



## All Party Parliamentary Group on M.E.

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

**AGM held Wednesday 12th June, 2.30pm, Room Q, Portcullis House,  
Westminster**

### Minutes

#### Present

**Parliamentarians:**

Annette Brooke MP

Russell Brown MP

Tom Clarke MP

The Countess of Mar

**Secretariat:**

Sonya Chowdhury (Action for M.E.)

Charles Shepherd & Nicki Strong (ME Association)

**Parliamentary Office Representatives:**

Christine Payne (Office of Annette Brooke MP)

Alex Dunn (Office of Ian Swales MP)

Amarit Singh & Stephen Gallagher (Office of Tom Clarke MP)

Tom Woolhouse (Office of Stewart Jackson)

**All Party Parliamentary Group Members**

Janice & Bill Kent, reMEMber

Mary-Jane Willows, AYME

Jane Colby & Anita Williams, TYMES Trust

Christine Harrison, BRAME

#### Apologies

Dave Anderson MP

Mark Garnier MP

Pat Hopkins MP

Caroline Lucas MP  
Karen Lumley MP  
John McDonnell MP  
Rt Hon Nicholas Soames MP  
Martin Vickers MP  
Sue Waddle, ME Research UK  
Doris Jones, 25% Group

**1. Welcome by the Chair**

The Chair welcomed everyone to the meeting.

**2. Minutes of last AGM held on 4 July 2012**

The minutes were approved as an accurate record of the meeting.

**3. Matters Arising**

There have been some good events and achievements over the year:

- **APPG:** Regular meetings have been held and there have been a number of external presentations focusing on specific issues/areas.
- **UK CFS/ME Research Collaborative:** Charles/Sonya provided an update on the launch which was very successful, with approximately 120 people attending including representatives from virtually every research group in the UK. The first Executive Board Meeting has been held and they are going through the processes required to establish membership and the membership model. The Board will be representative with nursing, clinicians and others involved. Observer role will enable the mainstream funders and others to be engaged. Hoping that input from a pharmaceutical company (neurosciences) will be achieved. Also planning to set up a meeting between the charities and the Science Media Centre to discuss concerns. Plus a two day RC meeting in March 2014.

Annette fed back that she, Margaret and Russell all attended the launch and that it was exciting, particularly in relation to the nature of collaboration and the aim of increasing funding into research.

Annette has re-tabled the Early Day Motion welcoming the Collaborative. It will help draw the attention of more parliamentarians to it. Annette said it is the biggest step forward for some time and that working together in this way should yield results.

- **Atos:** managed to secure attendance from Atos representatives to an APPG meeting. Important to have this engagement but disappointing that there has been little impact as a result. However, Annette and Margaret will be visiting Marylebone assessment centre tomorrow and have a lot of questions. They are going to ask them for a template of how assessments are carried out. Margaret reported that that Atos do not keep a record of how many of their decisions are overturned at appeal. Tom Clarke added that about 40% of their decisions are overturned.

Christine reported that she was with Capita last week, as part of the Personal Independence Payment working group and was looking at the manuals for assessors. Christine suggested that representatives should be invited to a future APPG meeting. Christine has shared concerns that she has with Margaret. She has also written to Esther McVey at the beginning of the year and has not yet had a response. Margaret is meeting Lord Freud next week and will raise this.

Janice suggested that it may be worth asking how many Atos doctors have been referred to the GMC for unethical behaviour. However, Margaret and Annette stated that this information is not recorded, only about those which have been upheld. Russell Brown said a letter had been sent to the Minister about this to which there had been no reply. Margaret will bring this up at the next meeting.

#### **4. Election of Officers**

All Officers indicated their intention to re-stand for election. Alex confirmed that Ian would also like to re-stand.

It was unilaterally agreed to reappoint all Officers:

- Chair – Annette Brooke MP
- Joint Vice Chairs – Countess of Mar and Ian Swales MP
- Secretary – Russell Brown MP
- Treasurer - the vacant treasurer post does not need to be filled in order for the Group to remain properly constituted. No funds are managed by this Group.

Thanks were formally recorded by Christine on behalf of the M.E. organisations for all the work that MPs do for people with M.E. Annette acknowledged this and stated that she can't think of one MP that doesn't have someone with M.E. who attends their surgery thus highlighting the importance of MPs' involvement in the Group.

#### **5. Forward Planning**

A number of ideas were discussed including:

APPG on M.E. Chair-approved AGM Minutes 12.6.13

- Capita: as per discussion above re Personal Independence Payments.
- Minister – Lord Freud – to invite to a meeting in Autumn.
- Evidence based review of WCA is now in progress and will finish in July with approx. 1,000 claimants. Mid August – preliminary data. More detailed analysis with aim to bring changes in WCA in early 2014.
- Paul Litchfield has taken over from Professor Harrington and therefore it would be good to meet with him.
- More DWP questions to be generated and shared between MPs. Oral questions.
- Children: Jane reported back on the lack of progress in respect of children since the work with the Chief Medical Officer over 10 years ago. There are ongoing issues within education. There are some children that are still hidden and where children are not getting the education they are entitled to. The DfE Guidance on Sick Children released earlier this year new guidelines are still not known about by Local Education Authorities; it is down to parents themselves to find them. There continue to be many children who are not getting education, being forced into school when they're not well, subjected to unnecessary child abuse investigations and occasionally even taken into psychiatric units. Tom suggested that it is time for another debate to draw out all of these issues.
- Janice highlighted the potential for the group to do something that explores how to make ME/CFS treatment centres more balanced, to attract more physicians to join the multidisciplinary teams.
- NICE Guideline review – the expected review involving stakeholder input will not happen due to the changes that NICE have implemented. We do not know whether there will be an internal review of the Guideline. Charles suggested addressing this. Margaret said that she invited someone from NICE to Forward ME and they declined. The APPG will consider inviting someone. Christine highlighted that there are many who are using NICE Guidelines as criteria for diagnosis and that this had never been the intention. Therefore there is a clear need for reviewing them to ensure they are up to date and accurate.
- Burrswood: Hannah Clifton has established a charity to help fund this private facility (which also accepts some NHS-funded patients). Annette suggested inviting her to the group. Margaret said that she has been invited to Forward ME. Mary Jane reported that AYME has worked with a few young people who have received helpful treatment there. There was discussion about the lack of NHS residential provision and whether this is something that the group should consider working on, particularly in relation to NHS England.
- Clinical Commissioning Groups: there is likely to be a significant impact as a result of the changes. Janice suggested inviting someone from their local Group with whom they are currently working.
- GP education: ME Association has been approached in relation to some educational material that is being produced for a RCGP publication. It was acknowledged that the GP plays a crucial role in the care and protection of

people with M.E. The Group could invite Clare Gerada to a future meeting (or her replacement). Christine identified the importance of a unified voice in the development of materials for GPs.

- Patient involvement.
- Medical student training – how to integrate M.E. within training. This is challenging as individual medical schools have autonomy and there is varying information and from different perspectives which offers a lack of consistency across training provision. Charles said there is an organisation which has overarching responsibility for medical school training. Mary-Jane said that Tony Pinching had played a large role in such training.
- Centres of excellence (NHS England).
- Voices from the Shadows DVD screening for MPs – Russell Brown keen to hold this. Apparently an half hour version is in production which is a more suitable length for busy MPs. Charles said Dr Nigel Speight had offered to come to talk about the film. Annette says this also needs to be worked into the proposed programme below

Proposed programme for future meetings:

1. Health – to include:
  - Training (GPs and medical students)
  - Clinical Commissioning Groups
  - Patient voice/involvement
  - Voices from the Shadows showing
2. NICE Guidelines
3. Welfare reform – invite Lord Freud to attend.

Additional activities:

1. MPs to initiate debate on children with M.E. and education.
2. MPs to ask more questions regarding work capability assessments and Personal Independence Payments.

## **6. Date of next meeting**

TBC.

## **7. Any other business**

- **Social media activity after meetings:** Sonya suggested that at the end of meetings it was agreed what information could be shared immediately after

meetings via social media. This would help respond to queries that are received immediately after the meetings. Detail would be given in minutes which are subsequently available but a couple of key points from the meeting would be good to feed back immediately. All agreed.

- **Judicial review challenging the fairness of the Personal Independence Payment consultation:** Sonya has been asked to respond to three questions by the legal team acting for the individual bringing the challenge. Sonya will respond on behalf of Action for M.E. but would be interested to hear responses from any others that also responded to the consultation. Sonya to circulate the questions to the charity representatives.