EUROPEAN NETWORK ON MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME

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MC Chair
September 8, 2017

RĪGAS STRADIŅA UNIVERSITĀTE
VITA BREVIS ARS LONGA

cost
EUROPEAN COOPERATION IN SCIENCE AND TECHNOLOGY

COST is supported by the EU Framework Programme Horizon 2020

Aim/Primary objective

- Promote multidisciplinary strategies in ME/CFS research and foster a full chain of translational research

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Grant period 01/05/2017 – 30/04/2018
WG tasks

WG 1 Epidemiology

- T2 Synchronisation;
- T3 Biobanks and protocols;
- T4 Ethical framework.

WG 2 Biomarkers

- T4 Data synchronisation

WG 3 Socio-economics

- T2 Direct loss calculation;
- T3 Indirect burden.

WG 4 Clinical research/diagnostic criteria

- T2 Optimal set;
- T3 Treatment efficacy.

WG tasks

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».

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 New member states

MM1

Grant Period 1: 01.05.2016 – 30.04.2017

	Cost networking tools	Budget Plan (EUR)	Expenditures (EUR) on 7 September 2017
1	Meetings	50900.00	41999.71
2	Training school	0.00	0.00
3	STSM	15000.00	6640.00
4	COST action dissemination	4500.00	4499.78
5	OERSA	34.75	28.00
	Total Science expenditure	70434.75	53167.49
	FSAC 15%	10565.21	7975.12
	Total grant	80999.96	61142.61
	LOST money in the period 1		19857.35

MM1 Modra Murovska; 05/09/2017

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.

Grant Period 2: 01.05.2017 – 30.04.2018

	Cost networking tools	Budget Plan (EUR)	Expenditure (EUR) on 7 September 2017
1	Meetings	31902.00	
2	Training school	17654.47	17653.52
3	STSM	15000.00	
4	ITC Conference grants	17500.00	
5	COST action dissemination	4220.00	1800.00
6	OERSA	0.61	
	Total Science expenditure	8627.08	19453.52
	FSAC 15%	12941.56	
	Total grant	99218.64	

Short term Scientific Missions

Amount per STSM:		2500 EUR
Number of foreseen STSMs:	6	15000 EUR

At present 2 candidates from Latvia, one - Serbia

Dissemination

Webpage EUROMENE.EU maintenance: 1500 EUR

Financial and Scientific Administration and Coordination (FSAC)

MAX. 15% = 9459 EUR

What is done?

- **Training School «Omics Technologies and Bioinformatics Applications in ME/CFS Research»** Monday, July 17 – Friday, July 21, 2017
- **Project application:** Wellcome Trust Application «Harnessing the success of the UK ME/CFS Biobank through the development of a global resource for ME/CFS research»(**Luis Nacul** et all.)

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Publications

- Raising awareness about chronic fatigue syndrome in Serbia (**Sekulic S.**, Petrovic A., Redžek-Mudrinic T., Peričin-Starčevic I., Murovska M.) MD-Medical Data, 2017, 9(2): 075-079.
- The European ME/CFS Biomarker Landscape project: an initiative of the European network EUROMENE. (**Scheibenbogen C.**, Freitag H., Blanco J., Capelli E., Lacerda E., Authier J., Meeus M., Castro Marrero J., Nora-Krukle Z., Oltra E., Strand E.B., Shikova E., Sekulic S., Murovska M.) J Transl Med. 2017, 15(1): 162. doi: 10.1186/s12967-017-1263-z.
- ME/CFS – evidence for an autoimmune disease (**Scheibenbogen C.** et al., in preparation).

I. Meetings

1. Title: **MC/WG1 meeting on synchronisation**

Type: Management Committee Meeting, Working

Group No 1 Meeting

Date: 07/09/2017

Location: Belgrad (Serbia)

Participants: 22

Reimbursed: 20

Travel costs: 14200 EUR

Support grant: 1000 EUR

2. Title: **MC/WG 2 meeting on synchronisation**

Type: Management Committee Meeting, Working Group No 2 Meeting

Date: 08/02/2018

Location: Sofia (Bulgaria)

Participants: 22

Reimbursed: 20

Travel costs: 14200 EUR

Support grant: 1000 EUR

Secondary objective 1

- Explore the potential of existing cohorts through workshop and seminar programmes as sources of potential cases of ME/CFS and the advancement of the epidemiological understanding of the disease. Exchange information facilitating the development of synchronised adequate local systems for the collection, storage, and cataloguing of biological samples for research purposes. Exchange information on local ethical issues and discuss on common ethic's framework.

Secondary objective 2

- Coordinate usage of innovative high-throughput technologies (genomic, transcriptomic, proteomic, and metabolomics strategies) for new biomarker recognition. Develop guidelines for usage of infection-associated biomarkers and immunological biomarkers in ME/CFS diagnostic.

Secondary objective 3

- Survey 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. Optimise models of prevention in health aspects.

Secondary objective 4

- Facilitate the development of adequate local systems for case finding, data collection and storage via best practice exchange. Synchronise diagnostic criteria and develop common strategy protocol to identify and understand the biological disease pathways in a stratified way. 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 infection-associated biomarkers research for ME/CFS” and following training school on-omics and bioinformatics in ME/CFS research. Organize STSMs, accomplish them and monitor results.

Secondary objective 6

- Establish communication links with small/medium-sized enterprises (SMEs). Exchange on technology transfer capabilities.
- Maintain project webpage.

Training possibilities for STSM

Lab specialization	Topic	Contact
Antibodies and immune metabolism in CFS/ME	Flow cytometry, cellular and molecular immunology	Prof. Dr. med. Carmen Scheibenbogen Stellv. Leiterin Institut für Med. Immunologie, Berlin, Germany Carmen.scheibenbogen@charite.de
Sleep disorders in CFS	Polysomnography, multiple sleep latency test, actigraphy	dr. Els Tobback University Hospital Ghent, Ghent, Belgium Els.tobback@uzgent.be
Antiviral and antibacterial antibody in CFS/ME	Multiplex analysis	Prof Dr med. Jonas Blomberg, Clinical Microbiology, Uppsala University Hospital, Uppsala, Sweden. Jonas.Blomberg@medsci.uu.se
micro RNA expression and analysis of microbiota and mycobiota in ME/CFS	qRT-PCR; 16S rRNA and ITS1 amplicon sequencing	Prof. Enrica Capelli Dept. Scienze della Terra e dell'Ambiente and Centre for Health Technologies/Univ of Pavia, Pavia, Italy Lab immunology and genetic analyses. enrica.capelli@unipv.it
Biomarkers of mitochondrial metabolism dysfunction. Nutritional supplement interventions in ME/CFS	Mitochondria biology, western blot, ELISA, & clinical trials	Dr Jesus Castro Vall d'Hebron University Hospital Collserola Research Institute (CFS/ME lab) Barcelona, Spain jesus.castro@vhir.org

Immunological alterations in CFS/ME. Use of Multicolor flow Cytometry	T B and NK cell fucntion	Dr JUlià Blanco IrsiCaixa/IGTP Hospital Germans Trias i Pujol, 08916 BADALONA, SPAIN Jblanco@irsicaixa.es
CFS/ME Clinic Unit	CFS/ME medical assessment based on clinical case definition. CFS/ME phenotypes, fatigue stratification, and other comorbid conditions - CFS/ME symptoms measure questionnaire (PROMs)	Dr Jose Alegre Vall d'Hebron University Hospital CFS/ME Clinical Unit Barcelona, Spain jalegre@vhebron.net
Viral biomarkers in ME/CFS	Virology, molecular virology	Dr. med. Modra Murovska, Dr. med. Zaiga Nora-Krukle A.Kirchenstein Institute of Microbiology & Virology, Riga Stradins University, Riga, Latvia. Modra.Murovska@rsu.lv; modra@latnet.lv; Zaiga.Nora@rsu.lv