CILT's Parenting with a Disability Bulletin

Volume 7 Issue 4
December 2004

PDN ACTIVITIES

2nd Annual Mid-Winter Get Together & Family Social

Mark your calendars!

The PDN and Prime Timers are joining forces once again to host the 2nd Annual Mid-Winter Get Together on **Saturday, February 12, 2005 at CILT.**

Come join us for food and live music by the dynamic duo, Melody Mist.
Stay tuned for more details coming to your mailbox in January!

Seasons Greetings!

The PDN and CILT wish you and your family a safe and Happy Holiday!

BIRTH ANNOUNCEMENTS

The PDN is thrilled to announce two new family additions!!

IT'S A BOY!

Congratulations to PDN member Nilta Romao Chiotti and her husband Andre, proud parents of Dylan Francois Romao Chiotti. Dylan was born at 8:06 am on October 31, 2004 at Mount Sinai Hospital, weighing a healthy 7 lbs, 5 oz. Dylan's parents say he is absolutely "perfect" and everyone is doing well!

IT'S A GIRL!

Congratulations to the Fearnley family! We are pleased to announce the birth of Moira Anne Fearnley, daughter to PDN member Susan and her husband Derek Fearnley. Moira Anne was born on December 2, 2004 weighing a healthy 6lbs, 12 oz. Both mom and baby are doing well!

PARENT'S CORNER

Parenting - imagine the possibilities!!

By Lynda Roy

On October 23rd and 24th a truly remarkable event took place in Toronto. A convention was held on a rare neuromuscular disorder called Nemaline Myopathy (NM). The event took over a year to organize and was comprised of four organizers - three of them local!

This convention was remarkable for several reasons. To begin with, it was the first convention specifically dedicated to NM. For my sister and I, this was extremely significant as we had been on a journey that had started four and a half years ago, when in the spring of 2000, my younger sister who also has NM, was hospitalized with respiratory failure. For the first time in years we were once again exposed to the medical community and realized quickly that we both needed to do some research into our disorder to better advocate for ourselves in the future. Secondly, the whole concept of a convention had literally evolved out of a relatively small e-group founded five years ago by a man in Edinburgh, Scotland who also has the disorder. To date, this e-group has 106 members registered from around the world. Taking into consideration the size of the e-group what is most impressive is that the NM convention drew in 78 participants and four researchers as well as other speakers on a variety of related topics. The fundraising, marketing and planning was, for the most part, organized by four individuals with a personal stake in the success of this convention. In retrospect, what is truly amazing, is that a small internet community of individuals and families whose only commonality was a rare neuromuscular disorder could come together and share ideas, information and provide support.

Admittedly, however, in the beginning stages of organizing this convention the fact that none of us were really affiliated with a charitable organization or hospital proved to be a point of great distress and seemingly insurmountable obstacles. How were we going to raise funds without being a registered charity? How would we get researchers on board to speak at our convention? Most importantly how could we plan a convention that would provide both the research based information that was so necessary to so many of us and also provide a forum to explore other aspects of living with a neuromuscular disorder. What became apparent very early on was that each of the organizers would contribute not only their expertise but also part of their own personal history into the process.

As stated earlier, my sister and I both have this disorder and have had it since birth. As many can appreciate, living with a rare neuromuscular disorder has its uncertainties, particularly in terms of what is in store for the future. Also, having a rare disorder, I feel, made us more vulnerable to being medicalized. In various times throughout both our lives I remember being labelled as "a very interesting case." As a result we were often subjected to a medical culture that would expose us to discourse that would compartmentalize our bodies. Also, not having a lot of information at our disposal left us more vulnerable to medical intervention. We would comply in the hopes of possibly gaining more information. Over time however, I began to internalize this in a variety of ways, some of which would be self-apparent and some of which would become so innate that I would not even question my own beliefs. Ultimately, for me, the experience of being medicalized meant that, during my adolescence and early adulthood, I drew my focus inwards to what my body could not do rather than outward to what structural supports could help me accomplish a richer and fuller life.

So, when I began to contemplate whether or not I wanted to have children I can remember some of the thoughts I had on this subject. I worried about the pregnancy and giving birth. Would this further reduce my own physical abilities? I had attended a segregated school throughout my primary school years and the one positive aspect of this experience was that I had come in contact with a wide circle of young people with disabilities. Some of my own friends had older sisters with neuromuscular disorders who had children. I felt comfortable that while my disability had a different label there were enough similarities to make me confident that it was physically possible to conceive and carry a pregnancy to term without long-term consequences. However, as my disorder was rare and my future uncertain, I wanted more information on the types of supports that were out there in case my abilities changed over time. My experience of having a rare disorder has meant that I also worry tremendously about the future. Sadly, my worries translated into decisions of not having children. I could not live in the moment. My focus was solely on what the future might have in store.

In the planning of this convention it became apparent that most of us confuse the ability to conceive and carry to term with actual parenting. However, these are two distinct issues. Some of us can and some of us cannot safely carry a pregnancy to term. Some of us have very few problems with a pregnancy but the actual physical needs of a child may be hard or even impossible to carry out. Realizing this we contacted CILT's Parenting with a Disability Network for suggestions and they referred us to Enza Ronaldi, a mother of two healthy children who happens to have spinal muscular atrophy. We wanted someone with an obvious mobility disability because we wanted to convey to young women, men and parents of children with NM that parenting was indeed an option to consider in the future. We felt it was extremely important that the person have an obvious mobility disability because parenting is more than just taking care of the physical aspects of a child. Good parenting is providing a safe, loving and nurturing atmosphere for a child.

Enza shared her own personal experiences of going through genetic counselling, the decision-making process and ultimately the birth of her first and then her second child. She also discussed the supports she insured were in place before becoming a parent.

At the end of her talk we, the organizing committee received some very positive feedback about the presentation. Participants from other parts of Canada, the United States and the UK were extremely impressed with Ontario’s Nurturing Assistance Project which, as Enza explained, was a time limited service designed to provide physical assistance for parent(s) with a disability. Enza also elaborated that the program was NOT a baby-sitting service but that it was, as the name of the program name suggests, *assistance* which was designed to insure that physical assistance was given under the direction of the parent who was present at all times. Perhaps the most important message of this presentation was that nurturing is not simply changing a diaper. If nurturing were simply looking after our physical needs then many of us would have an extraordinary attachment to personal support workers! Nurturing is being able to give your child a sense of security and love that comes from spending quality time together.

That evening, following Enza’s presentation, many of us met informally over dinner and drinks and the topic of Nurturing Assistance came up yet again. Many expressed enthusiasm and were extremely impressed with the program. A few indicated they would bring information about this model back to their own community. As the convention drew to a close my sister and I began to reflect back on what had brought us to this point. We had stumbled across an internet site created across the pond in Scotland. With very little resources and formal support a group formed and a convention evolved that brought together not only leading researchers into the study of NM but also people with neuromuscular disorders living life in a variety of different ways but living life well.

In closing I would like to make one last point. Recently, the media has been focusing on the negative aspects of the Internet. However, I have been involved with something that I strongly believe would not have been possible without the Internet. If a cluster of people can get together over cyberspace and create a vision of a convention and see it through to its completion then the possibilities for more formal social movements holds many promises - imagine the possibilities!!

Discipline and Teens

The following article originally appeared in the February 1999 issue of the Parenting with a Disability Bulletin.

My name is Ora Prilleltensky. I am a mother with a physical disability and a psychologist who has worked with children and their parents. The Parenting with a Disability Network Coordinator has asked me to respond to some parenting questions posed by a parent with a mobility impairment. Like most other things in life, these questions do not have simple, clear-cut solutions - and I certainly do not purport to have the perfect answers. However, it may provide some food for thought as we cope with the joys and tribulations of parenthood.

1. How do parents with teenagers deal with "attitude"?

Recognize that you are in good company! Having what is humorously called "a kid with an attitude" is shared by many, if not most, parents of teenagers. Several years ago I ran a focus group for mothers with disabilities where many humorous stories were shared about attitude problems and about "raging hormone syndrome."

Humour aside, it is important to distinguish between a healthy dose of disagreement and even rebellion against certain parental beliefs, and outright defiance and disregard for parents. Going through a stage where almost everything mom and dad say is debated and contested is irritating yet harmless and, perhaps, even useful.

In the process of developing their identities, teenagers sometimes need to clarify for themselves what they stand for and against - and home represents the best training ground!

On the other hand, there is attitude and there is attitude, and it is important to know where to draw the line for children. Families differ in what they tolerate and find acceptable in terms of children's behaviour. It is important to decide where you stand and to give a clear message about what the limits are and what is the consequence for crossing them.

Parents and children alike have a right to be treated with dignity and respect. Rude, insulting and/or impudent behaviour should not be brushed off as "teenage attitude". For the well being of our children, as well as our own, we need to give them a clear message that we have certain behavioural expectations and that certain privileges (allowance, use of the family car, etc.) are contingent upon meeting these expectations.

The main issue to understand is that there should be clear boundaries, and they need to be clearly communicated.

2. What do you do when you cannot go looking for a truant/late arriving teen?

Parents with disabilities can have very similar parenting issues to their non-disabled counterparts. However, as this question suggests, having a disability can certainly make some parental tasks more_difficult to perform. Generally speaking, it is much better to be proactive and deal with minor infractions than to wait until a child's behaviour is out of control.

In other words, a curfew that has been discussed, negotiated and agreed upon by the parents and the teenager has to be maintained. Being very clear about what the curfew is and what the consequences are for not meeting it should suffice in most situations.

Under normal circumstances, parents, disabled or non-disabled, should not have to go and look for late arriving teens. Nor should they train their teens to expect this "search service".

Of course, there are situations that warrant going out and looking for a teenager, primarily when parents have reasons to suspect that their youngster may be at risk. In those situations, non-disabled parents may indeed have an easier time than disabled parents. Knowing yourself, your youngster and the particulars of your disability will allow you to make a plan for those rare occasions when you know that you do indeed have to go looking for your teenager. Making "emergency plans" with a friend or a trusted neighbour can give you some peace of mind. However, it is important to keep in mind that this is a "just in case" plan rather than a solution.

Any parent, disabled or non- disabled, should be concerned if their teenager is truant and does not adhere to curfews on a regular basis. A youngster who skips school and is away from home for hours at a time without the parents knowing of his or her whereabouts likely needs more intensive intervention. Knowing when to reach out for professional help is an important component of being a responsible and responsive parent.

3. How do you deal with messy floors of teen space when a wheelchair cannot walk over/around it?

Many a parent has lamented, at one time or another, about the catastrophic state of her child's bedroom. A parent who is also a wheelchair user is further challenged by the physical barriers that such a mess can create. As with most other family matters, parents have varying degrees of tolerance for "teenage mess" and will therefore choose to handle these matters accordingly. One parent

I know decided to "let that one go" in order to lessen the level of conflict between herself and her daughter. The two were having many disagreements and she decided that this was a battle not worth fighting. She drew the line, however, at having her daughter eat in her room and leave dirty dishes. The message was "Your room is your own, but the house belongs to all of us and we don't want bugs and other unwelcome guests marching through it". Cleaning arrangements were left entirely up to the daughter.

Other parents may be uncomfortable with such a laid back attitude and may insist that the room be cleaned at least once a week. The important thing is to decide what you are comfortable with and what you can live with - and communicate this to your teenager. For families to work and live together, everyone has to be willing to give and take a little and consider their own needs as well as the needs of other family members.

As to the accessibility issue, a parent who is a wheelchair user will have to decide how important it is for her to be able to wheel around in her teen's bedroom. If it is important - then it should be conveyed in no uncertain terms.

My own pre-adolescent son knows that although I walk, I shuffle my feet and cannot step over the various things that he leaves lying around. I do need to go into his bedroom in order to help him with homework, organization, etc. and I therefore insist that these items be picked up before I enter. As with everything else, what works for me may not work for someone else.

10 Ways to help your Teenager Develop Self-Discipline

By Diane Wolf

Reprinted from www.dianewolf.com with permission.

1. Don't rescue.

As difficult as it is to watch our teens flounder, it is far worse to raise young adults who cannot take responsibility for their actions and expect Mom or Dad to rescue them. This is a lot easier to enforce when they are young and the consequences of their actions are less serious. I would rather have a child in Grade 5 forget a lunch and have to rely on classmates to share, than to have a high school student forget a major essay at home on the day it is due! If you are always reminding your children to take their lunch, books etc., then don't be surprised when your teenager is calling for you to bring his gym bag or science project. As tough as it seems, you can't always be available to rescue your child, so let them learn that early.

2. Gradually work yourself out of a job.

I believe it was the late Erma Bombeck who described parenting as gradually becoming redundant. By the time your teens reach young adulthood, you will want to make that transition from parent/advisor to friend. It is easier to go through this process if it is gradual. Start when they are young to let them make decisions about clothing etc. so that when they are this age they are experienced decision makers.

3. Let them experience the consequences of their own actions

Whenever possible (and if not dangerous), let them experience the consequences of their own actions. It may be really obvious to you that your teen cannot possibly do a complete essay in 2 hours on Sunday evening, but nagging him all weekend will only make YOU the bad guy. Why not let him discover on his own just how un-glamourous pulling an all-nighter really is!

4. Give one word reminders.

Teenagers have a notoriously short attention span, especially for nagging. Saying just one word "Garbage" is really more effective than a 5 minute lecture on the importance of taking responsibility, or a litany of all the chores you had to do when you were her age. They really do tune out after the first word or so, so make it count!

5. Trust them in the little things, and let them grow.

It is human nature that we tend to live up to the expectations placed upon us. If someone believes that I am dependable, it makes me really want to be as dependable as possible. So show your teen that you trust them by giving them opportunities to prove they are trustworthy. If your teen has shown in the past that he or she is NOT trustworthy, give them the chance to become trustworthy by starting small and working up to more important tasks.

6. Keep your sense of humour.

Don't take yourself too seriously. If your teen thinks you are the meanest parent in the world, don't take it personally. I used to tell my kids that I graduated top of my class in meanness school, and I was glad that they didn't think I needed a refresher. This was NOT said sarcastically, but with a smile and warmth. The message came through that telling me I am mean is NOT an insult.

7. Give them regular responsibilities.

Running a household is a job requiring a TEAM effort, whether or not there is a full-time parent in the home. Make your teen feel that they are an important player on the team by giving them tasks that are significant to the well-being of the family. I bet you have never looked at setting the table or taking out the garbage quite that way before.

8. Pick your battles wisely.

The teenage years are an emotional mine field. Don't turn every issue into a Waterloo. Decide which things are REALLY important and don't worry about the little things. As Ann Landers said "Don't sweat the small stuff." For example, you may decide that body piercing is absolutely taboo, but then ease up on make-up or hair colour.

9. Insist on excellence.

There is a common strategy among teens and children to avoid having to do chores by doing them so poorly, that we give up and decide it is easier to do the job ourselves. Don't give in, this is a scam! Teach your teen the standard you expect for the task, and insist that it is done to that standard or it will need to be redone. It may take 6 weeks of agony and constant inspection, but they will eventually learn that it is easier to do it right the first time, than to re-do it 10 times.

10. Always give unconditional love.

We need to separate the feeling of love from the deliberate choice to show love. We can't always FEEL very loving, but our teens need to know that we will love and support them NO MATTER WHAT! Love is not a reward for a job well-done, it is a constant state of being accepted by our families, when things go well and when our flaws are obvious, warts and all.

Husband Abuse: An Overview of Research and Perspectives

Written by Leslie Tutty for the Family of Violence Prevention Unit, Health Canada.

Health Canada did a recent study on "husband abuse." No issue has divided researchers and front-line service providers in the violence prevention and shelter movements as much as husband abuse. However, even the most vocal advocates of the view that husband abuse is not a significant social issue in Canada don’t deny that some men are indeed abused by women partners. The existence of husband abuse is not an issue; the debate centers around how common it is and the degree of harm inflicted.

It took a long time before the issue of wife assault was taken seriously; people used to chuckle when the term "wife assault" was first mentioned. Now, wife abuse/battering is realized as a significant social problem that demands serious attention. Recently, men's advocates have started asking whether husband abuse does not deserve similar attention. If husband abuse is more serious and more widespread than we think, should new policies and services be developed to address men's abuse in the same way that services for women have become available? Then you add the disability factor into the bag and you really have a social problem rendering immediate attention.

This study on husband abuse in Canada raises questions about the controversial issue of men who are abused by their intimate partners. The study examines three sources: (1) research on husband abuse and gaps in our knowledge about the issue; (2) a summary of the few studies in which abused men describe their experiences; and (3) conversations with representatives from approximately 40 family violence treatment programs and men's issues groups. The overview concludes with suggestions about where male abuse victims can seek help and some policy implications of acknowledging husband abuse.

CILT has a copy of this paper in our Resource Library. If you would like to take a look at it, please contact Susan DeLaurier at library@cilt.ca.

UPCOMING EVENTS

OMOD Geneva Park Winter Weekend

January 28-30 & February 25-27, 2005.

The Ontario March of Dimes (OMOD) invites consumers to join new and old friends at the YMCA's Geneva Park Conference & Resort Centre in Orillia.

Come out, relax and have some fun in an accessible environment. Vacationers are encouraged to participate in and enjoy the great Canadian outdoors.

Indoor and outdoor activities such as dog sledding, ice fishing, arts & crafts, and socializing provide an unforgettable wintertime experience.*

Attendants will be on staff to provide attendant services as required.

For more information, call Indra Parsan at **416-425-3463 x360**.

**Some activities are subject to favourable weather conditions.*

COMMUNITY

2005 Access Awards

The City of Toronto is calling for nominations for the 2005 Access Equity and Human Rights Awards. Among the awards being presented is the Access Award.

The Access Award is given to a person, group or organization that has significantly contributed to improving access for people with disabilities in the City of Toronto. "Access" can include designing new or renovated structures; an employment program; a transportation system; a recreational or leisure program; or anything that contributes significantly to people with disabilities living independently.

Do you know someone who has made a difference in the City of Toronto? Have their accomplishments recognized by nominating them for an award. Nominees must be residents of the City of Toronto.

The nomination deadline is March 15, 2005.

For information, please contact Diversity Management and Community Engagement, Strategic and Corporate Policy/Healthy City Office, Chief Administrator's Office, City Hall, 10th Floor East Tower, 100 Queen St. West, Toronto, ON M5H 2N2.

You can also contact the office by phone at 416-392-8592, TTY 416-338-0889, fax 416-696-3645 or email diversity@toronto.ca. Multilingual Services, call Access Toronto at 416-338-0338.

GET INVOLVED

SCCC Swim and Social Program for 2005

Mondays & Thursdays 6pm to 8:30pm

The Swim and Social Program is a social-recreational program for adults with physical disabilities. It is free of charge to any interested persons with disabilities who are a member of Scadding Court Community Centre (SCCC).

The Scadding Court Community Centre is wheelchair accessible with ramps and an elevator. Their Swim and Social program includes:

- an elevator chair that lowers you into the water

· Coffee, tea and fresh fruit before and after the swim

· The opportunity to meet new people and make new friends

Please note that this program cannot provide one-on-one care. Participants should make arrangements for attendants if they require such care/assistance.

For more information please contact Walter Quan or Mohsin Khattak at 416-392-0335.

Activate Your Winter at Birchmount Bluffs!

Birchmount Bluffs Neighbourhood Centre offers access to integrated and adapted active living and learning programs, and persons are free to participate at a level suitable to their ability and choice:

- **Chair Tai Chi**: enjoy the practice of low-impact movements in this gentle wellness class. Starts January 10, Mondays, 11:45 AM-12:45 PM. 10 weeks ($20).
- **Fitness and Wellness Classes**: the centre offers access to integrated and adapted fitness/wellness classes. Classes include yoga and Aqua Fitness, yoga in the hot tub, low impact fitness classes.
- **Stress-reduction Group:** practice easy to learn breathing and relaxation techniques that reduce stress in a safe, supportive group setting. 3rd Thursday of month, 2-3:30 PM (Free). Loaned audiotapes provided for home practice.
- **Workshops:** enjoy monthly workshops on a wide range of topics including health/wellness, self-advocacy, community services, etc. 3rd Tuesday of month, 2-4 PM (Free).
- **Barrier-free Access to Swimming Project**: this program begins Tuesday, January 25 and offers attendant-supported access to an integrated lane swim. Runs to early June. Tuesdays: noon-3:30 PM. For info, call: 416-690-8804 (free).
- **Information and referral Services**
- **Informal Counseling and Advocacy**
- **Workshops on disability-related topics**

The winter session begins the week of **Jan 3, 2005**, and registration began on December 6. Annual membership is $4 and subsidies are offered to offset program fees for those who face financial barriers.

Location: Birchmount Community Centre, 93 Birchmount Rd. (at Kingston Rd).

For more information, please contact David Meyers at **416-396-7606**.

United Nations International Day of Disabled Persons

The United Nations International Day of Disabled Persons is an annual day of observance, held on **December 3rd** with the aim to build a better understanding of the needs, rights, talents and contributions of over 600 million citizens with disabilities throughout the world.

This year's international theme was "Nothing About Us Without Us." In celebration of the day, the Canadian Association of Independent Living Centres held their 3rd annual national kick-off event in Ottawa and broadcasted it live over the Internet.

CILT invited its members and volunteers to join staff to celebrate the day by watching the live webcast from our office in Toronto. We had a large turnout and the event was a great success!

If you weren't able to take part in this year's celebration but would like to see the webcast, you can view the archived version by logging on to CAILC's website at www.cailc.ca.

Click on "International Day of Disabled Persons" on the homepage and follow the links!

WEBSITES

CANADIAN PARENTS

www.canadianparents.com

Provides a wide range of information on parenting and pregnancy. Includes messages boards, expert advice, recalls on baby and child products and more.

CANADIAN TOY TESTING COUNCIL

www.toy-testing.com

Focus is on learning through play. Produces annual report on best toys and recommended book, all tested by Canadian children.

NEMALINE MYOPATHY

www.davidmcd.btinternet.co.uk

Information about Nemaline Myopathy(NM), the 2004 NM convention, resources, discussion groups, FAQ and more.

PARENTING WITH A DISABILITY BULLETIN is a publication of the *Centre for Independent Living in Toronto (CILT) Inc.*

To become a member of *the Parenting with a Disability Network (PDN)* or to submit an article to the PARENTING BULLETIN, contact *CILT* at:__205 Richmond St. West, Suite 605, Toronto, Ontario M5V 1V3_Tel: 416-599-2458_Fax: 416-599-3555_TTY: 416-599-5077_E-mail: pdn@cilt.ca_Website: www.cilt.ca

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