

**European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
(EUROMENE) COST Action - CA15111**

Minutes of CG Meeting

London, London School of Hygiene & Tropical Medicine, 13th September 2018

The Core Group meeting was chaired by Prof Modra Murovska (MM) (Latvia)

Following attendees were presented:

Dr Eliana Lacerda (EL) (Vice-chair - UK),

Dr Uldis Berķis (UB) (Grant holder - Latvia),

Dr Fernando Estévez-López (FEL) (WG 1 Epidemiology – Netherlands),

Prof Carmen Scheibenbogen (CS) (WG 2 Biomarkers – Germany),

Prof Derek Pheby (DP) (WG 3 Socio-Economics – UK),

Prof Jerome Authier (JA) (WG 4 Clinical Research – France),

Prof Evelina Shikova-Lekova (ESL) (WG5 Training Schools and Conferences - Bulgaria),

Apologies were received from the Lorenzo Lorusso (WG 6 Dissemination – Italy).

Prof Murovska highlighted some points of the Progress Report on first part of the CA15111 Action that was submitted to COST, to be considered by the group, who consequently agreed on a course of action (presentation attached - London CA meeting_11.09.2018).

The questions discussed are summarised as follows:

1) Problems with the Working Groups not working properly/inadequate leadership – WG1 and WG4. Following conclusions were made:

- MM will write official letter to Elin Bolle-Strand (Leader of WG4) about ongoing position as group leader; will also contact Jesus Castro-Marrero about stepping down leadership role of WG1;
- JA agrees to take leadership role of WG4 pending Elin Bolle-Strand response; but agrees to responsibility;
- FEL anticipates return of Jesus Castro-Marrero to leadership role, but is concerned that he is not taking the role seriously enough; FEL was happy to carry on the responsibilities of leadership role for short time but would like to be acknowledged for his work.

2) Manuscript (based on a draft paper) from WG4 was placed on the EUROMENE website as the Deliverable (as it was planned in the EUROMENE project from the beginning).

- There were couple of objections regards this Deliverable: a) it was placed on the web site by naming co-authors that hadn't seen the final draft; b) some authors from the original discussion during Paris meeting were not named.
- MM explained that the Deliverable is not the publication, because the manuscript could be or could not be published. There is enough of time to make all necessary corrections

with input of all potential co-authors. The planned journal for submission of the manuscript is PLoS One (included in the Budget plan).

- Responsibility of the members that attended the Paris meeting is to take charge of the manuscript on behalf of the rest of the group – then dissemination of final draft to all members before submission.

3) Emerging topic:

- ERA-NETs – other fields have a better base than ME/CFS: try to find other specialists in fatigue, in MS/cancer etc. to work with and apply;
- UB to send information about call on biomarkers.

4) Deliverables according to the GP3 Work and Budget plan:

- WG2 – there was misunderstanding on the immunology biomarkers Deliverable. It was agreed that the published paper in *Autoimmun Rev* “Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - Evidence for an autoimmune disease” in reality could serve as the Deliverable but short introductory part should be written with the statement on current situation concerning immunology biomarkers. CS agreed to do it.
- D11: JA will be able to prepare the Deliverable on time, the question was regarding the manuscript draft prepared by Dr Carmen Adella Sirbu and it was decided to continue to work on it;
- D12: Common strategy protocol for ME/CFS diagnosis: synchronisation between centres, research component integration - (MM) discrepancies between the countries should be taken into account, all EUROMENE participating countries is to be surveyed by sending e-mails, teleconferences etc.;
- D13: is in progress

5) Dissemination:

- Brochure: (MM) call for what members would like to be published; working group information on the achieved results (not outputs); brochure has to be focused at scientists, clinicians, not patients;
- Manuscript is planned to submit to PLoS One. Another manuscript is submitted and accepted to J Translational Medicine – financial support for it was not planned for GP3 but there is the financial balance from the Training school which could be used to cover publishing expenses. Changes in the WBP should be communicated to the COST Association and after agreement approved by MC;
- ESL should prepare the reports on training school and evaluation of training school;
- ITC countries conference grants – 5 grants and no applications up to now;
- STSM – only one used during October, 2018 (Romania), no other applications.

Summary points:

- Final year: Conference for dissemination; publications;
- Possible change of leadership in some working groups – possibly done by next meeting, management meeting and WGs 2 & 4;
- Report sent to COST about dissemination – Latvia to be taking over, except in case of website;
- EL presenting position of EUROMENE in Bristol next week;
- Approached by the charity Action for ME to sign a document to lobby WHO to keep ME/CFS as a biological disease and not psychiatric.