

Opinion

‘Our remarkable village’ in region rich with resources

This week marks World Down Syndrome Day, and I want to share its significance to our family with a personal story.

I am the mama of Emberly, a 7-year-old little girl with Down syndrome, and Arlo a 3-year-old little boy without Down syndrome. I will never forget my family’s first interaction with the Down syndrome community. It was at the Centre Region Down Syndrome Society (CRDSS) fall Buddy Walk event. Emberly was just a baby, and I wore her in a carrier the entire time. She slept peacefully while we took in the festivities as two wide-eyed and exhausted parents – thrilled to finally get an in-person peek at people of all ages with Down syndrome. Our first experience in our new community was life-changing.

The director of CRDSS also visited my family with a home cooked meal along with stories and advice (when asked). That act of kindness gave us such confidence in our future. She answered our questions, shared hope, and connected us with the greater community.

Over time I wanted to interact more deeply than I could get from online support groups - not wanting to miss a

thing for my daughter. But I quickly realized that our own community here in centre region was what brought me true understanding and connection.



What I have learned over and over, is every family has their own journey, their own diagnosis story, their own victories and their own struggles. Not everyone is ready to dive into full immersion like me.

I found I had a place in connecting with other parents and caregivers who are still figuring out what the diagnosis means for their loved one. I now have the pleasure of helping new families in

our region connect by serving on the board of CRDSS. Our remarkable village that has open arms and support beyond measure. I continue to share the hopeful possibilities of what their experience can be. Emberly is my beloved example of a life filled with joy.

And yes, we have struggles too.

When Emberly was born in 2016, we thought that Down syndrome would be our biggest challenge. Little did we know that our bigger challenges ahead would come with names like celiac disease and Type 1 Diabetes. Emberly’s challenges carry big differences. If we were given a chance to cure her autoimmune conditions, we would do so in a heartbeat. But Down syndrome is a big part of what makes Emberly, Emberly. Raising a child with Down syndrome has taught our family about community, humility, authenticity, empathy, patience, persistence, acceptance, and so much more.

Our region is rich in resources. There are more than 100 families that are connected to the Centre Region Down Syndrome Society, and we are eager to serve more – to share support with the Enrichment Fund, a reimbursement

program for life enriching equipment and activities, and a speaker series to help educate caregivers on the latest research as well as daily coping mechanisms.

Today I take my passion for this community further by working at Strawberry Fields as their Social Enterprise Operations and Development Supervisor and oversee the Good Day Café – a popular state college coffee shop which “brews opportunity” by providing meaningful employment for adults with disabilities. We believe everyone deserves a chance to contribute to their community, become more independent, and know they matter.

I encourage you to learn about our village, and show you care. Recognize World Down Syndrome Day and be aware and supportive of our wonderful individuals with special needs and their families. Be champions of inclusivity and help pave the way for new generations. And next time you are in the Good Day Café please look me up and say hello! Making connections brings me joy.

***Katie Feliz
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