

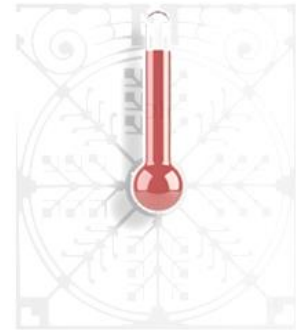


CURE-ME Newsletter

December 2015

CURE-ME

*Creating clinical and biomedical Understanding through
Research Evidence – For the ethical study of ME/CFS*



Our mission

To conduct high quality, ethical investigations into ME/CFS and to create an open biobank resource enabling translational research for the clinical and biomedical understanding of the illness, fostering cooperation and collaboration between researchers and thereby enhancing the opportunity for breakthrough discoveries.

First and Foremost – Thank you to our participants and colleagues!

As 2015 draws to a close, there is much to celebrate! We are delighted to announce that by year's end we will have enrolled, seen, and gathered samples from our target number of people with ME/CFS (both mild/moderately and severely affected). Meeting these goals only has been made possible by those of you who volunteered to take part and put the word out to friends and family directly as well as via social media. Many of you have contacted friends with MS, which has proved hugely helpful (in fact, we'd still benefit from recruiting any people with MS in the Greater London and Norfolk areas who meet the inclusion/exclusion criteria and would be interested in participating). We can't thank you enough for your help.

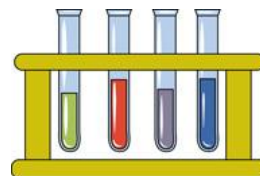
The Norfolk teams, who have seen the bulk of our participants, have been an incredible asset - accommodating, flexible, efficient, and a delight to work with. The UCL Biobank staff have been extraordinarily accommodating of the changes (sometimes daily) that are part and parcel of recruiting people with an unpredictable disease; we are grateful for their professionalism and efficiency. Thank you.

As the research nurse based at LSHTM, I have had the privilege of visiting almost 60 of you in your homes, where I have always been most welcome. I have met people at the Royal London Hospital for Integrated Medicine and the Royal Free Hospital; many of the healthy control volunteers at these sites have explained that they are there to support a person with ME/CFS whom they know and love.

I want to give my personal thanks to each one of you who has helped to make the task of enrolling and seeing participants such a pleasure and privilege. I look forward to meeting many of you again in 2016 and hearing more of your amazing stories.

Caroline Kingdon
CURE-ME Research Nurse

UK ME/CFS Biobank progress to date



The UK ME/CFS Biobank project was launched in August 2011 with the generous support of [Action for M.E.](#), the [ME Association](#), [ME Research UK](#), and a private donor. With this pilot funding, we established the Biobank and then secured a [U.S. National Institutes of Health grant](#) for biomedical research on ME/CFS.

We now have over **500 people** participating in the Biobank project – people with ME/CFS, Multiple Sclerosis, and healthy people – some of whom have donated blood samples twice.

We now have over **25,000 aliquots (samples)** stored at the [University College London/Royal Free Hospital BioBank](#) (UCL/RFH BioBank), a state of the art facility, ready to be used for biomedical research. In fact, we're set to open our biobank to researchers worldwide in early 2016!

2015 has been a busy and rewarding year – we've expanded both our Biobank and our team, and presented research findings at the UK CFS/ME Research Collaborative in Newcastle. Moreover, the team co-authored the proposal EUROMENE – European Network for ME/CFS, which has been awarded a grant under the EU COST programme. This project will facilitate inter-institutional collaboration within the ME/CFS research world.

Grand Opening of the UK ME/CFS Biobank to Researchers Worldwide

Thanks to the generous support of those who contributed to our Big Give campaign last year and the ME Association, we're thrilled to announce the official opening of the UK ME/CFS Biobank to scientists worldwide in early 2016. Researchers will be able to use our samples to conduct their own experiments at their home institutions using our high-quality blood samples and clinical data from well-characterised participants.

To add yourself to our registry and receive information about our Biobank, please either:

1. Scan the QR code with your smartphone, then enter your name and contact info
2. Email us: mecfsbiobank@LSHTM.ac.uk or
3. Sign up here: <http://tiny.cc/biobank>



Recruitment – we need your help!



We are actively recruiting people with Multiple Sclerosis in the Greater London area as well as 20 healthy controls. If you or someone you know is interested, please email our Research Nurse, Mrs. Caroline Kingdon, at mecfsbiobank@lshtm.ac.uk.

The Team

Our team is ever expanding! We're excited to welcome Hayley Curran, our new Biobank Coordinator and CURE-ME Project Manager, to the team. Hayley is a trained nurse and Medical Anthropologist with personal experience of living with CFS/ME (even writing her Master's dissertation on the topic) so brings along bags of enthusiasm. We're also pleased to be joined by Amit Arunkumar, a fourth year medical student from the University of California, San Francisco, who is joining our team for a year on a scholarship to study ME/CFS.

The CURE-ME team is a small but dedicated group invested in improving the situation for people with ME/CFS.

- Chief Investigator: Dr. Luis Nacul
- Project Lead: Dr. Eliana Lacerda
- Research Nurse: Mrs. Caroline Kingdon
- Research Fellow: Erinna Bowman
- Biobank Coordinator: Hayley Curran
- Medical Student: Amit Arunkumar



Erinna, Luis, and Eliana



Caroline



Hayley

[View our introductory video here!](#)

Read more about the CURE-ME team, our philosophy, the UK ME/CFS Biobank project, our team's papers, and stay updated on our progress at www.lshtm.ac.uk/mecfs.

To make a financial donation to our project, please visit: <http://www.lshtm.ac.uk/itd/crd/research/cure-me/donate/index.html>. We appreciate the generosity of each and every gift!

Join our mailing list

For the latest updates on our project, please email mecfsbiobank@lshtm.ac.uk with the subject "Newsletter".



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

