



January 2019

### Introduction

In our recent remembrance article for Anne Örtegren we mentioned that we were looking at a new initiative to help people with ME.

One of the many failings in the way ME has been handled over the last decades has been the lack of education and specialisation in ME.

Few clinicians have been able to accumulate enough experience and the disease is treated in healthcare with little regard, partly due to this failure – although also due to the negligent way it has been funded.

Those clinicians who have gained experience in treating ME patients and collaborate with biomedical researchers need to be encouraged and supported.

Our international conferences (now fourteen arranged) and research Colloquiums (nine arranged) have brought together researchers from around the world and been instrumental in forging new and promising collaborations.

Our European ME Research Group (EMERG) concept brought European researchers together. In a similar way, we feel it is important for experienced clinicians to share their knowledge on diagnostic and treatment methods and produce documentary aids for the research community focused on clinician guided treatment trials, identification of possible illness subsets, and observations of illness presentation.

The charity is therefore facilitating the formation of the European ME Clinicians Council (EMECC).

The charity Invest in ME Research has arranged an inaugural meeting of leading European clinicians who are involved in treating people with Myalgic Encephalomyelitis.

This meeting follows an American initiative that was started by Dr Lucinda Bateman and Mary Dimmock - more details of the American meeting [are here](#).

To this end, we have used the name given to the American group that met in USA early 2018 under the chair of Dr Bateman and we have provisionally named this group the **European ME Clinicians Council**. We have also borrowed extensively from their experiences and documentation and liaised with Mary Dimmock over the establishment

of this group. We would use the American meeting as a model and use similar objectives from there – though this can be amended as discussed by participants.

We feel that there is a need to build a network of clinicians in Europe who can support each other, work together, and do it immediately and have agreed to use the USA meeting as a starter for the European group.

As Dr Bateman's article states aggregating the knowledge of experienced clinicians on clinical sub topics related to ME/CFS and providing patients, caregivers, advocates, clinicians and the researchers the most up to date information is a critical outcome.

The aims of the meeting are therefore to bring together clinicians in the field of Myalgic Encephalomyelitis to review the current state of knowledge, to present and discuss the latest initiatives, and to foster collaboration.

We would like this to become a formal group that will work with the American initiative and be supported by European patient organisations. Indeed, the European ME Alliance (now representing fifteen countries) would be prominent in supporting this.

We plan for this group can continue to meet and build a network that can improve the knowledge of clinicians in Europe and act as a focal point for healthcare agencies and doctors wishing to know about the treatments and experiences for ME.

Kathleen McCall  
Chairman Invest in ME Research

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### **Objectives**

1. Advance collaboration across experienced European ME clinicians and propose a mechanism to support this collaboration over time.
2. To support each other in encouraging development of more science-based knowledge to tackle this disease and help patients by overcoming disbelief, misconceptions and stigmas that exist.
3. Provide information on what is needed in research from a clinical perspective based on clinical insight or data. This could include possible illness subsets and the significance of successful treatment interventions and could be delivered as a report or potentially published in a peer-reviewed journal.
4. Summarize key diagnostic and treatment methods and the science that supports them and what is currently known about the underlying biology of the disease and how it informs treatment practices in order to advance care of ME.
5. Rigorously distil the most important clinical knowledge and experiences that can guide and drive research. This could include recommendations for treatment trials, identification of possible illness subsets, and observations of illness presentation.

6. Establish a foundation of expert clinical knowledge, propose mechanisms to support ongoing clinical collaboration, and increase the pool of experienced ME/CFS clinicians within Europe.
7. Encourage other European clinicians and researchers to become involved in treating ME/CFS properly and provide the most efficient and effective ways to mainstream the illness within the medical community.
8. Produce a statement from meeting
9. Look to producing documents for publication to inform current and future medical providers. The intent is to produce a paper for publication in a peer-reviewed medical journal.
10. Establish next steps/next meeting(s)

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