

Extracts from Hansard Transcript of Westminster Hall debate on ME treatment and research.
21 June 2018

Via: Let's Do It for ME campaign to support Invest in ME Research Centre of Excellence for ME
<http://ldifme.org/parliamentary-debate-on-me-research-and-treatment/>

Sir Henry Bellingham (North West Norfolk)

I congratulate the hon. Lady on securing the debate. Is she aware that the UK charity Invest in ME Research recently opened a centre of excellence for ME research at Norwich research park? That was funded by patients and carers, who raised a staggering £800,000 for what will be groundbreaking, world-class research.

Hansard: <https://goo.gl/B8mDdw>

Video clip: <https://goo.gl/yvW33P>

Sir Edward Davey (Kingston and Surbiton)

I will move on to research. Looking at the work that Invest in ME Research has done, for example, setting out the calls for research in this country over two decades or more, I find it quite disturbing that those calls have been ignored. Only charities have enabled a meagre amount of research to be done. Some £5 million was set aside for the PACE trial; if we could have a small amount of that money to start real, biomedical research into ME, we would be making a step forward.

Andrew Selous (South West Bedfordshire)

Does the right hon. Gentleman share my concern that, as I understand it, there are roughly two and a half times more people with ME than with multiple sclerosis, yet there is 20 times more research on multiple sclerosis than on ME and, of what little ME research there has been, the vast majority has been through psychological and behavioural studies rather than the biomedical approach?

Sir Edward Davey

I share the hon. Gentleman's concern. I should say that we still need a lot of research into MS, so it is not one or the other, but given the incidence of ME, as he rightly says, the case for research into the biomedical aspects is strong. Invest in ME Research makes a number of proposals in its recent report. For example, it proposes a ring-fenced fund of £20 million a year for the next five years for biomedical research. That recommendation comes from a detailed report; it is not just plucked out of the air. That sort of figure would show that the Government mean business.

I am aware that Ministers cannot stand up at the Dispatch Box and say, "Yes, of course we will direct research money into this probe; I myself will do it." I am not suggesting the Minister can do that today. I know he cannot. He has to work with research councils and others to direct the research. I am also aware that if researchers do not make proposals, sometimes research moneys cannot be granted.

Sir Henry Bellingham

As I mentioned earlier, Invest in ME Research has set up a centre of excellence for research in the Norwich Research Park, and it is planning to create a hub for European biomedical research, which is good news indeed. It already has five PhD students and is hoping to push out a consultant-led clinical service. Here we have the infrastructure and base for that extra Government funding, to build on the money that has been raised by patients and carers.

Sir Edward Davey

The hon. Gentleman is absolutely right, and it is good that he is here to champion that centre. He makes the point I wish to make to the Minister: a pipeline of research proposals is likely to come

about not only from the centre in Norwich, but no doubt as offshoots from research elsewhere—particularly the United States, which is beginning to get its act together on the research side. There is a pipeline, and I urge the Minister to anticipate that, to talk to the research councils and to say with his colleagues, “We will be ready and we will have the funds ready so that when the research proposals come through”—as I am confident they will—“we will back them.” Then we can start making progress. I say to the Minister, please, not to wait to see whether they come through before he dedicates the money and starts pressurising the research councils, because we know that process can take too long. People have already waited too long.

I will conclude my remarks by underlining two points touched on by the hon. Member for Glasgow North West. The first is the need for respect for patients. Sometimes it seems, from the stories I have read, that some in the medical profession—I say some—do not appear to respect patients. They make comments that it is all in people’s minds and that they are making it up. That is no way to talk to adults. A constituent of mine who has been suffering from ME, who I talked to last night, recently went to see her consultant. The consultant said in terms, “All ME people are crazy, except you.” That did not make her feel very happy. I am afraid that type of view among senior medical people is not acceptable, and I hope Ministers will make it clear that they expect patients not to be treated like that.

That links to my final point, on the need to train doctors. We need better guidance and better training so they understand that situation. In that light, I am worried that we are seeing some pressure to reclassify ME. That is sending a dangerous signal, and I hope the Minister will say that the Government are questioning that reclassification and putting it on hold. Otherwise, the training for doctors will not happen, the respect for patients will not happen and we will not see the change that our constituents demand. I look forward to the Minister’s remarks and to the contributions of other hon. Members.

Hansard: <https://goo.gl/OKQmav>
Video clip: <https://goo.gl/XbwWZW>

Sir Henry Bellingham

I hope the hon. Gentleman will support my campaign to get the Government to invest in the Invest in ME Research centre of excellence in Norwich. I did not mention that it has a really good chance of forging first-class links with not only European biomedical research institutes but institutes in the United States and Asia, where other groundbreaking research is being done. The Government should support and invest in success.

Dr David Drew (Stroud)

I think that was aimed more at the Minister than me, but I totally agree with the hon. Gentleman. I gather that the National Institutes of Health in America has begun to grapple with this and to put some quite serious funding into it. ME is an international condition, so we should hope that the Medical Research Council is also able to provide that level of support.

Hansard: <https://goo.gl/NaUJrf>
Video clip: <https://goo.gl/gZSVRe>

Steve Brine (Parliamentary Under-Secretary of State for Health and Social Care)

I will now turn to the two issues that have primarily been debated today, research and treatment. On research, the Government invest more than £1.7 billion a year in health research via the National Institute for Health Research and the Medical Research Council through UK Research and Innovation. The NIHR and MRC welcome high-quality applications for research into all aspects of CFS and ME, which would certainly include the biomedical research that the hon. Member for

Glasgow North West spoke about in her opening remarks.

Since 2011, the MRC has funded seven projects on CFS/ME totalling £2.62 million, and it is ready to support further applications of the highest scientific quality, which is required to make those scientific breakthroughs. My hon. Friend the Member for North West Norfolk (Sir Henry Bellingham) is no longer in his place, but he spoke about the Norwich Research Park—didn't he push that a few times?—which sounds very promising. I look forward to hearing more about it, and I feel certain that he will tell me.

The MRC has had an open cross-board highlight notice on ME since 2003. It was updated in 2011 alongside a bespoke funding call in that year. ME research remains an area of high strategic importance for the MRC. Applications that focus on the underpinning mechanisms of ME are encouraged, with priority areas including immune dysregulation—[Interruption.] Sorry, I am distracted by someone shouting about stopping something outside—I think he is saying, “Stop ME!”. The priority areas include pain, improved sub-phenotyping and stratification of ME, and mechanisms of ME in children and young people.

A number of people mentioned the late Baroness Jowell. I was very privileged to meet her. I did so just the once, but I was left in no doubt about her resolve on the issue of brain tumours. Let me say in reference to her and to the research environment that, as my Parliamentary Private Secretary, my hon. Friend the Member for South Suffolk (James Cartlidge), reminded me, that journey started around the time of a Westminster Hall debate. Perhaps that is a good sign.

Our challenge with brain tumour research is the lack of high-quality research proposals that have come forward. The late Baroness Jowell was passionate about stimulating the research community to get that situation changed, and we have latched on to that. That is one of her great legacies. I would hazard a guess that her greatest legacy is yet to be reached, but that is one reason it is important to mention the late Baroness today.

Hansard: <https://goo.gl/VMT96v>

Video clip: <https://goo.gl/Ky1HYb>

Executive Summary for MPs and others by the charity on the Invest in ME Research Centre of Excellence for ME June 2018: <http://www.investinme.org/ce-cofeforme.shtml#exsu>

June 2018