

# Down Syndrome life is a life filled by love

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By Nicole Carter

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*This is a continuation of last week's Advertiser Democrat article. [For parents of children with Down Syndrome, respite is elusive but joy is not.](#)*

REGION — Parents who care for children with Down Syndrome face numerous challenges from the time they are born. But what their families have in excess is love and affection.

And having an extra chromosome does not mean that people with Down Syndrome do not possess the same aspirations and pride as everyone around them. During the Advertiser Democrat's recent round table to discuss National Down Syndrome Awareness Month, that was one point revisited several times.

"Daniel wants you to know," said Deb Twitchell, who Zoomed into the interview with her 30-year-old son. Tears welled in her eyes as she translated his feelings for him. "People with Down Syndrome have the same aspirations as anyone else."



Daniel Twitchell of South Paris proudly displays the prize he won for equestrian cart-driving at the Special Olympics. *Supplied photo*

"He likes to play video games. He has a blue belt in karate. He plays in a tennis tournament at Bates' College. He likes to spend time with his brother Joshua. He has a favorite uncle that he just did a pizza and movie night with his favorite uncle, Doug. He loves to spend time with family."

Aranka Matolcsy, mother to 10-year-old Colby, agreed.

"The 'more alike than different' is a tagline and it's true," she said. "Kids with Down Syndrome share more with their families than the characteristics they share among themselves. They have a tremendous capacity to learn and retain information, and adapt new skills."

Terry Lord of West Paris and his 33-year-old son Seth, who has Down Syndrome, live their lives as co-bachelors. They have weathered ups and downs – Lord's divorce from Seth's mother when he was still very young, battles for services and education, and personal loss as well. A recent event drove father and son to become snowbirds.

"One thing that's been hard on both of us," Lord said. "My significant other of 17 years passed away in April. Ironically, I figured at my age it would be easier. But it's not. We've both been dealing with that."

After that family unit shakeup Terry and Seth traveled to Florida to spend time with Seth's grandfather, staying for two months.

"I met a girl, in Florida," Seth said. Unfortunately, he has not been able to stay in contact with her but that could change if he and his father make Florida a regular destination.

"I don't know what our future holds," Lord said of losing his partner. "With her passing away? I feel like I'm chasing my tail, trying to figure out what to do. We're doing a little better."

Lord found a place for them to stay while visiting his father in Zephyr Hills.

"We were looking at those places (near my father's) and they were kind of pricey," Lord said. "I looked at this one little trailer over the fence, and it was like Knox Street to Paris Hill. Big difference. But we're guys, we can handle it."

"Austin is friendly and he is very determined," said Crystal Cochran of her 19-year-old son, who is in his final year of school with the Windham school district. "He has his own agenda and he sees himself as an adult. He achieves things on his own schedule, at his own pace."

She said his emotions are that of a younger child and he is affectionate. He greets everyone he sees in public with a hello and enjoys giving hugs, even if his emotions are getting the best of him.

"Even in a tantrum, in a store, he is still telling people hello," Cochran said.

"Colby is a builder, he's a swimmer. He's musical," Matolcsy said of her son. "He's tremendously artistic. Incredibly empathetic."

One of Matolcsy's fears while Colby was an infant in the neonatal ICU and she was processing his diagnosis and future was how he would ever fit in.



Colby Martel, left, enticed his mother Aranka Matolcsy to use a Wizard of Oz theme for their Halloween costumes last month. He went as the Scarecrow and wanted her to be the Cowardly Lion. *Supplied photo*

"I was lamenting that maybe our friends' kids would not want to play with my kid," she said. "And then I saw that he had an entourage of little girls at Club Rowe and Oxford SACC. His fourth grade teacher sent me a video where he's holding a girl's hand on the way out, making new friends.

"Their hopes and dreams and aspirations are just like every other kids."

"Daniel is unique in his learning potential," added Twitchell. "He has no real math skills and he is a functional reader. But he refuses to read picture books because he sees himself as a man. He likes to sit with adult books even if he can't completely read them."

"Colby is truly the best thing that's ever happened to me," Matolcsy said. "This is been the hardest thing I've ever experienced in my life but it's brought me to a place where I'm living my life in the most authentic and genuine way I've ever known and I've never known such gratefulness.

"He has brought all of that to me."

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