

Life with 'beautiful' Sydney — one family's story

by Abigail Cukier
Special to the Beaver

When Leanne Tovey's daughter, Sydney was born, Tovey looked at her newborn's beautiful face and told her husband, Scott, their baby had Down syndrome.

"When I asked the doctors, they whisked her away and said, 'Don't worry, everything is fine.' I thought, yes, she is fine, but she has Down syndrome," Tovey said

"(In a bid) to not upset me, there was no acknowledgement that she had Down syndrome. That was the first realization for me that people feel if your child has Down syndrome, your child is not a whole person."

Tovey, who is a teacher with the Hamilton-Wentworth District School Board, had taught in a classroom with students with developmental disabilities, including Down syndrome.

Daddy's princess

"I had known the love, the aptitude for what they could do and their joy for life," she said. "My husband, who hadn't had the exposure I had, didn't even blink. Right from the start, Sydney was his princess, his little girl. His strength has been phenomenal."

Sydney is now four years old and Tovey just registered her for kindergarten for September.

Tovey, a Milton resident, is chair of the Halton Down Syndrome Association.

Thirty-one years ago, five Halton families with children with Down syndrome came together to create the non-profit charity.

"At that time, people and governments did not understand how to support these families," Tovey said.

"Children were still sent away to institutions. These families fought the system and said, 'We are keeping our children.'"

Those five families are still involved with the association, includ-



Sydney Tovey

| photo courtesy Leanne Tovey

ing board member Allan McNeill, who has Down syndrome and is the son of one of the founders.

Local association offers programs

The Halton Down Syndrome Association provides programs, including a group for new parents. Preschool programs include music therapy and sign language.

School-age children can participate in programs like Sportball and

gymnastics and a high school program offers classes in areas such as cooking or how to handle certain social situations.

High school graduates enjoy social programs and classes including First Aid and CPR.

"We want to be there for families at all the transitional stages, from when you find out your new baby will have Down syndrome to being a new parent. We also support fam-

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Halton Down Syndrome Association chair

ilies with young children and help them navigate the school system," Tovey said.

"Our biggest goal is to support government in understanding people with Down syndrome are an asset to the workforce. We are not a political group, but we want to evolve as an organization and help the world evolve with us."

The association also wants to raise awareness. In March, it held a World Down Syndrome Day Contest for elementary schools within the Halton District School Board and Halton Catholic District School Board.

The contest encouraged schools to celebrate World Down Syndrome Day and create a digital media presentation highlighting their celebration.

The winner received cash for technology or assistive technology for their schools.

A matter of acceptance

"It's not about tolerance. It's about acceptance. Our son Aiden, who is seven, gets asked, 'What's wrong with your sister?' He says 'She's beautiful, she's Sydney and she does things in her own way.'"

Tovey says she knows there will always be struggles. Sydney has medical issues, including with her vision and her heart. She will have open heart surgery this summer.

"It may not be the journey you envisioned. We don't ever get that journey we envision. As soon as you let go of that, you are so much happier," Tovey says.

"There will be a lot of obstacles she has to cross, things we take for granted. With Aiden, we took for granted that he sat, crawled and fed himself. I wish people would look at Sydney and think it's amazing everything she does, how much harder it is for her to work at those things than any other kid. I look at her with amazement."

Saucy and hilarious

Tovey describes Sydney as saucy, hilarious and very smart.

"She is like any other four-year-old girl, putting on a dress and singing *Frozen* at the top of her lungs. She is the same, but she is different. It took so much for her to be able to stand, to form the words, to recognize the song and to sing. She is so much more than a little girl standing in a room wearing a princess dress."

Fundraising Go21

The Halton Down Syndrome Association is holding its Go21 Halton Walk for Down Syndrome Saturday, June 20, at Victoria Park and Hugh Foster Hall, in Milton.

The event will also include bouncy castles, food, entertainment and a silent auction.

For information, visit halton-go21.ca.