



# member to member connection

Breaking through barriers for workers who have children with special needs

Nº 29 Winter 2014

*A long time ago* I was a mother of 3 young boys. The two youngest were diagnosed with ADHD and Bi Polar type II. I live in a beautiful town called Smithers, BC, a small but tight community with growing families and population. There has been, and still is, a frustrating problem for families with special needs children to find resources, support and help up here in the North. I was a single mother working for Canada Post. It was a huge challenge to make sure my boys were up and ready for school on time as I started work at 6:30 am. Sometimes I had to drive back and forth and at times I couldn't leave my job at all and had to rely on my family or friends to help get the boys off to school. As teenagers they became more and more violent with each other and didn't listen. I felt myself slipping out of control. With no rest, nerves shot and my hair falling out, I pleaded with the Ministry of Children to help me find respite or some aid and support in this volatile situation. Time after time they shut their doors to me. I was losing my grip. It was at this time I knew I was having a break down. There was no help or support for me. It wasn't until I was at a CUPW meeting that I was told about the "Special Needs Project". "Could this be true, is this real?" I asked. I was SOON contacted by my new Special Needs Project advisor named "Sheila". To say this lady is an Angel is NOT over exaggerating. She pulled me out of my crisis with her gentle and most understanding nature and threw a blanket of hope around me. I felt the load lighten. She helped me find respite and saved my family from combusting.

My sons are now adults and I wanted to write a letter to tell my story. This Program is so IMPORTANT. I am weeping writing this. The dire need for programs like this is vital to Canadian families. Sheila, it is because of you my sons are solid, because you helped make me solid.



Thank you for all you have done for me and many others like me. Sheila, to my family, you were a light in our storm....and you and this program MAKE A DIFFERENCE! All my love and admiration.

**RSMC**  
Smithers, BC



“Life’s journey is challenging.”



John’s children: Toyin, Ganiu, Kareem and Lanre. Seated - Abbey

**Ten years ago** John Adeshigbin wrote a letter for the December 2004 newsletter. We checked in with John to see what life looks like now.

“Life’s journey is challenging for challenging for John Adeshigbin’s sons Abbey, Lanre and Kareem. All have sickle cell anemia. There are many symptoms of sickle cell anemia, and John’s sons have experienced most of them. But John, and his wife Jumoke, have an extraordinary ability to provide for their sons’ health needs. John explains the sickle cell crisis as a “truck rolling you down.” He says that the level of pain is unimaginable – and it’s something that you cannot ignore. His sons are put on morphine and hospitalized when they have such a crisis.

Abbey, age 29, is a positive and well-spoken person. He had a stroke at age 5 as a result of sickle cell anemia, and is blind and in a wheelchair. Abbey experiences many symptoms of sickle cell anemia, including sickle cell crises. He had a hip replacement 5 years ago. His wounds don’t heal and he is in and out of clinics every week. Abbey receives support from the Ontario Disability Support Program, which pays for everyday needs and a support person for outings.

Abbey completed a special program at Humber College for people with disabilities. While employment agencies have tried to find Abbey a work placement, it hasn’t happened yet due to his physical disabilities. John continues to hope for employment for Abbey.

Lanre, age 24, is studying at York University. He wants to be an English teacher. While Lanre is in his final year of studies, he may need additional time if he has any interruptions from sickle cell symptoms. He had a hip replacement last year and has many pain crises. He is waiting to have his other hip replaced.

Since his oldest son’s diagnosis, John feels that there has been much improvement in what is happening for children with sickle cell anemia in Canada. The medical profession has learned much about the condition, its symptoms and treatments.

So what about Kareem, at age 13 the youngest of the Adeshigbin boys? Kareem has a blood transfusion every month. He doesn’t have health crises as severe as his brothers. In fact his symptoms are quite minor – stomachache or headache. Kareem has been hospitalized, though, for a major sickle cell headache (worse than a migraine). Kareem is in middle school now and will go to high school next year. John feels that Kareem will be very successful. Kareem likes mathematics and sciences – and hopes to be a doctor.

And what about John? Well, it is getting close to the time for him to retire! Jumoke is planning to go back to work after she completes her schooling in geriatrics. John is looking forward to the next stage of his life – along with his wonderful family!”

"Our children are stronger than we think."



*Simon on skateboard  
"The sky is the limit! We should always remember  
that our children are stronger than we think."*

*Simon and Caroline (Mom and son)  
"The best is yet to come!"*

**We hope you meet good people this year to help  
your precious children make progress.**

**Relief Letter Carrier**  
Anjou, QC





"Have a great winter and happy holidays!"



Left to right: Wayne, Hannah, McKenzie, Sandra. Jacob is in the front.

*This picture* was taken in 2007. Hard to believe it was over 7 years ago.

"Jesus Is The Reason For The Season!"

**Wishing everyone a very Merry Christmas and a Happy New Year.**

**RSMC**  
Halifax, NS

*My daughter Cara* has benefitted greatly from the Special Needs Project. It has enabled me to purchase specialized activities and tutoring to help her overcome obstacles as she approaches adulthood. I am very grateful to both the project and CUPW for the good that comes from this amazing initiative.

**Letter Carrier**  
Sarnia, ON



Karen

*Thank you* to the Special Needs Program.

**Have a great winter and happy holidays!**

**Letter Carrier**  
Quebec, QC



Karen and Johanne



**Ten years** ago Susan Clough wrote this letter to the Member-to-Member Connection.

*“On March 11, 2004, a superior court judgment came down for my son, Jared, concerning individualized funding. The 3-judge court found that the government had been both unfair and unreasonable in their funding response to the needs of my son. They were ordered to go back to 2001 and review and reassess Jared’s individualized funding agreements based on the court decision and develop and implement a procedure, with appeal process, for this type of funding. It is my hope that this decision will have far reaching positive effects for all families with special needs kids/adults.”*

We called Susan to ask how life looks ten years later. Here is what she told us.

If there is a word that captures Susan Clough’s parenting over the last 15 years, you could say it is “inspire.” Susan has worked tirelessly to make sure that her son, Jared, is treated with the dignity and respect he deserves, and she stands as an inspiration to others.

Jared is Susan’s wonderful and sweet 21 year old son. He has a dual diagnosis of autism/bipolar disorder with significant developmental delays. Jared faces many challenges in his life, but he is not alone. Susan is by his side and says that Jared teaches her much.

Susan filed three separate Ontario Human Rights complaints on behalf of her son. The most recent, the “Blocker Shield” issue, addressed how and why Simcoe County District School Board (SCDSB) uses equipment (such as foam shields) in working with individuals with autism. As a member of the SCDSB’s Special Education Advisory Committee, Susan advocated against the use of these blockers and the harm and negative student image they create.

The cumulative effect of these complaints has been a change in how programs, services and supports are delivered to individuals with autism. The SCDSB has a new program for transitional aged youth (aged 18 to



Jared

21) that meets their individualized needs with community integration and skill building essential for moving to the adult world.

With a Superior Court of Ontario judgment, Susan was able to achieve more comprehensive individualized funding for Jared. But this government decision focused on children with complex needs only. Susan now purchases the services and programs to support

Jared, but the process is still parent-driven and her responsibility. While Jared has benefited from this significant achievement in service improvement, Susan wishes that this kind of funding could be available to more individuals with autism and other needs.

How is Jared doing now as a young adult? While Susan envisions Jared in a sustainable home setting with the supports and services he needs, she fears that this may not be attainable in the current system.

Right now adult services are sorely lacking in Ontario. Jared is on every waiting list. But because of his high needs, even when he gets to the top of the list he cannot access the programs or services because they don’t provide the level of support he needs.

Susan is tired from the many years of fighting for her son’s rights. She knows how difficult it is for parents to advocate for what their children are entitled to. But she also knows that only through strong advocacy can effective change be made.

So despite her fatigue, Susan has inspiring and stirring words for other parents. She urges parents to realize that there is little available in adult services. Planning for our children should start early. Parents need to think long term. And although advocacy is exhaustive work, parents are the best way to ensure that their children receive what they deserve, with dignity and respect.



" Best wishes for 2015."



Jacob (10) and Hannah (8).

**Merry Christmas from my family to yours. Best wishes for 2015.**

**UPCE-PSAC  
Senior Resolution Specialist  
Hanwell, NB**



**Season's Greetings from Mattias.**

**PCarrier  
Fort Frances, ON**



Nathan, Erin, and Cohen covered in Christmas wrap on Christmas morning, 2013.

**RSMC  
Port Hawkesbury, NS**





## Advisor understands the challenges

Lisa Villani is an amazing woman whose personal life experience enables her to identify and empathize with the families she supports as an Advisor in the Special Needs Project.

For Lisa herself has a health diagnosis from her early years. She remembers how her mother reacted to Lisa's diagnosis. Because of those memories and impressions, she relates with incredible respect and understanding for parents whose children have special needs.

Lisa has been an Advisor with the Special Needs Project for over three years. Previously she worked for many years as a social worker in youth protection and teen/youth centres at the Local Community Service Centre (CLSC) in Montreal.

Now Lisa works part time at the Marie-Enfant Rehabilitation Centre in Montreal, part of the St. Justine Children's Hospital. Lisa's job includes reception, evaluation and orientation of requests for services.

While Lisa enjoys her work at the Marie-Enfant Centre, she is thrilled at the opportunity she has to talk with parents through her Advisor role in the Special Needs Project. And Lisa is a remarkable person to speak with – she is trilingual, speaking Italian, French and English! While the majority of the families she supports in the Special Needs Project are French speakers, there are a few bilingual French/English parents as well.

One of the highlights of Lisa's work in the Special Needs Project was the day she met one of the parents at her job at the Marie-Enfant Rehabilitation Centre. This parent was the first parent Lisa had ever contacted through the Special Needs Project! Lisa was getting to know this parent and had been able to provide her with some resources. Lisa said that this face-to-face meeting was 'enormous' for her – she just loved having the chance to meet the parent she had come to know over the phone!

Through her work at Marie-Enfant and the Special Needs Project, Lisa gets to see a lot of families and children who have extra needs. She feels that people who work with children with special needs are able to put the children first as they collaborate to support families.

Lisa has a busy life – she is caregiver for her father and, along with her partner Patrick, rescues dogs. Her current canine companion is 'Sugarcrisp,' a most beautiful and generous 7 year old Golden Labrador Retriever.

What has Lisa learned from her role as an Advisor? Lisa sees so much growth in the families; she



sees how parents change over time from when they first learn of their child's diagnosis, becoming strong and resourceful as they develop a sense of a new 'normal' with their child.

Lisa has an overwhelming respect for the families in the Special Needs Project, who continue to teach her so much about people. Lisa says that these parents “give me strength, and they don't even realize it!”





"He is making good progress, at his own pace."



*It is almost 5 years* since Arvin was diagnosed with autism. We celebrated his 9th birthday July 2014. During the last 5 years there was not a single day that passed without challenges. I wish we had him checked much earlier but it was only at age 4, when he started junior kindergarden, that the school psychologist told us about his disabilities. When he was diagnosed my wife and I tried our best to connect him with kids his own age. Thanks to the Special Needs project for supporting Arvin to continue his school and sports activities. He loves ball hockey and summer camps. Thank you.

**PO-4**

Kanata, ON

*Alexis is* a 10-year old boy who still does not speak. He goes to Horizons-Soleil school in Saint Jérôme. He is making good progress, at his own pace. To communicate, he uses pictograms, but he also understands a few common phrases. His preferred activity is swimming. He swims like a dolphin and can spend hours in the pool without getting out. He also likes to play on the swings, take walks, mostly to look at trees, and go for motorcycle or car rides.

Thank you very much for your support.

**Letter Carrier**

Ste-Therese, QC



*I hope everyone* who is in need gets the opportunity to know your program. There are no words to express how much my spouse and I appreciate it.

**Season's Greetings and Happy New Year!**

**RSMC**

Lac Baker, NB

You can now submit your stories and photos to the Member-to-Member Connection newsletter by visiting our website at [www.specialneedsproject.ca](http://www.specialneedsproject.ca).

Share Your Story new  
For CUPW and UPCE Members.



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

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Don't forget you can set up an RDSP if you qualify.



## *What should parents be aware of when filing their taxes, especially when they have children with a disability?*

### **What's New?**

1. Family Tax Cut found in (ITA S. 119.1) is a new credit to the higher income spouse, similar to the dependent credit (ITA S. 118(1)). This is a new credit that is computed if your spouse has a lower or no income. The maximum refund is \$2,000. Refer to TD1 federal for other credits. Family Tax Cut will not be listed. It's not possible to claim this new credit on a TD1 during the year (ITA S.153(1.3)(b)).
2. The UCCB increase (Universal Child Care Benefit) is accumulated Jan-June 2015. \$420 per child will be paid in July.

**Calculate tax returns** for the entire family as a group. Age is not a factor when a child is infirm, or disabled. Consider all relatives who are dependant - siblings, nieces, nephews, parents, grandparents, great aunts... There are other credits and expenses that can be split or claimed as an expense or a credit (whichever is more beneficial).

**Transitioning** from youth to adult results in many tax changes; and requires assessment of competence to sign tax returns and to negotiate and sign contracts including the Registered Disability Savings Plan.

**Child care expenses** do not have to be incurred for each child. If a family has multiple children, add dollar limits (see Form T778) for child care together. If the taxpayer spends everything on one child, claim the combined maximum for that family.

Example, limits can be added together and for 2014 are \$7,000 for a 3 year old, \$4,000 for a 12 year old, and \$10,000 for an adult child with a disability. Remember, there is a claw back of the supplementary child disability amount for the child with the disability. The rules are not congruent. Consult a tax preparer who understands these rules.

If the spouse with lower or no income is 'infirm', a spouse with higher income may claim child care, family caregiver 'infirm' amount; and the Family Tax Cut.

Students can transfer some unused credits for tuition, education and textbooks to parents or grandparents, remainder carried forward by the student. There are extra credits, and loans and grants for children with a disability or infirmity.

The information and materials in this article are provided for general information purposes only and are not intended to constitute legal, accounting or tax advice or opinions on any specific matters. Laws and regulations change frequently, and their application can vary widely based upon facts and circumstances involved. You are responsible for the applicability and accuracy of information as it relates to your specific situation.

Eileen Reppenhagen, CPA, CGA, TaxDetective®, Certified QuickBooks ProAdvisor writes about tax, and keeping records for tax. <http://www.taxdetective.ca>



### **Checklist**

1. Review disability and infirmity definitions for eligibility criteria.
2. Make sure the completed form or letter (infirmity) from the qualified medical practitioner says what you think it should say before submission to CRA for approval.
3. After approval by CRA, request retroactive credits and review medical, attendant care, disability supports and child care for potential additional claims triggered by qualifying for these credits.
4. Amend to correct prior filing and depending on the outcome for each year, for each person involved, consider the Taxpayer Relief | Form RC4288 which allows you to go back ten years if there are refunds.
5. The Voluntary Disclosures program | Form RC199 provides relief from penalties if you owe tax for prior years.
6. Don't forget to set up a Registered Disability Savings Plan (RDSP) if you qualify.
7. Investigate other federal and provincial programs that depend on qualification for disability or infirmity.

*Please go to [specialneedsproject.ca](http://specialneedsproject.ca) to read this document and click on the live links.*



"I am proud of him when he keeps on trying."



**My son and daughter** have been in the Special Needs Project with great success. We truly thank you and Sharel, our advisor, for all your help. My son has dyslexia and is reading at a grade 2-3 level but is in grade 5. He finds it very difficult to see each word and remember them. We go over and over the basic words with great effort on his part with some success. One minute he knows them, the next time he doesn't. He would like to read like his friends do and sometimes this is very frustrating for him. I see him trying very hard and I am proud of him when he keeps on trying. With your assistance, he is getting help with extra tutoring and special courses through the Scottish Rite Foundation. This is a picture of him with the award he won at a learning disabilities training day put on by the school board. He is learning to use technology to help him with his daily work so he can keep up with his classmates. He is excellent with math and science and is very artistic. Reading is coming along slowly but with your help, and the help of the school, he will be making great progress. Thank you.

**MSC**  
London, ON



**Elizabeth** just turned 27 (May 29) and I look back and think of all the opportunities that she has had. She has LCA (Leber's congenital amaurosis), is blind and developmentally delayed. She horse back rides, swims, bowls, cooks, crafts and socializes. And no, our Moving On project doesn't cover all of these activities financially but I know that it supports us and enables us to seek out these activities. I love the support that we have received over the years from our advisors and our interviews and the topics that we discuss. I am so grateful to CUPW for the Special Needs fund and then the Moving On Project. Yes CPC funds it but it's my union that makes it work – with our great advisors and the staff at Family Place. No the project doesn't fix everything but I know we are not forgotten or alone. Thanks to everyone from Elizabeth and me.

**PO-4**  
Coburg, ON



*After 7 years* of trying to conceive our miracle we were elated that we made it through the nine months of waiting and all checkups were routine. After hours of labour and a last minute C-Section our daughter Marinella was born. There were no words spoken upon seeing our daughter. We felt only fear, confusion and hopelessness. The doctors could not tell us what she had but Sick Children’s Hospital was alerted and pediatric specialists were on their way. Though the only thing we saw was our little baby with large brown spots covering her face and body, we were in love. We felt that she could see right through us with her beautiful eyes. It’s as though she was telling us “Hold on mama and papa. I am here and it’s all going to be okay.” The hours immediately after her birth were the worst. We didn’t have any information about what it was, how she got it or if it would affect her life. Marinella endured hours of probing before finally being diagnosed. Eventually it was confirmed that our daughter had Large Congenital Melanocytic Nevus (LCMN), a rare skin condition that affects 1 in every 500,000 births. It was a hard pill to swallow because there was no cure.

LCMN is a type of birth mark or mole that covers more than 2% of the total body, is pigment based, and is present at birth. The area covered by a melanocytic nevus often produces hair and has no sweat glands or subcutaneous fat.



Some will also have other neural tumors within the border. Although a large nevus doesn’t generally cause pain, some aspects of the affected skin can be uncomfortable. Nevus skin can itch and since there is often a lack of fatty tissue it may be more affected by continuous pressure. It can also be more fragile and prone to tearing. LCMN is not only an appearance challenge. A number of people born with a Large Nevus develop malignant melanoma & neurocutaneous melanocytosis (NCM). Malignant melanoma is a form of skin cancer and NCM is when the nevus cells are in the central nervous system (brain or spinal cord). NCM can cause seizures, hydrocephalus, developmental issues, unconsciousness, vomiting, and certain reflex and eyesight issues. During the first hours of Marinella’s life she had a brain and spinal ultrasound that revealed she had NCM on her right temporal lobe. This meant she would have to be consistently monitored by

a neurologist, neuro-oncologist, dermatologist and optometrist. She has had 4 surgeries but is asymptomatic of any behaviour or cognitive difficulties.

Marinella was 3 in October 2014 and is an amazing child wise beyond her years. She is a smart, funny, beautiful, happy little girl. The first year of her life was more challenging for us than for her. My wife and I spent our time indoors for fear of stares, glares and questions. We joined a support group and have found a network of friends who share the same journey. It has taken us almost 3 years to share our story. We have gained an enormous amount of knowledge about CMN. We realized that we have to advocate for our daughter and provide her with opportunities to face and confront ignorance, yet be empowered to live a long and happy life in her own skin. We have faith that our story will open people’s minds so that they understand that it’s okay to be different. After all, beauty is only skin deep! We are so grateful to the CUPW Special Needs Project for all the support we have received in times of need. Thank you for listening to our stories and for having a shoulder to cry on when we first came on board.

**Letter Carrier**  
Scarborough, 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.  
 Anne G.  
 Arlie R.  
 Bernadette M.  
 Charmaine M.  
 Cherie G.  
 Daniela B.  
 Donald G.  
 Donna M.  
 Dorothy H.  
 Ellen B.  
 Enna M.  
 Janet M.  
 Janice S.  
 Jessica C.  
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 Marie-Hélène M.  
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 Nadia J.  
 Nancy B.  
 Normand R.  
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Rhonda A.  
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 Sharel S.  
 Sheila S.  
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 Susan B.  
 Suzanne C.  
 Tatiana K.  
 Theresa A.  
 Vicki S.

## Family Place:

JoAnna LaTulippe-Rochon  
 Gail Holdner  
 Dorothy Keigan  
 Cary MacDonald  
 Doris Tremblay

## CUPW:

Cindi Foreman  
 Jamie Kass

## UPCE-PSAC:

François Paradis



*Cary MacDonald, Gail Holdner, Dorothy Keigan*



*Doris Tremblay*

May peace, joy and prosperity  
fill your home now  
and throughout the new year!

**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.

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