### > Building the Foundation

At The FPIES Foundation, we not only recognize the need for research to help future children and their families, but we also recognize the need to help our families and medical professionals now by providing education, advocacy and support resources, online and in our global community. We will:

Hear the voices of families and doctors,

**E**ducate and support in order to better meet the ongoing needs of the FPIES community,

Lobby for improved standards of care in FPIES treatment, and

**P**rovide funding for research and other professional endeavors

#### Current programs include. . .

- Providing a toolbox for parents
- ➢ Hosting an informative website
- Conducting educational in-services for families and the medical community

#### Future programs include. . .

- > Funding ongoing research programs
- Lobbying to create standardized protocols for effective FPIES diagnosis and treatment
- Providing funding for professional efforts exploring diagnosis and management options
- Supplying information at conferences and scholarly meetings to further awareness and support FPIES education

### ~ Fast Facts and Resources~

- FPIES is a rare type of food allergy, typically affecting infants and children
- FPIES is a clinical diagnosis based on medical history and ruling out other conditions-- there are no official tests to positively confirm an FPIES diagnosis
- FPIES reactions can be emergent and require immediate medical attention
- ANY food can induce an FPIES reaction and different children can react to different foods

For Families: www.fpiesfoundation.org/for-families

For Medical Professionals: www.fpiesfoundation.org/for-healthcare

FPIES Q&A by our Medical Advisory Board: www.fpies foundation.org/fpies-questions-and-answers-fromthe-medical-advisory-board

To Find a FPIES-Familiar Provider: www.fpiesfoundation.org/find-a-healthcare-provider

> The FPIES Foundation Blog: www.fpiesfoundation.blogspot.com

FPIES Awareness Apparel and Gifts: www.cafepress.com/thefpiesfoundation



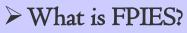
For More Information, Please Contact: The FPIES Foundation P.O. Box 304 ~ Stewartville MN 55976 <u>contact@thefpiesfoundation.org</u>

# Awareness is Action



# Taking Big Steps for The Smallest of Patients

The FPIES Foundation is a 501(c)(3) non-profit organization dedicated to overcoming the challenges of FPIES by offering tools for education, support and advocacy to empower families and the medical community.



**Food Protein-Induced Enterocolitis Syndrome** (FPIES) is a type of food allergy affecting the gastrointestinal tract.

**Classic symptoms** include profuse vomiting, diarrhea and dehydration. These symptoms can lead to severe lethargy, changes in body temperature and blood pressure. The classic reaction pattern generally occurs 2-3 hours post ingestion of the causal food.

**Chronic symptoms** can include a pattern of increasingly severe

vomiting, diarrhea and poor growth, possibly progressing to an illness mimicking a severe totalbody infection.

Unlike "typical" food allergies, **symptoms may not be immediate** and do not show up on standard allergy tests.

## ➢ If You Suspect FPIES

If you suspect your child may be experiencing FPIES symptoms, it is important to reach out for **support and resources!** First things first:

- 1. Take a deep breath and get ready to **research**! Go to <u>www.fpiesfoundation.org</u> for more!
- 2. Record the details of your child's reaction(s) and the suspected foods involved
- 3. Find an FPIES-friendly medical practitioner
- 4. Keep a **daily food journal**, detailing what your child eats and what his/her response is
- 5. If your suspicions are confirmed, seek out other affected families, online or in community **support groups.**

FPIES can be overwhelming at times and finding support from families in similar situations, as well as your own friends and family, can help you and your little one on your journey to happier and healthier days ahead.

## ≻ An Essential Toolbox

We provide tools for families and the medical professionals that serve them.



On our website, families can access documentation to bring with them to the **emergency room**, helping to explain their child's condition.

Our FPIES-familiar **medical provider database** connects knowledgeable practitioners and affected families nationally and abroad.

Medical professionals can access **an extensive list of scholarly journal articles** related to the various aspects of FPIES. They can review the **FPIES Q&A** to learn what our esteemed medical advisory board has to say about various aspects of diagnosis and management.

## > Awareness IS Action!

The FPIES Foundation recognizes the importance of awareness for this **rare disorder**. Because FPIES is rare, families may experience difficulty finding medical providers that are familiar with this diagnosis.

Awareness can help to **bridge this gap,** educating families and practitioners about FPIES, and providing better care for affected infants/children.

Let's all **dare to be rare** and speak out, bringing FPIES education to families and medical professionals alike.

You can be a part of the action! From guest speaking to letter writing campaigns to community events, you can raise your voice on behalf of children affected by FPIES. Keep these **key awareness concepts** in mind:

- 1. Clearly and concretely **define** FPIES
- 2. Make it personal-- include a personal story to make your cause more identifiable
- 3. Plan your platform to address groups with **potential invested interests**, such as parent groups or pediatric health professionals
- 4. Maintain contacts and follow-up
- 5. For **support and resources**, access the the "get involved" section of our website and/or contact us today!



Foundations of Fundraising

When you are able, we'd love your help fundraising! At our website, we have great no-cost options to participate in that will help to raise funds, such as signing up for igive, goodsearch, and others!

For those wanting to facilitate both large and small scale fundraising events, be sure to check out the downloadable **Fundraising Packet** on our website for resources, family-friendly event ideas, and more! <u>www.fpiesfoundation.org/fundraise</u>

