



COST action CA15111

European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Minutes of the 21.04.2016 1 st Management Committee meeting, second part:

Chair: Modra Murovska

Co-chair: Eliana Lacerda

1. 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).

2. Following tasks for the first period of the project 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 criteria 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 criteria used in EU countries to set-up diagnosis of ME/CFS,
- Analyse existing clinical criteria 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.

3. Following deliverables according to the project 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).

4. Budget proposal for the First Grant Period

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

The MC approves the overheads for Financial and Scientific Administration and Coordination – 15%.