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Racing the darkness: Blizzard

As her boys' eyesight deteriorates, a mom fights to ensure they'll have the help they will need

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With the miracle of Cochlear implants, Pam Aasen's two boys, who were born deaf, can hear. But it turns out that was just the first mountain to climb.

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Pam Aasen and her two sons are having a little fun, unwinding in their Mississauga home after a day at school.

Ethan, 9, tells his mom about music class at school that day. They'd learned what music makes them happy and what makes them sad.

Talk turns to hockey. Six year-old Gavin tells his mom he dreams the great Canadian dream: He'd wants to be a hockey player.

Sadly, though, a devastating diagnosis both brothers got 18 months ago puts all their hopes and aspirations a little farther out of reach than those of other youngsters.

Both brothers were born profoundly deaf.

With the miracle of Cochlear implants, though, they hear very well. Ethan can tell his mom what the happy music sounded like in class. And Gavin cheerfully bobs his head in time with the music on his iPod.

"The implants were very successful," explains Aasen.

Once that hurdle was out of the way, she and her husband, Angel Morrobel, thought they were finally making progress.

"We thought we'd reached a great place in life. They were doing very well," she recalls.

As a special-ed teacher, Aasen was troubled when she noticed the boys had problems with their motor skills and with balance. Negotiating unfamiliar stairs was difficult.

Finally, an eye specialist at the Hospital for Sick Children dropped the bombshell.

Both boys have Usher Syndrome, a rare genetic disorder. Typically, children are born deaf.

In later childhood, their eyesight deteriorates. By the time they are in their mid-teens, both boys will have severely limited vision.

“It was like climbing a mountain,” she recalls.

“We got to the peak, and then someone threw us back down the mountain — and moved the bottom deeper.”

Aasen is determined to prepare her sons for the future.

“We’re thinking positively,” she said.

She’s working with the [Foundation Fighting Blindness](#), raising money for research into the cause and prevention of Usher Syndrome.

“The future is very uncertain,” she said.

“We don’t know how exactly things are going to work out for them.”

Aasen wants to make sure they have meaningful, productive lives.

She’s worried about proposed changes to government funding for intervenor services for the deaf/blind.

Intervenors provide the eyes and ears deaf/blind people need to live independently. They help them with shopping and other daily chores.

As a result of a human rights ruling, deaf/blind services were recently expanded to include different groups. Funding wasn’t increased at the same time. It’s caused a schism within the community between those who were born blind and those who were born with sight.

While her sons don’t need an intervenor right now, Aasen is looking down the road. Services for people who are fairly self-sufficient and can live alone would be cut back drastically.

“All people should be treated equally and have equitable access,” says Aasen.

“At the same time, we need to do what we can to help them maintain their independence, while treating their condition.

“We want the government to invest in their future so they will lead meaningful, independent lives,” she said.

Despite their balance issues, her two brave little boys ski and, with great tenacity they’ve hung in and learned to skate. Not well, she admits. But they skate.

They may never make the NHL. But when it comes to courage and determination and the ability to overcome overwhelming odds, they’re both true winners.