

Richmond & Kingston



ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

NEWSLETTER

No 2, 2021

Inside — Reclaiming Chronic Illness Seminar — Review of *Mindfulness for Health* — DecodeME's New Project — What Our Members Are Doing — And More...

ME and the Corona Virus and Vaccines

Quite a few people with ME have raised concerns about the impact upon their ME symptoms of both the Corona Virus and the various anti-Corona vaccines that are being offered by the NHS.

I: ME and the Corona Virus

Many people with ME have found that their symptoms have deteriorated after having undergone a stressful experience, for example), a general anaesthetic, a viral infection (or a further one if a virus had triggered their ME, or a serious emotional crisis. It is not at all surprising that people with ME are concerned that catching the Corona Virus could well exacerbate their ME symptoms, not least when it is well known that there is a close connection between viral infections and the contracting and exacerbation of ME.

Action for ME have compiled a preliminary report on the impact of Corona Virus infection upon people with ME. A survey announced in late March received 220 responses over the following three weeks, and 154 respondents (77 per cent) stated that their ME symptoms had worsened after they caught the virus, with a deterioration of their cognitive and physical functioning. Just under 11 per cent stated that their symptoms had not worsened, and the remainder were not sure. Of the respondents whose condition had deteriorated,

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rated, 70 per cent stated that this worsening had lasted for more than six months and still remained unresolved, and 72 per cent had new continuing symptoms.

The following chart gives a breakdown of the new symptoms experienced by the respondents whose ME symptoms had worsened.

New Symptoms	%
Post-exertion malaise	72.7
Pain in muscles and joints	71.4
Muscle fatiguability, weakness or twitching	69.5
Poor temperature regulation — sweating, hot flushes, feeling very cold	63.6
Headaches, migraines	63.0
Flu-like symptoms	58.4
Gastrointestinal symptoms — nausea, abdominal pains	57.8
Unrefreshing sleep	54.5
Heightened sensory sensitivities	46.8
Orthostatic intolerance — unsteadiness when standing	41.6
Food and drink intolerance	30.5

The report also comments upon the impact on respondents' ability to engage in education, work or voluntary activities. This, it states, 'was likely to have decreased, with 59 per cent of respondents reporting they were less likely to be able to do these activities'. Furthermore, 55 per cent of the respondents reported that their use of health care services had increased since catching the virus.

The report concludes:

These preliminary findings highlight the terrible impact that Covid-19 has had on many people with ME. We will continue to monitor the results and... prepare a full report with detailed analysis to provide evidence which we will use to campaign to get the support that people with ME need. There is a strong need for research into this area, to ensure people with ME receive appropriate care and support as the pandemic continues.

The report states categorically that 'it was clear from the findings that Covid-19 has resulted in worsening of multiple ME symptoms'. This high proportion of respondents whose ME symptoms have been exacerbated after having caught the Corona Virus strongly suggests that there is a causal relationship between the two factors, rather than their coincidence being purely by chance. Other authorities agree: the ME Association, having studied feedback from members, consider that if people with ME/CFS catch the virus 'it is likely to cause a significant exacerbation or relapse of their ME/CFS symptoms'.

II: ME and the Virus Vaccines

Following on from the matter of the impact of the Corona Virus upon people with ME is the question of the impact upon them of the virus vaccines. With vaccination there is always a danger that with some people the vaccine will trigger adverse symptoms that can be more intense and longer lasting than the usual short period of post-vaccination discomfort, and occasionally will even result in a serious impact upon a person's health.

Most people who have had the Pfizer or the Astra-Zenica vaccine for the Corona Virus have experienced short-term symptoms, often similar to mild flu symptoms, for a day

or two after being vaccinated. This is quite normal for many different types of vaccinations, and they indicate that the vaccine is taking effect. However, a small number of people have been experiencing longer-lasting symptoms or serious debilitation after having had their Corona vaccination. Anecdotal evidence from within the Richmond and Kingston ME Group has suggested that these trends have been replicated amongst people with ME.

The ME Association has recently released the results of a survey carried out in March in respect of responses to the virus vaccination. A total of 1956 people responded, and the following chart gives their reactions to the vaccine.

Reaction to Vaccination	%
I felt fine; no discernible issues even after a few days	7
I felt surprisingly better for a few days after the vaccine	2
I experienced side-effects, for example, sore arm, increased fatigue, headache, chills, slight fever, etc	19
I had some of the above side-effects and an increase in ME/CFS symptoms	12
I had some of the above side-effects but no increase in ME/CFS symptoms	9
I had all of the above side-effects and an increase in ME/CFS symptoms	12
I had none of the above side-effects but had an increase in ME/CFS symptoms	1
I had significant side-effects and/or a significant increase in ME/CFS symptoms and had to consult my doctor	4
The issues resolved within days of the vaccination	10
The issues resolved within a week of the vaccination	8
The issues took longer than a week to resolve	9
The issues remain unresolved and have led to a relapse in ME/CFS	7

The MEA state that somewhere between five and ten per cent of people with ME are reporting a more severe or persisting exacerbation of their ME symptoms after having been vaccinated. On the other hand, the Health Rising website states that there is anecdotal evidence that some people with ME have found that their symptoms have actually decreased after their having been vaccinated.

The MEA state that so far they have had very little feedback from people who have had a second dose, and an even smaller number of responses from people who had a bad reaction to the first one and who have had a second dose. Their report concludes: 'Having the second dose should obviously provide a further boost to immune system protection against the virus and possibly lengthen the time this protection lasts. But this may be at the expense of having another exacerbation of symptoms.'

Health Rising asked several GPs about the balance of risks between having a vaccine and suffering after-effects, and not having a vaccine and catching the virus. One, Dr Bela Chhada, said: 'I am recommending that ME/CFS/FM patients get vaccinated. Based on the current data, the risk of getting complications from getting Covid seem higher compared to potential side-effects from the vaccine.' She added that if people are still experiencing worsened ME symptoms a month after the first dose, they should consult their GP. Dr Eleanor Stein said that 'the benefit/risk ratio is decidedly in favour of being vaccinated'. She added that people should consult their GP before having a vaccination if they have previously had an anaphylactic reaction to any of the ingredients of a vaccine.

For people with ME, the Corona Virus has added a further range of problems to those which we already are obliged to confront. When we take two factors into consideration — that medical authorities are reckoning that the virus will have to be dealt with by contain-

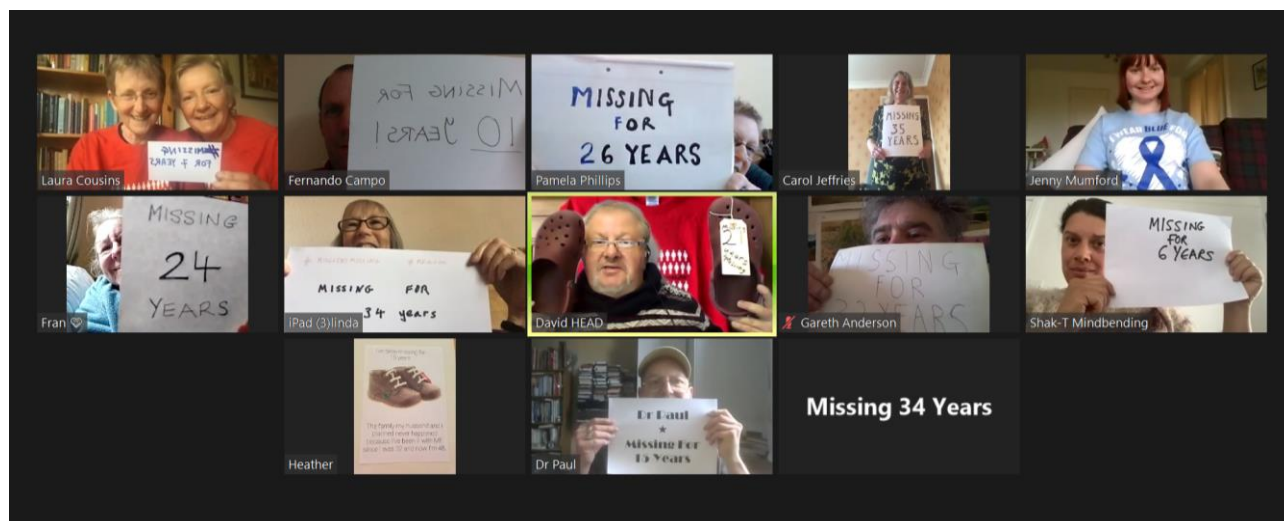
ment (at least in the short to medium term) rather than through its elimination, and that new variants of the virus may well require additional rounds of vaccination — it is important that the manner in which both the virus and the vaccines affect people with ME is regularly, extensively and carefully monitored in order that definite conclusions in respect of their impact upon us can be drawn.

Paul Flowers

ME Awareness Week 2021

The ME Awareness Week ME events for this year were, because of the Corona Virus, for the second year largely conducted on-line.

The Richmond and Kingston ME Group took part in the proceedings, with photographs taken at an on-line meeting and of the customary boots and shoes being broadcast across the internet. Below on the right are [REDACTED]'s shoes, and also below is a screen-shot of our meeting, showing how long our members there have had ME.



ME Action issued a call to artists 'to share their work', and more than 50 artists covering a wide range of mediums responded and attended their on-line Artists Salon 'to share their art, enjoy and embrace the art of others, and be witnesses to the stories shared'. ME Action said that they were 'blown away by all the songs, paintings, sculptures, writing, and other works that poured in from the global ME community', and were 'so inspired as these artists empowered one another through showing their talents, often with art that was inspired by their own journeys living with ME.'

Betsy Barker from Los Angeles shared two short pieces that focused on her experience of living with ME. Diane from Ithaca wrote about her beloved cat, Stash. Betsy Unger, who has severe ME, shared a photo 'The Ocean Floor' that 'illustrates the experience of temporary paralysis in Very Severe ME' and an accompanying poem, which we reproduce below. Whitney Dafoe, who also has Severe ME, shared two



photos. Kristine Nilsen Oma gave a wonderful dance performance. Kaeley Pruitt-Hamm of KPH and The Canary Collective sang a song that moved everyone. Sarah Ramey was going to read from her new book *The Lady's Handbook for Her Mysterious Illness*, but instead decided to sing. Christina Baltais from Toronto shared many pieces featuring paintings, make-up and a series of body casts entitled *Broken Body/Enduring Spirit* which is a sculptural representation of her experience with ME/CFS.

Betsy Unger, *The Ocean Floor*

Betsy wrote that the photo 'illustrates the experience of temporary paralysis in Very Severe ME. Caged in pain and sunk beneath the weight of the entire sea above unable to even cry out. There but not there, waiting to rise again to the top, afraid this will be the time I won't.' Betsy takes her photos unplanned in the dark, with eyes closed on an iPad. It is not composed, but she believes it captures an experience of Severe ME of which is rarely spoken.

Below is the poem that Betsy wrote to accompany this photograph.



Underway

This is no bed, it's a boat —
 a great grey ocean liner
 with a bellow in its throat.
 No tossing and turning, she just ploughs straight ahead,
 splitting the platinum night sea,
 her windows a twinkle with swirling lights
 of pleasure, ease and greed
 No thought of fate
 or storms
 or ice
 or disease.

This is no bed, it's a boat —
 a kayak entirely self-propelled.
 It can roll and keep on going;
 it can't be taken down.
 With it I explore my memory dreams
 of the kettle ponds at twilight.

My paddle cuts the purple liquid mirror,
 two of everything.
 I poke at the lily pads

with their long stems
reaching deep into the shimmering silt
anchored in all that waits.
I will not pull on those stems;
I am not ready to know what's ahead.

This is no bed, it's a boat —
a dented aluminium dinghy,
dragged to the lip of the bay.
I am too small for its wooden oars and
they slip again and again from their oarlocks.
But my father is waiting for me.
He wears his red and blue-striped seventies shirt and
stands in his *Day Sailor* with its mouldy
life jackets, salty ropes and splintering cabin
big enough just for me.
The light and the water dance furiously.
There is nothing ahead but journey.
We raise the sapphire spinnaker.
It clangs and flaps, teases and floats
then suddenly snaps, fills and flies.

This is no bed, it's a boat —
no sickness, no pain,
no end, no doubt,
just pure, blue grace.

The ME Action Artists Salon can be viewed in full at <https://www.youtube.com/watch?v=EDX8og0XDNE>.

Mindfully Evie: Thoughts for 'Millions Missing'

This week is ME awareness week and the start of #millionsmissing.
I always find this week bittersweet.
It's good, because thousands of people across all corners of the world come together in
solidarity to raise awareness and bring a voice to an illness that has been silenced for
far too long.
It's makes me so emotional to see all the support and stories of others.
But it's sad, because it reminds me how millions of people across the globe are struggling,
often with little or no help.
I think one of the worst things about ME is that people don't often realise the scale of just
how many people have it because we always suffer behind closed doors.
Our illness requires us to retreat; into the silence and away from society.
So it means we can literally disappear from the world, and unless you have access to
social media, you can be left completely isolated.
We're not the people you see at hospital, receiving treatment.

We're not the people you see on the streets, telling you about our illness.

We're the people whose illness means we often literally drop out of society, sometimes suddenly, sometimes gradually.

We're the people who are forced to leave school or work, never to return, and often with no explanation to others why, as we don't even have a name yet for our unexplained symptoms.

But I hope this week you can see us.

I hope this week you take the time to look at the #millionsmissing and honour our presence.

I hope this week you think of the people living with ME behind closed doors.

We are the millions missing.

Mindfully Evie's website is at <https://mindfullyevie.com/about-me/>.

Reflections On Our On-Line Meetings

One of the unexpected benefits of the pandemic for the Richmond and Kingston ME Group, in my opinion, was that it kick-started our programme of on-line meetings.

Unable to meet in person, we started experimenting with meeting virtually. We did this initially on Houseparty, as it is a flexible platform that more closely mirrors our previous café experience. Quite soon we moved a lot of our activity to Zoom, capitalising on greater familiarity among members due to the rapid spread of this program among families and friends trying to stay in touch. We offered some technical support to members, but mostly we found that people, sometimes quickly, sometimes over months, got themselves on-line and joined a meeting. At first we ran 'chat' meetings, but, in response to a member's suggestion, we started some shorter and quieter meetings, which have also proved popular.

As of 17 June 2021, we have run 87 online meetings, settling down currently at eight per month.

Currently we have four 'chat' meetings comprising three coffee meetings (at 11.00am or 2.00pm) and one pub meeting at 6.00pm, and four 'quieter' meetings, comprising two mindfulness meditation, one crafting and one silent reading group. Some members might turn up in any meeting, but mostly there is a slightly different audience for the different meetings. On average, we currently get attendance of about nine people to our chat meetings and seven to our quieter meetings. Over a quarter of the group — 43 people — have attended an on-line meeting.

On-line meetings have allowed us to connect with (or reconnect with) people who are unable to come to face-to-face groups, some of whom have been deprived of social contact for a long time. I have come to see this as perhaps our most important function. On-line meetings facilitate access to a community for members with limited mobility who may have previously been quite isolated.

But more than this, our group members are spread geographically quite widely. On-line meetings are accessible to everyone, not just the people who are both near enough and have sufficiently good transport options to make any particular face-to-face meeting.

On-line meetings are easy to attend, so if you can only manage five minutes, it is feasible, whereas it would be impossible if you had to spend 30 minutes travelling to a

meeting. You can attend from wherever you are (like bed from which I host most of my meetings). If you usually go to face-to-face meetings but don't feel up to it that day, you still might be able to attend an on-line meeting — if only for a short time.

We have experimented with breakout rooms on Zoom when we have a lot of attendees to create the option of more intimate conversations. As we have all become more familiar with the platform and with each other, I think individually we have become better at managing on-line conversations (though I should probably say less!), and we use breakout rooms less often; people seem to welcome the larger group perspective.

However, on-line meetings are not quite the same experience as meeting face to face, and many members find them quite tiring. Some members find it hard to engage with them. So, as and when it feels safe as well as legal to meet in person, we will certainly revive these meetings. But no one on the Committee can imagine going back to offering only face-to-face meetings: on-line meetings are here to stay!

Book Review: *Mindfulness for Health*

■■■■■ reviews Vidyamala Burch and Danny Penman, *Mindfulness for Health: A Practical Guide To Relieving Pain, Reducing Stress and Restoring Well-Being*.

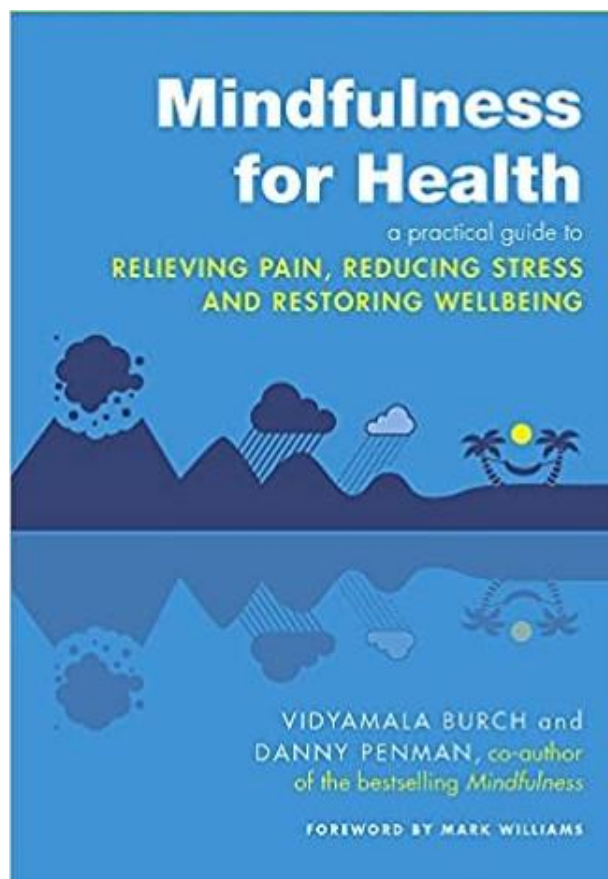
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This book covers Vidyamala Burch's eight-week MBPM (mindfulness-based pain management) programme and comes with a CD of eight meditations which can also be downloaded.

I found this book very clear and easy to read, persuasive, full of helpful and practical information, and well-chosen examples and anecdotes that demonstrate the points they are making. Quite literally, I could not put it down.

The book starts by briefly listing some of the many proven benefits of mindfulness, including the positive impact of mindfulness on pain generally and fibromyalgia specifically, on IBS, as well as depression and anxiety.

There is then a chapter on the science behind mindfulness and how it dissolves pain, suffering and stress, and restores well-being. Pain is a danger signal with two components: primary pain — the raw information fed into the brain (from the insult to the body), and secondary pain — the mind's reaction to the information (including thoughts, emotions,



and memories associated with the pain). The brain has a volume control over pain intensity and duration. It focuses on pain and looks for past patterns of this pain, to understand the danger, and tries to make sense of what is happening, also creating stories and emotions about the pain. In chronic pain, this can result in fine-tuning the brain's ability to sense pain and develop pathways to shortcut the time to process the information. The pain becomes worse, faster. The body tenses against the pain, which tends to increase it and a vicious cycle is established. The pain experience is all 'real', but some of it can be reduced or eliminated by mindfulness which trains the mind (and changes the brain; fMRI scans show a different brain structure for meditators). So while mindfulness cannot change your primary pain, it can alleviate the secondary suffering, which can make a huge difference to how bad you feel.

Mindfulness is a practice, and to reap the benefits you follow a simple programme; this is very clearly yet concisely explained, and very well thought through (she has had decades to get it right!). The programme includes:

- ★ Ten minutes of meditation twice daily (six days a week is suggested).
- ★ Habit-breakers (ten minutes in nature, watch the sky, random acts of kindness).
- ★ Practical exercises (for example, very gentle mindful movement, pacing evaluation).

During the first few weeks of the programme, you learned to focus your awareness on the breath and the body. You learned to give up your weight to gravity, rather than creating more tension by straining against it... You then moved on to extending the natural flow of the breath into the larger movements of the breath through Mindful Movement exercises...

Next you went on a journey to discover your own 'mindfulness rhythm' through pacing, to avoid slipping back into a boom-or-bust cycle as well as helping prevent over-stressing your body and mind... you learned to counteract tendencies to be overly harsh or critical of yourself by cultivating a sense of acceptance and compassion towards yourself. And you learned to turn towards discomfort with kindness and tenderness. This, in turn, opened a door to the appreciation of pleasure once again. Reconnecting with the pleasant aspects of daily life was one of the most important skills you learned. You then discovered how to broaden your awareness... to hold both pleasure and pain in the mind simultaneously... and to live with more of a sense of 'flow'... creating a sense of balance and stability... [then] you learned to expand the focus of your awareness from yourself to others.

This helped to transform your perspective from one of separation and isolation to one of connection... Learning to respond to your own experiences — rather than reacting to them — with warmth and compassion, can lead to a richer and more fulfilling life.

I can't recommend this too highly. If you read one thing on mindfulness, make it this one.

DecodeME Research

Funding has been secured for a very large study to analyse DNA from the saliva of people with ME/CFS to see whether the disease is partly genetic and, if so, to help pinpoint what causes it. The study should help scientist understand the disease and ultimately to find treatments.

Professor Chris Ponting (Principal Investigator) at the University of Edinburgh is responsible for successfully delivering the project. Working alongside Chris are a number of co-investigators from both the university and the Management Group. Sonya Chowdhury, on behalf of Action for ME, chairs the Management Group. The project team is supported by numerous people with ME and carers, who are helping with recruitment, communications and marketing.

As you probably are aware, *20,000 participants* are needed. If you're interested, please let DecodeME know as soon as you can, so that when the study launches in autumn 2021, they can start reaching out to potential participants and collecting samples immediately. It will be a huge challenge to do the largest ever biomedical study of ME/CFS, so they need our help.

DNA is the master-molecule of life, containing all the information needed for our bodies to grow and function. We inherit our DNA from our parents. It's a double helix, which looks like a twisted ladder. The important parts of the ladder are the rungs, and each rung of the ladder consists of a pair of molecules called bases. There are four bases and they are usually referred to by the first letter of their names: A, T, G and C. The sequence of these four letters along the DNA molecule carries all our genetic information, much like letters do in a book. The DNA bases, or letters, always pair up the same way in the rungs of the DNA ladder. A always pairs with T, while C always pairs with G. This means if you have the sequence of one strand of DNA, you can always work out the sequence of letters on the opposite strand. Which mean that researchers need only study one of the strands.

In total, our total genetic information is made up of over three billion DNA base-pairs, which is known as our genome. The genome includes all our genes, which are the stretches of DNA that tell the body how to make all its proteins. Proteins are the body's 'doing' molecules, such as muscle fibres, and enzymes used to digest food. Every cell contains the entire genome, which stretched end-to-end would reach about two metres.

DecodeME have chosen to look at DNA because significant differences between the DNA of people with ME/CFS and healthy controls must reflect biological causes of the illness. This is different from studying other biological molecules, such as proteins, where differences might simply be an effect of the disease and not what causes it. However, all people keep the same DNA they were born with as it remains unchanged by disease, meaning that any DNA difference linked to the disease must be a cause of disease rather than an effect.

DecodeME's study of ME/CFS is a genome-wide association study (or GWAS, pronounced 'gee-was') — a very large genetic study that aims to uncover some of the biological roots of disease. A GWAS is a relatively new technique that focuses on small differences in DNA between people. Humans are 99.9 per cent identical at the level of DNA, yet there are still millions of places along the human genome where these individual letters can vary from person to person. For example, one person might have a G while another has an A. Each site where the letters vary is called a single nucleotide polymorphism, or SNP (pronounced 'snip').

DecodeME will collect saliva from people with ME/CFS who have a clinical diagnosis and meet their criteria, and they will extract their DNA from the saliva. They will then look at the SNPs at approximately one million locations where people are most likely to differ, searching for significant differences between people with ME/CFS and healthy controls (data for large numbers of healthy controls is already available in the UK Biobank).

The GWAS might find only a handful of differences, but each one will be a clue to what is going wrong in people with ME/CFS at a biological level. Specifically, it should help identify genes, biological molecules and types of cells that probably play a part in causing

ME/CFS. Any significant DNA differences revealed by the GWAS will be strong scientific leads that researchers can pursue with new studies. They hope that their future work will lead to the development of diagnostic tests and targeted treatments for ME/CFS.

Indeed, GWAS in other diseases have already revealed valuable information. They have led to a better understanding of the molecular causes of rheumatoid arthritis, which involves painful inflammation of the joints. Scientists are developing new drugs as a result of these insights. Ten new significant biological pathways have been identified for inflammatory bowel disease. For Alzheimer's disease, GWAS showed that microglia — the immune cells of the brain — play a key role in the illness. And in Type II diabetes, GWAS have helped to identify genes that affect the production of insulin in the pancreas and the action of insulin on fat cells. GWAS have also helped to identify an unsuspected role for a protein that transports zinc into cells, and so drugs targeting this protein are being developed as treatments.

A GWAS has enormous scientific potential for ME/CFS, and with the help of patients, this powerful new technique can help us to find some of the biological causes of this disease.

DecodeME don't expect to find just one gene that explains ME/CFS. If there were just one, it would probably have been found by now. Instead, GWAS usually pick up DNA differences that individually play a small role in the disease but which can still reveal a great deal. Because they looking for small effects, they need very large samples to get robust results, which is why they want 20,000 people with ME/CFS to take part.

If you would like to be a participant on this study, please register your interest on their website: <https://www.decode.me.org.uk/>.

Group E-Mails

Some members have told us that they have not been receiving our Group e-mails in their in-box.

Please check your 'spam' and 'junk' folders, as it's quite possible that our e-mails have been directed there automatically by your Internet Service Provider.

Reclaiming Chronic Illness Seminar

This excellent seminar on chronic illness inclusion, held on 18 March, was hosted by Doria Pilling of Disability and Inclusion. The speakers were Catherine Hale, who has ME and campaigns for people with invisible illness, and Dr Anna Ruddock of the Chronic Illness Inclusion Project, reporting on their research into people with invisible chronic illness (who are disproportionately women), for example, ME, fibromyalgia, auto-immune diseases.

Catherine spoke about their research into the experience of people with chronic illness:

As 'insider' researchers, we believe that experience of living with chronic illness can, and must, be transformed by changing the way society responds to us as disabled people, as well as through advances in medical treatment for particular diseases.

They started their research with two questions:

1. What is it that binds our community together?
2. Why are we not on the map of disability? Why are we only talking to ourselves, unlike other disability groups who have external advocates?

People with invisible chronic illness have:

1. A shared lived experience beyond language: we currently do not have the language to express the reality of our illness to others. For example, words like 'fatigue' frequently producing the response 'I get tired too', or 'malaise', which is not understood.
2. A shared lived experience of oppression related to disbelief that is both structural and systemic.

Looking at these issues:

1: Shared Lived Experience Beyond Language

They assembled a diverse sample and asked: Do you consider yourself disabled? And got a lot of 'yes but...' or 'no but...' answers. The narrative runs like this: My fatigue is disabling so I had to stop working but fatigue is not counted as a disability — it's bottom of the hierarchy of problems, it doesn't fit with society — I don't feel I'm entitled to call myself disabled, and when I do identify as disabled I'm viewed with disbelief.

Yet in chronic illness, the top symptom is fatigue or limited energy (almost half) followed by pain (one quarter). Looking at impairment type among disabled people, they found that the category 'stamina / breathing / fatigue' is second only to mobility in prevalence and yet it is excluded from categories for impairment and disability.

Conclusion — Reframing Chronic Illness Language: Their first suggestion is that we need to reframe chronic illness as energy-limiting chronic illness (ELCI). And that in place of 'fatigue' we need to talk of energy impairment (that is, loss of function).

2: A Shared Lived Experience of Oppression and the Need to Assert Our Identity as Disabled People

- ★ The oppression is mainly invalidation and disbelief.
- ★ Disability is stereotyped as a fixed and visible form of difference.
- ★ Pathological fatigue is dismissed as a universal experience of 'tiredness'.
- ★ Only 25 per cent met the definition of disabled in the Equalities Act.
- ★ Sixty per cent fear rejection if they identify as disabled, and 43 per cent agreed with the statement: 'I feel like an imposter if I identify as disabled.'
- ★ Microaggression of Disbelief: a consistent pattern of being undermined.
- ★ People start to doubt themselves: 'I get tired because I'm fat/lazy... that is, it's my fault.'
- ★ Ninety-two per cent get told: 'You don't look disabled.'
- ★ Eighty per cent agreed that the public general attitude is: 'Everyone gets tired.'
- ★ Eighty-three per cent met with the attitude that they 'should try harder'.
- ★ Sixty-four per cent avoid asking for help or support through fear of being dismissed as fraudulent.
- ★ Eighty-one per cent feel judged in public.

Conclusion

- ★ Identifying as disabled takes time and is a labour of self-belief.
- ★ There is a need to navigate hostility, dismissal and disbelief, and a need to overcome internalised invalidation and to assert lived experience.
- ★ There is a need for advocacy for people with Energy-Limiting Chronic Illness.

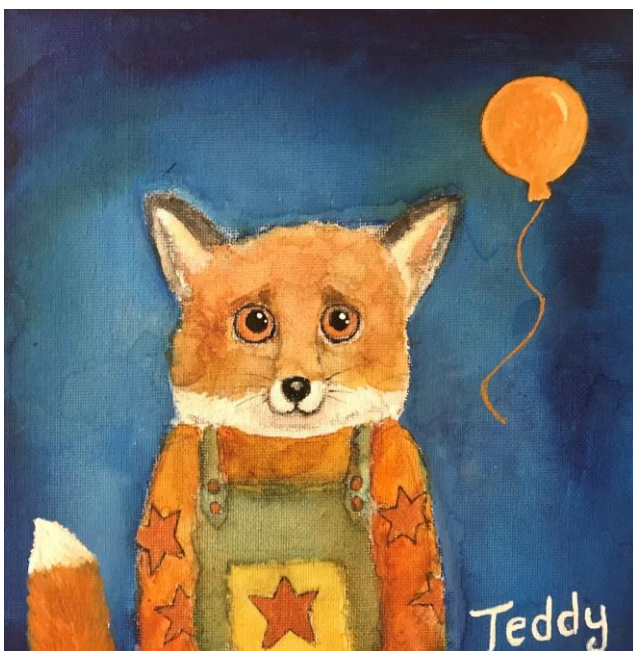
A pamphlet, *Energy Impairment and Disability Inclusion: Towards an Advocacy Movement*

for *Energy-Limiting Chronic Illness*, can be found on-line at <https://www.centreforwelfarereform.org/uploads/attachment/681/energy-impairment-and-disability-inclusion.pdf>.

What Our Members Are Doing

Done anything exciting, inspiring, interesting? Although ME does its best to make our lives miserable, and the Corona Virus adds yet more botheration, this does not prevent us from trying to make our lives as fulfilling as we can. So do let us know what you're up to.

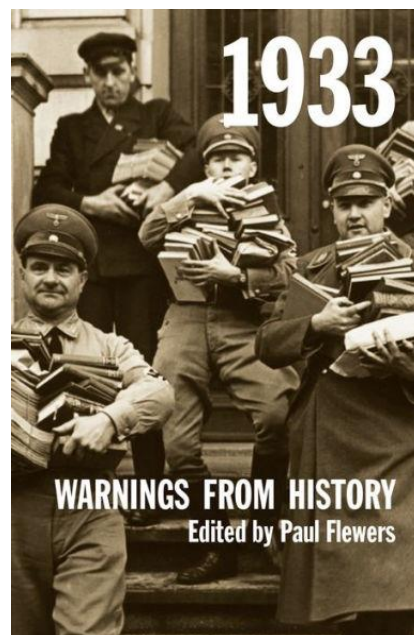
██████████ has continued with her painting, and has produced quite a few new ones, including a fox with a balloon and a dog with a kite. Also displayed below are a couple of mugs that she painted for her pals. You can contact her at ██████████.



Paul Flowers has just had a book he has edited published by Merlin Press. *1933: Warnings From History* is a collection of eye-witness accounts of the final years of the Weimar Republic in Germany and the coming to power of Hitler in 1933. It will be of interest to anyone interested in modern European history.

The main work in *1933* is the text of Peter and Irma Petroff's *The Secret of Hitler's Victory*, which was first published in 1934, just a few months after the authors escaped from Nazi Germany to Britain. The Petroffs not only vividly describe the events on the streets of Berlin, but they also cast a critical eye at the political parties in Germany and investigate the reasons why these powerful organisations, some of which had sizeable armed militias, did not prevent the Nazis from taking power.

If you'd like a copy of this book, e-mail Paul at trusscott.foundation@blueyonder.co.uk.



Contingency Fund

Please remember that you can apply for help from the Group Contingency Fund not only to pay for taxis or other travel expenses to see your GP/Consultant, but also to pay for their medical report and your medical information in the NHS system in order to support your benefits application. We have received lots of feedback about the difficulties of applying for PIP and other benefits; therefore, we consider that it is essential that you obtain an updated report from your GP, which usually costs between £25 and £50. Remember that this fund can also be used for such things as attending Group meet-ups and benefit assessments, or in a family emergency.

If you wish to apply for a payment from the fund, please contact any member of the Committee. The maximum you can claim is £50 per year and you will need to submit the receipts with the application form. If your circumstances are such that you need the money in advance because you're running low on funds or are needing more than £50, or if you aren't able to provide a receipt with your application, please contact our Treasurer to discuss your situation before you apply.

The Disability Law Service

The Disability Law Service (DLS) provides free advice via information factsheets, training courses, and telephone and written advice. Within its current funding it is able to provide telephone advice in areas of welfare benefits, housing, community care and employment and discrimination law. The DLS does not provide tribunal representation in court (although this could be possible for housing benefit). The DLS is based at the Human Rights and Social Justice Centre at the Foundry, 17 Oval Way, London SE11 5RR (near the Oval). The benefit advisor at the DLS is Richard Conway. To contact him, call 020 7791 9800, and then use option 5; leave a message and he will call you back. On-line advice can be obtained via its website: <https://dls.org.uk/free-advice/online-advice/>.

Library Suggestions

If there are any ME-related video, audio, pamphlet or book resources that you think the Group Library should hold, please e-mail your suggestions to [REDACTED] at [REDACTED].

Benefit Queries

If you have questions in respect of your benefits that need answering, please send them by e-mail to [REDACTED] at [REDACTED] or Heather at [REDACTED], and they will be forwarded to Ken Butler, the expert on benefits at Disability Rights UK, who will attempt to answer them.

Listening Line

The Group's Listening Line is a support service to help members with the emotional burden that comes with living with ME. [REDACTED], who is in charge of it, is a friendly person with previous experiences of helping people through counselling. She will be there to listen to you when you're feeling down or isolated and needing to talk to someone. Please bear in mind that this is not a helpline dealing with benefit applications, emergencies or anything critical.

Like the rest of us, [REDACTED] is dealing with the challenges of having ME and therefore she might not be immediately available when you call her, but she will call you back as soon as she can. You only need to dial or send a text to our answerphone number [REDACTED], leave your name and a phone number, and [REDACTED] will call you when she is available. Please be aware that she will not be able to answer your call after 6.00pm as she needs to rest.

Helplines

The Action for ME's Welfare Advice and Support Service provides free confidential advice over the phone on welfare benefits, disability discrimination and employment issues to people affected by ME. It is open on Monday to Friday from 10.00am to 4.00pm. Call 0117 927 9551 or e-mail welfare @actionforme.org.uk.

The ME Association runs ME Connect. It provides support for people with ME and those who live with or care for them. It is open every day of the year between these times: 10.00am to 12.00 noon, 2.00pm to 4.00pm, 7.00pm to 9.00pm. The telephone number is 0844 576 5326. There is an e-mail contact at meconnect@meassociation.org.uk.

Richmond and Kingston ME Group Committee		
Chair	Vacant	
Secretary	Vacant	
Treasurer		
Membership Secretary		
Project Coordinator		
Members' Support	Vacant	
Committee Member and Group Library		
Committee Member		
Social Secretary		
Newsletter / Website		

The following members are not on the Committee but carry out important work for the Group.

Facebook		
Listening Line		
Interview Tape Recorder		
Twitter		

Group Website — <http://www.richmondandkingstonmegroup.org.uk>

Facebook — <http://www.facebook.com/pages/Richmond-and-Kingston-ME-Group>

Twitter — @randkmegroup (see our tweets on home page of the Group website)

Disclaimer: While as a Group we prefer and endorse the term ME (Myalgic Encephalomyelitis), there may be times when articles printed from other sources contain the term Chronic Fatigue Syndrome. Any information in this newsletter must be checked by you, as we cannot accept responsibility for it. The use of alternative medicines or therapies is a matter for the individual. The views expressed are personal and not necessarily those of the Richmond and Kingston ME Group. Reference to any products or services is for information only, not an endorsement.



The Richmond and Kingston ME Group is grateful for the generous financial assistance that has been provided by Waitrose.