Richmond, Kingston & West London

ME Group

NEWSLETTER

No 2, 2025

Inside — Annual General Meeting Account — [redacted]'s Recovery Plan — ME and Me — And More

DecodeME Report: A Big Step Forward

The results of DecodeME's investigation into ME were recently released, and they provide some very interesting information.

DecodeME is a collaboration between the University of Edinburgh, Action for ME, the Forward ME alliance of charities, and people with ME. Its investigation compared the DNA of 15,579 people with ME — a much bigger sample than most ME investigations — with the DNA of 259,909 people without the illness, all of European descent (research is continuing in respect of people of other 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.

The investigation discovered that a person's genes contribute to the

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chances of his or her developing ME, and that people with ME have significant genetic differences in their DNA compared to the general population. These DNA differences exist in eight regions of their genome, and these variants therefore inform us about possible biological causes of ME. DNA does not change with the onset of ME, and therefore these findings reflect causes rather than the effects of the illness.

Overall, the results show that ME is partly caused by genes related to the immune and nervous systems. This indicates that there are immunological and neurological causes to the illness. At least two of the variants relate to the body's response to infection. Other variants point to the nervous system, one of which researchers previously found in people experiencing chronic pain, reinforcing neurological contributions to ME. These variants align with how people with ME describe their illness. No variant is related to depression or anxiety, and nothing was found to explain why more females than males get ME (the sex chromosomes have not yet been analysed, so this is likely where the answer for the sex difference lies).

Professor Chris Ponting of the University of Edinburgh, DecodeME's lead investigator, said:

> This is a wakeup call. These extraordinary results speak the language of people with ME/CFS, often recounting people's ME/CFS symptoms. DecodeME is now calling on researchers worldwide to join us in accelerating ME/CFS research. With our participants we have built an extraordinarily rich DecodeME data set, to which we continue to offer data access. We especially welcome researchers whose work is relevant to the eight signals we have identified, and who could bring their expertise to bear in highly targeted studies that would produce further ME/CFS insights and ultimately treatments.

Sonya Chowdhury, the CEO of Action for ME and a DecodeME co-investigator, added:

> These results are ground-breaking. With DecodeME, we have gone from knowing next to nothing about the causes of ME/CFS, to giving researchers clear targets. This brings ME/CFS in line with other long-term diseases which have genetic components. We are shining a laser light on eight precise areas of DNA, so that highly focused research can now be carried out. We hope this attracts researchers, drug developers, and proportionate funding to ME/CFS — and speeds up the discovery of treatments.

Anna Gregorowski, Chair of the British Association of Clinicians in ME/CFS, wrote:

> These findings represent a major step forward in validating the biological basis of ME/CFS. They offer hope for the development of a future diagnostic test and bring long overdue recognition to those living with the condition. The DecodeME research aligns with the Department of Health and Social Care's Delivery Plan, which emphasises the importance of research, improving understanding of individuals experience of ME/CFS, and enhancing education for health professionals. BACME strongly supports continued research into the biological mechanisms of ME/CFS and looks forward to seeing these insights translated into clinical practice — ultimately improving diagnosis, treatment and care for everyone affected by ME/CFS.

DecodeME is continuing with the project. It intends to continue analysing the dataset it drew up and publish updated findings, to encourage other bona fide researchers to use the world's largest ME dataset, and to seek funding for Sequence ME and Long Covid, which will use DecodeME data to analyse the entire genome.

The DecodeME investigation has revealed much information that reinforces the contention that ME is indeed a physiological illness and not, as some people still contend, some sort of imagined complaint. It is indeed a big step forward.

ME and Me

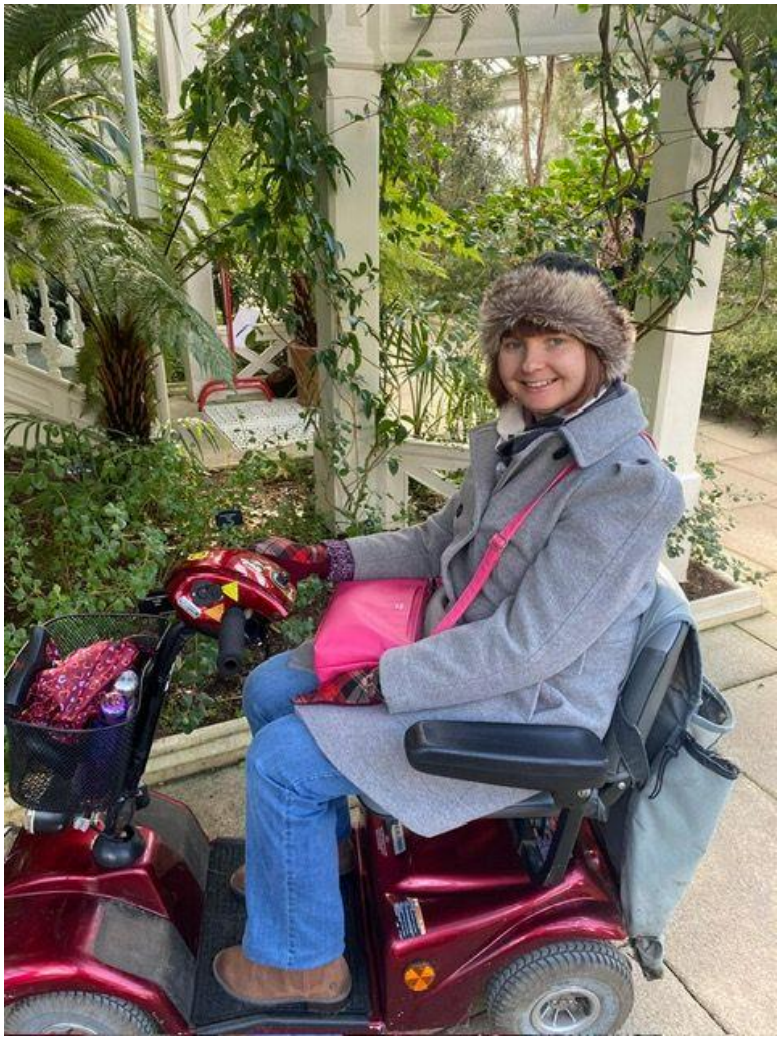
ME affects us in all sorts of ways; some we share in common, others are quite individual. Our new column 'ME and Me' is intended for group members to show how the illness affects them. [redacted], who has recently rejoined the Group Committee, gives her experience in a piece written for ME Awareness Day on 12 May. If you wish to contribute to this column, please contact the Editor, Dr [redacted], at trusscott.foundation@blueyonder.co.uk.

* * *

The twelfth of May is always a poignant reminder of my struggles with ME/CFS. It all started six and a half years ago. I was healthy and vibrant at 26 years old. I was super fit, doing spin classes each week and two 45-minute runs per week, sometimes even uphill too! I didn't even need to think about my health then and its real value in life. Without your health, everything else seems trivial, such as holidays and relationships. You are rudely awakened from your naivety, that all will be well and will remain so.

I vividly remember the day when I collapsed six and a half years ago at work, and being transported to hospital for an overnight stay, to investigate likely causes of my collapse. My inflammatory markers were raised, suggesting

an infection, but no definitive virus/bacteria was revealed. I was never able to work again. I tried to go back to work, but I just kept collapsing with crippling exhaustion, but not the kind of exhaustion I was used to feeling after my 12-hour nursing shifts. No, this level of fatigue was critically disabling and prevented me from remaining upright and conscious. The only way I can describe it is: imagine the worst flu day you've experienced multiplied a hundred-fold, combined with a severe hangover and no sleep for several consecutive days. Now, imagine feeling just like this but every single day, and then you begin to understand the suffering of the approximately two million ME/CFS patients within the UK who are out there, hoping and praying for more research into the biomedical causation of the disease.



ME/CFS is classed as a chronic neurological disease, but there is no current cure or effective treatment, only supportive drug therapy for pain and the patients pacing their activities accordingly. In some ways I am very lucky that I'm not one of the 25 per cent of sufferers who are bed-bound, tube-fed, with their internal systems beginning to shut down, due to their having no energy reserves left to perform basic cellular functions. Deaths do happen with ME and this is usually down to malnutrition/slow starvation, due to negligence from a healthcare system which is not set up to treat appropriately the complex array of symptoms we face.

I am moderately–severely affected by ME. I can no longer work and have to spend several hours a day resting/sleeping flat to regain energy needed to move my muscles again. I suffer terribly with flu-like symptoms, migraines, profound muscle weakness, breathlessness on minimal exertion and at times chronic unrelenting pain. I use a mobility scooter outside because I am only able to walk for five minutes on the flat, before I experience all of the above. The worst part is the loss of independence and not being able to choose when I do things, such as having a shower on my own. I often have to have

assistance with showering/meal prep, fetching fluids/meds, etc. I feel a sense of guilt that I am having to rely on family to address these basic needs, but I have no other choice. They are my carers and I'm lucky to have that.

I have no career, partner or children to focus on, but that doesn't mean that I don't crave all of the above. Things outside of your current grasp become magnified and all the more important to then materialise. I don't wish to think too far ahead of what will become of me because my gradual decline over the past six and a half years has made me somewhat biased. My only message of wisdom to others is please don't take your health for granted because it can so easily be cruelly snatched away from you, with little to no warning and no clear end in sight. That is ME for you, a never-ending tunnel with twists and turns. I just hope my turn comes soon and grants me some kind of recovery, however small. Believe it or not, I do have hope for the future, and I dream of a healthier me.

ME and Muscle Deconditioning

Recent research in the Netherlands has discovered that the muscles of people with ME/CFS and who have after-effects of the Corona Virus (Long Covid, LC) respond differently to those of healthy people.

Research carried out at the Amsterdam University Medical Centre and the Vrije Universiteit Amsterdam shows that fatigue and difficulty with exertion in people with ME/CFS and LC are not simply the result of poor fitness. Changes that have occurred in their muscles are different from those of healthy people who have been inactive for a lengthy period.

In the study, researchers compared muscle changes in people with ME/CFS and LC with those of healthy people who had been bedridden for 60 days. Whilst they all had less energy than active healthy people, and were less able to exert themselves, the cause for this turned out to be different.

Rob Wüst, an exercise scientist and the lead researcher, said: 'Patients often hear that they are simply out of shape. Our results show that this is not true. The changes in the muscles of these patients are different from what we see in healthy people who have been inactive for a long time.'

Remarkable differences emerged when the muscles of the groups studied were studied.

- ★ There was no muscle breakdown in ME/CFS and LC patients, while healthy people did have clear muscle loss (muscle atrophy) after bed rest.
- ★ There was a change in muscle fibres: ME/CFS and LC patients had fewer 'slow' fibres that are needed for endurance, and more 'fast' fibres that tire quickly.
- ★ There were problems with energy production in the muscles of ME/CFS and LC patients as a result of poorly functioning mitochondria — the energy factories of our cells.

★ There were fewer capillaries in the muscles of ME/CFS and LC patients, which may explain why they feel worse after exercise (post-exertional malaise).

These factors need to be taken into account in the treatment and rehabilitation of these patients.

AGM Report 2025

Our twenty-fourth Annual General Meeting was held at 14.00 on 22 February 2025. The annual review was presented, followed by a presentation by Dr Eliana Lacerda from CureME. We voted on a revised Constitution, and the financial results for the past two years were presented. The meeting concluded with a social.

Highlights of the Group's Activities: Annual Review

Membership: Membership increased from 212 in October 2023 to 237 in December 2024, with 38 new members joining during the 15 months, including an increasing proportion joining from well outside Richmond and Kingston, who we meet on-line.

Social Activities: We continued to run seven or eight on-line social meetings per month: two daytime coffee and chat, one evening 'pub', one crafting, one silent reading, one or two mindfulness. We also introduced new on-line meetings on mindful self-compassion and understanding haiku. In addition we ran one or two face-to-face meetings monthly (often including a new morning meeting), experimented again with a face-to-face pub meeting and organised six boat trips over last summer.

We joined the Kew Gardens Community scheme for the first time, which allowed us to offer free entry to Kew for 60 members and their carers, and we were then lucky enough to win 20 entries to Christmas at Kew last December. We ran a members' ballot for these tickets that was oversubscribed three times. [redacted] organised all the Kew activity and was helped by [redacted], who led the 'Christmas at Kew' group.

This extensive programme was possible in part through the new structure of a core Committee and ten Committee Associates. As you know, [redacted] stood back from the Committee in April this year, and we welcomed [redacted] to the Committee in June. [redacted] is responsible for organising and communicating the schedule of our social activities, and is helping with the administration of the group. We also welcomed new hosts for both face-to-face and on-line meetings.

Our face-to-face meetings have been hosted by [redacted], [redacted], [redacted] and [redacted]. [redacted] and [redacted], husband of our member [redacted], organised and hosted all our summer boat trips, in [redacted]'s wonderful

boat. [redacted], [redacted], [redacted] and [redacted] hosted our usual on-line meetings, while [redacted] ran a much appreciated haiku group, and [redacted] started a very popular series of meetings on mindful self-compassion. We welcome new ideas for meetings. In 2024 we had our first face-to-face Christmas party, organised by [redacted], ably assisted by [redacted] as our very own Santa!

Communications: [redacted] has continued to run our greetings cards operation, which we know is particularly appreciated by more severely ill members. [redacted] continues to produce our newsletters, which are also a very popular part of what we do. [redacted] has also taken on the job of posting these to members who need a paper copy.

We continue to run the closed e-mail group and two WhatsApp groups, one for everyone and one for Younger Members. Thanks to [redacted], [redacted], [redacted] and [redacted] for acting as admins on these groups.

[redacted] continues to do a marvellous job with our Facebook page, which has a wealth of information and is a significant source of new members. We maintain a presence on X through [redacted], and [redacted] has set up and manages our Instagram page. [redacted] keeps our website updated and relevant.

We publish an e-bulletin four times a year, including information about health issues and a directory of sympathetic GPs, sources of carers and consultants. The directory's information is entirely collated from members — so a big thank you to everyone who has given us feedback and helped keep this up to date.

We also send out literature — such as the new hospital booklet — to members on demand.

Fundraising and Cost Reduction: Fundraising has become more of a challenge, as all charities are finding. Our traditional sources of funds are no longer accessible. [redacted] made an application to the National Lottery and they have awarded us £1499, the full amount we requested, which will cover our communication costs for the next two years or more.

[redacted] also signed us up to Easy Fundraising in March 2024. In the first eight months we raised over £250. Although some of the shop donation amounts look tiny, it is staggering how much we can get for the group by adding one click to any on-line shop. And this is a stream of funding that, like Amazon, keeps our funding destiny in our own hands.

[redacted] has been awarded a new role of Chief Complainer, having managed to get £150 compensation from Nat West for the errors they made as we tried to change over the Treasurer role and bank signatories. To put this in context, this is almost a tenth of our usual annual income!

Moving us from LocalGiving to CAF Donate for on-line donations has saved £90 per year. [redacted] has started to fold the newsletter so paper copies can be posted as a letter, saving us £50 per newsletter edition. By bringing our 2024 survey in-house (and doing it all herself), [redacted] has saved us £2000.

Processes: Although these are a less glamorous part of what we do,

many of you may already have noticed and benefitted from the improvements to our processes made by [redacted], including the introduction of on-line (Jotform) member joining, renewal and GiftAid processes, and the introduction of on-line (Microsoft forms) event sign-up processes.

External Communication: We have been part of MELN (the group of local groups) thanks to one member who attends meetings and provides the Committee with a précis of the minutes. MELN are currently aiming to provide a resource for improving medical student education about ME, which is currently very limited. We have been able to make a substantive input into how this can work, thanks to [redacted] who has done this for over ten years and who wrote up her experience.

[redacted] produced an A4 poster for the group which we have sited at a GP surgery and two hospital locations. We now have some laminated copies which we hope are less likely to be removed once sited. We are also in the process of redesigning one of our leaflets following feedback from a group member, and to mirror the poster we hope to share.

[redacted] continues to update and develop our website; in 2024 she added a page on local outings and activities, https://www.richmondandkingstonme-group.org.uk/local-outings-activities, a page on Kew Gardens and a 30-minute video of Xmas at Kew made by one of our members, which we hope will be the first of many 'virtual visits', https://www.richmondandkingstonme-group.org.uk/past-events.

We continue to publish information about the Group to local and national organisations which publicise local support groups

Help with Benefits and Hardship: [redacted], and previously [redacted], have helped members with benefits signposting, and we have made eight hardship payments over the last two years. Our hardship fund is primarily designed to help people afford the doctor's letter they need to further their benefit application and to contribute towards the replacement of technology if necessary to continue to access group activities.

Overall, we are pleased to have weathered the loss of [redacted] to the Committee but delighted that he remains an active Committee Associate. We have welcomed a new Committee member and several Committee Associates.

However, over the last year we have devoted less time to campaigning (although we did, of course, meet on-line on 12 May) and less time liaising with external bodies (for example, Sutton CFS clinic) as all of the Committee are committed to (or maybe beyond) their maximum capacity.

Guest Speaker

Dr Eliana Lacerda of CureME generously gave us her time to tell us the latest findings from CureME's research.

CureME set up the disease-specific ME Biobank following widespread consultation with charities, researchers and people with ME with the aims of

facilitating collaborative, high quality, replicable research into ME. The care with which the Biobank was set up allows collaborative researchers access to large numbers of reliable samples while protecting the sample providers.

Striking features of CureME's approach have been the sensitivity with which they interact with the people with ME and their research interest in severe ME. CureME early identified that ME was associated with an altered immunological state, especially in severe ME (and some will recall the handgrip strength study).

In an earlier study, CureME found that hand grip strength (measured in a repeated test) declined with disease severity, and that on average people with ME had a weaker grip than people with multiple sclerosis and others with chronic fatigue, who in turn had a weaker grip than healthy controls. They found that symptom scores were worse in people with ME than those with MS.

In an extension of this work, the Biobank recently found confirmation of this hierarchy of effects in serum samples. The research describes how people with mild/moderate ME have cells which are more 'immunosenescent' (exhausted) and cytotoxic, which could imply that they are more frequently exposed to active virus infection. And again these results and the associated symptom score were distinct and more severe for people with ME than either those with MS or healthy controls.

Meanwhile the people with more severe ME have a more general pro-inflammatory response than people with mild or moderate ME. Together, these results suggest that the symptoms in the two groups may have different causes, opening up the possibility for different treatments and different expected outcomes to potential treatments.

Group Constitution

We wanted to update our Constitution for two main reasons: firstly, to update the document in the light of Long Covid, the new safeguarding law, and the high level of member attendance for an AGM to be quorate; and secondly, to move the AGM date to early in the new year so the financial report was more relevant.

Members were mailed three times with a draft revised version and a document highlighting the changes from the existing version (which was available on our website), firstly with the notification of the AGM and then two reminders were sent in the week leading up to the AGM. We asked members for feedback and, if they agreed with the changes, for approval by e-mail if they would be unable to get to the AGM. One member approved the document but suggested an amendment to the quorum required to change the constitution. This amendment was put to the membership at the AGM and the Constitution with this amendment was passed unanimously. Members who had voted by e-mail were informed of the amendment (which made a stricter quorum requirement for Constitution changes; no objections were received). Overall, 45 members (19

per cent) voted on the Constitution changes, all were in favour; 29 members attended the AGM, and 16 members voted by e-mail.

Treasurer's Report

Overall we have continued to balance the books despite doing more, and we are currently in a robust financial position.

Receipts: Subs and donations are very important. As we have grown membership and received some generous individual donations, this accounted for £1435 last year, a steady rise from £1110 in 2022. (The books balanced for the year on 20 December 2024.) Amazon and easyfundraising contributed £110 this last year (up from £69 two years ago). But easyfundraising actually raised £280 in the first eight months of the year, there is a lag on payment. So please, if you can, buy on-line through easyfundraising. Grants are progressively becoming harder for your Committee to access. However, [redacted] has managed to raise us £1499 from the National Lottery (received on 20 December 2024) which will solve our forecast funding gap for the next two years at least. [redacted] raised us £150 by successful complaining to our bank for their administrative errors.

Payments: Inflation: Most costs have gone up as you would expect. This year we spent £240 in contingency and hardship payments. We have made eight hardship payments over the period. This year we added boat trips, Kew entry (and Xmas at Kew for 20 lucky people) and a face-to-face Christmas party. However, we have found some cost savings in handling newsletter postage, [redacted]'s remarkable ability to buy cheaply, and, of course, by bringing the survey in-house, we saved £2000 that we would otherwise have needed to raise. In the last two years we have paused our donations to other organisations in order to help us balance the books.

Social

Following the AGM's formal business, we had a social meeting until 16.20. thereby demonstrating the stamina of those members who made it all the way through!

[redacted]'s Health Improvement Path

Below we publish the first part of [redacted]'s Health Improvement Path. This part deals with the effects of ME/CFS upon him; the second part, showing the improvements he has managed to achieve, will be in the next issue of the newsletter. It's a lengthy account, but we believe that members might find it useful.

Group members should bear in my mind that this is [redacted]'s personal experience and that the Group Committee doesn't subscribe to all the therapies, supplements, foods, theories, views and opinions that are mentioned in this article. We understand that everybody is different and that medications, supplements, foods and treatments work in different ways for individuals and each of us has his or her own ways of dealing with the illness.

* * *

I fell ill with ME/CFS in January 2011 and I was lucky that my GP had recently diagnosed another of his patients with the condition and knew what to do, referring me to a Mood Management Session programme to rule out depression and observing me for four months to determine if my symptoms would change, before referring me to the Chronic Fatigue Service at the Malvern Centre at Sutton Hospital (now called South-West London and Surrey CFS/ME Service). In the meantime, in my search for answers and a treatment, I saw two neurologists, one in England and a very experienced one in Venezuela, where my parents used to live. Both neurologists, although one spoke English and the other Spanish, said exactly the same: 'You can recover from this illness by eating healthily, resting a lot and exercising.'

I found this advice quite vague, not answering as to what I really had as an illness, and I was in denial that a cure didn't exist. My GP referred me to the SW London and Surrey CFS/ME Service in June 2011, after four months of unchanged symptoms (only three months of persistent symptoms are now required, as stated on page 15 of the NICE Guidelines 2021, for a diagnosis of ME/CFS) plus a letter from immunologist Dr Bansal confirming the diagnosis. I followed the good advice given there, in their Lifestyle Management Sessions, for patients to make lifestyle changes in order to live with the condition. I considered myself lucky because I had support from my GPs from the very beginning and had access to different services within the NHS. Although none of those services would cure me or make me feel significantly better, at least the Lifestyle Management Sessions advised me of good tools, such as pacing, to manage my life with the illness.

I spent from 2011 to 2014 exploring different treatments, therapies, painkillers, supplements and doctors in three countries without experiencing any significant improvement. I laugh when remembering that I had spoken to one of my friends, a biologist specialising in DNA, just to make sure that my DNA had not mutated and had become a mutant (I always felt like a zombie though; if you have ME or Long Covid, I'm sure you can relate to this). Having this illness made me feel not only disabled and frustrated, but also surprised and perplexed that a health condition could affect my whole body (mind, brain, cognitive abilities, memory, general mobility, digestive system, muscles, legs, feet, hands, fingers, arms, staying bedridden for weeks two or three days after any effort, being physically affected by other people's stress, etc) in such random

ways and without a scientific explanation. The scariest experience I have had with ME so far was paralysis, being unable to leave my bed when I wanted and needing help to go to the toilet or anywhere in the house. An excellent acupuncturist helped my body to retain a small amount of energy, and after a few sessions I could stand up by myself when I wanted and move around the house.

In 2015, I realised that my body had decayed, having no muscles, and my heart started to fail, as I would cough just by lifting my upper body from lying down in bed when trying to sit up on it. At that time, I received the help of a good osteopath, who could also give me massages, and joined the gym to use only the steam room for sweating, as my body wasn't doing this properly. In 2016 I started to do soft exercises at the gym, lifting light weights and always sitting down without running or standing up. Due to the complexity of my personal life, it took me a long while to find a baseline for a routine of exercises without causing strong post-exertional malaise (PEM), also known as post-exertional symptoms exacerbation (PESE), until eventually I found something helpful in 2018.

At the same time, a member of my family was diagnosed with Coeliac Disease, forcing me to change my diet, eating more gluten-free foods.

The pandemic arrived in 2020 and this disrupted my gym routine; however, I experienced a significant improvement with the first dose of the Covid vaccine Astra Zeneca (AZ). At that time, I had also started to eat more protein, especially more pork, which was always the meat that used to give me the biggest amount of energy and stamina. I tried the second dose of AZ and my improvement continued. A heavy relapse came with the third dose, this time Pfizer, which completely disagreed with my body. I collapsed in bed for three months and I caught Covid being in bed! I spent about five months with unusual side-effects from this vaccine, including among others tremors on my left arm, shaky vision, and reduction of my stamina.

In the summer of 2023, I went to the Gastein Valley in Austria and had the opportunity to try the radon baths. They soothed the pain in my body caused by Fibromyalgia (diagnosed in 2013) with a special sedative feeling. This helped me to increase the weight and the intensity of my gym routine. I also changed my diet significantly at this point and from here an onwards I started to have a constant improvement, with fluctuations but without relapsing.

Another of the most terrible experiences of having ME for me were the relapses. They could be so demoralising and hence it was so important to stay strong mentally. I found Cognitive Behavioural Therapy (CBT) very helpful for this purpose, as I could replace negative thoughts for positive ones or for good happy memories of my past and, when I couldn't find anything helpful, I would use comedy to laugh about them.

Looking back, I somehow understood the initial advice given to me by the two neurologists. Eating healthily, resting a lot and exercising have given me

an improvement throughout the years. I also include pacing, radon baths, steam rooms and saunas, CBT, glutamine and glutathione injections. However, when I saw a study discussing having a leaky gut and how exercise could make my intestines release more gut bacteria into my bloodstream, causing PEM/PESE, I imagined then, more or less, how this illness works. See the link below for this research: www.healthrising.org/blog/2023/07/19/convergence-gut-immune-metabolic-post-exertional-malaise-chronic-fatigue-syndrome/.

Apparently, this study was not conclusive, but in my head I made it conclusive and started to work towards ways of healing my guts by improving my diet. Weirdly enough, when I made this research conclusive in my mind, things started to make sense to me. This research analysed physical exercises and I assumed then, that, also mental and emotional efforts would release gut bacteria into my bloodstream. I visualised here the importance of pacing, like having a fictional 'bacteriometer' measuring the levels of gut bacteria in my bloodstream. A small level wouldn't cause strong PEM/PESE and I would need frequent rests to keep this level small, allowing my immune system to deal with the aggressors swiftly and without depleting my defences. Having no rests or having only small rests after continued hours of effort would release high levels of gut bacteria, depleting my defences and causing strong PEM/PESE. If this effort was too big then strong PEM/PESE would start the following day. If I had stress, strong PEM/PESE would start a few hours later; if the effort wasn't too big, then strong PEM/PESE would start two or three days later. I believe the reason for this delay is due to an accumulation of gut bacteria during more than 24 hours fighting my immune system, until it finally gets depleted. I also believe that I could be bedridden for a long time without making any effort if my guts are for any reason having a constant outflow of bacteria.

In the next instalment of my article, I'll be returning to the recommendations given by the two neurologists, and describing what I have found.

ME and Long Covid Symptom Similarities

When the Corona Virus epidemic took off in early 2020, not a few people with ME felt that a fair proportion of those catching the virus would end up having ME symptoms, that many of them would make a full or partial recovery after a few months, but that some would not recover more than a little or indeed not at all. This was not an unreasonable assumption, as many people with ME contracted the illness after having a virus, especially influenza.

These fears were borne out as many people who had the virus indeed did contract ME-type symptoms in the aftermath of the infection, which became known as Long Covid. A recent study based upon patient-reported treatment

outcomes in the USA, involving 3925 people, showed beyond doubt the similarities between the symptoms affecting people with ME and those with Long Covid.

Below is a chart showing the percentages of each symptom affecting the people in the survey. Not surprisingly, the most common symptom with ME is fatigue or low energy, which registers at over 95 per cent — that is, 19 out of every 20 people with the illness — post-exertional malaise at nearly 90 per cent, and brain fog at 80 per cent. These are also the most prevalent symptoms of people with Long Covid, albeit a little lower at 88, 79 and 72 per cent respectively. Some symptoms, such as unrefreshing sleep, sore or painful muscles, and sore throat, fever or flu-like symptoms, are more prevalent amongst people with ME, whilst others, such as chest pain and shortness of breath, are more prevalent amongst Long Covideers.

Most Troubling Symptoms	**ME/CFS (%)**	**Long Covid (%)**
Fatigue or low energy	95.62	88.28
Feeling worse after normal exertion (PEM)	89.74	79.39
Brain Fog	80.05	72.33
Unrefreshing sleep	74.45	55.28
Feeling of weakness	57.27	43.61
Memory problems	54.07	50.83
Sore or painful muscles	53.69	34.11
Insomnia	47.29	40.17
Headache or Migraine	45.32	40.06
Other digestive problems	44.00	29.06
Light-headedness or dizziness	42.64	38.50
Postural Orthostatic Tachycardia (POTS)	41.04	40.00
Fast, fluttering or pounding heartbeat	38.49	47.11
Stiff or painful neck	38.45	24.17
Sore throat, fever or flu-like symptoms	32.94	19.72
Joint pain or swelling	31.62	24.44
Shortness of Breath	31.48	40.44
Cold or discoloured hands / feet	28.89	23.11
Tinnitus	27.67	31.11
Muscle twitches, spasms, or fasciculations	27.25	20.39
Balance problems or sense of room spinning	26.16	22.56
Nausea and/or Vomiting	25.55	19.89
Numbness or tingling	25.36	26.39

Shooting, stabbing or burning pain	24.56	19.06
External or internal tremors	20.71	20.17
Chest Pain	17.27	31.39
Disordered taste / smell	9.04	15.61

The similarities between the symptoms of these two conditions and the obvious fact that Long Covid is the result of a virus should help reinforce the contention that ME is a physiological illness and not a matter of its being 'all in our heads'.

More details of the trial and its findings can be found on the website of the *Proceedings of the National Academy of Sciences* at www.pnas.org/doi/10.1073/pnas.2426874122.

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.

[redacted] has painted this delightful picture of a Blue Jay.

[redacted] had his review of Masha Karp's *George Orwell and Russia* published in *George Orwell Studies*, Volume 9, no 2. He is also having a seven-part investigation of Orwell's political ideas published in the *Weekly Worker* paper, the first four parts appearing in the issues for 29 August and 4, 11 and 18 September. He also submitted the files of *Confronting the Myth*, a collection of historical articles and reviews he has written over the last 30 years, to Brill publishers for their Historical Materialism series.

Kew Gardens

Don't forget that the RK&WL ME Group has subscribed to the Kew Gardens Community Scheme, and group members are eligible to enjoy free of charge the wonders of Kew Gardens. For more details and to make a booking, please send an e-mail to randkmegroup@yahoo.co.uk.

RK&WL ME Group Committee		
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The following Committee Associates are not on the Committee but carry out important work for the Group.

Facebook	[redacted]	smilingblue247@hotmail.com
Twitter	[redacted]	fercampo25@hotmail.com
Technical Support	[redacted]	randkmegroup@yahoo.co.uk

We also have Committee Associates running meetings for us: thanks to [redacted] (on-line, pub and face to face), [redacted] (on-line crafting and soirée), [redacted] and [redacted] (face to face), [redacted] (on-line haiku) and [redacted] (on-line mindful self compassion).

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

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

Twitter — @randkmegroup

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, Kingston & West London ME Group. Reference to any products or services is for information only, not an endorsement.

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