

What the experts say

by Susan P. Arena

CINCINNATI, OH — Experts in eosinophilic enteropathy are few and they are scattered.

One of the meccas for treatment of and research into who suffer from eosinophilic enteropathy is housed at Cincinnati Children's Hospital Medical Center where Jacque Fanning and Matt of Waterford travel at least four times a year for his evaluation and treatment.

Doctors who have worked with Matt, and other suffering similar symptoms that so radically change lifestyles, are enthusiastic about the start-up foundation, American Partnership for Eosinophilic Disorders (APFED), that's designed to help patient and their families — and to educate others about the rare disease.

Here's what the heads of the Children's Hospital eosinophilic enteropathy program told Jacque about the current research and the formation of American Partnership for Eosinophilic Disorders (APFED).

"APFED has launched an impressive campaign to assemble and disseminate information regarding the little known, but increasingly problematic Eosinophilic disorders. The support garnered will create the opportunity for patient education, medical conferences and additional research in the diagnosis and treatment of these

diseases."

— Philip E. Putnam, M. D. F. A. A. P., and pediatric gastrointestinal specialist and Matt's primary doctor at Children's in Cincinnati.

"Eosinophilic gastrointestinal disease in children have come to be more recognized mostly because of the persistence of the parents of those children who were not satisfied with simplistic answers to their children's problems.

"In many children I have had the honor to participate in their care, there was a long delay in making the accurate diagnosis, and once the diagnosis was made there was also a delay in initiation of management.

"Raising the awareness about the eosinophilic gastrointestinal disease in children through parent sponsored organizations will be of great help in making the diagnosis and providing treatment in a more timely manner. It will also assist medicine in recognizing the prevalence of these disorders, mapping their natural history, identifying precipitating factors and, most importantly, planning research for cure."

—Amal H. Assa'ad, M. D., allergist, immunologist, Children's Hospital Medical Center.

"We are trying to map the distribution of inflammation in the esophagus

in biopsies of eosinophilic esophagitis, and will begin studies of other inflammatory cells that may be important in the inflammatory response. I'll be happy to join APFED [advisory board]. You and your colleagues are the amazing ones!"

—Margaret H. Collins, M.D., Department of Pathology, Children's Hospital Medical Center.

"In our experience, eosinophil-associated gastrointestinal disorders represent serious medical problems worldwide. Our research studies have shown that classic allergic responses and the mechanism involved in asthma, are occurring in these patients. Our current focus is to determine the reason for the problem, its association with the allergy epidemic, and to define a treatment. I believe there are two main issues that should be addressed first: determination of the incidence, and I would not be surprised to see if these disorders affect greater than one percent of the population. Second, we need to establish if eosinophils are the main culprits or if they are just part of the disease process."

—Marc Rothenberg, M. D. Ph. D, he is doctor Jacque calls the mastermind behind all eosinophilic research at Children's in Cincinnati.

These physicians are all members of APFED's Medical Advisory Board.