

December 2017

DGMEFM Network

Support for ME, CFS, Fibromyalgia

Welcome all,

First of all thank you all for the response to the Gift Day and to those who contributed their time and thoughts to fill out the survey in the summer. There is a brief analysis of the findings in this newsletter. We can't promise to fulfil them all, but it gives us something to aim for and something to base funding requests on. Thanks to Louise who stood down from our committee when she moved away from the region and a huge vote of thanks to Kim Jacobsen, our secretary, who stands down, but remains on the committee. Her efficiency constantly amazed us. She was instrumental in creating the leaflets, contact cards and the survey - a huge amount of work for anyone, never mind someone who is working and coping with fibro. Welcome on-board Alex Thelwell as vice-chair and committee member Kim Dams who steps into the secretary's role from general committee.

One of the attractions of this region is its peace and quiet. However for those of us who are struggling unwanted isolation at this time of year can feel particularly harsh. Please know that you are not alone. If you need someone to speak to there is group support on the facebook page, there are people who are happy to meet up for a coffee or you can use the Network's whatsapp/phone number to contact me. I'm always happy to chat.

Wishing you all a merry Christmas and a happy, healthier new year, when it comes.

Craig Woods

Monthly Get-Togethers

First Thursday of every month 1pm – 3pm at Midsteeple, Dumfries



Dec 7th The usual social time from 1 – 2pm and then from 2 – 4pm a roundtable meeting with professionals working in health and social care, hosted by Action for M.E. Following on from our July meeting this will look at good practice and improving care within the region.

January 4th A social chat and a chance to compare notes on the festive season.

February 1st Check on facebook or the website for the theme of this meeting closer to the time.

Refreshments will be provided at the Midsteeple meetings. Entry is through the blue Box Office door. We use the meeting room on the first floor. Press and hold the lift button to call it and press and hold the button until the door unlocks on the 1st floor.

Pop-Up Meetings

Christmas lunches Sunday 10th Dec Stranraer and also **Saturday 16th Dec Dumfries**. Booking required. See the back page for details.

January 21st Sunday 1pm - 3pm social at Castle Douglas Garden Centre Coffee Shop.

February 18th Sunday 1pm – 3pm social at Brambles Tea Room, 1 Commerce Road, Stranraer.

Look out for other pop-up meetings on our Facebook page or website meetings page.

Contact us:

Phone/WhatsApp - 07437 602610

email - admin@dgmefm.org.uk

Registered Charity No. SC030641



Introductions

Hello, everyone! My name is Alex and I am your new Vice Chairman. Craig continues his great work as our chair, but I volunteered to help out as there is so much to do for all of us here at the DGMEFM Network. I don't have M.E., CFS or Fibromyalgia myself, but know the conditions well from my experience as carer. If you have any questions or comments, you can reach me at Alex@dgmefm.org.uk and I'll be happy to help.

And.....

A quick hello from your new secretary!

To make this all slightly more confusing: the person has changed, but the name hasn't. Kim J. has been doing a great job as our secretary and I am sure you'll all join me in thanking her. She will continue to look after our website and blog and stay on the committee.

I, Kim D, have already been a committee member for the last year and have now taken over as your new secretary. I have M.E., CFS and Fibromyalgia and have a lot of experience in disability awareness and equality rights and am currently trying to secure more funding for us.

If you have any questions or comments, you can reach me at KimD@dgmefm.org.uk

All the best, Kim (the one with the D instead of the J!)

Network WebPage

If you have access to the internet, we hope you will take a look at our Webpage: dgmefm.org.uk
The 'Local and National Links' page includes useful links including information on local monthly pain group sessions, to self-help material from 'Moodjuice' which covers 'Chronic Pain', 'Sleep Problems' and much more. Just click on the highlighted name e.g. 'Moodjuice' to activate the link to the Moodjuice web site.

The 'Resources' page will help you create a Facebook account if you wish to join our 'closed' Facebook page, and will show you a short video on how to access the Dumfries Midsteple Meeting Room where monthly 'open' meetings are held.

If there is something you feel could benefit being on the website, please get in touch at admin@dgmefm.org.uk

Monthly Website 'Blog'

You don't need to join our Facebook page to see some of the articles and news stories posted there. Every month we create a 'blog' which is posted on our website to capture key elements from our Facebook community posts. This includes links to the wide ranging articles and news stories posted by members, and an anonymised summary of members' discussions.

If you haven't joined our Facebook group you can keep up to date by visiting our blog page <http://dgmefm.org.uk/blog/>

THAT AWKWARD MOMENT WHEN



YOU DROP YOUR PHONE ON YOUR FACE.



SLOTHILDA.COM

Gift Day thanks

Grateful thanks to all who contributed to this year's Gift Day, and to those who now make regular payments to our bank each month. Your generosity has brought in almost £1000 and, with the Gift Aid that we'll be able to claim from eligible donations, this amount should cover the cost of our routine activities for the financial year (newsletter, website, meetings). This is especially helpful as our reserves fell last year with spending on the leaflets and contact cards which were distributed to Health Centres etc.

Easyfundraising

Did you know that whenever you buy anything online - from your weekly shop to your annual holiday - you could be collecting free donations for DGMEFM Network?

There are over 3,000 shops and sites on board ready to make a donation, including Amazon, John Lewis, Aviva, thetrainline and Sainsbury's – it doesn't cost you a penny extra! It's as easy as 1, 2, 3...

1. Head to <https://www.easyfundraising.org.uk/causes/dgmenetwork/> and join for free.
2. Every time you shop online, go to easyfundraising first to find the site you want.
3. After you've checked out, that retailer will make a donation to your good cause for no extra cost whatsoever!

There are no catches or hidden charges and DGMEFM Network will be really grateful for your donations.

Thank you for your support.



Together we've raised
over £18 million



Using our website or mobile app



1. Empty your shopping basket

If you're shopping with Amazon, eBay, Expedia or [Hotels.com](https://www.hotels.com), always make sure your basket is empty before you start shopping.



2. Use the easyfundraising website or easyfundraising app

Go to the easyfundraising website or app and search for Amazon, eBay, Expedia or [Hotels.com](https://www.hotels.com).



3. Click on the websites

Click to go shopping and we'll take you to their website - everything is exactly the same, even the price!



4. Go shop as normal

When you check out, you'll collect your free donation! Easy.

Food Train update

The Food Train has expanded its services into the Stewartry, for grocery delivery and help with household tasks, and its befriending service. Their services are for people aged over 65, however, they will accept referrals through social work or any NHS professional for customers aged over 55. The Stewartry service development officers, Shelley Tuchewicz and Isobel Henkelmann, can be contacted on 01556 288427. For further information about the Food Train and their services and charges, contact their Regional Manager, Helen McAnespie on 01461 207778 or visit the website: <http://www.thefoodtrain.co.uk/our-services/regional-branches/dumfries-galloway>

Nutrition

We were pleased to welcome Karen Scobie, Nutritional Therapist, to our meeting in November. Karen has developed particular interest in ME through helping her husband manage his condition. Here are a few of the pointers that she gave in her talk and answers to questions.

- 'It's not what you eat, it's what you absorb', and minerals and vitamins are key. We must ensure our digestive system is working optimally.
- The importance of blood sugar balancing.

To get the digestive system working better, firstly encourage production of stomach acid. For this take a teaspoon of apple cider vinegar in warm water, or celery juice on its own first thing, 15 minutes before breakfast. It is important to increase celery juice very gradually into the diet. Zinc is an important mineral for stomach acid production, and is found in green vegetables, pumpkin seeds, and walnuts for example. If taking a Zinc supplement ensure it's combined with copper. The use of probiotics can help to keep the natural balance of microflora in the intestines. Supplement advice should always come from a Nutritional Therapist or a health professional who can check for any contra-indications with medication.

You're not going to master the rest of your life in one day. Just relax.

Master the day. Then just keep doing that every day.

HealthyPlace.com

Magnesium deficiency is very common in ME/CFS and Fibromyalgia sufferers.

"A combination of magnesium and malic acid tops the list of recommendations for easing pain and fatigue, especially for those with fibromyalgia or ME/CFS. Magnesium (Mg) is one of the most important nutrients required by our bodies." *(quote from ProHealth.com).*

To boost magnesium levels Karen suggested starting with an oil spray or using Epsom bath salts before using any supplement, and that of the supplements, food based magnesium supplements are more easily tolerated. Food sources are plant based like beans and nuts, whole grains and green leafy vegetables.

Dietary tips:

- 'beans meanz wind' – soft beans such as butter beans and cannelloni beans are more easily digested; also cooking beans and lentils together with seaweed may minimise wind. If these have been out of your diet for a period of time, introduce these very gradually back into the diet.
- Seeds – pop, soak or grind them. Linseed tea may be helpful for healing the gut lining as it has a substance called mucopolysaccharide with in it and this has soothing properties. Soaked nuts and seeds, and sprouting seed increases the enzyme activity within them.
- Spirulina (an algae) is a good source of omega 3. Omega 3 is good food for the brain. Start with a quarter of a teaspoon and increase gradually up to two teaspoons per day in water.
- We need to eat at least 3 portions of fruit per day but we should choose low GI/GL fruits: berries (all types), apples, pears, cherries and plums. Limit dried fruit and fruit juices as these are concentrated versions of fruit and will send your blood sugar into a peak. Fruit sugars may be most helpful when it comes to healing our system from viruses and many people who suffer from CFS or ME have had a virus in the past that may still be within their system.

- ❑ Always eat a protein and carbohydrate at each meal. Eaten together, a protein slows the carbohydrates rate at which it hits the bloodstream; eat 3 meals and 2 healthy snacks and make sure you eat every 2/3hrs.
- ❑ Always eat breakfast, your blood sugar is at its lowest in the morning.
- ❑ Avoid refined carbohydrates such as white pasta, bread and rice and use whole grains instead such as brown rice, quinoa, wholemeal bread & pasta, oats.
- ❑ Keep hydrated – caffeine dehydrates. Caffeine also spikes blood sugars.
- ❑ Recipe: Sweet Vegetable Tea - onion, cabbage, carrot, winter squash in equal amounts. Cover with 3 or 4 times the water, allow to boil for 3 minutes and then simmer for 30 minutes. Strain the veg and keep the liquid. You can have a small cup of the liquid every day around mid-afternoon it may help with cravings and balance blood sugars.

Welfare benefits –PIP feedback request

The Scottish Government is currently holding meetings where they want to learn more about the experiences users of Social Security benefits have made so far. This is in preparation of some of the benefits being devolved to the Scottish Government in the near future. They are very keen to learn from our experiences as users, so that they can avoid copying a system that doesn't work well.

I have been attending some meetings so far and spoken about my personal experiences with the DWP, assessments, forms, phone calls and so on. I'll be writing up a more detailed report about my experiences soon. For now though a very last minute request:

I will be attending another meeting on the **4th December** and would welcome feedback from all of you about your experiences of Personal Independence Payments. This meeting will ask about feedback regarding the process of PIP. Things like how easy/difficult was it to find information, to apply, how was the assessment itself and when did you find out about the results, did you have to appeal, who helped you, how long did it all take...

It is not asking about specifics or names, everything is anonymous and confidential and it will be used to improve their own process once they take over.

There will be many more meetings for different topics in future and I'll write more information up soon. In the meantime though, if any of you have any feedback for me, something you'd like me to mention to the researchers about the PIP process specifically, please send me an email at: KimD@dgmefm.org.uk or call our Network phone on 07437602610 **by Sunday the 3rd December**.

Brain Fog Day To Do List:

*Find the to do list I already made
 Something else I was supposed to do
 Let cat out of wardrobe
 Look in fridge for coffee mug
 Remember where I wrote down
 passwords, in case I forget
 Check calendar every half hour
 so I know what day it is
 Find out if anyone knows if I
 took my pills*

sometimesitislupus.com

I know many of us have struggled with applying for PIP, especially also in regards to Fibromyalgia and M.E. or CFS making the process so much more difficult for us. I think this is a good opportunity to tell the Scottish Government what we would like to see improved in their own system in future, where the challenges and problems are and how they can help us.

Kim D

Feedback questionnaire

Many thanks to all who completed the feedback questionnaire this summer, and to the three prize winners Brian Conchie (£50), Craig woods (£25), and Mari Whillis (£15) whose donations back to the Network, with Gift Aid, resulted in a net gain for our funds!

A summary of the key findings from the questionnaire will be produced in due course and made available on the website, or paper copy by request. In the meantime.....

- **Newsletter**

Most respondents were happy with the newsletter and quarterly distribution. A number asked for it by email rather than post. We did previously try using 'MailChimp' to send in bulk by email to those who wanted that, but found it wasn't always being received, so went back to postal distribution.

Committee will have another look at how we could successfully distribute by email in bulk.

On content, respondents asked for more positive stories and anecdotes from other members, and how their illness affects them, how they cope, what has helped them live life to the full with their illness; reference to recent discussion and articles posted on our Facebook page; more on bio-medical research and scientific debate; more on beneficial alternative treatments/complementary therapy; community activities and social events suitable for disabled and low energy; a mixture of informative and fun items; and fuller information for members who don't have internet access.

We'll see what we can do within our current limitations, but it's helpful too for future funding applications that we can show how much more is wanted and the costs of that. As for members' stories.....please don't be shy.....

Members' stories

Members tell us how beneficial it is to hear from or talk to other members. Although everyone is different, we are all suffering in similar ways with illnesses that are mostly invisible which can be physically and mentally exhausting. Not everyone has someone to share what they are going through or talk to someone going through similar challenges. Some people can't or find it too difficult to get out due to their illness, so attending one of our monthly meetings is not an option. It can be tremendously reassuring just hearing that someone else suffers in a similar way or to pick up a tip that may help you cope even just slightly. Don't give up, keep fighting and stay positive. You are not alone.

If you feel able to share your story in one of our newsletters, please e-mail us at

admin@dgmefm.org.uk or write to DGMEFM Network c/o Craig Woods, Grooms Cottage, Gilmour Bank, Lochmaben. DG11 1RW.

- **Meetings**

Respondents wanted a balance of information and guest speakers, member's stories, and opportunity to socialise. A number commented that they would like to attend but would need assistance e.g. transport to get to a meeting. Of alternative locations, respondents asked for 'close to parking', Stewartry, Langholm and Stranraer. Preference for weekday afternoons and mornings were the larger groups, but weekends were favoured by a significant number with a few weekday evenings. There was a lot of feedback in the survey that Dumfries isn't suitable for some of our members, as Dumfries and Galloway is such a widespread area. We are looking into options for more meetings in other locations next year. For now though, there will be two Christmas lunches this year: one in Dumfries and one in Stranraer -all of the details are on the back page. There will also be 'pop-up' meetings in Castle Douglas in January, and Stranraer in February (see front page).

Research News:

Blood cells in chronic fatigue syndrome are drained of energy

Taken from an article in the New Scientist on November 3rd 2017, written by Andy Coghlan.

Thirteen years ago, Cara Tomas was rendered bedbound with chronic fatigue syndrome. It came on suddenly, she says, without warning signs. Even now she has good days and bad days due to the lingering effects of the disease. “A lot of people dismiss it as a psychological disease, which is a big frustration,” she says.

Tomas knows more about CFS than most. A PhD student at Newcastle University in the UK, she has just published a paper demonstrating that white blood cells in people with the disease are as listless as the people themselves often feel. “Now we’ve shown there’s a physiological difference, it could explain the whole-body fatigue shown by patients,” she says.

The finding adds to mounting evidence that the disorder has a biological explanation, and raises the prospects for new treatments and diagnostic tests.

“The CFS cells couldn’t produce as much energy as the control cells,” says Tomas. “At baseline, they didn’t perform as well, but the maximum they could reach under any conditions was so much lower than the controls.”

Tomas and her colleagues measured the efficiency of mitochondria, the energy-generating powerhouses in cells. The mitochondria are the dominant source of energy for all of our cells. The team found that mitochondria in CFS cells can’t produce energy properly. “We’ve shown definitively that it’s a fault in mitochondria,” says Tomas. “It points directly to a physiological, not psychological disorder.”

Tomas measured the oxygen consumption of cells in comfortable and stressed conditions, to see how well they could raise their game with glucose in short supply, a situation forcing the cells to consume more oxygen to compensate. Even at baseline, control cells consumed twice as much oxygen as the CFS cells. The disparity widened dramatically when the cells were stressed.

Metabolically exhausted

In another test that artificially pushed cells to their maximum capacity starting from baseline, CFS cells could only increase their mitochondrial output by 47 per cent, roughly half the 98 per cent increase achieved by control cells. The implication is that cells from CFS patients can’t raise their output to meet the energy demands of routine physical tasks.

“A major question now is whether the situation in these white blood cells reflects whole-body mitochondrial dysfunction in patients,” she says. To that end, Tomas is currently taking samples of muscle cells and testing them in the same way as the blood cells. “It would be good if we could get this repeated in muscle cells,” she says. “It’s important the patient population know we are looking into this. Patients sometimes think no one cares, but we do have interest, and want to find out what’s going on.”

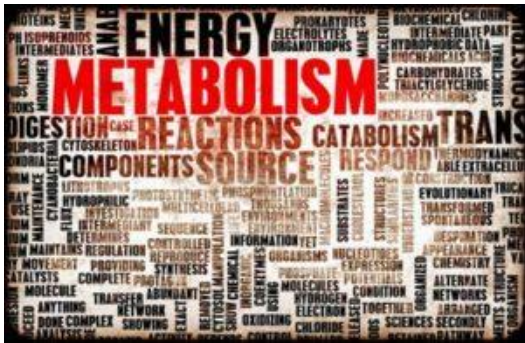


Comment Interestingly a couple of Network members have recently remarked on feeling well for up to 3 months each after blood transfusions during unrelated medical procedures. This would back up the findings of this research that there's something in the blood cells. To have quality research taking place in the UK, and in Newcastle, is heartening.

Some recent studies have also indicated problems with energy production in Fibromyalgia...

Metabolomics Study Points Finger at Energy Production in Fibromyalgia

From an article by Cort Johnson, Health Rising, Nov 6th 2017.



A 2013 study that differentiated FM from two other chronic pain diseases (rheumatoid arthritis, osteoarthritis) was encouraging in several ways. For one, it found that osteoarthritis and rheumatoid arthritis were metabolically similar but fibromyalgia was distinct. That made sense; all three are chronic pain conditions but osteoarthritis and rheumatoid arthritis are linked to distinct structural changes and a specific kind of inflammation. No distinct physical abnormalities, on the other hand, have defined FM. That study suggested that metabolomics might be a good fit for FM.

A 2014 fibromyalgia metabolomics study specifically examining the lipids in FM patients found increased levels of metabolites associated with the fragmentation of the lipid or fat membranes surrounding our cells. Injury to the lipid membranes is often associated with high levels of oxidative stress and further analysis indicated that other markers of oxidative stress are present in FM. High levels of oxidative stress are also often found in ME/CFS.

Because the metabolites involved have been linked to increased pain levels, it's possible that the increased oxidative stress is contributing to the pain FM patients feel.

One model suggested that the levels of just three metabolites in FM patients (creatine, succinic acid & taurine) were highly diagnostic for FM. Findings suggested that creatine and succinic acid may be contributing to the fatigue and pain found in FM as well.

Interestingly, given fibromyalgia's overlap with ME/CFS, and the studies suggesting energy metabolism is an issue in ME/CFS, these metabolites suggested problems with energy metabolism may be present in fibromyalgia as well.

Stop Press:- Reports emerge that Phase III Rituximab Trial Fails

As we start printing initial reports from the ME Association of the Norwegian Fluge/Mella trial of the intravenous leukemia drug Rituximab are that the trial has been stopped and the larger scale, third phase of the trial has failed. This is hugely disappointing news as it had shown a great deal of promise, with patients having been put into complete remission in the early stages. It is too soon to know what has gone wrong, and why phase III has failed after the successful early stages. We will bring you more news of the outcome in the next newsletter.

CFS, Fibromyalgia, IBS – or SFPN?

From Boston25News Nov 16th 2017

Researchers at Massachusetts General Hospital, Boston, have made a discovery that could ease symptoms for millions of people suffering from conditions such as chronic fatigue, fibromyalgia and irritable bowel syndrome. Dr. Anne Louise Oaklander says a good proportion of patients diagnosed with those health issues may actually have a disease called small fiber polyneuropathy, SFPN. This is a disorder in which nerve cells found under the skin are attacked by the body's immune system. The resulting damage can cause numerous symptoms including gastrointestinal discomfort and feeling like the skin is on fire.

“The problem is their skin looks perfectly normal, and there's no evidence that anything's wrong,” Oaklander said.

Along with others, Oaklander recently published a study in which they found that drugs called immunomodulators can be effectively used to treat SFPN, though these drugs may not work in every patient because every presentation of the disorder is different. She said patients who learn they have SFPN often feel liberated.

One of those patients is MaryEllen Talbot, who had initially been diagnosed with fibromyalgia before learning she actually has SFPN.

“This diagnosis is from a biopsy, so it's not subjective, it's objective. It's something they see on the lab,” she said. Talbot isn't alone. Because of the varying symptoms from case to case, Oaklander said the number of people with SFPN could be huge.

“Maybe it's tens of millions of people around the world who have it, maybe it's hundreds of millions of people, but either way this is not a rare disease,” she said.

Unrest – An ME Movie

Synopsis:- When Harvard PhD student Jennifer Brea is struck down at 28 by a fever that leaves her bedridden, doctors tell her it's "all in her head." Determined to live, she turns her camera on herself and her community, a hidden world of millions confined to their

homes and bedrooms by ME, commonly called chronic fatigue syndrome.

“It powerfully insists on giving a voice to victims whose greatest challenge, apart from their symptoms, is surmounting a world of indifference” From a review in The New York Times.

You may recently have seen some of the publicity surrounding a new film by Jen Brea, a sufferer of ME. The film has been very well reviewed and Jen, now coping better than some of the depths we see her at in the film, has been widely promoting it in the UK, with viewings in the Houses of Parliament and appearances on BBC Breakfast. The film is available to buy now on digital download, but we hope to organise showings in this region for Network members and the public in May to coincide with Awareness Day.





Xmas Lunches

There will be two Christmas lunches this year: one in Dumfries and one in Stranraer. All of the details are below. We have to all choose from the Christmas menus, as their normal menus don't apply for Christmas bookings.

If you want to join us, **please let us know the latest by Friday the 1st December for Stranraer, or Saturday the 9th December for Dumfries** and also send your food order before that date to our Vice Chairman Alex at: Alex@dgmefm.org.uk or contact us via phone on 07437 602610. Alex is happy to answer any questions as well and if you have any dietary requirements, please also let him know. We all pay for our own food on the day and no deposits are required.

If you need a lift please let us know and we will hopefully find a way to accommodate you!

We hope you will all be able to join us for a nice Christmas meal together in either Dumfries or Stranraer or even both!

Stranraer

Sunday, 10th December from 1pm.

It will be held at: Henry's Bay House, Cairnryan Rd, Stranraer, DG9 8AT.

You can choose from either a 2 course meal for £15 or a 3 course meal for £18.

The menu can be found here: <https://goo.gl/DmGQm1> or give us a call if you can't access the internet.



Dumfries

Saturday, 16th December from 1pm.

It will be held at: Solway Gate, Euroroute, Annan Rd, Dumfries, DG1 3JX.

You can choose from either a 2 course meal for £13.49 (kids £6.99) or a 3 course meal for £16.49. The menu can be found here:

<https://goo.gl/1GBJ7h> or give us a call if you can't access the internet.

DGMFM



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Registered Charity
SC030641

Please let us know if you no longer wish to receive the newsletter, or if you wish to cease being a member of the Network (all your details will be deleted from our files). In either case, contact admin@dgmefm.org.uk or text or phone 07437 602610.