



The FPIES Foundation
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The Honorable Pat Toomey
248 Russell Senate Office Building
Washington, D.C. 20510

Dear Senator Toomey,

Today I am writing to request your support of a resolution for FPIES Day (to read more, please see www.fpiesday.com). Let me introduce you to our family and share information about FPIES with you, demonstrating what makes this day an essential addition to the National Health Observance calendar.

FPIES (Food Protein-Induced Enterocolitis Syndrome) is a rare type of food allergy that involves the gastrointestinal tract. Any food protein can trigger a reaction and symptoms can be severe, including profuse vomiting, diarrhea/bloody stools, dehydration, and can even progress to shock. This disorder typically affects infants and children but cases have been reported in older children and even a few adults. There is no cure, no diagnostic test for this condition, and awareness of FPIES among even medical professionals and the lay community is extremely limited. All affected families, including our own, need your help and support. Attached, please see our story of life with FPIES.

FPIES Day is a day to mobilize the FPIES community-- patients, families and medical providers alike-- in order to affect the changes so desperately needed. According to a recent survey in the Global FPIES Patient Registry, 40% of families report that the duration between the recognition of symptoms and the official diagnosis was greater than six months. During such a time period, children may experience invasive medical tests and procedures, inappropriate management of emergency symptoms, and insufficient medical support. Earlier appropriate diagnosis, improved management strategies, and enhanced emergency services will all promote increased quality of life for affected individuals-- for our children and their families.

Our community is comprised of resourceful, informed, and compassionate families and medical professionals. FPIES Day will empower these individuals to reach out to their communities and educate government leaders, schools and institutions, medical professionals, and other families about this rare condition. The day will unify affected individuals across our nation and the globe, improving our ability to address specific issues, such as elemental formula coverage, creation of diagnostic management standards, and appropriate medical support for daily and emergency care.

Our challenges are what make FPIES Day an essential platform from which to advocate for patients' issues and to affect change. Our strengths as a community make this a day for empowerment, education and advocacy. We, in conjunction with FPIES advocacy organizations, invite you to join us and be the voice for FPIES-- please commit to approve FPIES Day as a National Health Observance Day today!

Sincerely,