

The **Grand Tale** of  
**GUS** (Previously Troubled) **THE ESOPHAGUS**



**WHO IS NOW TOTALLY HEALTHY, HAPPY & ENJOYING LIFE!**

Narrated by "Gus" the Esophagus with input from "Phil" the Eosinophil, this is a book to help kids understand eosinophilic gastrointestinal disorders.

Initially Phil and Gus could not agree on what foods to eat, but now, with professional help, they have found a diet that works and have become friends.

## Why do I need allergy testing?

EoE is commonly associated with allergies, so your doctor may recommend testing to identify food allergies as well as allergies to things in your environment such as grass, tree and weed pollens, animal dander, dust mites or molds.

## What foods do I eliminate?

There are three basic approaches to food elimination. Each approach depends on what you and your doctor decide.

- 1) One approach is to eliminate everything and replace food with an “elemental” formula. This approach is highly successful – almost all patients who follow this diet improve, but it can be hard to stay with. Once improvements are noted, foods considered to be safe can be added back in to the diet.
- 2) Another approach is to develop a diet that eliminates the foods that are thought to be problematic based on the results of allergy testing. This approach is not quite as successful as the elemental diet, although the majority of patients improve and are able to be more compliant.
- 3) Still another approach is removal of the commonly recognized allergenic foods (milk, egg, wheat, soy, peanuts, tree nuts, fish and shellfish). Obviously, consultation with an allergist and dietitian should be done prior to starting an elimination diet.

## How does an “elimination diet” work?

For many patients with EoE, the disease is triggered by a food allergy, but the symptoms differ from those caused by common food allergies. People usually think about food allergies causing hives or vomiting or swelling of the airway. In EoE the food allergy leads to inflammation in the esophagus, which causes the symptoms of EoE. The food interacts with the immune system to release chemicals that attract eosinophils to the esophagus, and those activated eosinophils cause inflammation. By avoiding the allergenic food(s), the signals that call eosinophils to the esophagus are turned off, preventing additional inflammation and



reducing symptoms. However, the inflammation typically does not improve quickly – it takes days or even weeks to see the difference.

Sometimes doctors eliminate the top 8 food allergens, just to be safe. It is very important to work with a dietitian in these cases to make sure you are getting enough energy and nutrients in your diet to play!

**Top 8 Allergens: milk, soy, eggs, wheat, peanuts, tree nuts, fish and shellfish.**



## What is an “elemental” diet?

Skin prick and patch testing are used to guide elimination diets, but it only takes one unidentified food allergy for the diet to fail. Sometimes a stricter diet – an “elemental” diet – is needed. An elemental diet means that all the nutrients are provided as fragments that are too small for the immune system to recognize. For example, rather than containing proteins, an elemental formula contains amino acids, which are the building blocks of proteins. All foods contain some protein, and even very small amounts can cause an allergic reaction. An elemental diet means that a special “elemental” formula is the only food used. As a result, no foods are eaten that can cause an allergic reaction. Usually elemental formulas are nutritionally complete (meaning they have all the good stuff you need to stay healthy) and are either a liquid or soft pudding. They also come in lots of great flavors and fun drink boxes!

Some people may need feeding tubes when their diet is too limited in foods and they can't drink enough formula. The options for feeding tubes include:

- 1) **NG TUBE:** (nasogastric) It goes through the nose, into the stomach.
- 2) **G TUBE:** (gastrostomy) It goes straight into the stomach through a hole placed in your belly.

## What if I eat “unsafe” foods that I haven't tested while on my diet?

Eating “unsafe” foods can make you sick. This will keep your esophagus from healing and your symptoms will not improve. You have to stick to a diet of safe foods until your esophagus has completely healed before testing the next food. When your doctor is trying to determine if the food elimination diet is

working, eating unsafe foods will delay how long it takes the doctor to correctly determine the right diet, and may cause you to feel sick longer. However, if for some reason you have not stayed on your diet, you need to let your parents and your doctor know.

### How does medication help?

Medication may decrease the inflammation in your esophagus and relieve the symptoms caused by the disease. Steroids are most commonly used in conjunction with dietary management. They can be administered topically (using a spray or thick liquid that is swallowed), in a pill, or given through a feeding tube or an intravenous line directly into the bloodstream. Unlike the spray and thick liquid, steroids given by IV or by a pill affect the whole body and are used only for short-term treatment, since long-term use of systemic steroids can lead to side effects.

### Why do I need to have another endoscopy after being treated?

Unfortunately, there is no way to reliably determine the activity of an EGID without taking a biopsy and looking at the tissue underneath the microscope. Therefore, after completing a treatment trial, another endoscopy with biopsies is performed to make sure that everything has healed and is going as expected. Some people with EGIDs have no symptoms, but still have inflammation and others have symptoms, but no recognizable inflammation. Untreated symptoms could worsen over time, causing damage to the digestive tract.

### What if my EGID goes untreated?

If the inflammation caused by an EGID remains untreated, then the symptoms will likely continue and could worsen over time.

### How do I live with this disease?

EGIDs make life more difficult, however you should be able to continue to do all the things you want (except eat certain foods). It will test your patience and require creativity and planning. Allow yourself, and your family, time to adjust and learn how to live well with your EGID. A positive attitude, creativity with your diet and a focus on non-food activities will go a long way in learning to live well with EGIDs. There are many skills and strategies you can develop to better manage your disease.

## SOME TIPS ON COPING:

**A healthy attitude goes a long way,  
so concentrate on what you CAN do!**

- Exercise and activities keep you active and your mind off food.
- Plan family time that does not include food.
- Having a feeding tube does not have to slow you down.
- Eating the wrong food can make you feel yucky again, so only eat what your doctors and parents tell you is safe.
- Learn what foods you can and cannot eat which will help you take charge of your diet!
- Let your special friends and teachers know about your EoE condition, you can say something like, "It hurts my body when I eat certain foods, which is why I really can't eat certain foods. I need to stick to my special diet."
- If eating lunch in the cafeteria is hard for you, try asking if you could find another place to go like the library or your favorite teacher's room or just bring your own lunch with food that is safe and delicious for you.
- Learn about EoE: become an expert. Seek out reliable information at the library and online at web sites like PubMed, apfed.org, and faanteen.org. You can also talk with your doctors and dietitians to learn more.
- If you are feeling sad, ask for help. Feeling sad is common when coping with an Eosinophilic Gastrointestinal Disorder. If you're having trouble coping, your doctor may be able to refer you to a specialist who understands and can help you feel better.
- Connect with others who struggle with similar issues by joining a local support group, or start your own support group.
- When you have the urge to eat the foods that make you feel yucky, remember how bad they will make you feel. You will never feel better if you eat – even in the smallest amount – the foods you should be avoiding.
- If prescribed, take your medicine on time and as directed. Talk to your doctor if you have questions about your medicine. If, for some reason, you haven't been taking your medicines, let your parents and your doctor know as soon as possible.



## Research, Organizations, Websites & More

- **Eosinophilic Disorders:** For more information about Eosinophilic Disorders and Food Allergies: American Partnership for Eosinophilic Disorders (APFED): [www.apfed.org](http://www.apfed.org) or 713-493-7749
- **Nutricia North America** and their range of elemental formulas call 1-800-NEOCATE, 8:30am-8:00pm, EST, Mon-Fri or visit their websites at [www.nutricia-na.com](http://www.nutricia-na.com) or [www.neocate.com](http://www.neocate.com)
- **Food Allergy and Anaphylaxis Network (FAAN):** [www.foodallergy.org](http://www.foodallergy.org) or call 800-929-4040
- **Tube Feeding:** For more information on tube feeding and support: Oley Foundation: [www.oley.org](http://www.oley.org) or call 800-776-OLEY
- **Health Care Professionals:** To find a board-certified Gastroenterologist or Allergist contact: North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN), [www.naspgan.org](http://www.naspgan.org) or call 215-233-0808
- **American Academy of Allergy, Asthma & Immunology (AAAAI):** [www.aaaai.org](http://www.aaaai.org) or call 414-272-6071
- **Apfed.org** has a DocFinder to help you find doctors familiar with treating EGIDs

THE GRAND TALE OF GUS THE (Previously Troubled) ESOPHAGUS is brought to you by Gus and Phil along with The American Partnership for Eosinophilic Disorders (APFED) in partnership with advanced medical nutrition leader Nutricia North America, makers of elemental products such as Neocate® Infant DHA ARA, Neocate® Junior, EO28 Splash® and Neocate® Nutra ([www.neocate.com](http://www.neocate.com)).

APFED is a non-profit advocacy organization for those living with eosinophilic esophagitis (EoE), eosinophilic gastroenteritis (EGE), eosinophilic colitis (EC), and other eosinophilic disorders. We are a resource for patients, their families, physicians and the medical community. APFED provides accurate, up-to-date information on eosinophilic disorders and related problems. Our goals are to increase awareness, educate patients and physicians, increase funding for research and provide support for the eosinophilic community. To learn more go to [www.apfed.org](http://www.apfed.org)





## The Grand Tale of GUS The (Previously Troubled) ESOPHAGUS

APFED\* and Nutricia North America would like to thank all those involved for their contributions in creating this book.

**This book belongs to:**

.....  
(your name here)

\* American Partnership for Eosinophilic Disorders

# Chapter 1

## YOU ARE NOT ALONE



## CHAPTER 1 – YOU ARE NOT ALONE

### Greetings from Gus! “Hi, how ya doin’?!”



I'm Gustavo - my friends call me Gus for short. I am an esophagus (ee-sof-a-gus!), which is the tube that connects the mouth to the tummy. I am in charge of getting food from the mouth to the stomach so it can be digested. Everyone has an esophagus!

I prefer Gus because it sounds better with my name - Gus the Esophagus - that just sounds cool, don't you think? I'm here to tell you about how I used to feel yucky and how I got better because I heard you might have the same problem as me. You see, I belong to a six year old boy named Max - I'm in his esophagus and I used to always get upset when he ate - making him feel sick and throw up - too much info, I know! I am actually a pretty cool esophagus, but certain foods make me feel sick and when I feel sick, Max feels sick too.

**What is this condition?** So, Max's Mom took him and me to the doctor to find out why we were feeling so yucky. The docs helped us figure out what was wrong and how to treat it so now both Max and I feel SO MUCH BETTER! We're hoping our story helps you feel better too!

The big official name the doctors gave to what Max and I have is **Eosinophilic Esophagitis** (pronounced ee-oh-sin-oh-fill-ik ee-sof-a-gi-tis) or **EOE** for short. It is part of a group of Eosinophilic Gastrointestinal Disorders (sometimes called EGIDs). I will explain more about that stuff later...

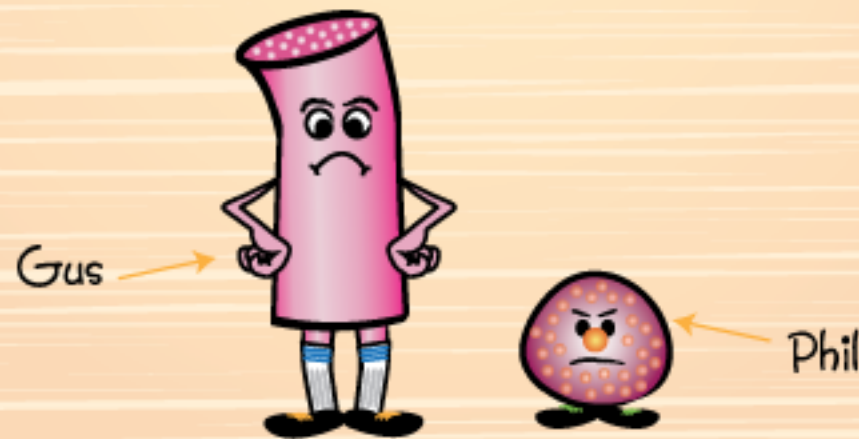
## So what's an eosinophil (ee-oh-sin-oh-fill) anyway?

Max and his family had no idea what an eosinophil was when they first heard about it, so let me tell you what they learned.

Everyone has blood running through blood vessels in their body to send nutrients (things that help you grow) to all their different parts. Inside the blood are different types of cells and they all have different jobs. There are red blood cells that carry oxygen and white blood cells that help protect your body from strangers like bacteria and viruses. An eosinophil is a type of white blood cell that defends certain areas of the body, like your lungs, skin, stomach and intestines, looking for foreign invaders and attacking them.

I already knew about eosinophils because I'm friends with one - **Phil the Eosinophil**. At first we didn't really get along. You see, when your body is having an allergic reaction, an eosinophil (like Phil) might get called on to come from your blood vessels, where they usually live. They think they are coming to help protect you against these strangers, but allergens are harmless stuff like pollen or dog dander or foods. Allergens usually aren't dangerous like bacteria or viruses, but sometimes your body makes a mistake and thinks they are harmful.

Before Phil, I hadn't met any eosinophils because normally they're not supposed to be in an esophagus. But when Max started to have EoE, Phil and his other eosinophil friends came charging in! They were all angry, causing lots of irritation. They don't mean to, but sometimes they can hurt me. **AND THAT'S NOT COOL!!!**

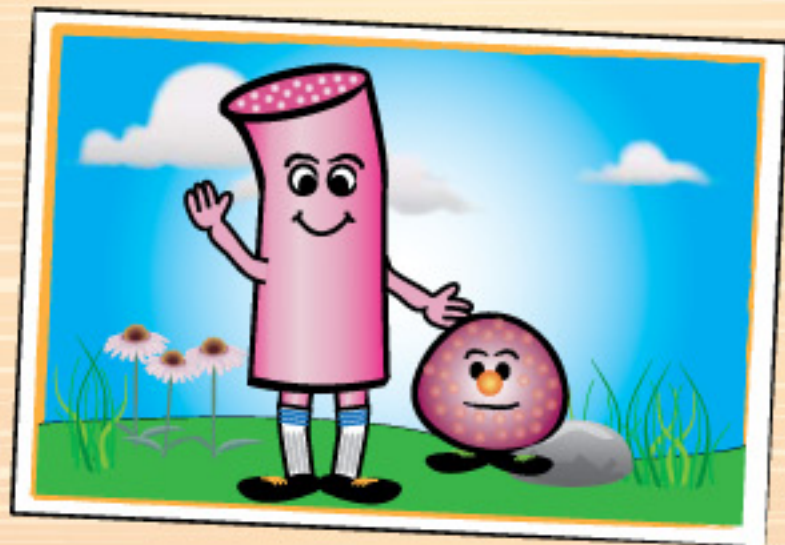


I'm not the only one who has problems with Phil and his friends. There are different places in your digestive system you can have problems with eosinophils - if it's in your esophagus, like Max, it's called **Eosinophilic Esophagitis (EoE for short)**. If it's in your stomach - it's called **Eosinophilic Gastritis**. If it's in your esophagus, stomach and intestines it's called **Eosinophilic Gastroenteritis (EGE)** and if it's only way down in your colon it's called **Eosinophilic Colitis (EC)**. These are all different types of **Eosinophilic Gastrointestinal Disorders (EGIDs for short)**.

### Symptoms of Eosinophilic Disorders

#### What to look out for...

The doctor told us that not everybody with this problem felt the same way Max and I did. Sometimes people with EoE don't even have symptoms! It is very important to let your family and your doctor know if you are feeling yucky and to describe what it feels like the best you can so they can help you feel better.



# Chapter 2

## DIAGNOSING AN EOSINOPHILIC GASTROINTESTINAL DISORDER



## CHAPTER 2 – MAX AND I SEEK HELP

**W**hen Max was born I was a little baby esophagus and at first, I liked it when Max drank his “mommy’s milk.” As we started to grow older (when Max was about three years old) I started to feel yucky when he ate certain foods. And, since I’m an important part of Max, every time I felt sick, Max felt sick too. I learned later that our problem can happen at any age – you don’t have to be a kid to get it, grownups get this too – but for us it happened when we were young.

Max’s parents got worried because he felt sick almost every time he ate and they didn’t know what was wrong – he would throw up and his chest hurt – stuff like that. He began eating less and not wanting to eat certain foods. It made them sad to see him in pain and getting sick – but I just couldn’t handle the food he was eating no matter how hard I tried. We were a mess!!

So his parents took us to get help from special doctors who understand **esophagi** (plural for esophagus) like me and other parts of the digestive system. The doctors were called gastroenterologists (tummy doctors) and allergists (doctors who study allergies). We also saw dietitians (food experts). These specialists are very important in helping patients like Max get much better. The gastroenterologist ran some tests and since I was the cause of the problem, he had to see me up close and personal. To do this,

he gave Max some special medicine so he would doze off, and then the doctor used this cool tube with a light and a video camera on it, called a scope, to take a look at me and check me out.

I was scared at first but it didn’t hurt either of us. The doctor said I didn’t look healthy when he looked at me – like I didn’t know that already! The doctor took a couple small pieces of me (called biopsies) to test in the lab. They needed to check to see how many of those eosinophils were inside me. Remember, normally there aren’t any eosinophils in an esophagus at all. I had way too many! I was filled with eosinophils and they were making Max and me sick!

That is when we found out Max and I had **Eosinophilic Esophagitis** – EoE for short. I dare you to say Eosinophilic Esophagitis 10 times fast!

**EoE, that was me!!!**







Finally, we knew what was making us feel so bad.

The doctor told us Eosinophilic Esophagitis is usually caused by an abnormal allergic response to food. Now it made sense why Phil and all his eosinophil friends were sent to visit me. It was time to take care of the EoE! This is where the allergists and dietitians came in.

Max, his parents, and the doctors agreed to start by looking at which food allergies Max and I had. They did this testing called [skin prick testing](#) where they poked the skin on Max's back with several small pins that had drops of different foods on their tips. This is to see if he would develop a small allergic reaction that looked like a bump at the site where he was poked. Some EoE kids are allergic to only a few foods while other kids are allergic to a whole lot of foods and other kids are not allergic to foods at all. The test showed that Max could not eat milk, wheat, eggs, nuts, peanuts, corn, rice, fish, shellfish, soy and more! Wow! Who knew? Not everyone is allergic to the same foods. You might be allergic to other foods, or none at all.

# Chapter **3**

## TREATMENT & DIET



## CHAPTER 3 – TREATMENT & DIET

### Feeling better with the right treatment

Once we knew Max and I had EoE, the doctors told us that there were a few things we could do to help us feel better. Eosinophilic Esophagitis is something doctors don't know everything about or have all the answers to yet. Doctors are doing lots of research on it and learning more every day to help us feel better.

### EoE : Special Foods for Special Tummies

After finding out what foods Max was allergic to, Max's parents and doctors had a long talk and decided that a special diet and a liquid food that doesn't contain any allergens, called an **elemental formula**, would help Max and me most. Not everybody needs an elemental formula, but Max and I did.

The special diet is called an **elimination diet**. The dietitian helped us understand which foods we could eat and showed Max and his parents how to read food labels so they knew which foods I could eat safely.

One cool thing the doctors told us was that once I healed up on the special diet, Max and I could slowly start trying to add some foods back in to his diet. But that's later down the line. First, they had to make sure Max and I were feeling better and understood what we had to do.

Max and I could not eat foods like pizza, pasta, yogurt, and milk (bummer!), **but we were able to eat other things like fruits, vegetables, and some meats**. We also got to talk to a really cool dietitian who was super smart at showing us all the things we **COULD** eat! Max's mom got some cookbooks for special diets like ours and made all sorts of cool and yummy food we didn't know about before EoE!

The dietitian helped to get us elemental drinks that were just right for us. We got to try different flavored ones to see which ones Max and I liked best. We even found some that were in drink boxes so Max could take them in his backpack on road trips or when we went to a friend's house to play. Max and I only had to drink a cup three or four times a day. The elemental drink helped make sure Max got enough healthy stuff to keep him (and me) strong and feeling good! Now I feel like a brand new esophagus!!

Once we figured out what foods were not good for me, Phil and his friends started to calm down and we started to get along. But then, it was time for him to go back to the blood vessels where he belonged.

Being on a special diet is sometimes hard for Max, but there is help for Max, his family and his friends. Look at the next chapter for help on dealing with being on a special diet.



So overall, we are now doing really well - Max feels SO MUCH BETTER and I am down here feeling like a million bucks!

Anyway, that's our story and we hope it helps you. Be sure to tell your family and doctors how everything makes you feel so they can help. And remember, there are lots of us out there dealing with Eosinophilic Disorders.

We all have good days and bad days - so hang in there, we're in this together. I'll see you around and tell your esophagus I said "BURRRRRRRP!" - that's how we say "Hi!"



# Chapter 4

WE ARE HERE FOR YOU



## CHAPTER 4 – SOME RESOURCES FROM GUS AND PHIL

**T**he next few pages have lots of great resources and information for you and your family to learn more about Eosinophilic Gastrointestinal Disorders (EGIDs). You can also get in touch with APFED or Nutricia North America for more information - they are really cool and knowledgeable about stuff like this and want everybody to be happy, healthy, and feeling great. I hope telling my story helped you understand things better.

- Gus

## Frequently Asked Questions About Eosinophilic Esophagitis

### What are symptoms of EoE?

- Feeling like you need to throw up (nausea)
- Throwing up (vomiting)
- Loose or watery poop (diarrhea)
- Growing slowly or not at all or losing weight (failure to thrive)
- Pain in your tummy or chest
- Stomach acid coming up in your throat that doesn't get better with treatment
- Trouble swallowing (dysphagia)
- Not wanting to eat (poor appetite)
- Feeling full after eating small amounts of food (early satiety)
- Food sticking in your throat (food impaction)
- Taking too long for food and fluid to move out of the stomach (gastroparesis)
- Filling up of your belly with gas (bloating)
- Low amounts of red blood cells (anemia)
- Blood in your poop (bloody stools)
- Poor nutritional status (malnutrition)
- Difficulty sleeping

### How is EoE treated?

The good news is that diet and medications are usually highly successful in controlling the disease, and preventing further damage. Treatment options vary depending on a number of medical factors. Diets can be adjusted to eliminate certain foods that trigger symptoms, and topical steroid medicines can be swallowed to treat the esophagus by decreasing inflammation. Elemental formulas are often used with diet and medication to promote growth and proper nutrition. These treatments (diet and medications such as swallowed steroids) can be used alone or in combination.