

## Testimony for Sub-Committee Meeting on October 7, 2015

My name is Laura Jackson, and I have been a food-allergy parent for over 25 years, raising two sons with life-threatening food allergies.

I know all too well the dangers of a severe allergic reaction, having witnessed it with my own child. Watching my son's symptoms progress from mild to severe in a matter of seconds – seeing his labored breathing – the panic in his eyes – racing to the emergency room and wondering if we could get there in time – knowing that a tragedy was possible -- living with the fear of it happening again – worrying at every meal.

These experiences inspired me to form the Kentucky Families with Food Allergies support group here in Lexington 10 years ago. There are many parents like me in our state, all facing the financial and emotional responsibilities that come from raising a child with a life-threatening condition. That is why Kentucky's food allergy parents are so concerned about the current EpiPen price increases.

For over 15 years, my family purchased 8 to 10 EpiPen two-packs per year for our sons who are now grown. We needed that many due to expiration dates, and also to ensure that the injectors would always be within reach at home, when traveling, or at school, because prompt administration can make the difference between life and death.

In 2013, we were thrilled to have a new option when the Auvi-Q injector came onto the market. It was compact and much more user-friendly, so we switched to the Auvi-Q when it was first introduced. In 2013, it cost my family roughly the same amount as the EpiPens injectors. But soon after we had already filled our prescription, the EpiPen manufacturer began offering significant discounts so that EpiPens were less expensive than Auvi-Q. Then, Auvi-Q offered discounts. I saw the cause and effect: now that EpiPens had a competitor, they found a way to lower the price.

Two years later in July of 2015, our insurance changed to a nearly unreachable \$5,000 deductible, so we began paying the cash price. At that time, our cost for an EpiPen two-pack or an Auvi-Q two pack was virtually the same at about \$390.

But within a few months, there were dramatic changes in price. In October 2015, Auvi-Q was recalled, and two months later our cost for an EpiPen two-pack shot up to well over \$600. That was an increase of over \$200. Since our insurance had not changed, I believe that the manufacturer was responsible.

When I asked my pharmacist why the price had increased so dramatically, he said, "They are the only game in town." It is my feeling that if Mylan had competition, the price would drop.

We went looking for an alternative. Unfortunately, there is no exact alternative. We opted to purchase a generic epinephrine injector, called Adrenaclick, that cost us \$116 for a two-pack, but it is not an exact substitute. That is why the pharmacy won't automatically substitute one for another. Some consumers might find the generic harder to use. In addition, many parents are not aware that Adrenaclick is available. EpiPen is well-known due to their advertising and marketing campaigns, but there is no marketing for the generic. That is another issue to address: how do we make sure consumers are aware of this lower-cost option?

My local school system is also affected. They tell me that fewer parents are sending EpiPens to keep at school, due to the cost. This creates a dangerous situation. In Fayette County, each building has four stock EpiPens for emergency use, but they are intended to be a safety net for the undiagnosed or for students whose own EpiPen is not available. Those EpiPens stay in the building. That means students are riding on busses without EpiPens, going on field trips without EpiPens, walking home without EpiPens, going to sporting events without EpiPens. The high cost is putting children at risk.

There are many families in our local support group who are struggling with this issue. Some parents are keeping EpiPens past the expiration date. Some parents are doing without. Many parents have told me they are frustrated that one company has so much control. We need this life-saving medication to be sold at a reasonable price so that every child can be safe. Please allow more manufacturers to produce epinephrine auto-injectors.