Operational costs for the UK ME/CFS Biobank (UKMEB)

Grant Amount	£180,395
Location	London School of Tropical Medicine (LSHTM)
Research Field	Infrastructure project
Lead Researcher/s	Dr Luis Nacul
Start Date	01/01/2024
Duration	24 Months
Status	In progress
Latest Update	Update: UK ME/CFS Biobank Steering Group
Publications	Publication list from the ME/CFS Biobank

BACKGROUND

The ME Association's Ramsay Research Fund (RRF) has been supporting the operational costs of the UK ME/CFS Biobank (UKMEB) since it was established in 2011. RRF is proud to fund the running costs for UKMEB each year, which exceeds £80,000 per annum.

The CureME team at the London School of Hygiene & Tropical Medicine (LSHTM) established the UKMEB with funding from the US National Institutes of Health and with donations from charities including the MEA; it enjoys an international reputation for quality and efficiency. One feature has been the inclusion of people who are severely affected by ME, who are visited at home by a research nurse for the clinical assessment and blood draw.

The UKMEB has provided samples and data to many ME/CFS research groups in the UK, Europe, North America, Latin America, and the Middle East. The true worth of the facility is underlined by the publications coming from the release of samples and the associated papers, which are widely cited in the literature and continue to serve to advance knowledge and understanding of ME/CFS.

Operational costs for the UK ME/CFS Biobank (UKMEB)

Blood samples are processed and aliquoted (separated) into serum, plasma, peripheral blood mononuclear cells (PBMC), red blood cells/granulocyte pellet, whole blood, and RNA.

The samples are then processed into different components and stored before being released to researchers whose research proposals have gone through rigorous ethical approval and peer review. An extensive clinical dataset (700 clinical and socio-demographic variables) enables comprehensive phenotyping (sub-grouping).

People with ME/CFS are carefully screened to make sure they meet diagnostic criteria for the disease. Blood samples are collected and rapidly transferred to the ME/CFS Biobank at the Royal Free Hospital in London – where they are processed and stored.

Making these samples available to other researchers increases the chances of achieving much-needed breakthroughs in the aetiology (cause) and treatment of ME/CFS, in the most cost-effective manner.

This is the only such project in the UK aimed at the study of ME/CFS and the supply of samples to outside researchers.

PROJECT DETAILS

The continued financial support for UKMEB's operational costs for a further two years will allow the CureME team at the London School of Hygiene and Tropical Medicine (LSHTM) to maintain and expand the Biobank's services.

Furthermore, in the next two years the team plan the following:

1. Replenish samples:

The team constantly replenishes the aliquots which have been depleted by recruiting additional research participants. This requires additional nursing time and the cost of clinical tests and of processing and storing samples.

The team is adding a sub-cohort of participants with Long-Covid, including those presenting with ME/CFS features, as well as people who had Covid but made a full recovery.

2. Increase clinical and educational work:

The team will continue to produce educational resources to people with ME/CFS, fellow researchers and healthcare professionals.

3. Grow communication and fundraising:

The team intend to appeal to major donors, with the help of the LSHTM's fundraising team, to enhance the UKMEB's global profile and to attract further users.

The goal has always been that the UKMEB would become self-sustaining and significant progress has already been made in this regard.

The long-term goal is for UKMEB to become **self-sustaining**, and significant progress has already been made toward this objective.

Find out more via the UKMEB's website: https://cureme.lshtm.ac.uk/

IMPORTANCE OF FUNDING

Fundamentally, the financial support enables UKMEB to continue facilitating crucial research and generating widely cited publications that contribute to global scientific knowledge on ME/CFS.

Additionally, the continued funding of UKMEB is vital for multiple reasons:

- **High quality samples:** the success of UKMEB is built on rigorous quality and operational control allowing easy direct comparison between samples and removing any collection bias.
- **Accelerating ME/CFS Research:** By providing reliable, high-quality biological samples, UKMEB enables researchers worldwide to investigate the biological underpinnings of ME/CFS and develop potential treatments.
- **Addressing Research Gaps:** The addition of a Long Covid sub-cohort will enhance understanding of overlaps and distinctions between ME/CFS and Long Covid.
- **Strengthening Global Collaboration:** The Biobank's reputation continues to grow, facilitating greater international research partnerships.
- **Supporting Patient-Centred Initiatives:** Educational resources will improve access to information for people with ME/CFS and healthcare professionals, fostering better clinical care.