

## **COST action CA15111**

### **European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome**

#### **Minutes, Sofia, 08 February 2018 Management Committee meeting and Work Group No 2 meeting on synchronisation**

**CA15111 MC Chair:** Modra Murovska

**Local Meeting Chair:** Evelina Shikova-Lekova

**Welcome:** Evelina Shikova, Local Meeting Chair; Mrs. Zlatina Karova, COST National Coordinator for Bulgaria

#### **Management Committee meeting**

**1. Welcome New Participating Countries:** Greece - Dr Giorgos Sakkas; Slovenia - Dr Uroš Marusič

**2. Modra Murovska,** Current GP2 situation - implemented measures and planned measures, clarification of the WGs plan for the next GP3 period (*MM\_Sofia\_2018*).

WG tasks for the Grant period 01/05/2017 – 30/04/2018 are:

- 1) WG 1 Epidemiology - T2 Synchronisation; T3 Biobanks and protocols; T4 Ethical framework;
- 2) WG 2 Biomarkers - T4 Data synchronisation;
- 3) WG 3 Socio-economics - T2 Direct loss calculation; T3 Indirect burden;
- 4) WG 4 Clinical research/diagnostic criteria - T2 Optimal set; T3 Treatment efficacy;
- 5) WG 5 STMS, workshops, conferences - T1 Training schools «Summer school on-omics and bioinformatics in ME/CFS research»; T2 STMS Training panels «Novel methods in potential infection-associated biomarkers research for ME/CFS».
- 6) WG 6 Dissemination - T3 Website; T4 Research projects.

Achieved results – one paper published, 2 – accepted for publication; one project application submitted, two participations at conferences/meetings with presentations

Used STSMs and COST Inclusiveness Target Countries Conference Grants: Bulgaria – 1/6 STSM; Latvia – 2/6 STSMs, 3 Conference Grants; Republic of Serbia – 1/6 STSM, 1 Conference Grant; Germany – 1/6 STSM.

Deliverables to be prepared:



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- **Deliverable 4 (24 month)** - Guidelines on ME/CFS biobank management and maintenance, catalogue synchronisation and integration with healthcare management systems (continuous updated);
- **Deliverable 5 (24 month)** - Guidelines for usage of infection-associated biomarkers in ME/CFS diagnosis for use in biomedical and clinical research
- **Deliverable 6 (24 month)** - Description and programme book of training schools and training events (renewed annually)
- **Deliverable 7 (24 month)** - Joint publication manuscript on ME/CFS European practices in diagnosis and treatment based on survey data;
- **Deliverable 8 (24 month)** - Summary of evaluated socio-economic impact and direct and indirect costs caused by ME/CFS in Europe.

### **Grant period 01/05/2018 – 30/04/2019 Goals**

**Aim/Primary objective** - Facilitate the understanding of ME/CFS and attract new resources to the field; develop guidelines for ME/CFS synchronized criteria and common strategy protocols; create a synchronized system to maintain biological samples for ME/CFS research purposes including ethical issues. Develop approaches to calculate direct economic loss and indirect burden due to ME/CFS. Facilitate involvement of relevant stakeholders, ECIs and clinicians in the WG activities.

**Secondary objective 1** - Exchange the information facilitating the development of synchronized adequate local systems for the collection, storage, and cataloguing of biological samples for research purposes. Develop common protocols for biobank creation in each participating country. Exchange information on local ethical issues, discuss and propose a draft of common ethics framework.

**Secondary objective 2** - Survey in EU countries existing data on infection-associated biomarkers; evaluate neurological symptoms associated with ME/CFS and usability in diagnostic. Promote synchronization of biomarker panels and interpretation. Discuss and analyze the existing data on biomarkers usable in laboratory and objective clinical diagnostic of ME/CFS.

**Secondary objective 3** - Survey in European countries existing data on economic loss due to ME/CFS. Develop approaches to calculate direct economic loss and indirect economic burden due to ME/CFS in order to optimize models of prevention in health and economy aspects (prevention models).

**Secondary objective 4** - Synchronise diagnostic criteria and develop common strategy protocol to identify and understand the biological disease pathways in a stratified way. Recommend optimal criteria set to minimize over- and under-diagnosis of ME/CFS; develop proposal for standardizing clinical diagnosis in collaborative global manner. Assess the efficacy/safety of available ME/CFS treatments in order to recommend optimal treatment approaches.

**Secondary objective 5** - Increase capacity by organizing training panel “Novel methods in potential immunological biomarkers research of ME/CFS” and “Summer school for translational research in ME/CFS”. Organize STSMs, accomplish them and monitor results. Increase PhD students and ECIs activity in ITC (grant applications for participating in international conferences/congresses).



**Secondary objective 6** - Foster the knowledge exchange via webpage, participation in various public activities and creation of booklet on EUROMENE activities. Establish communication links with small/medium-sized enterprises (SMEs). Facilitate development of guidelines and participation in common research projects providing information on open calls on EU level.

**Networking tools - ~ 100 000 EUR:** 2 meetings - 30100 EUR; training school - 29500 EUR, 5 STSM - 12500 EUR; 5 ITG Conference grants - 10000 EUR; dissemination: webpage maintenance -1500 EUR, publications - 1800 EUR, participation in conferences/dissemination activities -1 557 EUR; FSAC 15% - 13043 EUR.

1<sup>st</sup> Meeting: Core Group meeting /WG 3, WG4 meeting on synchronization - type: Management Core Group Meeting, Working Groups No 3 and No4 Meeting; Dates - 12/07/2018 - 13/07/2018 (could be changed); Location – London, Paris, Dublin or Bucharest (needs to be decided), participants- 15, reimbursed - 15, travel costs - 9000 EUR, support grant - 1000 EUR.

2<sup>nd</sup> MC/WG (as required) meeting on synchronisation - type: MC meeting /WGs (as required); Dates - 14/02/2019 - 15/02/2019 (could be changed); Location - (Slovenia or Greece); participants - 28; reimbursed - 27; travel costs - 18600 EUR; support grant - 1000 EUR.

#### **Training school: Summer school for translational research in ME/CFS**

Panel: Novel methods in potential immunological biomarkers research of ME/CFS  
Dates - 24/06/2018 - 29/06/2018 (could be changed); location - Berlin (Germany); lecturers - 4; students - 12; trainers - 4 invited lecturers for panel - 6500 EUR; travel costs- 18000 EUR; support grant - 5000 EUR.

#### **Deliverables of GP3:**

- Deliverable 9 (28 month) - Guidelines for usage of immunological biomarkers in ME/CFS diagnosis and therapy evaluation;
- Deliverable 10 ( 28 month) - Common consensus protocol for economic loss estimation and forecasting due to ME/CFS;
- Deliverable 11 (30 month) - Evaluation scales for assessment of neurological symptoms associated with ME/CFS and usable in diagnostic;
- Deliverable 12 (31 month) - Common strategy protocol for ME/CFS diagnosis: synchronisation between centres, research component integration;
- Deliverable 13 (36 month) - Protocol and guidelines for ME/CFS subgroups detection (stratification) according to the presence of symptoms and subject to potential biomarkers variation.

**3. Jesus Castro, Slobodan Sekulic, Activities of WG1 after Belgrade meeting (what is done, results) (see attached presentation [220170907belgrade-meeting-review](#));**



4. **Carmen Scheibenbogen, Enrica Capelli**, Activities of WG2 after Belgrade meeting (what is done, results) (see attached presentation *3EUROMENE\_WGBiomarker\_Sofia\_8.2.18 Agenda.pptx*);
5. **Derek Pheby**, Activities of WG3 after Belgrade meeting (what is done, results) (see attached presentation *4Sofia presentation\_ Derek Pheby*)
6. **Elin Bole Strand, Jerome Authier**, Activities of WG4 after Belgrade meeting (what is done, results) (see attached presentation *5WG4\_Sofia\_clinical enablers and diagnostic criteria*).
7. **Els Tobbak, Carmen Adella Sirbu**, current situation with STSM. How to increase activity of ECIs in participating countries (see attached presentation *Els\_pre*).
8. **Lorenzo Lorusso, Evelina Shikova**, Interaction with the COST Office Representative SILVIA ALEXE on dissemination (what is done, how to increase dissemination activity) (see attached presentation *7CommunicationofficerSofia*).
9. **Lorenzo Lorusso, Anne Marit Mengshoel**, Webpage, information and involvement of SMS and patients organizations (see attached presentation *8DisseminationSofia2018*).

### Conclusion

1. Thanks to involvement ECIs from various countries the WG1 has been activated after Belgrade meeting – manuscript is prepared and submitted as well as protocol sent for registration in PROSPERO.
2. WG2 on biomarkers is the most productive and active one. One paper is published, another one *in press*. All biomarker subgroups are successfully covered; more attention should be paid to neurologic biomarkers.
3. WG2 Leader Professor Carmen Scheibenbogen has agreed to organize of training school/ summer school for translational research in ME/CFS in Berlin because the Charité hospital is leading in the translational research.
4. WG3 activity should be increased and the work between the meetings activated. The WG3 meeting is planned as the next activity (will be included in the Agenda of next meeting) for consolidation of the obtained data and for detailed planning of the next work period.
5. WG4 activity should be increased in order to prepare the manuscript on recent situation in ME/CFS diagnostic and treatment in Europe and to create common guidelines for diagnostic and treatment. The WG4 meeting is planned as the next activity (will be included in the Agenda of next meeting).
6. WG5 - Regarding TIC Conference grants we have identified the problem with the payment. Advance payment is not foreseen for the TIC Conference grants. Taking into account that the salary of the young researchers/PhD students in the New Member states are ~300 EUR ECIs are not able to cover conference expenses are not able to use the grants. In this period 3 grants are used by Latvia and one by Republic of Serbia.
7. WG6 activity should be increased and 2 members have participated in the science communications trainings (organized by the COST Association. Web page of EUROMENE should be improved and all



actual information inserted without delay. Leaflets or brochures could be helpful. Attention should be paid to involvement of SMS and patients organizations.

8. STSM – activity is increased and 5 out of 6 missions are used however activity in the old EU participating countries should be increased.

## WG2 Biomarkers Meeting

### CA15111 WG2 meeting Chair: Carmen Scheibenbogen

The first session of the meeting started with a summary of the (unpublished) data from the Norwegian multicenter Rituximab trial in ME/CFS by Carmen Scheibenbogen. Next there were 3 presentations of research projects from the EUROMENE group. Santa Rasa from Riga presented a large study on the presence of active HHV-6, HHV-7 and B19 infection in a subgroup of ME/CFS patients. Bhupesh Prusty from Würzburg reported on his studies of the effect of serum of ME/CFS patients on mitochondrial function and the potential modulation by HHV-6. Ruud Vermeulen reported on his cohort studies on cardiopulmonary exercise testing in ME/CFS.

In the 2<sup>nd</sup> session an update of ongoing projects from the EUROMENE Biomarker WG was given. The first topic were the review projects. Franziska Sotzny reported on the autoimmunity review study, from which a paper was already submitted to Autoimmunity reviews (publication online since 13<sup>th</sup> of April: Sotzny F, Blanco J, Capelli E, Castro-Marrero J, Steiner S, Murovska M, Scheibenbogen C; European Network on ME/CFS (EUROMENE). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - Evidence for an autoimmune disease. *Autoimmun Rev.* 2018 Apr 7). Jesus Castro gave a comprehensive review on the Metabolism paper, Thomas Harrer on “Chronic Enterovirus and HHV6 Infection” and Julia Blanco on “Immune cell alterations”.

As an introduction to the Biomarker project Franziska Sotzny gave a brief overview of the European biomarker landscape project which was published in 2017 (**Scheibenbogen C**, Freitag H, Blanco J, Capelli E, Lacerda E, Authier J, Meeus M, Castro Marrero J, Nora-Krukke Z, Oltra E, Strand EB, Shikova E, Sekulic S, Murovska M. The European ME/CFS Biomarker Landscape project: an initiative of the European network EUROMENE. *J Transl Med.* 2017 Jul Review.) In the meantime an update had been done which included also non-European studies. All participants discussed then the existing data on biomarkers and which biomarkers might be of interest to be further studied within the EUROMENE consortium. Further it was discussed which calls might fit to get support for this study. Uldis Berkis presented information for the upcoming ERA-Permed call for projects on personal medicine. It was decided that Carmen Scheibenbogen was going to check if this call is feasible for an application for the EUROMENE Biomarker project.

