

## All-Party Parliamentary Group on ME: Biomedical Research Meeting Summary

**FOR RELEASE BY FORWARD ME MEMBERS 12.00PM, TUESDAY 17<sup>TH</sup> MARCH 2020**

The All-Party Parliamentary Group (APPG) on M.E. held its' first meeting on Tuesday 3<sup>rd</sup> March where biomedical research was discussed.



Twenty MPs attended or sent staff to hear about urgent need for biomedical research, following its inaugural AGM in January

Carol Monaghan, Dr, Charles Shepherd with some of the MPs who attended, and the research presenters (see below)

Chaired by Carol Monaghan MP, the meeting was the first in a series that will focus on key issues facing people with M.E. in the UK and will culminate in a parliamentary report setting out actions for change.

Members attending heard short presentations from Professor Chris Ponting, University of Edinburgh; Professor Julia Newton, Newcastle University, and Dr Eliana Lacerda, CureME Biobank, before taking the opportunity to ask questions.



## Professor Julia Newton

Professor Newton began by sharing the story of one of her patients with M.E., who waited more than 10 years for a diagnosis, and how patients were being badly let down by lack of high-quality research into both causation and treatment.

Describing symptoms involving the brain, muscles, and immune system, Professor Newton highlighted how clear abnormalities are being found.

However, these findings are often based on small research studies with small cohorts, and with small amounts of funding – mainly from the M.E. charity sector. This must be scaled up if real progress is to be made.



## Professor Chris Ponting

Professor Ponting picked up this point and highlighted the disparity in research funding allocated to M.E. when compared to many other medical conditions.

He presented a compelling case for sustained, ring-fenced investment, suggesting that a UK institute for M.E. research could be a world-leader.

“Funders must recognise that they need to incentivise early-stage career researchers to enter this field,” he said.

“They frequently cite the need for a robust evidence base to support research funding applications – but without funding it is not possible to achieve this.

We must break this vicious cycle.”

Highlighting the huge gains from patients, researchers and charities working together – an example being the recent M.E./CFS Biomedical Partnership application he is leading – Professor Ponting stressed the need for further and longer-term funding to sustain this momentum.



### Dr Eliana Lacerda

Giving a brief overview of the work of the CureME Biobank, and some examples of research where these blood samples are now being used, Dr Lacerda agreed that sustainability and infrastructure are among the significant challenges facing M.E. researchers.

### MP Reaction

MPs were taken aback to learn that the basic running costs for the Biobank have all been provided by the M.E. charity sector, that the bulk of the Biobank’s external research funding has come from the National Institutes of Health in the United States; and that Professor Newton has ceased M.E. research altogether – despite having access to a large patient cohort – because funding is so difficult to secure.

MPs asked what practical steps they could take to support M.E. research. Insightful follow-up questions focused on research into similar conditions, the search for biomarkers and the stigma still attached to M.E., with Professor Newton commenting that she had

been “appalled” by attitudes she had seen from some fellow clinicians.

The real possibility of a rise in post-infectious M.E. following the Coronavirus – Coronavirus was being debated in the Chamber at same time as this meeting – was also highlighted by Professor Ponting, serving to reiterate the seriousness of his intent, and the urgent need for proper research investment.

A briefing based on presentations from the meeting will be circulated to all APPG members; a list of MPs who attended is below:

Angus MacNeil MP (representative)  
Carol Monaghan MP  
Caroline Nokes MP  
Edward Davey MP (representative)  
Ellie Reeves MP (representative)  
Fleur Anderson MP  
Jacob Young MP  
James Davies MP  
Jason McCartney MP  
Jim Shannon MP  
Kate Green MP (representative)  
Laurence Robertson MP  
Liz Twist MP (representative)  
Mark Tami MP  
Michael Tomlinson MP (representative)  
Neale Hanvey MP  
Sally-Ann Hart MP  
Sharon Hodgson MP (representative)  
Siobhan Baillie MP  
Scott Mann MP

The next meeting of the APPG will take place on **Wednesday, 29<sup>th</sup> April 2020** – please encourage your MP to attend.