

From the Baroness Blackwood Parliamentary Under Secretary of State for Innovation

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Caroline Lucas MP

By email to: caroline.lucas.mp@parliament.uk

Dear Coolin

Thank you for your correspondence of 22 January to Steve Brine about chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME).

I am afraid that we have no record of your correspondence of 13 July. Please accept my apologies if that is due to a fault on the part of the Department.

I appreciate your concerns and am grateful to you for taking the time to raise them.

I agree wholeheartedly with your assertion that CFS/ME is a complex and often misunderstood condition. The two recent debates led by Carol Monaghan will hopefully go some way to addressing these and raising awareness.

You highlight the need for increased funding for biomedical research. The Government invests in health research through the National Institute for Health Research (NIHR) and the Medical Research Council (MRC), through UK Research and Innovation. Together, the NIHR and MRC welcome high-quality applications for research into all aspects of CFS/ME, which includes the biomedical research that you highlight.

Since 2011, the MRC has funded seven projects on CFS/ME, totalling £2.62million, and is ready to support further applications of the highest scientific quality. The MRC has had a cross-board highlight notice on CFS/ME open since 2003 and CFS/ME research remains an area of high strategic importance. Applications are encouraged that have a focus on the underpinning mechanisms of CFS/ME, with priority areas including immune dysregulation, pain, improved sub-phenotyping and stratification of CFS/ME, and mechanisms of CFS/ME in children and young people.

The NIHR has provided £3.37million of programme funding for projects and training on CFS/ME since 2011. Given that the causes and mechanisms of this condition are

still poorly understood, it is important that we carry out both biomedical research to further our understanding and applied health research to improve the treatment offered to people with CFS/ME and help to improve their symptoms and quality of life.

I can confirm that the NIHR and MRC recognise that CFS/ME is a debilitating condition and are speaking with the UK CFS/ME Research Collaborative and other groups about how best they can support a joined-up approach to high-quality research into this complex disorder.

As Steve said in a House of Commons debate on 24 January:

The Government fully recognises the strength of feeling on this issue, as it does for all those living with conditions and disorders which research is unable yet to help us fully understand. That is why we remain fully committed to delivering significant investment in our research programmes and infrastructure, but we need people to come forward with quality proposals.

Regarding the research centre in Norwich, researchers there are very welcome to apply to the MRC highlight notice or to the NIHR for funding.

Improved education for healthcare professionals was raised in both of the debates. The Royal College of General Practitioners (RCGP) includes CFS/ME as a key area of clinical knowledge that GPs should have as part of their qualifying exams, featuring it in the guidance for the Applied Knowledge Test, an important part of these exams. The RCGP has also produced an online course for GPs on CFS/ME that highlights common misconceptions and considers the challenges that surround this complex condition for patients, carers and primary care professionals.

Before the last debate, Steve spoke to Professor Helen Stokes-Lampard, who chairs the RCGP, and who is keen to come to the House to take part in a roundtable. If you would like to be part of this, please let me know.

You also raise the issue of hospital services and the vital role of multidisciplinary teams for patients and their carers. We do not believe that the Department is 'passing the buck' to NHS commissioners. Local clinical commissioning groups are best placed to respond to the needs of their communities and to plan their services accordingly.

I hope this reply is helpful.

NICOLA BLACKWOOD