OXFORDSHIRE MYALGIC ENCEPHALOMYELITIS GROUP FOR ACTION
OMEGA ME

Omega Newsletter

Volume 97 Spring 2017

ME Research

This edition of the newsletter has a special focus on research. Have a look on page 2 at the open letter to *Psychological Medicine* about the PACE trial, to which OMEGA has added our signature. There is also a response on page 15 to the *Private Eye* article that was featured in the last newsletter. Karl Morten's talk which he gave at the AGM is also discussed on page 16.

We are asking readers to contribute to Dr Silk's research and there is a separate questionnaire included with the newsletter.

Particular thanks to the Bateman Horne Center for permission to publish two very interesting articles. "My Story in Art" looks at how art can be used as therapy for ME, specifically with Donni Lockridge's story in pages 4-7. Her story features some beautiful artwork which may well resonate with our readers. "Simple Way to Assess Orthostatic Intolerance" is reproduced on pages 7-8. Orthostatic intolerance is a symptom which affects many people with ME/CFS, and causes the need to lie down. Most GPs do not know how to test for it and this article explains how to do so, including web links for detailed instructions.

L.A. Cooper (who helped to organise the Millions Missing events) tells her story on pages 9-14.

Included with this newsletter is a subscription form for renewing your OMEGA membership for 2017. If possible, please pay by BACS to save us time and money. If you are able to, please also make a donation so that we can continue with our projects.

Contents

It's ME Awareness Month in May - there are details of our events on pages 15-16. A warm invitation is extended to all OMEGA members well enough to come to our afternoon tea in Sandford-on-Thames, especially children, young people and their parents.

As ever, we hope you enjoy this edition. Happy reading!

Updated Leaflet

We have amended our OMEGA leaflet; those with paper copies of the Newsletter will have one enclosed.

We would like them to be widely distributed around Oxfordshire. If you feel able to help

with this and would like us to send some to you, please contact Tessa at tessamary_keys@yahoo.co.uk.

Suggested places to put them are GP surgeries, complementary heath practices, libraries, village and town halls, etc.

An open letter to *Psychological Medicine* about "recovery" and the PACE trial.

13 March 2017

Dr. Robin Murray and Dr. Kenneth Kendler
Psychological Medicine
Cambridge University Press
University Printing House
Shaftesbury Road
Cambridge CB2 8BS
UK

Dear Dr. Murray and Dr. Kendler:

In 2013, *Psychological Medicine* published an article called "Recovery from chronic fatigue syndrome after treatments given in the PACE trial" [1] In the paper, White et al. reported that graded exercise therapy (GET) and cognitive behavioural therapy (CBT) each led to recovery in 22% of patients, compared with only 7% in a comparison group. The two treatments, they concluded, offered patients "the best chance of recovery."

PACE was the largest clinical trial ever conducted for chronic fatigue syndrome (also known as myalgic encephalomyelitis, or ME/CFS), with the first results published in *The Lancet* in 2011 [2]. It was an open-label study with subjective primary outcomes, a design that requires strict vigilance to prevent the possibility of bias. Yet PACE suffered from major flaws that have raised serious concerns about the validity, reliability and integrity of the findings [3]. Despite these flaws, White et al.'s claims of recovery in *Psychological Medicine* have greatly impacted treatment, research, and public attitudes towards ME/CFS.

According to the protocol for the PACE trial, participants needed to meet specific benchmarks on four different measures in order to be defined as having achieved "recovery" [4]. But in *Psychological Medicine*, White et al. significantly relaxed each of the four required outcomes, making "recovery" far easier to achieve. No PACE oversight committees appear to have approved the redefinition of recovery; at least, no such approvals were mentioned. White et al. did not publish the results they would have gotten using the original protocol approach, nor did they include sensitivity analyses, the standard statistical method for assessing the impact of such changes.

Patients, advocates and some scientists quickly pointed out these and other problems. In October of 2015, *Virology Blog* published an investigation of PACE, by David Tuller of the University of California, Berkeley, that confirmed the trial's methodological lapses [5]. Since then, more than 12,000 patients and supporters have signed a petition calling for *Psychological Medicine* to retract the questionable recovery claims. Yet the journal has taken no steps to address the issues.

Last summer, Queen Mary University of London released anonymized PACE trial data under a tribunal order arising from a patient's freedom-of-information request. In December, an independent research group used that newly released data to calculate the recovery results per the original methodology outlined in the protocol [6]. This reanalysis documented what was already clear: that the claims of recovery could not be taken at face value.

In the reanalysis, which appeared in the journal *Fatigue: Biomedicine, Health & Behavior*, Wilshire et al. reported that the PACE protocol's definition of "recovery" yielded recovery rates of 7 % or less for all arms of the trial. Moreover, in contrast to the findings reported in *Psychological Medicine*, the PACE interventions offered no statistically significant benefits. In conclusion, noted Wilshire et al., "the claim that patients can recover as a result of CBT and GET is not justified by the data, and is highly misleading

to clinicians and patients considering these treatments."

In short, the PACE trial had null results for recovery, according to the protocol definition selected by the authors themselves. Besides the inflated recovery results reported in *Psychological Medicine*, the study suffered from a host of other problems, including the following:

*In a paradox, the revised recovery thresholds for physical function and fatigue, two of the four recovery measures were so lax that patients could *deteriorate* during the trial and yet be counted as "recovered" on these outcomes. In fact, 13 % of participants met one or both of these recovery thresholds at baseline. White et al. did not disclose these salient facts in *Psychological Medicine*. We know of no other studies in the clinical trial literature in which recovery thresholds for an indicator actually represented worse health status than the entry thresholds for serious disability on the same indicator.

*During the trial, the authors published a newsletter for participants that included glowing testimonials from earlier participants about their positive outcomes in the trial [7]. An article in the same newsletter reported that a national clinical guidelines committee had already recommended CBT and GET as effective; the newsletter article did not mention adaptive pacing therapy, an intervention developed specifically for the PACE trial. The participant testimonials and the newsletter article could have biased the responses of an unknown number of the two hundred or more people still undergoing assessments—about a third of the total sample.

*The PACE protocol included a promise that the investigators would inform prospective participants of "any possible conflicts of interest." Key PACE investigators have had longstanding relationships with major insurance companies, advising them on how to handle disability claims related to ME/CFS. However, the trial's consent forms did not mention these self-evident conflicts of interest. It is irrelevant that insurance companies were not directly involved in the trial and insufficient that the investigators disclosed these links in their published research. Given this serious omission, the consent obtained from the 641 trial participants is of questionable legitimacy.

Such flaws are unacceptable in published research; they cannot be defended or explained away. The PACE investigators have repeatedly tried to address these concerns. Yet their efforts to date in journal correspondence, news articles, blog posts, and most recently in their response to Wilshire et al. in *Fatigue* [8] have been incomplete and unconvincing.

The PACE trial compounded these errors by using a case definition for the illness that required only one symptom – six months of disabling, unexplained fatigue. A 2015 report from the U.S. National Institutes of Health recommended abandoning this single-symptom approach for identifying patients [9]. The NIH report concluded that this broad case definition generated heterogeneous samples of people with a variety of fatiguing illnesses, and that using it to study ME/CFS could "impair progress and cause harm."

PACE included sub-group analyses of two alternate and more specific case definitions, but these case definitions were modified in ways that could have impacted the results. Moreover, an unknown number of prospective participants might have met these alternate criteria but been excluded from the study by the initial screening.

To protect patients from ineffective and possibly harmful treatments, White et al.'s recovery claims cannot stand in the literature. Therefore, we are asking *Psychological Medicine* to retract the paper immediately. Patients and clinicians deserve and expect accurate and unbiased information on which to base their treatment decisions. We urge you to take action without further delay.

Sincerely,

****

There are over a hundred signatories, including OMEGA.

http://www.virology.ws/2017/03/13/an-open-letter-to-psychological-medicine-about-recovery-and-the-pace-trial/

Thanks to these UK groups:

25% ME Group, Tymes Trust (The Young ME Sufferers Trust), Invest in ME Research, Hope 4 ME & Fibro Northern Ireland

And thank you to these UK individuals:

Simon Duffy, Jonathan Edwards, Keith Geraghty, Ian Gibson, Ellen Goudsmit, Malcolm Hooper, Eliana Lacerda, Charles Shepherd, Leonie Sugarman, Tony Ward, William Weir.

[1] White PD, Goldsmith K, Johnson AL, et al. 2013. Recovery from chronic fatigue syndrome after treatments given in the PACE trial. *Psychological Medicine* 43(10): 2227-2235.

[2] White PD, Goldsmith KA, Johnson AL, et al. 2011. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *The Lancet* 377: 823–836

[3] Racaniello V. 2016. An open letter to The Lancet, again. *Virology Blog,* 10 Feb. Available at: http://www.virology.ws/2016/02/10/open-letter-lancet-again/ (accessed on 2/24/17).

[4] White PD, Sharpe MC, Chalder T, et al. 2007. Protocol for the PACE trial: a randomised controlled trial of adaptive pacing, cognitive behaviour therapy, and graded exercise, as supplements to standardised specialist medical care versus standardised specialist medical care alone for patients with the chronic fatigue syndrome/myalgic encephalomyelitis or encephalopathy. *BMC Neurology* 7: 6.

[5] Tuller D. 2015. Trial by error: the troubling case of the PACE chronic fatigue syndrome trial. *Virology Blog,* 21-23 Oct. Available at: http://www.virology.ws/2015/10/21/trial-by-error-i/ (accessed on 2/24/17)

[6] Wilshire C, Kindlon T, Matthees A, McGrath S. 2016. Can patients with chronic fatigue syndrome really recover after graded exercise or cognitive behavioural therapy? A critical commentary and preliminary re-analysis of the PACE trial. *Fatigue: Biomedicine, Health & Behavior*; published online 14 Dec. Available at: http://www.tandfonline.com/doi/full/10.1080/21641846.2017.1259724 (accessed on 2/24/17)

[7] PACE Participants Newsletter. December 2008. Issue 3. Available at: http://www.wolfson.qmul.ac.uk/images/pdfs/participantsnewsletter3.pdf (accessed on 2/24/17).

[8] Sharpe M, Chalder T, Johnson AL, et al. 2017. Do more people recover from chronic fatigue syndrome with cognitive behaviour therapy or graded exercise therapy than with other treatments? *Fatigue: Biomedicine, Health & Behavior*; published online 15 Feb. Available at: http://www.tandfonline.com/doi/full/10.1080/21641846.2017.1288629 (accessed on 2/24/17).

[9] Green CR, Cowan P, Elk R. 2015. National Institutes of Health Pathways to Prevention Workshop: Advancing the research on myalgic encephalomyelitis/chronic fatigue syndrome. *Annals of Internal Medicine* 162: 860-865.

My Story in Art

By Leigh Reynolds | September 26, 2016

https://batemanhornecenter.org/story-in-art/

When you are living with chronic illness like ME/CFS and Fibromyalgia, engaging in healthy grieving can be among the many challenges. You may face periods of shock and numbness, denial, anger, and intense emotional pain. Experts say it is essential that you engage your grief reaction and practice patience with yourself as you learn to express your feelings — journal, cry, sing, and talk to others about your pain.

Some, like Donni Lockridge, have found art to be a tremendous outlet for their feelings.

Donni is a person with ME/CFS/FM and she has generously chosen to share some of her body of work with us.

"I paint about our collective experiences, trying to give voice to our feelings through this medium."

It is Donni's hope that through sharing her art with a wider audience, someone else may connect with it and be better able to express their own feelings.

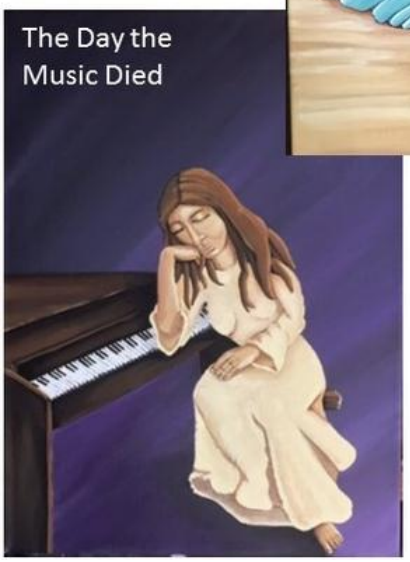
If you have artwork, poetry, music or a story to share, please let us know. Learn more about how you can make a submission to the *Patient Voice* **here**

https://batemanhornecenter.org/patient-voice/

My Story in Art by Donni Lockridge

It is often so hard to put words to our lives and feelings. I became ill with ME/CFS 8 years ago. I began painting last year. Images, stories conveyed on canvas, expressions of our pain, frustration, confusion, and the outside world's often lack of compassion or inability to understand what it is like to be locked into bodies that merely exist. So, the art was born.

I hope it brings a sense of understanding for sufferers and non-sufferers.



https://t.co/C68IFBnvjX

Simple Way to Assess Orthostatic Intolerance

https://batemanhornecenter.org/assess-orthostatic-intolerance/

By Lucinda Bateman MD, September 27, 2016

NASA 10 Minute Lean Test*

Orthostatic intolerance (OI) is an umbrella term used to describe abnormal autonomic nervous system response to orthostatic challenge. Orthostatic hypotension (OH), neurally mediated hypotension (NMH) [or neurogenic hypotension] and postural orthostatic tachycardia syndrome (PoTS) are terms used to describe variants of this response. The new evidence-based IOM clinical criteria for ME/CFS establish that orthostatic intolerance is a common and often overlooked feature of illness that is objectively measurable. OI may contribute to dizziness, fatigue, cognitive dysfunction, chest and abdominal discomfort, and pain manifestations.

We recommend that all ME/CFS and Fibromyalgia patients have a NASA 10-minute Lean Test to assess for orthostatic intolerance. In order to help facilitate the adoption of this test, the Bateman Horne Center has put together these simple instructions for healthcare providers in order to educate them on the process and encourage them to utilize it with their patients.

We encourage ME/CFS and FM patients to share a link to this post, or download the instructions below in order to share this information with their healthcare team.

You can download a copy of the provider instructions here:

https://batemanhornecenter.org/wp-content/uploads/2016/09/NASA-Lean-Test-Instructions_1_31_2017.pdf

You can download a copy of instructions for patients (to be used prior to taking the test) here:

https://batemanhornecenter.org/wp-content/uploads/2016/09/NASALeanTest_PatientPrepInstructions_1_30_2017.pdf

The test will be most revealing if measures that reduce orthostatic intolerance are withheld before testing. For example: limit extra fluid and sodium intake, do not wear compression socks and alter the intake of medications that might influence the test (see below). These treatments can be resumed after the test. Use continuous monitoring devices when possible.

Ask the patient to remove shoes and socks and lie down on a bed or exam table in supine position. After patient has been lying quietly 5-10 minutes, record blood pressure and pulse. Repeat a minute later. If repeat vitals are not similar, retake until two consecutive vital readings are relatively consistent. The goal is to determine the average resting supine blood pressure and pulse.

Next, ask the patient to arise, stand straight and lean against the wall, with only shoulder blades contacting the wall, and heels approximately 6" from the wall. Coach patient to relax as much as possible. Once the patient is leaning against the wall, start the timer and record the first standing blood pressure and pulse. Repeat blood pressure and pulse every minute for the next 10 minutes. Instruct patient not to talk and chat, except to report symptoms, and to resist moving feet or shifting weight. Observe patient for light-headedness or signs of pre-syncope and stop the test if the patient is about to faint. Observe skin and extremities for swelling or changes in colour and temperature. Assess cognition. Include any comments as applicable. A template that can be used to record blood pressure and pulse is shown below:

Orthostatic Vital Signs/The NASA 10-minute Lean Test

	Blood Pressure (BP)			
	Systolic	Diastolic	Pulse	Comments
Supine 1 minute				
Supine 2 minute				
Standing 0 minute				
Standing 1 minute				
Standing 2 minute				
Standing 3 minute				
Standing 4 minute				
Standing 5 minute				
Standing 6 minute				
Standing 7 minute				
Standing 8 minute				
Standing 9 minute				
Standing 10 minute				

General test preparation instructions, directed by provider, adjusted as appropriate for each patient.

Limit water/fluid intake to 500-1000 mL for 24 hours before the test.

Limit sodium intake for 48 hours before the test.

Do not wear compression socks or clothing on the day of the test.

Withhold medications, supplements, or substances that might affect blood pressure or heart rate, with timing based on the drug half-life and patient safety. Examples:

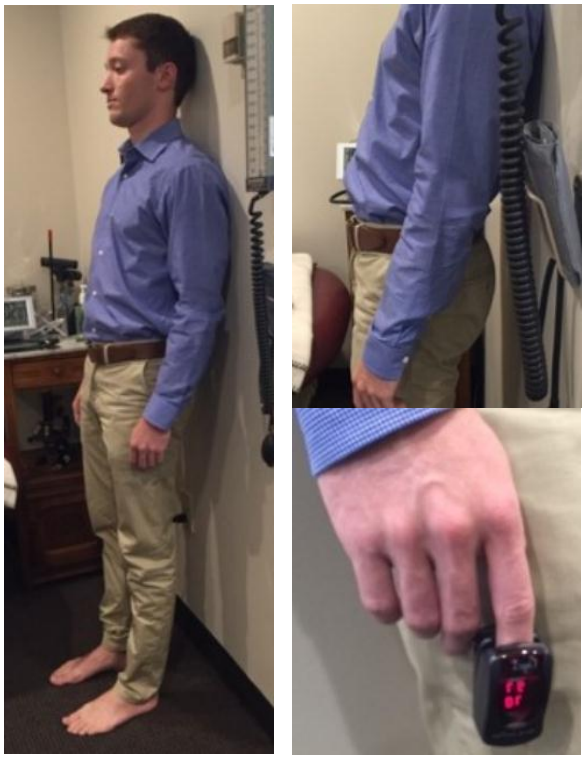
- midodrine or Northera
- fludrocortisone
- beta blockers such as propranolol, metoprolol or atenolol
- stimulants such as methylphenidate, dexadrine or caffeine
- tricyclic antidepressants (TCA)– amitriptyline, doxepin or cyclobenzaprine
- Serotonin Norepinephrine Reuptake Inhibitors (SNRI) e.g. Cymbalta or duloxetine
- tizanidine

*The NASA 10-minute Lean Test is a variant of a test used by NASA researchers to test for orthostatic intolerance[1]; it reduces muscular influences on venous return, a major cause of variability in orthostatic testing. Passive stand testing has been validated as an equivalent or superior measure of orthostatic intolerance as compared to head-up Tilt Table tests[2,3].

[1] Bungo, M. W., Charles, J. B., & Johnson Jr, P. C. (1985). Cardiovascular deconditioning during space flight and the use of saline as a countermeasure to orthostatic intolerance. *Aviation, space, and environmental medicine*, 56(10), 985-990.

[2] Shvartz, E., Meroz, A., Magazanik, A., Shoenfeld, Y., & Shapiro, Y. (1977). Exercise and heat orthostatism and the effect of heat acclimation and physical fitness. *Aviation, Space, and Environmental Medicine*, 48(9), 836-842.

[3] Hyatt, K. H., Jacobson, L. B., & Schneider, V. S. (1975). Comparison of 70 degrees tilt, LBNP, and passive standing as measures of orthostatic tolerance. *Aviation, Space, and Environmental Medicine*, 46(6), 801-808.



"On bad days the slightest move can cause anguish. I can't speak and I can't concentrate on anything"

L.A. Cooper is the person who organised the #MillionsMissing demo in this country.

http://thetab.com/uk/2017/02/07/bad-days-slightest-move-can-cause-anguish-i-cant-speak-i-cant-concentrate-anything-30634

by Isabella Eckert

The reality of living with ME, the disease doctors can't diagnose

It started at the age of 10, when L.A. caught a common stomach bug. She began sleeping for 20 hours a day, waking up to be "violently sick", then falling back to sleep. No one knew what was wrong with her, and she was diagnosed and medicated for countless illnesses she didn't have. It wasn't until she was 13, three years later, she was diagnosed with ME, myalgic encephalomyelitis – commonly known as "Chronic Fatigue Syndrome".

L.A. Cooper is now a prominent activist and campaigner for ME Action Network UK, "for British patients to empower each other to fight for health equality".

She told The Tab what it's like to live with and fight an undiagnosable and incurable disease:

Explaining what it's like to live with an incurable, untreatable disease that invokes such rife discrimination and mockery in the media and medical community is almost impossible. No matter how carefully I choose my words, how cautiously I construct my sentences, how eloquently I convey the pain of this, it's virtually impossible for someone who hasn't experienced it to truly know what having ME is like.

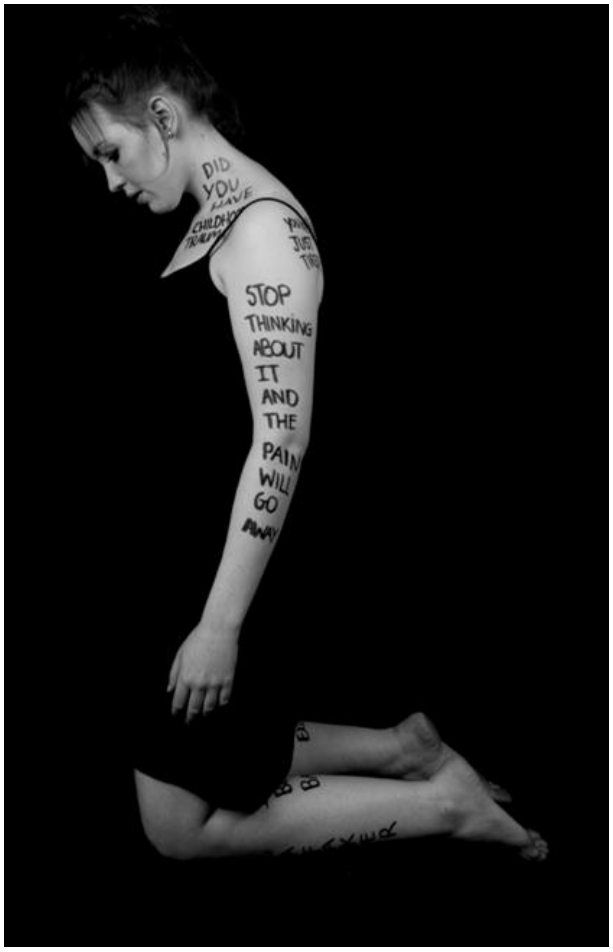
It's riddled in my body. Every ounce of me is affected from my muscles to my joints, from my stomach to my reproductive organs, from cognitive impairment – particularly aphasia – to heightened sensitivity to noise and touch. A single tap on my skin can ache on the worst days.

Pictured below: November, when I was hospitalised with sepsis.

The only way in which I can describe what having ME is like, is by trying to make you understand that I am in constant battle with my body. My spirit, my will, my mentality, my character, they all want to live. I want to live, but my body wants to destroy itself. It's as though something has taken aggressive hold and the only way my body knows how to react is to shut itself down. Like an attempt to self-contain

something deeply malevolent pulsing through my veins. And there's not only nothing that I, nor the most expensive and qualified specialists can do. There's also no way of knowing what form it will take next or how powerful it will become, leaving a grey smear in any thoughts of the future I have.

As a child, I was extremely athletic and I still love sports and activity. I joined my gym, I started running and weight training. A little over two weeks before my 10th birthday, my entire family came down with a virus, a really common stomach bug. By the Saturday night, everyone was getting better, and I was becoming steadily worse. On the Sunday, I was rushed to hospital in inordinate amounts of pain.



What followed for the next three years were some of the most difficult times of my life. I was in and out of hospitals, seeing specialists, being told that my tests were coming back irregular, that they could see I was extremely sick, that they didn't want to send me home under any circumstances, yet admitting that they couldn't detect what it was destroying my health. I was being juggled between wards, and I hardly remember anything outside of it all. I would be completely comatose for 20 hours a day, waking up to be violently sick, then passing out again. I went through numerous diagnoses, was put on medications for illnesses I didn't have. Nothing worked.

When someone mentioned "Chronic Fatigue Syndrome" I thought it was another pointless diagnosis. Firstly, because pointless diagnoses are all I had known. And secondly, because, while the fatigue was prominent, it certainly wasn't my biggest worry. The name didn't fit. It sounded like something you'd have after an especially bad cold or bug, something you'd get over. What I had was insidiously strong. A few months after I turned 13, I was finally explained all the symptoms of "CFS" and it made perfect sense. It was then that I was introduced to the name "Myalgic Encephalomyelitis" or "ME".

Going through my childhood, my adolescence and now living in my twenties with ME, I feel as though I've heard every cliched insult and misconception there is out there. One doctor told me that if I thought about the pain less, it would eventually go away. I was ten years old and curled on the GP's office floor wanting to scream because of the pain. I had authority figures insinuate I was faking it all, that I wasn't trying hard enough or that it was growing pains.

When I'm able to do something, many have treated me with suspicion and question me. When I can't do something, I'm told that I can't let my illness control my life. And truly, this is what stays with you.

Some days I can't move my head, I can't speak, my muscles have lightning bolts streaking through them. I can't stand for the aching in my chest, the burning in my skin or the throbbing in my head. I bully myself – I lay in a dark, silent room, unable to do anything but think about how I can't even control my own body. I think about how I push myself incessantly, how my expectations are too high and I need to make peace with the fact that whatever this is, it's not going away anytime soon. And yet, the next time I can get out of my bed, the cycle starts all over again, and I find myself making the same mistakes which land me in bed.

I'm a young woman who wants to achieve, who wants to learn and grow, who wants everything my peers have. It's a human trait to strive with

everything you have. It's just a shame the situation is so unnatural that it doesn't always permit me to.

Like anyone facing that level of sickness, I visited practically every doctor I could. Some were kind and tried to understand, yet their education in ME was severely lacking, and there was nothing they could do. Others were mocking and hurtful, and believed the common misconception that I was over exaggerating, or a hypochondriac. Faced with no healthcare, no treatment and little compassion, I knew the state of things for people with ME had to change. And it was that moment that I became an activist.

There will never be a day where this doesn't affect me, not while there's no treatment and little reliable research in the UK.

On days I call "good", my body feels heavy when I wake up. It's difficult to walk and talk, and the slightest noise feels as though it's banging inside my ear drum. After a few hours, I can study or work, I feel fairly cognitive and capable before an inevitable crash at 2pm, another lift an hour or so later, and an even deeper crash at 5 or 6pm. At night, I frequently struggle to sleep because of nerve and muscular pain, and my brain is wired, like it's tumbling around.

I wake up frequently throughout the night and I don't remember the last time I woke up feeling refreshed and energised. In many instances, sleeping can cause even more symptoms for me, but not sleeping can also have disastrous effects.

My bad days aren't something easy to explain. It's usually that I'm so riddled with muscular pain that the slightest move can cause anguish. I can't speak and I can't concentrate on anything, even pictures. But the worst aspect of it is I'm still awake. My brain is still going, and all you're left with is your own boredom and repetitive thoughts.

As far as coping mechanisms go, I've heard some truly inspirational ones throughout the years, and I can say that I've tried them all. There is only one prescription medication I've found to take the edge off the pain, but unfortunately it interferes with other symptoms so I only take it when I'm absolutely desperate. Herbal solutions and holistic solutions haven't given any relief, and while I enjoy doing yoga and swimming, they alleviate some discomfort for a short period of time before ultimately resulting in bigger and more painful setbacks.

L.A. Cooper
@lacooperUK
Follow

I had a *pretty* amazing view this afternoon... #MillionsMissing
2:49 PM - 27 Sep 2016
5 12

It's a somewhat cliched, boring solution, but positivity is the most helpful tool. I am naturally optimistic. I believe in the good of people and the intellect and drive of so many who do want to change the way ME is perceived and treated if they are given the chance. I remember that I

have the support of family and many, many genuine, caring friends unlike many with ME that I know.

I am continually aware that I am still able to get out of bed most days, however painful it is. I remember that I am able to have conversations, eat some solid food, enjoy some music and sunshine. So many basic pleasures in life have been refused to people with ME because of the severity of the condition. And that is something that I am always thankful for. And every ounce of my being will strive for change for those who cannot.

The fundamental tools that many people with incurable diseases are given are completely unavailable for people with ME. I know parents who struggle to get access to mobility aids for their children with the disease, or even a good education. I know people newly diagnosed who have had to worsen their condition by taking tests that show numerous counts of "proof" that the diagnosis is real, in order to receive the dispensation they need from work.

I know people who've had ME for decades and have drained their bank accounts travelling to countries that offer some hopeful treatments because not only are they not available in the UK, there is nothing available in the UK. People who have been ostracised by their friends and family, and must now try and face this alone because of the incorrect information forcefully pushed out there. Everything needs to change.

We need tests and biomarkers. We need trials for drugs that, in some cases are showing full remission in patients in Europe (this is an anti-cancer drug and is proving very successful for so many). We need terms such as "Chronic Fatigue Syndrome" to be differentiated from ME.

It's not just that we need funding for research (we do) or that we need our medical practitioners to be educated (we do), we need to start from scratch. Most believe that the defining symptom of ME is fatigue. It isn't. The defining symptom is exertion malaise, meaning that the more activity people with ME do, whether that be cognitive or physical, the worse the symptoms become.

This has proven the most detrimental misconception, as in many illnesses displaying fatigue, such as depression, exercise can do wonders. Yet prescribing exercise for someone with ME is like telling diabetics to treat their illness with sugar. This means that there have been many instances, people with ME have claimed that while they walk into graded exercise therapy (the only treatment offered in UK) they have been wheeled out, some being permanently disabled from the exertion.

Pictured left: L.A. at the #millionsmissing demonstration.

There is so little understanding of the core traits of ME, that individuals are forced to become their own doctors, their own scientists. Across the world, some 17 to 20 million (perhaps as high as 30 million) people are losing their lives to ME through degeneration of their bodies, complications or other diseases (it is highly common for patients to develop cancer) or suicide, which is highly prevalent after years of pain without care and isolation.

As strange as it seems, I'm not unhappy and I'm not depressed about my personal experience. I made a choice to use this disease as a way of looking at things differently. As a way of driving myself for change. As a way of becoming a more compassionate, understanding person towards others with physical, mental or emotional difficulties. I hope I've succeeded in that.

ME made me the way I am, and has given me an outlook that many are refused. The community is filled with inspiring, intelligent, kind, generous, giving people who are level-headed yet motivated to create a better world. My ME was like taking the red pill, seeing everything through new eyes, the beauty and the horror, and choosing to fight every day because and despite of it.

I can't sugarcoat what has happened with this disease. What has been allowed to happen to

people who never once asked for anything like this. Who've given their all as activists and often can't continue in the level of pain they were living in. For decades, this has been brushed aside as the "yuppie flu" or (specifically for female sufferers) as hysteria. When the scientific evidence proves it is such as a disastrous disease, yet we have not moved an inch closer to finding a cause and cure. I can't sugarcoat any of that, and I don't want to.

All I want is my struggle to pave the way for generations to come, for little nine-year-old girls to not have to endure what I have endured. And if I can create change, even in a minute way, this journey will all be worth it.

Answers to Can You Spot Mary?

This is the challenge from the last newsletter. Mary was in two pictures! Did you also find Jayne and David P?

Five points if you found them all – and bonus points if you also spotted other members of the Newsletter team and committee members: Catherine, Jo, Norman (two), Patricia, Pat, Tessa, Nicki, Iona and Priscilla (Max points 15).

Correspondence in *Private Eye*

These are three letters about the article we published in the last newsletter, from *Private Eye*.

...M.D. (Trial on Trial, Eye 1433) acknowledges that the PACE study on which many of the claims of successful treatment of ME/CFS depends, was controversial and that patients have had to fight to get access to the trial data. M.D. did not however reveal the extent of either the controversy or the obfuscation. The PACE trial was funded with £5m of public money, largely from the Medical Research Council (MRC), while follow up studies have received £100,000s more from the National Institute of Health Research. At least one other associated study (FINE) has received a further £1m from the MRC, giving a spend approaching £7m from the public purse on a very narrow and so far largely unrewarding focus of research.

One might think that having invested such large sums, the public would have access to the anonymised data that these studies have produced. This is not the case with PACE and its allied studies; the legal data holder Queen Mary, University of London (QMUL), not only forced patients to seek a judgement from the Information Commissioner but when that was successful, QMUL insisted on an appeal. In total QMUL racked up £250,000 in legal fees to stop patients getting insight into research that was supposedly carried out on their behalf.

Patients have been accused by researchers of being vexatious, while unfounded stories of harassment and worse have been uncritically reported by the BBC and the Guardian. When repeated by QMUL in its FOI appeal, these claims were roundly dismissed by the court. No one should support harassment of researchers, but neither should NHS researchers embark on a campaign of denigration of patients, nor should they obfuscate data that has been funded by the public.

N.A WRIGHT.

...Once again MD has struck a blow for the cause. I am housebound with the condition, my lifestyle in tatters. Raised awareness accompanied by informed comment represents one of the very few remaining straws left to clutch. M.D. I salute you!

BRIAN DONOGHUE,
Edinburgh.

More on ME and M.D.

Sir,

M.D. (Trial on Trial, Eye 1433) criticised the PACE trial of treatments for chronic fatigue syndrome, which we led, for not sharing data with others. We did not give data to a member of the public because we had no consent of our participants to do so, but have shared data many times with researchers who agreed to respect patient confidentiality. We promised participants that we would keep their data secure and confidential; that is one of the main reasons why Queen Mary University of London went to court – to protect this promise.

M.D. also says that we await further published analyses of our trial. We don't, because we have already published these analyses ourselves, available on the trial website. They made no difference to our conclusions that both cognitive behaviour therapy and graded exercise therapies are safe and effective treatments. We do agree with M.D., however, that further trials are necessary to help those who do not respond to these treatments.

PROFESSORS PETER WHITE,
TRUDIE CHALDER AND
MICHAEL SHARPE,

Queen Mary University of London,
Kings College London,
University of Oxford.

Notices

Free 3-wheel walker – Will be delivered free to a person with ME anywhere in Oxfordshire. enquire.omega@gmail.com

iPad request – Is anyone interested in teaching me to use my iPad, for a small payment? enquire.omega@gmail.com

Subscriptions

Included with the Newsletter this time is a subscription form for renewing your OMEGA membership for 2017.

The committee have decided to keep the annual subscription at the same level that it has been for a very long time: £10 or £5 (unwaged).

Many members also choose to make a donation, which you can do at any time during the year.

All funds go towards OMEGA's work to raise awareness of the illness and support members, including meetings and newsletters, leaflets and displays.

Talk by Dr Karl Morten

Rose Hill Community Centre on Saturday 15th October 2016.

After the AGM was held, the main event of the day was the talk by Karl Morton. I'd like to think that people were keen to find out more about OMEGA, but I think the good attendance was more likely to be due to the interest in Karl's research!

The research, in Oxford and Newcastle upon Tyne, will use samples from the newly launched UK ME/CFS Biobank, and will help scientists to better understand the molecular and biochemical basis of the disease.

Looking at chemical changes in the cells may help researchers understand what is going on in the metabolism of people with ME and how the mitochondria are affected.

There were many questions afterwards and Karl took everything in his stride, including a last minute change of rooms.

It is exciting to have biomedical research happening on our doorstep in Oxford, and OMEGA would like to support both Karl and Jamie in their work.

This talk was filmed by Aimee Winkfield from Rose Hill News and we are hoping that it will eventually be available for people to watch online.

See item on page 16 about the ME Association Appeal.

Pat Williams

OMEGA ME Awareness May 2017

We will again be following the ME Association's lead and "Going blue for ME" by wearing blue and/or our blue ribbons for ME

Awareness and inviting friends and family and potential new members who wish to know more about ME to our social/support groups.

As well as our usual groups we will also be hosting an afternoon tea, for all OMEGA members well enough to come and for children, young people and their parents, in Sandford-on-Thames (details below).

Of course we are aware that a lot of our members are not well enough to attend and we shall be thinking of them at these events.

Support / social groups in May

Tuesday May 2nd
Banbury group
12 noon – 1pm at The Mill, Banbury OX16 5QE
Contact: Oxley76@btinternet.com

Saturday May 6th
A special social group for **all** OMEGA members and for children, young people and their parents
Venue The Main Hall, Sandford-on-Thames Village Hall, Henley Road, Sandford-on-Thames OX4 4YN
Time 2.45 - 4.45pm for afternoon tea.
RSVP Please let us know if you intend to come and also if you have any dietary requirements
Contact: enquire.omega@gmail.com

Monday May 8th
Oxford group
1.15 pm onwards at
De Vere Hotel (formerly Thames Four Pillars Hotel), Sandford-on-Thames, Oxford OX4 4GX
Contact: Joandjohn36@aol.com

Monday May 15th
South Oxon group
12.30 – 2pm at Shillingford Bridge Hotel, Oxon, OX10 8LZ
Contact: tessamary_keys@yahoo.co.uk

Tuesday May 16th
WAGS Wantage and Grove ME/CFS Support Group
10.30-12pm at Cornerstone Cafe, 10 Savile Way

Grove OX12 0TP
Contact: anniekingsbury@talktalk.net

You smashed it! But our Christmas Appeal will stay open – and here's why

Story by Sarah Staples, 6 January 2016

http://www.meassociation.org.uk/2017/01/you-smashed-it-but-our-christmas-appeal-will-stay-open-and-heres-why-6-january-2016/

The ME Association's Christmas appeal to fund groundbreaking research – which hit its £50,000 target in less than four weeks – is to stay open, with money raised from it helping to build links between patients and researchers.

Helen Hyland, the charity's fundraising manager, said: "*Make ME Better* is the most ambitious campaign we have ever launched. To have raised its total in less than a month, it's beyond anything we dreamt of, an unbelievable achievement.

"So I'm delighted to announce that we have decided to keep the appeal running until its scheduled end date of February and that – after talks with Dr Karl Morten, who is leading the research – we have agreed other ways that we can support his team."

Make ME Better was launched to fund scientists from the University of Oxford and Newcastle University to study 300 blood samples from patients with ME and a control group, analysing metabolomics – chemical clues that left behind after changes in cells.

Identifying these changes could help find a simple blood test for the illness and open doors to attract pharmaceutical companies to invest in research for new drugs to help treat it.

Now it can be revealed that the extra money raised by *Make ME Better* will be used to recruit a part-time postdoctoral researcher to support Dr Morten and his colleague, Professor Jamie McCullagh.

The researcher will build new links with the Oxford Fatigue Service, recruiting patients with ME into a series of new pilot studies into the illness. Something that, in the eyes of Dr Morten, is crucial.

"There needs to be deeper co-operation between clinicians, researchers and patients. Taking on a researcher will mean that we can reach out to those worst affected by ME, who are often housebound and would otherwise find it physically impossible to be involved in studies," he commented.

"In addition we will establish links between the clinic and research laboratories which will be of fundamental importance when applying for larger grants from the MRC and Wellcome. Being able to demonstrate this clinical connection and provide evidence that we can recruit patients to studies will significantly increase our chances of success.

"These projects will be exploring the disease's biological basis and exploring areas such as the microbiome, developing biomarkers of energetic dysfunction, functional brain imaging and muscle spectroscopy."

The researcher will also help to analyse the large amount of data generated by the metabolomics study.

"Our goal is to make Oxford University a global centre for research into ME. The studies we do here will provide pilot data for future grant applications to pharmaceutical companies and charitable grants that will help us push the boundaries of ME research."

Helen Hyland added: "Personally, I'd like to shake everyone by the hand who has donated so far – although given people's generosity, it would be a very long line. So instead, I'd like to take this opportunity of saying: "Thank you!"

"But now the work goes on. We can't *Make ME Better* overnight, but it really feels as if we're on the start of something."

To donate to *Make ME Better*, visit our JustGiving page:

www.justgiving.com/campaigns/charity/meassociation/makemebetter

Diary Dates

Socials and OMEGA Regular Events

For further details of all events, please see: www.omegaoxon.org

OMEGA Meditation

Meditation groups are held monthly, on Fridays, from 11am-1pm. For more details email omega.meditation@phonecoop.coop

Banbury Support Group

Meetings are on the first Tuesday of the month, between 12 noon and 1.00pm.
Location: The Mill Arts Centre, Banbury, OX16 5QE.
We are a small, friendly and informal group who meet regularly on the first Tuesday of each month.
Driving: There is ample metered and some free disabled parking just outside.
On Foot: It is just across the canal from Castle Quay shopping centre.
Please feel free to pop in anytime, whether it is for a quick chat or longer if you wish. Family and carers are very welcome.
Facebook: Banbury ME Support Group
Email: megroupbanbury@btinternet.com for details.

OMEGA Oxford Area Social Gathering

The OMEGA Oxford Area Social Gathering takes place on the first Monday of every month (unless it falls on a bank holiday and it will then be the following Monday) from 1.15 pm onwards at the De Vere Hotel (formerly Oxford Thames Four Pillars), Henley Road, Sandford-on-Thames, Oxford, OX4 4GX. This is an opportunity for OMEGA members and carers to socialise with other ME sufferers. For more details, phone Jo and John. The event in May (ME Awareness month) will be on 8th May due to the bank holiday. The 3A city bus runs every half hour from Oxford to the hotel.

Wantage and Grove ME/CFS Support Group

Friday 21st April, 1-3pm, Cornerstone Cafe, Grove
Tuesday 16th May, 10.30-12 noon, Cornerstone Cafe, Grove
Thursday 15th June, 12 noon, lunch meeting at The Lord Nelson
Tuesday 4th July, 1-3pm, Cornerstone Cafe, Grove
Monday 31st July, 10.30-12 noon, Cornerstone Cafe, Grove
Wednesday 23rd August, 10.30-12noon, Cornerstone Cafe, Grove
Thursday 14th Sept, 12noon onwards, lunch meeting at The Lord Nelson

Cornerstone Café, 10 Savile Way, Grove, OX12 0TP
The Lord Nelson Pub, Charlton Road, Wantage, OX12 8HL
For further info phone Annie Kingsbury email anniekingsbury@talktalk.net

South Oxfordshire ME/CFS Support Group

We will be meeting on the following dates at the Shillingford Bridge Hotel, OX10 8LZ at the usual time of 12 noon – 2pm.
Monday 10th April, Monday 15th May ME Awareness Month (a week later due to the bank holiday), Monday 12th June, Monday 10th July, Monday 14th August, Monday 11th September.
The Thames Travel 139 bus no longer stops near to the hotel, but the X39/X40 Oxford to Reading bus stops on the main road in Shillingford near the turning to the hotel (five minutes' walk). There is also car parking on site.
For further information, email Tessa at tessamary_keys@yahoo.co.uk

For further details, please see: omegaoxon.org

OMEGA Contact Information, and Roles and Contacts

Oxfordshire ME Group for Action (OMEGA)

OMEGA website: www.omegaoxon.org

OMEGA Facebook page: http://www.facebook.com/- search "Oxfordshire ME Group for Action"

OMEGA on Twitter: Follow @omega_oxon

Membership Secretary	David Polgreen	david@hillviewers.net
Treasurer	Jayne Thomas	
Temporary Bookkeeper	Patricia	patricia.wells@phonecoop.coop
Chair	Priscilla	cilla.kew@gmail.com
Volunteers (Organiser)	Priscilla	volunteers.omega@gmail.com
Campaign Group (research/campaigning/NHS liaison)	Norman	norman.booth@physics.ox.ac.uk
Acting Minutes Secretary	Patricia	
South Oxon Social	Tessa	tessamary_keys@yahoo.co.uk
Oxford Social	Jo and John	joandjohn36@aol.com
Banbury Social	Mike	mikep4445@mail.com
Parent Support	Priscilla	
Enquiries	Susie	enquire.omega@gmail.com

Other useful contacts

Oxfordshire CFS/ME Service (Previously known as OCCMET)
Office only at: Windrush House, Windrush Industrial Estate, Witney, OX29 7DX,
telephone 01865 903757, Fax 01865 425133, Email: cfs@oxfordhealth.nhs.uk
http://www.oxfordhealth.nhs.uk/cfs-me Office hours: Mon-Weds 9-1.45pm, Thurs 9-1.30pm.

ME Association Support and Information Line
0844 576 5326
Every day: 10 am-12 noon, 2 pm-4 pm and 7 pm-9 pm

Tymes Trust
PO Box 4347, Stock, Ingatestone, CM4 9TE
http://www.tymestrust.org/
Telephone: leave your message on voicemail at 0845 003 9002

Action for ME (Support line)
0845 123 2314
Monday – Friday 11 am-3 pm
Email: support@actionforme.org.uk
Welfare rights helpline (AfME membership-only service):
0845 122 8648

OMEGA Newsletter production team: Nathan Smith, Pat Williams, David Polgreen, Mary Horan, Joanna Breheny, John Porter, Jo Porter, Liz Green, Catherine Rye and Susie Geddes

With thanks to: Pat Williams, Tessa Keys, Patricia Wells, Dr Anne Silk, Priscilla Kew and Jill for submissions and contributions.

The next newsletter copy deadline is Friday 9th June 2017, so please send any info, news, jokes, poems etc. to newsletter.OMEGA@gmail.com. Send articles, jokes, cartoons or letters for publication with "Editor" in subject line.

To receive your newsletter by email, put “email newsletter request“ in the subject line.

Disclaimer – Please note that views expressed in this newsletter are not necessarily the views of OMEGA.