

**NOTES OF THE MEETING OF THE ALL-PARTY PARLIAMENTARY GROUP
HELD ON 31st JANUARY 2001 AT THE HOUSE OF COMMONS.**

PRESENT Tony Wright MP (chair)
 Rev Martin Smyth MP (vice Chair)
 Christopher Gill MP
 Ivan Henderson MP
 Bill Michie MP
 Peter Pike MP
 Lionel Pilltnum vice David Amess MP
 Chris Jones

SPEAKER Dr E.G. Dowsett MB.ChB;Dip.Bact, Honorary Consultant Microbiologist,
 Basildon and Thurrock General Hospitals

1.0 MINUTES OF THE LAST MEETING

1.1 The minutes of the last meeting were agreed.

2.0 APOLOGIES

2.1 Apologies for absence were noted from

 Lord Tim Clement Jones

 Liz Blackman MP
 Graham Brady MP
 Tom Brake MP
 Ian Bruce MP
 Ross Cranston MP
 Margaret Ewing MP
 Donald Gorrie MP
 Simon Hughes MP
 Steven Iiesford MP
 Ieuan Wyn Jones MP
 Anne McIntosh MP
 John McDonnell MP
 Fiona Mactaggart MP
 Kerry Pollard MP
 David Rendel MP
 Marion Roe MP
 Chris Ruane MP
 Christine Russell MP
 Dennis Turner MP
 Dr Dennis Turner MP
 Rudi Vis MP
 Mike Wood MP

3.0 PRESENTATION

- 3.1** Dr Betty Dowsett gave a presentation on *The Late Effects of M.E.* Transcript of this presentation is contained in Appendix 1.

4.0 INFORMAL QUESTIONS AND ANSWERS

- 4.1** Chris Jones asked about the correlation of intensity in youth with onset later. Dr Dowsett replied that in her view if children were removed from school for as long as necessary rather than being sent back once the initial virus appears to be cured this would decrease the number of recurring cases. Children should be allowed to go at their own speed. She further suggested that people think that now polio has died away things should improve. This is not the case.

- 4.2** ... Asked about the accuracy of M.E. diagnosis to which Dr Dowsett replied that there are a multitude of questions that can be asked to assess the condition. Through the answers the signs of M.E. will be highlighted together with tests such as brain scans and PCR tests. An initial consultation will take between 1.5 to 2 hours. Her approach to the patient is to ask the patient to lie down and spend 30 minutes naming all their symptoms, followed by a further 30 minutes in which she explains what is going on and how the symptoms might be handled.

- 4.3** Tony Wright commented that the problem is that many doctors don't accept the reality of the condition. Dr Dowsett confirmed that many doctors have never seen a case of polio or tetanus but these conditions are in the textbook, unlike M.E. which is not in the medical textbooks.

- 4.4** Ivan Henderson asked for clarification on what work is going on at present to improve the situation. Dr Dowsett said that without drug company support, which is not common in the case of M.E., it is difficult to get research into the condition and suitable treatment. She again mentioned that there is nothing in the textbooks, nor are there inpatient units available for sufferers apart from one unit in Essex. GPs can be very helpful, but as soon as they let it be known that they are sympathetic to M.E. they can become overwhelmed by enquiries. Research into the condition can have an adverse effect on a doctor's career. Publishers also find it unhelpful to publish a book with M.E. in the title.

Ivan Henderson asked what is happening to make new GPs aware of the condition and Dr Dowsett said there is still little available. Everyone is looking for a quick fix; citing that conditions such as AIDS get a lot of coverage as opposed to M.E. which is not news worthy in the same way. She also said the information available from elderly people who had suffered was invaluable but they are mostly ignored. She commented that M.E. is a common cause for school absence.

- 4.5** ... Asked for clarification as to why M.E. was treated as a Cinderella and why nothing is published. Dr Dowsett replied that many cases were misdiagnosed in 1988 as Glandular Fever as the definition for this condition is fatigue, swollen glands and sore throat. However, M.E. is not like this as sufferers will have a window for energy during the day. She also mentioned that drugs sold as antidepressants are not good for M.E. as they can be detrimental when the brain is not functioning properly. There is so much vested interest in various treatments and M.E. research is the bottom of the economy.

4.6 Tony Wright thanked Dr Dowsett for her most informative presentation and expressed the group's gratitude to her for coming once again to speak to them.

5.0 ANY OTHER BUSINESS

5.1 Tony Wright had received notification of a draft protocol for CFS from Liz Blackman and suggested this might be the subject for a future meeting of the group.

6.0 DATE OF NEXT MEETING: Wednesday 21st March, 6.00 pm – ***to be confirmed***
This meeting will include the Annual General Meeting and it is hoped will be followed by a reception at 6.30 pm.

Signed _____

Date _____