

Matt from Page 1A

introducing food back into his diet," say Jacque.

Matt is fed through a tube that goes directly into his stomach, bypassing his damaged esophagus.

He ingests a liquid mixture that contains all necessary nutrients in a predigested form. The mixture, which costs \$40 a day, is in a bag connected to a small pump. Both are housed in Matt's ever-present backpack.

In other ways, Matt is like any other 10-year-old. He loves to lounge on the couch in the living room, watching tv cartoons. Action heroes seem to be a favorite.

He's busy playing computer games when he's not in school.

Matt also likes playing soccer and cross country skiing and he's on the school's math team. His DARE essay was chosen as example of excellence.

When Matt and his mother went to Cincinnati last August, Matt was nine and weighed 38 pounds. Normal weight for a nine or 10 year old is 60 to 71 pounds.

Because Matt was so undernourished, the doctors inserted the feeding tube.

It was a final resort since he could no longer get nourishment from eating food. The physician who performed the surgery told Jacque that Matt could not have survived much longer — his body was using up all his muscle tissue and body fat to keep him going.

The new system works.

Matt now weighs 64 pounds.

During the last trip to Cincinnati, Matt got the okay to participate in gym — something he particularly wanted to do.

Jacque says everyone at

Waterford Memorial School has been wonderful. Matt has been in the same class, with the same friends, since he started school. Each time there is a change or a new development, Jacque goes into the class, sits on the floor with the children and explains the ramifications. Matt doesn't talk much about his illness on his own.

"I can't find words for what the school's meant. Matt is accepted. The kids are so attuned. The school is our biggest support," says Jacque.

Fellow pupils help in many ways. When there's a little glitch with Matt's food pump, one of his buddies helps him make it right again.

Recently Jacque made a presentation on eosinophilic enteropathy to Camp Sunshine, a summer camp in Casco for seriously ill children and their families. She had hoped the camp could set a week aside for children like Matt, but it wasn't to be.

"I don't know why they turned us down, but they did," she says.

That may have been one of the final factors in the decision to found APFED — people, even professionals, don't have enough information on the disease.

His improvement also gives Jacque a little time to fight for her son in another way, by forming a national organization to fight for children — and for some adults — who suffer as Matt does.

Although APFED is only a couple months old, it has about 30 members. The group now has a sister foundation that has been launched in London, England.

"We will raise money and host an annual conference for eosinophilic enteropathy. Mostly we're about education. If we can just save some children from some of the pain they go through when they aren't diagnosed properly. . . ." she says with conviction.

Already APFED has a web site, www.apfed.org, which Jacque's husband, Tom, has built. Tom has worked for 24 years at Radio Shack in Auburn and is the webmaster of the APFED site.

So far no cure has been found for Matt's disease. It isn't fatal, but complications that arise because of it can be. Through education and research, the members of APFED hope to help others understand the disease and offer support to patients and their families.

"This disease has changed our whole lives," Jacque says.

She opens cupboards in her kitchen. In addition to the expected cereal, soup and spices, there are gauze pads, syringes and other medical supplies needed to keep Matt going.

"The boys [her other two sons, Nich, 12, and Ryan, 7] sneak out for Thanksgiving. Matt loves food, but he can't eat. He stays out of the kitchen now. We shy away from the foods he likes, but he says he wants to be a chef some day."