

FPIES FOUNDATION OFFERS "HOME BASE" FOR FAMILIES BATTLING RARE DISEASE DURING FOOD ALLERGY AWARENESS WEEK

May 6, 2013

Food Allergy Awareness Week is May 12-18, 2013. During this time The FPIES Foundation, a non-profit organization recently awarded 501(c)(3) status, is reaching out to those suffering from Food Protein-Induced Enterocolitis Syndrome (FPIES), offering its trusted resources to help comfort families. The Foundation is launching an "*Awareness is Action*" campaign.

A rare diagnosis, FPIES is a type of food allergy affecting the gastrointestinal tract. It is typically diagnosed in infants and young children. Classic symptoms of FPIES include profound vomiting, diarrhea, and dehydration. These symptoms can lead to severe lethargy, change in body temperature and blood pressure, and may require emergent medical attention. Unlike typical food allergies, symptoms may not be immediate and do not show up on standard allergy tests; furthermore, the negative allergy evaluation may delay the diagnosis and take the focus off the causative food. Nonetheless, FPIES can present with severe symptoms following ingestion of a reactionary food.

The goal of The FPIES Foundation is to provide support and encouragement, as well as the tools for managing FPIES on a day-to-day basis. Foundation Chair Joy Meyer says with the recent designation as a non-profit, The FPIES Foundation is truly a "home" families can trust. "We aspire to help families feel welcomed, to know that they have a place where they can get help, support, and a sense of community," says Meyer.

When families choose to "come home" to TheFpiesFoundation.org they will find:

- A *Toolbox* with tips for emergency room visits, keeping a food journal, checking symptoms, and streamlining doctor's visits.
- A *Provider Directory* to help find FPIES knowledgeable doctors in the United States and beyond.
- *Questions and Answers* from the Medical Advisory Board made up of some of the leading gastroenterologists, allergists and nutritionists treating FPIES.
- Inspiring personal stories, designed to give families hope that they too can manage FPIES.

At the core of The FPIES Foundation is the desire to bring families together, so they can learn from shared experiences. The Foundation provides a blog, and Facebook, Twitter and Pinterest pages as a way for families to connect with each other. Links to these accounts are found at TheFPIESFoundation.org.

"FPIES is a rare allergic condition and it can be isolating," says Meyer. "Well meaning family members and friends likely have never heard of it and we have found families rely on the online support system to get them through the ups and downs associated with the diagnosis."

In the spirit of empowerment, The FPIES Foundation also gives families the chance to do something to help other families. The Foundation can help set up support groups, as well as help organize donation, fund-raising, and awareness programs. There are also ample volunteer opportunities, including "*Hugs for Heroes*," a program that brings handmade blankets and stuffed animals to children suffering from FPIES who need extra comfort during in-hospital procedures.

The FPIES Foundation is an Incorporated 501(c)(3)Non-Profit Foundation. It is a collaborative effort of several families affected by FPIES whose relentless journey has sparked the desire to help other families find their way. FPIES is often under recognized and poorly understood. The organization's founders identified a dire need for tangible support resources for both the affected families and the medical community. The FPIES Foundation is committed to providing a credible and interactive support resource for this rare, oftentimes isolating diagnosis. It strives to make the everyday lives of FPIES children and their families easier.