The summer is here! I hope everyone has been enjoying themselves. I know a lot of kids have already been to camp and lots are still waiting to go; isn’t it quiet when our kids are away?

I’d first like to welcome OPACC’s Administrative Coordinator, Sarai Porretta. OPACC was able to hire Sarai as a result of our successful Ontario Trillium Grant application. Sarai has been working with us for a few weeks now and I’ve been impressed at the things she has already done. Sarai will help move our organization forward in so many positive ways. Welcome, Sarai!

We will soon be launching OPACC’s updated web site. A few months ago we looked at our site and realized we really needed to update it. Besides the update, OPACC has rebranded and has a new, fresh logo. The web site is crucial in this electronic age, so to be able to have the most up-to-date information and a site that our families will use and check back on is so important to connecting with families.

There are some other projects OPACC is working on as well. September is fast approaching. OPACC has been asked to participate in The Inside Ride happening in Toronto on September 16th. As part of the participation, OPACC will receive funds from the Coast to Coast Against Cancer Foundation who is putting on the National Inside Ride. Please check out the site http://toronto.theinsideride.com/ to register a team or donate.

Susan, OPACC’s Parent Liaison, has been meeting and greeting families at the Hospital for Sick Children for over a year now and building healthy relationships with the staff and families there. As Sick Kids is the busiest treatment centre for our kids in Ontario, OPACC felt it was important to concentrate on establishing our Parent Liaison program there. Susan not only meets families as they visit the outpatient clinics but also offers a weekly drop-in where families can come and chat with other families. She has also established some co-facilitated Parent Support Groups to help our families cope.

OPACC looks forward to a time when we can start providing Parent Liaison staff to other treatment centres in Ontario. In order to do this OPACC is continually searching for other sources of funding. OPACC’s families will never pay a membership fee, as we’ve all already paid our dues, but we also realize that our families are our biggest resource. If you can support us financially that would be great, but just as important to the growth of our organization is the spirit of volunteering. Many of us on the Board have given this important organization years of voluntary service, but we could always do with fresh ideas. Volunteering is another important way you can help the organization that wants to help you. Please contact us at info@opacc.org for more information on volunteering opportunities. Have a fun and safe summer!

Always,
Hannah’s Dad
Dave Munro
New Contact Info
Please be aware that OPACC has a new mailing address and phone number:

Ontario Parents Advocating for Children with Cancer
524 Bayfield Street North
P.O. Box 20005
Barrie, ON L4M 5E9

Tel: (705) 828-7965

Our Parent Liaison, Susan Kuczynski, has a new voicemail phone number at Sick Kids:
416-813-7654, ext. 28781

New Administrative Coordinator
OPACC received a funding grant from the Ontario Trillium Foundation to hire the necessary Administrative Support required to allow the organization to grow and prosper. Sarai Porretta joined OPACC on Monday, July 11th in this role and brings with her a wealth of knowledge, experience and passion that will help OPACC serve its families better.

A native of Florida, Sarai has resided in the Barrie area for the past decade and brings with her extensive experience in the field of professional office work and customer service. In her most recent role prior to being hired by OPACC, Sarai worked with a local non-profit cultural organization, where she gained further experience in the not for profit sector. In her current role with OPACC, Sarai will act as administrator for the charity, managing all aspects of the day to day running of the organization, helping with event planning, serving as the main point of contact for other organizations and the general public, and developing communications materials via print and electronic media, among other responsibilities.

The Ontario Trillium Foundation is a catalyst that enables Ontarians to work together to enhance the quality of life in their communities. OPACC applied for an Ontario Trillium Foundation grant in November 2010 and received the first installment of their grant in April 2011. OPACC undertook a search for the right candidate to fill this role and was excited to find a perfect fit in Sarai Porretta.

Website Update
We are working hard on updating our website to bring you a new and improved version soon. Our new website will aim to give you smoother navigation, updated links and resources, articles of interest, and lots more useful information. We will let you know when we launch our new website. In the meantime, our current website at http://www.opacc.org is still active.

Facebook Page
Did you know that you can find the OPACC family on Facebook? Join us to get the latest news, updates, and connect with other families. Just press <Control> and click on this link: https://www.facebook.com/group.php?gid=3057645252
**Canada Helps Donations**

You can easily make a fast, secure donation through our Canada Helps page - just press <Control> and click here:


**Parent Liaison Update**

OPACC’s Parent Liaison, Susan Kuczynski, meets with parents and families at Sick Kids and helps to address fears or concerns they may have. She passes out information on available services and can direct them to Parent Support Groups that may exist in their communities. Susan can be found at Clinic on Monday, Wednesday and Thursday mornings. Please stop by and see what free materials you might want to pick up. As well, she hosts a drop-in from 6:30-8:30 pm on Tuesday evenings in room 8704. In addition to support materials there is the opportunity to sit and chat with parents and enjoy refreshments in a comfortable setting. Susan is available for informal chats and visits wherever you might be in hospital and can be reached at 416-543-3701 or at liaison@opacc.org. Her voicemail at the hospital is 416-813-7654, ext. 28781.

OPACC and the Parent Liaison collaborate with HSC to run a co-facilitated Parent Support Group as well as continue to work with them in the development of additional needed supports for families. The co-facilitated group begins in October and will run every other Thursday evening from 6:30-8:30 pm in room 8704. The dates will be: October 6, October 20, November 3, November 17, December 1, and December 15.

**Inside Ride Toronto**

The Inside Ride is a fantastic 2-hour team-building, high energy musical event featuring Canada’s first indoor cycling celebration that supports children and their families living with and beyond cancer. It is hosted by the Coast to Coast Against Cancer Foundation. Susan is putting together a team – Susan’s Team OPACC - for the Inside Ride event on September 16th. The event will take place at Yonge/Dundas Square in downtown Toronto from 2:30-4:30 pm. The funds raised during this event will go to OPACC’s overall fund and will be disbursed to all our groups. You can pledge Susan’s team (tax receipts will be issued for any donation of $20 or more), become a member of her team, volunteer, or even create an OPACC team of your own! Susan’s personal fundraising site is here: http://my.e2rm.com/personalPage.aspx?registrationID=1180922.

Gold Ribbon Inside Ride for Childhood Cancer: http://www.toronto.theinsideride.com

**Photo Request**

We are collecting personal photos to include on our website and printed materials. We want to make this your OPACC and as such add a personal touch by showing real OPACC families on our website and communications! If you have a photo that you’d like to submit, please email us at info@opacc.org for a Photography Waiver and Release form that you’ll need to review and sign off on before submitting any photos.
Upcoming OPACC Board Meetings

- September 10, 2011 - Board Meeting and Annual General Meeting - Sick Kids, Room 8704 – 10 a.m. to approx. 2 p.m.
- Nov. 5, 2011 – Teleconference (details TBA)

Updates from Organizations

- **Candlelighters Simcoe Parents of Children with Cancer** supports families of children with cancer in Simcoe County, Muskoka, and the surrounding area. We have monthly parent support group meetings with a concurrent children’s expressive art program. All of our meetings are held the first Monday of each month at Gilda’s Club Simcoe Muskoka (10 Quarry Ridge Rd) in Barrie. New families are welcomed to join!

*Dragon Boat Races:* Come out and cheer on our team “Candlelighters Courageous Cancer Kids” on Saturday, August 27th from 8 am to 5 pm. We have a potluck going so bring some food and join in with our team and kids. Also we would like to invite you all to attend the memorial moment at 10:30 am by the pond at Heritage Park (downtown Barrie) where we will honour our children who have lost their battle with cancer. There is also a parade of teams the night before on Friday, August 26th at 6 pm. We welcome all families to join in our parade (meet at the team village in Heritage Park by the pond).

*Annual Pot Luck Dinner and AGM:* We always start off the school year with a potluck dinner for the parents; kids join us later for dessert. It will be on Monday, September 12th from 6 pm until 8:30 pm at Gilda’s Club.

*Inside Ride Childhood Cancer Awareness event:* This event which will be going on across Canada during September (Childhood Cancer Awareness month) and will stop in Barrie for a fundraising event on Saturday, September 17th from 12:30 pm to 2:00 pm at St. Joseph’s High School (243 Cundles Road East). Recruit teams, donate, or come and volunteer - all are welcomed! All funds raised at the Barrie event will stay with Candlelighters Simcoe. Go to [http://Barrie.theinsideride.com](http://Barrie.theinsideride.com) to sign up.

*Terry Fox Run:* Colleen Kelly-Desrochers is the Captain for the Terry’s Team Members (cancer survivors) this year and would like to invite Candlelighters Simcoe to join them on Run Day, Sunday, September 18th. Terry’s Team Members do not have to participate in the Walk/Run if they are unable to do so, but we would like their presence signifying their cancer survival.

For more information: Contact Barbara Johnson, President of Candlelighters Simcoe at [albarbjohnson@sympatico.ca](mailto:albarbjohnson@sympatico.ca) or call 705-737-4296.
Updates from Organizations, con’t.

- **K-W Support Group for Parents of Children with Cancer** Our group has been meeting every second Tuesday of the month for over 3 years thanks to the generosity of HopeSpring Cancer Support Centre (43 Allen Street West, Waterloo; tel: 519-742-4673). The group began when Lisa Skinner (whose son Cole had V.H.R. A.L.L.) read a story about Helen Robertson (and her son Liam who had stage 4 neuroblastoma) in the local paper noting that she wanted to start up a support group for parents. Children who are diagnosed with cancer living in Waterloo Region may be treated at one of three Children’s Hospitals, either in Toronto, London or Hamilton. As a result, we believe it is essential to have a support group for families here in our community. We have been communicating to parents through the Children’s Outpatient Clinic at Grand River Hospital. We have also attended POGO conferences as delegates and representatives of OPACC, providing information to those working in pediatric oncology about our local group and our provincial affiliate OPACC.

  For more information, contact either Helen or Lisa through HopeSpring. We meet the second Tuesday of each month (September through June) from 7:00-8:30 pm.

- **Gilda’s Club Barrie** We are celebrating our very first year as a cancer support community on Friday, September 16th from 5:30 pm-8 pm. Plan to join us for this family-friendly BBQ and celebration! To register for this event or for more information, please contact Gilda’s Club Simcoe Muskoka at (705) 726-5199 or program@gildasclubbarrie.org

  In recognition of Childhood Cancer month, we are pleased to host the airing of the Cancer Support Community’s radio broadcast series *Frankly Speaking About Cancer* with September’s special discussion on: “The Impact of Childhood Cancer on Siblings.” Please check out the monthly Program Calendar online for date and time: [http://www.gildasclubbarrie.org/](http://www.gildasclubbarrie.org/). To register for this event or for more information, please contact Gilda’s Club Simcoe Muskoka at (705) 726-5199 or program@gildasclubbarrie.org

  Interested in knowing more about the social and emotional support available for men, women, children and teens whose lives have been touched by cancer? Check us out! Visit us online [http://www.gildasclubbarrie.org/](http://www.gildasclubbarrie.org/) or stop by the Red Door for a tour of the Clubhouse!

- **Rebounders Canada** Rebounders has a "Round-up" for adult survivors of childhood cancer and their annual New Life Dinner fundraiser on Saturday, October 1st. This is an annual event bringing together survivors from across Canada to socialize, team build, share a day of fun, and join supporters for an evening fundraiser that includes an elegant reception & dinner, silent auction, knowledge, and inspiration. To register for the Rebounders Round-up please call Andrew or Jill at 905 338-1530 or email us at rebounderscanada@cogeco.ca. To order tickets for the New Life Dinner please contact Mary Curcic at 416 366-4228 ext. 241 or email mary.curcic@standrewsclub.ca
Updates from Organizations, con’t.

- **Brain Tumour Foundation of Canada**

  *Barrie Education Seminar*: Saturday, September 17th from 9:00 am to Noon at Gilda’s Club (10 Quarry Ridge Road, Barrie). Speaker topics featuring “Mind Matters: Moving Forward After Brain Injury” and “Managing Cancer Related Brain Fog.” For more information click here: [http://www.braintumour.ca/1560/barrie-education-seminar](http://www.braintumour.ca/1560/barrie-education-seminar)

  *London Information Day*: A day of hope and support. Theme of the day: “Your Health Care Team.” Kids conference also available. Saturday, October 15th at Four Points by Sheraton, London. Click here for more information: [http://www.braintumour.ca/630/london-information-day](http://www.braintumour.ca/630/london-information-day)

  **Brainwave**: BrainWAVE is a support program for families with a child (19 years of age or younger) with a brain tumour. Through the program, BrainWAVE offers you and your child/teen the opportunity to connect with other families in a similar situation and to obtain much-needed support, information and education. Several times a year, BrainWAVE families meet through fun activities such as trips to sporting events, historic sites, and other family attractions. These free events give members of your immediate family a welcome break from treatments and doctors’ visits. Our next event will be on September 24, 2011 at the Leaping Deere Adventure Farm and Market. It is free to sign up as a member of the program by contacting Joshua Peters at jpeters@braintumour.ca or 1-800-265-5106 x 234.

- **Camp Oochigeas**

  Just because summer is over, it doesn’t mean that camp has to end! Camp Oochigeas offers year-round programs for children aged 4-19 in three places: on the 8th floor at the Hospital for Sick Children, at our Urban Camp setting - Ooch Downtown (College and Bathurst), and up North in Muskoka.

  If you are an existing camper, you can expect to receive your registration package in the mail at the end of August. If you are a new potential camper, please email nshaughnessy@ooch.org for more information on programs happening at Ooch this fall. We would love to see you at one of our WACs (Weekends at Camp), or UOs (Urban Oochs) this fall! New this fall - we will be offering sleepovers at Ooch Downtown, as well as more family nights!

- **Basal Cell Carcinoma Nevus Syndrome Life Support Network**

  2011 Canadian Meeting - We hope you and your family will join us for a meeting and information day. This is a wonderful opportunity to meet others dealing with the same challenges, offer and receive support, to learn and share, and make new friends. We will also be sharing with you our plans for the future growth of our Canadian organization. Join us on Saturday, October 1, 2011 at the Ajax Hilton Garden Inn in Ajax, ON. Registration fee is $40.00 per person. To register, or for more information, please contact your Canadian Representative, Patricia Pearsell at (905) 668-4913, or at BCCNSCanada@hotmail.ca
Hearth Place Cancer Support Centre has recently launched a new Pediatric Cancer Family Support Programme to support families dealing with childhood cancer. Our new programme includes a monthly facilitated peer support group for parents, in home play, art and music therapies for children diagnosed with cancer and their siblings. We also offer sibling support programmes, individual counselling and practical support services.

As part of this program, Hearth Place will be holding a Family Fun Day in recognition of Childhood Cancer Awareness Month. It is being held on Saturday September 17th, 2011 in the gymnasium of Westminster United Church from 12:00 pm until 4:00 pm at 1850 Rossland Road East, Whitby.

Our Family Fun Day will include a pizza lunch, games, crafts, a puppet show and a drumming workshop for the whole family. We will end the day with special family presentations.

This Family Fun Day is open to all family members who have been impacted by Childhood cancer. Pre-registration for this program is required so that we can plan activities accordingly. For more information or to register for any of these programmes please call 905-579-4833 or email Janette Berthelot at hearthplacefamilyprogram@gmail.com

b.r.a.i.n.child

Paediatric Brain Tumour Education Day
November 13, 2011, 9:00 am - 1:00 pm
Location: Sick Kids
The Paediatric Brain Tumour Education Day will feature a new format. There will be a variety of speakers as well as posters from numerous b.r.a.i.n.child-funded projects. Participants will be able to go on a tour of the Arthur and Sonia Labatt Brain Tumour Research Centre (BTRC). The education day will be open to anyone 16 years and older. More information will be in the fall issue of b.r.a.i.n.source (b.r.a.i.n.child’s quarterly newsletter) and will be posted on the b.r.a.i.n.child website in the fall www.sickkids.ca/brainchild.

The b.r.a.i.n.child newsletter, b.r.a.i.n.source, is available in PDF format. Please send an email to karenhaas@rogers.com if you’d like to receive the newsletter via email.
OPACC Board of Directors

Dave Munro - President and Chair
Barbara Johnson - Director
Helen Robertson - Director
Lelia Amin – Director
Sarai Porretta – Administrative Coordinator/Recording Secretary (non-voting)

James Thomson - Treasurer
Lisa Skinner - Director
Stathi Afendoulis - Director
Susan Kuczynski - Parent Liaison (non-voting)

The diagnosis of a childhood cancer affects the whole family. OPACC is helping families cope with that diagnosis and is working to expand the Parent Liaison role throughout the province.

OPACC Educates, Advocates, Supports and Enables families of children with cancer [http://www.opacc.org](http://www.opacc.org)

Coast to Coast Against Cancer Foundation - Canada’s only national charity devoted to fighting childhood cancer [http://www.coasttocoastagainstcancer.org](http://www.coasttocoastagainstcancer.org)

Childhood Cancer Canada - Childhood Cancer Canada is a national, volunteer governed, charitable organization dedicated to improving the quality of life for children with cancer and their families [http://childhoodcancer.ca](http://childhoodcancer.ca)

Lainie’s Angels - Hope, Honesty, Compassion, and Support for the needs of the family with a child who has cancer [http://www.lainiesangels.com](http://www.lainiesangels.com)

Ontario Trillium Foundation (OTF), one of Canada’s leading grantmaking foundations, is an agency of the Government of Ontario. The OTF is a catalyst that enables Ontarians to work together to enhance the quality of life in their communities [http://www.trilliumfoundation.org](http://www.trilliumfoundation.org)