The FPIES Foundation
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FPIES FOUNDATION ANNOUNCES FIRST OF ITS KIND GLOBAL REGISTRY FOR FAMILIES
THE FPIES FOUNDATION GLOBAL REGISTRY OFFERS DOCTORS A VITAL FIRST STEP IN RESEARCHING THIS RARE ALLERGY

The FPIES Foundation is excited to launch 'The FPIES Foundation Global Registry'. 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.

The registry provides a vital, yet secure way for doctors researching FPIES to connect with FPIES families. The FPIES Foundation is 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.

"This is an incredibly exciting opportunity for our families, one we have been striving to achieve since our founding." says Foundation Chair Joy Meyer. "It is a chance for families all around to world to finally have a central database to put a voice to their child's experiences with FPIES. Doctors can finally look at all of the information in one place to look for patterns when trying to figure out the complexities behind FPIES."

The FPIES Foundation understands the sensitivities of our families and that privacy is incredibly important. We chose to partner with Patient Crossroads because of their multiple safeguards to protect patient privacy. The registry will assign a "code" to each child so no one, including the FPIES Foundation, can identify the child without a guardian's consent. If a researcher is interested in learning more, the researcher will ask Patient Crossroads to contact the guardian. A scientist will only receive identifying information after consent is given to Patient Crossroads.

Registered families also have the opportunity to participate in both questionnaires and research surveys and immediately see the results of those surveys. The information from our registry will connect with other registries including NIH Global Rare Diseases Registry Program and other esteemed partners globally. FPIES families will always own their information and be able to opt-in or opt-out of participations. Registered families receive notifications when new surveys are posted.

FPIES is a rare and often difficult diagnosis. It is a delayed food allergy affecting the gastrointestinal tract, typically diagnosed in infants and young children. Classic symptoms of FPIES include profound vomiting, diarrhea, and dehydration. These symptoms can cause severe lethargy, change in body temperature and blood pressure, and often lead to hospitalization. Unlike typical food allergies, symptoms may not be immediate and do not show up on standard allergy tests.

To join the 'FPIES Foundation Global Registry": https://connect.patientcrossroads.org/?org=fpies

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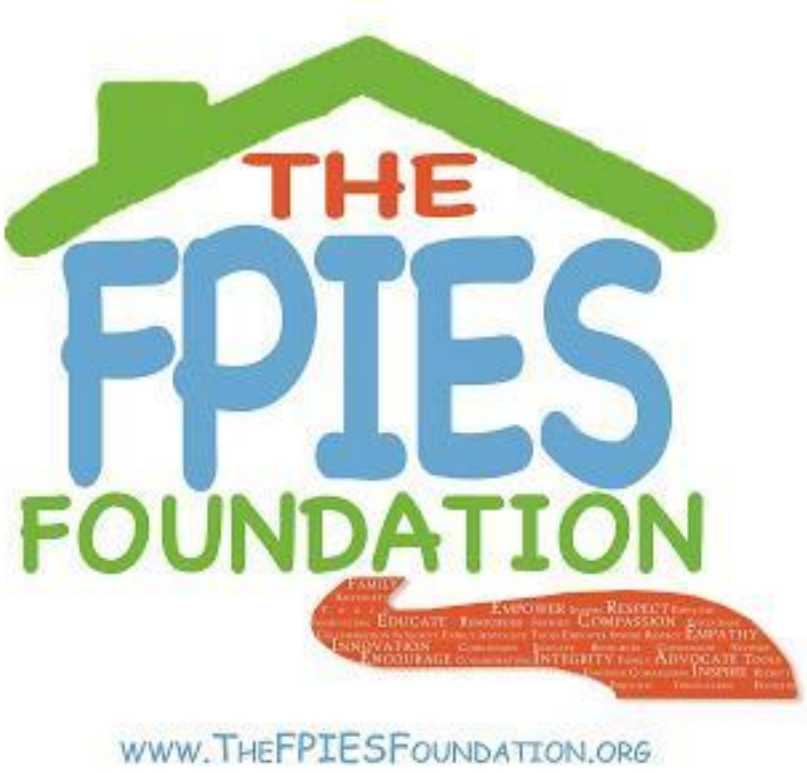
Educate. Support. Empower.



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.