



The FPIES Foundation
www.thefpiesfoundation.org
contact@thefpiesfoundation.org

Dear Family and Friends,

Thank you for taking the first step and trying to learn more about what life is like for our little one with FPIES and for us as a family. We do understand that sometimes you might not know what to say or do, and that you often wish you knew what you could do to help. Help doesn't have to be grandiose, complex, or expensive. The effort behind it can mean more to us than you may ever imagine. To get you started, here are some simple but very meaningful ways that you can help an FPIES family today.

Family Life:

We strive to maintain our home as a safe foundation. For us, this means keeping a nurturing environment for the siblings as well as for our child with FPIES. Play dates at our house, where the environment is set up for the safety of our FPIES child, are just as important as play dates/outings away from the home, even if we ourselves are unable to provide that for siblings due to the needs of the child with FPIES. When you offer to include my non-FPIES children on one of your family outings, this can help our children to feel included and to experience a sense of age-appropriate "normalcy" outside of the FPIES realm of their sibling.

We may spend a great deal of time going to medical appointments, some of which may even require extensive travel. This can interfere with family time we may have otherwise spent going to museums, parks, and so on. Helping us to find ways to schedule family time can aid us in further supporting the nurturing environment of our home and in reclaiming our family's foundation.

Spending time with all of our children is important to our family, and it is essential to touch base with each of them regularly, particularly when we may have been in a crisis situation with our little one diagnosed with FPIES. Offering to sit with our other children while we spend some needed 1:1 time with each individual child can help our children to reconnect and feel more secure during the "storm" that often accompanies reactions and/or other medical complications of their sibling.

Around the House:

Simple tasks, like grocery shopping, may be more extensively time consuming for our family due to constant label reading and seeking out specialty products that may be safe for our child with FPIES. When you offer to watch our children while we as parents attend to the shopping, you not only give our children a "break" from this task but also enable us as parents to have better focus on this activity.

When our child with FPIES experiences a reaction, knowing that we have family and friends to rely on to help with the other children can be an enormous relief to us as parents. Volunteering to be a part of our family "emergency plan" by coming to our house to stay with siblings while we accompany our child with FPIES to the emergency room or by picking up children from school when we need to be at unplanned doctor's appointments can help us to maintain a secure and calmer home environment for all members of the family.



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Medical Aspects:

The medical care involved for our little one may be overwhelming and even scary at times for all members of our family. As a friend or family member, reaching out to simply listen to us can be an enormous comfort. Taking care of our other children while we attend to our little one undergoing procedures can ease our already anxious minds. Cooking a meal for those family members not on a restricted diet can help us to spend more time focusing on helping our little one to better cope and heal. Offering to accompany us on a medical appointment to play with our child or to take notes on what the specialist may say can help us to better understand the doctor's assessment and directions for medical care for our little one.

Social Life:

Play dates, dinner parties, and even preschool can be anxiety-filled for our family. We do want to spend time with you and our other family and friends and do enjoy a fun night out, but we often don't know how to make it safe enough for our little one and low-stress enough for the rest of our family. Arranging for play dates to be at our house instead of popular "tot spots," organizing multiple family outings that are food-free, or helping us to interview caregivers and/or preschools that might be suitable for our child based on his/her special needs can be great ways to help our family and especially our little one feel included as well as to help us connect with all of you in a low-stress environment.

The Learning Curve:

Adapting to life with FPIES can be a steep learning curve, depending on what aspects are involved in our little one's day to day care. Some children require prescription formula, some need specialized medical equipment, and all children with FPIES require some dietary restriction. Helping our family to search online or through cookbooks for safe and family friendly recipes would be greatly appreciated. Pouring through insurance research with us to ensure coverage for formula or needed medical equipment for our children is not only helpful in a practical sense, but also in an emotional sense, as navigating this unfamiliar diagnosis can often feel very isolating.

No One Needs to Go Through This Alone:

Above all, the most important resources that you can give an FPIES family include your understanding, a shoulder to cry on, and an ear to listen. No one needs to go through this alone. The simple knowledge that there will be a comforting voice on the other end of the phone or that a friend can stop by and just "be" with your family during troubling times— these are the building blocks that support our family, which in turn enable us to better support the ones we love.

Thank you,

An FPIES Family