

**From:** Joy Sloan  
**To:** [Connie Beckett](#)  
**Subject:** HB2103  
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My granddaughter Ava Gregg, age 10, has eosinophilic esophagitis, gastroenteritis & colitis (EGIDS). She is allergic to eggs, peanuts, turkey & various fruits & vegetables. After being diagnosed with this disease she had to remove all dairy from her diet & after her next endoscopy/colonoscopy in February will have to give up wheat if she is not in remission.

Shortly after being diagnosed my daughter & I took Ava shopping to see what products were available that she might like to eat. After purchasing the food Ava started crying & told her mom "you can't afford this". I told her not to worry, that I would pay for her food & her parents could pay for the food for their other 3 children. Pancake mix (makes 11 pancakes) or brownie mix (8x8 pan) that is egg free & dairy free is \$8.50 per box. Vegan cheeses & butter are quite expensive too.

My son-in-law has good insurance through work but they still have to pay \$800 out of pocket for each scope which will be every 2 months until Ava is in remission.

I had planned on working until age 66 but will retire this year when I turn 65 so I can move to where they live to help out. The doctor highly suspects that Ava's little sister Hadley may have this disease also as she is starting to have some symptoms.

As a RN & a Certified Diabetes Educator I can honestly tell you that EGID makes Type 1 diabetes look easy & it's not. The abdominal pain, choking, vomiting & severe random muscle pain that goes with this disease is horrible. Both Ava & Hadley have awoke with such severe leg pain that they cannot bear weight & the pain can be for a few hours or up to a week. Hadley was diagnosed with Juvenile Arthritis when she was 3 but is now having muscular pain similar to Ava's.

I pray that my granddaughters never need the Amino Acid Medical Nutrition but I feel so sorry for the families that do. I can't imagine how they can possibly pay for that with all the other medical expenses they have.

Thank you for your time & for sharing this with Rep. Vickrey.

Sincerely,  
Joy Sloan  
Jsloan81@yahoo.com  
3166808710

Sent from my iPad