

# EUROPEAN NETWORK ON MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME

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VITA BREVIS ARS LONGA



EUROPEAN COOPERATION  
IN SCIENCE AND TECHNOLOGY



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Horizon 2020



# Welcome New Participating Countries

- Greece - Dr Giorgos Sakkas
- Slovenia - Dr Uroš Marusič

# WG tasks 01.05.2017 – 30.04.2018

## 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.

# Publications

- Scheibenbogen C., Freitag H., Blanco J., Capelli E., Lacerda E., Authier J., Meeus M., Castro Marrero J., Nora-Krukke Z., Oltra E., Strand E.B., 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 26;15(1):162. doi: 10.1186/s12967-017-1263-z.
- Sotznaya F., Julià Blancob J., Enrica Capelli E., Castro-Marrero J., Steiner S., Murovska M., Scheibenbogen C. on behalf of European Network on ME/CFS (EUROMENE). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome – evidence for an autoimmune disease. *Autoimmunity Reviews.*
- Estévez-López F., Castro-Marrero J., Wang X., Bakken I.J., Ivanovs A., Nacul L., Sepulveda N., Strand E., Pheby D., Alegre J., Scheibenbogen C., Shikova-Lekova E., Lorusso L., Capelli E., Sekulic S., Lacerda E., Murovska M. The prevalence and incidence of myalgic encephalomyelitis/chronic fatigue syndrome in Europe: the EURO-epiME study from the European network EUROMENE. A protocol for a systematic review. *Journal: BMJ Open*

# Project applications and presentations

- ❑ Wellcome Trust application: re-submitted the application from last year to the Wellcome Trust at the preliminary stage. The scope is very similar to the previous one, i.e. data and samples integration between ME/CFS UK Biobank and Europeans Biobanks.
- ❑ Lara Gitto – participated in the ESPCH (THE EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE) in London on 26-27 October, 2017
- ❑ Elin Bolle Strand – participated in a info-day on CFS/ME in the Europa Hall in Helsinki on 19 January 2018 with the support of the national CFS/ME-organisation in Finland (not accepted by Officer and Scientific Committee)

# DELIVERABLES

<b>Nr.</b>	<b>Month</b>	<b>Deliverable</b>
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

# STSMs and COST Inclusiveness Target Countries Conference Grants

Country	STSM	ITC Conference grant
Bulgaria	1/9	
Latvia	5/9	1 - 1330 EUR 1 - 1230 EUR 1 - 2500 EUR
Portugal		
Republic of Serbia	1/9	1 – 1980 EUR
Slovenia		
Rumania		
Germany	1/9	



# Grant period

**01/05/2018 – 30/04/2019 Goals**

# WG tasks

## WG 1 Epidemiology

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

## WG 2 Biomarkers

- T4 Data synchronisation;
- T3 Survey neuro – from the GP1-2

## WG 3 Socio-economics

- T4 Prevention models;
- T2 Direct loss calculation - from the GP2;
- T3 Indirect burden – from the GP2.

# WG tasks

## WG 4 Clinical research/diagnostic criteria

- T2 Optimal set;
- T3 Treatment efficacy;
- T4 Global criteria optimisation.

## WG 5 STMS, workshops, conferences

- T1 Training school «Summer school for translational research in ME/CFS»;
- T2 STSMs;
- T3 Training panel «Novel methods in potential immunological biomarkers research for ME/CFS».

## WG 6 Dissemination

- T2 Guidelines;
- T3 Website;
- T4 Research projects.

# 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 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 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

■ Meetings	2	30100 EUR
■ Training school	1	29 500 EUR
■ STSM	5	12 500 EUR
■ ITG Conference grants	5	10 000 EUR
■ Dissemination		
» Webpage maintenance		1 500 EUR
» Publications		1 800 EUR
» Participation in conferences		
» Dissemination activities		1 557 EUR
■ FSAC 15%		13 043 EUR
■ TOTAL		100 000 EUR

# I. Meetings

## 1. Title: Core Group meeting /WG 3, WG4 meeting on synchronization

Type: Management Core Group Meeting, Working Groups No 3 and No4 Meeting

Dates: ?/07/2018 - ?/07/2018

Location: Participants: 15

Reimbursed: 15

Travel costs: 9 000 EUR

Support grant: 1 000 EUR

## 2. Title: MC/WG (as required) meeting on synchronisation

Type: MC meeting /WGs (as required)

Dates: ?/02/2019 - ?/02/2019

Location: (Slovenia or Greece)

Participants: 28

Reimbursed: 27

Travel costs: 18 600 EUR

Support grant: 1 000 EUR

## II. Training schools

**Title: Summer school for translational research in ME/CFS**

**Panel: Novel methods in potential immunological biomarkers research of ME/CFS**

Dates: ?/06/2018 - ?/06/2018 or ?/09/2018

Location: Berlin (Germany)

Lecturers: 4

Students: 12

Trainers - 4 invited lecturers for panel: 6 500 EUR

Travel costs: 18 000 EUR

Support grant: 5 000 EUR

### III. Short term Scientific Missions

Amount per STSM:		2 500 EUR
Number of foreseen STSMs:	5	12 500 EUR

### IV. Conference grants Inclusiveness Target Countries grants

Amount per grant:		~2 000 EUR
Number of foreseen grants:	5	10 000 EUR

### V. Dissemination:

Web page maintenance		1 500 EUR
Publications		1 800 EUR
Participation in conferences		?
Dissemination activities		1 557 EUR

**VI. FSAC 15% - 13 043 EUR**

**TOTAL: 100 000 EUR**



## DELIVERABLES

Nr.	Month	Deliverable
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