



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

ANNUAL REPORT 2009-10

MEMBERS AND SUPPORT AND ENCOURAGEMENT

Peers and Members of Parliament readily gave their support and encouragement during the year including: LORD AHMED; DANNY ALEXANDER MP; RICHARD BACON MP; ANNE BEGG MP; ROGER BERRY MP; TIM BOSWELL MP; PAUL CLARK MP; JUSTINE GREENING MP; GREG HANDS MP; MARK HUNTER MP; LORD KIRKWOOD; SUSAN KRAMER MP; BARONESS MASHAM; LORD MCCOLL; DR DOUG NAYSMITH MP; BARONESS PITKEATHLEY; CAROLINE SPELMAN MP; BARONESS TONGE; ANGELA WATKINSON MP; BARONESS WILKINS and SIR GEORGE YOUNG MP.

All Members join in expressing their thanks to all the health professionals and the voluntary organisations and carers who are continually going the extra mile to ensure the highest possible quality of life for all people with limbloss nationally and internationally. The Consultant to the Group was Sam Gallop CBE. The Limbless Association provided administrative services.



OUTREACH

The caring support given by the staff in Justine Greening's office, and by all Parliamentary staff, greatly facilitated outreach, access and the conduct of business. In addition to Group Parliamentary meetings, meetings with and visits by individual Peers and MPs gave warm encouragement and new opportunities for service. Ministers, Departments, Trusts and Authorities gave much useful advice about present and future pathways in the best interests of both patients and providers. Welcome exchanges of views and ideas for positive actions also took place with representatives of following caring organisations: Association for Children with Hand or Arm Deficiency (REACH); Association of Rehabilitation Service Centre Managers; BRAKE; British Healthcare Trades Association (BHTA); British Limbless Ex-Servicemen's Association (BLESMA); British Polio Fellowship; British Society of Rehabilitation Medicine (BSRM); Cambodia Trust; College of Occupational Therapists (COT); Chartered Society of Physiotherapy (CSP); Contact A Family; Coventry University; Diabetes UK; Disabled Living Foundation; Douglas Bader Foundation; Handicap International; Help The Aged; International Society of Prosthetics and Orthotics (UK); Joint Committee on Mobility for Disabled People; Limbless Association; Limbloss Legal Panel; London Health Forum; London South Bank University; Meningitis Trust; Meningitis Research Foundation; Motability; Motivation; Murray Foundation; Muscular Dystrophy Campaign; National Health Service Supply Chain; National Prosthetic Managers Association; National Wheelchair Managers Forum; POWER International; Prosthetics, Orthotics & Rehabilitation Technology – Education & Research (PORT-ER); Remploy; Response International; Roehampton University; Royal Hospital for Neuro-Disability; Skills for Health; Society of Chiropodists and Podiatrists; Specialised Healthcare Alliance; Spinal Injuries Association; Steps Charity Worldwide; Thalidomide Society; University of Salford; University of Strathclyde; Whizz-Kids; and many other good and valued friends.

CHILDREN AND FAMILIES

The Group's Conference for Children with Limb Loss highlighted the needs, which will be pursued, to ensure not only that every Child with Limb Loss matters 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 Paediatric Service Specification.

Cuts in budgets for Cosmesis were noted with particular concern as research confirms the importance of appearance to self-esteem and social inclusion.

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 which must be addressed to help secure a better quality of life.

SERVICE PERSONNEL AND VETERANS



The Group welcomes the priority commitments from Government to Service Personnel and to all Veterans 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... be entitled to receive from the NHS an equivalent standard of prosthetic limb to those provided by Defence Medical Servicesa 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.”

The rehabilitation services provided by the Defence Medical Services at Headley Court are second to none. The active combined operations of the Ministry of Defence, the Service Personnel & Veterans Agency, the Department of Health and the National Health Services, are vital to ensuring, with steadily increasing and previously under-estimated needs, that the Government commitments are honoured and that there is parity of treatment nationwide with no gaps in services.

PROSTHETIC/ORTHOTIC SERVICES

The Government’s commitments to Veterans to date give no indication of the provision of the source of funding for the significant additional NHS resources required to met Veteran needs. Without such additional funding, existing NHS services must be compromised. Particular concerns expressed to the Group, about Prosthetic/Orthotic services, included:

- contracts exclude provision for education and training and research and development
- lack of national co-ordination of contracts/commissioning inhibits national standards
- profiles of the Prosthetic/Orthotic professions including Technicians and Assistants need to be raised – they are “invisible” in the NHS
- Low numbers of Prosthetists/Orthotists being recruited and retained mean that it will be increasingly difficult to provide the range and quality of services required

NHS SUPPLY CHAIN

To enhance product offers and related products including range extensions, the NHS Supply Chain recruited to Task Forces clinicians and practitioners, who specialised in the use and application of prosthetics and of orthotics. Feedback to user organisations was especially arranged to ensure that they were kept informed.

RECRUITMENT OF APPRENTICES

The Group welcomes the significant increases in the numbers of Apprentices across the entirety of health services – expected to more than double over four years with support from Skills for Health to employers – which is laying sure foundations for continued professional development.

REHABILITATION MEDICINE

The Group welcomes, under the leadership of the British Society of Rehabilitation Medicine, the reinstatement of National Amputee Data Base Statistics with the collaboration of Centre Managers and Contractors and the generous skilled services of the University of Salford. This data will enhance understanding and delivery concerning:

- Levels of limb loss, age profile, single or multiple limbs etc.
- Causation of amputation / limb loss
- Regional variations
- Service planning and succession planning.
- Training, teaching and research.
- Comparative data with other developed countries.
- Advances in technology.
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Concerns have been noted about the loss of employment opportunities for Rehabilitation Consultants, adversely affecting the quality of care, and unduly extending the roles of already hard-pressed allied health professionals.

WHEELCHAIR&SPECIALEATING SERVICES

The Wheelchair Services Users Charter was launched under the combined aegis of the Parliamentary Groups for Spinal Cord Injury, for Muscular Dystrophy and for Limb Loss. The Spinal Injuries Association is spearheading, with other concerned charities, a national information sharing network of wheelchair & special seating user groups. Support is readily being given to all such developments by the National Wheelchair Managers Forum, in parallel with the national review of services by the Department of Health.

PHYSIOTHERAPY

Physiotherapists recognise that, with the increasing emphasis on high quality specialised commissioning, there is a need to gain consensus for standardised therapy outcome measures. They are accordingly updating their Guidelines for the Physiotherapy Management of Adults with Lower Limb Prostheses; developing a guide to best practice for a holistic approach to the management of children with limb loss; auditing practice with reference to their Falls guidelines; further reviewing before publication Contra-lateral foot guidelines; and have launched the first version of the BACPAR Outcome Measures Toolbox.

OCCUPATIONAL THERAPY

Occupational therapists believe that all limbless children and adults have the right to be provided with services and equipment which meet their individual needs. People with limb loss have very specific requirements, requiring skilled assessments, followed by training for patients and their carers in safe practice. In addition to guidance on upper limb prosthetic rehabilitation, recommendations are being produced for occupational therapy for lower limb amputation. Concerning wheelchair services, any re-design requires a multi-professional, multi-organisational approach; greater involvement of Occupational Therapists would be welcomed.

REHABILITATION ENGINEERING & OLDER PEOPLE

Dame Joan Bakewell, the Government's official voice of Older People, was guest of honour at the opening of Coventry University's new Health, Design and Technology Institute. The Institute will develop products and services to improve the daily living of the ageing population, people with disabilities, and chronic illnesses. As Dame Joan puts it: *"The things that make life valuable are the same in your 80s and 90s as when you are younger: relative physical comfort, freedom from anxiety, fulfilling activity and the joys of family and friends. It is no exaggeration to say that the projects in prospect from the HDTI directly contribute to these objectives."*

KEEPING PEOPLE WITH CPD OUT OF HOSPITAL

It is proposed to convene a conference to demonstrate how, with significant savings to the NHS, Rehabilitation Services keep people with complex physical disabilities (CPD) out of hospital. National commissioning is further strengthening delivery of the highest quality of both cost-effective and patient-effective health services. Consultation is being developed to ensure that Specialised Commissioners in Strategic Health Authorities and elsewhere are kept informed of the benefits of Specialised Services for prosthetics, orthotics, wheelchairs/special seating, telecare and other assistive technologies, in keeping people with CPD out of hospital. They should then be enabled to live independently in the community, with maximum opportunities in education, employment, sports and recreation and public service. There is a need to ensure that such Specialised Services receive full credit for the savings they bring about in the budgets of other services.

IMPROVING ORTHOTIC SERVICE PROVISION

Members welcomed and thanked Professor John Hutton for his personal presentation of his York Health Economics Consortium team report on "Improving Orthotic Service Provision in the NHS". The report advises that *"Orthotic service provision has the potential to achieve significant health, quality of life and economic benefits for the NHS if a comprehensive, integrated service can be provided."* *"For every £1 spent on orthotic services the NHS saves £4. "Current procurement practice is too dependent on a commodity product procurement model."* Members undertook to press Ministers to secure the introduction of the required organisational and other developments. Members also welcomed the publication by the British Polio Fellowship of their leaflet advising Patients on *"What I have the right to expect from my Orthotics Provider"* and congratulated the Fellowship on their initiative.

ROYAL COLLEGE OF SURGEONS OF ENGLAND

With support from the Vascular Society, Cordis Endovascular and the Limbless Association, the Royal College of Surgeons of England hosted an Amputation Course for the surgical teams who undertake amputations. A multi-disciplinary faculty of vascular, plastic, orthopaedic, general surgeons, anaesthetists and rehabilitation experts, covered the techniques of all types of

amputation from digital to full hind quarter. Further improvements in techniques and outcomes with significant benefits to amputees will be secured.

INTERNATIONAL SERVICES

In difficult and dangerous circumstances the international Associate Members of the Group have continued to sustain their outreach which reflects greatly to their credit. Following up the circulation of the Early Day Motion for “ Human Rights to Personal Mobility and Access to Growth in Developing Countries”, sponsored by Dr. Doug Naysmith MP, Justine Greening MP and Mark Hunter MP, the Group noted with concern the requirements for still more aid to meet the increasing numbers of amputees internationally. Prosthetic, Orthotic and Wheelchair services must internationally be mainstreamed and adequate, thus enabling people with disabilities to join in pushing Growth up the Development Agenda. The Group were usefully reminded of the WHO “Guidelines on the Provision of Manual Wheelchairs in developing countries.”

LEGAL CONFERENCE

A conference with the support of the Limb Loss Legal Panel is planned to be held later in the year to help demonstrate that timely and comprehensive and sustained rehabilitation benefits both patients and health services. Best practices at the interfaces between Rehabilitation and the Medico-Legal Process should be illuminated.

CONCLUSION AND THANKSGIVING

In conclusion, all Members wish to express their thanksgiving for the precious time and well-tempered experience that so many very busy people have shared with them during the past year, and which have contributed significantly and positively to their proceedings and to the creation of productive pathways for the future.

Feedback to feedback@apllg.eu

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