



Associate Parliamentary Limb Loss Group

for the Promotion of the Prevention of Limb Loss and of the Provision of Prosthetic, Orthotic, Wheelchair/Special Seating, Medical and other vital Rehabilitation Services to persons of all ages suffering Limb Loss and associated Complex Physical Disabilities in the United Kingdom and Internationally

Minutes of the Annual General Meeting held at 5pm on Wednesday
7th July 2010 in Committee Room 6 at the House of Commons

PRESENT

MEMBERS: Dan Byles MP (Chair); Steve McCabe MP; Alison Seabeck MP; Lord McColl.

ASSOCIATE MEMBERS: Alan Tanner; Amy Edwards; David White; Denis May; Dominic Hannett; Graham Facey; Jenny Holt; Jerome Church; John Reid; John Ward; Jose Spring; June Facey; Louise Connolly; Louise Medus-Mansell; Louise Tisdale; Marie Gornal; Mark Davies; Penelope Morrison; Rory O'Connor; Sam Gallop; Simon Webster; Sue Charlesworth; Sue Walker; Tim Deeming.

Consultant Steve McNeice

Administrator David White

Apologies for absence were received.

1. ELECTION OF OFFICERS

AGREED the election of the following Officers:

Co-chairs: Dan Byles MP; Steve McCabe MP; Lord McColl; Alison Seabeck MP and Baroness Tonge;

Secretary: Anne Begg MP.

2. TERMS OF REFERENCE

AGREED the following Terms of Reference for the Group: *the Promotion of the Prevention of Limb Loss and of the Provision of Prosthetic, Orthotic, Wheelchair/Special Seating, Medical and other vital Rehabilitation Services to persons of all ages suffering Limb Loss and associated Complex Physical Disabilities in the United Kingdom and Internationally*

3. REGISTRY OF ENTRY

AGREED that the Registry of Entry for Cross-Party Groups be signed by the Secretary and be returned forthwith to the Assistant Registrar at the Office of the Parliamentary Commissioner for Standards, and that a copy be filed with the archive copy of these Minutes.

4. PARLIAMENTARY MEMBERS

NOTED that caring interest in both Houses was increasing and that Parliamentary Members to date included:

Lord McColl; Baroness Wilkins; Baroness Tonge; Lord Ahmed; Lord Tebbit; Alasdair McDonnell MP; Alison Seabeck MP; Anne Begg MP; Brian Binley MP; Charlotte Leslie MP; Dan Byles MP; Dan Rogerson MP; Desmond Swayne MP; Diana Johnson MP; Fabian Hamilton MP; Greg Hands MP; Ian Lucas MP; John Leech MP; Kate Hoey MP; Nick Brown MP; Nigel Evans MP; Richard Bacon MP; Sadiq Khan MP; Sian C James MP; Tim Yeo MP; Joan Walley MP; Mike Weatherley MP.

5. ASSOCIATE MEMBERS

AGREED the re-appointment of Associate Member organisations as listed in the Annual Report for 2009-10.

6. ANNUAL REPORT 2009-10

AGREED the Annual Report for 2009-10.

7. SERVICE PERSONNEL AND VETERANS

As demonstrated in the Annual Report, the Group welcomed the priority commitments from Government to seriously injured Service Personnel and Veterans including those with Limb and other losses. On behalf of BLESMA it was stated that, whilst impressed with the services provided for Service Personnel at Selly Oak (and the new Queen Elizabeth Hospital which replaces it), DMRC Headley Court and elsewhere, they were concerned that on discharge Veteran casualties would be susceptible to the vagaries of the post-code lotteries that pervade NHS provisions throughout the UK. Assurances had been given at Ministerial level in the MOD and the Department of Health that Veterans will continue to receive the high quality of support from their NHS that they received at Headley Court. BLESMA have yet to see this as a reality and have not seen any necessary additional NHS funding or indications of how such funding will be achieved. BLESMA notes that very few post 9/11 veterans (i.e. those who have benefitted from Headley Court prosthetic provision) have actually been discharged from the Service thus far - and that this will become a significant and high profile issue over the next 12 months as many more begin to leave the Service – if provision is found wanting.

It was confirmed that if additional funding for Veterans was not forthcoming to the National Health Services throughout the UK, then NHS patients also must suffer a further decline in services.

It was common cause at the meeting that everyone would like to see all limbless persons receive from their National Health Services throughout the UK the high standards of equipment and services available at Headley Court.

The proposal from Parliamentary Members that they should seek a corporate meeting with all Ministers concerned was welcomed. Further PQs could also be relevant. The MOD, the SPVA, the Department of Health, and NHS Trusts and Authorities were all involved and there was further scope for cost-effective and patient-effective combined operations. (The link is Steve McNeice on feedback@apllg.eu).

8. CUTS IN SERVICES

Concerning advice that there were already significant cuts in NHS services beyond efficiency savings, Associate Members welcomed undertakings by individual MPs that, given proper briefing, they would initiate representations to the Trusts responsible for Rehabilitation Centres in their constituencies. Liaison is proposed to be expedited by building on good work already ongoing to link individual MPs with the Chairs of the User Groups in their constituencies, (The networking link will be Dave White on davewhite.limblessassociation@yahoo.co.uk in collaboration with national User and Support Group Chairs.)

It was accepted that representations should also incorporate previously expressed, and sustained, concerns about the loss of services of REHABILITATION CONSULTANTS, adversely affecting the quality of care, and unduly extending the roles of already hard-pressed allied health professionals. Patients were in no doubt about the benefits of being seen by a Rehabilitation Consultant.

The amputee service at COLCHESTER, as a further and significant for instance, had been reduced from five days to two days per week without effective consultation, and following unilateral organisational changes which had not been beneficial

LOCAL AUTHORITY FUNDING for home aids, adaptations and social care was advised now to be insufficient and to be reducing. Such services had a major impact on:-

- Hospital admissions and re-admissions - health costs would increase if local authority funding was inadequate;
- Ability to provide solutions to long term problems (for example, access, independence and dignity);
- Quality of life for people with CPD, including limb loss.

9. KEEPING PEOPLE OUT OF HOSPITAL

The continuing cuts in services would it was advised have a knock-on impact on re-admissions to Hospital. Consultation was in process with Specialised Commissioners and Associate Members to implement the agreement to ensure that all concerned (or who should be concerned) were fully aware of the benefits of specialised services for prosthetics, orthotics, wheelchairs/special seating, environmental controls, telecare etc, in enabling people of all ages with complex physical disabilities to become and to remain independent and to keep out of Hospital. National and local Conferences are envisaged. The leads for local events will be User Group and Support Group Chairs. (see **Appendix A**).

10. CONTINUED PROFESSIONAL DEVELOPMENT

Following on a most effective and inspirational collaborative initiative from the Royal Hospital for Neuro Disability, and discussions with Providers of Services, a proposal (see **Appendix B**) was being put forward by the London South Bank University for a Foundation Degree in Clinical Technology. This proposal followed sustained and lengthy endeavours – so far unsuccessful – to ensure adequate opportunities for continued professional development for Prosthetists/Orthotists and related Clinical Technicians, seen as good both in themselves and as helping to remedy the difficulties in recruiting/retaining such vital staff. (For further information about the Foundation Degree proposal contact Geoff Goss on goss@lsbu.ac.uk).

11. MENINGITIS

NOTED with appreciation the paper circulated from the Meningitis Trust. Meningitis continues to be a prime mover of the continuing increase in the numbers of quadruple and other amputees. The several vaccines available do not protect against all strains of the disease. Feedback indicates a lack of specialist prosthetics and services which must be addressed to help secure a better quality of life. Interestingly in Texas, illustrative of the continuing risks, the Jamie Schonbaum Act has made vaccination mandatory for college students who live in student housing. (For further information contact Harriet Penning on HarrietP@meningitis-trust.org or telephone 01453 769018.)

12. NATIONAL SERVICE SPECIFICATION

NOTED with appreciation the National Service Specification for Prosthetic and Amputee Rehabilitation Services published by the National Prosthetic Centre Managers Group under the aegis of the Group with a Foreword by Lord McColl. (see **Appendix C**). (The contact is Susan Charlesworth on Susan.Charlesworth@lthr.nhs.uk)

13. EUROPEAN LIMB LOSS DAY

NOTED that consultation with MEPs to initiate a European Limb Loss Day was proceeding.

14. DYSMELIA UK PROJECT

NOTED with appreciation that the Thalidomide Society was hoping to set up a UK wide Forum for small organisations or groups whose members have disabilities, conditions or syndromes which are similar to those impairments caused by thalidomide and which will come under the broad definition of Dysmelia, the reduction or malformation of upper or lower limbs. The Society hoped collaboratively to hold a national conference in 2011. (The contact is info@thalsoc.demon.co.uk telephone 01462 438212).

15. WHEELCHAIR SERVICES

NOTED with appreciation the publication of the updated document “HEALTHCARE STANDARDS FOR NHS-COMMISSIONED WHEELCHAIR SERVICES”, collaboratively by the National Wheelchair Managers Forum, British Society of Rehabilitation Medicine, *emPOWER*, Posture and Mobility Group, Spinal Injuries Association, and Whizz Kidz. People referred to the wheelchair service are entitled to first class wheelchair services, and to lead – as far as their condition will allow – healthy, active, independent lives. These national minimum standards, supported by the people who use and provide wheelchairs, underpin the collective determination to ensure a first class service. They will be kept under regular review in order to improve performance, quality and safety of care. Regardless of the organisational form and structure of the Provider, it must not be a barrier to the quality of service provision. It is expected that, as a minimum, all Providers of NHS wheelchair services will adopt and adhere to these National Service Standards. (the contact is Louise Connolly on Louise.Connolly@herts-pcts.nhs.uk)

16. ALLOWANCES

Users confirmed widespread concern about possible changes in or the removal of Allowances such as Disability Living Allowance and Attendance Allowance. No firm information was available at present, and as soon as it was, concerns would be reported to Members. (The contact is Wayne Henderson on hendersonandgibson@yahoo.co.uk).

17. WORKING PARTY

Further consideration would be given to the need suggested at the meeting for a Working Party to progress business between meetings of the Group. (For further consideration the contact is John Ward on johnward@valkary.fsnet.co.uk).

18. DATE OF NEXT MEETING

AGREED that fixing the date of the next meeting be deferred until later in the year, bearing in mind the need to be advised of and to appraise expected significant Government proposals for changes in NHS services, including proposed increased powers for General Practitioners.

There being no further business the meeting then terminated.

Feedback on Minutes to Steve McNeice feedback@apllg.eu

APPENDIX A

KEEPING PEOPLE OF ALL AGES WITH CPD OUT OF HOSPITAL

Relevant comparative costs have been stated to be:

- Emergency Home Care £40 per day
- Nursing Home Placement £100 per day
- Hospital Inpatient £650 per day

Areas to be explored at national and at local conferences could include:

- Causes of and Prevention of Limb Loss and Re-Amputation
- Understanding the current services; what works well and the challenges they face
- Links and information sharing between referring clinicians / hospitals and the service providers
- Opportunities for sharing best / innovative practice
- Provision of information to service users / carers
- Listening to service users and considering the patient experience in the provision of their services
- Identifying quality indicators / outcomes of importance to service users and clinicians
- Identifying opportunities for strengthening relationships between Commissioners and Providers
- Interfaces between Rehabilitation and the Medico-Legal Process
- Requirements within the whole for Children
- Requirements within the whole for Older People
- Prevention of Falls and Pressure Sores
- Implementation of Specialist Definition Set No. 5 for People with Complex Physical Disabilities
- Increased powers to General Practitioners.

Note: Dave White at the Limbless Association will be networking with other concerned Organisations and Charities and with User Group and Support Group Chairs. For further information davewhite.limblessassociation@yahoo.co.uk.

APPENDIX B

FOUNDATION DEGREE IN CLINICAL TECHNOLOGY

This Appendix presents a draft outline of the aims of a proposed, yet to be approved, new Foundation Degree Course in the Faculty of Engineering, Science and the Built Environment at London South Bank University.

The Course would be designed to train Technicians working in prosthetics, orthotics and special seating (e.g. wheel chairs), environmental controls, telecare and other assistive technologies..

The aims of the course would be as follows:

- Prepare students for careers in the design and fabrication of orthotics, prosthetics and special seating (bespoke wheelchairs), telecare and other assistive technologies.
- Equip students with an understanding of existing technologies and the need for technological innovation.
- Provide knowledge and understanding of the relationships between orthotics, prosthetics, special seating and engineering design and manufacture.
- Provide an appreciation of how human anatomy, physiology and pathology, relate to biomechanics and how these impact on rehabilitation.

- Apply quantitative science to engineering problems in a medical rehabilitation context
- Support holistic person-centred long term rehabilitation and collaborative working in health and social care.
- Develop communication skills appropriate for working with clients with complex needs and their care givers.

Note: for further information contact Geoff Goss on goss@lsbu.ac.uk

APPENDIX C

NATIONAL SERVICE SPECIFICATION

Purposively the National Service Specification for Prosthetic and Amputee Rehabilitation Services published by the National Prosthetic Centre Managers Group states that Amputees and limb deficient patients are 'patients for life' - therefore it is extremely important that they receive continuity of care from their local Prosthetic Centre.

The service is provided for children and adults of all ages in the following groups:

- Patients who have undergone amputation of a limb or multiple limbs, at any level, due to disease or trauma or malformation
- Patients who are about to have or who are considering the option of elective amputation of a limb (pre-operatively)
- Patients and the parents of children with congenital limb absence or deficiency

The service will provide a comprehensive Consultant in Rehabilitation Medicine led multidisciplinary approach which will, within resources:

- Enable patients who have undergone amputation to achieve their maximum potential in terms of:
 - mobility
 - independence in their required activities of daily living
 - participation in work, education, social, leisure and personal life activities
 - achievement of individual rehabilitation goals
- Provide life long care and continuity of the ongoing provision and proactive, preventative maintenance of prosthetic limbs
- Provide advice and support for amputees and people with congenital limb loss, including those who are not able, or choose not, to wear a prosthesis
- Be cost effective and measurable with specific emphasis on quality of life measures

Note: the Full Specification is available from Susan Charlesworth on Susan.Charlesworth@lthr.nhs.uk