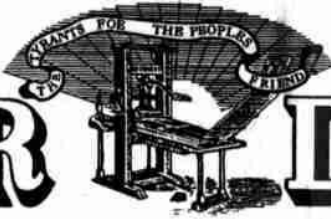


# ADVERTISER DEMOCRAT



A man cannot be too careful in the choice of his enemies. — Oscar Wilde

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## Local mother starts national group for children

by Susan P. Arena

**WATERFORD** — Jacque Fanning is a mom on a mission.

This Waterford mother of three has fought doctors, hospitals and those who were supposed to be experts to help her son. Now that she's won part of her battle and he's doing a little better, she's ready to take on another fight.

Her middle son, Matt, who's 10, suffers from a disease that has virtually destroyed his esophagus.

Her other two sons show signs of having the same disease, but not as severely.

"When people ask what's wrong with Matt, I can't really say eosinophilic enteropathy because they have no idea what that is," Jacque says.

She plans to change that. Jacque has joined two other moms — one from Texas and one from Ohio — to form a national organiza-

tion to help victims and their families cope. (see sidebar for an explanation of the disease).

The fledgling group, American Partnership for Eosinophilic Disorders (APFED), is concerned with getting the word out about the disease by creating awareness through education and plans to support research into causes and cures.

Jacque and the other founders of APFED believe that the only solution to the battle they fight every day is spreading the word so that more of the nation's doctors will understand the disease. They feel this will lead to earlier diagnosis which will, in turn, mean less permanent damage.

Jacque's single-minded determination is obvious as she quietly and professionally explains Matt's condition while sitting at her kitchen table. Her dark eyes snap with concern as she talks about the other children who suffer from eosinophilic

enteropathy that she and Matt have met during their trips from Maine to Cincinnati Children's Hospital Medical Center.

At least four times a year Jacque and Matt travel to Cincinnati for tests and evaluation. Jacque works as a substitute teacher for SAD 17 because that type of job allows her to make the frequent trips — and she can be home with her boys when they get out of school.

Jacque and Tom Fanning's kitchen — in fact the whole house — speaks of their love of their family. There are photographs everywhere in the neat cape which they bought as a shell and have been finishing as time and money allow. Notes and artwork by the three boys hang on doors and walls — each a little treasure.

A verse, carefully printed by the first grader in their family of her youngest son, 7-year-old Ryan,

hangs on a kitchen door. It reads:

"Matt is my best friend.  
He is 10,  
He look like me.  
We play army.  
We play computer.  
We watch tv.  
He shares with me.  
He is my brother."

The kitchen table where we are seated is large — big enough for a family of five. But Matt's chair is back against the wall. The table is pushed tightly against it.

Matt doesn't join the family for dinner. He can no longer eat. It is unlikely that he will ever be able to eat again.

Jacque — and the others involved in APFED — want the world to understand why. Education and earlier diagnosis are the keys, they feel. If the disease is caught early, the irreparable damage to the intestinal tract is less.

The news from Matt's last check-up was mixed. Slides from biopsies of his intestinal tract were the best ever. There was far less activity from the destructive white blood cells that cause the damage.

However, at least in part because it took such a long time to diagnosis Matt's disease, severe damage has been done.

Jacque went from doctor to doctor, from state to state trying to find out what was wrong. Some of the clinics were world-renowned, but still the real cause of Matt's difficulty could not be diagnosed.

Once the family finally found out what the problem was, they thought there would be a quick fix, but that wasn't to be either. The damage to Matt's esophagus had already been done.

"There is no possibility of ever

**Please see MATT Page 11A**



Jacque Fanning and her son, Matt