DGMEFM Network

Support for ME, CFS, Fibromyalgia



Welcome to this first newsletter of 2025, with the promise of Spring around the corner as the snowdrops and crocuses come into flower.

Bobbie has asked me to step in on her behalf with a Treasurer's introduction to this issue, while she recovers from a spell of poor health. So, don't worry, I won't bore you with numbers, but I will explain a bit about our funding as that determines what we can do.

Firstly though, I wish Bobbie and everyone else who has struggled this winter an early recovery, and better health in the year ahead. I know I'm looking forward to warmer

days easing joints and muscles a little, longer daylight, and the welcome cycle of renewal in nature lifting the spirits.

Talking of renewal, sadly we weren't successful in our bid for a fourth year from the Communities Mental Health and Wellbeing Fund, for social lunches and craft/wellbeing activities. We know how valuable these have been and we'll be doing what we can to keep them going, albeit that members will need to pay their own way for lunch/refreshments at social meet ups.

We've applied for a grant from the National Lottery's 'Fairer Life Chances' fund, which we should hear about by the end of April. If successful, it will mean we can look forward to offering regular meet-ups and craft and wellbeing events over the next three years, organised by a part-time Wellbeing Officer. If not, we'll look for other funding opportunities.

In the meantime, we'll carry on with lunchtime meet-ups and will still be able to offer some free craft/wellbeing events for the time being thanks to a grant from Corra Foundation's Henry Duncan fund. For those of you who don't know, Henry Duncan founded the first parish savings bank in 1810 at Ruthwell, near Annan. You can read about it here Home - Henry Duncan Savings Bank Museum.

In Castle Douglas, we'll carry on using the Gordon Memorial Hall and provide hot drinks, but members will need to bring their own food if desired. We'll hope to arrange some activities for those occasions as well as the usual social get together.

Christine will advertise events as usual - in these newsletters, emails to members, and on our Facebook group and website.

On a sad note, we lost another of our members to cancer recently, and my heartfelt condolences go to her family and friends, and thoughts to others of you living with or affected by that cruel disease. I know the impact of ME with cancer on my wife June, and the trouble we had at points along her journey to get the medical care appropriate to her needs. She would have gone without treatment at times when it was too difficult for her to access it, but eventually there were concessions. Whatever your circumstances, reach out if you need to - please don't be left feeling alone.

Lastly, back with my Treasurer's hat on, the Trustees have been discussing how best to direct our funds and we wondered how many members who receive the newsletter in the post would be willing to receive it by email instead. We do know many of you prefer the printed copy by post, but please let Christine know if you'd be happy to switch to an emailed version instead. Thanks, and best wishes to you all.

Paul Thompson, Treasurer

Lunch Meet-Ups

Stranraer – Thursday 20th March at Stranraer Library at 1pm.

Tea and coffee will be provided but please bring your own lunch.

Book your place using the Eventbrite link https://www.eventbrite.co.uk/e/stranraer-lunch-meet-up-tickets-1232798646939?aff=oddtdtcreator Also at this event, Tigger McGregor will be offering free touch massage. See below for more details.

Castle Douglas – Monday 7th April at Gordon Memorial Hall at 1.15pm

Tea and coffee will be provided but please bring your own lunch.

Book your place using the Eventbrite link https://www.eventbrite.co.uk/e/castle-douglas-meet-up-tickets-1244662281389?aff=oddtdtcreator After the lunch, there is an Iris folding craft workshop. See below to book your place.

Annan – Wednesday 23rd April at The Station, Kirkpatrick Fleming at 12.30pm Food and drinks must be paid for by each individual. Book your place using the Eventbrite link https://www.eventbrite.co.uk/e/annan-lunch-meet-up-tickets-1249274958029?aff=oddtdtcreator

Dumfries – Friday 16th May at The Stove, High Street at 12.30pm.

Food and drinks must be paid for by each individual. Book your place using the Eventbrite link https://www.eventbrite.co.uk/e/1256469426879?aff=oddtdtcreator

Booking on Eventbrite confirms your space. No actual ticket is required. If you have any difficulty with booking or any queries, please contact christine@dgmefm.org.uk.

Check out the website and Facebook page for more information on dates/locations of events over the coming weeks.

Craft and Wellbeing activities

Touch massage - Thursday 20th March at Stranraer Library at 1pm.

At the Stranraer lunch event (see above) local Massage therapist, Tigger MacGregor, will be joining us and offering short, gentle, clothed Chair Massage treatments after lunch (no charge). The treatments have been designed to soothe the nervous system and you remain in control of the treatment throughout. Tigger will be available to answer questions during lunch and there will be space to ask any more individual questions during the 1:1 treatment consultations, which form part of the Massage.

Please note that we can't ensure that there will be time to treat everyone who wants it, so please state your interest when you arrive.



Watercolour Workshop - Monday 24th March at Annan Old Parish Church Hall at 1.15pm. Come and learn to use watercolours and pens to create effective artwork. Tutor Laura will teach you different techniques and skills which you can use to create a greetings card (see example on the left). Resources will be provided which you can take away with you. Book your FREE place using the Eventbrite link https://www.eventbrite.co.uk/e/watercolour-workshop-annan-tickets-1232809960779?aff=oddtdtcreator

Iris folding – Monday 7th April at Gordon Memorial Hall, Castle Douglas at 2.15pm. This event will take place after the lunch meet up (see above). Feel free to join us for both. Paul Thompson will teach you the skill of iris folding (see example on the right). You will use this technique to create a card to take away with you. Book your FREE place using the Eventbrite link https://www.eventbrite.co.uk/e/iris-folding-workshop-tickets-1244674086699?aff=oddtdtcreator



Creative Writing Workshops – Wednesday 30th April at Turning Point meeting room, Dumfries at 2 – 3.30pm. Emma Davies (former English teacher) will lead this creative writing workshop. This is the first of what we hope will be a series of workshops. This workshop will be Photo Prompt themed where participants will be asked to write either a short piece of prose or a poem inspired by a photo. Book your FREE place using the Eventbrite link https://www.eventbrite.co.uk/e/creative-writing-workshop-dumfries-tickets-1249283623949?aff=oddtdtcreator

Online meeting - First Thursday of the month

Come and get to know us, chat, ask questions and make new friends. Sometimes we have talks or discussions from outside speakers. The next meeting is the **6**th **March at 2pm.** We are going to be sharing the work created by our self-portrait group at this meeting. Come along and see what our group have created. There will also be an opportunity for a chat afterwards.

You can join us by clicking this link

https://us02web.zoom.us/j/82063674933?pwd=3hYUDTttA8RiMbloAxlegVpvvSY6cT.1

or entering this info: Meeting ID: 820 6367 4993, Passcode: 1234

Upcoming Speakers

3rd April – Zoe Graham from D&G HEAT and Handyvan 5th June – Elinor Predota from We make the path CIC

Social Security Scotland information

In December, we had Jamie Crook from Social Security Scotland as our meeting speaker. He shared a lot of very useful information and has sent us some links that he thought it might be worthwhile for me to share with you:

A factsheet that summarises the benefits SSS currently administer: <u>A-guide-to-our-benefits-factsheet_Oct-</u>2024.pdf

A guide and some commonly asked questions about the case transfer process from DWP to Social Security Scotland: Social Security Scotland: Social Security Scotland: PIP to Adult Disability Payment

A link to upload supporting information to Social Security Scotland: Upload your documents - mygov.scot

If anyone would like the support of Jamie or one of his colleagues in the Local Delivery team in Dumfries & Galloway, please contact us on 0800 182 2222 and they would be happy to help.

If you missed this meeting and are interested in hearing what Jamie shared, the recording can be viewed using this link and passcode:

https://us02web.zoom.us/rec/share/nzz178Baj0HM1FCs6tJ3iCQ4uNjChmMfcmzerVOC7bOTBwMC58kRLC8wYv-twzi0.R ZseO3z7QI5rEE7

Passcode: vWSw+45C

Have you seen our Facebook pages?

Lots of information is shared on our Facebook groups and we don't want you to miss out! Search for <u>DGMEFM Network (support for ME, CFS, Fibro, Long Covid)</u> on Facebook or click this link and ask to join the group.

You will find lots of discussions, links to articles, up to date information on our planned events and loads of support from those who 'get it'.

We also have another group for the crafters among you – or those who like to look at others' crafts! Search for Get crafty with M.E. and Fibro on Facebook or click this link and join this crafty community.

Competitions

We ran 2 competitions at the end of last year and entries were collected in January.

Our poetry competition was judged by local published author Pam Mellor (pictured on the right). Pam was impressed by the entries she received but selected the one she felt stood out to her as the winner which was written by Paul Thompson. Congratulations go to Paul who received a £20 voucher. Paul's poem can be read further on in the newsletter.

Our recipe competition winner was selected at random. Our winner was Rhian

Davies with a tortellini recipe. Congratulations go to Rhian who received a £20 voucher. Rhian's recipe can be read below.

The other competition entries will be printed in future newsletters so watch out for those over the coming months. We would love to regularly print some 'Quick fix' recipes in the newsletter to help members who struggle to think of easy to prepare meals which have nutritional benefit. If you have any recipes you could share, please send them to christine@dgmefm.org.uk and look out for them in future newsletters!

Again, well done to Paul and Rhian and many thanks to everyone who entered the competitions.

Recipe competition winner - Rhian's Tortellini recipe

Ingredients

One pack of tortellini (precooked stuffed pasta found in the fridge section)
Small jar of pesto
Small bag of rocket
Tablespoon of olive oil (option 2)
Half a small red onion chopped (option 2)
Small handful of olives whole or chopped (option 2)
Small handful of sundried tomatoes whole or chopped (option 2)
Fresh ground black pepper to serve

Method

This is a very flexible recipe depending on your energy levels, dietary preferences, and number of people to cook for. You can even just do the tortellini without adding the pesto and the rocket.

Option 1

- Heat tortellini according to instructions normally 3 minutes on the hob in boiling water
- Drain
- Mix through a couple of teaspoons of pesto and a handful of rocket
- Serve season with fresh ground black pepper

Option 2

- Using the olive oil, fry the chopped red onion until soft
- Add in a handful of olives and sundried tomatoes
- Heat tortellini according to instructions normally 3 minutes on the hob in boiling water
- Drain and add to pan of fried onion, olives, and sundried tomatoes
- Take off heat and mix through a couple of teaspoons of pesto and a handful of rocket
- Serve season with fresh ground black pepper

Poetry Competition winner - What shade will you colour me today?

What shade will you colour me today?

A soft blue butterfly settles on the ivy A smile to my eyes watching quietly

We met before in another life but then as a dragonfly bold as the sky with darting flight and sparkling eye

Before ME slowly turning me grey....

But you all thought
I'd lost my way
Get back in the swing
let normality sing
in your veins again
I heard you say

What shade will you colour me today?

Little red robin hop bobbing along the seeds in my garden feeding his song We've met before but then as an eagle powerful and strong

Before ME laid me low It came as a blow took the wind from my sails and everything paled

Now silver surfer while I rest in my shell Do you see a golden aura when you say I'm looking well? Am I rosy through your glasses though it's not the tale I tell.

Does it matter what I say?

What shade will you colour me today?

By Paul Thompson

Easyfundraising

Did you know that DGMEFM Network is registered with easyfundraising? Easyfundraising is an online site that has over 7,000 different brands registered with them. Why you buy something, going through easyfundraising, you pay the same amount as you normally would but the company donate part of that amount to us! It is a very easy method for you to help us fundraise! Our link is: https://www.easyfundraising.org.uk/causes/dgmefmnetwork

All you have to do is register with them on a computer or laptop and download their browser extension (all of this is super easy to do – just follow website instructions). Then it will automatically pop up if you are shopping at a brand that uses easyfundraising! Look out for this logo:





Alternatively, you can download their app onto your phone or tablet which looks like this.

Please consider supporting us at no cost when purchasing online.

Taking my M.E. away with me



I was first diagnosed with M.E. 10 years ago and was too unwell then to venture far at all. But as the years passed, my health stabilised and I could begin to rely on it to cope with a bit of this and that. And that included foreign holidays. My first trip was a short cruise, as I thought all I would need to do, and be able to do, was sit around. From then on, I've got more and more confident in being able to manage all that holidays entail. I've become an expert in how to take my M.E. away with me.

I'm just back from my biggest adventure yet...solo travel through Rajasthan. Not only did I survive; I had the time of my life. So, I thought I'd share my

holidaying rules that I've discovered over the years work for me and enable me to thrive when away. Maybe it will give someone else the confidence to take their condition on holiday.

1. Sort out the airport and flight experience. When booking flights, look into the Special Assistance they offer. They all do. They all will provide wheelchairs at both ends. The big plus of this is the member of staff pushing. There brain IS working and they will navigate through all the queuing and signage reading needed to get where you need to go. Actually, I've never made use of this other than when I took my mother on holiday with her dementia. The only time I did book a chair for myself...in Doha, where we had just 50 minutes, in the middle of the night, to transit onto another flight and I knew my legs wouldn't be great...it wasn't there when I needed it! But they usually are, they are all there waiting at the exit of the tunnel when you get off the plane. You can also book assistance getting on and off the plane. This is all free of charge.

A big perk of flagging up that you need special assistance is, the long-haul airlines like BA, Qatar etc, then automatically let you choose your seat for free. Otherwise, it can cost over £100. You can select special assistance without actually booking a chair. British Airways, for one, has a Hidden Disability option. No questions asked. I have discovered aisle seats work best. Options for leg stretching into the aisle when leg trouble sets in.

2. Avoid group travel. For me, the company of others, no matter how much I like them, sucks energy out of me. Very draining. When I am alone, I can work with my energy levels...rest when I need to, go for it when I can. This can change from hour to hour, so if I'm tied into a group itinerary, it just doesn't work. Hence, I find solo travel works best for me.



- 3. Avoid guides to show me around. They walk, and talk, way too fast! I'm all done in after five minutes. Instead, I've become a master of slow tourism/mindful travel. I do a lot of sitting around and watching the world go by. What's more, I think I see much more than the folk speeding past with their guides. Jeep tours, on the other hand, work wonderfully well. Just sit back and enjoy the view.
- 4. Keep up an eating routine. Missing meals badly affects my energy levels. This holiday I took to carrying emergency bananas with me and that worked.

- 5. When arriving somewhere new, stake out the lying down in the sun, or shade, options. When I need to lie down, I need to lie down. Just getting horizontal for an hour makes a big difference.
- 6. Don't attempt a hire car. No matter how tempting it might seem, I cannot rely on my brain to

function well enough to be safe.



7. Take the easy options to get to and from the UK airport. Arriving back in the UK will be tiring and disorientating, so best not be driving straight from the airport. I once lost a bumper on a roundabout at Manchester airport, and that was BEFORE I had M.E!

I'm already planning my next trip, and the one after that! Life is for living, even if taken reclining for a lot of the time.

Sarah

Festive Fun

We had loads of activities going on just before Christmas. There were 4 festive lunch meet ups and 2 craft workshops in the space of 2 weeks! Here are some pictures of what we were all getting up to. A big thank you to members Caroline Maybank and Myra Little who stepped forward to lead these craft workshops.



Wreath making at Castle Douglas



Fabric bauble making at Annan



Festive lunch at Stranraer



Festive lunch at Dumfries

Parliamentary Q&A on Funding for ME/CFS delivery plan and Centre of Excellence for chronic conditions (taken from ME Association newsletter)

<u>Jo Platt</u>, Labour MP for Leigh and Atherton Commons asked the following Parliamentary question, which was answered by <u>Ashley Dalton</u>, The Parliamentary Under-Secretary for Health and Social Care and Labour MP for West Lancashire on 17 February 2025.

Question

To ask the Secretary of State for Health and Social Care, whether his department has plans to allocate additional funding towards the Government's myalgic encephalomyelitis/chronic fatigue delivery plan.

Answer

There are currently no plans to allocate additional funding towards the myalgic encephalomyelitis/chronic fatigue (ME/CFS) final delivery plan. The ME/CFS final delivery plan continues to be developed. The plan will focus on improving research, attitudes and education, and bettering the lives of people with this disease. The consultation responses, alongside continued stakeholder engagement via the ME/CFS Task and Finish Group, will inform the development of the final delivery plan for ME/CFS, which we aim to publish by the end of March 2025.

Question

To ask the <u>Secretary of State</u> for Health and Social Care, if he will make an assessment of the potential merits of establishing a centre of excellence for care and research for infection-associated chronic conditions.

Answer

We do not anticipate setting up a new centre of excellence for care and research specifically for post-viral or infection-associated conditions. The Department funds research on post-viral conditions through the National Institute for Health and Care Research (NIHR). The NIHR and Medical Research Council (MRC) remain committed to funding high-quality research to understand the causes, consequences, and treatment of post-viral conditions such as myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), and long COVID, and are actively exploring next steps for stimulating further research in this area. The MRC and NIHR currently fund research through a variety of routes, including infrastructure, research programmes, capacity building, for example research fellowships, and in the case of NIHR, research delivery to support recruitment to studies. Funding is available for infection-associated research.

We LOVE it when members contribute to our newsletters! Thank you to everyone who has contributed to this edition. If there's something you'd like to see in the next newsletter, or you feel able to write something for us, please do so and send to: christine@dgmefm.org.uk



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Please let us know if you no longer wish to receive the newsletter or if you want to change how you receive it. Also, if your contact details have changed or if you wish to cease being a member of the Network, please contact us on admin@dgmefm.org.uk or text or phone 07557 536110.