

LONDON, May 2019

International clinical and research experts participated in the first CPD-accredited European ME Clinicians Council (EMECC) workshop that took place over three days in London in February.

EMECC has been formed to bring together clinicians from across Europe and from various disciplines to develop a European foundation of high-quality clinical expertise on myalgic encephalomyelitis (ME, also known as ME/CFS).

Myalgic Encephalomyelitis (ME or ME/CFS) is classified as a neurological disease that affects patients' lives profoundly. The USA Institutes of Medicine (IOM) stated in its 2015 report that "it is clear from the evidence compiled by the committee that ME/CFS is a serious, chronic, complex, multisystem disease that frequently and dramatically limits the activities of affected patients".

In view of this, we are concerned to note the longstanding and continued promotion in many countries of the psychosocial view of this condition, whereby it is regarded as a "non-disease" caused simply by a combination of falsely held patient belief systems combined with deconditioning. In our view, this belief system has done immense harm to both the patient community and the prospects for research on this condition.

There is much misinformation for this debilitating disease where the current lack of any effective treatment aggravates patient suffering caused by mismanagement due to inadequate, and sometimes absent, policies of healthcare agencies regarding this disease. IOM state that physicians should diagnose ME/CFS if diagnostic criteria are met following an appropriate history, physical examination, and medical work-up.

EMECC aims to harvest effective strategies for patient management and treatment from the pooled clinical knowledge of physicians working extensively with ME/CFS patients. A further important aim is to provide or refine ideas for research in all aspects of the disease based on the extensive clinical, hands-on clinical experience of the EMECC members.

The meeting created a very positive and progressive atmosphere with a range of discussions around diagnosis, management and treatments, follow-up investigations, health personnel education and research and how the group will continue and expand.

Arranged by UK charity Invest in ME Research and endorsed by the European ME Alliance this workshop involved leading clinicians from Europe who are treating ME/CFS patients and who will be instrumental in creating a sea change in clinical care for the benefit of people with ME and their families. The group will fill a vacuum in clinical expertise that has allowed false beliefs about the real nature of the disease to be propagated.

This group will continue to meet in locations across Europe for follow-on meetings and be able to play an important role in clinical care, biomedical research and guidelines development.

The workshop was CPD-accredited and we look forward to this group of clinicians/researchers making huge progress in developing sound clinical care for ME/CFS patients - and with the collaboration with our colleagues in the European ME Alliance.

European ME Clinicians Council

For more information, please contact info@emecc.org