

Member-to-Member CONNECTION



SPECIAL EDITION • DECEMBER 2003

Sister and Brothers, Welcome to this very special edition of your Member-to-Member Connection newsletter. This edition consists solely of letters that we have received from members over the past year.

It is great to hear from you! Your letters help us to better understand your issues and needs as we work to support CUPW and UPCE-PSAC families. We are pleased to be able to share your words, your stories, and your experiences with others from across the country. Experiences of one family benefit so many other families when they are shared.

We would also like to wish you and your family much joy and peace as you enter into the holiday season. May this peace follow you as we close out one year and prepare to enter a new one.

In solidarity,

JoAnna LaTulippe-Rochon

Denis Lemelin

Luc Guèvremont



I would like to take this opportunity to “thank” everyone who put the time and effort into publishing *Moving Mountains*. I thoroughly enjoyed it, and I did shed a lot of tears. It was great. Thanks again.

An Offer

Hi, I read your interesting article in the TO Star about your special needs program. I have worked for 25 years with York South Community Living but recently cut back my hours to a few a month. I have a semi-retired horse that has been used for riding lessons in the past for one of my mentally challenged friends. His present job is letting my four year-old grand-daughter have riding experience. He is boarded in Ballantrae, just North of Toronto at a very nice stable with both an indoor and outdoor arena. If insurance matters could be arranged, I would be willing to lease him at a very reasonable cost to anyone in our area who would like to take advantage of riding opportunities with a very quiet, people friendly horse. I could easily teach a caregiver or parent how to put on his saddle and bridle. He is not very big–15hh to anyone who knows how horses are measured and is quiet and gentle. I have had him for 19 years and am now 64 but still riding him.

Anyone interested may call Jennifer at 905-294-6021.

My son Calvin—soon to be 9 years old, has Cri-Du-Chat syndrome. I am very proud of his progress—I just found out he is at a grade 1 reading level!! Considering he would not read at all!! We do still have a few behavior issues but mainly at school at times. He has been “really” talking a lot more lately—sentences. I have been waiting 8 years for this. He can now tell me what he did each day himself. All these little things which most people take for granted are such very precious and exciting things for us as parents (of children) with special needs to see. It keeps us going.

Thank you to the Special Needs Project. I am so very proud to be working for the post office. Keep up the good work, and I would love to hear from any other families. Here is a picture of Calvin this year.

Letter Carrier
Fort St. John, BC

Hi, my name is Maria-José

Bouey and I'm very happy to be part of the Special Needs Project. I read the booklet, *Moving Mountains* and I was very impressed with the quality and the amount of people there were. I'd like to thank CUPW for the special project, which helps my family as well as many others. I'm a kidney transplant patient with a colostomy. Contact me at bouey12@hotmail.com.

Miscellaneous Relief
Toronto, ON

Jennifer has just turned seven years old. We were down at Sick Children's Hospital in Toronto yesterday. It has been three years since her last genetic update. Unfortunately there is no new information re: Jennifer's partial diagnosis of Trisomy 12 p. It was a very emotionally draining day. We are thankful for her and are very pleased with her accomplishments even though they are slow. She's rolling into her seventh year and we know, we are so very lucky. It has been a struggle for my family, it's never ending. What does make it easier on us, though, is the help that we do receive from the Special Needs Project. Don't ever think that you do not make a difference—you really, really do. Thank you. Sincerely and ever grateful,

Letter Carrier
Orangeville, ON



Over the years as Jonathan has grown we have had to modify much of our summer time. Camp for him has been a wonderful experience and a successful family respite time for us. But now we are finding it harder to find camps that will accommodate Jonathan due to his age and needs. I believe many of us maybe in the same position and would like to know if the Special Needs Project could possibly co-ordinate a listing of handicapped camps. This doesn't mean we endorse them but make available some contact references we could all use. What prompted this is a brochure (included) to a camp for the handicapped. It is run by a man who himself is handicapped and has a great deal of care for the children. There must be many more out there if we pool our resources.

Editors Note: Good idea. We are now in the process of creating a resource list of members' suggestions of programs and resources.

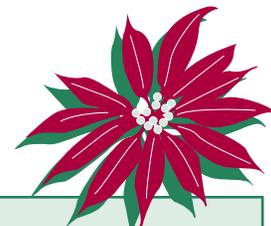
Letter Carrier Assistant—PO 2 Internal
Stoney Creek, ON

My husband and I have a fourteen year old and a twelve year old. Our 12 year old is the child that Special Needs Project helps us with. Bruce is Attention Deficit Hyperactive Disorder with aggression. We have our hands full finding something for Bruce to do, to keep him organized, as well as out of trouble. It is forever a challenge to try to keep his time occupied in a constructive way and in ways that will show him the right path in life (on the right side of the law) for his life. If there are any parents out there that would like to share ideas of constructive entertainment for their child and ways of dealing with various stresses in life, please e-mail me. Due to different time zones etc. e-mail would be the best way to get in touch.

Postal Clerk
Garson, ON

Thank you to the Special Needs Project for the generous amount for my son who has a learning disability. This money helps him to get that little extra help and programs that have made a difference.

Letter Carrier
Toronto, ON



I received a small booklet on people you've helped, and I could read about another family that is dealing with diabetes. I would like to read about more families and relate. I also may be going on strike soon, and I can't tell you how important your help will be to me and my son. Thanks.

Mail Clerk
Toronto, ON



This past summer has been a very special one for our family. Because of the CUPW Special Needs Project, we could finally reach a goal we have had for many years. Most families think that for their child being “one of the group” is normal, but for our son, Brian, it was something that might never be, until this summer.

With the help of a great organization called “Reach for The Rainbow” in Toronto, and the financial aide of the Special Needs Project, our son was able to go to a special needs camp run by the YMCA in Georgian Bay for 13 days. What a joy to see pictures on the Internet of our son “one of the gang”. For him it was a time of complete happiness. For us, a whole 13 days of peace, reconnection, and relaxation. Something we have not had in 13 years. Brian learned he could be “one of the group”; there are places out there for him. Thank you CUPW Special Needs Project, so much.

Cochrane, ON

When you are a child with special needs, summer can be a lonely and isolating time. While other children can take for granted the freedom of going out to play with friends in the neighborhood, for kids with physical or emotional handicaps, its never that simple. It is heart breaking for parents who face the challenge of keeping their child happy and stimulated through out the summer. We were lucky. My 11-year-old son, Collin is a dwarf. He has weak fine motor skills and limited physical abilities. He was able to participate in “normal” activities like bike riding, cooking, baseball, science and even sailing programs available in our area for children with special needs. The CUPW Special Needs Project helped us provide these opportunities. Thank you all very much.

Full-time Postal Clerk
London, ON

Colin started Gr. 5 this fall with his individualized program and with the same resource teacher for the third year. It is wonderful to see him progress at his own rate with reading, writing, and independence with his own classroom routines such as going to the shelf and getting his headphones, cassette, and book to read. We’re strong on integration for Colin in sports with his peers and will start with Special Olympics this fall. I put Colin into soccer since Grade 1 and not all parents approved of him. So there was always a struggle to decide whether to continue with soccer or withdraw him but the final decision was always to keep him in. Colin loves going to a gym and swim program for disabled children at our recreation center and this fall the staff has decided to give individual coaching for sports such as soccer, softball, and swimming. This extra help for Colin is encouraging enough for us and hopefully it will be encouraging for Colin.

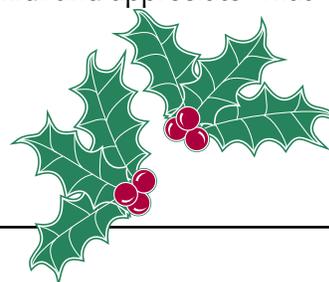
Colin would love a pen pal, especially someone interested in monkeys.

PO 4
Kelowna, BC

Great News!

Included you will find an award my 6 year old daughter, Ashley, came home with from Grade 1. It is for improvement in her motor skills. Why am I sharing this news with you? Because to me, it is a big deal. Yes!! Also, without your funding I could not afford to send her to much needed private occupational therapy. Since she has begun everyone has noticed huge strides. We are thankful and appreciate what you have done for us, especially for Ashley.

Ottawa, ON





Hello

everyone,
My name is Jean-Paul and I work as a MSC in Montreal. I'm the father of a boy, Shawn, who is now 10 years old. He was diagnosed as hyperactive when he was only four. Hyperactivity has this "wonderful" ability to make parents look like incompetents who don't know how to raise their children. My partner and I have tried everything to find some help, but in vain. Doors seemed to close before we could even open them. With time, what was simply hyperactivity quickly developed into excessive hyperactivity. Ritalin, the miraculous drug of the 21st century school system, apparently had no effect, or barely any, on my son. At the same time, he developed different behaviour disorders, including verbal and physical aggressiveness. He was then assigned to a self-contained class. Following several discussions with me and my partner, the school's principal was able to perceive our helplessness and told us that she may be able to find us some help through some of her connections.

My son was then admitted in the child psychiatry program at Ste Justine Hospital in Montreal. After many therapy sessions, he quickly became a sort of guinea pig because of the rarity of such cases of hyperactive children, with multiple behaviour disorders, who have no learning disability and who make a laughing stock out of the miraculous Ritalin. My son completed his second school year, not in school, but in the psychiatric ward of the Ste Justine Hospital so that doctors could study but especially help him.

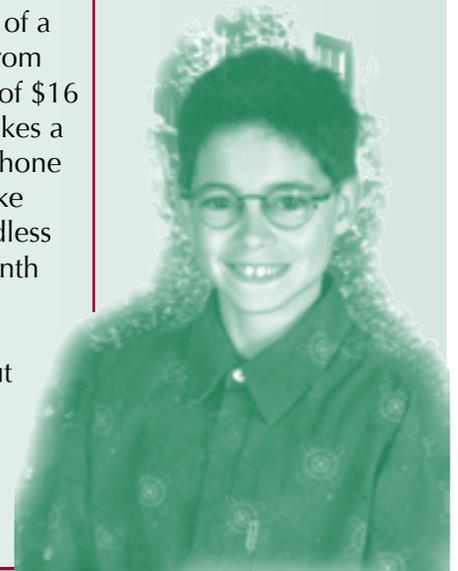
I take this opportunity to applaud the great and incomparable work accomplished by the whole medical team at Ste Justine Hospital. During the year that he spent there, my son made tremendous progress, and thanks to this marvellous medical team of child psychiatrists and special education teachers, he was able to go back to school the following year, provided he kept going to therapy two nights a week. This is when things started getting more complicated for me.

My personal life went by the wayside. To make things worst, my vehicle suddenly started having one mechanical problem after the other, and I finally had to get rid of it. After the separation, the purchase of a vehicle is definitively not something that I could have afforded. Considering the huge progress accomplished by my son, there was no question of him missing his therapy. Consequently, after my work day, I would take the bus in order to be at school at 3 pm to pick up my son, and we would then head for the hospital, which was at about twenty kilometres away, where we had to be for 4 pm. Accomplishing this feat became almost humanly impossible. So I contracted the services of a transportation company that could take my son from school to the hospital two days a week, at a cost of \$16 per trip. But, as everybody knows, your budget takes a dive after a separation. My heat, electricity and phone were about to be cut off, and I was unable to make the minimum payments on my credit cards. Needless to say that an additional expense of \$128 per month really did not come at the right moment.

During a union education session, I learned about the assistance program for children with special needs. I applied and was accepted. The program helped me cover a part of my son's transportation costs, which allowed him to continue his therapy.

Today, Shawn is in a regular class. He still suffers from excessive hyperactivity and still has some behavioural disorders. However, he manages a lot better thanks to the therapy services provided by Ste Justine Hospital and thanks also to the help I received from the assistance program for parents of children with special needs. At first sight it might look like financial help, but for me it was first and foremost moral support. I will never be able to thank you enough. Thank you, thank you, thank you...

Montreal, QC





Laurianne is autistic. Her favourite activities are swimming and bicycling. Since she isn't self-sufficient enough to "drive" a bicycle, we used an "extension" on an adult bicycle. When she got too big and heavy for that, we had to give up that activity. A friend suggested we buy a bicycle for two. I went to the store and when I saw the cost, I put this idea off until later. Fortunately, the Special Needs Project came to the rescue, by paying for half of the cost. We have had a very good summer. Thank you so much!

Longueuil, Quebec

On behalf of the Ley family, we would like to thank the CUPW Special Needs Project for your support over the past year. We would also like to share with our brothers and sisters that you should never lose hope. Shaylah recently went for her check - up with her orthopedic specialist, and we found out that she now only has one dislocated hip instead of the initial diagnosis of two dislocated hips. This miraculous news will open new doors for Shaylah and possibly a new plan of medical action. Shaylah will be seeing five orthopedic surgeons at the end of February to discuss possible surgery to relocate her other hip. My wife Wendi and myself, are extremely optimistic and we believe that Shaylah will one day be able to run with the best of them. Never lose hope brothers and sisters!

PO 4
Calgary, AB

I am a father of four children ages one to five (two diagnosed with Autism, one with severe developmental delays and one young baby of fourteen months). As one might expect, our lives are extremely hectic and extra costs for various things are more the norm. We are very grateful to the Special Needs Project and all that it has done to help us. My wife and I would love to hear from other families with multiple special needs children.

Letter Carrier
Calgary, AB

My daughter has struggled for a number of years in school because of her ADHD. She's going into grade 11. The money I am eligible for through the Special Needs Project has helped pay for a tutor to get her through each year in high school. She only failed one course this whole year because she was able to have a tutor for catching up and explaining her material. Thanks.

Miscellaneous (Call In)
London, ON



Please find enclosed a picture of Ryan Mogridge (age six years). It has come to light, through circumstances beyond his control, that he will be living with me for all time. Being classed as a "single parent", Ryan and I will tackle any obstacle positively and correctly. Even though young Ryan has special needs his friendliness & sensitive nature has placed him high in everyone's book. Without the support of the Special Needs Project, Extend A Family Project, Special Needs Workers and his EA program at school, we do not know where we would be, especially me. I would not know where to look for help and support. Keep up the good work.

PO 4
Hamilton, ON



Our daughter Victoria has a very rare condition called Aicardi Syndrome. There are very few kids in Canada with this condition and less than 500 diagnosed in the world. This syndrome varies quite drastically from one child to the next. Victoria has been very lucky in that her general health is very good. Her physical and mental abilities have not developed beyond that of a six-month-old baby. We waited four years for her to smile and now that she has mastered the cheeky grin she dazzles everyone she meets and flashes that grin at us any chance she gets. She is such a happy, content and loving child that we consider ourselves very lucky.

Victoria has one brother called Liam. He is a source of constant amusement to Victoria; there are times when only her brother can comfort her. She has him wrapped around her little finger! Liam is a very active 8-year-old boy so we manage to keep ourselves very busy between our two kids.

Thank you so much, CUPW Special Needs Project. With all the added stress and expenses involved in raising special kids it is wonderful to have some assistance. Now we have to hit the fund raising trail to raise a bit of cash for an elevator, lift system, wheel in shower, van and wheelchair lift and on and on it goes. All the best to all the other Special Need Project families from the Oram's.

Letter Carrier
Newmarket, ON



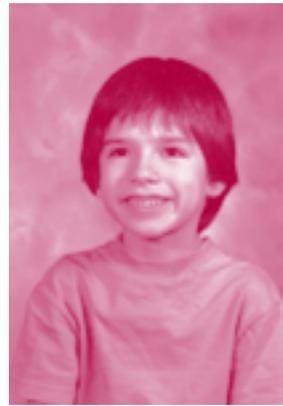
If anyone needs help with information on how to get help for their Autistic child (funding or Doctors) please call me at (905) 623-0550. (Only Durham, ON, residents)

Letter Carrier
Bowmanville, ON

This year we will be going with Myla-Kim to the Quebec Games. She will be taking part in the figure skating event in the Special Olympics category, which is for special needs children.

We are very proud of her. This proves that with perseverance, you can go far and everything is possible.

Ville-de-la-baie, QC

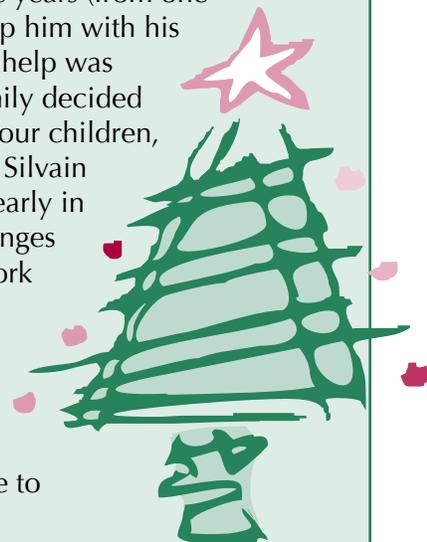


Gabriel has a severe cognitive disability (mental retardation) and severe autism. He was born on March 13, 1996. He has many behavioral problems, including self abuse and chronic night awakening. He uses some sign language and right now is using the special picture system to communicate for his every day needs at home. In closing I would like

to thank the CUPW Special Needs Project for the help and support that they provide. Thank you very much.

MSC Mail Service Courier
Toronto, ON

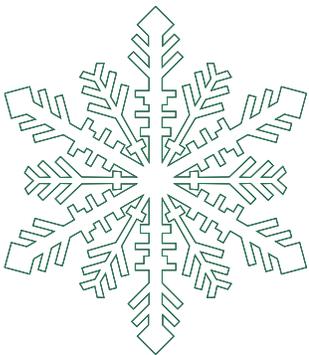
My husband Mike, is employed with Canada Post. Our son, Silvain, was diagnosed with ADHD at the age of six. He is now turning sixteen. He has had to face many challenges, one of which was a lack of help and support from the school system for his condition. I have withdrawn him from school for periods of time during those years (from one day up to two weeks) to help him with his schoolwork, since no other help was available. This year, our family decided to home school. (We have four children, three are school - aged and Silvain is the eldest). It is still very early in the school year, but the changes in his attitude and schoolwork are noticeable. If there are any other parents who face similar challenges and who are, or would like to, home school their child(ren) I would really like to hear from you.



Grenville, ON

My daughter has ADHD. Our world is full of frustrations, emotional outbursts, and disappointments. It is so frustrating to have to repeatedly instruct and explain to your child everything you want them to do, and the teachers don't have time and get frustrated too. We all get frustrated as work is forgotten, lost, or late and sometimes we all let her know our frustrations. This leads to emotional reactions and is not good for her self-esteem. She is so afraid to mess up, that she stays home most of the time and goes to school after the bell rings, so as not to interact. This is why I'm so thankful the Special Needs Project has been there for us. It has enabled us to enroll her in out of school activities to build self esteem and get her out there living life.

PO 4
London, ON



WANTED

Need Immediately - two car booster seats 75 lbs and over for disabled nine year old with low muscle tone. Also Windows 95 computer hard drive needed for his software programs. Also looking for reasonable priced recumbent tricycle and kick sled.

Letter Carrier
Bobcaygeon, ON



I encourage all citizens to get active with special needs issues. Especially since all government levels wish to cut budgets for our most valuable citizens. Involvement is easy as writing a letter to - MP, MPP, letter to editor, school boards.

You may wish to organize a day of Action on a budgetary or services cut. Please remember silence is acceptance and I for one do not accept the continuous barrage of cuts to the special needs citizens. Remember the Federal government did spend over \$1 billion dollars for a gun registry that failed.

PO 4 Clerk
Windsor, ON

My daughter, Davis Lundrigan was diagnosed with severe Spastic Quadrapelegic Cerebral Palsy. She is now mild Spastic Dipelegic, which means she can use her hands and will walk now. With a lot of aggressive therapy and her determination she has increased her function, and with the help of the funding, I can afford more private therapy for her.



Letter Carrier
Toronto, ON

Our son Hunter is Autistic and has asthma. He is a very loving and friendly child, but is awkward in his athletic endeavors. This past summer (2002) we enrolled Hunter and his younger brother, Connor, in a one-week karate camp at Steve Stewart's Martial Arts Center. This camp, sponsored by the Thames Valley Children's Center, is designed for special needs children and their siblings to learn the basics of karate.

Our boys were so enthusiastic about the camp that we have given them a two month trial membership. They are both getting some exercise and developing discipline, respect and self worth. This program has made a great impact on both of our boys and we are so grateful to the CUPW Special Needs Project for the idea. All of us are better off because of this program, thank you.

Permanent Full-time
London, ON

Thank you so much for the monthly financial help. Thomas would not get the supplements he needs. We would not get the other help that we need and the break. It makes a huge difference.

Ext. 01
Vancouver, BC

I am a parent of a 15 year old Autistic boy. I greatly appreciate the Special Needs Project. I don't know what I would have done without it. It helps me to get a break. But I am worried when my son turns 19. There are no services available in our community for low functioning kids. He will be out of school. In order to keep my son with me I will need even more help. I will be getting old and he will be stronger. The expansion of the Special Needs Project is my only hope.

PO 4
Hamilton, ON

I would only like to say I am so grateful for this project. Without these funds, Damen, my son, would not be able to get the tutoring that he needs. I would just like to say thank you.

Permanent Letter Carrier
Calgary, AB

Thank you very much for publishing our story and picture of Stephen and I in *Moving Mountains - Work, Family and Children with Special Needs*, the CUPW Special Needs Project book.

We were enjoying reading the articles and seeing the pictures and where these families were from; what they have and how they deal with their problems. When we turned a page onto the next story, there was our picture and our story! What a keepsake. Thank you for choosing Stephen as one of your special needs children.

MSC permanent Full-time
Mississauga, ON

Seasons Greetings
May there be peace in your hearts and homes now and in the new year from your friends at CUPW/UPCE-PSAC Special Needs Project

Special Needs Advisors:

Lisa B.	Sylvie G.	Pat M.
Donna M.	Lynda M.	Debra Jo P.
Michele T.	Pam M.	Nancy S.
Beth B.	Roberta M.	Maureen B.
Sheila S.	Ellen M.	
Monique D.	Sheila O.	Family Place:
Kathy L.	Arlie R.	JoAnna LaTulippe-Rochon
Sue M.	Bianca S.	Gail Holdner
Dianna S.	Christine D.	Dorothy Keigan
Shirley M.	Marie-France H.	CUPW:
Anne G.	Marie-Josée L.	Denis Lemelin
Agnieszka G.	Julie S.	Jamie Kass
Nancy B.	Pierre B.	Jocelyne Tougas
Suzanne C.	Wendy W.	UPCE-PSAC:
Lesley Ann C.	Tracey H.	Luc Guèvremont
Laura C.	Valerie D.	Marilyn Adlam
Debbie D.	Kelly H.	
	Bernadette M.	