

To Whom It May Concern (which is all of us),

I am writing today to share a bit of our family's incredible struggles with my daughter's medical conditions, P/P.

She had a normal childhood, hit all developmental milestones and then after being hospitalized with pneumonia and a couple of viruses at age 5.5, things changed. Her onset was not overnight like some kids, but the change was night and day. My sociable, curious, playful kid turned into a fearful, isolated insomniac with extreme anxiety and ocd.

We saw a number of specialists, doctors and therapists, searching hard to find the root cause of all the shifts. At least 3/4 of the docs we saw were not covered by insurance. And they typically charge \$300/hour (one was \$450/hour, plus labs and tests).

The shortage of pediatric specialists in oregon is astounding. There were/are 'typical' wait times of 3-18 months to get in for an intial Eval with most of them. One Doc called in a personal favor and got us into a specialist in just 10 weeks. That was a miracle. Except she also couldn't help us.

We saw doctor after doctor who said my daughter needed more time outs and more punishment. My daughter has medical root causes for her behavior. If a doctor told an MS patient they needed to be punished for forgetting things or slurring their words that would be malpractice.

When things got dire and my daughter had periods of extreme need (I'm not going to detail it here, given the amount of retribution we've heard about) and we went to the children's hospital on the hill, they brought in armed guards (grown men in uniform) to 'make my daughter calm down and protect the staff' after my 8 yr old threw a stuffed animal on the ground. My then 8 yr old was cowering in a corner of the room, crying and refusing to look up after a doctor told her she couldn't help her if she didn't stop crying and stormed out of the room (the adult MD stormed out). I picked her up and we left, with grandma, all of us crying.

When a panicked, stressed, worried parent turns to a medical professional for help and hope and is met with disdain and ignorance it is heart breaking. Every single time.

We've spent thousands and thousands of dollars, lost years of work and school and still are not out of the woods. We need help, we need integrated, coordinated care, we need accountability and a way for parents to come forward when innacurate/hurtful medical opinions are doled out, we need back up. P/P should not be a political issue. It's science, plain and simple.

Thank you so much  
for any and all help and advocacy you can provide.

Pam B.  
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