

2018 CMRC Conference Report

By Elinor Jones

This had the underlying theme of “Time to Transform CFS/ME Research” and an atmosphere of optimism and endeavour, bringing together academics, clinicians, students, patients and carers to showcase world-leading research and future pursuits to improve the diagnosis and treatment of ME/CFS.

After an opening welcome from Professor Stephen Holgate, CMRC Chair, Dr Nina Muirhead’s inspiring presentation as a doctor with ME and views on the education of medical students about ME symptoms, diagnosis, and management was particularly pertinent, since the majority of medical schools teach ME only fleetingly. She also touched on health disparities and the difficulties of diagnosis, such as seeing many different consultants.

Professor Alain Moreau focused on research ambition concerning microRNAs, small non-coding lengths that are involved in regulation and gene silencing. Specifically, he spoke about potential trigger events in ME/CFS. Dr Eliana Lacerda introduced EUROMENE, the European Network on ME/CFS, aiming to assess and link current and new knowledge, such as socio-economic cost and biomarkers.

A pharmaceutical light was shone on ME/CFS by Dr Mark Jones, who, through his family’s experiences is helping to encourage patient-centred drug development with UCB Pharma, as well as precision medicine through genetics, due to limited pharmacotherapeutic interventions for ME/CFS. Dr Rachel Hunter presented the cost of lost productivity and disease cost of ME/CFS, however this was not as optimistic.

Colorectal surgeon Rachel French turned attention to common comorbidities of each other: CFS/ME, IBS and Fibromyalgia, identifying that CFS/ME and Fibromyalgia patients are more likely to have bowel disorders, with potential common pathophysiology.

Professor Frances Williams presented work on a twin cohort – Twins UK – of 13,000, which investigated genetic link to chronic widespread and neuropathic pain perception, which were found to have common genetic factors.

Dr Luis Nacul from the UK ME/CFS Biobank presented on how global research in this field could be accelerated by the biological data stored within this bank, including blood products, clinical data, and questionnaire data that can be used for biomedical and social health research. Another approach to finding was presented by Jo Elson, who has been investigating a mitochondrial DNA mutation present in 50% of people with severe fatigue which could alter cellular usage of ATP. Cellular metabolism research was also presented by Tiffany Lodge, who’s initial findings have shown that factors present in the plasma of patients with ME/CFS have the capability of altering cellular function. However, this was a small pilot study.

Relative health disparities in ME/CFS were addressed by Pawel Zalewski from Poland, who has investigated the use of cryotherapy, suggesting that it can have a modulatory effect upon the cardiovascular, autonomic nervous, and immune systems, with preliminary results showing a short-term improvement in symptoms.

Closing the first day was Dr Neil Harrison, who's group are performing a series of studies into Post-Exertional Malaise and perception of symptoms.

Opening of the second day started with the Anne Faulkner Memorial Lecture by Professor Cathie Sudlow, about the use of big data in research to improve understanding of disease. Whilst intriguing, I struggled to relate the relevance to ME/CFS. Dr Elisa Oltra also focused on microRNAs, this time investigating the miRNA profiles of peripheral blood mononuclear cells, which could be potential biomarkers for ME/CFS as they are epigenetic regulators.

A new immunological model for ME/CFS was presented by Carmine M. Pariante, suggesting that interferon-alpha, a proinflammatory marker, could be involved, as seen in patients with Hepatitis C.

The following session saw parallel workshops running with different themes: research priorities, activity as treatment, and nutrition. Having attended the Activity as Treatment – Myths and Methods session run by Dr Sue Pemberton, I approached the question and answer-style workshop as a patient and a future practitioner. The difficulty with the format of such a session, whilst it is positive to have discussions that involve opinion, often the debates got personal and too emotional. Also, whilst it was interesting to learn the work of Dr Sue Pemberton and her clinic, most patients with ME/CFS do not have access to such facilities and treatment options, highlighting the inequality even in a condition with little funding. However, it was interesting to speak to practitioners, researchers and patients about treatment, which had not been the focus of the previous two days.

Stephen Simpson from Arthritis Research UK focused on the collaborative attitude being adopted by charities and research bodies to pool knowledge and share challenges – an idea that was highlighted throughout the conference.

In the afternoon, the focus was concentrated on the immune system once more, firstly on immune cell function in ME/CFS, suggesting a skewed phenotype in severe ME/CFS. Secondly, Professor Pariante discussed the link between the brain, behaviour and immunity, where a perceived threat activates the immune systems, such is found in depression, shown through high cortisol levels. Cara Thomas gave the final presentation on bioenergetics, ATP levels and respiratory function in ME/CFS patients.