



# C.H.A.N.G.E.S. Newsletter



## Down syndrome Support Group

**March 2004**

### C.H.A.N.G.E.S.

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### HENSON TRUST & FINANCIAL PLANNING WORKSHOP

Planning for your son/daughter's financial security.

*Speakers will be Peter Lillico L.L.B. & Linda O'Connor*

**DATE** - Wednesday April 14, 2004

**TIME** - 6:45-9 p.m.

**PLACE** - Five Counties Children's Centre  
872 Dutton St. Peterborough

**Registration is necessary. Seating is limited!**

Call Janet at C.H.A.N.G.E.S. 749-6695

**Childcare is available upon request**

### PLANNING FOR SUCCESS WORKSHOP

Strategies and skills to help the child with special needs to have the best possible opportunity to be successful in their learning

*Guest Speaker is Special Educator - Len Nicholson*

**DATE** - Thursday April 22, 2004

**TIME** - 6:45 - 9 p.m.

**PLACE** - Peterborough Library Community Room -  
Aylmer St. downstairs



**Registration is necessary. Seating is Limited!**

Call Janet at C.H.A.N.G.E.S. 749-6695

*Childcare is available upon request*

**Mission Statement:** To support each other in our quest to normalize and enrich the lives of our children so that they will reach their fullest potential.



## Valentine's Day Dance-A-Thon

C.H.A.N.G.E.S. and Crestwood School Band hosted a fundraiser at Sir Sandford Fleming College on Saturday, February 14<sup>th</sup>, 2004. It was an opportunity for our members and the school band members to dance and mingle and raise some much needed funds to support both organizations. There were 45 participants who

enjoyed a day of socialization and the chance to win some great prizes. Congratulations to Danielle Eales who won two ski passes to Devil's Elbow for collecting the most pledges.

Dancers donated over \$1,100 to C.H.A.N.G.E.S. to support their programs for people living with Down syndrome in the community.

Many, many thanks to those who generously pledged dollars and to the following who donated prizes and gifts in kind:

The Wolf 101.5  
Funtastic Promotions  
St. Veronus Café  
Last Tango  
Precision Optical  
Subway  
Jiffy Lube  
Craftworks  
Canada's Wonderland  
The Clarke Family

Shish-Kabob Hut  
McBain Wellness Consultants  
Great Blue Heron Charity Casino  
Rocky Ridge Drinking Water  
Community Service Order  
Spaghetti House  
Country Style Donuts  
Cottage Toys  
Devil's Elbow Ski Resort  
Baskin Robbins Ice Cream



*A special thank you to those members of the Crestwood School Band who collected pledges, volunteered and came out to dance! Thanks for making a difference!*

### Child Disability Benefit

The Child Disability Benefit (CDB) is a non-taxable supplement to the Canada Child Tax Benefit (CCTB) and the Children's Special Allowances (CSA). The CDB will provide up to \$133.33 per month (\$1600.00/year) to low and modest income families to help with the costs of raising children with a severe and prolonged mental or physical impairment. The first CDB payments will be issued to eligible families and agencies in March 2004, and will include a retroactive amount for the period of July 2003 to March 2004.

**Who can receive the CDB?** Not all children with disabilities will qualify for the benefit. In addition to being eligible to receive the CCTB for your child, the child must also qualify for the disability amount. The disability amount, also known as the Disability Tax Credit, is a non-refundable tax credit that reduces the amount of income tax that an individual has to pay. Form T2201, Disability Tax Credit Certificate, explains the eligibility criteria.

More information can be found at [www.ccra.gc.ca/cdb](http://www.ccra.gc.ca/cdb), or by calling 1-800-387-1193 for service in English or 1-800-387-1194 for service in French.

### Andrea's New Job

Hello, my name is Andrea and I want to tell you about my job. Every other Monday, I go to work at Community Care. My job at Community Care is shredding. I have to put the pieces of paper into the machine and turn the machine on. After all this is done, the paper is shredded. When I am done shredding the paper I put it in the blue box and I move it to another room. After I am done all of this, my job is done. I really like my new job.

Written by,  
Andrea Dowey

## TUTORING & FINE MOTOR SKILLS CLASSES

We are looking for new people to join our classes. **Tutoring** may take place after school hours or on Saturday mornings. Sessions are taught by a qualified Instructor and a fee for service is required. Tutoring may include literacy, computer skills, money skills or any other skills needed for success at school or in the working world.

**Fine Motor Skills Classes** are held on Thursdays from 6 -7 p.m. These sessions are taught by an Instructor assisted by Volunteers. The children learn a variety of skills to help them become more independent in their everyday living. i.e. printing, buttons and zippers, cutting etc. If your child needs practice or a chance to learn these necessary skills call Janet at 749-6695.

## Wee Ups and Downs

*The turnout at this get-together has been wonderful. There have been five families on a consistent basis.*

This Parent Support Group had the opportunity to meet with **Janet McCauley-Oliver, a Speech and Language Pathologist, specializing in Augmentative Speech**, from Five Counties Children's Centre on February 9<sup>th</sup>. She spoke about a variety of ways to communicate with your baby. She gave examples of gestures and signing that your child will learn to understand along with the spoken word and stressed the importance of communication at a very young age. Parents asked questions and shared experiences about communicating with their children. Janet was very informative and we enjoyed her presentation.

At the April meeting, a Nutritionist from the Health Unit will be joining us to talk about healthy eating and food concerns related to Down syndrome.

**This meeting will be on April 5<sup>th</sup>, the first Monday, due to April 12<sup>th</sup> being Easter Monday**

## WE ARE GROWING !!!!!

C.H.A.N.G.E.S. ,in partnership with Five Counties, Community Living and the Infant Toddler Development Program in Lindsay, will be hosting

### **Parent Information Night**

**Date:** Wednesday April 28, 2004

**Time:** 7:00 pm - 8:30 pm

**Place:** Lindsay Boys and Girls Club

This night is to give parents living in the Lindsay area, whose children are living with Down syndrome, an opportunity to meet each other and share experiences. This may give them common ground on which to decide to organize their own Parent Support Group. C.H.A.N.G.E.S. would take the same role as they do with Wee Ups and Downs, in that we offer resources and support to the group, including arranging for Guest Speakers. Anyone living in the City of Kawartha Lakes area is welcome !

Parents from Peterborough, are needed to join us at this meeting. If you are interested in supporting this new venture as a mentor please call Janet at 749-6695.

## More Websites To Check Out

Free Parenting Course Online  
[www.healthparenting.sk.ca](http://www.healthparenting.sk.ca)

Special Needs Workshop  
[www.snow.utoronto.ca](http://www.snow.utoronto.ca)

Books for Students with Special Needs  
[www.relevantpublications.com/studentsneeds.asp](http://www.relevantpublications.com/studentsneeds.asp)

Parent Support Groups  
[www.kspin.com/parent](http://www.kspin.com/parent)

Music & People with Developmental Disabilities  
[www.jkp.com/catalogue/book.php](http://www.jkp.com/catalogue/book.php)

## Coeliac Disease and Down syndrome

Research reports of the incidence of Coeliac Disease (spelled "Celiac" in American publications) in people with Down syndrome is currently put at about 4-16%, depending on the group studied. The incidence is about 0.4% in the general population.

Screening of all people with Down syndrome for Coeliac disease is being considered by the Down syndrome Medical Interest Group, and may be included in their "Health Care Guidelines" in the near future.

Dr. Len Leshin reports that a new blood test is currently being developed which will "even further narrow down a subgroup of people with DS who are at high risk for CD." See his web page on Celiac Disease for more detailed information about the screening process: [www.ds-health.com/celiac.html](http://www.ds-health.com/celiac.html)

### Coeliac Disease - a gluten free diet for life

For most children, fresh bread, heaping bowls of steaming pasta and decadent baked goods are diet staples. Wheat, oats, and barley are usually a part of breakfast, lunch, and dinner. But for one in 200 Canadians, these grains cause abdominal pain, gas, and diarrhea. That's because they have celiac disease. Celiac disease is a digestive disorder in which gluten, a protein found in wheat, oats, rye and barley, causes damage to the small intestine. The intestine is lined with tiny grass-like projections called villi. In children with celiac disease, the villi get flattened when gluten is eaten. If the villi are flat, they don't allow nutrients to be absorbed into the bloodstream and people can become malnourished. The only treatment for celiac disease is to follow a gluten-free diet for life.

Celiac disease can be diagnosed at any age in childhood. A wide range of symptoms may be present, including abdominal pain, diarrhea, gas bloating, weight loss, anemia, irritability, and fatigue. Some people also get a painful skin rash called dermatitis herpetiformis. Diagnosing celiac disease involves blood tests and a small bowel biopsy that is performed by a gastroenterologist.

Celiac disease has no known cure, but can be effectively treated and controlled with strict adherence to a gluten-free diet. Despite the restrictions, people with celiac disease can eat a well-balanced diet with a variety of foods, including breads and pasta that are made from gluten-free grains.

To replace gluten-containing grains, children with celiac disease should choose rice, potatoes, corn, millet, tapioca, soy, buckwheat and beans. Parents should meet with a registered dietitian to learn more about a gluten-free diet. Dietitians can help parents and children focus on what they can eat, instead of only what they need to avoid. Meat, fish, poultry, dairy product, egg, nuts, fruits and vegetables do not contain gluten, so these foods can be served aplenty.

Children with celiac disease also have to be careful when eating processed and packaged foods because they may contain hidden sources of gluten. Particular care should be taken in the selection of prepared meats, frozen foods and snack foods. To avoid gluten in packaged foods, be sure to read food labels carefully every time you buy groceries. You also have to know what to look for on food labels, as gluten can be disguised. For example, ingredients like malt, spelt, kamut, bran and graham all contain gluten.

To ensure that children with celiac disease continue to enjoy fresh bread, pasta, and a variety of baked goods, many companies make gluten-free varieties of these essential products. The Specialty Food Shop at Sick Kids carries a wide selection of breads, pasta, pretzels, cookies, crackers, and other baked goods made from gluten free ingredients and it delivers these products worldwide.

For more information, visit [www.SpecialtyFoodShop.com](http://www.SpecialtyFoodShop.com) or call 1-800-737-7976

Reprinted from **DownWrite** *Special* January/February 2004  
Down syndrome Association of Toronto





## First In Canada

On June 16th, 2003 the first Adult Down syndrome Medical Clinic opened in Ottawa with a fury of interest. Dr. Lise Poirier-Groulx is the very knowledgeable medical doctor behind its success while the clinic nurse, Barbara Green, is a very positive, friendly and also knowledgeable assistant. Together, this medical team has made history in opening the first clinic of its kind in Canada!

The clinic is open the third Monday of every month. With word spreading quickly and demand steadily increasing, the clinic will be open twice a month in the near future.

In addition to the Down syndrome Clinic, Dr. Poirier-Groulx maintains her own medical practice. Therefore, we are interested to hear of other doctors who would be interested in being part of the clinic. Thanks to the team for making this long awaited dream a reality!

*- Excerpt from DS Express November 2003 edition.*

## Thanks to our soldiers!

There was a run for Down syndrome recently. It was organized by a Dad who is stationed in Afghanistan. It was held in Afghanistan and managed to raise approximately \$2200. The Dad plans on delivering the cheque to Dr. Pothos when he returns in December. There were approximately 95 people who participated in the run. It was a great opportunity for the soldiers to unwind after two of their comrades were killed by a mine. Thanks to all our soldiers for serving our country. Not to mention, remembering our kids even in times of chaos.



*Excerpt from Down syndrome Association National Capital Region in Ottawa.*

**Do you know an adult who has Down syndrome that is "GOING PLACES" and doing things that other Canadians should hear about?**

The 2005 CDSS Calendar will focus on adults with Down syndrome who are contributing to their community and/or who are setting positive examples for others to follow. If you know of such a person, please send us their name and contact information to CDSS at 811-14th Street N.W. Calgary Alberta, T2N 2A4 so that we can include him/her in next year's calendar. We will also be honouring the children's pictures in the smaller, day boxes.



*Excerpt from CDSS Winter 2004*

## Membership/Donations

C.H.A.N.G.E.S., Peterborough & Area Down syndrome Support Group Membership Form

- Yes, I would like a membership with C.H.A.N.G.E.S., I have enclosed my membership fee of \$15.00
- Yes, I would like to subscribe only to the newsletter, I have enclosed \$10.00.
- Yes, I would like to make a donation to help keep these programs alive and support future initiatives for children, youth, and adults living with Down syndrome  
\$\_\_\_\_\_ Donation.

Charitable Registration # 124703737RR0001  
Receipts available for donations of \$10.00 or more.

Name: \_\_\_\_\_

Name of child/youth/adult with Down syndrome: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ Prov. \_\_\_\_\_

Postal Code: \_\_\_\_\_

Telephone: \_\_\_\_\_

E-mail: \_\_\_\_\_

Would you like your newsletter sent via email?  
\_\_ Yes \_\_ No

Please detach and mail with cheque, payable to:  
C.H.A.N.G.E.S.,  
360 George St. N. Unit # 24  
Peterborough, ON. K9H 7E7



## Beverly Assinck is on C.H.A.N.G.E.S. Board of Directors

My name is Bev Assinck and I am a Board member with C.H.A.N.G.E.S. I am new to the Board as I just started when my position began with KPRDSB as Special Education Consultant for students with Intellectual Exceptionalities and Students on the Autism Spectrum in September of 2003.

I have worked with special needs students both in and out of the Board, having worked for Community Living Peterborough, as well as deaf adults with developmental challenges. I have been a teacher in regular classrooms as well as a teacher in a Learning and Life Skills class at Crestwood.

One of my life passions is to help make sure that all people live lives that provide them with social justice, regardless of the challenge. This includes, race, class, gender, sexuality, intellectual ability etc.

I love my position here and am happy to be on the Board. I guess my main goal is to help enrich the lives of all Down syndrome folks by helping develop a positive working relationship between C.H.A.N.G.E.S. and the School Board. I am enjoying my time on the Board and welcome the developing relationships with the other Board members.

### *Thank You To C.H.A.N.G.E.S. Volunteers*



#### *Bingo:*

*Paul Guilfoyle, Jamie Jackson, Laurie Thomson, & Caley Caddigan*

#### *Office & Fundraising:*

*Laurie Thomson, Jenny Wang, Ling Yu, Sue Hatton, Heather Yoshiki, Arthur Peterson, Kate Fales, Monique Hartin & Krysten Deering*

