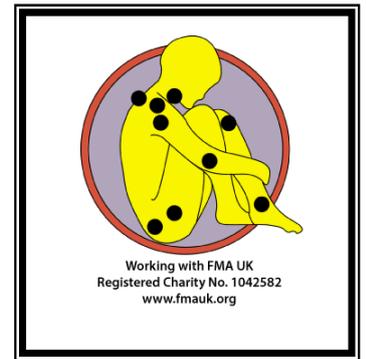




Welcome to Our December 2016 Newsletter.

Note from the Editor Maxine: Please remember no main meeting now until March 2017 and the AGM and social. Please see meeting down below. Please also see that the Prestwich socials have stopped. No yoga in-between Christmas and new year



Monthly focus.



Christmas



Free Yoga Classes, Jubilee Centre: Christmas/New Year dates.

Hi folks, just wanted to be sure everyone knew that our Tuesday yoga classes are on up to and including 20th December, but won't be happening between Christmas and New Year (27th December). Then we'll be starting back on January 3rd.

See you there!

Amazon

Sorry to say it so loud, but CHRISTMAS!! Yes, I can't believe it myself, but it's nearly here already. Seems like just yesterday I was buying Easter Eggs. Don't forget when you're panic-buying or splurging in the New Year sales, that the group gets a small commission on your Amazon.co.uk purchases.

To get the commission, you must first go to our website, www.mesupportgroup.co.uk and click on any of the Amazon links you see about, there's one on the left side all the time. You have to visit our site first each time you buy something for the transaction to be eligible.

Bolton Main Meetings:

Unfortunately we have had to find a new venue due to The Wildlife Trust having a staff shortage and organisational restructure. They have been very helpful, and welcoming and it's a shame to leave such a lovely, peaceful building, with wonderful views of wildlife outside.

The new main meeting venue will be **The Friends Meeting House** (The Quakers), in Silverwell Street, Bolton, **BL1 1PP**. The street is marked by an Italian restaurant, and opposite Nelson's Square. It is all the way to the bottom of this street, on the corner, with all the solicitors.

There is good provision of car parking between private land and street parking. They have a small car park, for about 11 cars, and next to that, is an NHS car park they are permitted to use, plus regular street parking bays and double yellow lines those with blue badges can use, which will be ample for our meetings.

Blue badge holders can go on yellow lines, all in close proximity to the entrance. It would be helpful if you are on a scooter/powerchair or are able to walk that bit further, to leave the nearer spaces, for others who may need them more please.

The building is warm and welcoming with friendly staff, quiet, a variety of comfy chairs are available, disabled toilet, kitchen facilities, all on ground level etc with well ventilated room with access to the small courtyard outside. We have looked into a lot of venues and this most meets our needs. The staff are extremely accommodating, so if there is anything you need or have a problem with on the night, they will be happy to try and help.

Meetings remain on the 3rd Thursday.

There will be no January or February meeting at the start of 2017. Our first meeting will be in March, for the AGM.

As the January and February meetings are always poorly attended, due to recovering from the festivities and battling against awful weather, as well as having the issue of people finding a new venue in the dark, we have decided to miss these meetings. We will still be active on Facebook and be sending out reminder emails, so please be on the lookout for those.

It's very important we get enough members at our Annual General Meeting in March when meetings resume at the new venue, or else we must do the unthinkable and hold it again. We will be sending out last year's minutes and ballot forms in the February newsletter (boring, I know, but necessary). We would be forever grateful if you could email or post the completed ballot forms back to us.

Bury and Bolton ME/CFS & Fibromyalgia Support Group Meeting Dates

Meetings will be as follows, on the third Thursday of the month at 7:30pm. Subject to change:

No meeting in January or February

Thursday March 16th 2017- our A.G.M and raffle (our first meeting in new venue). Please bring unwanted gifts or items for the raffle!

No meeting in April, as usual.

Thursday May 18th 2017 - TBC

Thursday June 15th 2017 – TBC

Thursday July 20th 2017 – our bring and share Summer social

No meeting in August, as usual

Thursday September 21st - TBC

Thursday October 19th - TBC

Thursday November 16th – our pre Christmas bring and share supper Social

No meeting in December, as usual.

Thank you.

Prestwich Socials:

Unfortunately we have decided to cancel the Prestwich socials after the December meeting. The turn out is too low and it is the same few members attending to ensure any new visitors are met. The last few times it's been the same 2-4 people, some travelling from Bolton or Westhoughton to get there.

We may organise the odd one off social now and again.

Members are free to set up any socials they want to arrange themselves if they fancy meeting up with others locally, but please be safe and meet in a public place if you have never met before.

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, SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANK-YOU.



DISCLAIMER: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Trustees, nor the Bury & Bolton ME/CFS & Fibromyalgia Support Group (Registered Charity Number: 1161356). Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

Reminders:

Volunteers: We are looking for volunteers who can help with all activities of running the group, when your energy permits, please contact Caroline. **We are really struggling to keep the group going;** we are just a small number of sufferers, so we need all the help we can get please. Please contact Caroline on 07851 647 550. caroline@mesupportgroup.co.uk or for more information.

We could do with help with the website, asking & searching for grants or donations, letter writing, writing and submitting newsletter articles and help at meetings.

Equipment to Borrow: We have a sparkly new manual wheelchair, and two electric mobility scooters (small enough to fit in car boot for days out or holidays) and two pairs of SmartCrutches (ergonomic elbow crutches). If you wish to borrow the scooters, please phone Pam on 01204 793 846. To try the SmartCrutches or manual chair, call Caroline on 07851 647 550.

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

Also our private Facebook group just for members is

www.facebook.com/groups/buryboltonmecfs/

And our new open page: <https://www.facebook.com/bbmecfsopen>

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. 07851 647 550, caroline@mesupportgroup.co.uk.

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. Via email where possible please.

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.

Gail Sumner: Group Meeting 20th October, 2016

Gail is a physiotherapist and Perrin Technique practitioner, who spoke about the recent blind clinical trial of the Perrin diagnostic test done purely by physical examination. It is hoped that G.Ps may be able to use this diagnostic test based on 5 specific physical signs to tentatively diagnose, or indicate if a patient may have M.E/CFS, to be referred on. The results are very promising indeed, but we can't say anything about the details yet, as the researchers are hoping to publish in a prestigious medical journal.

Dr Perrin gave a talk about the research at the recent international ME conference in Florida at the end of October, so you can look for details of that, but unfortunately we have been asked not to say anything as of yet.

Title: Examining the accuracy of a physical screening tool for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A Blind Controlled Study
A technique for chronic fatigue syndrome/myalgic encephalomyelitis: a blind controlled study

Authors: Lucy Hives, Alice Bradley, Jim Richards, James Selfe, Chris Sutton, Tarek Gaber, Bhaskar Basu, Annice Mukherjee, Kerry Maguire, Gail Sumner, Raymond N. Perrin

Gail told us about the recent work she has done with Dr Jesse Armine, founder of the Center for Bio-Individualized Medicine in the US (hence the spelling). In his experience, everyone with ME has inflammatory problems. Recent research shows that 85% could be identified just from a stool analysis, e.g., leaky gut, parasites, poor balance between good and bad bacteria. An inefficient digestive system can cause systemic inflammation, including yeast overgrowth. Dr Armine suggests the best way to take supplements is liquid form, as it's most easily absorbed, and the least efficient form is tablet.

Another exciting recent research by Dr Robert Naviaux: "Metabolic Features of CFS", discovered a chemical signature showing ME/CFS is a metabolic disorder implicating the mitochondria: they are the "engines" of each cell. In ME they seem to go on a "go-slow", which has been compared to a sort of "hibernation" which some organisms use as a response to environmental stresses.

Gail also mentioned the importance of good sleep patterns and rebalancing neurotransmitters. Also knowing your numbers: often we're told our blood tests are within

normal range, but the rule of thirds is useful. If your result is in either the top or bottom third of normal range then it needs improvement.

She also mentioned some promising new work using an individual's DNA profile which you can have done by companies such as 23andme. Then there is the MTHFR gene mutation theory, the theory of pyroluria, the importance of clearing toxins and heavy metals from your system, and so on.

She answered lots of questions and covered too much ground to go into detail here (plus, the tape ran out without my noticing, so this write-up is with the help of others), so lots of possible avenues to explore for ourselves.

Links:

Digestion and absorption (new clinical research ME/CFS and digestion) 'Chronic Fatigue Is Not In Your Head It's In Your Gut' <http://neurosciencenew.com/chronic-fatigue-microbiome-4581/>

Cell repair (clinical research on cell danger response and mitochondria) 'The Core Problem in Chronic Fatigue Syndrome Identified? Naviaux's Metabolomics Study Breaks Fresh Ground' <http://healthrising.org/blog/2016/09/01/metabolomics-naviaux-chronic-fatigue-syndrome-core-problem/>

Many thanks to Gail for speaking to us, we know a lot of us wanted to hear from her. Many thanks to Maria for writing the notes and Joanne for typing them up.

Medical Assessment Inaccuracy Complaints

I have heard first hand of 4 complaints about PIP assessments at the Bolton centre, just from our Facebook group this month alone. Complaints are mainly about the treatment received from assessors, their tone/attitude to both the claimant and attending carer/friend, and inaccuracies in the medical report. I have also heard of some good feedback from various centres though, so it does seem to be luck of the draw, as it has been for me personally throughout the years.

If you do not get the award for ESA or PIP you believe you are entitled to, because of inaccuracies or falsities from the medical report on which the decision was based, you absolutely must complain!

If you do not, and it goes to tribunal, they will wonder why you did not speak up sooner about the issues. The company also need to be aware of which assessors, and how many, are not adhering to their Customer Charter . You could also send a copy to your M.P. (http://www.atoshealthcare.com/downloads/PIP_Atos_Healthcare_Customer_Charter_Web.pdf).

Please do speak out, you will need to correct any inaccuracies to ensure you get the right award, and if their poor conduct goes unchallenged, it will carry on and more people will suffer.

Asking to record your medical will help with combating inaccuracies. Make a note of the time the assessment started.

Need to write a lot of notes about a phone call or assessment? You can email them to yourself so you have a time stamped record. Anything to do with the DWP, ATOS, utility companies, GP surgery, etc. Also note down any witnesses if you couldn't record it.

A true Case History

Mrs x has been an ME sufferer over 30 years and for many years tried to carry on working and bringing up her family.

At that time there was no knowledge of ME and of course no diagnosis and no help, so our friend struggled to carry on. Eventually her partner left and she was alone, very ill and tried to keep going.

Throughout these many years she has been in hospital several times and had the most appalling treatment when she has tried to explain that certain types of prescription drugs made her worse.

More recently she has had severe episodes of narcolepsy and when the ambulance arrives, as usual they said it was a hypoglycemic coma. They gave her glucose to no effect. Her GP's were unbelieving for a long time until she had an episode in the surgery.

The only health professional to try to help her was Dr Andrew Wright when he was at ME clinic many years ago.

Eventually she managed to save enough to go and see a consultant neurologist privately. He was very kind and made a referral to Hope hospital for her to have a test biopsy of her muscle tissue, in order to see if her mitochondria was damaged. This test was positive and showed that they were not working properly.

Mitochondria are present in every cell in the body and act as a power pack taking in oxygen and nutrients and converting it into energy. If they are not working very little energy is produced, and could also cause pain because when you over exercise there is a build-up of lactic acid in muscle which feels as though it is burning and aching.

When she returned to see the neurologist he said there is so very little known about mitochondria, but referred her to a team of researchers in Newcastle. They were doing a research study on women who have had multiple miscarriages, to see if it is caused by the defective mitochondria.

They repeated the biopsy test and confirmed that the mitochondria were damaged but not in the same way as the ladies that they were studying so they could not offer any help.

Our friend continued having severe episodes and feeling very ill but nothing further was done until she had a narcoleptic episode in a GP surgery. She was then referred to the senior neurologist team at Hope hospital again. They did several more tests in order to exclude other rare conditions with the final conclusion that her problems are related to the mitochondrial damage which affects all muscles and cells.

When she went back to see the neurologist he was exceptionally kind but so very sad to tell her that there is at present nothing that can be done to help. He said she should stop all medication as any chemicals entering her body could further damage her mitochondria and he advised only gentle herbal or hormonal supplements.

She has found this to be in some ways liberating because she is no longer looking for the magic pill that will make her better.

There is very little information available about mitochondria damage and virtually no research, so it will be sometime before any realistic help is available.

It is vital therefore that we look to ourselves and to lifestyle management to help control the situation and to continue to support one another.

We are very fortunate to have our ME clinic to support us in this.

I think it's important to take onboard how much the mindset is with any illness and addressing blockers in our mind, which prevents us from making small improvements in our symptoms.

Like anything, the lifestyle management is a lot of self discipline and a lot of saying no when really we want to say yes, but it's all for the greater good. It can take some time but the results are worth it, to then spend precious time with family and friends. Even if this is still limited, at least we can still do it, where this may not have had been possible at one stage.

The lifestyle management course has helped so many and is crucial to help change the way we think and help prioritise what is important in our life and health to enable us to live a more balanced way. This isn't always possible for everyone but baby steps can help and can make improvements even if only on a smaller scale.

This study was done by Mr Turnbull who is one of the top mitochondrial experts in the country. Mrs X has also been on Julia Newton's study but it was not related to mitochondria.

Many thanks to Joanne for typing this up.

Mhist – the mental health charity.

A lot of us suffer from depression, anxiety, OCD, stress or other mental health conditions which makes it even harder to manage and cope with the symptoms of our ME/CFS and/or FM.

A friend has recently recommended the groups that the Bolton Mhist charity has to offer. They offer information and advice, advocacy (tribunals, disputes etc, where you need support), dramatherapy, counselling, Mindfulness sessions (Mondays 10:30- 11:30) and more.

Mhist Contact Details:

Telephone: 01204 527 200. email:info@mhist.co.uk

MhIST, Hanover House, Hanover Street, Bolton, BL1 4TG.

Mhist have several support groups on offer. Some seem to be held at Havover House, and some seem to be upstairs in their Moor Lane charity shop. Please clarify before attending. Dates and times are correct according to their recently updated website and at the time of writing, but please confirm classes are still on to avoid disappointment.

Groups:

OCD. The OCD group meets fortnightly on Monday evening at MhIST in Room 8 from 6:30 pm until 8:30 pm. Speakers or socials.

Depression Recovery. Self Help 4U. The group offers an opportunity to talk to others who will understand, in a safe and non judgemental environment.

Thursday mornings at MhIST in Room 9 from 11:00 am until 1:00 pm, or Friday mornings at MhIST in Room 8 from 11:30 pm until 1:30 pm

Autism Connect for those on the autistic spectrum (Monday 5:00 pm until 7:00 pm),

Self-Esteem group, helping promote self esteem and confidence in ourselves and others through ideas and techniques. Contact MhIST first and a facilitator will contact you afterwards before attending this group. Meets every Tuesday at MhIST in Room 8 11:00 am until 1:30 pm

Craft & Socials Monday 1:30 pm until 3:30 pm The weekly sessions are ideal for people who undertake needlework, crafts, cross-stitch, lace-making, knitting, card making, drawing and embroidery etc. No experience necessary.

The group meets every Monday afternoon upstairs at The MhIST Charity Shop, 38 Moor Lane, Bolton, BL1 4TH

WRAP Wellness and Recovery thinking about mental health recovery and wellbeing. Please contact Mhist for the time and locations of the meetings.

Recreation and Activities group A social group with a range of activities of varying energy levels (board games, theatre trips, recipe swaps, a quiz gardening, etc.). Just turn up on the day, it's a weekly group that meets every Thursday 2:00 pm until 4:00 pm at Mhist.

Support over the Festive Season

It can be hard to cope this time of year, with stress or anxiety heightened, you might feel alone, or you might not be able to pace yourself due to festivities and suffer a bad relapse. Here are some details for charities that you can talk to.

The Sanctuary

0300 003 7029/ sanctuarybolton@selfhelpservices.org.uk/ @WeAreSelfHelp/

www.selfhelpservices.org.uk/sanctuary

a crisis support line during the day (6am – 8pm)

a place of 'safety and support' through the night (8pm – 6am)

Providing 24-hour support to adults who are experiencing anxiety, panic attacks, depression, suicidal thoughts or are in crisis. The Sanctuary offers a space to talk and assistance with coping after the initial crisis.

This service is available to residents (ages 18+) living in Manchester, Trafford, Salford, Stockport, and Bolton.

For more information about The Sanctuary Bolton visit The Sanctuary Bolton contact number: 0300 303 0581 / Facebook: [facebook.com/SanctuarySHS](https://www.facebook.com/SanctuarySHS)

Manchester, Trafford, Salford and Rochdale

T: 0161 226 3871

E: pws.manchester@selfhelpservices.org.uk

Stockport
T: 0161 480 2020
E: stockportpws@selfhelpservices.org.uk

Mind – the nationwide mental health charity and advocacy service
info@mind.org.uk

Text: 86463

Info line: 0300 123 3393

Open 9am to 6pm, Monday to Friday (except for bank holidays).

Get help with types of mental health problems, where to get help, medication and alternative treatments, advocacy and legal information.

Samaritans: Call 116 123. Email: Jo@Samaritans.org

24 hours a day, 365 days a year, you do not have to be suicidal and the number is free.

M.E Association's M.E Connect Line

Please phone 0844 576 5326. It is open every day of the year between these times: 10am-12, 2-4pm, 7-9pm. From most landlines calls to ME Connect cost 18p connection charge plus 7p per minute, of this charge the MEA receives approximately 3p per minute, towards the service. May be higher from mobiles, please check. Email: meconnect@meassociation.org.uk.



I'm sorry, we'll have to cut short the Christmas Party – Charlie's having a bad reaction to your bread growth enhancer. 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.

What about the young?

Very poor quality of life in young patients

Reprinted with kind permission from www.mereseach.org.uk. Breakthrough magazine, Spring 2016.

A decade ago, a postal survey of GP practices in the UK uncovered significant numbers of 5 to 19-year-olds with "unexplained severe fatigue", most of whom had a diagnosis of ME/CFS. These youngsters definitely exist, but you wouldn't know it from the TV or the newspapers, and their families are usually left to cope with the situation as best they can.

In Norway, the NorCAPITAL project ran for several years in order to explore ME/CFS in young people. All 20 paediatric departments in Norwegian hospitals, as well as many general practitioners, were invited to refer their patients to a central department of paediatrics for further investigation. Several scientific reports have already been published from the project data, and the latest, from the Institute of Nursing in Oslo, describes the health-related quality of life of 120 adolescents with ME/CFS compared with a group of healthy young people.

The investigators found that the average length of illness was 21.4 months, while school absence was 65% in the patients compared with only 2.1% in healthy children. Quality of life was dramatically worse in youngsters with ME/CFS: on a scale 0 to 100, they scored a full 44 points lower overall than their healthy peers. As regards specific aspects the ME/CFS patients scored 60 points lower than healthy children for physical functioning, 52 points lower for school functioning, 28 points lower for emotional functioning, and 27 points lower for social functioning.

Given their chronic illness, it was not surprising that the young ME/CFS patients had a much higher risk of depression-associated symptoms than did their healthy peers. However, statistical modelling of the data revealed that lower quality of life was associated with having ME/CFS rather than with being depressed per se. As the authors say, “Experiencing difficult thoughts and sad feelings (depressive symptoms) might not be surprising, considering the consequences of the disease, such as reduced school attendance and time with peers.”

These Norwegian researchers had previously investigated health-related quality of life in youngsters in remission after acute lymphoblastic leukaemia, and in children who had undergone renal transplantation. Crucially, they found that quality of life was more impaired in the young ME/CFS patients than in the patients with these two other conditions – a finding which chimes with ME Research UK-funded work at the University of Dundee (see page 13).

An important aspect of a dramatically reduced quality of life is the social isolation it brings, as the NorCAPITAL project found when it explored adolescents’ own experiences of living with ME/CFS. The lack of participation at school and social gatherings with other teenagers made them feel like outsiders.

As the researchers say, the young people “experienced loss of a normal life and the changes in friendships difficult, leading to loneliness and isolation”. Cruelly, this concatenation of events happens at a particularly vulnerable time of life when disruption to education and family life has the severest consequences.

Link between visual stress and discomfort during reading in ME/CFS patients

Reprinted with kind permission from www.mereseach.org.uk. Breakthrough magazine, Spring 2016

Problems with eyes and vision occur in around three-quarters of people with ME/CFS, yet these symptoms are rarely mentioned in scientific reports. Since 2012, Dr Claire Hutchinson and colleagues at the Vision and Language Research Group, University of Leicester have been working to identify and quantify vision-related problems in the disease. The Leicester programme was initiated with funding from ME Research UK and the Irish ME Trust, and has resulted in three robust scientific papers showing that ME/CFS

patients perform worse than matched controls across three specific aspects of vision – scanning, keeping attention on a target, and moving attention towards it.

Patients also had a problem with eye movement itself, and vision-related symptoms (sensitivity to bright lights, problems focusing, and eye pain) were shown to be significant clinical features which were severe in more than 30% of patients.

Pattern-Related Visual Stress

In 2014, we gave additional funding to the team to investigate visual discomfort during reading, a common activity which is important for optimal quality of life but which many people with ME/CFS find difficult. The first short report from this project has now been published in the journal.

The research team aimed to determine whether ME/CFS patients experience “pattern-related visual stress”, a form of visual hypersensitivity to patterns, such as a page of words. This is also known as Meares-Irlen syndrome after the two researchers who first noticed a connection between reading difficulties and the glare of a white page. Typically, this visual stress causes distortions of print, including text that appears to jump, swirling effects, and letters that can double, fade or blur. Pattern-related visual stress is associated with symptoms such as difficulty focusing, poor depth perception, and reading-related headaches, all of which seem relatively common in ME/CFS

In the current investigation, 20 ME/CFS patients and 20 control subjects took the standardised Pattern Glare Test, which involves reporting the number of visual distortions experienced when looking at three repetitive striped patterns of different levels of detail: low, mid or high spatial frequency (SF). The basic findings were that few visual distortions were reported by either group at the low SF pattern where distortion is relatively mild, while both groups reported distortions at the high SF pattern where distortions are relatively extreme.

It was in the mid SF pattern that differences between the groups were observed, indicating increased susceptibility to visual stress (see the graph above).

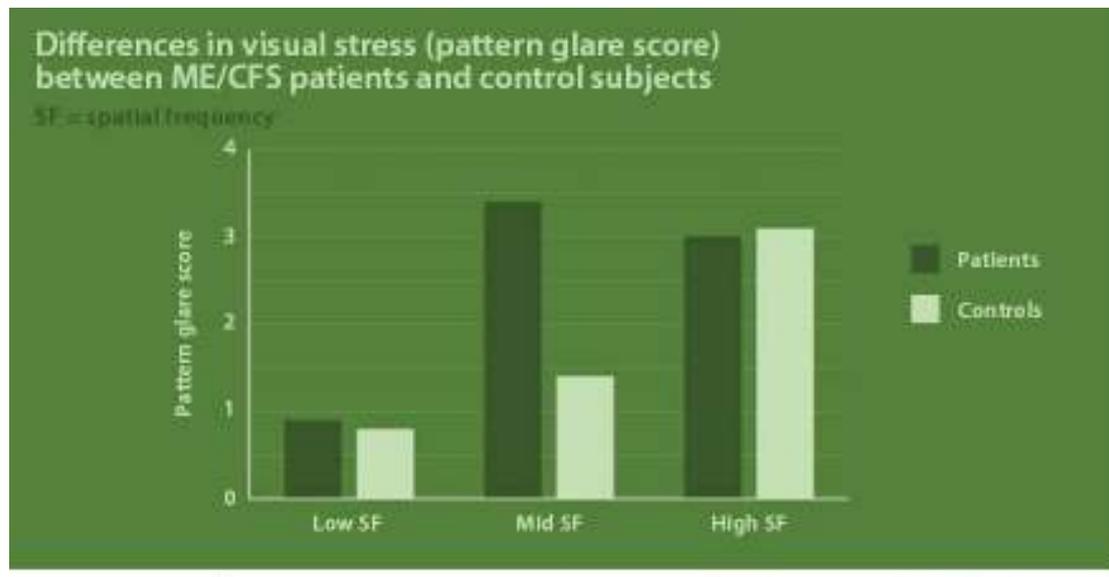
Also, the differences in the pattern glare score between mid and high SFs were significantly higher in the patients than in the controls. In effect, patients with ME/CFS experienced the kind of distortions in the mid SF pattern that healthy people experience at the high SF pattern.

Cortical Abnormalities

So, why do ME/CFS patients experience visual stress? Dr Hutchinson and colleagues speculate that cortical abnormalities in the brain may be involved, based on observations of visual stress in other neurological illnesses including stroke and migraine (see page 17 of this issue of Breakthrough).

If neurotransmission in the visual cortex is impaired, as seems possible, it would chime with the views of some scientists that chemical neuro-transmission is abnormal in this disease. This report adds to the growing body of evidence that problems with eyes and vision are important in ME/CFS. Dr Neil Abbot said in the Leicester University press release: “Dr Claire Hutchinson and her team have previously confirmed the existence of eye movement difficulties in ME/CFS patients, and that symptoms, including eye pain, can be severe.

Her new report in *Perception* extends these findings and raises the possibility that vision anomalies, including pattern related visual stress, may come to have a diagnostic role in the disease.” In fact, it may be time to include these symptoms in clinical and diagnostic guidelines, such as the NICE Guideline in the UK



Thank you to all our volunteers for your help this year with all aspects of running the group, and our members for your continued support. We hope you have a peaceful Christmas and a Happy and Healthy New Year. We look forward to seeing you when our meetings resume in March. Best wishes, The Trustees.