

The Cerebral Palsy Association of Manitoba

#### **JUNE 2012**

Inside this issue...

Westman News & Notes PAGE 3

Travel Adventures in England PAGE 4, 5, 6

The Retreat Weekend PAGE 10

### Upcoming Events...

September 4th: World CP Day (PAGE 12) and the CP Challenge begins (PAGE 11)!

## Membership Reminder...

Renew today or become one!



LIKE US on facebook!

# Transition is never easy on anyone

or for any organization. Having one person at the helm for 23 years is reassuring in this world of change, especially when that person is as great as Laura Schnellert. I'd like to thank Laura for her quidance and example. I'd also like to thank Marnie Loewen, Vic Warkentin, the Board of Directors. the Friends of CPAM and Especially the Members for welcoming me to the position. As a member myself; I want to share with you my dedication to this organization and my excitement in taking it into the future.

I bring different skills and point of view that I hope will result in goals and accomplishments relevant to you our members. I will do my best to think before I act, and to keep the best interests of the Association in mind at all times. As I stated in my interview, I plan to make changes is a slow and sustainable manner. This organization is NOT about me. It is about the members and all the people that invest there time, money and energy

into CPAM. It is about the mission statement: The Cerebral Palsy Association is dedicated to enriching the lives of individuals affected by Cerebral Palsy through programs, advocacy, education, and peer support.

It is about the Mission statement being translated into actions for all members, and for all that are affected by CP. That is why the Board of Directors and the CP Team have the following things on the go...

- World CP Day—September 4th 2012. Raise awareness
- CP Challenge—A virtual fundraiser (Month Long)
- Improve the profile of the association
- Develop different partnerships with other community groups to help all.

I would like to challenge all of our Members and Friends of CPAM to help craft a vision for the future. CPAM turns 40 in 2014, and the Bike Race is going to turn 25. How do you want to celebrate?

Thank you for the help & support during this Transition.

**David Kron** 

## Thank you note

Thanks so much for give me the money so that I can order my new bike. We picked up my new bike and I love it!!

I gone for some bike rides with it already I goin to get more bike ridin this year with it. I send a picture of me on the bike for you to see it. It is a grape color and I like it. I can go up some hills by myself and on my other bike I cannot go up some hills by myself. But this one I can. I don't need to get some help to get on and off of my new bike but on my old bike I needed to get help to get on and off. So thanks a lot you make it so easy for me to do more independently. That independent feeling about it is good and I just can ask if I can go for a bike ride and if someone can walk beside me then we can just go and it is more easy for the person to come along and they don't need to lift me or anything. I like the bike riding a lot because, one, it is a lot of fun and, two, it is a

lots of exercise and it is so good for me to do some exercises. So thanks for what you did to help my family get this bike for me

From Amanda Klassen and her grateful family:)

#### **Amanda's Awesome ASR**



# Partnerships are the key to getting things done.

I believe "That all of us are better WINNIPEG FOUNDATION

than one of us". Our front page highlighted the recent changes to CPAM, which have gone smoothly for the most part. For that, I would like to thank **The Winnipeg Foundation**, which provided us with a generous grant for my succession training with Laura. I am looking to growing our community partnerships. Stay tuned to our website and Facebook page for our Partnerships Page.

I would also send out a Special Thanks to:

- Cerebral Palsy Assoc. 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 Steve Myk
- The Bequests in Memory of Deborah Ann Gard
- United Way in the following Rural Campaigns: Altona/Gretna Carman & Community Morden & District Winkler & District





Each year our bike race is held in the Historic downtown area of Brandon at the Town Center. The Westman Chapter had our race on March 17th 2012. This year we made a new record with an approximate total of \$48,000.00 raised. It was a day of adrenaline and fun with a color of green in the mix. Every rider wore a green t-shirt for 2 reasons, celebrating St. Patty's day and our cause. However, Bryce Eakins made a huge commitment for the cause. As a Neelin High student, Bryce challenged fellow classmates to raise funds for the cause. If more than \$1000.00 was raised, Bryce would dye his hair green for the occasion and cut off his long locks during a school assembly. I had the honor of putting together a celebrity team this year again. A few of Brandon's

radio personalities came out to support the cause along with the rest of the community. A big special thank you to those personalities, Krystal Cane from 94.7 Star FM, Adam Taylor & Frank McGwire from KX 96 & 101.1 The Farm. Bike race for 2013, will be a bigger celebration for Westman, as we will be celebrating 20 years.

#### Brandon raised \$48,000!



# Johnny Reid

April 27th Country Star Johnny Reid made his way to the Westman Communications Group place, formerly known as the Keystone Center; to a sellout crowd for his "Fire it up" tour across Canada. 5,900 people filled up the WCG place. Fellow Canadian Carolyn Dawn Johnson opened the event with some popular numbers, Georgia & Complicated. Reid entered the stage to an excited crowd and delivered a powerful

performance like only Johnny Reid can. Johnny kept his audience's attention all night long, even jumping off the stage and working his way around the entire venue to acknowledge all of his fans. He shook hands, gave hugs and kisses, and even took pictures with his audience. Not only did I get a hug from Johnny, Robin Delmage got a hug from and even got her picture taken with him as well.

#### Avis' Place

Brandon has been graced with an awesome hang out for all individuals of all ages with a disability. Located on 6th street & Rosser Avenue, Avis's Place is a great place to meet others and participate in a variety of activities. It is fully accessible and is always looking for new members to join and take part. Stop by and have a coffee, take part in a pool/air hockey tournament, or join in on a movie night. You'll always have a friend at Avis's Place

THUNDERBIRD BOWL & Glow Bowling – 2140 Currie Blvd. Brandon, MB R7B 4E7

Open to all ages, accessible to all disabilities. (Wheelchair Ramp & Bowling Ramps available)

#### I ♥ London!

My mum's family comes from England and I always wanted to see what it was like. I've read so many great stories from England too like the Little Princess and The Secret Garden and, of course Harry Potter. I was eleven when Harry burst into books, also eleven. My Nan always told me about how pretty it was and how. We planned this trip, around my dad's sabbatical work. Mum got home from a business trip in Chicago the night before we left, a good idea for both of us we didn't arque on holiday at all. For anyone planning an eight-hour flight with her mum, I would recommend spending time apart before you take off.

On the night before we left, my best friend Wendy was here to get me ready and to drive us to the airport. We arrived early so Mum could help them with my power chair. At our gate, Mum transferred me to my manual

chair and disassembled my power chair, removing the back and the arm with my joystick on it. If you don't do this, you are going to be very sad when you arrive and your chair has been taken apart by people who don't know what they're doing!

In Minneapolis we found a place serving the best airport food. We chatted and laughed with two short dark charming men from Fiji who sat beside us at dinner. My first trans-Atlantic flight an eight-hour plane ride was both fun and annoving. Thank goodness we are two awesome sleepers and we managed to catch some sleep. Anyone with arms that are wild like mine, should bring a bear or a pillow to hug. I thought I didn't need one but once we got started. I cursed myself. We finally got there and this lady in a hajib like the soccer heroine from Bend it like Beckham called me "darling" in cockney. That began our holiday in London. I have never seen that many races and cultures

living together so well. They look different but they are all English.

Double-decker buses are designed for mums with prams and to squeeze into the tiny space, you have to get over your annoyance. Be a bit bossy. The sign says the space is ours. No one much listens but get over it, it's part of the adventure. Everything from the Tate Modern Art Gallery to hanging out with cousins Melanie and David, Holly, my Uncle John and others was my favourite but what really stands out is our visit to the Warner Brothers Studio where many of the Harry Potter movies were shot. You walk into the Great Hall at Hogwarts where Hermione. Ron and Harry and other favourite characters ate. You see where Harry slept under the stairs at the Dursleys and vou even experience Professor Dumbledore's study. They even showed us how they made the characters fly. It's all there. Where Harry, Ron and Neville

#### London cab.



#### Night bus in the rain.



slept was small. Did you know that when the boys grew taller, they had to hang their legs over the end of the beds, which is why you never saw their feet? In the movies they had to make Professor Snape's cape longer because in the books you pictured him dashing down the hallway with his coat flapping behind him. Book your tickets in advance; your attendant gets in free. We travelled on three buses and a train on that long cold day but it was definitely worth it. As my hoodie says

Gemma Yates-Howorth

# Travelling to England with two wheelchairs is not for the faint at heart.

Gemma and I set out on our multi-cultural journey to meet Ted, with plenty of travel experience. Ted's long Internet search netted us a fabulous hotel in Earl's Court. The Think Apartments really does have a wheel-in shower: in England it's a wet room. We wanted a place where we could walk out the door and be in London, not in an urban suburb and The Think Apartments accomplished that. Our suites had a small fridge, dishwasher and even a washer-and- dryer unit, which I never managed to master but used with clean results! That first night we plugged

in our newly acquired transformer to Gemma's battery charger. A loud bang, lights out and sparks skittered across the floor. I hastily unplugged it, fearing the worst. The chair was saved but the charger was toast. Next day, Ted travelled halfway across London for another costina €190. Buses in London are accessible: not all of the tubes (subways) are BUT each bus has space for only one. I negotiated with every driver, saving we could fold the second chair. Some shook their heads, leaving one of us stranded. Some agreed. Your able-bodied passengers purchase an Oyster card; anyone in a chair travels free.

Though Ted plotted every bus ride (www.tfl.com) some funny experiences happened. On our first bus ride together, we travelled about a mile before the driver informed us that the police had closed down the centre of London

because of a demonstration! We got off miles from our destination just as the skies opened up. It rained a lot in London. A couple of plastic ponchos costing two pounds kept us mostly dry and protected the power arm of Gemma's chair. We walked miles through the soggy city before reaching the Tate Modern. Queues of people piled into the glorious modern building, all of us simply glad to be dry! We gueued to see Damian Hurst's diamond-encrusted skull and were plucked out of line by a kindly security quard who rushed us to the front of the line-up into the tiny darkened room, where it was shown. Gemma was unable to buy a memorial hoodie because it cost €95! With every occasional burst of sun we visited a park. Close by, Holland Park had wonderful wilderness. beautiful parks, an exquisite Japanese garden, peacocks and even an accessible oldfashioned loo. It was so calm

#### continued from PAGE 5

after the crowds. No one should visit London without seeing the mid-nineteenth century Kew Gardens Palm House designed by Decimus and Nicole Burton. They've even managed to make it accessible—sort of! I was constantly awed by the way in which Gemma in her power chair and Ted in his manual managed to maneuver the crowds of people on every sidewalk.

We each chose an outing; my English family was my focus. Getting there was part of the fun: looking out bus windows at the House Guard in their plumed hats and uniforms riding horseback—palace guards, police and the public ride horses in downtown London!—gawking at famous department stores like Harrods, outlined in lights at night and staring at crowds streaming across the city with umbrellas up or striding in sandals or high boots. It's

a fashionable multi-cultural city where small stories play out daily. Anyone who says Londoners aren't friendly hasn't chatted on a bus or talked to strangers on the streets, as we did. Inevitably Gemma and I got lost when we were on our own but we eventually found our way. You can't plan more than one destination in a day. Getting there takes time. The spontaneous is fabulous: a trip to Leicester Square as the theatres are disgorging the beautiful and dishevelled: a brief break-dance competition at M& Ms; a latenight bus ride through a part of London we never intended to visit, with light rain falling; wandering through the night streets, watching. We ate fabulous food at Kew Gardens, pub food, yummy hamburgers at Black and Blue, whole sea bass at Jamie's Place (aka Jamie Oliver's less pricey restaurant)

in Westfield, Europe's largest most modern shopping mall; and fresh homemade pasta at a little Italian restaurant we stumbled onto during an evening walk. Shopping is awesome; Gemma and I could have spent weeks on the walk. It's a part of any holiday: bookstores, clothing stores, souvenir stands, galleries and museums. It's the streets, it's the people, it's home but not really. When you're leaving London, it's good to know that Heathrow has its own taxi service with 24-hour online booking (www.heathrow taxis.org). Use them or you spend hours looking for alternatives! Even the trip back was an adventure. Ted's hand cycle rested on my lap and after the first corner, the portable ramp rested on Gemma's arm. Fabulous fun. full of mishap but I wouldn't have missed it for the world! Sarah Yates-Howorth

April 19, 2012

Dear Cerebral Palsy Association of Manitoba,

I would like to thank you for helping to make my dream come true. It has always been a dream of mine to present at an academic conference and you've helped to make that dream a reality. Because of your contribution among others I was able to not only present my paper but learn from other academics and

disability advocates as well. I now have something to add to my resume and an invaluable experience to look back on.

This experience, as a whole, has given me much more than a trip to a beautiful location and the ability to speak to and educate others. The chance to speak at a disability conference about something that is so close to my heart was such an honour. I don't know if you

will ever know how much this experience has really affected me as a person, giving me more self confidence, validation, and independence. I will carry this experience and all it has taught me for years to come.

My sincerest thanks goes out to the Cerebral Palsy Association of Manitoba for enabling me to have this life changing experience. A million thank yous, Mindy Tucker

# Food for Thought

#### The World Doesn't Owe You Anything

I completed twenty five days of a thirty day bikram yoga challenge at Stafford Street Hot Yoga that ran from the end of February until the middle of March. My yoga teacher Ivanka told me she could tell that I was holding back and not pushing myself to my potential (or using the full extent of my ability) because I was afraid of doing things wrong, looking stupid, tripping, and falling. She told me that she falls out of poses all the time and that it was okay to fall. She wrote in the teachers' communication binder that I was no longer allowed to use the studio's barre for support during the balancing poses in the series; she wanted me to work outside of my comfort zone so that I would improve. The change was tough and humbling because I showed myself my limitations and weaknesses. I cannot yet balance on one leg for long enough to achieve the correct form of the balancing stick pose or the standing bow pulling pose, but I realize now that I wasn't able to do them correctly at the barre either. Ivanka's point was clear: everyone will fall out of poses and fall down on their asses but it's okay. It's natural. It's expected. It's human.

A few weeks after my yoga challenge ended, I was walking to a restaurant to meet a friend for lunch and I tripped and skinned my knee. I had either tripped over a crack in the sidewalk or tripped over my own sandal. I berated myself and then pulled myself together and got on my feet. I had a minor scrape on my knee and a huge dent in my ego. I was embarrassed, frustrated, and ashamed.

I hadn't fallen in months. When I was a little girl, I tripped and fell almost every day. I have had corrective surgery and have done intensive physiotherapy and pilates over the last few years to improve my gait patter, strength, coordination, and balance. The combination has reduced the frequency of my falls, but I still fall sometimes. Everyone does and everyone will. I attach emotional meaning to falling because falling is part of my experience with spastic diplegia, but I reminded myself that everyone falls down now and again and that it doesn't make me a bad person. I have fallen down many times before and I will fall down again many times for the rest of my life. It's okay.

Norah Myers



# JOIN US IN THE FOLLOWING

- Day in the Exchange District
  June 29<sup>th</sup>
- Day at Fort Whyte Centre July 13<sup>th</sup>
- ILRC Picnic at Little Mountain Park August 10<sup>th</sup>
- Access Together Picnic at Assiniboine Park August 16<sup>th</sup>

For more information on these events and to register please contact Yumna Gill at: outdoorrec@ilrc.mb.ca

Independent Living Resource Centre 3rd Floor Portage Place Mall (204)-947-0194

# **GENEROUS GRANTS**

# ABIG THAK

Past grant recipient

Past grant recipient Heather Boyko



Willow in his new sports chair





Victor's new bike made possible by a grant in partnership with the Goldeyes Field of Dreams.



## Happy Retirement

On April 29, over 150 Members and friends of the Association gathered to wish Laura Schnellert, a bon voyage to the next adventure of her life. Along with her family and daughter

Thank you Laura!

CEURENCE

CONTROL

CO

Karen, we told stories, shared laughs, even shed a few tears as we looked back at the 23 years Laura devoted to CPAM.

In the photo at right, we have a quilt that is made up of all the old Bike Race T-Shirts, a great gift, and the members

# Bike Race Quilt



presented Laura with a gift certificate for \$2700,00 for travel. Enough to get Laura off the ground in her new adventures. I would like to thank the organizing committee for putting in all the hard work, to make it happen. As Laura would say "Hugs" to Marnie, Laura K., Jodie, Charlene, Cal.

# Sincere Thanks for the Caring Thoughts and Generous Gifts

The thoughtful cards and beautiful words, the generous gifts and the warm wishes were all appreciated and I thank each of you so very much. Everyone who contributed in anyway to the delightful retirement reception in April made the event truly memorable for me.

I have had a gratifying and fun filled 23 years in the employment of the Cerebral Palsy Association of Manitoba. It has been a privilege to assist children and adults with a diagnosis of Cerebral Palsy and their families. I hope in some way that I have helped to make a difference. I was always happy to visit, phone or email in order to provide information and support. I felt we were a "family" of families and I was honoured to be part of that.

I have already started enjoying my retirement time and have travelled with friends to several places in the United States. I plan to visit family and friends in Western Canada this summer and take a holiday this winter to a relaxing hot spot some where in the sunny south.

Truly, I thank you for your friendship, your respect, your support and for making a difference in my life.

Hugs to all of you. **Laura Schnellert, Retiree** 

# THE RETREAT WEEKEND

Wow, I survived and no one got hurt, that is what I thought after the last camper got on the bus to go to Winnipeg from Camp Arnes. The 21st Annual Retreat weekend happened May 4 – 6th 2012. The retreat weekend is one of the oldest



and supporting each other. Thank you to the wonderful staff at Camp Arnes to put up with my many questions and all their hard work making our Retreat a success.

**David** 

traditions and events that CPAM has; only our Bike Race has been going longer. We had 43 members, families & guests at Camp Arnes this year. We had a wide variety of activities such as Scrapbooking, bingo, swimming and visiting the corral of horses and other animals. One of the highlights was a good old fashioned Campfire with

marshmallows and hot chocolate. I am thrilled to have one application for next year. I would like to Thank to all the people who jumped in to make it a success from schlepping equipment, assisting with activities,







### **FAST FACTS**

#### **GENERAL INFORMATION**

- ▶ World CP Challenge is an exciting 4 week team challenge
- ▶ 4 September to 2 October 2012

#### REGISTRATION

- Participants form teams of 4 people (Team Leader and 3 Team Members)
- ▶ Team registration is completed by the Team Leader at www.worldcpchallenge.org
- Cost \$25 per adult / \$10 per child
- ▶ Once registered, each participant will receive a World CP Challenge Kit their pedometer

#### **HOW IT WORKS**

- Participants wear their pedometers daily over the 4 weeks and enter their steps into their homepage on the World CP Challenge website or via a smartphone
- ► Participants can also carry out over 40 other physical activities which can be converted to steps on the website eg: 60mins of cycling = 7,909 steps
- As participants enter their steps or other activity, their team will be moved up a virtual mountain on the website with the aim to reach the top by the end of the 4 weeks

#### **FUNDRAISING**

- ▶ Participants can start fundraising as soon as they register
- Fundraising isn't compulsory but it will make a huge difference to the lives of people with cerebral palsy
- ► The website offers easy to use fundraising tools for online fundraising

#### **BENEFITS**

- Improve your health and wellbeing
- Increase motivation
- Be more productive
- Encourage teamwork
- Support the local community

#### CONTACT

If your organisation is interest in participating or would like more information please contact CEREBRAL PALSY ASSOCIATION IN MANITOBA I-800-416-6166 or office@cerebralpalsy.mb.ca

Did you know cerebral palsy is the most common physical disability in childhood? Sign up today and get active, have fun and support people with cerebral palsy!





# WORLD CEREBRAL PALSY DAL

CHANGE MY WORLD IN ONE MINUTE

# Tuesday 4 September 2012

**More Information Coming Soon!**