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## FOR IMMEDIATE RELEASE

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### **IAFFPE Announces Approval of ICD-10 Code for Food Protein-Induced Enterocolitis Syndrome (FPIES)**

*Organization spearheads successful campaign for a specific diagnostic code for rare form of food allergy*

**Howell, NJ** (June 3, 2013) – The International Association for Food Protein Enterocolitis (IAFFPE) announced today that an ICD-10-CM code has been approved for Food Protein-Induced Enterocolitis Syndrome (FPIES) by the National Center for Health Statistics (NCHS). Hundreds of patients suffer from FPIES, a rare non-IgE form of food allergy; until now, the condition did not have a specific code, making it difficult for the medical community to determine how large a percentage of the population has FPIES.

While suggestions for ICD-10-CM codes are not typically initiated by patient advocacy organizations, IAFFPE, in keeping with its proactive mission to raise FPIES awareness, was at the forefront of this request. Over the past year, IAFFPE has worked with the Centers for Disease Control and Prevention's NCHS to create a unique ICD-10-CM diagnosis code for FPIES. IAFFPE submitted its proposal to the NCHS in June 2012, and in September 2012, Dr. Anna Nowak-Wegrzyn and Fallon Schultz formally presented the request.

"The introduction of an individual ICD-10-CM for FPIES is a critically important milestone for the patients and the medical professionals taking care of them," said Dr. Nowak-Wegrzyn, IAFFPE medical advisor and Associate Professor of Pediatric Allergy and Immunology at Mt. Sinai. "The code will enable more accurate diagnosis and allow for tracking the frequency of FPIES diagnosis for epidemiologic purposes. I am thrilled to see this happen because of the IAFFPE initiative."

The ICD-10-CM coding system is an international classification system that groups related diseases and procedures for the purpose of reporting statistical information. ICD-10-CM codes provide a uniform language, and thereby serve as an effective means for reliable nationwide communication among physicians, patients, and third parties. ICD-10-CM codes are necessary for billing, insurance and medical records, disease management, treatment advances, research and national statistics.

IAFFPE pursued the ICD-10-CM designation due to a "code freeze" on new ICD-9 codes. The ICD-9 code sets currently used to report medical diagnoses are scheduled to be replaced by the new ICD-10 coding system in 2015. The passage of a new ICD-10-CM code for FPIES is particularly remarkable given that the passage of new codes is limited prior to this transition. The CDC has advised that the new code (K52.21) will not take effect until the ICD-10 implementation is completed in 2015.

"Approval of this ICD-10-CM code is exciting because it helps make the unknown known. It will allow for accurate classification of this condition and bring awareness of FPIES to a whole new level," said Fallon Schultz, IAFFPE Founder and Chair.

FPIES is a non-IgE gastrointestinal food hypersensitivity that manifests as delayed, profuse vomiting, often with diarrhea, acute dehydration, and lethargy. The most common triggers are milk and soy, but any food, even

those thought to be hypoallergenic (e.g., rice and oat), can cause an FPIES reaction. Unlike most food allergies that produce immediate reactions such as swelling and hives, FPIES reactions are delayed and usually begin two hours after ingestion of the trigger food. In some cases, the child will have such an extreme reaction that they go into shock and need to be admitted to the ER for immediate treatment with intravenous fluids.

At this time, little is known about FPIES, and few doctors are able to recognize and diagnose the syndrome. There is currently no cure or standardized treatment for FPIES. Unlike common food allergies, standard skin testing and blood testing for specific IgE allergies are routinely negative in FPIES patients. Due to the lack of awareness of this syndrome in the medical community and the general public, patients may wait months or even years to receive an accurate diagnosis.

“The passing of ICD-10 CM for Food Protein-Induced Enterocolitis is a major accomplishment for patients with FPIES and physicians who take care of these patients,” Dr. Jonathan Spergel, Chair of IAFFPE’s Medical Advisory Board, and Allergy Section Chief and Co-Director of the Center for Pediatric Eosinophilic Disorders at Children’s Hospital of Philadelphia. “ICD-10 coding will increase awareness of the disease, allowing us to understand how common it is. It will also allow patients to be classified correctly, enabling us to learn the natural history of the disease.”

Because of the lack of accurate reporting, the true prevalence of FPIES is not known, a problem IAFFPE feels the new ICD-10-CM codes will help remedy. A unique code will allow researchers to identify or track patients with this condition, develop new treatments, permit accurate reporting of FPIES, and improve awareness.

### **About the IAFFPE**

The International Association for Food Protein Enterocolitis (IAFFPE) is a 501(c)(3) non-profit organization whose mission is to improve the quality of life for patients and families affected by Food Protein-Induced Enterocolitis Syndrome (FPIES). IAFFPE strives to be a worldwide leader in FPIES awareness and the issues surrounding this condition. We seek to increase awareness by providing educational resources, support services, advocacy, and the development of groundbreaking research through our partnership with the medical community. For more information, please visit [www.iaffpe.org](http://www.iaffpe.org) or contact us at [contact@iaffpe.org](mailto:contact@iaffpe.org).