Millions raised to fulfill son's `destiny'

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Despite the heroic efforts of doctors and nurses at The Hospital for Sick Children, Daniel Povegliano suffered terribly from a rare disease every day of a life that ended in 1996 at the age of 4.

Grieving parents John and Anna, of King City, practically lived at the hospital for parts of their son's life, and they witnessed many other suffering children and their anguished parents.

A year after their son's death from systemic mastocytosis, a fatal skin disease that also attacks other organs, the Poveglianos' compassion for others and a desire to do something in Daniel's memory prompted them to form the Smiles of Innocence Memorial Charity in support of SickKids Foundation.

Their efforts to date have raised \$1.7 million and the goal is to hit \$2 million by the end of this year, John Povegliano says.

He proudly points out that 100 per cent of the money raised goes to the hospital.

"We have a gala every November and we have no trouble selling out in one day because of that."

Proceeds are also received from corporate golf tournaments, he says.

The money is used for several purposes. Some goes to purchase equipment such as incubators, cardiac monitors, beds and wheelchairs. Some supports a three-year fellowship for a doctor from Costa Rica, who can use her specialized training to help children in her own country.

Another share is directed to the Daniel Povegliano Endowment Fund. It now has about \$1 million, and when it reaches \$2 million, the investment income will be used to subsidize the purchase of an annual "wish list" of the hospital's greatest needs, to be determined by the foundation in consultation with the hospital's executive committee.

Povegliano, an industrial designer who runs his own business with his wife, call SickKids one of the wonders of the world. But he points out that it takes a tremendous amount of money to maintain that global reputation.

"I believe Daniel was put on this earth to fulfill a destiny we're determined to see to completion," he says, adding that he's grateful "forever grateful" to the hospital and its employees for keeping his son alive as long as they could.

"Every moment with him was cherished because we knew he was special and here on borrowed time. God blessed me with a wonderful son who taught me so many things in his short life.

"Daniel has made me realize there are so many children born every day with special needs and we must do whatever is necessary to help them."

When Daniel was born, his skin was blue and he had blemishes over his body. It was two weeks before his disease was diagnosed.

He was able to eat baby food for a few months, but after that he could never again eat through his mouth. He was then fed through a tube into his stomach, but as the disease progressed he couldn't digest food. So he was nourished by intravenous solution while he slept. He couldn't talk or walk, and by his fourth year he was deaf.

Daniel was able to live at home only briefly, but during that time his parents tried to make him as happy as possible.

"We saw the joy in his eyes as we'd give him little tosses in the air, or when we'd take him to the zoo, pulling him around in a wagon. We'd take regular strolls to the park playground, where I'd put him on my lap and take him down the slide."

The efforts for SickKids have helped the Poveglianos deal with their grief, although they say that wasn't the overriding motivation.

"It's phenomenal knowing that we're helping other children and their families," Povegliano says.