



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 2010-11

SUPPORT AND ENCOURAGEMENT

Peers and Members of Parliament and their staffs readily give their support and encouragement including:

ALISON SEABECK MP; ANDREW MURRISON MD MP; ANGELA WATKINSON MP; ANDREW SMITH MP; DAME ANNE BEGG MP; BARONESS GREY-THOMPSON; BARONESS MASHAM; BARONESS TONGE; BARONESS PITKEATHLEY; BARONESS WILKINS; CHARLOTTE LESLIE MP; CHERYL GILLAN MP; DAN BYLES MP; IAN LUCAS MP; JOAN WALLEY MP; JUSTINE GREENING MP; KATE HOEY MP; LORD BOSWELL; LORD MCCOLL; LOUISE BAGSHAW MP; MIKE WEATHERLEY MP; NICOLA BLACKWOOD MP; REHMAN CHISHTI MP; SIMON HUGHES MP; STEVE MCCABE MP and TESSA MUNT MP;

We express our thanks to all the health professionals and carers and organisations including those of our distinguished Associate Members, who continuously pull out all the stops to ensure equal opportunities and the highest possible quality of life for all people of all ages with limbloss nationally and internationally. The Limbless Association continues to provide vital administrative services. Voluntary advisors' serving the Group are Wayne Henderson, Sam Gallop and Steve McNeice.

The staff in the office of DAME ANN BEGG MP effectively and willingly ensured that all Parliamentary requirements and much more were prudently and effectively met, and greatly facilitated outreach, access and the conduct of business. Visits by individual Peers and MPs gave warm encouragement and opened doors to new opportunities. Ministers, Departments, Trusts and Authorities all unstintingly gave their help and advice.

SERVICE PERSONNEL AND VETERANS

The Government's commitments to Veterans to date give no indication of the provision of or the source of funding for the significant additional NHS resources required to meet Veteran needs. Without such additional funding, existing NHS services are being and must be compromised.

A welcome new Review into the effectiveness of prosthetics services in the NHS, for Veterans who have lost a limb or limbs due to activities while serving their country, was launched on 3rd January by Health Minister Simon Burns, in accordance with an earlier commitment by Defence Minister Andrew Robathan that: ***"The Government recognises the need to do much more to ensure our Armed Forces have the support they need, and that Veterans and their Families***



are treated with the dignity they deserve. Those who have served their country deserve the best possible care from the NHS for the rest of their lives and the Government is committed to making this happen.”

Lead by ANDREW MURRISON MD MP, the Review is assessing the prosthetic services currently offered to Veterans by the NHS and how these can be strengthened to meet future demands on the service.

The review is also looking at:



- the future funding of high specification, evidence-based prosthetics; services within the NHS and the possible contribution of personal health budgets and the inclusion of these in continuing healthcare arrangements;
- how regional variations in service can be minimised;
- how the transition from the armed forces' prosthetics care to the NHS can be improved; and
- the role of service charities in helping to meet the realistic needs of individuals over and above that which the NHS can provide.

During a meeting of the Group with Dr. Murrison, the following were among the opinions expressed to him for his consideration:

- The number of Veterans was small comparatively, but the impact on individual Centres already experiencing budget cuts against increasing demands, especially in the neighbourhood of Garrison Towns such as Colchester, would be especially disturbing.
- Despite exhortations to Centres to provide the additional NHS services required for Veterans with limb loss in accord with the Military Covenant there had been no additional NHS funding to date
- Doubt was expressed about the need for additional Centres of Excellence. The present NHS Centres had the necessary expertise, were dealing with severely damaged stumps akin to those suffered by Veterans, but had been, and were being, deprived of the necessary resources. Expertise and critical mass would be diluted by having more Centres.
- It was essential to Quality of Life in all aspects, and for cost-effectiveness and service-effectiveness, that all patients, including Veterans, were within reasonable travelling distance from home/place of employment to their Centre and back.
- Limb loss was for life; needs were constantly changing and varying; services must be sufficient, and skilled, and flexible, to meet those changing needs.

- For excellence of service, and to minimise post-code prescribing, there must be National Commissioning and Standards, through national contracts.
- Doubt was expressed about the relevance of Personal Health Budgets.
- The total service costs of a triple or quadruple amputee were proportionately much greater than three or four times the total service costs of a single amputee.
- The required additional NHS funding should be provided by the Ministry of Defence.
- Innovation meant that the Veteran might not wish for long, to have the prosthesis design or part thereof as delivered to him at Headley Court, after s/he had become an NHS patient.
- There appeared to be a multiplicity of charities involved and no shortage of goodwill. Charities should not be requested to or seek to deliver or fund prostheses. There were many other opportunities for deploying their welcome funding.
- There was an inevitable tension between recognising the obligations of the Military Covenant and not disadvantaging other National Health Service patients.

GUIDANCE ON NATIONAL COMMISSIONING OF SPECIALISED SERVICES

A guidance document on national commissioning of specialised services for people of all ages with limb loss, with a Foreword by Lord McColl, was produced for the Group by a task force of patient representatives and professional stakeholders, as the foundation of further healthy discussions and progress with Commissioners.

The Guidance benefits the Patient by:

- improving health and well-being outcomes
- facilitating and enabling Patient Choice and Putting People First
- eliminating post-code prescribing.

The Guidance benefits the Service by:

- reducing emergency bed days
- closer collaboration between Health and Social Care Services
- the implementation of the “Common Core Principles to Support Self Care”
- honouring the Cross Government guarantees to our Armed Forces, Veterans and their Families
- ensuring a competent workforce with the requisite continued professional development.



There is general agreement that NHS services for prosthetics, specialised orthotics, special seating and mobility, and assistive technologies, as embraced in National Specialised Definition Set Number 5, should be commissioned through the proposed new National Commissioning Board. Where Quality and Standards are concerned, one should not do many times what can be done once and more effectively.

PATIENT CONCERNS OVER SHORTAGES OF PROSTHETISTS/ORTHOTISTS

The Group welcomed a paper from the National Allied Health Professionals Patients Forum expressing Patient concerns about the current and future shortages of Prosthetists and Orthotists, whose importance is rightly indicated in Specialised Services National Definitions Set No. 5, with Patient needs and numbers increasing.



There is an exodus of the specialised skills and experience needed to enable patients of all ages with complex physical disabilities to remain mobile, dextrous and independent. If this trend is not reversed, there will continue be otherwise avoidable falls, pressure sores, diabetic foot and limb losses, needing additional health care treatments and increasing health care costs. This will also adversely affect Patient Outcomes and Quality of Life.

The Group is supporting Initiatives to help find solutions to the actual and increasing shortages. These include Foundation Degrees in Clinical Technology at London South Bank University, initiated by the Royal Hospital for Neuro Disability; wider implementation within the UK (as already in Germany) of the professional categories of the International Society of Prosthetists and Orthotists; enhanced career and academic progression for Technicians; and the vision of a Third School in the South East. But, more resources will still be needed for recruitment, retention and continued professional development, and for Apprenticeship salaries.

SPORTS & REHABILITATION

The positive publicity for the coming Paralympics will enhance inclusion and human rights for people with disabilities. Otto Bock UK has been appointed the official Prosthetic, Orthotic and Wheelchair Technical Services Provider for the London 2012 Paralympic Games; ***“I feel at home here with Otto Bock”*** says the International Paralympic Committee President Sir Philip Craven. BLESMA continue to provide their superb wide-ranging rehabilitation sporting events for Veterans including Golf, Ski-Bobbing and Sailing and Scuba Diving, and in collaboration with the United States Wounded Warrior Programme and the US Paralympics team. Using a PACE Rehabilitation device, above-elbow amputee Jon-Allan Butterworth has set a new 1km Para-Cycling world record. Team Ossur’s congenital double

through knee amputee Richard Whitehead (pictured right) became IPC world champion over 200m in New Zealand earlier this year and went on to complete the London marathon. 15 year old right-leg amputee Nick Cole has won a gold medal for the 100m butterfly. The Joint Committee on Mobility for Disabled People is taking a keen interest in ease of access to all sporting events. Amputee football teams are regularly taking the field and do not adapt that limb loss is a penalty. Wheelchair basketball and rugby and racing individuals and teams are reaching ever higher skills and levels endurance. These are just a few of many for instances - all the limbless charities with their supporters are generating excellent Sports+ programmes



OCCUPATIONAL THERAPY

People with lower limb amputations will benefit from the new National Occupational Therapy Guidelines published by the College of Occupational Therapists which will provide an evidence-based framework for occupational therapists working with people who have had lower limb amputations. ***“Occupational Therapy with people who have had lower limb amputations”*** has been produced using expert clinical and academic expertise from the College of Occupational Therapists’ Specialist Section for Trauma and Orthopaedics, and Brunel University. The guidelines are an essential reference tool for professionals and set vital standards of Occupational Therapy care for service users and their families.



PHYSIOTHERAPY

The British Association of Chartered Physiotherapists in Amputee Rehabilitation (BACPAR) produces internationally recognised evidence based clinical guidelines, and aims to promote best practice through evidence and education for the benefit of both patients and the profession. They are committed to research and education, providing a network for the dissemination of best practise in pursuit of excellence and equity whilst maintaining cost effectiveness. Recognising the need for continued and improved high quality and specialised commissioning of both services and equipment, Physiotherapists are enhancing and extending the scope and the application of the BACPAR Outcome Measures Toolbox among Specialist Multi-Disciplinary Teams. Measures for non-limb wearers and the pre-prosthetic phase will be included. Future research will include the long term benefits and cost-effectiveness of different models of physiotherapy for new lower limb amputees. The Chartered Society of Physiotherapy 2010 research priorities project was welcomed



PREVENTION

In England more than 70 amputations take place each week on Type 2 diabetes patients. It is thought that 80 per cent of these are potentially preventable. Barbara Young, Chief Executive of DIABETES UK says: ***"The existing situation around foot care and amputations is shocking, given that the majority of amputations can be prevented."*** Prevention is obviously better than Amputation. The services of DIABETES UK and the CIRCULATION FOUNDATION and the SOCIETY OF CHIROPODISTS & PODIATRISTS with the vital specialist healthcare teams are second to none but resources are limited. At a reception in the House of Commons, generously sponsored by the Association of British Healthcare Industries, we were privileged to have presentations from Professor Cliff Shearman, President of the Vascular Society of Great Britain and Ireland to share his guidance on the Avoidance of Amputation, and by Mr Iain Robertson, Vice President of the British Society of Interventional Radiology on Saving Legs, Secondary Care.



CONSULTANTS IN REHABILITATION MEDICINE

The need for Consultants in Rehabilitation Medicine is recognised in Specialised Definition Set Number 5 for Patients with Complex Physical Disabilities. The Set illuminates the steadily widening role of and the need for holistic Rehabilitation Centres covering Prosthetics, Orthotics, Wheelchairs and Special Seating and other Assistive Technologies, and their skills as Specialised Service Providers. Here again the Group is grateful for the support being received from Specialised Commissioners.



WHEELCHAIRS & SPECIAL SEATING

More than one half of people with limb loss need and benefit from the use of Wheelchairs and many also need Special Seating. As one user puts it, ***"My electrically powered indoor/outdoor wheelchair takes me out into the world which would otherwise pass me by."*** We welcome the support and collaboration of concerned and caring organisations including the Spinal Injuries Association, the National Wheelchair Managers Forum, and the Posture and Mobility Group. They all help to promote high standards of service delivery, research and development into users' requirements, encouragement of collaborative working, and the provision of adequate resources for the services and staff involved.



NATIONAL SERVICE SPECIFICATION FOR PROSTHETIC AND AMPUTEE REHABILITATION

The National Prosthetic Centre Managers Group are delighted that the Department of Health are using their **'National Service Specification for Prosthetic and Amputee Rehabilitation'** as relevant to effective Commissioning. They hope that any current fragmented Prosthetic and Orthotic Services commissioning arrangements will be brought within Specialist Commissioning, where they can be more appropriately managed.

FURTHER RECOGNITION OF ALL SERVICES CONCERNED WITH COMPLEX PHYSICAL DISABILITIES

Patient organisations look forward to further recognition of all Services concerned with Complex Physical Disabilities, in collaboration with other key players, including College of Occupational Therapists, Chartered Society of Physiotherapy, British Healthcare Trades Association, British Association of Prosthetists and Orthotists, Society of Chiropodists & Podiatrists, United Kingdom Branch of the International Society for Prosthetics and Orthotics, National Wheelchair Managers Forum, Coventry University, London South Bank University, Salford University, Strathclyde University, Posture & Mobility Group, Association of British Healthcare Industries, Royal Society of General Practitioners, Royal College of Physicians and the Royal College of Surgeons.

INTERNATIONAL SERVICES

International Needs grow apace. Ratification by our Government of the United Nations Convention on the Rights of Persons with Disabilities is a signpost which will hopefully lead to more specific funding for our Associate Members who are so active overseas, often in trying terrains. In developing territories they are setting the pace in the training of Prosthetists, Orthotists and Technicians, and in Wheelchair Design and Delivery. It is typical of the high standing in which they are held that the 2011 Hilton Humanitarian Prize was awarded to HANDICAP INTERNATIONAL for its work assisting people



with disabilities in situations of poverty, exclusion, conflict and disaster. The CAMBODIA TRUST is now the biggest provider of prosthetics and orthotics training in the world, with University Schools in Cambodia, Sri Lanka, Jakarta and the Philippines. POWER INTERNATIONAL has begun projects in Laos, Zambia and Mozambique to help disabled children gain access to education, and is helping to empower women with disabilities. The 20th Anniversary campaign of MOTIVATION, "Wheels out of Poverty", designs and delivers in Africa affordable wheelchairs flat-packed for local assembly to fit each individual user and especially for rough tracks and roads. REPOSE INTERNATIONAL is delivering emergency healthcare and water purification among the millions of victims of floods in Pakistan; their in-country team has been addressing health/disaster needs there for almost a decade. The CORNEL ROMANIAN

REHABILITATION CENTRE TRUST has established a Rehabilitation Centre in Cumpana which provides prostheses and orthoses, and trains local staff to design, manufacture and deliver.

EUROPEAN LIMB LOSS DAY

We have initiated the first European Limb Loss Day to be held on 3rd December. As **DAME ANNE BEGG MP** puts it, ***“It is good to see how our All Party Group can nurture and reach out through this first-time initiative. Patients, Carers and Professionals will be joining together to help ensure that throughout the European Union there is increased awareness of the growing need to deliver (not just chat about) prosthetics, orthotics, wheelchairs and other assistive technologies, all essential to wellbeing and maximum possible independence. National boundaries should become springboards to higher qualities of life.”***

CONCLUSION AND THANKSGIVING

In conclusion, all Members wish to express their thanksgiving for the valuable time and well-honed advice, so willingly given to them during the past year by so many very busy and experienced people, without whom the progress recorded in this Annual Report, would not have been possible.

Feedback to Wayne Henderson advisor@apllg.eu

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