

## European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

**COST action CA15111**

### Minutes of the 27 January 2017 Work Group meeting,

#### Participants:

Chair: Modra Murovska (Latvia)

Vice-chair: Eliana Lacerda (United Kingdom)

GH member - Uldis Berķis (Latvia)

WG1 leader - Jesus Castro-Marrero (Spain)

WG2 leader - Carmen Scheibenbogen (Germany)

WG3 leader - Derek Pheby (UK)

WG4 leader - Elin Bole Strand (Norway)

Participants of WG see WG

#### **1. Welcome – Carmen Scheibenbogen, local organiser**

**Modra Murovska, COST chair**

- Announced final call for STSM application,
- All MC members and all MC substitutes asked to indicate the first preferable WG and the second preferable WG, in which they would like to participate (information should be send to Modra Murovska - [modra@latnet.lv](mailto:modra@latnet.lv))

#### **2. Horizon 2020 Application StratifyME - Dr Eliana Lacerda**

Presentation of the evaluation for our Horizon 2020 Application StratifyME.

The proposal reached 6.5 points (required 8). It was discussed that this is a quite good result and that a 2<sup>nd</sup> application should be undertaken for a later call.



### 3. Reports of the WG leaders

#### **WG1 – Epidemiology – Leader Jesus Castro**

**Participants:** Modra Murovska, Eliana Lacerda and Slobodan Sekulic.

During the morning, we talked about the current situation of the differences in the estimated prevalence of ME/CFS in USA and E.U. countries. The few reports on ME/CFS epidemiology in Europe were presented. In addition, data from the epidemiological survey questionnaires on prevalence and assessment methods for ME/CFS were e-mailed to all members of the EUROMENE consortium, obtaining response from only 5 COST member countries.

At the WG1 meeting in the afternoon, the importance of overcoming gaps in this issue was highlighted. The agreements taken included: 1) to ask all COST members for epidemiologist in each EUROMENE participating countries; 2) find an epidemiologist in HUVH, who could establish new strategies and recommendations to move this topic forward; 3) to establish teleconferences via Skype with epidemiologists across Europe; 4) write an informative article about the lack of info/data for ME/CFS in Serbia and other E.U. countries, and finally, 5) to help with the process of deliverable.

#### **WG2 – Biomarker – Leader Carmen Scheibenbogen**

**Participants:** Bhupesh Prusty, Thomas Harrer, Zaiga Nora-Krükle, Helma Freitag

In the morning an overview was presented on the European biomarker landscape project. A biomarker search was initiated for all European countries participating in EUROMENE based on a PubMed search. These studies were then classified into 4 categories - metabolic, immunological, infection-associated and neurological. 55 studies were identified from 8 European countries so far. A map was produced, showing how many studies, produced by how many workgroups, were retrieved per country and how they were classified.



In the WG meeting Thomas Harrer, Zaiga Nora-Krūkle and as new member Bhupesh Prusty presented their work on the review on persistent infection markers with special emphasis on HHV6 and coxsackie virus. Carmen Scheibenbogen and Helma Freitag presented their summary on autoantibodies in CFS and a first clinical trial on immunadsorption in autoantibody-positive CFS patients. Henrik Nielsen did not participate but sent a project proposal on complement studies in CFS, which was discussed.

### **WG3 – Leader Derek Pheby**

**Participants:** John Cullinan, Elenka Brenna, Lara Gitto, Rachel Hunter, Dominic Trepel

The Economic Working Group convened for the first time in Berlin and Derek Pheby took the opportunity to introduce the group of economists that had joined this COST Action. Objectives for WG3 were overviewed to the wider COST Action group and preliminary findings of WG3 searches for relevance economic literature on MS/CFS were shared. WG3 then convened a breakout session to discuss their potential input to this COST Action and, whilst the group identified several important economic issues regarding to ME/CFS, it was felt that the working group would require greater time to agree specific objectives and work as part of the wider group. It was agreed that, within WG3, economists would circulate their research interests regarding ME/CFS with a view to working towards agreeing action for the start of the forthcoming new COST Action year.

### **WG4 – Clinical research enablers and diagnostic criteria – Leader Elin Strand**

**Participants:** Angelika Krumina, Patricia Grabowski, Jose Allege, Jerome Authier, Ingrid Helland

A brief summary of results from the survey among 12 of the countries were presented by the WG4 leader.

**Gaps:** The following topics representing gaps between countries, from the survey were discussed in the work group: application of diagnostic criteria, exclusion process, assessments and standardized tests and questionnaires as well as symptom treatment and management.



**National guidelines:** It was decided that we should look into the national guidelines on diagnosis and treatment/management that already exist in 4 of the countries and try to find common standards and guidelines based on them.

**Exclusion:** Also for the exclusion process it is necessary to have guidelines. It was suggested to develop an overview and a list of tests and questionnaires that already are applied and which can be used either as standard or as an optional part of the exclusion examination.

**Assessments:** Questionnaires applied in symptom assessments should be harmonized between countries and this is particularly important for the research.

**Symptom relief:** The symptom and illness management also varies between the countries. This topic should be further discussed, and we need to know more about research on symptom relief/management.

**Sharing materials:** Before the next WG4 meeting in Barcelona material such as the different national guidelines and questionnaires applied will be shared between the group members.

**Presentations:** In addition the group members will also have brief presentations in the WG about guidelines, diagnostic criteria and the evaluation process, implementation and flow of the assessment of patients in different countries, experiences with the use of questionnaires, as well as results from own studies if they have and/or of reviews on relevant topics from recent date. These tasks were distributed among group participants.

**Reminder:** In addition, a reminder will be sent to those participating EUROMENE-countries who have not yet answered the survey questionnaires.

#### **4. Brief discussion on harmonisation efforts**

Eliana Lacerda reminded the participants that the discussion on harmonising protocols should to be a topic to be considered by the WG in the next meeting, particularly WGs 1, 2, and 4 as this permeates all the EUROMENE Research Coordination Objectives, and the aforementioned WGs



deliverables. She offered to send the UK ME/CFS Biobank's protocols to the committee members as an initial reference for the WGs considerations, which was agreed.

## **5. Information on forthcoming meetings 2017**

At 16/17 March, the 2<sup>nd</sup> Core group meeting and Work group meeting will be held in Barcelona hosted by Jesus Castro and Julia Blanco.

A 3<sup>rd</sup> meeting will be held autumn of 2017, date and place need to be determined.



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