ME in Politics

ME ENGLAND UPDATE

Report on the APPG on ME Meeting 24.1.2012, Portcullis House, 3.30p.m.

Present at this meeting were Annette Brooke MP (Chair), Ian Swales MP, David Amess MP, the Countess of Mar, Russell Brown MP, Steve McCabe MP, Jim Shannon MP, Sir Peter Spencer (AfME), Dr Charles Shepherd (MEA), Tristana Rodriguez (AfME), Sue Waddle (ME Research UK), Christine Harrison (BRAME(, Jane Colby (Tymes Trust), Mary-Jane Willows (AYME), Doris Jones (25% ME Group), 3 parliamentary office representatives, and guest speaker Professor Sir John Savill (CEO Medical Research Council) with Amanda Chmura (MRC).

The following are extracted details from the chair-approved minutes of this meeting:

Professor Savill gave an overview of his background. He said he had a personal, as well as a professional, interest in M.E. The NICE clinical guideline 53 on CFS/ME had changed the landscape of ME research – work now focuses on establishing the pathogenesis, disease pathways and biomarkers of ME. The National Institute for Health Research (NIHR) are now responsible for RCTs, whilst the MRC does broader fact-finding research. He referred to Professor Stephen Holgate's earlier visit to an APPG on ME meeting when he gave a detailed account of the thinking behind the MRC's £1.6m funding initiative for biomedical research into ME.

He went on to update the group on work done so far, saying that applications had been of such a high calibre that they were able to commit more money than originally thought. Professor Savill stressed that he strongly believed in the merits of working with patient organisations, which would give patients and their representatives a chance to have a say in the design of studies. One study proposal had been produced in collaboration with the MEA. He said there were some very promising approaches relating to treatment in the approved studies, in relation to pain and muscle fatigue, which are important aspects of ME. There was also a real prospect of determining markers for ME in some of these studies. One of the studies apparently plans to use an existing cohort of patients in order to get a molecular handle on a finger-print of fatigue. Within that study there is a small group of patients who are being trialled with Rituximab, which means this study seeks to compare and contrast symptoms with a known study.

He finished his talk by asking for patience – it will take 2-4 years for these studies to be completed and for this investment to bear fruit. The MRC would support the dissemination of the results.

A prolonged Question and Answer session followed. Annette Brooke MP expressed delight about the MRC ring-fenced money for ME. The people represented by the group were very challenging – one of her constituents had commented that just one of the new studies was looking for a cure. Professor Savill replied saying it was useful to look at conditions which were similar in character. The MRC was trying not to ring-fence funds for research – there was no point in throwing money at poor quality studies, but he was confident the new studies would be of benefit to Ms Brooke's constituent. He added that it was difficult to generate interest in medical conditions where this was difficult to define.

Dr Charles Shepherd mentioned a discussion on the MEA's Facebook page which had generated a lot of support for a study of patients with Sjoegren's syndrome. However, there were concerns that this was restricted to patients with the syndrome, even though there was a service for people with ME in the unit in Glasgow where the study would take place. He asked if the Expert Group could meet again to look at these proposals. Professor Savill replied saying that detailed information on the MRC website was lacking, but that the study referred to would also involve CFS patients. He said he would discuss this matter with Professor Holgate and take steps to ensure that the MRC website descriptions are improved. The Countess of Mar said that communication is very important for people with ME because concentration is limited.

Ian Swales MP commented that it was important not to raise false hopes – the PACE Trial had enraged many people with ME because it suggested that GET and CBT were the best forms of treatment for ME. He asked if the MRC recognised that the ME community felt that biomedical research was what was needed. Professor Savill replied that discovery biomedical research was what the MRC supports. He said he was accountable for the quality of research for which the £1.6m was being used.

Christine Harrison welcomed the new MRC studies and asked if severely affected people would be included in the trials.

Professor Savill then asked if the Biobank* collections did include severely affected people. Sir Peter Spencer confirmed that they would. Professor Savill said a family member with CFS was housebound and gathering data on severely affected people was a very positive feature of the Biobank.

In response to Ian Swales MP's raised concerns whether the new studies understood ME sufficiently well, Professor Savill said that question could be asked of any study, but the Biobank based research was a positive step; there was an interaction between research and difficulties in maintaining a clinical service which would attract new talent.

Sir Peter Spencer stated that the Expert Group had started with a literature search of the previous ten years of research into ME and had established a clear objective of attracting new research talent and new technology into the field of ME/CFS research. He added there was a decline in funding for specialist ME/CFS services across the UK; it was hard to find any other clinical condition which had such an adverse affect on people and for whom so little was provided. Therefore the MRC was a beacon of hope.

Jane Colby mentioned the possibility of identifying viruses in a screening programme of occult blood in the bowels. Many members had tested positive for enteroviruses; she personally had tested positive for coxsackie B virus. She asked if the old style bowel acid test could be used for children. Professor Savill replied that there was a problem in determining links to infection for CFS/ME and other conditions like Lupus. All this showed was that there was a link between a virus and symptoms, but some studies were more rational because they used blood samples and tried to look at the body's response, which he felt was the right approach. Jane Colby replied saying that if the link between the polio virus and polio symptoms had not been determined, no vaccine against the virus would have been created. Professor Savill replied that very powerful tests are needed to identify viruses.

The remaining Q+A session focused on great hope which patients now have of the MRC trials – they need to have confidence in the quality of the studies. The Countess of Mar asked Professor Savill how GPs could be persuaded to look at the endocrine system of patients (an important query which had been raised by a patient). The Professor's replied saying it was not easy to identify which patients have the condition; many tests are needed to exclude other known conditions (e.g. Addison's or kidney disease) which could offer clues; a diagnostic test for ME was needed.

The question of further MRC funding for more biomedical studies into ME arose; lack of funding wasn't the issue, the Professor replied, what mattered was the quality of proposals. This led to the issue of if/when interest might be generated in industry; the Professor replied he would expect first steps to be taken by companies, especially in relation to diagnostic tests rather than treatment, which the MRC would support.

Dr Shepherd was concerned over maintaining the momentum of ME research, by further ring-fenced funding. The Professor said ring-fencing was uncomfortable, but a highlight notice on future funding may be beneficial. Unsuccessful applications to the MRC can be resubmitted within a year and often are successful. Sir Peter Spencer supported Dr Shepherd's request for further ring-fenced funding; the amount available was very small in relation to what was needed. The Professor replied saying what he had suggested had helped to sustain research; good use of charitable resources would be to identify people who were willing to participate in research. Sir Peter added that AfME, the MEA and MERUK have a queue of people willing to take part in research. (D.J. asked if smaller ME charities would be contacted with a request to nominate patients for the trials to which the Professor replied it was up to the individual research groups to make such decisions. This Q+A was unrecorded in the minutes.)

The Professor then mentioned an E-health initiative, which the MRC was supporting; Scotland had very powerful E-records which were of great value. Sue Waddle stressed the need for a long-term plan, endorsed by Ian Swales MP who enquired about long-term commitment. Professor Savill admitted there had been a problem in the relationship between researchers and patients in this area; charities play a key role in building bridges which will sustain activity. Ian Swales MP endorsed the Professor's comments, adding that a positive attitude was vital and not attacking the people who try to help.

The remaining time of the meeting covered follow-up questions on child-protection issues which had been raised at a meeting with Tim Loughton MP, the Children's Minister. The Countess of Mar had received a letter from the Rt Hon Paul Burstow in response to issues raised. Jane Colby said Tim Loughton had requested information on problems in the education service and Ian Swales MP added that further data on school absence for children with ME had been published.

Sir Peter Spencer said AfME are analysing FOI requests sent to all PCTs and Health Boards in the UK asking for data on services for ME, the final analysis of which would compare services for patients with other chronic conditions which would be submitted to MPs.

On a personal note I felt that although the new MRC-funded studies are of course very welcome, little more useful new information had emerged during this meeting.

By Doris Jones

28.5.2012

* *You can read more about the Biobank initiative in the research section on page 14*

There are also some details and discussion of the MRC funded studies in the research section.