



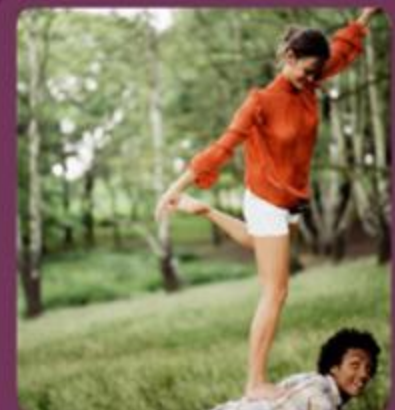
Improving Life on Nutrition Support



Welcome to the Webinar.
We will begin at 12:05 while
we wait for everyone to join us.



Improving Life on Nutrition Support



www.TheFPIESFoundation.org

Advocating for Your Child in the Healthcare System

Speakers



Nichole Huff, Ph.D., CFLE **The FPIES Foundation Volunteer/Guest Blogger**

Dr. Nichole Huff is the parent of a son with FPIES.

- Assistant Professor, North Carolina State University
- Family Sciences, Marriage and Family Therapy
- Certified Family Life Educator

Follow Dr. Huff on Twitter @soapboxmommy

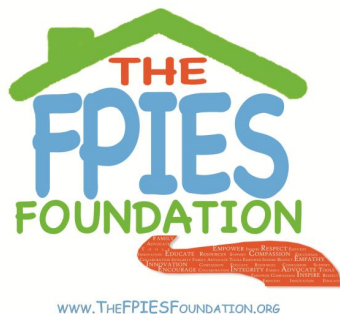


Abby Brogan **ThriveRx Outreach Coordinator**

- Daughter on nutrition support due to short bowel syndrome.
- Part of ThriveRx Consumer Advocacy team for past 7 years.
- Helps create and facilitate ThriveRx's educational Tips, Tools, and Webinars.

Mission

The mission of ThriveRx is to optimize the nutritional well-being of our consumers through our customized approach, while maintaining the highest standards in service and clinical care. Our mission is fulfilled by our outstanding team, who put our consumers at the center of what we do and work towards improving the quality of their lives.



The mission of The FPIES Foundation is dedicated to overcoming the challenges of Food Protein- Induced Enterocolitis Syndrome by offering tools for education, support, and advocacy to empower families and the medical community.



Objective

The purpose of this webinar is to help families navigate the healthcare system by providing advocacy actions, tools, and resources to assist them and their medical providers in caring for their children living with FPIES, or other medical conditions that are not easily understood.

You will learn:

- Actions that an effective advocate takes;
- Helpful tools to utilize when advocating;
- How to successfully coordinate care; and
- Strategies for strengthening your child's voice.

*Please find a PDF of this webinar,
along with further details and resource links, at
www.fpiesfoundation.org.*

Understand The Diagnosis

Educate Yourself

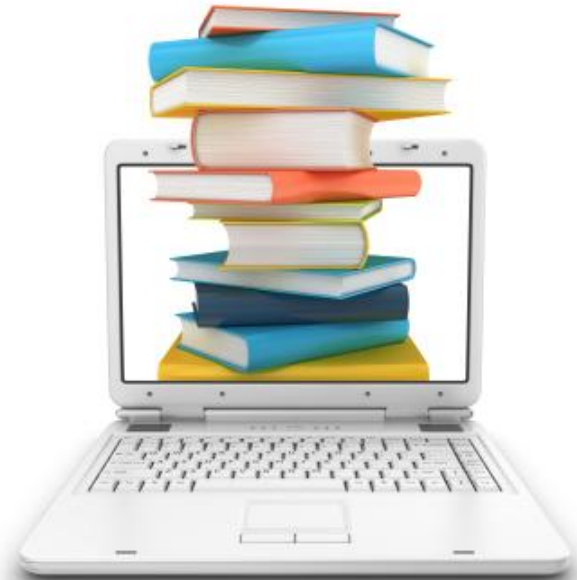
- ✓ Gain knowledge on FPIES
- ✓ Familiarize yourself with terms

Prepare for appointments

- ✓ Pre-write questions
- ✓ Bring notes from home
- ✓ Plan to take notes and prioritize concerns

Gain knowledge through your provider(s)

- ✓ Get specifics, ask for clarification.
- ✓ Request educational and support resources



Documentation: A Powerful Tool

Documentation provides:

- ✓ a clear picture of your child's health
- ✓ an additional VOICE for your child's care management

Remember, documentation is not only important when seeking a diagnosis....

Appropriate documentation is also essential for insurance coverage, nutritional support, medical supplies, and 504/IEP school plans.



Create and Access Useful Documentation

Effective Documentation . . .

- ✓ Is clear, concise, and objective
- ✓ Uses simple and descriptive language
- ✓ Is able to be understood by all who utilize it

Documentation you can provide for your medical team:	Documentation your medical team can provide for you:
<ul style="list-style-type: none">• Food journals, symptom logs• Daily logs from school/daycare• Photographs	<ul style="list-style-type: none">• Diagnostic test results• Laboratory results• Procedures results

Objective Documentation:

What does the symptom “look” like in your child?



Partner with Your Medical Team

Building Relationships with a Common Goal... **Your Child**

Communication is key!

- ✓ Gather the information needed to communicate with your team effectively.

Be honest and open

- ✓ Communicate your instincts and expect the team to do the same.

Partner in decision-making

- ✓ What is important to your family / your child's quality of life?



Facilitate Care Across Medical Settings



Outpatient

- Scope of practice
- Team approach
- Emergent vs. non-emergent

Inpatient

- Admission goals
- Discharge criteria
- Child's needs & schedule
- Care conference

Communicate and Coordinate Healthcare Needs

Care Plan: A Health Summary

- ✓ Age and Developmental Stage
- ✓ Medical/Physical Needs
- ✓ Psychological and Emotional Needs
- ✓ Social Needs



“A Care Plan should be a tool that you can use to communicate and coordinate your health care needs. ...This type of health summary can assist you in communicating your child's needs to all providers and can be used as a basis for a health plan at school.”

– Family Voices of Minnesota

Develop an Action Plan

Action Plans Help Monitor and Manage Symptoms

Action Plans may include:

- ✓ Definitions of individual degrees or stages of reactions
- ✓ Documentation of symptoms
- ✓ Communication with providers
- ✓ Medical interventions
- ✓ Follow-up care
- ✓ ER plan

<p>At baseline _____ (my child) feels well, baseline looks like:</p> <p>Management during baseline:</p>
<p>When symptomatic _____ (my child) does not feel well, and may include these symptoms:</p> <p>Management/Medical interventions:</p>
<p>During a reaction _____ (my child) is experiencing these symptoms:</p> <p>My Child's Emergency plan is:</p>

Be Prepared with an Emergency Plan

Emergency Plan:

A Specific Component of the Care Plan

- ✓ Includes ER letter (template or individualized)
- ✓ Is specific to your child's history with FPIES
- ✓ Includes information on how to contact your child's primary specialist for treatment directives
- ✓ **Considers the potential effect of a *crisis* on the whole child and puts in place tools and strategies to be utilized to best protect your child in such an event**



This plan is designed to **give protection** and a **VOICE** to your child in times of crisis.

Be Proactive: Emergency Care

- ✓ Preparing resources in advance will help to ensure that you can communicate more effectively with the ER team when your child needs it most.
- ✓ Keep in mind that the goal of the ER staff is to **treat** emergent symptoms rather than providing or confirming an FPIES diagnosis.

- FPIES information
- ER Bag
- ER Plan



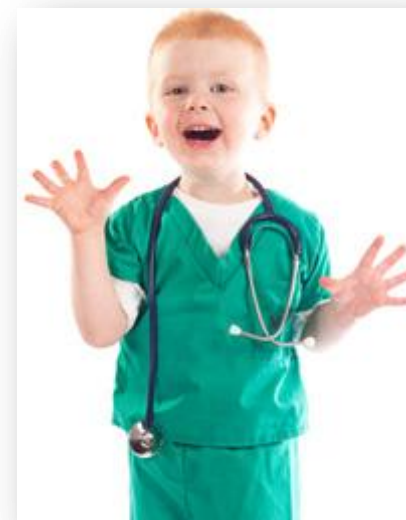
Be a Role Model: Teaching Your Child Self-Advocacy

Show your child how to be a part of his/her team

- ✓ Act as a model in your own interactions with medical providers.
- ✓ Help your child vocalize and express opinions, describe symptoms.

Help your child understand his/her diagnosis

- ✓ Provide education appropriate to the child's age and developmental stage.
- ✓ Seek a professional who can provide tools
 - Medical Family Therapist
 - Child Life Specialist
 - Social Worker



Addressing Communication Challenges

Identify the need

- ✓ Consider the long-term relationship with the medical team
- ✓ Is this practitioner the right fit for your family?

Speak up – you are a member of the team!

- ✓ Ask for clarifications
- ✓ Take time to address concerns

Seek Support

- ✓ Support groups and therapists
- ✓ Child/patient advocate



Remember to T.A.L.K.

Tone When advocating, remain ***calm*** and ***respectful*** in your vocal cues and body language.

Assertiveness Make notes of ***key*** points and address them ***clearly*** and ***confidently***.

Listening Demonstrate qualities of an ***active listener***. Take time to listen to the professionals with whom you interact.

Keeping Focused ***Stay on topic***, working toward resolution of each point addressed.



Summary

Communicate



Educate



Coordinate

Thank you!

ThriveRx

The FPIES Foundation

Joy Meyer	Co-Director
Amanda LeFew	Co-Director/Medical Liaison
Erica Allen	Volunteer
Jenn Booth	Executive Board Member

The FPIES Foundation Medical Advisory Board

<http://fpiesfoundation.org/leadership/>

Additional Resources

FPIES Foundation Advocacy Resources:

www.thefpiesfoundation.org/advocacy/

ThriveRx Advocacy Resources:

<http://www.thriverx.net/>

General Advocacy Resources:

- **Family Voices** <http://www.familyvoices.org/>
- **National Center for Family Professional Partnerships**
<http://www.fv-ncfpp.org/>
- **Kids as Self Advocates** <http://www.fvkasa.org/>



Redefining Differences

A Biopsychosocial Approach to Addressing Special Needs

Join the eXtension Child and Family Learning Network, along with human development specialist Dr. Nichole Huff, for a webinar on better serving individuals and families with special biopsychosocial needs. A biopsychosocial model (BPS) is one that acknowledges the distinct yet interdependent roles that a person's biological, psychological, and social systems play in their overall health and functioning.

The webinar aims to:

- (1) Teach professionals how to educate themselves on BPS differences;
- (2) Assist professionals in fostering empathy and understanding; and
- (3) Provide professionals with empowering instructional techniques to apply when serving individuals and families experiencing physical, cognitive, or emotional differences.

Join us Thursday, August 28 at 11am EST

<https://learn.extension.org/events/1684>



Dr. Nichole Huff
North Carolina State University



Upcoming ThriveRx Events



ThriveRx Children's Book Series

My Special Line:

Early Reader Children's Book

Let's Learn About Central Lines:

Elementary Age Children's book

Upcoming Webinars

- Understanding your TPN Label
- Managing the Day-to-Day of a Raising a Child with Tubes

To request a copy of these books or for information on our educational Tips, Tools, Webinars or to join our mailing list, visit ThriveRx.net or email us at info@thriverrx.net

Thank you for joining us.



For more information on FPIES
or today's webinar, visit
fpiesfoundation.org or
thrivex.net

