



Parents of Partially Sighted and Blind Youngsters  
Reg Charity 1104560 www.popsy.org.uk

## **e-Petition: 'Equal Rights for Tube-fed Youngsters' in Caerphilly – PERSONAL BACKGROUND INFORMATION**

I would like to add the following information for consideration at your meeting (that I will be observing from the public area) on the 16<sup>th</sup> April 2013 please:

Our daughter has the rare condition Warburg Micro Syndrome – with only 11 other similar children in the world. She is Blind, in a Wheelchair and is Tube-fed – she is also Life-Limited.

We asked for the flexibility of Direct Payments 2 years ago and the lack of a definition for a tube-fed, non-CHC child has resulted in a wrangling that would be bad enough with a disabled child to look after but unforgivable when trying to cope with caring for a terminally ill one !? What we need is JOINT help from Social Services AND Health and yet each deny that our daughter fits their criteria – even given her prognosis.

When I need a break the most - when she is ill - I cannot take my daughter to the Caerphilly overnight respite provision miles away and I do not get those hours back. In turn, when they cancel I am offered an alternative date which we sometimes cannot take up. When I am ill I have no help when caring for my daughter as my Husband works fulltime.

Caerphilly is one of only two or three Boroughs in Wales who will not allow tube-feed trained Personal Assistants (PAs) to be employed by families using Direct Payments. I have confirmed this with the Managers of various DP Advisory Groups eg. DEWIS Centre for Independent Living, based near Pontypridd. I have spoken with 3 families (who I have known since setting-up our POPSY Charity 10 years ago) in adjacent Boroughs who have non-CHC children that require tube-feeding and they employ several PAs (using DPs) who are NOT Nurses. Our Social Services 'Sitting' ladies that we still have for 3-4hrs per month are 'just' tube-feed trained - carrying out exactly the same duties we would need a PA to do.

We requested a meeting last year with high-level Management in both Social Services and Health in Caerphilly so that JOINT decisions could be made to finally 'define' tube-fed, non-CHC children – like our daughter (who has failed a CHC Panel 3 times) and this was refused.

What other avenues are open to us except dropping our daughter off somewhere and saying – over to you !? It will then cost over £500,000 PER YEAR to care for her ! What a position to put families in !

This e-petition highlights a problem that is being ignored in CCBC. An additional 'minor thing' is having a Social Services OT Assessment showing our daughter's need for a medical profile bed and Health unwilling to pay for this as she is not a CHC child – yet another JOINT funding 'loophole'?

**We are begging for a Joint Funded Care Package to help me care for Poppy – a weekly overnight and daily early morning (domiciliary) help to make her life as enjoyable and comfortable as possible and to give me a break from her exhausting regime of hourly tube-feeds, meds, therapies, stoma/contracture care, pain management, hospital visits - the list is endless ...  
Downing Street will not help us as this is a Devolved Issue – PLEASE HELP US !**

Dr Tymandra Blewett-Silcock

**Arwen Poppy Blewett-Silcock's (dob 2/12/2002) Mum and POPSY Charity Director**

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