



Associate Parliamentary Limb Loss Group

for the promotion within Parliament and Whitehall of the PREVENTION OF LIMB LOSS and the provision of prosthetic, orthotic, wheelchairs & special seating and other vital rehabilitation services/technologies for ALL PERSONS WITH LIMB LOSS in the UK and Internationally.

EVERY LIMB LOSS CHILD MATTERS

Associate Parliamentary Limb Loss Group with Harold Wood and Angela Watkinson MP Show the Way Ahead

“Limb centres like Harold Wood are very important to limb loss people – not only to get the limbs – but also the valuable support and advice that we receive. Unless you have a limb issue you will never understand how these centres work. When people know about children with limb loss they seem to have an admiration for them, not sympathy – we don’t want that – we are just like you – no different at all. I will always achieve my goals in life because I have so many people that believe in me. Just because I don’t have a hand doesn’t mean that I can’t have goals. I do! I just have to work that little bit harder and I know I will always succeed!”



These words, in person from 11 year-old Amy Marren, highlighted the determination of all present at an important conference on 25th November 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 (stop post-code prescribing)
- identify best practices and spread them around

The conference was opened by Dr Neil Brown, with a message of goodwill from Harold Wood’s constituency MP Angela Watkinson MP, who is also an active member of the Parliamentary Limb Loss Group.

Daphne Rose, now aged 55, and with childhood experience of the pain and heartbreak of limb loss, raised everyone’s hearts and minds with her message that, given the necessary skilled professional care and services, you can *“live a happy, reasonably active life”*.

She continued;

“I was born without the top part of my femur. Eventually, I had my lower leg amputated. I hope that nobody now will go through the experiences that I went through as a child. I am so glad to be able to say that my last 23/30 years at Harold Wood have been good. The treatment is excellent, the staff helpful, and the leg’s amazing.”

Health Professionals, and Directors of Voluntary Organisations and Parents (often wearing more than one hat) shared their visions and experiences as catalysts, and how to get out there and change things for the better.... a long hard slog!

The overall political situation and how to influence forward developments and ensure best use of additional Government funding was demonstrated from the viewpoint of the Council for Disabled Children.

Research results confirmed the importance of Cosmesis, sadly being one of the first targets in the present round of NHS cuts.

Meningitis was seen as a prime mover of the continuing increase in the numbers of quadruple amputees.

The stands of the Exhibitors from Otto Bock, OrthoEurope, Ossur, RSL Steeper and the Meningitis Trust, were the focus of lively interest and demonstrated best solutions for Patients and Practitioners – if only they had the necessary cash!



Where do we go from here with the battle to ensure the “Recognition of Rehabilitation” and its benefits to Health Economics and to Independent Living? To the next meeting of the Parliamentary Limb Loss Group at the House of Commons in February, letters to individual PCT Chief Executives asking them what they are doing with the additional funding they have received from Government for disabled children, and feedback to Neil Brown from delegates of their achievements and their frustration as the foundation of a research-for-action project.

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