

Serving ME/CFS patients, carers and interested parties

AGM / Awareness Event 2016

Saturday 14th May

2pm-5pm

Bethel Community Church

Llangranog Rd

Llanishen

Cardiff

CF14 5BJ



2-3pm AGM

3-3.30pm Chris tells her story

3.30-4pm MP Craig Williams

10 minute talk

followed by 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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MESiG Raising Awareness In

Age Concern Barry

17th November 2015

Yesterday, I was a spotty, day dreaming youth of seventeen summers.

Today, I find myself ambling along a damp and windswept road in Barry Town. I'm a foreigner here, and as I endeavour to seek out my destination, I quietly moan at the lack of identifying numbers on the shops as I pass by. Judging by its age and appearance, I assume that this part of town has seen its fair share of changes over the decades. The vacant and neglected facades pay silent witness to an era when the street possibly played host to butchers, bakers, and walking stick makers. Men who go down to the sea in ships are replaced by bingo halls and places that do lips.

My attempts at keeping the swirling rain from spoiling my day are of no consequence to those who scurry by and I twist and turn my umbrella in impatient defiance. Not another charity shop, I mentally register, and not only that, there is no number above it. I drift by neglected and smeared shop windows who display posters advertising that a circus is in town, albeit they were there in 2010. I see letters and circulars piled up inside empty shops and wonder as to how much more mail it would take before entry to the premises would be impossible. With wind and rain making their continued presence felt, I continue my journey until I see two friendly faces looking up through a large misty window as they arrange information on the small dining table commandeered for the MESiG display.

They confirm that I'm in the right place and I push open the door onto a welcoming room with carefully placed tables and chairs with a refreshment counter to my left. Chris and Ken are busily engaged in setting out MESiG pamphlets and one of the roller type posters is sitting on high advertising our presence. We exchanged greetings as I peel off my wet outer coat and look for a chair which I can temporarily call my own.

There is a smattering of people in the Age Concern drop in coffee shop and I spot someone who is younger than most, dispensing information to an eager listener. I assume that this service is a regular feature and I'm impressed that both parties are able to conduct their business against the backdrop of hustle and bustle.

We have arranged for five people to represent MESiG today and our perceived lack of attendees is answered by the prompt arrival of Dee and Miriam who pull up in Miriam's rain lacquered vehicle. Miriam putting on the parking brake is the signal for one of the Age Concern volunteers to abandon their post behind the drinks counter and to offer advice about running the risk of being 'booked for parking in that pull in' via the front door step and a tea towel. There is a brief mutual chat about the lack of parking spaces in Barry Town in general and which is temporarily addressed by way of Miriam setting out with wind screen wipers waving furiously to seek that elusive haven free of enforcement officers.

The morning coffee session is in full swing and the arrival of more friendly customers adds to the buoyant atmosphere. Inevitably, the conversation is dominated by the inclement weather and we tread the delicate pathway of being approachable without appearing interfering. We are not on home turf and who wants to be unavoidably distracted whilst talking with friends over a cuppa? One small and innocent mistake we make is to make use of a table which is regularly used by three ladies who frequent the centre on a Tuesday. Once we are made aware of the error of our ways, I reassure the three ladies that any return visit by us will include our boycotting of their frequently used rendezvous point.



Soon Dee is in the thick of it- the men are outnumbered here and the introduction of an unfamiliar female face is possibly more readily acceptable. As the name implies, the clientele at the centre are of a mature standing – people who can remember the Beatles in their heyday, mini skirts on their initial outing, when a telephone call cost four old pennies and when Elvis, “The King”, was merely a Prince.

We chat about ME and its devastating effect on patients and their families. We usually find that someone knows someone who knows someone who is suffering with ME and for those who are not familiar with this illness and its associated challenges, our news has quite an effect. This revelation is usually followed with a question as to what is being done on the medical front to combat this silent robber of “a normal life style”. We explain our aims and goals and what is happening in the interim. We are listened to with courtesy and interest but like many things, unless you are directly, or indirectly, affected, the illness is one which you count yourself fortunate to have avoided.

The tea, coffee and hot chocolate flow until its time to pull the plug on the stainless steel washing up sink. We exchange farewells along with “It was good to meet you” and we turn our attention to clearing up and putting away the MESiG material. The large windows on the centre have retained their film of condensation, a sign that the weather outside has not changed and that the centre has been busy with clientele. I slip my coat on and reach for my damp umbrella.

Yesterday, I was a spotty, day dreaming youth of seventeen summers. Today, as I retrace my steps away from the centre, I attempt to answer that elusive question faced by many who have retired from their job; just where did those fifty odd years go?

It was a special treat to see a previous member of MESiG turn up after many years of losing touch with us. People also came along to meet with us after seeing that MESiG would be attending on this day.

The Ageing Well programme in the Vale – The Senior Health Shop

**Each week older people attend the shop
where work to improve health & well
being is available by providing:**

Age Connects Cafe at 38 Holton Rd, Barry
is open Daily from 9am till 1pm.

To find out more about the Senior Health
Shop in Barry – Contact Nona Hexter,
01446 732385

- A place to meet, socialise, make new friends, at a café that serves beverages, and meals at a reasonable cost.

- Clubs & classes in the shop and across the Vale of Glamorgan.

- A one stop centre for information, and information clinics provided by partner organisations.

- Volunteering opportunities to get older people involved in the community.

- A low cost nail cutting service.

M.E Talk at Age Concern

12th April 2016

MESiG were invited back to Age Concern, 38 Holton Rd, Barry to talk about M.E 10am-12pm.

This meeting was very different to the one in November last year. In November's meeting, we had several people with ME and Fibromyalgia come along for advice. This time, we had representatives from several organisations come and connect with MESiG.

MESiG connected with ;

- ♦ Charlotte Singleton from Victim Support.
- ♦ Rhian Thomas –Consortium Development Officer from Glamorgan Voluntary Services.
- ♦ Ana Phillips Vale Third Sector Broker-One stop shop working with health and social care teams in the Vale.
- ♦ Christine from the Women's Institute who invited us to give a talk about ME.

MESiG extend their gratitude to all the organisations who came to connect, in order to provide better services to individuals.

Many thanks.

MESiG have been invited back a third time for November 8th 2016,

Tuesday 10am-12pm.

Chair Report 2015-2016

Greetings to one and all. Throughout the last twelve months MESiG has strived to raise awareness and make a difference in the lives of ME/CFS and Fibromyalgia sufferers in Wales. We remain committed to steadfastly working towards changing hearts and minds about these debilitating conditions.

Events

- 2.6.15 Chris and Dennis attend the Senedd for MESiG petition hearing.
- 6.6.15 The Interlink RCT Volunteer Awards Celebration took place in Ynysangharad Park, Pontypridd. Chris was honoured to receive a recognition award on behalf of MESiG.
- 14.8.15 The annual Tea in the Park event took place.
- 7.9.15 An Art Workshop took place at Bethel Church, Community Centre, Llangranog Road, Cardiff.
- 12.9.15 Maes Y Coed Community Centre was the venue for the annual fun day fair. Mesig had a stall and raised awareness.
- 22.9.15 Cross-Party Group for Neurological Conditions meeting took place in the Welsh Assembly. It was attended by Chris Bailey and Miriam Wood.
- 23.9.15 Chris Bailey and Miriam Wood attended a meeting with Professor Jonathan Richards and Anne Noyles to discuss policy aspects of M.E.
- 3.10.15 Chris and Ken take member to Burrswood Hospital for 2 week stay.
- 4.10.15 Nick Tatham completed the Cardiff Half Marathon on behalf of MESiG to raise awareness and much needed funds.
- 16.10.15 Chris and Ken pick up member from Burrswood Hospital.
- 28.10.15 MESiG was featured on ITV news. Rob Osbourne who is the Health and Social Affairs Correspondent for ITV Wales interviewed a sufferer in her home and also gave Chris Bailey the opportunity to raise awareness by informing viewers about the plight of individuals stricken by M.E.
- 30.10.15 Chris interviewed by ITV Newsweek.
- 1.11.15 Chris Bailey was invited to the ITV Wales studios and was interviewed by presenter Carl Edwards. This was aired today.
- 16.11.15 A member was referred and accepted to the Well Head Centre for a weeks retreat.
- 17.11.15 The MESiG team raised awareness at an event arranged by AGE Concern in Barry.
- 7.12.15 The annual MESiG Christmas party took place. The guest speaker was Jonathan Richards.
- 1.2.16 Dr Clare Bowen spoke at the ME support group meeting.

- 9.2.16 Miriam and Chris presented for 10 minutes on ME at the Wales Neurological Alliance meeting in the Welsh Assembly.
- 11.2.16 Chris travels to West Wales as ITV agree to film a sufferer who can't access support needed
- 18.2.16 Dee attends Wales Neurological Alliance meeting.
- 21.2.16 MESiG purchase new equipment from Lottery funding for group.
- 23.2.16 Miriam Wood attended a meeting where rare diseases and the ME condition was discussed. The meeting was attended by Darren Miller the Shadow Minister of Health for Wales.
- 1.3.16 Miriam Wood attended a Capita meeting – Assessors for PIP benefits.
- 2.3.16 MESiG attends Policy Forum For Wales.
- 4.3.16 Miriam and Chris represent a member in a tribunal.
- 7.3.16 Holly shared her ME recovery story with group members at the monthly support group.
- 4.4.16 Roy and Neil speak about the SoeMac machine and research.
- 12.4.16 Second talk on ME in Barry Age Concern.

I would like to extend my grateful thanks to committee members; Dee Penny, Rob Goodman, Peter Baxter, Miriam Wood, Mary Jones and all volunteers for all your hard work and support.



IMPORTANT NOTICE!

Change of Time For Support Group Meetings

MESiG have decided to change the time of the monthly support group meetings.

This decision has been made after taking on board your comments.

It's difficult as some people are better mornings, some afternoons and some evenings. We are very sorry if this is not ideal for you. Please do let us know either way, as we run these meetings for you.

**From June 2016 monthly meetings will be 2pm-3.30pm in
Bethel Community Centre, Llangranog Rd, Llanishen,
CF145BJ**



Dr Claire Bowen's Visit

MESiG Support Group Meeting.

1st February 2016

I first found out about Claire early last year while investigating the Airnergy machine, an Activated Oxygen device. Claire was very approachable and friendly, and after a couple of chats with her, she readily agreed to write a couple of articles for us in our Newsletter. Today she was coming to see us all the way from Worcester to give a talk on her experiences with ME/CFS.

This was of great value to us as Claire, as well as being a qualified Medical Doctor, had suffered severely for many years with ME/CFS. Not only that - she had found a way to make herself well after much trial and error, and medical investigation. She is now using that knowledge to treat people.

Claire arrived on time, with her husband Simon, Airnergy machines, SoeMac machines (a small portable activated oxygen device) and - her lovely baby daughter Amalie. What a joy she is! Drinks and snacks were put out for everyone, and Amalie was fed too, then she was taken off for a ride by Simon, while the rest of us settled down to listen to her mum:-

Claire told us all about herself and her many difficulties with the illness - much of this is in her Newsletter article May 2015. She then went on to tell us what she felt was important to aid recovery. She stressed that everyone is different and management needs to be tailor made for each individual, but that there are five areas very important for each person. The key areas are:-

DETOXIFICATION, OXYGENATION, HYDRATION, NUTRITION & PROTECTION Protection being the 'broadest' area to be covered, since it includes physical, environmental, mental and emotional protection, which in some ways can often be the most challenging aspect to address.

There were questions and answers, but some were anxious to try the machines, so Claire was kept very busy with all of this. Simon had brought his helpful CD's for both ME and Fibromyalgia - very inexpensive, so he sold quite a few and I bought one of each for my daughter.

We all made time to finish off the food and have a quick chat, but we had forgotten the raffle in all the excitement?! Never mind, there had been so much to digest. After sending Claire, Simon and Amalie on their way, we cleared up and went home on a 'High' with lots to think about.

One of our members had bought a SoeMac machine coincidentally and shared that she had an improvement from day one.



UNIQUE PERCEPTIONS

Contact Info

Unique Perceptions
Nr Great Whitley, Worcestershire
Phone : 01299 833 972, Email : info@uniqueperceptions.co.uk

By Dee Penny

Dates For Your Diary

MESiG AGM/Awareness Event

Saturday 14th May 2016

Bethel Church, Llangranog Rd, Llanishen, Cardiff, CF145BJ

2-5pm with MP Craig Williams

Speakers Attending Support Group Meeting

Monday 6th June 2016

Bethel Church, Llangranog Rd, Llanishen, Cardiff, CF145BJ

2-3.30pm

JILL SHELTON - CHAIR OF CAVOG - CARDIFF AND THE VALE OF GLAMORGAN COMMUNITY HEALTH COUNCIL.

STEVE ALLEN, Head of the Community Health Council, together with a Clinician to answer any medical queries.



Tea In The Park

Monday 8th August 2pm 2016

We meet in Roath Park café terrace, for a cuppa and chat.

Lake Road East, Cardiff CF23 5PG

All are welcome.

M.E Talk at Age Concern

8th November 2016

MESiG speaking about M.E 10-12pm Age Concern

Address: 38 Holton Rd,

Is Lyme Disease Responsible?

One Man's Story

"Having had symptoms of fatigue/anxiety for many years, last year my fatigue increased along with insomnia. I then began considering Lyme disease as a possible cause of my symptoms.

I've come to Lyme disease from an odd perspective. In 2008 I had an operation for a slipped disc. A month after the operation the disc became infected, I could hardly walk. I was admitted to the Heath Hospital in Cardiff and treated with IV antibiotics (cefotaxime and flucloxicilan), every 12 hours for 4 weeks. After a couple of days of treatment the anxiety which I have had for many years, disappeared. I was clear headed, able to read, concentrate and altogether transformed. This was a profound experience. My back pain was also improved but this didn't account for my change in mood. (NB cefotaxime has been used to treat Lyme disease)

Within a month of being discharged my anxiety returned. I asked my GP whether the antibiotics had affected my mood. He dismissed this suggestion and put my experience down to the placebo effect.

A couple of years later I saw a doctor specialising in chronic fatigue who, based on my experience on antibiotics, advised me to be tested for Lyme disease. This was the first time I had heard of Lyme Disease. The test came back negative. I was aware of reports of false negative test results but didn't pursue this diagnosis at the time.

In February 2015 I was signed off work mainly due to insomnia/ fatigue but I also had swollen

finger joints, a swollen lymph node and difficulty with memory/ concentration. At this time I became more convinced that I had Lyme, not least comparing my symptoms to those of Lyme patients as listed by Dr Burrascano. (Dr. Burrascano's Treatment Guidelines - Lyme Disease Network www.lymenet.org › BurrGuide200810)

I had a repeat test for Lyme in April 2015, this again was negative. By this time I was aware that the standard 'ELISA' test for Lyme disease was unreliable. (<http://www.lymediseaseaction.org.uk> under Lyme facts : "Lyme disease cannot be confidently ruled out by any current test.")

In May and June I saw two infectious disease specialists, one NHS, one private. Both told me there was no such thing as chronic Lyme disease. One even suggested my symptoms were psychosomatic.

My 'psychosomatic' swollen fingers were investigated for rheumatoid arthritis via blood tests, x rays and ultrasound. I was told the cause wasn't rheumatoid arthritis but not what was the cause.

In July I had blood sent to Arminlabs in Germany. The test was called an EliSpot. Although the result clearly stated that there was 'a weak response to borrelia burgdorferi' (the bacteria which causes Lyme disease) the Doctor who ordered the test concluded that I didn't have Lyme. I contacted Dr Schwarzbach who runs Arminlabs.

(<http://www.arminlabs.com/en>)

He confirmed that my blood test was positive for Lyme disease.

At this time I was still trying to persuade my GP that I have Lyme but he was still saying I had chronic fatigue. I was aware that getting treatment on the NHS was unlikely, even though there was more and more coverage of Lyme disease in the media eg on the 'Jeremey Vine' show and on 'This Morning', where John Caudwell had explained his experience of Lyme disease. (This interview is available on YouTube : <http://youtu.be/Y24QL-H5ZLU>)

Dr Schwarzbach gave me a list of therapists in Europe who might be able to help but the only one in the UK wasn't taking on patients.

In September I attended a conference on Lyme Disease in Cambridge, run by the charity, Lyme Disease Action. It was here I first met Dr Beryl Beynon.

In October I had a consultation with Dr Beynon, in Beverley. She was able to diagnose me with Lyme disease based on my symptoms and my test result from Arminlabs.

Since then I have been treated with various antibiotics; I'm currently on metronidazole.

I'm hoping that my symptoms will improve soon but I understand Lyme disease is difficult to treat, as well as being difficult to diagnose.

I've been lucky to have had support from friends and family, though it is difficult when there are no obvious physical symptoms. I have also been supported by MESiG. I think at one of the meetings someone had said that you first need to admit to yourself that you are unwell. For a long time I had been in denial about my health problems. That was the best advice and encouraged me to get help.

By Anon

Holly's Recovery Story

7th March 2016

Holly attended our support group meeting on the 7th of March to tell us a bit about her road to recovery from ME. Holly has found that the Forever Living products, especially the Aloe Vera gel has helped her. Holly was unable to eat several food groups but can now eat anything without adverse reactions or gut problems.

We were invited to try the products and were given free samples. One member had a rash on her arm which disappeared with one use of one of the products.

Chris Bailey



ITV Support



A big thank you to ITV. We have a couple in West Wales who are not getting the support they need. In desperation and with their permission, MESiG contacted ITV to see if they would film in order to raise awareness of their needs. ITV did accommodate but this wasn't aired as the couple involved changed their minds about going public.

Awards For All Lottery Funding

We are pleased to announce that our application to The National Lottery for funding to enable MESiG to undertake its operations during 2016/17, proved successful.

We asked for £5,000 to cover essential items and to assist in the day to day running of the organisation. The National Lottery assessors reviewed our application and paid us in full. Grateful thanks to those who contributed towards making this application successful.



MESiG Subscriptions Are Now Due For May 2016-2017

Your yearly subscription of £10 is now due.



Please fill in the subscription form included and post back to us.

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. Your membership secretary: **Chris Bailey**

Email: mesigwales@gmail.com

Lunch with Capita

1st March 2016

CAPITA | Health and wellbeing

Capita Personal Independence Payment Assessments

Personal Independence Payment (PIP) is a benefit for people with a long-term health condition or impairment. It is paid to make a contribution to the extra costs that disabled people may face, to help them lead full, active and independent lives. PIP is replacing DLA.

Capita carry out PIP assessments on behalf of the Department for Work and Pensions (DWP) in Wales, the West Midlands and the East Midlands. Assessments are focused how an individual's health conditions may impact on their daily life, rather than the health conditions themselves.

Following a review of the documents received from DWP our health professionals decide whether sufficient information is available to carry out a paper-based assessment. In these cases a qualified health professional will write a report using information from your application along with any other information we receive. For the remainder we undertake face-to-face assessments. Both assessments use using DWP guidance developed by the DWP based on criteria set out by the Government. A Capita Disability Assessor will complete the assessment and send a report to the DWP.

A DWP decision maker will then use all the information to decide whether the claimant is entitled to PIP. Capita do not make any decisions on entitlement to PIP. Our Disability Assessors are qualified Health Professionals who have been specially trained in carrying out PIP Assessments and have been approved by the DWP.

You can find out more about PIP, how it may affect you and how to claim by visiting the PIP page on the website <https://www.gov.uk/pip>.

March 1st was not only St David's Day but the day I went to lunch in the Bay with two representatives from Capita. I had previously attended a similar Stakeholder's meeting last Autumn, so knew what to expect this time. Many thanks to Graeme Butterworth from Diverse Cymru who put my name forward to attend on behalf of MESiG.

The meeting this time was very small with just a few of us around the table with two representatives from Capita. It is certainly a very good opportunity to get to know precisely how PIP works. I thought I understood it, more or less, but there is always room to learn. Each of us had a lot to say and questions to ask. I'm afraid we gave them a rather hard time.

It is good to actually know the people to whom we can address questions or to whom we can complain or make suggestions and have direct email addresses and a mobile number. They said that they appreciate our feed-back! On the day of the meeting I'd had a further distressed call from a person who had contacted Chris and was facing a particularly difficult situation regarding life and a PIP face-to-face assessment and was unable to attend a Capita Centre. The person was being pressed to go despite being house-bound and having other major difficulties. I was able to write this information down and give it to Rebecca from Capita, at the meeting. She phoned the next day and dealt with the situation immediately and rearranged for the assessment to be at the person's home at a suitable time, when I am also able to be there for moral support.

PIP is a fact of life when one has a long-term illness. It can cause people to become very stressed but it can be approached logically and difficulties can be dealt with. We can assist you to work on the PIP form and support you through the face-to-face. If all fails, we'll help you with the Mandatory Reconsideration and beyond, if it goes to Tribunal. However we prefer to get it right the first time round. Knowing the people from Capita has helped us to gain a greater understanding of the way things work and how to deal with various situations.

Miriam Wood

What Is M.E.?

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

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

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

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

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

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

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



In an attempt to persuade the Welsh Assembly Government and the Medical Profession that this is a serious ailment with many sufferers in Wales, we took the step of having a petition signed by as many people as we could. We expanded the written petition by making an e-petition to the Welsh Assembly.

E – petition

MYALGIC ENCEPHALOMYELITIS (M. E)

CHRONIC FATIGUE SYNDROME

FIBROMYALGIA

We, the undersigned, wish to register our aspiration to have a dedicated consultant/ clinic and medical support team for the above named illnesses. Currently there are no such facilities despite the fact that M.E affects many people living in the South Wales area.

We believe there is just cause to have a recognised clinic & staff and accordingly we request that this petition be treated as an official voice of ME sufferers, their families, carers and interested parties.

The petition, which was presented to the Petitions Committee, was totally in line with the hand signed petition, which we had all been circulating for signature, as seen on below:

The Petitions committee accepted our submission and it was considered. A report from the Committee was sent to the Minister, Mark Drakeford, for consideration by him and his committee.

Following completion of the time allowed to collect signatures, the Petitions Committee considered our petition on the 23rd September 2014 and forwarded their views to the Minister for opinion and response.

The Committee held further meetings with responses from the Minister. MESiG sent correspondence to increase their understanding of the ailments for the Committee to consider.

The following is a breakdown of the outcomes of the Minister's deliberations in response to the Committee's recommendations: -

It was noted that the Task and Finish Group had been re-convened and charged with giving consideration to the conditions.

It was also noted that World Health Organisation regarded the conditions as being Neurological, and should not be considered as being Psychological.

At it's meeting on 13 May, the Group agreed the detail of its terms of reference and sought chair and vice-chair nominations. Professor Jonathan Richards, visiting Professor of Primary Care at Cwm Taf University Health Board, has since agreed to chair the group and Carol Ross from Fibromyalgia Wales will be vice-chair.

Following the report on myalgic encephalopathy/chronic fatigue syndrome and fibromyalgia (CFS/ ME and FM) published last year, an all-Wales implementation group has been established and is taking forward the report's recommendations. Membership comprises of health board clinical leads and patient representatives from Fibromyalgia Wales and Working for ME in Wales (WAMES).

All health boards in Wales have nominated an executive board member and clinical lead to oversee and take forward the recommendations of the report. Health boards are progressing with the establishment of local multi-disciplinary stakeholder groups to develop effective care pathways, raise awareness of the condition, increase timely diagnosis and share good practice within the NHS in Wales. Health boards are currently preparing three-year action plans setting out how they deliver services, which meet the needs of their population.

Another recommendation is to raise awareness of ME/CFS and FM in primary care settings to support timely diagnosis and effective management of the condition. The implementation group considers this a key recommendation and is discussing ways in which it can support primary care teams to manage service delivery locally.

As of now the Wales Assembly Government is no longer considering our petition since the Committee believes that it can do no more.

We will have to wait to see what the new Minister, whoever that is, will do to expedite the recommendations, and to keep up the momentum, such as it is, checking on progress. We must keep an eye on the progress and apply pressure as when required.

By Dennis

Mesig Attend

Wales Neurological Alliance Event

18th February 2016



Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Developing a National Patient Reported Experience Measures: PREMs and Patient Reported Outcome Measures: PROMs for Neurological Conditions and Stroke

Invitation to Participate in Focus Groups – Informing the Measures

The Executive Committee of the Wales Neurological Alliance (WNA, the Alliance of over twenty voluntary organisations working with people affected by neurological conditions) is working with the Welsh Government Neurological Conditions and Stroke Implementation Groups.

One of the shared priorities that both groups have agreed is to develop the PROMs and PREMs for use by the NHS with patients across the acute and rehab process.

What are PREMs and PROMs?

PREMs - Patient reported experience measures aim to:

1. *Enable the NHS to understand what it feels like to be a patient with a neurological condition in Wales*

Enable the NHS to use the information to improve services.

PROMs- Patient reported outcome measures aim to:

1. *Support diagnosis and monitor progress in clinical practice*
 2. *Provide information for patients and clinicians regarding choice of treatment*
 3. *Support healthcare providers to improve service effectiveness and quality*
- Support healthcare providers to ensure that services are clinically and cost effective*

In order for the Measures to be developed and agreed for use, they need to be informed by people affected by Neurological Conditions, including Stroke. This includes patients, carers and former patients.

.....

Miriam and Chris are the experts when it comes to attending meetings, but both were busy on the day, so Miriam asked me to go, and I got Peter (my husband) to come too. I didn't really know what to expect.

We listened to our Hosts explain that they were collecting information to improve NHS services in Wales for patients of various neurological illnesses. Then we in turn, introduced ourselves and explained about the illness we represented, while our hosts made notes and added more suggestions to their long list, such as more research needed, more discussion and decisions made by the patient and more co-operation and communication between doctors, nurses and departments.

A lovely lady with Motor Neurone disease was accompanied by her husband/ carer. A man with a rare and serious eye complaint and severe arthritis was accompanied by his wife/ carer. An elderly couple whose two daughters had serious complaints - one who was in full time care, and the other one who was brain damaged, was looked after by themselves. Another man there had lost his wife last year to Huntingdon's disease, and there was a brave young man who sadly had M S. Last but not least, I was there to represent MESiG and put forward some of the problems that ME/CFS sufferers face.

Everyone voiced their difficulties in coping with the various illnesses and the support they would like to receive. Some carers were very stretched, and stated that any services they did receive, they had to fight for and were very often inadequate. The only person satisfied with his treatment, at present, was the young man with MS, who had a treatment plan in place with regular monitoring and co-operation between the various sections of the NHS that dealt with his problems. He said however, that care for his illness could be a lottery - depending upon where you live - which health authority you came under and its' funding.

After giving a brief outline of the symptoms and difficulties of people with M E/CFS, I explained that there is no NHS Specialist or Clinic in Wales to help sufferers - and many are housebound or bedridden. How much ignorance there is - even among medical people, and even if sufferers are lucky enough to get a diagnosis, GP's have nowhere to send them. Although M E/CFS was recognized by World Health and the BMA as a neurological illness since 1969, any research in this country is made by psychologists, and the NICE guidelines for treatment with CBT and GET is absolutely inadequate and often damaging to patients. ME is definitely a Neurological illness and must be recognized as such or we cannot go forward. That MESiG have campaigned and presented two petitions to the Welsh Assembly in recent years, for a Specialist Clinic in Wales to deal with this huge problem. This is still ongoing and unresolved, and in the meantime patients are suffering badly without much medical support, if any. The only treatment available is often private, expensive and doubtful.

Therefore our support group MESiG is vital, and sometimes the only support available to people with M E/CFS, both for information on the illness, services and benefits, as well as the social benefit at monthly meetings, and home visits for lone patients. An informative Newsletter is sent out to members twice a year, and we are having a website redesigned for easy access. This was something other groups had not considered, but now thought to take up the idea, to join or start a group themselves. I also said how helpful a GP's referral to these groups would be to patients of ME and that there is a doctor who does this and realizes how beneficial this can be. Everything was noted.

There are better co-ordinated services in Scotland and Ireland for ME. Why not Wales? There are pockets of research and successful small trials held in America, Norway and Holland, and many sufferers are treated successfully.

Peter said, 'Surely if the Welsh Assembly can spend millions on a New Bus and Train Station, they should provide Specialist care for very sick people'. And we all agreed that the neglect is disgraceful.

There will be more similar meetings with the Neurological Alliance on behalf of the Welsh Government in different areas of Wales, to gather yet more information. Hopefully services will be improved - maybe even for M E/CFS.

By Dee Penny

MESiG presentation At The Wales Neurological Alliance Meeting

9th February 2016



There are an estimated 100,000 people and their families in Wales living with a neurological condition that has a significant impact on their lives. The Wales Neurological Alliance is a forum of organisations and groups representing people affected by neurological conditions in Wales

ME comes under Neurological Conditions so we (MESiG) have been attending meetings of the Wales Neurological Alliance where we have been made very welcome. The meetings are held in Ty Hywel at the Welsh Assembly in Cardiff Bay. Representatives from the Groups who are members of the Neurological Alliance occasionally give a presentation. I had mentioned that we would be interested in presenting the needs of people with ME at one of the meetings and we were allocated a 10 minute slot during the meeting on February 9th. Mark Isherwood AM was, as usual, the Chairperson and there was a live link to the Neurological Alliance in North Wales. A large group of people were in attendance from various groups and professions.

Christalla and I were quite nervous, as you can imagine and had discussed how to present the topic clearly and comprehensively. On the night we were sitting at the top table with Mark Isherwood and had our names displayed in front of us. Prior to our presentation a representative from the Migraine Group spoke. It was very interesting to listen to him suggesting that the needs of people with migraine did not come very high on the agenda and how serious it really is.

Chris, ever resourceful, had found a clip on the internet that summed up ME perfectly. The technician set it up for us so that it ran without our intervention. The room became very quiet while it was shown and it seemed to be a moving experience for everyone. There was some discussion about the needs of both the Migraine Group and people with ME. I had previously spoken to Mark Isherwood about MESiG so he was already fully aware of the difficulties faced by people with ME. He had said that he would be very willing to assist us but as he represents North Wales as an Assembly Member he is limited to assisting individuals in the North not the South.

At the end of the evening the Neurological Alliance Group thanked Mark Isherwood for working for a long period with them and wished him well in the forthcoming elections, hoping that he will be re-elected and hopefully be able to continue the work he does with the Neurological Alliance.

MESiG are grateful to the Wales Neurological Alliance for allowing us to raise some awareness of ME and the issues faced by many.

By Miriam Wood

MESiG

Attend Policy Forum for Wales

Priorities for the future of health and social care policy in Wales 2nd March 2016

The Policy Forum for Wales aims to provide the premier environment for policymakers in the National Assembly for Wales, Welsh Government and government agencies to engage with key stakeholders in timely discussion on public policy issues in the areas that have been devolved to Cardiff Bay, or otherwise particularly affect Wales.

The Forum has in place a programme of consultation with members of the National Assembly for Wales, senior departmental officials, regulators, industry representatives, charities and action groups, professional bodies and academics, local government and others. We welcome input from any individuals or organisations with an interest in issues relevant to Wales.

The Policy Forum for Wales is completely impartial and has no policy agenda of its own. Whilst we are grateful for support and any advice on themes that we receive from sponsors, all editorial decisions

remain with the Forum in order to maintain impartiality. This event was held in the Park Inn Hotel in Cardiff. I normally attend these events if the matter under discussion is related to health. These events run all morning from 9am until 1pm and people come from far and wide as speakers or attendees. Small Charities are allowed to send one representative to attend free of charge. Larger Charities have to pay a fee.

The first Chair of the day was Professor Marcus Longley, Professor of Applied Health Policy and Director, Welsh Institute for Health and Social Care. Thereafter followed three ten minute presentations and questions from the floor. One of those speakers was Dr Rebecca Payne, Chair of the Royal College of GPs Wales. I addressed a question to her later:

“How is it possible for GPs to diagnose lesser known conditions such as ME/CFS within the time-scale suggested by NICE, when many GPs are not trained to recognise it and it is diagnosed by elimination other possible conditions, and there is no Specialist in Wales to whom they may be referred. It is very time consuming for GPs and, for example, one patient has waited for 5 years to be diagnosed and it is not yet obtained.”

Dr Payne replied, in part, that she is trained to recognise 'normality' and to see when it's not there. At least I brought the subject to the attention of those gathered, whether or not it brought any tangible result.

Following the coffee break the second Chair took over, Rob Osborne, Health and Social Affairs Correspondent, ITV Cymru. You may recall that last year Rob had responded to our request to film one of our members, Evette, who has severe ME and Chris had also been interviewed. I had a chat with him during the break and updated him on the lack of progress for her since he and the camera man met Evette.

The next section: Vision for the future of health and social policy in Wales involved speeches by **David Rees AM**, Chair of the Health and Social Care Committee, Welsh Labour, **Kirsty Williams AM**, Leader and Health Spokesperson, Welsh Liberal Democrats, **Elin Jones AM**, Deputy Leader and Shadow Minister for Health and Well-being, Plaid Cymru, and **Darren Millar AM**, the Shadow Minister for Health and Older People, Welsh Conservatives.

I found this fairly difficult to listen to as it was the chance for these Assembly Members to present their best intentions prior to the Elections. Such upbeat promises make me feel uneasy when I see what is actually happening to people behind closed doors, who cannot be seen or heard or even get a diagnosis for their condition, and for whom there is not even a readily accessible care pathway.

The AMs then beat a hasty retreat back to their duties at the Assembly. I found the last section of the day difficult to attend to. Councillor HUW David, Deputy Leader of

Health and Social Services, Welsh Local Government Association, spoke about the challenges of financially sustainable social services and integrated care. This was followed by more questions from the floor. I had a question prepared but did not have the opportunity to ask it. For your benefit I will share what I was planning to ask even though it went no further than my note

book: "Where does Community Health Care Funding sit within Health and Social Care? What are its benefits and is it over or under-subscribed? Is it a too lengthy and difficult a process to obtain in many cases? Is it only applicable for older people?"

On the day I made use of the opportunity to invited Darren

Millar AM to attend MESiG's AGM and Awareness Day on May 14th. Within two hours I received a reply from his office to say that, because of the forthcoming elections, he would be unable to attend but that they had invited Craig Williams MP to attend in his stead. A good response.

By Miriam Wood



MESiG Attend Wales Rare Disease Day Reception Tuesday 23rd February 2016

To mark international Rare Disease Day, Rare Disease UK hosted Parliamentary Receptions across the UK.

Our reception in Wales, hosted by Darren Millar AM the Shadow Minister for Health and Social Services, took place in the Welsh Assembly (The Senedd).

Speakers included:

- Alastair Kent OBE, Chair of Rare Disease UK and Director of Genetic Alliance UK
- Dr Andrea Edwards, Clinical Director of the All Wales Medical Genetics Service
- Ceri Hughes, Parent of Isaac who has the rare condition Moebius Syndrome

There was also an exhibition with the work of Ceri Hughes who runs 'The Rare Project'.

Rare Disease Day provides the rare disease community across the world with the opportunity to increase awareness of rare diseases and highlight this public health priority to government and health departments. It is recognised in countries all around the world and 2016 marks the ninth year that the international rare disease community celebrates Rare Disease Day.

We received an invitation to attend this event so I went to it with another MESiG member. The preliminaries, with enjoyable refreshments were somewhat long and by the time the talking began, my companion was feeling ill and had to take a taxi home. This must be quite a familiar experience for many people with ME who may have managed to attend an event, only to feel too ill to stay and become involved once there.

Darren Millar AM, Shadow Minister of Health, welcomed everyone and also gave the final remarks at the end of the evening. Alistair Kent OBE, Chair of the Rare Diseases spoke and also Dr Andrea Edwards, Clinical Director of the All Wales Medical Genetics Service, and there was a talk by a patient, Tony Esmond, who has a very rare disease, Alkaptonuria (AKU).

I began to feel that maybe ME is not such a neglect illness after all. Apparently everyone who is affected by a rare disease thinks that their illness is the least understood, the most difficult to diagnose, lacks research, or is the most neglected. Apparently there are FIVE new diseases identified every week. Can you believe that?

Alistair Kent mentioned that the delay in getting a diagnosis, not knowing what is wrong for years and not being able to get help, is very difficult for people. When a diagnosis is available then there is the chance to get together with other people and to get support. Yes! That definitely applies to ME and Fibromyalgia, doesn't it? He said that many people see five doctors before they get a diagnosis for their illness, and then it could be the wrong diagnosis, but there is a huge relief once a diagnosis is established. Lack of a diagnosis is a barrier and without it the person often cannot access help. No Care Package is set up and the person spends time travelling to and fro seeing various specialists to no avail. Many people want to take part in research to help themselves or to help those who come after them and the link between research and healthcare is beginning to happen.



Dr Andrea Edwards said that patients are the experts and we must all work together: Co-production. Yes! We have seen the problems where some of our members have gone to see a GP who had preconceived ideas about what the person is experiencing. They may have dragged themselves to the Surgery only to be given the brush-off, as they 'look fine' and tests have revealed nothing significant.

Two quotations I liked during the evening were:
'You have to become an expert in your own condition'.
'Understanding would help and go a long way!'

Darren Millar said that hearing the personal experience of someone is most important. Yes, we have found this over and over again, haven't we? It was an interesting meeting for everyone.

I must praise the staff at the Assembly. I am always able to book blue badge parking in advance whenever I go to meetings. They will supply a wheelchair, meet me with it and take me to the right place. The staff are fantastic, friendly people and do everything to make sure that exactly the right support is available at all times.

By Miriam Wood

MESiG Christmas Party with Professor Jonathan Richards

7th December 2015

This year was going to be a little different - We had a speaker booked for our Christmas Party.

Professor Jonathan Richards Chair of the ME/CFS Implementation group & Cwm Taff Clinical lead for ME,CFS and FM.

But before this, we arrived early to set up and get everything ready. We usually use the little Tea Room for our monthly meetings, but today we were expecting more members who would want to be at the talk and just as important, to join in the party!

So today we would be decking out the Hall. The Church's Christmas Tree was already resplendent on one side, so we covered the long tables with coloured cloths etc, then set about bringing in the savouries and cakes. The raffle was set up with bottles of wine, chocolates and even a Christmas Teddy, and the usual Bran tub gradually filled up, as each person who arrived put in their contribution, so everyone would have a Christmas present as usual.

When everyone had arrived, we settled down to listen to what Prof Richards had to say, except for Robert who was busy with the camera!

Prof Richards talked at length about his aims, while working in his position, to reorganize and improve many things. He emphasized that he recognizes ME/CFS as a Neurological illness and does not minimize it's severity, but that Neurologists are already swamped at present with illnesses like Parkinson's etc., in Wales. They already have more than they can cope with, so that ME would not get much attention at present as a neurological illness. However, he stated that while in his position as Clinical Director he is passionate about altering this situation and to bring about change. In the meantime he thought that the role of our support group is most important and that we had been doing the right thing in fighting for change and for our support of our members.

There were questions and answers and Chris thanked Prof. Richards, then the party began and Prof Richards joined in showing that he is a very approachable person. We all attacked the food and Mary was kept busy providing tea and coffee in the kitchen for everyone. Presents were exchanged, and the raffle was called - even the Prof won a prize much to his amazement! Everyone seemed to enjoy themselves and the Christmas Spirit was very much with us.

We have since heard that Professor Jonathan Richards is no longer in his post as Chair.

By Dee Penny

The Well Head Centre

The Well Head Centre is a registered charity which exists to give time and space to those who are facing emotional crisis, for example those going through 'life crises' such as divorce, bereavement, anxiety, stress, a feeling of hopelessness, having nowhere to turn or no one to talk to. We also offer this facility to those who are caring full-time for family members and need time-out from their current situation.

What We Offer?

We offer free short-term accommodation to adults over the age of 18 for up to six nights in a supportive and peaceful environment, bringing hope, direction and rest back into their lives.

How Is The Centre Funded?

The Centre is totally funded by gifts and donations and has been a registered charity since October 2011.

How Does The Well Head Centre Function?

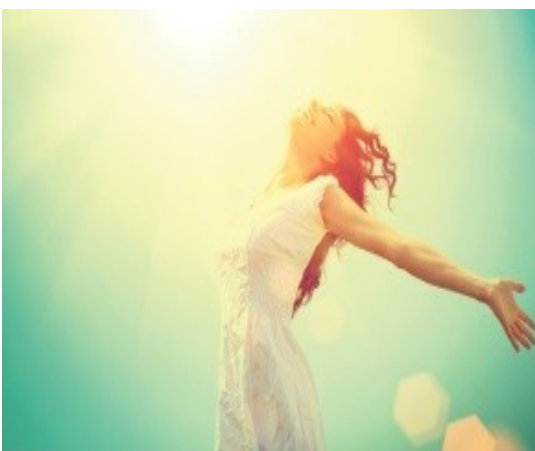
The Well Head Centre is run by a team of dedicated volunteers who are on site 24 hours a day bringing love, compassion and offering a listening ear to the Centre's guests. All guests are referred to us by a professional working within the community (e.g. doctor, nurse, health visitor, community support worker, Pastor of a church or someone in a pastoral role within the church).

Where Are We?

The Well Head Centre is in the historic market town of Bourne, Lincolnshire. It is 15 minutes from the A1, 16 miles north of Peterborough and 38 miles south of Lincoln on the A15.

Address: 12 Manor Lane, Bourne, Lincolnshire, PE10 9PQ

Website www.wellheadcentre.co.uk



Chris from MESiG is able to make referrals, and one of our members attended for a week.

If you think this is for you, please ring Chris on 02920762347.

Please keep in mind that you would need to be well enough to travel there and be able to self cater.

An ideal break for carers and those more able.

What is MESiG doing to help you?



In addition to the monthly Support Meetings what do we do to support you?

If you cannot come to us we can try to come to you. We support members who otherwise lack support, for example, when you have meetings with Social Services or you need to see your GP or attend a hospital appointment. At the best of times these are daunting when you already struggle to cope from day to day and travelling anywhere, near or far, is a problem. We may be able to arrange to pick you up, drive you to an appointment and support you once there, if required.

For example, one member who lives outside Cardiff, had to be at an appointment in a Cardiff hospital by 9am and there was no option for a later appointment. She explored the option of travelling alone on a very early train, despite the fact that mornings are definitely not good for people with ME. Then a train strike was announced for that very day! And when the day arrived, to add to the difficulty, there was torrential rain. So it was good that we had arranged to take her by car to and from the hospital. Also another member, who has several additional conditions, regularly needs to attend different hospitals for scans and check-ups and help to get to the dentist (especially after she fell and broke a tooth) and a clinic for foot care as well. Physically this is very difficult for her, not to mention extremely expensive by taxi. We try to help by taking her to some of these appointments.

Recently some of our members who were reliant on family members have lost that support. We have been able to visit them at home, allow them to share their problems and assist them with phone calls and letters.

Then there are the famous, fearful brown envelopes that drop through your letter box. We are able to support you to fill in applications for ESA and PIP if need be. We also arrange to be with you if possible, when you have the face-to-face assessment, either in an Assessment Centre or at home. We cannot guarantee that our help will bring the desired result but we have had a number of successful results. We currently have one case that has gone to Tribunal due to a lack of medical evidence. This case was brought to the attention of Mark Drakeford AM, Minister of Health because of the lack of a diagnosis and the lack of a medical service to provide it. Watch this space as this is work in progress.

By Miriam Wood

Roy's Talk on the Trial of the SoeMac

Oxy/Energy Machine

4th April 2016.

Roy-researcher and Neil- owner of the SoeMac Company, arrived before Chris had opened up the building. Our speakers travelled all the way from Mid Wales (Roy), and Neil from Nottingham! So when I arrived, I greeted them quickly and set about organizing some drinks, while Chris dashed home to get the microphone. Members soon arrived and there was so much chat and interest, that Roy's talk began a bit later than planned. He had come to tell us about his findings after the Trial of the SoeMac with Twelve members of the Nottingham M.E. Support group over many months. Roy explained:-

The SoeMac excites Oxygen to a higher energy level by drawing in normal air through a specific wave length of light onto a catalyst. This creates what you could call a photon cloud, that bombards the oxygen molecule to this higher energy level. Oxygen being a stable molecule does not stay excited, but reduces back, releasing the energy which is equal to 98 electron volts. Electron volts being the same energy that oxygen uses in the cell as a fuel, to break down glucose to make the universal body fuel called ATP (Adenosine Triphosphate). It is Roy's Theory, that the energy released is then imparted to the Bonds of all the Muscles linked to Oxygen in the ambient air that we breathe, and when these molecule bonds are cleaved within the chemical processes of the body, the extra energy is then released and can be used directly by the cells. Some molecules being more important than others.

When Roy started his research into the SoeMac, he didn't know where it would lead. He just followed all the logical steps to gather information.

1. He Reverse Engineered the Testimonials, to see what would be happening within the body to make the benefits true.

2. He Tested the Machine itself and measured what was coming out, and looked at the Science behind the Technology to see what he was working with.

3. He Researched the Evolution of the first cells and the Environmental Changes that took place to make the complex organism's we are today.

4. The information gathered, allowed him to look at medical research studies from around the world, to put together the common pathways the SoeMac uses. The Molecules used - Where they go within the body - and how they interact with the Body's Systems and cells.

All this had to hold together in a Logical Progression of Cause and Effect, which linked all the pieces together. The Research led to a list of areas in which it works within the body. The Lungs, the Blood Stream, the Autonomic Nervous System, the Mitochondria, the Brain, the Nerve Synapses, the Muscle Tissue, the Ion Channels, the Heart and others.

These Areas cover :-

Breathing, Circulation of Blood, Blood Pressure, Sleep, Hypoxia of the Cells, Detox, Alertness and Memory, Pain, Waste Clearance, Balancing of Free Radicals, Signalling and Reflex actions, Energy and others.

It led me to conclude that the SoeMac provided help to the body by providing a Homeostatic Balance to the many systems involved in a Protection and Repair effect which allowed these systems to Improve in Function.

After these findings, Roy started to work with people with M E/CFS, after reading Mary's Testimonial - Her Health improvement after using the SoeMac. M E is one of the most challenging illnesses that affects nearly all the body's systems in one way or another.

However, the results he got from his Research followed through into Practical Reality of working with people and the Benefits they have gained.

All the people who Stayed Long Term on the Trial, improved in Health and their Quality of life is better from using the SoeMac.



If there are any of our members who could not come to the meeting and want to know more, Roy is happy for them to contact him by email (rucc2@hotmail.com) Roy is independent of the SoeMac Co.

A Big Thank you to Roy for all his valuable research and for giving of his time and energy to come and talk at our meeting.

Also a Big Thank you to Neil for coming, and his generosity in loaning machines to a few of our members. Neil has a SoeMac Website and can also be contacted by phone at: 07957828891.

A SoeMac can be purchased by our members half price £209 and money is refundable up to 12 weeks if unsatisfactory.

Dee Penny



Community Health Council

The Cardiff and Vale of Glamorgan CHC was established in April 2010 following the reorganisation of Community Health Councils in Wales. We represent the interests of the patients and public of Cardiff and the Vale of Glamorgan in relation to local health services.

The 4 statutory duties/functions of the CHC are to:

1. Scrutinise the operation of health services in Cardiff and the Vale of Glamorgan, to make recommendations for the improvement of that service, and to advise the University Health Board upon such matters relating to the operation of the health service as the Council thinks fit. In carrying out its functions, the CHC must have regard to the need for systematic, continuous engagement with the local population and community groups within Cardiff and the Vale of Glamorgan, in order to appropriately represent the public's view on the operation of health services in their area.
2. Be consulted by the relevant Health Board and NHS Trust in respect of health services for which it is responsible.
3. Enter and inspect NHS premises.
4. Provide an independent advocacy service on behalf of the Welsh Ministers for those aged 18 and over.

JILL SHELTON - CHAIR OF CAVOG - CARDIFF AND THE VALE OF GLAMORGAN COMMUNITY HEALTH COUNCIL will be visiting us at our 6th JUNE Support Meeting. She will be bringing with her **STEVE ALLEN**, Head of the Community Health Council, together with a Clinician to answer any medical queries.

Conference

From the lab to the living room: the benefits of co-production in research into neurological conditions

April 14th 2016

Members of the MESiG Committee attended this day on Thursday 14th April 2016 which was held at the All Nations Centre in Cardiff. MESiG had a table to display information about ME. It was a conference which explored the benefits of a co-production approach for researchers and participants in the context of the current research environment in Wales.

Through an engaging mix of speakers and breakout sessions, the event demonstrated how co-production can increase the potential to translate research findings into real life outcomes that benefit people with neurological conditions. The event was aimed at academic researchers, clinical practitioners, people living with neurological conditions, funding bodies, policy makers, and relevant third sector organisations.

Contributors:

- ◆ Professor Jon Bisson, Director, Health and Care Research Wales
- ◆ Dr Danny Antebi
- ◆ Professor Chris Burton, Chair of Rehabilitation and Nursing Research, School of Healthcare Sciences, Bangor University
- ◆ Professor Monica Busse, Cardiff University
- ◆ Dr Laura Bunting, research manager for Health and Care Research Wales Brain Repair
- ◆ Natalie Simon, Public Involvement and Engagement Manager.
- ◆ Barbara Moore, senior Public Involvement and Engagement Manager
- ◆ David Murray, patient perspective
- ◆ Michelle Price, Consultant Therapist for Stroke and Neurorehabilitation
- ◆ Isabelle Abbey-Vital, Research Involvement Officer, Parkinson's UK
- ◆ Dr Sion Williams, School of Healthcare Sciences, Bangor University
- ◆ Phil Keir, Rex Seddon, Patricia Masterson
- ◆ Dr Jon Stamford, Cure Parkinsons' Trust

There were 6 exhibitors, 2 of them for ME: MESiG and Wames.

For further information please visit
walesneurologicalalliance.org.uk



LEFT

Dee and Miriam of MESiG

Ana Palazon of Wales Neurological Alliance

RIGHT

Chris and Miriam of MESiG



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

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

Contact and Support

ME Association

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

Tel: 01280 818968 9.30am - 3pm

Email: admin@meassociation.org.uk

Website : www.meassociation.org.uk

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

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

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

Brame

30 Wimmer Avenue
Winterton-on-sea
Great Yarmouth
Norfolk
NR29 4BA
UK

Tel/Fax: 01493393717

Email: info@brame.org

Association for Myalgic Encephalomyelitis

Website: www.afme.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: nmecent@aol.com

Website : www.nmec.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

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

Association of Young People

With ME (AYME)

Tickford House

Silver Street

Newport

Pagnell

MK160EX

Email: helpline@ayme.org.uk

HelplineTel: 03302211223 Mon-Fri 10-2pm

Website: www.ayme.org.uk

Main Office Tel: 01908 379737

The Young ME Sufferers Trust

PO Box 4347

Stock

Ingatstone

CM4 9TE

Tel: 0845 003 9002

Website: www.tymestrust.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

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

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

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

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