

# Allergic Diseases SIG

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Save  
the  
Date!

## UPDATES!

### SIG Resources, Activities, & Initiatives

#### **Welcome to our New Leadership Committee Members!**

We look forward to introducing our new leadership committee members at SPPAC next week! Our Fall newsletter will spotlight our new members, so please be sure to stay tuned.

- **Co-Chair:** Mallory Netz, PhD, Children's Mercy Kansas City
- **Research Chair:** Alayna Tackett, PhD, University of Southern California
- **Social Media Chair:** Melissa Engel, MA, Emory University
- **Student Representative:** Natalie Koskela-Staples, MS, University of Florida

#### **Measure Reviews**

Remember to visit the Allergic Diseases SIG website for our measure bank!

<https://pedpsych.org/sigs/allergic-diseases-special-interest-group/> Measure banks are updated periodically.

#### **SIG Initiatives**

The Allergic Diseases SIG is committed to mobilizing our knowledge to improve allergy management, health equity, access to care, and health outcomes for minoritized groups. Members are also in the beginning stages of compiling clinical resources relevant to the allergic disease populations. Please contact Amy Hahn at [Amy.Hahn@nationwidechildrens.org](mailto:Amy.Hahn@nationwidechildrens.org) if you would like to be involved in either of these initiatives.



#### **Please be sure to join us for the Allergic Diseases SIG Meeting!**

We meet via Zoom Monday, April 4 from 6-7 PM EST. During this meeting, we will provide updates on SIG activities and announce new members of our leadership team. We will also feature a presentation by our student poster award winner and discuss initiatives for SIG activities over the next year.

- Web Link: <https://pedpsych.org/sppac-2022-sigs-virtualaccess/>
- Password: sigmeetings2022

Please find a list of conference content relevant to allergic diseases and presented by SIG members below. We are excited that posters on allergic diseases are represented throughout many of the poster sessions. In particular, please check out all of the strong student submissions that will be presented during poster sessions 2 (Allergic Diseases), 3 (Adolescent and Young Adult), and 4 (COVID-19). We encourage attendees to support members of the allergic diseases research and clinical community and network with others working in these areas!

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## SPPAC 2022 Programming (Continued)

**Thursday, 4/7 (Preconference Programming)**

2:30-5:00 pm:

- **Anti-racism Efforts in Pediatric Psychology: Implementation of Training, Community, and Clinical Activism Efforts of the Anti-Racism Workgroup**, presented by: N. Fleischer, **A. Hahn**, S. Mulchan, C. Shneider, S. Fritz, E. Getzoff Testa, M. Germone, & C. Russell
- **So You Want to Start a Clinical Program? Best Practices and Considerations for Psychologists across Pediatric Healthcare Settings**, presented by: **L. Herbert**, J. Bernacki, C. Ackerman, & R. Streisand

**Friday, 4/8**

8:00-9:00 am, Poster Session 2: Allergic Diseases

- Student Poster Honorable Mention: **Pediatric Patient versus Caregiver Communication in Food Allergy Encounters and Factors Associated with Caregiver Participation**, presented by: **S. Voorhees**, T. Vasquez, **M. Netz**, C. Bylund, & **D. Fedele**

4:45-6:00 pm:

- **Experiences of Caregivers of Children with Food Allergy during the COVID-19 Pandemic**, presented by: **C. Roberts**, **T. Morgan**, S. Stutes, D. Atkinson, K. Gregory, C. Carter, L. Mullins, & **A. Tackett**
- **Interactive Digital Health Interventions During the COVID-19 Pandemic: Program Development, Patient Experiences, and Lessons Learned in Three Pediatric Populations**, presented by: C. Evans, C. Holbein, **M. Engel**, & R. Ramsey

**Saturday, 4/9**

8:00-9:00 am, Poster Session 3: Adolescent and Young Adult

- Student Poster Award Winner: **Caregiver-Youth Agreement on Medication Beliefs and Asthma Morbidity in an Ethnically Diverse Sample of Adolescents with Asthma**, presented by: **G. Cushman**, K. Durkin, S. Kopel, S. Dunsinger, & E. McQuaid

## Food Protein-Induced Enterocolitis Syndrome (FPIES)

Food Protein-Induced Enterocolitis Syndrome (FPIES) is an allergic reaction in the GI system. Typically, FPIES presents within the first year of life, and the majority (60-90%) of affected children outgrow FPIES by age 4. FPIES is receiving increased awareness within the allergy community, as it can be associated with significant adverse growth, developmental, and psychosocial outcomes for affected children. Below, two experts weigh in on specific aspects of FPIES diagnosis and management.

## ASK THE EXPERT

Dr. Jennifer LeBovidge, PhD, pediatric psychologist and Allergic Diseases SIG co-chair spoke with Dr. Lisa Bartnikas about the identification, treatment, and specific challenges related to FPIES management.



**Dr. LeBovidge:** What is FPIES? How is FPIES different from IgE-mediated food allergies?

**Dr. Bartnikas:** FPIES is a non-IgE-mediated food allergy that affects the gastrointestinal tract. Symptoms include delayed and repeated episodes of vomiting, typically 1-4 hours after ingestion of the trigger food. In some cases, there can be lethargy, pallor, low body temperature, low blood pressure, or delayed diarrhea developing up to 24 hours later. Many people with FPIES are able to recover at home with oral rehydration. But in severe cases when people become dehydrated or lethargic, they require evaluation and treatment in an emergency room. FPIES is strictly a clinical diagnosis based on a high index of clinical suspicion. Unlike IgE-mediated food allergies, there are no tests like allergy skin prick or blood testing to help the diagnosis. For many families and patients, the potential uncertainties in diagnosis and absence of diagnostic tests may lead to increased worry, stress and anxiety.

**Ask the Expert:**  
Dr. Lisa Bartnikas is an Assistant Professor of Pediatrics at Harvard Medical School and practicing pediatric allergist at Boston Children's Hospital

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**Dr. LeBovidge:** How do families manage FPIES on a daily basis?

**Dr. Bartnikas:** Daily management of FPIES is similar to IgE-mediated food allergies, with strict allergen avoidance to make sure the patient does not ingest the trigger food. Allergen avoidance includes purchasing foods that do not contain the person's allergens, reading food ingredient labels, and being watchful for signs of FPIES reactions. Healthcare providers can work with families on identifying foods for avoidance or safe foods for introduction.

**Dr. LeBovidge:** How do you treat a reaction?

**Dr. Bartnikas:** If there is a reaction, which typically consists of repeated vomiting, the most important thing is to make sure the person is able to stay hydrated by offering clear liquids by mouth. Examples of clear liquids are things like breastmilk or Pedialyte. Ondansetron (zofran) is a very helpful medication that can be used to treat FPIES reactions and leads to faster resolution of vomiting and decreased rate of hospitalization. I typically prescribe this to my patients to have at home in case of an FPIES reaction. If a person has a history of prior severe FPIES reaction, is unable to stay hydrated, or has lethargy or decreased consciousness, they should be brought to the Emergency Room for further care and monitoring. In some cases, they will need treatment with IV fluids or steroids to treat a more severe reaction. Thankfully, there have never been any reported fatalities due to FPIES reactions. However, people can still become quite ill, which can be very distressing for families.

**Dr. LeBovidge:** What are some of the common challenges related to feeding and nutrition for patients with FPIES?

**Dr. Bartnikas:** Experiencing repeated FPIES reactions may lead to feeding difficulties and growth disorders in children, and psychological distress in children and caregivers. Infancy, the period when FPIES typically is diagnosed, is a critical time for feeding skill development, and disruption by FPIES reactions or avoidance diets may lead to food aversions and impaired eating behavior acquisition. For reasons that are not well understood, patients with FPIES may be at risk for food aversion, poor growth, and nutritional deficiencies even following elimination of trigger foods. A recent study in children with FPIES showed that risk factors for food aversion were having multiple FPIES food triggers, and also having wheat as a trigger. Risk factors for poor weight gain were again having multiple food triggers, specifically having cow's milk as a trigger, and having chronic FPIES. Another recent study showed that children with FPIES also especially those with cow's milk allergy were at greater risk for poor growth, with growth stunting more common than being underweight. Nutritionists, feeding therapists, psychologists, allergists, and gastroenterologists are all important members of the multidisciplinary team that can help identify and address nutrition and growth concerns and support progression of feeding skills.

**Dr. LeBovidge:** When are you most likely to refer families to a psychologist for support?

**Dr. Bartnikas:** In both my clinical experience and research, I have found that families with children with FPIES have a high degree of psychosocial burden and can definitely benefit from referral to a psychologist for support. In our research, we found that risk factors for decreased quality of life include lower household income, avoiding a greater number of foods due to FPIES, and specifically avoiding cow's milk. We found that decreased parental confidence in managing their child's food allergy was associated with increased stress, worry, and anxiety. I speak with families about their psychosocial functioning at the time of FPIES diagnosis, after any FPIES reactions, and also periodically at visits as they are learning to navigate an FPIES diagnosis and incorporate management into their daily lives. Transitions such as when a child enters school or daycare are also important times to check in, since this can be an exciting time, but can also bring a lot of new stresses and concerns for families with any food allergy, and in particular FPIES. In our research, we found that 46% of families reported that their children with FPIES did not attend school or daycare, and of those not attending, 54% did not attend due to concern for FPIES. Psychologists can play a key role working with families and the rest of the medical team to help families with FPIES develop balanced coping skills and increased confidence in managing their child's FPIES, which can help improve quality of life for the patient and their family and support social inclusion and engagement.

### Research Spotlight

On March 8, Dr. Lucy Bilaver from Northwestern University presented to the SIG on disparities in food allergies. She highlighted her research on racial and ethnic differences in food allergy diagnosis, as well as disparities in food allergy management. Dr. Bilaver also discussed the economic burden of food allergies and food insecurity. She provided us with many useful resources, some of which can be found on page 5.



**IN THEIR OWN  
WORDS:**

**Experiences of an FPIES  
Parent and Advocate**

Fallon Schultz Matney, MSW, LCSW, CAM, is a parent of a child with FPIES and is the founder & president of the International FPIES Association (IFPIES). She recently spoke with Dr. Katie Peterson, the Allergic Diseases SIG research chair, about her experiences with FPIES advocacy.

**Dr. Peterson:** Tell us about your family's experience with FPIES.

**Ms. Schultz Matney:** I have a 13-year-old son, and we were involved in FPIES in the dark ages as I like to call it. When my son was born, he was exclusively breastfed, and within 2 weeks, he was vomiting, had bloody diapers, and we went through the whole gamut of diagnoses, e.g., acid reflux, laryngomalacia, trachymalacia, he was having upper GI series. I mean like 10 to 12 diapers filled with blood every single day, vomiting, skin covered in eczema that was bleeding. It was a very exhausting experience. I went through the worst anxiety I had ever experienced in my life. I would take him to the doctor - his pediatrician was fantastic, she knew that there was something wrong - but she couldn't place it. They encouraged me to stop breastfeeding; this was the dynamic for two years.

We saw 8-10 different specialists. And some of the feedback that I had gotten during that time included being told that I was a new, anxious mom, that I was "imagining" the blood clots in his diaper. It went so far as to receiving an anonymous letter in the mail accusing me of Munchausen's. And so I went through probably every single experience ... that really affected my confidence and my belief in being a mom. I would go to the shower and think "I am not equipped to be a mom." There was a lot of blame and responsibility put on me for my son's health. When we got [to the specialist], I will never ever forget that day for the rest of my life. I brought an accordion folder because I got into this perpetual state of having to prove myself. I was taking videos of him, I was taking pictures of his diapers, I was documenting because I almost started to believe maybe I was imagining it. Because of the feedback and lack of support I was getting from the medical community, I started to almost question my own sanity.

His GI doctor examined him and looked at his growth chart: he's failure-to-thrive, he's not gaining weight, his bottom is covered in blisters, "Who is telling you there's nothing wrong with this child?" He took the accordion folder, left the room, and I was thinking, "Oh my gosh, they are going to take my baby away from me." He came back in the room with a whole team and sat down and held my hand and said "Ms. Schultz, you're not crazy. There is something wrong. I don't know what it is, but I'm going to help you." And I just lost it.

It didn't end there because the insurance company wouldn't allow us to stay [with the specialist]... he had to have his first endoscopy, and I didn't know what was happening, I didn't know how to manage him. I was so weakened in my confidence as a mom, it was really traumatizing. His GI doctor fought, punted him to allergy, and within 10 minutes, my son was diagnosed with FPIES. His allergist said "He is one of the most severe cases." We had to take him off all food, only elemental formula. That was when the journey began.

**Dr. Peterson:** Tell us about managing FPIES in your family.

**Ms. Schultz Matney:** My son was kind-of like the trailblazer, the guinea pig. He didn't get diagnosed until he was 2, and that really affected him in a lot of ways; he needed feeding therapy. That was the first two years of my son's life. It was horrific. Literally, every day, throwing up, bloody diapers, screaming his head off, not one day of peace.

I couldn't work. I was a licensed clinical social worker, it affected my ability to implement my clinical skills because I was dealing with so much personally that I didn't have any space of release, work became so difficult to manage. We lost a home, we lost a car, my son's father and I got divorced. This really impacted our lives in a huge way. There is not one domain that was not impacted.

He was exclusively elemental formula fed. Back then there was no protocol, we would trial a food, and scope, trial a food and scope, so my baby was undergoing anesthesia constantly. I was at the edge of my seat. When he would have reactions, they would be so severe that he'd end up in a hospital fed on an IV for a week.

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**Dr. Peterson:** Tell us about managing FPIES in your family (cont.)

This is an important aspect - I am an Italian woman, we fix everything with food. People in my own family would say, he's starving, you're not feeding him enough.... My ex-husband's family would say, you're feeding him too fast ... I was getting it from all angles, instead of, "you're doing everything you can for this child." When he was in the hospital for the sweet potato trial, one of the fellows saw me crying, and she started talking to me. I turned to her and said, this is so hard, my family won't understand, they think I'm controlling. The next day, they called all of our family and had them come in and spent the time to educate them, saying, you need to listen to mom, he is very sick, he needs a very restrictive diet, there is no bending. That affected the dynamics within our family.

**Dr. Peterson:** Tell us about your advocacy work.

**Ms. Schultz Matney:** I spend a lot of time talking to parents all over, they can't get to places like NYU or Stanford. I spend a lot of time talking to them, I get calls at all hours... To be able to take my experience and be able to calm them down, it's a healing process for me. I am telling parents, you're not crazy, you got this, listen to me, I am with you, I am walking side by side, we are navigating this. There is so much support that's needed to navigate this.

We have a major problem in American medicine - it's fragmented. We think it's specialized, but it's fragmented. The way we practice medicine is not preventative, it's pigeonholed. They call it "specialized" but it's ... no one is putting pieces together. We become detectives, investigators, which is what science is supposed to be, but it's not in this country. There's a whole other side to research - there are so many secondary issues. What's interesting in FPIES, there are so many secondary issues, sometimes more prevalent, and because it didn't hit the "criteria" a lot of my role has been to debunk myths, things can be comorbid. When FPIES started, it was only acute, I had to push for chronic, I had to push for multiple triggers, I had to show it was "first foods of introduction" not just milk. All of that got put into the guidelines [for diagnosis and management of FPIES]. It takes a perspective that is not fragmented. I have the six pillars of food allergy: I have a child with it, I am a clinician, I'm a researcher, I'm an advocate, I have worked in legislation, and I myself have a rare disease. When you look at all these pieces, you have a much different perspective.

The clinical treatment recs are not inclusive of the practical management. You can make any recommendation you want but it doesn't apply in the practical realm. I am working with [medical providers] to change the framework of how they make their treatment plans to be inclusive of the reality of where the patient is. It's like a funnel, you have to see if there's trauma, if there's readiness, then come down into the clinical picture. It's fragmented medicine, we need to do a much better job.

I literally marched into the NIH three years ago and I sat down with the chief of the NIAID and the director and I think what I'm starting to see is a paradigm shift that's happening. I'm very real, very down to earth, I'll say it like it is, and that has been a big piece of restoring the confidence I lost in those first two years, I had to become very educated, someone who could stand on my own two feet with strong convictions but could back it up. I went in there and really painted the picture of the patient journey for them but colored it with the research, colored it with the gaps, the secondary issues, the costs, I really painted a pretty solid picture. I got this disease as far as I could get with no money. The guidelines, ICD-10 code, national awareness, all of these doctors worked for free for me for 10 years. They [NIH] said, what do you want? Take us to the moon, what do you want, and I told them everything I want, and they said okay. Let's get together, let's do an FPIES workshop, you will help select the speakers, I will only agree to this if it's not all allergy and immunology. I want fresh eyes on this, all of these different pieces, and they listened to me. I get to open up the FPIES blueprint that the NIH is going to fund. They valued that input. We are seeing a lot of fragments in this country, I think we're on the brink of seeing things changing. When you can show all the aspects and not just what fits in the box, you do capture the attention and you can move the needle.

**Dr. Peterson:** What do you think is the most important thing to know about FPIES for mental health providers?

**Ms. Schultz Matney:** While it's characterized as episodic, it 100% is a chronic condition. It impacts the patient 3 meals, 2 snacks a day. There is a very dysfunctional relationship with food, it starts in infancy, it is disjointed and it has multiple implications far outside the clinical picture and outside the psychological picture. This has a major impact on the family, relatives, school is difficult to navigate. So it's a disorder that begins and ends with trauma. Even the patients that I know who have outgrown it still don't know how to function and navigate with food. Which is a very important piece. This highlights how traumatic this disorder is. Even patients who have gone through OFCs and passed, they are still 5-10 years later living with the aftermath of disjointed relationship with food and also the fear.

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**Dr. Peterson:** What do you think is the most important thing to know about FPIES for mental health providers? (cont.)

The psychological support needs to remain in place even far after resolution of the disease (if you're lucky enough to get there). The other piece is, blanket statements don't work in this condition (e.g., all kids outgrow by 3, or it's only one food). This disorder behaves in a very wildcard way, and the disorders are bleeding into one another. I feel strongly we need to research the adults, we may be able to find the mechanism that is triggering this. I have learned a lot from adults [with FPIES] - it's a sense of doom before the symptoms start. Lastly, we need to listen to the patients. I feel like my story is a perfect example of that - look at how much I was dismissed in those first few years, how many times I was told I was crazy, but now I have people all over the world coming to me ... if you listen, you're going to get all the answers.

Will there be a cure in my son's lifetime? This is also an interesting angle, and I will leave you with this. It would crush my heart, my spirit, my soul, my being, and my purpose in life, if my son has to live it, AND if he has to watch his child go through it. If I can do anything to prevent my child from having to live with this and then have to experience this from the caregiver perspective, I will do whatever it takes to be sure he doesn't have it from both angles. To have to go through that double-whammy, I pray that by the time my son has kids, that there is something. That is my goal. No-one should have to go through that.

The International FPIES Association (I-FPIES, <http://www.fpies.org/>) is a non-profit organization that provides education, support, and advocacy for individuals with Food Protein-Induced Enterocolitis Syndrome (FPIES) and their families. The organization has resources for both caregivers and health care professionals including the FPIES University Video Library, <https://www.fpiesuniversity.org/>, a resource featuring dozens of free videos on FPIES and related topics for patients, caregivers, and healthcare professionals. Individuals need to create an account to view the videos.

### Additional Resources

#### Additional FPIES Resources

- Schultz F, Westcott-Chavez A. Food protein-induced enterocolitis syndrome from the parent perspective. *Current opinion in allergy and clinical immunology*. 2014;14(3):263-7.
- Peterson C, Gupta M. Psychosocial and neurodevelopmental aspects of food protein-induced enterocolitis syndrome. *Annals of allergy, asthma & immunology : official publication of the American College of Allergy, Asthma, & Immunology*. 2020;124(4):393-4.
- Maciag MC, Herbert LJ, Sicherer SH, Young MC, Schultz F, Westcott-Chavez AA, Phipatanakul W, Bingemann TA, Bartnikas LM. The Psychosocial Impact of Food Protein-Induced Enterocolitis Syndrome. *The journal of allergy and clinical immunology In practice*. 2020;8(10):3508-14.e5.
- Maciag MC, Bartnikas LM, Sicherer SH, Herbert LJ, Young MC, Matney F, Westcott-Chavez AA, Petty CR, Phipatanakul W, Bingemann TA. A Slice of Food Protein-Induced Enterocolitis Syndrome (FPIES): Insights from 441 Children with FPIES as Provided by Caregivers in the International FPIES Association. *The journal of allergy and clinical immunology In practice*. 2020;8(5):1702-9.
- Bartnikas LM, Nowak-Wegrzyn A, Schultz F, Phipatanakul W, Bingemann TA. The evolution of food protein-induced enterocolitis syndrome: From a diagnosis that did not exist to a condition in need of answers. *Annals of allergy, asthma & immunology : official publication of the American College of Allergy, Asthma, & Immunology*. 2021;126(5):489-97.

#### Food Insecurity Resources

- The Center for Food Allergy and Asthma Research, <https://www.feinberg.northwestern.edu/sites/cfaar/>
- Shroba, J., Das, R., Bilaver, L., Vincent, E., Brown, E., Polk, B...Gupta, R. (2022). Food insecurity in the food allergic population: A work group report of the AAAAI adverse reactions to foods committee. *Journal of Allergy and Clinical Immunology Practice*, 10(1), 81-90.
- Food Allergy Research and Education (FARE): Food Allergy focused food banks. <https://www.foodallergy.org/resources/food-banks-and-soup-kitchens>
- Food Equality Initiative <https://foodequalityinitiative.org/> is the nation's leading organization focused on increased access to allergy safe foods to food insecure individuals.

### Call for contributions:

We would like to use our newsletter to highlight the important work of our SIG members. Please reach out to us if you have a clinical or completed research project you would like to have spotlighted, or anything you would like to share with our membership!