



# C.H.A.N.G.E.S. Down Syndrome Support Group



NOVEMBER, 2004

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

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Unit #23  
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## C.H.A.N.G.E.S. Christmas Party

Date: Sunday, December 12th, 2004

Place: Kingswood Community Centre

Time: 1:30 pm - 6:00 pm



### Agenda

Swimming: 1:30 pm - 2:30 pm

Entertainment by Terry Guiel

A visit from Santa Claus

Dinner

*Adults must bring one present for each of their children for Santa to give out.*



**Please RSVP your attendance by December 8th, 2004**



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### UPCOMING EVENTS

We have received a number of tickets to the NHL Oldtimers vs. Police Oldtimers Hockey Game on Saturday, December 4th at the Memorial Centre. These tickets, donated by the community, will be available on a first come, first call basis to our office at 749-6695.

C.H.A.N.G.E.S. would also like to thank the Canadian Cystic Fibrosis Foundation and the community for their generous donation of tickets to the Variety Extravaganza at T.A.S.S. on Saturday, November 13th. Tickets were distributed to the participants at the Bowl-A-Thon. We hope everyone enjoys the show!

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.

## AGM REPORT



C.H.A.N.G.E.S. held their Annual General Meeting on Sunday, September 26th, 2004 at their office in Peterborough Square. Thirteen members enjoyed a pizza and dessert lunch prior to those attending the movies. A formal meeting followed to accept the minutes of the previous AGM, the agenda, the financial statements and reports from staff and Board.

Deb Reid continues to operate the day to day operations of our agency and we are excited to announce the hiring of a program co-ordinator, Judy Rafail. Judy brings many years of experience working with children and adults with disabilities and most recently at the Library Café's work program.

New programs and services were discussed as well as direction for the Board and staff for the coming year. We are very pleased to welcome Linda O'Connor from the Scotiabank as Treasurer of our Board.

### Board Of Directors 2004-2005

Teresa Glaeser - President

Al Peers - Vice President

Vicki Allen - Past President

Linda O'Connor - Treasurer

Janet Bolger - Director

Kelly Sinclair - Director

Allyson DeNoble - Director

Beverly Assinck - Director

### Outgoing Directors

Rick Gummer

Thanks to a generous contribution from the Edmonton Down syndrome Society, we have received a free DVD entitled "Medical Issues For Adults With Down Syndrome". This DVD was created from the videoconference footage of the Adults with Down syndrome Symposium held in Calgary in November, 2003. The information on the DVD has been divided into chapters to allow you to go directly to the topic of interest to you. The chapters include health monitoring, promotion, immunization, pain tolerance and health issues. The Canadian Down syndrome Society wants your doctors and other medical personnel to have a free copy of this DVD to ensure that Canadians receive accurate information about Down syndrome. This DVD is one of the ways to educate society about the issues that affect you and your family. If you know of a doctor or medical personnel who would benefit from receiving this helpful DVD, send your information via email to: [dsinfo@cdss.ca](mailto:dsinfo@cdss.ca) or call CDSS toll free at 1-800-883-5608. We also have a copy in the office for lending purposes.

### Useful Websites Worth A Visit!

1. <http://users.psln.com/sharing/Michael/mainMichael.html>—an inspirational website by Michael Juroque Johnson
2. [www.ualberta.ca/~jpdasddc/inclusion/](http://www.ualberta.ca/~jpdasddc/inclusion/) - inclusive education site
3. [www.learningpage.com](http://www.learningpage.com) - instructional materials
4. [www.easterseals.org](http://www.easterseals.org)—incontinence supplies grant
5. [www.dsscotland.org.uk/](http://www.dsscotland.org.uk/) - Down syndrome in Scotland—very informative

### Thank You Volunteers!

**Bingo:** Paul Guilfoyle, Jamie Jackson, Laurie Thomson, Tia Denike, Don McMaster and Rebecca Allen

**Office:** Cheryl Yelland, Luke Allen, Terri Lynn Nolan, Vicki Allen, Rebecca Allen and Heather Home.

### BEATTITUDES FOR MY FRIENDS

Blessed are you who take the time  
To listen to difficult speech  
For you help me to know that if I persevere  
I can be understood.

Blessed are you who never bid me to "Hurry up"  
And take my tasks from me  
And do them for me,  
For often I need time, rather than help.

Blessed are you who stand beside me  
As I enter new and untried ventures,  
For my failures will be outweighed  
By the times I surprise myself and you.

Blessed are you who asked for my help,  
for my greatest need is to be needed.

Blessed are you who understand that  
It is difficult for me  
To put my thoughts into words.

Blessed are you who respect me  
And love me as I am, just as I am  
And not like you wish I were.

— Anonymous

### PLAN AHEAD

May 12th to 14th, 2005  
Kitchener Waterloo  
17th Annual CDSS Conference  
*"Common Threads"*  
Planning, Adult and Teen Issues,  
Friendships, Education, Advocacy  
and more.

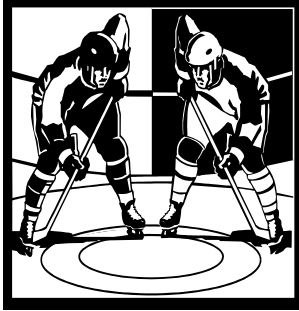
August 22nd to 27th, 2006  
Vancouver, British Columbia  
9th World Down syndrome Con-  
gress  
*"Making Waves"*  
Feature keynote speakers, world  
issues and family concerns.

### SICK 'N SUNSHINE

C.H.A.N.G.E.S. would like  
to wish Danielle C. and  
Melissa P. speedy recoveries  
during their hospital stays.  
Danielle is recovering from  
a health issue and Melissa  
is recovering from a serious  
car accident. Get well soon!

## Down syndrome Awareness Week

Mayor Sylvia Sutherland once again, declared November 1st to 7th Down syndrome Awareness Week. C.H.A.N.G.E.S. kicked off this special week with the 5th Annual Monster Mash Bowl-A-Thon which raised over \$5,000 for programs and services.



Tyler Green and Carly Hopkinson, both new members who attended our Summer Camp Program this year, represented our agency by participating in the ceremonial puck drop at the Petes games on Thursday, November 4th. A special thank you to these two young people who did a great job! Thirty five members from our agency were in attendance at the game as well.

### CELEBRITIES IN OUR MIDST!

Congratulations to Manny Clarke, Emilia Allison and Tyler Traynor, this year's Calendar Kids in the Canadian Down syndrome Society's 2005 Calendar! Calendars sell for \$10.00 and orders will be accepted until November 26th, 2004. They make great Christmas gifts so order yours today!

**LOOK OUT CALENDAR GIRLS,**

### Tutoring

We have eight students enrolled in our tutoring program. We teach literacy, math, money, communication and life skills. There are still sessions open on Wednesdays during the day. If you are interested, contact Judy at 749-6695 or by email at [jud@pipcom.com](mailto:jud@pipcom.com).

### Fine Motor Skills Classes

Our Fine Motor Skills Class started in September. We presently have two participants and have room for two more. The program is designed for children 6-14 yrs. Each session includes a variety of fine motor activities appropriate to the needs of each participant. The class runs from 6-7 PM on Thursdays. Contact Judy at 749-6695 or by email at [jud@pipcom.com](mailto:jud@pipcom.com) if you are interested in enrolling your child in this class.



### Cooking Classes

On Monday, November 1st, we started a six week pilot project to teach cooking and to provide a social outing for our members.

We meet on Mondays from 4-6 PM and due to space limitations have limited the number of participants to five.

Each week, with the help of a volunteer, we prepare a dish, talk about nutrition and safety in the kitchen, and enjoy a social time while we eat what we have prepared. We are planning to run this program again after Christmas.

## **ALLDown Study**

***Sponsored by Pediatric Oncology Group of Ontario (POGO)***

We are seeking volunteers for a developmental study at The Hospital for Sick Children in Toronto, Ontario.

### **Study purpose:**

The purpose of our study is to understand the impact of leukemia treatment on cognitive development in children with Down syndrome.

Children with Down syndrome have an increased risk of developing acute leukemia compared to children without Down syndrome. However, little is known about their cognitive development after leukemia treatment.

Our research team is investigating the unique challenges faced by leukemia patients with Down syndrome and their families. For a comparison group we are looking for children with Down syndrome between the ages of 6 and 17 years without a history of leukemia to participate in our study.

We hope that the results of this study will: a) help us learn more about the developmental outcome of children with Down syndrome who needed treatment for leukemia and give us valuable information for the improvement of future leukemia treatment in children with Down syndrome.

### **What is involved:**

The entire study takes approximately 4 hours (not including breaks). Appointments will be scheduled on Saturdays and will take place at The Hospital for Sick Children.

Your child will complete standardized tests of intelligence, language, visual-motor function, attention, memory, and academic skills. We will also ask one parent to answer questions to collect information about your child's developmental history and current adaptive skills.

You will receive a written report of your child's individual results at the conclusion of the study. If you wish, you may discuss your child's test results with a registered psychologist. All personal information will be kept completely confidential.

This study is headed by Dr. Caroline Roncadin, Postdoctoral Fellow at POGO and The Hospital for Sick Children, and supervised by Dr. Brenda Spiegler, Staff Psychologist at The Hospital for Sick Children.

Interested participants will be screened for eligibility by telephone prior to scheduling an appointment.

### **To inquire about participating in the comparison group, please contact:**

#### **Dr. Caroline Roncadin**

The Hospital for Sick Children, Department of Psychology

555 University Avenue, Toronto, Ontario, M5G 1X8

Tel: 416-813-8448 (messages will be returned)

E-mail: [caroline.roncadin@sickkids.ca](mailto:caroline.roncadin@sickkids.ca)

## **INDIVIDUALIZED FUNDING**

Individualized funding is a promising alternative model for financial government support of adults with special needs. It has proven successful in other parts of Canada and the world, and is slowly being considered here in Ontario.

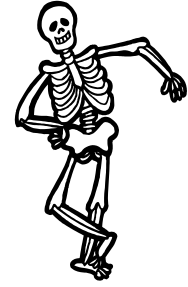
The current, traditional model is that when people with special needs leave the school system in their early adult years, they are placed on waiting lists for “service”. They become involved in segregated day programs, some are offered limited job placements, and some will go off to live in group homes. Many families are shocked and disappointed with the lack of opportunities in their communities for adults with special needs. Many find themselves having to spend countless hours seeking activities and becoming full-time companions for their adult child who is now spending most of his/her time at home, becoming increasingly more dependent and closed off from social contacts. Individualized funding means that money goes directly toward meeting the unique requirements of each person with special needs, rather than into funding special programs and building special facilities. The money allocated to a family can be used to hire a support worker who can provide whatever level of assistance is needed for the client to participate, contribute and live his/her life to the fullest—to have the same privileges and responsibilities that all adults have. This many mean living in a commercial apartment building with room mates of his/her choice, seeking and doing meaningful work, attending college classes, volunteering in the community, or enjoying recreational activities with friends. It allows the person with special needs to have direct input into making decisions about his/her own life, and ensures that decisions are made in his/her best interests. It opens up an endless array of possibilities! This model makes much more efficient use of government money in that the existing community infrastructure (stores, banks, apartment buildings, businesses, recreational facilities) is being accessed. There are even positive implications for the health care system with a likely decrease in illness, abuse, and depression which is often associated with individuals living and working in segregated settings.

In order to convince the politicians and bureaucrats to provide financial support using an individualized funding model, you must submit and negotiate a comprehensive plan to the minister in charge of the Ministry of Community and Social Services. The Family Alliance of Ontario has a great deal of knowledge about government requirements, as well as experience in drafting, presenting and following up with these proposals. They are willing and eager to give advice to families interested in seeking this type of support and can be contacted at [www.family-alliance.com](http://www.family-alliance.com) or Family Alliance of Ontario, Kinsmen Building, York University, 4700 Keele Street, Toronto, Ontario M3J 1P3.



## 5th Annual Monster Mash Bowl-A-Thon

***ONCE AGAIN, WE DID IT!***



Many thanks to everyone who bowled with us last Sunday, to the generous sponsors who donated prizes and raffle items listed below, and to our great volunteers and staff who helped make this event a tremendous success. Money raised from this fundraiser will assist *C.H.A.N.G.E.S.* with program needs and services in the community.

Congratulations to Claire, a 50's diner hostess and Colombe Hammond, Daffy Duck for winning the best costume contest. Special congratulations to Allyson DeNoble who raised \$419 to win the Box Suite tickets to a Petes game donated by Steve Doyle at Molson's. Second largest pledge collector was Shawna Jones who raised \$269 and won a dinner for two from Fusions and the third largest pledge collector was Luke Allen with \$201 who won club tickets to a Petes game donated by Bob Angione at Coyle Packaging.

Thanks to Gary Dalliday from Chex for being our master of ceremonies and to Bill Green from the Ontario Police Retirees Inc. who presented *C.H.A.N.G.E.S.* with a cheque for ten lane sponsorships. We would also like to recognize our volunteers; June Morrow, Shirley Gellatly, Rebecca Allen, Teresa Glaeser and Judy Rafail.

**We appreciate your support and hope everyone had a Happy Halloween!**

Thanks to the wonderful donors that supported our 5th Annual Monster Mash Bowl-A-Thon:

Americredit	Olde Stone Brewing	Mr. Transmission
Coyle Packaging Ltd.	The Wolf 101.5	Electric Clove
A & P Foods	Lakeview Bowl	Home-ology
Baagwating Community Assoc.	Police Retirees of Ontario	Mark Vitarelli
Binney & Smith Canada	Kelsey's Restaurant	Printer Paul
Burger King Restaurant	Little Caesars Pizza	Precision Optical
Lumsden's Cash & Carry	Nu Bodies Fitness	Community Service Order
Charlotte Anne's Rest.	Mark's Work Warehouse	The Main Ingredient
Charlotte Jewellers	McDonald's Restaurants	Baskin Robbins
Charlotte Paint & Wallpaper	Mexicali Rosa's Rest.	Wal-Mart
Charlottes Web	Windsor's Dry Cleaning	Mr. Sub
Kevin Dunn	Graeme Ross	Peterborough Naturopath
Coyle Packaging	Mister Transmission	Pepsi
Harvey's Restaurant	Sullivan's Pharmacy	Murphy Scarsella & Associates

## 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 with Down syndrome \$\_\_\_\_\_ Donation.

Charitable Registration # 86149 5547 RR0001  
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. North, Unit # 23,  
Peterborough, On K9H 7E7



## LINDA O'CONNOR, TREASURER OF THE BOARD

I am a Financial Consultant with Scotia Private Client Group, specializing in Wealth Management, Will, Trust & Estate Planning. I have completed the following designations- CFP, CSC, CPH and I am currently enrolled to earn the Elder Planning Counsellor Designation. I have 21 years experience in the Financial Services industry and graduated from SSFC with a diploma in Business Administration. I am a member of both the Peterborough & Victoria County Estate Planning Councils. I am married and enjoy life long learning. Welcome to our Board!



Harry Potter,  
Josh Peers

Wizard, Brianna  
DeNoble and  
Daffy Duck  
(a.k.a. Grandma),  
Colombe  
Hammond



Cowgirl,  
Vickie Allen;  
Cowboy,  
Luke Allen;  
M. C.,  
Gary  
Dalliday;  
Prez,  
Teresa Glaeser

Tiger, Matty Wilson;  
Groucho Marx, Deb Reid