Chairman Schumer, Vice Chair Maloney, Senator Klobuchar and members of the distinguished panel. I am Danielle Foltz of Rhode Island and the mother of Trevor Foltz. I want to thank you for this opportunity to speak today about our family's experience with Infantile Spasms and our journey to receive critically needed treatment for our son.

While I am speaking only on behalf of my own family, I would also like to acknowledge the support of the Epilepsy Foundation. The Epilepsy Foundation represents the 3 million Americans who have epilepsy and their goal is to help those individuals get access to the care they need. I know they will continue to follow this hearing and the path from here forward. Thank you.

I understand that today's hearing is highly political. But for us - and the two thousand families devastated by the diagnosis of Infantile Spasms each year - it's personal.

How do you find the words to describe the most horrific event of your life; your personal valley of the shadow of death? Because that is exactly the feeling that clamps your heart when you are at a place where the medication needed to rescue your child is unattainable.

For 7 ½ months we celebrated our beautiful third born, Trevor. In fact, we were packing luggage in anticipation of returning to our non-profit ministry & home in Tanzania, East Africa when we noticed the jerky, odd movements Trevor suddenly started making. It resembled a newborn startle reflex.

Devastated does not touch how we felt when we learned that those jerky movements were actually seizures! Trevor was having as many as 20 seizures in a 60 second span; up to 5 times a day. We knew it was serious when the neurologist told us to meet with him immediately following Trevor's first EEG.

In that meeting we were given the devastating news. Our beautiful 7 ½ month old son had the rare & catastrophic disorder called Infantile Spasms.

All three neurologists we consulted told us the same thing. If we did not get his seizures under control immediately Trevor's developing brain would be irreparably damaged. We were told the only thing between our son and a shot at a normal life was a drug called ACTH, marketed as Acthar gel by Questcor Pharmaceuticals**.**

Our neurologist prepared us that Trevor’s treatment would be pricey. He estimated around $10,000 per vial. We went numb.

We immediately notified our insurance company. The urgency of providing Trevor’s treatment was heavy and we needed to move forward as quickly as possible. As Trevor’s seizures intensified we read the information about IS online and the sorrow of what we were up against was emotionally overwhelming.

What we didn’t know was that 4 months prior to Trevor’s diagnosis, Questcor Pharmaceuticals had implemented a new business model. This business model included raising the price per vial of Acthar Gel from approximately $1000 each to over $30,000 a vial. And because Trevor was the first child to require ACTH treatment after the price increase, not even our neurologist was aware of just how dramatically the price had risen. What he thought would cost no more than $50,000 total would now be an astounding $150,000 for the medication alone!

In hindsight, we have no doubt the excessive price of this drug influenced the insurance company against originally approving it for Trevor.

My husband spent days on the phone fighting for Trevor to have coverage. We knew there was no way we could afford to pay for his treatment ourselves. One vial of Acthar was being quoted at a minimum of $30,000. And Trevor needed 5 vials. We could buy a nice 3 bedroom colonial is some areas of the country with that kind of money! But because we had given our lives to serve a non-profit ministry in Tanzania, we don't own that 3 bedroom colonial. We didn't have a house to mortgage as collateral for his treatment – which I've heard some families have been forced to do. All of our earthly possessions were in Africa. We had nothing to liquidate to come up with the money. But to wait was not okay. We needed to save our son NOW.

And so I was frantically looking for other options. Any options.

I called the Acthar support & assistance line because I read that Questcor offers the assurance that no child who truly needs this treatment will go without. I spoke with a call center representative and was informed that the approval process included paper-work for ourselves & Trevor's doctors to submit. When I asked how long the approval process would take I was informed it would be a minimum of 3 business days. When I asked if approval was a sure thing in a case like ours – I was told "no". At that point, my emotions got the best of me, and I informed her that I thought it was a sham! That if Questcor was really about providing a vital medication in a time of desperate need it wouldn't take three business days just to get a maybe!

When your infant's body is being wracked by forty plus seizures daily – you do not have THREE business days to play Russian Roulette waiting for a medication that could stop his seizures and right the world again!

Those days following Trevor's diagnosis were the most emotionally dark in our family's life. My husband & I were pretty much a puddle on the floor. Just getting that kind of a diagnosis shatters you, but then to add the guilt of knowing that you may not be able to rescue your son because you can't afford to? It's un-imaginable and unacceptable.

We literally thought it was possible that our son would go without treatment. Or that he would be forced to use a less effective medication that could leave him developmentally challenged forever. I wonder how many families are living that same nightmare right now? How many are being exploited in their hour of desperation?

Finally, on Wednesday November 21st 2007, the day before Thanksgiving, after numerous emotional phone calls between my husband & our employer we were told to move forward with the treatment. It had already been one day shy of a week since Trevor's diagnosis. And each day without treatment was stealing our son. We witnessed his physical regression and distress as the seizures became more violent.

We were admitted the following day. Trevor's first Thanksgiving was spent at Hasbro Children's Hospital.

Because ACTH must be injected into the thigh, a nurse had to teach us how to administer it once we went home. When she asked my husband if he was nervous about giving Trevor his shot for the first time, he answered that he was more nervous about holding $5000 in a single syringe. Or worse, dropping the vial!

I know that we were lucky. Our insurance ended up covering Trevor's 6 week course of ACTH; which has proven to be his miracle drug. Trevor has been seizure free since his fourth injection. Trevor is the poster child for why this drug needs to be available & affordable! Today we are celebrating our amazing miracle boy! We pray that Trevor will continue to be seizure free. But what if his spasms return? Will we again have to fight for ACTH?

I will leave this hearing today and go home. I'll return to my life of loving & advocating for my son. But my story is in-ex-tricably connected to the 2000 families this year- and the next- and the next - who will live this horrific diagnosis. What about them? My heart cannot help but be consumed for the other families that will be devastated by Infantile Spasms this year. Will they have access to this drug? Or will ACTH not even be an option for their child because they are priced out of the drug they desperately need?

In fact, in preparation for this testimony today my husband researched the current price of a vial of ACTH. Unbelievably, the escalation has not plateau-ed! The very same vial we ended up paying $26,000 to obtain six months ago, today can cost as much as $40,000. Where does it end? I'm not going to pretend that I understand the many layers of this issue. But what I can wrap my heart around is the terror a mom faces when she cannot rescue her baby. Not because his sickness is un-treatable but because financially she cannot access the medication he needs!

I implore you today to please consider my thoughts and to find a way to help families like mine get access to the medications they need.   Please help families dealing with Infantile Spasms get affordable access to the drug that can give them a miracle too.