



Hope 4 ME & Fibro

Northern Ireland is a registered charity,

run entirely by volunteer patients and their family members. Thank you for attending our annual conference!

T: 07712 892834 3-5pm weekdays E:hope4mefibro@outlook.com

- “ No one, no patient should have to fight for recognition of their condition. That many of you have had to do so, is a matter of great regret to me.” **Chief Medical Officer N.I., Dr. Michael McBride, during his opening address at Hope4ME’s September 2018 Stormont conference.**
- ME/CFS is a condition which medical science is continuing to decipher, this means that healthcare professionals are left being unclear as to how best to treat it. This hasn’t been helped by the fact, at one stage, ME/CFS was labelled as a psychiatric condition. Nowadays, it is widely recognised that ME/CFS is a physiological condition which is multi-system – affecting the immune, neurological and endocrine systems in the body.”
Exert taken from the Northern Health Trust 2018 newsletter.
- The PACE Trial, a controversial medical trial part-funded by the Department of Work of Pensions will emerge as “one of the greatest medical scandals of the 21st century.” **Carol Monaghan SMP, 20th February 2018 Westminster Hall ME Debate**
- Research from Newcastle University clearly demonstrates **misdiagnoses rates of over 40%**. There is no effective treatment. ME can follow a remission, relapsing pattern and 25% of patients decline into the most severe form of the disease. Men, women and children as young as six can be affected, **recovery is rare.**

Tickets Available Now on Eventbrite

Frontiers in M.E. – Transforming Patient Safety & Care

Wednesday 4th September 2019

Queen’s University, Riddel Hall Belfast

Registration from 5pm with optional buffet £10

FREE lectures begin at 5.45 pm

Schedule:

5.00pm Registration/buffet

5.45pm Welcome

5.50pm Hope 4 ME&Fibro N.I.

6.00pm Brian Hughes

6.45pm Caroline Kingdon

7.30pm Comfort Break

7.45pm David Systrom

8.45pm Q & A Session

9.15pm Close



This event is being supported by HSC R&D Division, Public Health Agency (DIS/5488/18 & DIS/5489/18) The content or views expressed are those of the author/presenters and do not necessarily reflect the official views of the HSC R&D Division.

3 CPD credits from Royal College of Physicians, London, applied for.

Are You ME Aware?

- **World Health Organisation.** 50 years ago, in 1969, the WHO classified Myalgic Encephalomyelitis/post viral fatigue syndrome as a neurological illness, not a psychological disorder. A false perception has more recently existed that the illness is just 'chronic fatigue' or 'extreme tiredness.'
- **NICE Guidelines for CFS/ME is under review, expected publication date, October 2020.** NICE continues to recommend GET (graded exercise therapy) and CBT (cognitive behavioural therapy), whilst these therapies ignore the physiology of the illness. In 2017 the US Centers for Disease Control and Prevention, dropped CBT and GET from their list of recommended treatments for ME.
- **The latest scientific research** is providing answers why, ME patients experience an abnormal systemic response to exercise/activity, when compared to healthy controls (or patients with other fatiguing illnesses). The use of invasive CPET by Dr. Systrom is helping to unravel the exercise intolerance, as there is growing evidence that patients have a defective energy metabolism.

Myalgic Encephalomyelitis Adult & Paediatric International Consensus Primer for Medical Practitioners', (ICP) provides easy-to-use diagnostic and treatment guidelines.

The Primer was compiled by a 26-member International Consensus Panel. Collectively, members have approximately 400 years of both clinical and teaching experience, authored hundreds of peer-reviewed publications, diagnosed or treated approximately 50,000 patients with ME. **A free copy is included in Hope4ME information packs, please recycle to a colleague when read.**

Schedule and more about our expert, guest speakers:

6.00pm: 'Off the PACE and not NICE- Challenges facing evidenced based practice in ME.'



Brian Hughes, is a Professor in Psychology, and advocates for higher quality research in psychology. He is the author of Psychology in Crisis (London: Palgrave, 2018), Conceptual and Historical Issues in Psychology (London: Pearson/ Prentice Hall, 2012), Rethinking Psychology: Good Science, Bad Science, Pseudoscience (London: Palgrave, 2016)

6.45pm: 'Severe M.E., What Do We Know' ME/CFS Biobank



Caroline Kingdon, is a Research Fellow Research Nurse and U.K. ME/CFS Biobank Lead. This is a disease-specific biobank for advancing clinical research into ME. Caroline is responsible for the recruitment to the UK ME/CFS Biobank and coordinate applications for the use of the samples and data.

7.30pm: Comfort break, refreshments provided

7.45pm: Neurovascular Dysregulation as a cause of Exertional Intolerance in ME/CFS".



David M. Systrom, is a physician at Brigham and Women's Hospital and also an assistant professor of medicine at Harvard Medical School. He is board certified in internal medicine and pulmonary disease and has authored over 130 peer-reviewed publications. Dr. Systrom's research work will further an understanding of the autonomic, small fibre neuropathy, and cardiovascular features of ME.

8.45pm: Question & Answer Session. 9.15pm: Close

