



# Associate Parliamentary Limb Loss Group

for the promotion within Parliament and Whitehall of the provision of prosthetic and other rehabilitation services to all persons suffering limb loss in the UK and internationally.

## Minutes of the Meeting held at 4 p.m. on Wednesday 19<sup>th</sup> July 2006 in Committee Room 8 at the House of Commons London SW1A 0AA

### PRESENT

**MEMBERS:** Lord McColl (Co-Chair); Roger Berry MP (Co-Chair); Justine Greening MP (Secretary); Susan Kramer MP; Baroness Masham; Baroness Wilkins

**ASSOCIATES:** Samuel Afolayan; Peter Gage; Sam Gallop; Carson Harte; Sarah Hodge; Alexander Hyde-Smith; Grania Hyde-Smith; Jeff Lindsay; Robin Luff; Ken McCrea; Steve McNeice; Penny Penton; Samantha Rennie; Simon Webster; Ben Grierson-Hill.

Apologies for absence were received.

### MINUTES

9. The Minutes of the Meeting held on 6<sup>th</sup> February 2006 were agreed as a correct record and signed by Lord McColl.

### ELECTION OF MEMBERS

10. **AGREED** to elect Susan Kramer MP and to elect Lord Ahmed as Members.

### ELECTION OF ASSOCIATES

11. **AGREED** to elect World Vision and to elect the Society of Chiropractors and Podiatrists as Associates.

### OUTREACH

12. **NOTED** the creation by Steve McNeice of the APLLG Website, and the encouraging visits and events involving Members including Nick Clegg, Paul Clark, Justine Greening, Jeremy Hunt, Sadiq Khan, Susan Kramer, Doug Naysmith, Laura Moffat, Joan Walley, Mark Hunter, Baroness Masham, Baroness Wilkins, Lord Ahmed and Lord Morris of Manchester.

## 400 MILLION R

13. **NOTED** that In reply to Lord McColl's letter of 23 March about the 400 million R campaign to raise awareness of the problems faced by disabled people in the developing world, the Secretary of State at the DFID The Rt Hon Hilary Benn MP had concluded in his response of 9<sup>th</sup> April *"I very much hope that 400 million R will work with other DPOs in the North and the South to raise the profile of disabilities internationally and in our partner countries. I believe this is the best way to achieve the improvements to the lives of disabled people in poorer countries to which we are all committed."* Sam Gallop, Philip Garvin, Zafar Khan and Adrienne Liron had met DFID officers on 8<sup>th</sup> May to indicate the proposed forward campaign path. Distinguished supporters to date included Archbishop Emeritus Desmond Tutu, Nippon Foundation Chair Yohei Sasakawa, Disabled Persons International Chair Venus Llagan, and the Rt. Hon the Lord Morris of Manchester.

14. **AGREED** that as soon as the expected significant additional international support for the 400 million R campaign was in place, a request for United Kingdom Government endorsement should be made to the Secretary of State.

## MAKING RIGHTS REAL

15. **AGREED** that the "Making Rights Real" draft discussion paper, after incorporation of any final amendments/additions from individual Group representatives to Sam Gallop, be sent by Lord McColl to the Secretary of State for International Development the Rt. Hon Hilary Benn MP, with a request for a personal meeting with Officers accompanied by Members and Associates to explore the issues posited in the paper.

## NETWORK OF PATIENT-LED USER GROUPS

16. **NOTED** that Steve McNeice was developing, building on good work already in hand, a Network of Patient-Led User Groups. These will be concerned with mobility, dexterity and independent living, seeking to enhance in collaboration with PCT Commissioners and Service Providers, clinical and cost-effective benefits in the commissioning and the delivery of services.

## 6C CHARTERS

17. **NOTED** the issue iteratively of

- Updated Charters for Prosthetics and for Orthotics Services.
- A new Charter GET MOBILE - STAY MOBILE, for the avoidance of limb loss, ulcers and pressure sores, through our vital Nursing, Orthotic, Podiatry, Prosthetic and Therapy Services, (attached as Appendix A to these Minutes).

## NHS WHEELCHAIR SERVICES

18. **AGREED** that against the background of the longstanding impossibility of being able to meet the corporate Wheelchair Services Standards, Representation should be made to the Secretary of State for Health the Rt. Hon Patricia Hewitt MP, about the continued and significant lack of adequate funding for staff and for equipment for NHS Wheelchair Services. Reducing delays in waiting for assessments only further increases waiting times for delivery of wheelchairs, and the frustrations of both staff and patients. Subject to their agreement through Roger Berry, the Representation to the Secretary of State should be jointly with the ALL PARTY PARLIAMENTARY DISABILITY GROUP.

19. **NOTED** concerning Powered Wheelchairs and Scooters that Sam Gallop was having tentative exploratory discussions with the Department of Work and Pensions, spilling into discussions with the Department of Health, about possible ways and means and obstacles to introducing/extending Motability type R2M services. No commitment by either Department was being assumed or implied.

## REHABILITATION FORUM

20. **AGREED** to welcome the formation of a Rehabilitation Forum *"To support the clinical and cost-effective commissioning of Rehabilitation Services"* including the NHS Purchasing and Supply Agency, British Society of Rehabilitation Medicine, International Society of Prosthetics (U.K.), British Association of Prosthetists and Orthotists, Society of Chiropodists and Podiatrists, British Association of Occupational Therapists, British Healthcare Trades Association, The Chartered Society of Physiotherapy, other Associates and Patient-led User Groups. *(See Footnote 1)*

## RESEARCH AND DEVELOPMENT

21. **NOTED** that that there was now no provision for R & D in prosthetic services contracts. Discussions were being initiated with the Department of Health to secure a collaborative review of their sources available for R & D funding concerned with limb loss. It was intended to raise awareness generally of the need for, and of the opportunities for, new proposals to help deliver the 6Cs. The Department of Health and Trusts and Authorities were responsible for the secure life-long funding of *Rehabilitation* services; that funding was an essential pre-requisite to the *Restoration* of Human Rights.

22. **FURTHER NOTED** that meantime a specific proposal for R & D into the achievement of socket comfort had been put by Steve McNeice and Sam Gallop to the Centre for Evidence Based Purchasing.

## MINISTRY OF DEFENCE

23. **NOTED** the welcome initiatives of the Secretary of State for Defence the Rt Hon Des Browne MP at the Defence Medical Rehabilitation Centre (DMRC) Headley Court for the rehabilitation of Service personnel and of Veterans who have lost limbs. (*See Footnote 2*) The Secretary of State was delighted that the services being provided by DMRC were recognised by the Associate Parliamentary Limb Loss Group, and he wished the Group every success for the future. Further information, a briefing, or a visit, would readily be arranged.

24. **FURTHER NOTED** that interest was being expressed in the welcome MOD funding of services for psychological injuries.

## NHS PURCHASING AND SUPPLIES AGENCY

25. **NOTED** that expenditures on individual artificial limb services for 2005-06 for each Centre had been requested as a priority from the NHS Purchasing and Supplies Agency with the British Health Care Trades Association, thereby updating in total the expenditures shown in Appendix B to these Minutes, but also including the Numbers of Patients served in 2005-06 by each Centre. Shared knowledge of these expenditures was essential to objective appraisal of the achievement of healthcare equalities by the Group with Commissioners, the Healthcare Commission, Strategic Health Authorities and Patients. This did not appear to be an area within the terms of reference of NICE.

## SCOTLAND, NORTHERN IRELAND AND WALES

26. **NOTED** that actions were in hand further to enhance the Group's liaison with Scotland, Northern Ireland and Wales.

## EDUCATION & CAREER DEVELOPMENTS

27. **NOTED** that further to enhance career prospects and training for Allied Health Professionals, curricula for national and international Foundation Degrees for Rehabilitation Technologists/Orthotic Assistants, meeting ISPO Standards, were being developed by St George's University of London/Kingston University. Approval/funding could not of course be assumed and would have to be negotiated.

## POSSIBLE OUTSOURCING OF SOME NHS SERVICES

28. **AGREED** that if individual Associates wished, they should send to Sam Gallop for further consideration, their concerns about various proposals which they understood were being contemplated or activated by Government, for the outsourcing of Commissioning or of Management of services at present undertaken within the NHS.

## FUTURE MEETINGS

29. **AGREED** to endeavour to fix a date convenient to Officers during the last week of October, in addition to a Portcullis Conference in November.

There being no further business the meeting then terminated.

*(Footnote 1) It is hoped to hold a meeting of the Forum at Portcullis, subject to availability of facilities, on Tuesday 28<sup>th</sup> November 2006.*

*(Footnote 2) Their Royal Highnesses the Prince of Wales and the Duchess of Cornwall opened the DMRC Complex Rehabilitation and Amputee Centre for the rehabilitation of Service personnel and of Veterans on 14 November 2005. The Amputee Centre provides all Service amputees with a complete and co-ordinated rehabilitation and prosthetic service on one site. This includes workshop equipment from Otto Bock and a contract with a prosthetic company (Chas A Blatchford) for prosthetist specialist care, provision of appropriate limbs and after-care throughout each patient's military service. It is linked to the delivery of rehabilitation treatment that ensures patient's return to duty as quickly as possible.*

*The new Centre will also provide 48 hour call-out support for Service amputees requiring limb technical support, courier service for limb component replacement for Service amputees on operational deployment, and a 'spares and repair' pack with education provision to ensure amputees are able to carry out basic first line maintenance in theatres of operations.*

***“In the United Kingdom every year  
5,000 people with diabetes have an  
amputation - that’s 100 people every  
week”***

***GET MOBILE-  
STAY MOBILE***

***and avoid***

***Limb Loss, Ulcers and Pressure Sores***

# Standards for Better Health

## PATIENT LED Health Care Standard For NHS NURSING, ORTHOTIC, PODIATRY, PROSTHETIC & THERAPY SERVICES

Developed Collaboratively and Iteratively  
Under the Aegis of the

### **ASSOCIATE PARLIAMENTARY LIMB LOSS GROUP**

*In continuing consultation with key Stakeholders including*

*Age Concern; Arthritis Care; Assist UK; British Association of Occupational Therapists; British Association of Prosthetists and Orthotists; British Orthopaedic Foot and Ankle Society; British Polio Fellowship; British Society of Rehabilitation Medicine; Chartered Society of Physiotherapy; Diabetes UK; Help The Aged; International Society for Prosthetics & Orthotics (UK); Joint Committee on Mobility for Disabled People; Leonard Cheshire; NHS Purchasing & Supplies Agency; Royal College of Nursing; Society of Chiropodists & Podiatrists.*

**Website: [www.apllg.org.uk](http://www.apllg.org.uk)**  
**Email: [feedback@apllg.org.uk](mailto:feedback@apllg.org.uk)**

## Foreword

Skilled, caring and vital multidisciplinary teams of Consultants, General Practitioners and Allied Healthcare Professionals (AHPs) combine and coalesce creatively and share resources to ensure timely and effective delivery of NURSING, ORTHOTIC, PODIATRY, PROSTHETIC, THERAPY - SERVICES & EQUIPMENT (hereinafter referred to as Services) to enable Patients to avoid Limb Loss, Ulcers and Pressure Sores and to “GET MOBILE - STAY MOBILE”.

This Charter supports Government welcome policies and initiatives that require improvements in Commissioning, including:

- “Tackling Hospital Waiting - the 18 week patient pathway”
- The National Service Framework for Diabetes, which stresses the importance of effective services and strategies to manage diabetes, and the Diabetic Foot Guide implementing the NSF standards;
- The Fair Access to Care Services (FACS) initiative, which aims to make eligibility for services dependent on needs and circumstances, not on where people live and where they first access services;
- The National Service Framework for Older People, which details the Government’s expectations of the services that should be available to older people, and the manner of their delivery as part of the NHS Plan;
- The National Service Framework for Disabled Children and Young People, to enable them and their families to live ordinary lives;
- The National Service Framework for Long Term Conditions to transform NHS and Social Services support through easier and quicker access to independent living;.
- Practice-based commissioning to give GPs, Trusts and Authorities the tools to influence and innovate local service developments.

This Charter applies to the delivery of Services in the full variety of settings, including NHS, Contractors to the NHS, and Voluntary sectors.

## **Patient Needs:**

Services should meet all of the following 6Cs from the National and International Charter adopted by the Associate All Party Limb Loss Group:

### ***Choice***

Patients need to be able to choose from a variety of convenient high-quality providers, with clear and consistent information and advice to back that choice, with money following the patient, and AHPs free to meet patients' expectations. Locations need to be convenient and accessible. Appointment times should meet the needs of an adult patient and any carer, or a child patient and his/her parents.

### ***Comfort***

Equipment must provide adequate support and comfort to enable the Patient to achieve optimal pain-free function and mobility.

### ***Capability***

Equipment must be appropriate to each Patient's requirements, safe, easily maintained and easy to use - instructions must be given which are suitable for and understandable to the patient - there should be a single point of contact for advice about maintenance/recreation/travel/safety etc.

### ***Cosmesis***

Where necessary for self-esteem, Equipment must be cosmetically acceptable commensurate with optimal function - needs for children and young people, at the early stages of developing a positive self-image, must be met.

### ***Competence***

All AHPs whether from the NHS, Contractors to the NHS, or the Voluntary sectors, must (be enabled to) have educational and career opportunities necessary to developing and sustaining their competencies and skills - generating mutually dignified and positive relationships with patients of all ages.

### ***Caring***

Caring is the Catalyst, whatever the age of the patient.

*Equipment includes footwear and coverings, orthoses, crutches, prostheses, and other mobility and risk-reducing aids.*

The **needs of the individual Patient will change**, or **new assistive technologies** will become available. Services should provide the Equipment (including a “second” if required for employment/independence/lifestyle) most appropriate for the individual Patient throughout each stage of his/her lifetime pathway.

It must be recognised that some apparent/assumed psychological problems (e.g. presumed inability to “cope”), may be due to not meeting one or more of the 6Cs, and that proposed psychological/counselling solutions or services could then be contra-indicated and absorb scarce resources.

## **Aims**

Despite the best endeavours of Staff current services may in certain aspects be found to be unsatisfactory because:

- There are unexplained variations in all aspects of service provision, bearing little relation to underlying levels of need;
- Quality of Services may owe more to custom and practice, rather than to a considered view of the contribution that Services could make to the overall needs of the population.

Co-working to drive up standards of care, Patients seek to help:

- Provide the detailed data analysis that underpins sound commissioning
- putting patients and service users first through more personalised care;
- a focus on the whole of health and well-being, not only illness;
- Give the individual - the patient, service user or client - more power to improve their care and drive the whole system
- Improve both quality and equality
- Address the needs of children as well as the adult population and their families and carers
- Secure prompt referral for support where needed
- Support new types of team working across organisational boundaries.

**Best practices require the provision of adequate resources and continued professional development, to “provide the right care, at the right time, and to the right quality without unnecessary delays.”**

## **Patient Pathways**

From GP or other referral to final delivery of equipment, including diagnostic tests and procedures and outpatient treatments, the patient pathway should not exceed 18 weeks.

Delivery will be in stages and the final outcome should include confirmation by the Patient that the 6Cs have been met, agreement of objectives, and validation of education of Patient and Carers.

“Pain-Stop” or emergency repairs should be offered on the same, or the day following, the day of request.

In support of the defined mechanism for Repairs & Maintenance, including regular reviews, Patients and Carers must keep the service informed of any relevant changes in their personal circumstances.

## **Opportunities for Commissioners**

Opportunities for Commissioners are to:

- Look across organisational boundaries, achieve better co-ordination of care, and recognise total savings;
- Ensure that reliable and relevant information is freely available to patients both generally and through User Groups;
- Secure that the necessary range of high-quality Services is more and adequately resourced;
- Improve prevention, treatment, rehabilitation and care, underpinned by holistic assessment of needs;
- Reduce falls risks;
- Reduce hospital bed occupancies; and
- Enable increased capacity to be put to optimum use by treating people as efficiently as possible and responding to their needs and expectations.

Patients support Commissioning to involve the Patient (and the Carer) collaboratively in the design and delivery of Services to achieve and maintain health, independence and well-being.

They welcome the obligations on Strategic Health Authorities to align the continuing NHS health care criteria they have inherited and establish common criteria across each health economy.

## Best Practices

Sources for information about Best Practices include:

- Diabetic Foot Guide from the National Diabetic Support Team - [NDST@prolog.uk.com](mailto:NDST@prolog.uk.com).
- National Institute for Health and Clinical Excellence - [www.nice.org.uk](http://www.nice.org.uk).
- Annual prosthetic and orthotic awards organised through the Douglas Bader Foundation and the Limbless Association
- Prizes sponsored by Age Concern, British Limbless Ex-servicemen's Association, British Polio Fellowship, Diabetes UK, Help the Aged and other key stakeholders
- Websites such as that of Associate Parliamentary Limb Loss Group - [www.apllg.org.uk](http://www.apllg.org.uk)
- British Society of Rehabilitation Medicine and the International Society for Prosthetics and Orthotics (UK)
- Rehabilitation Forum supporting clinical and cost-effective rehabilitation services
- User Groups

Domains, to which regard should be had, looking at services across healthcare organisations, include:

- Putting service users first through more personalised care;
- a focus on the whole of health and well-being, not only illness;
- safety
- care environment and amenities
- clinical and cost effectiveness
- governance
- patient focus
- accessible and responsive care
- public health

## **Equal Opportunities and Access**

Patients are committed to supporting equal opportunities and access for all, irrespective of age, disability, gender, marital status, race, religion and belief, sexual orientation, transgender and working patterns, all with openness and transparency of process.

They agree that “effective care involves a partnership between patients and professionals and all decision making should be shared.”

## **Quality of Care and Assessment and Prescription**

The Patient assesses Quality of Care by its Effectiveness - the extent to which, and the quality with which his/her needs and informed expectations are met. Effectiveness requires Services to be organised and managed around Patient and Carer needs and to deliver maximum possible health and independence for both adult and child patients. AHPs should, subject to health and safety requirements, advise the Patient of the optimum solutions to his/her needs, through a process of Collaborative Realistic Attainable Goal-Setting, and such advice should not be compromised by resource constraints, realistic though immediate (not long-term) recognition of the latter must be. Assessment by the Rehabilitation team and should result in a written Report of Assessment to the Patient (or for a Child the Parent/Carer), which should, with his/her consent, be circulated to all relevant parties.

If, because of lack of funding or pressure on resources, the most appropriate solution (see 6Cs) cannot be prescribed, the reasons should be fully documented in the written Report of Prescription and circulated to all concerned.

## **Continued Professional Development**

Delivering the workforce skills to meet Patient rights and needs requires sustained opportunities for Continued Professional Development, and clear career “stepping stones” for all professional staff. Undergraduate and Postgraduate studies and training need to be accessible regardless of distance both geographically and academically.

Workforce budgets must facilitate:

- Involvement of AHPs in clinical/planning responsibilities and requisite post-graduate training leading to the appointments nationally of Consultant Practitioners
- Opportunities for Technicians and Assistants to take Foundation Degrees, and thereafter achieve further qualifications.

## Research & Development

Consultation with Patients before budget commitment should ensure that Research Proposals and Development proposals, both Local and National, are intended to meet specific Patient needs. Worthwhile innovations in technology and practice should be introduced effectively with minimum delay. Beneficial developments and knowledge achieved 'Locally' should be made available 'Nationally'.

It must be recognised that some apparent/assumed psychological problems (e.g. presumed inability to accept changed appearance), may be due to the Service not being resourced to meet one or more of the 6Cs such as Cosmesis. Proposed further psychological research into these "problems" could then be contra-indicated and absorb scarce resources which could more effectively be deployed in Service provision.

## Not a Blueprint

This Patients' Charter is a pathway to sharing improvements and best practices - not a blueprint for how services should be delivered. It recognises the need for mutual respect between patients/families/carers, and the providers of services whose skills and commitment are essential to maintaining the right mix of incentives, transparency and plurality of providers, practice-based commissioning and patient choice.

## Feature

# NHS artificial limb service spend increases/decreases

Sam Gallop, with information helpfully provided by NHS Purchasing and Supplies Agency, compares 2004-05 with the previous year

The following table shows the changes in spending in total by NHS artificial limb service centres in 2004-05, compared with previous years.

	2000/01	2001/02	2002/03	2003/04	2004/05	Change
Limb Components Actually	11,259,586	11,133,271	12,307,194	13,396,230	14,071,843	5.04%
Conventional Limbs now inclusive in components	575,000	525,000	500,000	inc	inc	
Silicone Cosmesis Actual	0	265,000	447,062	687,913	832,616	21.04%
Prosthetic Socks Actual	550,000	6,000,000	650,000	515,321	503,086	-2.37%
P & (O) Services Actual	21,390,157	22,083,268	22,285,451	23,383,608	24,206,935	3.52%
Total Ex VAT	33,774,743	34,606,539	36,189,707	37,983,072	39,614,480	4.30%
Total incl VAT	39,685,323	40,662,683	42,522,906	44,630,110	46,547,014	4.30%

Limb Component spend rose by 5.04% (1.79% in real terms) due largely to the continued increase in the issue of specialist liners and functional components. Users are increasingly aware of the range of quality components available on contract and that some Centres have the funding to meet the SCs in full. Continuing re-use schemes at certain Centres enabled better utilisation of products and budgets.

Conventional Limb spend, vital to certain Users, has again sensibly been subsumed within the total limb component spend. Ortho Europe now run a training course for prosthetists and technicians to raise expertise in conventional limbs not otherwise available; thereby providing earlier diagnosis of problems; facilitating improved adjustment at trial fitting stage, and reducing retrials and delays in final delivery.

The increased spend of 21.04% on Cosmesis largely resulted from some Centres receiving new, additional or recurrent funding. There has been greater awareness of

competitive prices, and extensive promotion by NHS Purchasing and Supplies Agency and Users. It appears that a minority of Centres still have nil budgets but this may be due to nil reporting.

Prosthetic "socks" experienced a (-2.43%) reduction in sales, in part due to more use being made of liners in lieu. Remploy have helpfully produced prototypes of prosthetic socks, with metallic fibres woven in, which may have properties that reduce bacteria and phantom limb pain. User trials are planned. There is some indication that issue of prosthetic socks by individual Prosthetists rather than by other Centre staff results in more appropriate use and care of socks by Users.

Prosthetic services increased by 3.52%, which was more than general inflation (Retail Price Index was 2.4% in year to April 2005). Payroll costs (the major component) were subject to higher National Insurance, Health Professions Council compliance and increased pension contributions. In addition

overheads increased due to higher energy and insurance costs. NHS Trusts, in general, have taken due account of these factors when negotiating with the service companies.

In summary and in total, there was an increase of 4.30% in 2004-05 in the NHS spend on prosthetic services and related products. It is for each individual NHS Authority/Trust/Centre and each User Group and User, in accordance with the Government's sensible devolution of NHS responsibilities, to assess whether sufficient of the welcome extra money Government is investing in the NHS is now flowing and flowing effectively into prosthetic services. I estimate that significant increases will be needed to meet the requirements of the NHS National Service Frameworks for Children, for Older People and for Long Term Conditions.