

## LUNCH PANEL

### **Special Interest Groups: International Research Networks**

#### **David Patrick, Ph.D., Moderator**

Professor and Director

School of Population and Public Health

University of British Columbia, Canada

#### **European Network on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (EUROMENE)<sup>1</sup>**

U.Berkis, E.Bole Strand, J.Castro-Marrero, **E.Lacerda**<sup>1</sup>, L.Lorusso, M.Murovska, D.Pheby, C. Scheibenbogen, E. Shikova-Lekova

**Background:** Research on ME/CFS in Europe is characterised by the absence of a collaborative approach between research centres, while at the national level research and health services provision is usually concentrated in a few centres of competence.

**Objectives;** The main objective of the COST Action CA15111 “European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (EUROMENE)” is the establishment of a sustainable network of researchers in Europe working in diverse fields, to tackle the challenges arising from unknown aetiology, clinical variability, lack of diagnostic biomarkers, limited treatment options, and a high associated socio-economic burden. The initial task of the project is to harmonize the fragmented European research resources on ME/CFS by building a biobank platform with harmonized protocols and a bioinformatics repository.

The task objectives during the runtime of the Action are:

- Exchange of best practice for collecting population-based data on the prevalence and other epidemiological data of ME/CFS, to establish a synchronised European database;
- Promote co-operation among research groups for accessing potential ME/CFS biomarkers, by establishing special interest groups and harmonising infrastructure efforts;
- Determine unified ME/CFS case definition and diagnostic criteria for clinicians and researchers, to promote case finding, synchronisation of diagnostic criteria, prevention and treatment guidelines;
- Determine the social impact and assess economic consequences of ME/CFS.

**Methods:** The network will promote multidisciplinary in ME/CFS research and foster of the full chain of translational research further capable to develop the much needed treatments and prevention strategies for improvement quality of life.

**Results:** 14 countries are participating in the network: Belarus, Belgium, Bulgaria, Denmark, France, Italy, Germany, Greece, Latvia, Norway, Rumania, Serbia, Spain, and the UK. Most of the involved groups have already developed long-term research on ME/CFS within their disciplines of interest, including epidemiology, biobanking, molecular biology, immunology, clinical research, diagnosis, treatment and research on social aspects in ME/CFS. The Action activities are organized in six working groups: on epidemiology; biomarkers; clinical research enablers and

55

IACFS/ME • 12<sup>TH</sup> BIENNIAL CONFERENCE • OCTOBER 2016

diagnostic criteria; socio-economics; conferences, seminars, and training schools; dissemination and exploitation, patient involvement, and digitalisation.

1. Eliana Mattos Lacerda, MD PhD Clinical Assistant Professor, London School of Hygiene & Tropical Medicine, London – WC1E 7HT, UK. Eliana.Lacerda@lshtm.ac.uk

2. The Action CA15111 is funded by COST – European Cooperation in Science and Technology

3. The authors have no conflicts of interest