

OPACC Newsletter March 2011

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COAST TO COAST FOUNDATION AGAINST CANCER HELPS ONTARIO PARENTS ADVOCATING FOR CHILDREN WITH CANCER

Ontario Parents Advocating for Children with Cancer (OPACC) has received the first installment of a 3-year grant from the Coast to Coast Foundation Against Cancer. The funds from Coast to Coast will be used to further develop and enhance the Parent Liaison role that OPACC has funded in the Hematology/Oncology program at Toronto's Hospital for Sick Children (HSC). OPACC's Parent Liaison role was established on a part-time basis in 2009 thanks to initial 5 year funding from Lainie's Angels. OPACC strives to place this value added service in all pediatric oncology treatment centres in Ontario as well as in the satellite treatment centres where there is a need for this service.

A Parent Liaison has already experienced the difficulties of having a child with cancer. They understand the complexities and impact this journey can have on the family and can soften the negative emotional, financial, and social impacts. Siblings of diagnosed children have often been described as the forgotten patient and can often struggle in school as they adjust to the new roles their parents must undertake in caring for their child with cancer. OPACC's Parent Liaison is there to offer first hand support to help ease the impact of a child's cancer diagnosis for these families.

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 susan-kuczynski@rogers.com. 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.

Recently Chai Lifeline Organization hosted a free fun-filled day for families at the Woodbine Centre. Many thanks to them for including our OPACC families!

Candlelighters Simcoe Parents of Children with Cancer supports families of children with cancer in Simcoe County, Muskoka and 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 in Barrie.

Upcoming meeting:

Monday April 4, 2011 7pm: Special guest speaker Barb Williams from POGO will discuss the SAVTI (Successful Academic Vocational Transition Initiative) program. She will talk about how to help students with cancer transition to high school, post secondary, work etc.

Special events:

August 27, 2011 Annual Dragon Boat Races fundraiser for our Candlelighters Courageous Cancer Kids team of parents and teens

September 17, 2011 Coast to Coast Against Cancer Foundation National Inside Ride will stop in Barrie for a fundraising event that day, supporting our local families.

For more information: contact Barbara Johnson Parent Liaison/President of Candlelighters Simcoe at albarbjohnson@sympatico.ca or call 705-737-4296

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 W. Waterloo 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 3 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 - once again, we meet the second Tuesday of each month from 7:00-8:30 pm September to June.

OPACC Board of directors:

Dave Munro - President and Chair	James Thomson - Treasurer
Barbara Johnson - Director	Lisa Skinner - Director
Helen Robertson - Director	Stathi Afendoulis - Director
Lelia Amin - Director	
Susan Kuczynski - Recording Secretary (non -voting), OPACC Parent Liaison	

OPACC would like to introduce our newest board member, Lelia Amin. She is an Occupational Therapist, and she is also a graduate student in the Department of Rehabilitation Sciences at McMaster University doing her thesis project in the area of cancer survivorship. Specifically her interests include understanding survivor self-management behaviours and parents' roles in supporting survivors as they enter adulthood. She comes to board with volunteer experience at HSC and Camp Trillium and as a bereaved sibling.

Upcoming OPACC board meetings:

May 14, 2011 in person (Toronto)

Sept. 10, 2011 in person (Toronto)

Nov. 5, 2011 teleconference

OPACC is interested in recruiting new board, or committee members with specific skills in fundraising, media/public relations and finance. For further information please contact

info@opacc.org or look for us on the web at www.opacc.org

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.

Coast to Coast Against Cancer Foundation Canada's only national charity devoted to fighting childhood cancer

Lainie's Angels Hope, Honesty, Compassion and Support for the needs of the family with a child who has cancer.

OPACC Educates, Advocates, Supports and Enables families of children with cancer.