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NEW OPACC BOARD:

In February 2006, OPACC realized one of its most important goals by becoming an incorporated organization. We are in the process of applying for our charitable status. In March 2006, our board of directors was elected and they are:

Dave Munro:
President/Chair-Director

Deirdra Redden:
Treasurer-Director

Teresa Reardon:
Director

Susana Malowaniuk:
Director

Maryann Istiloglu:
Director

James Thomson:
Director (Elected August 2006)

Barb Johnson:
Recording Secretary (member)

If you have any questions regarding this board or wish to become a member of OPACC, please email Barb Johnson at albarbjohnson@sympatico.ca.

MISSION: OPACC is the provincial voice of families and parent support groups dedicated to helping families touched by childhood cancer.

OPACC HISTORICAL: Established in 1995 OPACC is comprised of representatives from parent groups/parent contacts across the province. The members are parents, guardians, survivors or close relatives of a child/teen diagnosed with childhood cancer.

OPACC meets three to four times a year in Toronto either in person or by teleconference.

OPACC has advocated on behalf of our children/teens and our families with appropriate regional, provincial and national bodies such as POGO (Pediatric Oncology Group of Ontario), Childhood Cancer Foundation – Candlelighters Canada (CCF) and the Canadian Cancer Society (CCS) Ontario Division.

We have supported, collaborated and had input into initiatives such as:

- ? Pediatric Oncology Working group report for the Ministry of Health-1994
- ? Development of Satellite Oncology program as well as long-term follow-up clinics in the province
- ? Financial Assistance program for families of children/teens with cancer through POGO and CCS
- ? CCS pediatric handbook and children's cancer brochure
- ? POGO handbook on provincial resources for families of children with cancer in the province
- ? CCF National Conference-2000
- ? Steering Committee/cluster groups for POGO 5-year plan for Ministry of Health and Long Term Care-2005
- ? Past representation on POGO Psycho-social committee, CCS Pediatric Advisory committee and the Childhood Cancer Foundation Candlelighters Canada board.

OPACC'S CHALLENGES: A diagnosis of childhood cancer is a long and difficult journey for families. There are many issues to deal with from the requirements of treatment to emotional ups and downs, the need for information and how to navigate the system, financial, employment and schooling concerns to name just a few. While the health care teams are invaluable in helping parents through this difficult time, many parents also find it helpful to have contact with a parent who has been through the experience and can help them cope with some of the many things they face.



THE SOLUTION: In keeping with our mission, OPACC strongly believes that in order to address the challenges that parents encounter in their journey of childhood cancer, a parent liaison position should be added to the healthcare team in a paid professional role at each of the childhood cancer treatment centres as well as satellite centres. OPACC is committed to making this a reality. Such a position has been piloted on a volunteer basis at the Hospital for Sick Children and from all reports both the parents and healthcare professionals found the parent liaison a valuable resource.

The parent liaison role is intended to compliment existing resources or fill the gaps where there is a lack of services.

The following are just a few examples of what the role of a parent liaison will entail*:

- ? Assist families in becoming more comfortable with the surroundings of the Treatment or Satellite Centre
- ? Facilitate the families' understanding of the day-to-day operation of the hospital and clinic.
- ? Alert the parents to the services available to them at the hospital, clinic or local community such as: parent support groups, wish foundations, cancer camps, service clubs, community resources etc.
- ? Distribute resources from Childhood Cancer Foundation, POGO, parent support groups, cancer camps, Carla Can Sing Dolls etc.

*Parent liaisons will be part of the healthcare team, however they may not be trained medical professional and they will not be allowed to offer medical advice and will be instructed to refer parents and patients to their primary care doctor or nurse.

WHAT'S HAPPENING!

CHILDHOOD CANCER AWARENESS MONTH IS SEPTEMBER

In conjunction with Childhood Cancer Awareness Month, OPACC will launch our new website www.opacc.org on September 1, 2006. We are accepting stories and article submissions for our website and newsletters. Please send your submissions to Deirdra Redden at daredden@spectranet.ca.

OPACC MEMBERS: Throughout the Province of Ontario, we have a number of representatives:

Barrie: Barb Johnson/ Dave Munro
Candlelighters Simcoe Parents of Children with Cancer;

Waterloo: Juanne Clarke/Maryann Wilford
Parent contacts;

London: Colleen Zrini, Childcan;

Ancaster: Deirdra Redden, Parent contact;

Oakville: Joanne McLeod, Parent contact;

Oshawa: Lorraine Frederick, Parent contact;

Ottawa: Patti Dillabough/Sharon Ruth,
Candlelighters Childhood Cancer Support Programs Inc.;

Port Hope: Jane Ashmore, Cobourg/Port Hope
Candlelighters;

Sudbury: Brenda Verdiel/Carol Gallo; Northern
Ontario Families of Children with Cancer;

Toronto: Susan Kuczynski/ Teresa Reardon
Parent contacts; Carol Saunders Mohammed,
Brainchild;

Windsor: Susana Malowaniuk, Parent contact
**Rebounders Adult Survivors of Childhood
Cancer**

Andrew and Jill Sprawson



OPACC needs new members from all areas of the province especially Kingston and Hamilton. Show support by becoming an OPACC member. If you are interested in OPACC membership or in a board position, please contact:

Dave Munro-Chair:

Parents in Eastern Ontario

Phone: 705-725-0747

davidmunro@rogers.com

Barbara Johnson-Secretary:

Parents in Northern and Central Ontario

Phone: 705-737-4296

Email albarbjohnson@sympatico.ca

Deirdra Redden-Treasurer

Parents in Southern and Western Ontario

Phone: 905-648-0337

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Newsletter Team:

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