

Dear Chair Noor and members of the committee:

My name is Tram Nguyen, district 61, and my daughter, Sadie Sava, is disabled. She has many medically complex diagnoses and needs 24 hour care. I am writing for you to eliminate TEFRA parental fees (SF 1201) and is included in the Omnibus Bill SF2934.

Many of you on the committee are parents, you love your children and will do whatever it takes for them to have a loving and fulfilled life. Many of you are lucky enough not to have a child that has this many complexities and so understanding these challenges isn't easy. To give you perspective, we've had to pay anywhere from \$17,000 to a minimum of \$10,000 in TEFRA fees in addition to paying for private insurance for our family. We pay into TEFRA because we've had to buy a van to modify it with a ramp to transport her safely and modified our home with ceiling lifts as she is 60 pounds and growing. All these things are needed to keep her safe and the caregivers (grandmother, dad, PCA, and myself) safe as lifting 60 pounds and more will continue to get tougher. Aside from the financial burden, it's stressful to work through the entire process of waivers to even achieve these various services.

We did not know until after birth that Sadie was born with a chromosomal anomaly. She is deafblind, epileptic, low muscle tone, cognitively delayed and receives nourishment via feeding tube. However even with all these obstacles she loves music, swimming and being with her friends like any other 7 year old little girl. It's unfair that we tax more to families because they have a loved one that is disabled. The financial burden is stressful to all of us. It can break marriages up and create mental and physical anguish which is not good for our children who need us to care for them.

I hope that the entire committee will seek to understand this pain point of this community and vote to support the OMNIBUS bill SF 2934 to eliminate SF1201.

Sincerely-

Tram Nguyen

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