



Contact

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2000
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Childhood Cancer and the Family: Together in 2000

It's Almost Here! Have You Registered?

This year's outstanding conference in Toronto is just about here. Registrations are arriving daily from across Canada and around the world. The speakers, children's programs and a gala fun filled evening are all geared to make your stay at the conference the best ever.

If you are planning to register and bring your family please register as soon as you possibly can.

The Colony Hotel will hold our conference rooms until **July 31**. After that the rate will increase greatly and our conference attendees may not be able to get a room at the hotel.

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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Fax: (416) 489-9812

Candlelighters on the Internet

Please visit us at:
<http://www.candlelighters.ca>
email:
staff@candlelighters.ca

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

Childhood Cancer Foundation Canada
Candlelighters

Conference Highlights

SPEAKERS

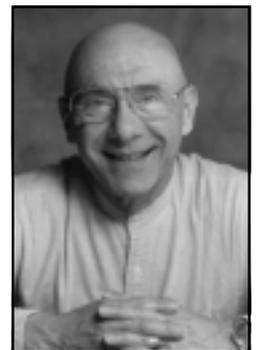
Dr. Bernie Siegel's messages of hope and inspiration have helped thousands of people think in new ways about their health and illness. He is a facilitator of healing and an advocate of caring. His message is that love heals and miracles do happen.

Sr. Frances Dominica is a world-renowned expert in hospice and palliative care for children with chronic diseases. She runs Helen House in Oxford, England. Helen House is a beautiful and compassionate setting for children and families.

Nancy Keen is a parent of a child who has survived cancer. She is also an author who has published several excellent resources for parents of children with cancer.

Dr. Marla Shapiro, a medical doctor, parent of a survivor of childhood cancer and a bereaved parent is a well-known TV personality. She will share her experiences and practical suggestions about bridging the parent – professional gaps.

Dr. Lauren Woodhouse is a certified laughter therapist whose presentations are a must for anyone trying to cope with change while staying sane and successful, resolving conflicts and managing stress.



Dr. Bernie Siegel, one of this year's conference speakers

...more



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Design by Sheri-Lynne McSpurren

Layout by Michelle Williams

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...more conference highlights

ENTERTAINMENT

A gala dinner and entertainment by the newest and coolest musical group soulDecision are guaranteed to capture the hearts of every adult and child in the audience. A silent auction adds additional excitement to the evening as you wait to hear if you have the winning bid.

Lots of additional events are planned throughout the conference for adults and children.

CHILDREN'S AND TEEN'S PROGRAM

The children's programs are a conference highlight. Baby-sitting is available for infants and toddlers under 4 years. Friday brings a day of three separate fun filled programs for all ages of children and teens. Saturday offers a choice of exciting excursions.

If you have not received your preliminary program and registration form please call the conference office at 416 489-6440 or 1-800 363-1062.

Kid's Drawing & Creative Writing Contest

Health Canada and Candlelighters Canada are offering all children with cancer and their siblings a great opportunity to get their stories and pictures about their experience with cancer in a new and revised edition of "This Battle Which I Must Fight". As well as in *This Battle* ...winner's pictures, poems or short stories will be posted in newspapers, displays and on the website.

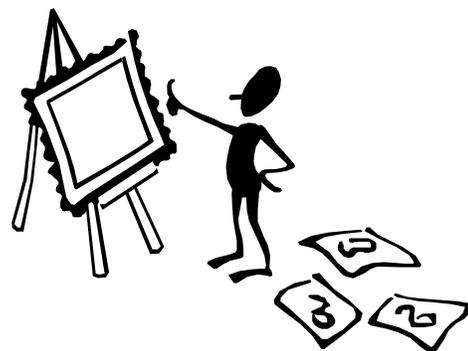
Whether you are at home, at camp, in the hospital or at school get your pencil and paper, computer, crayons, watercolours or oils ready and start now. You can enter as many times as you wish.

Watch for fliers and brochures about the contest in clinics, units and camps. Send your entry or entries by **July 31st** to:

Canadian Childhood Cancer Control and Surveillance Program
Kid's Drawings and Creative Writing Contest
Cancer Bureau
Laboratory Centre for Disease Control
LCDC Bldg #6,
Tunney's Pasture, 0601C1,
Ottawa, Ontario K1A 0L2

Winners will be announced at the Candlelighters Conference in Toronto, August 19, 2000

Prizes will be awarded at Childhood Cancer Awareness Day in September 2000 for the best picture and creative writing in each age group, under 5 years, 6-10 years, 11-13 years and 14 and older.





Special Message About Hepatitis C Class Actions

If your child, as part of his or her treatment for cancer has been infected with the Hepatitis C Virus through receiving blood transfusions between January 1, 1986 and July 1, 1990 you may be eligible for compensation.

If your child with cancer received blood or blood product as part of his or her treatment during the times noted above, and you have not had your child tested for the Hepatitis C Virus we would urge you to have this done as quickly as possible. It is a very simple blood test.

Some children with cancer did receive tainted blood and are now positive for Hepatitis C although at this time they do not display any symptoms related to the hepatitis.

Information packages and an application form have been made available from the federal government. The form will have to be completed by the parent or survivor and the treating physician.

To receive the application or to learn more about the claims process please contact:
The 1986-1990 Hepatitis C Class Claims Centre
P.O. Box 2370, Station D
Ottawa, Ontario, Canada
K1P 5W5

Phone: 1-877-434-0944
Email: info@hepc8690.com
Website: hepc8690.com

Dreams

By Chandrika Venkatesan

*Right now, clouds are drifting through my head
As I'm dreaming sweetly in my bed
I forget about my problems, all my worries, all my cares,
While I dream about such things that seem all so very rare.
I dream about unicorns, rainbows, stars and clouds.
I dream about parades and bands, that play their music loud.
Sometimes my dreams are very sad, depressing, even teary.
Sometimes my dreams are horrifying, frightening and eerie!
But mostly all my dreams are happy, bright and free.
I guess it all depends on what happens in a day in the life of me!
So next time, make the best of your day,
no matter how dull or boring it seems.
Because you'll find one day for sure it reflects upon your dreams!*

Chandrika was born in Doncaster, England on February 22, 1978. After living in England, Wales and Saskatchewan she moved with her family to London, Ontario. Most of her poems and stories were written when she was aged 9-12. She was diagnosed with leukaemia in December 1980 and died from complications of leukaemia on December 6, 1990. She enjoyed music, art, dancing and writing.

Chandrika's stories, poems and art work have been published in *Stars, Hearts, Rainbows, Wishes and Dreams* available from the Childhood Cancer Foundation Candlelighters Canada Resource Centre (price \$10.00). Proceeds from the sale of the book go to ChildCan in London and Candlelighters Canada.

READER MAIL



Reader Mail will help you

- Communicate with others with the same diagnosis
- Find a Penpal
- Write to other siblings! Obtain information or share your thoughts with others
- Express concerns about a diagnosis or long term effects of treatment

It's easy to use Reader Mail

- 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
- To answer send your reply with the number clearly on the lower left corner of the envelope

Candlelighters Reader Mail

c/o the editor

The Childhood Cancer Foundation ~ Candlelighters Canada
55 Eglinton Avenue East, Ste 401
Toronto, Ont. M4P 1G8

CALLING ALL TEENS

The Teen Network is really beginning to move quickly. This summer they will be meeting in Muskoka through the generosity of Mentor College in Mississauga, Ontario. They will use this first opportunity to get together to plan for an incredible trip to the Turks and Caicos Islands next summer. Once again this trip is being planned through the generosity of Mentor College. To raise funds for these trips Candlelighters and the teens will be selling really cool bandanas – everywhere we hope!

Please contact your Candlelighters Teen Canada reps:

National Co-ordinator

British Columbia -

Corrie Messerer,

messerer@pacificcoast.net

Provincial Representatives

Nova Scotia -

Norma Jean MacPhee,

Eastern Region

Co-ordinator, nmcp@mta.ca

New Brunswick - Jill Allen

(506) 847-9627

Quebec -

Pierre-David Letourneau,

odett@globetrotter.qc.ca

Ontario - Matt Parker,

matt.parker@hwcen.org

Ontario - Nikki Parkinson,

7ncp@qmlink.queensu.ca

Ontario - Kevin Rabjohn,

(905) 727-6485

Manitoba - Patricia Dubeau,

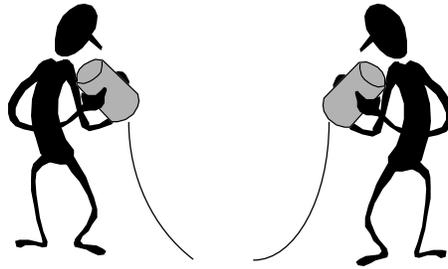
pdubeau@hotmail.com

Saskatchewan - Vanessa Mollier,

(306) 949-3318

Saskatchewan - Devan Brisebois,

dbrisebois@hotmail.ca



Alberta - Tina DaSousa,

cats@home.com

**Alberta - Karen Bourgeois, Western
Region Co-ordinator**

British Columbia - Pamela Finnie,

candlebc@rockies.net

If you want to be part of this teen network, or to learn more about it and how to get involved, please contact your provincial co-ordinator, Corrie Messerer or Margie Thomas at mthomas@pactt.nf.net. It is a chance to meet other teens, make friends and have a great time. The next big get-together will be in Muskoka from August 11-17, 2000 where there will be a week of swimming, hiking, kayaking

and planning the next year's big trip to the Turks and Caicos Islands. After the week at Muskoka we hope the teens will come to Toronto to the Candlelighters year 2000 conference to spread the word and meet with a CanTeen representative. There is a good chance that lots will be happening in each of the provinces before then. The teen network promises to be a great success and there is a lot of energy behind getting the network up and running really well.

Please let Matt Parker know of your ideas for a newsletter.

Please take this opportunity to reach out and meet other teens. As Paula Clarke said at her first meeting, "we have each braved a lot in our lifetimes - chemo, radiation, hair loss to name a few ... and we have many challenges to face in establishing this network for teens."

To Contact Corrie Messerer please phone her at: (604) 732-4194, email her or contact Candlelighters National Office and we will forward your information to Corrie.

NEEDED

Information Liaison Parent Volunteers

Parent volunteers are needed to act as an information liaison for areas that do not have an active Parent Support Group. You would receive information to be distributed to families in your area. You would also send information to Candlelighters at the request of these families. We are not asking you to start a Support Group at this time.

Please contact Helen Pastoric, Parent Support Chair through the National Office.



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.



Do You Know What Candlelighters Can Do For You?

Do You Know How to Access the Candlelighter's Services and Programs You and Your Child Need?

The goal of the Childhood Cancer Foundation~Candlelighters Canada is to ensure that our programs are available for all children living with cancer and their families in every city and province in Canada. If you are not receiving this service now and would like information or your questions answered about any of the following programs that are offered please contact the national office and ask for Janet Evans in her new role as Programs and Services Manager

As a family with a child with cancer you can access these programs from the National Office

- The Resource Centre catalogue and access to all resources
- Quarterly newsletter, *Contact*
- National library for on-site use
- Touch the Sky, a guided imagery kit for all newly diagnosed children
- Bursaries
- Parent Support Groups
- Teen Network
- Benevolent assistance for referred families
- National conferences and provincial workshops
- Out-of-country health insurance for children with cancer
- Personal health record to assist in obtaining standard rates for insurance
- The Candlelighters-Interlink nursing program. At present this service is available only in Ontario. Plans are underway to introduce this service to all provinces.
- Back to School program which will be available late fall 2000
- Holiday gift drive



A Very Important Notice

To All Parents of Children and Teens With Cancer Travelling out of Canada

Medical Coverage is now available for your child

Medical Coverage is now available for your child. The Childhood Cancer Foundation~Candlelighters Canada is pleased to confirm out-of-country medical coverage can be arranged through:

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

The process is very straightforward:

- call their 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
- allow 4 weeks for processing
- insurance does not take effect until confirmed

Candlelighters Vision ...

The Childhood Cancer Foundation~Candlelighters Canada:

- is a recognized leader in a national childhood cancer network
- ensures that all children and their families have equal access to resources throughout their experience with childhood cancer
- works collaboratively towards a cure



New Resources for You and Your Family

Childhood Cancer Survivors A Practical Guide to Your Future

By Nancy Keene, Wendy Hobbie and Kathy Ruccione
price \$37.95

Nancy Keene's newest book has been described as a survivors' dream. Kathy Ruccione and Wendy Hobby were one of the first teams to publish a book on long-term effects. They have now combined their skills with those of Nancy Keene. Readers will benefit from the work of parents and professionals. The book is informative, accurate and easy to read. It addresses topics such as the medical late effects of various treatments from childhood cancer, the emotional aspects of surviving cancer, schedules to ensure excellent follow-up, challenges in the health care system, lifestyle choices to maximize health and issues of discrimination in employment or insurance. This valuable resource should be in the hands of every survivor and his or her family.

Me and My Marrow A Kid's Guide to Bone Marrow Transplants

by Karen Crowe illustrated by Norm Bendell
download on the web at www.meandmymarow.com
Cristina who was diagnosed with leukaemia and had a bone marrow transplant spoke up several years after her transplant and said, "There should be a book for kids that explains all about transplants". This is the book. The text is easy to read and understand, in small "bite size" pieces. The illustrations are sure to please both children and their parents. Topics such as getting ready, what is a bone marrow transplant, what is bone marrow, how to make things easier, how to talk to your friends, how to be comfortable and not scared in the hospital. Questions are asked and answers provided. Coping techniques are a very important part of this book. This little book will do more to help a child or teen who will have a bone marrow transplant than just about anything anybody else could say.

All these books are available from the Candlelighters Resource Centre at 55 Eglinton Ave. East, Suite 401, Toronto, ON M4P 1G8

Send your Reader Mail to:

Candlelighter's Reader Mail
c/o Readers Mail
55 Eglinton Avenue East,
Ste. 401
Toronto, ON M4P 1G8



Candlelighters Catalogue

The catalogue and flier update are available. If you haven't received yours please let us know. You can also receive your catalogue from your treatment centre, or Parent Group.



Childhood Cancer and the Family: Together in 2000, Candlelighters Childhood Cancer Foundation Conference

August 18 - 20, 2000 in Toronto, ON

The fourth international conference is co-hosted by the Parent Groups of Ontario and The Childhood Cancer Foundation~Candlelighters Canada. Dr Bernie Siegel will give the opening keynote address. Other well known speakers include: Sr. Frances Dominica, an international expert on children's palliative care and hospice care; Dr Lauren Woodhouse, a laughter therapist; Dr Mark Greenberg who will speak on long term effects. This child and family conference will bring Candlelighters into this new century. Special events are planned for the children who will be spending their time with children's experts from the two Ontario childhood cancer camps. The children and teens will have a choice of a day at the zoo, exploring the sports world and a baseball game or Much Music tours.



This is a conference for everybody, parents, survivors, siblings, professionals and volunteers.

The pre-conference parent group facilitator workshop is a must for parent group leaders and those who want to become parent group leaders.

Please review the information in the Preliminary Program. Complete the attached registration form and return it as soon as possible to the conference office.

A special message for all Parent Groups: please contact your Provincial Director for tips on raising funds to assist families to come to the conference

Any further questions you want answered, or additional information you require, can be obtained from the conference office, Candlelighters Canada, 55 Eglinton Avenue East, Suite 401 Toronto, Ontario M4P 1G8, Ph: 416 489-6440, 1 800 363-1062, Fax 416 489-9812, email: staff@candlelighters.ca

The International Confederation of Childhood Cancer Parent Organizations

October 4-7, 2000 in Amsterdam, The Netherlands

The ICCPO is holding a one-day parent conference in conjunction with The International Society of Paediatric Oncology and the American Society for Paediatric Haematology/Oncology. Sessions for parents will be held throughout the SIOP conference, which is being held September 14- 17. The conference provides a unique opportunity to meet and exchange ideas with parent from around the world.

Information can be obtained from the Secretariat, c/o Candlelighters Canada, 55 Eglinton Avenue East, Suite 401 Toronto, Ontario M4P 1G8, Ph:416 489-6440, Fax 416 489-9812

3rd Annual Childhood Cancer Awareness Day with a twist - "Clowning Around For Kids with Cancer"

This year is very exciting. We are launching Childhood Cancer Awareness Day nationally. We will have a carnival event in New Brunswick, Halifax, Ottawa, Toronto, Winnipeg and British Columbia. Come and support your local regions.

First we will kick off our events on August 31st, 2000 in Toronto and then all of the other groups will have their first ever Carnival Day on September 16th, 2000.

There will be fun for the entire family to enjoy.

The day will include **games, giveaways, face painting** and lots of smiles because you helped a child with cancer and their family.

If you want to get involved by volunteering or just coming out to this exciting event please call Renae Addis, Director of Development at 416-489-6440 ext. 13 of 1-800-363-1062.

Upcoming Events

**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)

Other (please specify)

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.