Cystic fibrosis

Family finds happiness despite dreaded disease

Brett Pearce, 4, likes putting together his toy train and tearing around the house at full speed.

His identical 3-year-old twin sisters, Kimberly and Kristie, confuse their mom by switching outfits and help keep the noise level in the house to a happy high decible.

But Brett and his sisters face a fight which most children their age can't imagine. They have cystic fibrosis, a disease which attack the endrocrine glands, such as the lungs, liver and pancreas.

The disease's symptoms resemble those of asthma in the severe lung problems which plague sufferers.

Children who have cystic fibrosis can't digest their food and undetected cases suffer from malnutrition.

But once detected there are drugs which will help them digest their food and gain weight. But there isn't a cure for the disease which often proves fatal by the time the children reach their twenties.

With early diagnosis and prompt treatment, many live beyond their twenties, according to the Cystic Fibrosis Foundation.

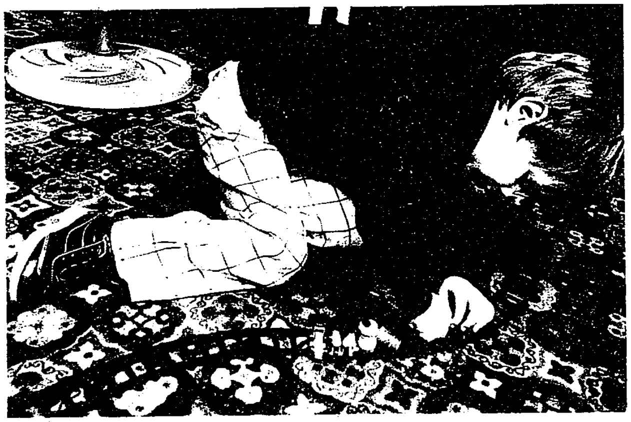
It's a hope to which parents of children with cystic fibrosis cling.

LYNN PEARCE

IT'S SUCH a hope which Mrs. Lynn Pearce carries.

"I think about them growing up and having children of their own. I think usually that they're going to make it."

She and her husband, Randy hope that a medical breakthrough will help their children by the time they reach adulthood.



Brett Pearce doesn't let cystic fibrosis stop him from enjoying the fun things in life like playing with his train. (Staff photo)

> *'I think about them growing up and having children of their own. I think usually that they're going to make it. I want them to have a full, good life.'*
>
> *— Lynn Pearce*

That hope was born when their son Brett was diagnosed as hanving cystic fibrosis when he was eight months old. The diagnosis was preceded by eight months of going to various doctors searching for an answer to why their son was so sickly.

"He wouldn't eat. He wouldn't sleep. It was hell," says Mrs. Pearce.

Finally, Mrs. Pearce, who worked as a nurse before her child was born, took Brett to a pediatrician with the announcement: 'I think he has cystic fibrosis.'

When the diagnosis was verified, the Pearces found it difficult in the beginning to cope with the situation.

"Once you know what you're dealing with, it's a lot easier to handle," she says.

But she admits it was hard to deal with the diagnosis which spelled a short life for her children.

"You have to enjoy life to the full. I want them to have a full, good life," she adds.

AND SHE WANTS her children to help others to have a better life. That's one reason she volunteered her children to become poster children for the Cystic Fibrosis Foundation.

"People look at twins. And you're advertising for funds," she says.

Her children, like most cystic fibrosis youngsters, look healthy. There isn't much of an outward sign that they aren't as healthy as their playmates.

After Brett was discovered to have the disease, the Pearces went ahead on their decision to add to their family. They had a three out of four chance that the next child would be healthy.

"I didn't even know I was carrying twins until I had them," Mrs. Pearce says. "I always wanted twins. If I could have picked out a family, I would have chosen twin girls and a boy."

It was difficult to face the fact that the girls were found to have cystic fibrosis when they were 10 days old.

But Mrs. Pearce is determined to keep her children as healthy as she can. Instead of telling them to take their medicine because they are sick, she emphasizes that they are taking it to stay healthy.

WHEN HER SON asks about the enzymes that he takes before he eats so he can digest his food, Mrs. Pearce explains that the medicine helps make him big and strong. She stresses their health instead of a lack of it.

Therapy to purge mucus from their lungs takes up about three hours of the day. Mrs. Pearce turns it into a story hour, a music period and a time to enjoy holding her children.

Look again if you think these two young ladies are one and the same. Actually they are twins,Kristie (left) and Kimberly (right). With the dedication of their mother, they are fighting cystic fibrosis.(Staff photos by Randy Borst)

"I try to be positive. I get to hold and talk to them every day. I think I have a close relationship with them because of that."

Still, it hasn't been an easy task to raise them.

Friends like Jeaune Oumedian helped Mrs. Pearce when her children were babies.

"Her son worked with my husband at AMC. She was a stranger and she volunteered to babysit for us. She never let me know she was working full-time at Northville Hospital and got up at four in the morning," says Mrs. Pearce.

Now, with the children out of the cradle and into the toddling stage, she and her husband try to make more time to enjoy themselves and indulge in a few hobbies.

" I want my children to see me enjoying myself. I don't think it's good if I have only my children to occupy my time."

SHE WANTS to make sure her children enjoy their lives, too. They plan to take a trip to DisneyWorld soon.

And she realizes that she will be faced with discussing dying with her children someday.

"I don't want them to be afraid of death."

THE INSIDE * ANGLE

By LOUISE OKRUTSKY

ALTHOUGH WE'RE WELL into January, there's still some talk of holiday gifts. One woman Angles met around town the other day fessed up to receiving a gift certificate for five bowls of chile at her favorite lunch spot. (That sets her up for a chile work week.)

A SCENE THAT had Angles shaking its hypotenuse in wonder involved a young woman dragging a vacuum cleaner down Farmington Road the other day. It's not often IA sees a vaccuum being pulled behind a pedestrian. (Angles realizes some residents take seriously their task of keeping the town clean, but isn't this a bit much?)

CROSS COUNTRY SKI fans are hoping and praying for some glorious snow. The Farmington Community Center folks took one look at the less than wintry scenery around town and pushed back their cross country skiing class schedule by one week. No snow, no slick slopes, no skiing.

THERE'S STILL time to get in on adult high school in the Farmington school district. Second semester begins on Jan. 28 during day or evenings. It's free. It can open new doors for a better job or the knowledge that you finally finished it off. Call 474-5233 for further information.

ANGLES SAW ace rug maker Pat Das in town the other day. Ms. Das, as you may remember, spent a portion of last summer trying to find someone to take a special rug to Rome for her to present to the Pope. The fathers at Orchard Lake Seminary answered her call for help. And in the mail this fall, Ms. Das found a thank-you note from the Pope. "Oh, I Just love him," beamed Ms. Das as she revealed yet another rug-making project. This one's a portrait of the Pope for one of the priests who took her first masterpiece to Rome.

AN EARLY WORD from the Cystic Fibrosis Foundation: Kiss your baby. If your babe in arms tastes salty, make a doctor's appointment for him or her. One of the symptoms of cystic fibrosis is a high salt level.

DOWN AT BOTSFORD Hospital, that man in public relations, Russ Tuttle, is waiting to turn into a grandfather pretty soon. (Congratulations, RT.)

OAKLAND COUNTY Health Division will offer a free immunization clinic in Farmington from 9 a.m.- noon Jan. 10 in First Methodist Church, Warner and Grand River. Immunizations for measles, German measles, mumps, polio, diphteria, tetanus and whooping cough are available. A parent or legal guardian must accompany a child under 18-years-old and bring any previous records of immunizations. If you are going to bring children other than your own, a release form must be obtained from the Oakland County Health Division or personnel at the clinic.

TWO MORE BUSES will leave the parking lot at Orchard Ridge campus of Oakland Community College at 4:30 p.m. Jan. 8 for the Teens Downhill Ski program. A few of the teens who tried to sign up for the program were turned away because Farmington Hills Parks and Rec didn't have enough buses. But with two more added, there's still time on Monday to sign up for the extra seats at the Parks and Rec Department. For further information, teens can call 474-6115.

IT'S MEA CULPA time for Angles. How could IA possibly have even thought that Treshold (Rick DeForge, Edgar Kalns, Jeff Franchi and Buryl Hill) could be anything but a rock 'n' roll band? They don't disco. (Ditto with lighting persons Dave Sutton, Bill Carter and Dough Lynch.) And Treshold is independent of the school which the above mentioned attend. But IA was right in reporting that the group played up a storm for the folks at the Farmington Training Center this past holiday season. (Is IA forgiven or must Angles listen to another tape of Ted Nugent describing how he shoots his own supper?)

THE 126 UNDERGRADUATE chapter and more than 300 alumnae chapters and clubs of Alpha Gamma Delta in the U.S. and Canada are working on service projects and fund-raisers to help the Juvenile Diabetes Foundation. The Detroit North Suburban Alumnae Club of Alpha Gamma Delta will hear Roger Winchester, chairman of the speakers' bureau of the local chapter of the juvenile diabetes foundation at 8 p.m., Jan. 8 at the home of Mrs. B. James Theodroff, 240 Warrington, Bloomfield Hills. The Wayne State University Chapter of Alpha Gamma Delta, Alpha Pi will attend the meeting, also.

ED LANE of the Farmington Chamber of Commerce will be one of the 2,100 delegates to the White House Conference on Small Business in Washington D.C. Jan. 13-17.

TELEPHONE CONNECTIONS

To connect with the Farmington Observer use the following numbers:

- **Staff - 477-5450**
- **Delivery — 591-0500**
- **Classifieds — 591-0900**
- **Legal Ads, Display Ads — 591-2300**