

## **The Latest in Eosinophilic Gastrointestinal Disorders**

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Glenn Furuta, M.D.

Dan Atkins, M.D.

Elizabeth Mays

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### **Introduction**

#### **Andrew Schorr:**

Hello and thank you for joining us once again on Patient Power live on HealthRadio.net. We are so excited about this program. We're going to connect you with leading experts in a condition that has touched my family. I've been dealing with it for several years. My daughter Ruth who is now 14-1/2 going on 25, and you know how that is if you have a teenage girl. It was a number of years ago when she was anemic, and we were trying to see well what was going on, and finally she was scoped, had an upper endoscopy, and it came up with this diagnosis of something I had never heard of, eosinophilic gastroenteritis. What's that? I knew something about eosinophils. As a leukemia patient I knew there were different blood cells. Eosinophils are designed to fight parasites and things like that, and we'll learn more during today's program, but the point is, Ruth was in pain, she was anemic, and her stomach was inflamed. Where does that come from?

Well, like many of the people who are probably listening today, you went on an odyssey of trying to find out what this was, if that was the diagnosis, or another eosinophilic disorder involving digestion. What's going on for your child, and what do you do about it, and where do you get expert information?

Today on Patient Power in a live program we're going to connect you with really four experts. We're going to connect you with two doctors, one a pediatric gastroenterologist, one a pediatric immunologist and allergist from two of our leading institutions in the country both based in Denver, Colorado, and then we're also going to connect you with a mom who became an expert when she got mad and wanted to know what was going on with her kid, and then she founded, with the help of other parents, a national organization that has helped provide information and expertise to families and the medical community throughout the country.

#### **Andrew Schorr:**

So let's get started. We will take live calls later, and many of you have sent in e-mails as we talk about the latest in eosinophilic gastrointestinal disorders. I want you to meet a woman who I met via the Internet as we searched for information for our daughter, Ruth,

and I've come to love her, Beth Mays. Beth is, I've described, a fiery patient advocate from just outside Houston, Texas, in Richmond, Texas, and Beth founded the American Partnership for Eosinophilic Disorders, but Beth it came out of your own concern of what was going on with your two-year-old, Charlie, right?

## **Beth's Story**

### **Beth:**

Absolutely Andrew, I was very frustrated as you were when I was given this very strange name for all the pain that my son had been enduring at that time.

### **Andrew Schorr:**

And he was vomiting and not thriving and terrible. Maybe you could just describe what was going on with him.

### **Beth:**

At that time he vomited daily, projectile vomiting ten to fifteen times a day. His stomach wasn't digesting food properly. We would see old food come back. He was not thriving. He was in continuous pain. He wasn't sleeping well. He was growing somewhat, but perhaps maybe not as he should have, and just all around this was not your typical two-year-old way of life. It was a continuous barrage of every day slowly getting worse before our eyes.

### **Andrew Schorr:**

We'd like to think that we as parents could go to the pediatrician, describe the problem. They could see the kid and, 'There you go, I know what that is, and I know what to do about it, and we have a solution. We have a plan.' You did not find that in Houston, did you?

### **Beth:**

I did not. We went to a lot of different doctors, including a gastroenterologist, and this was six years ago, which in the timeline of eosinophilic diseases I guess is a long time now because we've come so far with it, but back then there was not as strong of an understanding of this disease here in Houston and in many places around the country, and we did everything we thought we were supposed to do. We went to the pediatrician. We did all tests they told us to do and as we watched him slowly spiral downward, nobody could actually put a name to it. We got a lot of misdiagnosed guesses, but nothing at all until he wound up in the hospital just shy of Thanksgiving when he was two years old and ultimately got an endoscopy that came back loaded with eosinophils and still not really any clear answers.

### **Andrew Schorr:**

The happy story that we're going to tell is that you finally, you really got mad, Beth, I know, and you started seeking out information and found out that there were

subspecialists who were studying this group of conditions we're going to learn about, these eosinophilic gastrointestinal disorders and the allergic conditions that go with them. Charlie was connected with that, and today he's a first grader, eight-and-a-half years old, and while he certainly has treatment and has visits to the doctor, and we're going to meet Charlie's doctors in a minute, Charlie's doing better. Can Charlie say hi to us for a minute?

**Beth:**

Absolutely.

**Andrew Schorr:**

Okay.

**Charlie:**

Hello?

**Andrew Schorr:**

Charlie, how are you doing? It's Andrew. So how are you feeling today, Charlie?

**Charlie:**

Good. Real good.

**Andrew Schorr:**

And do you think you're making progress with the eosinophils? You're doing better?

**Charlie:**

Yep.

**Andrew Schorr:**

Okay, and I understand this summer you're going to try some new foods.

**Charlie:**

Yes I am.

**Andrew Schorr:**

Okay, all right, well I know that your doctors are hoping we can find good foods for you to eat that don't make your tummy feel bad. You're having a good day at school?

**Charlie:**

Yes.

**Andrew Schorr:**

Now we should mention, Charlie, you take a lot of your food through a tube right into your stomach, right?

**Charlie:**  
Yes.

**Andrew Schorr:**  
And is that a big deal? Have you learned to do it pretty well?

**Charlie:**  
Yeah.

**Andrew Schorr:**  
Yeah, good, good, good. All right Charlie, well we're going to let you go. We'll talk to your mom again in a minute, but we want to meet your doctors, and I think you know who they are, Dr. Glenn Furuta who's up at Children's Hospital of Colorado, right? So let's talk to Dr. Furuta. Dr. Furuta, welcome. There's your patient, Charlie, and I know you're Director of the Gastrointestinal Eosinophil Diseases Program at Children's Hospital of Colorado, and of course you're an associate professor in the Department of Pediatrics, you've got a long title, at the University of Colorado Denver School of Medicine. Glenn thanks for being with us.

**Dr. Furuta:**  
Thank you, Andrew, for having me on the show today.

**Andrew Schorr:**  
Well, you have a multidisciplinary program going on there, and so there you are at Children's Hospital of Colorado and down the street almost you have one of the top hospitals in the world also related to respiratory conditions like asthma but allergic conditions, and so we have with us also a gentleman who works closely with you, and that's Dr. Dan Atkins, who's the medical director of the Pediatric Day Program, Assistant Professor of the Department of Pediatrics at the National Jewish Medical and Research Center in Denver. Dr. Atkins, Charlie is your patient too. Welcome to the program.

**Dr. Atkins:**  
Thanks for having me.

### **Diagnosing Eosinophilic Gastrointestinal Disorders**

**Andrew Schorr:**  
So, let me start with Dr. Furuta. Dr. Furuta, what are these conditions, eosinophilic disorders? What are they, and are they increasing, and if so, do we know why?

**Dr. Furuta:**  
Well, Andrew, these diseases are characterized by intestinal symptoms that can have a very broad category in the sense of ranging from vomiting, abdominal pain, problems with swallowing, diarrhea, and not growing well, so they can be very nonspecific types of

symptoms, and when those symptoms undergo investigation, and the usual, maybe more common, diseases that cause those symptoms are not identified, an endoscopy is typically performed.

At the time of endoscopy when biopsies are taken, they are looked at under the microscope, and in the tissue we see that there are large numbers of cells called eosinophils, and those cells have classically been associated with allergic diseases in the past. We're learning more about them now, and they may in fact be associated with other kinds of diseases including autoimmune diseases or infections. So when all other causes have been ruled out for the increased numbers of eosinophils and there are symptoms associated with that, we have classified these diseases as eosinophilic gastrointestinal diseases. They have received names according to their locations so that patients may have only the esophagus that's affected, and that is termed eosinophilic esophagitis and as you go down the intestinal tract they can encompass other different names including eosinophilic gastritis, gastroenteritis, or eosinophilic colitis.

One of the problems with making the diagnosis today is that the normal values for eosinophils are somewhat unclear as of to date, and we're trying to establish those presently.

**Andrew Schorr:**

Okay, let me ask a question of Dr. Atkins. So, Dr. Atkins, some people may have other allergic conditions, you know, asthma or other things, things that show up on their skin, and all kinds of things. We understand allergies in that way. Food allergies seem to be less understood by us, and also it's unnerving if somebody then goes to an allergist, let's say they seem to be affected by one of these eosinophilic gastrointestinal disorders, and you go to the local allergist and you have patch testing, and it's negative. Does that mean that there's not an allergy going on or is it one that we haven't identified yet, or is it just simply autoimmune like Dr. Furuta was describing. Where are we with that today?

**Dr. Atkins:**

Usually if you present to your allergist with these sorts of symptoms, I mean these entities are becoming better known in the allergy community, so I think the potential for a patient having eosinophilic esophagitis or an eosinophilic gastrointestinal disorder is well recognized now, and usually we start with skin testing to see if the patient has evidence of IGE mediated or classical allergies to foods because a number of patients who have these disorders have other allergic disease like you mention like asthma or allergic rhinitis or food allergies. So oftentimes we're skin testing these patients first using the pricked skin test where you put a little drop of the allergen on the skin and prick through the skin, and a number of these patients will have a large number of positive skin tests to foods, and then we work to sort out which of those foods are playing a role in triggering a reaction if any of them are.

But as you mentioned, there are patients who have negative skin tests to foods in this fashion, and sometimes those patients are patch tested to see if there's another mechanism that's involved in causing the eosinophils to remain in the gut, and when the patch tests are negative, then you have these patients who don't appear to have allergies that are playing a role in driving the symptoms, so in those situations sometimes we do go on to try elemental diets, not elemental, but elimination diets to see if it makes a difference in their clinical course even when the tests are negative just to see if that makes a difference. There are other patients where that doesn't make a difference, and you're left with thinking that there may be an allergen that we haven't discovered yet, or it may be a different type of inflammation that's causing their problem.

**Andrew Schorr:**

I just want to go back and make sure I understand what eosinophils are. So, Dr. Furuta, you're a professor, tell me if I get this right and what kind of grade I get for my explanation. So the way I thought about it was eosinophils are in your immune system, and they have a job. In the case of the stomach anyway, with what we were dealing with in Ruth, the job was to let's say fight a parasite that might be there, and that the cells might have a little bee sting to kill the parasite, but if there's no parasite, the little bee sting is inflaming the wall of the stomach and in her case maybe cause some bleeding and inflammation and pain certainly. So it was happening inappropriately, and then as we were just describing with Dr. Atkins, well was something triggering it? Could we figure that out? Is that what eosinophils are? They're part of your immune system, and they're just being marshalled for the wrong reason?

**Dr. Furuta:**

Right, so you get a high grade for your answer, Andrew, and I think that you're exactly right in the sense that they are, they're normally in the intestinal tract, and we know that they're present there. As I mentioned before, the exact numbers that define what normal means is still unclear, but because they are present, we think that they participate in maintaining the health of the intestinal tract. Exactly how that happens is not yet clear. In disease states, we know that they increase and that they contain a number of different chemicals and products that may in fact cause damage to the intestine or make it not be able to function as it normally does and thus causes the symptoms we had mentioned including pain or diarrhea or dysfunction of the intestinal tract.

You had mentioned before just wanting to know about how common these diseases are. We think there are two different places this has been examined in depth in Cincinnati as well as in Switzerland with Dr. Rothenberg's group and Dr. Straumann's group, and they've shown that the range is somewhere between one and six per ten-thousand people, and we really don't have other figures yet that have identified exactly what the incidence and prevalence are in other parts of the world, although it's beginning to become more investigated now.

## **Treatment Options**

### **Andrew Schorr:**

All right, well let's take some calls and questions as we go on, and I know we'll really cover the gamut. We described Charlie who has a tube that helps him with his diet, and he has a limited number of foods that Beth has told me, seven foods and you looking at maybe testing four more this summer. So is it Dion who is with us from Arizona? Is that your name?

### **Caller:**

Yes it is.

### **Andrew Schorr:**

Hi Dion. So my understanding is you've got a two-and-a-half year old son who has, is it the eosinophilic gastroenteritis?

### **Caller:**

Yes, it is.

### **Andrew Schorr:**

Okay, and he's, you're looking at managing the diet now. What's your question from there?

### **Caller:**

My question is you hear about so many children who end up on feeding tubes with the elemental formulas, and you know, we're new to the diagnosis, and he's still very young, and my concern and question is, is it almost inevitable that they end up doing that form of treatment at some point?

### **Andrew Schorr:**

Okay, good question. Dr. Furuta?

### **Dr. Furuta:**

The approach that we've really taken in trying to understand this disease and treat it is to have a tailored approach to treatment, and by that I mean that we don't really understand all there is to know about what the different subtypes of this disease are. There are probably patients who have abdominal pain, or there are patients who have vomiting or diarrhea, or problems with their swallowing. I think the broad category of the eosinophilic gastrointestinal disease is now being defined as to what kinds of symptoms that patients may have, and that may reflect how treatment may be applied.

So there are some patients, who respond very well to dietary management, and whether that management is by a formula that has been very digested or a diet that has limitations in the sense of identifying foods that can be eliminated. There are certainly

patients who respond to that. There are other patients who may require medical treatment including steroids either in a pill or liquid form or topical steroids. So I think what we're understanding now is that each patient probably has a little bit of a different treatment approach, and that's how we try to approach individual patients.

**Andrew Schorr:**

I was just going to mention one other thing, Dr. Furuta. I think it's implied in what you're saying. I think, and I know Beth would echo this, that if your child is diagnosed with this or as you're growing older and you're an adult with these conditions, and that happens too, I think you want as part of your team a consultation at least with a subspecialist like Dr. Furuta, like Dr. Atkins, there are others, many of them are associated with Beth's organization, the American Partnership for Eosinophilic Disorders. These folks eat, drink, and sleep this and research it. You mentioned Dr. Rothenberg a minute ago, Dr. Furuta, in Cincinnati. So these are folks who are devoted to it and have labs related to it, and I think as we go down this route a consultation like that is helpful.

Here's a key question Dr. Furuta and Dr. Atkins. I'm sure you get asked this twenty times a day. Jessica writes in from Georgia where she too has a young child, I believe, and she wants to know if she's dealing with this with a two-year-old though, is there any hope that the child will outgrow the disorder? Can you outgrow it? Dr. Atkins, do you have any thoughts about that?

**Dr. Atkins:**

Yes, there are children who outgrow this disorder, although if you look at some of the eosinophilic gastrointestinal diseases, they tend to be more of a chronic relapsing disorder. In particular, eosinophilic esophagitis appears to be one of those disorders, and that's why we plan to follow these patients for long periods of time and monitor their clinical course and see if they're improving, but there are children who start out with increased numbers of eosinophils and difficulty feeding, and over time their immune system matures a bit, and they outgrow some of their sensitivities to foods and can go on to do quite well.

I'd like to mention one thing about one thing that you said, and you talked about consultation with specialists, and I think the other important aspect of that is a group of specialists that work together and talk to each other about individual cases so that you're not seeing these specialists in isolation, that they're talking and sharing information about your child and helping you develop the best plan.

**Andrew Schorr:**

Yes, and my understanding, Dr. Furuta, let me see if I've got this right. This is what you've built in Colorado is a multidisciplinary team. So you have allergy, you have gastroenterology, and you have other aspects of it; a nutritionists, counselors, the whole ball of wax.

**Dr. Furuta:**

Yes, that's true, and included in that are also feeding specialists who help us to understand really what might be going on after we're able to take care of the inflammation. Children with these problems oftentimes will have many problems with their swallowing or eating, just the daily function, and even though the inflammation or the irritation may be resolved, we need their expertise in the sense of proceeding with further treatment.

**Andrew Schorr:**

Okay, we're going to talk a lot more about it. We're going to buzz through just as many questions as we can that affect so many people. We'll come back right after a little short break. We are visiting with really renowned experts in this, and that is Dr. Glenn Furuta who is the director of the Gastrointestinal Eosinophil Diseases Program at the Children's Hospital of Colorado, and also working with him at National Jewish Medical and Research Center is Dr. Dan Atkins.

So, Dr. Atkins is an immunologist and allergist, and Dr. Furuta is a pediatric gastroenterologist, and then as you heard, there's a whole team that works with them. Also, we'll join again with Charlie and Beth Mays who are with us from outside Houston living with the condition, and of course Beth is the founder of the American Partnership for Eosinophilic Disorders devoted to helping doctors, nurses, nutritionists, and families touched by this around the country and around the world be smarter about it so we can all work together and get the care that's best for the person in your family who's affected by this. We'll be back with much more right after this.

Welcome back to a live edition of Patient Power. Andrew Schorr broadcasting live from Seattle where it's kind of cold and cloudy, and I hope we have the little league game for my 11-year-old Eitan today and the track meet for my 18-year-old, and my 14-year-old Ruth who's affected by eosinophilic gastroenteritis I should say has not had a feeding tube and is doing pretty well. Her problem continues to be sometimes anemia and some pain, but overall she's doing pretty well, and we will continue to try to get to the bottom of it for her to do even better, but I want to give people a great deal of hope.

We're talking about the latest in eosinophilic gastrointestinal disorders, and we have some real experts with us, and I promise you folks we'll do other programs on this too because there is a lot of ground to cover.

With us again is Dr. Glenn Furuta. I knew him when he was back in Boston and he moved from there to the Children's Hospital of Colorado where they've set up a whole multidisciplinary team dealing with, they have a whole gastrointestinal eosinophil diseases program, and then there's a wonderful partnership with the National Jewish Medical and Research Center, and Dr. Dan Atkins joins us from there too, and they all work together with this team that we've described, and we want to get you answers now.

One question is, when there's no clear "knock the ball out of the park" medicine to use, and we hope there will be, then people say, or somebody says, 'Well maybe there's this medicine you can get in Mexico,' or 'My brother-in-law, Harry, said try this and try that.' And there is a medicine that Renee from Colorado asked about, ketotifen, if I've got it right, Dr. Furuta, from Mexico, and wonders should they be getting that from Mexico? There are claims about it that it can have the disease go into remission. If it's used in other countries, is it part of any clinical trials here, and should she be running to Mexico to get it for her kid?

**Dr. Furuta:**

Well, ketotifen is a medication that has been used in the past to treat allergic diseases. We always like to try to think of treatments in the sense of the pathophysiology of the disease or what makes the disease happen. Ketotifen helps to calm the effects of mast cells, one of the other allergic cells that are present in this disease, and that's been shown by work from Mount Sinai, Dr. Shehadi and her group, and we think that they may participate in the disease itself, but we don't really know whether this medication will help. Some work by Dr. Liacouras and his colleagues at the Children's Hospital of Philadelphia have looked at similar medications and not shown an impact yet.

I think one of places we are in this disease presently is identifying the clinical features of the disease, and now as we try to understand the pathophysiology really performing well characterized studies to try to understand how we can treat patients the best, and in that light there has been an organization, The International GI Eosinophil Research Consortium, that has been developed in conjunction with the Pediatric GI society, NASPGHAN, and with assistance of the Children's Digestive Health Foundation, and there's a website there, [www.cdhnf.org](http://www.cdhnf.org), where there can be more information found about a research consortium that will be happening in the future.

**Andrew Schorr:**

Okay. Now one of the things that I've seen as I've learned a little bit about it is some of these conditions seem to run in families, and Dr. Atkins you were mentioning about how people may have other allergic conditions and then this shows up. Jennifer joins us from New Mexico. So, Jennifer, you have a son with these conditions?

**Caller:**

I do. I have a 4-year-old son, and he has eosinophilic esophagitis and eosinophilic colitis.

**Andrew Schorr:**

How is this treated now?

**Caller:**

He is being followed at Cincinnati. He does have feeding tube, and he is on an elemental formula, and he trials his foods every two months.

**Andrew Schorr:**

Okay, doing the food trials like we're talking about with Charlie. What's your question, Jennifer?

**Caller:**

My question is he has both of them but has no delays, and I feel guilty sometimes when I'm talking with other parents who have children with eosinophilic diseases because he has no delays, and I didn't know is that something that's normal, is that something that we need to look out for? Is he going to start having delays?

**Andrew Schorr:**

Do you mean delays in his growth that he's growing and thriving? Is that what you mean?

**Caller:**

Exactly, and development as well.

**Andrew Schorr:**

That's all good news. Don't feel guilty. Be thankful, but Dr. Atkins, I know you do a lot there at National Jewish in supporting families that are dealing with a wide range of conditions. What about this about where they should expect that that can show up at some point, or it's just variable among kids?

**Dr. Atkins:**

Right, well it is variable among kids, and that's why when we're following these patients there is another group, the psych/social team that we see a very important group to help us follow the development of these children. You know, a number of kids who have chronic illness and don't feel well can fall behind developmentally, and sometimes there are other medical reasons for that, and sometimes there are psychological reasons, you know, not feeling well or depression, and also these are difficult disorders. I mean when you talk about changing children's diet or having to use feeding tubes and things like that, a lot of times there are questions that children have about that, and it can be difficult for them emotionally, and so having a psych/social team involved as part of the team to monitor the child's development and make sure that it's proceeding appropriately and also to make sure that the family is functioning well and getting questions answered about development or other stressful aspects that result from the illness is quite helpful.

**Andrew Schorr:**

Yeah, I'm going to echo that.

**Dr. Atkins:**

What I would say is, you know, a 4-year-old child doing well, that's great. You just want to keep checking in about how they're processing things developmentally and how things are going.

**Andrew Schorr:**

I just want to echo that. Again, with Ruth, she did get on an elemental diet orally, not through a tube, food that I guess we'd all agree tastes like vanilla cake, which isn't bad, but she was doing it for weeks, and she could not, she had difficulty keeping it up, and she needed a lot of emotional support as we did as she was doing it. So there's a lot of support you need and over a long time, and certainly she's not, you know, every kid wants to feel like everybody else and has the energy and the growth, and why do they need to take this medicine. For awhile we were doing shots, so I can't stress enough the need to seek out the support for you and your child as you go down this road.

**Research for Eosinophilic Disorders**

**Andrew Schorr:**

Dr. Furuta, we have questions about where is treatment headed, so we know you're individualizing it, and I'm going to want to come back to Dr. Atkins about patch testing in a minute to understand what that is, but where are we now with what you're investigating that's promising? Randy from Memphis and about forty other people want to hear your answer on that.

**Dr. Furuta:**

There are presently two accepted forms of treatment in the sense of medical treatment, which can either be steroids that are swallowed in a pill form and the topical steroids, which can apply steroids basically to the lining of the esophagus, and that has been shown to be quite effective in helping patients with their symptoms as well as their treatments in several different studies. I think the next line is certainly the nutritional form of treatment, and the challenge there is to identify which foods may be impacted by this disorder.

One of the other issues that we're wrestling with now is could it also be things that are swallowed that may not be food particles. In fact, airborne allergens that could spark this response, and then I think are there other things that may be happening in an autoimmune sense that could be causing the body to react to the esophagus itself, and in that realm there have been a number of different studies now that are suggesting that antibodies that can be synthesized and administered to the body, so monoclonal antibodies that could be given to the patients that may help to influence that inflammation and help symptoms improve themselves, and there have been several studies recently, primarily based out of Cincinnati and work that Dr. Rothenberg has done that's suggested this may be helpful and shown that it may be helpful in certain patients. I think the other molecules that may be developed are certainly underway and suggested by their basic science and animal models.

**Andrew Schorr:**

Okay, so I've got a question. I was in a clinical trial for my leukemia, and eight years ago I got the treatment that's used worldwide now, and here I am to tell the story. So I

imagine there in Denver you have clinical trials that people could inquire about, and I know in pediatric leukemia, for example, trials have made a huge difference in how most kids are cured now. So that would be an appropriate discussion should they come to your center I imagine.

**Dr. Furuta:**

Certainly. Well we do have some clinical trials presently that are beginning looking at the use of these antibodies. There are several different types, and we have studies right now that are beginning to try to help patients who may be in fact appropriate and can be helped by these treatments.

**Andrew Schorr:**

Okay, so again, underscores for me, which is why I live in Seattle. The specialists in what I have are in Houston down where Beth is, that's how I got to meet Beth in person first, and so you go where there are people really knowledgeable in what you have.

So Beth, there's a question we got from Carolyn in San Francisco, and she says, 'Is there a database somewhere online that lists the doctors who are knowledgeable about possible EG and not just in children but also in adults?' Beth?

**Andrew Schorr:**

Actually, that's an excellent question, and it's something that APFED the organization is currently working on getting online. We just developed the database, and we're gathering information. It's a very structured database. The physicians will be self reporting their information, but we've got a pretty good little survey of information from how many patients, how many years have they been treating, what institutions have they worked with, are they with adults or children or both because a lot of allergist and immunologists treat both, and that will be going up on our website in the coming month. There is no other central database available for patients, but we are working as fast as we can to get it up because pretty much every single day I take a phone call from someone trying to find a physician near them who specializes in it.

**Patch Testing for Allergies**

**Andrew Schorr:**

Right, and [www.apfed.org](http://www.apfed.org). Now, Dr. Atkins, just along the way you mentioned about patch testing, and I know that's something we considered for my daughter where the skin testing was negative. What is patch testing, and what's the likelihood that it could give you information on like what Dr. Furuta was saying? Is there something else going on that could cause an allergic reaction?

**Dr. Atkins:**

Right, well when we, again as I mentioned to you, there are a couple of different tests. There's the pricked skin test that's used, and the answer to the pricked skin test is

available in about 15 minutes after you apply the allergen to the skin because you develop a bump like a mosquito bite that itches and is surrounded by an area of redness, and that particular reaction is mediated by an antibody called IGE, and that's the antibody that people who are allergic make more of than people who aren't allergic, but there are different kinds of inflammation, and there is a kind that involves lymphocytes and other inflammatory cell types in the body.

One way to see, and it's a little bit more a delayed reaction, and to try to understand more if foods are playing a role in triggering that sort of response people have used patch testing, and the way you do that is you have something called a Finn chamber that's a small little piece of aluminum that's kind of a flat piece of aluminum that's indented, and you can put foods in there, you process these foods and put them what's call a Finn chamber and then place it on the skin and tape it on the skin where it can be held in contact with the skin for 48 hours. At the end of the 48-hour period, the patch test is removed, and it's read 20 minutes later, and then the patient comes back 24 hours later, and it's read again at 72 hours. The thought is that that might help us determine whether this other type of inflammation is involved and causing the reaction.

The point to mention is that patch testing is certainly helpful in some people's hands. Jonathan Spergel has done an excellent job in developing patch testing at his center, and he's used it a lot and has found it to be helpful. There are discussions about how to make this a little more uniform. People are using different reagents, let me put it that way, and so we need to work a little bit on uniformity, and there is an art to applying these things and how they're read, and so it's something that takes a lot of work and practice with to use well, and so it's just one of the different approaches that's used to help us to try to determine which allergens might be playing a role in triggering symptoms.

**Andrew Schorr:**

What I get out of all this and having lived it ourselves is there's a lot of art to medicine in general, and there's certainly a lot of art to understanding what's at work in an individual patient, and again I'd say that's why you want to have this sort of consultation.

**Listener Questions**

**Andrew Schorr:**

Beth, here's a question for you, and then I want to get to our ladies who have been holding on the phone. Renee from Colorado said, 'We have people close to us who don't believe this is a real disease because of the attitude that food could not cause so much harm. What do you suggest that patients do to help educate others in their own community and maybe more broadly and to spread awareness?'

**Beth:**

Well, this is obviously a very real disease as you and I both know and as our physicians know. Educating a family is a slow process that has to be taken on very directly and very

firmly, but at the same time these are the people that you love and you spend time with, so APFED has moved forward to help create ICD9 codes, that's the diagnostic insurance codes, for this disease with the U.S. government, and certainly that step forward helps legitimize the disease is present, and so just by telling your family, this is a real disease, here's the code, and for some parents and grandparents and aunts and uncles, that might be enough. For others, having them come to your home and letting them see what your life is like. Food obviously can be very harmful in that people are anaphylactic to foods, and they can kill you, so the fact that a lot of smaller reactions or different location-type reactions are certainly possible. People are allergic to many foods. It's just where the attack is happening; as opposed to getting hives, you're getting attacked in your digestive system.

**Andrew Schorr:**

Right, right. We're going to move on. I know you have a lot of work even in Congress trying to help federal legislatures know, and so again I want to urge people to take a look and join APFED. I know the doctors are involved as well, [www.apfed.org](http://www.apfed.org).

Let's take a call from Stacy who's joining us from Connecticut. Stacy, how are you touched by these conditions?

**Caller:**

We have a 6-year-old, and first I want to say thank you for doing this.

**Andrew Schorr:**

Oh, my pleasure.

**Caller:**

My son and I are actually doing a speech tonight at a local community college to help spread awareness, so you're doing a good thing, and I wanted to quickly say thank you.

Our son is six, and he is elemental only through a feeding tube, and my question is, why, we do patch tests, we do the skin tests, we do all the testing, and all the tests come out negative. We try the foods, do the endoscopy, the scope, and he's got eosinophils infiltrated top to bottom. It doesn't make any sense, and I'm wondering if maybe somebody can make sense of that for me?

**Andrew Schorr:**

Dr. Furuta? She's at her wit's end, you know, doing the best they can.

**Dr. Furuta:**

Sure. Well, you know one of the things I think that's very important is to make sure it's the right diagnosis. There is a list of things that can cause eosinophils to be present in the intestinal tract, and you want to make sure that it is the right diagnosis, and I think that what we've come to understand is that we don't know exactly what makes the disease

happen, and even though the test may be negative, it doesn't mean that foods often can't cause this allergic response. We're just not sophisticated enough yet to understand how foods cause these and then how to test for them, so unfortunately many patients do remain stuck with, in a certain sense, having to use these kinds of formulas for their treatment.

I would also try to emphasize the fact that this is a disease that's occurring in adults, and we're beginning to understand that more, and I hope that that information that we're gleaning from studies is going to help us understand more about the pathophysiology and the importance of treating patients over the long run. There's been groundbreaking work done by Amir Kagalwalla and by Dr. Gonzales in Chicago looking at this as well as in Indiana by Dr. Gupta, so hopefully those things are going to give us more clues as to understanding this disease in a better way. The other thing that I think will be important to emphasize then going back to the treatment aspect of this is that there are potentially novel ways to apply these medications, and Dr. Aceves in San Diego has done much of the work in trying to understand other ways to apply these kinds of treatments, but getting back to the patient's question, we don't understand completely how these diseases happen, and the testing for them and identifying the specific foods remains difficult.

**Andrew Schorr:**

One quick question. I know there's a drug sort of making it's way through sort of the FDA process to deal with hypereosinophilia, especially in adults, might that have application more broadly in kids and more broadly throughout these conditions?

**Dr. Furuta:**

Yes, there was a recent article in "The New England Journal of Medicine" showing an impact of anti-IL-5 antibodies in hypereosinophilic syndromes. I think that again is a very broad categorization of a syndrome or a group of diseases. Hopefully those kinds of treatments will have an impact that will help certain patients who have eosinophilic gastrointestinal diseases.

**Andrew Schorr:**

Okay, I know that the main thing is like you've been doing in allergy for a long time, Dr. Atkins, is knowing what is a patient's specific situation. What are their triggers, what can we know, and as you hear from all of us, the frustration if you don't have a test to identify what's going on.

Let's take one other call. This is from Christine in New Hampshire. Christine, are you there?

**Caller:**

Hello.

**Andrew Schorr:**

Welcome to the program. What's your question?

**Caller:**

My question is my two-year-old was just diagnosed with eosinophilic esophagitis in December. That was after two years of, or the most part of two years, trying to figure out why he would not eat food, and at that point we began doing naturopathic remedies and did find that he did gain a considerable amount of weight. He had become a failure-to-thrive child, and so we were feeling that he was doing better, but he did have two sort of asthmatic-like episodes during that time, but what we did to continue to research the disease was to contact Cincinnati, and he is going to be going there for treatment starting in August, but in the meantime we have him on an elemental formula only.

**Andrew Schorr:**

What's your question Christine? I'm just a little short on time.

**Caller:**

Sure, sorry. My question is, we started with the Neocate as an elemental formula, and then after having what we felt was a severe reaction switched to EleCare. He seems to be doing much better on that but he does vomit randomly after having a meal, and I didn't know if this was an indication of a reaction to that or if it's common, and we can expect this to continue basically. What does this mean?

**Andrew Schorr:**

Dr. Furuta, I know it's hard to be specific, but any guidance there? Could it be the formula or is it the disease?

**Dr. Furuta:**

Well, I think one of the things that we've learned over the years is that there is probably a spectrum of symptoms that can occur with inflammation of the esophagus. So although we pin the symptoms on one specific disease, such as eosinophilic esophagitis, there may also be some association with reflux disease or other things that can cause the esophagus or the intestinal tract not to work well. So while the symptoms could be due to the disease itself or potentially a reaction to something that may be administered, there may be other diseases like reflux that could be participating in this.

**Andrew Schorr:**

Christine, we're going to have to go. I think the point that I'd emphasize again, you're going to one of the centers, Cincinnati Children's, Dr. Furuta and Dr. Atkins, or I'm so glad I'm in the west and now I can sort of get at them, they're in Denver. So there are different centers where they will at this 25 ways from Sunday, and I would urge people again, and Beth I know you help direct people to that too, to really consult with subspecialists because this is a moving target both in your own child and in an understanding of the group of illnesses together.

I just want to get some final comments. We're kind of short on time. Dr. Atkins, are you hopeful that we can do better?

**Dr. Atkins:**

Oh absolutely. There's just a lot of research now going on about different inflammatory mechanisms and about food allergens in particular and allergic inflammation that I think we're learning more about the chemicals that are involved in that, and as Dr. Furuta mentioned there are antibodies being developed against some of these mediators that might well be helpful, so I think certainly we've got a lot more to learn, and we're learning more about this disease every day, and I think it's really looking bright.

**Andrew Schorr:**

Well, I wish you well, thank you. Dr. Furuta, I'm just going to say thank you to the work you and your whole team with Dr. Atkins are doing and your institutions with your eosinophilic diseases program, and I wish you well. I'm going to come see you in person, but I want to thank you for being with us today, and I take it that you're feeling upbeat too.

**Dr. Furuta:**

Absolutely, and I thank you for the opportunity, and would just mention that there are a number of organization such as APFED, the CURE, the Campaign for Urgent Research, the Food Allergy Project, all of which are really contributing to a fantastic network and TIGER's consortium that will help to I think understand more about these diseases over time.

**Andrew Schorr:**

Right, right. Thank you so much Glenn. Thank you so much Dr. Atkins. Thank you Beth Mays. My hat's off to you. Can we just say goodbye to Charlie? Get him quick. Charlie?

**Beth:**

Well he was right there, there he is.

**Charlie:**

Hello?

**Andrew Schorr:**

Hey Charlie? You've got to go back to school, but I want to thank you for cutting classes to be on the radio with us, okay?

**Charlie:**

Okay.

**Andrew Schorr:**

And we wish you all the best with your tummy, okay?

**Charlie:**

Thank you.

**Andrew Schorr:**

Take it easy buddy. Do your homework. Okay, well this is what we do, and it's really a labor of love for all of us who've been with us. We know you worry about your kids or if you're an adult dealing with this, but I really believe that if we all work together we can make tremendous inroads. Thank you so much for being with us. The replay will be posted on [www.patientpower.info](http://www.patientpower.info) as soon as we can get it. We'll add a transcript. Be in touch with [www.apfed.org](http://www.apfed.org), and we'll do more programs. Let us know how we did. Just send us an e-mail to [questions@patientpower.info](mailto:questions@patientpower.info). Have a great day. All the best. Remember, knowledge can be the best medicine of all. I'm Andrew Schorr signing off.

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