



## Newsletter

December 2016

### UK ME/CFS Biobank

We are delighted to announce that we have reached our participant recruitment goals and have now banked close to **30,000** aliquots (blood samples) in the Biobank. Our samples represent people with mild/moderate ME/CFS, severe ME/CFS, multiple sclerosis and non-ME/CFS chronic fatigue as well as healthy participants - providing a unique cohort in the field of ME/CFS research. As you may already know our research and recruitment to the biobank has involved a longitudinal study so we have also collected samples from many participants at two points in time (baseline and another point 6-12months later).



Some of the Biobank samples have already been accessed and are being used by teams of researchers here at the LSHTM as part of the work planned for the original NIH grant. We were excited to hear that Professor Eleanor Riley has been awarded \$132,224 to further her team's work exploring the associations between human herpesvirus infection and ME/CFS.

On International ME Awareness Day (13<sup>th</sup> May 2016), the opening of the UK ME/CFS Biobank to researchers both nationally and internationally was announced with a launch held at LSHTM. We were humbled by the number of researchers, participants, stakeholders and participant advocates who made the effort to attend this landmark event, and we would like to thank those who were unable to attend but cheered us on from afar.



Since opening we have had significant interest in the Biobank from researchers across Europe and the United States with a number of applications expected in the New Year. As you can imagine, the research application process is a long-winded affair as ethical approval and funds need to be secured; thankfully we have built strong relationships with those interested in our samples and are offering our support in this process. This is an exciting time for biomedical research in ME/CFS and we are pleased to be able to offer premium quality samples to enable cost-effective research in an area where funds have been limited. We know how precious and valuable each of these tiny tubes is, and the process for their distribution ensures that research proposals are robust and ethical and will help better understanding of the mechanisms of and possible treatments for ME/CFS.

We wish to reassure our participants that any intention to use our samples by any research group will have to comply with the Biobank's mission. We will prioritise research proposals that intend to test or generate new hypotheses on the pathophysiology of ME/CFS, improve diagnosis (biomarkers) and phenotyping, and/or basic science. Stringent application and review procedures will continue to be monitored by our Steering Committee.

### A continuing and special thank you to all our participants from our Research Nurse

One of the delights of meeting research participants on a regular basis is to see how positively many respond to being able to take part in the ME/CFS Biobank project. *'We are so grateful to you and the team...'* is a recurring theme – while we consider that any gratitude belongs to each and every individual who takes part: those with ME/CFS, with MS or who act as healthy controls! People with ME/CFS have an understandable interest in the progression of the research the biobank samples will facilitate and often healthy controls tell me that they have a friend or relative with the disease; more surprising is the reaction of those with MS for whom taking part is truly without any foreseeable benefit. Yet, historically, people with MS were as stigmatised in the earlier part of the

twentieth century as those with ME/CFS are a century later and some have talked about relatives who had the disease but never the reassurance of a diagnosis. Reassurance may seem a strange word to use in this respect, but to know that there is an organic reason for the many symptoms of either disease brings some comfort; at least there are measurable changes in MS that help to explain the overwhelming fatigue often experienced in common with ME/CFS. *Best wishes, Caroline Kingdon*

### **Activities & Conferences 2016**

This year we have hosted two interns (Amit from UCSF Medical School and Vageesh from King’s College London Medical School) who worked on individual projects based on data from the Biobank. We have also welcomed researchers from Latvia who collaborated with our extended team in gene expression and biostatistics. Dr Eliana Lacerda and Dr Luis Nacul visited Brussels and Riga this year as UK representatives for the EUROMENE (European Network for ME/CFS, an EU COST programme) and have developed strong relationships with European researchers interested in the various aspects of ME/CFS research (epidemiological, physiological, neurological etc.).

Our team has been well represented at ME/CFS-focused conferences this past year. Both Luis and Eliana presented at the liME conference in June with topics focused on “*Protocols and Patient Databases for ME*” and “*Biobank Samples and Protocols for ME/CFS research in the UK/Europe*”. They were both invited speakers at the IACFS conference in Fort Lauderdale during a Special Interest Group session where 4 posters were presented from the rest of the team. These conferences provided us with an excellent opportunity to network with researchers and have led to significant international interest in our work, future collaborations and, of course, the Biobank.



We heard recently that 4 papers on the work of establishing the Biobank and some preliminary results have been accepted for publication. We are confident that this is just the beginning of a number of publications, so watch this space! All publications are open access and will be posted on our website once published.

### **Spring meetings planned**

In the spirit of continuing to work alongside our participants to seek the best way of doing things, we hope to meet with some project participants with ME/CFS to discuss the results and how these can be most effectively disseminated. We hope to hold participatory meetings in London and Norwich, and news of such will be available on the Biobank website and social media outlets soon.

### **Stay Connected with CureME**

During 2016 we launched our new website ([cureme.lshtm.ac.uk](http://cureme.lshtm.ac.uk)) and social media accounts on Twitter and Facebook (@mecfsbiobank). If you are interested in finding out more about our research and the Biobank, please follow us or have a look at our webpage (where you can also sign up to our newsletter distribution list if you aren’t already on there).



Please feel free to share this newsletter with your networks.  
Best wishes for a happy and healthy holiday season!

