

Gibson Inquiry – Day 1 April 18th 2006 - Group Testimonies.

Comments by Professor Malcolm Hooper 21st April 2006

Introduction

I attended this meeting as a member of the Public in order to listen to the evidence presented by the groups represented.

Dr Gibson introduced the members of the Panel and checked to identify the Groups/Representatives/Individuals who were present. I was impressed by his courtesy and consideration, especially for those who were obviously ill and disabled. He welcomed everyone and reminded the meeting that although he was aware that many people felt 10 minutes were insufficient for their presentations to be fully made, he was asking for this time limit to be respected so that everyone would be able to have their say. He called for respect for the views being expressed even if these were forcefully opposed by others in the meeting- everyone would have their say.

It is to the credit of all participants that these requests were honoured throughout the meeting, which lasted until approximately 18.10 hours, some 30 minutes over the allotted time. I had to leave just before it ended to catch my train home.

The Panel

Dr Ian Gibson, Dr Richard Taylor, David Taylor, Michael Meacher (all from the House of Commons) and Baroness Julia Cumberledge (former Minister for Health), Margaret Countess of Mar, Lord Leslie Turnberg (House of Lords), with Ian Woodcroft acting as Administrator. Apologies from Anne Cryer MP and Desmond Turner MP.

The Groups

MEA - Beth Llewelyn and Dr Charles Shepherd

AfME – Trish Taylor

MEACH Trust – Sheila McGovern and Sue Sherlock

TYMES Trust – Jane Colby

CROME – Colin Parrot with Ray Gibbons?

25% GROUP – Geoff Crowhurst and others.

OSTEOPAT GROUP – Raymond Perrin and Steve Briggs

AYME – Mary-Jane Willows

ONE CLICK GROUP – Jane Bryant and Angela Kennedy

WORCESTER ME SUPPORT GROUP- Rosemary Whinnall and Jill Pigott.

BRAME - Christine and Tanya Harrison

PETERBOROUGH ME SUPPORT GROUP – Di Newman

The compressed time frame of the meeting and the table/room lay out meant it was not possible to hear and write down everything.

I am aware that I am a relatively new “boy” to the world of ME and I have tried to avoid the internal politics of some of the groups represented and I am still learning about the views of some on the Panel. I am aware that some participants on the Panel and among the groups represented may have more extensive agendas than those under consideration on this day. Many people I had anticipated being there were not present.

Given all these caveats, I have tried to report as accurately as possible the events of the day and not to read hidden agendas (if they exist) into what was said by the people present.

Major Aspects of Many Presentations

1. Several severely ill patients told their own stories. These were universally stories of great sadness and loss as well as of bravery and dignity in facing the worst ravages of ME. I found these

accounts deeply moving and felt that the Panel did so as well. Some seemed almost 'shell-shocked' by these personal disclosures that included both sufferers and their helpers.

- 2.** No one could have listened to these stories without recognising the seriousness of the illness and its costs in blighted lives and hopes or realising that there has been a lamentable failure of the current health and benefits system in providing for their needs. There were repeated pleas for properly targeted research and funding to understand, treat, and provide for all the needs of sufferers and carers.
- 3.** The term ME was almost universally used by all participants in talking of the illness.
- 4.** There was a strong emphasis on the WHO classification of ME under ICD-10 G.93.3 as a neurological illness but some added that immunological and endocrinological aspects were also important.
- 5.** The symptoms presented were accurately described and consistent with the lists in the published work. The 25% Group in a powerful presentation set out 61 symptoms of which some 31 were very common and most severely ill people had over 20 different symptoms.
- 6.** There was widespread rejection of the use of the label "fatigue". The subterfuge of attempting to label ME as a fatigue syndrome with behavioural and mental associations as under ICD-10 F.48.0 was exposed by reference to the debate led by the Countess of Mar. What was described was severe disabling total exhaustion following any effort and needing a long recovery time that was accompanied by numerous symptoms of which severe and persistent pain and massive disruption of cognitive functions were most frequently mentioned.
- 7.** Repeatedly, the failure of the MRC to support or fund any research into the biological basis of ME and possible treatments was asserted, usually coupled with the lack of any such research in fulfilment of the recommendations set out in the CMO's working group report.
- 8.** Whilst some GPs were regarded as very supportive, helping as best they could with sympathy and understanding, the general attitude of the medical establishment was one of dismissal, impotence and ignorance – "I can't help you", disbelief, and rejection, particularly when benefits and insurance claims were involved.
- 9.** A very powerful part of the 25% Group presentation included a pack of tissues referred to as a tissue of lies about ME. This included medically unexplained symptoms, de-conditioning, depression, and that the disorder can be cured by CBT and GET.
- 10.** The work of MERGE was mentioned as an illustration of the lack of official funding that left this work to the ME research charities.
- 11.** Several people mentioned the importance and significance of the Canadian Criteria and the need for the development of diagnostic criteria, with better understanding of the various sub-types. One presentation pleaded with the Panel to read, if nothing else, the Canadian Criteria and the Jason paper on the need for subtypes.
- 12.** The psychiatric (including somatisation and the biopsychosocial) model was vehemently dismissed and only one group, AYME, had anything to say about it having any value. The PACE, CBT

and GET trials were regarded as irrelevant, as nonsense, as a waste of money, or as fraud, with no reliable scientific basis. Many spoke of the exacerbation of the illness when GET was introduced into the management.

13. A number of groups had collected large data bases with extensive information about the nature of the illness and difficulties in finding help and support. Some of these will be made available for public information and use in research. They provided useful statistics about the costs and impact of the illness.

14. Several groups expressed concern about the latest Government initiative aimed at getting people back into work that might be used to force chronically ill ME patients into employment that would only lead to the very worst experiences of the illness being repeated. Generally I gained the impression that ME patients and their carers sought a return to work that was within their limited ability to make sustained effort and concentration.

15. Several groups positively acknowledged their role as campaigning and support groups with no capacity for research but all recognised the need for research into the biological basis of the illness that was well funded and uninfluenced by policy dictates and any political agendas.

Comments on Individual Presentations

Action for ME (AfME)

AfME described itself as not primarily a research organisation. It was a campaigning catalyst for collaboration and help.

- a.** It reported a survey of >2000 people and some analysis of their data. 25% were housebound, 75% had lost their jobs, 77% had very much reduced social contacts and 92% were not helped by GET.
- b.** It judged the MRC to have no coherent strategy and lacked any robust studies.
- c.** There had been no progress on biological studies as recommended by the CMO's working group.
- d.** An ME Observatory involving the Universities of East Anglia, Hull and York was reported that would look at epidemiology and social research.
- e.** Diagnostic criteria were essential.

The ME Association

Beth Llewelyn gave a very moving account of her own illness and the commonly experienced failures of the medical and benefits system.

- a.** Her GP refused to follow up the many medical reports associated with her illness, which was not recognised.
- b.** The family had been accused of all sorts of things because she did not get better.
- c.** 62% of GPs in Wales do not believe in ME.
- d.** She collapsed on the second day of GET.
- e.** Dr Charles Shepherd followed with his assessment of the illness as predominantly neurological, taking his cue from the ICD-10. Much more research is needed.
- f.** He provided papers and diagrams that identified the major areas of the brain that were affected and comments on techniques used to make published studies. These included the 5-HT, dopamine pathways, hypothalamus, MRI scans showing a decrease in cortical grey matter, reduced blood flow, especially in the brain stem, and changes in the cerebrospinal fluid.
- g.** The MRC had provided no support for such studies.

MEACH

This new charity seeks to provide ME Accommodation Care Homes for the severely ill.

- a.** Sue Sherlock movingly described her experiences and needs as a patient – at one point she had been bed-bound for 9 years but was diagnosed with menopausal depression.
- b.** The present provision for such ME sufferers was described as totally inadequate with the special needs unrecognised eg. for stress-free, quiet facilities with subdued lighting.
- c.** Many symptoms were described, with multiple neurological problems including brain fatigue, general fatigue, lack of bladder control etc, requiring a total reliance on others for care.
- d.** The only real help had been listening and care without stress. Stress was a key aspect of the illness in her experience.
- e.** There is a desperate need for residential care for the severely affected, who had been excluded from research studies.

- f. Continuing care is essential.

TYMES TRUST (The Young ME Sufferers Trust)

Jane Colby spoke of her own illness (Coxsackie B related) and the special needs of children with ME.

- a. ME is an immunological disorder/disease.
- b. She referred to Dr Betty Dowsett's investigations, J. Chronic Fatigue 1997, that identified children at the epi-centre of ME outbreaks – evidence presented to the Select Committee.
- c. ME is the largest single illness causing loss of schooling.
- d. She drew attention to the Chia paper that re-evaluated the enteroviral nature of ME and confirmed the earlier studies in this field.
- e. Many ME sufferers had high antibody titres years after the onset of the illness.
- f. Renewed studies were now needed.
- g. ME should be made a notifiable disease.
- h. A medical microbiologist would be a useful addition to the Inquiry Panel.
- i. Anti-viral treatment is effective and needs to be carefully explored.

CHROME (Case History Research on ME)

Colin Parratt and Ray Gibbons described their data base of patient stories that it is intended will be placed in the public domain via the TYMES Trust web site when all the data protection legislation has been complied with.

- a. With the aid of patients' stories they illustrated the nature of the illness – brain fog, loss of communication were by far the worst aspects.
- b. An holistic approach was needed; acupuncture and Chinese herbs had proved useful for some, and gut, heart and emotional problems all improved.

- c. Many unhelpful treatments were advocated and the threat of sectioning for the severely ill was always there.
- d. Symptoms had worsened in a new house, pointing to the possible involvement of (organophosphate) pesticides.

25% GROUP for the Severely Affected

This was a very powerful presentation made with passion and commitment by Greg Crowhurst.

- a. His wife's distressing story was told with pain and humour. Very severe pain was for them the most destructive symptom. Fatigue is not a meaningful term for his wife's illness. It is much more. Temporary paralysis was a key symptom
- b. They have tried everything.
- c. They had produced a major report from their 800 members that needed to be read by the Panel.
- d. His 61 symptoms "fliers" and the tissue of lies made a big impact on the meeting.
- e. There has been no debate on the ME despite the WHO classification
- f. "People are being wronged" by the psychiatric lobby, the pharmaceutical industry and the insurance industry who all misrepresent the illness as psychiatric.

The Perrin Clinic- Osteopathy and ME

Steve Briggs told his personal story of a viral illness that left him spiralling downward into the typical losses of an ME sufferer. After 8 years he made a full recovery thanks to the treatment of Dr Perrin.

- a. Dr Perrin described ME as a pre-viral condition that lead to an overstrained sympathetic system associate with increased permeability of the blood-brain-barrier and the accumulation of toxins in the brain. Chemical sensitivity was one characteristic of the condition.
- b. Since the brain lacked any lymphatic drainage system secondary drainage had to be facilitated resulting in the eventual metabolism and elimination of toxins via the liver and kidneys.

- c. He regards ME as a functional biophysical mechanical disorder marked by other postural problems. Tender points are characteristic with lymphatic varicosities and dermal striae being prominent.
- d. Treatment involves gentle cranial massage to increase drainage via the cerebrospinal fluid.
- e. Organophosphates are among the many toxins involved.
- f. Dr Perrin went on to claim in response to a question that to another speaker that GET was helpful when recovery had begun. This was strongly challenged by other speakers, who made it clear that GET was dangerous and damaging and it was not possible to be sure when recovery had begun in any particular person.

AYME (Association of Young People with ME)

Mary-Jane Willows presented the story for young people who are a very significant group in the UK.

- a. She described one severely affected young person who had to have a “peg” inserted to provide vital nourishment and intra venous support since she was too ill to eat and absorb any nutrients.
- b. ME, she asserted, was a complex, serious and neurological illness with many triggers that resulted in extensive multi-system damage with a high morbidity.
- c. Isolation was a major feature of the illness.
- d. Some 25,000 young people are affected of which 41% had not been seen by a medical specialist.
- e. GPs with specialist interest in ME were urgently needed and should be encouraged.
- f. There was an urgent need for a validated definition.
- g. Treatment had as yet no sound scientific basis and choice of treatments was essential.
- h. She was the only person who made any positive comments about the newly created 11 National Centres for ME and reported that PACE, CBT, GET offered some progress but only when provided by fully trained staff. She asserted that outcomes in Bath were good.
- i. Nonetheless there were many large gaps in knowledge and understanding.
- j. She relied heavily on the Royal College of Paediatrics and Child Health (RCPCH) guidelines (even though these have been much criticised).

- k. She felt that genetic studies in adults could not be extrapolated to children.
- l. Child protection services that threatened actions against the parents and the child were not helpful.

THE ONE CLICK GROUP

Angela Kennedy and Jane Bryant made their joint presentation in characteristic robust fashion.

- a. They described One Click as a pressure group against the psychiatric diagnosis of ME and pointed to their web site that they claimed received many hits per day.
- b. They reported that borreliosis was a major player in ME and Gulf War Syndrome with 95% of ME patients being positive for borrelia antibodies.
- c. Many children including their own were ill with ME.
- d. Psychiatrists had walked out of the CMO's Working Group yet ironically it was only they who had benefited from any implementation of that report.
- e. ME is an organic multi-system illness that has been ignored by NICE.
- f. The pacing, CBT and GET studies were part of a cultivated ignorance towards ME. The research in this field was highly flawed in a manner that amounted to fraud.
- g. Simon Wessely's words that, "ME is simply a belief" were quoted to support this conclusion.
- h. The £11 million spent on the promoting this belief and the fraudulent treatment was roundly condemned.
- i. Suicide was an aspect of ME that needs to be recognised and investigated.
- j. Biological factors have been ignored and the Oxford, London and Fukuda criteria used without any criticism. These are seriously flawed and contribute to the fraud.
- k. Politics was getting mixed up with the science so avoiding the urgent need for biomedical research.
- l. Lack of medical investigation, denial of benefits, hostility by GPs and forced mistreatment including the Ean Proctor story were all presented in a devastating critique of current attitudes.
- m. They asserted that the failure of AfME to hold an AGM placed it outside the legal processes governing a charity.

- n.** In response to questions from the Panel, Angela and Jane refused to moderate their statement about fraud and justified it with reference to their statements surrounding the controversy about ICD-10 G.93.3 (neurological disorders) and F.48.0. (mental and behavioural disorders)
- o.** Dr Richard Taylor commented that Lyme disease should be readily diagnosed by a GP from available tests.
- p.** Michael Meacher asked why was the DoH not picking up and responding to these comments. He was referred to Dr Margaret Cooke's article in the Scotsman.

Worcester ME Support Group

Jill Piggot and her friend Rosemary, out of their experience with their children with ME (now 34 and 22), spoke movingly of the pain and cost to carers and patients of this biological illness with its comprehensive effects that almost defy description.

- a.** This is more than fatigue; relapses are common; 75% suffer cognitive losses, and work becomes impossible or very limited.
- b.** Symptoms can fluctuate markedly and rapidly.
- c.** The illness encompasses central nervous system, immunological and endocrinological dysfunction.
- d.** Help and support are essential and patients continually chase therapies and recommended supplements, which are expensive and not available through the GP and NHS.
- e.** The provision at Kidderminster hospital through Dr Mark Roberts is greatly appreciated but the commitment to occupational therapists, dieticians, and psychological support has been compromised due to budget restrictions.
- f.** Regular home visits and assessments by GPs are important as is help and support for the carers.
- g.** Blood tests can be useful.
- h.** Any other medical staff and support agencies that are to be involved in ME must be properly trained and educated about the illness.
- i.** CBT and GET are not relevant.

- j.** The importance of biological studies and research was emphasised through their link with MERGE.
- k.** A top priority is a diagnostic test that leads to effective treatment.
- l.** Comments and questions from the Panel – Baroness Cumberledge mentioned the use of specialist Nurses and a scheme similar to that involving such nurses and pharmacists in the management of Parkinson’s disease.
- m.** Lord Turnberg asked if early diagnosis helped. The answer was yes -- rest was important from the beginning.

BRAME (Blue Ribbon Awareness of ME)

Tanya Harrison, supported by her mother Christine, told her distressing story bravely at the end of a long day. She had had a bright future and was a high academic performer whose life suddenly nose-dived into the bleak pit of ME. Her symptoms were numerous - pain, sleep problems, nausea, brain fog with loss of reading and word recall and usage, ulceration, and photophobia. “You have to live with the illness to understand it”. The body is totally compromised and the recommended surgical operations had been disallowed because of the illness.

- a.** ME is an acquired biological illness involving multi-system and multi-organ failure. It is neurological and not an illness of belief.
- b.** CBT and GET are rubbish and make matters worse. Clinicians adopting these procedures are responsible for patient rejection, disbelief about the illness and psychosomatic diagnoses.
- c.** PACE supports the psychiatric and biopsychosocial model of ME.
- d.** There is psychiatric bias in papers on ME.
- e.** Research funding has not been provided by the Government/MRC but been left to the ME charities.
- f.** Prognosis is poor for such patients and cardiomyopathy and pancreatic dysfunction are major problems. These should be given high priority.
- g.** Some blood tests are abnormal eg. high ESR, low iron levels. Cardiovascular responses are also abnormal as are hormonal levels. Multiple chemical sensitivity is common.
- h.** They raised the question – where is the money for biological research into the illness.

- i. A recent death of an ME patient resulted in a *post mortem* that identified unequivocal inflammation of the dorsal root ganglia associated with a herpes infection.
- j. Classification is a key issue. The Canadian guidelines and the Jason paper on the need for subtypes should be read by every member of the Panel.
- k. The NHS is perpetrating injustice and inequality in its treatment of ME patients.

PETERBOROUGH ME SUPPORT GROUP

Unfortunately I had to leave for my train as Di Newman began her short contribution

There were several outbursts of spontaneous applause throughout the presentations that reflected considerable agreement between all attending.

CONCLUSIONS

This was an excellent meeting that was well handled and allowed every participant to make their case. It is difficult to see how the following conclusions can be avoided by any Panel that espouses independence and evidence-lead medicine and science.

∅ The psychiatric theories of ME, under whatever name, are dead. They have been exposed and placarded as flawed and invalid through the testimonies, pain and distress of those suffering from ME and the imposed sacrifices of their carers. They must be abandoned forthwith.

∅ A new strategy must be implemented that addresses ME as a profound biomedical illness affecting the neuro-endocrine and immune systems that is initiated by viruses and other micro-organisms, and exposure to toxins.

∅ The current strategy and funding for ME centres can no longer be justified and must be abandoned and the money used to support patients and carers, biomedical research for treatments consistent with this understanding of the illness.

∅ There is an abundance of well-founded science and medicine in published peer-reviewed literature that must receive immediate attention.

∅ The example of MERGE must be followed in providing innovative biomedical research studies that must be funded by Government through the MRC with monies matching the current allocations for the flawed PACE, CBT, GET studies that should be abandoned.

∅ The Canadian Criteria must be espoused and implemented with due attention to the WHO ICD-10 G.93.3 classification.