

# Contact

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## Childhood Cancer Foundation ~ Candlelighters Canada

### The need to support childhood cancer research

**Max J. Coppes, MD, PhD**

*Co-Chair of Research Committee,  
Candlelighters Canada*

*Professor of Oncology and Pediatrics  
University of Calgary, Alberta*

You can help support these efforts with a tax-deductible donation directed specifically towards our research program. You can do so online, at [www.candlelighters.ca](http://www.candlelighters.ca), by mail to the address on the front page of this newsletter, or by telephone at **1-800-363-1062**.

Over the past four decades, considerable gains have been made in curing children with cancer. In the early 1960s, for example, less than 10% of children with acute lymphoblastic leukemia survived. Today, however, over 75% are expected to do well after about a 2-year treatment. These successes have been achieved through intensive research from individuals or individual institutions. In North America, this gave rise to the Children's Cancer Group (CCG), the Pediatric Oncology Group (POG), the National Wilms Tumour Study Group (NWTSG) and the International Rhabdomyosarcoma Group (IRSG), which recently merged into the Children's Oncology Group (C.O.G.). As a result of the efforts of many clinical investigators, and the generous participatory support of thousands of parents, prognosis for children diagnosed with ALL, Hodgkin and non-Hodgkin lymphomas, and Wilms Tumour, has become excellent. Unfortunately, for some children and adolescents with, for example, metastatic bone and soft tissue tumours, high-risk leukemias, several brain tumours, and metastatic Neuroblastoma, outcome remains poor.

Several challenges need to be addressed sooner rather than later. First, access to existing clinical trials needs to be made available to all eligible childhood cancer patients, including adolescents. In general, teenagers have not benefited as much as toddlers and children from the considerable advances made by childhood cancer researchers. Second, it has become clear that for some childhood cancers, truly novel approaches are required to impact outcome. We hope that a better understanding of the molecular genetic changes present in cancers will allow us to design new strategies. Specifically, this information should help us to design effective monoclonal antibodies, biologic response modifiers, and cancer vaccines. In addition, these new approaches are expected to help decrease the price that certain children pay for their cure. As the number of children being cured from their cancer increases, we have come to recognize some considerable unwanted late side effects of therapy (heart problems, infertility, intellectual challenges, and second malignancies). Not surprisingly, childhood cancer survivors are more likely to be denied life insurance or be required to pay higher premiums.



This newsletter was made possible through the generosity of the Bay's "Well Into The Future" program

In order to address these considerable challenges, research has to remain a vibrant area of childhood cancer care. Candlelighters Canada recognizes this need and is committed to raising awareness for the specific needs of childhood cancer researchers. In addition, Candlelighters Canada has initiated a National campaign to raise the necessary funds to ensure that the future of tomorrow's children and adolescents with cancer will be brighter than that of today's.

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## Chief Executive Officer's Message

For those of you who have spent any time around me since I took on the role of Chief Executive Officer in May, 2001, you will have heard me say repeatedly that the Childhood Cancer Foundation ~ Candlelighters Canada is undergoing an exciting and major re-engineering.

It is part of our mission to provide the most excellent and accessible programs to children with cancer and their families, to fund research that seeks to eradicate childhood cancers, and to be advocates for those affected by childhood cancer. With this utmost in our minds, we are in the midst of restructuring our team, streamlining our operations, evaluating our programs, conducting needs assessments, collaborating more with our stakeholders, raising our profile, and gaining increased corporate and individual support. We are bringing on people who possess the expertise that will assist us in increasingly providing quality programs that have a significant impact on childhood cancer.

The result of this restructuring will be a rejuvenated and strategically driven Candlelighters Canada that will be better equipped to meet the emerging needs of children and their families touched by cancer.

As Canada's only national non-profit organization dedicated to childhood cancer, sustainability of our programs and accountability to our donors and volunteers is paramount to our success. We exist solely at the mercy of passionate individuals and philanthropic corporations and foundations, which graciously donate their time, money and services so that we can continue to provide programs to the children and families we serve. We owe it to these donors, and especially to the children and their families, to be prudent and effective in our programs. You have my promise that we will do so.

You can take an active role in our efforts to rejuvenate and restructure Candlelighters

Canada. We are currently forming a program committee that will assist us in conducting needs assessments and evaluations of the programs we currently deliver as well as the ones we plan to offer in the future. I would like to take this opportunity to invite you to consider participating on this committee. Or if you would simply like to voice your thoughts and opinions on our programs, and offer suggestions for future programs, please email me at [betty@candlelighters.ca](mailto:betty@candlelighters.ca).

Important and challenging initiatives are underway as Candlelighters Canada moves forward in our efforts to be the voice for children with cancer in this country; adding your voice to the chorus will aid us in all the important work we do.



*Betty Ferreira*

**Betty Ferreira**  
Chief Executive Officer

## Back to School Program aims to educate classmates and teachers

School provides today's youth with the knowledge to prepare for the world's future obstacles. It is the heart of some of the most important learning that a person will ever be exposed to. For a child diagnosed with cancer however, the challenges transform into hurdles. The Childhood Cancer Foundation ~ Candlelighters Canada has managed to significantly decrease the transition obstacle for a cancer patient leaving the hospital and returning to school.

Candlelighters Canada has developed a Back to School kit designed to

help children with cancer ease their way back into the school environment. The Royal Bank and Imperial Oil Charitable Foundations sponsored the kit. It aims to provide education, sensitization, comfort and guidance to the child or teen with cancer, and aid their classmates, teacher, siblings and parents to understand the experiences of the returning child.

### Where did the idea come from?

The Back to School Program was inspired by the Dutch childhood cancer organization, Vereniging 'Ouders, Kinder en Kanker' (VOKK). Like Candlelighters Canada, VOKK has several kits, aged accordingly, that it lends to schools across the Netherlands free of charge.

### What's in the kits?

To appropriately address the maturity and education of the

cancer patient and their classmates, the Back to School kit contains four cases for age groupings; 5-7, 8-10, 11-13 and 14+. Classrooms are entitled to keep the Back to School case for one month. Each portable carrying case comes equipped with books, videos and interactive games that explain childhood cancer, its affects and how others can help the patient.

### How will the kits be presented into classrooms?

The kits are being housed at local distribution points across Canada where oncology nurses, social workers and/or community liaisons will distribute the supplies to schools within their area. In addition, many of these representatives will speak to the class and teachers to introduce the resources and help facilitate discussion within the classroom.





"We have collaborated with many Oncology professionals who are already running school re-entry programs in their local areas. Our program is a great fit with many of them as they now have resources they can leave with the class after their visit and the students and teachers will have time to process the materials", said Karen Herder who is responsible for establishing the contacts across Canada.

A child's schooling is more than just the basic learning skills of math, science and language. By providing a venue of emotional and social support, the child returning after treatment for cancer will have a less traumatic re-integration to school.

**To order a Back to School case** for your child's class, please find contact information for your local distributor at [www.candlelighters.ca](http://www.candlelighters.ca). Also found on our website, teachers and parents can purchase all items in the kit online through the Resource and Catalogue Store.

*For more information contact:  
Karen Herder, Program Coordinator  
Email: [kherder@candlelighters.ca](mailto:kherder@candlelighters.ca)  
Phone: (416)-489-6440 ext. 15  
Toll-free: 1-800-363-1062*



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

**The Childhood Cancer Foundation ~  
Candlelighters Canada  
launches new website!**

### **Information on Childhood Cancer**

Now you can access information on childhood cancer, including brief overviews of the various types of childhood cancer, read through the oncology glossary of terms, and check out links to other cancer related organizations in Canada and around the world.

### **Parent Support Groups and Teen Network Directory**

If you are looking for peer support groups, you can now access a list of our parent support groups in your area and teen network representatives from our site. Search the list for local representatives and contact them to find out more about the programs and services in your area.

### **Online Store!**

You can also surf through our online resource catalog and store, and purchase resources online! Check out any of the 26 categories in the catalog such as Cancer Treatments and Nutrition; each category lists resources on that topic and offers brief overviews of each resource. Worried about shopping online? .... Don't be! The Candlelighters Canada online store has been secured through the Bank of Nova Scotia, and their Scotiawebstore technology. We also take orders over the phone and via fax (just print the online order form and fax it to us with your order). Check the website for further information.

### **Information on our Programs**

Want to know more about the programs we offer? Check our website and read about programs such as Back To School, Touch the Sky, and our National Bursary Program.

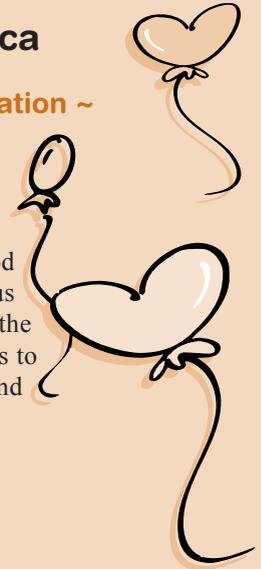
### **News and events**

Interested in reading our latest newsletters, checking press releases and hearing about upcoming events? Click on our "News and Events" section to read all about it!

### **Donate online**

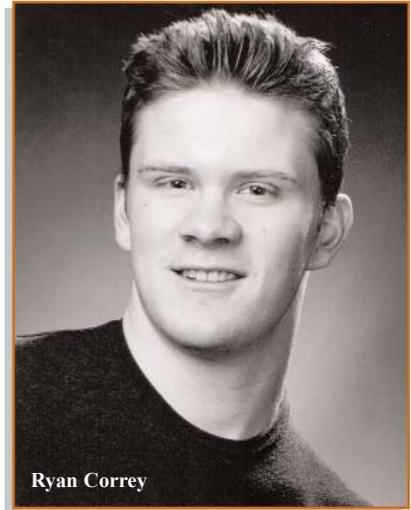
Too busy to get out your chequebook, write the cheques, find a stamp and mail your donation? Donate quickly and easily online by clicking on the "Donate Now" icon at the top left side of each page, then follow instructions. Donating online is safe, and is secured by Charity.ca.

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





Join the Ride for Life - in Summer 2002!



Ryan Correy

## Ryan Correy,

organizer of the Ride for Life, has stepped up to help the Childhood Cancer Foundation Canada address the most urgent concern that children with cancer and their loved ones face - finding a cure for childhood cancer.

We would like to invite you to unite with the Ride for Life to raise **\$1,000,000** for cancer research. Both the Childhood Cancer Foundation Canada and the Lance

Armstrong Foundation will benefit from this fundraising endeavour.

The Ride for Life, is a 14,000 km bicycle tour that began in Ryan's hometown, Calgary, on June 7, 2002 and will take him across Canada, down and around the United States, concluding at the end of August back in Calgary. You have an opportunity to join Ryan in a once in a lifetime journey by supporting the cause or by creating a fundraising event as the Ride for Life rolls into your town!!

Please contact Albert Lee at  
**416-489-6440 ext 16**  
**1-800-363-1062** or via  
 email [alee@candlelighters.ca](mailto:alee@candlelighters.ca)  
 for more information or check out Ryan's  
 website [www.rlyansdream.com](http://www.rlyansdream.com)

## For the Love of Charity

### The Sparkles Campaign - A Great Success!

In 2000, The Childhood Cancer Foundation ~ Candlelighters Canada became one of the Bay's four charitable partners in its Well Into The Future program - a program that supports Canadians living with cancer. Based on our objectives, the Bay selected our organization to be a continuing recipient of the Sparkles Bear campaign for the second year running.

The Sparkles campaign was designed as a sophisticated marketing program that married the point of sale shopping to cause-related marketing. The end result was a program designed by the Bay to influence the purchasing behaviour of their consumers, and to realize the Bay's potential to make a significant philanthropic contribution.

With the creation of the Sparkles charity bear that retailed for \$9.99 at Bay stores across Canada, five dollars from every sale was donated to Candlelighters Canada. Last year the Bay donated \$892,000 (gross) from the sale of Sparkles.

### 2000 - 2001 Campaign Donation Summary

Over the past year, funds from the 2000 - 2001 Bay campaign were applied to the following:

**28%** supported the development of the childhood cancer research program,

**78%** supported existing programs (such as Back to School, Touch the Sky, Interlink Program, National Resource Centre & Library) and marketing.

For the 2001-2002 program, our goal was to benchmark the partnership between Candlelighters Canada and the Bay, to increase public participation and public interest in the purchase of the Sparkles Bear and to raise money for Candlelighters Canada.





## Helping Fathers Feel Welcome in Mixed Parenting Groups

For parents of children diagnosed with cancer, parent support groups provide an environment of emotional support as well as much needed information. To promote the participation of fathers in these groups, which are often well represented by mothers, try implementing some of the following strategies.

1. Be yourself and allow the fathers to be themselves. Accept them where they are at in their parenting journey.
2. Have a male co-facilitator if possible.
3. Schedule sessions at a time when fathers are available (weekends, evenings).
4. Recruit more than one father to the group, so that they won't feel alone.
5. Encourage fathers to attend rather than of merely inviting them.
6. Include topics of special interest to fathers.
7. Make "no male bashing" a part of your group agreements.
8. Provide a hearty snack.
9. Choose icebreakers that aren't too "touchy-feely".
10. Create a father-friendly environment: display books on fatherhood, put up posters showing fathers and children, etc.

*By Rick Hein. First published in Play & Parenting Connections, Winter 2001.*

## Endocrine Problems Following Treatment for Childhood Cancer

### Introduction

The endocrine or hormone-producing system consists of several organs or glands (eg, the thyroid, adrenals, testicles, and ovaries) that are under the control of the pituitary gland, which is located in the brain, just behind the eyes. Each of these organs produces one or more substances or hormones that can affect many important body functions. These endocrine organs can be damaged as a result of surgery, radiation therapy and, less often, by chemotherapy. For the endocrine glands that come in pairs (eg, the adrenals, testicles), removal of just one gland does not usually cause a problem.

The risk that a cancer survivor will develop an endocrine problem depends

on many factors and differs greatly between individuals. The major risk factors include age at treatment, diagnosis, and treatment with radiation. Endocrine problems develop most often in individuals who have received radiation to the brain, chest/neck areas, pelvic region, and those treated with total body radiation for a stem cell transplant. Most problems can be easily diagnosed with routine blood tests. The following is a brief overview of the most common endocrine disorders that occur after cancer therapy.

### Pituitary Problems

The pituitary gland makes at least 5 different hormones. Pituitary problems develop in individuals who have a tumour and/or surgery in that area of the

brain as well as in those who receive radiation to that area of the brain. The problems are more common in those treated with higher doses of radiation. Additionally, the problem(s) may not become apparent for many years after treatment has ended.

### Growth Hormone Deficiency

Loss of the ability to make normal amounts of growth hormone is the most common pituitary problem seen after radiation therapy to the brain. It can occur after low doses, especially if the radiation is given over a few days (eg, 1000-15000 cGy total body radiation). Following radiation doses of 3500 cGy or greater to the head, 75-100% of individuals will develop growth hormone deficiency. As its name suggests, growth hormone is essential for normal physical growth; children who are deficient in growth hormone grow slowly and are short when they reach adulthood. Growth hormone also affects bone strength, cholesterol levels, amount of body fat, and stamina.

Treatment is available for children who are growth hormone deficient and for selected adults with severe growth hormone deficiency.

### **Early Sexual Maturation**

Young children treated with radiation to the brain tend to start their pubertal development at a younger age than the general population. This problem is seen more often in girls than boys. Early puberty, while not a serious medical condition, can lead to a shorter final height; specific drugs are available that can temporarily "postpone" puberty.

### **Obesity**

Young adult survivors of childhood cancer are at increased risk of becoming overweight. Radiation to the brain appears to be an important risk factor, especially for girls treated at a young age. Young adult survivors who have a tendency to gain weight need to pay careful attention to their dietary habits and need to incorporate a sensible exercise regimen into their regular routine.

### **Thyroid Problems**

The thyroid gland, a butterfly-shaped organ situated in the neck just above the collarbone, is often damaged following radiation to the neck or upper chest. Thus, individuals treated with spinal

radiation, total body irradiation, and neck/chest radiation are at risk. The most common condition is hypothyroidism or an under active thyroid. Symptoms of hypothyroidism can be subtle and often go unnoticed. Moreover, it may take more than 20 years after treatment for the problem to develop. The problem can be easily treated with a thyroid pill taken daily.

In addition to an under active thyroid gland, prior therapy with radiation increases the chance of tumours of the thyroid. Fortunately, most of these tumours are benign and easily cured. A complete examination of the thyroid needs to be part of the yearly check-up for anyone who has received radiation to the neck region.

### **Testicular Problems**

The testicles perform two separate functions: (1) they produce the male hormone testosterone, which is needed for sexual development (eg, beard growth, muscle growth, and maturation of the sex organs) and (2) they produce sperm. These two functions are affected very differently by cancer therapy. The male hormone-producing cells are rarely damaged by the treatments except for males who have received high doses of radiation directly to the testicles. The sperm producing cells, however, are often damaged by a variety of chemotherapy drugs (eg,

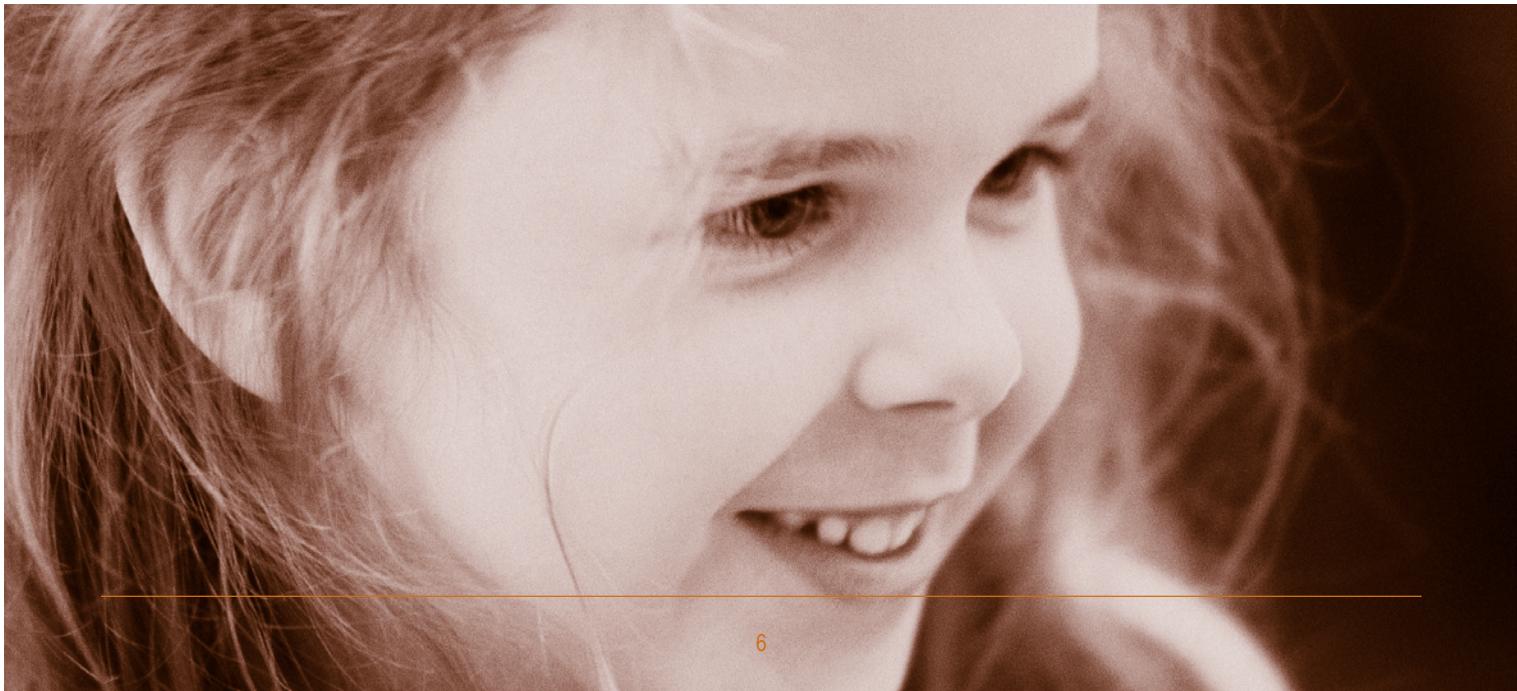
cyclophosphamide, busulfan) and low doses of radiation. A sperm analysis is required in order to determine if a male survivor is fertile.

### **Ovaries**

The ovaries also perform two separate functions as described above (eg, produce female hormones, estrogen and progesterone, and produce eggs). However, in females, these two functions are affected equally by the treatments. Thus, when the ovaries are damaged, there is loss of both hormone production and egg production (fertility). This usually results in lack of menstruation. The ovaries are most often damaged when the treatments are given in late adolescence and following radiation to the pelvic area. Some women who continue to have regular periods after cancer therapy are at risk of entering menopause at a younger age than the general population.

Many new techniques are now available to assist cancer survivors who experience problems of infertility. It is important that you speak to your healthcare providers if you have questions or concerns about any of these issues.

*Written by Charles Sklar, MD, Director, Long-Term Follow-Up Program, Department of Pediatrics, Memorial Sloan-Kettering Cancer Centre, New York City, NY*



# Coming off Treatment: Now What?

This is a scenario based on The Children's Hospital of Eastern Ontario's (CHEO) Oncology Team's appr

Your child is due to finish treatment soon. People may be expecting your family and child to be excited, relieved and to celebrate with a party or other ritual. However, this finishing treatment benchmark can also be a time of fear of the unknown future without the intensity of medical support that you and your child have come to depend on. These fears are quite normal and this is why it is important for you to address these concerns with the team who have cared for you and your child throughout their treatment process.

This article is meant to give you a brief overview of some immediate follow-up concerns you may have for your child, and to address the typical questions people have as they resume regular activities after treatment is completed. It is important to note that these views and this program information is from CHEO. Please ask your Oncology team what programs exist in your area.

## **How long will my child need to be followed at the Oncology Clinic?**

The simple answer is your child will need follow-up for their entire life. However, the visits become less frequent the further away from being off treatment and remaining in remission they become. Depending upon the policy of your centre, when your child is 18 years of age, they are transferred to an adult follow-up clinic to continue off treatment evaluation. At a certain point, the purpose of follow-up tends to change from monitoring for recurrence of disease to monitoring for late effects of treatment.

## **How will the Oncology team monitor my child?**

At first, your child will be monitored very closely, approximately every month in the first year off treatment. Monitoring includes a visit, blood work, and often times regular x-rays, CT and MRI scans. Depending on the disease of the child, each child will have an individualized follow-up schedule of visits and tests. Eventually, most children require visits and tests yearly.

## **When can my child's portacath or BROVIAC\* catheter be removed?**

Normally CHEO recommends keeping the portacath in for about 6 months after stopping treatment, however

each child is different, so it is best to discuss this with your Oncologist.

## **How long does my child continue to take Septra or Dapsone or Pentamidine?**

Your child's immune system will need several months to completely recover from the treatment. CHEO usually suggests staying on your medication for 6 months after treatment is completed. Post bone marrow transplant patients will be managed a bit differently, so please consult your Oncologist before discontinuing any medication.

## **When can my child resume immunizations?**

Your child's immune system will be weak for several months after stopping treatment. CHEO suggests that your child not resume immunizations for 1 year after treatment is complete. Children who have undergone a bone marrow transplant require complete re-immunization; please discuss this with your Oncologist, family doctor or Pediatrician.

## **Should we still be concerned about chicken pox contacts?**

Yes, if your child has never had chicken pox, you should be concerned about suspected contact, for the first year off treatment. Each child will need to be assessed individually. When there is suspected contact, call the Oncology clinic. Your child may require an injection of "ZIG" within 72 hours of the contact.

## **Can my child play and participate in activities?**

This is not a problem for most children. As the child moves further away off treatment CHEO would encourage their participation in sports and all normal activities. Special consideration must be given to children with certain types of cancer and it is important to discuss this issue with your Oncology team.

## **Whom do I take my child to for common concerns and check-ups?**

CHEO's practice recommends that families stay in touch with the family doctor or Pediatrician throughout their treatment. Then when the child has completed therapy, it will be easier to return to the child's doctor for regular check-ups for things such as immunizations and common health concerns.

## **If my child and/or family have difficulties returning to normal activities, what should I do?**

Please address these concerns with the clinic staff. You may be referred to one of the in-hospital services available in your area (i.e. social worker, psychology, psychiatry) or be referred to an appropriate community agency.

### How about returning to school?

Most families and children find the initial return to school challenging because of having been away from the routine and demands of school life. If you experience difficulties during this time, please alert the Oncology team, who may be able to provide support and assistance. (Also learn about Candlelighters' Back to School Program in this newsletter)

### Long Term Follow-Up: After Cancer Treatment Clinics

After approximately two years off treatment at CHEO, your child will enter into the long-term follow-up clinic. Depending upon your location, there may be different levels of after care or long-term follow-up for your child. It is important to discuss these plans with your Oncologist.

For example, at CHEO, our after care clinics are divided into:

Neuro-Oncology  
Ortho-Oncology  
BMT/Haematology/Oncology

Once a child reaches the age of 18 years, they will be followed at the Transition Clinic located at the Ottawa Regional Cancer Centre (ORCC) at the Ottawa General Hospital site. Adult and Pediatric Specialists will provide this service.

*Written by: The Children's Hospital of Eastern Ontario, Oncology Team*

### Recommended Readings...

Can Survive: Reclaiming of life after cancer. Ellis J., Nessim, S. (1991) Houghton Mifflin Co. \$20.35

Childhood Cancer Survivors. Keane N., Hobbit W., & Ruccione, K. (2000) O'Reilly & Associates Inc. \$37.50

Both resources can be purchased from the Childhood Cancer Foundation ~ Candlelighters Canada. Call us direct at **416-489-6440 ext 18**, toll free at **1-800-363-1062** or at our website [www.candlelighters.ca](http://www.candlelighters.ca) in the Resource Catalog and Store.

## Obtaining Out-of-Country Travel Insurance for Your Child: INGLE Health

The Childhood Cancer Foundation ~ Candlelighters Canada has developed a partnership with **INGLE Health** that provides medical coverage for children with cancer when traveling outside of Canada. Candlelighters Canada recognized the need to advocate for out-of-country medical insurance for children with cancer. Our advocacy efforts were successful, and INGLE Health now provides this necessary medical coverage.

### To arrange for the purchase of this insurance contact:

INGLE Health  
438 University Ave, Suite 1200  
Toronto, ON M5G 2K8  
Tel: 416-340-8115  
Toll free: 1-800-216-3588

### The process is straightforward:

- ♦ call the number
- ♦ ask for a medical questionnaire
- ♦ complete the questionnaire
- ♦ obtain a letter from your pediatric oncologist regarding your child's medical history
- ♦ send the completed questionnaire and the letter to INGLE Health for underwriting.



# Parents as Partners

## the complete child care team

The family is a child's strength and support. The parents are the experts on their child. Health professionals are the experts on health and disease. Everyone's role is important. What we all do together is greater than what any of us can do alone to achieve the best health for our children. Partnerships work best when health professionals and families:

- Treat each other with respect and consideration;
- Freely exchange information;
- Make choices and decisions together and collaborate to plan care;
- Help each other with the care and emotional support of the patient and value each other's contribution;
- Follow through with plans, be honest with each other if unable to do as agreed;
- Have reasonable expectations of each other and understand the stress of life in and outside of the hospital;
- Maintain the privacy and confidentiality of all.

### It takes a team to treat a child: Knowing who is doing what and why...

Many different health care professionals will treat your child. Meeting so many people in a short time can be confusing. As each new person comes to the bedside:

Introduce yourself (otherwise you may be "Mom" or "Dad").

Ask the person to explain their role and what they will do for your child.

Make notes to remember the roles and titles. Remember, YOU are an essential part of your child's care team as well.

### Who's the doctor? A who's who of titles...

**Attending physician:** specialists in child health (Pediatrician) who takes overall charge of your child's health care plan. They may also have a specialization such as cardiology (hearts) or oncology (cancer).

**Consultants:** doctors who have specialized in one particular body system. They give expert advice to the team.

**Residents or fellows:** fully qualified doctors who are now training as specialists. They provide most of the day-to-day medical care. They work under the guidance of the specialists.

### Some tips on how to learn more about your child's condition

1. Tell team members up front that you want to be informed about the condition of your child and kept up to date on test results and treatment changes
2. Write down your questions so you don't forget them. Make them as specific as possible. Careful questions are more likely to get quality answers.
3. If you need an in-depth discussion, phone the attending physician's office for an appointment. This is better than grabbing them in the corridor.
4. The nurses, therapists, pharmacists and other health professionals can often give you the information you need. They may be more available to talk with you.
5. Different health professionals may give you somewhat different answers to your questions. Some parents find this frustrating, perceive it as confusion among the team and worry that their child is not getting the best care. Each person may view the medical situation with a different experience. Treatment decisions are made taking everyone's experience and the individual child into account. When in doubt, ask to speak to the attending physician.
6. Increase your understanding by reading about your child's condition in your hospital's resource centre or online at [www.candlelighters.ca](http://www.candlelighters.ca).

*Reprinted with permission from 'Family Issues', the newsletter for families of patients at B.C.'s Children's Hospital*

## TELL US YOUR STORY

Dave Munro, of Barrie, Ontario wanted to give back to The Childhood Cancer Foundation ~ Candlelighters Canada for all that they had done for him and his family. Never did he think that his daughter's story would touch the lives of people all over Canada. But in a joint initiative with the Canadian Blood Services, that is exactly what Hannah's story is doing. (See p. 13)

We would like to take this opportunity to invite you to share your story with us. The personal experiences brought together will work to help those starting similar journeys. Our hope is to highlight a story in each newsletter we produce and potentially expand it to involve the website as well. "Every story is important..." as Dave so aptly puts it, "...we can definitely learn from each others' experiences."

If you would like to share your story with us, please forward it to Albert Lee, by email at: [alee@candlelighters.ca](mailto:alee@candlelighters.ca) or mail it to our business address (to Albert's attention).

## Advice on Antibiotics

Antibiotics save millions of lives. But, taking antibiotics when we don't really need them, when they won't help anyway, or taking them in the wrong way, is harmful.

### **When antibiotics won't help...**

Not all infections improve with antibiotics. Antibiotics can destroy the germs that belong to the bacteria family. However, they are of no use against the germ family known as viruses. Most coughs, colds, runny noses and 'flu' come from virus family germs. Viruses also cause most, but not all, sore throats. Even a doctor cannot tell, just by looking at a throat, whether it will get better with an antibiotic. The doctor needs to take a throat swab so it can be checked in a lab. 'Strep' throats may need an antibiotic. It is the same with ear infections; some need treatment with antibiotics while others do not. After an ear infection or cold, some children have fluid in their middle ear for a few weeks. This usually goes away without treatment. It is true that a bacterial infection sometimes follows the viral infection but using antibiotics to PREVENT the bacterial infection does not work.

### **What is wrong with trying an antibiotic to see if it might help?**

Think about it like this. You have a weapon to protect yourself against an enemy. But every time you use the weapon, you give your enemy a chance to learn how it works. Would you use the weapon carefully or carelessly? We know that bacteria are becoming 'resistant' to antibiotics. There are already some types of bacteria 'superbugs' that no known antibiotic can destroy. We need to get a lot more careful about when, and how, we use the antibiotics we have!

### **How do we use antibiotics correctly?**

Some infections do need treatment with antibiotics. If you and your doctor agree that your child needs an antibiotic, give all the doses. Do not stop because your child feels better. The weaker bacteria die off first, leaving the strong, more resistant ones to survive if you cut back on the antibiotic doses. So, when you don't complete the doses, you leave the strong bacteria to get stronger.

*Reprinted with permission from the 'Family Issues' newsletter at B.C.'s Children's Hospital. This information comes from the Antibiotic Resistance Education Project: Departments of Pediatrics & Family Practice, UBC.*

## Food

### *Your Child's Fuel for Fighting Cancer*

*Kids can be like little soldiers in their battle with cancer and good nutrition helps to provide them with the energy, strength and stamina they need to fuel their fight. In order to ensure that your child is best prepared from a nutritional standpoint, parents can arm themselves with the knowledge of how the immune system reacts to treatment and the role nutrition plays.*

*The immune system is basically the body's defense system that helps to guard against infection. This system produces "neutrophils", which can best be described as little soldiers that help fight infections of all sorts. When the number of neutrophils (which are found in the blood) falls to a low level, a condition known as neutropenia occurs.*

*Neutropenia affects as many as one in three patients receiving chemotherapy treatment for cancer. Cancer cells grow and divide very quickly. Chemotherapy works mainly by quickly dividing cells. Unfortunately, the chemotherapy drugs can't tell the difference between a growing tumour and normal cells, such as neutrophils (the "soldiers"), which also divide quickly. As a result, neutrophils are also killed by the chemotherapy.*

*People with neutropenia get infections easily and often. Most of the infections occur in the lungs, mouth, throat, sinuses and skin. Painful mouth ulcers, gum infections, ear infections and periodontal disease are common. Severe life-threatening infections may also occur. Some signs and symptoms of neutropenia are fever, chills (especially at night), loose bowel movements, burning or pain on urination, coughing and a sore throat. If there is any reason to suspect infection, tell the doctor right away. Often hospitalization is required and intravenous antibiotics are administered.*

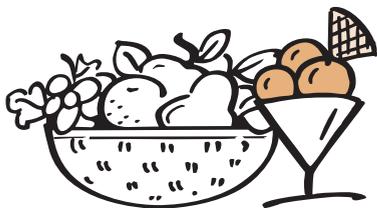
*With proper nutrition, your child may cope better with the negative side effects associated with their treatment. A healthy diet helps to promote a stronger immune system and also prevents body tissues from breaking down.*

*A loss of appetite, the treatments themselves, and taste changes often contribute to weight loss for children undergoing treatment. The best way to combat weight loss and to protect your child from neutropenia is to introduce calories, proteins, vitamins and minerals into their diet. Proteins are essential in helping the body heal itself and fight infection. Foods such as meat, fish, poultry, eggs, milk, yogurt and cheese are all great sources of proteins, as well as sources of vitamins and minerals.*

It is very important to consult with your child's doctor or registered dietician to ensure that your child is getting the proper nutrition needed while in treatment. Canada's Food Guide to Healthy Eating is also a great tool in building a well-balanced diet for your family's menu.

Kids can be picky eaters and it can be more challenging when your child's tastes change during treatment. However, this is where you can get creative in finding new foods that your child will like. Keep in mind that proteins often take on a bitter taste during treatment, however some protein enriched foods (cheese, lunch meat, ice cream, milk shakes and pudding) will taste better when served cold.

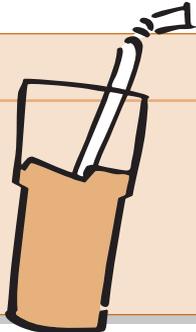
**Get creative** by finding ways to add calories to foods. Here are a few tips to help add calories to already tasty foods:



- Add ice cream to canned fruits
- Add sour cream or yogurt (without live cultures) to potatoes
- Add butter to rice and muffins
- Use 10 - 18 percent pasteurized milk for milkshakes or cereals
- Add sugar or honey to milkshakes and cereal
- Add jam to crackers or yogurt
- Add peanut butter to milkshakes

By being imaginative with foods that provide good nutrition, you're helping to strengthen your child's body in its fight against cancer. Try this great recipe your child is sure to enjoy:

<b>Peanut Butter Cup Milkshake</b>		
250 ml	Milk	1 cup
200 ml	Ice Cream	¾ cup
50 ml	Skim milk powder	¼ cup
30 ml	Peanut butter	2 tbsp.
30 ml	Chocolate syrup	2 tbsp.



Combine ingredients in a blender and mix thoroughly. Makes one serving.  
 This and other recipes can be obtained from *The Cancer Survival Cookbook* available at [www.candlelighters.ca](http://www.candlelighters.ca) for \$21.50 + applicable taxes.

## Tips to Prevent Neutropenia

### At home

- Frequent and careful washing of hands by all in the household.
- Safe handling, cooking and serving of food is necessary to prevent bacteria and other micro organisms from multiplying and causing food poisoning
- Change the dishcloth and dishtowel daily. Wash with bleach.
- Place kitchen brushes and sponges in the dishwasher daily.

### At the Grocery Store

- Check expiration dates.
- Place meat and poultry in plastic bags.

### Storing Foods

- Place uncooked meats in separate plastic bags.
- Thaw meat in the refrigerator not on the counter.

### Preparing food

- Keep everything clean.
- Use separate plates and utensils for meats.
- Cook meat, poultry and fish thoroughly.
- Cook stuffing separately from poultry.

You can purchase your copy of *The Cancer Survival Cookbook* from Candlelighters Canada by visiting our website at [www.candlelighters.ca](http://www.candlelighters.ca) and clicking on "Resources" or by calling 1-800-363-1062 or 416-489-6440 ext 10.

*Written by Tommy Turner*

## Where can I find a Parent Support Group?

As long as children get cancer, parents will try to find the resources to aid their children and themselves. In so doing, many parents reach out to one another and find, join or create local groups. Group activities differ according to the needs of parents, and the resources available to them. Across Canada, The Childhood Cancer Foundation ~ Candlelighters Canada has many different local Parent Support Groups.

Province	Region	Contact name / Phone # / email
British Columbia	Vancouver	Dan Mornar 604-875-2345 ext 6477 The British Columbia Childhood Cancer Parents' Association <a href="mailto:dmornar@cw.bc.ca">dmornar@cw.bc.ca</a>
	Kelowna	Mrs. Gerri Cottle 250-763-7970 The Parent Support Group Rainbow Centre <a href="mailto:cottles@okanagan.net">cottles@okanagan.net</a>
	Golden	Ruth Finnie 250-344-2171 Golden Candlelighters <a href="http://candlebc@rockies.net">candlebc@rockies.net</a>
	Prince George	Mrs. Frankie Pasowicz 250-964-9744 Candlelighters Prince George <a href="mailto:fpasowicz@hotmail.com">fpasowicz@hotmail.com</a>
Alberta	Calgary	Mrs. Sandy Bessette 403-730-9922 Candlelighters Childhood Cancer Association of Southern Alberta <a href="mailto:Sandycandlelighters@shaw.ca">Sandycandlelighters@shaw.ca</a>
	Edmonton	Kids with Cancer <a href="http://kids@icrossroads.com">kids@icrossroads.com</a> Subject: Attn: Parent Support
Saskatchewan	Saskatoon	Mrs. Deb DelFrari 306-463-6314 Saskatoon Candlelighters <a href="mailto:dmdelf@sasktel.net">dmdelf@sasktel.net</a>
	Regina	Mrs. Tangy Achter 306-790-5820 Regina Candlelighters <a href="mailto:dwachter@sk.sympatico.ca">dwachter@sk.sympatico.ca</a>
	Prince Albert	Mrs. Janet Thompson 306-764-7863 Candlelighters Prince Albert
Manitoba	Winnipeg	Lannie Bosman 204-667-3161 Childhood Cancer Foundation ~ Candlelighters Manitoba <a href="mailto:lbosman@shaw.ca">lbosman@shaw.ca</a>
	Winnipeg	Shawna Loewen 204-275-0531 Childhood Cancer Foundation ~ Candlelighters Manitoba <a href="mailto:Umloew17@cc.umanitoba.ca">Umloew17@cc.umanitoba.ca</a>
	Brandon	Mrs. Amber Phipps 204-725-4092 <a href="mailto:baphipps@mts.net">baphipps@mts.net</a>
Ontario	Ancaster	Joann Fabrizio 905-648-0221 Help a Child Smile <a href="mailto:jfabrizio2@cogeco.ca">jfabrizio2@cogeco.ca</a>
	Cobourg	Mrs. Jane Ashmore 905-885-6422 Port Hope Candlelighters
	Kingston	Gerilyn Anglin 613-382-5771 Kingston Parent Support Group <a href="mailto:tyjo@kingston.net">tyjo@kingston.net</a>
	Kitchener / Waterloo	Mary Anne Wilford 519-846-0015 or 1-800-966-0631 Grand River Candlelighters <a href="mailto:jeffwif@enoreo.on.ca">jeffwif@enoreo.on.ca</a>
	London	Jennifer Thompson / Lois Grimes 519-685-3500 ChildCan <a href="mailto:childcan@lon.imag.net">childcan@lon.imag.net</a>
	Markham	Mrs. Carol Mohammed 905-294-7315 BrainChild and Markham Area Candlelighters <a href="mailto:carolmo@3web.net">carolmo@3web.net</a>
	Mississauga	Dianne Parkinson 905-276-5219 Families of Children with Cancer
	North Bay	Doug Zimba 705-474-4306 <a href="mailto:dougz@efni.com">dougz@efni.com</a>
	Oakville	Andrew and Jill Sprawson 905-338-1530 Rebounders Canada - The Adult Survivors of Childhood Cancer Group <a href="mailto:sprawson@look.ca">sprawson@look.ca</a>
	Oakville	Mrs. Joanne McLeod 416-675-6622 ext 4592 Parents of Children with Cancer <a href="mailto:Jmcleod27@cogeco.ca">Jmcleod27@cogeco.ca</a>
Peterborough	Mrs. Brenda Babcock 705-742-2411 <a href="mailto:Rbabcock7@cogeco.ca">Rbabcock7@cogeco.ca</a>	
Simcoe County	Mrs. Barbara Johnson 705-737-4296 Candlelighters Simcoe <a href="mailto:albarbjohnson@sympatico.ca">albarbjohnson@sympatico.ca</a>	
St. Catharines	Lyn Beckett 1-800-653-4227 Help a Child Smile / Candlelighters <a href="mailto:Helpachildsmile@sympatico.ca">Helpachildsmile@sympatico.ca</a>	

Province	Region	Contact name / Phone # / email
Ontario	Sudbury	Lorraine Chartier 1-877-253-2585 Northern Ontario Families of Children with Cancer <a href="mailto:nofcc@vianet.ca">nofcc@vianet.ca</a>
	Toronto	Susan Kuczynski Families of Children with Cancer <a href="http://www.fcco.org">www.fcco.org</a> <a href="mailto:Susan-kuczynski@rogers.com">Susan-kuczynski@rogers.com</a>
	Thunder Bay	Ellen Davis 807-622-8969 Thunder Bay Candlelighters <a href="mailto:edavis@tbaytel.net">edavis@tbaytel.net</a>
	Windsor	Jocelyn Brent 519-974-4095 Windsor Parent Group <a href="mailto:jtbrent@sympatico.ca">jtbrent@sympatico.ca</a>
Quebec	Montreal	Sylvie Desmarais 514-933-5384 Association Lueur d'espoir / Lamplighters Association <a href="mailto:alela@iquebec.com">alela@iquebec.com</a>
New Brunswick	Saint John	Wanda McLean 506-755-3366 Candlelighters ~ Saint John <a href="mailto:mcleand@nbnet.nb.ca">mcleand@nbnet.nb.ca</a>
	Fredericton	Ann Ouellette 506-452-5725 Dr. Everett Chalmers Hospital - Social Work Department
Nova Scotia	Antigonish	Dawn MacIntosh 902-386-2337 <a href="mailto:robdown@ns.sympatico.ca">robdown@ns.sympatico.ca</a>
Newfoundland	St. John's	Wendy Chaulk 1-866-745-4448 The Candlelighters Association of Newfoundland and Labrador <a href="mailto:mail@candlelightersnflab.nf.net">mail@candlelightersnflab.nf.net</a>
	Corner Brook	Mrs. Gale Stevenson 709-785-5265 The Candlelighters Association of Newfoundland and Labrador (West Coast) <a href="mailto:galestevenson@hotmail.com">galestevenson@hotmail.com</a>

## The Childhood Cancer Foundation ~ Candlelighters Canada Joins Forces With Canadian Blood Services

In December of 2001, Candlelighters Canada entered into a partnership with Canadian Blood Services to help in the promotion of their Holiday Blood Drive Campaign. The theme for the campaign was "Sometimes the best gifts come in small packages." The program, which was launched in Toronto, helps to promote the need to give blood and plasma during the holiday season.

It is the goal of Candlelighters Canada to educate the public on the needs of children with cancer. This year, Hannah Munro of Barrie, Ontario, helped Canadian Blood Services promote the campaign. Together with her family, Hannah explained what the gift of life means. During her chemotherapy treatment, Hannah received more than ten transfusions of whole blood and five donations of platelets at The Hospital for Sick Children.

Hannah and Candlelighters Canada want to encourage all eligible

Canadians to donate blood or plasma because, "You never know when you will be needed to help save a life." Today, Hannah is healthy, happy and alive because of the blood donors who gave her the gift of life.

In February, Candlelighters Canada and Canadian Blood Services scored a winner with a blood donor clinic aimed at youth. Students from four Toronto-area schools were bussed to the Air Canada Centre where they got the chance to watch the Toronto Maple Leafs in practice. Approximately 79 units of blood were collected from the 109 students in attendance. Now that's teamwork!

For this year, Canadian Blood Services has started the "Roll up your Sleeves, Canada!" challenge. Their goal is to attract 160,000 new regular donors to ensure that hospital demand for blood is met in the future. To date, the campaign is well on its way, having attracted

7,700 new regular blood donors since its launch.

Canadian Blood Services encourages Canadians to call 1-888-2-DONATE (1-888-236-6283) for blood donor clinic information, eligibility information or if you would like to organize a blood drive in your community.



CANADIAN BLOOD SERVICES  
SOCIÉTÉ CANADIENNE DU SANG

Blood. It's in you to give.

## Parent Support Group Provincial Update: Saskatchewan

Last year a busy and productive year for the Saskatchewan Candlelighters groups, with many changes and new developments underway. Saskatoon and Regina both have active groups that have been well supported by their communities. Some of the highlights of our activities throughout 2001-2002 included parties for the children, as well as at Christmas and Easter, in addition to a highly successful family camp that was held at Lake Diefenbaker and funded by the Progress Club. I'm pleased to say that the Progress Club has committed to supporting these camps in the coming years. The Make

A Wish Foundation was a meal and entertainment sponsor for the camp. Thanks go to all who contributed to the success of all of our events.

In the past few months, I met with the Make A Wish Foundation and the Progress Club in an effort to ensure that good quality programs are offered to our children diagnosed with cancer as well as their families. We plan to meet once a year. The Progress Club invited me to speak on behalf of Candlelighters at their Camp Circle of Friends charity fundraising dinner and we continue to support them in June with their camp for children.

That same month we also held our first Candlelighters conference in Regina and Dr. Mark Greenberg was the main

speaker. We are busy planning another conference as well as setting up new Candlelighters' Programs such as the Back to School Program. Additionally, we are planning a family-to-family support system with the clinics in the treatment centres and are moving forward with our family camp and family gathering parties throughout the year.

In closing, I would like to thank Tangy Achter and Debbie DeFrari, our coordinators in Regina and Saskatoon, who have worked hard with me to move Candlelighters forward in Saskatchewan.

*Ilene Thorpe*  
Saskatchewan Provincial Director  
Board of Directors

# Canadian Childhood Cancer Surveillance and Control Program

The Canadian Childhood Cancer Surveillance and Control Program (CCCSCP) was announced in July 1992 as part of the federal government's Brighter Futures Initiative. The CCCSCP was designed as a nationally integrated program to fill knowledge gaps in Canadian childhood cancer control. The goal of the CCCSCP is to contribute toward reducing mortality, improving the prognosis, and reducing the suffering and burden of childhood cancer. The CCCSCP is a partnership of several Canadian organizations concerned with childhood cancer (i.e. Health Canada, pediatric oncology centres, provincial cancer registries, universities, and voluntary agencies/support groups). A management committee composed of childhood cancer experts and representatives from interest groups oversees the program.

The original program was designed to integrate four components:

1. Children with cancer and population controls recruited to enrol in a national enhanced childhood cancer surveillance system to study potential causes of childhood cancer (etiology studies);
2. Tissue bank for storage of biological samples;
3. Surveillance of treatment and outcome among children diagnosed with cancer; and

4. Long-term survivors identified both retrospectively and prospectively, and followed up to monitor psychosocial and physical late effects.

### For more information, please contact:

Childhood Cancer Section, Cancer Division  
Health Canada, Tunney's Pasture PL#0601C1  
Ottawa, Ontario  
K1A 0L2  
Canada  
ph: (613) 952-9509  
fax: (613) 941-1732  
email: [CCCSCP@hc-sc.gc.ca](mailto:CCCSCP@hc-sc.gc.ca)  
Website: [www.hc-sc.gc.ca/hpb/lcdc](http://www.hc-sc.gc.ca/hpb/lcdc)

Printed with permission from CCCSCP, Les Mery Head, Childhood Cancer Section, Cancer Division, Centre for Chronic Disease, Prevention and Control Population and Public Health Branch, Health Canada.



## How does the The Childhood Cancer Foundation ~ Candlelighters Canada comply with Canada's Privacy Act (Bill C6)?

Currently more than 50,000 Canadians financially support the work of the Childhood Cancer Foundation. We continually strive to improve the quality of life for families experiencing the effects of childhood cancer, through the provision of resources and programs, parent support and through research. One of the ways we accomplish our mission is to approach the supporters of other related good causes. In return, we make our list of supporters available to these organizations by means of exchange only. We do not rent or sell any part of our list; nor do we disclose financial information and only exchange the name and address.

Three times a year we inform all donors on our list of this practice and offer them an opportunity to have their name excluded from this exchange. We will not provide the list directly to another organization, but use a bonded mailing house to coordinate the exchange. The organization can only use the list once and the donor's name is only added to their organization's list if that person donates to them. We also monitor every organization's appeal and specifically request seeing the package, before the exchange takes place.

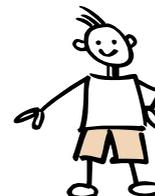
Please remember that by allowing Candlelighters Canada to exchange your name, you are still supporting the mission and vision of our organization. If you feel strongly that you would like to 'opt out' of this practice, just cut out the statement below, write your name and address clearly, and mail it to our Toronto office.

I have read the above article on how my name and address helps Candlelighters Canada with its work. I still do not want my name exchanged on a one time reciprocal basis.

Signed \_\_\_\_\_

## Who's Working For You?

The staff of Candlelighters Canada is here to help you. Please feel free to contact us with your questions or ideas concerning childhood cancer and the work of the foundation in general.

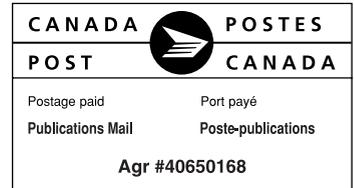


<b>Betty Ferreira</b>	Chief Executive Officer	416-489-6440 ext 20	<a href="mailto:betty@candlelighters.ca">betty@candlelighters.ca</a>
<b>James Lee</b>	National Director of Development	416-489-6440 ext 19	<a href="mailto:jlee@candlelighters.ca">jlee@candlelighters.ca</a>
<b>Rachna Rohatgi</b>	Administrative Coordinator	416-489-6440 ext 18	<a href="mailto:rrohtagi@candlelighters.ca">rrohtagi@candlelighters.ca</a>
<b>Traci Williams</b>	Executive Assistant to the CEO	416-489-6440 ext 10	<a href="mailto:twilliams@candlelighters.ca">twilliams@candlelighters.ca</a>
<b>Karen Herder</b>	Program Coordinator, Back to School & Teen Network	416-489-6440 ext 15	<a href="mailto:kherder@candlelighters.ca">kherder@candlelighters.ca</a>
<b>Albert Lee</b>	Marketing Communications & Special Projects Manager	416-489-6440 ext 16	<a href="mailto:alee@candlelighters.ca">alee@candlelighters.ca</a>
<b>Maria Rowe</b>	Accounting	416-489-6440 ext 14	<a href="mailto:accountant@candlelighters.ca">accountant@candlelighters.ca</a>

### Board of Directors 2002

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<b>Karen Wagenaar</b>	Provincial Director - Alberta	<b>Jacques Chenier</b>	Francophone Representative
<b>Steve McElroy</b>	Member at large		

Childhood Cancer Foundation~Candlelighters Canada  
 55 Eglinton Ave. East, Suite 401,  
 Toronto, ON  
 M4P 1G8



## Buy an Angel Pin and support the Candlelighters' Angel Program

**The Candlelighters' Angel Program** is a special fund dedicated to help families living with childhood cancer. The funds raised are directed to our programs. Each Angel Pin is carefully handcrafted and is available in either a gold or silver tone, for the price of \$14.80 (which includes tax and shipping). Please complete the order form and return it to Candlelighters, 55 Eglinton Ave. East, Suite 401, Toronto, ON M4P 1G8. Or fax your order to us at 416-489-9812.

*"My mom says angels are all around us, they show us how to care,  
 and how to share, and fill our hearts with love."*

Name:		Card Number:	exp
Phone:		Card Holder:	
Address:		Signature:	
		Quantity:	#___Gold + #___Silver @ \$14.80 ea.
Method of Payment:		<input type="checkbox"/> Visa   <input type="checkbox"/> Mastercard   <input type="checkbox"/> Cheque Enclosed	

