Contact

Fall/Winter
2000

A quarterly publication from Candlelighters Canada

IN THIS ISSUE

The publication and distribution of this newsletter is one of the free services of the Childhood Cancer Foundation~Candlelighters Canada.

Candlelighters is a national volunteer charitable organization dedicated to improving the quality of life for families experiencing the effects of childhood cancer, through the provision of resources, parent support and the promotion of research.

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With help from your tax deductible donations. Charitable donation number: 13189 7654RR 0001

Childhood Cancer Foundation Canada
Candlelighters

Launching Sparkles at the Bay

Come on out to your local Bay store and meet "Sparkles" the adorable charity bear.

The Bay has launched a new community partnership entitled "**Well into the Future**" and the Childhood Cancer Foundation ~Candlelighters Canada is one of their partners. The partnership includes Candlelighters Canada, Wellspring, Look Good Feel Better and The Canadian Cancer Society.

The Bay's charitable program supports Canadians living with cancer. The program links all corporate donations, cause marketing and charitable partnerships under one umbrella and allows the Bay, Bay associates and Bay customers to contribute to the program through special campaigns.

Candlelighters Canada is extremely proud and grateful to be a part of such a unique and collaborative initiative. The Bay is a strong community partner and their support of children with cancer and their families is enormous.

The Charity Bear Program has been launched in all Bay stores across Canada on November 2nd, 2000. "Sparkles" the bear is being sold all during the holiday months. The Bear sells for $9.99 and $5.00 from the sale of each bear will be donated to Candlelighters Canada to help increase our programs and services across Canada.

This little bear needs a home. I am sure that he/she would love to come and make a home with you! Remember when you support the Bay Charity Bear Program you are supporting Candlelighters Canada and the services that we offer, and hope to expand, across Canada.

"Clowning Around for Kids with Cancer" was the theme of our 3rd annual Carnival in the Courtyard. The event was held in August 2000, and raised over $20,000.

(see pgs. 8-9 for photos and info)

Newsletter Editors
Eleanor Pask and Renae Addis

Design by Sheri-Lynne McSpurren
Printing by Weller Publishing Co. Ltd.

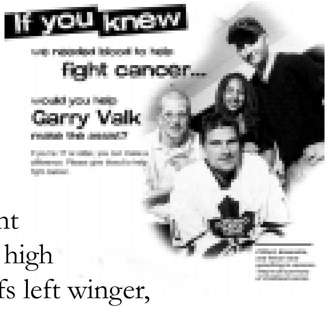
Words of strength from friends of our children:

Please remember to stay strong and fight hard to get well because a lot of people love you and are praying that you will be well and strong again soon. We know every day is hard but know that we care and want to help you and your family in the fight against cancer.

I am not afraid of the future because I have seen the past... I wish you only bright days ahead.

Community outreach program touching teens at school

The Childhood Cancer Foundation~Candlelighters Canada and the Canadian Blood Services, in partnership with the Toronto Maple Leafs, are making a play to support kids with cancer.



Trevor, Cliff and Alexandria all have one thing in common; they are all survivors of childhood cancer and required blood and blood products throughout the course of their treatments. Beginning in October 2000, and running until March 2001, their positive stories as recipients of blood will be a broad recruitment campaign for the Canadian Blood Services throughout high schools in the Ontario region. The Toronto Maple Leafs left winger, Garry Valk, is an official Maple Leaf in this community outreach campaign.

The High School Challenge is one element of the campaign. The goal of the program is to raise awareness for the need to give blood and recruit new blood donors in their late teens, and to educate people about childhood cancer.

The Maple Leafs are strong role models for today's youth and we thought this made them the perfect fit for this campaign. This campaign will be geared towards youth and aims at educated youth about the need to give blood and how it is commonly used to treat their peers, like childhood cancer patients.

Our Most Sincere Apologies

to those who requested Contact, but did not receive it

Candlelighters National Office has just learned that due to a most unfortunate computer processing problem in our database program, hundreds of new names have been incorrectly processed. This has meant that those people who requested Contact over the last few months most likely did not receive it. We have responded to several people who called to ask why they had not received it and our investigation led to this most unfortunate of results. We are certain that now all those names which had been incorrectly processed are now firmly and correctly placed in the system. We very much regret this problem and we hope that you will accept our apologies. If you would like to receive back copies of any of the issues you had hoped to receive, please call, fax, or email Candlelighters National Office.

Medical Update - Childrens Oncology Group (C.O.G.)

New Cooperative Group Created to Cure and Prevent Childhood and Adolescent Cancer

Reprinted with permission from Candlelighters Childhood Cancer Foundation, The Quarterly Newsletter, Vita Lerman, June 2000. pg.1-3.

Children's cancer trials have lead to increased survival

The majority of Canadian children with cancer are registered in one of the four international children's cancer study groups. Advances in pediatric cancer research have been phenomenal. The overall cure rate is now at 75% and survival rates for some childhood cancers (Hodgkin's Disease and Wilms') [may] exceed 92%. These recent statistics from the National Cancer Institute (NCI) are extremely encouraging to patients, families and researchers, particularly since less than 10% of children survived their cancer 45 years ago, when the first cooperative clinical trials group for children's cancer was founded.

Increased survival and pediatric cancer clinical trials go hand in hand. Clinical research has been responsible for the discovery of virtually all of the groundbreaking treatments for childhood cancers. Better survival rates have also been linked to participation in pediatric cooperative clinical trials, which offer the most advanced therapies available for children and adolescents with cancer.

New C.O.G. to further improve cure rates and quality of life

To further improve cure rates, the four pediatric cancer cooperative groups – the Pediatric Oncology Group (POG), The Children's Cancer Group (CCG), The Intergroup Rhabdomyosarcoma Study Group (IRSG) and the National Wilms' Tumor Study Group (NWTSG) – decided to join forces and create the new **Children's Oncology Group (C.O.G.).** Building on the tremendous progress to date, the new C.O.G will accelerate the search for successful treatments and continue to improve the quality of life for the growing numbers of childhood cancer survivors.

With unified resources, increased efficiency and more patients on clinical trials, C.O.G. will be able to complete studies faster and make better cancer treatments more readily available. In future research, the new group also intends to conduct more extensive survivor follow-up, to address health care economics, and to create the national childhood cancer registry.

The merger of the pediatric groups will also benefit adolescents and young adults with cancer. C.O.G. is strongly committed to ensuring that more adolescents and young adults gain access to clinical trials. So far this group has been highly under-represented on clinical trials mainly because adolescents and young adults are not usually referred to pediatric cancer centers for treatment. And yet, these are precisely the institutions that offer the most appropriate trials for adolescents, since adolescent cancers are more similar to children's cancers than the types of cancer common in adults. Through a special initiative, C.O.G. plans to increase adolescent enrolment in C.O.G. trials by making the referring physicians, patients and families more aware of the need and the benefits of adolescent participation in clinical studies. C.O.G. also intends to target more treatment studies specifically to the adolescent and young adult population.

How will the new C.O.G. work?

All the pediatric groups, and the newly emerging C.O.G., are NCI-sponsored clinical cooperative groups. In 1955, the NCI formed a clinical studies panel and suggested that the study of leukemia would advance more expeditiously if investigators joined to collaborate on clinical trials through a "cooperative groups" mechanism. CCG was formed in 1955 and POG in 1979. The IRSG and the NWTSG were formed as Intergroup study groups (i.e. composed of POG and CCG member investigators and institutions) in order to study very rare childhood cancers – Rhabdomyosarcoma and Wilms' tumors).

The job of the new childhood cancer cooperative group, C.O.G., will be to develop and coordinate cancer clinical trials conducted at the 238 member institutions, which include all major teaching hospitals and universities throughout the U.S. and Canada, as well as sites in Europe and Australia. The trials at each institution will be centrally monitored and the study results published in peer-reviewed scientific journals. The citations of published studies will be available to patients and families through the new C.O.G. website which is currently under development.

C.O.G. progress and how it will affect patients

Now, only two years after the merger of the pediatric cooperative groups was conceived, the groups are essentially functioning as a single streamlined organization. On the immediate level, however, the merger will not change anything for patients already on POG, CCG, IRSG, or NWTSG studies. These studies will continue as before until [their] completion.

The main difference will be felt with new studies. Starting July 2, 2000, all patients entering new C.O.G. studies at member institutions will be registered through a web-based remote data entry system. Through this system,

continued on page 4

Introducing... Cory the Caterpillar!

Cory the Caterpillar is a special book for kids to help them deal with cancer. Read more about him (and how to get a free copy) on page 15. Thanks to Janssen Ortho Inc.

Medical Update - Childrens Oncology Group (C.O.G.) cont.

patient responses to therapy will be centrally collected and analyzed. This new system will help develop and manage studies more efficiently which ultimately will lead to faster scientific progress and quicker dissemination of study results.

C.O.G. will address survivor issues

The new protocols will reflect crucial survivor issues, such as late effects research, that C.O.G. views as a growing priority. For example, the first C.O.G. Phase IV study for high risk neuroblastoma incorporates questions relating to the quality of life of survivors and aims to describe potential late effects that surviving patients may experience. C.O.G. will particularly focus on studying late effects in diseases with high survival rates, such as Hodgkin's disease. Already a number of studies are testing new treatments for prevention of known side effects, and this trend will continue with the developing C.O.G. studies.

In order to track late effects and create safer treatments, long-term patient follow-up after completion of therapy is crucial. This requirement is written in to each protocol. However, often patients become lost to follow-up for a variety of reasons – when they change their name or address, for example, or when they transfer to an adult treatment facility.

Former patients and their families can help C.O.G. evaluate long term effects of cancer therapies by maintaining current contact information a the treating institution in the years ahead.

C.O.G. welcomes patient advocate participation

At its first groups meeting in April 2000, the new C.O.G. formally welcomed the participation of patient advocates in all aspects of the clinical trials process. The newly established C.O.G. Patient Advocate Committee, which consists primarily of parents of children with cancer, will ensure that the needs of patients and families are heard and addressed by the new groups. The Patient Advocate Committee contact information will be available on the new C.O.G. website.

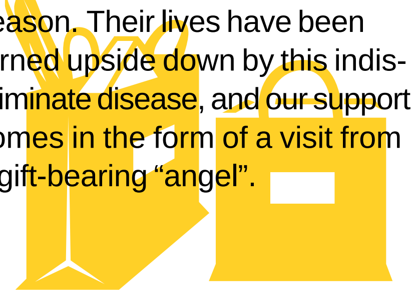
Vita Lerman is the Communications Coordinator for the Pediatric Oncology Groups and now also for the Children's Oncology Group. She is the editor of the "Children's Oncology News", the C.O.G. quarterly newsletter, and is involved in the creation of the new C.O.G. public website. Vita has lost family members and a close friend to cancer, and hopes that through increased awareness and access to clinical trials, more patients will become survivors.

Holiday gift drive for families gears up for 2000

Candlelighters Canada is once again launching our Holiday Gift Drive in hopes of helping over 100 families across Canada this holiday season.

In an effort to meet these needs, the Childhood Cancer Foundation ~Candlelighters Canada has started the Corporate Angel Fund. Last year, generous donations from Corporate Angels such as: **General Motors, Sterling Commerce, Procor Ltd, Twinpak Inc., Rio Algom, The Bank of Nova Scotia, Nesbitt Burns, TrizecHahn Corporation, CIBC Wood Gundy Children's Miracle Network, Revlon Canada, SCI Canada, Magna International, The Caldwell Partners, The Casual Way, Scholastic Press**, and many others enabled Candlelighters Canada to help more than 80 families across Canada enjoy a memorable holiday. We were delighted to exceed our goals.

The funds and items collected are distributed amongst families touched by childhood cancer who are in the greatest need of support, especially during the holiday season. Their lives have been turned upside down by this indiscriminate disease, and our support comes in the form of a visit from a gift-bearing "angel".



Thanks from all of us to all of you!

Thanks to our Angels: We are always so appreciative of all the donors that support our much needed programs and services. Without your continued support we would not be able to offer them to families across Canada.

Thanks to our Corporate Angels: The Childhood Cancer Foundation~Candlelighters Canada is expanding and implementing new programs across Canada with the support of the following organizations:

The Back to School Program: **Imperial Oil Charitable Foundation** has increased their partnership and continues to be a supporter for Candlelighters as we implement the Back to School Program across Canada. The **Royal Bank Charitable Foundation** has continued their support for 2000, and is a large supporter of the Back to School Program. Together, these two community leaders are partners in the Back to School Program.

Research Funding: We have received some very generous donations from corporations and donors that are committed to the recently launched Candlelighters Research Program.

Marion Dowdell kindly gave us a very generous donation for our new Research Program Launch and we are grateful for her support.

Other supporters include:
Royal Bank Charitable Foundation
Oracle Corporation
TrizecHahn Corporation
IBM Employee's Charitable Fund
Schering Canada
Bank of Nova Scotia

The Teen Network: **Mentor College** in Mississauga, ON has chosen Candlelighters Canada as one of their charities to support. With their help and dedication Candlelighters has launched and will be expanding the Teen Network (a recent initiative) across Canada.

Angels to other programs and services:
Mackenzie Financial Corporation
Maple Leaf Foods
Magna International Inc.
CIBC Children's Miracle Foundation
Nesbitt Burns
Nortel Networks
T. Donald Miller Foundation
The Salden Foundation
The Nelson Arthur Hyland Foundation
Amcor Twinpak

A special thank you to **Johnny K Sports** that had their 1st Annual Golf Tournament in support of Candlelighters. They did a super job!

Also, to **Golfer's Green** for their continued support of Candlelighters. Their dedication to children with cancer has been wonderful and the funds that are raised go to support our various services.

Thanks again!

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

Buy an Angel pin and support 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 two programs: **Family Assistance** and the **Candlelighters/Interlink Community Cancer Nurses**. Each Angel pin is carefully handcrafted and is available in either a gold or silver tone. Please complete the order form and return it to Candlelighters, 55 Eglinton St. East, Suite 401, Toronto, ON M4P 1G8. Or fax your order to us at 416-489-9812.

Order your Angel pins today!

Name: ______________________________
Phone: ______________________________
Address: ______________________________
____
No. of pins (@ $12 each, plus taxes) ________
Total $ ______________________________

Card Number: ________________________
Expiry Date: ________________________
Cardholder: ________________________
Signature: ________________________

Method of Payment (please circle one):
Cheque enclosed
Visa MasterCard

Children's Cancer Resources on the Net

Today, parents of children with cancer are faced with an increasing array of information on the internet. Some is helpful, reliable and informative. Some is not. Sorting through the myriad of sites and links is a daunting task. Sorting out the good from the not very helpful is even more daunting.

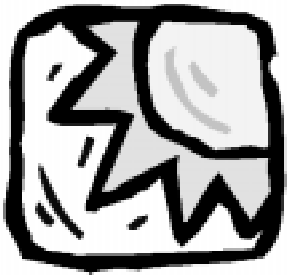
Dr. Juanne Nancarrow Clarke, medical sociologist at Wilfred Laurier University, mother of a childhood cancer survivor and author of Finding Strength: A Mother and Daughter's story of Childhood Cancer, has designed an online directory of web sites on all aspects of childhood cancer. Working with Naomi Anatol, she has provided organized and easily accessible information that parents will find useful in understanding and coping with their child's cancer diagnosis and has provided some tools for evaluating web sites.

This website, **www.childrenscancer.20m.com**, is an online directory of websites on all aspects of childhood cancer for parents, caregivers, healthcare professionals and children too. The site lists hundreds of websites.

All the websites are listed in the following specific categories: Advocacy, Alternative Therapies, Bereavement, Brain Tumours, Camps, Causes/ Prevention, Charities, Chatrooms/Listserves, Diet/ nutrition, Hospitals/ Cancer Centres, Leukaemia/ Lymphoma, Links and Resources, Medical Flight Organizations, Medical Information, Neuroblastoma, Palliative care, Personal Pages, Publications, Research, Support, Wish Granting Organizations.

Within each category, links to the websites are arranged alphabetically and by geographic location where applicable. Just click on the website you want to view.

As Dr. Clarke points out, this website can provide immense help for parents searching for information, but it is not a substitute for consultation with your doctor or physician. Always seek your doctor's advice on medical matters.



Planning for some fun in the sun?

Call INGLE first

Medical coverage is available for your child with cancer when travelling outside of Canada

The Childhood Cancer Foundation ~Candlelighters Canada is pleased to confirm that out-of-country medical coverage can be arranged through:

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

The process is very straightforward:

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

Now, go enjoy your well-deserved holiday

Surviving the Holidays

“Feeling all alone stinks!” The language may not be polished, but it cuts to the heart of one of the deepest hurts we experienced when we are grieving. We may struggle with fear, anger or guilt, and depression is often very powerful, but few things derail us as quickly and sadly as the rude awakening, “I am all alone.”

Let your feelings be gifts to you

Feelings of loneliness come and go, for the bereaved, for those struggling with physical, emotional or other stressors, and they require diligent care and self affirmation to guide us through. To be alone is real. To feel that loneliness penetrates how we feel about ourselves, how we relate to others, and how we cope with life and life events. “Alone” is a state of being; “lonely” is a feeling. Both can be very tough.

The feelings come and go, but some triggers can really catch us, often by surprise. Maybe an article in the newspaper reminds us of our sorrow and the pain returns. A hurtful remark. A new issue. Not feeling well. Being overly tired because you can’t sleep at night. People keep asking more and more of you when they are unwilling to ask how you are doing (and patiently and non-judgementally allow you to tell them).

Don’t run from the holidays and special days

Holidays and special days can refresh us, comfort us and inspire us. They also can drag us down. Even those holidays wrapped in spiritual and religious meaning are included. These special days are always about people, traditions, stories, rituals... about living and maybe, for some, whether we even want to live like this. For the bereaved, holidays may, if we are careful and patient, give us a few minutes of peace, joy and hope. It can be a long ride to those brief glimpses, for we may only see:

“I have too much to do.”
“I don’t care about the holidays.”
“I’m too tired.”
“I don’t know what to do.”
“My loved one took care of this.”
“People expect me to be happy.”

Holidays and special days are special or significant because of the meanings we give to them, and those meanings are rooted in past experiences, hopes and expectations, and the place that loved ones

continued on page 15...

Some Key Strategies for Recruitment of New Members for Your Group

From: Chester and Chesney, Cancer and Self Help: Bridging the Troubled Waters of Childhood Illness, Madison and Wisconsin Press. 1995. Presented at the ICCCPO/SIOP conference in Montreal Quebec, September 1999.

Parent Support Groups lend the kind of support to parents that no one else can provide, but it is not always easy to recruit new members. The following suggestions from two Parent Support Group experts may help:

- Realize that few parents join in the first three months after diagnosis; give families time to respond to the initial shock, but try to reach out and help them through this period.
- Remember that parents are often overwhelmed by physical and emotional stress.
- Time and energy are at a minimum, give parents a reason to become involved and provide assistance in terms of transportation and child care.
- Minimize travel time and distance from parents’ homes to the group meeting place.
- Remember that some parents are afraid that the group’s discussion will increase anxiety and anger.
- Remember that everyone has his or her own coping strategies (and ways of dealing with, or denying stress); not every parent will (or should) choose to come to the group regularly, or at all.
- Keep the group open, reduce factions and cliquishness, and keep time spent on group “Business” to a minimum (let those who love to do business do it at separate meetings).
- Perception of the groups as all white, all middle class, all women, or all anything will turn some people away.
- Have the health care team talk in positive terms about the group to parents of newly diagnosed children.
- Make some group activities visible with posters and announcements in clinics, or on hospital wards.
- Provide a wide range of activities, at different times, so that parents with different needs can all find assistance within the group.

Please note: the next issues of Contact will feature follow-up suggestions on ‘‘How to Maintain a Support Group“, ‘‘How to be a Good Group Member”, How to Start and Build your Resource Library.” Please send us your ideas and experiences that have made your Parent Support Group successful, or send us questions and we will try to find the answers for you.

Third annual Carnival

Clowning Around for Kids with Cancer

This year was very exciting. We launched Childhood Cancer Awareness Day nationally and it was entitled **"Clowning Around for Kids with Cancer"**. We had a carnival event in New Brunswick, Halifax, Ottawa, Toronto, Winnipeg and Vancouver. Many people came out to support their local regions.

National Candlelighters kicked off the events on August 31st in the Toronto TD Centre Courtyard, with a lot of support from our corporate sponsors (TD Bank Financial Group, Rogers Cablesystems and Procter & Gamble) and volunteers. We were able to raise over $20,000 to support the event across Canada.

There were games, giveaways, face painting and lots of smiles in every region. The following pictures will tell much of the story. It was such a success that groups are already preparing for next year.

This is the first ever truly national Awareness event that the Childhood Cancer Foundation~Candlelighters Canada has undertaken, and everyone is so pleased that it was such a wonderful success.

Our “Clowning” around helped us to raise over $20,000 for childhood cancer!

with a twist . . .

Pictured on opposite page:
Top Left - Domer, the Skydome mascot, in the play area.
Top Right - Rozie Summers belted out tunes for the crowd.
Bottom Left - Shooting hoops was one of the many games.
Bottom Right - A brother and sister take to the ring.

Pictured on this page:
Top Left - Our clown got lots of smiles from the kids with balloon animals.
Top Right - Two businessmen get “pulled” into the fun.
Bottom Left - A big bear hug from Carlton, mascot for the Toronto Maple Leafs.
Bottom Right - Taking a leap to the finish line on the obstacle course.
Bottom Lower Right - Staff from the Canadian Blood Services talk to some event goers, while a man eyes the Rogers booth nearby.

We also celebrated in Manitoba...

and in New Brunswick...

Who is Max Wilms?

And why did they name a cancer for him?

German surgeon Max Wilms prepared his famous monograph on children's kidney tumours in 1899 at the beginning of his medical career. A dedicated physician, he later studied ulcers, burns, tuberculosis and the uses of radiation, and co-edited a book on surgery. At the end of World War 1, Dr. Wilms operated on a French soldier who infected him with diphtheria from which he died in 1918. But his early work was so thorough that his name was linked forever to a children's cancer with a high mortality rate.

There has since been remarkable progress in curing Wilms' tumour in children. For all the patients combined, the cure rate is now over 80%. For those with the type of kidney tumour most responsive to chemotherapy, the cure rate for all stages of the disease is an amazing 90%.

The treatment routine is usually to surgically remove the tumour and the affected kidney, then give chemotherapy. In Europe, survival rates are about the same, but it is more typical there to administer chemotherapy before surgery. Doctors with the National Wilms' Tumour Study Group (NWTSG) believe that treatment may make it more difficult determine if the cancer has spread to another spot.

According to Dr. Michael Ritchey, a surgeon with the NWTSG, there has been great success in treating Wilms' tumour because the tumour is more chemo-sensitive than some others. "Even when the cancer spreads to the lung, Stage IV tumours that have favourable histology respond well."

Dr. Ritchey is Professor of Surgery and Pediatrics, and Director of the Division of Urology, at the University of Texas, Houston Medical School. He operates on children with all types of kidney problems. He says it is essential that Wilms' tumour patients have careful follow-up: CT scans or ultrasound exams of the abdomen on a regular basis. The patient's remaining kidney may be at a greater risk if the pathology of the removed kidney revealed certain lesions called nephrogenic rests.

In the future, says Ritchey, researchers will try to understand what triggers those precursors, the nephrogenic rests – which are present in the kidneys of many perfectly healthy infants – to develop into cancer in only certain children. They will also concentrate on the biology and genetics of Wilms' tumour, in order to determine in advance which children require more or less therapy. Certain chromosome abnormalities can predict a poorer prognosis, he says, and treatments can be planned accordingly.

There have been genes specifically identified as related to the behaviour of the Wilms' tumour: WT-1 and WT-2. However, most children with Wilms' tumour don't have WT-1, and only a small number have WT-2. So it may be that a different mutation, not yet recognizable, is to blame. More research of this area, too, is needed, according to Dr. Ritchey.

Max Wilms would probably be surprised to learn that his name now denotes this childhood cancer. But Dr. Wilms would be been more surprised – and delighted no doubt – to learn how many children can now be cured of Wilms' tumour.

Facts on Wilms' Tumour

✓ About 500 children and teens develop Wilms' tumour in the U.S. each year.

✓ The highest incidence is in the first two years of life.

✓ In seven percent of the children with Wilms' tumour, both kidneys are involved at diagnosis.

✓ In only one percent of the children who have a kidney removed due to Wilms' tumour, the cancer later re-appears in the other kidney.

✓ Possible risk factors in the environment of the parents, or the child, which might cause Wilms' tumour have not yet been determined.

✓ There is a family history in only one percent of the cases.

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Really? How Expensive Is Your Child?

This information was sent to Candlelighters from a previous Board Member, Frankie Pasowicz. Unfortunately the author is unknown. We thought you might enjoy it.

The government recently calculated the cost of raising a child from birth to 18, and came up with $106,140 for a middle-income family. Talk about shock! That doesn't even touch college tuition. For those kids, that figure leads to wild fantasies about all the things we could have bought, all the places we could have travelled, all the money we could have banked if not for the child. For others, that number might confirm the decision to remain childless.

But $160,140 isn't so bad if you break it down. It translates into:
$8,896.66 per year,
$741.38 per month,
$171.08 per week,
or, a mere $24.44 per day.

Just over a dollar an hour. Still you might think the best financial advice says don't have children if you want to be rich. It is just the opposite!

There is no way you can put a price tag on:

$ Feeling a new life move for the first time and seeing the bump of a knee ripple across your skin.
$ Hearing someone cry, "It's a boy!" or shout "It's a girl!" then hearing the baby wail and knowing that all that matters is that he or she is healthy.
$ Counting all ten fingers and toes for the first time.
$ Feeling the warmth of fat little cheeks against your breast.
$ Cupping an entire head in the palm of your hand.
$ Making out "da da" or "ma ma" from all the cooing and gurgling.

What else do you get for your $160,140?

$ Naming rights, first, middle and last.
$ Glimpses of God everyday.
$ Giggles under the covers at night.

$ More love than your heart can hold.
$ Butterfly kisses and Velcro hugs.
$ Endless wonder over rocks, ants, clouds and warm cookies.
$ A hand you hold, sometimes covered with jam.
$ A partner for blowing bubbles, flying kites, building sand castles and skipping down the sidewalk in the pouring rain.
$ Someone to laugh yourself silly with no matter what the boss said or how your stocks performed that day.

For $160,140 you never have to grow up.

$ You get to finger paint, carve pumpkins, play hide and seek, catch lightning bugs and never stop believing in Santa Claus.
$ You have an excuse to keep reading the adventures of Piglet and Pooh, watching Saturday morning cartoons, going to Disney movies and wishing on stars.
$ You get to frame rainbows, hearts and flowers under refrigerator magnets and collect spray painted noodle wreathes for Christmas, hand-prints set in clay for Mother's Day and cards with backward letters for Father's Day.

For $160,140, there is no greater bang for your buck!

$ You get to be a hero just for retrieving a Frisbee off the garage roof, taking training wheels off the bike, removing a sliver, filling the wading pool, coaxing a wad of gum out of bangs and coaching a baseball team that never wins, but gets treated to ice cream regardless.
$ You get a front row seat to history, to witness the first step, first word, first bra, first date, first time behind the wheel.
$ You get to be immortal. You get another branch to your family tree, and a long list of limbs in your obituary called grandchildren.
$ You get an education in psychology, nursing, criminal justice, communications and human sexuality that no college can match.
$ In the eyes of your child you rank right up there with God. You have the power to heal a boo-boo, scare away monsters from under the bed, patch a broken heart, police a slumber party, ground them forever, and love them without limits.

So one day they will, like you, love without ever counting the cost.

Showcase of Contest Winners

Congratulations to all the Winners of the Health Canada and Candlelighters Canada Colouring and Writing Contest

And the winners are...

4-7 years olds

Lucas Wilford of Alma, ON
Megan Hayward of Greely, ON
Miranda Waugh of Lively, ON
Jamie Martin of Kitchener, ON

8-12 years old

Kristn LaRocque of Moosejaw, SK
Lauren Wilford of Alma, ON
Jessica Longtin of Halifax, NS
Lucy Joe Markus of Kingston, ON

13 and older

Vanessa Pastoric of Oakville, ON
Kenneth Morrisseau of Winnipeg, MB
Trevor Johnson of Barrie, ON
Jonathon Schwartz of Watson, SK

Editor's Note: We would like to thank everyone who entered this national contest. It was a great success and as you can imagine the judging was very difficult. The judging was done by Conference 2000 registrants, parents, professionals, volunteers and children with cancer. In each issue of Contact, the art work and writing submitted to the contest by both the winners and other participants will be featured.

My Brother

By Miranda Waugh, 4 ½ years old

My brother is 3 years old. I am 4 ½ years old.
Riley is wearing a cast because he has a broken leg.
He has to have white medicine.
He has to go to the hospital in Sudbury and Toronto.
He cries when he needs a pick.
I think he is brave.
I play with him lots.
We play lions.
I take care of him.
I love him.

Drawing by Kristn LaRocque

The poem inside the globe reads:

Start each day with a smile,
Roll with the punches,
Take it day by day,
Make things as best
as they can be!

Candlelighters Mission . . .

The Childhood Cancer Foundation~Candlelighters Canada is a national volunteer charitable organization dedicated to improving the quality of life for families experiencing the effects of childhood cancer, through the provision of resources, parent support and the promotion of research.

Pack Your Parachute: a Sequel
The Pediatric Oncology Group of Ontario (POGO)

Wednesday, November 29, 2000, Faculty Club, University of Toronto, 40 Willcocks Avenue, Toronto, ON

Many aspects of childhood cancer will be addressed in a day highlighting excellent speakers and information. Dr. Donald Meichenbaum is returning by popular demand to address "Coping with Stress: Applications to Oncology Practice". Several sessions address Phase l trials, concepts, process, challenges, quality of life issues and ethical concerns. Information and registration can be obtained from POGO, 620 University Avenue, Suite 702, Toronto, ON M5G 2C1

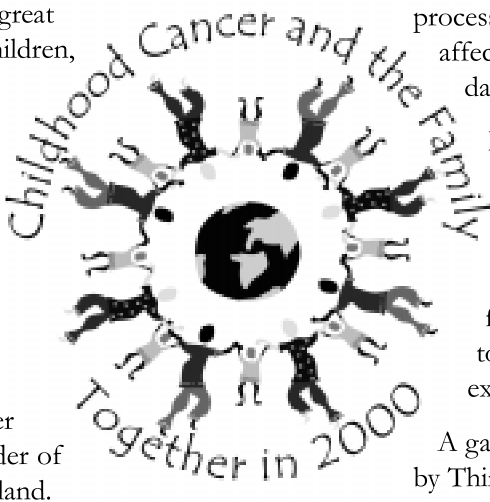
Candlelighters Childhood Cancer and the Family 2002

Summer 2002, British Columbia

The candle signifying the close of the Candlelighters 2000 conference was passed to the Director of British Columbia, Ruth Morely. The 2002 conference planning will get underway very shortly. Each issue of Contact will bring you more details, but please plan to attend and make this BC conference as successful as the Ontario one in 2000.

A look at the recent Candlelighters Canada and OPACC Conference:

Childhood Cancer and The Family: Together in 2000



This year's conference was a great success. Over 350 parents, children, professionals and volunteers participated. The opening keynote speaker was Dr. Bernie Siegel, who gave inspirational messages from his books and from his heart. Words that everyone could take home and live in their daily lives.

Other speakers included Sister Frances Dominica, the founder of Helen House in Oxford England. Sr. Frances showed videos and told so eloquently of the respite Helen House provides for families of chronically ill and seriously challenged children. It is a model that would serve families well in Canada.

Dr. Marla Shapiro, a parent and a physician, told the registrants how they can survive in the world they enter upon diagnosis of their child. This world is dominated by health care professionals, new experience and new language. She provided practical advice on asking questions, advocating for your child and above all understanding the process of communication as it affects parents' experiences on a day-to-day basis.

Dr. Lauren Woodhouse, a laughter therapist, closed the conference with a wonderful presentation about laughter and humour and where to find it and how to respond to it when living through the experience of childhood cancer.

A gala dinner, live entertainment by Thinktank Fish and a fundraising silent auction were the social highlights of the conference. The staff of Camp Oochegeas and Camp Trillium had an outstanding programme for the nearly 100 children who attended. They had a choice of one of four off-site trips. They participated in the closing ceremonies and each child probably went home exhausted but with great new friends.

Special thanks to the Conference Planning Committee chaired by Helen Pastoric and Joanne McLeod, all the volunteers and the staff for a great experience.

A Sick Story

Reprinted with permission from Today's Parent, August 2000, p.8.

Picture the mother of a child dying with cancer. Picture that mother having to go to a psychiatrist for a note that says she's nuts so she can take a "stress leave" from her job to be with her child.

Picture another mother of a little boy named Zachary with cerebral palsy, who has had four operations in a row and been in the hospital some 50 days. Her husband sleeps there at night, then goes to his job as an electrician by day. She comes by in the morning (after nursing her younger son), singing "Swing Low, Sweet Chariot" the way Zach likes. Also in the room are Master's students jotting down notes that she dictates about the policy formulation they are working on, while she rocks her three-year-old son. The project has a deadline and the mother has a mortgage; she doesn't want to lose her job, so she drags her students to her child's bedside.

These are just two stories I heard from Ottawa-area mothers I met on June 16. We were all at a workshop on "finding solutions for working parents with sick children" presented by the Canadian Alliance for Children's Healthcare (a non-profit board I sit on, along with far more notable people like Jean Wittenberg, head of infant psychiatry at the Hospital for Sick Children and Senator Landon Pearson, a well-known advocate for children's rights).

Zach's mom, Jennifer Epsey, rightly pointed out that the workshop's title disturbed her since parenting is her real work – much, much harder, much more rewarding than the work she does to pay her mortgage as a policy analyst. In her third role as chair of the regional Easter Seals, she has seen the price other parents have had to pay, trying to eke out a living while caring for a child with special needs. "A lot of parents I have met through Easter Seals are incredibly overwhelmed. We're in crisis."

It's hard enough when you have to use up your own vacation to take care of kids with chicken pox. But imagine what it is like if your child has a chronic, or critical illness, or disability. Why aren't there resources before parents are over the edge, the workshop attendees wondered? Why do employees have to lie to get leave, give up their jobs, perhaps give up their kids to foster care, and in the worst scenario, be forced into poverty? Why do you have to be declared mentally ill before you can spend time with your terminally ill child? Why, in a country like Canada, is there no national social policy to help?

Before her participation in the workshop, Jennifer went to StatsCan and Health Canada to amass and analyze the substantial stats there must be on this topic. And guess what? She found none. There is some documented research, but collected haphazardly by individual organizations, such as a particular union or parent support group. (Here's one interesting statistic from a study Jean Wittenberg cited: When parents are present in hospital, children reduced the length of their stay by 31%).

The overall lack of attention paid to this issue is appalling. Says Jennifer: "For someone who works in Ottawa in policy, there's nothing louder than that kind of silence."

But there doesn't need to be silence. The anecdotal evidence of the financial and emotional toll workplace demands take on these parents comes through loud and clear. And you can add to that evidence. If you are a mother or a father with a story to tell – someone stressed to the max by trying to take time off for your child's dialysis, or neurology appointments, or chemo treatment – please write to me (see addresses below). Tell me how you've had to cheat the system in order to survive, or deal with a front-line supervisor who just doesn't get it. Tell me if you have had to quit your job, or cut your pay, or haven't taken a vacation in a decade. You are not alone. I will take your testimonials to the ongoing task force that was struck at the workshop.

On June 16, in the space of a few hours, we came up with concrete suggestions – including possible changes to EI and the tax structure – that could make a real difference. The task force is going to make recommendations soon – to governments, employers and community groups – while the National Children's Agenda is still in vogue.

As Zach's mom put it so simply and so eloquently, "All children have a right to a family." And if a Canadian family can't be at a child's bedside because they have to put bread on the table, or can't put bread on the table because they have to be at their child's bedside, it is not just the child who is sick.

Candlelighters Editor's Note:

Candlelighters has played an active role in the development and submission of the proposal which has been submitted to the Premiers' Meeting in August, to the Liberal Caucus in September, and will continue to actively support and participate in this process. It is our feeling that by working together with the strong voice of the coalition spearheaded by the Canadian Alliance of Children's Healthcare, we can make a difference in the definition of illness and disability, the tax credit system, parental supplement when a child is ill and with employers.

Please help us, write your stories and write your Members of Parliament. Prime Minister Jean Chretien has stated in his platform that he wants to double the duration of maternity and parental leave under the Employment Insurance Programme, and to double the tax credit for families caring for a disabled relative. Our goal is to have parental leave, a parental supplement, a change in the definition of disability and increased tax credit for families of all children who require "extraordinary care".

Please help us strengthen our approach by sending your story to: Linda Lewis, Editor in Chief, Today's Parent, 269 Richmond St. W., Toronto, ON M5V 1X1; Fax (416) 596-1991, email mailbag@todaysparent.com

New Resources for You and Your Family

Corey the Coping Caterpillar

Original concept and written by Kim Cooper and Monica Saxon. Available at no charge.

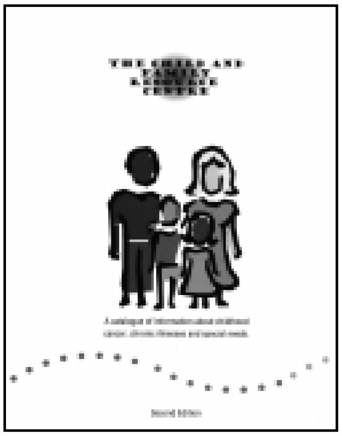
Special funding from **Janssen Ortho Inc.** has made this charming resource available for all children. The illustrations are wonderful and appeal to children and adults alike. Corey highlights some of the problems children encounter in their treatment and gives simple practical suggestions on how to cope with them. A colouring book accompanies Corey. Corey and will be available in all treatment centres over the next few weeks.

Send Reader Mail to:

Candlelighter's Reader Mail
552 Dalgliesh Dr., Regina, SK   S4R 6L8

Want to communicate with others who have the same diagnosis? Want to find a pen pal? Need to obtain information or share your thoughts with others? Simply send a note explaining what you would like published in **Contact**, include your name and address. You will be assigned a number and only that number will be printed - your name will not appear. Your replies will be sent to you and you can answer all your mail.

Candlelighters Resource Centre Catalogue



Work is underway to bring you the **2001 Candlelighters Resource Centre Catalogue**. It contains over 50 new reviewed resources bringing the total listings to over 350.

As in the past, wherever possible, it is our policy to pass discounts from the list price on to our customers.

We will welcome your comments, and as always, we welcome your suggestions on new books or resources that you have found that you think will be of help to other families.

A new **catalogue listing resources in French** will be available in 2001. Following the printing of the revised English catalogue in January, work will begin on a catalogue containing available resources in French. These books and other resources are currently being reviewed.

The Annotated Catalogue of International resources is available from Candlelighters Resource Centre. This lists resources available in a variety of languages and indicates where they may be obtained.

Surviving the Holidays cont'd

hold (or held) for us with them. My mother skipped the first Christmas after my father died. She said it was because she couldn't find the lights of the tree. Her actions and inaction said, "Christmas doesn't matter any more since your father isn't with me."

For caregivers and friends

For caregivers (professional and volunteer) and friends, it is imperative that you remain sensitive to the needs of the bereaved (and those with other struggles), so that you can be an invitation to them to claim what they want, if anything, from the holidays. Be alert for them. Seek them out, but don't burden them or obligate them. Listen. Include them. Let them adjust the holidays to meet their needs. Respect their feelings. Stay tenderly with them as they share their hurts and seek comfort for their loneliness. Be an opening to their spiritual connections, but don't dump religious expectations on them.

For the bereaved

For the bereaved and others for whom these days may be difficult

1) You do not have to be alone. Seek out a person or group where you are safe and free to be yourself. Sometimes a few minutes of "safety" is a breath of fresh air.

2) Pick and choose what parts of the traditions and rituals may be helpful to you. Don't worry about the ones you don't get to. It isn't about satisfying others, but of comforting yourself. Don't be afraid to create some new traditions and rituals.

3) Seek your spiritual connection. It is right there within you and also around you. It hugs you when no one else will.

4) Don't use the holidays to "fix" all of your problems. You can't buy your way through, and such attempts demean the worth of your loved one and the validity of your feelings.

5) There are no rules, no "right way." Bend the rules or change them. Be safe, be smart, be good to yourself.

6) Watch the credit cards.

7) Believe in tomorrow. Celebrate today! You really will survive.

This article was written by the Rev. Dr. Richard B. Gilbert, BCC Director of Chaplaincy Services Sherman Hospital, Elgin, IL. (A gift of The World Pastoral Care Center)

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

It is better to light one candle than to curse the darkness.

- Candlelighters Canada

○ **Please add me to Candlelighters Canada mailing list.**

Name: ____________________

Address: ____________________

____

Institution (if any): ____________________

City: ____________________

Province: ____________________

Postal Code: ____________________

○ **I would also like to make a donation to Candlelighters Canada in the amount of $** __________ ***(cheque enclosed)***

Please indicate if you are:

○ **A parent of a child with cancer**

○ **A patient with cancer**

○ **A health professional** ***(please specify)***

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○ **Other** ***(please specify)***

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As part of its free services, the Childhood Cancer Foundation~Candlelighters Canada is pleased to offer you *Contact*, a quarterly Canadian newsletter featuring articles for families of children with cancer. You will also receive information on new resources and upcoming events. Simply complete and return this form.