Cystic Fibrosis: cause found, but no cure yet

By NANCY BARKER
Staff Writer

Young victims of Cystic Fibrosis are literally "human guinea pigs." Children who suffer from this most serious lung disease are constantly undergoing treatment for the symptoms, but as yet, there is no cure.

"It's something you live with," said Mrs. C.G. (Colleen) Cunningham, Sandy, mother of two C.F. children, Tanya Rae, nine, and Robin Kae, two, and president of the Oregon Chapter Auxiliary of the National Cystic Fibrosis Research Foundation.

"We lead a normal life," she added. "It's just part of our way of life."

Normal life has become more hectic than usual for the Cunninghams, lately. They are involved currently in the 1973 Cystic Fibrosis House-to-House March. The campaign kicked off Monday with the Billy Casper Shotgun Pro-Am Golf Tournament, coincides with Children's Lung Disease Week.

"Robin is the Oregon poster girl for 1973, and Tanya has starred in a short film about Cystic Fibrosis," mentioned their proud mother.

Funds from the campaign will go toward research on Cystic Fibrosis, which is carried out at 39 research centers in the United States, according to Mrs. Cunningham. Research, begun soon after the disease was discovered in 1939, has finally isolated the cause this year.

"One reason research is slow on Cystic Fibrosis is that symptoms cannot be duplicated in any animal," explained Mrs. Cunningham.

The cause, reported to the 13th annual international meeting of the International Genetics Society last month, is a small molecule present in the circulating blood of cystic fibrosis victims or carriers of the disease. It is not known yet what the factor does.

"When they find out what the factor does, they should be able to control C.F. or reverse it," commented Mrs. Cunningham, who like other C.F. parents, hopes this will happen soon.

In the meantime, diagnosis and treatment are imperative. While the disease is progressive and incurable, many C.F. children, such as Tanya and Robin, lead active lives because these two things are available through the Oregon C.F. chapter at the University of Oregon Medical School.

"We're very fortunate to live where we have treatment," Mrs. Cunningham said gratefully.

Cystic Fibrosis, which occurs in one of every 1500 newborn babies, is extremely difficult to diagnose. It frequently masquerades as other diseases which have similar symptoms, such as asthma, celiac disease, or bronchitis.

"When I first joined the chapter, I heard of a child who was treated for kidney disease for years, but turned out to have C.F." related Mrs. Cunningham.

"You can't just say, 'look for this and this and this'," she continued. "Every case is individual; not all children have all symptoms. Robin has had no symptoms."

But she does have C.F.She was diagnosed at the age of three months by the most reliable method of diagnosis: the pilocarpine iontophoresis sweat test. In this test, the sweat of the suspected victim is analyzed for sodium and chloride concentration. One main symptom of C.F. is excessive salty sweat.

"We didn't find out Tanya had C.F. until she was two and a half years old," remembered Mrs. Cunningham. "She was a much sicker baby; she had pneumonia, which many C.F. children do."

Other symptoms include recurrent wheezing, daily cough, excessive appetite, and clubbing (enlargement) of the ends of the fingers.

"Babies have to be three months old to take the sweat test. Some babies when born have C.F. so severely that they don't live, but others aren't diagnosed until they are older," stated Mrs. Cunningham.

Treatment is also difficult, since it is somewhat experimental. Because the symptoms cannot be duplicated in animals, medication cannot be tested on them either. Consequently, treatment is individual too.

"This stuff is kind of controversial," said Mrs. Cunningham. "All doctors have different ideas. The goal is toward loosening up the mucous in their bodies.

"Of course, before anything can be used on these children, it must be tested in labs first."

For most C.F. children, treatment includes physical therapy, mist tents, vitamins, and enzymes to supplement their special diets. Hospital care is required for some, but moderate cases are treated at home and outpatient clinics. Part of the treatment is prevention of colds and other infections.

"Because of their lung condition, these children are susceptible to infection," Mrs. Cunningham stressed. "A cold could very easily turn into something more serious because of their lung condition."

Along with treatment, parents of C.F. children receive genetic counseling, since C.F. is a hereditary condition. It is estimated that as many as one person out of every 20 is a carrier of the disease. Most are unaware of this, that is, until two of them marry, and have a child with C.F.

"We're both healthy," said the Sandy mother of two, "There's just no way of knowing."

With benefit of early diagnosis and treatment, C.F. children can have active childhoods. Like Tanya Cunningham, a fourth grader at Sandy Elementary, many attend regular schools, and thrive on it.

"There haven't been many problems for Tanya at school," according to her mother. "She has adapted very well."

Both girls are crazy about horses, and both ride. Their grandparents in Cornelius keep horses for them, and Robin constantly chatters about "my horse."

"She became interested because Tanya was riding, mentioned Mrs. Cunningham. "She actually gets on and goes for horseback rides. They're both horse nuts."

Problems in the Cunningham household are infrequent which is a testimony to the serenity displayed by Mrs. Cunningham. However, she admits that Cystic Fibrosis has very definitely affected her family's life.

"It's hard to accept something like this," she said. "When you find out, it's a shock. It has made us much closer.

"When disaster strikes, most of us have to grow. I have developed a faith I can live by. Life has a new meaning."

If anything upsets Mrs. Cunningham, it is people who deliberately remain blind to misfortune in order to avoid coping with it. Parents who don't appreciate their children get no sympathy either.

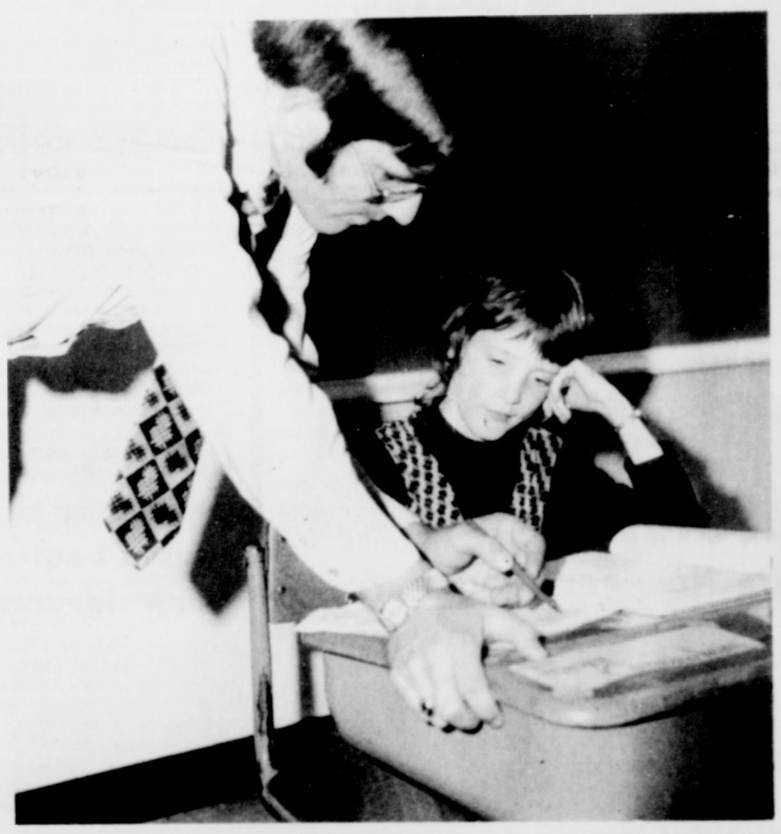
"I enjoy my children while I have them. Most people think 'someday they'll grow up and leave home:' I think 'will my children grow up and leave home?'"

"People don't realize how short life is. To me, it's much more full of love now that I know what it is. Being alive is very precious and fleeting."

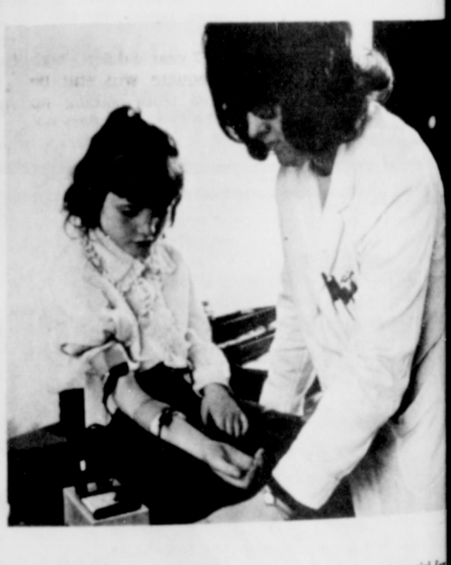
ALTHOUGH SHE is a very active toddler, Robin still likes to be held by her mother Mrs. C.G. Cunningham now and then. She likes to hold replicas of her favorite animal. (Post Photo)

CYSTIC FIBROSIS must be diagnosed by a sweat test, demonstrated here by Tanya Rae Cunningham, Sandy, who receives treatment at the University of Oregon Medical School. C.F. children undergo tests and treatment continually, and take them in stride. (Media West Photo)

"I'M GOING to ride my horse," says Robin Cunningham, who at two is a very young equestrian. (Post Photo)



TANYA CUNNINGHAM, fourth grader at Sandy Elementary, gets help from teacher Ron Berglund. Although she has C.F., Tanya participates in most school activities, has no real problems at school. (Post Photo)



ROBIN KAE Cunningham, Oregon C.F. poster girl for 1973, adds her two bits to this year's collection in a golf ball bank held by Don Schollander, honorary campaign chairman. Campaign started off with a "bang" Monday, date of the Billy Casper Shotgun Pro-Am golf benefit tournament. (Media West Photo)

CF campaign needs support

The fund raising campaign conducted by the Oregon chapter of the National Cystic Fibrosis Research Foundation officially ends tomorrow. However, the need for help, financial and otherwise, does not end then, according to Mrs. C. G. Cunningham, president of the Oregon chapter auxiliary.

The foundation, which benefits related diseases such as asthma, celiac, and emphysema, constantly needs funds to conduct research. The local chapter auxiliary needs interested volunteers.

"Many C.F. parents are so busy caring for their children, that they don't have much time for the volunteer work. Giving these children their therapy takes up a lot of time," commented Mrs. Cunningham, a Sandy resident.

The Oregon Chapter conducts a clinic at the University of Oregon Medical School, which currently treats about 125 patients. These patients, who come from all over Oregon, and from southern Washington, are treated for related diseases as well as C.F.

The auxiliary is mainly composed of C.F. parents, but is open to anyone who is interested. Mrs. Cunningham feels there is a need for additional members, and that the more people involved, the sooner C.F. will be conquered.

"Sometimes, people don't want to face problems like this," she said, "but that doesn't make them go away."

If you would like to help, or would like infromation, call Mrs. Cunningham at 668-4537, the Oregon chapter office at 227-7855, or contact the National C.F. Foundation, 202 East 44th St., New York, N.Y.10017.