

<u>Welcome to Our June 2014</u> <u>Newsletter</u>

Note from the Editor Maxine: I have been trying to get Cameron, my grandson and my baking products together but it has failed me. But since I asked for something we both could do I have made the baby biscuits from last month's news letter. He enjoyed the final outcome at least. In our house I don't like almonds and my husband doesn't like desiccated coconut I ended up doing both.



Do you really think it's fair to not recover after all these well meant tests and therapeutic efforts? With thanks to Invest in ME (www.investinme.org) for their kind permission to reprint this cartoon from the calendar available to download from their website.

Contents of June's Newsletter.

Dates for your Diary	Page 2
Reminders	Page 3
Mercure Bolton Health Club Discount	Page 3
Hydrotherapy	Page 4
Benefits & Work Guides	Page 4
Bury/Bolton ME/CFS Support Group Meeting May 2014	
- Dr Raymond Perrin	Page 5
PLEASE HELP – Chaperones Required Due to Start Soon	Page 8
Our Yoga Sessions	Page 8
University of Bolton Patient and Carer Involvement Programme	Page 9
Sick of Waiting	Page 10
Dr Sarah Myhill Webinar	Page 10
Nom de Plume	Page 10
Late Edition	Page 12

<u>DISCLAIMER</u>: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Committee, nor the Bury/Bolton ME/CFS Support Group. Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

June 2014

Dates For Your Diary

Longsight, Harwood Meetings: Our main meetings, often with guest speakers, are held at Longsight Methodist Church (the big stone building with an elongated wheelchair ramp outside, not the smaller church hall opposite), Longsight Lane. Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). There is a car park and blue badge parking on the street and the building is wheelchair accessible. Entrance is £1. Tea, decaf coffee, water, biscuits, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email caroline@mesupportgroup.co.uk.

Thursday 19th June 7:30pm Tracy Hughes, Holistic Therapist: She does reiki and massage and has been recommended by members. She is based in Tottington.

<u>Thursday 17th July 7:30pm Bring and Share Supper Summer Social:</u> Our second annual bring and share summer supper, where we all bring food to share. There are always plenty of leftovers and lots of gluten/egg/dairy free, etc.

<u>Yoga Classes:</u> Are 3:15pm-4:15pm on Tuesdays at the Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX. Please arrive around 3:10pm. Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Our yoga classes are currently being funded by Comic Relief and The Co-operative Membership Community Fund.

Radcliffe Socials: From June, our Radcliffe social will move from the Sparking Clog, to the **Bradley Fold Garden Centre.** They are on the first Wednesday of the month at 2pm. They next ones will be **Wednesday 4th June** at 2pm and **Wednesday 2nd July** at 2pm. There is disabled parking and is wheelchair accessible. If you use the entrance, you will have to walk around the garden centre to get to the café. It is a much shorter walk if you use the "exit" doors and take an immediate left to get to the café. The café serves hot and cold drinks and food and snacks. We will put our newsletter on the table, so you can recognise us. The address is Moor Road, Radcliffe, Bury, M26 3WY.

Prestwich Socials: Our Prestwich socials are now at **The Church Inn, 40 Church Lane, Prestwich, M25 1AJ.** This has level access and free parking outside. This has got the thumbs up! The staff were friendly and helpful and we could hear each other a lot better.

July's meeting is provisionally set for the usual second Wednesday of the month-Wednesday 9th July at 2pm. Please check on Facebook first to check it is still going ahead, as that's the quickest and easiest way, or call Maria on 07867 862 341 if you are not on Facebook. Apologies to those not online, but it is either this, or stop them altogether.

If you are thinking of attending any of our socials, whether you are a new member or a member who hasn't been able to attend for a while, please remember that you can bring along your carer or a friend. We don't bite, but we understand that meeting new people or if you have been house bound for a while, it can be quite daunting going out by yourself and we look forward to seeing you. PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANK-YOU.



Reminders:

Equipment to Borrow: We have a wheelchair and two electric mobility scooters (small enough to fit in car boot for days out or holidays). If you wish to borrow any of these, please phone Pam on 01204 793 846.

Social Media: Please follow us on twitter on: @BBMECFS

Also our Facebook page just for members is www.facebook.com/groups/buryboltonmecfs/ Don't forget our own web page http://www.mesupportgroup.co.uk/

Recommended GP's: Don't forget, we have a list of recommended GP's! If you have a sympathetic or helpful GP, please let us know, as people ask us for one in their area all the time. 01204 525 955, caroline@mesupportgroup.co.uk.

Radar keys: Currently sold out and no date to when new stocks can be sourced.

Newsletter Articles: Please carry on sending us anything you would like to share with the rest of the group; whether it is a whole page, or just a few lines, it all counts! It could be recipes, tips, experiences, book reviews, etc. Deadline for the newsletter is the last day of the month. Please send your contributions to: maxine@mesupportgroup.co.uk.

Benefit and Work guides: Remember, for anyone filling in benefit forms or if you have appeals/tribunals, we have excellent guides available via post or email (saves us funds). Phone Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk.

Amazon: The group gets 5% commission when you shop at www.amazon.co.uk, but only if you follow the link from our own website www.mesupportgroup.co.uk.

Mercure Bolton Health Club Discount: The Bolton Mercure branch has kindly agreed that our members can use the swimming pool and sauna for only £3.50 per visit, and accompanying carers will pay the same (no charge if they don't use the facilities). The usual price is £8. Just say that you are a member of our group! The best times to use the club are before 4pm weekdays, Saturdays 1-5pm, and all day Sunday (but is busier if it is raining). Their address is: Mercure Bolton Georgian House Hotel, Manchester Road, Blackrod, BL6 5RU. Tel: 0844 8159029. If you would like help in approaching your local club for a possible discount for our group, please get in touch!

<u>Hydrotherapy</u> sessions: Preston and Chorley Fibromyalgia and Chronic Pain Support Group have kindly offered to let our group attend their private hire hydrotherapy sessions. From June, there is now a Saturday session as well as the Friday one.

The sessions are 12pm - 1pm on the first Friday of the month, and the third Saturday of the month at 1:15 - 2:15pm. They are at the Jubilee Pool, Tennyson St, Bolton, BL1 3HW. It is £3 per person and carers are free. The sessions will be on: Saturday 21st June 1:15 - 2:15 Friday 4th July 12 – 1pm Saturday 19th July 1:15- 2:15 Friday 1st August 12-1pm

The pool is 34.9 degrees and air temp is 38.9 degrees so it is lovely and warm. They supply pool noodles, hoists and they have a stair case to get into the pool. I went in April for the first time and I thought everyone was really friendly and welcoming.

Please text or phone Natalie on 07855 777636 if you are planning to attend, so they know how many people might be going.

Thank you to group leader Natalie for the generous offer to our members. If you have any questions or are interested and want more information, please contact Caroline on 01204 525 955.

Benefits & Work Guides:

The guides are created by a welfare rights expert and a barrister. They are essential reading for anyone filling in a benefits application or renewal form, attending a medical, or faced with an appeal. **New guides.**

The group's subscription allows us to make these guides available to our own members for FREE. If you can get to our meetings, socials or yoga classes, you will be able to pick the guides up in person. Alternatively we can email them to you - if you do not have internet access yourself, perhaps a friend or relative could help out.

<u>Please note</u> that we will only ask you for a donation if we need to post the guides out to you, because some of the guides are rather lengthy (number of pages in brackets below) **Please return the guides to us if you can, as they are expensive to print and very popular!** Please look through the list below and if you need anything phone Ruth on 0161 766 4559 or email ruth@mesupportgrop.co.uk

Personal Independence Payments:

Claiming Personal Independence Payments (PIP) (70) Example PIP Diary Extracts for CFS (3), FM (2), arthritis (3), mobility (3), anxiety & depression (2), blank template (2) <u>*NEW*</u> PIP Appeal Submissions (33) <u>*NEW*</u> Ways to Challenge a PIP Medical Report: Over 50 Grounds of Appeal With Sample Texts (24) <u>*NEW*</u> I've Been Awarded PIP, What Else Can I Claim? (12) <u>*NEW*</u>

Attendance Allowance:

AA Claims On Physical & Mental Health Grounds (44) ***REVISED*** The best possible support for clients with DLA and AA appeals (44)

Disability Living Allowance:

DLA claims for adults physical grounds (61) / mental health grounds (53)

DLA claims for children on mental/physical grounds (67) 70 questions you are likely to be asked at your DLA medical (5) The best possible support for clients with DLA and AA appeals (44) Appealing against a DLA decision (19) DLA adult renewal claims on physical (58) and/or mental health grounds (50) Changes of circumstances for people claiming DLA (8) Giving persuasive information about how far you can walk (13) Challenging the claim a bottle or commode will replace the need for help (8)

Employment Support Allowance:

Being transferred from Incapacity Benefit to ESA (22) Understanding ESA (42) ESA claims for mental health difficulties (86) ESA claims on physical grounds (84) ESA Appeal Submissions (26) ESA Mandatory Reconsiderations and Appeals (40) Permitted Work (6) Pathways to Work Interviews (10)

Other:

Which benefits can I claim? (9) Getting help with your benefits (12) Getting better treatment from the DWP (12) If I do any work can I continue to claim? (4) Caution, may not count as voluntary work (6) Am I covered by the Disability Discrimination Act? (9) Reasonable adjustments: Employers and Jobseekers (9) Work and benefits for people with long term health conditions (7) Bedroom Tax Case-Law Round-Up (7) <u>*NEW*</u>

Bury/Bolton ME/CFS Support Group Meeting May 2014 - Dr Raymond Perrin:

For our May meeting, the first in our new home in the church, our old friend Raymond Perrin came to bring us up to date with a summary of the Stanford University Symposium. It was the 11th International Association of CFS/ME Conference held in San Francisco in March.

Raymond said it was the first such conference attached to a university and was the best yet. He told us that Stanford University has massive funding available for research.

The International Association of CFS/ME was started following an outbreak in the 1980s in a small American town. This resulted in many specialists getting together to form the IACFS. they found that the water in the town was contaminated with arsenic.

There were 400 people attending the conference, many of them doctors or scientists, also representatives from patient groups. Stanford is the top medical research facility in the world and at its head is Dr Jose Montoya who believes wholeheartedly in ME.

The first speaker was Elizabeth Unger who discussed numbers of patients and grouping. In the USA they believe most patients are between 40-50, most are women with a ratio of 3-1, the incidence is highest in ethnic minority groups, most are ill for longer than 5 years, only 50% seek medical care, only 16% are diagnosed. Factors associated with ME are infection, stress and genetics.

Next was Jared Younger who spoke about the daily fluctuation of cytokines in ME. Cytokines are toxins made of large protein molecules, they have shown 13 different cytokines in CFS/ME. The one which matches symptoms most is Leptin, this has an effect on feelings of hunger as it regulates that activity. Some people with ME put on a lot of weight whilst others never feel hungry and lose weight. So too much Leptin is a problem but so is too little.

The unique thing about Leptin is micro glia; glial cells are packing cells, but toxins become stored in glial cells. Glial cells are fatty and toxins are attracted to fat. Microglia need to have toxins drained from them (Raymond first postulated this idea 25 Years ago).

The brain drains toxins from the microglia and if the drainage system isn't working well we become ill with neurological illnesses such as ME, Alzheimer's and many more. Because of this lack of drainage the primed microglia have become oversensitive; the result of this is that any virus (which is not the cause of ME) becomes the trigger for the microglia to become active, causing inflammation in the brain and it becomes neurotoxic. Leptin primes the microglia more than any other cytokine. Astrocytes (other protein molecules) are also damaged and they also prime microglia and this then allows very large molecules to enter the brain. When the small arteries in the brain become blocked so that they can't remove toxins and drainage doesn't occur it affects the hypothalamus; which controls sleep and emotion and all the activities of life become difficult.

The next speakers were Mark and Marcia, a married couple and she has ME. This couple have done encephalogram studies when people are awake to look at the delta waves in CFS/ME patients during the awake cycle. This finding shows that there is hyper arousal and sleep is disturbed both night and day. Delta waves are usually strongest during deep sleep at night. It is when delta waves are strong that the metabolites are cleared from the brain so sleep drives this clearance therefore no delta wave sleep means no drainage of toxins.

In response to all this hyperactivity, the hypothalamus has a small area called the locus curruleus which produces nor adrenalin which makes you fee "wired"; in ME patients it is up and down all night and all day causing endless sleep disturbance and continuing the problem.

Also within the brain is the pineal gland which produces melatonin, this hormone regulates the body's 24 hour clock and promotes sleep, melatonin supplement can help sleep.

The presentation by Prof Anthony Kamaroff stressed the physical nature of ME, he asked "why isn't ME just depression?"

- 1. there are differences in the neuroendocrine studies of the hypothalamus and its action
- **2.** treatment does not cure ME
- **3.** there are several findings in CFS/ME that are not found in depression
- 4. formal assessment of patients show less than half have ever suffered depression

He said that evidence of central nervous system involvement include cognitive problems, that is being unable to do things you would normally do on automatic pilot such as riding a bike. Also there is evidence of autonomic disfunction, the autonomic nervous system is responsible for such things as heart beat, breathing, digestion, thinking. Prof Kamaroff said many studies of the brain show something is wrong; but he feels that they do not say it is permanent.

He added that there is now solid evidence that CFS/ME can follow a new infection, that it is triggered by infection but not caused by it. There are several agents associated with perpetuating ME.

As for treatments, he said there is no pharmacological treatment for CFS/ME although some of the treatments for similar illnesses may help such as pregabalin and gabapentin. He also spoke of the Rituximab trials. In a double blind study patients were given tablets twice, two weeks apart; there was a clinical improvement in 10 of the 15. The mean response time being 25 weeks. Although they stated that there are no side effects of the treatment he said a side effect can be death, but longer phase studies are underway.

The next speaker was Ian Lipkin and Raymond said he is the virus detective, he said that different viruses could be involved in ME. He then went on to talk about tick bites and borrelia, which carried by ticks. He said there are many kinds of tick, not just the ones on deer, many animals carry ticks.

There was a showing of the film Voices from the Shadows; which was made by Josh Briggs and Natalie Boulton. It is about Natalie's daughter and other severely affected sufferers.

Dr Jesus Castro has done studies on ME in families and he found that 13% of ME patients have a family history of ME.

Raymond described the next speaker as being very dynamic, Pro Abraham Verghese, he has written his family history in a book called Cutting for Stone. He talked about the doctors round and said at one time doctors looked at patients, talked to them and touched them. He said the doctors round has now become square and they need to get back to basics.

Prof Noel Rose is an immune system specialist and he said many patients have autoimmune problems such as psoriasis, lupus etc as well. he feels that balance of immune systems vital. There was also a discussion of Lynn Gilderdale whose mother helped her to die. At autopsy it was found that Lynn had spinal cord abnormality, which is a major problem; she had dorsal root ganglionitis which can be caused by a build up of inflammatory toxins in the spinal fluid; this causes sympathetic nervous system overload, leading to dysfunction, leading to retrograde lymph flow, leading to increased toxicity which then leads to to further overload thus becoming a vicious circle.

The Conference summary was that ME is not a primary psychological disorder although the pathogenesis is still obscure and there may be multiple causes. It is felt that the case definition probably covers several illnesses.

Thank you to Pam for taking notes on the night and Hilary for typing them up. We have an audio recording on the Dr Perrin talk, available to download on the website, in MP3 format, if you would like to listen. It is one hour and twenty minutes long.

http://www.mesupportgroup.co.uk/BBMEperrinmaymeetingMay2014.mp3

We can also put it on a CD for you to listen to, for those who cannot access the internet. Please call Caroline on 01204 525 955 if you would like a copy.

Dr Charle's Shepherd from the ME Association has done an 8 page report from the IACFS/ME Conference in San Franciso, that Dr Perrin attended, available at: http://tinyurl.com/lqf2bup You can order paper copies from the ME Association.

PLEASE HELP - Chaperones Required Due to Start Soon:

Dr Perrin and Dr Gaber are to start their research to examine the accuracy of a physical diagnostic technique for CFS/ME.

Patients attending the Wigan ME Clinic will be invited to take part, they will then be seen by one of the two physiotherapists that Raymond has trained. The physiotherapist will not be allowed to speak to the patient and will not see any notes of the patient's history. They will attempt to accurately diagnose the patient purely by touch. There will of course be some people amongst them that do not have ME.

Earlier this year there was a "trial run" and one of the physiotherapists accurately diagnosed 6 patients and 3 non sufferers and the other physic was just not sure on one patient but got the 5 other patients and 3 non patients correct.

If this research fulfils its potential it will be a massive step forward in accurate diagnosis of ME; a major breakthrough because at present there is no diagnostic test.

A chaperone will be present while the physical examination is carried out primarily to listen, observe and verify what is discussed and carried out. They must ensure that no conversation is carried out between the practitioner and participant with the exception of asking if there is any pain or tenderness on palpation of certain regions. The chaperone will also be there to safeguard both the practitioner and participant to identify any unusual or unprofessional behaviour. They will also witness the diagnosis and conclusion of the practitioner and validate the documentation by signature.

For the success of this project they need chaperones to volunteer for five hours on at least one Sunday from July 2014 to June 2015. They need three chaperones per day and there will be 10 Sundays during the research project that we will be seeing participants in Wrightington. So they need 30 volunteers in total (if you want to do more than one day...Great!)

Anyone is allowed to be a chaperone, whether they are, or have been a patient of his, or have friends or family who would be willing (it is not like the rules for being in the trial itself, where he cannot have met them before).

To be a chaperone on one of the 10 Sundays of the research, at Wrightington Hospital, please contact Elaine at the Perrin Clinic 0161 773 7288. Thank you.

Our Yoga Sessions:

Our new yoga teacher, Julia Silver-Wren has written about what happens at our weekly yoga sessions, in case any of you are nervous about going. Should you have any more questions, please contact her on 01204 394 768 or email juliasilverwren@talktalk.net. The classes are kindly funded by The Co-operative Membership Community Fund. Julia writes:

The body loves to stretch, lengthen, expand and move in meaningful ways. It also loves to relax, to rest and breathe deeply.

Yoga (meaning "to unite") is a health system that supports the body's wish for well-being, balance and comfort. Yoga helps us to explore and achieve this and, with regular practice, to maintain it.

Yoga postures are timeless and therapeutic. It is different from most practices in that there is the significant and beneficial connection of movement with breath. Every inhale and exhale corresponds to flowing movements the same duration as the breath. As we allow our breath to naturally expand and lengthen, our movements become full and free to experience a wonderful sense of relaxation, rejuvenation and restoration (the 3 Rs of Yoga). We learn with yoga to elongate and extend rather than to push and pull. The practice is effortless and without strain.

Our one-hour session (3.15-4.15 pm) takes place every Tuesday afternoon at the Jubilee Centre in a warm, clean, sun-filled room with low lighting. We begin with several minutes of relaxation, mindfulness and expansion of the breath followed by a gentle series of sitting, kneeling and standing postures linking breath with movement and movement with breath, all of which you take at your own pace. There are modified versions of all postures which are presented from Levels 1,2 and 3 for your comfort, safety and enjoyment.

Mats, blocks and bolsters are provided. Bring a blanket if you feel you will need to cover yourself during relaxation. Take this weekly opportunity to experience and practice the 3 Rs of Yoga for yourself and I look forward to meeting you.

<u>Biog:</u> Julia has been practising yoga & meditation for over 30 years and has been teaching it for the last 14. She holds the British Wheel of Yoga Diploma.

Pam, who regularly attends the yoga, says: "I would recommend our yoga sessions to everyone. You are welcome even if all you can do is to lie on the mat and enjoy a peaceful hour switched off from the cares and worries of the day, we relax and do mindful breathing for about 15 to 20 minutes .Then Julia takes us through gentle stretches and movements, but of course you do as much or as little as you feel able. Hope to see you there."

University of Bolton Patient and Carer Involvement Programme:

Ty Warburton, from Bolton University has been in touch to ask if we could spread the word about their new Bolton Patient and Carer Involvement Program.

They have a brand new undergraduate program that is currently in the development stage and they want public and patient involvement in this from the outset. Please see the enclosed information sheet for more info.

You do not have to live in Bolton to participate, as long as you can get to Bolton One where the events are. The new program is in partnership with Lancashire teaching hospitals, so it may well be with your local hospital.

Introductory Session One -16 th June, 18:00 - 19:30Introductory Session Two -19th June, 14:00 - 15:30

Both sessions will be held in room 03/03/029, this is on the third floor of Bolton One. Please contact Ty Warburton on 07871 552 690 or Tw2ext@bolton.ac.uk for more information. I'm quite looking forward to this, as it seems a very valuable opportunity to provide feedback to future health-professionals, based on our experiences, to explain to them just how debilitating ME/CFS can be, and widen awareness of our group. Ty has been very receptive to feedback in my communication with him and they are very keen for everyone's feedback and to develop discussion. Please participate if you are able. Caroline

Sick of Waiting:

If you rely on hospital transport to get to appointments, please check out this campaign: http://www.transportforall.org.uk/news/sick-of-waiting-our-new-campaign-on-patient-transport.

Sick of Waiting is the campaign for reliable, accessible patient transport for everyone who needs it. The way that patient transport is commissioned has recently changed, with Clinical Commissioning Groups holding more power. So there's never been a better time to tell hospital trusts that they must guarantee that patient transport works for patients.

They've joined up with the National Kidney Federation (NKF), Age UK London and more. They want to see **minimum standards on** things like waiting time and eligibility criteria written into patient transport contracts. They want to ensure that hospital Trusts have the power to hold to account the private companies who deliver patient transport.

Good or bad, they would like your reports of patient transport, to use this evidence to help convince Trusts that patient transport contracts must put patients' needs first.

Please contact Transport for All before July 31st on contact them at www.transportforall.org.uk / 020 737 2339 with your experiences.

You can also send them the survey by post: Transport for All, 336 Brixton Road, London SW9 7AA. The survey can be found at http://www.transportforall.org.uk/files/survey.pdf

Dr Sarah Myhill Webinar:

Following the recent launch of her book "Diagnosing & treating Chronic Fatigue Syndrome: Mitochondria not hypochondria", Dr Myhill recorded a webinar in May, focusing on the practical application of her successful and comprehensive treatment approach. She has treated over 5000 patients with CFS since 1982 and worked in NHS and private practice. Sarah lectures regularly on organophosphate poisoning and chronic fatigue syndrome. She has made many appearances on TV and radio.

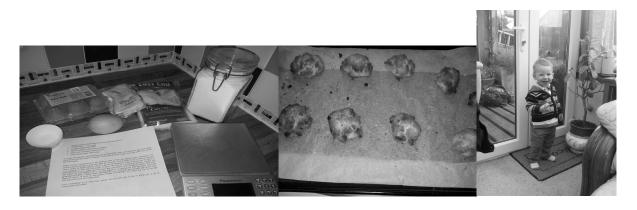
You can watch the webinar here: http://www.youtube.com/watch?v=BG_v6-U1a8g You can also find the webinar via her website http://www.drmyhill.co.uk/

<u>Non De Plume –</u>

Last month I put a request in for something i could make with my 18 month old grandson. But with everything that's happened last month I never managed to bake with him. I did how ever make the baby biscuits.

I'm afraid that I didn't go organic but used the store cupboard ingredients I already had, but that's life. I had to go and buy the coconut and almonds. Last time I look for coconut it was in baking not anymore it's in world foods for future reference.

I found the recipe very easy and bunged it in my food processor. Then put it in a dish and put in dish and then fridge. Only took a short time to put on baking tray to pop in the oven. My daughter turned up at sampling time and said the coconut ones have to be eaten warm! But as you can see grandson enjoyed the final product.



Pow pow pancakes

My love and I almost broke up by the side of a plate of pancakes. Over

Seventeen years ago, I arrived at his student digs unannounced and full of unnecessary angst just as my love was drizzling maple syrup over the biggest plate of pancakes I'd ever seen. The pile was so high that I had to concentrate extra hard so as not to get side tracked into asking all about his breakfast. I was in a real state, but despite this, even I had to secretly applaud his skill and appetite.

Pancakes may evoke wholesome family life for many, but it's taken me a long time to shake that initial encounter off.

Of course we never did break up, if anything it was a dish that helped consolidate our commitment, nonetheless pancakes didn't make an

appearance in our kitchen until I was sure I could out do that encounter. It is proving to be a slow but steady progression. Perhaps because some

memories are harder to shake off, particularly when they relay ones worst fears. But I am not one to be bullied for long, I may be down but I ain't beaten yet....

3 large organic eggs
300 Mls of unsweetened almond milk
1 tbsp of organic nut oil
1 heaped tablespoon of stevia, agava nectar or organic honey
A dash of almond essence
1 tablespoon of organic coco powder
1/2 tablespoon of sea salt
150 Mls of organic rice flour
150 Mls of organic ground almonds
Enough oil to coat the base of a frying pan
1 organic banana
A slug of organic maple or golden syrup

Break and beat all three eggs into a mixing bowl; add to this the Almond milk,nut oil, stevia, almond essence, coco powder and sea salt until evenly combined. Whisk in the rice flour and ground almonds until no dry lumps remain. Cover the bowl and let the batter stand at room temperature for 1 hour or in the refrigerator overnight. When ready to cook, heat a lightly oiled frying pan over a medium to high flame. Meanwhile peel then thinly slice the banana. Now carefully place large spoonfuls of the batter around the sides of the frying pan, arranging a generous mound of banana slices on top of each battered disc. Cook until bubbles form and the edges are dry and crisp. Flip and cook until browned on the second side. Repeat with remaining batter.

Pour a liberal slug of syrup onto the pancakes before serving them hot.

Late edition – May 2014

Here's a brief roundup of some of the recent articles covering CFS/ME and Fibromyalgia during May.

The diagnosis and definition of CFS/ME could soon be redefined as a new Institute of Medicine (IOM) study gets underway, and commissioned by the U.S. Department of Health and Human Services (HHS). The team will be reviewing the existing evidence and will report back in spring 2015. If the team comes up with a new definition, it could help drug developments, carers, physicians, treatments and diagnosis. Baffling Chronic Fatigue Syndrome Set for Diagnostic Overhaul – Scientific American - May 16 The Open Medicine Institute (OMI) and Affymetrix announced that they will begin development of a biomarker for Chronic Fatigue Syndrome (CFS) and other prevalent, chronic but difficult-to-diagnose diseases. If successful, this would also have similar benefits to those in the IOM study above. The Open Medicine Institute (OMI) to Develop First-ever Biomarkers for Chronic Fatigue Syndrome and a Range of Complex Diseases – PR Newswire - May 21

A new brain scan study has spotted the first evidence of a connection between nerve cell inflammation and the onset of CFS/ME. Despite a small sample of 9 patients, the researchers believe these results are the first to show that neuro-inflammation is a distinct feature of CFS/ME. Consequently the areas of the brain affected are linked to fatigue, pain, depression, and thought-process difficulties long associated with the syndrome. Brain scans spot possible clues to chronic fatigue syndrome – Medical Express - May 3

Patients may be misdiagnosed with CFS/ME after a head injury. Instead they may have Post-traumatic hypopituitarism (PTHP), something which is missed by doctors who haven't been issued with the necessary clinical guidance. The trauma affects the pituitary gland and means upto 30,000 patients each year will suffer as they're not getting the right treatment. How doctors are failing to spot the brain injury that could be behind 30,000 cases of 'chronic fatigue'- Daily Mail - May 17

One woman's discovery of Facebook, Twitter and other social media sites shows how she connected with other sufferers and helped herself. She made lasting friendships with people who really understood her condition. Social Media: An Open Window Into the World for ME/CFS – Empower Her - May 28

Researchers at the Indiana University found that whole-body vibration exercise might be the best therapy for reducing symptoms of pain and improving quality of life among those diagnosed with fibromyalgia. Vibration Exercise Lowers Pain and Enhances Quality of Life in Fibromyalgia Patients – Science World Report - May 30

This piece contains links to other articles to help you address the brian fog associated with Fibromyalgia and CFS/ME. It ranges from modern "brain training" excercises to meditation, which has been practiced for thousands of years. Combatting Brain Fog with Fibromyalgia & Chronic Fatigue Syndrome – About.com – May 27