

EUROPEAN NETWORK ON MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME

CORE GROUP MEETING, 13th SEPTEMBER 2018

**London School of Hygiene & Tropical Medicine
(LSHTM), London, UK
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VITA BREVIS ARS LONGA



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Progress Report on the first part of CA15111 action

What is included in the Progress Report:

- Deliverables
- Objectives
- Joint publications – only with co-authors at least from 3 participating countries
- Dissemination – participation at conferences (co-authors at least from 3 participating countries)
- Home page – WG participants (all participants in the Minutes, publications etc)
- Difficulties
- Suggestions for improvements
- Emerging topics/developments
- Sustaining the network beyond the Action

Difficulties in implementing the Action

1. At the beginning there was **imbalance of participation across the WG** - WG2 and WG4 were bigger and stronger than WG1 and WG3. It was because there was a lack of specialists in epidemiology and socio-economics. At present the WG1 and WG3 are reinforced by specialists who are interested in this work and all groups are equally strong.
2. Representatives of majority of participants countries are actively participating in all activities and MC meetings. However **representatives of some countries did not participate** in any of the meetings. Taking into account that majority of the MC members are already in Professors position (far from the ECIs) the work regarding involvement of ECIs is not always satisfactory.

Suggestions for improvements to COST framework/ procedures

1. To increase the involvement of ECIs the pre-financing of STSMs should be foreseen not only for the grantees from the ITCs but also from so called EU old member states.
2. For sure pre-payment should be foreseen for ITCs Conference Grants because registration fees, hotel bookings etc. should be done long time before the conference, and taking into account the salaries of ECIs in ITCs are comparatively low and young people simply do not have such money.

Emerging topics/ developments in the field of the Action

One of emerging topics are different ethical requirements, EU data protection regulation and restrictions for taking, storage and use of biological samples of human being in CA15111 participating countries which hinders the creation and use of a joint biobank (diagnosis or population based for research purposes). Therefore important future development will be common in all EU countries ethical rules and requirements to biobanking for research purposes. Another emerging topic is difficulty to involve government-level policy makers in decision making of health and research problems and in support of research on illnesses that affect mostly young people, thus causing huge economic losses to the national economy. According to this such COST activities as Actions S&T Conferences with participation of health, science and economy politicians at government-level could be helpful.

Sustaining the network beyond the Action

1. If there will be proper call in H2020 grant application/s will be prepared and submitted. We are looking also for other instruments, like ERA-NETs, two part collaboration possibilities etc. Possibility to submit new COST application will be discussed at the next CG/MC meetings.
2. Networking building and collaboration with researchers from Canada and US could not be excluded.
3. Much more attention will be paid to convincing Health policy makers in EUROMENE participating countries on importance of ME/CFS in public health and economy in order to increase financing for this type of research in the EUROMENE participating countries.
4. Sustainability will be ensured also by bridging in PhD studies and Post-Doc research programs.

We hope for at least some positive result allowing to attract finance and continue research not only in Europe but also in a broader sense.

Progress GP3 Work and Budget plan

- Deliverables
- MC meeting, WG No 2 and No 4 meetings
- Short Term Scientific Missions (STSM)
- ITCs Conference Grants
- Dissemination
- Attention to joint publications, joint projects
- Attention to collaborattion with SMEs

Deliverable 9: Guidelines for usage of immunological biomarkers in ME/CFS diagnosis and therapy evaluation

Month deliverable due 28 - August 31, 2018 (WG2)

Deliverable 10: Common consensus protocol for economic loss estimation and forecasting due to ME/CFS

Month deliverable due 28 - August 31, 2018 (WG3)

How far are we?

Deliverable 11: Evaluation scales for assessment of neurological symptoms associated with ME/CFS and usable in diagnostic
Month deliverable due 30 - October 31, 2018 (WG4)

Deliverable 1Common strategy protocol for ME/CFS diagnosis:
synchronisation 2: between centres, research component
integration
Month deliverable due 31 – November 30, 2018 (WG1, WG2, WG3, WG4)

Deliverable 13: Protocol and guidelines for ME/CFS subgroups detection (stratification) according to the presence of symptoms and subject to potential biomarkers variation

Month deliverable due 36 – April 30, 2019 (WG2, WG4)

Deliverable14: Collaborative research project on ME/CFS based on synergy with other initiatives and resources integration

Month deliverable due 38 – June 31, 2019 (all WG, all Members and Participants)

MC meeting, WG No 2 and No 4 meetings

Type: Management Committee Meeting, Working Group Meeting

Dates: 14/02/2019 - 14/02/2019

Location: Bucharest (Romania)

Participants: 25

Reimbursed: 24

Travel costs: EUR 19 440.00

Support grant: EUR 1 080.00

Short Term Scientific Missions (STSM)

- Amount per STSM EUR 2 500.00
- Number of foreseen STSMs 5
- Total EUR 12 500.00

Documents submitted from Stefania Diaconu, RO , mission in Belgium in October

ITCs CONFERENCE GRANTS

- Amount of ITC Conference Grant – EUR 2.500
- Number of foreseen ITC Conference Grants -5
- In total – EUR 11.225

No interest up to now. One-two candidates could be from Latvia.

Dissemination

- Home page – EUR 1.500
- Brochure – EUR 898 – **task for all WGs**
- «The prevalence and incidence of myalgic encephalomyelitis/chronic fatigue» BMJ Open, planned – EUR 1 514.00, **paid-up EUR 1900.00**
- «Survey of the use of diagnostic criteria and routine clinical assessments in Europe» PLoS One, planned - EUR 1 201.00
- «Chronic viral infections in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)» Journal of Translational Medicine, **financial support not planned**, paper submitted and in general accepted

Training School

«Novel methods in potential immunological biomarkers research of ME/CFS»

Time: 24 – 29 June 2018

Venue: Institute Medical Immunology, Charité Campus Virchow
Klinikum , Berlin, Germany

Trainees – 12 (2 Bulgaria, 2 Germany, 2 Serbia, 1 Belarus, 1 Latvia, 1 Netherlands, 1 Norway, 1 UK)

Trainers – 6 (P.Grabowski, C.Scheibenbogen, B.Prusty, F.Solzny, E.Lacerda, L.Nacul)

Outcomes:

- Report on Training school as input for WG5,
- Report on evaluation of the Training school as input for WG5 and WG2.