

**P-04-452 Equal Rights for Tube-fed Youngsters- Petitioner to the Committee. 29.01.16**

Hi there,

My last response was to say whilst our Direct Payment fight was successful almost 2 years ago – to get PA help for a tube-fed child we still face a position where our daughter is not CHC so if she needs new equipment/services there will still be the CCBC 'fight' to decide who will pay for this vital help we need in the future. This taking place between Health + Social Care.

So whilst we got publicity to show how there is no definition for this '3rd type of child' when asking for help and whilst Health + Social Care may say they will 'endeavor to look at each child on an individual basis and work together' it remains to be seen if this is the case when she next needs help....?

Thanks, Tymandra

Dr Tymandra Blewett-Silcock

Director, POPSYP (Parents of Partially Sighted and Blind Youngsters)