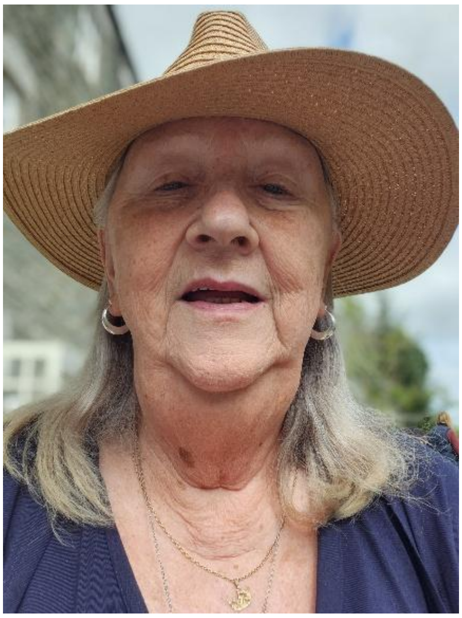
September 2025

DGMEFM Network
Support for ME, CFS, Fibromyalgia

Welcome from the Chair



I write this nearing the end of August and, this summer, we've had yellow weather warnings for heavy rain and we've had temperatures soaring into the mid-20s. It's not that I want to be flooded out, but my garden and pot plants are desperately needing watered and you will all no doubt recognise that feeling of, "I don't have the strength right now to do it myself".

Even if you feel good enough to go out, you can't when there are raging winds and rain and, if you're like me, you can't stand the extreme heat either.

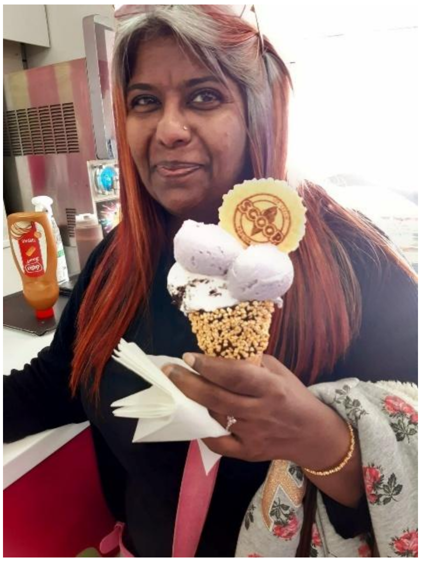
That's the thing with conditions like fibromyalgia. You can feel relatively good some days and others, you're good for nothing. I know I'm going to sleep earlier than before and getting up later, but still feeling washed out. Maybe a change of season from summer to autumn will do us all some good, who knows?!

We're currently gearing up to celebrate the 25th anniversary of the DGMEFM Network having been launched. We're all celebrating that the Network has survived for so long where many charities don't, through lack of funding. We on the DGMEFM Board sincerely hope that we can continue to provide activities for our members, both in person and online, that you will appreciate and enjoy.

Bobbie

Our new Wellbeing worker – Kalpana Ratnam-Roarty

Hi everyone
Thought I'd give you a little update on what I've been doing this past wee while. I can't believe a month has passed already, I've been a busy bee. You may have seen on Facebook that I have been asking a LOT of questions. For those of you who aren't on Facebook, I want to know what you want, when you want it and where you want it. Feel free to contact me on kalpana@dgmefm.org.uk . Thank you to everyone who has contributed to the polls. I am happy to say that we have quite a busy calendar till the end of this year, we are swimming, gin touring, art making, star gazing and having animal therapy! Just a few of the face-to-face things happening across the region. Online, we are having an introduction to expressive writing offered over a 5-week block. We also have a region-wide music group for anyone who enjoys playing an instrument of any description. We are also looking at a region-wide movie club, which I am still working out the finer details, watch this space. If you would like to know more or sign up to any of the workshops, please email me on kalpana@dgmefm.org.uk



Annual General Meeting (AGM) 2025 Notification

Notice is hereby given that a Members Meeting of the Dumfries & Galloway ME and Fibromyalgia Network will be held on 6th October 2025 at 2pm. 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/87286534537?pwd=7Vxsnlt1NFuP8wt3DKLSMb30AJkWJF.1
Meeting ID: 872 8653 4537
Passcode: 981729

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 craft activity led by Kalpana where she will teach us marbling and cyanotype printing for anyone wanting to take part.

We would love to see as many people attend as possible! For those attending in person, pre-ordered sandwiches will be provided at 1.15pm. 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 on or before 30th September 2025 to confirm if you wish to attend and if this will be in-person or via Zoom. Please include if you would like to order lunch and whether you would like to take part in the craft activity.

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 or telephone 07557 536110; forms to be returned to us by 4th October 2025. 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.

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 be great. 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.

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 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 with your current information.

Events and Activities

Thanks to funding from The National Lottery Community Fund and Corra Foundation Henry Duncan Grants, we are able to offer a range of activities across the region and online.
Keep an eye on the website https://dgmefm.org.uk or Facebook group www.facebook.com/groups/dgmefm for up-to-date information on activities over the coming weeks.

Online – **Introduction to Expressive Writing workshops** Come and join the amazingly lovely Carolyn Hashimoto for a 5-week block, over ten weeks, of intro to Expressive Writing. Workshops will take place over zoom on Wednesday afternoons 2-4pm starting Wednesday 10th September and resources will be sent out to you. Please email kalpana@dgmefm.org.uk to book your space.

Annan – Coffee and Cake meet up Friday 19th September at Powfoot Golf hotel at 3pm.
Enjoy a drink and cake paid for by us whilst meeting and chatting with others. Book using the Eventbrite link https://www.eventbrite.co.uk/e/1536355924929?aff=oddtdtcreator or email christine@dgmefm.org.uk

Dumfries – Cupcake and biscuit making and decorating workshop Monday 22nd September at St. John's church hall, Newall Terrace at 10am.
Come along for a fun and delicious cupcake and biscuit making and decorating workshop. Enjoy a cuppa and chat while the goodies are baking. Please book your FREE place by emailing kalpana@dgmefm.org.uk

Kirkcudbright – Dark Space Planetarium Monday 22nd September at 2pm.
We are blasting of for a star gazing talk and visit to the planetarium as well as having the opportunity to get hands on with some interactive exhibits and they even have FREEZE DRIED ASTRONAUT food!!! what more could you ask for? Transport has been provisionally booked to support those a bit further away to get there. Please book your FREE place by emailing kalpana@dgmefm.org.uk

Dumfries – Gelli printing workshop Monday 29th September at John's Church hall, Newall Terrace at 11am.
Create beautiful and colourful pieces of unique art with tutor Julie Stephen. Please book your FREE place by emailing kalpana@dgmefm.org.uk

Castle Douglas – Gelli printing workshop Wednesday 8th October at Castle Douglas Community Centre at 1pm.
Create beautiful and colourful pieces of unique art with tutor Julie Stephen. Please book your FREE place by emailing kalpana@dgmefm.org.uk

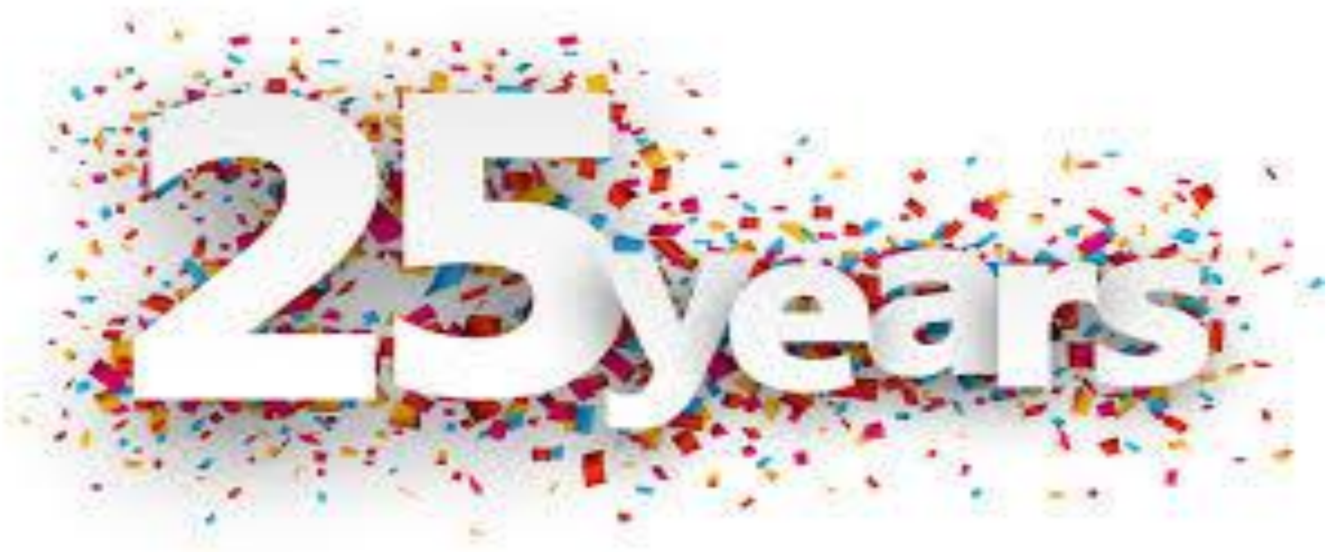
Wigtownshire – Gelli printing workshop Thursday 16th October at South Machers Community Centre, Whithorn at 1pm.
Create beautiful and colourful pieces of unique art with tutor Julie Stephen. Please book your FREE place by emailing kalpana@dgmefm.org.uk

Stranraer – Gelli printing workshop Thursday 23rd October at Millenium Centre at 1.30pm.
Create beautiful and colourful pieces of unique art with tutor Julie Stephen. Please book your FREE place by emailing kalpana@dgmefm.org.uk

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 or kalpana@dgmefm.org.uk

25th Anniversary of DGMEFM Network

On 30th September 2025, DGMEFM Network will celebrate the 25th anniversary since being registered as a charity in 2000. There have been many changes over that time and lots of ups and downs. Here is an account by Penny Lilley recalling the early history of our charity.



Myself and my friend Anne Laird, who both had been diagnosed with ME, started the ME Network in 1998. We had help from the Castle Douglas IT Centre with computer skills, which was vital. We began by having meetings of people with ME. My memory is of meetings that I attended in Castle Douglas, Stranraer and Sanquhar. I can't remember how we contacted people to invite them to meetings, but these meetings were later well attended and lively. We met once a month. The Sanquhar meetings were in a large, pleasant café (no longer open sadly), the CD one at the Parish Church Hall in CD and the Stranraer one in Stranraer library. We didn't have speakers, that I can remember, but just tea, coffee and biscuits and much chatting. I think for most of us it was a great relief to meet other people with ME. My feeling was that the meetings were friendly, inclusive and enjoyable.

Also, we created a newsletter which to our eyes now would be seen as basic and unattractive. But my computer skills were limited (as they still are) and the newsletter served the purpose of informing people of forthcoming meetings and being welcoming. There were people that became important (as I remember) including Craig Woods who initially attended with his mother as he was a teenager with ME. He developed into a competent leader and speaker on behalf of people with ME. Also, a couple from Lockerbie - Dennis and Norma Turner. Norma had ME but Dennis did not and provided entertainment with his electric organ and they were both an energetic and helpful part in our newly formed committee. All three were warm friendly, intelligent people who were good to work with.

Another important person early on was June Randell, Paul Thompson's partner. June was newly diagnosed when she got in touch, and she was really sad that she had had to give up her job as a farming and wildlife conservation adviser. She became a valued member of the committee. I found her love of nature inspiring and uplifting and her knowledge about health generally, really helpful. I was especially sad to hear of her illness and death.

Someone who helped create our first constitution was my former GP in Castle Douglas, Dr Ann Wilson. She herself had and has Multiple Sclerosis and has long been active in the Disability Movement in Scotland. She advised to make sure that most members of our committee were people with ME themselves, rather than being dominated by people without ME. She provided a basic constitution to work from and other advice. Her help was invaluable as the rest of us had no experience of writing constitutions.

Another person who was important was my then GP in CD, Dr Gregor Purdey. He, unusually at the time, understood about ME and taught me about it. He also worked part time for the health board in D&G, and pushed hard and long for a specialist service for people with ME in the region. I think he spoke about it later in the Scottish Parliament. He was a staunch advocate for people with ME. I think he was disappointed that he failed to get a service for us in D&G. I count myself lucky that Gregor Purdey diagnosed my ME and never disbelieved me. I think he may have spread his understanding of ME to other GPs in Castle Douglas at the time. While I lived in or near CD I had pretty good treatment from CD GPs. I hope this is still the case.

Very early our group became affiliated to the ME Association, but quickly this was dropped by them, as it created too many complicated financial arrangements for the ME Association. I was disappointed at the time, but later understood the reasons for the ME Association not having affiliated groups. As individuals, many of us benefitted from the information supplied by both Action for ME and the ME Association, which in turn helped our group.

My memory is patchy so apologies if I have omitted some important information about the very beginnings of the ME Network, as it was called then. We were not aware of Fibromyalgia at the time. I'm grateful that I met many, many lovely people with ME across the Region in those early days. We developed good friendships and a supportive community. Although I no longer take an active role in the ME/Fibro community in D&G, I am pleased to receive the newsletter and am part of the Facebook group, which I find helpful. I thank everyone who has continued with this work. It is frustrating that we still do not have a specific ME/Fibro service in D&G, and very few services in the whole of Scotland. Since Covid, research into ME and Long Covid seems to have increased in the UK, at long last.

Best wishes to all the ME and Fibro community in Dumfries and Galloway. Hopefully, one day we will get the service and support we need from the NHS.

Penny Lilley

Cold Water Dooking and Wild Water Swimming

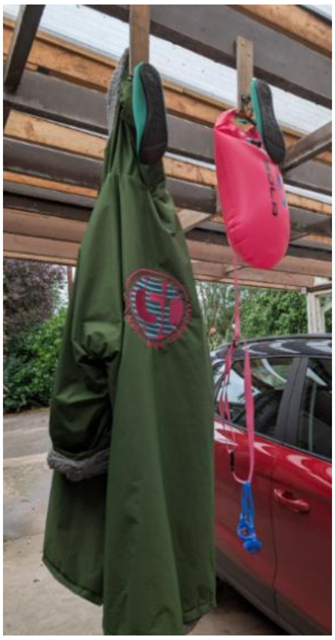
I would imagine I'm no different from the rest of us; constantly looking out for that one thing that might actually make a difference....to M.E. in my case. Then being constantly disappointed when it doesn't.

Cold water is my latest idea, and that's not as daft as it sounds. There is a growing body of evidence to support cold water immersion for all manner of conditions...inflammation, pain, poor immune system, obesity, insulin resistance...the list goes on. The benefits for mental health are also impressive. And it's not to do with swimming and movement. The beneficial biochemistry happens in the first minutes of emersion. You can then get out! Or have a swim.

I came across this idea recently from the blog of a woman with M.E., and the idea stuck with me. So, fast forward, and I now dook and swim in Mill Loch in Lochmaben once or twice a week. Between now and then, I joined the Facebook group for Southern Upland Dippers and Swimmers, and that gave me pointers for how and where, and, crucially, knowledgeable and supportive folk to swim with. I got the gear...dry robe, float, swim shoes...second hand or inexpensive on Ebay...and then did a half day course on 'An Introduction to Wild Water Swimming' in the Loch of the Lowes. This also involved the Wild Dook Sauna's mobile sauna. We did the classic get cold, warm up, get cold routine several times, which made the whole experience even more powerful. The training was around how to manage your emersion; breath control is key. Cold water shock is a killer, and that is what you work to avoid.

The instructor on that morning repeatedly told us, you're not the same person, when you get out of the water, as you were when you went in. I'm realising, that is so true. Now, a few weeks in, I am feeling GOOD. Good energy levels. No post exertional malaise. Very calm and cheerful. I know it may not last, and there will be bumps along the way, but I'll take it for now! My plan is to keep going as the water and weather cools and just keep on dooking right through to next summer. Wish me luck!

After the dook!



Sarah Chadfield

Why I Created a Mixed Media Self-Portraits Workshop…and What I Learned

In the winter of 2024, an idea came to me in kind of a sudden flash. I had been participating in some of the wellbeing art activities that DGMEFM Network offered on Zoom. I noticed it was really helping me feel more creative, capable, and connected to others. At the same time, I was thinking about ways of raising awareness of hidden conditions like ours. It occurred to me - and this is the flash part I mentioned - that maybe we need to literally put a face on hidden conditions and hidden disabilities.

I began to research and to think about what it would mean to do self-portraits in this age of the selfie. The digital world is chock full of candid snaps of people mugging for their own cameras. Initially, I did have a concern that a project like this might come across at first glance as self-centred. As I studied it, however, I began to understand the self-portrait as a way of claiming space in the world. And, of course, there is a long and storied history of it in the visual arts.

Although I do appreciate the power of photography, I didn’t want this project to be simply about having photos represent us as people with hidden conditions. I thought it would be important to *make* self-portraits, to imbue them with meaning, to really put ourselves into them. Though raising awareness is a big part of my plan for this project, the most important thing is the process itself, the act of making and the way that engaging with a deeply personal art project can have a transformative effect. I wanted it to be a project that participants might look back on and say *I did something important for myself*, or *I see myself in a new light*.

After talking it over with a knowledgeable local artist, I settled on using mixed media as I figured it would give people the most flexibility and options as well as being accessible for both beginner and experienced artists. I talked it over with DGMEFM Network and got the go-ahead to put together a workshop to be offered as an online wellbeing activity. I busied myself with preparing a materials list and announcement for the Network’s Admin Support Officer, Christine, who helped tremendously with this project. I then set about making guide materials, examples and presentations for the series of Zoom workshops which were scheduled to begin in late January 2025. I decided to call the workshops *Emergence: Creating Mixed Media Self-Portraits*.

The workshops themselves were meant to function as a place to communicate ideas and suggestions on how to go about making our self-portraits and to give participants a place to talk with each other about the challenges of life in general and also about their self-portraits. Work on the self-portraits was done between the workshops at the participant’s own pace. One takeaway for me as facilitator was that having several workshops or meeting times was an important part of the process and that participants needed time to integrate feelings and life experiences into their art. I learned that the process is at least as important as the outcome. After all, emergence is the *process* of becoming visible after being concealed. I guess the name of the workshop was a good call.

In reading a bit about self-portraiture, I came across this quote:

‘You are worthy of being the subject of your own art. It is okay to capture the process of your own becoming. To be your own kind and gentle and fierce witness. To learn the truth of your eyes and your skin and your bones. To choose to show what wants to be shown, to name what wishes to be named, to claim ownership of the story that is told about you by being the one to tell it.’ - Jeanette LeBlanc

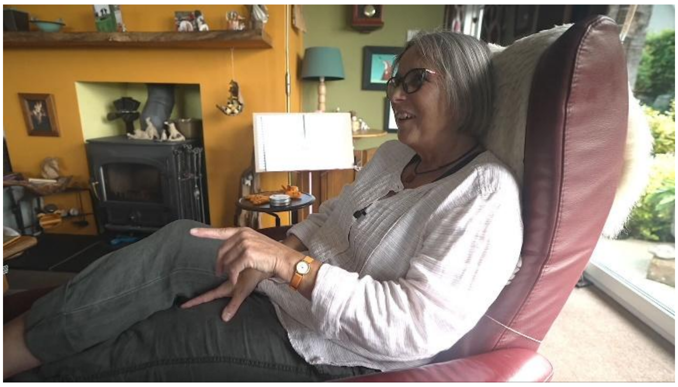
I commend each of our participants for claiming their space and their stories with the powerful self-portraits they created, and I thank them for sharing that journey with me. I look forward to seeing where we go from here.

D Rhodes

Art exhibition – 23rd September to 25th October at Gracefield Art Centre

I am delighted to let you know that the self-portraits that our members created will be shown in an art exhibition in Dumfries. The art exhibition beautifully coincides with our 25th anniversary of becoming a charity. By displaying our work in the exhibition, we not only showcase the talent and creativity of the artists, but it also allows us to raise awareness of our charity and the work we do supporting members. The self-portraits depict very clear messages about the challenges of living with our conditions but also how the artist can find joy and hope. The 6 pieces of art will be displayed at Gracefield Arts Centre, Edinburgh Road, Dumfries from 23rd September until the 25th October in the café gallery. The pieces of art are A2 in size and so this is a unique opportunity to see the finer details of each piece and really see the meaning behind these powerful self-portraits. We hope you can pop along to see the work.

Initial DecodeME DNA Results



A number of our members with ME/CFS took part in the DecodeME study which is the largest study of its kind in the world to date. Participants supplied data regarding their illness and symptoms as well as a DNA sample. Our very own trustee, Sarah Chadfield, spoke about her reaction to the study results on Channel 4 news. Watch the video on You Tube https://www.youtube.com/watch?v=DWCF1_-0yP0

Below is an extract from The University of Edinburgh's website and the full article and further information can be found at https://institute-genetics-cancer.ed.ac.uk/decodeme-the-worlds-largest-mecfs-study/initial-decodeme-dna-results

The DecodeME team is delighted to announce that the initial analysis of 15,579 DNA samples is complete, and we have important news to share.

Main findings from our analysis
Your genes contribute to your chances of developing ME/CFS.

- People with an ME/CFS diagnosis have significant genetic differences in their DNA compared to the general population. These lie in many places across the genome, and do not impact just one gene.
- Eight genetic signals have been identified. As DNA doesn't change with ME/CFS onset, these findings reflect causes rather than effects of ME/CFS.
- The signals discovered are involved in the immune and the nervous systems, indicating immunological and neurological causes to this poorly understood disease.
- At least two of the signals relate to the body's response to infection. Other signals point to the nervous system, one of which researchers previously found in people experiencing chronic pain, reinforcing neurological contributions to ME/CFS. These signals align with how people with ME/CFS describe their illness.

Results Summary
Myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) is a common, disabling illness. It affects more females than males, and in most cases, starts after an infection. Little is known about the biological mechanisms that cause ME/CFS, despite many attempts to uncover them, and it has no effective treatments.
To understand ME/CFS better, our study, DecodeME, compared the DNA of 15,579 people with ME/CFS with the DNA of 259,909 people without ME/CFS, all of European descent. DNA is a molecule that makes

up our genes. Our genes make many different molecules called proteins, each of which does very specific things in the body. Finding variations in genes that differ between people with or without a disease can therefore point to what causes it.

We found that people with ME/CFS are more likely to carry certain DNA differences in eight regions of their genome, and so these variants tell us about possible biological causes of ME/CFS. However, as these differences are also often found in people without ME/CFS they cannot cleanly separate who is at risk and who is not, and therefore do not provide a definitive test. Most of these regions contain several genes. Our methods did not allow us to conclusively locate the ones most relevant to ME/CFS in each region, but public data allowed us to pick out the most likely ones. Three of the most likely genes produce proteins that respond to an infection. Another likely gene is related to chronic pain. None are related to depression or anxiety. We found nothing to explain why more females than males get ME/CFS.

Overall, DecodeME shows that ME/CFS is partly caused by genes related to the immune and nervous systems.

Online Social Meet-Up: New Approach

For the time being, there will be no monthly meetings over zoom on the first Thursday of the month. These meetings were very poorly attended which was a shame for the speakers who gave up their time to join us. A few members had taken the opportunity to watch back the recordings of these meetings at a time when they felt up to it or which suited them better. With this in mind, we are rethinking how we invite speakers to engage with us and are planning a new approach. We will keep you informed once our plans are in place. If you have any suggestions, please contact kalpana@dgmefm.org.uk

National Trust passes

We had a huge uptake of those wishing to purchase a National Trust pass. However, we have 4 people who have purchased the passes who haven't received them yet as they have not confirmed the address they would like them be sent to. If this is you, please email christine@dgmefm.org.uk with your address and I will get them sent to you.

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: christine@dgmefm.org.uk

DGMEFM
Dumfries & Galloway
ME and Fibromyalgia Network
SC051578 | www.dgmefm.org.uk

Phone or WhatsApp: 07557 536110
Website: www.dgmefm.org.uk
Facebook: facebook.com/groups/dgmefm
Email: bobbie@dgmefm.org.uk (Chair)
paul@dgmefm.org.uk (Treasurer)
lesley@dgmefm.org.uk (Secretary)

OSCR
Scottish Charity Regulator
www.oscr.org.uk
Registered SCIO
SC051578

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.