



# Contact

Winter  
1999

*A quarterly publication from Candlelighters Canada*

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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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You can now visit us at our  
web site: [www.candlelighters.ca](http://www.candlelighters.ca)  
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[staff@candlelighters.ca](mailto:staff@candlelighters.ca)

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Childhood Cancer Foundation Canada  
**Candlelighters**

## Toronto Maple Leafs score a goal for Trevor – and score one for life

The Childhood Cancer Foundation ~Candlelighters Canada and the Canadian Blood Services, in partnership with the Toronto Maple Leafs, are making a power play to score a goal for Trevor.

Trevor is a childhood cancer survivor. Since October, we have been highlighting his positive, motivating story as a recipient of blood in a broad awareness and recruitment campaign.

The Toronto Maple Leafs left winger, Garry Valk, is the official Maple Leaf for this community outreach awareness campaign.

It will combine the fun of Maple Leaf hockey with the necessary health care treatment provided by Canadian Blood Services and the programs offered by Candlelighters Canada for children undergoing cancer treatments.

The high school challenge which will run from October 1999 to March 2000, is one element of the campaign. The goals of the program are 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. Approximately 120 high schools will take place in this challenge and the top schools have the opportunity to win Maple Leaf box seats.

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 educating youth about the need to give blood and how it is commonly used to treat their peers with childhood cancer.



The 2<sup>nd</sup> annual Carnival in the Courtyard was a great success. Over \$18,000 was raised and over 1,500 people participated in the event.

see more pics and info  
on pages 6 & 7

## BOARD OF DIRECTORS

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# Yeah Baby!

Bell Mobility hosted their 8th Annual Celebrity Gala event on October 21st, and this year's theme was



Austin Powers 1960's era, and this year's recipients of the gala's proceeds were the Childhood Cancer Foundation~Candlelighters Canada and Junior Achievement of Toronto. We were thrilled to be a part of such a successful event. There were celebrities from all over Canada like Rod Black from CTV Sports, Camilla Scott, Michael Burgess, Dini Petty, Amy Sky, the Leafs, Jeanne Beker from Fashion Television and of course Mike "Pinball" Clemons from the Toronto Argos. The event raised \$30 000 for Candlelighters and our programs. The entire night was a glittering success! Candlelighters is very grateful for the support of Bell Mobility!

We salute Bell Mobility for their work with Candlelighters to help make tomorrow a better place for our children.

## Groovy Baby!

## New Candlelighters Catalogue available

The new enlarged and revised catalogue is now available. If you haven't received your copy, please let us know. You can also receive your catalogue from your treatment centre or Parent Group.



With my best wishes for continuing good health in the future. D.M.

Have courage and keep smiling. Very difficult to do - but so necessary. God bless you and help you.

## Words of Hope and Encouragement from our Readers



*Look for more inside this issue...*

Hi, keep your chin up and your spirits high. A lot of people are praying and have lots of hope for all of you. Love, Shirley

May you find joy and hope for life through the love and inspiration of others! I have a grandson who will be 20 in October who was diagnosed with leukemia at age 1 ½! Miracles happen! With love to you! Mavis

Dear cancer fighter – we're rooting for you. Sincerely, Ron & Gloria



## Important message about Hepatitis C

For the past several years, the news has been filled with articles about Hepatitis C and compensation for people who have been infected with the Hepatitis C virus through blood transfusions administered between January 1, 1986 and July 1, 1990.

It is important that all children with cancer who have been transfused during this window of time be tested for the Hepatitis C virus. We urge all parents to request the test for their child if the child has been transfused between 1986-90.

It is also important to consider retesting a child who was tested for hepatitis C when he or she was immun-compromised because of treatment. The blood test is for the HCV antibody and/or a PCR test.

The Class Actions Settlement affects those children who are hepatitis C positive and were

infected for the first time from a transfusion between 1986-90. (A class action is a lawsuit launched on behalf of a number of people.)

Candlelighters Canda has openly supported this class action. From our perspective, it seems to be the most fair and just compensation that could be offered. The compensation offers an amount of money "up-front" and then as symptoms appear over the years additional compensation is offered.

If you have not obtained your copy of the **Hepatitis C, January 1, 1986 - July 1, 1990 Class action Settlement** brochure, please contact Candlelighters' national office. The brochure contains important information about the claims process which has to be started as soon as possible.

# Congratulations to

## Winner of the 1999 YTV Achievement Award

*Candlelighters Canada would like to congratulate Pamela on winning the 1999 YTV Achievement Award. The following are excerpts from Pamela's words:*

When I was 10 years old, I was diagnosed with ALL, High Risk. We had just moved back to Golden, BC from Vancouver at the end of March 1994 and on April 14, 1994, the pain in my wrist was not just the tendonitis my doctors first thought, but cancer. We still did not have a home and my dad had just quit his job of more than 24 years with CP Rail, and taken over a business in Golden. From that day on, our lives changed forever.

I spent most of the next 5 years in Calgary getting chemotherapy and radiation. My Mom and I lived in the Ronald McDonald House in Calgary and my brother and father stayed in Golden.

I was out of school for the end of grade 5, all of grade 6 and part of grade 7, yet I kept my marks up by working extremely hard.

It was very difficult because I was a very active and sociable person. Now I had to spend my time away from the public because I was so immune compromised, but that didn't stop me from making the best of a bad situation. Even the avascular necrosis (the blood supply to both my hips and legs was cut off due to the chemotherapy), didn't stop me from achieving my goals. During the treatment, I got pneumonia, shingles twice, flus and colds.

The three years of treatment were painful and made me feel sick. I never used it as an excuse not to do something. In fact, I tried to take it as a challenge to do more.

# PAMELA FINNIE



I tried to share my experiences with others even when it didn't show my best side. I would do anything if it would help someone. Trying to be active and a giving member of the community is an important part of my life.

*Pamela has written more, but the following sample of her achievements tell how she has turned a "bad situation" into something positive.*

- .. Terry Fox Team Member, 1995-99
- .. Stories and Book - My Life with Leukemia - Poems
- .. Stories printed in Newspapers, *This Battle Which I Must Fight*, Contact, and the Ronald McDonald Newsletter in Calgary.
- .. Developed a game for children about cancer to help them express feelings etc.
- .. Bilingual, received a bronze for French speech in Grade 7
- .. Plays the flute, drums, piano, alto and soprano recorders
- .. Canvasses for the local food bank
- .. Honorary child to raise funds for the Bruce Denniston Bone Marrow Society, and the Leukaemia Society
- .. Responded to Senator Pearson's request and wrote a letter about childhood cancer which she used in a report to the Senate
- .. Canadian Ambassador to Jordan requested parts of my book to help other cancer victims in the Aman Hospital
- .. Presentation in Montreal Candlelighters Childhood Cancer Conference 1998
- .. YTV's Achievement Award winner of 1999

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

August 18 - 20, 2000

Toronto, ON

The 4<sup>th</sup> international conference is cohosted by the Parent Groups of Ontario and The Childhood Cancer Foundation~Candlelighters Canada. Dr. Bernie Seigel 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 the next century. Special events are planned for the children who will be spending a day at camp, as well having special sessions for them during the conference. Please watch for further information in each issue of *Contact*, but mark your calendars now.



## ***How to Help Dying and Grieving Children* The International Confederation of Childhood Cancer Parent Organizations**

September 13, 2000

Montreal, PQ

The ICCCPO 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 that is being held September 14- 17, 2000. The conference provides a unique opportunity to meet and exchange ideas with parent from around the world.

*Information can be obtained from the conference office, Candlelighters Canada, 55 Eglinton Avenue East, Suite 401 Toronto, ON M4P 1G8, Tel: (416) 489-6440, Fax: (416) 489-9812*

Upcoming Conferences

# Carnival

in the

# Courtyard



The 2<sup>nd</sup> annual event was held in the TD Centre Courtyard in Toronto, ON on August 27, 1999.





# WOW

**We raised over \$19,000  
with everyone's support!**



## - a big success once again!!!

(We'll let the pictures tell the story)



Thanks again to our main sponsors TD Financial Group, Rogers Cablesystems, Procter and Gamble, and our supporting sponsors FedEx and Cadillac Fairview. But most importantly, a huge round of applause for all our volunteers!





## **Oral Complication in Paediatric Oncology Patients**

Therapies for childhood malignant conditions have improved long term survival. These life saving therapies, however, involve aggressive treatments that often result in oral manifestations that cause severe discomfort that interferes with proper nutrition and may delay completion of cancer therapy.

Chemotherapy has little permanent effect on oral health, whereas radiotherapy can have direct effects, if the irradiated field includes the salivary glands. Both types of treatment can result in oral infections, salivary changes, and developmental disturbances in the dentition and surrounding tissues. Research shows that irreversible salivary gland injury can develop, but prepubertal children do not experience these complications to the same degree of severity as adults and adolescents. Radiotherapy may retard the growth of facial bones and affect the developing teeth. Affects on the developing teeth include incomplete calcification, enamel malformations, delayed or arrested tooth development, microdentia, missing teeth and alteration of the eruption sequence of the teeth.

A team approach that includes the pediatric dentist, pediatrician and pediatric oncologist is vital in the management of pediatric oncology patients. Dental evaluation and treatment before beginning cancer therapy minimizes the risk of infection and complications in the mouth.

### **Case Report**

Today, bonding of chipped or stained front teeth is an accepted treatment in modern dentistry. The beneficial, social and emotional impact, however, is often underrated. This is especially true when the discoloured teeth coincide with a previous life-threatening illness. In this case, the enhancement of the teeth signals a final passage to wellness.

The child presented with a history of Acute Lymphoblastic Leukemia at age four. Having undergone an extensive three year course of radiation and chemotherapy, there were severely discoloured areas visible on the upper front teeth. This permanent change in the enamel occurs before the teeth erupt into the mouth. New dental bonding techniques have allowed us the ability to cosmetically alter the tooth surface. This process was completed in only one appointment. This technique erases the constant reminder of a past illness and recreates a smile.



I have never known a child with cancer but I can imagine that you must experience difficult moments in your life. It must take a lot of courage, on your part, to wish to keep going, but that is what you are doing. I want you to know that I admire you greatly. I just wish we could meet, so that I could shake hands with you. Frank

# Teens get connected



**Please contact your CanTeen Canada reps:**

**NS - Norma Jean MacPhee, Eastern Region Coordinator, [nmcph@mta.ca](mailto:nmcph@mta.ca)**

**PQ - Pierre-David Letourneau, [odett@globetrotter.qc.ca](mailto:odett@globetrotter.qc.ca)**

**ON - Matt Parker, [matt.parker@hwc.ca](mailto:matt.parker@hwc.ca)**

**ON - Nikki Parkinson, [7ncp@qmlink.queensu.ca](mailto:7ncp@qmlink.queensu.ca)**

**ON - Kevin Rabjohn, (905) 727-6485**

**MB - Patricia Dubeau, (204) 257-5914**

**SK - Vanessa Mollier, (306) 949-3318**

**SK - Devan Brisebois, [dbrisebois@hotmail.ca](mailto:dbrisebois@hotmail.ca)**

**AB - Tina DaSousa, (403) 948-9865**

**AB - Karen Bourgeois, Western Region Coordinator**

**BC - Pamela Finnie, [candlebc@rockies.net](mailto:candlebc@rockies.net)**

**BC - Corrie Messerer, [lynnm@unixg.ubc.ca](mailto:lynnm@unixg.ubc.ca)**

At this time, we have good news and not so good news for the teen network.

The not so good news is that Paula Clark, who was the national coordinator of the teen network, has resigned. Paula has accepted a new position and she doesn't feel that she will have the time required to take the teen network to the next step. Paula has done a great job and we thank her, congratulate her and Paula we will miss you. As executive director of Candlelighters Canada, I personally have enjoyed working with you and have been inspired by your enthusiasm and commitment. Good luck in your new position.

In the interim, Margie Thomas, the Director from Newfoundland, will carry on with the network. She will be in touch with you by e-mail.

Please stay in touch with each other. Keep the network alive and ready to move. Keep planning for the year 2000 Candlelighters conference in Toronto.

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 coordinator, or Margie. It is a chance to meet other teens, make friends and have a great time. The next big get-together will be in Toronto at the Candlelighters year 2000 conference. But 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 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 Margie Thomas, please e-mail her at [mthomas@pactt.nf.net](mailto:mthomas@pactt.nf.net)***



## Mother's Day promotion sells over 1000 pins

The "Be an Angel, Buy your Mom a Pin" event held in April 1999 was successful across Canada. Over 1,000 angel pins were sold by Directors and local groups. Thanks to everyone who participated.

*(For more information on the angel pins, or to order some, see page 13)*

## An important message to readers about RESEARCH...

*This is a copy of the letter that was sent out to parent groups, treatment centres and other Candlelighters stakeholders. It reflects the new endeavour of Candlelighters to begin to fund research. The first step, which will occur in the spring of 2000, will be the partnership with the Medical research Council of Canada and the funding of the first Candlelighters research fellowship in paediatric oncology.*

### "Working together towards a cure for childhood cancer"

On behalf of the Board of the Childhood Cancer Foundation~Candlelighters Canada, the children with cancer and their families whom we serve, we are very pleased to inform you that our organization has confirmed plans to support childhood cancer research. As a national organization, we are poised to develop a program that will ensure increased funding for research into the many aspects of childhood cancer. The first step, and the key to the success of this programme, will be our partnering with the appropriate research institute.

A national survey in 1993, and a follow-up survey in 1998, identified the needs of children with cancer and their families and guided the strategic planning of Candlelighters. The initial decision was made by the Board to develop the services and programmes currently offered to families. These programmes, including the planned expansion of the Candlelighters~Interlink Children's Community Cancer Nurses, will continue.

Findings of both surveys identified the need for additional funding for childhood cancer research, clinical, translational and fundamental in nature. The Childhood Cancer Foundation is at this time prepared to support childhood cancer research. It is our intention to work closely with the board paediatric oncology professional community and appropriate agencies and organizations during the strategic development of our role. Initial work has been completed and over the next few weeks we will be exploring potential partnerships with various organizations including the Medical Research Council, the Canadian Institute of Health Research (most specifically the Institute of Maternal Child Health) and NCIC.

Candlelighters Canada will be working with Canadians to augment research funding on a national basis. We are committed to ensuring that funding requirements for childhood cancer research will be addressed. As we work together to find a cure for childhood cancer, we will keep you informed of our activities and progress.

Sincerely,

Bill Buchanan, President and Val Figliuzzi, Chair of Research Committee



# New Resources for you and your family

## **Non-Hodgkin's Lymphomas Making sense of Diagnosis, treatment and Options**

*by Loraine Johnston*

*price: \$35.20*

A very comprehensive resource for anyone wanting to know about Non-Hodgkin's lymphoma. It contains information for parents, professionals, survivors and siblings. The book addresses topics such as symptoms, diagnosis, tests and procedures, treatments, side effects and late effects. It answers the questions that people ask, "what are Non-Hodgkin's lymphomas?". It also covers such topics as dealing with hospitals, interacting with staff, financial implications and insurance and other resources.

## **Grief and the Healing Arts Creativity as Therapy**

*Edited by Sandra Bertman*

*price: \$41.95*

This book makes a unique contribution to the field of grief and therapeutic interventions. It is written primarily for professionals, but any parent or family member would benefit from it. It contains a special section which addresses paediatric oncology and the use of art, music or puppets. Written by well known children's experts in the field such as Barbara Sourkes, Suzanne Lister, Linda Nicholas and Brenda Eng. Other chapters cover topics such as the

role of movies, sculpting, therapeutic touch and the basic needs of grieving people.

## **Through and Beyond**

*Edited by Molly Field*

*price: \$15.95*

Without a doubt, this has got to be one of the best books written by teenagers for teenagers about their experiences with cancer. Thirteen teens share their experiences with cancer. They talk about the diagnosis, going bald, ups and downs, self-esteem, big deals, a new outlook and getting through and beyond. This is a book of honesty, inspiration and hope.

## **'You'll Get Over It'**

*by Virginia Ironside*

*price \$12.95*

An honest and sensitive book that doesn't try to provide all the answers. Rather, the author looks at the unique experiences of individuals going through what she describes as a very chaotic experience. It is down to earth and realistic, covering topics such as feelings of fear and powerlessness and addresses spirituality. An excellent chapter on "they don't know what to say" is one of the most valuable parts of the book.

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



To my dear friend, I'm sorry that you're in the hospital, but it is a very good place to be when you are sick, isn't it? I know that you can have a lot of fun with other children there, and that you can do lots of neat things. Keep smiling, and I hope you will get better really soon. Give my love to the other kids there also. Love Helen



Hi, I was diagnosed with cancer 10 years ago. I have now Hodgkins Lymphoma. I've had a lot of treatment and now almost all of the cancer is gone. I feel great, look a lot better now my hair is back, and I hope you will feel great too, real soon. Be a warrior! You can fight this disease and win. I know. Marc

# Thanks from all of us to all of you!

## Thanks to our Special Angels

At Candlelighters, we can never give enough thanks to our donors. They are the backbone of what makes us able to help so many children and families across Canada. We thank you for your generosity and continued support of our programs and services. We applaud you!

## Our Special Corporate Angels

Candlelighters continues with the great expansions of our programs and services that we offer families across Canada. The Candlelighters Back to School program is up and ready to launch, the Family Resource Centre continues to thrive and many of our other programs have remained very successful. Please join us in applauding the following very special Corporate Angels without whom our programs would not be possible:

**Imperial Oil** has continued their support of our Back to School Project and is one of the major corporate partners for this project along with the Royal Bank Financial Group.

**Humpty's Family Restaurants** has raised over \$9 000 for our programs and services with their 1<sup>st</sup> Tour to Hope across British Columbia lower mainland. The travelling Humpty eggs (on rollerblades) were a huge hit. They travelled from Nanaimo to Hope, all in support of children with cancer. Candlelighters is thrilled with their support of children with cancer in the BC community.

**TD Financial Group** once again supported our Childhood Cancer Awareness Day - Carnival in the Courtyard and was one of the main sponsors. Over 35 of their staff were in attendance to help lend a hand. We are very grateful.

**Rogers Cablesystems** has joined the Candlelighters Corporate Angel team and helped support our Childhood Cancer Awareness Day! They joined TD Bank in the role of Main Sponsor.

**Procter & Gamble** also supported our 2<sup>nd</sup> Annual Carnival in the Courtyard, all in support of Childhood Cancer Awareness Day.

**FedEx Canada** has joined Candlelighters to help with our Family Assistance Program. They have really lent a helping hand when it is needed most.

**Hummingbird Communications and Lego** also supported our 2<sup>nd</sup> Annual Carnival in the Courtyard.

**Pizza Hut Canada** and Candlelighters initiated an Angel Promotion in spring of 1999. Paper angels were coloured by children and hung on a Wall of Hope in over 100 Pizza Huts across Canada. Each picture cost \$1 and over \$10,000 was raised. Thank you Pizza Hut for your sponsorship and hard work.

Together we can make a difference in the lives of children and their families living with childhood cancer.



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

The **Candlelighters' Angel Programme** is a special fund dedicated to help the families living with childhood cancer. The funds raised are directed to two programmes: Family Assistance and the Candlelighters/Interlink Community Cancer Nurses.

The **Family Assistance Programme** is designed to help families cope with the added financial burden they must face after the diagnosis of childhood cancer. A family will spend 25% to 30% of their income after taxes on non-medical, out-of-pocket expenses related to the child with cancer. In some instances, families lose an entire income when a parent must leave their place of employment to provide care for their child. With the Family Assistance Programme, families can focus their energy on the support of their sick child as well as supporting the other children and family members through this very traumatising period of their lives.

The **Candlelighters/Interlink Community Cancer Nurses** are unquestionably a vital link between the hospital, the community and the family. Children with cancer are at risk. As they are released from hospital and returned to their homes as soon after diagnosis as possible, there is a critical need for a resource person to co-ordinate all of the services necessary for a family to cope with the disease at home and the demanding treatment. Parents who have had an Interlink nurse work with them throughout all stages of their child's cancer constantly express their gratitude for this. They name their Interlink nurse as absolutely pivotal in managing their child's health.

You can help ease the burden these families face and make a difference in the life of a child with cancer.

**Be a special angel. Buy an Angel pin and support the Candlelighters' Angel Programme.** Each Angel pin is carefully hand-crafted 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: \_\_\_\_\_  
\_\_\_\_\_

Number of pins (@ \$12 each) \_\_\_\_\_

Total \$ \_\_\_\_\_

Method of Payment (please circle one):

Cheque enclosed      Visa      MasterCard

Card Number: \_\_\_\_\_

Expiration Date: \_\_\_\_\_

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Signature: \_\_\_\_\_

I couldn't believe the phone call. Someone knew someone who knew where I'd moved... "You really should keep us informed of your whereabouts," the voice said, "unless of course you no longer want to be on the register!" The voice left it as an inquiry.

# *A Gift from the Other Side...*

by Leslie Sneyd

I was in the middle of something so I asked the voice to call back in 10 minutes and she did. This time it was someone I'd met in the course of my work with Candlelighters Childhood Cancer Foundation, Canada. I hadn't talked to her for some months, so we got caught up. She works for the Canadian Blood Services International Bone Marrow Registry. They tracked me down as they had found me to be a possible match for a needed transplant. Would I consider coming down for a second screening? It would involve a questionnaire, about a pint of blood for various tests and then a wait while a decision is made by the recipient's doctor. Of course, she knew I would - 99% of us who have had a child with cancer would do anything that was needed! I went to the CBS two days later.

During those two days, I thought a lot about my experiences with cancer and the bone marrow transplant that our son Adam had. Adam was diagnosed with Hodgkin's disease at age 12. Easily treatable, excellent cure rate, we were told, so we got on with it. It sounded like you would treat a broken leg and sure enough, Adam went into remission.

Adam relapsed in five months and treatment this time was a Bone Marrow Transplant supplemented by peripheral stem cells. It took over four agonizingly, slow months to get everything organized. I had to leave work as the stress of "doing it all" became unbearable for both my husband and myself. One of us had to work, and as Gary, my husband, made more money than I did, and I was more comfortable around the doctors and clinic (i.e. protecting our son), I took the time off. Funny enough, as our lives stood still in shock, the world around us went on most unfairly. Rent, utilities, groceries, car repairs - all had to be paid. As well, there were the hidden expenses of being at the clinic every other day - parking, coffee/tea, lunch, tempting snacks for our ill son (a child on cancer treatment doesn't eat very much and usually gets strange ideas of what will taste good NOW!), books, games, magazines to while away tedious waiting time.

Transplant time loomed and Adam, Gary and Erin (our daughter) entered the special ward in the hospital. I would stay with Adam sometimes as the days progressed. I knew Adam wished I would go away, but I wouldn't - not unless the teacher or other designated person was there. We had arranged for outside help in our home with family members and good friends. Erin had to get on with a "normal" routine of school, homework, sports, etc. I wanted either myself or my husband to be there for Adam. The hospital staff did the medical side, the school side, but we were there for the rest. The clean ups, the encouragement, the feedings.

"Yes Adam, I know you don't want it and it hurts to swallow - just 3 little swallows now. I'll release the straw full of milkshake (frozen apple juice or lukewarm soup) near the back of your mouth, so you can let it trickle down slowly. Three swallows every hour, Adam. You don't want the marrow to starve, you know you have to nourish it for it to grow. You've studied science - nothing grows without food. Open your mouth now..." This went on for 13 days, six days of chemotherapy, one day of rest, transplant day, five days post transplant.

Then came the day of the 0.1 white count. Next day 0.15 and 2.0 on to 0.3 and 1 platelet. On day 25 post-transplant we had sufficient counts to go home with care. The bullying had paid off and we had our son back! We were back in hospital a couple of times for low counts and infections but Adam was like, or almost like, any other 14 years old boy - perhaps a little more fragile still, but getting there.

His relapse in the fall was a shock. His determination to continue treatment and carry on with his life lasted for another year and a half. He learned to glide and competed in dual place competitions; he learned to drive a car; he completed his school term; and he travelled as often as we could afford it. We went to the Caribbean, the Canadian Rockies (Adam attended the biannual international parents conference on childhood cancer put on by Candlelighters). And finally, through the generosity of the Rainbow Society of Manitoba, he came to the '96 Farnborough Air Show as an invited guest. He was thrilled despite being in a wheelchair. Adam died four days later in Southampton Hospital. The BMT had given him 2 ½ extra years to live and live he did!

Adam, my husband and my daughter supported and encouraged my need to do something to help anyone in similar circumstances. I was already a blood donor, so going on to the Bone Marrow Registry and registering for platelet donation was the next natural step. Now there was a possibility of helping some other family.

The second screening took about an hour - mostly paper-work and explanations. I was told it could take three months for a decision. I was going to be in England for the summer so I left a contact address this time. I didn't really expect a call, but I did hope. The call came two weeks later at the beginning of May - I was the best of the possible matches. Would and could I donate my marrow mid July?

I asked the Canadian Registry to negotiate, if possible, the donation or harvest in England rather than my having to return to Canada. This was done successfully through the Anthony Nolan Bone Marrow Trust.

The autologous blood which would be returned to me after the harvest and my medical examination were done on a day trip to London. Then I waited. I wanted nothing to go wrong. On the Tuesday, pre-harvest, I received the call from the ANBMT: it was a go. I was so excited. I could give someone and a family a special gift - the gift that there was now a chance for life where there was none before.

I took the train to London on Wednesday and met my friend Sue who was my "escort" since my husband's work commitments were impossible to change. I checked in at the hospital and tried to contain my excitement. I was told I wouldn't be up for walking far upon my release so we decided to have supper out and walk around London until

*continued on next page*



May all your dreams come true for you and your family. God will love and protect you.

## *More words of Hope and Encouragement from our Readers*

Life is love and love is life. We must help all children and keep them smiling forever.

Dear little one – pray – let others help you to pray – fight – never give up, be positive – so many are praying for you and countless dedicated people are working for you to find a cure for your disease – pray for them too. God bless you.

Take courage and be brave! You have many people who love you and wish you well.  
Monique

Keep your courage up. Tomorrow may bring health and happiness to you. Hold your head high.



To all the little angels out there that are battling the fight with cancer. Hang in there, smile, laugh, have as much as fun as you can, you are loved tremendously. Your family and friends love you but most of all God loves you and me. It has been 10 years for me cancer free. I thank God above I'm still here.

Keep the faith little buddy, help is just around the corner for your illness. Try to keep positive and try smiling every day. I will be thinking about you every day.

Hold your head up high and be brave.

## A Gift cont'd..

it was time to be back. My harvest was the first of three on the morning's roster. They came for me at 7:50 a.m. and I went for a trip to the operating theatre.

The anaesthesiologist had talked to me already. I'd feel a small prick in the back of my hand as he inserted a "butterfly" into which he injected something clear than something pink and then the nurse was calling my name. I woke up completely; no nausea, no wooliness and no cotton in my mouth. My throat was sore and I had a drip connected on the side of my wrist. That was it?

I took mental stock of myself and I knew I was in the recovery room, my throat hurt probably because some tubing had been put down, but I had none of the expected pain. I was bitterly disappointed and felt that the operation hadn't been a go after all. It must have shown because the nurse asked me what was wrong and laughed when I croaked my reason. "They look 2 ½ pints, luv," she said. "You were given a pain reliever for bone pain before you left the theatre." I did a little shuffle of joy in the bed and realized my hips were sore and bringing my feet together was awkward. It wasn't painful, just stiff! I put my hand to my sore throat and got a shock - there was a bandage on my sternum. I immediately felt the front of my hips - no bandage there, strange.

The doctor poked his head into recovery, saw I was awake and came over. He was pleased that he was able to get what he required. He told me it took them longer than expected as my bones were hard to get marrow from, but by using my sternum as well he got the amount he needed. He checked my dressings, requested they be changed and then I returned to my room

About an hour later, I had to use the bathroom. I waddled across the room due to stiff hips. I checked in the bathroom mirror and I saw a bruise under the dressing on the left side and no bruise on the right. Immediately I wanted to know who worked left side and who worked right. I checked the dressing on my sternum - no bruise. Now I really wanted to know who worked where!

Shortly after I was back in bed, lunch arrived and not only was it served on pretty china, it was edible! Steak, tagliatelle and fresh fruit for dessert. I ate it all and promptly fell asleep. The nurse woke me up to change my dressing. She came back about an hour later, took my temperature, blood

pressure and joy of joys - removed the I.V.! I had brought some needlework to do, but the placement of the I.V. connection didn't allow me to hold it properly - my biggest complaint.

Starting off gingerly, I began to walk around the room as I needed some exercise to get over the stiffness. While I was sitting, I did ankle circles but only walking relieved the stiffness in my hips. Only direct pressure, i.e. a poke, caused any pain, except for my sore throat. Sucking on mints relieved that. I passed an unremarkable night except for when I dropped the remote on my chest. That hurt, it made my eyes water! Next morning I got up and checked my bruise - bruises now! I was very stiff, so I started on some mild exercises. I had blood taken for a haemoglobin check. It was a little too low due to the volume of marrow taken, the doctor informed me on his visit. He discharged me with iron tablets and pain medication.

While waiting for the doctor and discharge, I had a delightful visitor, Marjorie Gordon-Box from the ANBMTrust. We had a lovely visit. I told her that from the volume of marrow taken and my experiences, I thought the recipient was an adult male. I didn't really want to know but ... I did want to know if the transplant was successful. To be honest, I really wanted to be there to encourage the family, to share their joy when the counts started rising, to monitor the GVH, to bully if needed. My "job" in this was to provide the opportunity - the chance - the rest was not in my hands. My prayers were all I could add. I left the rest to fate - again.

Sue and I came home by train and taxi. We spent the evening not doing much. Getting ready for bed I noticed the bruises were already starting to change colour, to heal. Next day I took it easy - walked around the yard, napped and then decided to take a shower. I took the bandages off, showered, washed my hair and fell asleep on the couch! I woke up in time to eat a delicious dinner, go for a walk, watch some TV and then off to bed. It's now Sunday, three days post harvest. Apart from being more tired than usual I'm fine. Bruises are healing on my lower back and wrist, I no longer walk like John Wayne, or like I'm seven months pregnant. And unless I poke my sternum or hit my wrist directly there is no ache or pain. What a minor inconvenience for a wonderful opportunity.

Would I do it again? You bet! I hope the opportunity comes again.



# Reader Mail

## Reader Mail will help you

- ☑ Communicate with others with the same diagnosis
- ☑ Find a Pen Pal
- ☑ 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 Writer number printed clearly on the lower left corner of the envelope. Send your reply to:

**Candlelighter's Reader Mail,  
552 Dalgliesh Drive Regina, SK S4R 6L8**

## Our most sincere apologies to Writer #9901

### You wrote:

I am the mother of a five year old child who has just completed treatment for ALL that presented with chromosomal translocation 1-19. I would greatly relish the opportunity to correspond with parents of children with the same of similar diagnosis. I have been unable to locate someone with the same diagnosis.

### Our apologies

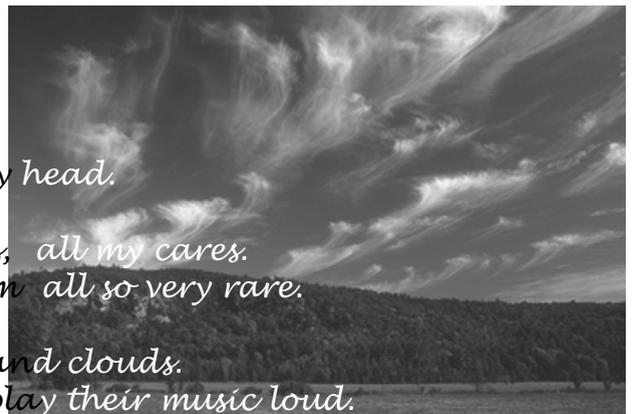
In all honesty, this has never happened before. But for some reason we have misplaced your return address. You have a letter waiting for you. Please contact the above address and it will be forwarded to you.

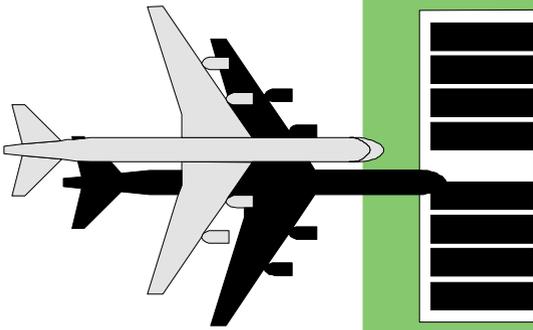
## Dreams by Candrika Venaktesan

*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 and 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 your day, no matter how dull or boring it seems.  
Because you'll find someday, for sure, it reflects upon your dreams!*





## Important Notice to Parents of Children and Teens With Cancer Travelling out of Canada

*Medical coverage is now available for your child*

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

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

The process is very straightforward

- call the above 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

## Michelin car and Driver One Lap of America

Garth Gullekson and Chris Kirby entered the Michelin Car and Driver One Lap of America event and raised \$10,000 for the Childhood Cancer Foundation. As promised, Garth shaved his head if the target was reached.

Thanks so much to Garth and Chris for their exceptional efforts. Thanks also to Object Time Ltd. and everyone that supported the Michelin Car and Driver event. Your support means so much!



*Garth and Chris are shown here with their Porsche 911 and with members of the Candlelighters head office staff.*



# Y2K READY

The Canadian Red Cross helps people prevent, prepare for, and respond to emergencies. We're in your neighbourhood every day, providing personal preparedness information and teaching classes in first aid and other lifesaving skills, to help keep families like yours safer.

For more information, please contact your local Canadian Red Cross. *Printed with permission of the Canadian Red Cross Society, Ontario Zone*

## What you should know...

For more than 100 years, the Canadian Red Cross has been at the cutting edge of disaster relief activities, helping people prevent, prepare for, and cope with disasters and other emergencies.

Canada is recognized as world leader in preparing for Y2K. Our governments, utilities and financial institutions are all reporting that they are prepared to meet the year 2000 with few, if any, anticipated disruptions.

While acknowledging that Canada does not expect to suffer from any major Y2K problems, the Canadian Red Cross recommends that you read the following information and take steps to prepare you and your family for any unforeseen emergencies. Planning for emergencies is always a wise move. Emergency preparedness starts with you.

## Frequently Asked Questions

"Y2K" refers to the year 2000. Why are people concerned? The Year 2000 technology problem, or Y2K bug, as it is sometimes called, was created in the early days of computers, when memory in computers was scarce and expensive. Programmers took shortcuts whenever possible to save space. Instead of using a four-digit code for year dates, a two-digit entry was used. This practice persisted, long after the need for saving space was eliminated. The two-digit code also was used in embedded chips, which exist in many devices that control processes, functions, machines, (e.g. home appliances), building ventilation systems, elevators, and fire and security alarm systems, which are part of our everyday lives.

When the year 2000 comes, programs that have been coded with two-digit year codes may not distinguish between the years 2000 and 1900. If the program includes time-sensitive calculations or comparisons, results may be unpredictable. No one knows what problems may occur, how widespread they may be, or how long they will last. The good news is that federal, provincial, and local governments; banks and other financial institutions; utility companies and many other manufacturers affected by this problem have been working to resolve it, and a great deal of progress has been made.

*cont'd on next page*

# More Y2K

## Frequently Asked Questions cont...

When could Y2K problems happen? Most people anticipate Y2K problems may happen December 31, 1999, at midnight. Many experts predict that there will not be a single “crash”; it is more likely to be a number of minor problems that will persist over time.

For example, there may be a computer-based problem with other dates, such as September 9, 1999, i.e. 9/9/99. In the past, a series of nines was sometimes used to indicate termination of a computer program, and some experts believe that when all nines show up in a date sequence, some computer systems could read it as a program termination command.

There also is some concern regarding fiscal year 2000 dates in organizations with fiscal years that start earlier than December 31, 1999. Also, the year 2000 is a leap year, and the leap year date 02/29/00 may be a problem for some computer programs as well.

## What kinds of things could happen as a result of the Y2K problems?

Although no one knows the extent of the problems that may arise due to Y2K, the following problems may arise: loss of power, telephones may not work, manufacturing and production industries may be disrupted, roads may be congested or grid-locked, computers may malfunction, (including embedded chips that drive everything from cars to VCRs), failed heating systems, and Automated Teller Machines may not dispense cash.

If you have questions about specific services or products, contact the service provider or manufacturer and ask them to answer your questions. You may find that they have already taken steps to address many or all of the related Y2K issues.

The 1998 Eastern Canada Ice Storm, along with recent floods and forest fires, have highlighted that Canadians are not immune from disasters. If you are unprepared for a disaster, it can cause major disruptions in your life. If you are prepared, the problems may only be minor inconveniences. Given the unpredictable nature of Y2K, expect conflicting information. You are the best person to assess your situation.

Because no one can be certain about the effects of the Y2K problem, the Canadian Red Cross has developed the following checklist for you (see next page). These are some easy steps you can take to prepare for possible disruptions. All of these recommendations make good sense, regardless of the potential problem.

# What can you do to be prepared - a Y2K checklist

- Check with manufacturers of any essential computer-controlled electronic equipment in your home to see if that equipment may be affected. This includes fire and security alarm systems, programmable thermostats, appliances, consumer electronics, garage door openers, electronic locks, and any other electronic equipment in which an “embedded chip” may control its operation.
- Stock disaster supplies to last from several days to a week for yourself and those who live with you. This includes having nonperishable foods, stored water, and an ample supply of prescription and non-prescription medications that you regularly use.
- As you would in preparation for a storm emergency of any kind, have some extra cash on hand to cover basic living expenses, for three or four days, in case electronic transactions involving ATM cards, credit cards, and the like cannot be processed. Plan to keep cash in a safe place, and gradually withdraw money from your bank in small amounts. Canada’s banks are widely recognized, both at home and worldwide, as a leader in managing Y2K, no major problems are anticipated in the Canadian banking industry.
- Similar to preparing for a winter storm, it is suggested that you keep your automobile gas tank full.
- In case the power fails, plan to use food that does not require cooking or use alternative cooking devices in accordance with manufacturer’s instructions. Don’t use open flames or charcoal grills indoors.
- Have extra blankets, coats, hats, and gloves to keep warm. Please do not plan to use gas-fueled appliances, like an oven, as an alternative heating source. The same goes for wood-burning or liquid-fuelled heating devices that are not designed to be used in a residential structure. Camp stoves and heaters should only be used out of doors in a well-ventilated area. If you do purchase an alternative heating device, make sure it is approved for use indoors and is listed with the Canadian Safety Association (CSA) or Underwriters Laboratories (UL).
- Have plenty of flashlights and extra batteries on hand. Don’t use candles for emergency lighting.
- Examine your smoke alarms now. If you have smoke alarms that are hard-wired into your home’s electrical system (most newer ones are), check to see if they have battery back-ups. Every fall, replace all batteries in all smoke alarms as a general fire safety precaution.
- Check with the emergency services providers in your community to see if there is more information available about how your community is preparing for any potential problems. Be an advocate and support efforts by your local police, fire, and emergency management officials to ensure that their systems will be able to operate at all times.
- Be prepared to relocate to a shelter for warmth and protection during a prolonged power outage, or if for any other reason local officials request or require that you leave your home. Listen to a battery-operated or crank radio or television for information about where shelters will be available.
- If you plan to use a portable generator, carefully follow the manufacturer’s installation and operating instructions. We recommend that any installation involving a home electrical system be completed by a licensed electrician in accordance with prevailing building and electrical codes. Generators should only be operated outdoors, away from any windows or air intakes that could draw toxic fumes back into your home.
- Talk with your neighbours and develop a joint plan for your street. (<http://www.utne.com/y2k>)



# Activities with local groups

## ***Candlelighters Association of Newfoundland and Labrador, East and West Coasts***

Newfoundland has been very busy these past few months raising lots of money and awareness for children with cancer in their communities. Way to go everyone! You should be very proud!

Newfoundland has held a number of events over the summer. Each was a great success and fun for everyone who participated.

- There was a **Car Wash** on June 12<sup>th</sup> at the Irving on Topsail Road. This was a fun day for everyone. It successfully raised over \$1,300 in just 8 hours!
- On July 18<sup>th</sup> success sailed in with the **Sail on the Bay**. It was a brain storm of Wendy Chaulk's, and was a great event that raised \$1200. They hope to make it an annual event!
- Two **softball tournaments** were part of the events this summer. On June 19<sup>th</sup> a tournament held at St. David's Field by the RNC on behalf of Andrew Chaulk raised \$1,200. On the weekend of Sept. 10-11<sup>th</sup> Worker's Compensation Commission held a tournament.
- Candlelighters Association also had their **Annual Fun Run** around the Lake in June. This event has the potential to be the fundraiser for Newfoundland. Even with a small turnout this year they still raised over \$1,200.

## **Newfoundland hosts a great Conference for their parent groups!**

Co-Sponsored by Candlelighters Canada and the Newfoundland Parent Groups the workshops were held at Hotel St. John's on Saturday, October 16<sup>th</sup>.

Workshop Topics included: Treatment and Effects, Grief, Canadian Blood Services, Stress Management, Camp and Candlelighters programs. The speakers included Dr. J. Hand, Oncologist; Dr. R. Singleton, Pastoral Care; Dr. Karl Misik; and Ken Reid, BSW. Our very own Eleanor Pask presented the Candlelighters Programs workshop to children and families in Newfoundland. This Workshop was designed for parents and professionals and is hosted by National Candlelighters.

Thank you to Pizza Hut Canada for hosting the lunch, to Jody Saunders for sponsoring the afternoon break, and Western Trust Limited for sponsoring the morning break for the families and professionals. We are very grateful for all of your support.

***Way to go Newfoundland!***



I am sorry you are in the hospital with cancer and hope with the help of the doctors you will soon get better and go home. I was treated for breast cancer last November and December. My six month checkup was a good one. My best wishes and prayers go to you. Hugs, Mary

Our grandson was diagnosed with leukemia when he was 3 years old. He had treatment for 3 years and now at the age of 10 he is playing soccer and hockey and is one of the best on the teams. Hang in there.



Dear child, keep up the fight. You will make it. Pray to God and ask him to help you. We all love you very much. I had cancer too, so I know how it feels. May God bless you.



Good for you keeping on at school. What you learn in school will be useful to you all your life. And it will help you to make the most of your life after you finish school. Well worth the effort. Good luck! You can make your dreams come true! Best wishes to you!!

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## **The Maritime Provinces host their 1<sup>st</sup> workshop for Parents and the Health Professionals who care for these families!**

PEI, Nova Scotia and New Brunswick worked together to create the first parent and health professional workshop and it was a huge success. The event was held in Halifax, Nova Scotia. With over 50 participants and great guest speakers the day was very inspirational. A lot of the health professionals from these regions were represented at the workshops. Topics included: Complimentary Therapy, Bereavement, Humour, Long-Term Follow Up and Back-to-School issues. There was also a presentation made by Eleanor Pask on Candlelighters Programs. The great lunch was sponsored by Pizza Hut in Halifax!

*Excellent work to all of you!*

## **Ottawa is also a happening place:**

Candlelighters Childhood Cancer Trust in Ottawa has been very busy this year! We, at National office, would like to extend a warm welcome to Jocelyn Lamont, the new Executive Director for Candlelighters Childhood Cancer Trust. We are thrilled to have her on board. Jocelyn has been involved with the local group since 1996. Jocelyn is a bereaved parent and a registered nurse and brings a great deal of hope and compassion to her new role. We thank you for your commitment and look forward to the future.

We also welcome the new board of directors for Ottawa. We are certain this new board are up for the tasks that lie ahead! What's been happening?

- Great news the mayor of Ottawa proclaimed September as Childhood Cancer Awareness Month for the community of Ottawa! Great work!
- Lance Pitlick, of the Ottawa Senators Hockey Club was named the honorary Chairman in February 1999, currently he is negotiating a new replacement for the role (he has currently been traded).
- The Ottawa Senators Foundation and Today's Colonial Furniture are new main sponsors for Candlelighters.
- The group has been working on their "Teens Together" program and it is a fireball. This new program for 13 to 18 year olds sounds like a lot of fun and excitement. There will be a teen movie library and outings for them throughout the year.
- On November 28<sup>th</sup>, 1999 they will host their Holiday party. This party has many families and there is usually over 400 people attending. They have a potluck lunch with cake and drinks. The children enjoy crafts, face painting, clowns, costume character. This will be great fun for everyone.
- There will also be a holiday in-patient dinner hosted by Candlelighters. This year they will have the Teen group host and help out at the dinner.
- Dr. Robert Buckman will be running a seminar in February 2000.

*Great work Ottawa, you have been very busy!*

**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: \_\_\_\_\_

Please indicate if you are:

A parent of a child with cancer

A patient with cancer

A health professional  
(please specify)

\_\_\_\_\_  
 Other (please specify)

I would also like to make a donation to Candlelighters Canada in the amount of \$ \_\_\_\_\_ (cheque enclosed)

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.