



# Associate Parliamentary Limb Loss Group

*for the promotion within Parliament and Whitehall  
of the Prevention of limb loss and the Provision of prosthetic and other  
rehabilitation services to all persons suffering limb loss in the UK and Internationally*

## Minutes of the Annual General Meeting held at 4 p.m. on Thursday 8<sup>th</sup> March 2007 in Committee Room 18 at the House of Commons London SW1A 0AA

### PRESENT

MEMBERS: Lord McColl (in the Chair); Mark Hunter MP; Doug Naysmith MP; David Marshall MP; Baroness Lockwood; Baroness Darcy De Knayth.

ASSOCIATES: Stephen Blatchford; Nichola Carrington; Jerome Church; Ray Edwards; Sam Gallop; Grania Hyde-Smith; Paul Hutt; Zafar Khan; Steve McNeice; Alison Orr; Samantha Rennie; Olivia Warham; Simon Webster.

### 1. APPOINTMENT OF OFFICERS

NOTED with appreciation the acceptance of appointment as Officers for the coming year as follows:

Co-Chairs: Lord McColl; Danny Alexander MP; Paul Clark MP; Mark Hunter MP;  
Secretary: Justine Greening MP

### 2. REGISTER ENTRY OF GROUP

NOTED that the updated Register Entry of the Group would be submitted by the Secretary to the Office of the Parliamentary Commissioner for Standards.

### 3. ANNUAL REPORT 2006/07

AGREED the Annual Report for the year ending 5<sup>th</sup> February 2007.

### 4. PROGRESS REPORT

The following progress report was NOTED:

The APLLG Portcullis Conference on 6 December was attended by more than 100 delegates, widely publicised and considerably raised the Group profile. Individual MPs had made welcome visits to Rehabilitation Centres and to Contractors in their constituencies.

The APLLG WEBSITE is now reaching out internationally as well as nationally.

Close relationships are being maintained with the excellent DEFENCE MEDICAL REHABILITATION CENTRE at HEADLEY COURT for the rehabilitation of Service Personnel and Veterans who have lost limbs.

The new NHS Supply Chain is being urged to support the formation of a REHABILITATION FORUM “to support the clinical and cost-effective commissioning of Rehabilitation Services”.

The 400 MILLION R CAMPAIGN continues to seek to improve access to Rights, Respect, Rehabilitation, Re-integration and Resources for the estimated 400 million disabled people in developing countries.

EUROPE LIMB LOSS DAY possibilities are being explored through Richard Howitt MEP, Chair of the European Disability Intergroup.

The CENTRE FOR EVIDENCE BASED PURCHASING has agreed to undertake a collaborative review of the design and fitting of ARTIFICIAL LIMB SOCKETS to maximise comfort and to minimise pain. A proposal is also being submitted to the CEBP for research into BATTERIES for electrically powered indoor/outdoor wheelchairs. Users suggest purchasing cheapest first cost batteries results in additional long-term costs, heavier weight and lack of innovation. 50% of all limbless persons have or need wheelchairs.

EARLY DAY MOTION 25 (follows) is being further progressed by a request for a meeting of Officers with the Minister concerned on behalf jointly of the APLLG and the All-Party Disablement Group.

#### EARLY DAY MOTION 25

*Tabled by Dr Roger Berry (Labour MP for Kingswood)*

*Seconded by Justine Greening (Conservative MP for Putney)*

*Seconded by Susan Kramer (Liberal Democrat MP for Richmond Park)*

*This House notes the concerns of the Associate Parliamentary Limb Loss Group and of the All-Party Parliamentary Disability Group about the unmet mobility needs of people of all ages; is concerned that this leads to significant loss of independence and increased costs of care; recognises the model examples provided by charities such as MOTABILITY and WHIZZ-KIDZ; and therefore urges the Government, in collaboration with the emPOWER Charities consortium, to encourage and support greater provision of powered wheelchair services, in collaboration with, and additional to, services at present provided by the NHS.*

## 5. FEEDBACK UNITED KINGDOM

Feedback from Members and Associates, appreciative of the caring endeavours of hard-pressed allied health professionals and other carers within limited resources, and with constructive Parliamentary Questions in mind, included the following concerns.

COMFORT OF ARTIFICIAL LIMB SOCKETS is the overriding priority for wearers of artificial limbs. The POST-CODE LOTTERY fosters discomfort. Services/products vary according to where you live and not to your need. Patient choice must be made a reality, instead of a Ministerial wish.

There could be a timely review of the possibility of Ex-Service limbless personnel being able to choose if they wished after their discharge to continue to go to the excellent facilities at HEADLEY COURT. Regard should also be had to the lifelong additional neurological and other injuries being sustained in addition to limb loss, and to combat stress. Since the beginning of

operations in Iraq and Afghanistan about 27 servicemen have lost limbs, and only 5 have left the services. The long-term future of Headley Court, as a Centre of Excellence, must be secured.

Concerns of the British Healthcare Trades Association (BHTA), who would submit a comprehensive Paper, include:

- The emphasis in purchasing prosthetic/orthotic services on reducing costs without considering the adverse effect on services and careers.
- The forecast decline in the total number of UK prosthetists and orthotists from the current level of around 700 to 350, and immediately the loss of specialist upper limb prosthetists.
- The need for a Third School in the South.
- Lack of funding for education and training during the early years of employment.
- Reduction of funding for Cosmesis, in which resources had been invested, contrary to Department of Health and Purchasing and Supply undertakings.
- The need for Foundation Degrees for Technicians, with opportunities for their seamless progression to Bachelor of Science degrees in Prosthetics/Orthotics, thereby enhancing workshop experience and empathy and career development.

Additional publicity, including the Internet, is merited for the valuable GUIDANCE ON REHABILITATION after Amputation available from specialist groups in the British Association of Chartered Physiotherapists and the College of Occupational Therapists, and from User Associations.

To meet length-of-stay targets and initiatives, amputee patients are being discharged earlier in their rehabilitation, sometimes to INTERMEDIATE CARE. Do the therapists in these settings have the required numbers, specialist knowledge, equipment or support? The ideal would be more amputee- specific rehab beds/centres in the community in the period between discharge from hospital and discharge home.

There is a scandalous SHORTAGE OF JOBS for Physiotherapists and for Occupational Therapists despite their being trained in increasing numbers to meet the urgent need for them.

There is a need to develop further training in the assessment of the "AT RISK" FOOT and for consistently high quality in the PROVISION OF SPECIAL FOOTWEAR.

The REFERRAL SYSTEM FOR BABIES born with limb loss is hit-or-miss, resulting in under-estimation of the potential demand for services

## 6. FEEDBACK INTERNATIONAL

Against the background of the requirement for an Action Model that would recognise the need to MAKE RIGHTS REAL AFTER LIMB LOSS - to "mainstream" rehabilitation within the flow of funding from Government - the following were among the needs expressed.

The need for more and adequate LONG TERM GOVERNMENT support and funding. Landmines, cluster bombs or other ordinance or medical conditions all disable amputees for life.

The need for longer EMERGENCY support and funding - the needs of people disabled by earthquakes or other disasters are not fully met within six months (when DfID's post-emergency money often ceases).

The need for more TRAINING OPPORTUNITIES, ESPECIALLY FOR WOMEN, to become prosthetic and orthopaedic graduates and technicians, physiotherapists etc in developing countries, to support

work following emergencies and in the long term. CULTURAL BARRIERS inhibit women from coming forward for training, to be fitted for limbs or to receive treatment from male staff.

The need for Government funding for Research into the:

- ECONOMIC IMPACT of disability in developing countries
- FULL-SCALE SURVEYS of the numbers and classifications (upper, lower, through hip, multiple etc) involved
- COST-EFFECTIVENESS of Rehabilitation.

A NETWORK OF INTERNATIONAL USER GROUPS is being developed to help secure first-hand information and collaboration.

The SOUTH AFRICA FEDERATION OF THE DISABLED has asked to meet the Group during their visit to the UK from 14-21 April, and Lord McColl is advising Hilary Benn accordingly.

APLLG should be significantly involved in the implementation of the forthcoming UNITED NATIONS CONVENTION for the Rights of People with Disabilities.

## **7. OTHER BUSINESS**

There being no other business the meeting then terminated.

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