

Educate

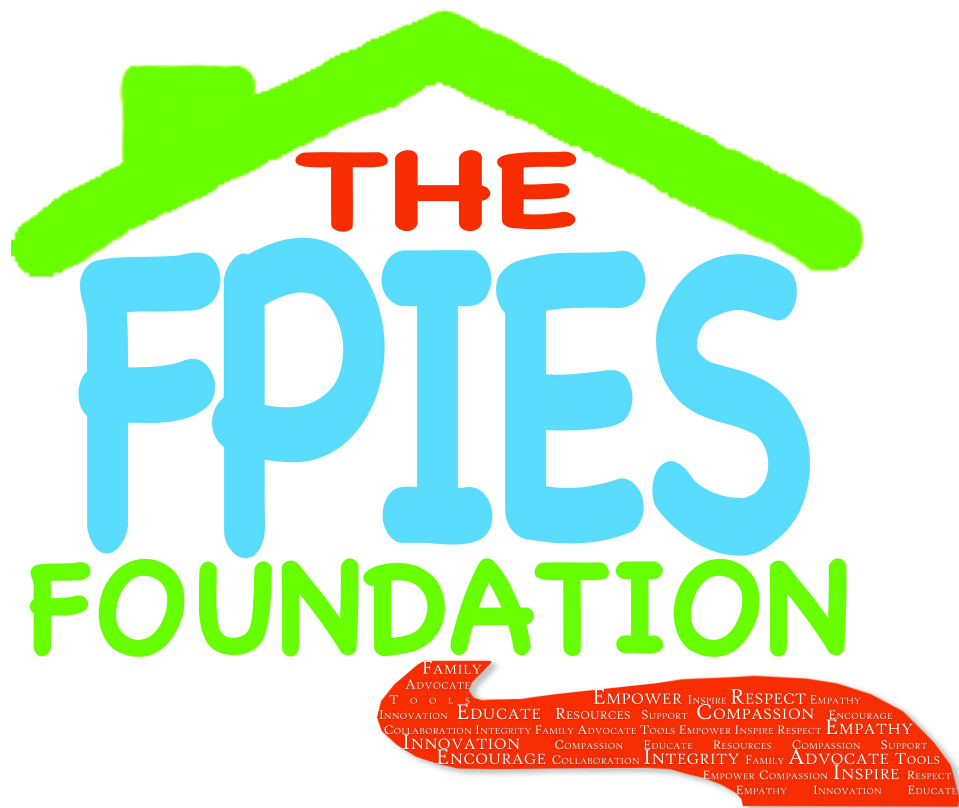
Support

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 2014



WWW.THEFPIESFOUNDATION.ORG

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

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Amanda LeFew, Co-Director

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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

Support us at:

WWW.THEFPIESFOUNDATION.ORG



Becoming The Voice: The Year of The Advocate

In 2014, we celebrated another year of spreading FPIES awareness and fostering advocacy, in the global community and among families and practitioners alike. This was truly the year of the advocate. This was the year igniting the spark in all of us to "Be the Voice."

Building awareness is an ongoing effort for this often misunderstood diagnosis. In February, The FPIES Foundation celebrated World Rare Diseases Day by initiating and [participating in several online and social media awareness campaigns](#). From participation in "Care About Rare" social media, to sharing photos taken with the [Rare Disease Day US](#) logo, or to raising hands in solidarity with families struggling from ALL rare diseases, we stood beside our partners in the rare diseases community, such as Global Genes. We were proud to further spread awareness when our ["FPIES, Now I Know"](#) video was included in the [Rare Disease Day](#) website. Rare Disease Day 2014 **focused on care**, encouraging everyone in the rare disease community to ["Join Together for Better Care"](#).

As communities and clinics become more AWARE, better and more beneficial CARE will be given to our affected infants and children.

Education has always been the cornerstone of our initiatives at The FPIES Foundation. Released this year, new FPIES awareness cards gave families a way to simultaneously educate their communities about FPIES while advocating for their children's safety. These cards were made available to practitioners and families, free of charge, either via download or if requested, in print materials.

Have you heard?

There are different types of food allergies...

Food Protein-Induced Enterocolitis Syndrome ("F-PiES") is a rare but serious type of food allergy.

- Symptoms of a reaction are delayed and may occur hours after exposure.
- Although there are 'common trigger' foods, any food can cause an FPIES reaction.
- A severe FPIES reaction can include profuse vomiting, pale skin, extreme sleepiness (lethargy), diarrhea, dehydration, and can quickly lead to shock.
- Signs of shock for an individual with FPIES are severe and include lethargy, pale/grey skin tones, and drastic changes in body temperature and heart rate.

Call 9-1-1 or seek prompt medical attention in the event of a severe reaction that includes fluids or IV resuscitation. (Note: EpiPen will not stop an FPIES reaction.)

www.thefpiesfoundation.org

Currently, the only safe treatment for children with FPIES is avoidance of any food that triggers a reaction.

How can you help?

- Serve and eat foods in designated areas only, making sure to clean up any leftover foods immediately after finishing a meal or snack.
- Always obtain parental consent before feeding a child.
- Follow proper emergency procedures by informing parents of a potential exposure or calling 9-1-1 immediately if a severe reaction is suspected.
- Educate others by passing this information along to everyone!

Just one crumb-sized portion of an allergen can trigger symptoms and put a child with FPIES at risk for a severe reaction

For more information, please visit
The FPIES Foundation @ www.thefpiesfoundation.org

**Free educational materials offer a platform for ADVOCACY,
Empowering families and practitioners to Be the Voice, worldwide.**

Everyday, hundreds of families are helping to Be the Voice for children living with FPIES. The month of May, devoted to Asthma and Allergy Awareness, brought continued opportunities for education, awareness and advocacy. We were honored to share a beautifully strong video for FPIES Awareness from our friends at FPIESUK, released during National Allergy Awareness Week in the United Kingdom. It was a powerful demonstration of the growing pattern of FPIES awareness on a global scale.

"...With the help of other FPIES families, we are making handling and care planning strategy a family business!" - An FPIES mom

FPIES (Food Protein-Induced Enterocolitis Syndrome) is a rare type of food allergy affecting the gastrointestinal tract. Classic FPIES reactions occur 2-6 hours after ingesting the "trigger" food and typically involve profuse vomiting, diarrhea, and can progress to shock.

THE FPIES FOUNDATION INVITES YOU TO CONNECT

WE ARE PROUD TO INVOLVE THE FIRST-OF-ITS-KIND, FPIES GLOBAL PATIENT REGISTRY. THIS REGISTRY WILL DEVELOP A STRONG FOUNDATION OF DATA, POTENTIALLY IMPACT TREATING AND FUTURE RESEARCH, AND STRENGTHEN THE COLLECTIVE VOICE OF THE FPIES COMMUNITY.

FOR PATIENTS DIAGNOSED WITH FPIES AND THEIR FAMILIES:

- PARTICIPATE IN SCIENTIFIC RESEARCH
- AN OPPORTUNITY TO MEET AND CONNECT WITH OTHER FAMILIES
- FREE REGISTRATION, FREE AWARENESS
- ACCESS TO THE PATIENT REGISTRY

FOR MEDICAL PROFESSIONALS SERVING PATIENTS DIAGNOSED WITH FPIES:

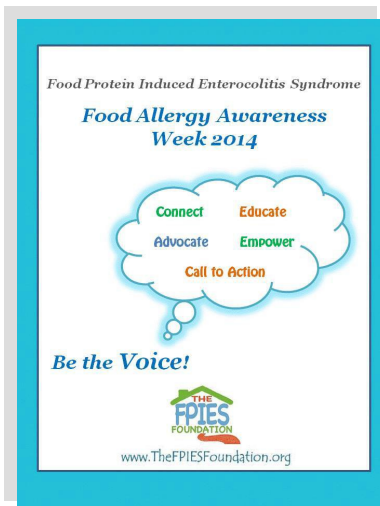
- REQUEST TO JOIN THE REGISTRY
- ACCESS TO THE PATIENT REGISTRY
- FREE REGISTRATION, FREE AWARENESS
- ACCESS TO THE PATIENT REGISTRY

CONTACT US: 800-833-8333 • 415-255-8333 • 415-255-8333 • 415-255-8333

In honor of National Asthma and Allergy Awareness month and FAAW, May 11-17, in the United States, The FPIES Foundation invited the community to help raise awareness for Food Protein-Induced Enterocolitis Syndrome and to “Be the Voice” in their local and global communities. The FPIES Foundation engaged the community in “[FPIES Be the Voice](#),” “[FPIES Share how you Care](#),” and “[Love your FPIES Selfie](#)” social media campaigns.

Responses from families were powerful and not only furthered the cause of awareness, but also fostered community support and solidarity. The tone of advocacy further resonated in the [Be The Voice](#) video, released during Food Allergy Awareness Week, empowering and encouraging families to support FPIES awareness, education and research.

Awareness is key and we are so thankful to have such a great community coming together to help spread awareness on days like [Rare Diseases Day](#), [Food Allergy Awareness Week](#), [Global FPIES Day](#), and EVERY day!



The first-of-its-kind FPIES Global Patient Registry is intended to present a “big picture” of FPIES, achieving a better understanding of this often complex diagnosis

Confirming The FPIES Foundation’s commitment to furthering research for this little understood diagnosis, two new surveys became available on the [Global FPIES Patient Registry](#) this year. Part of our ongoing partnership with the NIH-funded Connect program through Patient Crossroads, this registry allows families and medical professionals to view trends in patient-reported data regarding various aspects of FPIES. Participants can engage in registry surveys and immediately view the results, becoming an integral part of the research process.

As of 2014, doctors can now link to the data portal to see the de-identified results, giving greater insight into a wide span of patient-reported data from now over 400 participants.

To encourage more participants to engage and to further educational objectives, an informative blog series was released in July to facilitate greater understanding of the registry process and the benefits it offers the FPIES patient community and the medical community, on a global scale. Hundreds of practitioners across our nation received informative postcards about the benefits of participating in the registry process and how they can get involved. Engaging practitioners and families with a unified goal-- furthering understanding of FPIES and promoting research through the Global Patient Registry-- again fuels the flame of advocacy through education.



What We've Learned So Far. . .

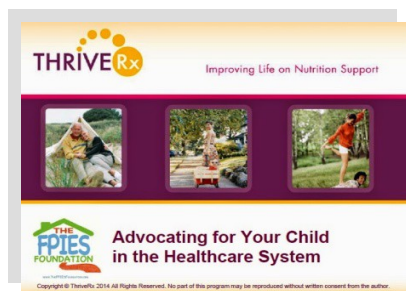
- **20% of participants** reported the process of receiving a diagnosis taking up to 11 months from the time symptoms were reported
- Approximately **50% of participants** reported visiting the doctor 2-6 times per year for diagnosis management
- **Over 20% of participants** reported the cost of FPIES management having a major impact on their family's finances
- The impact of the registry resonates in the community with **well over 400 current participants!**

PatientCrossroads™

We exist to provide tools--- to offer the support families need

To support their children

ThriveRx and The FPIES Foundation partnered to provide a FREE webinar: “Advocating for your child in the Healthcare System.” FPIES is a rare diagnosis that is often not fully understood, which can make it challenging for parents and medical providers. We created this webinar to help families better navigate the health care system, providing them with advocacy actions, tools, and resources, as they care for their children living with FPIES.



Following the webinar, families and medical professionals that support them could find a free recording of the webinar, corresponding slides and a comprehensive Advocacy section on the Foundation's website. This series of web pages is full of tools and supportive documents, including an emergency and action plan template. These plans are ideal for school, daycare and emergency planning use!

**An Emergency Plan gives a VOICE to your child
in a time of crisis**

Soon after our anniversary on August 31, we were proud to welcome Dr Sergio Negre Policarpo, MD, PhD, as the newest member of The FPIES Foundation's Medical Advisory Board. He heads the Pediatric Gastroenterology and Nutrition Unit at Quiron Valencia Hospital Pediatric Department in Valencia, Spain. An esteemed and compassionate professional, as well as a powerful advocate for FPIES both locally and globally, he has made Foundation materials even more accessible to family's and professionals by providing Spanish translations of essential documents.

On October 14, 2014, the voice of the FPIES community resonated world-wide with the establishment of Global FPIES Day. “There are days to recognize other food allergies and rare diseases, but FPIES is unique and the children are extraordinary. They deserve this day just for them,” says Joy Meyer, Executive Director of the FPIES Foundation.

Resources specific to the day were housed on a newly-released webpage, www.fpiesday.org, designed for the inaugural year and all those to come. Awareness gear and social media profile/banner pictures ignited community involvement; FPIES education and awareness packets-- free to download, available in Spanish and English translations, and customized for medical professionals or families-- empowered families and medical professionals with up-to-date resources. The innovative “Find Your Fourteen” campaign offered specific ways for all supporters in the medical and lay communities, world-wide, to engage in awareness and education opportunities for the fourteen days of October leading up to Global FPIES Day.



Our esteemed Medical Advisory Board rallied their support for Global FPIES Day by collaborating to create educational resources, by sharing their photos in the “I am the Voice!” social media campaigns, and even spreading the word through their own online outlets, such as Dr. Sergio Negre Policarpo in his blog “Día Mundial de FPIES.”

**We are committed to breaking ground in furthering awareness, promoting advocacy,
and fueling future research**

The fall of 2014 brought attendance at several awareness events including Free Allergy Day at Boston’s Franklin Park Zoo , the Food Allergy Support Group of MN Food Allergy Resource Fair, the FARE Food Allergy walk, and exhibiting at the Annual NASPGHAN conference.



Amanda LeFew, Co-Director of The FPIES Foundation, greeted families and raised awareness to FPIES while FPIES Foundation Panel Member, Victoria Warren, emceed this year's FARE Walk in Boston. Medical Advisory Board Members Dr. Lee, Dr.Yuan, and Dr.Shreffler were in attendance to support families, and we were excited to see a huge group of FPIES families at the walk! We are thrilled to stand together with the entire food allergy community in our ongoing efforts to research, treat and cure food allergies.

At our 4th year participation in the Annual FASGMN Food Allergy Resource Fair, Joy Meyer, Co-Director of The FPIES Foundation, was on hand to raise awareness to FPIES, and provide CheeCha Puff Samples donated by our partners at CheeCha puffs. Such events bring awareness and advocacy to the local community level, impacting and educating families face-to-face. We enjoy these opportunities to connect with families and supporters on such a personal level!



Our Impact at NASPHGAN

- 100 **dietitians** received FPIES educational packets
- 300 **doctors** received FPIES educational packets
- 900 **practitioners** were educated about the FPIES Global Patient Registry

At the NASPHGAN conference, co-director Joy Meyer met with Pediatric GI health professionals, including 1600 Physicians, Physicians Assistants, Nurses and Dietitians, all vital to our children's medical care, sharing a multitude of resources for professionals and for their clinics. A Nutrition Symposium for Dietitians was hosted by NASPHGAN and an informative seminar on FPIES was presented to Dietitians by Allergist Dr. Freedle, and Registered Dietitian Bailey Koch, a member of our esteemed medical advisory board.

We were honored to be part of an event furthering education for medical professionals, such as those who help to care for our children everyday.

A Global Reach: Extending Advocacy Through Online Resources

FPIES is indeed a rare diagnosis and it is our mission at the Foundation to expand our reach and resources to include all families and practitioners under one roof, world-wide. Providing resources in the online community extends that reach into homes in North and South America, clinics in Spain, military bases in Japan, and beyond.

Over the course of the year, our website expanded once more, including new and updated resources in line with the ever-growing need for tools and current information. Countless medical journal articles were added to our [FPIES Medical Literature](#) page, new documents and web resources expanded our [resource page](#), and even more FPIES-familiar practitioners were added to the essential "[Provider Database](#)," a resource allowing families to search world-wide for practitioners familiar with FPIES.

To kick-off the new year, we relaunched the "Kids' Spot, a special section on our website specifically designed just for kids. Content is written to be easier to read and simpler to understand than other areas of our website, helping to support parents as they seek to include their children in their own or their siblings care.

Kids are given easy-to-understand information about FPIES, the specialists that may be involved in their care, ways to cope, tools for school, and much more! A section for "Kids in Action," showcasing kid advocates worldwide, is particularly close to our hearts. **Learning how to be an advocate is not just a tool for coping with FPIES, but it is also a skill for life.**



In February, co-director Amanda LeFew offered insight and resources into process of organizing a rare disease non-profit in an online interview at a [Psychology Today blog](#). We strive to not only offer resources to our own FPIES community, but also to extend our reach to other rare disease communities. **By helping to strengthen the heart of the rare disease community, we further solidify our Foundation's mission.**

An updated logo released in 2013 illustrated the heart of the Foundation's mission. On the path, the words of ACTION 'pave' the way-- actions that families are doing everyday to thrive in the face of FPIES. The house remains a symbol of strength through a foundation of caring-- it represents community and acceptance, inviting families to feel included under one roof.

The FPIES Foundation aspires everyday to help families feel welcomed, to know that they have a place to find help, support, and a sense of community, a place to come home.

www.TheFPIESFoundation.org



Our social media reach covered a lot of ground this year-- keeping families up to date on free educational materials, the FPIES Global Patient Registry, fundraisers, community awareness events, and more!

A great way to stay in touch with the FPIES community and its supporters, social media has also afforded FPIES awareness opportunities on a grand scale.

Just this year, The Foundation's twitter following expanded to over 500, and we now have over 3000 "likes" on facebook.

For every follower and every "like," the community continues to spread FPIES education and awareness!

Our debut webinar received enormous support among the FPIES community, as well as in the general food allergy and rare disease communities. Not only did our webinar, "Advocating for Your Child in the Healthcare System," the product of our partnership with ThriveRx, provide essential tools for families living with FPIES, but the tools were flexible enough to be applicable to other disease communities as well. Released in time for our third anniversary, **this resource exemplifies the mission of The FPIES Foundation-- we strive everyday to educate, support and advocate in all of our initiatives and programs.**

In November, the FPIES Foundation once more achieved the prestigious honor of being awarded "Top Nonprofit" status by GreatNonProfits.com. Great Nonprofits is a website that houses nonprofit reviews and information, so that supporters can assess the credibility and reliability of such organizations. **Less than 10% of those eligible nonprofits receive this status** and it is truly an honor to be a recipient for the second consecutive year.

It starts with ONE. Advocacy starts at home; advocacy starts here, under our roof. Since its beginnings, The Foundation has tirelessly offered tools for families, practitioners and supporters to become strong advocates for children and infants affected by FPIES. As the community's needs change, our resources will continue to grow and diversify, providing a safe haven and a solid Foundation for education, awareness and support.

Social Media Highlights of 2014

- Over 3000 likes on Facebook
- Over 500 followers on Twitter
- Photo campaigns, reinforced solidarity among our community
- Global FPIES Day gave countless awareness sharing opportunities!

Multidimensional Resources for a Multifaceted Diagnosis-- Looking to the Future

The path that families travel in order to find a diagnosis, a knowledgeable treatment team, and enough safe foods to ensure appropriate nutrition for their little ones affected by FPIES, is a complex, often daunting one. It is our mission at The FPIES Foundation to shorten the time line it takes for affected infants and children to achieve these goals.

In the years to come, we will continue expanding the FPIES Global Patient Registry. Researchers, practitioners and families can learn from this huge body of information--- **as of the new year, over 400 participants from all over the world had been registered--** and this knowledge can spur new directions for research, treatment and management options. The ever-growing number of participants with each newly-introduced survey says it all-- the registry remains an essential tool for those affected by FPIES and those supporting the diagnosed infants and children, both today and in years to come.

Education and outreach will take center stage, even on a grander scale than before. In the past years, we solidified the building blocks of awareness and advocacy; now, we look to expand, diversify and localize the education and outreach initiatives directed at all those we serve. Current programs, such as the Provider Database and Free Online Learning, will continue to grow and new initiatives will build on the Foundation we have already created. FPIES truly is a multifaceted diagnosis, with still so little known about this condition. That said, as the research and interest of the medical community continue to grow, we will provide multidimensional resources to suit the varied needs that accompany this diagnosis. Needs specific to nutrition, daily management, quality of life, and quality of care will continue to guide our programs and inspire our initiatives.



A Word of Thanks, To Our Supporters



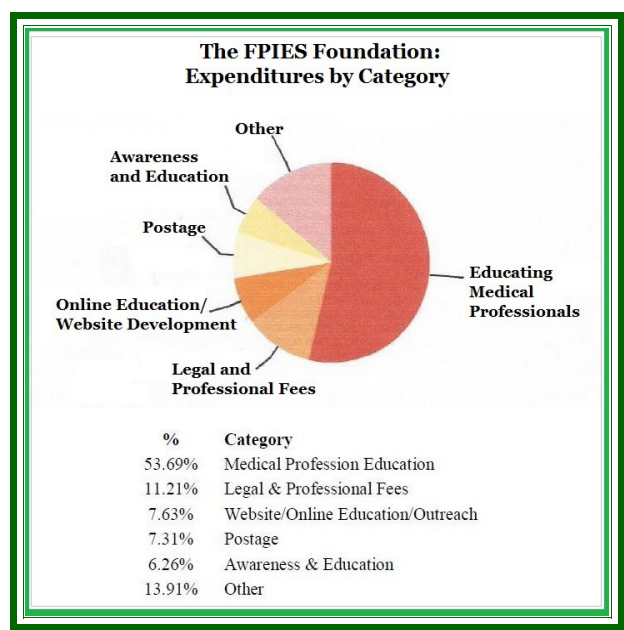
Our fundraising efforts continue to grow as our support base expands. As our funding blossoms, so will the programs available to families and the practitioners that support them. 2015 promises to be a year dedicated to focusing on both the medical and FPIES communities, specifically their outreach and educational needs. Every day, our supporters move us in the direction of diversified and targeted outreach initiatives. All of you give us hope-- hope for brightening our children's days, hope for helping them to achieve improved quality of life and better diagnosis management.

A special debt of gratitude is awarded to our dedicated volunteers and Medical Advisory Board, listed at the beginning of this document. They have reached out their hands and dedicated their time over and over again, committed to nurturing and growing the Foundation through resources, advocacy and support.

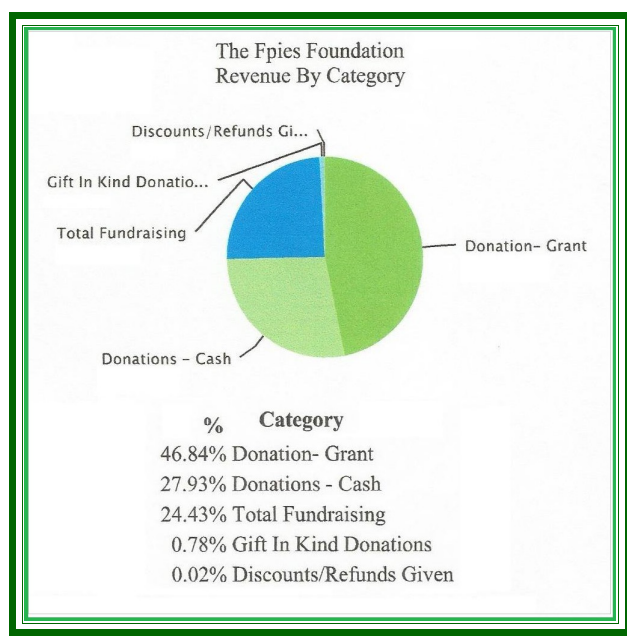
We would like to thank all of our supporters, who have given donations of time, talent, partnership and funding for the Foundation's essential initiatives. You are all helping us to fulfill the mission of the FPIES Foundation-- to provide tools for education, support, and advocacy. Thank you for helping us to build a strong Foundation for the entire FPIES community, one brick at a time.



Your support has been instrumental in helping us to create programs and deliver initiatives to the global community of families as well as the medical and scientific communities! Your contributions at work for 2014 resulted in:



Because of your gracious donations, including the generous giving of resources and time, we were able to fund necessary programs for this year and to initiate the process of creating future ongoing programs, helping families and professionals for years to come:



Grants:

Crystal Springs Foundation

On behalf of Joyce&Mike Murray

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In honor of M's birthday

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The FPIES Foundation would like to thank all of our donors and supporters of all kinds, from this year and from all years past. Because of all of your contributions, you have made possible a Foundation for FPIES awareness, education, advocacy and support, world-wide.

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Amazon Smiles

Bon Ton

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Label Your Stuff

**The Home that Awareness Built**

It was August of 2011 that the FPIES Foundation first announced its presence and released its website, forging a home for the FPIES community's culture of awareness and advocacy. The dream of our founders, to provide free and easily accessible resources to families and the providers that serve all those affected by FPIES, took form. Each year, that dream expands and our families and our support community of providers guide our course in providing expanded tools and resources to meet the needs of this diversified community.

Because of our tools, families are empowered.

Sarah, a mom of an adorable little boy diagnosed with FPIES, writes, "My little guy started having reactions when we introduced him to food at 6 months.

After not knowing what was causing him to get sick, I found the FPIES Foundation. I was able to arm myself with knowledge, get support, and find a knowledgeable doctor."

Because of our resources, medical professionals are educated.

Stephanie writes about her grandson's first FPIES reactions, ". . . My daughter knew that this was no ordinary flu that was going on with him. She poured herself into researching his symptoms and came across the FPIES Foundation.

When we took him to the hospital, we came armed with information about FPIES. **The doctors and staff had no clue about FPIES; they did after that visit.** We are so grateful that the FPIES Foundation, with all of their valuable resources and tremendous support, has helped us through this."

FPIES research and scientific endeavors are supported.

To date, over 900 doctors have received information about The FPIES Foundation's Global Patient Registry, a registry designed to collect patient-reported data about FPIES. Data from over 400 participants has been recorded in the registry in a confidential manner, giving families, medical providers, and researchers alike insight into potential trends in diagnosis, symptoms, and demographic information. Such information can fuel future research exploring improved diagnostic and management strategies, as well as potential treatment options.

With the help of our website and community connections, families and compassionate medical professionals can connect, together working to enhance the quality of life and the quality of care for affected infants and children.

Community Fundraisers:

T-Fund Global Day Fundraiser,
Jessie Richens

Jamerry Nails Fundraiser,
BreeAnna Lamb,
Organized by Jessie Richens

Nbern, Inc DBA
Jersey Mike's Subs

Half Pint Threads
from Lisa Hammer

"Thank you to all who support the Foundation! We started this Foundation to be a reliable resource for families and providers alike, as they care for those living with this still widely unknown and often misunderstood diagnosis.

There are so many aspects to this diagnosis that need care! We hope to provide a basis of the resources and support you need. The families who live through this diagnosis, like ours, continue to inspire us in all our programs and initiatives, and we look forward to growing in the years ahead!"

– Joy Meyer,
Co-Founder & Co-Director,
The FPIES Foundation

"Year after year, as I watch the Foundation grow and see how even more empowered the FPIES community has become, it becomes clear that we are all moving in the direction mapped out in that first formative year of the Foundation. We are giving voice to our children's stories, we are equipping professionals with the tools they need, and we are educating communities world-wide, fostering a greater understanding for this rare diagnosis. This gives me so much hope for my own girls and for all of our children."

-- Amanda LeFew, Co-Founder & Co-Director, The FPIES Foundation