



member to member connection

Breaking through barriers for workers who have children with special needs
N° 22 Summer 2011

This is a follow up to my letter in the last newsletter. I want to tell you how the detoxing of my son Jayden turned out. As I mentioned before the gut needs to be in good order to have proper brain function. Fresh probiotics are mandatory to maintain the proper amount of bacteria necessary between the stomach and the brain.

Results of blood tests indicated what needed to be removed from Jayden's diet. I also found out that he was low on iron. Apparently with brain function it is very important that iron levels are normal. Jayden needed detoxing from lead and to avoid all artificially flavoured, and coloured foods to which he had a strong allergic reaction.

Once we removed all the foods Jayden was allergic to from his diet and gave him some vitamins, we took him off Ritalin. He was very well behaved and was not naughty or rude. We did get complaints from school about his lack of concentration and incomplete work. The teacher moved his seat to the front and he was constantly being cued to be on task. All this eventually affected the relationship Jayden had with his peers. Jayden and I had decided that he needed to go back on ritalin in order to learn in school. The amount is lower than he was on last year.



Jayden with his niece Kai

Jayden is back to a strong "B" average. He is taking 30 mg. fast acting ritalin in the morning and a second and final dose of 20 mg. when he finishes eating lunch. This begins to wear off between 3:30- 4 pm. This is perfect. He is on 40 mg's lower than the amount of med's he took last year and his marks are the same.

I had no idea the rumours I'd heard over the years about dyes and artificial flavouring in the foods affecting concentration and behaviour were true. I had become accustomed to believing ADHD and ritalin was the way of life for my children. I am now convinced the process I described above is the only way my children will have a chance to do well in school and continue on to a possible chance at a career.

Letter carrier
London, ON





"She gets the most enjoyment listening to the families talk to her about how their children are growing up."

Advisor Sue Morrison

Working with people who have special needs is a part of who she is

For many years, Sue Morrison carried her passion for special needs beyond her work as a family counselor and into another longstanding passion: horseback riding.

The Special Needs advisor from Red Deer, Alberta, was a volunteer instructor for therapeutic riding for seven years before a back injury forced her to stop four years ago.

"I grew up with horses and was a rodeo queen," she says. "When I saw this [special needs equestrian program] I thought, 'Perfect, what a way to get two in one. I started as a volunteer and they snapped me up to become an instructor.'"

A memorable moment was when a girl in the program who had autism spoke her first words in the arena.

"When you do instructing," said Morrison, "you ask them to say, 'Walk on,' and the horse walks right away, so it's instant gratification. One day she just said, 'Walk on.' The parents were there and they cried, and everyone else clapped."

Morrison has a background in social work and has spent 25 years as a family counselor. For the last 15 years, she's worked in schools dealing with families and children who have a variety of challenges. She's been a Special Needs advisor for the last 10 years—a job that is "another way for me to connect



with parents of children with special needs and help them work through difficulties. It's an extension of what I do."

Morrison says she gets the most enjoyment listening to the families talk to her about how their children are growing up and the improvements they're making. The Special Needs Project and the people who administer it are "fantastic—people who don't even know these families but care enough about them to do something."

Over the years, she has noticed a pattern related to the parents' stress levels in the workplace: "When I talk to someone in the project who seems to have the most support in their work setting I'm talking to a much happier, engaged worker—it frees them up to be a lot more productive than in a working environment where they have to cross all the t's and dot the i's."

Morrison's family has always been involved in special needs issues. Her children—aged 15, 19 and 22—all volunteered with the special needs equestrian program, and her husband is a rehabilitation practitioner who supervises group homes for people with disabilities.

When she's not in the area of special needs, Morrison likes to be outdoors. She and her family are regular campers. She's also an avid hiker and gardener.



"We see the world from another perspective that only the parents of children like this can see."



DisabilityAwards.ca

The National Educational Association of Disabled Students (NEADS) is a consumer-controlled, registered charitable organization with a mandate to encourage the self-empowerment of post-secondary students and graduates with disabilities in Canada. NEADS recognizes and advocates for the right of every student with a disability to attend post-secondary education.

DisabilityAwards.ca is a fully accessible comprehensive online portal containing information on financial assistance for post-secondary students in Canada. The searchable portal provides disabled students with relevant disability-related financial aid information.

The portal contains information on all disability-based scholarships, awards, bursaries offered through: Canadian students from Canadian colleges and universities, non-governmental and charitable organizations, the private sector, as well as complete information on grant and loan programs available from federal and provincial/territorial governments.

Gabriel, our precious son, will be 15 on March 13th, 2011. There were many obstacles after his diagnosis of severe autism and developmental delay. It was a challenge to expand his horizon of hope and joy during his childhood and adolescence. Gabriel needs special therapy and care that help him to have fun and relaxation and be a happy kid while being "different". His need for support will be permanent but thanks to the support from the project we can deal with expensive therapies and care. As parents we sometimes feel overwhelmed and worn out but there is a glimmer of hope to continue life's work. We see the world from another perspective that only the parents of children like this can see. Blessings to you all.

Letter Carrier
Brampton, ON



Check out our website at www.specialneedsproject.ca

Thursday, 12 November 2009

English

 **Special Needs & Moving On**
Projects of CUPW/UPCE-PSAC

Breaking through barriers for workers who have children with special needs ...

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"I am being given another chance at life, and hope that everyone will do the same for those in need."

A year and counting...

When I was asked to write an update I was more than thrilled to jump at the opportunity!" wrote Maria-Jose. Maria-Jose Bouey wrote a very personal letter about her need for a kidney transplant in Member to Member Connection (Winter 2010, page 7). Her father is Christian Bouey an MSC from the Toronto local and for 13 years has been supported by the Special Needs and now Moving On projects

I share my story in hopes of bringing more light to this needy cause that is Organ and Tissue Donation. Thanks to CUPW, my story has become a household name to the Canada Post employees across Canada!

My goal last year was to inspire one person to sign their [organ and tissue] donor card and maybe they could inspire another and so on and so forth and one day there would be no wait list for organs. Now I have done just that. The moment CUPW published my article in Member to Member Connection, I began to receive messages from across the country! Current and past employees contacted me asking how they can help and what they could do for me. My goal was reached and surpassed! I knew that even if I had to be on dialysis 30 more years, someone out there might not have to be. Little did I know that I would also receive two blessings of my own.



In my mind, Fall 2010 was coming with the same routine. Dialysis. Eat. Sleep. Blog. Little did I know that my friend, Amy, and my cousin, Mauricio, were both getting all the necessary tests done to be my donor! My first news came via a Facebook message from the young, yet driven, Amy. "I love you and just can't hold it in. I am already a match so it's meant to be." With this came more news. We found out that secretly my cousin Mauricio was having the testing done too. He did not want to get my hopes up so was keeping quiet until he knew more. You can imagine me and my family's shock and joy! The light was back at the end of the tunnel.

Here I am a year into dialysis, and the news is in. I am the first patient at Toronto General Hospital to have two possible donors approved! With that said, it has been narrowed down to my cousin Mauricio. This has helped change his life as well. Before we can go through with surgery I will need

intensive drug therapy to make sure there is the least amount of risk possible. Mauricio also needed to lose some weight, as he struggled with his weight his whole life. He has now lost over 80 lbs. (!!) and is more than ready for surgery.

Thanks to all those who are now aware of Organ and Tissue Donation. I am grateful for all the blessings I have in my life. I keep blogging, and hope to inspire people to donate or just sign a donor card. I am being given another chance at life, and hope that everyone will do the same for those in need. I will keep you all in the loop and hope to have my second transplant in early fall 2011.

.... Until then, thank you, all of you, for your support, good wishes, and prayers.

Toronto, ON



Hi to everybody! Our son Julian has been making great improvements. School year 2011 has gone well as he is mastering "good behaviour". Before it was a real nightmare to get him showered and dressed but now there's not too many problems. Before dropping him at school was a bit of a problem, now it's not. All of these changes are due to the commitment of the school, respite and the team involved to help our son. We also started Julian with a nutritional supplement called Super Nu-Thera from Kirkman lab in USA. We like to encourage parents with autistic kids not to lose hope! There will be something out there in the world to help our kids. My wife Tanya and I always think God has something special in mind for parents with special needs kids. Be strong, be patient and believe that God will make the difference. See you soon.

Letter Carrier
Lethbridge, AB



Thanks to the CUPW Special Needs Project Michelina has been able to study singing and attends vocal lessons at Long and McQuade in Halifax. Michelina always wanted to learn how to read music and can now take a sheet of written music and play it on the piano and guitar. Michelina has written many songs of her own and is doing very well with her vocal lessons. She wants to someday be a music leader. Michelina will be graduating this year from high school.

PO-4
Halifax, NS



“What is he trying to show me?”



The Boy in the Moon *A Father's Search for His Disabled Son*

Written by Ian Brown Publisher: Random House Canada

“Walker Brown was born with a genetic mutation so rare that doctors call it an orphan syndrome: perhaps 300 people around the world also live with it. Walker turned twelve in 2008, but he weighed only 54 pounds, is still in diapers, can't speak and needs to wear special cuffs on his arms so that he can't continually hit himself. ‘Sometimes watching him,’ Brown writes, ‘is like looking at the man in the moon – but you know there is actually no man there. But if Walker is so insubstantial, why does he feel so important? What is he trying to show me?’”

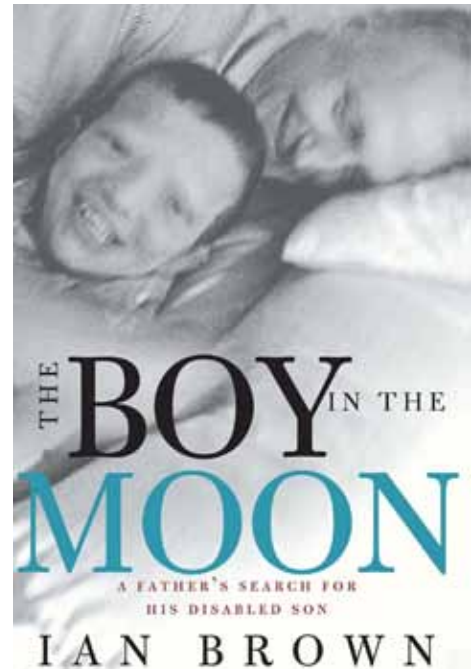
This is the publisher's description of *The Boy in the Moon*, by journalist Ian Brown—a book I was afraid might be too heart wrenching to read. I was only partly right. I loved this book. Brown speaks to the reader as if she or he is the only one listening. At times, he shares his thoughts as if they have just come to mind. He does not sugar coat life with Walker but speaks clearly of the challenges and gifts his son has brought to his family's life. Brown shares not only stories that make him a hero in my mind, but also the times he resented what was being asked of him.

Life with Walker challenges every aspect of the family's lives; the parents' careers (both are journalists), their marriage, their finances and their health. Brown shares what he has learned along the way. There have been many questions – often ones without answers. “What is the value of a life like this – a life lived in the twilight and often in pain?” The book is Brown's search for answers.

Genetic testing and finding other families of children with CFC were part of that search. Brown tells the families' stories and shares what they learned, “Who's to say my child is not happier in her world than I am in mine? And here I am feeling sorry for her because I'm trying to judge her by the standards of the world she isn't part of.” Brown's search for a future for Walker is, as all of life with Walker seems to be, an opportunity for growth.

Brown and his wife, Joanna Schneller, struggle to find the answer to the question that haunts all parents of severely disabled children: “What will happen to him when we're gone?”

This is a love story in many ways, and one well worth reading.



Ian Brown is an author and a feature writer for *The Globe and Mail* whose work has won nine Gold National Magazine and National Newspaper awards. He is the host of CBC Radio's *Talking Books*, as well as the anchor of TVO's two documentary series, *Human Edge* and *The View from Here*.

Awards

FINALIST 2010 - Governor General's Literary Award - Nonfiction

WINNER 2010 - Charles Taylor Prize for Literary Non-Fiction

WINNER - British Columbia's National Award for Canadian Non-Fiction

WINNER 2010 - Trillium Book Award

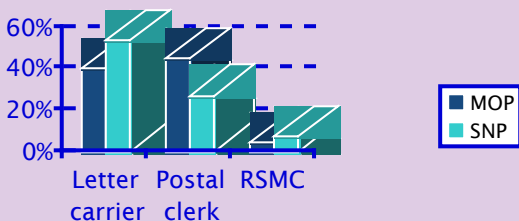


"My child just needs to be given a chance ...by peers, teachers or potential employers."

What you told us...

These are the results from our Fall 2010 survey of Special Needs Project (SNP) and Moving On Project (MOP) members.

- The primary job classification for CUPW members differed significantly from one project to the other (see chart).
- The SNP had twice as many RSMC members as the MOP.
- The job classifications for UPCE members were consistent from one project to the other.



- Fewer members in both projects are planning to retire compared to the last three years.
- 32% of MOP and 8% of SNP members had applied to the Registered Disability Savings Plan (RDSP) for their child.

Special Needs Project

Setting goals for acquiring life skills

Families can begin to prepare their child for adulthood by starting to set goals at an early age and making plans in all areas of the child's development. We asked members to think about what goals they and their child with special needs might choose and identify the areas that needed the most attention in their child's development:

- Learning self-advocacy skills was important to all parents, especially those with children 15 to 19 years old.
- Improving the child's social life was a primary concern for parents of six to eight-year-olds (56%), gradually diminishing to 29% of members whose children were 18 to 19 years old.
- Learning independent living skills was as

important to parents of children under six as it was to those with a child turning 19.

- School and work was a key issue the older the age of the child (73% for parents with a child 18 to 19), with the lowest concern expressed by parents with a child under six.
- Few members identified health and wellness as a priority goal. Parents of 12 to 14-year-olds showed the highest interest (30%) in helping children understand their special needs and how to work with their medical and support team. Responders' children had disabilities ranging from learning-related disorders to severe autism or global delays.

We asked members what would help them achieve their stated goals:

- More time to work on these goals (58%)
- Additional funding (54%)
- Programs to support their child's skill development (52%).

Some members felt goals were not attainable because their child's special need severely restricted her or his ability to participate. Others didn't set goals because their child was doing so well there was no need. Some members commented that their child just needed "to be given a chance" either by the child's peers, teachers or potential employers.

Moving On

Many struggles and worries

The concerns of members who have adult daughters and sons with disabilities have not changed from previous surveys.

One of the shifts families make as their child ages is to have one parent home full-time. Even so, most families still fight to find adequate programs and support. Challenges include:

- Finding and affording respite. Those who access respite often are left struggling financially.
- Difficulty finding programs or opportunities

“She is beaming with energy that she never tapped into before. Now she believes in herself.”



that will help their children develop the needed skills to get a job or volunteer.

- The worry, shared by all members, about what will happen to their children in the future: where they will live; how to find support to help them live on their own; whether they will be able to get and keep a job; and what will happen when the parents become ill or die.
- Work as a major source of stress. Parents cited running out of leave, having to be at work at times when their children needed them most, and exhaustion from being forced to work more hours because of staffing changes and forced overtime.
- Increased feelings of vulnerability, as well as higher physical and emotional tolls when parents themselves have health challenges.
- Stress on other members of the family. For example, siblings whose friends won't come over when the adult child with a disability is home; at-home parents feeling they carry the bulk of the load alone; and, ultimately, marital separations.

While some see only a “dismal future”, we also heard about those who manage to take in stride everything life throws at them, taking things one day at a time, setting priorities, following through with their plan and somehow managing to remain positive. There was also the occasional good news story, for example, one member's son who worked in the warehouse of a large furniture company five days a week who shadowed a regular employee. The company had seven employees with special needs and an educator to support them.



Thank you so very much for your generous funding. I am very grateful for the Special Needs Project. Since my daughter has been on the program she has flourished tremendously. Madison has been taking riding lessons at North Stone Farms. The quality of support and training that she has experienced there has been next to none. She has developed social skills and coordination. In addition she is beaming with energy that she never tapped into before. Now she believes in herself. Madison has met friends and her self worth has flourished as well. I cannot tell you how grateful I am to be a part of this program. I am proud to be an employee at CPC. Thank you.

PO-4
Brockville, ON





“Parents of children with special needs feel change immediately and more acutely than other workers.”

Workplace change should help not hurt



There's something wrong when a letter carrier who has a child with a disability wakes up unable to move due to excessive muscle strain from walking her extended route. Or when an employer forces a worker to take annual leave instead of Special Leave when her child is being hospitalized. Or when a lone mother gets put on the midnight shift even though her child with special needs can't be left unsupervised at night.

Forced overtime, staffing changes and anxiety about the Modern Post. Special Leave problems. Call centre layoffs. Fears about benefits for children with disabilities now and when they become adults. These realities have caused a wave of growing stress, exhaustion and uncertainty for parents in the Special Needs and Moving On projects.

Like the “canary in the coal mine”, parents of children with special needs feel change immediately and more acutely than other workers. What the Union learns from you deepens our understanding of the issues and how all our members and their families can be affected.

We took some of our issues forward in this round of bargaining, including strengthening the Child Care Fund. By the time you read this newsletter, we'll likely have concluded a new collective agreement, or been forced to strike because of the employer's unwillingness to work with us to solve these problems.

We continue to actively defend your rights on Special Leave through grievances and working to ensure locals understand the rights of the members to access this important benefit.

And we press governments to do their part too. That's why CUPW was an active coalition partner in Code Blue for Child Care during the last federal election. We helped make the case for a quality child care program that provides inclusive services for all of Canada's children. That's also why we continue to promote government policies that put families first.

While these policies are few, we actively urge parents to take advantage of the ones that do exist. An example is the Registered Disability Savings Plan (RDSP), which allows tax-free investment for people with disabilities. Our surveys show that only about 8% of parents in the Special Needs Project and 33% of parents in the Moving On Project have registered for this program. Many are unaware of the federal bond contribution they can claim even if they don't have money to put into the plan. If you haven't already done so, we urge you to look into the RDSP. Look at our Special Needs website <http://specialneedsproject.ca/> to get more information.

This is a tough time for workers in the Post Office, and even more so for those whose children have special needs. CUPW has always been in the forefront of workplace change. But our approach to change is all about ensuring a more compassionate and inclusive workplace. We put the workers and their families first. We'll never give that up.

Lynn Bue
2nd National Vice-President
CUPW

“(A person’s) discovery of their ability to be self-reliant is soul-satisfying.”



Learned Helplessness

By Celia Taylor

Letting go happens in small increments in the life of a parent. A child rejects the breast. He grabs the spoon to bring to his own mouth. Comforting himself becomes automatic when he wakes briefly in the night. Then he starts to have an opinion about what sneakers to buy and gets embarrassed when his mother kisses him. He shuts the bathroom door.

The progression of steps towards independence in kids with disabilities occurs as surely as it does with their typical peers. Although our children tend to linger in a particular stage longer, and the level of independence depends on the individual, our children can and must become as self-reliant as they are able to be. My children will grow up to have lives of their own. The skills I teach my typical children are the very same my child with a disability needs to learn. So why am I still picking out his clothes, making his sandwiches, pouring his drinks and putting his shoes on him?

On an intellectual level, I know he has to learn these things. At eleven I know he is capable of doing much more than he does. My reality is that I am hesitant to allow him to follow the natural progression towards self-reliance. It is a hesitancy borne of fear and love. Who in the world wants her child to fail, to get hurt, even to stumble? I recently watched as my son tried to get a game of Kick the Can started with the neighborhood kids. After seeing he couldn't get their attention, I intervened and did it for him. I couldn't bear to continue to watch while he sat with his head in his hands. The game did get started and he had a ball, but did I help him? Or did I just show him that he needn't bother to try next time?

A second reality involves old habits and expectations. If you have always gotten the bowl and cup out of the cupboard, chances are you'll continue to do it longer than you need to because daily routines are hard to give up. The expectation on the part of my child is also a factor. On one recent morning I discovered (my son) sitting at the kitchen table, ravenous, waiting for me to get his breakfast. He is fully capable of getting a cup



and bowl from the dishwasher, milk and juice from the refrigerator and cereal from the closet. But his expectation is that Mom is supposed to do it.

Reality also states that time is a factor in my everyday life. If being on time means putting on my child's coat and shoes, that is what will happen. At stressful times of the day I have always chosen what is most expeditious. I also have two other children. They are a definite factor in how my time is managed throughout the day. Less and less time seems to be devoted to creating an autonomous atmosphere for the child who needs it most.

Finally, there are times when I don't give my son enough credit. The assumption that he can't complete a task is unfair. Until he tries it, how do I know?

The reasons for my son's learned helplessness are just excuses. I have already started to re-examine the way I do things. Resolve has replaced languidness. My expectations are much higher and reflect what I believe he is capable of.

Our children and young adults with disabilities are capable, wonderful people. To keep them from developing to their potential is to cheat them of the autonomy and dignity they deserve. The same energy we put into teaching them to be helpless, unintentional though it may be, can be channeled differently. It is extremely difficult to "unteach" them after they've gotten used to having full-time servants. But the discovery of their ability to be self-reliant is soul-satisfying. It's the thing to remember when this wonderful, capable person tells you to go jump in the lake (or words to that effect) when you tell him, "You can do it yourself."

(Taylor is the parent of three. Thanks to the Aim-High Down Syndrome Society for allowing us to reprint this article.)



"We will survive and get past this."

I am so grateful my children are part of this wonderful program. With my husband downsized and out of work for more than 1 ½ years, my budget is being slashed even more. But because of the extra help of this program, my children will still continue with their tutoring and schooling. Thank you so much in this trying time of my life. We will survive and get past this.

MSC
London, ON



I'm a letter carrier in Windsor ON. My daughter, Emily, has developmental delays. We use her funding from the Moving On Project to pay for therapeutic horseback riding. I can't say enough about this riding program and the good it does for people like Emily as well as others with varying disabilities such as autism, cystic fibrosis and cerebral palsy. Animals, I believe, are a great healing tool in general and especially so for people, young and old, with handicaps. I'd like to express my heartfelt appreciation to those who run the Moving On Project, including my advisor. For Emily this program provides a great confidence – building experience and profound connection with horses.

Letter Carrier
St. Joachim, ON



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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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.

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