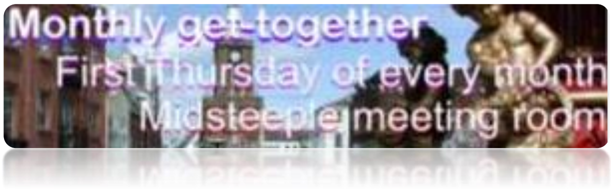
Dumfries and Galloway ME Network March 2015
Support for ME, CFS & Fibromyalgia

Welcome to the Spring newsletter from DGME Network.



At our AGM last November, members decided that we should continue as a charity for the coming year and see whether we could get the funding and help that we need to sustain us for future years.

At present our funding is limited. Membership of the Network is free but from time to time we ask for voluntary contributions, and gift aid where applicable. We are grateful to Denis Turner for his continued fund raising, and occasionally we receive other donations. This level of income allows us to undertake some low cost activities and occasional newsletters, but it cannot pay for more-able help or finance other potential developments.

Therefore, in the coming months we plan to make funding applications with the aim, as a first step, to buy in the more-able help that we need.

Firstly, for the purpose of the funding applications, we want to check that our current membership lists are up to date. You have received this newsletter because you are on our membership list. Please let me know if any of the following apply:

- You have recently changed your address
- You know of a member who has not received this newsletter
- You wish to cancel your membership
- You know someone who would like to become a member

You can contact me by email at paul.dgme@btinternet.com or by phone (afternoon/early evening) on ☏ 01556 610000.
Paul Thompson (Treasurer)

Benefits Advice Meeting

Because of the fluctuating condition of ME/CFS/Fibro many people who apply for benefits are unsure about what they can apply for and then have problems filling in the forms. To this end we have organised a Benefits Meeting which we hope will help you to negotiate the benefits maze.

Lochthorn Library, Dumfries

Speaker: Mr Ian Sneddon

(Inclusion Scotland, Rights Now! Project)

Also attending from 3pm for Q&A will be Rosie Hair, Visiting Officer from D&G Financial Inclusion and Assessment Team.

Thursday 16th April at 2pm – 4pm

Arrival from 1.30pm and tea/ coffee available.

Website

www.dgmefm.org.uk

We are launching a new website. The old website lapsed and its domain name was no longer available to us. The use of 'dgmefm' in the address of our Facebook page reflects both ME and FM in our membership. We wanted to replicate this in our website address and have acquired the above domain name. A basic website will be up and running in April, and we will be developing it over the coming months.

This will allow the wider public to access our Network…. to find out about us, to make contact with us, to know about our meetings and events, to follow links to other sites and to our Facebook page, to read our newsletters, and……more, yet to be decided.

DGME Network dedicated phone line: ☏ 07437 602610

Midsteeple Get-Togethers

Since you last heard from us we've held regular monthly meetings at the Midsteeple in Dumfries. They take place on the first Thursday of every month from 1-3pm. Access to the Midsteeple (in the middle of Dumfries High Street) is through the blue box office door. You will need to sign in. There is lift access to the first floor meeting room. Tea and coffee are supplied and there is no charge to attend. Please call our dedicated phone line if you wish to be met by one of our members in town prior to attending.

The next regular meeting is on Thursday, 2nd of April 1-3pm. There have also been one-off meetings in Annan, Lochmaben and Dalbeattie. Keep an eye on the facebook page and your email inbox for news of these pop-up meetings and please feel free to organise and share your own get-togethers.

Email Updates

We are now able to send out bulk emails using the marketing service MailChimp. This allows for us send out news and notification of events at short notice to all our members who have email. For example, the news that David Mundell MP and Russell Brown MP would be attending our March meeting at Midsteeple was too soon for us to let members know through this newsletter.

If you have an email address and did not receive our first update email, sent on 27th February, and if you would like to receive email correspondence from us, then please let us know and we will add you to the circulation list.

Contacts: craig.dgme@yahoo.co.uk paul.dgme@btinternet.com

Integration of Health and Social Care Services - Survey in Annandale & Eskdale

Members in Annandale & Eskdale are receiving a survey with this newsletter. It has been designed by SHAP (Safe and Healthy Action Partnership), on behalf of the Local NHS Health Improvement team, to inform the planning of Integrated Health and Social Care services

The purpose of the survey is: 'to identify what helps people keep and live well, in order to inform the integration of local Adult Health and Social Care services ……….There will be more of a focus on individuals taking responsibility for their own health and in order to do this people will require to have access to the support they need in their own community or as close to their home as possible.'

We were asked to distribute the survey to our members in the District and to offer our members support to complete the survey if needed. To this end we have drawn up and included guidance with suggestions for answering the questions. Freepost envelopes provided by SHAP are included for completed returns. This is an excellent opportunity for our members in the area to have their views heard and needs represented. As a bonus, SHAP are meeting the cost of postage for distributing the survey together with our newsletter to members in Annandale & Eskdale, and will fund us £2 for every survey returned to them. The survey results will be collated in April and participants will receive a report of the findings.

Integration of Health and Social Care Services – Survey in Nithsdale

The survey by the Health Improvement team in Nithsdale has now closed and a report is being prepared which should be completed mid-March and will be posted on their website. The next stage of the consultation 'to identify what helps people keep and live well' will be a number of focus group meetings to get finer detail on the findings from the survey. If you live in this area (postcodes DG1 to DG4) and would like to be involved in the consultation by attending a focus group, or by a 1-1 consultation, or by phone call please contact Diane Varie or Lindsay Murdoch on ☎ 01387 244401

Handy Hints – energy Saving

- Use Longlife or filtered milk to save you going to the shops so often.
- Use a steam mop rather than a traditional mop for cleaning floors.
- Batch cook food and freeze it.
- Record programmes then watch them back in manageable chunks.
- E-book readers are lighter to hold. Borrow electronically from libraries.
- Delegate where possible!

In The News

Already this year ME/CFS has been headline news on several occasions. Three big stories have broken. You could say it is 'the good, the bad and the ugly'.

First: 'The Ugly'

On 14th January research published in the Lancet Psychiatry generated headlines such as the following from the Daily Mail:

> Chronic fatigue victims 'suffer fear of exercise': Patients are anxious activities such as walking could aggravate the condition
>
> - Helping patients overcome fears was key to getting back to a normal life
> - Gradually increasing exercise regime can help overcome symptoms
> - Cognitive behavioural therapy was likewise effective
> - Both treatments enabled at least one in three to recover from the disorder
> - Syndrome leaves many bed-bound or in a wheelchair

The research published in the Lancet was an analysis of data from the very flawed PACE trial into the effects of Cognitive Behavioural Therapy and Graded Exercise Therapy. Patient advocate groups and many doctors, researchers and even psychiatrists disagreed with the findings and the trial's methodology. Problems with the PACE Trial include a very wide definition criteria of 'CFS', but accepting only moderately affected sufferers. The results were not blinded. 45% of the control group who received specialised medical treatment self reported a minor improvement. 14-16% more patients in the group receiving CBT and GET group self reported a minor improvement. However the report uses the word 'Recovery'. In this instance 'recovery' boiled down to being able to walk 56m further after a year. Indeed, the way the trial was set up it was possible to enter the trial, worsen slightly, and still be reported as 'recovered'. Interestingly this re-examination of the trial published pre and post-exertion heart rates that hadn't been reported in the previous trial. These did not show any improvement at the end of the study compared to the control group. Overall it is highly misleading at the very best.
Sadly, of course, the headline is what most people and most doctors see, and the vital background and subtleties is lost.

Secondly 'The Bad'

Actually that is probably unfair, maybe 'The Indifferent' or 'Cautiously Welcomed', would be better suited instead. This story is about the report from the Institute of Medicine in the USA of a study into redefining ME and renaming it.

The name they recommend is Systemic Exertion Intolerance Disease, SEID for short. (I prefer the acronym to be SEXI Disease!). It is undoubtedly an improvement on Chronic Fatigue Syndrome, not least by using the terms 'Systemic' and 'Disease' it is saying is it an illness that affects the entire body rather than a syndrome – which is a collection of unexplained symptoms. This is a very important distinction. Unfortunately, all most non-medical people will hear is ‘Exertion Intolerance’, which could have connotations of laziness to many.

While keen to see the end of the term CFS I feel the last thing we need is yet another name to add to the alphabetti spaghetti soup we are already labeled with. Already news reports have appeared talking about ME/CFS/SEID. With biological research, a new name will, most likely, suggest itself - or indeed the reasons for calling it Myalgic Encephalomyelitis or Myalgic Encephalopathy will be confirmed. Although the idea of the IOM report is to redefine the illness and trigger higher quality and standardised research I believe it’s a case of putting the cart before the horse. Perhaps more importantly is the redefinition of the diagnostic criteria. It is naturally less eye catching as a headline name-change however. In effect the diagnostic criteria the IOM report suggests are a shortened and simplified version of the Canadian Consensus Criteria. That is a big improvement over the likes of the very loose Fukuda definition (used by most psychiatric trials), but it is still more all-encompassing and less detailed than the CCC.

And finally: ‘The Good’

The headlines on the 27th of February were a lot more positive. The Telegraph’s headline being typical of the newspapers in announcing “First Biological Proof That ME is Real…”

While that claim was an exaggeration and many research efforts have found a lot of evidence before now it was none-the-less very exciting for its promise of a diagnostic blood test to come. The team, from Columbia University in the USA, discovered that early and late stage ME have clear differences. When they studied blood samples from the different groups, they found higher levels of a few dozen different cytokines, the chemical messengers that mobilize the immune system in response to infection, compared with the control group.

The lead author, associate Professor Mady Hornig, says “We know that the immune system should shut down after fighting off a virus or bacteria, but instead the system that regulates the cytokines themselves goes off the rails in the early stages of ME/CFS”. It suggests doctors could use the high levels to help diagnose the disease in the early stages. “There may be hope for early diagnosis”. Strangely though, the same cytokines that were high in the early stages drop to lower levels after three years. Knowing this should help researchers understand the origins of ME.

The team is now working on tracking individuals as their disease develops over time. This will help researchers understand whether ME develops similarly across all patients and it might help reveal treatments which could be aimed at resetting the immune system to its natural state.

First biological proof that ME is real found by scientists

Columbia University has found that changes to the immune system represent ‘the first robust physical evidence’ that ME is a biological illness rather than a psychological disorder

ME is characterised by fatigue, muscle aches and memory loss Photo: Alamy

Why your workforce’s well-being is a must
Being healthy has become an asset in the workplace. Find out more
Sponsored by VitalityHealth

By Sarah Knapton, Science Editor
7:00PM GMT 27 Feb 2015

Patients suffering from chronic fatigue syndrome show distinct changes in their immune system, scientists have shown for the first time.

Researchers say the immune changes represent ‘the first robust physical evidence’ that ME is a biological illness rather than a psychological disorder.

Until now doctors have only been able to diagnose the condition on reported symptoms alone, a problem which has led some to dismiss the illness.

But now Columbia University has found that there are specific patterns in 51 immune biomarkers for people with ME. The test also shows differences for short and long term sufferers.

"The message is not that once you're past the three-year mark," you've missed your chance, Hornig adds. "There may be different treatments that are effective in early-stage disease versus later-stage disease."

Please help DGME Network raise more money by using www.easyfundraising.org.uk every time that you shop online.

As most of you know DGME Network does not currently receive any funding and it is very hard for us to fund-raise as most of us are unwell. We only really have Denis Turner who raises funds for us by playing the keyboard at Gardenwise, Dumfries on every second Thursday in the month. Please go along to show your support and pop a donation in the tin.

Here is an easy way that we can raise some money for the group but your help is much needed.
DGME Network has been set up as a cause with the website easyfundraising.org.uk and all you need to do is register with the website and use the name DGME Network as your cause. Then every time that you shop online you use the downloaded toolbar or search on their website page for the shop you want to buy from (e.g. Next, Asda, Amazon etc) and when you purchase goods, that company will give a small donation to our group. It also works on smart phones and tablets via a free app. It does not cost you anything and if enough of us use the toolbar /page to search when shopping we can raise some much needed funds. We started in December and have 12 members raising money for us so far. The total raised at the time of writing is approaching £50 which is a great start to show how the pennies add up. Thanks to Helen for signing the Network up. For further information contact her at weeirishburd@gmail.com

Stop the press: The DGME Network is delighted and very grateful to have received a donation from Paul Riding for the fantastic sum of £400 at the March meeting. This will go a long way to supporting our work in the coming months and will help with match-funding for larger projects. Many thanks.

Action for ME Consultation held in Lockerbie, Oct 2014

Action for M.E. has published its *Hear me, influence M.E.* project report, detailing the next steps following the two open meetings held in October for people with M.E. and carers.

The meetings were held in Glasgow and Lockerbie under the *Hear me, influence M.E.* project, which has been funded by a Big Lottery, Awards for All Scotland grant. During facilitated table discussions, participants identified key goals and challenges for individuals and local support groups.

Examples of the overriding goals raised during the meetings include:-

- The establishment of specialist M.E. services in Scotland
- Development of high quality, patient approved, training programmes on M.E. for health and care professionals
- Establishment of a strong evidence base for treatment of the condition and translation into practice
- Establishment of a multi-agency professional interest working group for M.E. in Scotland.

Next steps
Based on the issues and ideas raised in the open meetings, Action for M.E. is taking forward the following activities during the first quarter of 2015:

- develop an information resource for newly diagnosed patients
- provide awareness-raising materials for local groups to display and distribute
- create a series of short videos on self-management aimed at people with M.E. by people with M.E.
- produce a campaigning toolkit for use in Scotland
- provide an advice session for local M.E. support groups on fundraising
- research on PIP experiences & impacts.

Meeting with the Region's Sitting MPs

Thursday 5th March, Dumfries

Politicians tend to listen to their electorate a little more keenly with an election looming and so we invited the region's sitting MPs, David Mundell in the East and Russell Brown in the West, to our March Midsteeple Meeting. It was made clear however that partisan politics were not to be discussed and the topic of conversation, I'm pleased to say, remained firmly on ME and fibro.

As it turned out the timing was very good with both MPs due to attend a meeting with the health board a week later and both intending to add the lack of care for ME and fibromyalgia to the agenda and to press the board to do something about it. Health is devolved to the Scottish parliament but their pressure could prove very useful. Having a smaller group than the 20 attending February's meeting meant that we could remain focussed, giving the MPs a good understanding of our needs. They both promised to report back.

We told them that the majority of our care comes from GPs, almost all either disinterested or lacking in any knowledge of the conditions, or worse, downright sceptical – Annan doctors being given as an example of the latter by RB. We said we wanted GPs to be better trained – but in conjunction with patients as there's so little knowledge in the NHS. We also wanted designated ME and fibro understanding doctors throughout the region. With health and social care looking like it's going to be more closely integrated it could be a good time to press for something akin to the specialist clinics in Keswick that some members have experience of. The Can-Do Centre which used to be behind the old Infirmary was given as an example of something that had worked very well in the past, and could suit the needs of ME and fibro sufferers well if there was a little specialist knowledge from a nurse or GP. They don't think that this is an unrealistic possibility. We pointed out that many sufferers are bed or house bound in this widely dispersed region.

Benefits and the welfare reform remains the responsibility of Westminster and took a large part of the discussion. We emphasised how difficult it is to make a successful claim with a fluctuating condition where the pain and fatigue are not visible. Both agreed the system is skewed towards permanent disabilities which fit much into the tick-box application forms. We all agreed that benefit applications need to be rigorously vetted, but take a lot more account of the specific needs of our conditions, and of our own GP's opinions. Reviews take place and input will be sought then. The move to single payment has had mixed results in the various trial regions. It is being rolled out to single people first, so hopefully should be functioning better by the time most of us are affected. Neither MP could offer us much reassurance that things will get any easier in the future with the budget yet to be balanced.

From benefits discussion turned to the lobbying and the campaigns by some psychiatrists and media groups against any acceptance of the biological origins of ME. The Science Media Centre was raised and their knocking of the recent breakthrough from Columbia University. We asked why the government has files on ME which are to remain secret for 80 years. DM took interest in this. It was agreed that more of the right kind of research is required – and indeed could prove cost effective when compared to the costs of long term illness.

Of great surprise and very impressive was Russell Brown's declaration that he reported to the GMC the doctor who removed from her family the young woman featured in the extremely harrowing film Voices From The Shadows. The young woman was seriously ill and didn't recover. Tragically she later died.

The discussion was positive and upbeat, with Russell Brown particularly knowledgeable about ME from his dealings with constituents and from sitting on the ME group in parliament. We left happy that the meeting was useful whatever the outcome of May's election.

We plan to write to the candidates from the main parties before the election and will share the responses on our facebook page. All being well hopefully a meeting can be organised sometime after the summer with our local MSPs.

Diary Dates

Thursday 26th March 12:30-2:30pm | Turning Point Scotland, Burns House, Stranraer
House, 30 Harbour Street, Stranraer, DG9 7RD

Held by Wigtownshire FM/ME Support Group
Please phone Janet on 01671 403 577 to confirm and for details.

Thursday 2nd April, 1-3pm | Midsteeple meeting room, Dumfries.
The Midsteeple is in the middle of Dumfries High Street, entry through the blue Box Office door. The meeting room is on the first floor, but there is a lift. You will need to sign in.
After March's heavier-going meeting with the MPs this will be a social get-together. Come along for a coffee/tea and blether. No agenda, just a chat. We will supply tea and coffee but feel free to bring along a snack.

Thursday 16th April, 1:30-4pm | Lochthorn Library, Dumfries, DG1 1UF
From 2pm Ian Sneddon from Inclusion Scotland will be giving us a presentation on the changes to the welfare system with particular emphasis on how it affects people with fluctuating conditions. Rosie Hair from D&G Council's Financial Inclusion and Assessment Team will join in the question and answer session which will follow. This could provide some valuable information given the massive changes already unrolled and with more to come.

Thursday 30th April 12:30-2:30pm | Turning Point Scotland, Burns House, Stranraer
Held by Wigtownshire FM/ME Support Group
Hopefully David Riley (Benefits Officer for D&G Council, Stranraer) will attend.
Please phone Janet on 01671 403 577 to confirm and for details.

Thursday 7th May 1-3pm | Midsteeple Meeting Room, Dumfries
No speaker has been arranged. Check the website, facebook or your email inbox for more details.

Future meetings
D&G ME Network's meetings take place in the Midsteeple on the first Thursday of every month, 1-3pm
Contact Craig on craig.dgme@yahoo.co.uk or call the Network's phone on 07437 602610 for more information.

Wigtownshire FM/ME Support Group's meetings (usually) take place on the last Thursday of every month at Burns House, Stranraer. Contact Janet on 01671 403577 for more info.

Pop-up meetings
Depending on energy we will occasionally host late-notice meetings around the region. These have taken place in cafes, bars and even on an alpaca farm. Keep an eye on our facebook page and the website (coming soon) for notice of these. If you'd like to organise a get-together of your own please feel free to share it on the facebook page and contact Craig if you'd like details emailed to members.

If you are able to help the Network in any way please get in contact. Particularly pressing is fundraising and funding applications. There are some exciting possibilities for future projects but these require money and for the effort to be spread more widely.

Wanted – Secretary

The Network currently does not have a secretary. To be able to continue we need someone to fulfil this role. The main responsibilities will be database management and minute taking.

This newsletter was written and created in a joint effort by Paul, June, Craig and Helen. If you would like to submit an article, event or artwork for the next edition please contact us or add it to the facebook page.

Useful Contacts

For those who cannot attend the benefits meeting there are other sources of help:-

Financial Inclusion and Assessment Team (FIAT) at Dumfries and Galloway Council

These advisers can help you to find out what benefits you are entitled to.
☎ 030 33 33 3008 E-mail: fiat@dumgal.gov.uk
Appointments are either at the local offices or at home.

Action for ME

Dedicated Benefits Helpline ☎ 0845 122 8648 or ☎ 0117 927 9551 to book a telephone appointment slot.
Action for ME also have information guides in how to fill in the ESA (Employment and Support Allowance) and PIP (Personal Independent Payment) forms. These can be downloaded free from their website or can be bought in their on-line shop or by writing to them.

ME Association

Help and Support ☎ 0844 576 5326
The ME Association also has guides to filling in ESA and PIP forms but they charge for these. We have limited copies of these available for you to borrow. If you would like to do so please phone Paul on 01556 610000 or e-mail him at paul.dgme@btinternet.com

For general information:

ME Association
7 Apollo Office Court
Radclive Road
Gawcott
Bucks
MK18 4DF £18 to become a member
☎ 01280 818964
Website: www.meassociation.org.uk
E-mail: admin@meassociation.org.uk

Action for ME
42 Temple Street
Keynsham
Bristol BS31 1EH £21 to become a member
☎ 0117 927 9551
Website: www.actionforme.org.uk
E-mail: admin@actionforme.org.uk

FMAUK (Fibromyalgia)
Studio 3007
Mile End Mill
12 Seedhill Road
Paisley
PA1 1JS
☎ 0844 826 9022
Website: www.fmauk.org
E-mail: charity@fmauk.org

Tymes Trust (For younger people with ME)
P.O. Box 4347
Stock
Ingatestone
CM4 9TE
☎ 0845 003 9002
Website: www.tymestrust.org

More information on meetings, news and support can be found on our Facebook page: **www.facebook.com/groups/dgmefm**. It's a thriving community and a very useful asset. As it's a closed group only members can see posts so if you're not already a member you will need to request to join.

- DGME Network website: www.dgmefm.org.uk
- DGME dedicated phone: ☎ 07437 602610