



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

MESiG Christmas/ “Hoot”enanny Party

Saturday 8th December
2018 2pm-5pm

NB There will be no Monthly Support
Group meeting on Monday 3rd December

Bethel Community Church
Llangranog Rd
Llanishen
Cardiff
CF14 5BJ



The Owl Sanctuary will come to talk to us and will bring some of their lovely rescued Birds.



All welcome!

Members • Friends • Family • Carers • Partners • Food will be provided •
Bran Tub *Please bring a gift up to £5 wrapped which goes in a box and we exchange gifts.

Please contact us to let us know you are coming or if you need a lift:

Email: MESiGwales@gmail.com Tel: 029 20196277

Text: 07930 535443

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Message from Emelyne

Dear MESiG members and friends,

It is firstly with warm greetings that I write to you as the days darken and winter draws in on us all. Some of you know me more than others, during the 1 year that I have been in the position of MESiG Chair, and the 5+ years that I have been a member of the MESiG support group, of which I've found to be invaluable knowing the people, connections and information sources it provides.



It is with regret, that after a year as Chair of MESiG, I am stepping down with immediate effect. It is because I need to preserve my health, understandably, plus it has proven to be a lot for me to manage my professional job as well as my volunteer role with MESiG, as well as the illness itself!

It has been a positive year on a wider scale for MESiG, with notable events being: the screening of Unrest for Cardiff University Medical Students, Millions Missing Wales demonstration held in Cardiff city centre and the recent Unrest at the Senedd event, to bring our calls for action to the forefront to be heard by the Welsh Assembly (see the articles further on for more about this).

MESiG has a tremendous heart at its core, with individuals selflessly supporting sufferers with home visits, benefits forms, accompanying to appointments, as well as running the monthly support meetings in Llanishen, and this bi-annual newsletter, over the years. The basic functioning of MESiG will continue.

We are however in a position now of calling out for any support that you or anyone could offer with the leadership, or coordination, for the Group's activities. Perhaps you have social media skills and would like to do this from home? Perhaps you know someone that has recently retired but that has a varied skill-set who would like to do some charity work and can help us coordinate? Perhaps you are unwell but your family and friends would be delighted to help at times of the year when there are events like Millions Missing? Do let us know.. however big or small.

Officially, the positions of Chair, Vice Chair and Website Facilitator are open.

We always need fundraisers too! So if a workplace, local school or church, or just you and your friends would like to do something to raise money to help our Group's activities continue to thrive, and support people with ME/CFS, Fibromyalgia and Lyme Disease in Wales, we would be ever grateful.

I am glad that I've been able to give this year of service to MESiG, in the capacity of Chair, and will stay on the 'radar' to help where and when I can.

I hope that you will enjoy this latest newsletter and particularly the upcoming Christmas Party on Saturday 8th December – where there will be a beautiful, furry surprise to share some Christmas joy!

Warmly,
Emelyne

Afternoon Tea at Llwynfedw Park 16th May 2018



Llwynfedw, in the Heath area of Cardiff, is a delightful location where tennis and bowls are played. I had been to a couple of celebrations there in the past. The Park had been taken over by the local residents, together with their local councillor.

I went to see Pam who was in charge of the bookings (after consulting with the committee) and she agreed that MESiG could have the Bungalow at Llwynfedw for a Saturday afternoon...free of charge...just a small deposit, returnable if we didn't do any damage?! I readily agreed and handed over the money. We would have our afternoon Tea, Saturday 9th May. However, we learned later that the Bungalow was having an electrical update, so we ended up having the Tea on the 16th to make sure it was all complete.

Mary and I planned the food together – and I put things by for the raffle. Members are very kind and donate lovely things. But unfortunately, the week before the event, I had a problem with my back and couldn't walk. What

would I do? Here I was trying to organize this Afternoon Tea and I wasn't mobile?! I needed extra help! Then I suddenly remembered that Rob, our past Secretary and Annette his wife, had said they would help if needed. I rang them and they readily agreed that they would come for a couple of hours. Relief! Phew! On the morning I managed to prepare the food sat down in my kitchen, with Peter's help. When we had finished, he put everything, including Basil and my wheelchair in the car, and off we went to Llwynfedw.

When we arrived, not only Rob and Annette were there, but Mary and Dennis, Mark and Emelyne's mum, and other members were there too. I just had to watch from my wheelchair?! It was nice to see the men in the kitchen though, giving out the teas and coffees.. Ha! There was a bowls match going on outside and things were generally busy outside. We set too, blowing up balloons and Peter and the others set out the food and drink. Mark sold the raffle tickets. We had people come and they soon settled in and tucked into the food and drink. Basil was pretty good, and was pleased to greet everyone and get a pat and a titbit in return.

When they stopped serving the drinks, Peter was able to take Basil for a well deserved walk around the park, and by the time they returned, and most visitors had gone, we gathered around and had some food and drink ourselves, and discussed what had been happening over the year. The film Unrest, and the cancelling of the NICE guide lines. But above all, the failure of the Welsh Government to provide us with a Clinic. The time had gone quickly, and I now had to watch everyone clearing up, again feeling very guilty that I had organised the Tea and then had to let everyone else do the work. Oh Dear! So a Big Thank you to Everyone for their support and hard work. We even collected some money for MESiG. Not a large amount of money was raised, but it all adds up, and thanks to all concerned.

D P

Poem by Jill Berret

A Horizontal Life

I am horizontal,
not whilst resting from furious waves, my body etched by
the movement of sand,
nor absorbing chlorophyll from newly mown grass as
I read my book.
There is no photosynthesis for me, no luxury lies in my lying.

I am propped and pinioned, padded by pillows, muscles
and joints soothed, softened by silver grey cushions.

You may say this is a strange life,
but I am one of millions.

We are rocky outcrops scattered,
left off the map.

We are the disappeared,
not by war or revolutions, famine or hunger

but by viruses, bugs, bacteria,
by caring too much and loving too long,
by throwing ourselves in front of the tanks.

If you want to seek us out, go look
in beds, on sofas, on floors, in hospitals,
in darkened rooms, in wheelchairs,
on every continent you will find us, linked by screens,
and the thread running through, our words travelling
where we cannot go.

Inside our bodies, inside our cells, inside our spinal chords and organs,
a strike has been called, our bodies closing down.
In cupboards sit boots and outdoor shoes waiting to be worn,
in lofts are racquets running out of patience,
in wardrobes are dresses dreaming of dance.

But inside I am growing back a life,
my heart vibrates to the sound of Japanese drummers,
the rhythm of rapping awakens my brain,
movement of a kayak on transparent water reflects on my skin.

Outside I am horizontal.
Inside I am climbing.

TEA IN THE PARK by Basil

6th August 2018

I always know when something is going on in our house. It was Monday and there was a lot of activity. Mum and dad were going out somewhere ?! So I was determined I wouldn't miss an outing and stayed close on their heels. But I soon got told off for getting under foot, so I hid under the chair and waited. Next I heard mum on the phone talking to Salvo. Ah! She was reminding him that MESiG would be visiting today for the Party. Hurray! We were going to Roath Park! I got so excited I started barking! Then I got told off again!



Mum gathered up a big bag for the Raffle. I knew it was the raffle because there was a big Teddy poking out of the top. I had tried to drag it out to play with, but she saw me and put it up high – spoilsport! Anyway, when they were eventually ready – I always have to wait for them, especially dad who takes an age, we piled in the cars. Mum went to pick up Peter Bax and I went with dad. When we arrived at the lake, dad parked the car and took me for a quick walk.

When we came back to the cafe mum and some of their friends from MESiG had already gathered in the conservatory. I know mum loves it here as she can see all the wildlife through the large windows, whatever the weather. But I like to run outside and chase the squirrels – but some hope – they are too fast for me; they scamper up the nearest tree, but I always have a good try?!

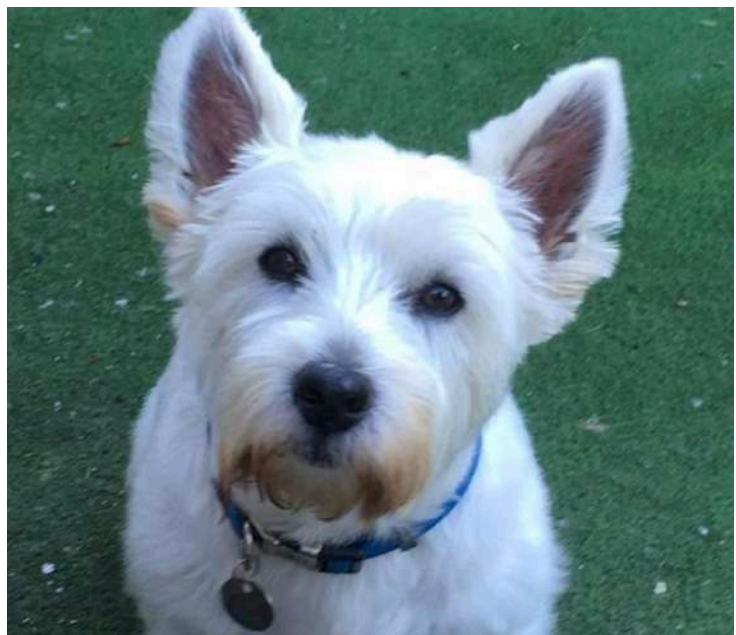
Anyway dad got some coffees and cakes and mum got a bowl of water for me. Salvo usually lets me in the cafe and so I get lots of pats and fuss, and I love that. More friends arrived and there were warm greetings and news exchanged, and more teas and coffees were drunk. After a while, mum set

about selling the raffle tickets, and I settled down under the table for a snooze. There was chatting and laughter and more pats and treats for me. Salvo keeps treats for me and my friends that come in. Then mum called the raffle ... and last of all, someone won the Teddy. Blow! And it wasn't me! Foiled again! After what seemed an age to me, it was time to go. They all said that they had enjoyed it and looked forward to meeting the following month.

Now it was my turn at last, and I was ready for another run in the park outside. Wuff!

PS. I disgraced myself at the August committee meeting at Mary and Dennis's home. I fell in their pond and got covered in mud. When I came in and walked all over the carpet, mum was so furious! She shouted and I was mortified, and dad had to take me out to the car. Mary was so kind and laughed. As soon as I got home dad put me in the bath and scrubbed me. Ugg! I won't do that again! A couple of days later we took some flowers to Mary to say 'sorry'.

Basil



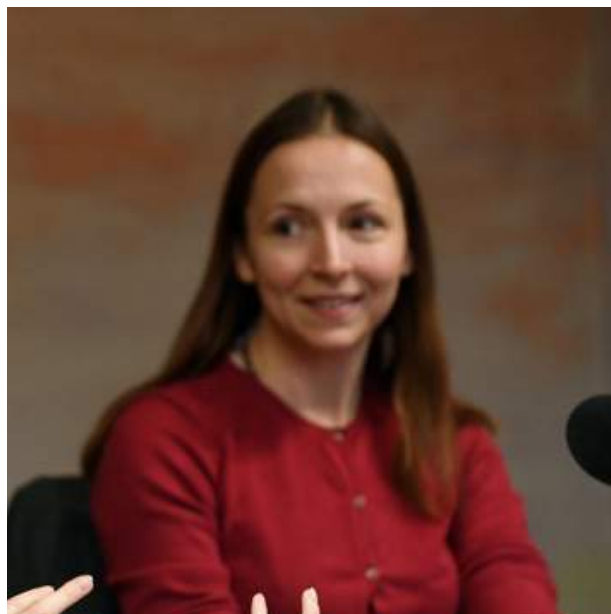
Call for willing patients

for Cardiff University medical student projects.

Nina Muirhead, doctor and sufferer of ME is working closely with the Dean and Faculty of Medicine at Cardiff University. She is trying to progress formal teaching of the subject.

Nina is calling out to any patients who would be willing to be involved in a project by a medical student.

The student projects are in March-April 2019 3rd years and May-June 2019 4th years.



It is so important that the patient 'voice' is heard properly by our young and trainee doctors, and in terms of syllabus it is going to be included under 'Understanding People'.

For the small scale project, students self select their special study modules so the hope here is that they will already have an interest in ME and be making an effort to engage with patients and show they care. It is possible that interested students may already know a friend or relative with ME and we hope that they will be showing kindness and compassion towards patients.

Projects may include:

- 1) Student 'case study' on a patient looking at the daily challenges they face - they would visit the patient in their home environment
- 2) Student video records 2-3 minutes of a small number (4-5 patients) or patients' send a short 3-4 minute video blog describing their experience of the illness which would be edited by students into a short 10 minute video to show their year-group. Students would assess 'before' and 'after' impressions of the illness of fellow students to raise awareness amongst their peers (a similar project was done previously on depression by students at Cardiff).
- 3) Patients 'volunteer' for the 10 minute NASA lean test to detect for Orthostatic Intolerance (Ideally we would need 20 volunteers for this). I need

to look into the ethics so will let you know more on such 'practical' projects.

4) Any patients with ME undergoing elective surgery of any kind (particularly if this is planned to be at Cardiff) who may be willing for a student to witness some of the difficulties surrounding this (getting up early/waiting in a seated waiting room/ post-exertional malaise from clinic appointments or pre-operative assessment/ differences with anaesthetics etc.) The student would be invited to write a report for the Royal College of Surgeons (RCS) bulletin. This would be especially relevant for operations or procedures that might include postoperative physiotherapy (Knee surgery or similar).

5) Any ME sufferers or their carers would be invited to share any experiences under the title 'Cardiff Hospital' or 'Surgery with ME' (no more than around 500 words) good or bad then one of the students may be able to do a project on this. Participants would be urged to state contact details and if they would like to be made anonymous - there are official forms that would be completed if this was intended for publication.

These ideas are in their infancy and full ethical checks will be carried out for each project. The aim is getting doctors to learn to listen to patients with ME and improve formal education about ME/CFS.

If you are interested or know anyone who is you can write to Nina Muirhead directly at nina.muirhead@btinternet.com and you can also copy in mesigwales@gmail.com

MESiG's AGM / Review of the Year

7th JULY 2018

This year has been quite different for MESiG, in that we had lost Christalla Bailey, our long standing Chair, who had been a great organiser and an inspiration. We would not be here today without her tenacity. As a very small committee at that time, we needed to consider what we should do. Would we be able to go on? We resolved that we would, but we'd have to keep things SIMPLE, for a while at least! But luckily we gained the support of new members to the committee soon after. New hope in the form of Emelyne.. our Chair, Andy, Emma James and also Emma Jayne who designs our lovely posters. So that this year has been one of Adjustment for our new committee members, especially hard those who are unwell.

Emelyne spoke of the events that had taken place over the past year. The Awareness Events at the Freedom Church in May 2017 – A wonderful, colourful concert of choirs and Indian dancing; Our Summer Party at Roath Park last year; Mark and Dee attended Community Health Council AGM; In the Autumn, UNREST premiered in the UK – the two Screenings in TRAMSHED Cinema and CHAPTER ARTS Centre with discussion after; GUY'S SKYDIVE for M E that raised £400; In Winter, we had our usual Christmas Party, and Bethesda Community Choir raised £1000 for M E; Mark gave a thorough researched presentation on Lyme Disease in December, to the Cross Party Group Neurological Conditions Meeting in the Senedd chaired by Mark Isherwood A M. Mark and Miriam continue to attend meetings with the Neurological Alliance.

Early in 2018 we had the UNREST screening for the Medical Students and over 90 attended at Cardiff University. When the film finished, rich and evocative discussions took place between the young medical people and the MESiG committee, and Dr Charles Shepherd, Emelyne and UHW Neurologist were on hand to answer questions.

Our monthly Support Meetings continued... with speakers:- Sara Beer from Disability Wales.. Art as a therapy or business for the disabled; Tom Martin, Wales journalist/photographer...his ongoing project with WAMES, 'M E and my World' M E Documentary ...People Like Us, with Clare Francis and Melissa Penny;

Sheila Damon, Hypnotherapist, talked us through a relaxation to aid sleep; Selma Chalabi, BBC Wales talked to our members in preparation for her half hour program on M E...Eye on Wales ...Radio broadcast 24th October 2018, and a Talk and Demonstration on Mindfulness followed.

But also important, we make time to talk, listen and support at our meetings. Emelyne thanked the MESiG Committee for their care and dedication, particularly Mark for his technical skills.

Awareness raising continued on May 12th, marked by the 100 Cities 'MISSING MILLIONS' Worldwide Demonstrations. We held our Demo in Cardiff, Thanks to Mark Nott (Son with M E) at St David's Centre and the support and participation of Cardiff lovely Student P R group. Julie Morgan supported us with a short speech, and ITV recorded Emma Jayne and MESiG members at the event with a Prime Spot on Evening News!

Also important, Emelyne and her Dad attended the NICE Stakeholder's meeting in London for the new M E/CFS guidelines. Nice are recruiting for the guideline writing committee.. 4 lay people, so felt it was hopeful, as NICE are open to listening to all feedback. New guidelines will not be released until 2020?! Wales will need to be converted, as they don't necessarily follow England. There is a need to campaign to suspend G E T and C B T until then... A message for our Assembly and medical people here.

Emelyne thanked the committee who devote themselves tirelessly to the work of MESiG and the Cause.

Dee thanked Emelyne and speaking of finances, was able to say that MESiG has a reasonably healthy balance at present, thanks to some generous donations, which have offset some of the expenses we incurred, insurance costs, website support, meetings, equipment, travelling, printing and Demo expenses etc.

We recently bought a pop-up pavillion we hope to use for fund raising and awareness. We have had donations from members that Miriam supports, Bryan Brewer, Guy's Sky Dive, Bethesda Community Choir in Dinas Powis, ... we donated half to THE M E TRUST, who opened their first clinic in East Surrey this year, and plan to open more in UK. Dr Worthley their M D was one of the advisors who gave information to the recent M E Debate in

Parliament this summer. But a big THANK YOU to ALL concerned from me. I have to keep MESiG in the BLACK!

The MESiG committee was voted in again, all business settled and then we were able to relax and listen to our guest speaker Jill, Chair of Community Health Council. She gave an overview of the role of the C H C. It's an independant voice that supports NHS patients and that it is made up largely of volunteers. Jill herself is also a volunteer with a big responsibility as Chair, who works tirelessly for the organisation. It was under threat of closure last year, but enough public protest kept it open. Jill has attended meetings with various bodies on our behalf, and her work for us is ongoing. Thank you Jill for your expert knowledge and support.

It was a very warm day and we were more than ready to have a drink and something to eat. There was a good selection, thanks to Mary and some of the members. Then it was time to have a chat with members and friends, discuss the year's events and exchange news. The party was a bit smaller than usual, but of course our AGM was very late this year, due to previous commitments, and on the day we had to compete with the Tennis and the football! However, those who could, came to support us and we had a good time. There was plenty for all, and leftovers were shared and taken home.

D P

#TimeForUnrestWales in the Senedd



Wed 24 Oct 2018

Eight AMs accepted the invitation from Mark Isherwood AM to join people with ME and carers at an event in the Senedd, the home of the Welsh Government. More AMs expressed interest and sent their apologies. [MESIG](#), the Cardiff Support Group presented an excerpt from the award-winning, and very moving documentary film Unrest. This was followed by the opportunity to hear ME stories from local people, and an update on the state of healthcare for ME in Wales and the campaign [#TimeForUnrestWales](#).

The message:

- ME wrecks lives and disrupts families
- Too few GPs understand enough about neurological ME to diagnose accurately & in a timely manner
- Lack of medical expertise in ME also leads to inappropriate treatment referrals and management advice, often leading to a deterioration in symptoms

People with ME are asking for:

- Welsh Government commitment to urgently provide finance and direction to enlist medical expertise and create a national training and awareness programme on neurological ME for NHS Wales
- A speedy response by the Cabinet Secretary to implementing changes following the 2018 Review of services
- Health Boards to be held accountable and assisted to implement training and awareness improvements in order improve diagnosis, management and access to generic services

An S4C news team arrived before the event to film and interview a group of people with ME and their families, who were standing outside the Senedd with posters, giving a visible presence to the event.



Mark Isherwood AM & attendees (patients, carers and supporters)

Assembly members in attendance:

Mark Isherwood AM – North Wales
Jane Hutt AM – Vale of Glamorgan
John Griffiths AM – Newport
Vikki Howells AM – Cynon Taff

Julie Morgan AM – Cardiff North
Jenny Rathborne AM – Cardiff Central
Hefin David AM – Caerphilly
Adam Price AM – Carmarthen

Mark Isherwood AM – North Wales

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**Jenny Rathborne AM – Cardiff
Central**

John Griffiths AM – Newport

Hefin David AM – Caerphilly



Vikki Howells AM – Cynon Taff



Adam Price AM – Carmarthen

Also present:

- Stephen Allen, Chief Executive of Cardiff & Vale of Glamorgan Community Health Council
- Christine Roach, Public Health Wales, seconded to the Welsh Government



ME stories (panel speakers):

- Deirdre Penny – parent carer of adult daughter with severe ME
- Millie Earp – young adult with ME
- Jon Vaughan – carer of fiancé with severe ME
- Dr. Nina Muirhead – medical professional (surgeon) with ME & lecturer at Cardiff Medical School
- Jan Russell – WAMES Chair and patient rep on the All Wales Implementation Group

ME Health & Social Care crisis in Wales – #TimeForUnrestWales



Jan Russell, Chair of WAMES & patient rep on the government's All Wales Implementation Group, explained how the recommendations in the Welsh Government's [2014 Task & Finish Group Report](#) had been designed to give practical steps to help Health Boards improve healthcare for people with ME & Fibromyalgia. 4 years later, many have not been implemented by Health Boards and **no** HB has implemented the recommendation to train and raise awareness with GPs and healthcare staff.

Emelyne Burkhard, Chair of MESiG and organising committee for the Unrest at the Senedd event. Involved with the event coordination, delivery and media presence to raise awareness for the event across Wales, plus encouraging patients & sufferers to keep sharing their stories to their AMs & MPs.



Dr Nina Muirhead, is a surgeon, person with ME & lecturer at Cardiff Medical School. Nina outlined her hopes and plans for Cardiff to be the first university to include neurological ME in medical students' education.

The speakers were followed by a lively discussion about why doctors and the NHS are reluctant to take ME seriously and what could be done about it. All contributions will be considered via the ME services survey, the All Wales Implementation Group (AWIG) and/or WAMES.



Article from WAMES, Photos by Tom Martin (Wales News Service)





Transcript of Dee's Talk in the Senedd

My daughter was only 11 when she got ill with M E. She just a few weeks settling into Howell's school. She was a bright girl and was enjoying making new friends, and everything there, until she had a bad attack of Glandular Fever. Then she returned to school after 3 weeks, played in a netball match and then collapsed. That night she had so much pain she could not undress or go upstairs. Her GP said to rest for a week, then she returned to school, but she was so unwell, she had to come home. She tried several times to go back to school, but she would collapse again with exhaustion and felt very ill. I was frightened and the GP didn't know what



was wrong. Eventually .. about 8 months later, we got a diagnosis from the paediatrician at Llandough. But all the while, she was pushed to go to school and exercise when she had energy...when she should have had complete rest. She was sent to a psychiatrist and school phobia was mentioned. Rubbish...she had chosen her school herself. We experienced so much ignorance and disbelief...so hard for her. Eventually, I had to take her out of her school so she could have home tutors, when she could cope. She seemed to improve with much rest,, and around the age of 13, went for a short time to Radyr Comprehensive, where she did well until she took part in the Sports..very soon after, she collapsed and that was the end of her schooling. Over the years, she went to another psychologist and a top psychiatrist, blood tests found very little and she experienced GET at UHW with disastrous effects that lasted many months. We finally saw Dr Finley at the M E clinic Romford Essex, At last we had understanding and a clear diagnosis of moderate/severe M E and treatment was offered. However, the welsh Authority would not pay for her treatment..so that was the end of that! We tried many different things over the years...all to no avail.

Despite repeated requests and petitions from patients and carers, there is still no provision for an M E clinic in Wales. No place for GP's to send patients. After years of campaigning for awareness and appropriate treatment, by MESIG and WAMES, nothing has materialised. We have even had AM's in tears here, but, then we have

been forgotten. There are 250,000 people/children with M E in Britain with this awful illness. A large number are unable to work and 25% are either house bound or bedridden and unable to do anything for themselves...and many of them here in Wales, so why is there not a clinic or Specialist. Surely, they have a right to treatment, just as much as other people who are sick? It is shocking and a disgrace to Wales.

The World Health Organisation and the BMA have recognised M E as a neurological illness since 1967, and yet the only things offered by NICE were CBT and GET. However, after many complaints from patients, at last the NICE guidelines have been ripped up and Patients and experienced doctors have been brought in to advise NICE on setting up new ones. But the new guidelines won't happen til 2020. In 2011, £5 million was spent of the Pace Trial using CBT and GET. Although the authors claimed 60% improvement in patients..it actually proved ineffective and flawed, when examined by independent Scientists. There is an important place for Psychiatry, but not as the main treatment for M E. Exercise for M E ...particularly if severe, can do so much damage and make them ill for months or even years, as we proved with my daughter. Very little has changed in the last 25 years. But surely, an illness that starts with an infection or a virus, merits biological investigation !

There are many pockets of patient funded Biological research all over the World, and even as close as Dundee and Glasgow University Hospitals, where abnormalities have been found in small patient trials, in the white blood cells. Doctors there are adamant that M E is a biological illness. Definitely not psychological. There are many others doing similar research around the World. Harvard and Stanford Universities in USA...M E Research UK here in England ETC. But we need Government backed Biological Research to take things forward.

In the meantime, the right medical treatment given to patients could improve their lives. Also GP's that could diagnose and give the correct advice. Resting initially is so very important.. and could even stop the illness progressing. Simple tests made routine, such as mineral tests, efa's...deficiencies can cause symptoms just like ME, are not readily offered. There are doctors who are experienced and are treating people and helping to cope with this devastating illness.

I am here because I have a personal interest and I am also part of MESiG. We desperately need a clinic fit for the purpose. Imagine if it was you or yours with an existence of pain and severe exhaustion, limited to being in a darkened room and having to isolate yourself from family and friends, month after month...year after year. This is what is happening among severely affected M E patients.

Message from ME Trust



The ME Trust Opens New Clinic in Crowborough for People with ME/CFS

On 20th July 2018, The ME Trust will open its first clinic for people affected by ME/CFS. The clinic, which will be based at the Outpatients department of Crowborough War Memorial Hospital, provides a desperately needed opportunity for people with ME to have a face-to-face appointment with an experienced doctor and/or physiotherapist able to provide individually-tailored help in managing their illness.

The ME Trust is registered with the Care Quality Commission (CQC) and is the only charity providing clinical services for people with ME. The Trust is committed to a whole-person model of care, helping people physically, emotionally or spiritually, in accordance with each person's individual needs. The clinical team is led by Dr Paul Worthley, who has 30 years' experience of helping people with all levels of severity of ME/CFS. The team also comprises an experienced physiotherapist, counsellors and chaplains. In January 2017, the Trust launched its well-received telephone/Skype and home visit service, and plans to open more outpatient clinics in the future.

The Crowborough clinic opens on 20th July and will take place on the 3rd Friday of every month. Dates for the remainder of 2018 are: 17th August, 21st September, 19th October, 16 November, 21st December.

Appointments at the clinic are available with a doctor, or physiotherapist, or both. Bursary support may be available for those in financial need.

"The ME Trust has provided me with ongoing expert support with managing my ME...I've had regular access to an understanding GP who has given me sensible and helpful advice covering medication, pacing and symptom management. It's such a relief to be able to talk to a clinician who actually understands the condition... I've not had a miracle recovery but thanks to the ME Trust I now feel hopeful for the future where I had once only felt despair."
J.

'Sue the physio is brilliant - so helpful, understanding and supportive ...' L

More details are available on the ME Trust website www.metrust.org.uk. To book appointments at the Crowborough clinic, please use the contact form on the ME Trust website or telephone 0208 7060036 (calls are charged at local rates).

Note to editors:

At least 250,000 people in the UK are diagnosed with ME which causes profound fatigue and is often accompanied by debilitating pain. Other common symptoms include sensitivity to sound, light and touch; difficulty with word recall and processing information; and sleep disturbance. For some, it leads to prolonged, profound illness and disability and makes everyday activities impossible. Despite the prevalence and seriousness of this illness, healthcare services are often lacking. Many people wait 3-4 years for a diagnosis and some parts of the country have no specialist services for people with ME.

Book Recommendation

Dear Miriam,

When I agreed to be part of Jen's film, I couldn't imagine it would touch so many lives all across the world and spark a movement that would bring Myalgic Encephalomyelitis as close to the mainstream as it had ever been. And it is with great pleasure that I invite you to take a deeper dive into my story of severe ME.

By now, you would have all seen Unrest and probably remember the girl with ME who spent her life bedbound, celebrating birthdays and day to day life in a single room. That girl now has a book out and wants you all to read it. The book is entitled [A Girl Behind Dark Glasses](#) and it is available now digitally online via kindle & iBooks and also in print via [Amazon](#) & [Book Depository \(World Wide\)](#). It chronicles 4 years of my life, from being a normal healthy teenager, to being completely incapacitated, on machines keeping me alive



From a darkened world, bound by four walls, a young woman called Jessica tells the tale of her battle against the M.E Monster. The severest form of a neuro immune disease called Myalgic Encephalomyelitis went to war with her at just 15 years old. From beneath her dark glasses, Jessica glimpses a world far different from the one she remembers as a teenage school girl. This true story follows her path as she ends up living in hospital for years with tubes keeping her alive.

This harrowing story follows the highs and lows of the disease and being hospitalised, captured through her voice activated technology diary called 'Bug' that enables her to fulfil her dream of one day becoming an author.

It provides a raw, real-time honesty to the story that would be impossible to capture in hindsight.

It means so much to me to have been able to give you all a glimpse into my world through Unrest and now that I am able to tell my own story in my own words through A Girl Behind Dark Glasses, it's like a dream come true. I hope it touches readers the way everyone's support and encouragement has reached me all the way in Kent, England. Please feel free to follow me and share my story through [Facebook](#), [Twitter](#), and [Instagram](#), and be sure to use the hashtag: #AGirlBehindDarkGlasses.



With love and determination,
Jessica Taylor-Bearman
www.jaytay.co.uk

FOOD FOR THOUGHT

13th November 2016

Miriam and I live in the same village of Radyr, about 3 or 4 miles North West of Cardiff. She phoned me one day, to say that a local group called 'Food for thought', wanted us (MESiG) to give a talk, and we were booked for Tuesday, 13th November at 1pm. Peter and Mark were



to accompany us. Mark, in his technical capacity. He takes our photos and films, makes recordings and has even made our posters, among many other things. We were to have the meeting in the community hall at Christ Church, our local Church in Wales.

We met up on the day, at Christ Church at 12.30pm to set-up the camera and projector, and also some posters and leaflets about M E. While we were doing this, our audience were busily eating a tasty lunch...made us feel hungry. Ha! There are about 30 of them, and they meet up bi-monthly to be fed, both physically and then mentally on different menu's!

Miriam opened up the discussion, explaining how she came to know about M E through the program 'Neighbours'?! she had become friendly with a young women who had M E, who also watched the program. Miriam looked after Ami, then at difficult times Miriam had her to stay. Eventually, Ami stayed with Miriam and her husband Lesley, for a whole year.

After this, Mark showed a film from a TV program called 'People like us', portraying people with M E and their difficulties. Clare Francis (Authoress and World champion boat woman) starred in this, and explained her difficulties over the ten years she was ill, but how she had been lucky, and it was sometimes possible to improve things very very gradually as she had, with diet, pacing and various alternative treatments. She stressed that M E is a very serious physical illness that is underestimated, and that Doctors need to be educated and the need for the illness to be investigated medically



(biological research) much more. My daughter and I with other patients were in the audience, and we were asked to voice our experiences, which we did. The program was presented well, and sympathetic to the plight of M E sufferers.

After the film, I explained about the symptoms of the illness, and some of the very difficult times my daughter had experienced over years. How she had been given the wrong medical advice, experienced so-called 'Graded exercise' on an exercise bike and a rowing machine... to her detriment for many months after; and a bullying psychiatrist among other things. I ended by telling our listeners about MESiG and what we do. Our monthly meetings, our website, and Newsletters, our Demonstrations ...Missing Millions, and our Senedd events... asking the A M's and Health Authorities for a Clinic in Wales...where there are none. How our lovely Miriam helps with form filling, caring and even goes to tribunals for patients. How we do our best to support our members and in doing so, gain comfort from each other.

We had been received so kindly and listened to so patiently, and now the questions came. We found one lady who had a relative with M E, and another who had a friend who was ill. So we gave out our leaflets and told them about the monthly meetings. Our audience could not believe that we had no treatment in Wales and showed great sympathy. We explained that that was why MESiG is so important to us. They gave us a round of applause and £35 donation. Great!

Dee Penny

Debate on Lyme Disease requested in the Senedd

20th November 2018

A Lyme Disease Awareness Event was held in the Pierhead Building on 20th November 2018, sponsored by Julie Morgan AM. This included a pre-recorded presentation by Dr Robert Bransfield, which can be found on Youtube using the QR code or search “Jenna Luche Thayer Bransfield”.



Following this event Julie requested a debate on Lyme Disease in the Senedd.

For full transcript see item 2:

<http://record.assembly.wales/Plenary/5365?lang=en-GB>



Julie Morgan AM
14:31:01

112 And, secondly, I wondered if it might be possible to have a debate on Lyme disease. One of my constituents from Cardiff North is campaigning on this issue, and, in fact, we held a meeting in the Pierhead today about Lyme disease, wanting to raise the profile of the disease, the fact that it is little known and that there are many different complications from it. And there have been debates in the Scottish Parliament, the House of Commons and the House of Lords, and will be in the European Parliament, but it does seem it is a little-known disease that causes a huge amount of misery for those people who are afflicted with it.



Julie James AM
14:32:30

113 Two very important points indeed.....

114 In terms of Lyme disease, in Wales, as well as everywhere else in the UK, cases of laboratory-confirmed Lyme disease have been increasing in recent years. This is partly as a result of better reporting, increased testing and increased awareness by the public and healthcare professionals. The Member will be pleased to know that we've recently communicated a comprehensive guidance on Lyme disease to healthcare professionals across Wales, and the NHS has developed appropriate public awareness materials. And I'm very pleased to say that that's an ongoing programme of public awareness and medical awareness across the piece.

Lyme Disease had also been raised in the Senedd in September :

19/09/18. “United Kingdom Independence Party Debate: Upland Livestock”

For full transcript see item 7:

<http://record.assembly.wales/Plenary/5350?lang=en-GB>



David J Rowlands AM

17:35

Due again, primarily, to a lack of grazing stock, we're witnessing an unprecedented explosion of tick species on our hills. Long grass is ideal habitat for ticks. This has resulted in a growing number of cases of Lyme disease, especially amongst the hill-walking fraternity and their pets. Lyme disease can have disastrous, debilitating effects on its victims and as there is limited knowledge of the disease amongst general practitioners—and, David, I make no particular comment as far as that's concerned—it can go undiagnosed for long periods, making its effects even more devastating. The long-term effect of this is that tourism will suffer as ramblers, et cetera, become less and less willing to expose themselves to the health risks involved with tick infestation. It is reported that in France, last year, some 60,000 people were affected by tick bites.

MESiG Subscriptions

Many subscriptions for May 2018-2019, are still outstanding. Subscriptions are £12 per annum. NB Members on benefits are exempt.

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: nmeacent@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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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.