

# Richmond & Kingston

## ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

# NEWSLETTER

**No 3, 2023**

**Inside** — [REDACTED]'s Ten Questions — Radon Therapy — What Our Members Are Doing — ME and a Healthy Diet — And More...

## **New Diagnostic Test for ME/CFS**

An innovative blood test has been designed to identify ME/Chronic Fatigue Syndrome. Potentially applicable to Long Covid and Lyme disease, it boasts a 91 per cent accuracy. Below we present an edited version of a report by Dr Victoria Corless on this new test.

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People with ME/CFS are well aware of the deep impact that the illness has upon their lives, with its symptoms of persistent and unexplained fatigue, along with a mass of symptoms that can often vary amongst patients and fluctuate over time. One of the greatest challenges is the fact that no definitive diagnostic tests or treatment options exist for this debilitating disorder.

David Polgreen, who has had ME/CFS for the past 35 years, told Dr Corless: 'Having something that nobody can put a finger on, something nebulous, something people don't understand, is distressing. I'd just rather know than live with uncertainty.'

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However, there is hope that this could one day change with the news of a new diagnostic test that can, for the first time, accurately identify hallmarks of ME/CFS in blood cells. The test has an accuracy rate of 91 per cent, and could be a much-needed beacon of hope for many.

This test is the subject of a study, 'Developing a Blood Cell-Based Diagnostic Test for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Using Peripheral Blood Mononuclear Cells', written by a team of researchers at the University of Oxford led by Dr Karl Morten and Professor Wei Huang, and published in *Advanced Science* (available at <https://onlinelibrary.wiley.com/doi/10.1002/advs.202302146>). Dr Morten and Professor Wei's team is one of the few that is looking to provide a solution to the longstanding problem of a diagnostic test for ME/CFS.

### **The Need For a Diagnostic Test**

In the absence of a precise diagnostic test, many people with ME/CFS are forced to rely on subjective assessments and a process of elimination in order to obtain a diagnosis. In some cases, they don't obtain a clear diagnosis at all.

As a result, patients find themselves navigating their illness without any clear understanding of what is happening to them. James Charleson, another of Dr Corless' correspondents, says that it is a common occurrence for people whose ME/CFS remains undiagnosed to continue to fight the fatigue, and so their condition worsens over time. This is why, he adds, that pacing and managing energy levels are critical to prevent the worsening of ME/CFS.

Historically, those suffering from ME/CFS have encountered significant challenges in gaining recognition and validation within the medical community. A common experience among patients with ME/CFS is an uphill battle and a long road to diagnosis. This can make the prospect of maintaining gainful employment an insurmountable challenge, and there is an added difficulty in not having a clear diagnosis surfaces when applying for welfare benefits.

### **A Test Based on Single Cell Raman Spectroscopy**

Dr Morten and Professor Wei's study focuses on a Raman-based test that characterises features of blood cells known as peripheral blood mononuclear cells, or PBMCs, that are unique to those suffering from ME/CFS.

Raman spectroscopy is a classic technique used by chemists to determine the structure of a molecule that is based on the way light interacts with its atoms and chemical bonds. When applied in biology, it has been used to determine the characteristics of single cells. When a laser beam is directed at a cell, some of the scattered photons undergo shifts in energy due to interactions with the cell's molecular constituents. These energy shifts, or Raman shifts, are characteristic of specific chemical bonds and molecular structures, allowing researchers to obtain a molecular fingerprint of the cell.

Previous studies have identified PBMCs in ME/CFS patients as exhibiting reduced energetic function compared to healthy controls. With this evidence, the team hypothesised that single-cell analysis of PBMCs might reveal differences in the structure and morphology in ME/CFS patients compared to healthy controls and other

disease groups. Dr Morten stated that ‘single cell Raman spectral profiles are complicated, with around 1500 individual signatures’, adding that ‘these signatures are complex and by eye there are not necessarily clear features that separate ME/CFS patients from other groups’.

However, this becomes simpler with the help of artificial intelligence. Dr Jiabao Xu, the study’s lead author said:

We used an approach called ‘ensemble learning’, in which individual machine learning models were combined to yield a more powerful one. Each individual model was not able to generate high accuracy, but ensemble learning takes the advantages and strengths from individual models.

Dr Morten added:

The AI looks at this data and attempts to find features which can separate the groups. Different AI methods find different features in the data. Individually, each method is not that successful at assigning an unknown sample to the correct group. However, when we combine the different methods, we produce a model which can assign the subjects to the different groups very accurately.

### **The Test’s Results and Prospects**

The current study included 98 participants, made up of 61 ME/CFS patients of varying disease severity and 37 healthy and disease controls. The team’s model was able correctly to identify patients with ME/CFS with a 91 per cent accuracy.

There is also hope that it could be used to diagnose other diseases for which the underlying mechanisms are still unclear, as Dr Xu says: ‘The timing is perfect as, although unfortunate, the emergence of Long COVID lifts the research momentum and infrastructure around those unexplained post-infection chronic diseases, which all have very similar symptoms.’ It is possible the approach could result in early diagnosis in multiple sclerosis and perhaps other chronic conditions, such as Alzheimer’s and Parkinson’s. Dr Morten adds:

This could be a game changer as we are unsure what causes these conditions and diagnosis occurs perhaps 10 to 20 years after the condition has started to develop. An early diagnosis might allow us to identify what is going wrong with the potential to fix it before the more long-term degenerative changes are observed. The triggers of Alzheimer’s, Parkinson’s and MS are unlikely to still be present when the late-stage pathology occurs. With an early diagnostic test potentially identifying new therapeutic areas, we could treat before the condition progresses to the point of no return.

Professor Jonas Bergquist, the director of the ME/CFS Research Centre at Uppsala University, Sweden, emphasises that what Dr Morten and his colleagues have achieved represents a significant piece in the puzzle of ME/CFS, adding that their work not only offers patients a path to closure and a way to manage their symptoms,

but also holds the potential to unveil crucial insights into the biological mechanisms underlying this condition.

Armed with this knowledge and a growing awareness of ME/CFS, researchers may one day be poised to develop effective treatments. However, for now, Dr Morten and his colleagues remain dedicated to refining their test. In doing so, they have already instilled hope within an under-served community of individuals. As James Charleston concluded: 'This demonstrating of clear differences in the cell biology of people with ME/CFS and healthy controls will hopefully help to dispel the notion that "it's all in our head".'

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## ME and a Healthy Diet

██████████ has been investigating the food that is most suitable for his ME/CFS.

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This is one of the most complex and controversial topics in respect of ME and for most illnesses in general. We don't have a scientifically proven clear diet to follow in order to recover, and some people with ME have seen qualified nutritionists without finding a helpful menu to improve their health. Moreover, we're all different and foods that are good for some people might not work for others.

As we published it in our e-mail *Bulletin*, 3/2023, some researchers are suggesting that our propensity for post-exertion malaise (PEM), or post-exertion symptoms exacerbation (PESE), is due to our developing a leaky gut that allows unhealthy bacteria to enter our bodies, especially after exercising, making us feel ill.<sup>1</sup> The Greek physician Hippocrates, traditionally referred to as the father of medicine, used to say nearly 2500 years ago that 'all disease began in the gut', and this still seems to be the case.

Yet, what is a healthy gut? And how do we achieve this?

██████████ had been exploring this topic for a while and he had been using artificial intelligence (AI) in the search engine of Microsoft Bing and also Google to find some answers. It was important for him to be aware that the information given by AI in this search engine was not necessarily a scientific proven fact or from an approved source. Also, it might not have content provided by reputable doctors and physicians. Sometimes it wasn't consistent as the search engine was being loaded with more information on a daily basis from different sources, meaning that what he could see there today could be different tomorrow. Having clarified this, his findings and experiences are described in the following paragraphs.

### A Healthy Gut

A healthy gut is one that can process all meals that we ingest and is able to absorb all the nutrients from them, breaking them down into individual components and distributing them through our bodies. In this process, a healthy gut develops an amount of wastage with toxins and unhealthy bacteria that needs to be disposed from our

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<sup>1</sup> See Cort Johnson, 'How Gut, Immune and Metabolic Issues May be Producing PEM in ME/CFS', 19 July 2023, at [www.healthrising.org](http://www.healthrising.org).

bodies as often as possible. Therefore constipation is a sign that one is not achieving the goal of having good health.

According to AI in ██████'s search, some sites on the internet would say that a healthy gut should produce wastage from three times per week to as many as you require on one single day. An efficient gut should do it after each meal, meaning three times per day or more if you ingest more than three meals. As everyone has a different body complexity, there is a correct healthy number of times for each person to expel this wastage per day or per week, ██████ set up the target of at least once per day.

The gut contain microbiota, also known as gut flora or intestinal flora, which is a complex ecosystem of micro-organisms that live in the digestive tracts and which have an impact on people's health, including effects on colonisation (invasion of bad bacteria), resistance to pathogens, maintaining the intestinal epithelium (cell layers that form the luminal surface — the lining — of both small and large intestines), metabolising dietary and pharmaceutical compounds, controlling immune function and sometimes behaviour through the gut–brain axis. Our microbiota is dominated by four bacterial phyla: Bacteroidetes, Firmicutes, Actinobacteria and Proteobacteria, Bacteroidetes and Firmicutes being the most common.

In a leaky gut, the intestinal lining becomes more permeable than usual. As stated above, this allows bacteria, toxins and partially digested food to enter the bloodstream. This condition is still strongly debated in the medical field and it's believed — there is no solid medical evidence of this yet — that it can cause inflammation in different parts of the body, thereby triggering an immune response.

With this basic information on hand, ██████ thought that he needed to find the foods that could assist him with keeping his intestines healthy. One of them was celery. According to AI in Microsoft Bing, celery is:

... a low-calorie vegetable that is rich in water, fibre, vitamins, minerals and antioxidants such as vitamin C, beta carotene and flavonoids that protect cells, blood vessels and organs from oxidative damage. Celery has anti-inflammatory properties that can help reduce inflammation in the digestive tract, cells, blood vessels and organs. It also supports digestion by improving the lining of the stomach and modulating stomach secretions. Celery is rich in vitamins A, K and C, plus minerals like potassium and folate. It has a low glycaemic index and can help manage blood sugar levels. Celery is also known to have an alkalisating effect on the body due to its minerals like magnesium, iron and sodium.

Eating celery raw with a spark of olive oil could assist with the recovery of ██████'s leaky gut. Celery is cheap to buy at the grocery shops or supermarket. Carrots, for example, are high in fibre, vitamins and nutrients. He ate them raw, after peeling their skin (this could have removed some of their nutrients), and their fibre assisted with bowel movements.

Good bacteria help to strength our immune system so it can fight colds and flu. A good start for ██████ to grow them up was by taking probiotics. He tried the UDO's Super 8 Immune Probiotic, which has a high rate for survival and colonisation in the gut with 31 billion live cultures or bacteria cells (healthy bacteria), protecting them from the colonisation of unhealthy bacteria. It could cost about £50 or so for 60

capsules, so it's a bit pricy. He suggests that if you take this supplement for a month without seeing any changes in your constipation, then you might have to try another probiotic, probably containing 40 billion live cultures or bacteria cells. If you experience diarrhoea with 40 billion then go back to UDO's Super 8, or to a similar hopefully cheaper probiotic with 31 billion cells, and take it for a longer time. (Probiotics might not be safe for everyone, so if you try them and feel unwell stop their consumption and visit your doctor if the bad symptoms persist.) He ate raw celery and raw carrots on a daily basis in order to have a good ground for these healthy bacteria to stay in his gut and promote bowel movements to get rid of the bad ones. Be aware that some people with IBS and gut problems could feel very unwell with celery. Other options to try could be chicory root, dandelion greens, Jerusalem artichoke, garlic, onions, leeks, asparagus, among others.

### Healthy Foodstuffs

Once ██████ achieved his goal, he started gradually to replace these expensive probiotics with foods containing good bacteria. These foods could be fermented cabbage, such as kimchi or sauerkraut, and kefir yogurt, pickles and miso for instance. ██████ tried a very good sauerkraut, a Polish speciality called Kapusta Kwaszona. You could find it in big Sainsbury's with a 'foods from the world' section and costs £1.30 for a big jar. He consumes a jar per week. This works out at £10.40 for eight weeks, which is much better than £50 for the UDO probiotic supplement.

██████ had been maintaining a balanced diet since he stopped the probiotics, with meals high in fibre and protein, some dairy and with five portions of different fruits and vegetables. He thinks that fruits and vegs are much healthier and effective when eaten raw than in juices and beverages or cooked. You could have some vegetables steamed for a certain period but if they get over cooked they lose their nutrients. He also ate watercress, which is very powerful and high in vitamin K, essential for blood clotting and healthy bones, as well as being high in antioxidants, which lower the risks of chronic diseases.

He uses olive oil as a helpful ingredient to have with his vegetables and meals because it helps the gut to absorb all the nutrients from foods. No wonder why it's always present in the Mediterranean diet, a diet that also includes herbs and spices, nuts and seeds, legumes, among others.

Now, the big question for him was what else to eat. He adopted the approach of trying different meals and seeing how he felt afterwards. Some foods gave him energy and then a crash, being the case of sugars or foods containing high levels of it. Other foods, like fish, gave him long-lasting energy.

As said before, which foods are suitable depends on each person's body and metabolism. To exemplify this, our member ██████ — who had changed the diet of her daughter ██████ following recipes from Anthony Williams 'Medical Medium' books, plus supplements and therapies with very positive results, curing her ME — told ██████ that eating pork wasn't good for his ME because it could cause inflammation in his body. However, he had observed that pork was the only meat that gave him long-lasting energy and he feels perfectly fine after eating it. ██████ also told him to avoid eggs as, apparently, they could feed the Epstein Barr virus (EBV) causing ME. There is no solid evidence of this and ██████ found mixed reviews using the AI

search, with some studies suggesting that eggs can negatively affect us if we have EBV; however, he had also noticed that he doesn't feel always well after eating eggs. Sometimes he feels nauseous with the sensation that he's going to be sick.

██████████ has the theory that there is a connection between testosterone and ME and he believes this could be a reason for ME to affect more women than men. He tried testosterone in gel rubbed on his skin twice a week, between February and April this year, and his blood pressure went high and he nearly got a heart attack, so don't try this at home!! However, he also experienced a significant increase in his vitality and stamina. Foods that can help him achieve a healthy level of testosterone, naturally and without affecting his heart or blood pressure, are onions, garlic, salmon, tuna, mackerel, beef liver, leafy green vegetables, cocoa (be aware that it's cocoa and not chocolate, unless it's a chocolate with 90 or 100 per cent cocoa beans), pomegranate, among others. If you would like to explore them, next time you eat them pay attention to how you feel with your energy levels afterwards.

### **Avoiding Negative Effects**

In his search, having being warned by ██████████, family members and other Group members, ██████████ paid attention to certain foods that could have a possible negative impact upon his body and therefore required great care in respect of their consumption, as apparently, according to the information found with AI, albeit that isn't necessarily scientifically proven, they are the ones that cause inflammation in our organs, especially in the gut, reducing its ability to absorb foods' nutrients. This doesn't mean that he should never eat them. Instead, it means that:

- He should pay careful attention to how he feels after eating them.
- Maybe he shouldn't have them on a daily basis.
- Maybe he should avoid them completely if he's feeling much better with his recovery process, at least until he's totally well, and once he had recovered he could eat them again if that still pleases him.

They are sugar, high fructose corn syrup, fried foods (crisps, mozzarella fingers, fish fingers, fish and chips, etc), refined carbohydrates (bread, pasta, pastries, some cereals, biscuits, cakes, sweets, sugary soft drinks and all processed foods that have added sugar and/or flour), excessive alcohol, processed meats (bacon, sausages, ham and smoked meats), farmed fish, pork, red meat (although Dr Myhill recommends eating it, showing that foods in this list do not necessarily affect everyone), corn, full-fat milk and related products, all foods containing gluten and all foods containing monosodium glutamate (MSG), 'natural flavours' and anything artificial. Also, he should be careful with eggs, dairy and soy products as some of them might not support his recovery.

██████████ still includes some of the foods mentioned in the previous paragraph in his balanced diet, especially pork and red meat as they give him energy, and he tries gluten-free pasta and gluten-free cereals, sometimes rice and tofu. He doesn't feel that well with eggs, gluten-free bread, white bread, fish and chips, yogurts, sugar and foods with a high sugar content, sugary soft drinks, corn on the cob, some sausages, pastries like sausage rolls and pork pies, full fat milk and all kind of milks from some supermarkets, chicken sandwiches (MSG), some crisps and, outside of this list, he feels unwell with lentils (they give him brain fog) and pineapple (causes a lot

of noises and weird movements in his gut). It feels to him that he has to be careful with most components of a typical British diet and he's been left with a small option for foods to eat without bad effects, but there are more than he's aware of and therefore he thinks that it's important to keep doing his own research, by trying other unfamiliar meals and by paying attention to how he feels afterwards.

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Please note that the R+KME Group Committee doesn't subscribe to Anthony Williams' 'Medical Medium' books or other related theories, or endorse foods and supplements mentioned in this article. We understand that everybody is different, and that foods, supplements and treatments work in different ways for each person. Have a try and see what works for you.

## Ten Questions

This time answered by [REDACTED].

- 1) **How long have you had ME?** Possibly as long as 18 years, without knowing it. I've been unable to function as normal for the past four years and I was diagnosed three years ago.
- 2) **What was the trigger that started it off?** I don't know but have always felt that stress and being forced to work night shifts turned my health upside-down. I never slept properly and I was so wired with stress for over 20 years.
- 3) **What is the worst thing about having ME?** Losing touch with the majority of people I knew.
- 4) **Has anything good come of it?** Yes, I now have a better relationship with my husband, because we know why I'm so limited and we can navigate around it. In fact, the NHS 'Taking Strides' course which I attended via Zoom during the pandemic taught me how to recognise that if or when I get cranky and impatient, it means I have overspent my energy. This has been such a revelation to me; it has helped me so much to understand that at that point I have to stop everything and rest.
- 5) **What treatment (prescribed or alternative) has helped the most?** Massage, both conventional, reflexology and Perrin Technique, I think it is probably because it improves lymphatic flow. But the effects only last a couple of days. I am experimenting with more lymphatic massage at home, including rebounding and just shaking arms and legs. Something that seems to help increase my deep sleep is wearing a castor oil wrap around my abdomen at night, it is very noticeable when I check my heart rate and sleep stats in the morning (I wear a Garmin Vivosmart heart-rate monitor to help me pace myself).
- 6) **And which was the most useless or did the most harm (to you or your pocket)?** Bioresonance.
- 7) **What do you like doing on a good day?** Gardening.
- 8) **Do you have any tips for getting through a bad day?** Resting by lying down on the bed, with my feet up against the wall if I can manage it. Rest is the best.

- 9) **What is the worst thing anyone has said to you?** There isn't just one thing, it's the drip-drip of 'thoughtful' and 'helpful' suggestions from people who don't have ME and who have no clue. One persistent person even contacted a yoga-trauma therapist on my behalf, who then emailed me to book me in for treatment! I was furious — and getting angry makes me crash so I was very unhappy with them.
- 10) **And the best?** That I am much more relaxed now and we therefore have more fun together.

Extra questions:

- 11) **Where would you like to be now?** I'd like to be in my garden in June, soaking up the sun and listening to the birds and insects, sniffing my roses and just gadding about out there.
- 12) **Tell us a joke/mantra/quote:** 'I can't remember what I was going to say.'

## Freedom from Fibromyalgia Summit

The Freedom From Fibromyalgia Summit 2023 was a seven-day online conference held in May, offering views on Fibromyalgia from a wide range of expert practitioners on the causes of fibro symptoms and what you can do about it. I found it really interesting and felt that many of the sessions would also have a lot of relevance and application to ME and Long Covid.

Conventional medicine did not really figure — there isn't a lot on offer for fibro, but, for example, the speakers' opinion of SSRIs was quite negative (and their reasons for this were explained). For me the most notable absence here was LDN, for which there is some supporting clinical research (for example, [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10039621/#:~:text=Fibromyalgia%20\(FM\)%20is%20a%20chronic,label%20treatment%20option%20in%20FM](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10039621/#:~:text=Fibromyalgia%20(FM)%20is%20a%20chronic,label%20treatment%20option%20in%20FM)). Cort Johnson of Health Rising was one of the interviewees (interesting as ever) and he discussed the cross-over with conventional medicine. But the phrase permeating the summit about conventional treatment was: 'There's a time and a place for it.' It was clearly a second choice.

The presentations/interviews are listed at <https://drtalks.com/freedom-from-fibromyalgia-summit/>.

The summit lasted seven days with seven or eight speakers each day — 50 in total! They ranged from a 10-minute (usually) intro by Rodger Murphree to start the day followed by 30 to 40-minute interviews with the experts involved. In other words, there were nearly 30 hours of interviews over the week.

The topics ranged from quite scientifically backed presentations (for example, fibromyalgia and osteoporosis from the bone coach) to what I would describe as 'woo'. But I did find that some of these 'woo' presentations had a lot more genuine and interesting content than I expected. For example, I was suspicious of Tami Stackelhouse but found her session interesting; and while Jane Hogan started with thoughts on energy that I wasn't sure about, she then presented some new (to me) practical exercises for breathing.

The summit was free if you registered but you had to watch the videos on the

day they were released. I watched some and downloaded the transcripts of all the rest. The videos remain available at \$1.99 each, but the *transcripts are free* (at time of writing) and you can get them here: <https://drtalks.com/videos/>. Use the search function to find the video that interests you and then scroll down below the video until you reach the button 'show full transcript'.

Rodger Murphree has been a fibro practitioner for over 20 years, and he focused on the bio-chemistry — his words — and provided seven interesting talks to kick off each day, on fibro 101, sleep, thyroid, why SSRIs are not the answer, fatigue, IBS and fibro, and a summary piece. I thought these talks were excellent: concise, informative and solution-focused (as the summit was). He spoke constantly about overcoming fibro rather than learning to live with it and as a functional medicine proponent looked at the whole puzzle (for the individual). I learnt a lot from him. I found Neil Nathan's talk also a very useful introduction.

Jacob Teitelbaum was the star first main speaker, talking about his SHINE programme (we have a very old copy of this book in the Library which remains relevant).

A lot of the interviews drew on Naviaux's cell danger response theory, although I found Eric Gordon's talk on this one of the least helpful. Here is an alternative health rising article: <https://www.healthrising.org/blog/2018/10/29/me-cfs-naviaux-cell-danger-response-freezing-nervous-system-threat/>.

Although there were people with things to sell, a lot of the presenters were offering access to free resources. The dodgiest presentations for me were Avacen — selling a \$10,000 machine (!), Gina Bria (whose TEDx talk was red flagged because of doubts about some of her claims), and Keesha Ewers (who has 'cured herself of RA and breast cancer naturally'). Other than that, while some of the talks weren't for me, they could be helpful for others.

Key issues that were covered in the summit:

- 1 Sleep (for example, Dr Murphree had some new ideas for me here, Ms Schaffner less so, Carroll).
- 2 Microcurrents/PEMF therapy/Microcirculation (I have tried versions of this without any impact, but I know it works for some) (Vanbergen, Pawluk, Forsgren).
- 3 Breathing (for example, Jane Hogan).
- 4 Mind-Body (Alex Howard, Ashok Gupta — not my thing but helpful for others).
- 5 Exercise: Pilates (Danielson).
- 6 Thyroid and Adrenals (Stackelhouse, Lalji).
- 7 Osteoporosis and osteopenia (Ellis).
- 8 Inflammation and chronic infection (Jockers).
- 9 Central sensitisation/Pain and the Brain (for example, Downey, Stein, Whitten, Eliaz, Kan).
- 10 Energy (and rest) (for example, Frontiero, Whitten, Dalton-Smith, Wayne, Hirsch).
- 11 Mould, Lyme and Toxins (Kennedy, Brand, Danner, Ingels, Moore).
- 12 Autoimmune responses (to trauma/mast cell activation) (for example, McCann).
- 13 Fascia (connective tissue) and fibro (Hansen).
- 14 IBS (Wahls protocol/Dempster brain-gut connection/Osborne grain-free diet).

There was way too much info here for me to process; I hope this might give you a start if you wanted to follow up a topic of interest.

I believe this has been an annual event and if it comes up again, I will certainly

register (expecting to see a number of these presenters with another presentation — but probably covering similar material).

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## Radon Therapies Can Ease Your Pain

Some patients with Fibromyalgia have reported a significant improvement to their symptoms following the use of radon baths. Radon is a radioactive inert gas that is taken in predominantly via the respiratory passages and the skin. It stimulates the body's cellular metabolism, reduces free radicals and activates healing-promoting and anti-inflammatory messenger substances, which in turn encourages the body's self-healing capabilities. The mild overheating provided in a therapy programme can assist the effect of the radon and lead to long-lasting pain relief. Radiation and moist heat can also regulate the autonomic nervous system when it is being imbalanced by a range of chronic diseases, including autoimmune and pain ailments.

It's estimated that, on average, the radiation dose from a three-week healing therapy is below the annual radiation exposure from natural sources. The positive effects of overheating (hyperthermia) have been known for thousands of years and are scientifically proven on a wide-ranging basis. Several high-quality studies have been carried out by the Gastein Research Institute and the Paracelsus Private Medical University of Salzburg in Austria, which scientifically prove the effect of radon therapy.

There is an old goldmine in the Gastein Valley of Austria called Radhausberg that was converted into a health centre called Gasteiner Heilstollen, as the mine contains water vapour with radon. This mine was reactivated in the 1940s to extract any gold remaining from a previous era, when its exploitation was vast and constant. Some of the miners then started to experiment a relief of their rheumatic symptoms and reported this improvement to their supervisors. Puzzled by this mystery, scientists from the GRI and the University of Innsbruck were invited to the mine to carry out comprehensive tests, leading to the ground-breaking discovery in the 1950s of the benefits of short exposures to radon.

This research and testing have not only provided valuable findings for the understanding of the operation of radon, but has also helped health centres to meet the criteria of evidence-based medicine. The therapies' success rate speaks for themselves: Heilstollen's, for example, is around 80 per cent.

As said before, some patients with Fibromyalgia have reported a significant improvement of their symptoms, up to a degree at which no medication is needed. The pain will remain, as there is no cure for ME and Fibromyalgia, but it is more manageable and tolerable.

██████████ visited the Gastein Valley last summer, looking for thermal waters. He likes the various spas with real thermal spring waters as he finds them beneficial and helpful for his health. He said: 'They were used by the Roman Empire to heal their wounded soldiers for many years, why shouldn't they help us nowadays?' He saw the information about radon baths and thought: 'Bah, this might be one of those con

treatments recommended for Fibromyalgia that takes your money away, leaving a small improvement or no improvement at all!

Nonetheless, he saw that the Kurzentrum Health Centre in Bad Hofgastein was offering radon baths for 20 Euros and thought he could give it a try. He asked for information and was told that a bath would last a maximum of 20 minutes plus another 20 minutes lying in an electrically warmed bed, so that the body could absorb the water with the heat. He tried it and felt a bit of numbness afterwards, rather like being sedated, but quite nice like having a good day with his symptoms, although fatigue was still there a bit in the middle. He then received an offer of three baths plus an appointment with a consultant for 85 Euros. He wished he could use this consultant's report to apply for PIP in Britain, what a bargain!! But it isn't that comprehensive alas! Anyway, he had two baths per week for two weeks and his symptoms did improve. He could move around more and do more activities as a consequence. He increased his base line of activities significantly when he returned to Britain — he reckons by 50 per cent — and went a bit over the top rather than having a small gradual change. (He was like a poor guy when he wins big on the lottery!)

The effect lasted three weeks only and he thinks that if he had kept the same baseline as before, or increased it by only 10 per cent, the effect would have easily lasted for two months. Nevertheless, his base line of activities is still higher than before, which is an improvement.

He met two other patients with Fibromyalgia at the centre and they told him that they used to go there every summer and sometimes in the winter. They could take about eight baths in two or three weeks and the effect would last for six months or so, depending on the impact of stressful events and the activity loads they had to deal with.

Another interesting fact is that these treatments with radon are covered by the national health services and health insurance companies in Germany and Austria, meaning that they definitely have a soothing factor. ██████ did a quick check in Google for radon baths in Britain and Spain, sadly without finding somewhere to go. He saw a link in Spanish saying, 'Careful with radon, stay away from it, it gives you cancer in the lungs!', and in Britain you will see some stats indicating that from 2000 to 3000 people die of lung cancer per year due to long exposures to the gas.

If you're taking a holiday in Europe, have a quick look at radon baths in the area you will visit. You might be lucky to find somewhere nearby where you could have a try too. For more information about the therapeutic benefits of radon, visit the following link: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2477705/pdf/hormes-05-48.pdf>.

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## What Our Members Are Doing

Done anything exciting, inspiring, interesting? Although ME does its best to make our lives miserable, 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 some new ones, including this very timely Peace emblem. ██████ can be contacted at ██████, if you're interested in her artwork, and some of her work is for sale.

██████████ has produced this lovely flower arrangement on a tile. ██████████ has also won the Mary Clarke award at the Epsom Riding for the Disabled Association.



██████████ had an historical article 'Cold War Adumbration', on the political impact in Britain of the Finnish Winter War of 1939–40, published in the *Weekly Worker* paper on 7 September, and 'USSR Positives' in the 31 August issue, a letter on the theoretical legacy of *Critique* journal.

## ME Medical Research Meeting

On Friday, 8 September I represented our members at a meeting about ME/CFS/FM medical research at Sussex University entitled 'Looking Forwards: Formulating Next Steps'. Presentations on recent studies carried out into ME/CFS/FM at Brighton and Sussex Medical School were given by Dr Jessica Eccles, Professor Kevin Davies, Professor Harm Van Marwijk and Dr Monica Bolton, who is a recovered ME patient.

Representatives from a number of NHS Specialist ME/CFS services attended, including clinicians from the Sussex-wide service and the Kent and Medway service along with Anna Gregorowski from BACME and a good number of other professionals. Patient groups represented included EDS/connective tissue disorder and MCAS as well as ME.

The meeting was part of preparation for an application for funding for a Low Dose Naltrexone research trial. The meeting was perhaps almost unique — one of the professors commented that in many decades in medicine he couldn't remember

consultation with patients themselves being part of any other preparation for a research funding application.

For me, the meeting was an eye-opener. It became quite clear that the requirements of medical research don't fit at all well with ME — our lack of a biomarker; ME's range of presentations; the variability of symptoms in the same person from day to day and indeed sometimes from hour to hour; the difficulty for ME patients of getting to appointments; the difficulty for many patients even of responding to questionnaires from home, etc, etc... all present significant hurdles for someone designing high quality medical research. I wonder if this may be one reason why so few proposed studies into ME are successful in gaining funding.

I've read that some funding bodies claim ME research proposals are often weak. I suspect it's not the proposals or the researchers which are weak — it's the poor fit between the illness that is ME and research proposal assessment processes. Illnesses with biomarkers and measurable symptoms are likely to tick more boxes if 'scoring' includes, for example, how precisely participants are proved to have the illness (biomarkers/specific measurable symptoms), or if precise measurement of exactly how the illness changes as a result of the treatment is required — how can anyone measure change with certainty when ME fluctuates from day to day anyway? I hope you get my drift!

While I found the researchers very impressive and their plans and engagement with patients exciting, I came away feeling that the requirements and protocols of medical research as it is at present may work against funders supporting researchers whose aim is to find a cure for ME.

People who aren't used to the ME community are often shocked by the way some people with ME experiment with supplements and regimes without the oversight of medical professionals. Prior to the meeting I'd thought of this as a stop-gap until medical research solves the conundrum and gives our doctors answers and treatments. Now, I find myself hoping Long Covid research discoveries may have implications for ME too.

And wondering whether the ME community may find and take the next steps forward before ME medical research is allowed beyond first base.

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## Benefit Queries and Helplines

If you are thinking of applying for Employment and Support Allowance (ESA), Personal Independence Payment (PIP), Attendance Allowance (AA), Universal Credit (UC) or any other benefit that applies to your circumstances, please note that ██████████ (██████████) and ██████████ (██████████) are available for any question you may have regarding this matter. You should contact one or the other of them before you request your application form from the DWP, as once you do this you have only four weeks to complete it and you may need more time to do this or to obtain medical evidence to support your application. ██████████ and ██████████ can also send any queries on your behalf to Ken Butler, the benefits advisor from Disability Rights UK, who will attempt to answer them.

There is an excellent group on Facebook for anyone with ME who is applying for benefits — UK ME & Chronic Illness Benefits Advice, at [https:// www.facebook.com/groups/278260135547189/?multi\\_permaLinks=3943774848995681](https://www.facebook.com/groups/278260135547189/?multi_permaLinks=3943774848995681). If you don't have a Facebook account, please contact [REDACTED] or [REDACTED] and your query will be referred to this group.

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](mailto: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](mailto:meconnect@meassociation.org.uk).

The Disability Law Service offers free advice on 020 7791 9800, and online advice can be obtained via its website <https://dls.org.uk/free-advice/online-advice/>.

## 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.

### Postcode Society Trust's Grant

The Postcode Society Trust and Localgiving have given a grant of £500 to the R+KME Group via their Magic Little Grants scheme. The Postcode Society Trust is funded by players of the People's Postcode Lottery, a not-for-commercial-gain organisation owned by the Novamedia/Postcode Lottery Group. The award received by our Group is to help pay for our annual subscription to Zoom for our online meetings. We are grateful to Localgiving and the players of the People's Postcode Lottery for their support, and we wish them all the best with their endeavours.

Richmond and Kingston ME Group Committee		
Chair	Vacant	
Secretary	Vacant	
Treasurer	[REDACTED]	[REDACTED]
Membership Secretary	[REDACTED]	[REDACTED]
Committee Member and Group Library	[REDACTED]	[REDACTED]
Committee Member	[REDACTED]	[REDACTED]
Social Secretary	[REDACTED]	[REDACTED]
Twitter	[REDACTED]	[REDACTED]
Newsletter	[REDACTED]	[REDACTED]

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

Facebook	[REDACTED]	[REDACTED]
Project Coordinator	[REDACTED]	[REDACTED]
Interview Tape Recorder	[REDACTED]	[REDACTED]

**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 and Kingston ME Group. Reference to any products or services is for information only, not an endorsement.

The Richmond and Kingston ME Group is very grateful for the generous financial support provided by the People’s Postcode Lottery, the Postcode Community Trust, Local Giving and Magic Little Grants.

