

A 3-Course Meal: Advancing FPIES from the Parent, Practical, & Clinical Perspectives

Fallon Schultz, MSW, LCSW, CAM

International FPIES Association (IFPIES)

CEO & Founder

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Learning Objectives

1. Explain the role patient advocacy plays in the development, awareness, & advancement of FPIES
2. Identify three areas of need for the day-to-day nutritional management of FPIES.
3. List 3 common obstacles & creative solutions impacting the quality of life of patients living with FPIES.



What is FPIES?

FPIES =

Food
Protein-
Induced
Enterocolitis
Syndrome

A non-IgE cell-
mediated food allergy
that can be severe and
lead to shock.

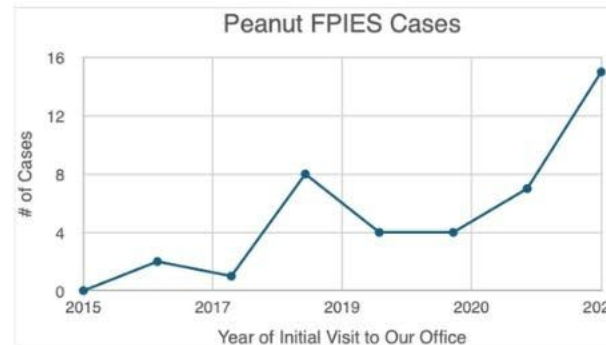
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Scan me

- Established 2011
- Personal journey
- Patient & provider focused
- IFPIES has modeled the shift to patient-centricity

FPIES Phenotypes



Rotella K, Lee ASE, Lopes JP, Sicherer SH, Kattan JD, Baker MG. Food protein-induced enterocolitis syndrome (FPIES) to peanut: Characteristics and long-term outcomes of a large cohort. *J Allergy Clin Immunol Pract.* 2023 Oct 17;52(13-2198):2301141-8.

FPIES AGE SPECTRUM

FPIES is no longer only a disease of infancy. Recent studies demonstrate prolonged courses into teenage years with conversion to IgE mediated FA & adult onset of FPIES



Estimated USA Pediatric & Adult prevalence

2,300,000

The Role of Advocacy in Shaping FPIES

An ecosystem of partnerships towards a biomarker, diagnostic, & treatment

Accomplishments

IFPIES has spearheaded multiple initiatives shaping the clinical, research and advocacy landscape of non-IgE mediated food allergies.

- Creation of ICD-10 Code, K52.21
- Publication of the International Consensus Guidelines for the Diagnosis & Treatment of FPIES
- Congressionally supported National FPIES Awareness Day, May 4th
- Inclusion of FPIES in the Consortium of Food Allergy Research (COFAR)
- First-ever awarded NIH Grant, \$2.5M
- FPIES University

THE FPIES "MACRO-BIOME"

An ecosystem of partnership towards a biomarker, diagnostic and treatment



PATIENT NEEDS

Individualized management that strengthens resilience, empowerment and lessens the burdens of FPIES

GLOBAL PROVIDER COLLABORATION

An unwavering commitment of global medical collaborators tasked to advance a biomarker, diagnostic and treatment.

DATA ANALYSIS & RESEARCH

Ethical, compliant research that directly engages the patient community to improve patient-outcomes, support scholarly publications and refine clinical care.

CORPORATE PARTNERSHIP

Industry engagement to forecast and pave the legacy of research, clinical care and drug development in FPIES

CARING FOR THE FPIES CHILD

Quality of Life matters

CURRENT TREATMENT MODEL

- Evidence-Based, yet data lags the lived-experience
- Clinically-focused-yet pathophysiology remains unknown
- Emphasizes and encourages utilizing RD, yet access is very limited at best
- Acuity vs. Chronicity of FPIES-primarily a social disease
- Clinical-Practical-Parental- A model in reverse

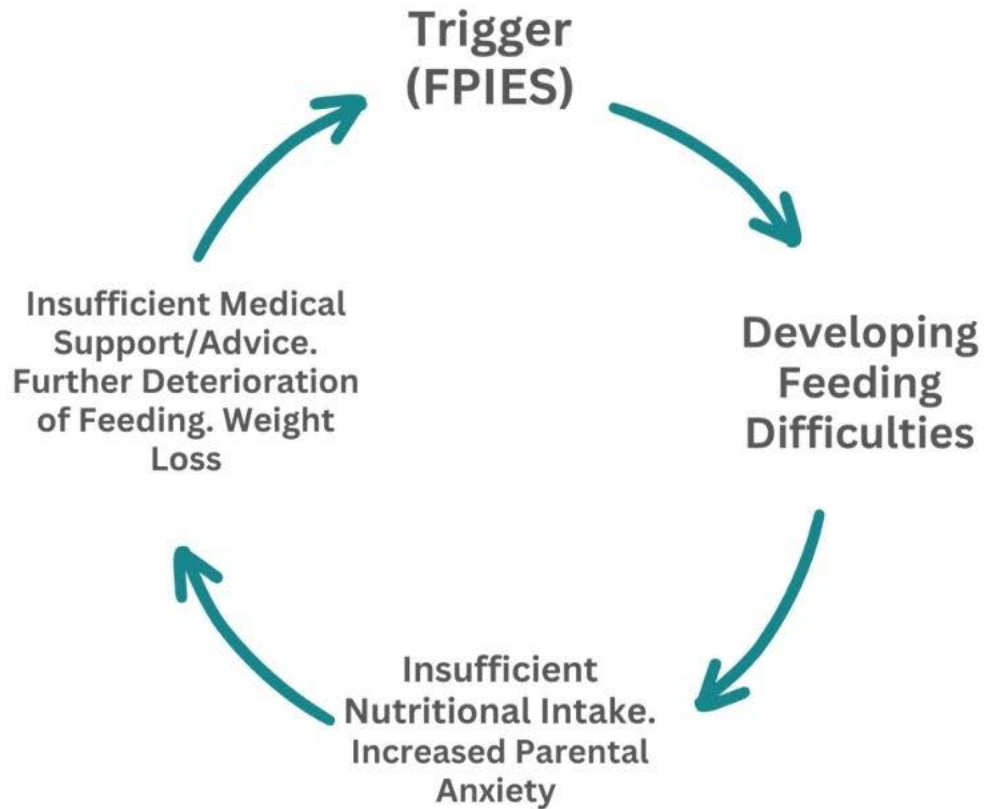
MASLOW'S HIERARCHY OF NEEDS



UNDERSTANDING COMMON OBSTACLES IN FPIES

NUTRITIONAL MANAGEMENT

The Cycle of FPIES



A New Model of Care



FPIES Nutritional Management 2024

- Trauma-informed care
- Day-to-day practical management tools
- Shared-decision making



TRAUMA INFORMED CARE

Assess parental stress and coping obstacles



COMBATING TRAUMA- 20% OF THE FUNNEL

- Has food become something you fear?
- Do you feel safe and comfortable introducing new foods?
- Do you prefer to introduce foods at home or in a clinical setting under supervision?
- How much of your day is consumed by meal preparation?
- Do you feel you have enough safe foods in your diet?
- Are you hungry?
- Who is supporting you through this experience?
- What social environments do you feel safest in?
- Do you feel isolated from support and others?
- Who do you trust?

Solutions

- Integrate an allied health team early in the process
- Identify supportive networks; IFPIES, support groups, connect with other patients and families
- Mindfulness-based stress reduction
- Give a sense of control back to the patient & family
- Telehealth support more frequently

PRACTICAL MANAGEMENT TOOLS

Disjointed relationship with food



SOCIAL DISEASE- NEARLY 70% OF MANAGEMENT

- Get curious
- Focus on safety, love and belonging, esteem building
- Assess all quality of life domains; school, caregiving, social, special occasions
- Three meals, two snacks per day
- Chronicity of FPIES lies in the practical management
- Understand resources are very limited
- Access to support is scarce
- Clinical goals are not always the same as parent/patient goals

Solutions

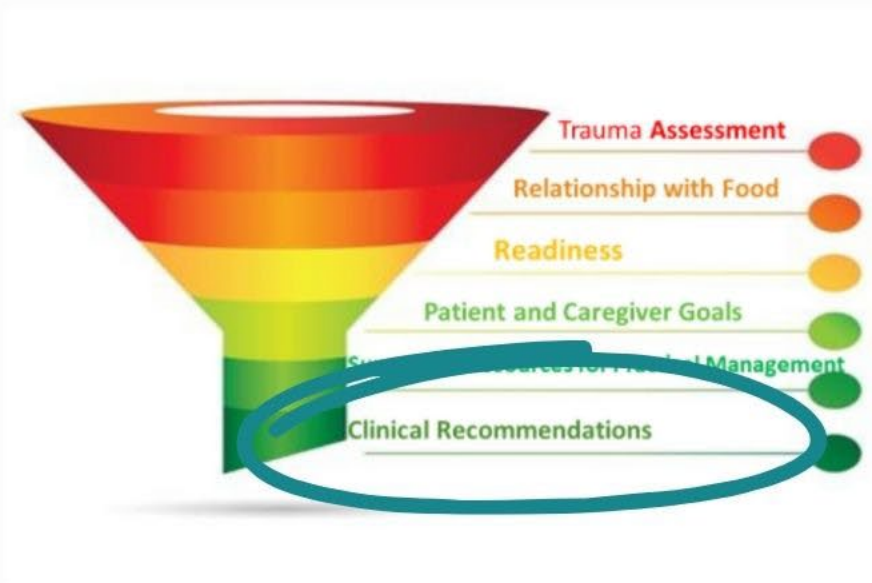
Shift the focus from avoidance to substitutions

- Focus on foods with versatility; potato, coconut, almond (liquid, a semi-solid, a flour, solid)
- Create a safe space for safe foods- shelves, fridge, play kitchen
- Get creative! Foodless cakes, freebie foods, shapes & colors
- Grow a garden of safe foods
- Cook together - sensorial experiences
- Engage your school - "SHOP" for safes
- Create experiences - themed parties, pinatas, trick or trade?

SHARED DECISION MAKING

Encourage patient autonomy in navigating clinical obstacles & choices

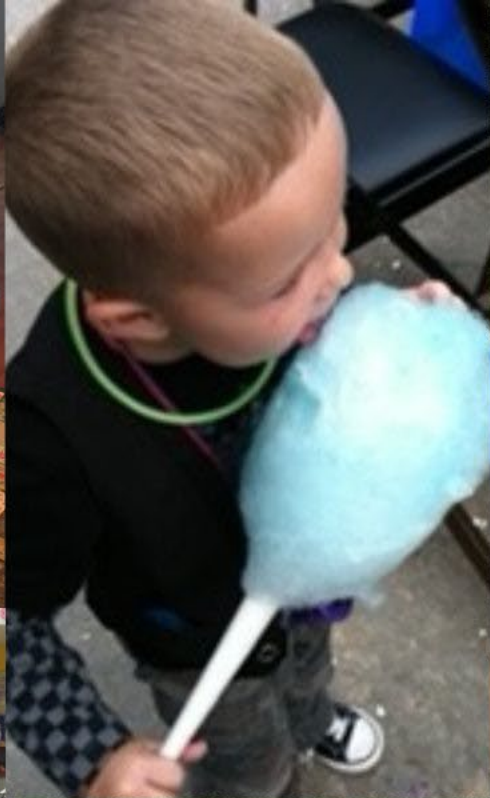
ACUTE CLINICAL CARE: 20% OF MANAGEMENT



Empowerment	Improved Communication	Tailored Care	Comprehensive Support
<ul style="list-style-type: none">- Promotes active participation in care and have a voice in treatment plans- Leads to a sense of control and ownership over health	<ul style="list-style-type: none">- Facilitates open/honest communication between healthcare providers and patients.- Leads to better understanding, trust, and improved outcomes	<ul style="list-style-type: none">- Permits tailored treatment plans that align with patient preferences, values, and lifestyle	<ul style="list-style-type: none">- Encourages healthcare providers to address overall well-being— including psychosocial health

Solutions

- What are your goals? Maintain or advance diet?
- EDUCATE: What will happen? When? Where?
- Challenges: At home, in clinic, avoid
- Assign someone to call for help
- Engage Child Life
- Create a sense of empowerment - Superhero Capes
- Sign a "no-no"- IV placement
- Provide clinical resources: ER letter, Caregiver Action Plan, Dining Out Card, IFPIES FAST Pass
- Industry: Honor a birthday



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