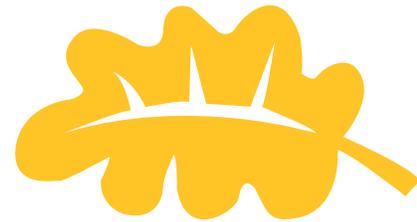


Member-to-Member CONNECTION



Number 13 • Fall 2006

Dear Sisters and Brothers,

I hope that you and your children have had a good summer, and that funding and support from the Special Needs Project played a part in making it all happen.

We've been incredibly busy with educational and websites.

At the beginning of June, we held a one-week residential educational, Child Care Now, in Port Elgin. It was a wonderful and rich opportunity for our members, along with UPCE-PSAC members and people from our child care programs, to talk about the importance of child care advocacy.

More than 40% of members who attended were parents of children with special needs. Everyone shared stories and experiences. Many members talked about how moved they were by the stories of their sisters and brothers who have children with disabilities, and how much they learned about the challenges, at work and at home, of parenting a child with special needs. Others talked about how they gained new understanding and strategies about their own children. Many made a commitment to become advocates and work with coalitions and community groups for a quality, inclusive child care system for all parents and children.

Exciting plans are underway to launch our new website later this fall. The site will feature the latest developments in the Special Needs and Moving On projects, community resources with web links, and most importantly an opportunity for members to share ideas. We will also have a calendar of events and important dates. Stay tuned!

In Solidarity,

Denis Lemelin
2nd National Vice President
CUPW



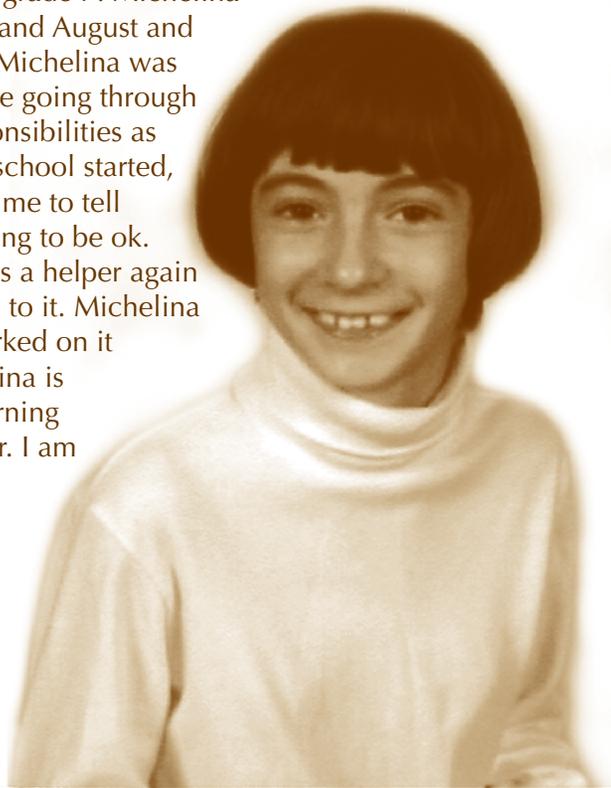
A few weeks before Christmas (2005), we received a call from Laura of Hitchon's Hearing Centre (Belleville) who said that Santa had stopped by and left a special gift for Hanna. Due to the bad weather over the next few days, we were unable to get Hanna to their office. Mom was able to stop by and pick up the gift. When Hanna opened it that evening she was very surprised to find a beautiful pink Teddy Bear with his own blue hearing aids. This was a special gift.

Letter Carrier
Picton, ON



Michelina attends Oxford School and is in grade 7. Michelina attended summer day camp all through the summer months July and August and really had a ball. When the time came for going back to school, Michelina was worried about the upcoming year at school because she would be going through a new change. She was told that there were going to be big responsibilities as she would be starting the school year in Junior High. Just before school started, I received a telephone call from a teacher at the school. She told me to tell Michelina not to worry about a thing and that everything was going to be ok. Last year, Michelina's helper was taken away but this year she has a helper again because Junior High does have a lot more responsibility attached to it. Michelina brought home her first report card of the year and everything marked on it was 100%. The teacher wrote that Michelina is a delight. Michelina is autistic but is very smart; although she may be a little slow at learning some things, she can now do her homework on her own this year. I am very pleased with Michelina's progress at school this year.

Halifax, NS



Dear members

of CUPW Special Needs Project,

Once again we would like to express our sincere thank you for the support you give to our daughter. With three girls at home the finances are demanding. This extra funding ensures our daughter with cerebral palsy gets opportunities we otherwise could not afford. We are grateful for this wonderful extended benefits you give to your members. Thank you for everything.

Toronto, ON

It's getting harder

and harder to find items that my 15 year old ADHD son is interested in to keep his mind growing/developing and help assist him to keep being/becoming a good person. Does anyone have any suggestions on what to do or what works for them?

Garson, ON



Excellent websites:

www.linguisystems.com
(teaching material and software)

www.pwd-online.ca
(Federal site – Persons with Disabilities Online) Bilingual

www.attainmentcompany.com
(teaching materials and software)

www.archdisabilitylaw.ca

Burlington, ON

We currently have 3 children in the family, two healthy girls, 7 and 17 months, and a 4 year old boy with autism. In 2001 a beautiful healthy little boy was added to our family. During the first year of life David met all his developmental milestones and was engaging, interactive and happy baby. However, following his first birthday our family began to notice a change in David. He no longer turned in acknowledgement when his name was called, his eye contact became scarce and then he stopped adding new words to his vocabulary and stopped saying the ones he knew (mama, dada, bye ...). It was as if someone was slowly stealing my child's spirit and we knew something was very wrong with him although doctor's and other family members disagreed with us in an effort to ease our worries. David was finally diagnosed with autism at the age of 2.5 years old when his obvious issues could no longer be denied or ignored by family and professionals.

Upon receiving his diagnosis we came to the cruel realization that everything capable of helping David came with extensive government waitlists (we are still waiting over 2 years later) and very limited or no employer funding. So our family embarked on an uphill battle to try to recover David or at least help him reach his full potential on our own. We conducted research on what causes autism and found the DAN organization in the US that believes that vaccines and its ingredients, thimersol, has caused the escalation of ASD around the world. This organization is committed to recovering children biomedically. This theory made sense to me since the prevalence of development disorders that fall under the autism spectrum (Autism, PDD, Asperger's, ADD, ADHD) have exponentially increased in conjunction with the pediatric recommended vaccination schedule, placing those children with compromised immune systems or genetic predispositions at risk of acquiring these disorders. We read books such as 'Children with Starving Brains' (J McCandless) which gave us great direction on moving forward biomedically.

We began an in home IBI (Intensive Behavioural Intervention) program at 20 hours per week paid privately since the government wait list could take several more years before David is picked up. David is in inclusive J.K. and trying to learn appropriate social skills. In addition we are in the process of implementing RDI (Relationship Development Intervention) essentially retraining the brain on how to engage socially through simple activities and games. We are determined to continue to help David and considering the cost of all these therapies the help offered by the Special Needs Project is very much appreciated.

Maple, ON



My seven year old

is bringing home one hour of homework each day in grade two that he is too distracted to finish in school. I forged his hand writing for months and now I sign at bottom of his work scribed by Mom. I have 2 children with special needs. One is 18 years old the other is 7 years old. My 18 year old daughter did so much work last year she received an award for 80 % average in her subjects. I was expecting more of the same this season. She has skipped school many days however. The days she stays away are the ones that a paper is due. I have so much contact with her school still through all these exhausting years. I am always explaining and making up excuses for this 18-year-old ADHD kid. Every time she has a success, she has a failure the following week. I do not know her marks yet from her last term, however I fear it may not be good with all the problems that have been related to my daughter this first half of the year. Sincerely exhausted Mom in London, ON.

London, ON

As my daughter

Elizabeth turns 19 this May. I have been reflecting on our participation in the Special Needs Project. It has always been so much more than the money; the acknowledgment that having a 'special child' is slightly different to our other child, who is very special in his own way too! To having the contact with our advisors who truly care about what is happening in our lives and the lives of our children; and lets not forget Sharon Hope-Irwin, Gail, JoAnna, Dorothy and especially Jamie Kass, who all keep us going! I will never be able to thank my union members – past and present who support our childcare fund – who had the vision to see that this was necessary and to strive and succeed in implementing this! So there is a touch of sadness as Elizabeth and I are 'Moving On' but there is also the joy and happiness in having been part of this for many years and knowing that there will be joy and happiness for other parents and their children.

Hugs and Solidarity,

Coburg, ON

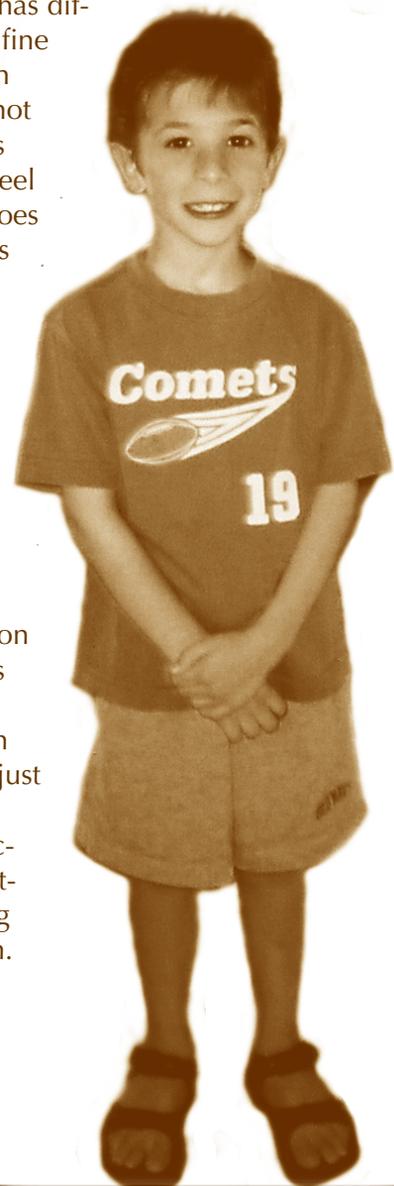
My husband and I

would like to thank the Special Needs Project for offering financial aid to CUPW members that have children with disabilities. We would also like to thank our advisor, Sheila, for her knowledge and understanding.

Our nine-year-old son, Jacob, was born 9 weeks premature. Jake has been diagnosed with a severe learning disability and ADHD. He also has difficulties with his fine motor skills. Even though Jake cannot tie his own shoes or ride a two-wheel bicycle yet, he does have a gregarious personality and the most beautiful brown eyes. The Special Needs Project has enabled us to obtain much-needed tutoring for Jacob. Jake attended Sylvan Learning Centre on a bi-weekly basis for the past several years. Sylvan Learning Centre just awarded Jake a certificate for successfully completing the Beginning Reading program.

We attribute many of Jake's achievements to the direct support of the Special Needs Project. My husband and I feel that the Special Needs Project should take great pride in knowing they have assisted a lot of exceptional children with overcoming their barriers.

Barrie, ON





My own experiences living with an undiagnosed and then untreated hearing loss child for four years have made me aware of the importance of early detection. Disability has come a little further out of the closet because today there are supports for families that were not there in early years including audiologist assessments, electronic improvements in hearing aids, FM systems, speech therapists, teachers of the deaf and hard of hearing.

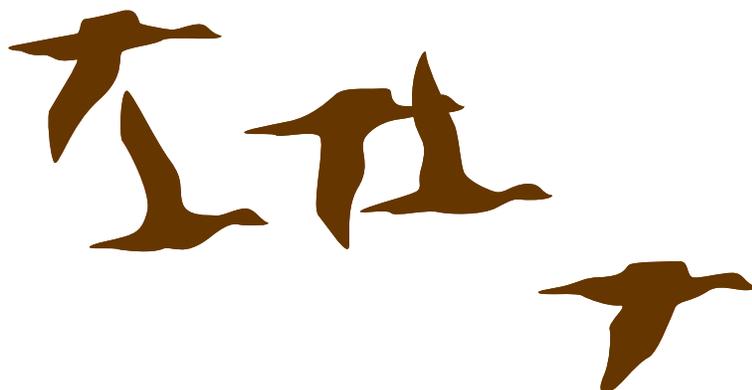
How I Feel, by Brittaney Amponsah, Age 12

Having a hearing aid has been a challenging experience and having other people who have gone through the same things has helped me so much. I was born with a mild to moderate loss in both ears. I learned to lip read and speak without help of a hearing aid. My parents did their best by taking me to doctors to be tested and all came negative until at the age of four. I quite remember the first time my parents took me to a conference with other kids who were also hard of hearing. I was filled with excitement but also nervous. But as soon as I walked in that room I found that everyone treats you kindly and that you feel at home. From my perspective as a hard of hearing person, improving a child's ability to hear and to comprehend his or her world is one of the important contributions we can make to the child and his or her family. It is not enough to say we can do better we must do better. My sincere thanks goes to Special Needs Project, which advises and supports me financially. Because of Special Needs Project, I have improved in my studies and socialized much better.

Coquitlam, BC

I used Special Needs funding to get initial testing done with Dr. Phillip Souvestre of Vancouver. Doctor Souvestre is an expert at restoring the function of people that have suffered a concussion (or hypoxia incident). He explained that a lack of function is either caused by damage, resulting in scar tissue forming, or destruction. Neurological dysfunction occurs when the brain shuts down certain systems even though the tissues are okay. Stimulation of the nerve ganglions (using non-invasive methods) can result in a full restoration of function. My son has improved greatly as a result of this treatment. So far we have reduced the neurological dysfunction by 1/2. Tom is one of the lucky ones that have no damage – only dysfunction. Dr. Souvestre has had staggering good success recently with a little girl that had epilepsy. Her story can be seen at Dr. Souvestre's website at www.neurokinetics.com. Sadly, Dr. Souvestre's work falls outside the scope of regular medical plans.

Burnaby, BC



I am confident that the Special Needs Project of CUPW is a very useful project. This project helped us financially, emotionally and psychologically. Now I can feel that we are not alone. There are many other parents like us who also have children with disabilities. I personally appreciate this project a lot. The Special Needs Project allowed my son to attend the diabetic children's association in Vancouver BC. Thanks.

Surrey, BC

We would like to thank Andrew Fleck Child Care Services in Ottawa for letting us reprint this article. Alexandre Simard is the son of Nicole Delorme, a UPCE-PSAC member and part of the Moving On Project.

Where are they now?

Through a series of articles, the CISS (Children's Integration Support Services) team takes a look at some of the children that they have supported through the years to discover "where are they now"?

Who:

Alexandre Simard born June 8th 1986, with Down Syndrome, a ventricular septal defect and Hirschsprung's disease for which he had surgery at 5 days old. He has an older sister and he lives with his mother.



Supports in the Early Years:

Alexandre received Occupational and Speech-Language Therapy supports at a young age. He attended Gloucester Home Child Care, went on to Aladin Child Care Services with supports of a Resource Teacher. He learned how to walk, within two months, due to the inspiration of his peer models. He then returned to GHCC where he received supports from Children's Integration Support Services. He also participated in a behavioural program pilot project called Positive Reinforcement at CHEO.

Supports in the School Years:

Alexandre was integrated in regular class settings at both l'École des Pionniers and l'École Arc-en-Ciel and attended the before and after school program offered by la Coccinelle. Supports from CISS continued in the licensed program. He attended summer camps through the City of Ottawa and MIFO, a French Cultural Centre. Next, he attended l'École secondaire Garneau. At the age of 13, his mother and his sister began to teach him the skills to enable him to stay home alone before and after school, as well as during PD Days. He learned how to use the microwave and when not to answer the telephone or the door. At the age of 15, he was able to stay home by himself for 3 PD days. In July of 2003, through a subsidy from The Canadian Union of Postal Worker's Special Needs Project, he was able to get home tutorial support for his English.

In September of 2003 through a program at his high school, he had Co-op work experiences at la Résidence Belcourt, the Orleans Complex, his school's cafeteria and others.

Recreational and Life Experiences:

Alexandre enjoys cooking and baking because he loves to eat pizza, cookies and muffins. He is very skilled at vacuuming the house and washing the dishes. He also enjoys bowling and had joined a league. Curling has become one of his favorite interests; he has been playing once a week, for the last four years, including tournaments in Kingston. Alexandre participates in the "Can Do Sports" program at the YMCA once a week and plays softball with the 'Challengers' during the summer. He knows how to use the cellular phone that he received for his 18th birthday.



Present Accomplishments:

In the summer of 2004, he participated in an intergenerational program at la Résidence Saint-Louis where he volunteered for 40 hours of community work. His responsibilities include selling ice cream, helping the residents at meal times, reading stories and so on.

During the last three summers, he has also participated in a program called "Ado au Boulot" which gave him the opportunity to work at the Your Independent Grocer in Orléans where he was teamed-up with a "job-coach". He had to travel to and from his job site by OC Transpo and received a \$20.00 a week pay.

Hi, all members. Book Corner

We are glad to have the CUPW/UPCE-PSAC Special Needs Project as our helper. Having a hyperactive autistic child is a great blessing, but means high challenge. Julian now is improving with more focus and attention. We absolutely think that gluten free and yeast free products are helping our child. We hope Julian's improvement continues every day. The diet, the natural remedies such as valerian root and probiotics, and the music therapy with personalized music are making a big difference in Julian's life. So please parents of an autistic child, get information and read about these topics. The decision is yours to make.

Lethbridge, AB

Battle Cries: Justice for Kids with Special Needs
By Miriam Edelson; Sumach Press, Toronto. 2005

In the first sentence of Miriam Edelson's *Battle Cries*, we learn that her son, Jake, died while she was writing this book. Jake had a serious neurological disorder. Yet this amazing woman continued on to complete this work, an expression of her vision of a society where children with disabilities and their families enjoy lives of respect, dignity and comfort in a supportive community.

Battle Cries is an involved book. The first section briefly introduces us to the eight families that Miriam interviewed for this work. The author then discusses topics such as services and supports, funding, social model of disability, respite care, integration and citizen engagement. These are all important and challenging issues, but do make for serious reading.

Most readers will want to know more about the families and will be satisfied and captivated by the personal stories in the second section of the book. Here we meet families who live in Toronto, Winnipeg, Victoria, Ottawa, St. John's and Stockholm, Sweden. The families include Mathieu, who has two children with severe hearing loss; Sharon, whose daughter lives with a form of cerebral palsy that affects her digestive system; Mary Ellen and her son who was born with Down Syndrome; and Lillian and her son with profound brain damage.

Through sensitive and well written portraits, we hear each family's story: birth, services, education, family relationships, community, advocacy and planning for the future. We learn of family struggles, frustrations and accomplishments. Miriam weaves the story of her own family and life with Jake throughout all of the interviews and portraits.

We also hear of the inadequacies and challenges of the health, social service and education systems across this country. The author provides hope and inspiration for change through the last portrait: Dave and Lisa. Dave is a Canadian father living with his multiply-disabled daughter in Sweden. Miriam describes the Swedish support system that includes funded respite care and personal assistance with government wage scales that help insure consistent caregivers.

The final section of the book "Some Tips About Advocacy" is a must-read for families. This book has something for everyone: parents whose sons or daughters have disabilities, service providers, social justice advocates and community members. Don't miss it!

The Child Care Fund is administered by the Canadian Union of Postal Workers and financed by the Canada Post Corporation.



Forced Overtime a Problem?

Traditionally, letter carriers have been required to finish delivering mail on their routes, regardless of the volume of mail. However, some members have commitments such as child care or appointments with doctors that make it very difficult to work extra hours. Parents of children with special needs may have more of these special commitments than other members.

In the 2003 contract negotiations, Canada Post (CPC) gave CUPW a letter in which CPC Vice-President Mary Traversy committed to the Union that, "In the case of family problems, appointments, or other legitimate personal needs, efforts should be made to offer the work, on a voluntary basis, to other letter carriers in the installation instead of the holder of the route, either through overtime or additional hours."

The letter goes on to say, "For those situations where an employee is working overtime virtually every day, the supervisor needs to intervene to see what corrective actions can be taken to eliminate the problem with the route."

Parents of children with special needs who face forced overtime situations may be able to make use of this letter to help get their route problems corrected or to avoid a conflict with an appointment or childcare commitments on a particular day.

Special leave, under Article 21 of the Urban Operations contract may be appropriate in some situations. Those with problem routes can also ask for a verification of their routes under Article 50 of the contract.

If you need a copy of the forced overtime letter, or want more information about special leave or about requesting an Article 50 verification, ask your shop steward or call your local CUPW office.



Here is an article about our support group choir – The Filipino Canadian Autism Support Group. There are four children whose parent's work with Canada Post.

Excerpt from Filipiniana News, October 2005:
"Research shows that music has now become a tool for people with communication deficiencies to express themselves. It has been used to treat children with speech difficulties. It is therefore in this concept and innovative idea of learning that the Filipino-Canadian Autism Parent Support Group (FCAPSG) formed a choir consisting of autistic individuals and their families. The choir is one of a kind in Ontario and is funded by The Ontario Trillium Foundation. On Sunday, September 18th, 2005 The Filipino Canadian Autism Parent Support Group (FCAPSG) held their Second Music Festival in Bramalea, Ontario with over 200 people in attendance."

Thanks

Mississauga, ON

Although she spends a lot of time at Sick Kids, my daughter still wants to become a doctor and work there. Because of the Special Needs Project we can get her the tutoring she needs. She may one day reach her goal. The financial relief alone is a God-send. The extra help has relieved a lot of stress for both of us. Seeing the joy on my daughter's face with her first ever B on a school paper makes it all worth while. Thank you CUPW.

West Hill, ON

There are two things that really helped my son Thomas who is 10 years old and autistic. One is the picture exchange system; the other is hyperbaric oxygen therapy. I would like to connect with families who live in Ontario, Toronto-Hamilton area and have an autistic child. Please send me an email or call me. Thank you to the Special Needs Project for helping and making all this possible.

Maple Ridge, BC



Hi, I'm sending you some pictures of our daughter Martine. Thanks to the Special Needs Program, we can enroll Martine in various sports such as skiing, track and field and bowling. It's very good for her self-esteem, her confidence and her social and physical development. For her as for most teens, it's very satisfying to belong to a group of peers. Through her skiing club "Les Harfangs de Stoneham", she has the opportunity to ski and run competitively in a number of cities in Quebec. This gives her a great sense of belonging. Because of this financial support, we can help our daughter Martine develop her skills to her full potential. Thank you very much.



Beauport, QC

Thanks to the Special Needs Project for the report of our son, Gabriel that was posted in Member-to-Member Connection. Reading all the people's letters, their emotions and experiences makes us more strong and we can overcome the very difficult times that we face daily with our lovely autistic son Gabriel. Thanks for the financial support from the Special Needs Project.

Toronto, ON

Websites to note:

Inclusion Tool Kit

The New Brunswick Association for Community Living is involved in a community inclusion project which is funded by Human Resources Development Canada. Check out the project's bilingual website at www.inclusiontoolkit.com. This virtual tool kit provides information, tips, strategies and resources to help create inclusive communities. Check to see if your local ACL has a kit you might borrow.

Centre of Knowledge on Healthy Child Development

The Centre of Knowledge on Healthy Child Development gives parents and others access to important and up-to-date information on child and youth mental health issues. Information is based on the best scientific research currently available. The website is designed to help you sort through all the conflicting information about what promotes, and what hinders, healthy child development so you can make better choices that will result in better outcomes for children. Check out information on moods, anxiety, behaviour and attention, development and learning at this site created by the Offord Centre of Child Studies at McMaster: <http://knowledge.offordcentre.com/>

Health videos in American Sign Language

The Ontario Government has health videos in American Sign Language, including info about West Nile Virus. Visit http://www.health.gov.on.ca/english/public/program/pubhealth/westnile/wnv_facts_asl.html

Disability savings plan

The Federal Government acknowledged one of families' greatest concerns - securing the future - when Minister Flaherty tabled the budget on May 2, 2006. Minister Flaherty made the following commitment: "An important consideration for parents and grandparents of a child with severe disabilities is how best to ensure the financial security of their child, when they are no longer able to provide support. The Minister of Finance will appoint a small group of experts to examine ways to help parents save for the long-term financial security of a child with severe disabilities, and provide their recommendations to the Minister within six months."

The budget included several additional disability related measures, including:

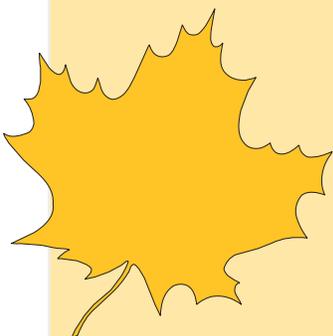
- A commitment to implement additional measures recommended by the Technical Advisory Committee in their final report
- Improvements to the Child Disability Benefit
- An increase in the refundable Medical Expense Supplement
- Doubling the disability-related expenses that can be claimed by a caregiver.

Source: PLAN's website:

http://www.plan.ca/SocialPolicy_PolicyUpdates.php

Have you signed the petition "Create A Disability Savings Plan" to the Prime Minister? This petition was created by Planned Lifetime Advocacy Network and written by Jack Styan. Over 4,000 people have already signed the petition. You can find the petition at www.petitiononline.com/2603655/petition.html





Advisor Profile: Anne Grewar, Manitoba Special Needs Advisor

“What an honour!” was Anne’s response when asked if she would be the featured Advisor for this Member-to-Member Connection Newsletter.



Anne’s response describes her enjoyment and appreciation working as an Advisor for the Special Needs Project. Over nine years ago, Anne was approached by Sharon Hope Irwin to be the Manitoba Advisor for the Project. Since that time, Anne has been an Advisor to members in Manitoba, all living in Winnipeg. Just recently a member from outside the city joined the Project. Anne currently is the Advisor to 13 Manitoba members.

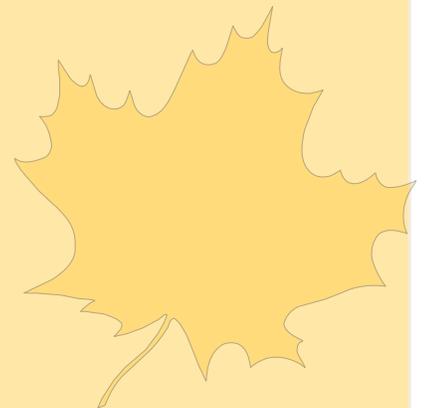
For Anne, the best part of being a Special Needs Advisor is talking and supporting members. When Anne phones members, she feels like she is talking to “old friends.” And Anne has grown with many of these members, as their children move from preschool to elementary school through high school and beyond.

When *Moving Mountains* was launched in Winnipeg, Anne was there and met two of the Winnipeg members in the Project. Anne hopes someday to meet all of the members and families she knows through the Project.

Anne works full time as the Child Care Resource Coordinator at The Family Centre in Winnipeg. She also teaches in the “Studies in Special Needs Child Care” program through distance education at Red River College. Anne is able to connect all of her work, sharing resources and information about programs and supports for families. All of the students in Red River College’s program now receive copies of *Moving Mountains* in their course resource package!

Anne married her best friend and nine years ago they adopted a little girl. Anne enjoys many activities with her family, including skiing, biking and swimming. Last summer the family spent many mosquito-free weeks at their cottage in Lac du Bonnet on the Winnipeg River.

Anne is thrilled to be part of the Special Needs Project. Her open and sharing approach enable her to both give and learn from members. The “honour” is ours, Anne!



Pre-authorization

Our members regularly submit receipts to Great West Life only to have them returned without reimbursement. This is often because Great West Life requires further medical documentation before paying out any money. This process can take awhile.

To avoid delays in receiving reimbursement, it is wise to get pre-authorization for any important dental work, expensive or new drugs and treatment and even the purchase of medical supplies. While not always necessary, getting pre-authorization allows you to know up front what is covered or what else you need to get from your doctor to have a claim reimbursed. You may find that certain drugs are only covered at a certain dosage (250 mg vs. 500 mg) or by a certain method (orally vs. injection). By seeking pre-authorization first, you and your doctor will be able to make a better and more informed decision.

As with anything, it is important to get pre-authorization in writing. If any problems arise after submitting a claim, having the pre-authorization from Great West Life will help tremendously.

It is important to note that members have to fill out a pre-authorization form for certain drugs Great West Life covers. Drugs automatically needing pre-authorization include:

- Anti-obesity drugs,
- Fludara,
- Thyrogen,
- Botox,
- Gleevec,
- Fuzeon, and
- Remicade/Kineret/Enbrel.

Special Leave

Two myths are currently circling around the issue of special leave. One myth has been around for a very long time and the other is recent. Myth number one is that it takes a letter from a supreme being in order for Canada Post to approve special leave. Myth number two is that if I belong to CUPW's Special Needs Program, I cannot be denied special leave. While opposing, both myths are incorrect.

What is special leave?

Special leave is paid leave to be used "when circumstances not directly attributable to the employee, including but not limited to illness in the immediate family....prevent his or her reporting for duty." Arbitrators have found that this leave covers parents taking their children to out-of-town pre-arranged medical appointments.

Is special leave automatic if I am in the Special Needs Project?

No, special leave is not automatic. You must apply and submit documentation proving the circumstances of your absence. This could mean getting a doctor's note regarding an appointment or a statement from your usual caregiver stating they were ill. You also need to prove that you had no alternative care and had to attend to the matter yourself. For example, it might be necessary to speak with your child's doctor about how she/he is coping with new medication or treatment. When the matter is of an ongoing nature you need to submit proof that alternate care arrangements could not be made. For example, our Extended Health Care Plan covers private duty nursing. Arbitrators look at whether an attempt was made to arrange for alternate care.

What if I need help?

When in doubt about whether you are entitled to special leave, apply. Unfortunately, many of our members are denied. If you are refused, contact your local to see if you have grounds for a grievance.



All photos are from members unless otherwise indicated.