

## **Leslie Rogers Testimony SB 409: Pharmaceutical Importation 1-30-2019**

Chair Monnes Anderson and Vice Chair Linthicum members of the committee my name is Leslie Rogers. I am here today to speak in support of SB 409 to allow the importation of pharmaceuticals. I hope that my family's story can be used as an exemplar as to why we must change the pharmaceutical system's structure in the United States. My daughter developed a seizure condition called Infantile Spasms that is treated by a prescription drug called ACTH that was invented in the 1930s. Questcor now Mallinckrodt bought the drug that treats this condition ACTH, and raised the price from 40 dollars a vial to now over 45,000 dollars a vial over 10 years or so. Mallinckrodt also bought the rights to and then blocked a 200 dollar a vial synthetic ACTH treatment Synacthen used in Canada from coming to market in the US. Hospitalization and treatment drove my family to the edge of bankruptcy, and my daughter was left tube fed and suction dependent due to the treatment delays fighting with insurance over the drug price.

The second front line treatment for Infantile Spasms is Vigabatrin. When Lundbeck saw what Mallinckrodt got away with Lundbeck raised the price on Vigabatrin from the 1500 a month I had to pay in 2014 to 26,000 a month in 2018. Lundbeck was trying to capitalize on Vigabatrin before it came off patent, but when the generics entered the market they came in only a few hundred dollars less than the name brand. When vigabatrin came off patent and generics entered the market there was a shortage and the price has stayed near 20,000 a month. The shortage left thousands of children to seize for days waiting for these prescription drugs that are readily available and 60 dollars a month in other countries, but due to the price gouging in ours are unavailable in the United States. This price gouging has led thousands of children to suffer the same fate as my daughter severe brain damage, cerebral palsy, reliance on tube feedings, and many have died. Most of the surviving children require health supports costing untold millions a year, and many of them would be far better off if we were able to get the medications to these children when they needed them. We need to do more to get these desperately needed medications to the children suffering from Infantile Spasms in a timely manner to avoid lifelong consequences. Additionally the story of Valeant pharmaceuticals and others shows this type of price gouging is not an isolated incident, but a tactic of pharma.

Out of respect of the committee's time I have submitted the rest of my testimony in writing detailing the intricacies of the egregious pharmaceutical price gouging in the market to treat Infantile Spasms with links and references. Thank You.

1. FTC Fine of Mallinckrodt [fined 100 million by the FTC](https://www.ftc.gov/news-events/press-releases/2017/01/mallinckrodt-will-pay-100-million-settle-ftc-state-charges-it) <https://www.ftc.gov/news-events/press-releases/2017/01/mallinckrodt-will-pay-100-million-settle-ftc-state-charges-it> . In response to the fine Mallinckrodt just raised the price even more and years later Synacthen is still not on the market.
2. 60 Minutes ran the story, "The Problem with Prescription Drug Prices" about ACTH and the pharmacy middleman Express Scripts [The problem with prescription drug prices](https://www.cbsnews.com/news/the-problem-with-prescription-drug-prices/) <https://www.cbsnews.com/news/the-problem-with-prescription-drug-prices/> .
3. CNN also ran several stories about ACTH in the last few years this one on the 97,000% price increase. [CNN Acthar Price Increase article](https://www.cnn.com/2018/06/29/health/acthar-mallinckrodt-questcor-price-hike-trevor-foltz/index.html) <https://www.cnn.com/2018/06/29/health/acthar-mallinckrodt-questcor-price-hike-trevor-foltz/index.html>
4. The growth in off label use of ACTH costing Medicare [CNN ACTH Medicare Costs Article](https://www.cnn.com/2018/06/29/health/acthar-mallinckrodt-medicare-claims-doctor-payments/index.html) <https://www.cnn.com/2018/06/29/health/acthar-mallinckrodt-medicare-claims-doctor-payments/index.html> .
5. This article talks about specialty Pharmacy relationships. Mallinckrodt's partner pharmacy for the prescription drug ACTH is Express Script ...p.s. they were a nightmare to work with and led to many times where delays would mean we would be running out of the prescription drug and it could cause a catastrophic relapse of seizures <http://www.businessinsider.com/jim-chanos-mallinckrodt-express-scripts-2017-5>
6. Here is an article on the financials of ACTH, and it is costing medicare over 500 Million Medicare spending on Mallinckrodt drug tops \$500 million - St. Louis Business Journal <http://www.bizjournals.com/stlouis/news/2016/12/27/medicare-spending-on-mallinckrodt-drug-tops-500.html>
7. Mallinckrodt sees the ACTH train coming to an end and they are taking similar action with running up the price of their new drug (this article from Regulatory Affairs Professional Society also highlights other examples of price gouging in the industry) <https://www.raps.org/regulatory-focus%E2%84%A2/news->

[articles/2017/5/senator-seeks-more-info-from-mallinckrodt-on-price-increases-of-acetaminophen-injection](#)