



All Party Parliamentary Group on M.E.

Chair: Annette Brooke MP
Vice-Chairs: Countess of Mar
Ian Swales MP
Treasurer: Martin Vickers MP
Secretary: Russell Brown MP

**Minutes of meeting held Tuesday 24th January at 3.30pm
Room N, Portcullis House**

Present:

Parliamentarians:

Annette Brooke MP
Ian Swales MP
David Amess MP
Countess of Mar
Russell Brown MP
Steve McCabe MP
Jim Shannon MP

Secretariat:

Sir Peter Spencer (Action for M.E.)
Dr Charles Shepherd (MEA)
Tristana Rodriguez (Action for M.E.)

Charities:

Sue Waddle (ME Research UK)
Christine Harrison (BRAME)
Doris Jones (25% Group)
Jane Colby (Tymes Trust)
Mary-Jane Willows (AYME)

Parliamentary office representatives:

Alex Dunn (Office of Ian Swales MP)
Olivia Phoenix (Office of Peter Luff MP)
Michael Robinson (Office of Mark Pritchard MP)

Speaker:

Professor Sir John Savill (Medical Research Council)
Amanda Chmura (Medical Research Council)

Apologies:

Oliver Heald MP
Elfyn Llwyd MP
Lord Puttnam
Mike Hancock MP
Caroline Lucas MP
Grahame Morris MP
Karen Lumley MP
Sir Roger Gale MP
Robert Walter MP
Dave Anderson MP
Andrew George MP

1) Welcome by the Chair

The Countess of Mar opened the meeting and welcomed attendees.

2) Speaker: Prof Sir John Savill, CEO, Medical Research Council (MRC)

Professor Savill gave an overview of his background and told the group that he has a personal and professional interest in M.E.

He said that the landscape of M.E. research has changed as result of NICE clinical guideline 53 on Chronic Fatigue Syndrome/Myalgic Encephalomyelitis.

Work is now being done to establish the pathogenesis, disease pathways and biomarkers of M.E.

The National Institute for Health Research (NIHR) have now taken over responsibility for Randomised Control Trials (RCTs) and the MRC does broader fact-finding research.

Professor Savill noted that Professor Stephen Holgate had attended a meeting of the APPG 5 months ago and given a detailed account of the thinking behind the MRC's £1.6m funding initiative for biomedical research into M.E.

Professor Savill went on to update the Group on the work done so far and said that applications had been of such a high calibre that they had been able to commit more money than originally thought.

Professor Savill said that he believed very strongly in working closely with patient organisations so that patients and representatives could have a say in the design of the studies.

One study proposal had been produced in collaboration with the ME Association.

There are some very promising approaches in relation to treatment, and pain and muscle fatigue, which is an important part of M.E. There is also a real prospect of determining markers for M.E. in a number of the studies.

One of the studies plans to use an existing cohort of patients to get a molecular handle on a finger print of fatigue. Within that study is a small group of patients who are being trialled with Rituximab, so this study seeks to compare and contrast symptoms with a known study.

Professor Savill finished by saying that he would like to counsel patience. It will take two to four years for this investment to bear fruit, but that the MRC would support the dissemination of the results.

Question and answer session

Annette Brooke MP said that the Group was delighted to hear that the MRC ring fenced a sum of money for M.E. The people represented by the Group are understandably very challenging. She has a constituent who says that only one of the approaches submitted to the MRC is really looking for cure.

Professor Savill said that there is merit in looking at conditions of similar character. The MRC rightly tries not to ring fence funds for research. There is no point in throwing money at poor quality studies and he is very happy with the studies that are there. He said that he was confident that the funded studies would result in real benefit for Ms Brooke's constituent. He also said that it is difficult to generate interest in conditions where that condition is difficult to define.

Dr Charles Shepherd said that a discussion on the M.E. Association's Facebook page has generated a lots of support for a study of patients with Sjögren's syndrome, but that there were concerns is that the study restricts itself to Sjögren's patients, even though there is also a service for people with M.E. in the unit in Glasgow where the study would take place. It would be helpful if the Expert Group could meet again to look at these proposals.

Professor Savill explained that the detail of the information on the MRC website is lacking. The study into patients with Sjögren's syndrome actually also involve CFS patients. He said that he would like to discuss this with

Professor Stephen Holgate and suggest that the MRC website descriptions of the projects could be improved. Scientific writers have missed some important details. He also said that he would take the suggestion of a further meeting of the Expert Group back to the MRC.

The Countess of Mar said that communication is particularly important for people with M.E. where concentration is limited.

Ian Swales MP said that it was important not to build up false hopes. The PACE Trial has enraged many people with M.E. by suggesting that graded exercise therapy (GET) and cognitive behavioural therapy (CBT) are the best forms of treatment for M.E. He asked whether the MRC recognised that the M.E. community feel that biomedical research is what is needed.

Professor Savill said that discovery biomedical research is what the MRC does. He said that he is the accounting officer for MRC in parliament and as such is accountable for the quality of research that the £1.6m is used for.

Christine Harrison said that she welcomes what the MRC are doing. Severely affected people have never been included in trials. Will they be?

Professor Savill asked whether any of the Biobank collections would include severely affected people.

Sir Peter Spencer answered yes they will.

Professor Savill said that he had a family member who had been affected with this condition, and who has not been out of their house. He thinks that gathering data on people who are severely affected is a very positive feature of the Biobank.

Ian Swales MP asked whether the studies would have sufficient understanding of M.E.

Professor Savill said that he has not read the studies in detail, but one could ask that question of any study. He feels that the Biobank based research is a positive step. There is an interaction between research and the difficulty of maintaining a clinical service which will attract new talent into it.

Sir Peter Spencer said that the Expert Group started its work with a literature search of the previous ten years of research into M.E. and established a clear objective of attracting new research talent and new technology into the field of M.E. /CFS research.

Sir Peter said that there is a decline in funding for specialist M.E./CFS services across the UK and suggested that it is hard to find any other clinical

condition that has such an adverse affect and for whom so little is provided. The MRC is a beacon of hope.

Jane Colby said that it is possible to identify viruses through a screening programme of occult blood in the bowels. Many members have tested positive to enterovirus. She herself tested positive for coxsackie B virus but it is a very invasive test. Could the old style bowel acid test be used for children?

Professor Savill said that there is a problem in determining links to infection for CFS/ME and other conditions such as lupus. It is impossible to show what this postulates. It shows a link between a virus and symptoms. Some of the studies are more rational as they use blood samples and are trying to look at the body's response. He thinks that this is the right approach

Jane Colby said that if the link between the polio virus and the symptoms had not been determined, the vaccine would not have been created.

Professor Savill said that there were very powerful tests to identify viruses.

Sir Peter Spencer said that the MRC's great success is to bring new interest into this field. The patient group are bewildered by the number of small scale studies which have been conducted into M.E. They need to have confidence in the quality of the studies funded by the MRC.

The Countess of Mar asked how GPs could be persuaded to look at the endocrine systems of patients.

Professor Savill said that there is not necessarily an easy way of identifying that patients have the condition. Many tests are done on patients as they traverse the journey and as known diseases are excluded. Some of these clues may look like Addison's or kidney disease. He sees these tests as a way of excluding these other diseases, but what will really help is a diagnostic test for M.E.

Ian Swales MP asked whether Professor Savill would have liked to provide more funding.

Professor Savill said that there was a clear divide in the quality of the proposals which were approved for funding and those that were not. Those that were, were not turned down due to a lack of funding.

Ian Swales MP asked, given the prevalence of M.E. in young and if the research successful, at what point interest might be generated in industry.

Professor Savill said that he would expect the first step to be taken by companies as the route to becoming commercially ready is much quicker for diagnostic tests than it is for treatments. The MRC is attuned to adding value to such propositions.

Dr Charles Shepherd asked what plans the MRC has to maintain the momentum of M.E. research. Could Professor Savill clarify whether there would be any more ring fenced funding?

Professor Savill said that it may be beneficial to keep a highlight notice on any future funding to sustain activity. Ring fencing is uncomfortable and should not be applied indiscriminately. All unsuccessful applications to the MRC get feedback, can resubmit within a year, and are often then successful.

Sir Peter Spencer said that he believes there is a very strong case for another round of ring fencing because the amount of money available is tiny in relation to what is needed to and a small fraction of the total research funds available. He would like Professor Savill to understand that this should be sustained.

Professor Savill said that the mechanism he has suggested has helped to sustain research in the past. He thinks that a good use of charitable resources is identifying people who would be willing to be part of research.

Sir Peter Spencer said that Action for M.E., the ME Association, and MERUK have a queue of people who would be willing to take part.

Professor Savill said that there is good news in terms of the E-health initiative. The MRC is supporting game-changing approaches in linking up electronic health data. Scotland has very powerful E-records due to historical chance which have been of great use.

Sue Waddle said that they needed to know that there is a long term plan. She gets the impression that Professor Savill has a personal interest in the field.

Ian Swales MP asked whether there is a long term commitment that there will perhaps be somebody who is looking out for this condition.

Professor Savill said that there has been a problem in the relationship between researchers and patients in this area and that charities are key in building that interaction. That is what will sustain activity.

Ian Swales MP said that Professor Savill had made comment on a positive community. He feels that charities have a key role in maintaining that community and advises an attitude of positivity and not attacking the very people who are trying to help.

3) Minutes of last meeting

The minutes of the meeting held on 3rd October 2012 were approved as a true record.

Mary-Jane Willows asked whether there had been any feedback regarding the child protection issues which had been raised by the Group when they had met Tim Loughton MP, Children's Minister.

The Countess of Mar said that the Group had received a letter from Rt Hon Paul Burstow in response to the issues raised, but had not discussed it as a Group yet.

4) Date of next meeting

To be determined

5) Any other business

Jane Colby said that Tim Loughton MP had requested information on any problems in the education service. She said that Tymes Trust details of a social service investigation which was being conducted into a child with M.E. and highlighted the statutory guidance on allowing child a voice. She thinks that the family would be willing to be identified to illustrate the problems.

Ian Swales MP said that since the meeting with Tim Loughton MP, further data about school absence for children with M.E. has been published.

The Countess of Mar said that she has written letter to Lord Hill, Minister for Schools to discuss this research.

Sir Peter Spencer said that Action for M.E. are currently analysing Freedom of Information requests which have been sent to all Primary Care Trusts (PCTs) and Health Boards in the UK asking for data on services for M.E. The final part of the analysis will be a comparison of services for patients with M.E. and other chronic conditions. The data will be produced in the form of colour coded maps and Sir Peter will then write to MPs with this data.

Ian Swales MP said that this evidence of the postcode lottery in gaining access to M.E. services will add fuel to the discussion.

The Chair called the meeting to a close.