

## European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

COST Action - CA15111

### Deliverable 6

#### **Description and programme book of training schools and training events (renewed annually)**

One of the main tasks of WG5 is to organize two training schools: "Summer school on -omics and bioinformatics in ME/CFS research", and "Summer school for translational research in ME/CFS". First training school "OMICS TECHNOLOGIES AND BIOINFORMATICS APPLICATIONS IN ME/CFS RESEARCH" was organized and conducted during GP2. Second training school was organized and conducted during GP3.

#### *SECOND TRAINING SCHOOL*

#### **"SUMMER SCHOOL FOR TRANSLATIONAL RESEARCH IN ME/CFS"**

##### **Description**

- **Organizer:** Institute Medical Immunology, Charité Campus Virchow Klinikum, Berlin, Germany Prof., Dr. med. Carmen Scheibenbogen
- **Venue address:** Föhrerstr. 15/Südstr. 2 13353 Berlin, Germany
- **Dates:** June, 24 – 29 (2018)
- **Purpose of training school:** Disseminating knowledge on translational research in ME/CFS to increase the skills of Early Career Investigators (ECI) involved in ME/CFS research
- **Topics included in the training:**
  - Clinical approach to ME/CFS (pathomechanism, clinical picture and diagnosis, assessing symptoms and diagnostic tools)
  - Biobanking, data management
  - Biomarkers
  - Theoretical and practical sessions
- **Trainers:**

Prof. Carmen Scheibenbogen/Pathomechanisms of fatigue;  
Dr. Eliana Lacerda/ Assessing symptoms and diagnostic tools in ME/CFS;  
Biobanking, data management, ethics;  
Dr. Luis Nacul/ Clinical and socio-demographic data;

Dr. Bhupesh Prusty/ Metabolic and Infection biomarkers in CFS;

Dr. Patricia Grabowski/ Clinical picture and diagnosis of ME/CFS;

Dr. Franziska Sotzny/ Soluble biomarker in CFS.

- **Maximum number of trainees** to be accepted for reimbursement according to the EUROMENE plan: 12

- **Important dates**

**Deadline for applications:** JUNE 1

**Selection results:** JUNE 6

**Training school in Berlin:** 24 – 29 JUNE

- **Selection procedure**

Eligibility criteria:

- Young scientist part of the COST Action - CA15111 European countries
- Early Stage Researchers (PhD students, PhD + 5 years)
- Knowledge on basic molecular methods
- Preference to scientists working in the field of ME/CFS, but others are not excluded

How to apply: Send a CV, a motivation letter and calculation of travel costs to the Scientific Committee e-mail:

[Carmen.Scheibenbogen@charite.de](mailto:Carmen.Scheibenbogen@charite.de)

- **Scientific Committee:** Carmen Scheibenbogen, Enrica Capelli, Modra Murovska, Evelina Shikova
- **Applicants by country**

Country	Number of applicants
Latvia	1
Germany	2
Bulgaria	2
Serbia	2
Poland	1
Norway	1

Netherlands	1
UK	1
Belarus	1
All	12

### Conclusions

- "Summer school for translational research in ME/CFS" was an efficient instrument for disseminating knowledge to increase capacity of ME/CFS research by involving Early Career Investigators (ECI), including from new EU member states
- Approx. 33% (4/12) involvement of ECIs from the new EU member states (Bulgaria/2, Latvia/1, Poland/1); 50% (6/12) from ITCs (+Serbia/2)

### *SECOND TRAINING SCHOOL*

#### **"SUMMER SCHOOL FOR TRANSLATIONAL RESEARCH IN ME/CFS"**

#### **Programme**

<b>Sunday, 24 June 2018</b>	
<b>17.00 –</b>	<b>Prof. Carmen Scheibenbogen</b> Welcome and Introduction into the course
<b>19.00</b>	Dinner
<b>Monday, 25 June: Clinical approach to ME/CFS</b>	
	The Monday will start with short presentations about the background and work of the students participating in the summer school. We will then give an overview of the complex differential diagnosis and pathophysiology of fatigue. The afternoon topic is clinical presentation and diagnosis of ME/CFS.
10:00	Participants' presentations (10 min each)
12.00 – 13.00	<b>Prof. Carmen Scheibenbogen</b> Pathomechanisms of fatigue
13.00 -	<b>Lunch</b>
14.30 – 15.00	<b>Dr. Patricia Grabowski</b> Clinical picture and diagnosis of ME/CFS

15.15 – 16.00	<b>Dr. Eliana Lacerda</b> Assessing symptoms and diagnostic tools in ME/CFS
16.00 - 17.00	Discussions
<b>Tuesday, 26 June: Biobanking, data management</b>	
9.00 - 12.00	<p><b>Dr. Eliana Lacerda</b>, London School of Hygiene and Tropical Medicine, UK Biobanking, data management, ethics</p> <p><b>Aims:</b></p> <ul style="list-style-type: none"> <li>- To provide information about the use of biobanks to enhance biomedical research in ME/CFS,</li> <li>- To show how to use this information for planning and establishing high-quality bio-sample collections for current and future ME/CFS research,</li> <li>- To categorise disease-specific and general biobanks, and discuss the advantages/disadvantages for their use in diseases, such as ME/CFS,</li> <li>- To discuss the current ethical, legal, and social issues associated with biobanks.</li> </ul> <p><b>Learning Outcomes:</b></p> <p>At the end of the session, a successful student will expected to:</p> <ul style="list-style-type: none"> <li>- identify advantages and disadvantages of using biosample collections and/or established biobanks to use in their ME/CFS research</li> <li>- evaluate if a biosample collection or biobank is compliant with the current ELSI, and if the samples are adequate their own study plan data collection (that would enhance the samples analysis) and data management for potential future studies.</li> </ul>
12.30 -	Lunch
14.00 – 17.00	<p><b>Dr. Luis Nacul</b>, London School of Hygiene and Tropical Medicine, UK Clinical and socio-demographic data - research questionnaires and measurements</p> <p><b>Aims:</b></p> <ul style="list-style-type: none"> <li>- To instruct students about the main research instruments for ME/CFS research,</li> <li>- To discuss the implications about the (lack of) standardisation in ME/CFS research,</li> <li>- To present a purposely-built database for enhancing ME/CFS research.</li> </ul> <p><b>Learning Outcomes:</b></p> <p>At the end of the session, a successful student will able to:</p> <ul style="list-style-type: none"> <li>- discuss the importance of standardization of procedures in ME/CFS research,</li> <li>- identify information that would be needed for future ME/CFS studies, and employ it to assess data collection instruments,</li> <li>- chose appropriate data collection instruments for ME/CFS research,</li> <li>- develop a data collection and data management plan for potential future studies.</li> </ul>
<b>Wednesday, 27 June: Antibodies and soluble biomarkers</b>	

	Biomarker include both markers with a certain sensitivity and specificity for diagnosing ME/CFS as well as those which may allow to classify subtypes of the disease, be of value as indicators of prognosis, and to be predictive for response to treatment. We will give an overview of the EUROMENE Biomarker project and discuss potential markers of interest. In the practical work detection of specific antibodies by cytometric bead array will be performed.
9:00	<b>Dr. Franziska Sotzny</b> Soluble biomarker in CFS
10:00	Laboratory practical activities: CBA
13.00	Lunch
14.30 – 17.00	Laboratory practical activities: CBA
<b>Thursday, 28 June: Metabolic biomarker</b>	
	Metabolomics: Mitochondria plays a key role in cell metabolism as well as multitudes of other cellular processes. CFS is known to be a mitochondrial disorder where mitochondrial dynamics as well as metabolic pathways associated with mitochondria are affected during the disease progression. During this session, we will discuss about known facts about alterations in mitochondrial metabolic state. We will also discuss about potential factors behind mitochondrial metabolic alterations. This lecture will also provide new insights into novel ideas and technologies being developed to study mitochondrial alteration in CFS. ROS are produced in mitochondria. In the practical work ROS will be assessed by flow cytometry.
9.00 -	<b>Dr. Bhupesh Prusty</b> Metabolics in ME/CFS
10.00 -	Laboratory practical activities: ROS
13.00 -	Lunch
14.30 – 17.00	Laboratory practical activities: ROS
<b>Friday, 29 June: Infection biomarker</b>	
	Chronic Infections: This lecture will cover a brief session on known knowledge behind chronic infection and CFS. In addition, this lecture will also discuss on scientific and technical difficulties in chronic infection studies in CFS. We will also discuss potentials of novel ideas in this field and how to implement them to know more about role of chronic infection in CFS. We will also discuss about possible sample selection methods and what to expect from them. In the practical work EBV will be assessed by PCR
9.00 -	<b>Dr. Bhupesh Prusty</b> Chronic infection in ME/CFS
10.00 -	Laboratory practical activities: EBV PCR in Plasma and PBMCs

13.00 -	Lunch
14.00 – 16.00	Laboratory practical activities: EBV PCR in Plasma and PBMCs

## TRAINEES EVALUATION - SUMMARY

Ten Evaluation forms were submitted by trainees. Each day of Training school (according to the Training School Programme) and the organization of Training school were separately evaluated by the attenders. The data from all ten evaluation forms are summarized in Table 1.

Table 1.

	Very good	Good	Moderate	Learned little	Learned nothing
<b>Day 1</b> <b>Clinical approach to ME/CFS</b>	11/11	-	-	-	-
<b>Day 2</b> <b>Biobanking, data management</b>	10/11	1/11	-	-	-
<b>Day 3</b> <b>Antibodies and soluble biomarkers</b>	9/11	2/11	-	-	-
<b>Day 4</b> <b>Metabolic biomarker</b>	9/11	2/11	-	-	-
<b>Day 5</b> <b>Infection biomarker</b>	7/10	3/10	-	-	-
<b>Organisation</b>	9/10	-	-	-	-

All marks were “very good” and “Good”. No marks “Moderate”, “Learned little” and “Learned nothing”. All marks of “day 1” (11/11) and “organization” of Training school (10/10) were “very good”. Evaluation of Day 2, Day 3, Day 4 and Day 5 – most of marks “very good” (35/43) and 8/43 “good”.

Comments/suggestions:

### Comments

**Most participants:** gained valuable knowledge in ME/CFS

**1 trainee:** perfect balance between theory and practice

### Suggestions

**3 trainees:** Practical sessions - "not 3 lab practice days in a row"/"one lecture day between laboratory practice days" is suggested

**1 trainee:** Information about potential small grants for ECR

**1 trainee:** Information about main researchers and research projects in Europe/world

**1 trainee:** Tags with names and countries of participants could be useful

**1 trainee:** To have the dinner all together in the second day instead of in the first day