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******U.T. Health Science Center doctors rescue Down's child from mysterious disorder.

DALLAS--Doctors in Kevin Pryor's hometown were baffled as they watched him struggle for breath. Periodically his breathing would stop, his skin would turn blue then black and his eyes would gaze into what his mother calls a "death stare."

"Let him die," one doctor said. "After all, Kevin is a Down's child so what can you expect? I wouldn't want a child like this. He's only going to be a burden." But with those remarks, Barbara

Pryor only became more determined not to give up.

The two and a half-year-old child with Down's syndrome had spent most of his life in hospitals. From four months of age he experienced multiple episodes in which his breathing would stop. After seconds of fighting for life, he would become lethargic and begin to die. Kevin technically died many times and was rescued only by resuscitation.

Each time Kevin went into respiratory arrest, Barbara would suction mucus from a temporary tracheotomy tube, change the tube or "bag" Kevin by pumping air from a special bag into his lungs

through his mouth.

Kevin's abnormally enlarged heart and his diseased lungs, the result of lack of oxygen, preoccupied doctors. For this reason, the underlying cause was missed until recently.

Two weeks before Christmas, Kevin was sent to Children's

Medical Center in Dallas. There a team of doctors from The University of Texas Southwestern Medical School began treatment of Kevin, continuing to focus upon heart or lung conditions.

Dr. John Herman, an expert on sleep disorders, was called in as a consultant and identified the cause of Kevin's problem as a disorder similar to obstructive sleep apnea in adults. Herman says Kevin's severely labored breathing, wheezing with every breath, hinted of an obstruction blocking air flow into the He believed that this obstruction could lead to Kevin's pulmonary and cardiac conditions.

Herman then called Dr. Donnell Johns, a medical school authority on speech, breathing and swallowing.

Johns found that Kevin's soft palate, the tissue at the back of the mouth separating mouth from nasal cavity, was abnormally long. At times, particularly while crying or swallowing, it would protrude deeply into the throat. Tonsils and adenoids were also greatly enlarged as was surrounding tissue in the throat. Some of this enlargement was swelling due to inflammation and infection, said Johns. Combined, the enlarged areas blocked all air flow into Kevin's lungs.

The problem was not apparent from looking into Kevin's mouth since the enlarged structures were usually above mouth level.

The abnormality was confirmed when Johns, who holds a doctorate in speech pathology and is an associate professor in Plastic Surgery, gave Kevin barium through the nose to define airway size and took rapid, motion picture X-rays using a process called "cineradiography." Pictures were taken of Kevin's swallowing and breathing, revealing that no air was passing the obstruction.

Johns immediately called Dr. Orval Brown, assistant professor of Otorhinolaryngology at Southwestern. Johns diagrammed the tissue to be removed and assisted Brown in performing the surgery, clearing away excess tissue blocking respiration,

trimming the palate and removing the tonsils and adenoids. This opened an airway that permitted continuous oxygen exchange without effort. Kevin's enlarged heart and diseased lungs are now returning to normal.

Kevin was a foster child, one of nine whom Danny and Barbara Pryor have kept during the past three years. Most of the nine foster children have some form of mental handicap. But Kevin seems brighter than the rest. Doctors call him a "high level Down's." With all the care he required, the Pryors, who have one biological daughter, became very attached to him and formally adopted him last October.

Life will change drastically for the family now that Kevin is improving, says 34-year-old Barbara. During the times he was hospitalized, she stayed with him virtually 24 hours a day.

Breathing was especially difficult for Kevin while sleeping

Breathing was especially difficult for Kevin while sleeping so that he found only one position in which he could lie. He would lean his head back as far as it could go and throw back his shoulders in order to establish an airway. After that position failed in permitting air to enter his lungs, he would toss and turn repeatedly. "His bed would shake with every breath," said Kevin's mother.

One of the hardest experiences for Barbara was the time she had to revive Kevin while driving on crowded Airport Freeway, steering with one hand and bagging Kevin with the other. When she found a place to pull over, she couldn't get anyone to stop and help.

Another time, one doctor examined Kevin and told her he was fine. As they talked, she looked over the doctor's shoulder to see Kevin, playing on the floor with a toy, start to turn blue and slowly fall over. The two picked him up and hurried him across the hall where they worked to revive him. The doctor told her Kevin would probably die and was about to give up when Kevin started breathing again.

Kevin comprehends as well as a normal child, says his mother, and even learned his colors in an intensive care unit. The periods without oxygen haven't seemed to make a difference, she

Johns, who sees about 125 children a year with some form of obstructive or palatal problem, says Kevin's problem was not necessarily the result of Down's syndrome nor was it hereditary. Johns, the former clinical director of the Callier Center for Communications Disorders, well-known for his work in palate abnormalities, says the malformation would have been impossible to detect without evaluation by cineradiography.

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Photos available upon request.
Tear sheets appreciated.
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