



member to member connection

Breaking through barriers for workers who have children with special needs
Nº 25 Winter 2012



With a new year on the horizon,

it's time to say good-bye to the old and welcome in the new. We would like to acknowledge your children, both young and adult, who are supported by the Special Needs and Moving On projects.

We've been moved and inspired by all the hard work and effort your children have made to overcome life's challenges.

We are proud to be playing even a small role in helping them along their journey.

We wish all members the very best for 2013. We hope that each and every member's child experiences renewed health and strength in the new year.



"It's because we are different, that each one of us is special."

Family pictures are always a chore for moms to coordinate. "Who's wearing what?"; "Not those shoes, your nice shoes."; "Show me your nice smile...no that's a fake smile." Moms always want their family picture to look perfect! Having special needs kids and planning for a family picture is very trying. Thank god for digital cameras 'cause on average we take about 200 pictures to get a few good ones! Family pictures are very important to us. We try to get them done every year. It's a "snapshot" in time but the memory will last a lifetime.

Letter Carrier
Tecumseh, ON





"Juggling all this is not easy."

My son Brandon was diagnosed with autism at the age of 2. He was quite shy, and wanted to be away from crowds of people. In elementary school he began to have tantrums, mostly crying and shouting. He is now heading into high school. He likes to draw with a crayon, especially animals. But he is out of control – heavy tantrums, hitting himself, biting his fingers and arms, hitting others. It is hard to find a worker for him.

Brandon's favourite thing is going to the Dollar Store to buy plastic animals toys. This can lessen his tantrums on our way home. If we don't purchase an item he will get mad. We think that he can remember things but his ability to communicate is very limited.

The big burden in our family came when my high-school aged daughter began thinking about running away as she hated our situation at home. She doesn't want to accept the reality of our family life.

We had the help of my mother-in-law but she passed away October 2011. I don't know how I can stand everything but I think, I feel, the help of prayers will keep me strong.

Letter Carrier
Mississauga, ON



My oldest, Laurianne, who is 11 yrs. old, has always experienced major difficulties both socially and academically. Since 2009, we've had to work very hard at helping her. Her ADHD and number blindness have required remedial instruction, homework assistance, the services of a social worker and a psychologist, as well as medication. Juggling all this is not easy. It represents a lot of expenses for a single mom, but the Special Needs Project has been a big help.

Jasmine is now 6 yrs. old. She was 4 when I learned, in April 2011, that she had acute lymphoblastic leukemia. This came as a shock. She needs two years of weekly chemotherapy treatments. She misses school often; her immune system is extremely weak. She can't risk getting the flu. She can't play in the sand or go to public places. If we need to go to a public place, she has to wear a mask. Her treatments will end in June 2013, but she will require regular follow-ups for the next five years. Thanks to the Project, she has benefited from therapeutic riding twice a month, which forces her to exercise her legs. The chemo has affected her legs, and it's difficult for her to walk or go up and down stairs normally



Jasmine

PO-4
Laval, QC



Thank you for your continued support. Ava is making great progress. The Special Needs Project helps our family tremendously.

Richard Mina
Mail dispatcher
Ingersoll, ON

"She has developed many life skills and become a confident young lady."



Just wanted to express my gratitude to the Special Needs project for supporting my daughter Madison. Madison is now 14 years old and has been a member for 4 years. Because of your generous support she has developed many life skills and become a confident young lady. She made it to the Ontario championships in her riding class. Unfortunately her horse Aiza came down with a stone bruise and they were only able to finish one of her riding classes. Despite this Madison enjoyed it immensely. She finished in 7th place in the South Eastern Division in her class in the Trillium circuit Hunter 2 ft 6 division. Madison has so much more confidence and self esteem! Thank you once again for your support.

PO-4
Brockville, ON



Hi, my name is Joe and my son's name is Justin. We have been with the Special Needs Project for 3 years. My advisor's name is Lesley Anne. She has been very helpful with filling out forms and providing strategies for coping with a child with special needs. Justin has been able to release his anxieties through playing sports where he has excelled and has made many friendships along the way. Thanks to the Special Needs Project for the funding and thank you to my advisor Lesley Anne for all your help and guidance.

Letter Carrier
Hamilton West, ON



You can now submit your stories and photos to the Member-to-Member Connection newsletter by visiting our website at **www.specialneedsproject.ca**.

Go to our home page and click on the icon of the newsletter in the top right hand corner.

Share Your Story new
For CUPW and UPCE Members.





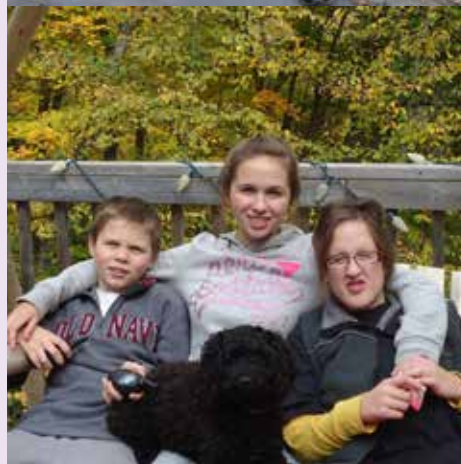
"We have to give our kids lots of love and expect from them as much as we can."

My oldest daughter is 19 years old.

She has chromosome 7q disorder. She is small and walks funny. Her spine is curved and her learning is very delayed. She still only thinks like a 3-4 year old. As a mom, you always ask your self, "Why did this happen to me, why me?" You're looking for an answer and you would do whatever it takes to help your child. You would give up everything for them to be a typical and healthy child. It is very hard for a parent to have a child with special needs. With all of my experience being in and out of the hospital for the first four years of Nicole's life I can say that most marriages break because of the complications of having a special needs child. It is very hard every single day but at the same time we should be happy for it could always be worse. This is why we should always enjoy the time with our kids and make them the happiest they can be. We also have to give them lots of love and expect from them as much as we can. For me, the best medication for not becoming depressed, miserable and thinking I am not a "full mom" is my two other healthy children. I want to thank the Special Needs/Moving On Projects for helping us parents and helping our kids live an easier and happier life. Nicole uses the money you give us for her speech tutoring, horses and swimming that she loves dearly.

PTPO4

Kitchener, ON



My son Levi has benefited from the Special Needs Project for some time now. Without this excellent program he would not be where he is today. This project gives Levi opportunities I normally wouldn't be able to afford. Levi has learned life skills, social skills, and how to be independent. With respite support I get the time I need as well as time I can spend with my daughter. This extra quality time improves all of our lives. Levi enjoys skate boarding and the Air Cadet's program. He even enjoys school! He is an excellent and very responsible dog and cat owner and has recently worked hard at getting his learner's license. Look out everyone on the sidewalks! Haha, just kidding! He's a very good driver. Living and learning every day. Thanks.

Letter Carrier

"My students are able to move forward with their lives and find their own place."

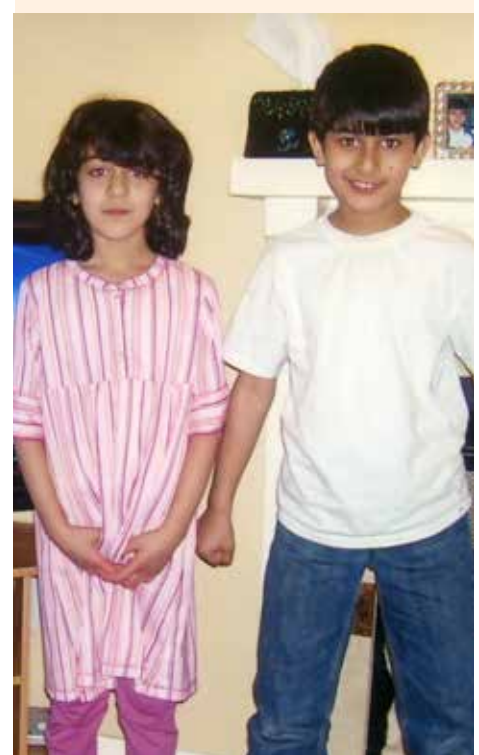


Hello, my name is Nadia Julien.

I live in the Gentilly area of Bécancour, in the countryside, surrounded by fields and forests. For the past three years, I have been an advisor for the Moving On project. Since I was working for more than 11 years with differently-abled adults, I was very familiar with some of the challenges they and their families experience. I first worked in a community organization that provided social integration and recreational services for the differently-abled. For the past five years now, I have been teaching adults with permanent or persistent learning disabilities on a full-time basis. This work fascinates me because even though my students are different, they are able to move forward with their lives and find their own place. The aim of our school program is to allow students to integrate into society by becoming as independent as possible, which helps improve their self-esteem and self-confidence.

Personally, my work as an advisor for Moving On allows me to learn more about what families have to do when their child transition into adulthood. I also believe that listening to parents provides them with support and I hope that I can make a small difference in their lives. To all the children of our members, I say keep moving, going to school, making friends and having fun, and you'll continue to grow!

Nadia Julien
Moving On Advisor



The Special Needs

Project is helping us meet the needs of my two children. Both kids are attending Kumon to get help with their reading and math skills. Kumon charges \$220 per child per month. I would not have been able to send my kids to Kumon without the financial help. Both my son and my daughter are now doing well at school. Thanks to the Special Needs Project for the support.

PO-4
Surrey, BC





"I have always had to think about what was best for Samantha when making choices in my life."

Don't get me wrong I love my daughter with all my heart and would do, and have done, everything and anything to make her life better. It has been a real challenge at times to provide everything that she needs to improve her quality of life. There have been numerous extra expenses and fights with various agencies, schools boards and government for funding. I have always had to think about what was best for Samantha when making choices in my life. I became a letter carrier because as a single mother I was not able to get quality, affordable reliable child care while I worked the afternoon shift. At that time you needed 25 years seniority to get day shift. My only option was to become a letter carrier, a job I never really wanted but it worked for us at the time. I was lucky to meet a wonderful man with a big heart and was able to deal with all of Samantha's disabilities and health issues.

We have a very good family life however at 23 years old Samantha is still at home. She functions at about the level of a 3 year old. She requires help with almost every daily life skill from using the toilet to getting dressed. She is non-verbal, only 4 feet tall and about 60 pounds. I feel that she is the perfect victim as she is unable to speak, unable to accuse or be a reliable witness should someone hurt her. Our greatest fear is that Samantha will be a victim of assault at the hands of someone that we have entrusted with her care.

This leads to a whole host of problems. I would like to have the life that a normal mother of a healthy 23 year old young lady would expect. My husband and I want to travel before we are too old or too sick. Our long-term plan has been to find a group home for Samantha by the time she turns 25.

When Samantha was 18 we did have an opportunity to place her in a group home that met our criteria. We wanted a home that was all female residents and all female staff. We wanted an agency and staff that would show our daughter respect and dignity. We wanted her to live in a safe community with safe parks. Most importantly we wanted to be comfortable in knowing that we had found a safe place for her to live where she would be cared for in the same manner that we cared for her. We wanted her to be safe.

The day we moved her to the group home was the hardest day that I have had as a mother. It was a very



short drive there and a very long lonely drive back. Many tears were shed on my route homealone.

To make a long story short Samantha lived at the group home for almost a year but there where many changes with the agency. The level of care suffered, as did Samantha, so we moved her back home where she continues to live. We are now members of the C.A.R.E. Housing Society in Edmonton (Creating Accessible Residential Environments). We have met other families that already have or are waiting for homes for their children. We work with these families to raise funds to buy, renovate or build homes for our children.

We feel comfortable that we have found a home for Samantha to share with three other young ladies. We are hopeful that our goal of "freedom 25" is still possible. We will still have Samantha stay in our home over weekends and holidays as she is a wonderful, loving young lady with a great sense of humor and we enjoy her company. We wonder what Samantha would be like and what she would be doing with her life had she been able. Maybe we would still be hoping for "freedom 25" but had she been born healthy she would have had the ability to make these choices for herself.

**Letter Carrier
Edmonton, AB**

"The reality is we had to purchase almost all therapies we provided to our son."



This year my son Sergio will be 21 years old and in his last year of secondary school. During the last two years we had meetings with government agencies to understand how he could qualify for Passport funding. We also applied and registered for the DSO (Developmental Services Ontario). We had two lengthy one-on-one meetings with them after which we thought he would qualify to receive the community participation section of the passport funds. This would have been over and above the respite portion he already received. We were planning to use these funds for much needed job coaching that would greatly improve his prospects for an independent life. Much to our disbelief the lady from DSO told us that there was no money available for Sergio. As frustrating as this was it was consistent with many other instances when we required help and couldn't get it, including speech and other therapies he couldn't access because they said he was about to enter the school system and he would receive everything there. The reality is we had to purchase almost all therapies we provided to our son. It is obvious any help he currently needs will have to come from the same personal source if we want to increase my son's odds for a more independent life. All those hours of meetings ended up being nothing more than empty promises creating false expectations.

Letter Carrier
Maple, ON



I came to Canada 10 years ago for a better and brighter future for my family. During these years, subsequent to our hard work, our dreams began to come true. My husband and I got jobs to support our two sons and all my family believed that the success really offset the effort.

Moreover, I was very happy since my eldest son was enrolled in the Building Renovation Technology program in George Brown College and my youngest son was in Business Management in York University

Our life changed completely two years ago, when my eldest son, Luis Felipe, who was in his 3rd year of studies, started to have physical difficulties which eventually led to him having to leave school.

He saw many doctors and specialists but for a long time none of them was able to provide the right diagnosis. Finally, on April 13th, 2012 a neurologist diagnosed my son with significant Primary Progressive Multiple Sclerosis. We were devastated but found the courage in our despair to give our son the family support he needed.

For my family that diagnosis was the worst thing that had ever happened to us. It was not easy to watch my son's sadness, worries, and fear. His future was now unpredictable and his plans almost destroyed. He is a strong young man and we are walking hand-in-hand with hopefulness that everything can change to allow him to reach his dreams.

We know that he is going to have good and bad days for the rest of his life, but we will be always ready to support and give him our love as a family. We love Luis Felipe very much.

Letter Carrier
Richmond Hill, ON



Season's Greetings from your friends at the Special Needs and Moving On projects

Special Needs and Moving On Advisors:

Agnieszka G.
Angelia B.
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Cary MacDonald

CUPW:

Cindi Foreman
Jamie Kass
Doris Tremblay

UPCE-PSAC:

Yvan Bélanger



Here's wishing this
season brings you
happy memories to
cherish always.



Member-to-Member Connection is
the newsletter of the Special Needs and
Moving On projects. It is produced by
the Canadian Union of Postal Workers
and the Union of Postal Communications
Employees—Public Service Alliance of
Canada.

Phone: **1.800.840.5465**

Fax: **1.902.295.2296**

E-mail: **info@specialneedsproject.ca**

Web site: **www.specialneedsproject.ca**

Please send letters by e-mail or to:
P.O. Box 237, Baddeck, NS B0E 1B0

The CUPW/UPCE-PSAC Child
Care Fund is administered by the
Canadian Union of Postal Workers
and financed by Canada Post Corporation



Thank you to the children at First Avenue School
Aged Program at the Glebe Parents Daycare
Centre in Ottawa for the drawings.