



Brussels, 29 April, 2016

Article I. Subject | Minutes of the First Management Committee Meeting of COST Action CA15111: "European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (EUROMENE)"

*Brussels, Belgium
21/04/2016*

1. Welcome to participants

The participants were welcomed by Dr. Inga Dadeshidze, Science Officer and by Ms Jeannette Nchung Oru, Administrative Officer of the Action. Dr. Inga Dadeshidze chaired the first part of the meeting, including the election of the Action Chair, Vice Chair, and Selection of Grant Holder Institution that was carried out under agenda item 8.

2. Verification of the presence of two-thirds of the participating COST Countries

CSO Approval: 30/10/2015

Start of the Action: 21/04/2016

End of Action: 20/04/2020

Total number of COST Countries having accepted the MoU: 11 (**Annex 2-Action Fact Sheet**)

Total number of COST Countries intending to accept the MoU: 0

Number of parties present at the meeting: 11

The quorum (2/3 of COST Countries participating in the Action) was reached: 11 COST countries out of 11 attended the meeting (COST doc. 134/14 "COST Action Management Monitoring and Final Assessment" Annex I, Article 8).

3. Adoption of the agenda

The agenda (**Annex 1**) for the 1st Management Committee (MC) meeting was adopted.

4. Tour de table/ introduction of the MC members

The list of officially nominated delegates and the participants of the meeting with their contact information is presented in **Annex 3**.

5. General information on COST mechanism and the funding and reporting of coordination activities

Dr. Inga Dadeshidze presented the COST overview, policies, and COST Actions : participation, Management Monitoring (**Annex 4**). Ms Jeannette Nchung Oru continued with an introduction to the COST Grant System (**Annex 4**).

Relevant information is on the COST website at <http://www.cost.eu/participate> and <http://www.cost.eu/participate/networking>, including the following reference documents:

- Rules of Procedure for COST Action Management Committees (COST doc. 134/14, Annex I)
- COST Grant System Vademecum



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the EU Framework Programme
Horizon 2020

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- Grant Agreement Template
- Guidelines for Action management, Monitoring and Assessment

6. Agreement on the internal rules of procedure for the MC of the COST Action

The Rules of Procedure for the Management Committee (**Annex 5**) were presented to the MC.

7. Setting the frame for the Action

The recommendations by the Scientific Committee were presented to the MC by Dr Inga Dadeshidze. (**Annex 4**). The budget allocated to the Action for the 1st Grant Period was communicated (**Annex 4**). At the day of the kick off, 11 parties had officially joined the Action. The budget 81 000 EUR (corresponding 16 countries participation) for 1st GP has been allocated considering that the Action will grow during first GP. The Action MoU objectives, specific goals and deliverables were discussed. The WBP drafting and eCOST Action management tool were presented.

8. Election of the Chair, Vice-Chair,

Professor Prof Modra MUROVSKA (LV) was unanimously elected as the Chair.
Dr Eliana LACERDA (UK) was unanimously elected as the Vice-Chair.

9. Selection of the Grant holder institution (GH Scientific representative appointment) and FSAC rate

Riga Stradins University (LV) was selected as the Grant Holder Institution.
Dr Uldis Berkis (LV) was appointed as the Scientific Representative of the Grant Holder Institution.
The MC decided 15% as FSAC rate for the Grant Holder institution.

10. Presentation and discussion of the Action

The elected Action Chair presented the Action, its objectives and implementation plan.

Leaders and Vice-leaders for the following WG as well STSM Coordinator and Vice-coordinator were elected:

WG on epidemiology – Leader Jesus Castro-Marrero, Vice-leader Slobodan Sekulic (Serbia),
WG on biomarkers – Leader Carmen Scheibenbogen (Germany), Vice-leader Enrica Capelli (Italy),
WG on socio-economics – Leader Derek Pheby (UK), Vice-leader Julian Blanco (Spain),
WG on clinical research enablers and diagnostic criteria – Leader Elin Bolle Strand (Norway), Vice-leader Jerome Authier (France),
WG on conferences, seminars, training schools – Leader Evelina Shikova-Lekova (Bulgaria),
WG on dissemination and exploitation, patient involvement, digitalisation – Leader Lorenzo Lorusso (Italy), Vice-leader Anne Marit Mengshoel (Norway),
STSM coordination – Coordinator Els Tobback (Belgium), Vice-coordinator Carmen Adella Sirbu (Romania).

11. Action implementation planning

Following tasks for the first period of the Action were approved:

a) WG on epidemiology:

- Explore of ways to collect population based data on the prevalence of ME/CFS,
- Explore of the potential of existing cohorts,
- Review the characteristics of existing clinical databases maintained by collaborating institutions;
- Survey existing epidemiological data on ME/CFS in participating countries.

b) WG on biomarkers:

- Establish special interest groups within the network able to take fragmented research in a harmonised way,
- Survey in EU countries existing data on potential immunological biomarkers of ME/CFS (cytokine profiles, lymphocyte subsets, adjuvant use epidemiology),
- Survey in EU countries existing data on potential infection-associated biomarkers of ME/CFS (viral, bacterial and fungal infections),
- Survey in EU countries existing data on potential genetic and epigenetic biomarkers,
- Survey in EU countries existing data on neuro-imaging biomarkers.

c) WG on socio-economics:

- Survey in EU countries existing data on economic loss due to ME/CFS,
- Analyse existing clinical criterions guidelines in order to find-out optimal criteria set allowing excluding over-diagnostic and un-diagnostic,
- Develop approaches to calculate direct economic loss due to ME/CFS.

d) WG on clinical research enablers and diagnostic criteria:

- Survey clinical criterions used in EU countries to set-up diagnosis of ME/CFS,
- Analyse existing clinical criterions guidelines in order to find-out optimal criteria set allowing excluding over-diagnostic and un-diagnostic,
- Survey in EU countries existing data on neurological picture of ME/CFS (including association with similar diseases and symptoms, like fibromyalgia),
- Analyse the used ME/CFS treatment and its efficacy/safety in order to find-out optimal treatment approaches lowering severity of clinical course.

e) WG on dissemination and exploitation, patient involvement, digitalisation:

- Create project webpage,
- Survey of existing small/medium-sized enterprises (SMEs) in the pharmaceutical, biotechnology and ICT industries in each participating country in order to develop collaborative research.

f) STSM coordination:

- Analyse of target group (PhD students/candidates, ECIs, young principal investigators, researchers, clinicians, health policy makers, patients) for training events,
- Explore capacity and background for training in collaborating institutions,
- Develop questionnaire to select candidates for training events.

Following deliverables according to the Action were approved for the first period:

Deliverable 1

Survey on ME/ CFS including epidemiology, diagnosis and health/social care in Europe from participating countries and from ECDC datasets (Month – 12),

Deliverable 2

Report on existing ME/CFS biobanks, deployment and access, data availability and restrictions (Month - 12),

Deliverable 10

Survey for capacity development target groups: PhD students/candidates, ECIs, young principal investigators, researchers, clinicians, health policy makers (Month – 6).

The Work and Budget Plan for the First Grant Period was discussed.

During the first GP 3 meetings are planned:

Riga 29-30 September, 2016: MC meeting, Core group meeting, Working group meeting,
 Berlin 27 January, 2017: one-day Working group meeting about synchronization progress,
 Barcelona 16-17 March, 2017: Second Core groups meeting, Working group meeting, First Workshop.

Dissemination meeting: USA, Fort Lauderdale, 27-30/10/2016 12th International IACFS/ME Research and Clinical Conference: Emerging Science and Clinical Care. Presentation of COST Action 11511 EUROMENE - oral. International Association for Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (IACFS/ME) is the largest international group of clinicians, researchers, and other professionals dedicated to the care and research of patients with ME/CFS.

Total costs of meetings: 50 900 EUR

STSMS – there is budgetary frame for 6 missions, 15.000 EUR

Dissemination costs – WEB page – 4.500 EUR in first year

Banking fees – 34.75 EUR

Financial and Scientific Administration and Coordination 15% - 10.565,21 EUR

Total for 1st GP: 80 999.96 EUR

List of Annexes



Kick off Agenda

Annex 1- Agenda



Action Fact
sheet_032016

Annex 2- Action Fact Sheet :



Meeting 03032016

Annex 3- Attendance list



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Presentation

Annex 4- Science Officer & Administrative Officer presentation:

Annex 5- The Rules of Procedure for COST Action Management Committees (COST doc. 134/14, Annex I)
http://www.cost.eu/download/COST_Action_Management_Monitoring_and_Final_Assessment