Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

September 2017

Future dates

Open to all members and carers.

Please email our group for the latest meeting dates

Medical Abuse In ME Sufferers (MAIMES)

Source: http://drmyhill.co.uk/wiki/Medical_Abuse_In_ME_Sufferers_(MAIMES)

Would you like a UK public inquiry into the abuse of ME sufferers over decades of neglect? If you would like such a Public Inquiry, then please read on. Dr Myhill has formed the MAIMES campaign.

Associated you tube video: www.youtube.com/watch?v=IOXCjZPboFw

MAIMES

Definitions

- An Adopted MP = this MP has been contacted or is due to be contacted by a MAIMES volunteer. An adopted MP has not yet signed up to the campaign. MAIMES volunteers can still arrange to meet these MPs and try to convince them. See below for more details!
- A Signed Up MP = this MP has signed up to the MAIMES campaign to have a Public Inquiry into the abuse of ME sufferers

Simplified Overview

- This is a campaign to get MPs to sign slips that will be used to demand a Public Inquiry into the abuse of ME sufferers over the last few decades. This campaign is called MAIMES. [the slip calls for a Public Inquiry]
- The first goal is to sign up as many MPs as possible to the aims of MAIMEs. Once we have sufficient MPs on side we will approach the Secretary of Health to demand a Public Inquiry
- We first need “adopters” who are physically able to attend their MPs’ surgery and also who feel that they can explain the issues as detailed below in as convincing a manner as possible! Please - we don't want anyone to feel pressurised in any way to do this. Our goal is to make people better not worsen their condition by attempting something they are not capable of. This is why we also suggest family, friends or carers getting involved where this may be possible.
- If you can be such an “adopter” please email your details and your MP’s name and constituency details to Gail (gail@doctormyhill.co.uk)

- Gail will then send the adopter [ie YOU!] a free copy of Dr Myhill's new book second edition: "CFS/ME – it's mitochondria not hypochondria". Your chosen MP becomes 'Adopted' at this stage
- Attend your local MPs surgery, give him/her the copy of the book, show them Chapter 1 and try to convince to them to sign the slip!
- If you are successful, please scan the slip and return it to Gail (gail@doctormyhill.co.uk). At this point your chosen MP becomes 'Signed Up'
- If you cannot convince your MP to sign the slip, please leave them with the more detailed 'MAIMES letter' - see below for link to detailed MAIMES letter. Please also continue to contact your adopted MP and try to convince them via sheer persistence!
- **If your constituency MP has already been adopted by someone else, then you can still try and convince them - use the information below and either visit your MP or email them. The more people who contact their constituency MPs in this way, the better!**
- **Also if you want to go in groups to visit your constituency MPs then please do - this will also improve things as it will mean that there is less chance of brain fog getting in the way of persuasion - two heads are better than one!**
- **Or if you feel that friends and family or your carer or anyone could act on your behalf then that would be great too!**

Confirmation Slip for MP to sign
Here is the slip that we ask you to get signed by your adopted MP to support MAIMES' aim of having a public inquiry into the medical abuse of ME sufferers:

Campaign MAIMEs

DATE ……

I am the MP for ……

NAME ……

I agree with the aims of Campaign MAIMEs to establish that:
- ME is a physical disease with primarily physical causes.
- That this should be properly reflected by NICE Guidelines and by NHS treatments available to ME sufferers
- That this should be properly reflected by compensation, disability and pension benefits.
- That we require a Government funded, cross party Public Inquiry to establish the above.

SIGNED……

Date……

Witnessed by……

Here is Dr Myhill's message – launch date Feb 2017

Campaign MAIMEs (Medical Abuse In ME sufferers)

For decades PWME ('People With ME') have been subject to medical abuse by doctors who have repeatedly refused to accept that this illness has a physical basis. The evidence for this is:

- Patient testimony. PWME suffer clear physical symptoms but are told by their doctors that these are "all in the mind". They are made to feel like hypochondriacs. As a result, PWME have been denied proper treatments, compensation, disability and pension rights. See [1] below for details of this Patient Testimony.
- Such abused patients have organised themselves into support groups. These groups have lobbied valiantly but have failed to achieve proper recognition for their disease. These groups include: Gulf War Veterans, carbon mon-oxide poisoned PWME, Sheep Dip flu PWME, Aerotoxic pilots, 9/11 fireman, survivors of silicone PWME, sick building syndrome, mercury amalgam poisoned PWME, Lyme disease and co-infections and many others at home and abroad.
- PWME are at best referred to a team in which a psychiatric and symptom suppressing approach is applied. The psychiatrists employ two "therapeutic" tools namely Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET). These tools were subject to a Government funded trial (called 'PACE') which purported to show evidence of their effectiveness. This study has now been shown to be scientifically flawed. The PACE trial is at best incompetent and at worst a fraud and yet its conclusions are still believed and applied to PWME. In consequence, the above abuses were and continue to be perpetrated. Patients have been given wrong advice, their condition has worsened and state welfare and other benefits have been denied on the basis of this incompetent and potentially fraudulent study. Please see links [1] and [2] below for details of the harm that has been done to PWME and for details of the debunking of the PACE study.
- Doctors who recognise the seriousness and physiological basis of ME and treat them accordingly are targeted and prosecuted by the General Medical Council. Complaints against these doctors have arisen because their recommendations do not conform with conventional medical treatments and NICE guidelines.
- NICE Guidelines contain no logical, evidence based treatment for PWME. By contrast practitioners working outside conventional NICE Guidelines have established many effective treatments which are safe and efficacious and which get people back to work and off benefits. The British Society for Ecological Medicine, a group of likeminded medical doctors, spearheads many such techniques.

The above abuses have many parallels with the mental and physical abuse of children. Both groups are unable to properly defend themselves and are at the mercy of a misled, incompetent and ill-informed Establishment which employs many techniques to keep hold of its power-base, including cover-ups. Like the case of mentally and physically abused children it is time for a proper investigation into the abuse of ME sufferers.

Campaign MAIMEs is a drive for a Government Public Inquiry aimed at:

- Achieving proper recognition that this is a physical illness so that patients can properly access benefits and appropriate treatments. The abuses of PWME must be reversed.
- Rewriting NICE Guidelines using evidence based medicine that is logical, biologically plausible and with a proper scientific evidence base.
- Establishing that PWME should be treated by practitioners with specialised training in the physical causes of ME. These practitioners should include doctors, nutritional therapists and experienced patients.

Links

[1] – www.ncf-net.org/library/Reporting%20of%20Harms.pdf

[2] – www.tandfonline.com/doi/abs/10.1080/21641846.2017.1259724?journalCode=rftg20&

MAIMES update 20 July 2017 – 6 MPs signed up and another 84 adopted
Those in bold and 'starred' and "signed up" MPs and others are "adopted" MPs

AHMED-SHEIKH Tasmina - Ochil & South Perthshire
ALI Rushanara - Bow & Bethnal Green
BACON Richard - South Norfolk
BALDWIN Harriet - West Worcestershire
BARRON Kevin - Rother Valley
BLACK Mhairi - Paisley & Renfrewshire
BLACKFORD Ian - Ross, Skye and Lochaber
BLOMFIELD Paul - Sheffield Central
BRADLEY Karen - Staffordshire Moorlands
BRINE Steve - Winchester & Chandlers Ford
BROWN Lyn - West Ham
BROWN Nick - Newcastle upon Tyne
CADBURY Ruth - Brentford & Isleworth
CHALK Alex - Cheltenham
CHAMPION Sarah - Rotherham
CHAPMAN Douglas - Dunfermline & West Fife
CHURCHILL Jo - Bury St Edmunds
****DAVIES Chris** - **Brecon & Radnor****
DAVIES Dr James - Vale of Clwyd
DAVIES Glyn - Montgomeryshire
DJANOGLY Jonathan - Huntingdon
DRUMMOND Flick - Portsmouth South
DUNCAN Sir Alan - Rutland and Melton
ELLIOTT Tom - Fermanagh & South Tyrone
****ENGEL Natascha** - **North East Derbyshire****
EVENNETT David - Bexleyheath & Crayford
FRANCOIS Mark - Rayleigh & Wickford
FREER Mike - Finchley and Golders Green
GOVE Michael - Surrey Heath
GRADY Patrick - Glasgow North
GRAYLING Chris - Epsom & Ewell
GREEN Kate - Stretford & Urmstun
HAIGH Louise - Sheffield Heeley
HALL Luke - Yate, Thornbury
HARRINGTON Richard - Watford
HASELHURST Sir Alan - Saffron Walden
HENDRICK Mark - Preston
HENDRY Drew - Highlands and Islands
HEPBURN Stephen - Jarrow
HOWLETT Ben - Bath
HUNT Jeremy - South West Surrey
JOHNSON Alan - Hessle
JOHNSON Caroline - Sleaford & North Hykeham
KENNEDY Seema - South Ribble
KERR Callum - Galashiels
****LAING Eleanor** - **Epping Forest****
LEADSOM Andrea - South Northampton
LEIGH Sir Edward - West Lindsey, Gainsborough
****LESLIE Charlotte** - **Bristol North West****
LEWELL-BUCK Emma - South Shields
LUCAS Caroline - Brighton Pavilion
****LYNCH Holly** - **Halifax, West Yorkshire****
MAK Alan - Havant
MARSDEN Gordon - Blackpool, South
MAY Theresa - Maidenhead
McDONALD Stewart - Glasgow South
McNALLY John - Falkirk
MONAGHAN Dr Paul- Caithness, Easter Ross, East Sutherland
MORGAN Nicky - Charnwood and Lougborough
MORTON Wendy - Aldridge/Brownhills
MURRAY Ian - Edinburgh, South
OWEN Albert - Anglesey/Ynys Mon
PERKINS Toby - Chesterfield
POULTER Dr Dan - Central Suffolk and North Ipswich
QUINN Jeremy- Horsham
REES-MOGG Jacob - Bath and North East Somerset
REYNOLDS Emma - Wolverhampton North East
RICHIE Margaret - SDLP South Down
SAVILLE-ROBERTS Liz - Meirionnydd
****SHANNON Jim** - **Strangford****
SHEERMAN Barry - Huddersfield
SIDDIQ Tulip - Kilburn & Hampstead
SIMPSON David - Upper Bann
SMITH Jeff - Manchester, Withington
SMITH Karin - Bristol South
SOUBRY Anna - Broxtowe
STRINGER Graham - Blackley & Broughton
THOMAS Derek - West Cornwall & Isle of Scilly
TREDINNICK David - Hinkley
TRUSS Liz - South West Norfolk
TYRIE Andrew - Chichester & West Sussex
VAZ Valerie - Walsall South
WALKER Robin - Worcester
WEST Catherine - Hornsey & Wood Green

NICE decides to fully update its guideline on ME/CFS

Source: www.meassociation.org.uk/2017/09/breaking-news-nice-decides-to-fully-update-its-guideline-on-mecfs-20-september-2017

Following a stakeholder consultation, NICE have announced that they will now commence a full review of the guideline for ME/CFS, effectively overturning previous expert advice not to update it.

The following has been taken from the NICE website, and was shared across social media:
Sir Andrew Dillon, NICE chief executive, said:

"The strong message from stakeholders was that the continuing debate about the causes of this condition and the best approach to treatment argued for a review of the current guideline."

"We will now recruit a guideline committee which will include people with the condition and their carers, the healthcare professionals who treat them and the organisations which commission that treatment. As with all the guidance we produce, we will also ensure that stakeholders have the opportunity to provide evidence and insights throughout the development of the guideline."

'CFS/ME is a relatively common condition affecting around 190,000 people in the UK. It comprises a range of symptoms that includes tiredness, headaches, sleep disturbances, difficulties concentrating and muscle pain.'

'It can cause prolonged illness and disability and although some people have relatively mild symptoms and can still manage daily activities with additional rest, others have a serious illness that severely affects their everyday lives and may be housebound. The pattern of a person's symptoms, and their severity, can vary from day to day, or even in the same day.'

'Further details about the review, including a scope outlining what it will cover and information about recruitment to the guideline committee, will be published on the NICE website as they become available.'

Themes from stakeholder comments

'Several themes emerged from the comments received at consultation which are detailed below. Stakeholders highlighted concerns with the existing guideline related to diagnosis, and interventions for treatment and management. Additionally, stakeholders raised issues around service delivery in respect to variation in practice, definitions and particular sub-groups that the current guideline does not differentiate between.'

Definitions and aetiology

- Aetiology is outside the current scope. However many stakeholders raised the issue in respect to its impact on diagnosis and treatment.
- Interventions recommended in the guideline are based on the biopsychosocial model. Stakeholders raised that since 2007, much has changed with respect to biomedical knowledge. Biological models based on measurable abnormalities may need greater consideration.
- Newer terms for the disease are proposed e.g. US Institute of Medicine 2015 propose 'systemic exertion intolerance disease' (SEID) whilst other stakeholders advise that myalgic encephalomyelitis should be the preferred term.
- Severe ME is not well covered in the guideline and can cause profound issues. Some stakeholders indicated that parents of children with severe ME sometimes find that false allegations of child abuse are made against them due to poor understanding of symptoms, care and treatment by healthcare professionals and schools.

Diagnosis

- Oxford criteria (used to recruit to many studies included in the guideline) and NICE criteria are too broad.
- Newer diagnostic guidelines from the US Institute of Medicine (2015) and International Consensus Criteria (2011) are different from NICE criteria. Specific paediatric criteria have also recently been proposed.
- Late diagnosis is an issue.
- Concerns have been expressed over misdiagnosis and overlap with other conditions e.g. pernicious anemia, Ehlers-Danlos syndrome, and Postural Tachycardia Syndrome.
- Consideration of new research on metabolomics and biomarkers may be warranted.

Implementation, and information and support needs

- There is variation in primary care management, and there is evidence of unequal access to specialist services.
- Stakeholders noted that NICE's evidence reviews are not up to date, therefore patients are not receiving the full picture on recommended treatments (such as studies that have shown inefficacy of cognitive behavioural therapy [CBT] or harms of graded exercise therapy [GET]), nor being told about alternative treatments, which may affect informed consent.
- Greater support for GPs (many of whom feel ill-equipped in this respect) is needed to help with diagnosis, to provide accurate information (for example evolving evidence on risk and benefit of treatments), and to consider what an 'individualised management plan' might look like in practice.

Treatment

General

- A large volume of new evidence since 2007 needs to be incorporated.
- A separate section for children within the guideline should be considered.

CBT and GET

Against CBT and/or GET

- The US Centers for Disease Control and Prevention have dropped CBT and GET from their list of recommended treatments for CFS/ME.
- Evidence was cited of harms of GET, and pacing should be considered as an option.
- Key trials (particularly PACE [Pacing, graded Activity, and Cognitive behaviour therapy; a randomised Evaluation], but also Cochrane reviews of CBT and GET) have been criticised for inflating the efficacy of interventions. Issues include that some studies only require fatigue in the case definition, which may incorporate other fatiguing conditions with the potential to complicate results.
- There may be distinctions between people with CFS and with ME that should be accounted for.
- Patient surveys appear to contradict findings from randomised controlled trials and systematic reviews regarding the safety and efficacy of CBT, GET and pacing.

In favour of CBT and/or GET

- Large randomised controlled trials such as PACE and GETSET, and Cochrane reviews, appear to support the guideline recommendations on CBT and GET.
- A hospital department supplied data that patient reported outcome measures completed by patients receiving >18 sessions of CBT and/or GET improved 60% on the SF-36 (a patient-reported general health outcomes scale).

Other interventions
Additionally, stakeholders highlighted other interventions not currently covered in the guideline that NICE should consider. These included:

- Structured exercise programmes, for example the Klimas programme.
- Complementary and alternative therapies: co-enzyme Q10, magnesium supplementation, herbal medicine, acupuncture, the Perrin osteopathic treatment, gentle yoga/meditation and acupuncture/acupressure.
- Pharmacological treatment: rintatolimod, rituximab and anakinra.
- Faecal transplantation.'

CDC removes CBT and Graded Exercise as recommended treatments for ME/CFS

Source: www.statnews.com/2017/09/25/chronic-fatigue-syndrome-cdc/?s_campaign=fb&utm_content=buffer4065b&utm_medium=social&utm_source=facebook.com&utm_campaign=buffer

For years, people with chronic fatigue syndrome have wrangled with the Centers for Disease Control and Prevention over information on the agency's website about this debilitating illness. The website highlighted two treatments that became the de facto standards of care: a gradual increase in exercise and a form of psychotherapy known as cognitive behavioural therapy. The problem was that the evidence doesn't support these treatments.

This summer, after years of resisting pleas from patients, advocates, and clinicians, the CDC quietly dropped the treatment recommendations from its website. Its decision represents a major victory for the patient community — and for science. But the country's lead public health agency still has a long way to go to meet its responsibilities to the estimated 1 million Americans with this disease.

Exercise and psychotherapy might sound like the most benign of recommendations. But the hallmark symptom of chronic fatigue syndrome (also called myalgic encephalomyelitis, or ME/CFS) is that overexertion triggers relapses that can leave patients much, much sicker, as the Institute of Medicine documented in a landmark 2015 report. So a steady increase in activity can easily cause further harm, not benefit. In multiple surveys, more patients report getting worse, not better, from these "graded exercise" programs.

The theory underlying the two discarded treatments arose in earlier decades when the medical and scientific communities largely dismissed the devastating illness as illusory or psychological. According to that theory, such patients harbour mistaken beliefs that they suffer from an actual physical disease. As a result, they remain sedentary out of a misguided fear that activity will make them worse. They then develop severe deconditioning, perpetuating their symptoms.

However, more recent studies from Stanford, Columbia, Cornell and elsewhere have demonstrated that ME/CFS patients suffer from immunological, neurological, and other systemic dysfunctions. And scientists have reported that the bodies of ME/CFS patients generate energy inefficiently if they push beyond their limited capacities.

Moreover, the key piece of evidence the CDC once cited to support its recommendations of exercise and psychotherapy has been debunked.

That evidence was a multimillion-dollar British study called the PACE trial, the largest ever of the illness. The first results appeared in the Lancet in 2011, with other findings published in Psychological Medicine in 2013 and many other journals. But the trial had a host of flaws that render its reported results nonsensical and uninterpretable.

Most remarkably, the investigators relaxed their outcome measures so dramatically during the trial that participants could deteriorate during treatment on the key measure of physical functioning and still be declared “recovered.” Because of these changes, the findings were far more impressive than those the investigators would have obtained using the methods they originally proposed, as reanalyses of the trial data have shown.

The larger scientific community is up in arms over the problems with PACE. Earlier this year, more than 100 experts signed an open letter to Psychological Medicine (orchestrated and signed by one of us [DT]) stating that the trial’s flaws “are unacceptable in published research” and “cannot be defended or explained away.” The letter requested immediate retraction of the claim that patients “recovered” from the treatments. The journal refused the request.

Yet the trial and its claims remain hugely influential. In the U.S., Kaiser Permanente, the Mayo Clinic, and WebMD all continue to promote the therapies. So does Up-to-date, a popular decision-making tool for clinicians. In the United Kingdom, graded exercise and cognitive behaviour therapy continue to be the most widely offered treatments for the illness through the National Health Service system. However, the country’s National Institute for Health and Care Excellence, which creates clinical guidelines that are widely followed, recently announced that it will be conducting a “full update” of its current recommendations, citing the CDC’s decision as one reason for the update.

Despite the significance of the changes, few medical professionals are aware the CDC has dropped the exercise and psychotherapy recommendations. Nor do they know about the extreme care with which people with ME/CFS need to regulate their activity. If your doctor were to diagnose you with this condition today, the odds are good that you’d be advised to exercise your way out of it and to consult a psychotherapist.

While the CDC deserves credit for having removed information based on bad science that alone is not enough. The agency must also undo the damage it has caused.

First, the CDC needs to acknowledge that it got things wrong. So far, the agency has stated in response to questions that the changes were made because “there has been confusion about what we recommend related to exercise and therapy,” and the agency had not intended to recommend the PACE trial treatments despite using identical terminology. Given that ME/CFS advocates lobbied the CDC for years specifically about the problems with recommending these therapies, that explanation is hard to take seriously. An honest acknowledgement of error will go far toward re-establishing trust with the ME/CFS patient community.

Second, the CDC must actively disseminate the news that it no longer recommends these two ineffective and possibly harmful therapies and that no legitimate evidence supports their use. This should be part of a muscular plan, coordinated with the National Institutes of Health and other agencies, to counter the prevalent myths about ME/CFS among doctors, other health care providers, and the general public.

Third, the agency needs to reach out directly to health care and medical organizations, such as Kaiser Permanente and the Mayo Clinic, to urge them to stop recommending the treatments and ensure that the information they provide is truly up to date. That outreach should include the UK’s National Institute for Health and Care Excellence.

For decades, the ME/CFS patient community has been waiting for the CDC to get this right. The agency has finally taken a step in the right direction. Now it needs to redouble its efforts to find legitimate answers to the many outstanding questions about the illness and to investigate treatments that might actually work.

UNREST

In US theaters September 22 and UK theaters October 20

An ME film by Jennifer Brea

Jennifer Brea is an active Harvard PhD student about to marry the love of her life when suddenly her body starts failing her. Hoping to shed light on her strange symptoms, Jennifer grabs a camera and films the darkest moments unfolding before her eyes as she is derailed by M.E. (commonly known as Chronic Fatigue Syndrome), a mysterious illness some still believe is “all in your head.”

In this story of love and loss, newlyweds Jennifer and Omar search for answers as they face unexpected obstacles with great heart. Often confined by her illness to the private space of her bed, Jen is moved to connect with others around the globe. Utilizing Skype, she unlocks a forgotten community with intimate portraits of four other families suffering similarly.

Jennifer Brea’s wonderfully honest portrayal asks us to rethink the stigma around an illness that affects millions of people. Unrest is a vulnerable and eloquent personal documentary that is sure to hit closer to home than many could imagine.

Mon 16th October 2017

BFI SOUTHBANK
BELVEDERE ROAD, SOUTH BANK, LONDON, UK

Fri 20th October & Friday 27th October 2017

PICTUREHOUSE CENTRAL
CORNER OF SHAFTESBURY AVENUE AND GREAT WINDMILL STREET, PICCADILLY, LONDON, UK

Immune subsets?

Source: www.healthrising.org/blog/2017/07/15/immune-subsets-chronic-fatigue-syndrome-younger

Everyone with ME/CFS who's been around a bit must ask themselves at some point, "Do I have what she or he has?" Some people do great on treatments that others fail on. Some people get really, really sick while others maintain at least a modicum of health. The variety of symptoms, treatment responses, illness progressions, even illness triggers is astonishing. For every person who remembers the exact day their illness came crashing down, there's another who doesn't remember the day, week or even month they became ill, because their illness came on gradually.

There's the relapsing-remitting group which gets better and then worse, the plateaued group in which things remain much the same for decades and the progressive group where the illness gets progressively worse – sometimes to levels rarely seen in any nonlethal disease.
Most researchers concluded decades ago that ME/CFS must be littered with subsets. Just what those subsets are is a critical question, because as Jared Younger notes – a treatment that works for one subset probably won't work for another.

Some subsets appear to be showing up. Dr. Peterson's atypical subset typically has an unusual onset, an unusual course, has unusual comorbidities and is sicker than the rest of us. The immune systems of short duration patients (one subset) are on fire while the immune systems of longer duration patients (another subset) have run out of gas.

Jared Younger, in an unusual move, has released some early results from his big daily immune monitoring "good-day, bad-day" study to spread some early news on his findings.

Younger's "good-day, bad-day" study is an example of what the NIH does best: throw a boatload of money (> $1,000, 000 over three years) at a complex study. Younger's study allows him to track which immune factors track with a person's fatigue. A substance that rises and falls depending on how fatigued a person is, very likely has something significant about it.
The scale of testing is extraordinary. The study includes seventy people with ME/CFS, 20 healthy controls and 20 fatigued people with thyroid issues. The study involves twenty-five straight days of blood sampling from all 110 people, and each sample is tested for 51 substances associated with inflammation. If my math is right, that's approximately 140,000 tests for inflammatory substances over the life of the study. Each person will also report their fatigue levels daily on a personal handheld computer. All this data will be thrown into a computer to see what patterns emerge.

It's still early yet – the study is slated to run for several years – but in his YouTube video, Younger reported that some patterns may be starting to emerge.

The infection group?

C-reactive protein (CRP) levels are tracking with fatigue in about thirty percent of the ME/CFS participants. This suggests that a significant number of ME/CFS patients may have an underlying infection that's popping out during their bad days.

Â C-reactive protein is an "acute-phase" protein produced by the liver which shows up early in an infection, in cancer or in response to a tissue injury. Once immune cells called macrophages come into contact with dead or dying (infected) cells they release a substance called IL-6 which triggers the production of CRP (and fibrinogen) by the liver. When CRP binds to the surface of those cells, it gets the complement system involved which, in turn, helps more macrophages to find, engulf (phagocytyze) the infected cells and begin clearing them away.

The key to high C-reactive protein levels is plenty of dead or dying cells – something which usually occurs in the context of some infection (bacterial, viral, fungal), inflammatory diseases, malignancy or injured tissues. A very large (n=1125) fibromyalgia study recently found increased CRP levels in FM. It's not clear how high the CRP levels in the ME/CFS subset was relative to other diseases. but what is clear is that the high CRP levels would probably be swamped by the lower CRP levels in the two other ME/CFS subsets; i.e. CRP would not be elevated in the group as a whole.

Autoimmune diseases like lupus, Scleroderma, polymyositis, and dermatomyositis, on the other hand, generally have little effect on CRP levels. (In fact, one researcher proposed that CRP protects against autoimmune diseases.) That brings up the next group.

The Autoimmune/Autoinflammatory Group?

A substance called fractalkine – which is elevated in many autoimmune and inflammatory disorders – is tracking with the fatigue levels of another third of ME/CFS patients. Fractalkine, whose release is also triggered by damaged cells, promotes the production of pro-inflammatory cytokines.

Fractalkine is released by T-cells and other immune cells, endothelial cells and, most prominently, in the central nervous system.

In contrast to CRP, fractalkine is elevated in autoimmune diseases like rheumatoid arthritis, Sjogren's syndrome, systemic lupus erythematosus, and scleroderma, as well as diseases associated with systemic inflammation. In rheumatoid arthritis fractalkine directs immune cells to the joints. Fractalkine is also elevated in systemic inflammatory diseases like atherosclerosis and inflammatory cardiomyopathy.

Because fractalkine appears to be intimately involved in producing pathological pain, one wonders if these are the fatigue and high pain patients. One study has found increased fractalkine levels, not in the blood, but in cerebral spinal fluid in fibromyalgia. The study suggested that damaged neurons were triggering fractalkine release.

Because fractalkine plays a prominent role in producing inflammation, anti-fractalkine agents are being examined. Several existing drugs and supplements (baclofen, Apo-A1, resveratrol, epigallocatechin-3-gallate) may be able to suppress fractalkine production.

The Non-Immune Group?

In the last third of patients, Younger hasn't yet found a pattern, which suggests that the fatigue symptoms of this group may not be driven by the immune system. This, Younger suggested, could be a metabolic or other group.

Conclusions

Younger's "Good Day – Bad Day" study is looking for biomarkers in an entirely new way. Very different from the one-time shots at assessing immune problems that we usually see, Younger's study is tracking immune changes as they occur over time and pulling out the immune factors shown to be most associated with fatigue. Many other symptoms exist in ME/CFS, but as Dr. Lerner used to say, when the fatigue lifts the other symptoms follow.

Thus far the study suggests that the fatigue in ME/CFS may be being produced differently in the three subsets of patients: by an ongoing infection in one, by an autoimmune or autoinflammatory process in another, and by something outside the immune system in the third.

The most intriguing thing about Younger's study is its intensity. No one has examined the immune basis of fatigue in ME/CFS with Younger's intensity. It's no surprise, then, that Younger is getting results (CRP, fractalkine) new to ME/CFS – results that also, interestingly enough, fit with what we already know. Infection and autoimmunity, after all, have long been thought to be present in ME/CFS. Younger's early results suggests that they are present – but in different sets of patients.

If Younger's early results prevail and are validated, we should ultimately see radically different treatments for the two different subsets – immune activators and anti-pathogen treatments for one, and immune suppressants for the other. We'll also see studies focused on each subset and that could make all the difference in research.

Entire journal dedicated to the flaws of the PACE trial - **Journal of Health Psychology - Volume 22, Issue 9, August 2017**

Source: www.meassociation.org.uk/2017/07/the-pace-trial-the-making-of-a-medical-scandal-29-july-2017/
Further information: http://journals.sagepub.com/toc/hpqa/22/9

A Special Issue of the Journal of Health Psychology on the PACE Trial, is published and freely available online. It marks a special contribution of the Journal of Health Psychology to the literature concerning interventions to manage chronic health problems.

The PACE trial debate illustrates what can happen when researchers become entrenched in a particular point of view, and fail to engage in constructive exchange with critics and stakeholders.

It reveals an unwillingness of the Co-Principal Investigators of the trial to engage in authentic discussion and debate. It leads one to question the wisdom of such a large investment from the public purse (£5million) on what is a textbook example of a poorly done trial.

Unreliable at best, manipulated, at worst…
The Trial attracted unprecedented criticism, not only because it cost taxpayers an extraordinary sum (almost £5 million) but the trial itself was deeply flawed. The results are, at best, unreliable, and, at worst, manipulated to produce a positive-looking result. Patient groups have cried foul because they believe they are being sold a lie that talk therapy and exercise can cure ME/CFS when in fact many experience actual harm.

The PACE Trial was led by Professor Peter White of Queen Mary University London (retired), Professor Michael Sharpe of Oxford University and Professor Trudie Chalder of Kings College London. They published their results in the Lancet in 2011 with the contentious claim that CBT and GET brought 30% of patients back to normal while 60% improved.

The patient community reacted with scepticism and after a long battle with the PACE authors, a patient from Australia, Mr Alem Matthees, won a Freedom of Information Tribunal case to gain access to a small sub-set of the PACE trial data.

Reanalysis…
It was discovered that the PACE authors had altered the way in which they measured improvement and recovery to increase the apparent benefit of the therapies. Reanalysis showed that the improvement rate fell from 60% to 21% and the recovery rate fell from 22% to just 7% when using the original study protocol. The genie was out of the bottle.

In 2016 the Journal of Health Psychology published an Editorial by Dr. Keith Geraghty of the University of Manchester entitled 'PACE-GATE'. Geraghty suggested that the PACE authors had altered their procedures to make CBT and GET look more beneficial. The PACE trial team reacted with anger and submitted a cursory reply.

A host of experts on both sides of the debate were invited by JHP Editor Dr David F Marks to write Commentaries on the PACE Trial. All Commentaries were peer-reviewed. The majority agreed that the PACE Trial was flawed, that the PACE authors had altered their methods, breaking a fundamental principle of clinical trials, and that results from the trial were unreliable.

Conflicts of interest…
It also highlighted that the PACE Co-Principal Investigators had conflicts of interest by acting as consultants to large insurance companies and Professor White had also worked as an advisor to the Department of Work and Pensions, a main funder of the PACE trial, with a special interest in reducing social security benefits to disabled ME/CFS claimants.

Despite many serious concerns about the PACE Trial, the trial continues to be used by UK Governmental agencies, the NHS and the National Institute for Clinical Care Excellence (NICE) as part of the evidence-base to recommend CBT and GET to sufferers of ME/CFS. The current review by NICE of these treatments presents an opportunity to bring clinical practice properly in line with scientific evidence.

The Guildford & West Surrey ME/CFS Group newsletters aim to inform members of relevant news and treatment options. Use of the treatments is done at your own risk.