



Ontario Parents Advocating for Children with Cancer

*2008
ANNUAL
REPORT*

About Us

OPACC was established in 1995 and is comprised of representatives from parent groups, parent contacts, and other family members from across the province. Our members are parents, guardians, survivors, or close relatives of a child/teen diagnosed with childhood cancer. We have been a Registered Charity since 2006 under charity number 846324168RR0001.

OPACC meets four times a year: In person in May and September in Toronto and by teleconference in February and November.

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.

Mission and Goals

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

OPACC's overall goal is to be the voice for families with children diagnosed with cancer across the Province of Ontario. Other core goals include:

- To establish the Parent Liaison role where deemed appropriate in collaboration with local stakeholders
- Strengthen existing parent support groups
- Support the establishment of new parent support groups
- Establish a collaborative process for sharing and collecting information with parents through mentoring and educational activities
- Establish financial sustainability

President's Report 2008

A year has passed since our last Annual General Meeting and we are still crawling along as an organization in its infancy. I know it can be frustrating because we all want to be running but, in reflection, it is perhaps better that we crawl along and methodically grow the organization. During the past year we worked hard on trying to get OPACC established and some very positive things have come out of it.

In December I had the opportunity to attend the Public Health Agency of Canada's Roundtable Discussion on Childhood Cancer. There was representation covering the complete spectrum of childhood cancer. It was an interesting meeting where the medical community spoke about the fact that the whole family is affected by a childhood cancer diagnosis and there is a need to treat the whole family. Dr Maru Barrera spoke of the parents being the "Invisible Patient". If the parents are the Invisible Patient, as we know we are, then the siblings are the Forgotten Patient.

In February I met with POGO where I was told that perhaps now was the time to discuss OPACC running Parent Support Groups at Sick Kids. It was also mentioned that the Ministry of Health and Long Term Care had approved a new Interlink Nurse for the only region in Ontario that did not have one, Simcoe County and Muskoka as well as a new satellite clinic to be based in the Central Ontario area comprising of York Region, south Simcoe County, Northern Peel and Durham regions. Because of where I am employed full time I expressed that I would like to see that satellite situated at Southlake Regional Health Centre in Newmarket.

In May we received notice from Lainie's Angels that they would be willing to contribute a substantial amount of money if OPACC can get a Parent Liaison position established at the Hospital for Sick Children. During May and June a couple of the Directors worked extremely hard on the final draft of our Ontario Trillium Grant application. They worked with the lead organization, the Childhood Cancer Foundation, to get the application finalized for submission. The application was hand delivered by David Stones days before the July 1st deadline. A lot of hard work was completed and even though we had planned on submitting the application for the March 1st deadline July 1st was much more realistic considering the amount of work. Congratulations to all those who spent many hours working on it, you all did a fantastic job.

Through wrangling with Sick Kids we finally got a date set and met with them in July. They seemed to be more receptive of getting Parent Support Groups started there but first they set up a few more hurdles. Some of the Sick Kids folks mentioned that to focus only the inpatient families we would only capture a few of the hundreds of families they see in a week, they suggested we may consider a few different days a week to include clinic families as well. Upon their recommendation a draft survey was put together with our collaboration to be distributed to the parents on the ward and in the clinics. We sent in our comments and, just prior to this meeting, they sent it back to us for a final perusal before we meet with them on Monday, September 21st.

A few weeks ago we received notification through the lead organization that our Ontario Trillium Grant application was declined. Needless to say that was very discouraging news considering the amount of time a few individuals put into it. It doesn't mean we can't apply again and as such we contacted Trillium to find out what issues they had with our application and how we can make our next application stronger. Considering the work that went into the application some good has come out of it. The OTF application is very extensive and because of that we should be able to fill out other applications a lot easier as so much of the work has been done.

This brings me to something that I read at a Neuroblastoma Retreat last fall at Camp Ooch, a quote from Margaret Mead that I think sums up OPACC; "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has." While I was searching for that quote while writing this message I found another, very pertinent quote; "Even though the ship may go down, the journey goes on." Go on we must.

In July I learned that POGO had chosen the next satellite centre approved in their next five year plan. The site chosen was Southlake Regional Health Centre. I was so excited that Southlake was chosen as I will be able to meet some of the parents on clinic days and offer my support. While I was attending the POGO twenty-fifth anniversary celebrations at their offices it was indirectly pointed out to me that OPACC is making a difference, that we are starting to be heard. I came away from that celebration feeling refreshed and ready to push our agenda and goals further. Even though we are still taking baby steps we are beginning to make a difference in the lives of some of our families!

As we embark on another year I know we will be challenged but I also know we will rise to those challenges and move OPACC forward. Of course there will be discouragements along the way but, haven't we all faced discouragement as our children were being treated? And what did we do then? We kept on fighting. For the sake of the families of children and teens with cancer in Ontario we have an obligation to keep fighting for them.

Thank you

Always,

Hannah's Dad

Dave Munro

Treasurer's Report - Fiscal 2007/2008

TREASURER'S REPORT FISCAL 2007/2008 *(Un-audited)* **Year End May 31/08**

Report prepared by Deirdra Redden (Treasurer)

As Treasurer I can say it has been a very exciting year for OPACC. Donations are now being generated by CanadaHelps.org, and we are forging ahead with grant applications to Trillium and other sources.

STATEMENT OF REVENUES AND EXPENDITURES

Fiscal 2007/2008 (June 1, 2007 – May 31, 2008)

Year End May 31, 2008

REVENUES	May 31st 2007	May 31st 2008
Grants	-	-
Donations	1,314.32	534.56
GST Rebate		72.27
Bank Interest	0.41	0.37
Total Income	1,314.73	607.20
EXPENSES		
Bank Services Charges	28.43	0.00
GST Paid	3.60	0.00
PST Paid	4.80	0.00
Administration	1,609.84	0.00
Postage	0	31.04
Loan Payments	-	-
Total Expenses	1,646.67	31.04

EXCESS/DEFICIT OF REVENUES OVER EXPENDITURES	(331.94)	576.16
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BALANCE SHEET AS AT

May 31st 2008

Assets

Cash
\$878.72

Total Assets
\$878.72

Liabilities

Loan (Candlelighters Simcoe)
\$500.00

Retained Earnings/Equity
\$378.72

Total Liabilities
\$878.72

Board of Directors

David Munro, President and Chair
Deirdra Redden, Treasurer
Barbara Johnson, Secretary-Director
James Thomson, Director
Susan Kuczynski, Director
Stathi Afendoulis, Director
Susana Malowaniuk, Director

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