

Subject: RE: Sunset Commission Meetings | Texas Sunset Commission

From:

To:

Cc:

Date: Monday, June 23, 2014 2:50 PM

DADS

Cheri,

~~I am not able to attend, but I wrote this down. I wasn't sure what form to include this on. The witness affirmation form is the only one I see, but it has no place for written testimony, only personal information. I wasn't sure if I can't be there, if I should fill it out? If I can put it in the form you need, can you send me the name of the form you are talking about? I know you are slammed.~~

~~But here are some of our issues.~~



Anwen is only 7, but last year we were denied MDCP respite care because Anwen wasn't "ill enough". And yes, she is in relatively good health despite chronic infections and illness, skin picking and many open wounds, hip dysplasia, scoliosis, aspiration and growth deficiency as well as ADHD. What amazes me, however, is how behavior and mental issues are not a factor in determining respite care or health services like Medicaid. The complications that can arise because of PWS are never considered - only after or until they occur. There is no preventative care. And the food issues with PWS -the issues that kill- are so very serious and the preventative care is the only thing that keeps them safe. Without additional help and support, many parents/caregivers are overwhelmed and exhausted. Food is everywhere and it is extremely dangerous. Without another person who is an expert on the condition, we are often isolated and in a chronic state of fear for her life.

Other issues include going to doctor's office's and them not believing Anwen has PWS because she has an average IQ and is thin. (She is thin because of our strict diet, locking of food and exercise routine as well as the GH.) We had this experience with our orthopedist who sees her for scoliosis where they offer her lollipops. PWS is not one size fits all, but we experience bias often. Endocrinologists are also

extremely behind the curve, unless a family can afford to travel to Florida. I had to inform my endocrinologist about the papers and research about PWS and Central Adrenal Insufficiency. After that, she was tested. On top of the poor care we receive because of the lack of proactive doctors who care enough about PWS to do the research, there is a complete lack of mental health professionals who know about PWS. We are about to enter the world of anxiety management and there is no one who can provide us with direction here in Texas.

Educationally, we have been lucky that our school meet our need 100%. But I am all over the school and extremely involved. I do this mainly so I am aware of the level of services she gets and ensure the teachers, principal and staff know me and Anwen. I believe if I am there, they are more likely to work with us. We are lucky that I can be at the school so often. We'll see what happens when we get to middle and high school.

Additionally, while we are not in a place where we are seeking residential placement for her, we do fear that we may not have an option for her when she is of age because there are so few places in Texas that work specifically with PWS. We greatly fear that part of our future. We have talked about moving out of state.

Hope this helps.

Thanks!

Rachel