



## Childhood Cancer Foundation ~ Candlelighters Canada

# A Strategic Partnership

*Forging the future of Candlelighters Canada*

The Council of Canadian Pediatric Hematology/Oncology Directors is comprised of the institutionally appointed medical directors of the 17 pediatric hematology/oncology programs across Canada. The co-chairs of the Council are Dr. Victor Blanchette (Toronto) and Dr. Max Coppes (Calgary); the secretary treasurer of the Council is Dr. Paul Rogers (Vancouver). These three physicians form the Executive of the Council.

The Council was established at an inaugural meeting held in Calgary in the summer of 2001. The rationale for formation of the Council was to create a national body that could advocate on behalf of children with cancer resident in Canada. This goal is reflected in the vision of the Council: "all Canadian children, adolescents and young adults with cancer or a blood disorder will receive excellent healthcare and achieve optimal outcomes," and the mission statement of the Council "to provide national leadership for childhood cancer and blood disorders through advocacy, research, education and excellence in care."

The second annual meeting of the Council was held in Toronto in 2002 and the Council will meet in June 2003 in Newfoundland.

A major impetus to form the Council was a growing concern about the following three issues:

- ① a critical shortage of pediatric hematologists/oncologists to care for the approximate 1100 children diagnosed with cancer each year in Canada; and
- ② an outdated training program in the specialty, pediatric hematology/oncology
- ③ the need for a national advocacy group for children with cancer and chronic blood disorders. A body that consisted of the medical leaders to which other organizations, groups, governmental agencies could approach for information, participation and strategic planning.

To address these and other issues, the Council has been extremely active over the past two years. The achievements of the Council during this two-year period include:

- ① designation by the Royal College of physicians and Surgeons of Canada of a new specialty pediatric hematology/oncology. The new specialty will oversee a revised three-year program in pediatric hematology/oncology. A Task Force, comprised of the following individuals has been established to develop the new training program: Dr. Victor Blanchette (Chair); Dr. Max Coppes (Calgary); Dr. Sara Israels (Winnipeg); Dr. Michèle David (Montreal); Dr. Isaac Odame (Hamilton); and Dr. Dorothy Barnard (Halifax). This very important milestone, achieved after two years of dialogue with the Royal College, harmonizes the pediatric hematology/oncology training program in Canada

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# New leader reinforces Candlelighters core vision

## *Candlelighters appoints new Chief Executive Officer*

The following was issued from the Chairman of the Board, Val Figliuzzi.

The Childhood Cancer Foundation ~ Candlelighters Canada, a national advocate dedicated to improving the quality of life for families of children with cancer, would like to announce the appointment of Kal Tobias as our new President and Chief Executive Officer.

Kal was most recently President and CEO of DHL International Express Ltd., the world's leading international express and supply chain management company.

DHL operates in 220 countries, around the world, and has a leading market position/share in all of those locations.

Kal's 18-year tenure culminated in repositioning DHL as one of Canada's leading logistics and supply chain management companies.

Kal's track record of determining and championing winning strategies that differentiate and build the business, increase operating profits and reposition organizations as leaders in highly competitive marketplaces; will contribute significantly to Candlelighters' drive to become a prominent, 'top-of-mind' national charitable organization in Canada.

Kal is eager to meet the challenges ahead of him as he focuses on improving Candlelighters' "good works" percentage

and creating an effective long-term strategy that will help Candlelighters improve the quality of life for all children living with cancer in Canada.

Please join me in wishing Kal all of our best.



## "...strategic partnership" cont'd

with its counterpart program in the USA, and will guarantee the next generation of specialists to care for children with cancer in Canada.

② election of the Council of Canadian Pediatric Hematology/Oncology Directors to the Governing Council of the Strategy for Cancer Control in Canada. This milestone, achieved with the support of Candlelighters Canada, is a very important signal that the Council, despite its relatively short history, is increasingly recognized as a voice for pediatric oncology across Canada by key stakeholders e.g. the National Cancer Institute of Canada (NCIC), the Canadian Institute of Health Research (CIHR), the Council of Provincial Cancer Agencies (CAPCA) etc.

③ completion of a national survey relating to physician resources in pediatric hematology/oncology across Canada. This survey, completed in 2000/2001 and reflecting information from 1999, has been used by many pediatric hematology/oncology centres

across Canada to lobby for urgently needed physician resources.

The future of the Council is very bright. At the 2003 annual meeting formal incorporation of the Council will be discussed and Candlelighters Canada will present to the Council a proposal that would see Candlelighters as a major supporter of the Council through its fundraising activities on behalf of children with cancer in Canada. Already, the relationship between Candlelighters and the Council is strong. Candlelighters have, at the request of the Council, approved funding for a full-time assistant to facilitate the processing of requests for new drugs used in the treatment of children with cancer entered on cooperative, cancer clinical trials e.g. the Children's Oncology Group studies. This individual is located in the pediatric oncology program at Ste-Justine Hôpital and reports directly to one of the members of the Council, Dr. Mark Bernstein. In a reciprocal fashion the

Council is supporting the Coast-to-Coast fundraising initiative of Candlelighters that will occur across Canada in June, 2003.

Finally, the following statements from leaders in pediatric hematology/oncology in Canada is presented as an example of a growing relationship between Candlelighters Canada and the Council.

**Quotes** *"The support from Candlelighters Canada for the activities of the Council is already yielding benefits in the field of pediatric oncology in Canada; much has been achieved in a very short time. We value and enjoy our strong and growing relationship with Candlelighters Canada."*

*- Dr. Victor Blanchette, Chief, Division of Hematology/Oncology, The Hospital for Sick Children, Toronto*

*"It has been a true privilege to work with the new leadership of Candlelighters Canada. In them we have found true soul mates in our fight against childhood cancer and my expectations of what we can achieve together as a country have never been this high".*

*- Max J. Coppes, MD, PhD | Co-Chair of the Council and Professor of Oncology and Pediatrics, University of Calgary*

# Shaping the futures of cancer survivors

Cancer treatments are like a double edged sword. With one swing the sword cuts cancer from the body, and like a pendulum, the sword swings back and strikes the survivor with long term physical and mental limitations. The back swing is relatively unknown. Society focuses on the cure, and not on the side effects.

Serious long-term physical and mental side effects from cancer treatments include primarily cranial and

full body radiation. Slower mental and physical abilities have left many cancer survivors unemployed and unable to participate in today's fast-paced society. In their battle the reward is life, but on a life lived on a disability cheque and isolated from society.

The entrepreneurial spirit of Andrew and Jill Sprawson is the beginning of a new wave of support for the phenomenon of adult survivors of childhood cancer. Known as Rebounders Canada this duo envisions connecting with survivors to teach them the life skills they need to compete and be productive.

With the generous help of the construction company, DOI Residential & Commercial Design/Build, Rebounders Canada will fulfill their dream through the Rebound Centre scheduled to open in early 2004.



*Model rendering of proposed Rebounders Canada site*

Located in Oakville, Ontario, this three-story building will be the heart of Mr. and Mrs. Sprawson's outreach program. As childhood cancer survivors, Mr. and Mrs. Sprawson have a distinctive view on the needs of their supporters. Their approach to life is thriving, not surviving. They will share this message through the Rebound Centre.

The Rebound Centre will provide workshops covering life skills: shopping, cooking, basic computer skills and simple financing. Many survivors live at home with parents; their independence will start with the teaching of these bare

essentials. Other workshops are being designed to enhance the survivors' existing talents.

"Many survivors have incredible talents such as woodworking and horticulture. We want to work with their existing talents to help them create a marketable product," said Mr. Sprawson. "We don't want people to buy their products because they feel sorry for them, but because they are useful."

The Rebound Centre plans to have a Café and Retail Outlet to encourage relations between survivors

and the public and the sale of their products.

For more information  
about the Rebound  
Centre or Rebounders  
Canada call:  
1-877-330-7836

# Coast to Coast Ride 2003 soars to success

*Annual fundraiser glides to new heights*

Editors Note: We were thrilled when we received word from **Coast to Coast Against Cancer** that we were chosen as one of this year's main recipients. We are excited about this partnership and what the future holds.

"Coast to Coast" was founded by Jeff Rushton in 2002 to commemorate his father's successful battle against cancer. An avid cyclist, Jeff established this annual cycling event as a means to raise awareness and funding for charities intent on supporting individuals and families dealing with this devastating disease.

In 2002, Jeff Rushton and his friend Kevin Wallace, whose mother succumbed to cancer, each rode 5100 km **coast to coast** from California to Florida in just 24 days raising over \$175,000 for two cancer charities. This year, starting on June 14, a team

of six cyclists will depart from Vancouver and ride 24 hours per day arriving in Halifax, N.S. just 10 days later; a distance of 7200 km. Rotating shifts, each cyclist will be pushed to the limit pedaling 12 to 15 hours across 360 km per day.

Originally, the organizers had set their



goal this year at \$350,000, but prior to the initial unveiling of this year's website, they had already reached that goal and have now set their sights on raising \$500,000. One hundred percent of the monies received will be going into research.

One very important component of

"Coast to Coast" is recognizing individuals and families that have been impacted by cancer. Each 100 km stretch will be dedicated to groups of these courageous people.

Dedications will be announced to the cyclists at the start of each 100 km stretch and posted on the web site. If there is someone you know who you would like the **"Coast to Coast"** riders to dedicate a 100 km stretch to, please email Albert Lee at [alee@candlelighters.ca](mailto:alee@candlelighters.ca) or call the office at 1 (800) 363-1062 ext. 16. You will be required to provide a picture and a brief writeup.

For more information on the event, please visit their website at [www.coasttoastride.com](http://www.coasttoastride.com). They will also be holding an online auction; please spread the word and take a moment to bid on an item.

## Sports heroes assist Candlelighters ~ Ottawa

*Ottawa Senators Foundation helps raise funds for kids with cancer*

On Monday, November 4th, 2002 the Ottawa Senators Foundation and Sports Radio 1200 "THE TEAM" presented the 4th Annual Sports Collectibles Auction in support of Candlelighters.

This year's auction featured a celebration of the induction of Senators Assistant Coach Roger Neilson into the Hockey Hall of Fame. Special auction items were made available to commemorate this special evening. In addition, a video tribute was shown during the event, and the Hall of Fame Induction Ceremony was being shown on the big screen and throughout O'Connors Irish Pub, the auction location.

Guests at the event were encouraged to wear their best "Roger Neilson" tie (Roger is renowned for his tie collection) with prizes being awarded throughout the evening for the most outrageous ties.

Ottawa Senators hockey players Chris Phillips and Marian Hossa, Candlelighters' Honorary Chairmen, were joined by teammates Daniel Alfredsson, Martin Havlat, Wade Redden,



Patrick Lalime, Radek Bonk, Magnus Ardverson, Mike Fisher, Jason Spezza, Chris Neil and Todd White to name but a few.

Chris and Marian worked hard at gathering memorabilia from their opponents and auction items included autographed items from Mario Lemieux, Curtis Joseph, Mats Sundin and Joe Thornton.

Mr. Hockey Trivia, Liam Maguire was on hand throughout the evening awarding prizes to the many attendees whom he engaged in hockey trivia.

The evening was a huge success raising \$15,000 in support of Candlelighters, but it also showcased our long-standing relationship with the Ottawa Senators Hockey Club and the ongoing support we receive from the players. We are truly proud of our association with the Ottawa Senators and grateful for all they do to . . .

**Keep Our Kids Smiling!**

# "He'll always be my hero."

## *Learning to focus on the important things*

In the early winter months of 2001, I'd noticed that occasionally the right eye of our two-year-old boy seemed to "wander." With time, the pupil of that same eye no longer seemed black; it seemed closer to "beige" in colour. One quiet Sunday evening, while Little Ricky was comfortably nestled in my lap watching "Little Bear" cartoons, I decided to try to figure out what was going on with that eye. My world was crushed with a couple of simple tests - he couldn't see out of it at all.

In complete shock, my wife Michele and I wrapped up Ricky and his three-month-old baby brother and raced to the Emergency in Chilliwack. The doctors performed quick exams and immediately sent us to B.C.'s Children's Hospital in Vancouver for a more accurate diagnosis. By 2 am Monday morning, we had it - a mass in Ricky's right eye. It was almost certainly cancer. His beautiful little eye was probably going to be removed. And they don't do eye transplants.

Cancer had invaded the eye of our treasured 25-month-old boy. That very day he was going to lose his right eye, and at the time we had no idea how far the cancer had potentially progressed. We were shattered and prepared ourselves for the worst.

Somehow I managed the seventy-minute drive back to Chilliwack. In the dark and cold of the night, we were preparing for the unknown. Michele and I packed up some clothing for the family and got back into the car, heading once again for Children's Hospital. The two tiny angels slept soundly in their carseats, oblivious to the situation Ricky was facing. We arrived at Children's by 7:30 am that same morning. Three doctors' exams and a CT scan told us that there was calcium in the mass in Ricky's eye. The

calcium meant with certainty that my little guy had a cancerous tumour called "retinoblastoma". The odds of getting this childhood disease are lower than one in 20,000. The nightmare of the disease is that it quickly spreads to the second eye, blinds and kills thereafter, and it had been some time since Little Ricky had seen out of that eye. We still had no idea how far into his body it may have developed.

We were advised that the blastoma was past the stage of radiology or chemotherapy. There was a single option. So, less than 24 sleepless hours after discovering my boy was blind in his right eye, I signed the release for the surgeon to cut it out. I could barely hold the pen. My hand was lead.

Three hours of surgery later when he came out of the anesthesia, we raced in to see him. The first thing I said was "Hey, Bud, give me five," and with all the mass of tubes poking out of him and a huge round bandage over the right side of his head, he weakly raised his arm and softly slapped my hand with his. When we got him to his room, he slowly raised his head to give his baby brother Angela a kiss on the head.

My hero.

Later that evening, the surgeon explained that she was confident that there was little chance of further spread of the cancer. But we weren't out of the woods just yet. Final test results wouldn't be in for another four weeks. By that time, my little buddy would have a shiny new little glass eye.

The four of us spent three emotional days with Ricky in his room in the oncology ward of the hospital while he recovered. As we slowly emerged from the fog of pain and bewilderment, we



realized that others on the ward had it worse. Even our dark hours were minor compared with the grief of other families dealing with their children's cancers. We were grateful for the fact that our boy would be returning home. Not all the other children would be.

Regular test results over the past year have shown no further spread of the cancer. Even with this wonderful news, both Michele and I have gone through countless hours of pain, anger, self-blame, confusion and a thousand other emotions. We've relived the emotions when we've had to get everyone up in the cold early hours, drive to Children's Hospital and have both boys put to sleep for comprehensive eye exams to ensure that neither one has developed further problems. We've come to terms with Ricky's situation, and we work hard to feel blessed for what we have today, not what was taken from him, and not what might be tomorrow. Ricky has a lifetime ahead of him to do the same.

Teaching was a big part of what excited me about having children. Not so much what I'd be teaching my children, but about what I would learn from them. I'm not totally clear what Ricky's teaching me here, unless the lesson is simpler than I've imagined, but it's still brought change and growth in me. In the weeks prior to the surgery, my life felt hectic and full of challenge; *Cont'd*  
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# What to do while you wait

Waiting for results to arrive, health professionals to come, assessments to be given and prescriptions to be filled can be quite tiresome. You can easily spend endless hours waiting for tests to be done. Waiting just can not be avoided.

Here are some suggestions for making good use of your waiting time:

## FOR ADULTS

- ✓ Write letters and cards to friends and relatives. (Keep cards and letters that need answering in a large envelope/bag with pen and paper. You can pick this up as you prepare to leave for the hospital).
- ✓ Make up your Christmas card listing or your Christmas gift list and start filling in some ideas.
- ✓ Make up a birthday book and then enter all birthdays into this year's calendar.
- ✓ Redo/update/create an address & telephone book.
- ✓ Balance your chequebook.
- ✓ Work on a personal budget.
- ✓ Plan the menus for the week and make the accompanying shopping list.
- ✓ Do the mending. Take up, or let down, the hem on that skirt!
- ✓ Compile a heritage album for your children and their children - collect as many old photos of the family as you can and build them into a family tree with notes and anecdotes about the people in the photos.
- ✓ Make a scrapbook of family photos, cards, and other memorabilia
- ✓ Read some of the articles in the magazines you have set aside because you had no time at home. (Have a bag into which you drop the magazine, newspaper articles, catalogues, etc. for reading while you wait at the hospital. You can then simply take the bag along with you rather than have to start hunting up the articles before you rush out the door).
- ✓ Start a project - knitting, needlepoint, writing poetry, origami. You might even make some handmade gifts this way.
- ✓ Write in a journal or diary.
- ✓ Do a crossword puzzle.
- ✓ Try listening to a story on a Walkman. Taped stories are available from your public library.
- ✓ Update children's medical records.
- ✓ Give yourself a manicure.
- ✓ Catch up on friendships developed in hospital.
- ✓ Borrow books or videos from the Family Resource Library, which can help you learn some stress management techniques.
- ✓ Practice some relaxation exercise - there is a video in the Family Resource Library that can help with this: "Relaxation & Inspiration."
- ✓ Take time just to sit and daydream.
- ✓ Check with your nurse and, if possible, go for a walk.

## IDEAS FOR CHILDREN

- ✓ Read to one of the other children while waiting
- ✓ Bring a video to share with others who are waiting
- ✓ Make birthday cards for all your friends
- ✓ Have a box with a craft activity: beads, models, paper folding, calligraphy, to mention just a few. Keep this activity ready at all times.
- ✓ Make gimp or embroidery 'friendship' bracelets
- ✓ Listen to a Walkman
- ✓ Make a list of jokes and riddles to share with friends
- ✓ Be imaginative and make up fun games with a pair of dice
- ✓ Draw pictures or create a comic book
- ✓ Create a scrapbook
- ✓ Play card games - solitaire is a great one person game
- ✓ Write a letter to your favorite singer/actor/person
- ✓ Read magazine or comic books
- ✓ Start a book club with your friends and read the books during your clinic time
- ✓ Learn the words for a song you enjoy
- ✓ Keep a bag of activities and games that comes with you to the clinic and that you play only during waiting times
- ✓ Play eye spy

read call a friend  
SEW friend  
MAKE CRAFTS  
Write



**fyi**

Handy hints on how to cope while in bed and bored.

*Helping your child beat the boredom when he or she is sick and bedridden can often be a problem for parents and families. Bridget Pepper sent us the following tips for younger children, which was featured in the Great Ormond Street Hospital 'REACH Bulletin Board.'*

## LOOKING GAMES

These include the 'old faithfuls' such as I-Spy, but once you put your mind to it, variations can be made to suit all ages. Try counting the items on a mobile or the number of different animals on the curtains. There are numerous diversions around the child's bed or cot - how many circular/square objects can they spot?

## TACTILE TOYS

There are a wide variety of these available now and most are not too expensive. Children love colourful 'putty,' soft balls that make squidgy noises when pressed and one of the most popular of all, bubble wrap! Choose the type with larger bubbles for easier 'popping play.' (Take care to supervise at all times and never leave the plastic with the child afterwards particularly if they are young and prone to eating it!)

## LISTENING AND LOOKING

Song and story tapes are obvious choices for children of all ages from babies upwards. Your local library should have plenty available if you exhaust the supply on the ward. But don't forget the pleasure children get from making their own recording. You can 'interview' them in order to make a tape for a friend, or better still, let them interview you! Sand pictures are interesting if your child is too sick to follow a story on TV; and don't forget either the pleasure of story reading to young children. You could also practice your own artistic skills by demonstrating the 'Cat's Cradle' or performing magic tricks. Finally, children often simply enjoy talking especially about a happy time in the past or something they can look forward to when they are feeling better.



## Don't shoot the messenger

Breaking the news of a child's serious illness is one of the most difficult tasks that the practice of medicine demands. This type of conversation is viewed with dread by all levels of seniority in the medical profession, but expertise can be developed with experience as Dr. Elisabeth Macdonald, Consultant Clinical Oncologist, explains...

**Doctors** usually choose to enter the speciality of paediatrics and look after children because they feel they have a rapport with the young and wish to care for them. Doctors in this speciality are acutely aware of the vulnerability of their patients and instinctively wish to protect them from further harm as well as to treat their illness. ■ Perhaps it will surprise you to learn that paediatrics as a speciality is not necessarily highly respected by colleagues in adult medicine. Nevertheless in recent years it has been highly competitive. There are relatively few posts in comparison with those in adult medicine and it therefore requires dedication to pursue a career in this speciality. ■ In anticipation of a conversation dealing with bad news most doctors will try to prepare themselves adequately. It is important to get the facts of the case straight and look up some statistics if these are likely to be helpful in explaining how common or rare the condition is and what the likely outcome may be. Most doctors will try and anticipate parents' questions and aim to approach the conversation in a calm, friendly manner using straightforward language, which avoids too many scientific terms. Most of all they will try hard to avoid being patronizing. We are aware that doctors in white coats can seem intimidating, especially when we use obscure and unfamiliar medical vocabulary. For this reason paediatricians often dispense with their white coat and dress in a relatively informal manner. ■ When talking through difficult subjects we often find that sketches can be helpful. Simple drawings illustrating anatomy or explaining how a treatment works can be more easily understood than complicated ideas. Some patients and parents find it helpful to look at the x-rays or scans. This helps them visualize the size of the problem under discussion. However if parents are "squeamish" then looking at scans can make matters worse. I often find that parents also like to have the diagnosis written down so they can take this information away with them, discuss it with their GP or look up further information. In addition it can prove useful to provide contact details of support groups and information networks.

**Ongoing process** Breaking bad news does not entail the communication of a single unwelcome fact. Rather, it is a process of conveying information at many levels covering many aspects of the central fact. Doctors will therefore try and hold such a conversation in a safe, protected and private environment with the support of other staff. In particular the nursing staff with whom the patient and family are familiar. Because of the volume of information, which needs to be imparted, this process is necessarily time consuming. ■ Most families are initially in a state of shock when the diagnosis is mentioned and it may be that nothing else said during this conversation is neither heard nor retained. Doctors know therefore, that a single conversation is only the start and that a series of conversations will be necessary to explain the details of the diagnosis, symptoms, the treatment envisaged and the ultimate prognosis.

**Difficult conversation** In breaking the news of a life threatening illness, doctors realize that they are required to communicate the news which parents dread most of all. They are aware of the strain this news imposes on parents as individuals as well as on the relationship with their partner. Parents not only have to cope with the sense of frustration at their inability to protect their child, but also a feeling of guilt that they may in some way have brought this misfortune upon their child. They also have to cope with the complex reactions of their other children. ■ We know from experience that parents' reaction to bad news, which may be angry and resentful, can readily be transferred to the bearer of bad news. As doctors we learn to absorb this anger, understand it, forgive it and ignore it. This can be difficult especially when doctors are tired, overworked and disappointed about the news they have to bring.

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## Dr. Victor Blanchette

Dr. Victor Blanchette is Chief of the Division of Haematology/Oncology at the Hospital for Sick Children and Professor of Paediatrics at the University of Toronto. He is also a Senior Associate Scientist in the Research Institute and a Clinician Investigator in the Department of Paediatrics. Dr. Blanchette received his medical training at the University of Cambridge and St. Bartholomew's Hospital in the United Kingdom. His post-graduate medical training included a paediatric residency at Johns Hopkins Hospital in the United States and a fellowship in paediatric haematology/oncology at McMaster University Medical Centre in Hamilton, Ontario. Dr. Blanchette's research interest is in the area of the congenital and acquired bleeding disorders of children. He is Director of the Paediatric Haemophilia and Thrombosis/Bleeding Disorders Programs at the Hospital for Sick Children and is Chairman of the Factor Prophylaxis Subcommittee of the Association of the Hemophilia Clinic Directors of Canada (AHCDC). Dr. Blanchette is Chair of the Canadian Paediatric Thrombosis and Hemostasis Network and a founding member of an Intercontinental Immune Thrombocytopenic Purpura (ITP) Study Group. Dr. Blanchette is Principal Investigator for the Hospital for Sick Children in the Children's Oncology Group (COG), and he is Co-Chair of the recently formed Council of Canadian Paediatric Haematology /Oncology Directors Group. Dr. Blanchette is a member of the Boards of the Pediatric Oncology Group of Ontario (POGO), Camp Oochigeas, Camp Trillium and Candlelighters Canada. Dr. Blanchette is an elected fellow of the Royal College of Physicians and Surgeons of the United Kingdom.



**“We welcome our new Board Members.”**

- Val Figliuzzi, Chairman of the Board

## Theresa Firestone

Theresa Firestone joined Pfizer Canada in January 1999 as Vice President, Government and Public Affairs, after serving as President and CEO of the Canadian Wholesale Drug Association (CWDA). In her current role, Theresa is responsible for Market Access, Outcomes Health Research, Pharmacy Relations, Health Policy and Corporate Affairs for Pfizer Canada. Pfizer is best known for bringing innovative drugs to patients including Aricept, for Alzheimers Disease, and other well known products such as Viagra. Theresa built most of her considerable experience in the healthcare field in various posts with the Ontario Ministry of Health. As Director of the Drug Programs Branch she was responsible for the development and implementation of the Trillium Drug Program. Prior to that, she was Director of the Drug Programs Reform Secretariat where she developed strategies for the redesign of Ontario's prescription drug programs. Early in her career, Theresa worked in Home Care, Legislation Policy, Public and Mental Health and also held the position of Director of Psychiatric Hospitals Branch where she was responsible for the overall operation of Ontario's 10 psychiatric hospitals. Theresa has a Bachelor of Applied Science in Family Studies from the University of Guelph. She was an active past board member of the National Ovarian Cancer Association. She is currently a member of the Canadian Paraplegic Association of Canada Advisory Board, an active member of various committees with Rx&D, as well as a number of other health care advisory committees.



## Jeff Rushton



As president of the U.S. Division of Fujitsu Consulting, Jeff Rushton leads a team responsible for the business strategy, the go-to-market initiatives and revenue growth of this management and technology consulting services firm. Skilled in operations and managing change in organizations, Mr. Rushton is also rebuilding and expanding the U.S. division of Fujitsu Consulting to become the value-add leader for clients in the strategic areas of value management, managed services and enterprise mobility solutions. Fujitsu Consulting is the global consulting arm outside Japan of the \$38 billion Fujitsu group. Mr. Rushton brings a wealth of expertise from previous executive roles in IT service companies in the U.S. and Canada, including two years serving as President of Americas for Netigy Corporation, an innovative professional services firm. Mr. Rushton also served as a senior executive with MCI Systemhouse, a \$2 billion systems integration and software company and he exercised the dual role of CFO/COO at Roger's Communications, the Canadian telecommunications company. He also has several years of experience running his own consulting company, with a focus on strategy and change management. Mr. Rushton graduated from Wilfrid Laurier University in 1985 with an Honours Bachelor of Business Administration. He completed an MBA with Distinction at University of Toronto in 1989. He also earned the distinction of Certified Management Accountant in 1987.

**“We welcome our  
new Board Members.”**

## Glenn Fraser



Glenn Fraser founded The Taligent Group - formerly Fraser Cellucci and Associates - in 1992. From earlier lessons learned as a chartered accountant at a mid-sized public accounting firm, he saw that firms were not properly supplying manageable information readily to clients. As well, many clients were encountering unnecessary reporting or compliance issues due to weaknesses in their accounting systems and personnel. Based on this, Taligent was founded; to provide professionally managed bookkeeping and controllership services to companies in need. Today, Glenn and his team provide the necessary leadership in the accounting department to help business owners and managers make the right decisions at the right time. Glenn has also been a Director of the Pollution Probe Foundation since 1996, as Chair of the Finance Committee and as a member of the Executive. Prior to Taligent, Glenn worked for Mintz & Partners from 1988 to 1992. At the same time, Glenn successfully passed the UFE and obtained his CA designation. Glenn started as a junior accountant and progressed to supervisor before leaving Mintz in 1992 to start The Taligent Group. In Taligent's first year, he also completed his MBA at York University and concentrated on Marketing and Human Resources. Glenn also possesses a Bachelor of Business Administration, concentrating on accounting, which he received from York University in 1989.



**Special events are a great way to unite a group or raise money for a cause. Everything from a bake sale to a black tie awards gala needs to be thought through to make the chances of unwanted surprises a minimum.**

**Step One: Ask the Right Questions First**

Should I hold an event? Do I have enough money? How much can I set aside? What is the purpose? Does the purpose justify the financial outlay?

**Step Two: Take the S.M.A.R.T. Approach with your Objectives**

**Specific** - Only attempt to accomplish one thing per event. i.e. Raise money

**Memorable** - Try to have a creative twist in your event to make it stand out. i.e. Have a celebrity, themed attire, etc.

**Achievable** - Keep within your realm of ability. i.e. Don't expect to raise \$7 million

**Realistic** - Be creative, but know your limits. i.e. Don't expect to have the Queen of England as your celebrity

**Timely** - Know what other events are planned for that day so you don't compete with them. i.e. A firefighter fundraiser

**Step Three: Research**

Know that research reduces risk. Risks like nonattendance, financial failure and embarrassment to the sponsor are all very real. By doing research, you can minimize your chances of these things happening. Research can include a S.W.O.T. analysis. Outline all of your Strengths, Weaknesses, Opportunities and Threats so that you are prepared for anything. Think of Strengths and Weaknesses as internal factors, such as a dedicated team as a strength or lack of experience as a weakness. Opportunities and Threats are external factors that are beyond a person's control. For example, an opportunity could be cancer awareness month and a threat could be bad weather for an outdoor event.

Bottom line: Be prepared for anything.

**Step Four: Design**

Brainstorming is the key to designing an event. The first thing to remember about brainstorming is that there are no bad ideas!

Every idea put on the table leads to something. Answer the five w's while you are designing your event: Who, What, Where, When, and Why. Leave no stone unturned.

**Step Five: Planning**

This is where you answer the 'How' of your event. How are you going to go about making your event a reality? The longer you spend on your research, the shorter your planning process should be. Here all you have to do is iron out the logistics. Who is supposed to be where at what time.

Try to remember that each step in the plan takes time. Don't try and do it all yourself, this will just lead to burnout.

Consider the time restrictions of your team, the time it will take to carry out your event, the location of your venue, whether your venue is suitable, etc. Have a checklist on hand and check things off as you accomplish them; this way you will stay organized.

**Step Six: Coordination**

Make the event coordinator a macromanager. Macromanagers see the "big picture" as opposed to analyzing every little detail. Macromanagers will designate people to look after the little details freeing them up to oversee the entire operation.

For example, for an auction, a macromanager should assign someone to sell tickets to the event, someone to direct people where to place their goods, someone to accept the money, someone to run the bidding, etc. Essentially, they coach, correct, and provide direction to the team.

Also, think about job descriptions (for everyone!). This will help the team enormously - this way everyone knows what's expected of them, and there are no surprises.

Working with volunteers is great, but think also about running the event with a 'right-hand' person with you, so that you can mentor and give these people a chance to

learn what it takes to run the event from a manager stand-point. This could be useful, should you want to keep the event running for years to come; you can pass it onto someone else and not have it take up all your time.

**Step Seven: Evaluation**

For those who want to make their event a recurring affair, evaluation might be the most important step. This way the team can evaluate what went right and what went wrong, what they would do again and what they would change for next time.

Some common methods of evaluation are surveys, monitors (people who wander the event with a checklist or conduct impromptu surveys during), telephone calls, mail, e-mail, face-to-face conversations, or word of mouth impressions. These are good ways to find out how people enjoyed your event. Above all, did you achieve your objectives? These will assist you in making your event a success.

**Step Eight: Celebrate!**

Always take time after an event to celebrate your successes. This is a great way to recognize and thank everyone who was involved and even update volunteers on how successful the event was. Celebrating successes is an effective tool in keeping an excited and available volunteer/event roster.

It can be reassuring to know that even the biggest special events run by the most experienced professionals after years of evaluations can still run into unforeseen problems. Unless it is something major like your food didn't show up at your sit-down dinner, chances are your audience won't even notice a small glitch in your plan.

Stay calm and organized, and have fun! Your event will be for a worthy cause and all in attendance will be grateful that you did it.

# Candlelighters sharpens focus on grief counselling

*Dr. Bill Webster offers unique and important insight*

*The Childhood Cancer Foundation ~ Candlelighters Canada is proud to welcome Dr. Bill Webster to our organization as a consultant in the area of grief counselling. His expertise and skill will serve as invaluable in contributing to our newsletter as well as our Cancer Resource Store with his many published books and audio tapes.*

Dr. Bill Webster was born in Scotland, and attended university in Glasgow and London England, undertaking work in arts and theology. While in England, he met his future wife, Carolyn, and came to Canada to be married. Sadly in 1983, his wife died suddenly and unexpectedly of a heart attack, leaving Bill struggling to cope with his loss, as well as the responsibility of looking after his two sons, then only nine and seven years old.

In 1983, Dr. Bill Webster returned to school, completing a degree in psychology at Wilfrid Laurier University in 1986, before registering in his doctoral program at the University of Toronto. Part of his project for that program was the development of community grief support programs which he did through a local funeral home. After graduating in 1990, seeking to develop this grief support work, Dr. Webster founded the Centre for the Grief Journey, of which he is the Executive Director. Bill has authored several books, including: "Grief

Journey," "When Someone You Care About Dies," "When Someone You Care About is Grieving," "A Not-So-Jolly Christmas," and "Now What," as well as many articles and recordings. Dr



Webster's 5 one-hour video series entitled "From Mourning to Dawn," along with a total package of support materials and manuals, provides agencies across the country the resources to provide grief support to its constituents.

In October 1998, Dr Webster began producing and hosting a nationally broadcast weekly television program entitled "Living with Loss" which is specifically designed to bring comfort and encouragement to those in a grieving process. Dr. Webster is a member of the American Association for Death Education and Grief Counselling and the Bereavement Ontario Network.

**We hope that this is only the beginning of our new efforts to bring on a roster of experts to share their knowledge and expertise with our support groups, staff and other stakeholders. We hope you will take this opportunity to learn more about Dr. Webster by going to his website: <http://www.griefjourney.com>**

## Letter from the heart



*Dear Candlelighters,*

*I can still remember way back during the video taping of "One, Two, Three... Ouchless." I could not imagine then, what is true now, that I would see this day. Yet, you have hopes and dreams for all children - like Crystal - who survived childhood cancer.*

*Thank you for your strength, leadership and the ability to dream.*

*God bless you and your work.*

*Sincerely,*

*Cecilia Wong  
Mother of Crystal Wong*

# CBS enhances safety for donors and recipients

## Action plans to protect blood system from West Nile Virus

Canadian Blood Services has created a comprehensive action plan to reduce the risk of West Nile Virus (WNV) to the blood system this spring and summer. According to Dr. Graham Sher, Chief Executive Officer of Canadian Blood Services: "Our primary focus is to introduce a blood screening test on or around July 1. But beyond that, there are many things that we can do prior to the availability of a test to reduce the risk to the blood system and, ultimately, to patients. By having the plans in place now, we are in a position to act swiftly and decisively."

### Surveillance

The challenge of WNV is its unpredictability.

It cannot be predicted when, or even if, the virus will begin to affect the human population. Nor can it be predicted where it will affect people in this country. Canadian Blood Services is working closely with Health Canada's surveillance group and public health units across the country to ensure it is immediately

notified of the presence of the virus. Information about mosquitoes, birds and animals will be tracked, however such information does not necessarily predict the presence of the virus in the human population. Some contingency plans will only be activated once there is evidence of the virus in people, and the plans may be contained to the area or region in which the outbreak has occurred.

### Screening test

Canadian Blood Services has made the implementation of a screening test at the earliest possible date its greatest priority. As announced previously, Canadian

Blood Services has contracted with Roche Diagnostics (Canada), a division of F. Hoffmann-La Roche Limited, to implement a screening test on or around July 1, 2003. Roche has advised Canadian Blood Services and Health Canada that the development of the test is on track. Canadian Blood Services is preparing its laboratories developing its work instructions, and training its staff to ensure its readiness to implement the test.

As of today, the test's sensitivity and selectivity has not yet been fully established although early indications are that its performance in Roche's laboratories meets Health Canada's criteria. It will be approved by Health Canada as an Investigational Test and donors will be required to provide consent for their blood to be tested in what could be called a "nation-wide clinical trial."

The system provided for investigational use will have near fully automated features. Refinements to the test or its automation features are possible for the future. The practice of introducing screening tests as Investigational Tests has

been used in recent years in Canada and around the world in order to offer the highest possible amount of risk reduction at the earliest possible date.



**Platelets** are one of the components required to make blood clot. They are approximately one quarter the size of red blood cells and are not in fact, whole cells, but fragile cell fragments. Platelets originate from giant cells called megakaryocytes, found in bone marrow. As the megakaryocyte matures, small fragments break off and are released into the blood stream. These fragments are platelets and have a shelf life of only five days.

Patients with prolonged bleeding associated with some diseases (e.g. cancer, hemophilia) need large quantities of platelets as part of their treatment.

All main Canadian Blood Services donor clinics have a plateletpheresis program, because the plateletpheresis programs differ from location to location. If you are interested in becoming a platelet donor, call the above number during regular business hours and select option "1" from the automated voice system to speak to a member of our medical staff.

# Helping kids feel like kids again

## Imperial Oil and the Back to School program - Partners in Education

### GOALS:

I want my best friend to come back to school. I'm running out of cookie-protectors.  
-Jaka



**RESULTS:** Jaka, the former friend, is away, the teacher that used to be here. That's why 8000 supports the Childhood Cancer Foundation - Candlelighters Canada, and to help feel like and friends about the effects of childhood cancer. The kit is used by teachers, classrooms and teachers for a welcoming environment, making the transition back to class for children with cancer more comfortable. It's a program safely dedicated to help kids feel better, which is exactly what all the kids want.

Over the years, Imperial Oil has contributed \$100,000 in support of this program and has been one of the top donors for Candlelighters. This relationship has been an active one as Imperial has brought Candlelighters into the spotlight by making us the featured charity at its 2001 Customer Appreciation Golf Tournament. This gave Candlelighters a great deal of exposure by bringing together Imperial's customers for a fun day of golf while introducing them to our cause. Shortly afterwards, the company went on to create a highly effective ad campaign in the fall of 2001 which highlighted Imperial's special relationship with the Back-to-School program. ( See Ad Left. )

Both Candlelighters and Imperial Oil believe in the value of children and the need for education. This is why we make such a great team. Through Imperial's support over the past six years, this program has grown to offer 120 kits through 10 distributors across Canada. The kit itself has also grown and changed in format, now containing almost \$500 worth of various resources to help the teacher, the returning student and his/her classmates.

"Imperial Oil is very pleased to support Candlelighters, a recognized leader in helping children and families and now schools cope with the effects of childhood cancer. The Back-to-School kit is such an important resource in helping children return to school," said Barbara Hejduk, president of the Imperial Oil Foundation.

We are proud to have this partnership with the Imperial Oil Foundation and look forward to accomplishing great things in the future together.

Contributing to communities has been a way of life for Imperial Oil for more than a century. From its earliest days, when the company gave its first donation of \$100 to a fisherman's mission in Newfoundland, Imperial's tradition of giving has continued. The company focuses its community involvement in four main areas: 1) Charitable donations through the Imperial Oil Foundation; 2) Hockey and other sponsorships; 3) University Research Awards; and 4) a Volunteer Involvement Program for the company's employees and retired employees.

The Imperial Oil Foundation's emphasis is on children and education with over two thirds of Imperial's donations going to programs that enrich (the lives of children).

That commitment is clearly evident in the relationship that has existed between Imperial Oil and the Childhood Cancer Foundation ~ Candlelighters Canada since 1998. Imperial's support of children and education led the company to become a major sponsor of Candlelighters' Back-to-School program that helps create a welcoming environment for students returning to the classroom after coming off of treatment.



**Imperial Oil  
Foundation**

# CONGRATULATIONS!

## **Candlelighters helps celebrate 100 candles for the teddy bear!**

**The Bay marked the 100th birthday of the teddy bear by introducing Wellington, the Bay's newest charity bear. The charity bear is sold in Hundson Bay Company stores across Canada to raise money for its Well into the Future program, which Candlelighters is a part of. Wellington made a life-sized appearance at the birthday party held in the toy department of the Bay's Queen Street location in Toronto along with 100 local children to make crafts, sing songs, and eat a delicious Wellington-shaped birthday cake. Hannah Munro, Adam Dixon, Laura Ann Malm and other cancer survivors participated in the festivities by cutting the cake with the Bay's president Marc Chouinard.**

**Candlelighters has been a part of the Well into the Future program for three years and has received about \$1.5 million from Charity Bear sales and other Bay initiatives in that time. Wellington was on sale at all Bay locations for the 2002 holiday season.**



## "...don't shoot the messenger" cont'd

**Effect on patients** In breaking bad news, doctors are aware that proper investigation of the condition may involve uncomfortable investigations and complex treatment which can be frightening and unpleasant, such as surgery, chemotherapy or irradiation. All this requires a sustained effort and fortitude on the parts of both the child and family. ❖ Looking ahead, the doctor will be aware that there are further problems to be confronted. When a child returns to school, they may be teased and bullied as a result of physical problems or hair loss. As a result of missed classes, there are also difficulties with schoolwork and re-establishing relationships with friends. In the long term, interference with growth and intellectual development can lead to emotional difficulties and problems with personal relationships and employment. ❖ For this child and this family, life is never going to be the same again. The burden of this knowledge may lead doctors to appear unduly sombre. ❖ Nevertheless most doctors will try to lighten the conversation by maintaining an attitude of realistic optimism and by explaining as clearly and concisely as possible exactly what information is already known, what (if any) further investigations are required, what the likely course of treatment will be and what the realistic spectrum of expectation may be in terms of time in hospital, absence from school and ultimate prognosis.

*- reprinted with the permission of the UK Children's Cancer Study Group*

## "...be my hero" cont'd

the tasks of running a growing new business, while having to help Michele chase two new little people around the house seemed overwhelming. It's a lot to bear, but I see now that those problems were simply irrelevant compared to the health of my child.

I've always been someone who has loved living a full life, but today I treasure the important things even more than I did in the past. I'm thankful we caught Ricky's cancer in time. I'll always take the time to make a full life my first priority and be grateful for each moment I'm given. I'm blessed to have him and his little brother and mom with me. Those three come before all else.

In his lifetime, I know Ricky's going to face challenges and adjustments, but he'll feel joy and happiness, too. For as long as I can and for as long as he needs me, I'll make sure he knows that I'll be there to hold his hand all the way. No spoiling, but given good tools to make him grow into the very best young man he can be. He'll always be my hero.

## WE WANT TO HEAR FROM YOU.

We are always looking to hear from you. We are even looking for story ideas. Have you heard about a new treatment or interesting clinical trial? Or do you know someone who has an inspiring story to tell? Give us some details and/or contact information and we'll do the rest.

If you would like to share some news with 'Contact', please forward it to Albert Lee, by email at: [alee@candlelighters.ca](mailto:alee@candlelighters.ca) or mail it to us at Childhood Cancer Foundation - Candlelighters Canada, 55 Eglinton Avenue East, Suite 401, Toronto, ONT, M4P 1G8

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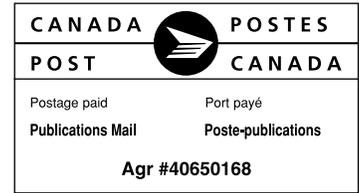
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**100%** of your donation goes directly to Candlelighters

**[www.coasttoastride.com](http://www.coasttoastride.com)**

Find out all about Jeff Rushton and his team's ride across Canada for childhood cancer on page 4.