

People

Child expected never to walk, approaches 16th birthday

By KATE GILDERDALE
Correspondent

To the casual observer, Azeem Kayum is a good-looking young man with a finely developed sense of humor and a warm, engaging personality.

To those who know him and his family, he is a walking, talking miracle, whom doctors predicted would not survive his first year. Azeem, who celebrates his 16th birthday Dec. 8, was born paralyzed from the neck down and required a battery of life support systems to keep him alive.

His mother, Laila, vividly recalls the day of his birth. "They told me that he wasn't well and they would like permission to transfer him to The Hospital for Sick Children. When we started asking what was wrong, nobody could answer."

Answers continued to elude them as Laila and her husband, Faizal, struggled to come to terms with their son's plight. Three months after his birth, one of the doctors acknowledged that Azeem's condition could have occurred during delivery.

The family's experiences have been documented in Laila's moving book, *For A Breath of Life*. "After numerous questions and much prying, we learned that Azeem suffered from a very rare disease," his mother wrote.

His condition arises from a neurological lesion in the brain stem and can be the result of high cervical cord damage. Because the lesion interferes with his ability to breathe automatically, Azeem must rely on a ventilator at night.

"The bottom line is, every night he has got to be hooked up to the machine," explained Faizal. "He may look fine during the day, but at night it's a constant worry. A lot of times, mucus gets into the tubes and it has to be suctioned off every so often."

As well, Azeem has a portable device for emergency day time use and constant vigilance is essential to his well-being. "His disposition has always remained quite optimistic and positive and that has helped us cope," stressed his father. "If he was bitter it would be very discouraging for us."

The first 376 days of Azeem's life were spent at Sick Kids. During that time he underwent constant tests, battled severe pneumonia and suf-



Azeem Kayum and his mother Laila.

Photo: SJOERD WITTEVEEN

fered a series of cardiac arrests. A few weeks before his second birthday, however, the boy one neurologist predicted would

never walk or talk took his first steps.

When he was two-and-a-half, his parents took him to visit

family in Trinidad but he had to be flown back to Sick Kids by air ambulance after being taken ill five days before the family was due to return home. He suffered two cardiac arrests and was comatose for almost two weeks.

In April, 1982, he underwent a tracheostomy to create an opening in his throat for the insertion of a breathing tube.

The problems he faces, both physically and developmentally, impose their own restrictions. "He has been under 24-hour supervision most of his life," Faizal pointed out.

"He hasn't had a chance to get out there and make mistakes, he always has somebody with him."

Azeem attends Markville High School and has a nurse with him during the day. And

although he has made astonishing progress, the Kayums keep hoping for another miracle which would allow their son the independence and future prospects enjoyed by his peers.

"I've gotten used to my disability and I can live with it, but I do get frustrated, especially in my school work," he said. "I haven't got too much free time because I'm busy studying or doing homework."

But life is by no means all work and no play, he admitted with a cheerful grin. "Sometimes, especially on the weekends, I do find myself in front of the TV watching wrestling."

A portion of the proceeds from the sales of *For a Breath of Life* will be donated to The Hospital for Sick Children. Copies are \$14.98, including GST, and can be obtained by calling 642-0002.

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