

# EpiPen Prices: Once I Felt Grateful To Mylan, Now I Feel Co-Opted

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By Ruth LovettSmith

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When I entered the hotel restaurant, I saw a long table covered in china, flatware and wine glasses. So many wine glasses. This was my first experience being courted by a large company.

It was early 2013, and because I wrote [a blog on food allergies](#) back then, I had been invited to an exclusive, all-expenses-paid trip to New York City. The large company was Mylan and the event at the Strand Hotel was dubbed the Mylan Summit.

On the first evening, we food allergy bloggers were treated to a three-course allergy-friendly dinner. Many bottles of wine filled the many glasses. Day 2 was a full-day conference that involved hearing about the latest in allergy research from a pediatrician and author. Bloggers also received social media and blogging tips from a social media expert.

I remember a Mylan representative asking us what our concerns were within the food allergy community. I felt deeply grateful to be asked. It was the first time it seemed like someone who could make a difference was really listening.

Now, given the recent reports on Mylan's astronomical EpiPen price hikes, I can see how parent bloggers like me become co-opted by companies that make the products we need. Most of us are not investigative journalists; we're parents who want desperately to help our children. But still, I wonder: Did we accidentally trade in our integrity for a four-star dinner and a night at a posh hotel?

I started blogging about food allergies in 2009. It was my way of connecting with others who understood the issues and a way to share all that I had learned. Life-threatening food allergies are scary and anaphylaxis is even scarier. When my son had his last anaphylactic episode, he said, just as I was about to jab the EpiPen into his thigh, "Wait, stop. If I die, I just want you to know that I love you." He was 11 years old.

He's 13 now and we've come a long way. But it wasn't always easy. When he was 5 years old, I spent months fighting with his school so that he would not have to eat lunch alone. I've had to explain to well-meaning friends and relatives that no, he can't just have a little taste. I've shown coaches and parents how to use the EpiPen and have watched their panicked expressions. Because of that, I rarely leave sports practices, birthdays or playdates. That last reaction he had, it was at a baseball practice.

Through the years, I've volunteered my time as a support group team leader for the Asthma and Allergy Foundation of America New England Chapter, and later joined its board of directors. I wanted desperately to help and give back to the community.

In 2013, when I got the call from Mylan, I was skeptical at first. What would this pharmaceutical company want in return? But they never demanded anything. They just sent me regular emails and press releases that I could share with my readers. Sometimes I did and sometimes I didn't.

I'm not sure whether the Mylan Summit was a huge success or if Mylan had a plan all along. I received an invite for a second Mylan Summit about six months later, and a third summit in April 2014. My expenses were covered for each trip.

The attendees ranged from well-known authors and bloggers, to representatives from national and nonprofit organizations. What started as seeking information from the food allergy community slowly morphed into sessions on what Mylan was doing *for* the food allergy community.

Discussion topics included the School Access to Emergency Epinephrine Act that President Obama signed in November 2013. Known as the EpiPen Law, it provides a financial incentive to states that require schools to maintain an emergency supply of epinephrine and develop a plan to ensure that an EpiPen-trained individual is available during school hours.

We also discussed Mylan's "EpiPen4Schools" program, which offers four free EpiPens and other materials to schools. We covered Mylan's EpiPen brand update: full-page print ads in magazines and a series of television commercials. And then there was the EpiPen "\$0 co-pay" card: a coupon card that allows those eligible to save up to a maximum of \$300 per EpiPen 2-Pak.

In my opinion, these were all good things. Mylan was getting the word out about food allergies. Kids were getting access to emergency epinephrine in schools. Parents were saving money. Like my fellow Mylan Summit bloggers, I was thrilled to share this information on my website and social media.

Then life got busy. Over time, I stopped blogging about food allergies and moved on to other ventures. However, I still kept in touch with my fellow food allergy bloggers, and in May 2015, I read about the most recent Mylan Summit: a big trip to Disneyland. It seems that Mylan has partnered with Disney so that all parks have EpiPens stocked at their first aid stations.

"Another great thing," I remember thinking. And then, "Boy, this Mylan Summit is really growing." Beyond that, I didn't give it much thought. Not until these last couple of weeks.

A social media firestorm seemed to crop up out of nowhere. Recent headlines included:

- [Why Did Mylan Hike EpiPen Prices 400%? Because They Could](#)
- ["How Marketing Turned EpiPen Into a Billion Dollar Business"](#)
- [Mylan CEO's Pay Rose Over 600 Percent as EpiPen Price Rose 400 Percent](#)

As I read more and more, I started to feel sick and a little used. According to The New York Times, the 2007 list price for a pack of two EpiPens was a little more than \$100. Today it is well over \$600. Most of the increase has come in the last three years.

The first Mylan Summit occurred in 2013. Since then, food allergy bloggers have been sharing and re-sharing Mylan's news. Readers have been sharing and re-sharing. Over three years, Mylan has done what many in the community have seen as numerous good deeds. All the while, it was increasing the cost of the EpiPen significantly and rewarding Mylan CEO Heather Bresch with [total compensation of \\$19 million](#) by 2015.

What is most interesting to me is that many of the Mylan Summit attendees I know have remained quiet on the issue. Even numerous food allergy nonprofits have remained silent. A few Mylan Summit attendees have spoken out, saying that the system is broken. However, from what I've seen, many are tiptoeing around the price hike issue — with the major exception of Kelly Rudnicki, a single mother of five who spoke out and [resigned publicly as a spokesperson](#) for Mylan.

After her resignation, many in the community asked how she could possibly not have known what was going on. I can't speak for her. But as someone lucky enough to have insurance that covers the EpiPen, I can say that my out-of-pocket cost has consisted of only a co-pay of \$30 for every two-pack of EpiPens. I was unaware that the price of the EpiPen was reaching an all-time high and it never came up in any of the Mylan Summits I attended. Looking at some of the write-ups from the most recent Disney Mylan Summit, it appears as though there was some price discussion, but I wasn't there.

Naïve as it might sound, I attended the Mylan Summits with the hope of finding an ally for the community. Some have argued that Mylan is a for-profit business, that what is happening is good business and legal. Others have said that Mylan is not to blame, that it is the system.

Some of that might be true, but does it make it right? Can you make a profit without taking advantage of a community?

Food allergy bloggers have used their voice to help Mylan to get where it is today. Now is the time for them -- for us -- to use that voice to demand change.

*Ruth LovettSmith is a Massachusetts-based writer and artist. She shares DIY, art and design projects and tips on her [website](#).*

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- [Maker Of EpiPen To Sell Generic Version For Half The Price](#)
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