



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

Minutes of the Annual General Meeting held at 5.30 pm on Thursday
6th July 2011 in the Thatcher Room 6 at Portcullis House

PRESENT

MEMBERS: Dame Anne Begg MP (Chair); Steve McCabe MP; Alison Seabeck MP; Richard Bacon MP

GUEST SPEAKERS: Andrew Murrison MD MP; Margaret Hickish of the Olympic Delivery Authority

ASSOCIATE MEMBERS ORGANISATIONS: Representatives of Associate Member Organisations present included the following:- Association of Rehabilitation Service Centre Managers; British Association of Chartered Physiotherapists in Amputee Rehabilitation; British Healthcare Trades Association; British Limbless Ex-Servicemen's Association; College of Occupational Therapists; Chartered Society of Physiotherapy; International Society of Prosthetics and Orthotics (UK); Joint Committee on Mobility for Disabled People; Limbless Association; Limbloss Legal Panel; Occupational Therapy in Trauma and Orthopaedic and many other good and valued friends.

Apologies for absence were received.

1. ELECTION OF OFFICERS

AGREED the election of the following Officers:

Co-chairs: Dan Byles MP; Steve McCabe MP; Lord McColl; Alison Seabeck MP and Baroness Tonge;

Secretary: Dame Anne Begg MP.

2. TERMS OF REFERENCE

AGREED the following Terms of Reference for the Group: *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*

3. REGISTRY OF ENTRY

AGREED that the Registry of Entry for Cross-Party Groups be signed by the Secretary and be returned forthwith to the Assistant Registrar at the Office of the Parliamentary Commissioner for Standards.

4. MEMBERS

NOTED the resignation of Mike Wetherley MP and welcomed the appointment of Louise Mensch MP

5. ASSOCIATE MEMBERS

AGREED that Associate Member organisations listed in **Appendix A** to these Minutes be re-appointed.

6. REVIEW OF PROSTHETIC SERVICES

Andrew Murrison MD MP explained that he had recently submitted the Report of his Review of Prosthetic Services to the Prime Minister and so could not comment directly on his recommendations until they were made public.

However, he was able to discuss the key themes that emerged during the review and he also shared some of his experiences, all of which were appreciated by Members. He would be happy to return to the next Meeting to discuss. In the discussion after his talk aspirations were expressed that:

- Prosthetic Services to all patients with limb loss should be strengthened;
- Services should meet the needs of all patients;
- Regional variations in services (post-code prescribing) should be minimised;
- There must be agreed National Guidelines and that these were lacking;
- Services should be commissioned through the National Commissioning Board;
- Full advantage should be taken of the beneficial catalytic stimuli of the high quality services and innovations being generated at the Royal Centre for Defence Medicine in Birmingham including Selly Oak, the Defence Medical Rehabilitation Centre at Headley Court, and Garrison towns such as Colchester and Plymouth;
- There were fewer than 200 Prosthetists available, which further highlighted the importance of additional recruitment, retention and continued professional development.

Furthermore, it was noted by Dr Murrison and reinforced by Members present, that, whilst technical wizardry was important, the key patient priority was a pain-free, accurately-fitted socket enabled by choice of and liaison with his/her Prosthetist on each visit to the Limb Centre, where that Prosthetist had been in place long enough to establish a strong and knowledgeable relationship with the amputee.

7. NATIONAL COMMISSIONING OF CPD SERVICES FOR QUALITY AND EQUALITY

NOTED that concerns continued to be expressed about pressures on health professionals and patients involved with the provision of PROSTHETICS, ORTHOTICS, WHEELCHAIRS and other ASSISTIVE TECHNOLOGIES and recognised the need for ongoing action. Discussions were proceeding with the Department of Health to secure National Commissioning (with reduction in post-code prescribing). A higher focus was being sought on Quality, Recruitment and Retention of Health Professionals, Continued Professional Development, and Innovation. Trusts continued to cut back on these vulnerable services and to increase waiting times in order to reduce their debts.

8. WORLD HEALTH ORGANISATION/WORLD BANK REPORT ON DISABILITY 2011

NOTED that there has been no response from Government to date on the joint World Health Organisation and World Bank Report and that this requires action. The report showed an increase worldwide in the proportion of the population with significant disabilities from 10% to 15%. Feedback would be sought on the implementation of the recommendations in the Report. International Associate Members of the Group continued to reach out, despite financial constraints, to increasing needs for their services. Also see Associate Member update in **Appendix B**.

9. EUROPEAN LIMB LOSS DAY

NOTED that this day will be launched throughout the European Union on Saturday 3 December 2011 and that under the auspices of the APLLG, in collaboration with the INTERNATIONAL SOCIETY FOR PROSTHETICS & ORTHOTICS, this will be preceded by a Parliamentary Reception on Tuesday 29 November.

10. CONCERNS ABOUT PROPOSED DISABILITY LIVING ALLOWANCE REFORMS

Arising from the Government's proposals to replace Disability Living Allowance ("DLA") from 2013/14 with a new benefit entitled "Personal Independence Payment" ("PIP") and the attendant reviews of current DLA recipients; the following were among the views expressed for consideration by Members of Parliament who were present. These were that:

- Consultation with disabled individuals and their representative organisations was not perceived to allow for any real possibility of change in the proposed measures;

- The assessments would be conducted under time and financial constraints, which would limit the assessor's ability to gain a proper understanding of each individual's condition;
- The assessors might well lack adequate experience in the specific conditions pertaining to applicants and even in general medical rehabilitation, which means that they might not appreciate, recognise or record the variable, unpredictable and fluctuating conditions that accompanied limb loss (the good days and the bad days);
- The assessments should take into account the pain and discomfort experienced by the majority of limb wearers;
- There was the misconception that after amputation the wearing of an artificial limb would return the patient to full mobility, which the many amputees present pointed out was a false conception;
- Wheelchairs were extremely useful but not if the house had not been adapted to accommodate them;
- Speedy and effective repair & maintenance services were just as important as timely and effective issue of the artificial limb(s);
- There were mixed experiences about the equity of treatment of older amputees, some good and some bad;
- Doubt was expressed about the restrictions on "passports" for patients with severe complex physical disabilities, which could bring additional personal stress and increasing administrative overheads;
- There was an increasing shortage of Therapists;
- All assessments should be a positive experience, bringing into regard and reality the positive as well as the negative outcomes of limb loss, if and when the required prosthetic/orthotic/special seating services were prescribed and provided.
- The main aim appeared to be to reduce the total cost of benefits, indicating a need to change criteria and to offer more information to patients.
- Therefore there was a risk that individuals who rely on DLA for genuine reasons may suddenly lose this support and lose their ability to live a normal life, as a result of a poorly conducted assessment;
- Consequentially the Government runs the risk of many appeals that would end up costing more than is saved;
- Therefore specialist advice should be sought from Consultants in Medical Rehabilitation and from Expert Patients in the conduct of assessments, or even from charities that have experience in this area;

Additionally there was comment that reviews of DLA recipients, if they were conducted with care and with a proper understanding of the full situation for an amputee, would be an understandable process for the Government to follow.

MPs asked for any further comments to be sent to them for consideration and Anne Begg MP explained that her committee, the Work and Pensions Committee, would be announcing an inquiry into the proposal to replace DLA with PIP, and that she too would welcome input to that inquiry. [Note: This has since been announced on 12 July]

11. PARALYMPICS AND OLYMPIC ACCESS

The Group received with applause a presentation by Margaret Hickish, Advisor to the London Mayor, on the special and comprehensive access arrangements in hand for the forthcoming Paralympic and Olympics. To spread the good news as widely as possible an APLLG Newsletter would be circulated.

FEEDBACK FROM ASSOCIATE MEMBER ORGANISATIONS

12. PHYSIOTHERAPY

NOTED that the British Association of Chartered Physiotherapists in Amputee Rehabilitation (BACPAR) had, with the United Kingdom Rehabilitation Council and the Department for Business and Skills and the British Standards Institution, had contributed to the development/launch of the new (PAS150) Code of Practice for the Delivery of Rehabilitation Services for disabilities and health conditions for both short and long term needs. BACPAR's annual

conference will take place in Leicester on 14/15 November 2011. Updating of their Guidelines for the “Physiotherapy Management of Adults with Lower Limb Prostheses” is in hand.

13. OCCUPATIONAL THERAPY

NOTED that the motto of the British Association of Occupational Therapists is “*Helping People to live their Life the way they want to*”. Robin (pictured right) for instance has Type 2 diabetes and had to have both his legs amputated. As a result he now has to use a wheelchair at home and can no longer carry out his former job. An Occupational Therapist assessed Robin’s needs, recommended home adaptations, and provided guidance to enable Robin to carry on the day-to-day home activities necessary for maintaining his independence and quality of life. As Robin puts it: “*My life is no longer empty by any means. In many ways it is a lot better.*”



14. INTERNATIONAL SOCIETY OF PROSTHETISTS AND ORTHOTISTS

See **Appendix B** to these Minutes.

15. ANANDWAN PROJECT

See **Appendix C** to these Minutes.

16. MOTIVATION PROJECT

See **Appendix D** to these Minutes.

17. DOUGLAS BADER FOUNDATION

See **Appendix E** to these Minutes.

18. LONDON SOUTH BANK UNIVERSITY

NOTED that the first ever Foundation Degree in Clinical Technology will be launched in September at the London South Bank University. Links with the internationally recognised Educational Categories of the International Society of Prosthetics & Orthotics continue to be explored.

19. DATE OF NEXT MEETING

Members should note that the proposed date of the next meeting is WEDNESDAY 26TH OCTOBER 2011 AT 5.30 pm

There being no further business the meeting then terminated.

Feedback on the Minutes please to Wayne Henderson on feedback@apllg.eu

ASSOCIATE MEMBERS

Age UK; Association for Children with Hand or Arm Deficiency (REACH); Association of Rehabilitation Service Centre Managers; British Association of Chartered Physiotherapists in Amputee Rehabilitation (BACPAR); BRAKE; British Association of Prosthetists and Orthotists (BAPO); British Healthcare Trades Association (BHTA); British Limbless Ex-Servicemen's Association (BLESMA); British Organisation of NGOs Development (BOND); British Polio Fellowship; British Society of Rehabilitation Medicine (BSRM); Cambodia Trust; College of Occupational Therapists (COT); Chartered Society of Physiotherapy (CSP); Chronic Pain Policy Coalition; Contact A Family; Cornel Romanian Rehabilitation Centre Trust; Coventry University; Diabetes UK; Disabled Living Foundation; Douglas Bader Foundation; Foundation for Assistive Technologies; Handicap International; International Society of Prosthetics and Orthotics (UK); Joint Committee on Mobility for Disabled People; Landmine Action; Limbless Association; Limbloss Legal Panel; London Health Forum; London South Bank University; Meningitis Trust; Meningitis Research Foundation; Mines Advisory Group; Mobile International Surgical Teams (MIST); Mobility Trust; Motability; Motivation; Murray Foundation; Muscular Dystrophy Campaign; National Health Service Supply Chain; National Prosthetic Managers Association; National Wheelchair Managers Forum; New Limbs for New Lives; Occupational Therapy in Trauma and Orthopaedic (OTTO); Patient Partnership Group; POWER International; Prosthetics, Orthotics & Rehabilitation Technology – Education & Research (PORT-ER); Rehabilitation International; Remploy; Response International; Roehampton University; Royal Hospital for Neuro-Disability; Skills for Health; Society of Chiropodists and Podiatrists; South African Federation of the Disabled (SAFOD); Specialised Healthcare Alliance; Spinal Injuries Association; Steps Charity Worldwide; Thalidomide Society; The Circulation Foundation; The Lindsay Leg Club Foundation; University of Salford; University of Strathclyde; Whizz-Kids and many other good and valued friends.

INTERNATIONAL SOCIETY OF PROSTHETISTS AND ORTHOTISTS UPDATE

Launch of the World Report on Disability

The World Report on Disability was recently released by the WHO and the World Bank during a launch event at the United Nations headquarters on 9 June 2011.

As a follow on document supporting the United Nations Convention on the Rights of People with Disabilities, the report is a call to action and makes nine recommendations for concrete provisions as follows:

1. Enable access to all mainstream policies, systems and services
2. Invest in specific programmes and services for people with disabilities
3. Adopt a national disability strategy and plan of action
4. Involve people with disabilities
5. Improve human resource capacity
6. Provide adequate funding and improve affordability
7. Increase public awareness and understanding of disability
8. Improve disability data collection
9. Strengthen and support research on disability

ISPO warmly welcomes this major step in putting disability on the international policy agenda and calls on the World Health Assembly to adopt these recommendations through a World Health Assembly resolution.

www.ispoint.org Monday, 11 July 2011 09:21

A full copy of the report is available from the World Health Organisation website on the following URL www.who.int/disabilities/world_report/2011/en/index.html

ANANDWAN PROJECT UPDATE

NEW LIMBS FOR NEW LIVES by Penny Penton

News from Navchaitanya (the unit for orthotics and prosthetics at Anandwan in India, which opened February 2007)

It was two years since I had visited to see how the orthotics and prosthetics unit, Navchaitanya, New Limbs for New Lives, was progressing. Meryl and Kate, who both continue to be involved with the hand surgery programme for those who have had leprosy and their rehabilitation, return home regularly with news. But I was keen to see the work for myself and see whether we could be of further help. This time I was pleased to be able to take with me Mary Jane Cole, a physiotherapist with particular skills in amputee rehabilitation whom I met many years ago at Queen Mary's Hospital, Roehampton.



After battling with our taxi we met with the Otto Bock chiefs in Mumbai. This is the international orthopaedic company which has played the vital role in supporting the unit with equipment and installation, supplying everything needed including recruiting personnel, technical training and monitoring since Navchaitanya was opened. Otto Bock are now opening beautifully designed new units all over India as well as supporting the less smart ones like ours, with a realistic contract. Their on-going support and concern became increasingly evident as they welcomed us to their new unit in Nagpur and a few days later we ran a clinic together in Anandwan.

We had a very warm welcome from Dr. Bharati, our medical director, who confirmed that all the resident amputees are now fitted with prosthetics. With Otto Bock staff visiting as needed from Nagpur, new limbs and alterations are made by the technician, Sunil, who has been trained to spot any problems and can call on their advice when needed. Together we saw seventeen amputees, most of whom had lost lower limbs through leprosy, and selected seven who needed more detailed help with better fit and improvement to mobility, either altering or remaking prosthetics or just adjusting their walking style, exercise regime, stump care or



new socks. We were delighted that two skilled orthotists from Otto Bock in Nagpur were willing and able to give up their Saturday at a day's notice, to join us in for busy clinic with team work also including a medical officer, technician and therapists. Our brief stay was busy, and very worthwhile.



The village itself has many new buildings, including improved individual living space for the elderly and new kitchens with solar panels. The traffic has increased, students often have motor bikes. Tractors are beginning to replace the oxen carts and the allocation of 2 saris a year has been increased to 3. The gardens looked beautifully tended, many newly planted, full of flowers and produce with a mass of marigolds and chrysanthemums around Baba's grave. Baba Amte was the founder who set up this village for the care of those with leprosy over 50 years ago.

We visited the hospital where Dr. Pole proudly showed us round and told us of the number of medical camps he runs benefiting many hundreds from the surrounding countryside. These include eye surgery, obstetrics, gynaecology and hand surgery, with 300 receiving treatment for leprosy, which continues to be an endemic problem. There are 1,200 leprosy inhabitants in total but a large increase in the number of visitors with coach loads of students visiting the workshops, special schools and classes, and the many eco projects. The success of the weekly market where villagers can buy and sell produce is also evidence of the reduced fear and stigma of leprosy.



We continue to support our unit through a small charity 'New Limbs for New Lives'. Indian friends of Anandwan, both at home and abroad are also giving generously. The team are now in a position to begin to run outlying clinics and open this valuable service to surrounding communities, which is very exciting. This brief newsletter is to send a warm thank you and let you know how your help, encouragement and support has led to great changes in people's lives and is now looking way into the future in a way we would not have thought possible. It has allowed me to be involved in a hugely rewarding experience for which I am sincerely grateful.

MOTIVATION UPDATE

WHEELS OUT OF POVERTY - MOTIVATION'S 20TH ANNIVERSARY CAMPAIGN

Stuck in bed; reliant on the care of others; suffering or dying from preventable infections; this is the reality of thousands of disabled people in Africa where Motivation has worked since 1999. In developing countries such as Zimbabwe, Tanzania and Uganda disabled people are 82% more likely to live below the poverty line than those without disabilities. Disabled men, women and children regularly experience humiliation, powerlessness and brutal hardship. Disabled people living in poverty are prone to very poor health and more likely to die prematurely. It needn't be like this and Motivation plan to improve the situation for 5,000 disabled people through their **Wheels out of Poverty** campaign. This will give disabled people the means to 'push' themselves out of poverty by providing low-cost wheelchairs that have been designed especially for the rough tracks and roads of the local surroundings.

Motivation's response to the need for wheelchairs is individual - they design affordable wheelchairs that arrive flat-packed, ready for local assembly to fit each individual user. There are fewer breakable parts and use only standard and easily available and maintainable components.

FAUSTINA'S STORY.... Aged 24 and pregnant with her first child, a car accident left Faustina Urassa paralysed. Discharged from hospital to the care of her parents, Faustina was unable to move



independently and became a virtual prisoner at home. Unsurprisingly, she became depressed and had no confidence that she could raise her child. Through Motivation Faustina received a wheelchair and rediscovered her old energy, determination and spirit. Building on her loving relationship with her daughter, Faustina works with other wheelchair users, teaching essential skills that enable them to wheel themselves out of poverty and lead happy and productive lives. Faustina's experience is surprisingly common, alongside distressing tales of mothers encouraged to reject, abandon or harm their disabled babies and children. A wheelchair gives mobility, status and independence; it can bring back self-belief and help someone to help themselves. **It can help keep or bring a disabled person out of poverty.**

MOTIVATION'S WHEELS OUT OF POVERTY CAMPAIGN will help 5,000 people like Faustina enjoy happy, healthy and productive lives - away from poverty.



DOUGLAS BADER FOUNDATION UPDATE

The Douglas Bader Foundation 'Bader Braves', is a recent concept inspired by Douglas being made a Chief of a Canadian Indian Tribe and the Bravery of children with limb loss and other physical or learning disabilities in their efforts to live normal lives.

Sir Douglas Bader being honoured as "Chief Morning Bird" by the Kainai Indians

Bader Braves supports these children (and their families) by offering unique Experiences and improving life-skills to increase confidence.



Bader Braves holds Flying days

providing children with limb loss and physically disabled youngsters from 6-16 with the opportunity of experiencing flight in a light aircraft

Bader Braves holds short break outdoor multi-activity long "Challenge" weekends at the Calvert Trust venues at Kielder Water in Northumberland and Exmoor. These centres offer a fantastic residential and activity programme of sailing, canoeing, archery, climbing, abseiling, orienteering all specifically designed to enable full participation by children with physical disabilities



There are also a number of anniversaries' coming up, which we will endeavour to celebrate and share more widely including the 6th August 2011, which is the 70th anniversary of Douglas Bader's last war time flight. This is being celebrated with an event at Tangmere. Whilst September 2012 is the 30th Anniversary of Douglas Bader's death and October 2012 is the 30th Anniversary of the Douglas Bader Foundation.

For further information please www.douglasbaderfoundation.com

