

This letter/email serves as an overview of medical condition, just so that you are aware of what [he/she] deals with, and are equipped to address any concerns that may arise at school. [he/she] will have an Individual Health Care Plan, Asthma Action Plan, and 504.

What is [student name] condition?

[student name] has an Eosinophilic Gastrointestinal Disorder, or EGID. The type of EGID she has is Eosinophilic Esophagitis, also called EoE.

What is EoE?

Eosinophils are white blood cells that function in immune response. They usually fight parasites and other invaders, but in those who suffer from EGIDs these eosinophils mistake swallowed triggers for enemies and fight the perceived threat by releasing their toxic payload of chemicals into the esophageal tissues. This results in the destruction of healthy tissue. EoE is diagnosed by endoscopy with biopsies that reveal greater than 15 eosinophils per high powered frame in the esophageal tissue. A healthy person should have zero eosinophils in his esophagus. (what was [he/she] count?) When [students name] was diagnosed in October of 2010, the prevalence of EoE was about 52/100,000 people, but due to increased awareness and other unknown factors the prevalence has skyrocketed to nearly 1/1000 over the last 6 years. There is more general information on EGIDs in the enclosed links.

How does EoE affect [student name]?

Most of the Eos Kids suffer from severe food intolerances and often food allergies that result in extreme dietary restriction. [student's name] does fall into these statistics. [he/she] is on a strict elemental diet with only a handful of foods allowed by mouth.

[he/she] has been repeatedly tested for allergies and EoE triggers, using different testing modalities, and [he/she] has only tested positive to pork, fish, mangos, & gelatin. However [he/she] avoids all food at this time unless [he/she] has passed a food trial for that specific food. Allergy tests are not fool-proof, and often fail to reveal triggers.

In addition to a food restricted diet, [student name] must also be on an amino-acid base formula to help supplement [he/she] nutrition. [he/she] is currently at 550ml of formula daily, which [he/she] receives at school at 9:30 am and at home at 3:30pm. The school nurse has specific instructions on how to set up feeds, care for the site, and anything else medical [student name] may need while at school. [student name] had a feeding tube placed in September of 2013. [he/she] has an AMT Mini Glow Button. [he/she] site is normally quite clean, however there may be a slight discharge from time to time. [he/she] prefers a split 2 x2 sponge on the site. [he/she] will have extra in her back pack as well in the nurse's office.

[student's name] has symptoms which may include pain, swelling, skin rash, hives, reflux, choking, difficulty swallowing, nausea, vomiting, loss of appetite, abdominal cramping, diarrhea, fever, esophageal rings, protein loss, anemia, and malabsorption. Most EoE patients who can identify their triggers find that they are usually foods, as well over 90% of EoE patients can achieve disease remission by removing all trigger foods from their diet, so as of now [students name] is in the minority as her disease is fully active.

What are [student's name] main symptoms?

One common symptom is "functional" or "idiopathic" abdominal pain. This is a painful disease. [he/she] will indicate this pain as located just above [he/she] naval and it is incredibly painful. [he/she] is also experiencing lower abdominal pain due to dehydrated intestines.

The other symptom [student's name] most-often experiences is reflux and/or vomiting. [he/she] will excuse herself from a room without notice to deal with the reflux and/or vomiting. [he/she] may come to you and state [he/she] has "thrown up" in [he/she] mouth. When this happens, we encourage [he/she] to get a drink of water and rinse out [he/she] mouth. Vomiting is rare but does occur. We do not make a big deal out of it. [he/she] is very sensitive and will be embarrassed if it is made to be a big deal. This is normal to [he/she] and should be treated as such.

What can we do when [student's name] is in pain?

We tried many things to help with the pain. There is nothing we can do to prevent her from hurting, as [he/she] disease is exceedingly well controlled, and there is no treatable cause of the pain. To help [he/she] manage we offer rest and distraction seems to work at times.

Please note----One result of living with pain is a skewed sense of pain. When Abigail is in pain, especially if the pain is internal, [he/she] may not react to it as you would expect. There were several days last year when [he/she] came home from school and [he/she] immediately complained of belly pain, and when I asked [he/she] how long she'd been hurting [he/she]'d answer that pain began much earlier while at school, but [he/she]'d simply failed to alert anyone and chose to tough it out- then [he/she]'d go ball

up on the couch. [student's name] a pretty tough kid, so if [he/she] does complain of pain at school, it is probably bad by that point. [he/she] does have prescription pain medicine, but a parent will need to be notified as only they can dispense it.

What can we do when [student's name] has reflux and/or vomiting?

[he/she] is already on a very high dose of antacids daily. There isn't much we can do about it. We encourage [he/she] to drink plenty of water and rinse [he/she] mouth out daily, especially if [he/she] makes a complaint. If [he/she] does vomit at school, we request to be acknowledged immediately.

However, we do not wish it to be made public, or a big deal out of. As I have already stated, [student name] is very sensitive and will become embarrassed easily. [he/she] should not feel ashamed of something [he/she] cannot control. Please have [he/she] lay down with a cool toweling on her forehead until I can get to [he/she]. Little movement is the best option for [he/she] at that point.

How is [student's name] EoE managed?

Currently [student's name] is on an elemental diet. [he/she] receives all of her nutrition from [he/she] formula, Neocate, which is administered by [he/she] feeding pump both at school and at home. [student's name] trials each food individually, and then has an endoscope procedure to see if there is any internal damage or irritation to the specific food. We treat [student's name] EoE-associated reflux with Prevacid. Eosinophils thrive in acidic environments, so the Prevacid also helps keep [he/she] esophagus less friendly to the eosinophils.

Some of the options for treatment of EoE are: -do they need this part? You referred to a lot of it earlier...and described her treatment above

-Remove all food, place patient on an elemental formula, and try foods back one at a time to identify any EoE triggers. This requires frequent endoscopies w/ biopsies to check for eosinophilic infiltration of the esophagus as each new food is introduced. The formulas are not very palatable, and proper nutrition is gained only by consuming large volumes, which often leads to the placement of feeding tubes for children on elemental formula.

This is done for more severe cases like [student's name].

-Remove the top eight allergens (eggs, wheat, nuts, peanuts, dairy, soy, fish, and shellfish) and see if this makes the patient better. This is successful in many children, as those are the most common food triggers for EoE.

-Try medications, such as the Budesonide slurry and antacid medications can also be used in conjunction with elemental or restricted diets.

What other conditions does [students name] have?

As you will note from [he/she] paperwork, [student's name] also has asthma, immunodeficiency, postprandial hypoglycemia, and an enzyme deficiency in [he/she] intestines. [he/she] also has eczema as well. EoE is an inflammatory disease, and therefore other such inflammatory diseases are common in the EGID population. When [student's name] asthma flares, so does [he/she] EoE, and vice versa. It is important to keep [he/she] asthma well-managed so that [he/she] is not wheezing and creating a vacuum in [he/she] chest that would trigger his EoE-associated-reflux and irritate [he/she] already fragile esophagus.

We treat [Student's Name] asthma with Alvesco daily. We add Albuterol or Budesonide via nebulizer when needed. [Student's Name] also has an inhaler in case of an asthma attack. During weeks consisting of gym, [he/she] will need to stop into the nurses to use [he/she] inhaler before gym class. [he/she] also has an epi-pen for [he/she] food allergies but has never had the need to use it. It will be at school just in case, but hopefully [he/she] will not need to use it.

[Student's Name] also has immunodeficiency disorder. At this time [he/she] doctors are unsure of the exact deficiency; however it has been narrowed down to pneumococcal related. [he/she] has already received the pvac 23 booster shot prior to the school year, and [he/she] will be receiving a specific flu shot made for those with low immune systems in the fall.

[he/she] immune system is very weak and almost nonexistent. We are constantly reminding [he/she] to wash her hands. I will provide hand sanitizer for [he/she] to use at school if she is unable to wash [he/she] hands. [he/she] is not allowed to use the water fountains. In 2013, [student's] had meningitis caused by a strain of pneumococcal strep. It was at that time [student's name] was diagnosed by an immunologist with immunodeficiency disorder. Currently there is no medical way to prevent infections. The only measures we have available to us is hand washing, and keeping [he/she] "area" as clean as possible.

[Student's Name] has postprandial hypoglycemia as well. This is mainly due to [he/she] liquid formula diet [he/she] has sustained for the past few years. [Student's Name] was solely reliant on formula, but has now been able to add solid foods to [he/she] diet. However, most of [he/she] diet consists of fruit. The sugar burns quickly. [he/she] pancreas is now used to working immediately after eating to break the down the sugars found in [he/she] diet. So, it over produces the amount of insulin [he/she] needs. Since [he/she] food now takes longer to break down, the sugars are not immediately absorbed, causing [he/she] sugar levels to drop after consuming food. [Student's Name] has a glucometer in the nurse's office to measure [he/she] sugar levels if [he/she] is feeling unwell. Symptoms may include clammy hands, shakiness, dizziness, and headache. If [he/she] sugars are low, fruit juice and fruit will be kept in the nurse's office to help bring up [he/she] sugar levels.

In addition to the juice, I will also be providing a large water bottle for [he/she] daily. Over the summer [student's name] was diagnosed with a dehydrated intestine due to an enzyme deficiency. [he/she] needs to consume 62 to 72 fluid ounces daily. At this time, [he/she] medical teams are still working on treatments. The water also tends to fill [he/she] stomach and provide a cooling sensation when [he/she] is having acid reflux, which is in addition to [he/she] EoE.

What does the future hold for [student's name] regarding her EoE?

Skipping or stopping medications or failing to treat EoE is not an option. Recent studies have shown that poorly managed or un-treated EoE will lead to remodeling of the esophageal tissues, causing deep tissue damage, strictures, stiffening and narrowing of the esophagus, and eventually swallowing difficulties, food impaction, and the inability to swallow often requiring esophageal dilation and sometimes feeding tubes.

If you ever have the pleasure of meeting another "Eos Kid" you'll find that [student's name] is one of the easiest to understand. [he/she]'s very well-managed and very verbal, so [he/she]'s a good historian and able to describe what's going on inside [he/she], often using the correct anatomical terms. EoE is a very dynamic disease. Things can change unexpectedly.

Should you notice that [he/she] is complaining of pain more often than usual or acting as if [he/she] is a little "off", or complains of reflux more frequently, or exhibiting any new or unusual behaviors, please let me know.

Should you ever have any questions, please feel free to contact me.

[Parent's Name]

[\[Parents's Contact Info\]](#)

What is an EGID?

www.curedfoundation.org