



SPECIAL NEEDS • MOVING ON

member to member connection

Breaking through barriers for workers who have children with special needs
Nº 21 Winter 2010

My daughter

Stephanie is 23, has ADHD and is in college. It will take much longer for her to get an education than others her age. She can do very well at her studies with incentives and the support of a tutor but still may fail or have to drop a class. She tries so hard. She has not given up so I won't either.

My son Jayden is 12 and also has ADHD. Last summer we stopped Jayden's medication. It took a week or so for his body to adjust and not show the usual 'crashing' that occurs when medication is not administered. Prior to this I had him checked for food and environmental sensitivities at the naturopath. He was allergic or sensitive to many food items. I also spent \$825 to have his blood checked for candida yeast, hair samples for metals, and more blood work. I heard that leaky stomach along with the candida yeast makes it impossible for someone with Attention Deficit to concentrate. New research shows that the signals in the stomach work together to transmit our thought patterns to our brains. This means that you have to fix the gut in order to fix the mind. I have removed the foods my son is sensitive to and Jayden is taking vitamins and probiotics. With his change in diet I have seen a change in his level of hyperactivity. Jayden is having no luck concentrating at school but he is not having any behavioural

Happy Holidays!



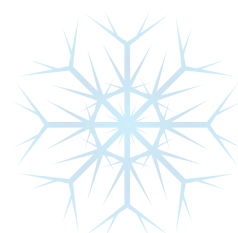
Jayden and Stephanie

problems. My hope is to detoxify Jayden so that he will need only the most minimal amount of Ritalin. It is worth the money and testing to know exactly what your child is allergic to and remove these from his/her diet. When your body does not have to fight with the allergens that make you sick it can regain more of its proper functions.

A parent who wants my child to have the best quality of life possible,

Letter Carrier

London, ON





"It is critical to build inclusive communities by thinking creatively."

Advisor Susan Beayni

Creative solutions help build a good life

When Moving On advisor Susan Beayni talks with the project's parents about the challenges of having a son or daughter with a disability, she speaks from personal experience. One of her daughters, Rebecca, was born with a developmental disability.

Beayni, who lives in Toronto, believes it is critical to build inclusive communities by thinking creatively and through "relationships that are freely given, because where there is mutuality and sharing of gifts this is what keeps us safe, secure and leading meaningful lives."

Rebecca's life is a case in point. Over the years, she and her family have built a network of supporters and friends who will be with her for the long-term. Rebecca, 28, lives in her own apartment (attached to, but separate from, the family home) and works with community groups, a museum and as part of a dance group whose dancers have different abilities.

Beayni first became involved with Moving On when she substituted for a Canadian Association for Community Living colleague at the project's foundational meeting. An advisor since 2005, she is also director of family services for newly-formed PLAN (Planned Lifetime Advocacy Network) Toronto. The organization is dedicated to supporting families to



plan so that their sons or daughters will continue to live a meaningful life into the future, including when their parents are no longer able to care for them.

"I love all of the families [in the Moving On project]," she says. "The courage and resilience are absolutely huge and the love for their son or daughter is over the moon. Nobody talks about their son or daughter as being a burden and sometimes it's difficult to get the parent to say what's hard because they don't want to imply their son or daughter is a burden."

Nonetheless, parents do have challenges, says Beayni, and one of the greatest is financial stress. "There are lots of expenses that are not covered and when you consider the 24/7 support costs when young people are out of school then that's massive."

Beayni knows that the families value being part of Moving On. "They are delighted with whatever comes through on the project." She also knows they appreciate the project's advisors, saying she was "absolutely touched from the bottom of my heart at some of the things they said [in Member-to-Member Connection] in terms of how meaningful our conversations were to them."

Beayni is impressed by the way the project's administrators "are open to new ways of looking at things and will fund new things because of the way families are describing [their needs]."

This type of flexibility is rare in programs for those who have special needs, she says, and "it is really powerful". It is also a perfect fit for someone like Beayni, who believes the way forward is all about innovation and caring.

"Don't despair. Follow your instincts as a parent. Don't give up."



My son, Jonathan

Lambert, began experiencing additional problems after starting school. He attempted self-mutilation and suicide when he was around seven years old. We took him to Ste-Justine hospital, where he spent about four months in child psychiatry. He was diagnosed with pervasive developmental disorder (PDD) or Asperger's syndrome, but we had doubts. He also had an obsessive compulsive disorder (OCD) and an attention deficit hyperactivity disorder (ADHD).



He attended special classes, but nothing was working. The older he got, the more aggressive he became and between the ages of 13 and 14, we had to call the police and the ambulance between 10 and 12 times. It wasn't easy!

The school kept calling me to go pick him up. Despite special classes and medication, nothing was working. Canada Post was becoming impatient and no longer wanted to pay for special leave even though my presence was absolutely necessary. I have legal custody of my son as his father no longer cares for him. I had to request a placement in a rehabilitation centre for Jonathon (long wait) and a new assessment. Now, he's been placed, at least for one year. It hurts as a mother, but it was worth it because he's been doing better for two months! Don't despair and always follow your instincts as a parent, and most of all, don't give up.

Letter Carrier
Laval, QC

Communication Facts

- 93% of communication is non-verbal
- You must hear something 3 times before remembering it.
- When hearing a contradictory message we have a tendency to believe the non-verbal hints we receive.
- Touch is the most direct form of communication. For this reason, it could also be seen as a threat.
- 65% of what we learn about another person when communicating is by observing non-verbal body language.
- 83% of adults learn visually
- 7% of communication is what you say (words), 38% is how you say it, and 55% is body movement.



Check out our website at www.specialneedsproject.ca





"My advisor always listens, never judges. What a great lady!"



I would like to thank the Special Needs Project and my advisor. Over the past two years, I've received funds to pay for remedial education and sports activities for my son. As a result his self-confidence has never been better.

He had been experiencing behavioural problems and had to attend a special class. I used to have to stay with him from 8:00 a.m. to 11:00 a.m. two or three days per week to avoid having him expelled from school. But today, he's in a regular class and has a B average.

PO-4

Ottawa, ON

My advisor Anne G. has always called when I most needed to talk to someone. She always listens, never judges. What a great lady!

Analyst

Winnipeg, MB

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



When we were kids you did your Roman Catholic sacraments with your class at school. These days it's different. When Chloe, Carter and Cameron entered 2nd grade, my wife Valerie started asking questions about their First Communion. Unfortunately, we were on our own to find a church "accepting" of Chloe and Cameron. We first went to a French church since the kids attend a full-time French school. Sadly the French church was not an option. So my wife went on a mission to find a church "accepting ALL kids". On Sunday June 6th 2010 after weeks of practising and preparation for their First Communion, the kids successfully participated not only in the hour mass but in the ceremony carrying up the offerings as well as the group picture at the end. The Priest was amazing and SO accepting, it didn't matter that Chloe watched her Dora DVD with her headphones on or that Cameron needed stickers or said "backpack" during the service as long as the kids were there. We are so proud of them!

Letter Carrier

Windsor, ON

Know what you're asking for. Know what is essential, what is negotiable and what is doable.



Effective Advocacy

Characteristics of a Successful Advocate

Attitude: Positive, persistent, prepared – think out strategies before the meeting.

Flexible: Know WHAT you really need – be flexible on HOW it is done.

Fair: You are in this for the long haul – listen as well as talk! Look for “win-win” solutions.

Organized: Do your homework, know what you after, “build a case”, keep good files and logs. We track our investments – your child is your most important one.

Informed: Know what you are talking about, your rights and the legislation – learn the systems protocols and jargon.

Published: Send letters, “thank you” notes, meeting notes, reflective letters.

Problem-solver: We are all responsible for solving the problem – not just the school.

Advocating for Success

1. Prepare, Prepare, Prepare
2. Know what you are asking for.... What is essential, what is negotiable and what is doable
3. Be evidential, not emotional
4. Be the adult, the professional
5. Know when to say “call it a day....”
6. Rehearse away your emotions.... Know your limits
7. Learn to use your “team”develop a strategy, have cues and roles
8. Anticipate (the Heinz Rule) and counter
9. Do a dry run....”role play”
10. Control the environment – location, seating, materials, documentation, “feel/tone”

The 4P Rule: “Prior Planning Prevents Problems”

Positive persistence is more important than popularity.

Permission to reprint granted by Lindsay Moir, Comhnadh Consulting
www3.sympatico.ca/l.moir/

I have two children

with ADD and ADHD, both on Concerta, and both with learning disabilities. When the public school system failed to help them I sent them to a private school in Ajax called Wasdell Academy for Innovative Learning. Phone 905-426-3241 Website: wasdellcentre.org. The director's name is Elizabeth Moxley-Paquette. This school runs a brain based exercise program for kids of all ages to correct any learning disabilities. It has greatly improved my daughter's academic abilities and her life. She graduated this year from a regular high school without an IEP or Special Education assistant. My son is currently at Wasdell for a second year to help him catch up with the regular school system. I highly recommend this incredible program. They have on-line tutoring for people who live out of the area. If you want a personal perspective email me and I will explain it in greater detail or leave me your phone number so we can talk. Also, if your child has behavioural issues due to a learning disability, their behavioural outbursts mellow as their brain gets a good work out thru the program.

Letter Carrier
Scarborough, ON





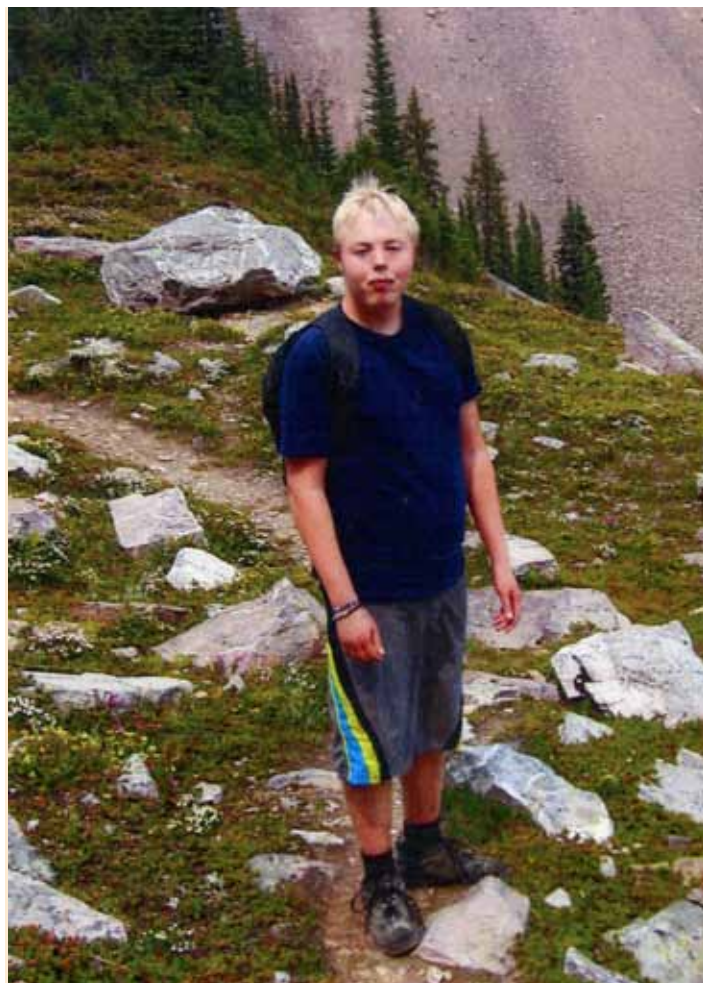
"The information you have given me will continue to make Dawson's life better."



A huge thank you to my advisor Catherine D. and the Special Needs Project for the knowledge and encouragement they gave my daughter and me. Alexandra won two medals - one for weight throwing (Gold medal) and a silver medal for volleyball at this years defi-sportive 2010. Thanks everyone!

CSP

Laval, QC



I am writing to inform you that as of August 2, 2010 Dawson Jackson is no longer in my care. We were having a hard time dealing with him the last few months and there was an opening in a group home in Cranbrook BC. We have had Dawson on a waiting list since last October but we asked them to push it through since he was getting more aggressive with the other kids in the house. I would like to take this opportunity to say thank you for all you have helped us with. You guys were my light at the end of the tunnel. The information you have given me will continue to make Dawson's life better. Without you guys I would still be looking for resources. That or in a mental institute, HAHA. What you do for families is so wonderful. Thanks again. The Jackson family.

RSMC

Golden, BC



*"We live in a world where saving someone's life is possible.
Help make a difference."*



My name is
Maria-Jose Bouey.

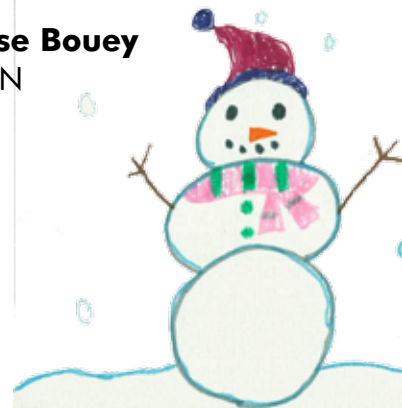
I am the daughter of a 20 year seniority MSC, Cristian Bouey. I have been privileged enough to be part of the Special Needs Project for over 15 years. No words can explain how much of an impact the Special Needs Project has had over the years on my life and my family. Without this type of support disability patients like myself would be facing more struggles then what is already involved in the day-to-day medical issues. Along with CUPW, the Moving on Project has helped facilitate in removing some the stresses that are part of living with illness. The stresses for both the patient and family are sometimes more then one can handle and I am truly grateful for everything you have done.



I am currently in university, working part time and pride myself in being able to "pay it forward" through volunteer work. My second part time job is Dialysis. On April 19, 2001 I received a life saving kidney transplant, where my mother was the donor. I was able to live almost 10 years with stable drug therapy and dialysis free. However this past winter I was re diagnosed with End Stage Renal Failure, meaning the kidney that my mom gave me was no longer working and I would need a new kidney. Being in the adult system I was immediately opted for full time dialysis, which required me to change my "normal" life to a life depending on a machine. Currently I am on dialysis 3 days a week for 4-6 hours a session. I have become use to doing classes after treatment and working on odd days and weekends. My problems these days are no longer the stress of treatment but the urgency of finding a donor. Currently the adult donor list for my blood type is a 7 to 9 year wait. Left with little hope of receiving a kidney soon, I took myself to the web and began video blogging my journey through renal failure. This opened my eyes to the need of organs across the world and has made me more inspired to come forth and say I NEED A KIDNEY! I believe no one should have to wait for an organ donation if the Living Donor option is possible. I am 22 years old and want to change the world, but I need the help of others to do so.

I am looking for a donor, my blood type is A+ and I am able to match with all A's and O universal blood types. I hope this inspires even one person to get tested and help save someone's life, let alone my own. We live in a world where saving someone's life is possible. Help make a difference.

Maria-Jose Bouey
Toronto, ON





What you've told us

We asked members from both projects similar questions over the last couple of interviews. Here is some of what we've learned.

Vitamin Benefits

CUPW and UPCE-PSAC members who are covered under the Great West Life health plan with Canada Post can apply for coverage to support medically necessary vitamins for their children with special needs listed on the plan. 28% of members have a child that fits this criteria. Less than one sixth of eligible members had previously applied with only half of these being successful. The majority of members who applied but did not receive coverage said it was because the vitamin submitted did not have a Drug Identification Number (DIN).

Special Leave for CUPW Members

Over 50% of members from the Special Needs Project (SNP) and the Moving On project (MO) applied for special leave in the last 5 years to support their child with special needs.

MO members were three times more likely than SNP members to identify having a spouse at home or a system in place which did not rely on the member accessing special leave to support his or her adult child with a disability.

Reasons requesting Special Leave (SL) (Top two reasons)	Percentage of all SL requests SNP (MO)	Percentage of requests approved SNP (MO)
1. Child had a scheduled appointment which required the member's support.	60% (57%)	72% (54%)
2. There was an emergency related to my son or daughter's needs.	18% (14%)	59% (50%)

Special Leave was denied:	Percentage of times this was the supervisor's response SNP (MO)
1. Denied request and told me to take annual or vacation leave	25% (16%)
2. They said I could have made other arrangements	25% (32%)

Many members were told to take leave without pay. Others reported being told,

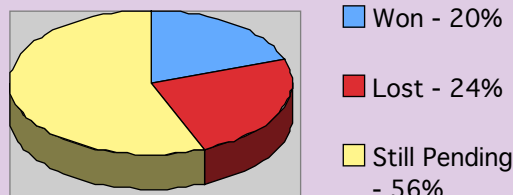
- "Special leave is not recognized for inside workers."
- "CUPW members did not qualify for special leave."
- "Special leave is no longer being approved."
- "Your child is over 16 years old and can go (to appointment) by himself."

Many members chose not to even try accessing special leave. "Member has given up applying for special leave as it's never granted." Others knew they couldn't count on the request being approved. "Approval has been hit and miss depending on the supervisor and his/her mood." Most adapted as best they could. "Member off shifts with her husband. No need for special leave for children's needs." "Runs through her route to accommodate child's needs."

It was a rare supervisor who responded in a compassionate fashion. "Supervisor has been very supportive. Member feels that this is the case because the supervisor has met her son." "The supervisors will tell you 'this is your issue not ours'."

Grievances for Special Leave

Special Needs Project

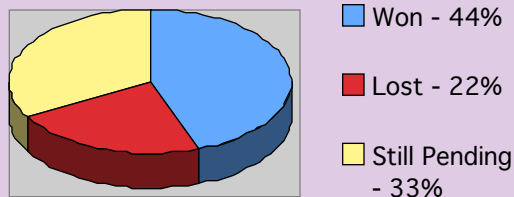


60% of members on the Special Needs Project were denied all or part of their special leave request in the



last five years went to their union for support. Over 2/3 of these members ended up filing a grievance. Of those who filed over half are still pending review.

Moving On Project



56% of Moving On members who were denied all or part of their special leave request in the last five years went to their union for support. 90% ended up filing a grievance. Only one third of the grievances are still pending.

Some of those who didn't file a grievance said they feared the backlash from management if they did. One member said he "didn't want a target on his back". In some cases the union rep did not feel it was worth filing a grievance.

A third of members who chose not to go to the union for help identified that the process was too much hassle and it was too long a wait to get the time back. Others who did not seek union's help identified that they weren't aware support was available. In some cases members felt the union rep could be better informed. "The steward said grievances always get rejected so didn't try."

Benefit coverage for adult son or daughter

In the May 2010 interview we learned that close to half of Moving On members applied for continued health benefits from Great West Life for their adult child with special needs after the adult child was 21. 9% of members either did not realize there was coverage available or assumed it would just automatically continue. 58% of those who applied found the process to be relatively simple and smooth. "It took time and money for the reports but was simple." 23% found it confusing as many forms had to be filled out. Great West Life approved coverage for close to 90% of the members who applied.

Colin Kelly is graduating from grade 12 this June. He has been with the CUPW Special Needs Project since he was in kindergarten. Colin has been on a modified classroom program with a special education teacher throughout his school years but always included in the classroom. Being included with your peers is monumental progress. The Kelly family is thankful for CUPW's stance on inclusion. Here is Colin's career planning introduction.

WHO AM I?

I, Colin Kelly am a great person. I am very friendly to people I know and I am always wanting to meet new people. I try to treat every person I meet the same. If I see a person needing help, I try to assist them. I would not think about ever swearing at anybody. I try not to be rude to anyone. I believe I am a gentle person.

My passionate interest is working with metal and tools in an occupation of welding. The main reason I like working with metal and tools is it is hands on. I like watching two pieces of metal, melting together, to form a new shape. I enjoy seeing the finished metal heated and buffed for a completed project.

I also enjoy weight lifting as I like to keep my body in shape. I believe muscles are important as welding involves lifting heavy things. I often look at pictures of different models of race cars. The things I look at are the different bodies and engines which gives me an understanding of how metal can be shaped and formed.

In the past, people have said I am a good worker and a very friendly person. I believe that when a person is working with others, they have to be easy to get along with. I can't remember any time that I have not been able to get along with another person.

I want to be healthy, happy and successful in my job. I believe in a job I have to use tools correctly and be safe all the time. Having a job will earn me money so I can buy a house and a car.

PO-4

Kelowna, BC



"I was trying to tell myself 'I can do it, I can do it'."

"My life, my pride, my joy"

Until he was three, Shelden Miller had been "above average in everything", says his mother, Sonia Payne, a postal clerk in Toronto. Then "all of a sudden he stopped talking, slowed down."

Soon after, Shelden was diagnosed with autism. "It was tough, but I had to accept it to get the help that I needed for him," says

Payne, a single mother of four. Shelden, now 22, lives in a group home in Pickering 15 minutes away from his mother. He comes home every other weekend. Another son, Shaun, 18, has a milder form of autism and obsessive compulsive disorder.

Shelden has difficulty interacting with others and is "always moving around."

There were times when Shelden was growing up that Payne "felt helpless—the behavior, the uncontrollable outbursts, the banging of his head. I didn't know what to do, I cried a lot and it was very difficult. I would have to leave work because the school would call me to come and pick him up."

Deciding to put Shelden in a group home when he was 12 was also hard. "I was trying to tell myself 'I can do it, I can do it', but the reality is I had to think about myself and the other children."

Close friends, a twice-a-year parent support group and her religious faith have been very helpful to Payne throughout the years. And so have work and her union, although each in different ways. "Work relieves a lot of my stress. Even though it's draining doing midnight work, I'm around people and not thinking so much about my problems."

Shelden is part of the Canadian Union of Postal Worker's Moving On Project and Shaun is with the Special Needs Project. The projects help them with socialization and care, and provide some respite for Sonya. Shaun has a worker every Saturday for an hour or two who also takes Shelden when he's home.

"Mostly I sleep," says Payne, who ends her overnight shift on Saturday morning.

"When they come home I am alert." Another worker stays overnight when Shelden is home because he wakes up two or three times a night.

Payne says her daughters Shenelle, 28, and Shevonne, 20, have also been affected by the extra time and energy their mother has had to devote to their brothers' special needs. Shenelle in particular feels that more responsibility was placed on her while growing up.

To other parents in similar situations, Payne advises love, patience, accepting your child for who she or he is, a support group and a good doctor.

"My children think Shelden is my favourite," says Payne. "Maybe so, because of who he is. He is my life, my pride, my joy."

What is autism?

Autism, also referred to as autism spectrum disorder (ASD), is the most common neurological disorder affecting children. Autism (or ASD) is a wide-spectrum disorder. This means no two people with autism will have exactly the same symptoms, and symptoms range from mild to severe. People with ASDs have varying degrees of difficulty in social interaction and communication. They may also show repetitive behaviours and have unusual attachments to objects or routines. ASDs are four times more common in boys than in girls.

Sources: *Autism Society Canada; Medical News Today*





Strong family love braves the challenges

Julian Renteria was born in Colombia in 1998 with his umbilical cord wrapped around his neck, which blocked oxygen. "We saw him having difficulties, but we never expected it would become autism," says his dad Luis, a Lethbridge letter carrier.

The diagnosis of pervasive developmental disorder – autism, came in 2001 after the family had immigrated to Canada. Ever since, Renteria and his wife, Tany, have been looking for answers.

"The doctor said there is no cure and nothing that will help him, just medications that will calm down his behavior," says Renteria. "We still think that there is something out there for him."

The Renterias have been trying to get an overnight electroencephalogram (EEG) for Julian, but doctors are reluctant to order one because the boy does not have seizures (the EEG study assesses the risk for seizures and other underlying abnormalities). But for Renteria, anything that might shed light on Julian's disorder should be pursued. "We know his brain is not working perfectly so why can't we have more analysis and find out what side of the brain is not working properly and attack the problem there?"

The Renterias' lives revolve around caring for their son. He is in school during the day and has two educational assistants who work with him. However, getting him ready and to school, as well as back home, involves time, patience, and emotional and physical strength. Julian cannot talk, moves back and forth

a lot, and will throw things and bang his head. His parents take care of transportation because he finds the sound of a car stressful. "At least when we are in the car we put on music and are talking to him, but in another car (for children with disabilities) he goes wild."

At home, two people come Monday to Friday for a few hours to walk and socialize with Julian. The Renterias work with their son on his fine motor skills and other exercises. The Special Needs project helps to defray the costs of Julian's special diet, which Renteria feels has eliminated his son's acid reflux and helped improve his eye contact.

The Renterias' two other children, Johnny, 21, and Diego, 18, have been deeply affected by having a brother with a severe developmental disorder. The family long ago gave up eating together because one parent has to take care of Julian. "They [Johnny and Diego] never go with us anywhere. Sometimes we understand that they don't want to go with him."

The Renterias live a mostly isolated life. They have one family friend and no family in Canada. At Canada Post, Luis says, "We have relations as workers...but as people we don't share."

A strong family love, patience, hope and religious faith are what sustain Renteria, who recently went on disability because of heart problems. "Everything is related to the situation we are living. Having teenagers, plus this situation, and also our language and cultural situation makes it so stressful."

Nonetheless, Renteria and his wife "know we can do the best for Julian. We want to be together with him."





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

Special Needs and Moving On Advisors:

Bernadette M.
Shirley M.
Donna M.
Marie-Josée L.
Roberta M.
Suzanne C.
Pam M.
Arlie R.
Anne G.
Sylvie G.
Pat M.
Sheila O.
Ellen M.
Sheila S.
Lesley-Anne C.
Nancy B.
Agnieszka G.
Sue M.
Brenda G.
Sharel S.
Enna M.
Norma C.
Janet M.
Betsy S.
Catherine D.
Kathleen J.
Donald G.

Susan B.
Normand R.
Cora B.
Genevieve P.
Theresa A.
Trina S.
Kathleen B.
Chantal T.
Jean C.
Laura M.
Marie Hélène M.
Tatiana K.
Lori A.
Nadia J.

Family Place:

JoAnna LaTulippe-
Rochon
Gail Holdner
Dorothy Keigan
Cary MacDonald

CUPW:

Lynn Bue
Jamie Kass
Doris Tremblay

UPCE-PSAC:

Richard L. DesLauriers

Wishing you
all the best
in 2011!



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**

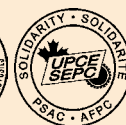
Fax: **1.902.295.2296**

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



The letters you are reading have been edited in an effort to include as many of them as possible. Visit our website at **www.specialneedsproject.ca** to see all the letters we received in their complete form.