

September 2024

# DGMEFM Network

Support for ME, CFS, Fibromyalgia

## Welcome from the Chair



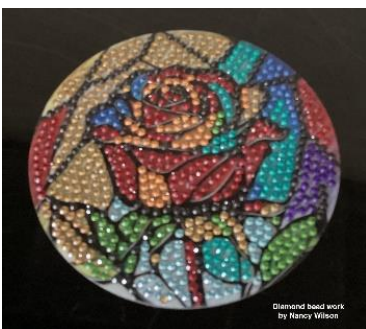
Hello and welcome to the September issue of the DGMEFM Network Newsletter. I had hoped to welcome everyone with a large dose of sunshine which seems to work wonders for our weary bones. But no, the weather hasn't been that kind to us so far this summer.

Never mind, though – DGMEFM Network has been able to offer you a varied range of activities over recent and coming months to take your mind off the weather, from our usual lunch meetups to mindfulness sessions, swimming, handloom weaving and even carriage driving.

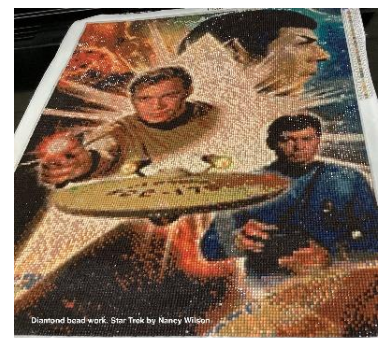
I would encourage you to sign up to the activities we provide. It would be good to see more of our members out and about, where possible, especially when we know that we're with non-judgmental friends of similar capabilities to ourselves.

We held an online quiz in mid-June which was great fun, although not very many attended. We've heard from some members, though, that internet reception where they live can be very patchy, so not everyone is keen on Zoom meetings or other online activities.

However, if reception is good where you live, I do encourage you to join in any of our online classes or quizzes as they can be very entertaining or help bring out the inner artist in us. I have enjoyed the recent series of Art Classes and Sketching Classes run by Taking Art Home. Information about the next block of workshops can be found in this newsletter if you fancy having a go. Believe me, if I can produce something even moderately artistic, anyone can!



Speaking of artistic, here are some beautiful diamond bead works by our long-time member, Nancy Wilson. The smaller item is a coaster while the larger work is, you've guessed it, a depiction of Star Trek. I'm sure you'll agree they're both stunning.



Our colleague Kalpana is going to teach us self-hand massage techniques at Castle Douglas on Monday 9<sup>th</sup> September. I'm looking forward to that myself as I'm suffering with numbness and pins and needles in one of my hands due to nerve compression in the neck and I'm hoping this can help.

There is so much on offer for you, our members, so please don't hesitate to sign up for everything and anything you feel could be beneficial to you and that you're able to attend, whether in person or online. After all, that's what we're here for.

Our AGM will be held in The Gordon Memorial Hall in Castle Douglas on Thursday 10<sup>th</sup> October. We will have our lunch of sandwiches and cake prior to the AGM and we trust that as many members as possible will attend. Even if you're from the Dumfries, Newton Stewart or coastal areas, do please come along and hear about our activities and have your say on certain matters. We will also be offering a video link in case you're not able to attend. See *Annual General Meeting (AGM) Notification 2024* below for more information.

Lastly, I hope the sun eventually makes an appearance and that you can perhaps enjoy sitting out in your garden or getting out and about. Please don't hesitate to contact us if there is anything you'd like to ask or any activities you'd like to join in with.

P.S. Here's a photo of me with my husband and grandchildren visiting the alpacas at Penfillan, near Thornhill. A great time was had by all – except that now, the grandchildren are begging Mum and Dad to buy them a pair of alpacas...



Bobbie

## Annual General Meeting (AGM) 2024 Notification

Notice is hereby given that a Members Meeting of the Dumfries & Galloway ME and Fibromyalgia Network will be held on 10<sup>th</sup> October 2024 at 2.15pm. This will be a hybrid meeting so participants can attend in person at Gordon Memorial Hall, 68 St Andrew Street, Castle Douglas DG7 1EN or join via zoom link <https://us02web.zoom.us/j/85942547498?pwd=03WJBod2vSogIhhRKoZDRKffuW34B9.1>.

The meeting will include the annual report from the Chairperson, Bobbie Jeal, on the activities of the charity; consideration of the annual accounts for the charity from the treasurer, Paul Thompson; and election / re-election of charity trustees. If you would like a copy of the accounts, please get in touch beforehand. Afterwards there will be a volunteer celebration of the work done on our Befriending and Peer Mentoring project, which is coming to a close. Our volunteer coordinator, Kalpana, has worked tirelessly to train some befrienders and peer mentors and we will be celebrating their work and efforts. Afterwards, Kalpana will be leading a wet felting craft activity for those who are there in person.

We would love to see as many people attend as possible! For those attending in person, pre-ordered sandwiches will be provided at 1.45pm. Members are welcome to bring a 'plus 1' to come too however please note that only DGMEFM Network members can nominate board members / trustees and vote at the AGM.

To assist us with registration, let us know you are coming by emailing [christine@dgmefm.org.uk](mailto:christine@dgmefm.org.uk) on or before 7<sup>th</sup> October to confirm if you wish to attend and if this will be in-person or via Zoom.

If you are unable to attend the meeting, you can nominate either another member or the Chairperson to represent and vote on your behalf, by completing a 'Members Proxy Vote Form'. For this form, email us at [admin@dgmefm.org.uk](mailto:admin@dgmefm.org.uk) or telephone 07557 536110; forms to be returned to us by 4<sup>th</sup> October 2024. The quorum for a members' meeting is 8 members. Only DGMEFM Network members are permitted to vote. In the past the AGM has had to be rescheduled due to poor attendance, so it is really important that you come along.

## Pop up Meet-Ups and Events

Thanks to funding from the Communities Mental Health and Wellbeing Fund, we are able to offer lunch free of charge at our meet-ups. Members will need to pay for their own drinks (at Castle Douglas meet up drinks are provided due to venue).

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

**Annan** – Friday 6<sup>th</sup> September at The Maltings, Annandale Distillery at 12.30pm

Book your FREE place using the Eventbrite link <https://www.eventbrite.co.uk/e/annan-meet-up-tickets-927166218117> or email [christine@dgmefm.org.uk](mailto:christine@dgmefm.org.uk)

Next date for your diary at Annan is the Christmas lunch on Friday 6<sup>th</sup> December at Westlands Country Park at 12.30pm. Please book your FREE place for lunch using the Eventbrite link

<https://www.eventbrite.co.uk/e/annan-meet-up-tickets-947906713497> or email [christine@dgmefm.org.uk](mailto:christine@dgmefm.org.uk)

**Castle Douglas** - Monday 9<sup>th</sup> September at Gordon Memorial Hall at 1.15pm

After lunch there will also be a workshop on how to self-massage your hands led by Kalpana.

Please book your FREE place for lunch using the Eventbrite link <https://www.eventbrite.co.uk/e/castle-douglas-meet-up-tickets-828621789077> or email [paul@dgmefm.org.uk](mailto:paul@dgmefm.org.uk)

If you wish to attend only the hand massage session, please email [christine@dgmefm.org.uk](mailto:christine@dgmefm.org.uk) to book.

Next date for your diary at Castle Douglas is the Christmas lunch on Monday 25<sup>th</sup> November – same time and place.

To book your FREE place for lunch use the Eventbrite link <https://www.eventbrite.co.uk/e/castle-douglas-meet-up-tickets-926840875007> or email [paul@dgmefm.org.uk](mailto:paul@dgmefm.org.uk)

A wreath making workshop will take place after the lunch. Spaces are limited so to book your place, use the Eventbrite link <https://www.eventbrite.co.uk/e/wreath-making-workshop-tickets-944941053127> or email [christine@dgmefm.org.uk](mailto:christine@dgmefm.org.uk)

**Dumfries** – Tuesday 10<sup>th</sup> December at The Hitching Post, Eastfield Drive, Dumfries at 12.30pm.

Please book your FREE place using the Eventbrite link <https://www.eventbrite.co.uk/e/dumfries-meet-up-tickets-972084740627>

**Stranraer** – Friday 29<sup>th</sup> November at Craignelder Hotel, Cairnryan Rd at 12.30pm.

Book your FREE place using the Eventbrite link <https://www.eventbrite.co.uk/e/stranraer-meet-up-tickets-947896131847> or through the Stranraer Whats app group.

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](mailto:christine@dgmefm.org.uk).

## Be Kind

Whatever troubles your mind,  
be kind.  
Be kind  
to yourself and others you find  
along your way.  
Be kind,  
and kindness too  
will come back to you.

Paul



## Trustee recruitment

Want to help make the Network even better?



DGMEFM Network has a great bunch of trustees who do a brilliant job. We really want some more trustees to join us! It could be you, a family member, friend, carer – just someone you know who would do a great job. Ideally the trustee should have some understanding of ME/CFS, Fibro or Long Covid but this isn't essential.

The role involves attending 4 Board meetings per year and also attending our AGM. Beyond that a trustee can take on extra roles if they wish.

We really want to grow our trustees so that we can continue to support and benefit our members. If you have someone in mind, please ask them to contact our chair [bobbie@dgmefm.org.uk](mailto:bobbie@dgmefm.org.uk).

## Taking Art Home Art Workshops

If you fancy having a go at creating some art, you may want to join these online art sessions run by 'Taking Art Home'. A few of our members attended the previous block already and found it very enjoyable. Jeni Alison has shared the following information and invited our members to participate. Although this block will have started by the time this newsletter goes out, Jeni has assured me that it is fine to register later in the block and still take part in the remaining sessions.

*Taking Art Home is a project run by Art in Healthcare for people living in Scotland who find it difficult to get out and about due to long term health conditions.*

*We have 2 online groups running weekly, and materials are sent out in advance.*

*During a series of free relaxed weekly art sessions, artist Jeni Allison will introduce you to a range of techniques chosen to promote fun and relaxing creative making. Don't worry if you can't make every week, we will have pre-recorded versions available via YouTube. No previous art experience is required.*

*We're going to have two groups - an art group where we'll try out lots of different techniques, and a more meditative sketching group. Both groups will start W/C August 12th and will run for 10 weeks. We will have a week off W/C 16<sup>th</sup> September. The last week of this block will be W/C October 21st. You can join one or both groups:*

### **1. Taking Art Home art group - Wednesdays 2pm – 3.30pm**

*Relaxed weekly art class exploring different materials and techniques. Activities will be suitable for doing from home and can be adapted to suit any access requirements. You will receive materials in advance.*

### **1. Taking Art Home online sketching group -Thursdays 10am – 11.30am**

*Sketching group travelling around Scotland and internationally from your living room. You'll receive a sketchbook and some art materials in advance.*

*We hope that these classes will be chance to take time out of your week to do something creative and will let you meet likeminded people facing similar circumstances. We'd love you to join us, to register your interest please contact Jeni - [jeni@artinhealthcare.org.uk](mailto:jeni@artinhealthcare.org.uk)*

*We also have specific groups for people living with Long Covid. If you'd like to find out more about them please email Jeni: [jeni@artinhealthcare.org.uk](mailto:jeni@artinhealthcare.org.uk)*

## The diagnosis of fibromyalgia syndrome - UK clinical guidelines

We know some of our members were diagnosed with Fibromyalgia by their GP, and some diagnosed at Rheumatology, so we were surprised to hear of a patient being referred by their doctor to Rheumatology for such diagnosis only to have the referral rejected.

In reply to a question about this by one of our members, with an invitation to come and speak at one of our meetings, a Rheumatology specialist at DGRI explained on behalf of their team.....

“.....we think it would be unhelpful for us to talk on this matter as our role in Rheumatology is to exclude an inflammatory arthritis when a patient is referred with suspected Fibromyalgia. We do not consider ourselves to be experts in the management of Fibromyalgia but rather we are experts mainly in excluding inflammatory arthritis as an alternative cause for chronic widespread pain. Fibromyalgia is a condition that is appropriately diagnosed and managed in Primary Care for the most part and although a pathway will be forthcoming on the Rheumatology referrals website in due course, this will be in order to advise when referral to Secondary Care is not needed if an inflammatory arthritis is not suspected rather than advising Rheumatology led management strategies for Fibromyalgia itself. This is the same for Rheumatology departments across the UK, though I am aware that in other countries things are different. I am sorry therefore to decline your offer to come and speak as this would send out the wrong message to the group that we are the team with expertise in its management”.

When Hazel Boreland of FMAUK joined our Zoom meeting in May, I asked of her understanding across Scotland and she concurred that in the most part diagnosis was made at Primary Care level. She also advised of recent new guidance for fibromyalgia diagnosis, by the Royal College of Physicians.

### The diagnosis of fibromyalgia syndrome | RCP London

“Fibromyalgia syndrome is common, yet its diagnosis can be challenging. Symptoms vary, are commonly multiple and can fluctuate. It can often be difficult for patients to articulate an array of symptoms, and for both patients and healthcare professionals to fully make sense of the complexities of the condition. Because of this, patients may be diagnosed inaccurately with alternative conditions, only receive an FMS diagnosis after years of delay, or sometimes be inaccurately diagnosed with FMS.

These guidelines aim to support clinicians in the diagnosis of FMS. They are particularly for patient-facing clinicians who are specialists in areas other than complex pain conditions. They neither aim to dictate the setting in which FMS should be diagnosed, nor who should make the diagnosis. Any diagnostician (eg a GP or physiotherapist) is well-placed to consider a diagnosis of FMS.

Produced by a multidisciplinary guideline development group which included representatives from general practice, surgery, nursing, occupational health, rheumatology, orthopaedics, rehabilitation and physiotherapy as well as patients diagnosed with FMS, the guidelines aim to provide succinct, relevant information for clinicians and patients about what FMS is, and what it is not.

They are not intended to summarise the management of FMS or treatment pathways as other evidence-based guidelines are available to cover these areas. However, notably where conducted well, a consultation that leads to a diagnosis can have therapeutic and reassuring effects which should not be underestimated.

It is hoped that the guidelines will lead to better understanding and awareness of FMS, enabling timely diagnosis and management.



Alongside the full guidelines, a diagnostic worksheet and two information sheets providing summary information for clinicians and patients are available to download.” from <https://www.rcp.ac.uk/improving-care/resources/the-diagnosis-of-fibromyalgia-syndrome>

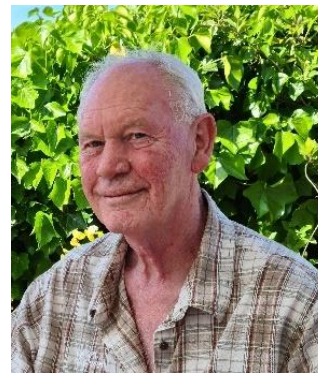
These are the links:

[the-diagnosis-of-fibromyalgia-syndrome-guidelines\\_1\\_2\\_0.pdf](#) (rcp.ac.uk)

[fibromyalgia-syndrome-diagnostic-worksheet\\_1\\_0\\_0.pdf](#) (rcp.ac.uk)

[information-sheet-for-clinicians\\_0.pdf](#) (rcp.ac.uk)

[fibromyalgia-information-sheet-for-patients.pdf](#) (rcp.ac.uk)



*Paul*

## Befriending and Peer Mentoring Project

We have another bio from a befriender, Lesley, who has shared a little bit about herself.

### Lesley - Befriender

Hello everyone



My name is Lesley, I have been a member of the network now for about 8 years ish. I was first diagnosed with Fibromyalgia in 2011 after years of painful joints, going back and forward to the Dr, being poked and prodded, having blood tests after blood test. Then eventually a diagnosis by a rheumatologist at the hospital. He handed me a leaflet and wished me good luck. That was that, on my own in limbo not knowing what to do next or what was going to happen to me.

I eventually found out about Dumfries & Galloway M.E. and Fibromyalgia Network. I get very anxious going places I've never been before so it took me a few months before I plucked up the courage to go along to the support group. I'm so glad I did because it changed my whole outlook on my illness. I was given a lovely warm welcome by everyone there, as soon as I peeked around the door Nancy got up, introduced herself and made me a lovely cup of tea.

I spend most of my time with my two dogs, pottering about the house or in the better weather we are out in the garden. When I can I love to get out into the countryside with my camera, making images of landscapes is one of my favourite thing to do, it makes you appreciate more what's out there. We have a campervan and love getting away traveling around the country, although we always seem to navigate towards the north of Scotland, especially the west coast.

Joining the Befriending Project is a good way to meet new people, talking to someone who has lived experience with M.E or Fibromyalgia can help deal with what's ahead. Even just chatting and getting out the house for coffee can make a huge difference.

If you would like to have the support of a Befriender or a Peer Mentor who can support you with navigating a new diagnosis, learning tips and techniques to deal with symptoms or have someone you can chat with who understands, please email [kalpana@dgmefm.org.uk](mailto:kalpana@dgmefm.org.uk) who can discuss your needs and pair you with someone suited to you.

If you would like to become a befriender or peer mentor, this is your last chance to get involved. The last set of 4 training dates are: Tuesday 10<sup>th</sup> September 10am – 4pm, Thursday 12<sup>th</sup> 10am – 4pm, Tuesday 17<sup>th</sup> 10am – 4pm and Friday 20<sup>th</sup> 10am – 4pm. If you are interested in being trained and can make these 4 dates, please email [kalpana@dgmefm.org.uk](mailto:kalpana@dgmefm.org.uk) for further information.

## Is your information up to date?

We want to keep in touch with you and share ways for you to benefit from the Network. We have many members who do not have an email address registered with us. This means you will miss out on information shared via email. If you have an email address but do not currently hear from us by this method, please email [christine@dgmefm.org.uk](mailto:christine@dgmefm.org.uk) to update your records. Also, if you have moved house or changed phone number, please remember to let us know. If you are unsure if your details are up to date, please [christine@dgmefm.org.uk](mailto:christine@dgmefm.org.uk) with your current information.

## Online Social Meet-Up: First Thursday of the month

Join us for a brew and a blether. Come and get to know us, chat, ask questions and make new friends. Sometimes we have talks or discussions from outside speakers.

**5<sup>th</sup> September speaker – Hazel Boreland from Fibromyalgia Action UK**

**Please note that there will be no meeting in October as we have the AGM the following week.**

We meet on the first Thursday of the month. Meetings take place over zoom only for the time being. Join any time between 2pm – 3:30pm.

You can join us by downloading 'Zoom Cloud Meetings' on your smart phone or tablet or go to [www.zoom.us](http://www.zoom.us) on your computer. Enter this info: Meeting ID: 820 6367 4993, Passcode: 2024

Look out for updates on Zoom meeting topics and guests on our Facebook page, website or in your email inbox.

## Ceramic Painting workshop

One of the activities offered by the Network was an afternoon of ceramic painting in Kirkcudbright, enjoyed by seven members from as far afield as Dumfries, Gatehouse-of-Fleet and Newton Stewart.



The venue was the Wee Pottery, housed in The Johnston Centre beside the Dark Space Planetarium. The Johnston was a 19<sup>th</sup> century school and we definitely all looked like very studious pupils as we worked away.

Time flew by as we painted our chosen pieces of pottery - a plate here, a teapot

there - and we all agreed we couldn't wait till the glazed and fired items came back to us.

Here's a photo of us with our works and big smiles after a very enjoyable afternoon.



Bobbie

## Members on Fire at Chariots of Fire!

Thanks to the Admin team coming up with this wonderful idea, four of us enjoyed a morning out at the Chariots of Fire premises in Boreland, near Lockerbie.

The team here offers riding and carriage driving lessons and specialises in working with young people and those with disabilities or additional needs. They even have carriages that can hold a wheelchair for drive outs.

Four of us arrived all ready and eager for our lesson in the school first and were soon doing figures of eight through the cones and picking up toys at one end to be dropped into a bucket at the other. Not always an easy task to grab a small object, hanging out of a moving carriage going round a corner!

Then, it was out onto the open road with the occasional forestry juggernaut overtaking us. It's a very regular occurrence on this road and the tutors – and the ponies, thank goodness! - are all very used to it. We then turned into a minor road and into the woods before circling round and returning to the stables, highly elated at what we'd achieved in so little time.

It was soon time to go home after spending some time petting the ponies and talking to the tutors. We all agreed that we'd had a wonderful time and thoroughly enjoyed this activity. Thank you so much to DGMEFM for organising and funding something that we would probably never have been able to do on our own.

If you'd like to try carriage driving out yourself, or indeed riding, please check out the website: <https://www.chariotscic.org.uk/>.

Bobbie



Member contributions are very valued.  
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: [admin@dgmefm.org.uk](mailto:admin@dgmefm.org.uk)

**DGMEFM**



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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](mailto:admin@dgmefm.org.uk) or text or phone 07557 536110.*