

**Aspects of Balance – Priority Setting Partnership – Awareness Meeting
18th May 2010 at the Royal College of Surgeons**

Those Present

- * **Lester Firkins** – Chair James Lind Alliance, Strategy and Development Group
- * **Martin Burton** – British Society for Academic Otolaryngology, Consultant Otolaryngologist, John Radcliffe Hospital
- * **Linda Luxon** – Professor of Audiovestibular Medicine, UCL
- * **Steve Sharp** – Knowledge Manager NHS Evidence – ENT and Audiology
- * **Andrew Higgins** – Patient Representative
- * **Jo White** – ENT UK, Administrative Support for the group
- * **Natasha Harrington-Benton** - Director of the Ménière's Society
- * **Humphrey Bowen** – Patient, Trustee for Research Ménière's Society
- * **Rosalyn Davies** - British Society of Audiology, Registrar in Neurology at the Middlesex Hospital
- * **Katherine Harrop-Griffiths** - Consultant Royal Free Hospital

Lester explained that 30 people had been invited to the meeting, of which 20 had expressed an interest in attending. A number of these could not attend because of time conflicts. All those attending hoped that the meeting would increase an awareness of balance disorders and would have some influence on the research carried out in this area. In addition, a very strong plea was made for problems that are suffered by babies and children to be considered as different from adults. The point was made that the Ménière's Society is concerned with all balance problems that are caused by some malfunction of the inner ear and has good links with its 5000 members. This also includes links with the equivalent patient groups in the USA (VEDA) and Australia (Ménière's Australia). It was emphasised by the doctors present that the Ménière's Society would need to change its name if it wished to "capture" all dizzy/imbalanced patients and be equivalent to VEDA in the US.

Lester then explained the background to his involvement with The James Lind Alliance (JLA) and what they were trying to achieve. The JLA was set up in 2004 as a means of getting the Patient's and Clinician's voice heard in setting research priorities in the medical field. It is funded by the NHS via NIHR and the Medical Research Council and has had some success in getting its results accepted by these bodies. Lester was a banker by profession, until he lost his eldest son Ellis to vCJD in 2001. Lester was part of the parent group consulted on what research should be done. He has been surprised from later experience at how in other "conditions" little real consultation was made with patients and clinicians how the research agenda was dominated by what the academics thought were the main priorities. He then described how the JLA approaches priority-setting with reference to two recent studies into Asthma and Urinary Incontinence which have had some effect on priority-setting.

The methodology is to obtain from patients and clinicians what they perceive to be problems or "uncertainties" in their treatment, in their own words. Then speciality experts review this list and see whether there are duplications, i.e. the same problem expressed in different ways. This usually results in a reduction by about 30%

. A group of patients and clinicians, led by the steering committee, will then examine each of these uncertainties and attempt to rank them through several iterations. Having tackled a number of diseases, the JLA thought it would be very interesting to see whether the methodology they had developed would be beneficial in a general medical area. and this co-incided with an approach to them by Martin Burton

Martin Burton then described how from ENT they came to select balance. Basically ENT covers such a wide area and range of specialities, that it was difficult to know how to tackle it. A number of sub sets were considered- ear related problems only, balance problems, and audiological problems. A discussion with a small patient group in Newcastle on Labyrinthitis convinced them that there was a nucleus of patients who were at ease in discussing their problems and that it was worth starting with balance.

Linda Luxon then spoke, emphasising that the needs of children are very different from those of adults, that loss of balance can be very costly to the NHS because it can lead to loss of time from work and falls and that the understanding of balance problems by GPs is patchy. There is a lack of training in Vestibular Medicine. The length of time to get a diagnosis in older people is unacceptable (a paper from East reported one of the commonest treatable vestibular disorders took 92 months from presentation to diagnosis, admittedly before the 18 week target for diagnosis to treatment came into force.)

Andrew Higgins then recounted some of his experiences. He was surprised that in his case review, three GPs and two Consultants were seen before a diagnosis was made, but the condition of MAV was only diagnosed when he personally identified Professor Luxon (through www.labyrinthitis.org) and referred himself. Many patients would not be able to do this. He was most concerned about misdiagnosis of balance problems. In his view, there was a serious primary care gap in knowledge relating to balance disorders.

He referred to the RCP report, published in 2008, on Hearing and Balance Disorders, which stressed that balance is a severely neglected area of medicine in the UK, and a huge problem in geriatric medicine. He cited one example in the Report which said that over one third of people over 65 fall each year, and many of these present with dizziness.

Steve Sharp introduced the DUETs database and explained how it can be used to help assess the relevance of research to the patient. DUETs is a database which records the uncertainties that cannot currently be answered by referring to reliable up-to-date systematic reviews of existing research evidence. Sources of uncertainties include clinicians, patients/carers, research recommendations and ongoing research. Steve showed how DUETs was launched in response to disparities between the research priorities of patients and those of the research community (see attached slides). He showed that the vast majority of research was on drugs, yet what patients wanted was different.

In a study of osteoarthritis, the patient's top two requirements were more effective knee replacements and better education and advice. The study showed that out of 460 trials, 380 were on drugs (admittedly these might have been linked with better knee replacements), and only 14 on better education. In rheumatoid arthritis, most trials based their success criteria on pain reduction, whilst patients wanted to reduce their fatigue caused by the condition.

The meeting then turned to how patients' views on balance research might be collected. The small (about 20) very active Labyrinthitis.org Group was one starting point. Another was the Ménière's Society with about 5000 members with a good track record of getting replies from members. It was suggested that the Migraine sufferers should be contacted as many of them also suffer from balance problems. Concern was expressed that this would not give a good representation of all balance sufferers. It was suggested that contacting leading professionals explaining what is required might be a way of widening the audience. The Ménière's Society has a list of those who have proved helpful in the past. It was agreed that the group should try to get a list of topics for research within six months and, if it proves practical within three.

It was agreed that Jo would circulate with the minutes a list of those organisations and people who have already been contacted about this initiative by the JLA and also the form that has in the past been used to collect patients' views on what research would be beneficial. In return, all participants at the meeting would let her know of other organisations and people who could usefully be contacted.

Humphrey Bowen