



Charity Number NIC100184

NICE guidelines on graded exercise therapy for ME/CFS are challenged by science

Our “Seeking Solutions” conference
will give you up-to-date information on the
cutting edge research . . .



Seeking Solutions
for ME & Fibromyalgia
Tuesday 30th May 2017 @ 2pm





Seeking Solutions

for ME & Fibromyalgia

Tuesday 30th May 2017 @ 2pm



This event, hosted by Robbie Butler MLA in the prestigious Long Gallery at Stormont, is a unique and unmissable opportunity for healthcare professionals to gain a deeper understanding of myalgic encephalomyelitis and fibromyalgia.

Local charity, **Hope 4 ME & Fibro Northern Ireland**, has gathered a strong panel of international experts, who will address the challenges faced by medical professionals in treating these diseases.

Schedule:

1.30 Registration	3.10 COMFORT BREAK
2.00 Welcome: Jo-Anne Dobson	3.20 Prof Olav Mella
2.10 Hope 4 ME & Fibro NI	4.20 David Tuller DrPH
2.20 Linda Tannenbaum	4.50 Dr Christine McMaster
2.50 Dr William Weir	5.00 Questions to the experts
	5.30 Buffet & Refreshments

Experts from USA, Norway and UK, will explore how existing beliefs on disease aetiology are now being challenged by new evidence, and also expose the significant flaws in evidence currently underpinning NICE guidelines for ME.

This new information should lead to a complete turnaround on the way that ME is treated, and may lead to additional caution being applied to the advice for fibromyalgia.

ME is recognised by the World Health Organisation as a neurological disorder (*section G 93.3 of ICD10*), and fibromyalgia as a soft tissue disorder (*section M 79.7 of ICD10*).

As Northern Ireland has an estimated 7,000 ME and 23,000 fibromyalgia patients, this event should be a priority for all those meeting these patients in a professional capacity.

Please book your places early and share the link below with any colleagues who might be interested:

<https://seekingsolutions.eventbrite.co.uk>

The £35 ticket price will include an extensive information pack and buffet refreshments after the event - to allow for relaxed networking and informal discussions with speakers and other delegates.

Note: 'Seeking Solutions for ME and Fibromyalgia' has been approved by the Federation of the Royal Colleges of Physicians of the United Kingdom for 3 category 1 (external) CPD credits.

Key Note Speaker:

Professor Olav Mella
Neurologist/Oncologist
Head of Department of Oncology
Haukeland University Hospital,
University of Bergen, Norway.



Find out how two Norwegian Cancer specialists have come to be at the centre of a major research programme into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, and how their research has caused a seismic shift in the way ME/CFS is viewed.

The story starts in 2004 when, together with his colleague Dr. Øystein Fluge (Chief Physician in the Department of Oncology), Professor Mella observed that a patient's ME/CFS symptoms improved substantially while undergoing chemotherapy treatment for a concurrent diagnosis of lymphoma. This observation led the oncologists to carry out some small studies in ME/CFS patients using the B-cell depleting monoclonal antibody, Rituximab and they published peer reviewed articles in 2009 and 2011 with the results.

The positive results of these studies have now lead to a large national, randomised, double-blind and placebo controlled multicentre phase III study using Rituximab in patients with ME/CFS. The results are expected early in 2018. A smaller phase II study investigating the effect of treatment with the chemotherapy drug Cyclophosphamide is also in progress.

With their now expanded ME/CFS research team at the oncology department they are presently also looking at other research areas including in: biochemistry, immunology, cell metabolism, genetics, and autoimmunity. Blood vessel endothelial functioning, exercise and gastrointestinal sub-studies are also being carried out. The researchers have even conducted three autopsies of people who suffered from the ME/CFS. The purpose of this research is to identify disease mechanisms and biomarkers for the illness.

So, if you think ME/CFS is just about fatigue and can be treated with exercise, think again!

To find out much more about the Norwegian research, other biomedical research developments in ME/CFS, and the controversy surrounding graded exercise therapy as a recommended treatment, book your place here:

<https://seekingsolutions.eventbrite.co.uk>

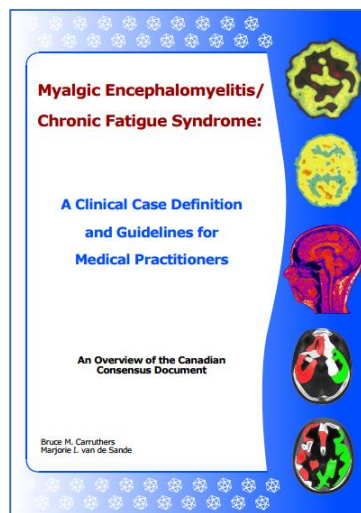
Can't attend our conference?

More information is available from Hope 4 ME & Fibro Northern Ireland.

Either email us at hope4mefibro@outlook.com or request an information pack via the link on the GP Intranet. These packs will be distributed to all conference attendees.

Included in the pack is an overview of the Canadian Consensus Criteria (CCC) which has wide support amongst ME researchers and medical ME/CFS specialists. Images below show the front cover and a table indicating the abnormal responses of ME/CFS patients to exercise - both from the CCC.

Available online: http://www.investinme.org/Documents/PDFdocuments/Canadian_ME_Overview_A4.pdf



Response to Exercise	Healthy People	ME/CFS Patients
Sense of well-being	Invigorating, anti-depressant effect	Feel malaise, fatigue and worsening of symptoms ^{1,12}
Resting heart rate	Normal	Elevated ^{13,14}
Heart rate at maximum workload	Elevated	Reduced heart rate ^{13,14}
Maximum oxygen uptake	Elevated	Approximately 1/2 of sedentary controls ¹³
Age-predicted target heart rate	Can achieve it	Often cannot achieve it and should not be forced ^{13,14}
Cardiac output	Increased	Sub-optimal level ^{13,14}
Cerebral blood flow	Increased	Decreased ^{15,16}
Cerebral oxygen	Increased	Decreased ¹⁵
Body temperature	Increased	Decreased ¹⁷
Respiration	Increased	Breathing irregularities: shortness of breath ¹⁷ , shallow breathing
Cognitive processing	Normal, more alert	Impaired ¹⁸
Recovery period	Short	Often 24 hours but can last days or weeks ^{1,12,19}
Oxygen delivery to the muscles	Increased	Impaired ¹³
Gait kinematics	Normal	Gait abnormalities ²⁰

Hope 4 ME & Fibro Northern Ireland



is a registered charity run by patients and volunteers. We receive no core government funding and rely entirely on small grants and voluntary donations to operate.

Activities:

- **Monthly support meetings** on the 1st Tuesday of each month in the Mourne Country Hotel, Newry, at 7pm with regular guest speakers.
- **Annual Conferences** with international researchers and leading experts in ME & Fibromyalgia.
- **Working towards Specialist Biomedical Care in N.Ireland** with support from the Patient & Client Council NI, the Department of Health, and the Health & Social Care Board.
- **Campaigning** for the CCC to be adopted as current best practice advice on the treatment of ME so ensuring treatment is based on sound physiological evidence.
- **Fundraising** to support above & towards biomedical research projects.

Further Information:

Phone: 07712 892834

Email: hope4mefibro@outlook.com

Website: <http://hope4mefibro.org>

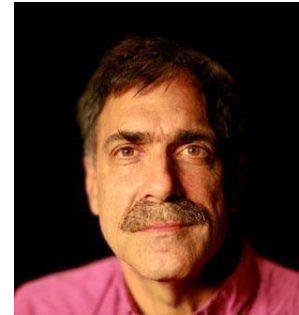
Facebook Group: Hope 4 ME & Fibro Northern Ireland

Speaker: David Tuller DrPH

will be exploring the controversial PACE Trial during his talk:

“The UK PACE Trial: An exploration of the ‘evidence’ for graded exercise therapy for ME”

This £5 million trial was published in 2011 with further papers appearing later. From the outset scientists and patients questioned the methods, analyses, and conclusions of the trial. When a Freedom of Information request (and lengthy court battle) resulted in the release of the data relating to “recovery” it was found that according to the PACE authors’ own original protocols, the result was null. There was no recovery with graded exercise therapy.



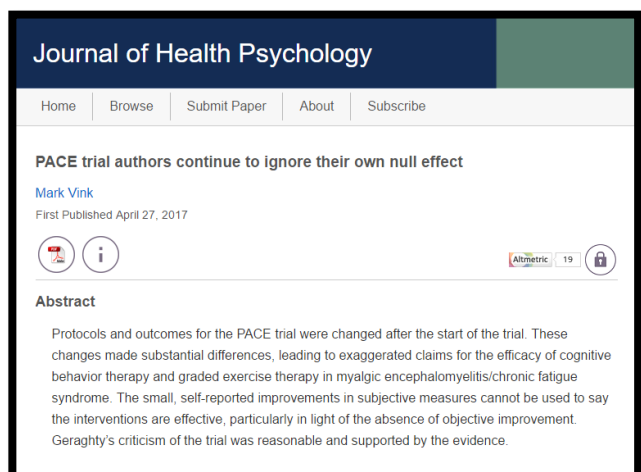
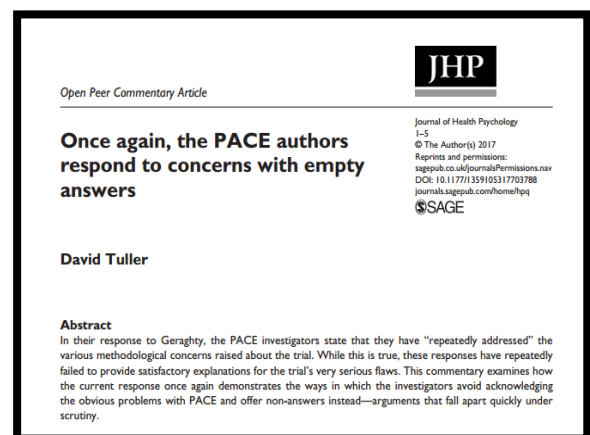
Meanwhile, patients continue to report that graded exercise therapy is harmful and NICE guidelines continue to recommend it as being of benefit.

The PACE trial saga is ongoing as scientists attempt to secure the remaining data for independent analysis.

These screen captures give a flavour of the current situation. Note that PLOS one added an “Expression of Concern” to one of the PACE papers on 2nd May 2017.

For the full story attend our Seeking Solutions conference

<https://seekingsolutions.eventbrite.co.uk>



Seeking Solutions - Speaker Details:

Professor Olav Mella, Bergen University Hospital (Norway)

“Rituximab – Treatment for the future?”

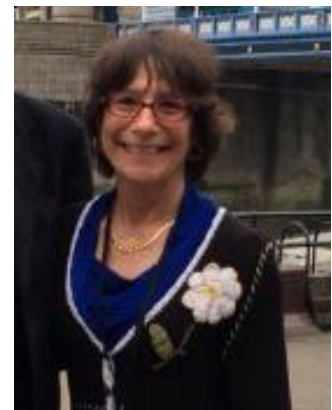


Olav Mella, is director of the oncology department at Haukeland University Hospital, Norway. Along with Øystein Fluge, a researcher and oncologist, from the same hospital, he is conducting a phase III trial of rituximab in chronic fatigue syndrome/myalgic encephalomyelitis patients. Professor Mella and Dr Fluge have published a paper: *"Benefit from B-Lymphocyte Depletion Using the Anti-CD20 Antibody Rituximab in Chronic Fatigue Syndrome. A double-Blind and Placebo-Controlled Study"*.

Linda Tannenbaum MB. CEO of Open Medicine Foundation (USA)

“Research Hope for ME & Fibromyalgia”

With years of executive management experience as a clinical laboratory scientist, Ms. Tannenbaum owned and ran a successful independent clinical laboratory for over 21 years before starting two non-profits to raise funds for ME/CFS research. Fulfilling a promise to their daughter, who came down with sudden onset ME/CFS at the age of 16 in 2006, Ms. Tannenbaum and her husband had started their first non-profit Neuro-Immune Disease Alliance (NIDA) to raise funds from family and friends. Ms. Tannenbaum soon realized that open, global collaborative research was lacking and founded Open Medicine Foundation (OMF) in 2012 to take the efforts to a much larger level to fund and facilitate large research projects to find a cure for ME/CFS and other similar chronic illnesses. Linda Tannenbaum received her degree in Bacteriology from UCLA in 1978 and her Clinical Laboratory Scientist/Medical Technology license in 1979.



<https://seekingsolutions.eventbrite.co.uk>

Dr William Weir FRCP, FRCP (Edin). Consultant Physician (UK)
“ME & fibromyalgia: History, politics and the need for change”

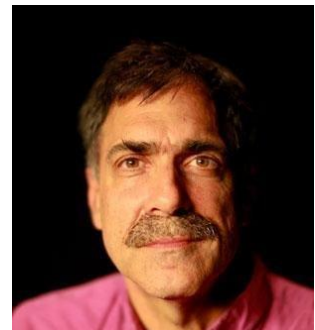


Dr Weir qualified from St Andrews and Dundee University Medical School 1972. He has held Senior House Officer posts in Nephrology, Cardiology, Neurology, and Chest Medicine. During his senior career, he worked in The Hospital for Tropical Diseases, London, and later at the Royal Free Hospital where he was appointed a Consultant in Infectious Diseases (and Tropical Medicine) RFH 1987. Dr Weir also spend two years at Ahmadu Bello University Medical School in Nigeria. Although formally retired, he now does freelance consultancy work in hospitals around the UK. He has a longstanding interest in ME and is Medical Advisor to Hope 4 ME & Fibro NI. Dr Weir now regularly sees ME patients privately, and advises on disease management and treatment.

David Tuller, DrPH (USA)

“The UK PACE Trial: An exploration of the “evidence” for graded exercise therapy for ME”

David is the academic coordinator of University of California Berkeley's joint masters program in public health and journalism. He frequently writes for The New York Times and in 2016 was recipient of both the IACFS/ME Special Service Award for Outstanding Personal Effort and Contribution, and of the Tymes Trust Award for Scientific Journalism.



Dr Christine McMaster, Consultant in the Public Health Agency
“ME & Fibromyalgia Care in Northern Ireland – Recent Developments”

Dr McMaster, is currently supporting efforts to improve health services for ME patients in Northern Ireland. She will offer a progress report since her work on this, and collaboration with the charity trustees, commenced in November 2016



<https://seekingsolutions.eventbrite.co.uk>



Hope 4 ME & Fibro Northern Ireland

Registered Charity NIC100184

25 - 27 McShanes Rd, Bessbrook

Newry BT35 7LZ

hope4mefibro@outlook.com

07712 892834

FAO: Health Care Professionals

Please note the following when considering advising “exercise” for ME & fibromyalgia* patients:

- 1. Patient surveys demonstrate that graded exercise therapy (GET) can be harmful:**
The ME Association survey from 2015 shows that 74% of patients doing GET report a worsening of their symptoms. Some of the anecdotal stories at the end of the survey make harrowing reading. E.g. *“GET made me significantly worse. Before I didn't use a wheelchair, now I use one full time. It caused harm.”* Thus, the risks of giving exercise advice need to be carefully considered. Survey can be downloaded here:
<http://www.meassociation.org.uk/2015/05/23959/>
- 2. NICE guidelines for CFS/ME (although imperfect) include using a heart-rate monitor** to keep exertion levels to within a range of 50-70% of age-calculated maximum heart rate. Patients who have monitored their heart rate often report that even gently-paced activities of daily life can be enough to exceed this threshold. Thus, the conventional understanding of the word “exercise” is inappropriate.
<https://www.nice.org.uk/guidance/cg53/chapter/1-Guidance> See section 1.6.2.19. Further thoughts from one of our Trustees here:
<http://www.slideshare.net/SallyBurch/heart-rate-monitoring-and-nice-guideline-for-me>
- 3. The PACE trial**, which has been used to underpin GET as a recommended treatment, has now been academically challenged, and a re-analysis of the PACE data using the original protocols has shown that both GET and CBT are ineffective.
<http://www.virology.ws/wp-content/uploads/2016/09/preliminary-analysis.pdf>
- 4. Questions have also been raised in Parliament** about possible fraud with regards to the PACE trial. Seven questions relating ME (or CFS) were asked by Kelvin Hopkins MP in November 2016. Shortened link directly to questions here: <http://tiny.cc/gjp9gy> General link here: <http://www.parliament.uk/business/publications/written-questions-answers-statements/>

The NICE guidelines for ME are coming up for review in 2017. We sincerely hope that GET will at last be removed from NICE recommendations, and that CBT will no longer be used to promote increased activity to this vulnerable patient group. In our experience, patients who rest and carefully pace their activities, have the fewest long-term health problems.

Trustees for Hope 4 ME & Fibro Northern Ireland.
November 2016

*We include fibromyalgia in this note of caution because of the significant symptom overlap between ME and fibromyalgia. Our concern is that some patients diagnosed with fibromyalgia may also have ME.