Patrick Dole Belfast LD 346

Good Afternoon everyone and thank you for being here today. My name is Patrick Dole and my wife Andrea and I have two children 1 "normal" 5 yr old and 1 "special needs" child named James. Thank you for this opportunity to share my thoughts on this bill. I'm sure many of you have children here, and I'd like you to think back to right before they were born. Remember that time right before you or your wife was about to give birth, when you said your prayer for a healthy child and for everything to go well as every parent to be does. Then your baby is born a short time later and you are told some hard news. The doctors let you know your child is not healthy. They tell you that your son or daughter will never walk, never talk, never feed themselves or be out of diapers, they also tell you that you will have to watch them pass away soon. In our case they told us we had 2 weeks to 2 months. This was our experience with our son James.

So now you are looking down a path you did not expect to be on, full of stress, wondering if every night could be your sons last, wondering if you fall asleep will your son choke or have a seizure while you sleep. Then in waking hours you are learning about feeding tubes, mickey buttons, complex nourishment needs, seizures and what to do, medications, emergency protocols and so on. I remember the first time James grabbed his feeding tube and yanked his mickey button out. The food that was going into his belly is now going on the floor and the food in his belly is now seeping out. This is not in any parenting book, but you learn because there is no choice.

Our son James is now 7 years old, close to 50lbs, and caring for him is not easy. He needs to move and play like any 7 year old and someone has to do that with him, someone eats with him, sleeps within earshot, dresses him, bathes him, everything, absolutely everything is done by someone else, mainly that person is my wife Andrea, or one of the nurses she has trained to do this job in the way James needs it done.

Its a road no one asks for or dreams of. And there is no other way to say it then, being a parent of these special kids is work. Being a parent is always work but this is a very different kind of work, without well tracked milestones and no promise of them caring for themselves in the future or "growing up".

Now id like you to imagine you are here in your office where you work. Its your job, but imagine you were forced to take this job. Now imagine you can never quit, or actually leave your job. And now imagine you don't get paid. However everyday other people come to work. They work normal hours and get paid a good wage for doing the same work you do. Except when they arrive you have to train them so they can do the job correctly. They come knowing the basics of the job description but not the particular daily requirements. So you teach them, and after a year or sometimes even a week they leave and you have to get someone else trained to do the job. All the while you are the one responsible everyday for the work getting done. When someone calls in sick, or its snowing to hard, or they take a personal day, you are the one that has to step up because the work has to get done because its someones life.

I don't know how this works but I hope you all have stayed with me and imagined living these truths and will agree that a wage for this type of work is not only appropriate, and justified but completely deserved. And if you agree please approve this bill AND make sure it gets funded.

Thank you Patrick Dole