what we can for MESiG and our members.

Before I tell you a little about myself, I want to say here that if you have any skills, time or capacity that you would like to bring forward to volunteer for MESiG, or know others who might be able to, we would be so grateful. Many hands make light work! We all have a belief that we can be stronger together.

We saw the way that Wales and the world came together for Millions Missing. Never before has there been a campaign for ME on this scale. MESiG has had a positive 2018, some highlights include being at the NICE stakeholders meeting along with the Unrest screening for medical students at Cardiff University, on which we had the ME Association's Dr. Charles Shepherd on the panel. We continue to make our voices heard in Wales as well as running our monthly support meetings - to support, listen, care and share.

My background is that I am 28 years old and in my last year of university, 6 years ago, a virus floored me from which I never fully regained my health. I'm a mild to moderate ME/CFS sufferer and I've had some severe times, including two surgeries. I'm fortunate that I've been able to work, with flexibility, over the past years in Marketing for Celtic English Academy in Cardiff. I studied French and English so working with languages, in a global environment, but here at home in Wales, has been greatly rewarding. I also couldn't thank my employer enough for their support - for seeing me and not just my illness.

Life continues to be constant management but I'm grateful for all that I can do and try to focus on the moments of light. I'll never forget dancing freely and living to my souls' full extent, and am blessed when that's possible again. It is hard to find beauty in a storm yet when you're carrying symptoms each day, which I'm sure many of you reading this do, be reminded that even when we feel most alone in our sufferings, we are not alone, we are together.

I hope that with time I'll get to meet or talk with a few more of you. For now I hope you'll enjoy catching up on the MESIG news and events.

Warmly,
Emelyne - MESIG Chair

Introducing MESiG Vice Chair - Andrew Dalgleish



I am originally from Edinburgh but have lived in Wales for nearly 30 years, working as a librarian at the University of South Wales. My wife Michelle has faced the challenge of ME for many years. She made me aware of the wonderful work that MESIG does and that has motivated me to contribute to the committee this year. The potential impact of the film Unrest, and building the momentum of the Millions Missing campaign has made it has made it an exciting time to be involved.

Introducing new committee members

Emma James



Having known an M. E. sufferer from a distance, I decided to step in and offer some time to the cause. Upon researching M.E and the relating disorders, I was unsettled and saddened for the sufferers but also to the families who were giving their lives to care for these unseen, unheard chronically ill people. I have a fantastic therapeutic job dog walking. I like to squeeze in a few classic novels in between all the muddy field walks and beautiful views of Cardiff.

Emma - Jayne Lloyd



Hi, my name is Emma-jayne and I'm delighted to be able to join the MESiG committee so I can try to make a difference. I have suffered with ME for 20 years but was mis-diagnosed until 18months ago! I gave up teaching art after 15 years because of my illness but have found that channelling my creativity in different ways has helped me to deal with my illness. I live in Cardiff bay with my fiancé and three legged cat called Lois who keep me sane and happy through this frustrating illness. I hope to be able to use my creative skills to help promote the charity and assist the

passionate members that are working so hard to raise awareness. I would like to help other sufferers to discover or develop their creative side to help them stay positive on those difficult days.

A Fond Farewell to Christalla



As you probably know by now, we have lost our long term Chair, Christalla (Chris). It was a very sad moment for us. Not only was she Chair, but as well as being at the Helm, she was at the Heart, and held several positions latterly. When our numbers decreased, she kept everything going – and steered the rest of us in the right direction! Among the many things that she did to spread awareness of the seriousness of M E/ CFS as a Biological illness, Chris spoke in the Senedd, on radio and TV and gained the support of Julie Morgan A M, among others. She travelled many miles to meetings and also to help isolated M E sufferers and is a true friend and champion of MESiG.

I first met Chris in 2009 when I joined MESiG and the group were then meeting in the Church Rooms on Excallibor Drive, at Thornhill. Chris was pretty poorly then and for many years she had great difficulty with her health. Luckily for us she has a very strong will and somehow kept the Group going.

Several times we have been at meetings and poor Chris has collapsed, and had to be carried to the car and taken home or to hospital.

Happier Times came, when Ken Bailey came into her life, though she still had to battle with her illness. But she has a very strong Faith, and it eventually led her to Ffald y Brenin, where she was healed, after twenty-three years of suffering from M E. This was a very happy time for them, and soon after, she and Ken were married. Still Chris continued to support all of us, as well as all her Church commitments and her other causes. But it has all been too much and her health has suffered yet again.. Now she needs to put her energies into a new career and she and Ken are looking for a new home.

We wish her well and know that she will always be in the background if we need advice. A Big Big Thank you for everything you have done for MESIG. We would not be here today without your tenacity, hard work and dedication.

Dee Penny

MESIG'S CHRISTMAS PARTY DECEMBER 2017

Gosh! Another year had gone by and we were preparing for our Christmas Party again. At our November committee meeting we had discussed everything, and decided that Mary and Dee would see to most of the food preparation this year...Usually we would enlist the help of Mr Sainsbury, but this year we would do it ourselves; and usually, several of our kind members brought something nice to add to the spread, so we thought we would have plenty on the day.

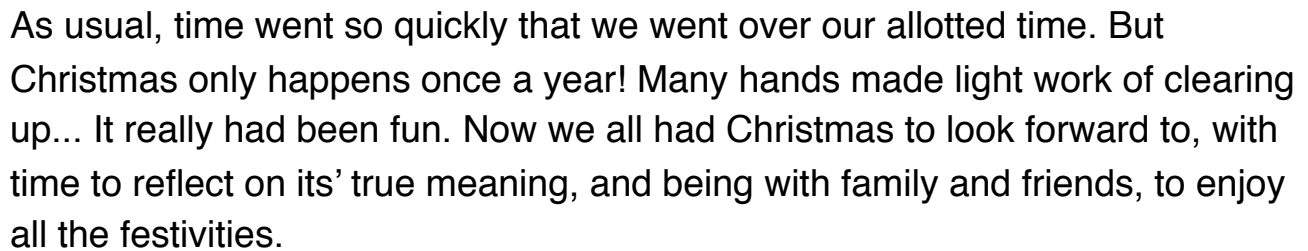


Mary is famous for her lovely cakes, particularly her Lemon Drizzle. Between them, they would make the savouries too. The colours for the tables etc. would be a bright Christmas Red and gold this year, and Dee had fun searching the shops for what she needed, and a great time in 'WHAT' and 'THE RANGE' among all the extravagant assortment of Christmas decorations displayed; from lighted Christmas trees to sleighs and snowmen and much more.

After a morning of preparation on the day, our committee arrived early to set everything out for the Party. Tables were laid, food set out and the raffle prizes grew and grew, as generous members arrived and added to them....so that later, the draw went on 'for ever' and some lucky members went home with more than one prize.



This year, Miriam had arranged for a Classical Guitarist to come and entertain us. It was lovely to listen to his range of both classical and Christmas themes, and sometimes to join in. We felt decidedly Christmassy!

[illegible]

Unrest screening at Cardiff University



I was very pleased to be at the showing of UNREST for the Medical Students at Cardiff University. I had wanted to attend since I first heard about the event but we initially thought that it was not open to members of the public, so it was a good surprise to hear that outsiders were welcome.

I wondered how many students would attend, as it was a film with a story about a person rather than an in-depth medical film. I had no idea of how many students normally attended this student organisation.

We, the outsiders, arrived early and were very happy to meet Dr Charles Shepherd and have a chat with him ahead of the evening's programme. And then the students began to pour in through the doors. It was quite amazing to see them arrive and so satisfying to see that they were keen to attend this event.

I think we'd all wondered how the Psychiatrist, due to be on the Panel later in the evening, would react to the film. I was feeling anxious about his possible views and reaction. When it was announced that he had sent his apologies as he was sick, I felt somewhat let down by his absence and therefore his Psychiatric input would be lacking. However there were Psychiatric students present who brought up the issue of 'what does it matter' if M.E is treated under Psychiatry, making the point that illness covers all aspects of a person

and it wrong to split up what is physical and what is mental as everything overlaps.

Two other things I noticed: there was no laughter at points in the film where audiences normally laugh. Why did the students not react? Was it considered inappropriate to laugh as 'this is a serious subject' so the lighter points were not acknowledge.

In the interval all the food provided was of a very high standard and we'd never seen pizzas disappear so fast! The Medical students were definitely not anorexic!

It was my privilege to have the last word with Dr Shepherd as I gave him a lift back to his hotel. It was a good experience to round the evening off by spending this time with him.

Miriam Wood

Some 80 people, mainly Medical Students in the latter stages of their education, attended the showing at the Hadyn Ellis University of Wales building of the "Unrest" film, about those who suffer from M.E and Chronic Fatigue.

We hope that everyone of those students will take with them an awareness and understanding of these totally debilitating ailments, into their practises.

We noted, in discussion after the showing, that some were aware of the problems because they knew of family members or friends who are sufferers.

The need for research was emphasised and, hopefully, understood, along with the need to spread the word throughout their professions.

Mary Jones

It was good that so many medical students attended this event. It was interesting that they said they didn't have any particular training about ME or Lyme disease. One of the students questioned why was it considered that a psycho somatic diagnosis was less acceptable than a physical diagnosis. It was explained that a psychosomatic diagnosis was simply not an appropriate diagnosis for ME.

MM

"The Cardiff University Unrest screening for students of the Cardiff MedSoc and Psychiatry societies was extremely well attended with the lecture hall full of 90+ students as well as people from the community. The students were deeply engaged with the evening, after seeing the Unrest film (and enjoying Dominos pizzas kindly provided for all during the break!)

There were a number of poignant questions raised that brought to the forefront the stigmas and debate of the illness being psychological vs. physical. However, it was really good to see the students thinking critically and even challenging each other with questions - all key parts of learning and understanding.

In particular, Dr.Charles Shepherd, myself and Sylvia from WAMES, were able to demonstrate answers to their questions that represented with integrity the situation for people with ME/CFS. The journals brought by Dr. Shepherd from the ME Association, were swept up by the students at the end (almost as hastily as the half-time pizza!)

I hope that we will continue to see more education, discussion and training opportunities for our medical professionals of tomorrow and the Unrest film has proven to be a great tool to open the conversation. We have been fortunate to reach Cardiff University Medical school students in this way and I know it's only another university in Ireland, and possibly one in England, that have been able to do this so far."

-

Emelyne, MESIG Chair

Unrest Screenings at the Tramshed and Chapter

MESiG attended both screenings of Unrest at the Tramshed and one of the screenings at the Chapter Arts Centre.

Dee spoke at all these events, spreading awareness about ME.



Dealing with Fibromyalgia

Why I have made this silly little guide?

I worry waaay to much what people think!! This is my solution.

I don't want to show the symptoms of fibro but sometimes it's unavoidable and trying to hide them can make me look antisocial/a bit mad.

If you know about it you can make sense of any odd behaviour....

But then to be able to ignore the condition the rest of the time if that makes sense!

What is fibromyalgia?

A pain and fatigue condition that never goes away – but it gets better and worse on an almost by-the-minute basis. I can feel fab one minute and ready to pass out the next, even though nothing has seemingly changed.

The pain is in muscles, tendons and ligaments – not joints – and is caused by changes in chemicals in the brain and nervous system. Symptoms are very wide-ranging and the severity of symptoms varies from person to person. This is just info about how it affects me – I'm affected more by fatigue than pain.

What are the main symptoms?

- I run on about 70% energy compared with average person
- This can suddenly drop to about 20% - can't easily walk, talk, think etc. – body shuts down.
- Have migrainey headaches a lot of the time
- Have a useless body thermostat so am always illogically hot and cold
- Super sensitive bladder – like being a girl times 100!
- Really bad pain in shoulders and hips
- Mega sensitive skin – a pat on the arm can feel like a punch
- Painful bloating/stomach cramps
- Depression and anxiety – both are well under control but still often mean that I can't face seeing people
- Being so drained I can't join in conversation
- General clumsiness/lack of balance
- Complete brain fog – can't connect words/ideas
- Numb fingers and bad shooting pains in arms
- Restless leg syndrome – makes it hard to sit still
- Totally rubbish sleep – fall asleep so easily but then wake up 5 or 6 times a night

- Crying! When I'm too exhausted to trying to hide how tired I am
- Feeling all the time like I've just had an awful bout of flu and am in that weak recovery stage when its too soon to go back to work
- Generally feeling under the weather, shattered, useless and out of sorts

What I worry people are thinking

- Everyone gets tired so don't be so dramatic
- You were fine a minute ago. I think you're making it up when you remember to
- That can't possibly hurt as much as you're making out
- Yesterday you had loads of energy and could do much more challenging things – you're just not trying as hard today
- You want to feel this way/you're giving in to it – you're obviously not trying to help yourself
- It's all in the head

What helps?

- Knowing that people understand – then I stop worrying as much and worrying less reduces symptoms
- Accepting that I have to slow down my overall lifestyle a bit – then I am more able to push myself for special occasions. This is work in progress.
- Being able to sit down occasionally e.g. getting a cup of tea while out and about
- Going to bed if I need to
- Sometimes being able to sit in on a conversation without contributing, but knowing that people understand that I'm not being antisocial

What makes it worse?

- Trying to hide it - this uses valuable energy and make me worry so much that people think I'm rude or bored
- Trying to pretend to myself that I can keep going at 100% or that exercise/activity is going to help. Sometimes it can. But not when I'm that exhausted
- Overdoing it – I can run on adrenalin for a bit but the come down is long and dramatic ha! But sometimes it's worth it.

Article Submitted by Linda Tatham

Christmas Carol Concert and other Donations

Donations to MESiG this year.

We have had so much generosity from people backing MESiG over the years, Linda Tatham's son, Nick has run marathons and half marathons, several times for the last few years and collected hundreds of pounds for us. We are so grateful to him.

Guy, bravely did a Skydive for MESiG last Autumn and donated several hundred pounds to us

However, last Christmas, Mark, the Choirmaster of Bethesda Community Choir at Dinas Powis, chose MESiG and The M E Trust, to donate the proceeds from their Christmas Concerts. They held 3 Carol concerts; MESiG attended two of these events helping to raise awareness of ME. True to their promise, they gave us a very generous donation. The choir perform every year and donate to a different charity each time. A Big Thank you to Mark and Bethesda Choir for all their kindness. There is more about the choir in a previous issue.





Also Bryan Brewer, who regularly donates to MESiG each year, generously gave again this year. I met Bryan and his late wife, Enid many years ago. Enid suffered from M E and Bryan looked after her. Sadly, Enid contracted another illness and died some years ago. I remember her with fondness. Enid was a lovely person always more concerned about other people than herself, especially my own daughter. Thank you Bryan for your kindness.

Dee Penny

Lyme Disease Talk at the Senedd by Mark Morgan

MESiG are part of the Wales Neurological Alliance who arrange Cross Party Group Neurological Conditions meetings at the Senedd, chaired by Mark Isherwood AM.

In December I was invited to give a 10 minute presentation on Lyme Disease.

Here is a copy of my talk:

Lyme disease is a bacterial infection caused by the bite of an infected tick. The name of the bacteria is *Borrelia*. The bacteria can be a spiral shape, so generically it is known as a spirochaete. This is generally agreed by the whole medical profession, however there is much disagreement beyond these simple statements. The World Health Organisation for instance, say that Lyme disease can also be contracted by the bite of an infected mosquito or an infected horsefly. [Ref \[1\]](#)

There have been studies in the UK into the prevalence of infected ticks.

In 1998 Professor Guy at Singleton Hospital in Swansea did a study in which he found that 37% of ticks in South Wales carried the *borrelia* bacteria. [Ref \[2\]](#) He recently told me that this was a small study but that its results did concur with a similar unpublished study carried out in the south of England.

More recently in 2017 the University of Bristol as part of the Big Tick Project, carried out a study across the UK where the average number of infected ticks was 2%. [Ref \[3\]](#)

I take from these two studies that it is difficult to say with certainty the exact risk associated with a tick bite but that there is a danger.

One possible symptom of Lyme disease is a bulls-eye rash. This symptom should be recognised as a definite and unambiguous criteria for the diagnosis of infection with the *Borrelia* bacteria. Unfortunately doctors don't always treat this symptom as Lyme disease. Even more unfortunate is that less than 50% of people bitten by an infected tick will develop a Bulls-eye rash, or any rash, so doctors are left to make a diagnosis based on patient reporting being bitten by a tick. [Ref \[4\]](#) However not everyone will notice they have been bitten by a tick.

Doctors tend to rely on a positive blood test in order to make a diagnosis. There is much dispute about the sensitivity and specificity of Lyme disease blood tests.

Unlike the two studies I have just referred to, that relied on a PCR test which look for the *Borrelia* DNA, the standard Two Tier test for Lyme disease looks for a limited number of antibodies which the immune system produces in response to an infection based on a specific strain of *Borrelia*. [Ref \[5\]](#)

The problem here is threefold.

Firstly if the test is carried out too soon then there has not been enough time for the immune system to have developed an immune response. [Ref \[6\]](#) Secondly there is an issue in that some doctors say Lyme disease can take different forms and enter into cells to avoid the immune system. [Ref \[7\]](#) Thirdly some doctors say that the bacteria, in a similar

way to HIV, can inhibit the immune system response so the antibodies are not produced. [Ref \[8\]](#)

Therefore an negative Two Tier Lyme disease test could be false negative. Some states in the US are legally bound to declare to patients who have a negative Lyme disease test, that this does not rule out the possibility of having Lyme disease. [Ref \[9\]](#)

We need better testing but in the meantime doctors needs to be trained to consider a clinical diagnosis of Lyme disease which is how doctors have diagnosed illness for thousands of years.

I'm concerned about the possibility of transmission of Lyme disease by the transfusion of infected blood. I recently had a letter from the Health Minister to say that there is no evidence that Lyme disease is transmitted in this way. There is however evidence of infection in blood supplies. A study was carried out in 2015 that showed 4.2% of blood in Scotland was infected. [Ref \[10\]](#)

I would call on the Welsh Assembly to urgently assess the risk infection by contaminated blood. Of course any assessment based on antibody testing would not be sufficient based on the limitations of this type of testing.

What happens to people diagnosed with Lyme disease ?

The NHS treats Lyme disease with 2 to 3 weeks of doxycycline. [Ref \[11\]](#) This is not sufficient. The way antibiotics work is to attack the bacteria when it is reproducing. The reproduction cycle of borrelia is approximately a month, so treatment for over a month is necessary if not longer. [Ref \[12\]](#)

Late stage or chronic Lyme disease is a much more difficult proposition. [Ref \[13\]](#) At this stage the bacteria has colonised the body. It tends to migrate to soft tissues, away from the bloodstream so it's pot luck as to whether it affects the brain and the central nervous system (neuro borrelliosis), the heart (lyme carditis) or the joints (lyme arthritis). [Ref \[14\]](#)

At this point I would like to say point out that some doctors still say chronic Lyme disease doesn't exist. I would refer such doctors to a list of articles compiled by Dr Bransfield, a former President of ILADS. This is a list of 700 articles which provide evidence that borrelia can persist in the body. [Ref \[15\]](#)

I'm aware of someone associated with the Wales Neurological Alliance who was very ill with Lyme disease and was successfully treated in Cardiff with long term intravenous antibiotics. Unfortunately in my experience this is the exception. Many people in the UK have to rely on foreign blood tests in order to be diagnosed with Lyme disease. They then have to seek expensive treatment abroad and they are effectively medical refugees. I'm aware other young student living in Cardiff who has recently travelled to Europe for antibiotic treatment.

Treatments for Lyme disease range from antibiotics to less conventional herbal treatments and managing symptoms using diet. The only thing that has helped me is aggressive treatment with intravenous antibiotics however this hasn't cured me.

Some doctors say that longer treatments with a combination of antibiotics, intravenous or oral offer a better prognosis. [Ref \[16\]](#)

There are a number of groups which supports people with Lyme disease in the UK.

Namely :

Lyme Disease Action [Ref \[17\]](#)

Lyme Disease UK [Ref \[18\]](#)

VIRAS [Ref \[19\]](#)

Caudwell LymeCo [Ref \[20\]](#)

visavis symposium [Ref \[21\]](#)

Fight Lyme Now [Ref \[22\]](#)

These groups don't always see eye to eye.

The NICE guidelines on Lyme disease are currently in the process of being drafted. A draft of the new guidelines was recently produced. All of the Lyme groups have commented on these new guidelines and they are united in their condemnation of the proposed changes to the guidelines. [Ref \[23\]](#) Additionally doctors have condemned these draft guidelines which restrict the treatments that can be given and do not explain the complex clinical criteria needed to diagnose Lyme disease. [Ref \[24\]](#) The guidelines continue to support the two tier lyme disease test which is not reliable.

How widespread is Lyme disease ?

In the UK the official annual number of cases of Lyme disease is estimated to be between 2000 and 3000. [Ref \[25\]](#)

According to official figures on lyme disease it is about 10 times more prevalent in France than in the UK and 100 times more prevalent in Germany. [Ref \[26\]](#)

Caudwell LymeCo have estimated that there are up to 45,000 cases in the UK but yet again no one really knows not least, since Lyme disease is not a notifiable disease. [Ref \[27\]](#)

Many people with Lyme disease have previously been given a diagnosis of ME. [Ref \[28\]](#) In the UK there are 250,000 cases of ME of which there are 12,000 are in Wales. [Ref \[29\]](#) ME is a diagnosis of exclusion, however lyme disease is not routinely considered and tested for before making a diagnosis of ME.

To be clear I'm not saying all cases of ME are caused by Lyme disease but, without a reliable test, many cases could involve Lyme or a Co-infection associated with Lyme disease. The NICE guidelines for ME allow for Lyme disease to be considered as a differential diagnosis but in a very restricted manner. [Ref \[30\]](#)

Lyme disease has been dubbed the Great Imitator; like syphilis, also a spirochaete, it manifests itself in many different ways.

Doctors have found evidence of Lyme disease in patients with multiple sclerosis, motor neurone disease, dementia an other neurological conditions and also in cases of stillborn babies. [Ref \[31\]](#) [Ref \[32\]](#)

Again to be clear I'm not saying anyone with these conditions are infected with the Borrelia bacteria but I am urging that Lyme disease should be investigated thoroughly using DNA techniques to look for infection by Borrelia or one of the associated co-infections. [Ref \[33\]](#)

Many of these neurological conditions are deemed incurable and treatment is limited to managing symptoms. I believe the medical profession should consider whether these conditions are caused, triggered or related in some way to an ongoing infectious disease process. The treatments being used for Lyme disease may be helpful with these conditions.

The UN is currently due to update the International Classification of Diseases. The limited codes to cover Lyme disease have not been updated for 40 years. Jenna Luche-Thayer has submitted a proposal for codes to be added to cover the extensive number of ways Lyme disease can manifest itself. She is saying it is a human rights abuse for people with Lyme disease to be denied treatment. [Ref \[34\]](#)

Lyme disease has been debated at Westminster [Ref \[35\]](#) and in Holyrood [Ref \[36\]](#). Worldwide Parliaments are also debating Lyme disease. [Ref \[37\]](#)

I would urge the Welsh Assembly to consider debating the issue of Lyme disease in the Senedd.

A copy of this, including references, can be accessed using the following link :
https://drive.google.com/open?id=112MoWZAWA-cVvzXC_a9wvGpidM1QeETe

Friends of Nant Fawr have kindly included a poster raising awareness about Lyme disease on their new notice boards :



MISSING MILLIONS EVENT IN CARDIFF 12TH MAY 2018



We crossed our fingers and toes and prayed for fine weather for our Missing Millions Demo., and lo and behold our prayers were answered and the weather was Great! We had all done our bit to bring it all together, and ONE HUNDRED CITIES WORLDWIDE WOULD BE DEMONSTRATING on the SAME DAY. Among them, London, Birmingham, Edinburgh, New York, San Francisco, cities in Japan, Australia, Europe...many many more. We were in effect, telling Governments and Health Boards, particularly the Welsh Government here, that we won't go away until there is True Awareness of the seriousness of ME/CFS, Fibro and Lyme Disease. ME/CFS has been ignored for many years, and much too long, and we need appropriate treatment by a Specialist Clinic and importantly, Government backed Biomedical Research.

At one stage we thought we would have to pay Cardiff City Council £200 plus for a site for our Demo. But after a lot of hard work by Emelyne our Chair, she and her father were able to negotiate with the Manager of St David's Centre for a prime site at The Hayes, actually owned by the Centre, and outside the Library. Thanks to them, we didn't have to pay anything at all. We had an excellent position there in the busy thoroughfare.

Extra T shirts were ordered with MISSING MILLIONS emblazoned, posters and badges were purchased, and shoes were gathered from various people

to represent our members who were housebound or even bedbound. Mary and Dennis produced the various labels that we needed for the shoes, describing the difficult lives of some of our members. Mark brought the excellent placards made for a previous Demo, and also phoned an ITV Director who had promised to publicise and interview us at this time. Peter had told him about our aims at the 2016 Missing Millions Demo and he had promised to support us.. Our lovely young Uni' students who were helping with publicity and the media, also had arranged for us to be interviewed by BBC Welsh Radio early on the Saturday morning, but at the last minute, they pulled out !

However ITV came up trumps and came to interview Emma Jayne at her home at 11am that morning. She did so well, explaining the problems that the illness cause in her life and it was really sensitively portrayed. Then at midday their camera man came to us again, and filmed everything on site.



He continued the interview with Emma Jayne, and also interviewed Emelyne, who voiced our desperate need for medical services here in Wales, where there is nothing to help sufferers at present. Then it was all shown on the ITV News that evening! Hurray! It was a shortened version, but the message we wanted, came over well. We are so grateful to ITV !

When we had donned our Red T shirts , set up the tables, put out the posters, and Mark had put out his placards, we were ready to engage with the public. We were a bright colourful spectacle ! All in Red ! People stopped to look and talk, and we explained about the illness and our problems in getting treatment and the need for research etc. We were also able to tell them about MESIG and the support we endeavour to give our members; Our monthly meetings, the website we have, newsletters twice a year (be this one late I'm afraid) and visits to people on their own and more.

Particularly the support that Miriam is able to give with form filling and at Benefit Tribunals for members. She is our expert; she is wonderful and works tirelessly for several of our members. Twice on the day her advice was needed. So glad you came Miriam ! We chatted to a couple of Doctors, one of whom did not know much about M E. But we were there to educate and spread Awareness..

To crown our day, our faithful supporter, Julie Morgan A M came to see us and say a few words about us, on camera, and she brought her lovely grandson too. Thank you so much Julie, and everyone who contributed to a very successful Day.

D P

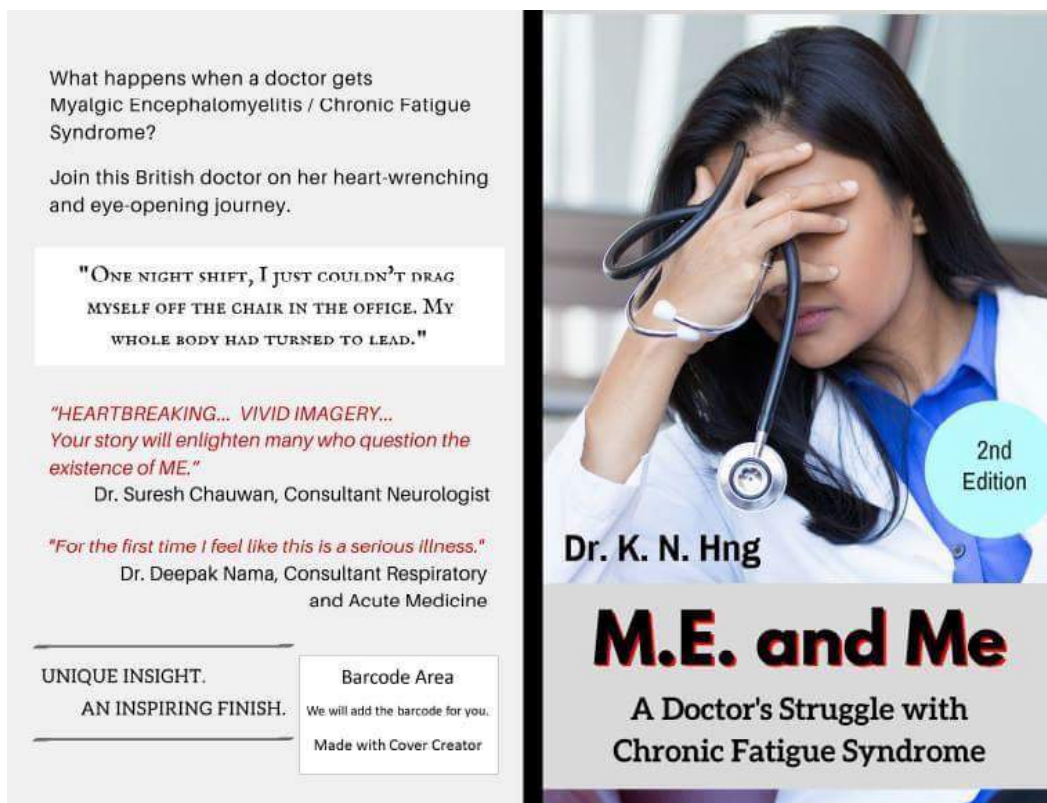


Book Recommendation

I was all set to become a Consultant Gastroenterologist. Except that I wasn't good enough. I wasn't fast enough, I wasn't productive enough. Not to mention the fact that one night I ceased to function completely. That is a dangerous situation indeed, when you are the most senior physician on duty in a 950 bedded hospital running on a skeleton out-of-hours staff. What is one to do, when you have no idea that you are seriously ill, in a world where not doing isn't an option, and tiredness isn't a reason?

My story explains what's wrong with you. Get one for you doctor - now they will believe you. Get some for your friends - now they will understand you. Get one for your MP - and help change policy.

Dr Hng is going to send MESiG a complimentary copy of the book for our library.



This book is available via Amazon : <https://amzn.to/2G4bb8V>

National Doughnut Day donation!

On Monday May 14th, staff and students at Celtic English Academy in Cardiff, had some fun marking National Doughnut Day!

Packets of Sainsburys' bakery doughnuts were bought and shared in the student lounge. Then there was an epic contest between a German student and Celtic's Director of Studies to see how many doughnuts they could eat in a minute. If you've ever seen the TV programme Man vs. Food, well... that can give you an idea of what those 60 seconds entailed...

Celtic English Academy welcomes students from around the world to study English. Over 50 different nationalities take short, mid- or long- term English language programmes at the academy each year, coming from all over the world to Wales; Japan to Brazil, France to Saudi Arabia. Students come to improve their level of English here in the UK, whether that be for their education, their career or the simple pleasure of being able to communicate more easily in our global world of today.

During their time studying English they also enjoy exploring Wales, as well as getting to know the British and Welsh culture. Days like the 'National Doughnut Day' are fun days to break down communication barriers and give staff and students a chance to socialise in between their study or training programmes.

Celtic's Director of Studies kindly decided to donate the collection pot raised from the doughnut eating contest towards our organisation, MESIG. £28.84 was donated to ME Support in Glamorgan. We are very grateful and send a big THANK YOU, as the organisation relies on donations and every penny counts to ensure that MESIG can continue to run and offer its' services, events and support for our members.

If you have any ideas to do a fundraiser for MESIG, do let us know! Perhaps your family, friends, partner or carer could lead a fundraiser, big or small in their workplace or school?



MESiG EVENTS



- 02.07.18.** No support Group meeting in lieu of AGM
- 07.07.18** AGM with speaker Jill Shelton from the Community Health Council 2-5pm
- 06.08.18** Tea In The Park 2pm Roath Park Cafe
- 03.09.18** Sheila Damon (hypnotherapist) to talk about sleep overcoming sleep problems.

General Data Protection Regulation (GDPR)

The General Data Protection Regulation (GDPR) has come into effect. It concerns the information we hold about our members. MESiG holds information about you and with that, you also have the improved rights regarding your data.

You need to be informed of what information we hold on you and your rights.

What is this all about?

As you may be aware, Data Protection legislation is changing in the UK with the advent of the General Data Protection Regulation and the forthcoming Data Protection Act 2018.

We are therefore contacting you to confirm the data we hold about you as a member of MESiG, the reasons and lawful basis for doing so and the arrangements that are in place to ensure its security.

MESiG is the Data Controller for the purposes of managing the data associated with your role as a member. We take your privacy seriously and have safeguards in place to ensure that your data is kept securely, accessed only by those committee members who need to process it, and kept for no longer than necessary.

What information does MESiG hold ?

In line with the requirements of the ICO, we record the following information about you:

- Your name.
- Your date of birth
- Your contact details, which may include address, email address and phone numbers(s)

All the above details are processed under the lawful basis of Legal Obligation (ref. GDPR article 6), as they are required to allow us to manage the relationship with you.

MESiG collects this information in a variety of ways. For example, data is collected through application forms and correspondence with you

Data is stored in different places, including in a spreadsheet and in MESiG's email system.

Who has access to data?

Your information will be shared internally with committee members, if access to the data is necessary. Where required the Data Protection Officer may also have access if appropriate for processing subject access request or investigation of any potential data breaches.

The organisation will not transfer your data to countries outside the European Economic Area.

How does MESiG protect data?

MESiG takes the security of your data seriously. MESiG endeavours to try to ensure that your data is not lost, accidentally destroyed, misused or disclosed, and is not accessed except by committee members in the performance of their duties. We also review our processes, to help us keep improving how we manage data, and to learn from best practice developed and used by other organisations.

For how long does the organisation keep data?

MESiG will hold personal data of our members until membership lapses.

Your rights

You have increased rights as a data subject under the GDPR, as shown below:

- The right to be informed
- The right of access
- The right to rectification
- The right to erasure

You have the right to make a complaint if you feel that MESiG is using your personal identifiable information unlawfully and/or holding inaccurate, inadequate or irrelevant personal identifiable information which, if used, may have a detrimental impact on you and/or has an impact on your rights.

NICE Scoping Workshop – London – 25 May 2018

After on-going pressure and advocacy in recent times, the National Institute for Health and Care Excellence (NICE) in England is reviewing the national guidelines for ME / CFS. This is excellent news! It will then be up to the devolved administrations and local health boards to determine how they will apply the revised guidelines due to be released in October 2020.

The review has been prompted by widespread concern (and evidence from the PACE trial) that many sufferers find that the current guidelines (i.e. CBT - Cognitive Behavioural Therapy and GET - Graduated Exercise Therapy) actually make the condition worse, with many suffering more.

My Dad and I recently attended a NICE ME/CFS **guideline scoping** workshop, on behalf of MESIG, in London on 25 May. Leading medical professionals including Dr. Charles Shepherd, Dr. Paul Worthley and Dr. Raymond Perrin were in attendance, along with members of organisations and groups across the UK. There were about 60 individuals present during the meeting lasting from 13:30 – 16:30.

Members of NICE noted that they were taking a far more consultative approach to reviewing this guideline due to the controversy surrounding the existing advice and informally welcomed the constructive and collaborative approach of the sufferers, carers, parents and numerous health care professionals who participated in the workshop. (We'll see this in their choosing to welcome four lay members onto the NICE committee, instead of the usual two.)

The workshop reviewed a draft scoping document and the proposed composition of the Review Committee (which is due to be formed in the coming months). Views expressed ranged from using a better definition of ME/CFS and identification of the illness and nature for diagnoses along with the remit for management and care of the condition. The encouraging attitude to welcoming all views extended to flagging up a recruitment process for the Committee to include four lay representatives and requesting particularly ideas on how to best access and represent the views of those most severely affected by the condition.

The next steps include publishing the revised scoping document and the Review Committee recruitment process on June 21 (see notes for timeline). The aim is to publish “clinical and cost effective” guidelines by October 2020. We have asked for regular progress reports and an earlier sight of draft

guidelines. The public are invited to comment on the scope guideline in the coming weeks. See here to do so and to see more information and documents:

<https://www.nice.org.uk/guidance/indevelopment/gid-ng10091>

Everyone can be involved with commenting on the draft online and they welcome the sharing of information like research papers or relevant, evidence knowledge they may not be aware of. All stakeholders are encouraged to consider individuals that might like to apply to be on the Review Committee. If you think you're suitable, or know someone who is, you're welcome to ask us more.

Finally – we were delighted to see that the Vice Chair of the Review Committee is Baroness Ilora Finlay of Llandaff. The Baroness is a Welsh doctor, past President of the Royal Society of Medicine and someone who has done much to improve healthcare in Wales and beyond. We are hopeful that the NICE guideline re-writing process will be in good hands with Baroness Ilora at the helm.

Emelyne (Chair – MESIG) and Phil Burkhard (Emelyne's father, MESiG volunteer)

Notes:

Provisional Schedule

Committee member recruitment	21 June 2018 - 19 July 2018
Draft scope consultation	21 June 2018 - 19 July 2018
Draft guidance consultation	14 April 2020 - 26 May 2020
Expected publication	14 October 2020

Email enquiries

If you have any queries please email CFSME@nice.org.uk

MESiG Subscriptions

Are Now Due for May 2018-2019

You can subscribe on our website:

<http://mesupportinglamorgan.co.uk/subscription-form-new-members/>

Or by post payable to 'MESiG' send to 20 Theobald Road, Canton, Cardiff CF5 1LP

Your subscriptions go towards enabling ME Support In Glamorgan to keep going. We are a charity which is run by unpaid volunteers only. We have outgoing costs for the printing of the newsletter, postage, hiring of the hall monthly for the support group meetings, teas and coffees, petrol costs for home visits and appointments, insurance, etc.

We attend meetings and raise awareness wherever possible.

Up to date we have been blessed by your donations and those who have fundraised for us but we need funds to keep coming in. We do welcome anyone who is willing to fundraise for us. This can be as simple as a coffee morning or asking a work place to donate for a day.

It would also help if you can send subs as soon as possible. If you wish to stop subscribing please let me know, so I can take you off the membership list. We keep making allowances for those who haven't paid as we know that people forget etc. So it would help if you just clarify your situation. We don't want anyone to miss out due to the effects of ME.

Many thanks

Email: mesigwales@gmail.com

Contact and Support

ME Association

7 Apollo Office Court,
Radclive Road,
Gawcott,
Buckinghamshire MK18 4DF
Tel: 01280 818968 9.30am - 3pm
Email: admin@meassociation.org.uk
Website: www.meassociation.org.uk

Brame

30 Wimmer Avenue
Winterton-on-se
Great Yarmouth
Norfolk NR29 4BA
UK
Tel/Fax: 01493393717
Email: info@brame.org

ME Connect

DO YOU NEED HELP?

ME Connect is the telephone and email helpline service of The ME Association. It provides support for people with ME and those who live with or care for them. ME Connect provides a safe and understanding opportunity to people with ME so that they know they are being heard and understood.
Tel: 0844 576 5326 10am-12noon, 2-4pm and 7-9pm every day
Email: meconnect@meassociation.org.uk

National ME Centre

Long Term Conditions Centre via Kings
Park Estate
Gubbins Lane
Harold Wood
Romford
Essex, RM3 0AR
Tel: 01708 576250
Email: nmeccent@aol.com
Website: www.nmec.org.uk

Action for M.E.

42 Temple Street,
Keynsham,
Bristol BS311EH
Tel: 0845 123 2380 / 0117 9279551
Mon - Fri: 9am - 5pm
Email: admin@actionforme.org.uk
Website: www.actionforme.org.uk

MCS Matters (Multiple Chemical Sensitivity)

Gordon D McHenry
UK Co-ordinator
Global Campaign for recognition of mcs
Website: www.mcs-international.org
Tel Helpline: 01446 794 700
Tues & Thurs 2-4pm and 6-7pm

25% ME Group

21 Church Street, Troon
Ayrshire KA10 6HT
Tel: 01292 318611 9.30am-5pm,
Monday- Friday
Email: enquiry@25megroup.org
Advocacy worker: 01415702938
11am-3pm Wednesday and Thursday
Website: www.25megroup.org

Association of Young People With ME (AYME)

Tickford House
Silver Street
Newport
Pagnell MK160EX
Email: helpline@ayme.org.uk
Helpline Tel: 03302211223 Mon-Fri 10-2pm
Website: www.ayme.org.uk
Main Office Tel: 01908379737

CONTACT AND SUPPORT.

Fibromyalgia Association

FMA UK
Studio 3007
MileEnd Mill
12 Seedhill Rd
Paisley PA11JS
Helpline Tel: 0844 887 2444 (10am - 4pm
Mon - Fri)
Email: charity@fmauk.org
Website: www.fmauk.org

Welsh Association of ME & CFS Support (WAMES)

Helpline Tel: 029 20515061 (Mon-Fri
before 7pm)
Email: enquiries@wames.org.uk
Website: www.wames.org.uk
WAMES Young People
Email: michelle@wames.org.uk

C.L.I.P- Coping and Living in Pain.

Tel: 02920693852
Email: pain.help@ntlworld.com

Useful Contacts

Benefits: Citizens Advice Bureau
Website: www.citizensadvice.org.uk
Disability Advice: 08088003333
Website: www.scope.org.uk
Diverse Cymru: 02920368888
VEST: for help with local lifts and transport
for the disabled
Tel: 029 20490325 and ask for an information
pack.
Carers Line 08088087777
The Samaritans: 116123

The Young ME Sufferers Trust

PO Box 4347
Stock
Ingatstone CM4 9TE
Tel: 0845 003 9002
Website: www.tymestrust.org

Association for Myalgic Encephalomyelitis

Website: www.afme.org.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

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

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M.E.S.I.G

(M.E. Support in Glamorgan)

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Cardiff CF5 1LP

Telephone: 029 20196277

Online:

mesupportinglamorgan.co.uk

Email:

mesigwales@gmail.com

Have something to contribute?

Please send us anything you wish us include in the next newsletter e.g. poem, recipe, personal stories, questions etc.

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 treatment.