



Associate Parliamentary Limb Loss Group

for the promotion within Parliament and Whitehall of the PREVENTION OF LIMB LOSS and the provision of prosthetic, orthotic, wheelchairs & special seating and other vital rehabilitation services/technologies for ALL PERSONS WITH LIMB LOSS in the UK and Internationally.

Minutes of the Meeting held at 2:15pm on Wednesday 3rd March 2010 in Committee Room 13 at the House of Commons, London, SW1A 0AA

PRESENT:

MEMBERS & OFFICERS: Justine Greening MP (Chair); Dr. Doug Naysmith MP; Angela Watkinson MP.

ASSOCIATES: Stephen Blatchford; Nichola Carrington; Jerome Church; Tony Combes; Colin Dance; Tim Deeming; Amy Edwards; Simon Fielden; Philip Garvin; Christopher Harwood; Glyn Heath; Wayne Henderson; Dr Fergus Jepson; Professor Jai Kulkarni; Louise Medus-Mansell; Joyce Naylor; Michael O'Byrne; Sharon Osbourne; Gary Phillips; Terry Pond; Dr V Qurashi; John Reid; Scott Richardson; Jennifer Rogers; Ernie Stables; Stephanie Stuart; Simon Webster; Barbara Whibley; Phil Yates.

Advisor – Sam Gallop CBE

Administrator – Alex Hyde-Smith

Apologies for absence were received and recorded.

1. MINUTES OF PREVIOUS MEETING HELD ON 28th October 2009

APPROVED the [Minutes](#) of the previous Meeting held on 28th October 2009

2. NEW ASSOCIATE MEMBERS

Sharon Osborne on behalf of the Amputee Nurses Network and Louise Medus-Mansell on behalf of the Thalidomide Society were welcomed as new Associate Members.

3. CHILDREN AND FAMILIES

a) Conference for Children with LimbLoss

The report to the Group from the Conference for Children with LimbLoss, opened by Dr. Neil Brown with a message of goodwill from Angela Watkinson MP, highlighted the needs to ensure – not only that every Child with LimbLoss mattered – but also to

- raise awareness of service needs
- maximise outcomes for commissioning and resource allocation
- address gaps in services and stop post-code prescribing
- identify best practices and spread them around
- design and deliver a National Service Specification

The Group noted with particular concern the cuts in the budgets for Cosmesis, especially as research confirmed, particularly for girls, the importance of appearance to self-esteem and social inclusion.

Feedback from the Conference indicated that it would be hugely beneficial to bring together children's limb loss services nationally, in terms of looking at best practice and addressing gaps in service delivery. If expertise can be gathered for example, from clinicians, charities and user groups to write national paediatric service standards of practice or guidelines, this could provide a benchmark aspired to by all services.

b) Meningitis

The Meningitis Trust reported that although there were several vaccines available these did not protect against all strains of the disease. With cases of Meningitis still occurring every day, Meningitis was seen as a prime mover of the continuing increase in the numbers of quadruple amputees. The total estimate was that there were 6,000 new cases per annum. 10% died and 15% lost limbs. As many as 500,000 people living in the UK today have had either viral or bacterial meningitis. Up to 10 million adults in the UK – one adult in every four – knew of someone who has had the disease. The demand for the Trust's support services was growing. They regularly received feedback from people they helped, about the lack of other specialist resources available to them, such as specialist prosthetics. This was a need that must be addressed to create a better quality of life for the people who continue to be affected by meningitis in the UK every day.

c) Douglas Bader Foundation

The Douglas Bader Foundation reported that 2010 was a significant year for the DBF - the 100th anniversary of Douglas Bader's birth and the 70th Anniversary of the Battle of Britain. To mark this the DBF had launched 'Bader Braves' with: 5 Flying days; two short break outdoor multi-activity long "Challenge" weekends at the Calvert Trust venues. and programmes of sailing, canoeing, archery, climbing, abseiling, orienteering - all specifically designed to enable full participation by children with physical disabilities. Fundraising activities included a three day Hike along Hadrian's Wall in summer 2010 (all participants are welcome!).

4. LIMBLESS SERVICE PERSONNEL AND VETERANS

a) Minister's Statement on Medical care for Veterans

On 11 January the Minister of State, Department of Health (Mike O'Brien) stated that *"The Government is committed to ensuring that those who are seriously injured or who develop mental health problems whilst in the service of their country will receive the best possible care from the National Health Service for the rest of their lives... I have worked closely with my hon Friend the Minister for Veterans (Kevan Jones) to put in place new arrangements with the Ministry of Defence for life care planning, together with a guarantee that all those seriously injured will receive an early and comprehensive assessment of their long term needs."*

"The Department has previously undertaken to ensure that recent Service leavers who have lost a limb while serving will – where clinically appropriate - be entitled to receive from the NHS an equivalent standard of prosthetic limb to those provided by Defence Medical Services. Today I can announce that this undertaking will be extended to all veterans who have lost a limb whilst serving, where clinically appropriate. The Department will also ensure that a responsible Director within strategic health authorities, together with primary care trust champions for the armed forces are identified to advocate for them and to ensure that their needs are fully reflected in commissioning plans and service provision."

b) Advice from BLESMA

Welcoming the Minister's statement, BLESMA pointed out that the whole business regarding the treatment of amputees from Iraq and Afghanistan had boosted the profile of prosthetics into the public domain. The MoD funded prosthetic service at Headley Court had shown "The art of the possible", and BLESMA believed that all organisations involved in this area should work closely together to seize the moment. Above all BLESMA wanted to see transparent funding, meaningful

and mandatory national standards and a service fully accountable to the user. BLESMA had visited in excess of 130 personnel, the majority of whom were amputees, the others “loss of use” of limbs or loss of eye (eyes) or sight. To date there were 6 Triple Amputees and 20 Double Leg Amputees, the youngest of whom was 19. These figures would undoubtedly increase.

c) Impact on NHS Rehabilitation Services

Bearing in mind the Minister’s new undertaking that the high standard of prosthetic limbs issued by the Defence Medical Services (Headley Court) should be extended from Iraq and Afghanistan amputees to cover all Veterans who have lost a limb whilst serving where clinically appropriate, and the undoubted continuing increase in the number and the severity of Veteran amputees who might also have other wounds, the Group expressed their concern that no indication was given by the Minister of the provision or source of the additional NHS funding required. Veterans now reasonably had high expectations; if the guarantees to them were not fulfilled their morale and faith in Government would be adversely affected. Without additional NHS funding existing NHS amputee standards must be compromised. There should be consultation with other relevant Parliamentary Groups.

It was agreed that an appropriate parliamentary question be put to the Minister.

d) Rehabilitation Activities

BLESMA continued to run an extensive range of challenging adventurous events for their Members, designed to give them back their confidence and self esteem. Events in the UK and abroad included sailing, skiing, ski bobbing, parachuting, sub-aqua, and golf. An all amputee crew was sailing in the Royal Ocean Racing Club 600 race. Rehabilitation Activities were seen as absolutely key in the overall rehabilitation of injured personnel – when newly amputated, and through life.

5. PROSTHETIC AND ORTHOTIC SERVICES

Representations continued to reflect concerns that:

- contracts continued to be written in product provision language thus excluding education and training and R & D
- work by the former NPSA on co-ordination of service contracts had been discontinued by the NHS Supply Chain, fostering extremely differing levels of service provision across the UK, and inhibiting national standards/appraisals;
- the Prosthetic/Orthotic professions including Technicians and Assistants were still largely invisible to the NHS; terms and conditions of contractors’ staff might not be equivalent to NHS directly employed staff;
- low numbers being recruited/retained meant that it was and would be increasingly difficult to provide the range and the quality of services required.

During discussion the following were among the points made:

- National Amputee Data Base statistics were required (to be reinstated) and the Minister should be requested by Parliamentary Questions to secure these, and support for renewal of work on the co-ordination of service contracts and national standards;
- Collaboration among Centre Managers and Contractors could produce requisite national summary limb loss levels and expenditures totals
- Services should be priced on the basis of a national patient-centric tariff that recognised the main cost drivers, amputation level and activity and needs of the patient, transferable between service centres and with maximum patient choice
- The specialised services involved should receive the benefits in additional funding of the savings they made in other NHS and Community budgets – silo budgeting should cease

- Improvements in User Quality of Life should be measured and publicised
- The history of unfulfilled purchasing guarantees of additional hypothecated funding for Cosmesis was not encouraging
- Further information should be sought from the Service Personnel and Veterans Agency about Welfare of Veterans
- Value for money and for the patient from collaborative pilots joining PCTs and Local Authorities was encouraging and might hopefully be extended to other locations
- Liaison with Commissioners needed to be established/strengthened
- Decisions on what was “clinically appropriate” required medical input with prescriptions unbiased by financial considerations although the latter might thereafter have to come into play overtly
- Despite severe cuts in budgets, offering NHS limb wearers the purchasing by top-up payments of higher than NHS standard limbs and services was illegal and not acceptable to User representatives;

6. WHEELCHAIR SERVICES USERS CHARTERS

The launch of the Wheelchair Services Users Charter, under the aegis of the Parliamentary Groups for Spinal Cord Injury, Muscular Dystrophy and Limb Loss, was noted with appreciation. It coincided with the initiation of a review by the Minister for Care Services Phil Hope, through a National Wheelchair Services Advisory Group, of the impacts (both positive and negative) for users of a proposed new model for transforming wheelchair services, suggesting alternative or mitigating courses of action where appropriate.

7. KEEPING AND STAYING OUT OF HOSPITAL

Consultation was being developed to ensure that Specialised Commissioners were fully aware of the benefits of specialised services for prosthetics, orthotics, wheelchairs/special seating, telecare etc., in enabling people of all ages with complex physical disabilities, to become and remain independent and out of hospital.

8. INTERNATIONAL CONCERNS

Following up the circulation of the Early Day Motion in the names of Dr Doug Naysmith MP, Justine Greening MP and Mark Hunter MP, the Group noted with concern the requirement for still more aid to meet the needs of the increasing number of amputees internationally because of earthquakes, other environmental disasters, and conflicts and their aftermaths. Prosthetic, Orthotic and Wheelchair Services must be mainstreamed and adequate thus enabling people with disabilities to be included in pushing Growth up the Development Agenda. The Group had usefully been reminded of the WHO ‘Guidelines on the Provision of Manual Wheelchairs in less resourced settings’, bringing together the disparate field of wheelchair provision in developing countries. <http://www.who.int/disabilities/publications/technology/wheelchairguidelines/en/index.html>

9. PHYSIOTHERAPY

The report from the British Association of Chartered Physiotherapists in Amputee Rehabilitation ([Appendix A](#) to these Minutes) recognised inter alia that with the introduction of Commissioning, the use of quality metrics and standardised data sets, there was a need to gain consensus for standardised therapy outcome measures. An outcome measures toolkit was available.

10. OCCUPATIONAL THERAPY

The report from the College of Occupational Therapists ([Appendix B](#) to these Minutes) concentrated on wheelchair provision for people with limb loss, believing that all limbless children and adults in the United Kingdom who required wheelchairs had the right to be provided with chairs which met their individual needs. There were concerns about the lack of consultation preceding the

development and the announcement of the proposed new model from the Department for the re-design of NHS wheelchair services.

11. REHABILITATION ENGINEERING

Dame Joan Bakewell, Government's official Voice of Older People, had been guest of honour at the opening of Coventry University's new Health, Design & Technology Institute. The focus would be on developing assistive technologies for the individual.

Recruitment was ongoing for the new B.Sc. in Rehabilitation Engineering.

12. LEGAL CONFERENCE

A joint conference with lawyers with the theme COLLABORATION NOT CONFRONTATION was to be held later in the year, to help demonstrate that timely and comprehensive Rehabilitation benefits both the patient and the NHS.

13. INVOLVEMENT OF DIETICIANS IN REHABILITATION

On behalf of Users it was urged and it was agreed that ways and means should be explored of enabling Dieticians as Allied Health Professionals to play a prominent role in the rehabilitation pathway in both hospital and community service settings. Limbless patients' weight change and obesity risks through lack of awareness of good nutrition and exercise lead to high cost socket materials and remakes.

14. OTHER BUSINESS

This was the final meeting of the Group before the General Election and Associate Members expressed with applause their thanks for the sustained and caring support given by Peers and MPs, despite the many demands on their time, throughout the life of the present Group. It was hoped that a LimbLoss Group would be established in the new Parliament.

There being no further business the meeting then terminated.

**Feedback to
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