

## **COST action CA15111**

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

#### **Minutes, Belgrade, 07 September 2017 Management Committee meeting and Work Group No 1 meeting on synchronisation**

CA15111 MC Chair: Modra Murovska

Local Meeting Chair: Slobodan Sekulic

#### **Management Committee meeting**

**1. Modra Murovska**, Current GP2 situation - implemented measures and planned measures. (*MM\_Belgrade\_2017*).

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.

Weaknesses noted by COST Scientific Commission: New Member states should be more actively involved in the action; ECR's should be more actively involved in the action activities.

Measures: Training School «Omics Technologies and Bioinformatics Applications in ME/CFS Research»; 3 additional STSM grant applications included; MC meetings held in the new member states.

Additional Budget: The COST Association has been granted extra budget (EUR 6.67 million) from the European Commission in the frame of the Specific Grant Agreement signed between both parties. Accordingly, it has been decided to allocate this additional budget focussing on Networking Activities mainly by increasing the budget provided to all running COST Actions. Considering this, and in order to minimise disruption to the Action, the COST Association will unilaterally amend your COST Action Grant Agreement and Work and Budget Plan and increase the budget provided to your Action. The extra budget will be allocated to the new **Networking Tool "Inclusiveness Target Countries Conference Grants"** since this tool was not available at



the time of preparation of Work and Budget plan, and considering that Inclusiveness Target Countries spending remains a priority.

**2. Evelina Shikova, Enrica Capelli**, Information on Training school in Pavia - a review, problems to consider when organizing next school, evaluation from the trainers and trainees side (Evaluation Questioner's summary). (*MCmeeting\_WG5\_Shikova\_Belgrade; Training school feedback*).

Training school entitled: "OMICS TECHNOLOGIES AND BIOINFORMATICS APPLICATIONS IN ME/CFS RESEARCH" took place from 17th to 22nd July 2017 in Pavia. Purpose of training school was dissemination of the knowledge on the latest generation technologies to increase the skills of Early Career Investigators (ECI) involved in ME/CFS research for biomarker discovery using theoretical and practical sessions related to next gen technologies, miRNA identification and quantitation, microbiota characterization and bioinformatics. 15 people attended training school. Only two of them had attended previously similar training school. Training school was marked as relevant from 14 attenders, 12 of them marked facilities and logistic of the training school as excellent or good. Most appreciated (useful) topics were: new methods/new informations (bioinformatics; metagenomics/microbiota; miRNAs) for 11 attenders, exchanging/share experiences for 3 attenders, pitfalls in ME/CFS research for one attender. Most common suggestions were: more informatic modules with practical sessions, and more practice (analysis of miRNAs).

**3. Els Tobbak, Carmen Adella Sirbu**, current situation with STSM. The question how to increase activity of ECIs in participating countries was discussed. For next round of STSM so far four applications has been identified and two applications submitted. It is suggested to inform all young carrier researchers in the field of epidemiology, biochemistry, neurology, internal diseases, and infectious diseases of possibility to learn more about Myalgic Encephalomyelitis/Chronic Fatigue Syndrome thru STSM in representative European Medical Institution. Possibilities for STSM are identified in LSHTM - 2 places, minimum for 2 weeks on clinical and epidemiology research (Training on diverse aspects of clinical/epidemiological research in ME/CFS; or biobanking) and in Oslo, Norway - 5 days stay in Oslo including the possibility to learn about clinical practice and research about CFS/ME. The program will be adapted to the applicant's interests being either mostly clinical practice or research (Hosts: the National Advisory Unit for CFS/ME, Rh, the CFS/ME Centre, Aker at Oslo University Hospital by Elin B Strand and Ingrid B Helland and the University of Oslo, Medical Faculty, Dep of Health Sciences by Prof. Anne Marit Mengshoel). Department of Health Sciences employs an interdisciplinary scientific staff with backgrounds as health professionals, from medical sociology and humanities working broadly with clinical research as well as more theoretically. This involves the research group SELF-MANAGEMENT where the members mainly have a background as health professionals. The research group aims to perform clinical relevant research related to self-management for various patients with chronic illnesses. The aim is to develop knowledge about how it is like to live with chronic illnesses and for health professionals to work with these patients.



National Advisory Unit for CFS/ME, Rh, and OUS is a national resource institution for CFS/ME. The Advisory unit has presentations all over the country on research, diagnosis as well as multidisciplinary counselling. The CFS/ME center is a clinical unit with an out-patient clinic and a ward for severe ill patients. In addition a biobank and a thematic register with ongoing data sampling is part of the Centre. There is also collaboration with various research groups and a close collaboration between the advisory Unit and the CFS/ME Centre.

. In this invitation our contribution will especially focus on:

- CFS/ME diagnosis/exclusion;
- multidisciplinary CFS/ME counselling;
- CFS/ME thematic register and biobank sampling and associated research;
- fatigue in chronic illnesses;
- patient-reported outcomes;
- effect studies on non-pharmacological therapeutic approaches;
- qualitative interviews of patients' illness experiences.

**4. Lorenzo Lorusso, Evelina Shikova**, Interaction with the COST Office Representative SILVIA ALEXE on dissemination (what is done, how to increase dissemination activity).

**5. Jesus Castro, Slobodan Sekulic**, Activities of WG1 after Barcelona meeting (what is done, results).

Activities were related to publishing first paper of the WG1. Article related to raising awareness about MS/CFS in Serbia was published in Journal Medical Data: Sekulic S, Petrovic A, Redzek-Mudrinic T, Pericin-Starcevic I, Murovska M. Raising awareness about chronic fatigue syndrome in Serbia. Medical Data 2017; 9(2): 75-79. For the second paper activities were related to search relevant databases (MEDLINE, SCOPUS, WEB of SCIENCE), quality assessment, data extraction and analysis. Manuscript is written and it is in preliminary stage.

**6. Carmen Scheibenbogen, Enrica Capelli**, Activities of WG2 after Barcelona meeting (what is done, results). ([EUROMENE\\_WGBiomarker\\_Belgrad\\_7.9.17](#))

Survey in EU countries existing data on potential biomarkers in ME/CFS: Immunological, infection-associated, neuro-imaging. Milestones: survey data on existing biomarkers and detection approaches, protocols of meetings – synchronisation panel and personalised care roadmap. Deliverables: guidelines for usage of infection-associated biomarkers in ME/CFS diagnosis; guidelines for usage of immunological biomarkers in ME/CFS diagnosis; evaluation scales for assessment of neurological symptoms associated with ME/CFS and usable in diagnosis. Achievements is published article: Carmen Scheibenbogen, Helma Freitag, Julià Blanco, Enrica Capelli, Eliana Lacerda, Jerome Authier, Mira Meeus, Jesus Castro Marrero, Zaiga Nora-Krukke, Elisa Oltra, Elin Bolle Strand, Evelina Shikova, Slobodan Sekulic and Modra Murovska [The European ME/CFS Biomarker Landscape project: an initiative of the European network](#)



[EUROMENE](#) Journal of Translational Medicine 2017 15:162. Current work in progress is – 1. Establish special interest groups: identify markers of interest, confirm in small/larger cohort studies, write reviews (autoimmune markers, persistent infection markers, genetic markers, immune phenotype markers, complement markers, metabolic markers); 2. Survey on neuro-imaging in Europe. 3. Presentation of achievements from interest groups and neuro-imaging during Biomarker Meeting on February 2. 2018. in Sofia. Further planned activities: Develop a roadmap for Task 4 (to discuss and analyse the existing data on biomarkers usable for laboratory and objective clinical diagnosis of ME/CFS, to promote synchronization of biomarker panels and interpretation, to evaluate digitalization and big data capabilities).

**7. Elin Bole Strand, Jerome Authier**, Activities of WG3 after Barcelona meeting (what is done, results).

**8. Derek Pheby**, Activities of WG3 after Barcelona meeting (what is done, results). (*Note re WG3 220917*).

All participants were informed about changes in MC and WG3 Vice-chair. Task was to estimate the burden of ME/CFS to society and provide long-term trend estimates for societal impact. It appears that no European country collects these data routinely or systematically with respect to ME/CFS. There are problems of interpretation of published material. Very little literature is published relevant to the tasks. Considerable problems of interpretation, because of lack of comprehensive case ascertainment, lack of consistency of case definitions, impact of case definitions on prevalence estimates. Therefore there is a need for: pan-European agreement on a case definition for ME/CFS, consistent methodology to be developed to enable comparable prevalence data to be collected in all participating countries.

**9. Lorenzo Lorusso, Anne Marit Mengshoel**, Webpage, information and involvement of SMS and patients organizations. Current organisation of web pages provides adequate information about EUROMENE COST Action and dissemination of relevant data.

**10.** All MC members, International conferences/congresses, local activities (activities in the participating countries) planned during GP2.

**11.** Other issues (prepared and submitted projects, next MC meeting etc.). [Prof. Evelina SHIKOVA-LEKOVA](#) informed management committee about progress of preparing next meeting: Sofia/February 8, 2018: MC meeting and WG2 meeting on synchronization.

### **Work Group No 1 (Epidemiology) meeting**

Leader **Jesus Castro-Marrero**, Vice-leader **Slobodan Sekulic**

#### **1. Report on WG1 results.**

Article related to raising awareness about MS/CFS in Serbia was published in Journal Medical Data: Sekulic S, Petrovic A, Redzek-Mudrinic T, Pericin-Starcevic I, Murovska M. Raising awareness about chronic fatigue syndrome in Serbia. Medical Data 2017; 9(2): 75-



79. Manuscript “Prevalence and incidence of CFS/ME in Europe” is in final stage of preparation.

**2. Activities of WG1 after Barcelona meeting.**

Activities were related to publishing first paper of the WG1 and this was also the first published paper of this COST Action. For the second paper activities were related to search relevant databases (MEDLINE, SCOPUS, WEB of SCIENCE), quality assessment, data extraction and analysis. Manuscript is written and it is in preliminary stage. *(20170907belgrade-meeting-review)*

**3. Problems that need to be addressed to activate the WG1 work.**

Work in WG1 has already started. One article is published and second is final stage of preparation. Epidemiologist from Spain is first author of this manuscript, F. Estevez. To improve work it is necessary to obtain epidemiologists from other participating countries and make an epidemiology net to intensify the network activities. It is necessary to have real data about prevalence of CFS/ME in Europe.

**4. How to involve real epidemiologists from participating countries?**

Inform epidemiologist from countries involved in EUROMENE with lectures about existence of COST Action CA 15111, its aim and significance of ME/CFS. It is necessary to explain them that their work is critical in first steps of proper management of this syndrome.

**5. How to collect current epidemiological data on ME/CFS epidemiology?** It is necessary to determine prevalence in each country involved in EUROMENE. If there is no central registration unit for this syndrome in particular country it is necessary to determine prevalence of ME/CFS with random selection of the population and then stratification of the sample.

**6. What should be done to increase visibility of ME/CFS epidemiology in Europe?** Dr Adela Sirbiu from Romania will write manuscript about ME/CFS research in EUROMENE participating countries before and after they have entered the COST activity, including current status of the incidence, biomarkers, availability of biobanks related to ME/CFS. After 4-5 or 10 years this study could be repeated to evaluate what happens in meanwhile. It is necessary to make in each country national organisation of the patients with ME/CFS. Activities of those organizations should be directed toward informing society about this syndrome. Web presentation of the societies as well as of this COST Action will also increase visibility.

**7. How professional and non-governmental organizations can help to increase the visibility.** Professionals could organize series of lectures to health workers. Target group should be epidemiologists, neurologists, specialists for infectious disease and internal medicine specialists. Non-governmental organizations and patients organizations with various actions (concerts, public appearance with promotion) could give the input.

**8. Clarification of the WG1 plan for the next GP2 period (till Sofia meeting).** Finish the manuscript “Prevalence and incidence of CFS/ME in Europe”. After that teleconference involving authors and epidemiologist is planned.

**9. Biobanking in WP1.** Make contact to existing biobanks. Get familiar with local ethic rules about access to materials from biobanks. Find the way to obtain material for ME/CFS study.



10. **Local projects and support schemes for biobanks.** Biobanks are collections of donations of biological material and could be very valuable for research into human diseases. It is necessary to change role of patients in biobanking from being seen as donors, to actual collaborators in the design, development and the running of biobanks. National societies of CFS/ME patients could alleviate process of obtaining material for studies related to CFS/ME.
11. **Ethical issues.** Ethical issues in the participating countries are different. In some countries the permission of Ethical Committee could be obtained only for a particular study without permission to use the samples in other studies as well. Also there are limits of sample size and amount of biomaterial therefore not all participating countries could be involved in biobanking activities. It is decided to continue to work with documents for Ethics Committee approvals at European level, to facilitate the involvement of participating countries in samples collection.

