



# Associate Parliamentary Limb Loss Group

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

## Minutes of the Annual General Meeting held at 3PM on Wednesday 23<sup>rd</sup> April 2008 in Committee Room 8 at the House of Commons London SW1A 0AA

### PRESENT

**MEMBERS:** Sir George Young MP (in the Chair); Justine Greening MP (in the Chair); Lord McColl; Baroness Tonge and Dr. Doug Naysmith MP.

**ASSOCIATES:** Steve McNeice; Sam Gallop; Christopher Harwood; Gail Welling; Jenny Rogers; Robin Luff; Stephen Mottram; Ruth Mayagoita-Hill; Jonathan Wright; Gary Phillips; Julia Skelton; Meryl Glover; Ken McCrea; Peter Graham; Nicola Carrington; Ernie Stables; John Connelly; Stella Morris; Phil Yates; Rebecca Reynolds and Zafar Khan.

### 43. MINUTES of Meeting held on 5<sup>th</sup> December 2007

**APPROVED** the Minutes of the previous joint meeting with the All-Party Parliamentary Landmines Eradication Group held on 5<sup>th</sup> December 2007.

### 44. APPOINTMENT OF OFFICERS

**NOTED** with appreciation that Lord McColl, Danny Alexander MP, Mark Hunter MP, Dr. Doug Naysmith MP and Susan Kramer MP had accepted appointment as Co-Chairs for the coming year, and that Justine Greening MP had accepted appointment as Secretary.

### 45. REGISTER ENTRY OF THE GROUP

**AGREED** the Register Entry of the Group for submission to the Office of the Parliamentary Commissioner for Standards.

### 46. ANNUAL REPORT

**APPROVED** the Annual Report for the year ending 5<sup>th</sup> February 2008.

#### 47. **EARLY DAY MOTION**

AGREED to progress the following Early Day Motion:

### **HUMAN RIGHTS TO PERSONAL MOBILITY & ACCESS & GROWTH IN DEVELOPING COUNTRIES**

Sponsored by:

John Battle (Labour MP for Leeds West)  
John Bercow (Conservative MP for Buckingham)  
Dr. Vincent Cable (Liberal Democrat MP for Twickenham)  
Ann Clwyd (Labour MP for Cynon Valley)  
Justine Greening (Conservative MP for Putney, Roehampton and Southfields)  
Mark Hunter (Liberal Democrat MP for Cheadle)

This House, mindful of the concerns of the All-Party Parliamentary Group for Human Rights and the Associate Parliamentary Limb Loss Group and the All-Party Parliamentary Group on Overseas Development, welcomes the forthcoming adoption by Her Majesty's Government of the United Nations Convention on the Rights of Persons with Disabilities which should empower Persons with Disabilities as a distinctive group, to be included in mainstream programmes such as, Gender Equality, Education, Employment and Growth;

realises that the eight important Millennium Development Goals (MDGs) agreed by the United Nations and which Her Majesty's Government support contain no reference to disabilities;

advises that for the full achievement in Developing Countries of the aims of the Convention and of the MDGs it is vital to secure and sustain Human Rights to Personal Mobility and to Access;

and therefore urges Her Majesty's Government through the Department for International Development, the Foreign & Commonwealth Office and the Cabinet Office, collaboratively to ensure that financial support for Prosthetic and Orthotic and Wheelchair Services in Developing Countries is mainstreamed and adequate thus enabling people with disabilities to be included in pushing Growth up the development agenda.

#### 48. **AMPUTATED SERVICE PERSONNEL AND VETERANS**

AGREED that in consultation with BLESMA, a paper should be prepared for submission to the appropriate Ministers in Defence and in Health, expressing appreciation of the excellent services being provided at Headley Court, and seeking advice about future plans for extending services to amputated Service Personnel and to amputated Veterans, in the light of the sadly increasing long-term numbers and needs. A particular point was the need to ensure that National Health Services would have the necessary funding to ensure that Veterans would continue to receive, when they left Headley Court, the high quality of care and equipment that they had received at Headley Court.

#### 49. **THIRD SCHOOL**

NOTED that endeavours were continuing to secure a Third School enabling Technicians to obtain Foundation Degrees and the opportunity to progress to Bachelor of Science degrees.

#### 50. **HEALTHCARE THERAPY CUTS**

NOTED that, in consultation with the Colleges of Physiotherapy and of Occupational Therapy, and BACPAR, a document should be prepared for consideration for submission to the appropriate Ministers, highlighting the concerns about service cuts and unemployment and lack of career progression among Physiotherapists and Occupational Therapists, whilst expressing appreciation of the actions so far taken to remedy the defects that had resulted from short-term planning. Relevant documents are attached as appendices A & B.

#### 51. LINKED GROUPS IN SCOTLAND, WALES & NORTHERN IRELAND

NOTED that consultations continued to establish linked Groups in Scotland, Wales and Northern Ireland.

#### 52. CENTRE FOR EVIDENCE BASED PURCHASING

NOTED that, with welcome funding from the Centre for Evidence Based Purchasing, a 'Which' type guide to Batteries for Powered Wheelchairs/Scooters would be published shortly. It was further NOTED that, pursuing earlier work funded by the Centre, it was intended to publish an EBook of best practices in socket design/development by Prosthetists.

#### 53. WHEELCHAIR SERVICES

NOTED that, in collaboration with the All-Party Disability Group, endeavours were still continuing to secure a meeting with the appropriate Minister around the urgent need further to expand Wheelchair Services. There had so far been three deferrals.

#### 54. CHILDREN

Arising from concerns expressed by representatives from STEPS and from REACH (See Appendix C) and shared by others, about the increasing shortages of services for Children, it was NOTED that:

- a document should be prepared for consideration for submission to the appropriate Ministers, highlighting the concerns about service cuts
- STEPS and the Meningitis Trust and the University of Southampton were holding a conference on 28<sup>th</sup> June entitled "Children's and Young People's attitudes to their Prosthesis" [www.steps-charity.org.uk](http://www.steps-charity.org.uk)
- Harold Wood Disablement Services Centre in London was taking the lead, in consultation with all Centres and Users and the All-Party Parliamentary Children's Group, on the holding of a Conference, hopefully at a Westminster venue, to which the appropriate Ministers would be invited.

#### 55. ORTHOTICS

##### INTERNATIONAL SOCIETY OF PROSTHETISTS & ORTHOTISTS (ISPO)

Arising from concerns expressed about the present wastage of Orthotists, difficulties of recruitment to the profession, of maintaining cost-effective high-quality services, and of continuity of care, it was NOTED the ISPO, arising from their concerns about the future of Orthotics Services, would be holding a national conference, to promulgate such concerns and to raise them with the appropriate Ministers.

#### 56. PROSTHETISTS

##### BRITISH ASSOCIATION OF PROSTHETISTS & ORTHOTISTS (BAPO)

NOTED that BAPO were concerned about shortfalls in the funding of Prosthetic and Orthotics nationally, particularly in the South East, about the inequalities in provision among different Centres (the postcode lottery), and prescribing difficulties in implementing best practices and professional standards.

It was further NOTED that concerns continued from the BHTA and from BAPO about the wastage of Prosthetists, the lack of opportunities for professional development and career progression, and difficulties of recruitment. Further evidence and representations should be forthcoming.

**57. BRITISH HEALTHCARE TRADES ASSOCIATION (BHTA)**

NOTED that BHTA Prosthetic and Orthotic members, arising from previously expressed concerns, would welcome further action to bring about comprehensive representations covering all the issues involved.

**58. CHIROPODY AND PODIATRY**

NOTED that the Society of Chiropractic and Podiatry was concerned that the increasing use of "Needs Assessment" as the access tool for NHS care, would restrict the availability of Podiatry services to Diabetic and other "Foot at Risk" patients, with the risk of increasing numbers of otherwise unnecessary amputations. It was suggested that national/regional commissioning approaches were needed contrary to the standard Ministerial response that "this is a matter for local PCT decision." A draft submission from the Society to the Minister Ann Keen would be considered.

**59. DIABETES**

NOTED that the User Group at Roehampton Rehabilitation Centre was helpfully following up the outcomes of the Joint Conference with the All Party Parliamentary Diabetes Group, including the role of the Pharmacist, held at the Centre in the presence of Justine Greening MP on 9<sup>th</sup> November 2007.

**60. HUMAN RIGHTS**

NOTED that a Joint Conference with the All-Party Parliamentary Group on Human Rights was being planned to be held at the West Midlands Rehabilitation Centre in Birmingham, to demonstrate and promulgate the human rights and the economic benefits of rehabilitation.

**61. TRAINING OF SURGEONS IN AMPUTATION**

NOTED that Lord McColl would discuss with the President of the Royal College of Surgeons, the possibilities of reviving the highly successful one-day training courses for Surgeons in Amputation, accompanied by a welcome offer of funding from the Limbless Association.

**62. NATIONAL SERVICE FRAMEWORK FOR LIMB LOSS SERVICES**

NOTED in pursuance of earlier discussions that under the auspices of the Group there would shortly be circulated consultatively, and for continuing development, a document setting out a National Service Framework for Limb Loss Services including prevention.

**63. DATE OF NEXT MEETING**

The next meeting will be held at 3PM on Wednesday 5<sup>th</sup> November 2008 in the House of Commons.

There being no further business the meeting then terminated.

-- END --

# APPENDIX A



THE CHARTERED SOCIETY  
OF PHYSIOTHERAPY

14 Bedford Row  
London WC1R 4ED

**DIRECT LINE 0207 7306 6607**  
**DIRECT FAX 0207 7314 7844**

Justine Greening MP,  
Secretary,  
Associate Parliamentary Limb Loss Group

5<sup>th</sup> August 2008

Dear Justine Greening,

### **Provision of services for the rehabilitation of people with limb loss**

The Chartered Society of Physiotherapy (CSP) is the professional, educational and trades union body for the UK's Chartered physiotherapists, physiotherapy students and assistants. Physiotherapy is Britain's fourth largest health profession and continues to grow.

The CSP recognises the British Association of Chartered Physiotherapists in Amputee Rehabilitation (BACPAR) as its clinical interest group specialising in limb loss rehabilitation and the group represents the CSP in this field.

The CSP has consulted with members on the issue of service cuts and responses have revealed the following concerns regarding service provision for people living with limb loss.

It is reported that many existing services have no direct funding and managers are currently engaged with PCT's in a commissioning process.

As with other provisions for rehabilitation in long term conditions, people with limb loss do not appear to have access to ongoing physiotherapy and associated services. This is especially evident for those who manage their independence by self-referring into rehabilitation services when they, or their carers, acknowledge a dip in their condition.

Our members report that there are budget cuts in the region of 5% year on year imposed on services, even though most have reported increased referrals into their services. For the majority of these teams, the only budget is for staffing the service and therefore cost cutting has an impact upon the workforce. For some teams, this has been seen as an opportunity to re-evaluate the skills and capabilities within the team, leading to workforce reconfiguration and more patient focused AHP integrated working.

In the case of natural wastage, positions have been lost, but in one case where the medical consultant post was vacated, the replacement medical consultant spans a greater breadth of rehabilitation, spreading the cost for this position and a consultant physiotherapist has been recruited with the remaining balance.

Other services have had less capacity for flexibility, which has meant less staffing each year and examples have shown losses to the service of administrative support, prosthetist time and qualified and assistant physiotherapists.

The effort to manage cost cuts has been to reduce services for in and outpatient amputees, reducing treatment times by several sessions per week, often from five sessions to two out-patient sessions week, in spite of evidence and identified need for higher intervention.

Physiotherapy is committed to the practice of audit and service review based on patient need and clinical evidence of best practice, to ensure excellence in service provision. However service review for the purpose of continual cost-cutting of the workforce and service provision is not a sustainable exercise for delivery of quality and timely interventions to encourage, maintain and establish independent self-management. Once a service has been reviewed to deliver optimal provision with adequate resources to ensure up front service provision, those resources must be secured to establish prevention of long term need and dependency and promotion of autonomy and patient responsibility in their wellbeing.

Investment in specialist services which provide timely and efficient support provide a firm platform from which individuals may achieve their potential, lead fulfilling lives and for many, to engage in employment. In turn their independence relieves the burden on incapacity benefit and dependence on social care.

These services describe cuts across the limb loss services. Upper limb and Children's services are even more specialist and requiring consolidation of skills in dedicated teams to best serve patients.

Please do not hesitate to contact the CSP for additional information.

Yours sincerely

Dr Jill Higgins MSc MCSP  
Director of Practice & Development

cc Mr S McNeice

Annex

### **Service Examples to highlight concern and to promote best practice**

Concerns from a unit where patients have historically re-referred themselves are now required to attend a GP surgery for referral into the service. Increased bureaucracy may deter people from seeking help at an early stage, instead waiting until the problem has escalated before contacting services.

A service manager cut her own hours rather than failing to make the 5% budgetary cut.

A multi-professional team has reported loss of administrative staff, half time prosthetist and reduction in physiotherapy workforce. The impact has been passed to patients, in that there are fewer staff to process or treat and the number of patients brought to the rehabilitation unit also reduced on health and safety grounds.

Review of services has reduced the medical model of provision and introduced a revised workforce with an improved skill mix to meet patient need.

# APPENDIX B

# BACPAR REPORT - APRIL 2008

To date BACPAR have 146 members (115 full, 16 departmental, 2 students, 13 associates)

The BACPAR exec meets twice a year and 'meets on-line' once per year.

Last BACPAR exec meeting 14.02.08

## BACPAR Website

As a group we have concerns about our public web site, mainly that it is not up to date. At present we have to rely on the Chartered Society of Physiotherapy (CSP) to update it. We are in the process of rectifying this.

## Innovation

Considering setting up an E journal club via iCSP (interactive network facilitated by CSP for Physiotherapists)

## Guidelines

"Evidence based clinical guidelines for the Physiotherapy Management of adults with Lower Limb Prostheses" 2003 - available on CSP website, and at

<http://www.library.nhs.uk/guidelinesFinder/SearchResults.aspx?searchText=lower%20limb%20prostheses&tabID=288>

"Clinical Guidelines for the pre and post operative Physiotherapy Management of adults with lower limb amputation" 2006 -available from the CSP and at

<http://www.library.nhs.uk/guidelinesfinder/ViewResource.aspx?resID=280334&tabID=288>

CSP has Sold 162 copies of the 2006 guidelines

Falls Guidelines have been developed as part of Bradford post graduate course and are awaiting peer review and feedback before publication.

We have discussed future guidelines could focus on assistant and technical instructor competencies, Paediatric amputees, and manual handling of amputees

## Education

Student Education Guidelines have been updated and are available on icsp  
Bradford PG Certificate in Amputee Rehabilitation (MSc). This course was initially available to physiotherapists, now expanded to include occupational therapists and potentially prosthetists.

## Study days

National - A 2 day study day planned for November, in Wolverhampton, focusing on physiotherapy research and development presented at 12<sup>th</sup> World Congress ISPO, Vancouver, Canada 2007

## Research

BACPAR has been asked to comment on update Cochrane Review on prosthetic ankle/ foot mechanisms

## SPARG (Scottish Physiotherapy Amputee Rehabilitation Group)

BACPAR maintains a close relationship with SPARG

PPAM aid guidelines have been updated and are now available from SPARG

## iCSP

The BACPAR exec feel we are using the site well, important we are involved in its management to give authority, to have specialist knowledge to manage content, build ownership and participation in the network. Helped with peer support, no advertising on this site other than related to BACPAR



## Cuts to occupational therapy posts: effects on people with limb loss

In October 2007 we reported on the reduced quality of patient care and services to help people with limb loss achieve optimum function, health and wellbeing and return to work, following cuts to lead occupational therapy posts.

We continue to hear about cuts to occupational therapy posts, which is becoming more wide spread. It is now having a direct impact on the availability of health and social care provided by multi disciplinary teams that comprise the necessary range of skills and competencies.

### Two recent examples are:

1. Patients with limb loss who attend the BMI hospital in Cheadle, Cheshire will not be able to access a full range of rehabilitation services to enable them to achieve optimum function and return home. This hospital advertises a wide range of services including rehabilitation after accident and orthopaedic surgery. Last week we heard that the whole occupational therapy service was cut.
2. In Devon, there are threats to the long term help and support available to disabled and older people, including those with limb loss. This week we heard from UNISON that Devon County Council proposes to cut 32 full time equivalent occupational therapy posts, leaving just 25 across the county.

### As a result:

Service users will miss out on the benefits of occupational therapy. These include:

- Safe discharge from hospital to home – e.g. to ensure the home is accessible, safe and any necessary equipment and support is in place.
- Help, advice and re-training to carry out daily activities – e.g. to ensure safe use of the toilet, bath or shower and to get dressed and make a drink or a meal.
- Restoration of function and independence – e.g. through graded activities to be able to carry out tasks such as sitting, writing, using a wheelchair.
- Maintaining autonomy and independence – e.g. through equipment or modifications to the environment to enable access in, out and around the home.
- Return to work or school – e.g. through adaptation of a work station, practicing work tasks or developing key board skills to return to school.

Occupational therapy\* makes an essential contribution to the delivery and governance of rehabilitation, and health and social care to support and help people, including those with limb loss and their families / carers.

For more information contact: [Peggy.Frost@cot.co.uk](mailto:Peggy.Frost@cot.co.uk)

\*Occupational therapy is based on the belief that people are occupational beings. By doing tasks and taking part in activities we have purpose and autonomy, we gain confidence and independence, and this, in turn, improves our health and wellbeing.

# APPENDIX C



The Association for Children with Hand or Arm Deficiency  
*Patron: Vacancy*

Correspondence Address: 2 Walden Cottages, Westwood Lane, Normandy, Guildford, GU3 2JB

2 April 2008

Dear Mr S McNeice,

I am writing to the Associate Parliamentary Limb Loss Group on behalf of the trustees, parents and children of Reach, to express our serious concerns for the future of the NHS Limb Centres, with particular concern for upper limb services for children.

Over the past couple of months the Trustees of Reach have heard from several respected sources within the field of prosthetics. These sources have agreed that the future of Limb Centres is looking worrying and bleak. With year on year budgets cuts in the Limb Service it is going to be difficult for them to provide what is required by the patient. Limb centres are unlikely to be able to provide a good quality service which is patient lead.

The number of upper limb patients to lower limb patients, according to one source is a ratio of 1:9. Our concern is that any further cuts in funding will more severely affect the minority, which is the upper limb service. Does this Government really want children to be excluded from activities, sports and education purely because the local Limb Centre cannot afford to give that child a prosthesis which they can effectively use.

The other reason for grave concern is that with continued budget cuts we are fast losing our experienced Prosthetists and they are not being replaced because of a shortage of people training in this field. Very soon even if Limb Centres have the available budgets they will not have the experienced staff to provide a good quality service.

Future developments in the field of prosthetics are likely to come from the USA, partly due to provision for the wounded military personnel coming back from conflict zones such as Afghanistan and Iraq. New developments are emerging which may well benefit our children but will they have a Limb Service able to provide them with these new technologies. At the moment we believe that the answer is "NO".

Please make it your priority to make sure that now and in the future there is a well-funded local Limb Centre that will provide the best prostheses, fitted by world-leading experts, to enable our children to get the most out of life and be our future.

We would be grateful for any feedback you may be able to give on what is being done to ensure an upper limb service in the future.

Yours Sincerely

Gary Phillips CEng MBCS CITP  
Chairman  
T 07044 080 140  
E chairman@reach.org.uk

Head Office: PO Box 54, Helston, Cornwall, TR13 8WD

*Support, Contact and Advice*

'REACH' IS A CHARITY REGISTERED IN ACCORDANCE WITH THE CHARITIES ACT 1960 REGISTERED NO. 278679



## To Members of Associate Parliamentary Limb Loss Group

10<sup>th</sup> April 2008

Dear Mr S McNeice,

I am writing to endorse the letter of 2<sup>nd</sup> April which you have received from REACH regarding year on year budget cuts within the Limb Service, but I would like to make a case for all children's services whether Upper or Lower Limb.

Children's services in a predominantly adult based service are always vulnerable particularly because individually they tend to be cost heavy users of the service, however in the Limb Services their numbers are so small they can easily become overlooked. The latest published report from the National Amputee Statistical Database 2005/06 shows that less than 3% of new referrals were for children under the age of 16. However children disproportionately make up the more complex cases with 9 out of a total of 18 new referrals having multiple levels of amputation, it should also be noted that the downward trend of new referrals for congenital amputation prior to 2004 has been reversed.

With these facts in mind we would ask Associate Parliamentary Limb Loss Group to consider how good quality children's services within the Limb Service can be maintained and developed, particularly at a time when more children are being referred with higher levels of complex needs.

I would be grateful for any feedback you may be able to give on what is being done to ensure that all children and their families can continue to expect the best possible level of care within the NHS Limb Fitting Service.

Yours sincerely,

Sue Banton  
Director

*We don't take walking for granted*

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