

Having A Child With Special Needs...No One Will Fight Harder Than You

By Pam Lindemann

When my daughter Katherine was born, she was diagnosed with cerebral palsy and a congenital brain deformity. One of my dear friends at the time was Judy, who had been a Speech Language Pathologist, so she had a lot of experience working with children with special needs and their families.

When Judy met Katherine for the first time, when she was just a few months old, Judy looked at me, and with the most serious look on her face, and the most serious tone in her voice, she said, "The quality of this little girl's life will depend on you. No one else will fight harder for her than you will." I never forgot those words, and they forever influenced the way I sought services, quite successfully, for my daughter.

As a parent of a child with special needs, your job is not to be liked by your child's teachers, therapists, doctors or other professionals. Your job is not to be their friend. Your job is obtain the best services possible for your child. Your job is to be respected.

Now, that does not mean that you turn into a wild banshee, yelling, demanding and being rude to people to get what you want. That certainly won't work. However, you do have to be determined, persistent, creative, on the offensive, and you have to summon enough energy to do just one more thing, when what you really want to do is lie down in bed and go to sleep for six months.

Is it hard? Absolutely. Is it exhausting? Without a doubt. Is it lonely? Painfully so, but you have no choice and if you don't do it, no one else will. Will you make mistakes? Sure. I've made plenty of wrong decisions. There are things for my daughter I didn't pursue, that I probably should have. I invested countless hours of energy pursuing new therapies and programs that really didn't benefit her at all, but at the time I thought it was the best for her.

The key is to do *your* best, whatever that is for you at the time. Maybe for a couple of weeks the best you can do is get out of bed, take a shower and put on clean clothes for the day. There will come a time when you're feeling pretty strong and focused, and then you can make appointments with a new specialist, or talk to your child's therapist about new goals, or ask the doctor to consider a different drug.

Everything cannot be a priority at the same time. Looking back over the past 11 years of Katherine's life, I can see where physical therapy was the most important thing for awhile, and then I would focus more on OT and SLT. Sooner or later I would come back to PT.

Most of all, be kind to yourself, and know that you're not alone. Don't be afraid to ask for help. The responsibility is overwhelming, but there are a whole bunch of parents who feel like you do, who understand you, and who will help you. Yes, it is a fight, but it's not one that you have to do alone.