

INFORM



The Cerebral Palsy Association of Manitoba

NOVEMBER 2012

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Renew today
or become one!



LIKE US
on facebook!

Donations

I'm going to tell you a few stories about donations and support. They come into this office in many forms and sizes. All of them are valuable. Over the last few months, it never stops to amaze me the giving nature of people in Manitoba.

My niece has just turned eight years old. Instead of presents for her birthday, she asked her friends to bring her money. This was not for her American Girl collection. She wanted to give it to the CP Association. At the end of her day, I received a nondescript brown paper envelope stuffed with loonies, toonies, quarters, and other assorted coins. This was not a pay off from the Montreal Construction industry but a glorious generous gift from an eight-year old girl who wanted to make a difference.

Support also comes in the form of experience and knowledge. Chris Moffett, our IT and computer guy, supports us by volunteering his expertise. That expertise has allowed us to update our website and make the Association run just a little smoother. He added the on-line donation for the bike race, a wonderful tool to make the Bike Race collection operations run a little better. In addition to Chris, a friend of mine, Susana Schanel, a graphic designer and marketing guru has been helping update the Association's look.

Supporting the Bike Race every March in Winnipeg and in Brandon is another way for all of us to support the Association. If you do not have time or the ability to put in a team or ride a bike; then how about giving a donation? Or helping another rider or Volunteer raise the funds? Support can be as simple as putting the event on your Facebook Page. You never know whom you are going to reach.

And while I'm still talking about donations and support, I would like to personally thank everyone who supported the CP Challenge and the World CP Day. It was the first year for the event and one I'd like to see grow. With support from our first challengers, we made money on the adventure and raised the awareness of CPAM and cerebral palsy, reaching out to folks who may not get involved with our major bike race fundraiser. We will learn from the venture and get it even better next year. Did anyone hear the ads on Breeze 100 or Energy 106 Back in August?

It's all about getting out there and spreading the word and sharing what you have, whether it's money for fundraising or expertise from which we can all learn and grow.

Thank you everyone

David Kron

Walk for CP in Flin Flon

The Walk for CP was held September 15th in Flin Flon.

\$2300.00 was raised for the Cerebral Palsy Association of Manitoba.

Thank you—Ryan Nelson and Walkers.



CPAM Sales Corner



Samantha's Van

We would like to offer our wheelchair van for sale to a local family with a wheelchair user. We have no idea what the appropriate price would be. Here are the details:

Mileage: 153611
Year: 1997
Make: Chev Model: Astro

Condition: Consistently maintained, runs well, good tires, raised roof, equipped with fully functional wheelchair lift, side load,

sliding door. There are a few rust spots, especially around the sliding door. There is some minor internal damage from contact with the electric wheelchair. It starts in any weather without block heater. No collisions ever that I am aware of.

Price \$10,000 OR best offer

Contact: Grant
204-988-0352
gmitchell@tmlawyers.com



For Sale - Safety Mat

Made of dark blue leather (As used in personal Care Homes)
76" X 30" X 3"
Asking \$100.00
Call Larry (204) 832-9959



For Sale - 2003 Pontiac Montana

3.8 L engine
36, 700 km
Handi-capable conversion
Removeable passenger front seat & rear seats
Air conditioning
New muffler

Asking price: \$23, 000 O.B.O.

Call Jody at (204) 224-0147



A “Playground for Everyone”

A “Playground for Everyone” was opened just in time for summer, located at Meadows School in Brandon was built by an army of volunteers and lots of generous sponsors. The Cerebral Palsy Association of MB, the Westman branch raised 1937.60 to help make the play structure accessible. The new playground has a “knitted” compact layer that allows a variety of mobility devices, to move

around the structure and we provided molded bucket seat, stationary cycler and Accessible Reach panel.

Chris Austin & David Kron



Thank you note from Bryce

Dear Westman,

Thanks for my new evolve stand I really like it, I try to use it every day as a part of my physio routine. Thanks for the money it really helped the cost. I am avidly involved and was glad some of the money raised from the CP bike race helped me get the stander.

YOUTH PARTICIPATING IN COMMUNITY ACTIVITIES: HOW CAN WE IMPROVE IT?

Are you between the ages of 12-18?

Do you have cerebral palsy and have difficulty participating in leisure activities?

We would like to invite you to participate in our study that looks at ways to increase participation in leisure activities for youth with cerebral palsy.

If you agree to participate, an occupational therapist will come to your home and work with you and your family to identify goals for participating in after-school leisure activities. The occupational therapist will then work with you and your family over a period of weeks to achieve these goals. Strategies will be developed to remove barriers in the environment that make it difficult for you to participate.

For more information about this study or to volunteer for this study, please contact the research coordinator: Erin Fonseca at 204 999-8985 or leisureparticipation@gmail.com

go4kidds
Great Outcomes for Kids Impacted
By Severe Developmental Disabilities

GO4KIDDS Health Care & Service System Survey

We're looking for parents of Canadian children and youth (age 10-16 years) with severe developmental disabilities, to participate in a survey regarding their needs and access to healthcare and other services.

- There are **three different parts** to the Survey (30 minutes each) and will comprise questions about you and your family, your child's behaviour, disability and the services he/she received or needs, and your feelings about the rewarding and challenging aspects of parenting a child with disabilities.
- After completing all three parts of the survey, you will be eligible for **\$50.00 as a thank you for your time**

How can you be involved?

- Complete our Health Survey online at www.surveymk.com/s/gohealth1 or by emailing gohealth@yorku.ca
- Spread the word to other parents of children with severe DD who are between 10 and 16 years old
- Visit our website for more information on other opportunities to be involved

Contact Us!
York University, B5B 220
4700 Keele Street
Toronto, Ontario
Canada M3J 1P3
www.go4kidds.ca
Phone: 416-736-5662
Toll free: 1-877-233-4337
gohealth@yorku.ca



UNIVERSITY
OF MANITOBA

www.go4kidds.ca

Member Profile

Some people deny their 60th birthday, preferring to be forever twenty-one! Not so, Alexandra Michaels. She threw a bountiful party for herself sharing food, friends and family.

Family lore about her difficult birth and subsequent illnesses ensured the longtime CPAM member never took life for granted. "I think for myself, learn what I need to know to get better and work to maintain my health and mobility."

Her Serbian parents met in a German prisoner-of-war camp where they married after the War. Three years later, her father sailed to Canada, signing a two-year contract for agricultural work, in Saskatchewan and Manitoba. The farm family loaned him the money to bring his wife and daughter to Canada. Four and a half years later with the debt paid off, they moved to the top floor of a house on Dufferin Avenue. With government help, Mr. Milovanovich retrained as a bricklayer and mason; her mother worked as a seamstress.

Throughout her childhood AM's father built her mobility devices and encouraged her independence. Alexandra enrolled at Red River College in

a computer analysis program with two other friends, the first students with disabilities in the college, thanks to the President's intervention. He had a daughter with cerebral palsy and sought acceptance for them all, not as an exception for his daughter but as a college principle.

That first day, with students hugging the walls and her arms laden with books, Alexandra fell. Her books went flying. Embarrassed, she told the registrar, "That's it, I quit." Instead, they found an old library cart for her to push around laden with books. Classmates later decorated it.

Alexandra had learned to fall without hurting herself from her physiotherapist, who "when I was five stood me in front of a full-length mirror and pushed me, telling me not to let her push me down!"

When 1010 Sinclair first opened, August first 1975, Alexandra moved in. "I sat on the arm of my chair and looked around, thinking this is all mine. Wow!"

Her old high school teacher offered her a job at Ellen Douglas School (now Lord Roberts), writing computer programs based on individual children's needs. The class where she provided one-on-one training was known as a Class for the Mentally Trainable

Handicapped. Thank heavens language has changed! She taught for eight and a half years, two days a week from September until the end of March, took a month off, and worked fulltime from May until the end of August.

Many of us first met AM when we joined the CPAM. She was our role model, a successful independent adult living with disabilities. Art has been integral to Alexandra's life: a source of inspiration and support. She used a manual typewriter to create imagery from which she made Christmas cards and sold them to us all.

When the PACE program started 10 years ago, Alexandra wrote the payroll program, for ILRC. It is still being used today but she does not make alterations. A whiz with numbers, Alexandra volunteers with Revenue Canada doing income tax returns. Her involvement with new immigrants has given her new family. Today, more than one child loves her as a grandmother. A role model to many, to me, she's just a friend and a lifeline whenever I'm in trouble with the homecare payroll program. No matter my errors, she gets it right!



Sarah Yates



September 2012 - Toronto ON

I had the opportunity to go to this conference, which had over 900 in attendance, from more than 30 countries. If there is research in the field of Cerebral Palsy, it is reported on at this conference. I want to highlight two of the presentations I attended.

1) Special Needs Apps for Children & Adults: A broad overview of the Apps out in the field, and the use of the assistive technology with individuals with complex communication needs through natural speech and/or language.

Some helpful websites: www.rjcooper.com - switches and hardware for your IPAD.

www.ablenetinc.com - Bluetooth switch for IPAD

www.bridgingapps.org/ (Run by the Easter Seals of Texas - Houston) - reviews Apps and is a great place to get started if you are a parent, teacher or therapist. It has wonderful "How To" videos

www.techinspecial.com - searchable database of IEP goals to Apps

www.wonderfulstorybooks.com - "Living books" for the IPAD - I have more information at the office. Please let me know if you want the complete list.

2) Development of stem cells: This research is going to be the next big thing, whether it's about cerebral palsy or other neurologic conditions. Neither myself or the CP Association will advocate any treatment over

another, but it's amazing what researchers are just starting to do, including using neural stem cells to repair areas in the brain. Currently, Dr. Michael Ferhling's group is doing research about CP on mice, but we are years away from a real breakthrough. If you want to learn more about a Clinical Trials, by law it has to be listed in the following site: www.ClinicalTrials.gov <http://www.ClinicalTrials.gov>. This is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world. If there is some interest in learning more about this, I could get more information and get a medical professional to write something for our newsletter.

www.neurodevnet.ca

NeuroDevNet is a Canadian-based organization that is doing great research and is in the process of developing a database for researchers of individuals with Cerebral Palsy. Currently the registry is active in British Columbia, Alberta, Quebec, Ontario, & Newfoundland. The Canadian Cerebral Palsy Registry aims to create a database to assess the prevalence and distribution of cerebral palsy, identify the risk factors for CP and document the disabilities of children with CP in order to improve the quality of care. This database is an essential precondition for future research, and to share knowledge with individuals that are affected by Cerebral Palsy. There are currently CP registries in the UK, Australia, and Norway.

Volunteer Opportunity

Have experience with Access and willing to donate your time? Looking for someone who knows Access and can help me update our database? Call David @ 204-982-4811



THANK YOU

for your participation
in the **World CP Challenge**



in support of people with cerebral palsy!



Partnerships are the key to getting things done.

I believe "That all of us are better than one of us". An ongoing partnership is with Open Access Resource Centre...Back to School Workshops. For dates & information, call Doris at 949-2430 or send her an email at doris@oarc.ca.

OARC will be holding regular training workshops on the programming of iPad/iTouch apps. The workshops are free to those who currently have devices out from our Equipment Loan Program. The cost for all others to attend is \$30/person. All sessions are from 1:00 p.m. to 3:00 p.m. at OARC, 316 Tache Ave.



I would also send out a Special Thanks to:

- Cerebral Palsy Association Members
- City of Winnipeg Employee & Retirement Charitable Fund
- Manitoba Hydro Employees – Thompson
- Government of MB – All Charities Campaign
- Brandon Jeans Day
- Alfred E. Deacon Foundation
- Dreams Take Flight
- The Bequests in Memory of Mavis Burr
- The Bequests in Memory of John Ruta
- The Bequests in Memory of Richard Large
- **United Way** in the following Rural Campaigns:
Altona/Gretna
Carman & Community
Morden & District
Winkler & District



**Cerebral Palsy Association of Manitoba
ANNUAL GENERAL MEETING (AGM)**

Date: Monday, November 12, 2012

Time: 6:00 – 8:30 PM

Place: Viscount Gort Hotel
1670 Portage Ave. Main floor

PROGRAM - times are approximate

6:00 – REGISTRATION – socializing, snacks, beverages

6:30 - President's Welcome and Remarks

6:40 – Guest Speaker – Dr. Wendy Josephson, Professor of Psychology. University of Winnipeg Topic: STOPPING the BULLIES, Prevention & Techniques for Children

7:15 – AGM & Reports

8:00 - Presentations & closing remarks

8:15 – Board of Directors meeting – Election of Executive

You must be a current paid up member to vote at the Annual Meeting. There is no cost to attend the AGM but please phone or email your attendance by the deadline date of November 8, 2012.

1-204-982-4842

1-800-416-6166

office@cerebralpalsy.mb.ca

**HOLIDAY
BOWLING
PARTY**

Academy Lanes
194 Academy Rd.
Winnipeg, MB

Sat., December 8
2–5 p.m.

Cost is FREE for Members & their personal attendants or interpreter.

Great Christmas Prizes to be won!

Contact the office for more details at 1-204-982-4842 or 1-800-416-6166.



Two Very Successful
STATIONARY BIKE RACES

THANK YOU - to everyone who took part and donated in anyway.

Winnipeg – over \$175,000

Westman – over \$47,000

Winnipeg Bike Race is Sat., March 9, 2013
Westman Bike Race, Brandon, is Sat., March 16, 2013

For information on Sponsorship or entering a team please contact the CPAM office:

1-800-416-6166 or 982-4842

Bike Race Coordinator, Marnie Loewen
bikerace@cerebralpalsy.mb.ca

CPAM BBQ

CPAM held it's annual BBQ / Picnic at Kildonan Park on September 22nd, 2012. It was well attended by approximately 45 members and families. We roasted Marshmallows, filled ourselves with hotdogs, played games and had fun. Look forward to seeing all next year.



Tara and her new bike

Generous Grants

***A BIG THANK
YOU FROM
TARA!***

Gladys is 90!

It was a very special day for Gladys Sobieski on 27 October 2012. It was her 90th birthday. Gladys is one of our longest current members and an inspiration to many. Born at home in 1922, Gladys started off life as a 2 1/2 pound baby. There was no neonatal intensive care unit (NICU) in 1922. With a caring family and a will to live, Gladys has out lived many. See you for your 100th Birthday Celebration, Gladys.

