

## **P-05-817 Specialist prosthetics for child amputees – Correspondence from the Petitioner to the Committee, 04.12.18**

### **Petitioner's response to Welsh Health Specialised Services Committee (WHSSC) statement dated November 2018.**

I noted with disappointment that not one of the 5 applications for a specialist limb was granted through the Individual Patient Funding Request. I understand that the NHS does not comment on individual cases, and as such are unable to give details of why the requests were refused, however one would sincerely hope that it was not purely a cost-cutting measure. Their response to the first question, 'Why there appears to be a distinction made between upper and lower limbs' gives me cause for concern.

Stating that specialist upper limbs are freely available because upper limb amputation / aplasia accounts for only 10% of patients nationwide is an admission of discrimination against lower limb amputees. Specialist prosthetic limbs should be granted on the basis of the positive impact they will have on a patient's mobility and quality of life; and **not** based on the number of amputees who share your disability. If patients with upper limb amputations are automatically entitled to specialist prosthetics, then the same should and must apply to patients with lower limb amputations. This distinction should be removed to ensure fairness and equitable treatment for ALL amputee patients.

Regarding the cost of providing specialist prosthetics such as sports blades: the WHSCC could/did not provide an estimate of the cost. However, there were only 5 amputee applications for an IPFR during the last two years in the whole of Wales. Even allowing that some of them may have been double amputees (like my daughter) and would require two blades, then the cost of granting these IPFRs would have been in the tens of thousands, rather than hundreds of thousands. (It is difficult to find an estimate of cost, however as stated in the BBC article below, a specialist running blade for a child costs around £1000 on the NHS:

<https://www.bbc.co.uk/news/health-38517649>.) I would not consider this to be exorbitantly expensive.

Under the current IPFR criteria, children like my daughter would most likely be ineligible for specialist sports prosthetics as it would be difficult to demonstrate a 'clinical need' for them. WHSCC's apparent reluctance to grant any of the IPFR suggests that if the status quo continues, in a few years' time my daughter's application will also be unsuccessful.

I stress that my petition is not about 'clinical need'. It is about improving a child amputee's quality of life and lightening some of the burden of their disability. If NHS England sees the value of giving specialist sports prosthetics to children and deems it to be advantageous enough to their welfare to warrant a £1.5 million investment in prosthetics for children and young people, then surely NHS Wales must acknowledge the same principle and give Welsh children the right to access specialist limbs in the same way, without bureaucracy or being made to feel that our request is unreasonable?

I reiterate the point I made during my initial petition: we are not asking for millions in funding. We are not asking for untried or untested treatment. We are simply asking that young Welsh amputees have equality with their English peers, and that they have the prosthetics they need to reach their full potential.

I make no apology for ending with a personal plea – because for me, this is a deeply personal issue. This petition was created on behalf of my daughter, who is 4 years old and a double amputee. Learning to walk was a protracted struggle for her, and even now her strength, speed and stamina are not comparable with other children of her age. It grieves me when I remember that there is no magic cure for her amputation – all her life she will have to wear prosthetic legs or else be confined to a wheelchair. It grieves me unspeakably that this is something I cannot fix. I cannot take her disability away from her. All I can do is try my very best to help her overcome the challenges life has thrown at her. We plan journeys and activities carefully, make adaptations where possible, and let her set the pace of our lives. When her strength fails, when her prosthetics leave her sore and tired and uncomfortable, we abandon or change plans, adapt, and occasionally end up giving her a fireman's lift home. But she is growing fast. Planning ahead, the things we see as most essential for her comfort and independence are a pair of 'running blades'.

Specialist sports blades have been proven to help children become more active, and there is anecdotal evidence that they are lighter, more comfortable and can be worn for longer than normal prosthetics. Our prosthesis maker and her manager have both agreed that our daughter would benefit from them once she is older.

The only argument I can see for not giving child lower limb amputees access to specialist sports prosthetics on the NHS is a financial one. I hope I have given you a small glimpse into the reality of living day-to-day with such a life-altering disability; and that as a result you and any of the decision makers will see be able to see beyond the balance sheet. This is about quality of life; about enabling and empowering child amputees and making their young lives easier and more fulfilling.

My little girl is as deserving of support as a child who has lost an arm, or a child amputee living in England. I ask you please, make specialist sports prosthetics available to ALL Welsh child amputees.