

Jan. 18, 2003

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Monday, December 30, 2002

## Experimental treatment may give boy 2nd chance

By Tim Bonfield  
The Cincinnati Enquirer

**WHITEWATER TWP.** - In 1999, Eric Page was considered an inspiration to others with Crohn's disease, a progressive digestive disorder, because he was managing his difficult illness while pursuing the bone-jarring sport of motocross.

the success of reforming the police department - and installing a new era of police-community relations - is not about him at all.

Three years later, Eric is a high school sophomore who weighs just 85 pounds and can barely keep up with school, much less pursue his sport.

Conventional treatments have failed to control Eric's disease and now his parents are hoping for help to raise \$75,000 to \$100,000 to pay for an experimental treatment provided only in Chicago.



Eric Page sits in his bedroom with some of his motocross trophies.

(Gary Landers photo) | 200M |

"The idea is to give Eric a rebuilt immune system," said his mother, Cheryl Page. "This treatment is the closest we've come to hope. We don't even say cure. All we want is a remission, so his body can heal and grow and he can finish high school."

Crohn's is a fairly common, but often misunderstood disease that attacks the digestive tract. About 100,000 children and about 600,000 adults nationwide have Crohn's disease, although very few cases are as severe as Eric's.

While rarely fatal, the lifelong disease causes inflammation and blockages in the colon and intestines that can make it difficult to eat without suffering painful cramps and vomiting.

Many cases require repeated surgery to remove diseased parts of the intestine.

Some sufferers can keep the disease in check for decades by following strict diets and taking a variety of medications. Others, like Eric, have tried nearly everything doctors can think of without success.

Eric, now 15, was first diagnosed with Crohn's when he was 7. For several years, Eric maintained an active lifestyle even though he needed tube feedings every night and often struggled to control his abdominal pain.

His bedroom shelves are lined with trophies and photos from motocross from his healthier days. But Eric hasn't been able to finish a race in months, and has suffered several injuries from thinning bones, a side effect of the steroids he takes to control inflammation from his disease.

Since 1999, Eric has broken both his legs in motorcycle spills. He broke a wrist and an ankle in other falls.

Eric has had two surgeries to removed diseased parts of his digestive tract. But doctors now say he has disease in areas that surgery cannot effectively treat.

The teen has tried several medications, including Remicade, an intravenous drug that costs about \$6,000 a dose and takes about four hours to receive in a hospital. The drug has helped some people with Crohn's disease, but Eric was allergic to it.

To gain weight in hopes of better tolerating the proposed treatment in Chicago, Eric spent the summer using a non-removable feeding tube that ran from his nose through his stomach to place formula directly into small intestine.

## Disease threatens life goals

Eric's father, Tom, is a fleet mechanic for a mobile phone company. His mother is a part-time dental assistant. They live in Whitewater Township with Eric and his two younger siblings, Jessica, 12, and Shane, 8.

Their comfortable house is immaculately maintained and decked out for the Christmas holidays.

## HOW TO HELP

Family members have started the Eric Page Benefit Fund at Fifth Third Bank and people can donate at any Tristate branch. Family and friends also have organized two fund-raising events:

- A benefit dinner is 5 p.m. Jan. 18 at Dayspring Church of God, 1060 Smiley Ave., in Forest Park.

- A charity auction is Feb. 15 at St. John the Baptist School, 5375 Dry Ridge Road in Harrison.

For information about the events, call Diane Frank, (513) 202-0506, or Rose Page (513) 353-1435 or Craig Baston (513) 385-0113.



Eric is a student at Harrison High School but he has missed so much school that he depends on home tutors. Tired of losing ground in his eight-year battle with the disease, Eric says he's ready to take a chance with potentially fatal treatment.

If the treatment can put his illness in check, Eric hopes to graduate from high school, find a job in auto painting or body repair, and live something closer to a normal life. Right now, his disease is so debilitating he couldn't maintain a summer job at a Miamitown motorcycle shop.

"I'm just not getting better," Eric said. "I'm good for a week, then I'm out for a week. Then there's too much work (schoolwork) to make up and it turns into a huge snowball."

Without improved treatment, his parents fear that Eric will not be able to support himself as an adult, much less raise a family of his own someday.

"We don't want to see Eric wind up on disability or public assistance," Mrs. Page said.

Until now, the family insurance plan had covered virtually all of Eric's medical bills, which have exceeded \$60,000 a year. The family has had to dip into retirement savings, but has been able to handle the out-of-pocket expenses that often top \$5,000 a year.

But the new treatment is a different story.

## Resetting the immune system

While searching for better answers on the Internet about a year ago, Mrs. Page met an oncology nurse from Massachusetts who has a son with Crohn's disease. That son was among the first to participate in a clinical trial in Chicago.

That treatment, performed at Northwestern Memorial Hospital, is called an "immunotherapy stem cell transplant." It combines harvesting stem cells from blood with intense chemotherapy, similar to the treatment some children get for leukemia.

The theory behind the treatment is that Crohn's disease is caused by a defective immune system. Reset the system and, in theory, people with Crohn's disease will stop over-reacting to food.

Doing this isn't easy. First, doctors harvest stem cells from the patient's blood, then use chemotherapy to destroy the patient's damaged immune system. Then, the stem cells are returned to rebuild a fresh immune system.

During this time, the patient must spend two weeks in the hospital in a sterile environment because exposure to even mild bacteria and viruses could be fatal.

Dr. Richard Burt, chief of immunotherapy at Northwestern Memorial, did the first such stem cell transplant in the world for Crohn's disease in 2001. A half dozen patients have been treated since.

If the funds can be raised in the next few months, Eric could be the youngest person to be entered in the clinical trial.

So far, the results from previously treated patients appear promising. But no one knows how long the benefit may last. It may take following a large group of patients for five years before results can be considered conclusive.

In the meantime, some have cautioned that the risk of the treatment may outweigh the benefits for all but the most severely ill Crohn's patients.

According to the Crohn's and Colitis Foundation of America, "Scientists have yet to determine whether stem cell transplant can initiate a long-term remission in people with Crohn's disease. In addition, the potential benefits must be weighed against the risk of infection."

Some insurers have covered the costs of the experimental treatment. . But after three rounds of appeals, Eric's insurer has continued to reject payment because "experimental and investigational treatments are not a covered benefit," according to a letter from the insurer dated Nov. 12.

Eric was told six months ago that he qualifies medically for the study. But the family has to pay \$75,000 before treatment can begin.

The treatment includes three months of follow-up care that requires families to live within walking distance of the hospital.

The Pages have been told that renting an apartment near the hospital could cost \$3,000 a month.

Factoring in lost income, travel and three months of living expenses, the Page family figures they need to raise about \$100,000.

"(Turning to the public for help) isn't something we wanted to do," Mr. Page said. "But this is his best chance."

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