



# Rapport

*Newsletter of the Northern Ontario Families of Children with Cancer (NOFCC)*

*Striving to improve the lives of families dealing with childhood cancer.*

## NOFCC Introduces Enhanced Programs to Help Families

Thanks to generous donations and excellent fundraising efforts over the last couple of years, the NOFCC is proud to announce enhancements to our core programs, as well as new initiatives, in an effort to better serve the needs of Northern Ontario families dealing with childhood cancer. Northern families are treated at Toronto Sick Kids and at CHEO in Ottawa. Many families stay at Ronald Mc Donald Houses, however more and more families are making frequent shorter trips and are often having to stay in hotels for a few days, or in hospital with their child. To keep up with changing times and the changing needs of our families, the NOFCC has initiated the following:  
~Grocery voucher program weekly allowances have been increased, and now

include the option of vouchers for Dominion, Loblaws, or hospital cafeteria coupons to accommodate the varying needs of families

~ The long distance calling card program, as well as the parking pass program at Sick Kids will continue as they are so appreciated by our families. We have been able to enhance the parking program to include tokens at the Cancer Centre in Sudbury

~ The NOFCC will be providing gas coupons in situations when children are in hospital away from home for weeks and months at a time, when trips are not covered by Northern Health Travel Grants. This will make it easier for the parent staying home with siblings to visit.

~ After a successful pilot this past year, the NOFCC is expanding its laptop computer lending program (see KeepConnected article)

~ The Emergency Crisis Program will be able to offer a variety of programs and assistance for families in exceptional situations.

Thank you to all who have made these programs possible.

### Currently Helping...

At any given time, there are over 30 children in northern Ontario on active treatment for cancer. Many treatments last over 2 years!

## Calling All Fishermen!

### ***Fishing 4 Children's Charities Supports NOFCC!***

The NOFCC is thrilled to be the charity of choice for this year's Pike Tournament, hosted by Fishing for Children's Charities. This annual event raises over \$7000 for charitable organizations, and this year all proceeds will go to support the programs of the NOFCC. This year's tournament will be held on Whitewater Lake in Azilda on July 16, 2005. First prize is \$5000, with many other cash prizes and donated gifts. Entry fee for this one day event is only \$200 per team of two. If you or someone you know would like to register for this event, please fill out the registration form included with this newsletter, or contact Fishing 4 Children's Charities at 969-8664.

### **How Can you Help?**

- Many volunteers are needed on the day of the event to help the tournament run smoothly.
- A sponsor for a boat so one of our kids on treatment can enter the tournament.
- Tournament Sponsors: all cash donations to this event go directly to help the NOFCC, and your business will be actively promoted during the event. Donations of gifts (products, gift certificates, etc) are also needed and are given to participants.
- To donate or volunteer, please contact Louise at 969-8664 or Micheline at 983-4497.

Your support of this event is greatly appreciated. The NOFCC can't thank Fishing 4 Children's Charities enough for their generosity!

### **Inside this Issue**

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- ✓ Taxes
- ✓ PEBBLES update
- ✓ Summer Camps
- ✓ Sponsors
- ✓ ...much more!

## PEBBLES Update

A year ago, Rapport brought you a story about PEBBLES, a robotic student allowing students to be virtually present in their classroom, even though they can't be there in person. The following account was written by Stephanie Roy of North Bay. Stephanie's son Daniel has been treated for cancer, and had the opportunity to use PEBBLES:

Daniel had the opportunity to participate in this great robotic program while living at Ronald McDonald House in Toronto. We also had the pleasure of meeting a few people who were part of the team making PEBBLES a reality. Daniel used PEBBLES from his room when he was feeling well, usually for short periods of time. Daniel's school faxed worksheets to Ronald McDonald House so that he could complete assignments and participate in the class. The PEBBLES system places one robot with the sick child, and it's pair in the child's classroom. The students in his class were fascinated with PEBBLES, who looks a bit like R2-D2! The hand controls Daniel used for PEBBLES were similar to Playstation controls. PEBBLES also had a few games Daniel could lay when he wasn't going to school.

We were also able to meet with folks from Ryerson University who are working on adapting PEBBLES to the Secondary School setting, and we had a wonderful technician, Bertha Konstantinidis, working with us as we used PEBBLES. I thought the main purpose of PEBBLES was to keep Daniel active in his education so that he wouldn't miss any important concepts. However, a purpose just as significant is to keep the children connected socially to their peers and allow them to be part of a "normal" environment. PEBBLES allows for both the patient and the classroom students to be aware of each other's circumstances, ask questions, and continue on with daily routines as much as possible. Daniel felt a part of his class, and stayed connected to his friends. They were reminded that he was still a part of the group, even though he wasn't physically there, helping with Daniel's sense of belonging.

Daniel and his Mom with Pebbles.

## KeepConnected...NOFCC expands its laptop lending program

After a successful year piloting a new program which would have the NOFCC lending donated laptops to kids receiving cancer treatment in order that they can keep up with school and keep connected to friends and family, the NOFCC is working hard to expand this valuable program.

KeepConnected is based on a program from Candlelighters Ottawa, and strives to provide children and teens who have to miss school and/or be away from home for treatment. Education suffers when kids are away from home or school for cancer treatment. This program allows kids to work at their own pace, and when they feel well enough, as well as providing a source of entertainment during long hours of treatment. The majority of kids will return to school, and it is important that they keep up with their peers in the meantime.

Laptops are often beyond the financial means of families. The NOFCC lends laptops during the times they are most needed, along with age appropriate programs and equipment.

### **KeepConnected needs donations...**

...of mice, mouse pads, educational and/or fun software, blank recordable CD's, earphones, new or used laptops, backpacks, and so on.

**Are you computer-savvy?** KeepConnected needs volunteers on occasion to 'clean up' laptops as they are returned in preparation to lend them out to the next child.

## It's Tax Time...

Any family dealing with childhood cancer knows that the financial burdens of treatment can be great. Did you know that certain medical expenses can be claimed on your tax return? These include several out-of-pocket expenses like meals,

mileage, parking, and accommodations. Receipts are generally required, especially for hotels and parking, but certain pre-set amounts are allocated daily for meals and per kilometre without receipts. You may need confirmation of your

appointments over the last year, which can often be obtained from a physician or nurse on your child's treatment team. The following sources may be of assistance: A T1 tax form, line 330 (with documentation) and [www.cra-adrc.gc.ca](http://www.cra-adrc.gc.ca).

## Farewell to Judy Mayer

After 10 years as the Pediatric interlink nurse for Northern Ontario, Judy Mayer has decided to move on. She will be missed by so many families whom she has helped over the years.

The following comes from Micheline Ferguson:  
Thank you to Judy Mayer for everything she has done for

northern families. A lot of us would not have survived without her continuous support. My daughter Melissa was Judy's first patient in November of 1994 when she started with Interlink. Now, 10 years post diagnosis, Melissa is a happy and healthy teenager. Judy will always have a special place in the

hearts of my family. We wish her well in her future endeavors, and hope that she knows the impact she had on my family and on so many others.

Allison Hicks has assumed Judy's position, and we welcome her. Allison has already been a great help to the NOFCC, and the NOFCC

reminds families that your Interlink Nurse is your voice. The NOFCC encourages families to talk to Allison about your needs, as this enables us to tailor our programs to best serve the needs of northern families.

## Time to Think About Summer Camps...

Well, the warmer weather is finally upon us and with it two months of summer vacation! There are many camping options for kids on or off treatment, as well as their siblings. Summer camp is a chance for kids to be kids, a chance which is often too rare for kids dealing with a cancer diagnosis. Camp Quality, Camp Trillium, and Camp Oochigeas are located throughout Ontario and provide a variety of summer camp choices including residential camps, day camps, and family camps for children on and off treatment

and their families. These camps are staffed by qualified volunteers as well as a physician and nurses to accommodate children on treatment.

For children who prefer to attend a different camp, the Cancer Recovery Foundation can often help financially. For example, they helped a couple of teens off treatment to attend a riding camp last year. The choices are endless.

For more information, contact the camps or your Interlink Nurse.

### Camp Quality Northern Ontario

1-800-899-3380

[www.campqualitynorth.ca](http://www.campqualitynorth.ca)

### Camp Trillium

1-888-999-CAMP

[www.camptrillium.com](http://www.camptrillium.com)

### Camp Oochigeas

1-416-961-6624

[www.ooch.org](http://www.ooch.org)

### Cancer Recovery Foundation

1-866-753-0303

[www.cancerrecovery.ca](http://www.cancerrecovery.ca)

## Upcoming NOFCC Events

### **2<sup>nd</sup> Annual RBC Golf Tournament**

In Support of the NOFCC

Watch for information on this exciting annual event coming up this fall at the Golf Course in

For registration, information, or to make a prize or cash donation, please call Micheline at 705-693-7282

### **NOFCC Meetings**

The NOFCC meets monthly, usually the 4<sup>th</sup> Monday (unless it conflicts with a holiday). We meet at the cancer centre in Sudbury from 7-9pm in the Supportive Care meeting room on the 1<sup>st</sup> floor. New members are always welcome, if you have some spare time, we'd love to see you there!

#### **Next meetings:**

Monday April 25<sup>th</sup>, 7-9pm

Monday May 30<sup>th</sup>, 7-9pm

Monday June 27<sup>th</sup>, 7-9pm

### **Buy-One-Get-One-Free Cards**

These coupon cards are for sale through the NOFCC, as well as at Credit Unions in the area. For a \$15 card, get up to \$400 in savings at these merchants:

Pizza Hut\*The Home Depot\*Future Shop  
William's Coffee Pub\*Arby's\*Ruckers\*A&W's  
Play It Again Sports\*Dairy Queen\*Arctic Tan  
Joey's Only\*Penzoil 10 Minute Oil Change  
Tennessee Jack's

*Call the NOFCC for your card, or if you are able to help sell.*

### **Pepsi Challenge**

Watch for this fun family event in the parking lot of Super C on Lasalle Blvd. in Sudbury this spring. Date, time and details will be announced on local radio.

*Be sure to come out  
and support the NOFCC!*

*Volunteers Needed!  
Call the NOFCC to help out.*

Fishing 4 Children's Charities

## **PIKE TOURNAMENT**

*All Proceeds to Support NOFCC*

**Whitewater Lake, Azilda  
July 16, 2005**

(fish picture)

**First Prize \$5000!**

**See Article on Page 1 for Details**

**A big thank you to our sponsors and donors -  
We couldn't do it without you!**

**Recent Donors**

Brent Labre  
Minnow Lake Lion's Club  
Family and Friends of Reneissa Boeswald  
Club Richelieu  
Family and Friends of Noah Daoust  
Darlene Ruby and Dennis Venturi  
Family and Friends of Chadwell Kennedy  
Dinosaur Mini Golf  
Family and Friends of Jonathan Hetu

Thank you to the

**SUDBURY  
KINSMEN**

for your continued support

*Thanks to all the community  
Groups, including  
Lion's, Kinsmen,  
Knights of Columbus,  
and others for their generous  
donations over the years.*

*By supporting these groups,  
you also help the NOFCC.*

Thank you to all those who helped make our  
**3<sup>rd</sup> Annual NOFCC Christmas Party**  
a Huge Success!

Batistelli's Your Independent Grocer - Briere's Your Independent Grocer  
Costco - Dana Brake Parts Canada - Dowling Valu-Mart  
Dumas' Your Independent Grocer - Garson Foodland  
Grandmother's Pie Shoppe Inc. - Steve's Your Independent Grocer  
Bob's T-Shirts - MCTV/Lion's Club Christmas Telethon  
Loeb Canada Inc. - Moose Lodge - Pat & Ryan McGuire  
Pepsi Bottling Group - Pizza Hut - Praxair  
Smith's Markets Inc. - Ten Rainbows Foundation - Tim Horton's

## Making Compassionate Care Benefits More Accessible

A couple of years ago, the federal government introduced Compassionate Care Benefits, a program through Employment Insurance, which allows for six weeks of paid leave to care for a seriously ill family member. This program was seen by many as a good start, but restrictions made it inaccessible for many who most needed it. In order to qualify, the patient must have a serious illness putting them at significant risk of dying in the next 6 months. Parents of children with cancer note that this requirement is unreasonable and not something which can be accurately predicted. In addition, with a disease such as childhood cancer, six weeks just is not enough.

As many parents can attest to, having a child with cancer is a full time job. Often one or both parents must leave work for months at a time, and be with their ill child 24-7. For example, take a child with ALL (acute lymphoblastic leukemia). The first month after diagnosis is spent admitted at a children's hospital, often far from home. For the next six months, this child must spend one of every three weeks in hospital. The child is generally not in school, and doctor's appointments, lab checks, and so on are frequent. Treatment then continues for at least another two years. Treatment varies greatly depending on diagnosis, but generally speaking, there is a period where one or both parents are away from work for extended periods to care for their child. A few families have been successful in recent months in applying for and receiving Compassionate Care Benefits during the initial phase of their child's illness, but this has been relatively rare.

Recently, the Ottawa and District Labour Council passed a motion to support Bill C-256, legislation targeted at amending the Compassionate Care Benefits. In a nutshell, this bill would extend the time frame to something more realistic, and focus less on imminent death. The original program was a good first step, but Bill C-256, if passed, would make much needed improvements to this program. Spread the word, and let your MP know your opinions on Bill C-256.

## The NOFCC Needs YOU!

Over the last 5 years, the NOFCC has helped hundreds of families by making their experience with childhood cancer just a little bit easier through their many programs. The small but dedicated group who started this group from nothing have worked tirelessly over the years to promote and fundraise for the NOFCC, allowing it to expand to what it has become today.

As with any business, expansion and success means more people power. The NOFCC may not be a 'business', but we *are* in need of more volunteers. Whether you or someone you know can help on a one time or ongoing basis, we'd love to hear from you. Whatever commitment you are willing to give, the NOFCC is happy to have.

Here are some ways you could help the NOFCC:

- Assisting with planning and implementation of various fundraising initiatives throughout the year
- Distributing donation boxes, then collecting and counting funds from these boxes located in local businesses (volunteers needed in Sudbury, North Bay, Timmins, and Sault Ste. Marie)
- Secretarial support (assisting with mailings, thank yous, tracking of equipment, etc.)
- The NOFCC is based in Sudbury, but helps families in North Bay, Timmins, Sault Ste. Marie, and all points in between. If you live in one of these areas and are willing to donate even a little time, the NOFCC will be happy to have you aboard. We have contacts in these areas, but have difficulty keeping up with them from Sudbury.
- If you are willing to help, we are thrilled to have you. Contact us and let us know, we'd love to hear from you.

## Thinking of Higher Education?

There are several bursaries available to survivors of childhood cancer pursuing post-secondary education.

Camp Quality Northern Ontario offers the Sharon Evans O'Shaughnessy bursary to current or past Camp Quality campers who meet the applicant criteria, including an application form and essay. Applications are due May 12, 2005, and are available by contacting Camp Quality (see Page 3).

Other bursaries are available for cancer survivors, including from Candlelighters and other such organizations.

### Contact Us:

Northern Ontario Families  
of Children With Cancer  
(NOFCC)

41 Ramsey Lake Road  
Sudbury, Ontario P3E 5J1

1-877-253-2585  
email: [nofcc@vianet.ca](mailto:nofcc@vianet.ca)

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