

M.E. at Westminster

All Party Parliamentary Group (APPG)

The APPG on M.E. was first convened in 1999. Its purpose: "To raise awareness on ME and support the improvement of health, social care, education and employment opportunities for people affected by ME". There have been several meetings since we last reported, in summer 2013's Quarterly (issue 35).

AGM 2013

The 2013 Annual General Meeting was held last June. In addition there was a forward planning discussion, including on:

"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 [Shepherd, MEA] said there is an organisation which has over-arching responsibility for medical school training. Mary-Jane [Willows, AyME] said that Tony Pinching had played a large role in such training." (excerpt from minutes)

Speaker: Minister of State at the DWP

Mike Penning MP was guest speaker at the APPG meeting held on 3rd Feb 2014. He began by explaining his role in office as Minister of State for Disabled People: "This position has been promoted from a junior position to a Minister of State position with an expanded role: it is intended to co-ordinate disability policy across government so very different from previous role and includes health and safety."

The substance of the Minister's speech was fairly brief, and included: "... they are very conscious about issues relating to who is being asked to come in for [Work Capability] reassessment. He also acknowledged the challenges with fluctuating conditions (such as M.E.) and hidden illness The Minister stated it is taking time but things are moving forward. The Minister attended a WCA tribunal where he was able to experience first-hand the difficulties that individuals subject to the process have. One positive development that has occurred in the last couple of months is that they are now getting feedback from judges."

We had been asked to submit questions in advance for the Minister, to be posed via the secretariat. We asked:

Will the Minister please ensure that the continuing manifold problems experienced by severely affected ME patients in obtaining appropriate award of ESA are finally addressed and corrected? These were summarised last year following a survey by the 25% ME Group and kindly conveyed to Lord Freud and the Minister by the Countess of Mar and Annette Brooke MP respectively (Key Issues / Problems arising from 25% ME Group Members' ESA Experience), but more recent feedback from patients indicates that sadly little has changed.

Response (as minuted): *"The Minister stated that if there are issues with diagnosis and misdiagnosis then this adds further complexity to the issue of WCA. He also highlighted that assessors are not expert not diagnose. With the new portfolio, the Minister explained that he can come out of the DWP focus and focus on outcomes. He also acknowledged that the fluctuating nature of the illness is also an issue. The Minister said he will also look into home visits/assessments and why these are not happening."*

We are not at all sure that this actually responds to the issues raised. In a similar vein, a written response to this and all other questions posed at the meeting was later provided. On the plus side, our report - *Key Issues / Problems arising from 25% ME Group Members' ESA Experience* - was taken point by point. However the content of the answers represent a first class example of ministerial speak. The summary as presented to the Minister was already several steps away from the reality of raw experience. Such is often the way with a synopsis. (The drawback of any other approach being that the document is less likely to be read at all.) So when the response skites off the surface, we have a situation very far from what one would hope for *i.e.* providing politicians and decision makers with material that puts them in touch with the problems that their policies and related practice are making for vulnerable citizens.

AGM 2014

The 2014 AGM of the APPG was held on the 1st of July. Issues discussed included:

Diagnosis: There has been little progress in securing a meeting with the Royal College of GPs (RCGP) to discuss concerns about diagnosis/misdiagnosis, amongst other things. Agreed that Sonya [Chowdhury, AfME]

will liaise with Annette [Brooke MP, chair] to send an invitation.

Access to specialists: The Countess has had a response to her letter regarding access to specialists out of area from Lord Howe which has been shared with the community.

NICE Guideline: Prof Mark Baker met with Forward M.E. last week and outlined issues with the NICE Guidelines, but also confirmed that there is no scope for the Guidelines to be removed from the static list [see P 32]. Sonya provided feedback at the meeting about the work that they are doing with a guide for patients and suggested that this could be built on. One option would be to produce a patient decision-making aid in the way the newly produced atrial fibrillation one recently launched by NICE. This could be a collaborative piece of work across Forward M.E. This suggestion was welcomed.

ICD-11 Sonya led on a joint letter also signed by Annette, Countess of Mar and Charles which was sent to key WHO and ICD-11 revision personnel on 18 March 2014, requesting specific clarifications. No response has been forthcoming from anyone at WHO or ICD-11 revision despite a follow-up letter being sent a month ago.

M.E. in Northern Ireland

Here is quick round up of some ME initiatives in Northern Ireland, since we last reported (Issue 34 Winter 2012).

'Practice & Research Priorities' Event Feb 2014

The long gallery, Stormont, was the venue for an NHS Continuing Professional Development accredited event on the theme of 'Practice & Research Priorities' on Tues 4th Feb 2014.

Prof Mark VanNess [University of the Pacific, California] spoke on *post-exertional immunological, autonomic and neuroendocrine responses; importance of early diagnosis; warning of hazards of exercise therapies (sic.)*. We cover Prof Van Ness's work in the pull out feature starting on the next page.

There were also presentations by Dr William Weir [Consultant]; Dr Vance Spence [Chair, ME Research UK]; and Horace Reid [ME Patient, Newry & Mourne Support Group].

Horace Reid made some interesting points, including:

- ME was first defined by an Ulster doctor, Sir Donald Acheson, in 1956.
REF: *The Clinical Syndrome Variously Called Benign Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia*. E D Acheson. American Journal of Medicine: 1959: 569-595
- All too often, ME patients cannot obtain basic elements of care within the NHS in Northern Ireland. In an effort to secure competent management, local support groups fly in their own specialist from England: Dr. William Weir. Once a month he takes a weekend off from his NHS commitments and comes to Belfast to see patients.
- The CFS clinic run by an Occupational Therapist at Belfast City Hospital is the only dedicated NHS ME facility in Northern Ireland. In 2010 the Belfast Trust tried to close this clinic down.
- The consultant attached to the Belfast City Hospital (BCH) clinic has now retired. He hasn't been replaced, and the clinic is now in difficulties.
- There was a chance to train a replacement consultant. In 2012 American expert (Dr Derek Enlander) offered scholarships in ME management for two medical registrars from Northern Ireland, at a teaching hospital in New York, free of cost. That would have provided exactly the kind of training that is so lacking here. That generous American offer has never received a response from the NHS.
- The Board has actually failed to maintain existing services. In 2008 there were 3 consultants in Northern Ireland with nominal expertise in ME. Six years later, now there are none.

- ME patients have put their own money into private research charities like MERUK. Money from Northern Ireland helped fund preliminary investigations by Julia Newton at Newcastle University. Our funding was instrumental in helping her obtain a recent grant from the MRC.

REF: *Understanding the pathogenesis of autonomic dysfunction in chronic fatigue syndrome and its relationship with cognitive impairment.*]

- So far as we can see, the NHS in Northern Ireland simply isn't working for ME patients. If we want competent medical care, or curative research, or effective medical education, we have to provide it ourselves. We have to bring our own medical specialist from England; we have to fund biomedical researchers in the UK; we have to fly experts across the Atlantic.

The event was hosted by Dominic Bradley MLA, and arranged by Newry & Mourne ME/fibromyalgia Support Group with funding from the Big Lottery Fund (Awards for All).

This follows a 'Voices from the Shadows' event held at Stormont in Feb 2013 where the powerful documentary film of the same name was shown. MLA Sue Ramsey, then chair of the Health Committee, and Antonette Chrisite, chair of ME Support Northern Ireland [MESNI], welcomed guests.

Reporting on the event, MESNI say: *The Long Gallery was completely silent for the one hour duration of the film. MLAs stayed for the entire viewing.*

ME Awareness Week May 2014

ME Support Northern Ireland successfully elicited the help of the Belfast City Council to have the Belfast City Hall lit up Blue in order to '*Shine a Light on ME*'.

Petition to have the 'Canadian Criteria' adopted

On the 30th of June 2014 a public petition asking the Minister of Health to fully adopt the internationally acclaimed 'Canadian Consensus Criteria' was presented to the legislative assembly by Dominic Bradley MLA. This petition was the brain child of the . Mr Bradley said that he was "*honoured to present the petition to you [the Speaker] on behalf of the [Newry and Mourne ME/Fibromyalgia Support] group.* He hoped that the response from the Health Minister would be positive.

The speaker stated that the petition would be forwarded to the Chair of the Health Committee as well as to the Minister of Health, Social Services & Public Safety.

We are planning a feature on M.E. matters in Wales for the next Issue of The Quarterly