

# A rare disease has this 10-month-old battling to breathe

By **Faizan Haider** in Gurgaon

LITTLE Muaaz Ahmed has been on ventilator ever since he was born. The 10-month old is suffering from a rare disease called Ondine's Curse or congenital central hypoventilation syndrome (CCHS). It is a respiratory disorder which involves a failure of automatic control of breathing and the body forgets to breathe during sleep.

Muaaz's father and grandfather are both doctors but they themselves don't know how to save their child. According to doctors, CCHS is a rare disease which happens to one child in 15 years.

"I remember only three such cases in the past 20 years. The last case I heard was seven years ago in which the child was on ventilator for 10 days but could not survive," said Dr Sanjeev Bagai, director (Pediatrics), Rockland Hospital. "In this disease, the child faces difficulties in breathing or has shallow breathing. This results from discontinuation of oxygen supply and therefore the body needs ventilation," he added.

## His family spends Rs 2 lakh per month on treatment

Muaaz's grandfather Dr Akhlaq Ahmed said the family is doing everything possible to save the child but it appears to be a losing battle.

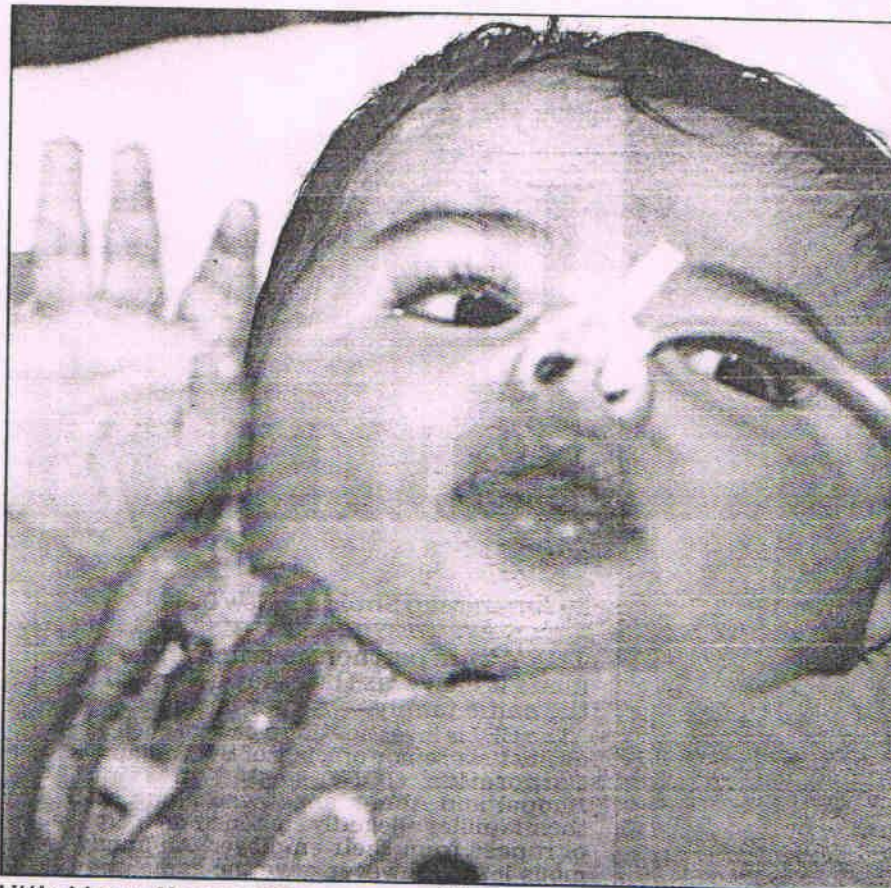
"In the disease, oxygen supply of the patient is locked when he is asleep. We have had all the check-ups and everything is normal, but we can't let him sleep (without ventilator). Muaaz was put on ventilation just after he was born. We know his future is dark, but we are trying our best," he said.

Muaaz is admitted to his grandfather's hospital in Gurgaon, Sector 15-A. The family spends more than Rs 2 lakh every month for the baby's treatment. "We are giving him oxygen through tracheal tube and feed him through a nasal tube. He is under the supervision of top doctors of

other countries who have told us that there is a possibility of survival if Muaaz lives on ventilator for two years. But it's highly unlikely, because there are sideeffects of ventilator. Muaaz has already suffered from pneumonia three times," said Dr Mohammed Ahmed, the baby's father.

In most cases, children die even before the disease is diagnosed. The first symptom of the disease is poor breathing or complete lack of spontaneous breathing, especially during sleep.

The only treatment of CCHS is



Little Muaaz Ahmed has been on ventilator since his birth.

## What is Ondine's Curse

CONGENITAL central hypoventilation syndrome (CCHS) is a respiratory disorder in which a person suffers from respiratory arrests during sleep. This very rare form of central sleep apnea involves an inborn failure of autonomic control of breathing. About one in 200,000 infants has

circumstances, can result from severe brain spinal trauma, such as an automobile accident, stroke, or as a complication of neurosurgery.

CCHS is also known as Ondine's Curse, a reference to the myth of Ondine, a water nymph. Her