

Dear Healthcare professional,

We are a UK based charity which aims to provide information and raise awareness of a serious form of non-IgE mediated food allergy which typically affects infants and young children. **Food Protein Induced Enterocolitis Syndrome (FPIES).**

Presentation

Infants with **FPIES** typically present 1-6 hours after ingestion of the offending food or formula with repetitive vomiting and marked lethargy. Although many infants recover at home, up to 20% will present in 'shock'. Some will have diarrhoea and may be pale or appear blue.

Full Blood count frequently shows an increase in White Blood cells with a 'left shift' which is often misinterpreted as infection.

The majority of affected children have only one or two foods which cause **FPIES** reactions but studies show a small number (approximately 5%) can have as many as 6 or 7 different food triggers. It should be noted that children with **FPIES** can also have concurrent non-IgE mediated food allergies to other foods, and whilst the symptoms associated with these foods are less severe they can still cause substantial morbidity. Common Non- IgE mediated food allergy symptoms are frequent intermittent vomiting or 'reflux' and/ or chronic diarrhoea or constipation and abdominal pain. Eczema, anaemia, hypoalbuminaemia and failure to thrive may also be seen.

For children with **FPIES**, misdiagnosis is all too common, with a number of infants unfortunately undergoing invasive tests such as lumbar puncture or unnecessary abdominal surgery. Common misdiagnoses include viral gastroenteritis, sepsis, meningitis or surgical abdominal conditions.

Common trigger foods

The most common **FPIES** inciting foods in a recent **FPIES UK** member's survey (over 100 acute reactions), were cow's milk, rice, poultry, oats, soya, wheat, fish, beef, banana, broccoli and Sweet potato. However, **any** food can potentially trigger a reaction. It should also be noted that reactions do not always occur on first ingestion of the food and it may take several ingestions before a reaction is seen. FPIES reactions through breast milk are very rare, babies who do react via breastmilk more commonly display the non-IgE mediated food allergy symptoms listed above. Some babies are asymptomatic whilst exclusively breastfed and symptoms are first seen on introduction of formula or solid foods.

Prevalence

Whilst **FPIES** was once thought of as a rare disease, recent studies have suggested this may not be the case. In a birth cohort of 13,019 infants under 12 months old in Israel, 0.34% were diagnosed with Cow's milk FPIES during the physician-supervised oral food

challenge. Although it is difficult to extend the results from Israel to other patient populations, this study suggests that there may be as many as 1 in 300 infants with **FPIES** to Cow's milk. A similar level of incidence in the UK as type 1 diabetes.

Diagnosis

Diagnosis of **FPIES** is based on clinical symptoms and patient history, having excluded other possible differentials. Oral Food Challenges (OFC) are considered high risk procedures in **FPIES** infants and should only be used when the clinical history is unclear or to establish when tolerance has been achieved. It is recommended that should an OFC be required it is conducted under close supervision in a hospital setting.

Treatment

Treatment of **FPIES** involves strict avoidance of the offending food, and slow cautious introduction of new foods. Infants who react to cow's milk formula will likely need to be prescribed an amino acid based formula. Soya formula is not recommended as a cow's milk substitute in these infants as up to 40% of those who react to cow's milk also react to soya.

The article "Nutritional management of food protein-induced enterocolitis syndrome" discusses the nutritional management of **FPIES**, is available free online and is written by **FPIES UK** medical board dietitian, Dr Carina Venter. Links to this article and many others can be found on our info for HCP's page on our website.

Prognosis

The prognosis for children with **FPIES** is very good with the majority of children outgrowing their triggers by 5 years of age. There are however a small number of teenagers with **FPIES** and **FPIES** to fish and shellfish has been diagnosed in adults.

*I hope this short introduction to **FPIES** has given you an insight into the condition and its common presenting signs. Please take your time to read the further information provided in this pack and visit our website fpiesuk.org for up to date information and links to the most recent FPIES research. Also please visit fpies.org, the website of the International Association of Food Protein Induced Enterocolitis whom we are proud to have supporting us.*

We would appreciate it greatly if you could share this knowledge with your colleagues and co-workers. Increasing awareness is the key to prompt diagnosis and treatment.

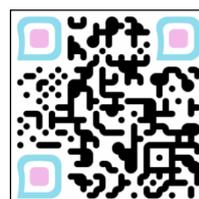
Many Thanks,



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Founder & Chair

FPIES UK



www.fpiesuk.org