Introduction

The UK ME/CFS Biobank (UKMEB) provides human tissue samples to internationally based biomedical researchers. Academic, non-commercial and commercial researchers are eligible to apply to use samples and/or data if they present a sound scientific rationale and have ethical clearance. Once the MTA/DTA is signed by both parties, the teams at the UCL/RPH Biobank prepare the requested samples to be shipped and CureME transfers the appropriate accompanying data. International distribution of samples involves logging the temperature of samples whilst in transit, and being aware of local differences in working days and customs requirements for the import of biological materials. Further information about the application process can be found at cureme.lshtm.ac.uk.

The case study 'Differential microRNA profiles in PBMCs and plasma EVs of severely affected ME/CFS patients' describes work from Dr Elisa Oltra and team at the Universidad Católica de Valencia after successfully applying to use UKMEB samples.

Objectives

- To support researchers internationally by providing high quality samples and extensive accompanying data to enhance research in ME/CFS, as described in the chosen case study
- To ensure harmonisation of sample and data collection internationally to facilitate collaboration and validation
- To encourage international collaboration, capitalising on the research capabilities of people in other institutions
- To provide resources for the validation of earlier studies

Methods

In this case study, the application process (Figure 1) for UKMEB samples began in February 2017 with samples released in June 2017.

Application Review

Outline Application Review is by the UKMEB Guardian Board (Proposed research must be covered by scope of participant consent, sufficiently funded or otherwise resourced, and deemed high priority)

Applicant seeks local ethical approval

Successful application reviewed by UCL-RPH Biobank Ethical Review Committee (B-ERC)

Signature of Material Transfer and/or Data Transfer Agreement by all parties

e.g. Application to Research 

Application in progress

Shipment of samples and/or transfer of data to applicants within one week of signing relevant agreements

Method(s)

- The current case study of differential microRNA profiles in PBMCs and plasma EVs of severely affected ME/CFS patients' describes work from Dr Elisa Oltra and team at the Universidad Católica de Valencia after successfully applying to use UKMEB samples.

Results

- After sharing preliminary results with CureME, 'Differential microRNA profiles in PBMCs and plasma EVs of severely affected ME/CFS patients' results were presented as a research poster to the ME/CFS biomedical and patient community at the international CMRC conference in Bristol, England (Sept, 2018). The full paper, the first report of paired PBMCs and EV microRNA profiles of ME/CFS patients is pending publication; therefore the results cannot be presented here.

- Since the launching of the UKMEB as an open access resource in late 2016, there have been >15 formal applications to use UKMEB samples and data (Table 1), six of which were from internationally based research groups. Four international groups are already working with UKMEB samples and/or data, with some preliminary results presented in international conferences.1,2

Table 1 – Applications for UKMEB samples and data

<table>
<thead>
<tr>
<th>Applicant</th>
<th>Institute</th>
<th>Country/Region</th>
<th>Status</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professor Eleanor Riley and team</td>
<td>LSHTM</td>
<td>UK</td>
<td>Samples delivered</td>
<td>2016</td>
</tr>
<tr>
<td>Dr Kari Morten</td>
<td>University of Oxford</td>
<td>UK</td>
<td>Samples delivered</td>
<td>2017, 2018</td>
</tr>
<tr>
<td>Professor Hazen Dookeran and team</td>
<td>LSHTM</td>
<td>UK</td>
<td>Samples delivered</td>
<td>2017</td>
</tr>
<tr>
<td>Professor Dockrell and Professor Joao Camillo collaboration</td>
<td>LSHTM/University of Cambridge</td>
<td>UK</td>
<td>Samples delivered</td>
<td>2018</td>
</tr>
<tr>
<td>Professor Dockrell and Professor Sit Stephen Riley collaboration</td>
<td>LSHTM/University of Cambridge</td>
<td>UK</td>
<td>Samples delivered</td>
<td>2018</td>
</tr>
<tr>
<td>Professor Faisal Khan</td>
<td>University of Dundee</td>
<td>Scotland, UK</td>
<td>Application in progress</td>
<td>Released planned 2018</td>
</tr>
<tr>
<td>Professor Chris Porting</td>
<td>University of Edinburgh</td>
<td>Scotland, UK</td>
<td>Application in progress</td>
<td></td>
</tr>
<tr>
<td>Professor Duncan Baird</td>
<td>University of Cardiff</td>
<td>UK</td>
<td>Application in progress</td>
<td></td>
</tr>
<tr>
<td>Dr Elisa Oltra</td>
<td>Universidad Católica de Valencia</td>
<td>Spain</td>
<td>Samples delivered</td>
<td>2018</td>
</tr>
<tr>
<td>Professor Eran Segal</td>
<td>Weizmann Institute of Science</td>
<td>Israel</td>
<td>Samples delivered</td>
<td>2018</td>
</tr>
<tr>
<td>Dr Rachael Hunter (Economics Working Group)</td>
<td>EUROMENE</td>
<td>Europe</td>
<td>Data transferred</td>
<td>2018</td>
</tr>
<tr>
<td>Professor Derya Unutul</td>
<td>The Jackson Laboratory</td>
<td>USA</td>
<td>Application in progress</td>
<td></td>
</tr>
<tr>
<td>Dr. Francisco Westermeyer</td>
<td>Institute of Biomedical Science, Graz</td>
<td>Austria</td>
<td>Application in progress</td>
<td></td>
</tr>
<tr>
<td>Professor Mercades Rincón</td>
<td>University of Vermont</td>
<td>USA</td>
<td>Application in progress</td>
<td></td>
</tr>
</tbody>
</table>

Figure 1 – Procedures for researchers to access samples and/or data

Conclusions

- The international sharing of samples is being accelerated by the UKMEB with three international institutions currently working with UKMEB samples and data, with further research groups expected to start soon. CureME works to standardise protocols for collecting, and distributing data and samples, acting as a model biopreservation for the integration of ME/CFS bi-resources, promoting synergy of protocols and maximising available sample sizes for ME/CFS research.

- Further to the success of the UKMEB, CureME has contributed expertise to projects in Europe, the US, Canada and Australia. Members of CureME participate in a range of committees and networks in the UK and abroad, including as contributors to the working groups of National Institute of Neurological Disorders and Stroke (NINDS) – Common Data Elements.

- Recently hosting a European meeting in London, CureME team members participate in the leadership of EUROMENE, a group funded by a COST Action to accelerate research into ME/CFS. A number of publications have emerged since the formation of this collaborative network.3,4

- The UKMEB has been showcased as an example of biobanking at international conferences (USA, Canada, and the UK).5,6

References

11. Lacerda, E. (2014). Oral presentation - The lay-scientific partnership that shaped the development of the UK ME/CFS Biobank. IACFS – Conference, San Francisco, USA