

Dear Mr Rowlands,

I thank you for the copy of Mr Gething's letter dated May 8th. I read the WHSSC documents with interest, hoping that when the Prosthetic and Amputee Rehabilitation Service Specification CP89 stated that '...The Service should have... Separate paediatric facilities and be responsive to the special needs of children with limb deficiency, limb loss, and limb deformity' this would include automatic provision of specialist limbs for children and young people.

Yet the document goes on to list exceptions to standard prosthetic limb provision. Currently, specialist limbs/digits are provided under the following categories:

- War veterans
- Provision of a Water Activity Limb for an Adult
- Provision of a Recreational Upper Limb for a Child
- Provision of a Custom Made Silicon
- Provision of a Myo-electric Upper Limb Prosthesis

It is notable that no mention is made of specialist lower limb or sports or recreational prosthetics for either adults or children. No reason is given for this omission. The same document states that anyone wishing for an additional prosthetic limb must make an IPFR request:

It should be noted that Centres do not normally supply additional recreational limbs, and any requests for recreational limbs excluded from CP89 Prosthetic and Amputee Rehabilitation Services Version: 1.0 Page 15 of 17 the list above should be treated on an individual patient basis, and a request for funding would need to be made based on exceptional circumstances

(CP89, Page 14/17)

If the client's needs cannot be managed within the agreed range of equipment, and the prosthetic and amputee clinical team believe that there are exceptional grounds for providing equipment outside of range, then an Individual Patient Funding Request (IPFR) can be made to WHSSC...

(CP89, Page 15/17)

Mr Gething's letter does not mention whether any IPFRs are made on behalf of young amputees were successful or not. One would hope that they are, however this extract taken from the IPFR patient leaflet does not fill me with hope:

When considering applications the panel will only consider the clinical evidence provided. They will not consider any non-clinical circumstances. For example, factors such as a patient's ability to work or study, care for dependents, or meet financial commitments can't be considered as part of the IPFR process.

Child amputees can 'manage' on ordinary prosthetics, and arguably any 'recreational limbs' would not be essential to their day to day living; nor would a child's ability to work, study and play necessarily be considered under the IPFR assessment criteria.

However my petition is not about 'managing needs', but rather about enhancing lives; about helping children suffering from limb loss to live the most active and fulfilling lives they possibly can. Being able to keep pace with their peers and participate fully in physical activities will have a lasting and positive effect on young amputees, mentally, physically and socially. My daughter already deals with a myriad of problems other children her age do not have to face – fitting problems, gait re-learning, heat rashes, pressure sores and pain management. Although the care we receive at Wrexham is

excellent, these problems are part and parcel of being an amputee. Even before you consider the psychological effects of being disabled and 'different', these problems are a burden she will continue to shoulder for the rest of her life. Childhood is a time when life should be at its most exciting and care free. Putting aside clinical aspects; if specialist prosthetics can greatly improve a child's quality of life and mental wellbeing, then they should be offered without the need for an IPFR.

It is my firm belief that if children can be provided with a recreational upper limb as an exception to the usual provision, then the same must also apply to recreational lower limbs. I hope the WHSSC will concur and make both upper and lower specialist prosthetic limbs available to all young amputees, without the need to submit an IPFR. If this petition is successful then the next time the Prosthetic and Amputee Rehabilitation Service Specification is reviewed, point 4.4.2 will read: Provision of a Recreational ~~Upper~~ Limb for a Child.

Yours Sincerely,

Rebecca Roberts