

## **Dying boy in wheelchair barred from public skate**

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A terminally-ill, disabled three-year-old was refused entry to a public skate at a Hamilton arena on the weekend.

Kari Patterson was told she couldn't take her son Tucker onto the ice in his wheelchair when she called North Wentworth Arena in Flamborough to inquire about bringing him to the public skate from 2 to 4 p.m. on Sunday.

"I was angry," said Patterson. "They just said no."

Skating is big for the Patterson family. Tucker is named after hockey star Darcy Tucker and his twin sister and older sister both take skating lessons.

The Pattersons wanted to spend the afternoon skating as part of their quest to pack a lifetime of memories into the short time they have with Tucker. He's dying from a rare genetic disorder called Leigh's disease which causes progressive degeneration of motor functions, one of the diseases investigated by McMaster University's Dr. Mark Tarnopolsky.

Tucker can no longer eat, talk or walk.

"It's something we can do as a family," said Patterson about going skating and pushing Tucker around the ice. "We're limited in what we can do together."

City recreation manager Bill Atanas said Tucker should have been allowed on the ice.

"Unfortunately it was a situation with a staff person that wasn't familiar with the policy," he said. "I have spoken with the staff person and advised them of our policy."

The city is also having a staff meeting today to make sure everyone is aware of the policy that allows wheelchairs on the ice during public skates.

Tucker is well known in Waterdown, where his family has raised thousands of dollars for Tarnopolsky. The Hamilton doctor is Tucker's best hope for treatment.

Each year the Pattersons hold a golf tournament called Tucker's Time to support Tarnopolsky's internationally-acclaimed work in muscle function.

Last year hockey star Tucker, a former Maple Leaf who now plays for the Colorado Avalanche, came to the tournament.

This year's tournament is July 23 at the Carlisle Golf and Country Club.

Tarnopolsky's innovative treatment so far is not a cure but has helped Tucker beat the odds. Most kids with Leigh's disease die within a year of being diagnosed. Tucker has lived nearly 18 months since he was diagnosed at age two.

His mom says Tarnopolsky has worked hard for Tucker, even calling the family while he was on vacation in Italy when they needed his help.

While Tucker has lost most of his ability to function, his mom says he still loves life.

"It hasn't taken his spirit," says his mom. "He's the happiest boy I know. He laughs and it comes from his belly."

His family knows they're on borrowed time and are working hard to give Tucker as much of a childhood as possible. It's one of the reasons it was so devastating to be refused the chance to skate for the afternoon.

But Tucker will get on the ice. His parents are taking him to the Toronto Maple Leafs Skate for Easter Seals Kids Feb. 7. His dad will wheel him around the ice with the Leafs at their practice facility in Toronto.