

# Richmond & Kingston

## ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

# NEWSLETTER

**No 4, 2022**

**Inside** — What Our Members Are Doing — ■■■'s Recovery Diary —  
Annual General Meeting Report — And More...

## This Year's Millions Missing Event

On Tuesday, 13 October, #MillionsMissing held its first live event for three years. People gathered in Parliament Square to listen to researchers and MPs talking about ME, to ask Welcome to allocate more money to ME research, and to show that we are all connected.

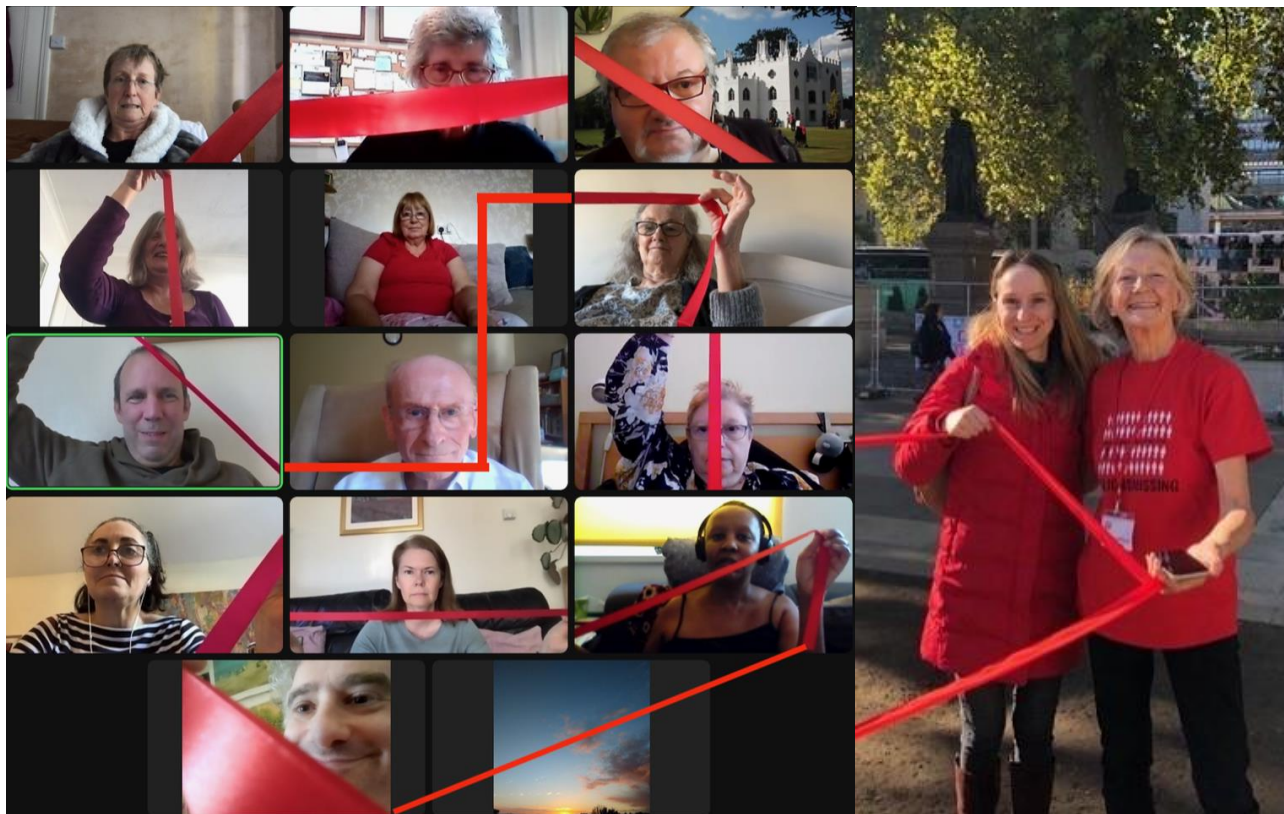
The speakers were interesting, and the meeting was well attended (especially considering this was the second attempt at holding it). Our members ■■■ and ■■■ represented the group at the event. ■■■ wrote a poem for the day, which we've published below.

Meanwhile, on Zoom, other group members held a meeting, also to show that we are all connected. This turned out to be quite challenging logistically — look at the concentration on our faces! — and we looked a lot more relaxed when we went freestyle with our ribbons!

**Helplines Information: See Page 15**

And those who couldn't make the meeting on the day sent photos to show once more that we are all connected.

Below are some pictures from the day: some of our Zoom meeting attendees, and [REDACTED] and [REDACTED] in Parliament Square.



## A Word of Encouragement

Maybe don't tell me to do yoga  
 Or that the only reason I can't sleep is cos I spend too much time on my  
 phone  
 I long for the energy to do yoga  
 and even when I fast from phones I don't sleep much  
 or wake refreshed  
 and feel ready to do anything useful or functional.

Kindly refrain from offering me your unsolicited advice right now  
 I may actually know something about illness  
 having suffered for many years...

*Do* offer me your support, your encouragement, your love  
 your more able body for some heavy lifting  
 if you are able  
 your less addled mind for sorely needed medical research.

That would be most welcome!

And please be assured  
when you are an expert in electroceuticals as well as pharmaceuticals  
can distinguish between vagal tone and muscle tone  
are versed in the philosophy of autophagy  
know your 5-HTP from your PHGG\*,

At that point be assured I will welcome your advice  
I will certainly need your advice  
Then we will join in putting the world to rights  
Then we will — at last — book that yoga class  
Then we shall finally salute the sun together.



## 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 quite a few new ones, including a portrait of a pal's dog, a fox and a Christmas wooden deer plaque (overleaf). ██████████ can be contacted at ██████████, if you're interested in her artwork, and some of her work is for sale.



██████████ had a short letter in the *Guardian* on 29 October about bureaucratisation in the civil service, and an article 'Follow the Leader', about the



strange mutation of some of his old political pals, in the *Weekly Worker* on 27 October.



will be telling us in the next newsletter how she finds doing jigsaws helps with her ME symptoms. Here are four she's recently completed.



The Group's on-line Crafting Meetings give the opportunity for members to display and discuss their creations. If you've not attended one of them and would like to, visit our website to find the date of the next meeting.

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## **Postcode Society Trust Grant**

The R+KME Group has received a grant of £500 from the Postcode Society Trust and Localgiving via their Magic Little Grants scheme. The Postcode Society Trust is funded by players of the People's Postcode Lottery.


The PPL is a not-for-commercial-gain organisation owned by Novamedia / Postcode Lottery Group, the creators of the postcode lottery brand. This group has been operating since 1983 with the goal of contributing to a better world through the operation of charity lotteries, media and publishing activities, raising funds for charities and good causes, and increasing awareness of their work. Its sole objective is to support charitable and social initiatives worldwide. Licensed by the Gambling Commission, the PPL manages charity lotteries for 20 Postcode Trusts.

The award received by our Group is towards our annual subscription to Zoom. With this subscription, all our on-line meetings can be accessed by pressing just one link or by introducing a single ID and password for all meetings, facilitating the admission for all our members, especially those with tremors or shaking hands as a consequence of the illness.

On-line social meetings are nowadays crucial to reducing isolation among our members. Whether you're feeling terrible or at your worst or simply hate on-line meetings, you could easily join with your camera off and your microphone on mute. In this way you could listen to others' conversations and feel that you are part of a community facing your same challenges, and with empathetic people completely understanding your personal situation. We are grateful to Localgiving and the players of People's Postcode Lottery who fund the Postcode Society Trust, for their support and wish them all the best with their endeavours.

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## **Letter From ME Research UK**

, Operations Director from ME Research UK, wrote the following letter to the Group on 17 October.

On behalf of all of us at ME Research UK, I would like to thank the Richmond and Kingston ME Group so much for its continued support and for the donation of £75 received this afternoon. In keeping with previous years, I have credited the donation to our Research Fund —



100 per cent of which is dedicated to funding biomedical research into the causes and consequences of ME/CFS.

Our charity year finishes on 31 October and 2021/22 has been marked by increase research interest and in applications for funding becoming more numerous and complex. We have settled research commitments of almost £900,000 this year, as well as funding PhD-level research and more projects are about to be announced. Also, the results of previous year's research is imminent — a truly exciting time which we believe will bring concrete answers to ME/CFS. Without the support and faith of our friends, none of this would be possible.

Once again, I would like to thank the Richmond and Kingston ME Group so much for the donation; every penny helps us in our quest to make the breakthrough that ME/CFS sufferers deserves.

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## Annual General Meeting

Our twenty-second Annual General Meeting, held on-line, was attended by 23 members. Our guest speaker was Caroline Kingdon, Specialist Research Nurse at the UK ME/CFS Biobank from the CureME Research team at the London School of Hygiene and Tropical Medicine, who gave a most informative speech on the role of the Biobank in research into ME/CFS. For reasons of space, we regret that we are unable to publish her speech in this issue of the newsletter, but it will appear in the next one.

After Caroline's speech, which was well received by our attendees, we turned to business, starting with [REDACTED], who read a list of our achievements. He said that considering that 2022 had been another unusual year, the committee felt pleased with their achievements in the year from October 2021.

### **Social Activities**

- ★ We ran eight on-line social meetings per month: three for coffee, one for pub, two for mindfulness, one for crafting and one for silent reading. We started face-to-face coffee meetings combined with the on-line ones when the lockdown was lifted, up to three per month, which we reduced to one per month as turnout was very low. We reduced the number of on-line coffee meetings from three to two in August to avoid a clash with the sole face-to-face meeting.
- ★ The on-line meetings continue to be well attended and have allowed us to reach members who are usually housebound and therefore unable to attend our events. They also helped us to keep going with our activities during the lockdowns.
- ★ We have two WhatsApp groups, one for young adults and the other for all members.

- ★ We sent out over 350 greetings cards to members of the Group.

### **Information Dissemination to External Parties**

- ★ We promoted the results of our 2019 Survey among social care organisations, such as Healthwatch in Richmond and Healthwatch in Kingston, as well as informing them about the new NICE Guidelines.
- ★ We were in touch with the Chronic Fatigue Service at Sutton Hospital, providing feedback for the implementation of the new NICE Guidelines.
- ★ We e-mailed the new NICE Guidelines to the Clinical Commissioning Groups for Richmond and Kingston boroughs.
- ★ We gave edited versions of our newsletters to partner organisations and doctors interested in ME.

### **Information Dissemination Within the Group**

- ★ We shared a list of consultants with feedback in our e-mail bulletins which has been helpful for some of our members.
- ★ We continue to keep and share updated lists of wellbeing resources and friendly GPs.
- ★ Our Library has acquired two new books.
- ★ Our website has been improved and updated.
- ★ We sent out four newsletters and four e-mail bulletins during the year.

### **Support**

- ★ We supported three members via our Contingency Fund, giving a total of £235.60, in issues related to GPs and consultants' letters for PIP applications and new devices to connect to our on-line meetings.
- ★ We supported six members applying for PIP.
- ★ We are also supporting people with Long Covid; we now have four members with this condition.

### **Fundraising**

- ★ We applied for and received a small grant from the Kingston Charitable Foundation to pay for our subscription to Zoom.

### **Campaigning**

- ★ We met on-line for the ME Awareness week and the #MillionsMissing Day on 12 May. A substantial amount of information was displayed on our Facebook page.
- ★ We gave £75 in donations to ME Research and another £75 to the ME/CFS Biobank from the Cure ME project based at the London School of Hygiene and Tropical Medicine, who are working tirelessly towards finding a biomarker for the illness.
- ★ We spread the word for the signing of petitions to release funds for the implementation of the new NICE Guidelines and encouraged members to write to their MPs in order to attend and support the APPG for ME/CFS on 25 May, noting that the Secretary of Health at the time, Sajid Javid, had recognised ME as an illness that needed more funding and research.

## **Social Meetings, Campaigning, Library and Website**

██████████ reported that the on-line social programme had stayed well attended over the year.

In total, since the last AGM, we ran 98 on-line meetings. For most of the year, we ran eight social meetings a month: four livelier chat meetings (three coffee in the late morning or early afternoon and one pub meeting in the evening), and four quieter meetings (two mindfulness meditation, one crafting and one silent reading). On-line meetings continue to be generally well attended with an average of about eight people at chat meetings and seven at the quieter meetings.

Last year we held our Christmas party in December which 17 people attended and we hope to repeat this on 20 December this year. We participated in the virtual #MillionsMissing event for ME awareness on 12 May with 13 members attending, and we hope to celebrate ME awareness next year. Later this month, on the 18th, we will hold our 'we are connected' meeting in support of the in-person #MillionsMissing event.

Just over a year ago we subscribed to a Zoom Pro account, which has improved meeting set-up and access for everyone, and we have renewed it for the coming year.

Members can join any on-line meeting of their preference and if they don't want to talk and/or be seen they could turn their cameras off and/or have their microphones muted.

During the year we also ran an on-line book group working through Vidya-mala Burch and Danny Penman's *Mindfulness for Health*. This attracted a lot of initial interest (over 20 people were interested) but in practice it needed more energy than most of us could make available and we became a very small book group by the time we finished the eight-week programme (over 16 weeks). Several people, who managed more or less all of the programme, kindly got in touch to say that one or the other of the book group, the book or the programme had been helpful.

We reintroduced face-to-face meetings in April and increased the number until we ran three in July (the rate we ran face-to-face meetings before Covid); overall we ran 11 meetings between April and October. However, attendance had been very low (typically attended by one or two members and the host). We decided to revert to one per month until attendance picks up, and we are trialling running them on different days to the on-line meetings. We thanked ██████████ for hosting several of these.

Looking forward, we plan to run seven on-line meetings per month (three chat and four quieter). In this configuration we will have one late morning, one afternoon and one evening chat meeting. In addition, there may be exceptional additions such as the AGM and the #MillionsMissing event this month.

One specific event we hope to mark is our two hundred and fiftieth on-line



meeting, which should fall sometime in February. We are the only ME support group in the country which will have managed this; we aim to gather as many people who have ever attended on-line as possible for a group photo of this occasion.

We really need some support to maintain this level of meetings. And if anyone would prefer more chat meetings and would be happy to host on-line meetings, please get in touch.

██████ then turned to the Library, saying that interest in borrowing from it had been very low this year, and we are now taking a very cautious approach to buying new books. Perhaps the most useful aspect of the Library's book holding is to provide books for review in the newsletter.

We continued to provide a list of available free or cheap 'wellbeing' resources (meditation, yoga, Qi Gong, breathing, tapping, relaxation, etc). ██████ said: 'Please continue to send us information on any you find useful, or to let us know if anything you try is no longer available or suitable.'

We have updated the resources, the useful links, and the Library pages on the Group website.

And talking of which, ██████ said that over the year we had revised it, improved signposting and added a search function, and had reorganised the structure to make it easier to find what you're looking for. Material have been updated and new ones added. We have made the site more usable and interesting by adding pictures and a consistent layout. ██████ said that ██████ had suggested some of these changes for us and has implemented them all and offered to continue to update the website. We are very grateful to ██████ for the time and expertise she has given us for this.

### **Membership, Treasury, Committee Election**

████████ continued the meeting, talking about our membership (here we go, he and his boring numbers!). He said that we had 178 active members, with 13 new joining us so far this year. Of the total membership, 84 per cent was female and 16 per cent male. The ME severity level of the 75 members who returned the questionnaire last year was Mild: eight (11 per cent); Moderate: 35 (47 per cent); Severe: 28 (37 per cent); and Very Severe: four (five per cent).

Twelve (16 per cent) of these 75 members had reported their GP as being supportive and informed, 41 (55 per cent) supportive but uninformed, and 19 (25 per cent) non-supportive. Three (four per cent) didn't answer. In terms of stability of the illness, 14 (18 per cent) of these members have reported being stable, only five (seven per cent) improving, 39 (52 per cent) deteriorating, and 17 (23 per cent) fluctuating. Only three respondents (four per cent) said that they had received care from social services, and 24 (32 per cent) of members had a carer. It was important to remember that this was a sample representing a little under half, 42 per cent, of the total Group membership.

Seven (46 per cent) of our new members had heard about us via Google and on-line searching, one (seven per cent) didn't want to say how they found us, one (seven per cent) via a social worker, one (seven per cent) via another member of the Group, three (20 per cent) via Sutton Hospital, and two (13 per cent) via the ME Association.

In terms of areas, we had 37 members from Richmond (we used to have more than 40 in this borough), 36 from Kingston, 16 from Hounslow, 12 from Elmbridge, 11 from Wandsworth, 10 from Merton, seven from Spelthorne, four from Epsom and Ewell, 13 from other areas of London such as Camden, Croydon (two), Ealing (two), Enfield, Kensington and Chelsea, Lewisham (two), Southwark, Sutton (three) and Westminster; 25 from other areas of the south of England, such as Bagshot, Berkshire, Buckinghamshire, Dorking (three), Dorset, Dover, East Sussex (two), Guildford, Hampshire (three), Hertfordshire, Isle of Wight, Reigate and Banstead (two), Runnymede (three), Southend, Wiltshire (two) and Windsor; four from the Midlands (Derbyshire, Leicestershire, Oxfordshire and Rugby), one from Abergavenny in Wales, and one from Oban in Scotland. (Our Group is gradually conquering Great Britain!)

██████████ said that we had four members with Long Covid, three with Fibromyalgia, five with ME and Fibromyalgia, and two with Lyme Disease.

One member was begging for mercy after being tortured with all these numbers, but she was relieved to know that she could read them later, more calmly and in detail, in our newsletter, as you're doing now.

██████████ then talked about our meetings with Healthwatch in Richmond and in Kingston, providing helpful information for our members. He mentioned that we had two WhatsApp groups where members with smartphones could share different information and express their feelings when needed.

He highlighted the importance of the Contingency Fund in helping our members for their PIP, ESA or AA and other benefits application, as they could have more evidence supporting their cases by using any of the consultants mentioned in our e-mail bulletins. If you aren't receiving our e-mail bulletins, please give your latest e-mail address to ██████████ and check your spam/junk folders, as they could be identified by your e-mail provider as a scam. Besides the consultants, our e-mail bulletins contain a list of helpful GPs, wellbeing resources, a link to a Facebook page where you can ask and find information about benefits application, as well as other relevant information.

Our member ██████████ suddenly intervened to thank ██████████ for visiting her at St George's Hospital and bringing the Grace Charity for ME hospital booklet (also mentioned in our e-mail bulletins). The booklet was ignored by two senior doctors but taken on board by a junior one, who moved ██████████ to a quieter ward with less noise, light and chemical smells. This booklet is very helpful if you need to be an in-patient, so do contact any member of the committee for a hard copy if you are going to hospital as an in-patient.

██████████ moved to the Treasury, reporting that so far we had collected

£220 from subscriptions, £314 from general donations, £0 from special donations, £0 from Waitrose, as due to the pandemic the company was only supporting specific projects related to the Partnership, and had received £200 from the Kingston Charitable Foundation (previously called Love Kingston) to cover the expenses for our subscription to Zoom in order to help our members with tremors, and other difficulties to access the software, caused by the illness. We had collected £72 from gift aid and £37 from Amazon for a total of £843. He thanked all the members who have paid their subscription and given a bit more in donations and gift aid, especially under the current circumstances when inflation is hitting harder and organisations are struggling to get funds. Also, many thanks to everybody using the Amazon link on our website.

He continued saying that our expenses were led by postage with £545, mainly spent in second-class stamps for large and standard envelopes, followed by £241 spent in our telephone, website and social media, £236 from the Contingency Fund supporting three of our members with their medical reports for their applications to PIP benefit or new devices to access our on-line events, £166 in subscriptions to Localgiving, Disability Rights UK and ME Association, £152 for meetings and events (mainly on Zoom), £150 given in two donations: £75 to the ME/CFS Biobank from the Cure ME Research Group based at the London School of Hygiene and Tropical Medicine, and £75 to ME Research UK, who were also working tirelessly with biomedical research into ME; £118 in stationery, £118 in printing and photocopying, £55 in sundries. In total, our expenses were £1781 and the total funds available in our account were £2208, with no liabilities owed to other organisations. He highlighted that our total income for the year 2021 was only £1021, being the lowest the Group had ever collected in the last 13 years! Hence the greater importance that our members who can afford to pay their subscription renewals, please do so. Hopefully, we might receive a much-needed help of £500 from the Postcode Society Trust via Localgiving in November (which we eventually did!)

Before [REDACTED] moved to the election of the new Committee, he thanked, on behalf of this one, our helpers: [REDACTED] for hosting some of our coffee meetings, [REDACTED] for meeting the medical students. He thanked [REDACTED] for running our Facebook page — it had 430 Likes and 449 followers; [REDACTED] did another sterling job again during the ME Awareness week this year — [REDACTED] with the recording machine for benefits assessments, [REDACTED] for all his support with our communications to other organisations, [REDACTED] for her fantastic updating of the website, and [REDACTED] for being our Membership Secretary for more than 18 months during the pandemic. He said that members of the committee were: [REDACTED], [REDACTED], [REDACTED], [REDACTED] and [REDACTED]. The general consensus among the attendees was in favour of keeping this team for the next year! [REDACTED] thanked [REDACTED] for sharing her vast experience when it was needed, [REDACTED] for the delivery of the greetings cards, her key input in our activities for



supporting the membership, [REDACTED] for our newsletters and helping hosting the on-line coffee meetings, and finally a big thank to [REDACTED] for her great work organising and hosting the on-line social meetings and activities, for updating the Library, compiling a list of wellbeing resources, writing books reviews, being in touch with other support groups and campaigning. [REDACTED] also thanked [REDACTED], on behalf of the committee, for organising and chairing our committee meetings, keeping the Treasury under control, assembling the e-mail bulletins, supporting the committee and the membership, and helping with on-line and face-to-face meetings.

[REDACTED] had her third-best AGM ever as again she didn't have to organise food, snacks and beverages for our members (we're now worried she's getting used to this!). She will be still smiling by the time you read these lines (and possibly until October 2023!).

We had a good time and lots to celebrate in spite of having another difficult year!

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## [REDACTED]'s Health Journey

### Part II: October 2022

You may remember reading about my daughter in the newsletter 3/2021, where I transcribed the diary that I kept to track the progression of [REDACTED]'s illness, my attempt to cure her, and the results. I wanted to give you an update exactly one year on from that point.

So here we are, having given to [REDACTED] for over 18 months now the diet recommended by Anthony William in his book *Medical Medium*. That being no wheat, dairy, eggs, soy, corn, monosodium glutamate (MSG), 'natural flavours', artificial flavourings or pork, but filling up on all fruit and vegetables, herbs, wild foods and celery juice plus a few supplements along the way, such as Cat's Claw and chaga mushroom. She could still eat chicken, fish and other meat. She also had some wonderful acupuncture treatments, which really supported her physically and emotionally along the way.

[REDACTED] turned 18 in February, and as per our goal set last September 2021 of going on holidays as a family at Easter 2022, we managed to go, and [REDACTED] did physical activities every day, though she did have to rest a little in the afternoons.

By May this year, she was not experiencing any symptoms. No fatigue, no brain fog, no muscle and joint pain, no twitches, spasms, etc — they were *all* gone.

We thought perhaps she could start to reintroduce some wheat or cheese, and we tried that in June, but she would feel constipated, so we went straight back to the diet. The *Medical Medium* did say it could take up to 18 months,

depending on how long the ME had lasted and how severe it was. I would say that [REDACTED] was ill for five years and by the end was severe enough to leave her on the sofa all day and losing her friends one by one.

So, we tried again in September to see if we could ditch the diet, and I am pleased to say that we have been reintroducing wheat and dairy bit by bit and she has stayed symptom-free! Our love of good food remains and we eat as healthily as possible regardless. [REDACTED] has also learnt to cook and makes herself delicious meals using all the foods that she has come to love over the past 18 months.

I am now describing my daughter as cured. We have discovered the key to full health and wellbeing. This has been an epic journey and one that has taught me more than I could ever imagine. Firstly, about the power of food as medicine and also about energy healing, of which acupuncture is one type. This in turn has led me to wanting to help people get better from all manner of illnesses and ailments. I have also become a trained Reiki Practitioner. I have ditched my old job as a Practice Manager (in Architecture) and I am now attempting to become a full-time Reiki healer, with a little nutritional advice alongside.

I really hope our story can inspire you to consider this option as a way to help you too to get better. I am more than happy if anyone wants to ask me a question. You can contact me at [REDACTED].

All the very best wishes  
[REDACTED]

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Please note that the R+KME Group Committee does not endorse any therapies or supplements, including those mentioned in this article. We understand that everybody is different, and medications, supplements and treatments work in different ways for each person. See what works for you!

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## **Simple Recipes – Italian Chicken and Bacon Stew**

Here's a very nice Italian dish. It's enough for two people.

### **Ingredients**

Chicken, 200g, preferably pre-cooked  
Bacon, 100g, preferably pre-cooked  
One medium onion  
Three medium cloves of garlic  
One tin of chick peas, drained  
Tomato purée, two tablespoons  
Plain yoghurt, two tablespoons

Fresh thyme, teaspoon  
Fresh parsley, chopped, tablespoon  
Bay leaf  
Black pepper, ground, a little  
Salt, a little  
Olive oil, one or two tablespoons  
Pasta or rice, sufficient for two people

### **Cooking**

- ★ Chop the chicken and bacon into small pieces. If the bacon and chicken are raw, they can either be gently stir-fried in olive oil with the onions and garlic, or cooked in the stew.
  - ★ Mix the tomato purée, yoghurt, thyme, parsley and pepper in a bowl.
  - ★ Chop the onion and garlic into thin strips, and fry gently in the oil until the onions are translucent.
  - ★ Add the mix from the bowl and stir in thoroughly.
  - ★ Add the chicken, bacon, chick peas, bay leaf, salt and some water.
  - ★ Stew gently for 30 minutes (if the meat was raw and then stewed, check for thorough cooking); add more water if necessary.
  - ★ Boil the pasta or rice with some salt, and allow to drain.
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## **Group On-Line Social Meetings**

Our Group on-line social meetings have been very helpful for our bedbound and housebound members, as they enable them to interact with other members from their beds and sofas after months or years of isolation. Some severe ME members have attended with their cameras and microphones turned off and just listen to the conversations, finding in this a very helpful companionship.

If you haven't been able to join us but might like to, please get in touch by contacting [REDACTED] at [REDACTED]. If you need better equipment in order to access our on-line meetings (a new PC, laptop, tablet or smartphone), we can assist you with £50 via our Contingency Fund.

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## **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.

## 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 [REDACTED] ([REDACTED]) and [REDACTED] ([REDACTED]) 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. [REDACTED] and [REDACTED] 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 on-line advice can be obtained via its website <https://dls.org.uk/free-advice/online-advice/>.

<b>Richmond and Kingston ME Group Committee</b>		
Chair	Vacant	
Secretary	Vacant	
Treasurer		
Membership Secretary		
Committee Member and Group Library		
Committee Member		
Social Secretary		
Twitter		
Newsletter		

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

Facebook		
Project Coordinator		
Interview Tape Recorder		

**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.

