



All Party Parliamentary Group on M.E.

Chair: Des Turner MP
Vice-Chairs: Andrew Stunell MP
Tony Wright MP
Secretary: Ian Gibson MP
Treasurer: David Amess MP

**Minutes of meeting of All Party Parliamentary Group on M.E. held at 1pm,
Tuesday 2nd July 2008 Committee Room 20, House of Commons**

PRESENT

Dr Des Turner MP
Dr Ian Gibson MP
Andrew Stunell MP
Tony Wright MP
The Countess of Mar

Koyes Ahmed (Office of Dr Des Turner MP)

Sir Peter Spencer, Action for M.E.
Dr Charles Shepherd, ME Association
Tony Britton, ME Association

Mary-Jane Willows, Association for Young People with ME
Jane Colby, Young ME Sufferers Trust
Christine Harrison, BRAME
Joanna Smith, parent of child with ME (with Jane Colby)
Ian Webster, parent of child with ME (with Mary-Jane Willows)
Joy Birdsey (Kent and Sussex Alternative Group for MEE)
A Gold (Patient Observer)
Janet Taylor (Kirklees Independent ME Support Group)
Di Newman (Peterborough ME and CFS Self-Help Group, and Cambridgeshire
Neurological Alliance)
Augustine Ryan (Person diagnosed with ME)
Anna Tagliaferro (Person diagnosed with ME)
Bill Kent (reMEMber)
Janice Kent (reMEMber)
Jo Dubiel (Person with ME)
Nicky Zussman (Kent and Sussex Alternative Support Group for ME)

1. Welcome

Dr Des Turner welcomed everyone to the meeting.

2. Apologies

David Amess MP (group treasurer), Ann Cryer MP, Andrew Dismore MP, David Drew MP, Mike Hancock MP, Dr Brian Iddon MP, Peter Luff MP, Kerry McCarthy MP.

Heather Walker (Action for ME), Doris Jones (25% Group), Colin Barton (Sussex and Kent ME/CFS Society).

3. Minutes of the last meeting

Christine Harrison (BRAME) challenged the minute of the meeting of 22 January 2008, in particular the record of discussion with Ann Keen MP, Parliamentary Under Secretary of State for Health Services. What had crucially been omitted was the agreement reached with the meeting chairman Dr Ian Gibson before the arrival of the Minister for three key questions to be put to Ann Keen. The questions put by Sir Peter Spencer and Dr Shepherd had been included, but there was no mention of her own question.

In her complaint, Mrs Harrison wrote that the minute should show that BRAME formally asked Ann Keen for an urgent meeting between Ann Keen, Lord Darzi, BRAME and representatives of other ME organisations that would address the health inequalities and problems faced by people with ME within the NHS, and this could include Dr Chris Clough, if they wished.

Mrs Harrison wrote that she had also pointed out to Ann Keen that the Cabinet Office, in its Effective Consultation document in 2007, has as its key points on the front cover: Asking the right questions; Asking the right people; Listening to the answers. To date, in relation to ME, consultations had: Asked the wrong questions; Asked the wrong people; Listened to their flawed answers.

Mrs Harrison wrote that the relevant paragraph of the minutes should read: "Dr Gibson responded to BRAME's question and Ann Keen's response, by saying that he felt that such a meeting was necessary, it needed to be arranged as soon as possible, and the APPG on ME would help in any way it could".

Subject to these amendments, the minutes of the meeting of 22 January were then agreed as an accurate record.

4 Matters Arising

There were no matters arising.

5 Presentations on Child Protection Issues by Jane Colby, executive director of The Young ME Sufferers Trust, Mary-Jane Willows, chief executive of The Association of Young People with ME, and two parents of children with ME, Joanna Smith and Ian Webster.

Two or three minutes into Jane Colby's opening presentation, Dr Gibson said there were now sufficient members of the APPG in the room to hold the AGM. Rather than risking losing the quorum if members had to go elsewhere, he called for the AGM to be held immediately, and apologised to Jane Colby for the interruption. This was agreed.

Annual General Meeting

(i) Election of Chairman

Mr Wright proposed the re-election of Dr Des Turner MP. This was seconded by Dr Gibson and agreed unanimously.

(ii) Election of Vice-Chairmen

Dr Gibson proposed the re-election of the vice-chairmen, Andrew Stunell MP and Tony Wright MP. This was seconded by the Countess of Mar and agreed unanimously.

(iii) Election of Secretary

Mr Stunell proposed the re-election of Dr Ian Gibson MP, This was seconded by Dr Turner and agreed unanimously.

(iv) Election of Treasurer

Although absent, Dr Turner said he understood that David Amess MP was willing to stand again, and proposed his re-election. This was seconded by Dr Gibson and agreed unanimously.

Sir Peter Spencer (Action for ME) expressed the thanks of those present for the willingness of the officers to stand again, which enabled the work of the APPG to proceed without interruption. There was applause for the newly re-elected officers.

Dr Turner said this concluded the business of the Annual General Meeting, and added his thanks to fellow group officers.

5. Presentation on Child Protection Issues (resumed)

Jane Colby

Ms Colby said sick children and innocent families were caught up in a web of professional misunderstanding about ME. It appears to these families that the presumption of innocence enshrined in British law does not apply to them.

Proceedings held in the Family Courts do not demand the same level of evidence as the criminal courts. Secrecy adds to the difficulties.

Two principles established in the children's chapter of the Department of Health Report of 2002 are not being followed – (1) that evidence indicative of harm should be obtained before the convening of child protection conferences or initiation of care proceedings and (2) that neither the fact that a child or young person had unexplained symptoms nor the exercising of choice in the selection of treatment or education constituted evidence of abuse.

Jane Colby discussed case law in respect of Munchausen's Syndrome by Proxy (now called Factitious Induced Illness) and the legal reasoning adopted by the UK High Court in the Family Division in which the hope had been expressed that MSBP would be 'consigned to the history books'. However, the term FII was still in use in its place.

If a child is suspected of child abuse, the following procedure is applied:

- Within 24 hours: an initial decision is made about whether to pursue a child protection Section 47 investigation.
- Within 7 days: an initial assessment must be done which involves seeing the family.
- Within 30 days: a core assessment must be done.

The process moves so swiftly that parents are unprepared as to how to fight it. In practice, it appears that families in this situation are not being adequately informed of their rights or of the procedures being followed. These procedures are laid out in the Department of Children, Schools and Families' statutory guidance in relation to child protection, 'Working Together to Safeguard Children'.

There was another important theme to the guidance: the wishes and feelings of the child should always be sought, as should the child's account of what has been happening to them. Jane Colby described useful techniques to assist this process.

The Young ME Sufferers Trust called for the following action:

- The Department of Children, Schools and Families should urgently alert Social Services professionals to the frequency of misunderstandings in cases of ME
- A leaflet clarifying the procedures that should be adhered to by professionals in child protection investigations should be given to families under suspicion, and they should be informed of their rights.

Jane Colby then introduced Joanna Smith, a senior adviser with Brunel University Students' Union and governor at the school attended by her two teenage daughters, both of whom have ME

Joanna Smith

Joanna Smith recalled how her older daughter Patricia became ill in 2001; it took six years for her to be diagnosed.

Mrs Smith said she was bitterly disappointed at the attitude of the consultant in the adolescent health clinic at Great Ormond Street Hospital, who not only referred to ME as "fatigue" but conducted a battery of psychological tests, spending less than 15 minutes of a three-hour visit on physical symptoms and needs. The physiotherapist there ignored her daughter's pleas that she would rather not use the exercise bike because she was exhausted and nauseous and worried that she would fall. Her daughter suffered a severe relapse afterwards. The consultant would not support an application for disability benefit.

Educationally, things were not much better. Patricia managed to stay in top sets at her High School despite falling attendance. In year 11, she was not able to attend at all. In that year, Mrs Smith said she received one call from the LEA and a few emails from the Head of Year – none offering practical support.

"Patricia by then was suicidal from pain, insomnia and distress. And, when I say suicidal, I don't mean she vaguely thought about it – she actually attempted to take her life."

Mrs Smith said the LEA only admitted to serious shortcoming in provision of education for her daughter only after a year-long complaint, when she had the assistance of a specialist solicitor.

In February, her younger daughter Emily became ill. The family's "Child Protection nightmare" began.

The school asked for a diagnosis – a legitimate request as during a prolonged absence. The vicious circle started again: a GP refusing to acknowledge ME, a long wait to see a paediatrician and pressure from the school for medical evidence.

The school would not believe that there is a tendency for clusters of ME in families, even after she sent them to scientific papers. The school started to send harsh, terse letters about de-registration and penalties.

Mrs Smith said a social worker referred by the school paid a visit, without prior warning. The school wrote to the social worker that Emily was copying her older sister, did not look unwell and was not reporting health problems to the school nurse. Mrs Smith said the social worker knew nothing about ME. A few days later, the social worker called to explain there was no case to answer, the file was closed and there was no need to continue the assessment.

“Yet the worst came recently when I was informed that, on the advice of a Child Protection-nominated nurse, the school is requesting Social Services to re-open the case. No explanation why, no information about allegations, no advice where to seek support. I was ill with shock....

“The irony of it all is that one of my responsibilities as a Governor is child protection issues. Also, please note that I am talking about the same Local Authority which already admitted inadequate support in the case of my first daughter.”

At this point, **Dr Turner** described the presentations as “harrowing experiences” for those involved. Many of the problems would not have arisen if all doctors were aware of the contents of the Chief Medical Officer’s Report. He said the Family Courts system was by nature secretive and arbitrary, and should be improved.

Janet Taylor commented that similar cases were occurring elsewhere. If adults with ME were not being treated properly what chance for children then being treated appropriately? Janice Kent asked if something could be put in place to provide redress when people’s characters were besmirched.

Tony Wright MP said that one of the problems was that many doctors still did not believe in ME and this was a societal problem. **Christine Harrison** said that, while the CMO Report in many respects was a good document, its recommendations on medical education and training had not been implemented. But poor communication with social services was not universal; Mrs Harrison said that when her own daughter had been unable to attend school, the family had a lovely social worker who spoke up for them.

Nicky Zussman complained that one of the Sussex health trusts still categorised ME as a mental health disorder. It was listed in a key document next to psychosis. Against this background, it was difficult to see how progress could be made. **Dr Turner**, as a Sussex MP, said he would be prepared to take this issue up directly with the trust, if he could be provided with a copy of the offending document.

The Countess of Mar recalled that the history of chronic illness was littered with examples of callous disbelief. Until very recently in history, for instance, both Multiple Sclerosis and Parkinson’s Disease had been dismissed as psychosomatic illnesses. The Countess said she had recently discussed the situation affecting children with ME with the Chief Inspector of Social Services, but this had not produced a satisfactory result.

Di Newman said there were similar problems in her area with social workers who had “a psychiatric reading” of ME.

Dr Turner said he would raise the issues discussed with both the Secretaries of State for Health and Children, Schools and Families to see what procedures could be put in place to improve the situation.

The discussion then returned to the main presentations.

Mary-Jane Willows introduced Ian Webster, whose 14-year-old daughter Victoria has severe ME.

Ian Webster

Mr Webster said his daughter had probably had ME since she was two years old but she was only diagnosed in 2005. Currently, she is bedbound and had not been to school for three years.

In July 2007, Victoria was assigned a social worker following a referral on the grounds that adequate medical assistance was not being provided. But the social worker had little understanding of the condition. In January 2008, Veronica was seen by a paediatrician, Dr Esther Crawley, who devised a care plan, provided training for local professionals involved (although not all attended) and offered ongoing support (which was not taken up).

In April 2008, the social worker involved applied to put Veronica on the At Risk Register. Mr Webster said the criteria for placing a child on the register were whether there was risk of physical, sexual or emotional abuse or neglect. The correct procedure would have been to treat Veronica as a Child in Need. Social Services failed take account of or even grasp the concept of “boom and bust” which had been fully explained by Dr Crawley as key to his daughter’s recovery. Progress may be slow but needed to be taken at Victoria’s pace with her goals at the centre of any decisions made.

At the hearing, no evidence was offered of abuse or neglect. Both the police and Victoria’s doctor gave evidence that the case did not meet the criteria for entry on the At Risk Register and, with the chairperson’s consent, no vote was actually taken. Victoria was not placed on the register. A letter from Dr Crawley offering to support the family whatever the outcome was not even mentioned by the social worker. “My impression is that the proceedings were being driven by non-medical professionals. Bearing in mind that this was an illness case, and that the welfare of the child is paramount, this is worrying.”

The hearing was administrative in nature rather than judicial. Mr Webster said he and his wife were represented by one of his business partners; Victoria was represented by Mary-Jane Willows. The professionals made their case but the family was unable to cross-examine them. What became clear was that the professionals were not communicating either with each other or adequately with the medical professionals and were not acting as a team.

The proceedings were stressful for the family and disrupted Victoria’s the recommended therapy. All she has ever tried to do was get better. She was told by the professionals that she was not doing enough and now feels that the professionals do not trust her. The proceedings resulted in deterioration in her condition.

Mr Webster said child protection proceedings should not be used in illness cases in the absence of evidence of abuse or neglect. There were insufficient checks and

balances to prevent non-medical professionals overriding the wishes and advice of medical professionals.

He said there should be a presumption that the child is a Child in Need and not a Child at Risk. If ME is diagnosed or suspected, a service plan should be developed – involving parents, child and all relevant professionals. The instigation of child protection proceedings resulted in breakdown of trust and the ability to work as a team.

In illness cases, the team leader must be a doctor with ME experience. Parents must have legal representation and legal aid should be available. The welfare of the child was paramount.

Mary-Jane Willows

Mary-Jane Willows said the Association of Young People with ME (AYME) had supported families like the Websters for 12 years. It was hoped that, after the Chief Medical Officer's Report in 2002, things would improve – they didn't! The publication of paediatric guidelines by the Royal College of Paediatrics and Child Health in 2004 raised expectations of improvement. For a while, certainly among healthcare professionals, there did appear to be a mind shift but it did not last. The NICE Guidelines, published last year, have been used by AYME as a tool to fight for care of their members and have had positive outcomes. They have been positive outcomes but, like the cases heard today, they have not been universally applied.

Mary-Jane Willows asked: "What good is all the money spent on this guidance if no one reads it or takes any notice of it, or chooses to misinterpret it?"

AYME supported 37 crisis cases in the last year, most of which were families threatened with Child Care Proceedings. All were put under protracted periods of additional stress and anxiety – sometimes for many months – while professionals gathered information that would have been readily available if they had looked in the right places.

Most AYME cases were referred by education professionals while some had a background in social care. Even when parents, advised by AYME, provided all the guidance mentioned, the proceedings still went ahead. Quoting from some of those involved, the reasons included "We just want to speed up the process", "get things moving", "break the close bond the parents have developed with their child" (as if that is a crime), "get them back to school where they belong with their peer group".

Mary-Jane Willows commented: "How offensive is this for parents to hear? Don't they know that, if only it were that easy, we would have a queue a mile long. These parents will do anything to help their child, sometimes spending a fortune chasing miracle cures which we know don't work. Who can blame them when only 25% of the country is provided with specialist CFS/ME services."

Another vital point to consider was that all the Guidelines, including NICE, make it absolutely clear that no one should be forced into a treatment programme they don't agree with. To quote Dr Crawley. "There is no evidence base for the best way to proceed in children who are severely affected. I advised the family based on experience and the evidence for adults. However, even if the family did not engage with this, there would be no reason for this to be a child protection issue. How much more clear could she have been but they still chose to proceed, even though Dr

Crawley made it clear she would speak in court should it come to that for the family.”

Mary-Jane Willows said the position was being exacerbated by the drive and pressure in education for attendance figures to be met, to meet targets and rate highly on league tables.

In 2007, AYME chaired a working party of respected professionals from health education and social services, all with a child protection background and developed Child Protection Guidance for professionals in education and social services. But cases continue to rise.

“When I first joined AYME, I supported a young person who was forced against her and her family’s wishes as a ward of court into hospital. It took 18 months and re-mortgaging the family home at a cost of £60,000 and a High Court battle to get her home. In court nothing was ever produced, no evidence was made available to prove why this action had been taken. The understandable result is a young woman and family who have lost faith and trust in all professionals. They now struggle on alone rather than asking for help of any kind, except from the charities that support them.”

AYME called for the following actions to be taken:

1. A directive to be issued by the RCPCH for all paediatricians to refer to the college’s guideline when treating children and young people with ME.
2. ME to be included in the training of all GPs and paediatricians.
3. All parents under suspicion of putting their child at risk should be informed of their rights and given the details of organisations which can support them.
4. An investigation into the cost of pursuing these cases.

Following the main presentations, **Dr Turner** asked Jane Colby and Mary-Jane Willows to produce a short summary of all the essential points which he could then send to the Chief Medical Officer and the Secretaries of State. They agreed.

In the ensuing discussion, **the Countess of Mar** said she also proposed calling a meeting with the chief executives of the national ME charities to hammer out areas where they shared common ground. It was vital to present a united front on key issues affecting people with ME when communicating with the Government.

Dr Turner also announced that he intended to mount an inquiry into the state of NHS services for people with ME – in much the same style as the inquiry into the state of research chaired by Dr Ian Gibson, which reported in November 2006. The services inquiry would call for written evidence and select key witnesses who would be asked provide oral evidence to the inquiry team. He said he would ask the APPG secretariat to meet with him to discuss terms of reference and the administration. In answer to questions from **the Countess of Mar** and **Sir Peter Spencer**, he said he expected the inquiry would be taking evidence on progress made since the CMO Report in January 2002.

6 Oral Reports

(a) NICE Guideline: Judicial Review hearing, 17 June

Charles Shepherd reported that, after an exploratory hearing which he attended in the High Court lasting nearly two hours, Mr Justice Cranston agreed that the application for a Judicial review on the NICE Guideline on ME/CFS should proceed to a full hearing in the autumn. Two named people had initiated the legal challenge,

which relates to the processes and procedures by which NICE produced the guideline, with ME and one unnamed person.

(b) House of Lords, 2 June

Dr Shepherd said that during House of Lords questions to Lord Darzi on 2 June, which he attended, the Countess of Mar asked whether his NHS review would include consideration of ME/CFS as a long-term neurological condition. In response, Lord Darzi stated that: "The long-term conditions pathway is one of the care pathways that strategic health authorities are examining as part of the NHS next-stage review. The review will increase awareness and ensure better care for people with ME./CFS and will help to support local delivery of the National Service Framework for long-term neurological conditions." In response to a further question from Baroness Howe, Lord Darzi said that the Government believes that ME/CFS should be classified as a neurological illness and that he would encourage the Royal College of General Practitioners to take account of the WHO classification. There were also questions from Lords Swinfen, Elystan-Morgan and Earl Howe on children with ME and care proceedings, and one on medical education from Baroness Tonge. **The Countess of Mar** said she had nothing to add, apart from the fact that she shared an office with Baroness Howe so it was relatively easy for them to work together on issues in which they were both interested. **Christine Harrison** said she had also attended the session; Lord Darzi had mentioned four times that ME was a neurological condition.

(c) Royal College of General Practitioners classification

Charles Shepherd said the ME Association had been in correspondence with Dr Bill Reith at the RCGP about their decision to include CFS (using the neurological Read Code F286) as a mental health disorder in a curriculum training document. The RCGP had agreed to examine this decision but say that their administrative procedures meant that no change in position could be taken and confirmed before January 2009. The MEA is trying to fix a meeting to discuss the GP training in ME/CFS with Dr Reith.

(d) Lord Darzi and the NHS Review

Charles Shepherd said that, at the last meeting of the APPG, health minister Ann Keen agreed to try and arrange a meeting between Lord Darzi, APPG members and charity representatives. Despite several approaches to Lord Darzi, no such meeting took place. Lord Darzi published his NHS review on Monday 30 June. Three specific recommendations that might relate to people with ME/CFS were: (1) All patients with long-term conditions will have personal care plans (2) Five thousand people with long-term conditions will have pilot personal care budgets (3) NICE appraisals of new drugs and treatments will be speeded up so they take a maximum of six months, rather than two years.

(e) Consultations by the Strategic Health Authorities on the NHS Review

Christine Harrison said BRAME and other local groups had been extremely active in promoting awareness of ME issues in their local SHA consultation on the NHS Review. In East Anglia, the consultation will close on 14 August. She spoke about the importance of the consultation and urged other groups to make similar representations to their SHAs. BRAME had draft template letters that others could use. **Joy Birdsey** reminded members about using the local LINKs network to

promote discussion and awareness; organisations in the Medway area of Kent were using this system successfully..

(f) NHS Plus occupational health leaflets – update

Charles Shepherd said that, following a joint initiative involving local and national charities/organisations, Dr Ira Madan – clinical director of NHS Plus – had attended the APPG last year to discuss our concerns about their occupational health guidance for ME/CFS. Revised versions of all three leaflets had now been published, and were available at the NHS Plus website. Although not perfect, the revisions had incorporated a large number of changes requested by those involved in the discussions and represented a significant improvement in content.

(g) DWP Medical Guidance

Charles Shepherd said it was now almost a year since the DWP had published their revised medical guidance for decision-makers considering applications from people with ME/CFS for Disability Living Allowance and Carers Allowance. Since then, it had been impossible to objectively assess the outcomes for claimants because up-to-date information on refusals, appeals taking place and successful appeals had not been published. The ME Association continued to receive anecdotal reports of people being refused DLA – both existing and new applications but there had been a reduction in the overall number of calls and emails relating to DLA problems in 2008. One example of a letter sent to the MEA was read out: “Until May 2008, I was on high rate mobility and medium-rate care. Now I have been told I will get nothing” – from someone losing both components of his existing DLA Awards. This person had also reported that, after being placed on a graded exercise programme at a specialist NHS service, this had severely increased his bone, muscle and joint pain because of too much activity. “As a consequence of the way I was treated, I refused to attend this service any more”. Other charity representatives reported similar experiences with DLA problems and **Sir Peter Spencer** referred to the Action for ME patient survey which revealed that many people were still having to go to appeal, where they were often successful.

6. Any Other Business

(a) **Di Newman** objected that items she had asked to be considered in detail – (i) a template for a UK-wide module for ME services, and (ii) consideration of the implications of the Mental Health Act and Mental Capacity Bill for people with ME – had again found themselves at the bottom of the agenda. **Dr Turner** apologised, saying the meeting had run out of time. He offered to place them on the agenda for the next meeting.

7. Date of the Next Meeting

Dr Turner agreed to call the next meeting early in October, the exact date to be agreed with the secretariat

The meeting closed at 3pm.