

PUBLIC COMMENTS IN SUPPORT OF MAKING GLUTEN AND ALL GLUTEN CONTAINING GRAINS TO BE CONSIDERED A TOP FOOD ALLERGEN IN THE UNITED STATES

My name is Seth Tegal and my daughter Adina, was diagnosed with Celiac Disease in 2018, at the age of 8. Since then, my wife, daughter and I have had to not just adjust our way of living, but truly change almost every single little detail about how we buy, consume, cook and store food at home, in addition to limiting, changing or restricting the stores, restaurants, and public and private events we attend and patron. This does not take into account undergoing the overwhelming task of learning the logistics and minor details of living a gluten free life and maintaining a gluten free household. Because gluten is a protein and not a bacteria, non-stick surfaces (eg pots & pans), wood cooking utensils and cutting boards, plastic storage containers and other porous items often cannot have the gluten cleaned off of it. In our home, we had to literally change out all of our Tupperware containers, pots and pans, cutting boards, travel mugs and more because we were a gluten-eating household, prior to Adina's diagnosis. This was a very costly adventure, to say the least.

For almost all of Adina's childhood, we knew something was "different" about her. Despite having shorter than average parents, Adina's height and weight was substantially low on the growth charts, her hair paper thin and never grew past her chin until she was off of gluten, her bones brittle and prone to breaks, and she constantly had stomach and digestive issues, many which went unexplained for years. I vividly remember many instances where Adina would feverishly scratch her head while eating a meal that contained gluten. Me, being the naïve father I was, I honestly thought her hair became greasy because of dirty fingers touching her scalp. Little did I know, Adina had a cluster of hives on her scalp, every single time she ate gluten.

Countless sleepless nights sitting on the floor in the bathroom with Adina curled up in a ball, laying in excruciating pain with us sitting there, helpless, watching her. That same helpless feeling we have as her parents, every time she has to be taken out of school for an upper endoscopy to monitor the maintenance of her gluten free lifestyle.

There are many things that are disrupted when raising a child who has Celiac Disease. First and foremost, it's the immediate feeling of being excluded and the worry, anxiety and discomfort that accompanies it. When Adina was first diagnosed, she felt "different" right away, and even almost 6 years after her diagnosis, she still feels different from her peers. Even though we had a 504 and IEP plan, her public-school teachers were reluctant, though willing to try their best to accommodate her needs. Whether it was constantly washing everyone's desks with soap and water after snack or lunch, or after arts & crafts, her teachers struggled. Let's not forget every elementary schooler favorite part of school – classroom pizza parties. What better way to make a kid feel excluded than a class-wide pizza party. There were even times when her teachers made her eat lunch or have snack at a separated desk in the corner of the room to try and prevent cross contamination.

Adina will be 13 years old in March 2024 and even to this day, she struggles with anxiety related to being able to feel included in all aspects of life, whether school, sports or other related

activities. There've even been times when she'd been inadvertently glutened while eating with friends during holidays. The only place she can safely eat without worry, is at home.

The "joke" in the Celiac community is "Life's a picnic", because you literally have to bring your own food, everywhere you go, and it doesn't matter if you're a child or adult, this will always carry the feeling of exclusion whether you're at school, summer camp, a friend's house, work or restaurant – living with celiac disease means taking a risk, every time you leave your home or "safe space".

It is my personal opinion that Gluten and any and all gluten-containing grains should be counted as a top allergen in the United States. According to the FDA, a top food allergen requires an anaphylactic response, however not all people with a peanut, dairy, egg or other food allergen is guaranteed to trigger anaphylaxis. Likewise, environmental allergens trigger differing responses in different people, likely no two people the exact same, yet it is allowable for the definition of a non-food allergen to be much broader. Knowing that 80+ other countries in the world consider gluten as a top food allergen, I simply don't understand why the United States is unwilling to evolve its requirement for a food to be considered a top allergen, and get up to par with almost 44% of the rest of the world.

Thank you for your time and consideration.

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January 2024, Adina sleeping in the car on a road trip after being accidentally glutened while at her great-grandmother's 100th birthday celebration.



July 2022, St Croix Regional Medical Center - Adina in the hospital while recovering from a potential glutening from an antibiotic- the event that triggered the ADINA Act.



Feb 2023, Adina's 5th Endoscopy (check-up) after being diagnosed with Celiac Disease and EoE in 2017