

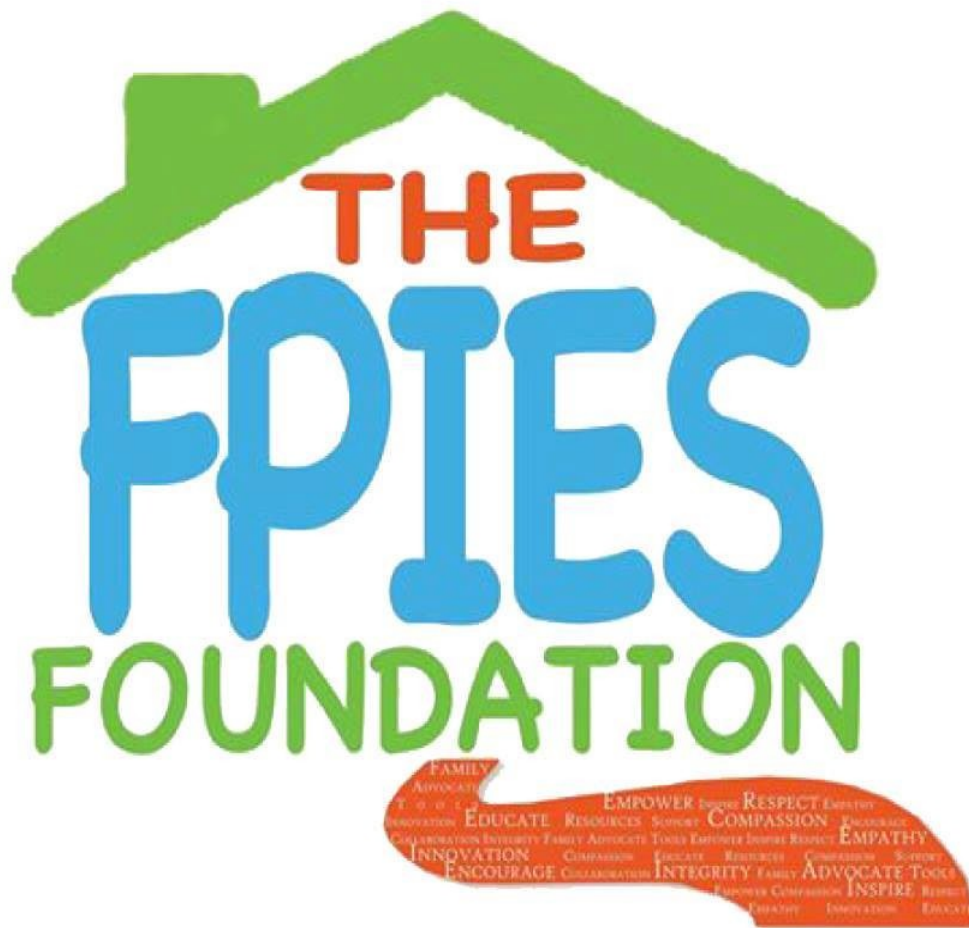
Educate

Support

Empower

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.

## The FPIES Foundation Annual Report 2013



[WWW.THEFPIESFOUNDATION.ORG](http://WWW.THEFPIESFOUNDATION.ORG)

The Leadership of The FPIES Foundation consists of collaboration between The Executive Board, Medical Advisory Board, and Volunteer & Parent Advisory Panel.

<p><b><u>Executive Board of Directors</u></b></p> <p>Joy Meyer, Co-Director/Board Chair Amanda LeFew, Co-Director/Board Treasurer Cyndi Merrill, Board Member</p> <p><b><u>Volunteer Board &amp; Parent Advisory Panel</u></b></p> <p>Erica Allen Jenn Booth Sarah Clements Katie DeLong Dulik Crystal Martin-Lentz Natalie Middaugh Kendall Nelson Carrie Summers Victoria Warren</p>	<p><b><u>Medical Advisory</u></b></p> <p>Sakina S. Bajowala, MD J. Andrew Bird, MD April Clark, RD/LD Glenn T. Furuta, MD Benjamin D. Gold, MD Harumi Jyonouchi, MD Bailey Koch, RD, CSP, LD John J. Lee, MD Fred Leickly, MD, MPH Tara McCarthy, MS, RD, LDN David R. Naimi, DO Wayne Shreffler, MD, PhD Luqman Seidu, MD Qian Yuan, MD, PhD.</p>
--	--

The FPIES Foundation provides a lasting and secure foundation for the FPIES community, for families and medical professionals alike. In all of our activities, we continuously strive to explore treatment options customized to enable growth and healing for today's children as well as those of the future. Together with families and medical professionals, we will make changes today to create a lasting foundation for tomorrow.



FPIES (Food Protein-Induced Enterocolitis Syndrome) is a rare type of food allergy affecting the gastrointestinal tract. Classic FPIES reactions occur 2 or more hours after ingesting the "trigger" food and typically involve profuse vomiting, diarrhea, and can progress to shock.

There is no cure for FPIES and there are no diagnostic tests to confirm diagnosis. Food trials are the only way to determine whether or not a food is safe for each child. Any food can trigger an FPIES reaction and different children react to different food(s).

FPIES is not well-known, even within the medical community, and awareness is desperately needed to facilitate better diagnosis and symptom management for affected children. Together, we can raise awareness and help to improve the quality of life for affected children and their families.

Contact The FPIES Foundation TODAY for ways that you can help!

[contact@thefpiesfoundation.org](mailto:contact@thefpiesfoundation.org)

Support us at:

[WWW.THEFPIESFOUNDATION.ORG](http://WWW.THEFPIESFOUNDATION.ORG)

## The Mission of The FPIES Foundation is dedicated to overcoming the challenges of FPIES by offering tools for education, support, and advocacy to *empower families and the medical community.*

In 2013, we carried out our mission through family-focused outreach, education and support while building awareness in medical and lay communities worldwide.



**Building awareness** of FPIES is an ongoing priority of The FPIES Foundation. Starting in February, we reached out to our expansive online community with a [blog post](#) and social media shares honoring **Tube Feeding Awareness Week** (Feb.10-16), raising awareness to the children requiring feeding tubes to thrive through this diagnosis.

FPIES is a rare food allergy of the gastrointestinal system, and we were honored to once more participate in **Rare Diseases Day** (Feb.28), "Rare Disorders without Borders." As an official Rare Diseases Day partner organization, The FPIES Foundation empowered families and their communities to take action through a variety of interactive activities, illustrated here our in [Rare Diseases Day blog post](#). With ongoing increased awareness, the FPIES community will continue to break down these borders. This will not only connect us across miles and communities, but also between patient and practitioner, between families and researchers, schools, childcare, and all aspects of our children's lives that will continue to keep them safe and thriving with this rare food allergy.

## Improved Connections Lead to Enhanced Care.

The FPIES Foundation honored **Eosinophilic Awareness week**, sharing highlights from [The story of Ryker](#), a little boy diagnosed with FPIES and Eosinophilic Colitis (EC), and how his community is rallying around his family.

**Awareness is the cornerstone** to building a foundation of active support for FPIES children. By participating in one of our leading annual awareness campaigns, [Food Allergy Awareness Week \(FAAW\)](#), May 12-18, 2013, we spread FPIES awareness through our website, social media and additional online tools. Along with initiating interactive [awareness programs](#), we launched new awareness videos, "[FPIES, Now I know](#)", and "[Awareness is Action](#)" on our YouTube channel for online viewing and sharing. All activities emphasized the theme, "Awareness is ACTION"!

## Together, with collaboration of families and medical professionals, we continue to make changes today to building this lasting foundation for tomorrow

To further awareness of FPIES in social media circles, and to show support for The FPIES Foundation, we added a **“Proud to Support The FPIES Foundation”** button to our online tools.

In November, the **Today's Dietitian** publication, *“FPIES: The Hidden Scourge of GI Food Allergies”* raised awareness of FPIES to nutrition professionals nationwide.

The FPIES Foundation MAB member Bailey Koch, RD, CSP, LD, and Co-Director Joy Meyer, DTR, were interviewed for this article about FPIES in this leading Nutrition profession magazine.

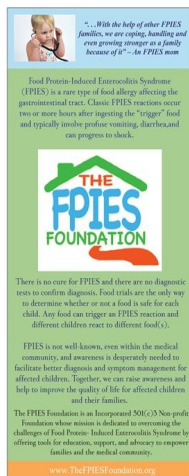


We are proud of families living with FPIES who seek to build FPIES awareness by participation in food allergy events, such as:

Family members from **'Sarah's FPIES Clubhouse'** who represented FPIES on September 8th in the “Strides for [Safe Kids Walk](#)” at the Kids with Food Allergies (KFA) Food Allergy Expo in Philadelphia.

**Team FPIES Foundation**, whose spirits were not dampened as they walked through the rain, representing FPIES Awareness at the Food Allergy Walk for FARE in Boston.

FPIES families who walked at the Food Allergy Walk for FARE in Virginia Beach, making **'Big Steps for FPIES'** and raising awareness



**Awareness is Visual---** The FPIES Foundation released simple, eye-catching and information-packed flyers (see [Foundation Awareness Flyers](#)). These were designed to provide an easy way to communicate The Foundation's mission and FPIES information simultaneously when advertising for fundraisers and awareness events. The flyers can also be used for distribution at more casual events, such as parent support groups.

FPIES Awareness gear provided an active and attractive way for families to raise awareness daily! **“FPIES Rare.but Real”** designed by FPIES mom, Crystal Lentz, was a popular [Booster T-shirts sale](#) of cute t-shirts to raise FPIES awareness. Funds raised were graciously donated to The FPIES Foundation.



**Expanding alliances took priority in 2013**, such as those with the Global Genes Foundation Alliance, Patient Crossroads and additional [partnering organizations](#). These alliances not only continued to spread awareness, but have led to the creation of powerful tools addressing current and future initiatives in education, advocacy and research, for both families and the medical professionals who support them.



We ended the year with an ever-expanding social media program designed for raising awareness and support. With over 2000 “likes” on [Facebook](#), 300 followers strong on [Twitter](#) spreading [#FPIES](#) awareness, and with growing ‘pins’ on [Pinterest](#), The FPIES Foundation continues to spread awareness, one resource at a time.

Our social media presence allows us to raise awareness of FPIES, illustrating resources and tools for daily living. We can keep families and medical providers alike informed of FPIES in the news, of awareness events nearby , and of medical developments that may affect those in the FPIES community.



**In building family-focused outreach**, The FPIES Foundation participated in events such as [Boston Zoo Day](#), a free family day event hosted by Boston Children's Hospital on Saturday, September 28, 2013. This offered a rare treat for families living in and around Boston, presenting a chance to meet each other face-to-face and even to ask BCH Allergy experts questions about the latest research and treatments available.

The FPIES Foundation hosted an informational booth, once more raising FPIES awareness and presenting resources available to families living with FPIES at this event.

In December, for the 3<sup>rd</sup> consecutive year, the FPIES Foundation also presented a booth at the [Food Allergy Support Group of MN Food Allergy Fair](#), raising awareness to FPIES and resources available to families living with this allergy.

Sample products from Foundation friends at CheeCha puffs and Manitoba Harvest were donated to The FPIES Foundation for distribution at this event.



Inspire  
 Educate  
 Empower  
 Inspire  
 Educate  
 Empower  
 Respect  
 Connect  
 Engage  
 Inspire  
 Educate  
 Empower  
 Inspire  
 Educate  
 Empower

[www.TheFPIESFoundation.org](http://www.TheFPIESFoundation.org)

[WWW.THEFPIESFOUNDATION.ORG](http://WWW.THEFPIESFOUNDATION.ORG)

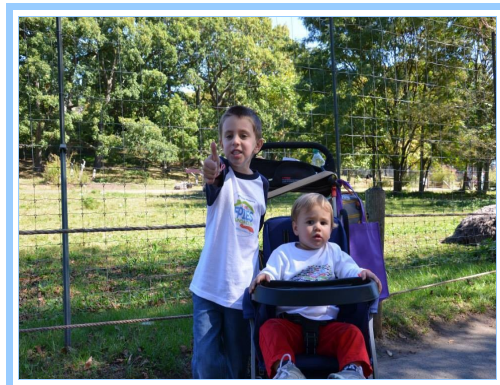
## It Starts with ONE

**O** ONE family reaching out  
**N** ONE medical practitioner  
**E** speaking at Grand Rounds  
ONE school educating its staff

The October edition of **The Big Y “Living Well” Newsletter** featured The FPIES Foundation. Amanda LeFew, Co-Director and Medical Liaison of The FPIES Foundation, was interviewed for this informative newsletter article, raising awareness to Food Protein Induced Enterocolitis Syndrome in the general population. The article addresses frequently asked questions such as “Does my Child have FPIES?” and “What should I do if I suspect my child has FPIES”, to “How is FPIES tested?”, bringing further awareness to this allergy for its readers.

**"We strive to provide a network of caring,  
the support you need to support your child."**

Demonstrating visual support, the release of [FPIES Wordle 2013](#) T-shirts through our Cafe Press store delivered the all-important message of **"You Are Not Alone."** The design was inspired by Jill Terwey and Tina Darling, and it was created by Vicki Garding-- truly, another example of collaboration and camaraderie among FPIES families.



We once more set the tone of caring and support through the release of the [How to start your own support group/meetings](#) tutorial. Once more, another Foundation publication inspired families nationwide; in this occasion, inspiration led to creating local meet-ups, such as the [Virginia Zoo Meet Up](#), organized by Natalie Middaugh, and the "Nuthin' But Good Times" NorthEast family meet ups, organized by Erica Allen.

## EDUCATE SUPPORT EMPOWER



The FPIES Foundation was honored to be featured in an article of the online publication [Complex Child E-Magazine](#) highlighting [Advocacy](#), a subject near to our hearts. This article shared the story of Founders and Co-Directors' (Amanda and Joy's) inspirations behind the establishment of The FPIES Foundation.

This year we also continued expansion on our blog, [FPIES Home, the Blog of The FPIES Foundation](#), including collaboration with families living with FPIES, guest bloggers, and interviews. We [introduced Dr.Huff](#) for monthly posts focused on child development, parent-child communication, and bio-psycho-social health. Her posts emphasize empowerment, such as in **'Advocating for your child in school setting'**, as well as offer healthy perspectives in coping, such as in **'FPIES a Diagnosis, not a Definition'**. Additional blog posts aimed at day-to-day living with FPIES, resources, educational elements and more appeared throughout the year.

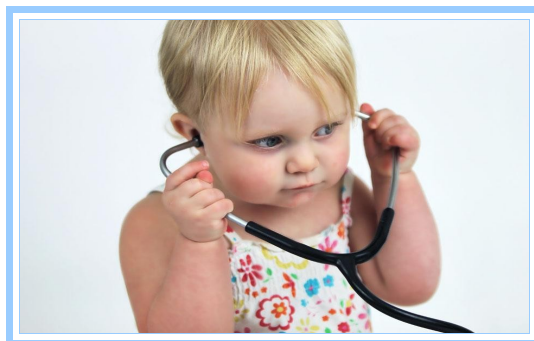
In November, The FPIES Foundation announced the first of its kind [Global FPIES Registry](#) for families. The registry is a ground-breaking opportunity to directly bring families affected by Food Protein Induced Enterocolitis Syndrome, FPIES, together with doctors and researchers interested in learning more and trying to understand this rare allergy. Through this registry, we are partnering with Patient Crossroads CONNECT program, a part of the National Institutes of Health (NIH) Global Rare Disease Registry Program to provide this important tool. We are so proud to invite all families to register and CONNECT, put each FPIES story on the map!



## Online Expansion-- Connecting Families with Resources and Support

Our new website launched in the fall of 2012; significant expansion continued through 2013. Content continues to grow as we seek to provide further resources for education, support and advocacy, empowering families and the medical community.

**Information provided on our website complies with the HONcode standard for trustworthy health information on the internet** and has been awarded certification from HON. HON (Health on the Net) Code, the code of ethical conduct, is “the commitment to reliable health and medical information on the internet.”



Our fundraiser program pages expanded to include increased fundraising resources, such as the [Foundations of Fundraising](#) webpage, to help guide supporters through raising FPIES awareness and achieving fundraising success! Once more, emphasis was placed on contributing one's VOICE in order to raise awareness, **as well as ongoing, simple no-cost fundraisers**, such as igive, goodsearch.com, and most recently, amazonsmile.com! **The FPIES Foundation understands** the financial strain families are often under and will continue to avoid burdening affected families with costly, time-consuming fundraisers.

The FPIES Foundation introduced new awareness programs packed with online tools and resources, including the informative [Awareness Events Near you](#) page and the empowering [Start the Conversation](#) resource page that includes our popular “It Starts with One!” YouTube video.



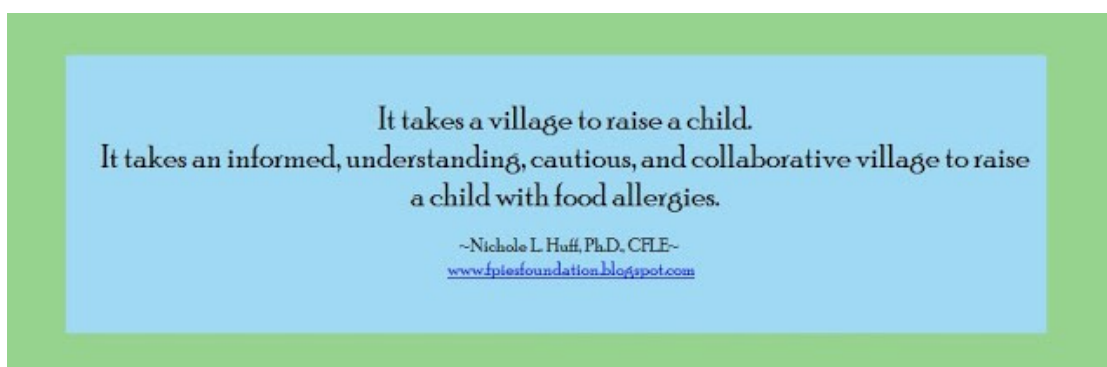
Additional multimedia online resources introduced this year included a [slide show](#) of money-saving tips for food allergy living (released in July), and an expansive, up-to-date [Medical Literature](#) page to include the latest in FPIES research and publications. Not only is our medical literature page user-friendly for medical professionals and families alike, with brief

synopsis of article content accompanying most citations, but it also provides **the most extensive available list of FPIES medical journal articles**, individually compiled, for online viewing.



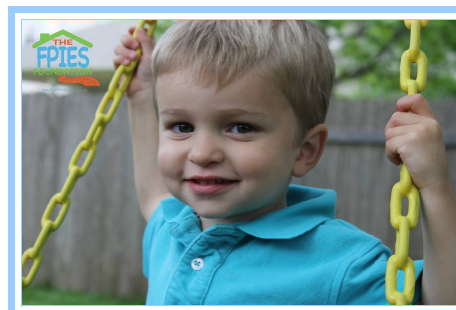
**Children are the cornerstone of The Foundation. We strive everyday to educate, advocate and empower the families and medical professionals who support them.**

The end of 2013 brought about a very special event-- the launch of our section "For Kids!" The FPIES Foundation introduced [the Kids' Corner](#) to provide a unique tool for helping children to better understand life with FPIES. Directed at children living with this diagnosis as well as children supporting others who are affected, kid-friendly language and themes address educational, supportive and functional elements involved in navigating life with FPIES.



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. 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. Fueled by inspiration from families, who assist and support **us** every day, we achieved so much this year, from our accomplishment of [501c3 Non-profit designation](#) in January 2013 to our ground-breaking announcement in November, when the FPIES Foundation launched the first of its kind Global FPIES Registry for families.

The registry is a ground-breaking opportunity to directly bring families affected by Food Protein Induced Enterocolitis Syndrome, FPIES, together with doctors and researchers interested in learning more and trying to understand this rare allergy. Through this registry, we are partnering with [Patient Crossroads CONNECT program](#), a part of the National Institutes of Health (NIH) Global Rare Disease Registry Program to provide this important tool. We are so proud to invite all of you to come and register-- CONNECT with us and help to put each FPIES story on the map!



### Other major developments and highlights from 2013 included:

- In February, we added a [Volunteer Advisory Board](#), a group of active members of the FPIES community volunteering their time and talents for the mission of The Foundation.
- In August, we [celebrated our 2<sup>nd</sup> Anniversary](#) with a look back at how The [FPIES Foundation came to be](#).
- In September, we received the 2013 Top-Rated Nonprofit award from Greatnonprofits, a great honor with less than 10% of eligible nonprofits have receiving this distinction.
- Throughout the year, we have expanded the Multidisciplinary [Medical Advisory Board](#) leaders in FPIES treatment and management, with the additions of:
  - **Dr. Luqman Seidu, Dr. Benjamin Gold, and Bailey Koch, RD** from Atlanta, Georgia
  - **Dr. Wayne Shreffler and Dr. Qian Yuan**, bringing Allergy/Immunology and Gastroenterology expertise from Massachusetts General Hospital Food Allergy Center
  - **Tara McCarthy, MS, RD, LDN** from Boston Children's Hospital, Massachusetts.

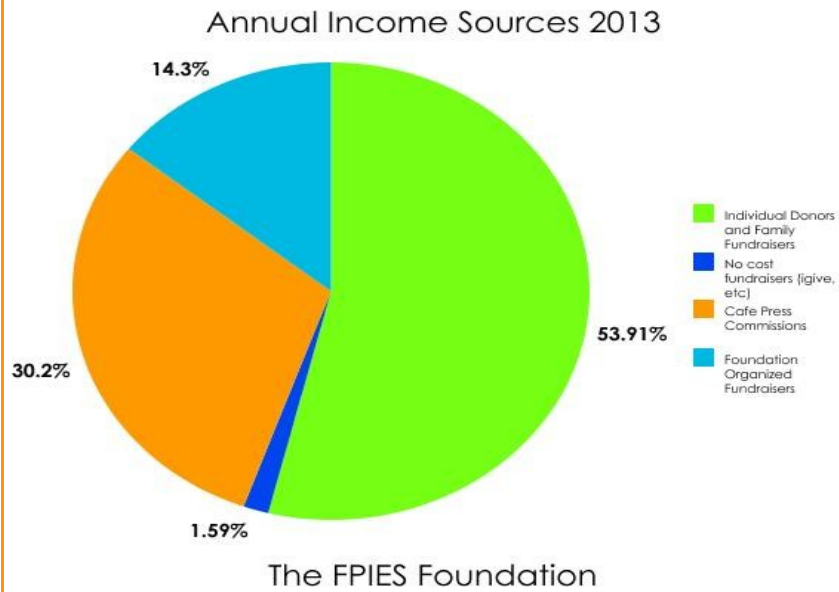


The FPIES Foundation wants to give [A BIG Thank You](#) to all of you, families, supporters, volunteers and donors who help make the work we do possible.

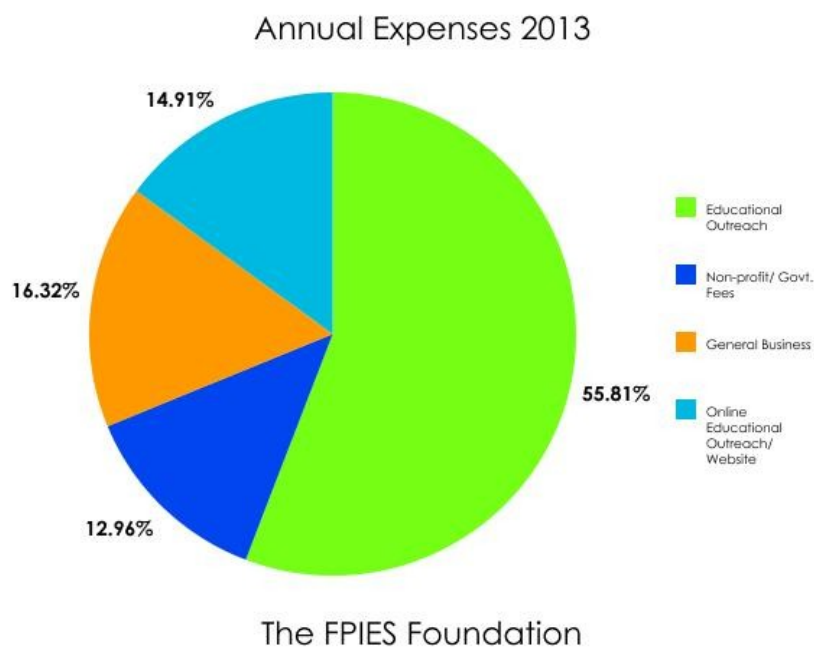


Our income comes from a variety of sources. **This year, the bulk of our income came directly from our supporters.**

Efforts of personal donors, family fundraisers, and those participating in no-cost fundraisers, such as igive, goodsearch and others, have allowed The FPIES Foundation to further **expand existing and develop new educational outreach programs.**



The FPIES Foundation will continue to invest in **families** and the tools and resources that support the care of their children: **advocacy, education and research.**

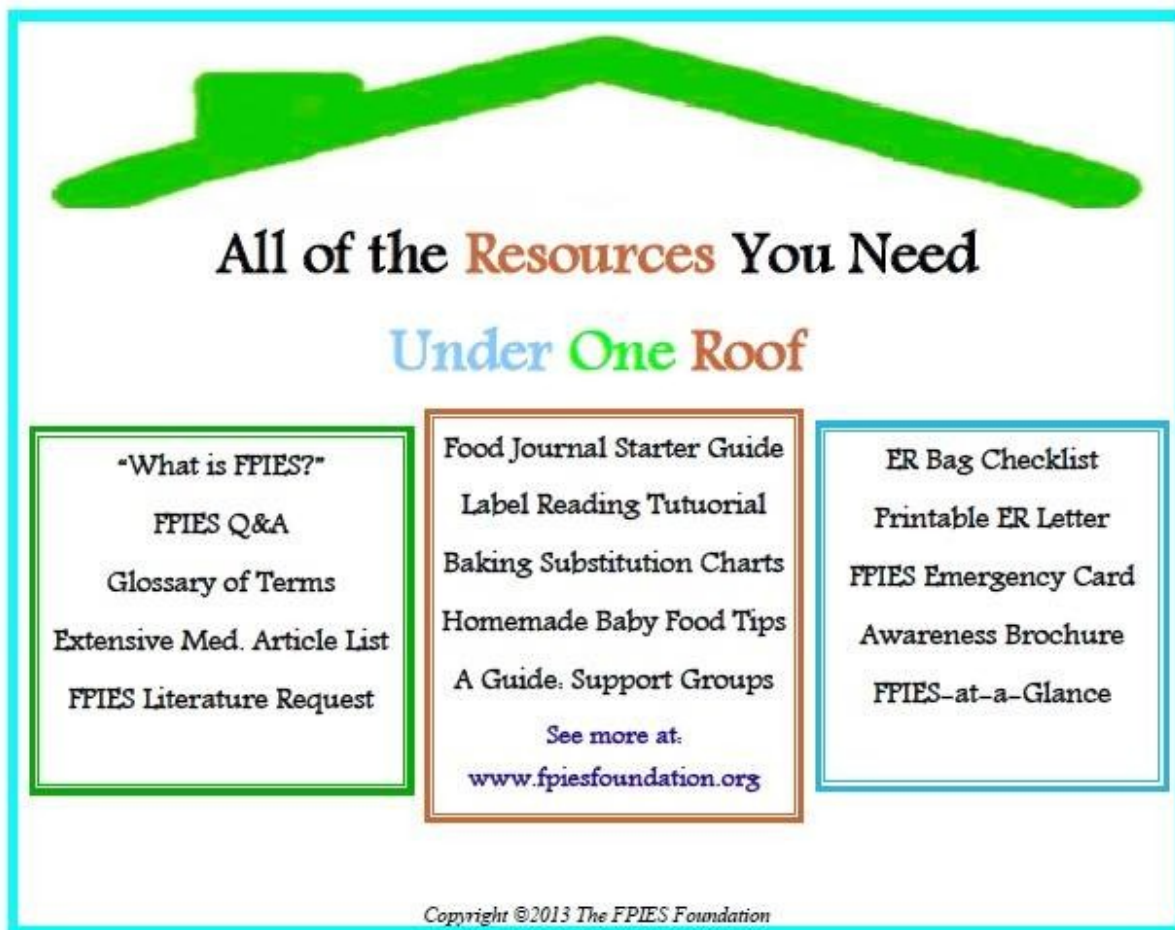


**Expenses for this year were concentrated on continued outreach:**

- Funding creation and distribution of educational materials
- Expansion and maintenance of online resources
- Providing educational materials for families and professionals

## The FPIES Foundation remains committed to providing a credible and interactive support resource for this rare, oftentimes isolating diagnosis.

During the Foundation's second year, our focus encompassed family outreach and education. Continued expansion of web-based programs, educational content, and the re-visiting of seasonal programs both supported and enhanced this focus. Looking ahead in the organization's third year, the primary focus will expand to educating medical professionals, globally and nationwide, about the multidisciplinary care essential for the child living with FPIES. **With this focus, we continually strive to make the everyday lives of FPIES children and their families easier.** As in past years, building FPIES awareness, supporting outreach and fostering education programs for families will remain at the core of The FPIES Foundation's mission. **Together, with collaboration of families and medical professionals, we continue to make changes today to building this lasting foundation for tomorrow.**



### All of the **Resources** You Need Under **One Roof**

<ul style="list-style-type: none"><li>-What is FPIES?</li><li>FPIES Q&amp;A</li><li>Glossary of Terms</li><li>Extensive Med. Article List</li><li>FPIES Literature Request</li></ul>	<ul style="list-style-type: none"><li>Food Journal Starter Guide</li><li>Label Reading Tutorial</li><li>Baking Substitution Charts</li><li>Homemade Baby Food Tips</li><li>A Guide: Support Groups</li></ul> <p>See more at: <a href="http://www.fpiesfoundation.org">www.fpiesfoundation.org</a></p>	<ul style="list-style-type: none"><li>ER Bag Checklist</li><li>Printable ER Letter</li><li>FPIES Emergency Card</li><li>Awareness Brochure</li><li>FPIES-at-a-Glance</li></ul>
--	---	--

Copyright ©2013 The FPIES Foundation