

The Ottawa Regional Cancer Centre presents

# Challenge



Fall/Winter  
2002

Round the  
world with  
Ride to  
Survive

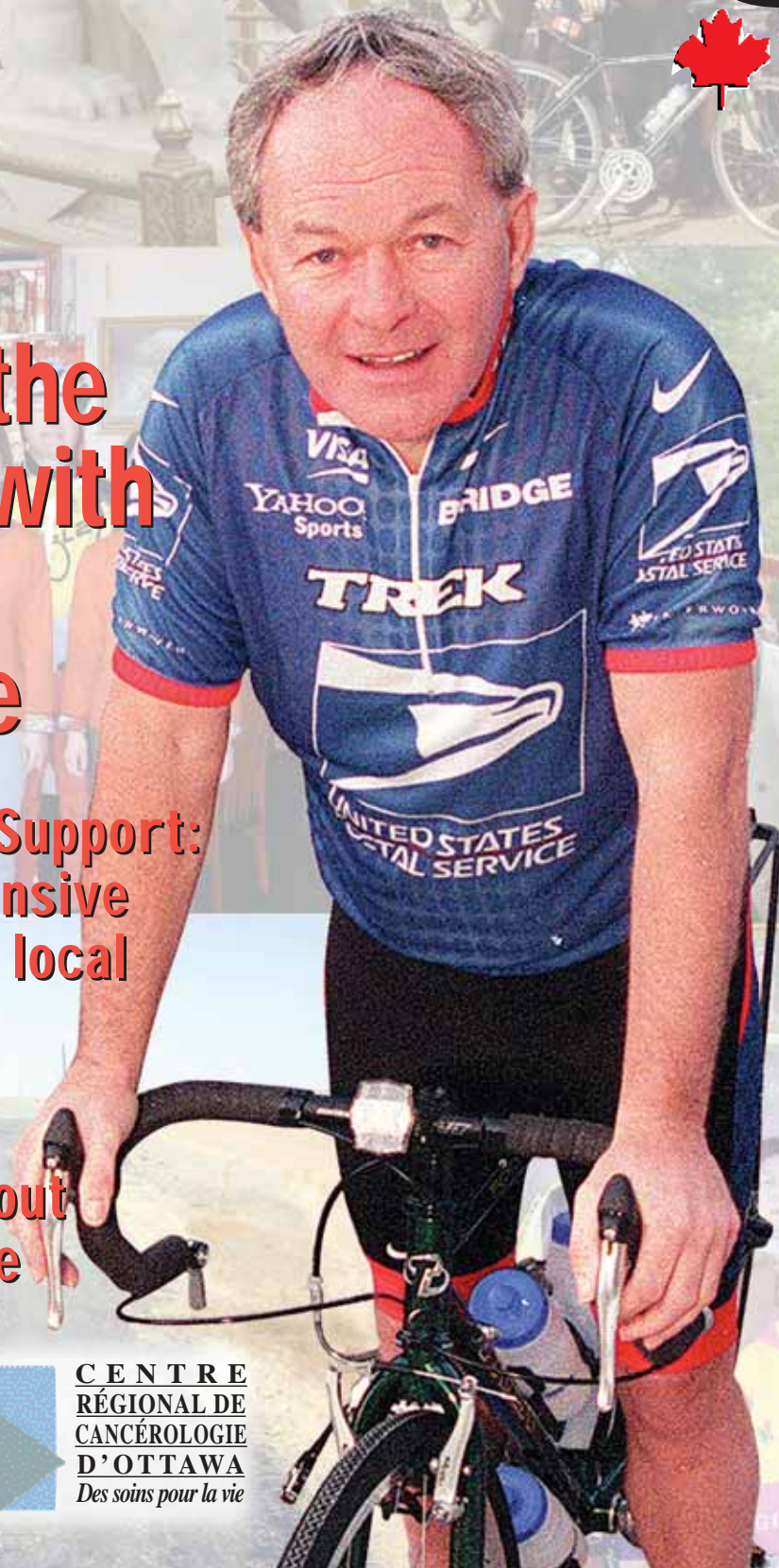
Community Support:  
A comprehensive  
round-up of local  
resources

Removing  
the guilt about  
respite care

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# Challenge

Life with Cancer 

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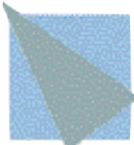
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Volume 6, Issue 2 – Fall/Winter 2002

## FEATURES

Could it be back? <i>Coping with survivor worry</i>	4	The final journey <i>Cynthia Nyman Engel extols the value of respite care</i>	10
Quitting time <i>Message from Ottawa's Medical Officer of Health</i>	5	Community Support <i>A comprehensive round-up of local resources</i>	11-24
Round the world <i>Wife and sister are motivation behind Ride to Survive</i>	6		

## EACH ISSUE

Keeping Spirits Up <i>Barry Bokhaut looks to the future</i>	8	On the Frontier <i>HRT: a case study in media coverage</i>	28
Ask Kate <i>Working during treatment</i>	25	The Foundation Page <i>A how-to of third party fundraising</i>	31
Check it Out <i>Sources of information on brain tumours</i>	27		

## Letter from the Editor

Cancer patients and their families have a lot to think about, and information overload is the last thing you need.

*Challenge* magazine wants to help make your life easier, to provide information on community resources and coping. That's why we've chosen a focus on community support for this issue.



When the Ottawa Regional Cancer Centre Foundation began this magazine six years ago, our mandate was to provide information on medical advances, prevention of cancer, support services, and patient stories.

We had a combined target audience of hospital professionals, cancer patients and their families, and the general public.

While our editorial mandate has changed only slightly since inception, we have made a variety of changes in distribution, to try to get the magazine out economically to those who need it most. We're delighted that as of this issue, *Challenge* will be available at City of Ottawa community centres. You can read a message from Dr. Robert Cushman, the city's Medical Officer of Health, on page five.

We appreciate your letters and e-mails, your suggestions, and your ideas for future issues, and look forward to continued positive evolution in the months ahead.

*Louise Rachlis*

# Worry: Shifting out of overdrive

By Sandra Steinhouse

**W**henever you feel sick, what are the first thoughts that jump into your head? For me, thoughts whisper and murmur in my head, "Cancer? Could it be back?"

Let me start by saying that I know how fortunate I am – a seven-year, normally happy, breast cancer survivor with loving, supportive family and friends.

The health care system has been first-rate for me. But as soon as I feel any pain my mind goes into overdrive, "Do I feel a lump there? Has the cancer gone to my whatever?"

Sometimes I think I am being so petty. In fact, I feel guilty about these inner thoughts and taking doctors' time (after all, I am one of the lucky ones); maybe that's why I have never talked about those lurking fears.

"It's just an upset stomach so stop thinking like that," I tell myself. "You had upset stomachs before the cancer. Everyone gets stomach pains."

But the stomach pain continues for three days. Those big 'C' thoughts have become too profound to ignore and my mother died of colon cancer, I further rationalize. I phone my GP who sees me immediately due to 'my history'. Sure enough she tells me not to worry but call her if I still feel sick next week.

"What does she think of me?" I was just there two months ago, scared, as I had a lump in my finger. (Turned out to be a cyst.) And what about the severe back pain a few months before that? I ended up having a CAT scan.

What happened to the 'Me' who always thought, "It will go away. I'll stay tucked in bed for a day and I'll be better." Symptoms of disease didn't used to pop into my head with persistent regularity; But I know what happened, I was diagnosed with breast cancer.

I live with the knowledge that I am a cancer survivor but have I also become a hypochondriac?

Merriam-Webster Collegiate Dictionary defines hypochondriasis: "Morbidity concern about one's health especially when accompanied by delusions of physical disease." It sure sounds like me, though I hate to think that I am delusional.

However, on examination, it seems quite rational to me that cancer survivors have a "morbidity concern about one's health..." We never know if the cancer 'has gone away' or if the cells might be on their travels to other parts

of our bodies. So my Survivor-Hypochondriasis (It's fun to create new terms; SH for ease) is not another disease but a sensible reaction to my experiences.

Now that I realize my skulking thoughts are part of SH - my mind's reasonable responses, now that I have talked about my SH, will that help decrease my fears or my guilt? Only time will tell.



Sandra Steinhouse

## A social worker comments:

By Diane Manii

This article is one person's perspective on living with the fear of reoccurrence post cancer treatment, and finding the balance between healthy vigilance and obsession. It is reminiscent of two questions a patient's husband once asked me: 1) What can my wife do to prevent cancer ever returning? 2) What can I (the husband) do to stop her worrying about reoccurrence?

I am afraid he was not too impressed with my answers, because besides following your physician's recommendations and living a healthy lifestyle, it is unclear what patients can do to prevent cancer reoccurrence.

In my experience it is only as time passes that those who have had cancer gradually learn to have renewed faith that their bodies and minds are healthy. For some people it is helpful to think of cancer as a chronic disease, because even though the disease has gone, the concern and worry about recurrence never completely leaves.

As with coping with active disease, reading or learning about how

other people find a balance post cancer treatment can be helpful. The following two books deal with the issues which face cancer survivors when treatment is over: They are available on loan at the Ninon Bourque Patient Resource Library at the General division of the Ottawa Regional Cancer Centre (737-7700 ext.6980).

- "Dancing in Limbo: Making Sense of Life After Cancer" by Glenna Halvorson-Boyd and Lisa K Hunter. San Francisco: Jossey-Bass, 1995.
- "Facing Forward: Life After Cancer Treatment." Bethesda, MD: National Cancer Institute, 2002. (also available on line at [www.cancer.gov](http://www.cancer.gov))

For some, talking to others about their fears and concerns can be very helpful. This is one of the reasons the support group "Healthy Connections" was established. It has been developed to offer a source of support and information for those who have finished cancer treatment. For information and registration please call Linda Corsini at 737-7700 ext. 6856.

# Everyone loves a quitter

*A Message from  
Dr. Robert Cushman,  
Medical Officer  
of Health,  
City of Ottawa*

I am pleased to announce that this magazine, *Challenge...Life with Cancer*, is now available at City of Ottawa community centres.

We are delighted to be able to assist the Ottawa Regional Cancer Centre in getting out their important messages about prevention, research and community support.

One area of shared concern is the support of a smoke-free Ottawa.

On the subject of tobacco use, I would like to say a few words to those reading this magazine who have been thinking for a long time about quitting smoking.

You may have already tried to quit unsuccessfully and now feel discouraged. But, as the saying goes, quitting takes practice. It usually takes several quit attempts before people become smoke-free. What may work for one person might not work for another. Quitting on your own can be done, but it's tough. So why not take advantage of some of the programs offered in the City of Ottawa?

Remember, smoking is a powerful addiction, so give support to friends and family who are trying to quit.

Here's what you can do:

- Call the Public Health Info Line (PHIL) at 724-4179 to get counseling over the phone. Call that same number to obtain a quit-smoking package, which includes the Call it Quits brochure.
- Participate in the Ontario Quit Smoking Contest. Applications will be available in pharmacies and other venues throughout Ottawa for people 19 and over. The deadline for handing in your application is October 15, 2002. The contest, sponsored by CTV, offers prizes including a Honda Civic and digital cameras.



Dr. Robert Cushman

- Talk to your doctor, dentist or pharmacist about quitting. Ask about nicotine replacement (gum or the patch) and other smoking cessation aids.
- Register for a group quit-smoking session. (Accessible Chances for Everyone to Stop Smoking – ACCESS). The sessions are free of charge and are offered in English and French.
- Ask your employer or workplace health representative to find out about the Stages of Change quit-smoking computer program for workplaces.

For more information on any of these suggestions, call the Public Health Info Line at 724-4179.

There are a lot of good reasons to quit. Within eight hours of quitting, carbon monoxide blood levels drop and oxygen levels increase. Within three months, circulation and lung function improve, and walking becomes easier. The chance of getting heart disease is reduced by half with-

in a year. Quitting smoking puts you at a much lower risk for cervical cancer, bladder cancer, and of course, lung cancer.

Other potential benefits: you'll save money, you'll stop feeling guilty, and your back won't be sore from coughing. Your hair, clothing, and home will smell good. You won't get asked for cigarettes all the time. You'll help prevent fires, as half of all fires are caused by cigarettes. You'll stop feeling that your life is out of control.

I have heard from a number of people who say that the City's smoke-free bylaws in public places and workplaces have helped motivate them to quit. Ex-smokers also find that the new regulations have helped them stay smoke-free. A recent federal and Ontario tobacco tax increase also aims to reduce smoking rates, particularly among youth.

We are proud to do whatever we can to reduce cancer risk.



A stop at a school in Mongolia on Paul Throop's 29,000 km journey.

# Getting the word out for cancer prevention around the world

## *Wife and sister are motivation behind Ride to Survive*

By Louise Rachlis

**W**hen Paul "Boomer" Throop decided to cycle the world to raise cancer awareness, his wife Heather, a two-time cancer survivor wasn't surprised.

"He's a very special man," says Heather, 53, who met her future hus-

band when she was 10 years old. Her family used to ski in Collingwood, Ont., and he was born there in 1945 and grew up there, "so our paths intertwined for many years."

The couple were married in 1978, and moved to Chelsea, Quebec, north of Ottawa. Boomer is executive sales manager for VMI Medical Inc., a biomedical company that engineers echo cardiograph software, for specialized use in pediatrics and heart center cardiology.

It has been a dream his whole life to do this, says Heather, who had cancer twice, in 1994 and 2000. "During that period his sister Anna was ill too, with colorectal cancer," she says, "and the idea for the adventure took shape in his mind. My health is good now, and our children are pretty independent;

Megan is 19 and Amy is 23. It occurred to him that all factors were in good shape for him to proceed with this. The timing seemed excellent."

By the end of July, he had already completed 13,000 km on his way towards 29,000 km. "He calls a lot," she says. "He sends e-mails to me and my daughters."

While nothing he does surprises her, she was still taken aback when three weeks ahead of schedule in July, he showed up at their cottage on Georgian Bay, arms laden with flowers.

He couldn't get a plane into St. John's, Nfld., as scheduled, but got into Toronto where her brother had secretly picked him up at the airport and brought him to the cottage.

He and her brother drove back to

St. John's for his ride from St. John's to Quebec City. He was in Ottawa the first week in September and then she will see him again at Christmas, when he'll fly back to Canada from Mexico.

"We are very appreciative of any help you can give us to raise the level of cancer prevention awareness, both across Canada and around the world," he said via e-mail from the Ukraine in July. "This can assist important fundraising for our growing number of cancer organization partners in Canada and in other countries."

The money raised locally goes to the Ottawa Regional Cancer Centre. The ORCC is currently working with the Chinese government as well as a Sri Lankan health group.

Boomer says that his role represents a very small part of a much larger Ride to Survive team effort "by a growing number of wonderful Canadian cancer volunteers."

"We deliberately decided to start our mission on March 22nd, 2002, in Tokyo, Japan," he says, "to build the necessary and important program momentum we'll need to be successful, in order to capture the public's attention and support. There were never enough advance resources for our volunteer organization to do this an easier way – and so, we decided to start riding and working hard with our cancer partners around the world to capture the public's interest and participation."

So far, so good, he says. "We're getting started okay. We have learned that a cancer victim in Mongolia expects, for instance – and this is the case in other Asian developing countries – that life is over when they discover they have cancer. No help to speak of will come from their governments. There are no non-profit cancer-fighting organizations such as we have in Canada; In many countries, the government's general attitude is, there's no sense in investing tax dollars in fighting cancer. If you're unlucky enough to suffer cancer, nothing can be done. It's a very sad state of affairs. These countries are years behind the Canadian approach to fighting cancer."

He says Canadians are very lucky. "There is so much to do. Canada has so much to offer; we could be transferring a lot of proven cancer infor-



The Throop family: "Boomer," daughters Megan and Amy and wife Heather.

mation and practices to these developing countries at relatively low cost. There is no transferring effort taking place from what we have seen. What a missed opportunity to kick start cancer prevention and treatment in these countries. They need to catch up somehow and fast."

Their important last ride will start from Victoria, British Columbia, in March 2003, and finish in Ottawa, July 1, 2003. "This will be the stage to deliver the financial results we are after for the cancer objectives mentioned earlier, to help fight cancer across Canada, and for our cancer partners in other countries. The trip home across Western Canada will be the test of all our efforts."

Their plan was to start their winter ride across North America from St. John's on Labour Day, travelling first through the Maritime capitals, then heading south from Quebec City October 1st to bike around the east, south and western United States.

A competitive junior alpine skier, Boomer's fearless runs down Collingwood's steepest pitches earned him the nickname that stuck.

He was also an avid Nordic skier, and won a spot on the Ontario cross-country ski team from 1969-72. In 1970, he took a five-week, 5,000 km bike trip through Europe after a summer job with Splitkein Skis of Norway. He has followed the seasons to ski in the southern hemisphere, hitching rides across the Pacific on tankers and container ships so he could ski in New Zealand.

More recently, he has become an enthusiastic participant in the annual RAGBRAI bike ride across Iowa. Started 30 years ago by two reporters from the De Moines Register News, the ride has grown to become something of a carnival, featuring an estimated 20,000 cyclists participating in a seven-day, 1,000 km bike ride that begins with the riders' back tires dipped in the Missouri River, and ends with their front ones dipped in the Mississippi. Boomer, Heather and their daughters have made the ride an annual summer pilgrimage, leading a small band of friends and relatives.

"I think the secret to living with cancer is mental attitude," Heather says. "You have to think that it's a disease you can control rather than it controlling you."

She is proud of what her husband has done so far. "He has done some amazing work in Mongolia and China," she says. "He is already making a difference. A really important thing – my mother is 92 years old, in very good health, but has had cancer twice during her life. When people hear the word cancer they think it's a bleak future. But his campaign is one of success stories."

To follow his endeavors or to contribute, you can view [www.rideto survive.com](http://www.rideto survive.com).

# Looking to the future – and being able to say, ‘I used to have cancer’

By Barry Bokhaut

**I**t was January 2000, and I was on the top of the world. I was on a diplomatic assignment at the Canadian Consulate in Hong Kong; living in one of the world’s most exciting cities. Work was challenging and rewarding. “Life was good.”

I developed a pesky little cough and congestion in my throat that didn’t go away after a few weeks. I saw a doctor in Hong Kong, who thought it was due to pollution.

A minor inconvenience, I thought.

My wife Barb joined me in Hong Kong, and we spent a blissful three weeks in March traveling through Thailand. I didn’t think much of the discomfort in my throat – maybe the spicy food. Things would get back to normal once I got home.

Back home I was still feeling the discomfort. Time to see my own doctor. I felt foolish describing what was basically heartburn, and answering that no, I hadn’t thought of taking an antacid. Dr. Isserlin prescribed one. A week later I had no relief, and he prescribed a stronger medication, and sent me for a barium swallow. Barb’s colleagues at the hospital she worked at thought that I was wasting my time with the test.

I received a call two weeks later from the doctor standing in for my regular doctor, asking me to see him that afternoon to go over the test results. I remember mumbling “there’d better be a good reason why he can’t just give me the results over the phone. Does he just want to log in another office appointment?”

It was a strange conversation. The doctor described a growth in my esophagus and arranged an early appointment with a gastroenterologist for further testing. And it would be better if I postponed my trip to Vancouver. I couldn’t believe that a delay of a week in going for testing would



Barry Bokhaut’s wife Barb has supported him throughout his cancer treatment.

## Keeping Spirits Up

Advice from our readers

be so bad. I had been preparing for the conference in Vancouver for months, and felt that I had to be there to lead it.

He didn’t use the word cancer. It was Barb who asked to see the report. We read the conclusion together. “To be considered carcinoma unless proven otherwise.” I wasn’t worried. It didn’t say I had cancer. And I grudgingly gave up on going to Vancouver.

I read about esophageal cancer on the Internet that weekend, and slowly started to come to the realization that maybe I could have cancer. Barb suggested I call Henri Hofmann, family friend and a radiologist. The tone of his voice was chilling. “Barry, this isn’t a good cancer to have.” It was the worry in his voice that unnerved me.

He gave me the facts of esophageal cancer, and what it would do to me. He gave me advice as a brother, words

that became my mantra through the most difficult of times. “You have one chance at fighting this; give it everything you’ve got, and do not delay.”

It was my surgeon, Dr. Tadros who used the words “you have cancer.” I was ready. It didn’t come as a surprise, and I wasn’t shocked.

So what to do? In life I weigh alternatives, assess the options, evaluate the possibilities. Dr. Tadros gave me no options. He would do surgery in a week. He described the surgical procedure he would do. I could think about radiation and chemotherapy once the operation was completed.

At this most critical time of my life, I didn’t ask about options. I didn’t request a second opinion. It’s incomprehensible, but despite what was going on, I had an inner peace and calm. My doctor impressed me with his confidence, and I trusted him implicitly. While my family encouraged me to seek a second opinion and explore options, Henri’s words echoed in my mind. “Don’t delay.” I didn’t. I had surgery a week later.

Months after surgery and treatment, I joined an esophageal cancer

Internet support group. And I found that there are options for surgical procedures and choices for having radiation and chemotherapy before surgery. I found ratings of the most experienced esophageal cancer surgeons and best rated cancer hospitals. There were those who thrived without any surgical intervention. I do not regret for one moment the fact that I didn't have options to consider.

I went into surgery thinking that this would soon be over. They would cut out the cancer, give me some treatments, and my cancer would be over with. I was so naive.

The surgery went well, and I quickly started to recover. I even started thinking about getting back to work. Then the medication they pumped into me to relieve my pain stopped. I found that eating with my new digestive system was a real challenge. I couldn't get enough nutrition in me, whether by mouth or by the feeding tube that had been inserted during surgery. My weight continued to drop.

Next was chemotherapy and radiation; the worst of my ordeal. While there was an unbelievably long list of possible side effects to treatments, I fixated on nausea, and became nauseated just thinking about the treatment, which I thought about constantly.

A self-fulfilling prophecy? By the second round of treatment I had to have a nurse come to my home and give me injections of anti-nausea drugs because I couldn't take them orally. Being into my fifth week of daily radiation therapy compounded the chemo problems. I felt that I was going downhill, and the treatments were draining me so badly that if I continued with the third and fourth round of planned chemotherapy, I wasn't going to pull through.

My oncologist, Dr. Rakesh Goel of the Ottawa Regional Cancer Centre, postponed, then cancelled my last two treatments. I was disappointed in myself that I didn't have the courage to fight all the way, that I didn't "give all that I've got," as I had promised myself. Yet I felt that I knew my body well enough to know when I was getting to the point where I was doing more harm than good.

What was hardest to take was the fact that even with everything that I was putting myself through, and Barb

through, my doctors could not assure me that the radiation and chemotherapy treatments would in fact prevent the recurrence of my cancer. They were honest with me. I was going through this misery because it might help. It was very difficult discussing my situation with my teenage sons, Yossi and Michael, trying to convince them that things weren't that bad, and that I would pull through.

I thought often about the courage and fortitude others have displayed; those who have led a close to normal life while on treatment; those who, perhaps because they had no choice, managed to go to work and support their family's regular activities.

I could do no more than shuffle from one room to another, being lovingly tended to by Barb, sapping her strength as she unselfishly catered to my needs. She wasn't working at the time, and she made it her job to care for me.

It is now two years since surgery. I never thought that after this length of time my life would still revolve around my fight with cancer. I'm finally starting to regain some of the energy and

the weight I lost. But it requires a special diet with supplements, enzymes, protein powders, hours at the gym every day, and spending time resting from the exertion of exercising.

Going back to work part-time is an option that I am now just able to consider. Although I am secure in my knowledge that I am beating cancer, that my odds of survival are increasing every day that I live, I am still consumed by my cancer, just as it had consumed by body. I still read the daily posting of my Internet cancer group, keeping myself informed of medical developments, learning from others who are at my stage of cancer, investigating what might still happen to me.

Yet life is finally taking on some degree of normalcy. I'm preparing myself, mentally and physically, should the other shoe drop, and I have to face the challenge of the cancer returning. But I am confidently looking to the future, a future at least three years away, when I can qualify to say, and when I can believe myself when I say, "I used to have cancer."



People drive success.  
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made us the world leader  
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to make a difference in  
our community... where  
what we do today,  
ensures a stronger  
tomorrow.

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efforts of everyone facing the  
challenge of life with cancer.*

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# Palliative Care Outreach eases final journey

By Cynthia Nyman Engel

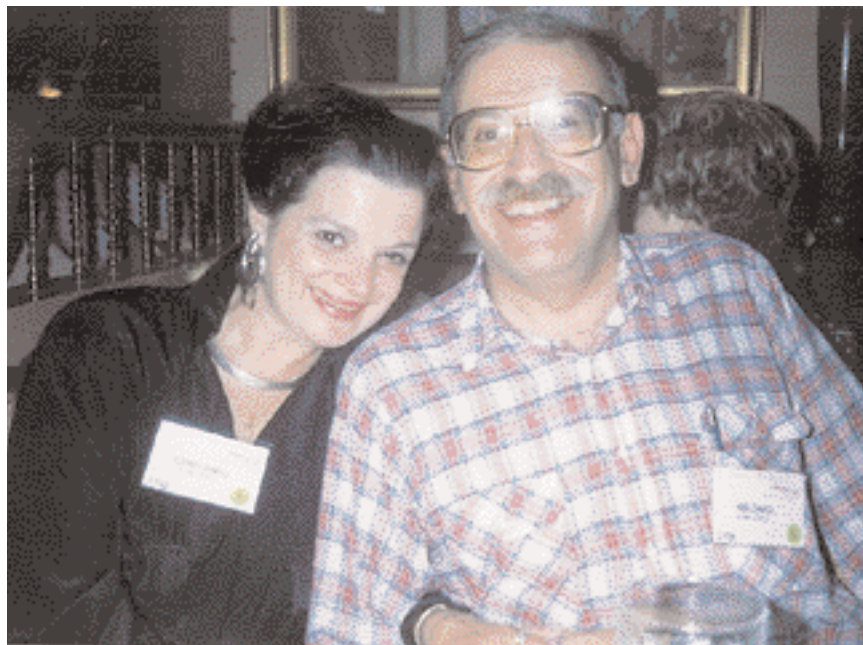
I opened the front door, took one look at the woman standing before me and thought, “Thank you, God.”

It was a sunny July day. Beloved wasn't doing so well, and neither was I. He'd had femur replacement surgery six months earlier, in January 2001, because the prostate cancer – diagnosed in '97 – had spread to his right leg. The steel femur was meant to give him quality of life and it had: he was completely ambulatory, if somewhat slow. However, between January and April, 911 crews were at our home so often we were practically on a first-name basis. On the fourth emergency call Beloved, whose condition was complicated by raging diabetes, was ambulated to hospital where he remained for four long, angst-filled weeks.

He was sprung on May 7, and I became his primary care giver. He was very ill and I was very frightened. Writing, not medicine, is my game and, in the intervening weeks until the door bell rang, I had become increasingly overwhelmed by self-doubt.

Enter Dr. Margaret Farncombe, palliative care specialist extraordinaire. Dr. Farncombe walked into our home on that brilliant July day, bringing her knowledge, her wisdom, her compassion and a gentle but firm manner that inspires and empowers both patient and caregiver. Within minutes of meeting Dr. Margaret Farncombe, Beloved's life and mine began to turn around: We ceased dying of cancer and began living with it.

And live with it we did, for 11 love-and-laughter-filled months. Yes, Beloved ultimately succumbed to his illness. He died on June 8, 2002, completely pain-free – as Dr. Farncombe had kept him for the past 11 months. He died surrounded by his loving family, who miss him terribly but whose remembrances of his struggles



Memories of happy times.

are punctuated by happy memories because his final journey was eased.

Dr. Farncombe is head of the Palliative Care Outreach Program, a unique clinic at 1455 Woodroffe Avenue. Along with a staff of two superb nurses, a couple of administrative staffers and an in-house masseur, Dr. Farncombe ministers to the terminally ill from Cumberland to Carp and all points in between. And, in so doing, she enables the medically uninitiated care giver to tend to his/her precious charge.

A typical day sees Dr. Farncombe and a staff nurse visit six to eight patients. Always with smiles. Always with encouraging words. Always professionally on top of the situation. Then, of course, there are the in-clinic appointments, the telephone visits and the 24/7 pager for emergencies.

The program was instigated by patients requesting to be able to stay at home rather than in hospital. “This isn't a job you can do just to have a job,” says Dr. Farncombe. “You have to love what you're doing or you

couldn't survive. For every person we help, we know there are many more out there needing to be helped.”

Nurse Caroline Tibbles, R.N. insists the team's strength comes from chocolate. “Well, not entirely,” she admits with a smile. “We simply are blessed to have the best patients. Our patients give us positive energy and that's what keeps us coming back.”

Patients are often referred to the Palliative Care Outreach Program by their doctors. “The only way patients will be able to stay home is to have teams that allow for the interaction between the professional and the family,” says Ottawa Regional Cancer Centre Oncologist Dr. Roanne Segal.

“Cancer is a disease with an evolution and what you need at each stage are individuals with individual skill sets. With her Palliative Care Outreach Program, Margaret Farncombe contributes tremendously at a time when there is no longer effective therapy.”

## Social Work Counselling Services at Ottawa Regional Cancer Centre

By Diane Manii

**I**t is natural to feel distressed and anxious when faced with a diagnosis of cancer.

A diagnosis of cancer impacts the person with the disease as well as family members. While there are some similarities in reactions and coping patterns, each person and family is unique.

Every patient benefits from support and research indicates that about 35 per cent patients and families would benefit from professional counselling.

Many patients and families need support in navigating the health care system as well as support in accessing supports such as disability insurance and drug benefits.

The challenges of life are amplified with a diagnosis of cancer. What may have been seen as a minor concern, such as access to childcare, can become an urgent problem. The needs of patients and families also change over the duration of the illness. Reoccurrence or spread of cancer to other parts of the body presents a different level of treatment and challenges. It is very important to view the ability to access counselling services as an essential part the health care team. There are often questions about services and coping that patients and families worry about that may have easy and quick solutions. It is important to seek help.

The individual and family living with cancer is unique, the support system around them must have a level of flexibility to respond to individual needs. At ORCC we have developed a system that has something for everyone, when and if they should need it.

The counselling services are offered by four social workers working



Counselling services are an essential part of the health care team.

full time, and one social worker working half time. They are divided between the Civic and General sites. See below for names, telephone numbers, location and languages spoken.

### Civic site:

- Diane Ford 737-7700 ext 6852 (English)

### General site:

- Linda Corsini 737-7700 ext 6856 (English, French, Italian)
- Michele Holwell 737-7700 ext 6855 (English, French)
- Diane Manii 737-7700 ext 6852 (English)
- Liane Murphy 737-7700 ext 6858 (French, English)

It is usual after a referral to meet with a social worker and discuss those issues that are most difficult or urgent. At the end of the meeting the social worker will suggest some strategies or services appropriate to your needs.

This may involve individual, family or group counselling at ORCC. It may involve referral to other services outside ORCC, or referral to one of the psychiatrists working with the Centre. For some patients and families the information and support provided in one meeting will meet their needs, but the social worker remains available for follow up in the future.

Research has demonstrated the benefits of group support for those living with cancer. It not only improves quality of life but some research has shown that attending a group can improve *quantity* of life. At ORCC we have a choice of groups that provide support at particular times of difficulty, and provide the opportunity to learn new skills, and learn from the experience of others. For many, life-long friendships are made that continue after the group has finished and outside group meeting times.

A listing of support groups follows on page 12

# Community Support

*A comprehensive round-up of local resources*

*Continued from page 11*

## Coping with Cancer Stress

This is a four-week classroom style course, and is open to men and women and their loved ones. This is of particular interest to those who are newly diagnosed. Methods of coping with the emotional aspect of cancer are taught as well as stress management techniques. This is a new course to ORCC and will be offered at the end of October. It is based on a successful course taught by Dr. Alastair Cunningham at Princess Margaret Hospital in Toronto.

Contact: Diane Manii MSW RSW

## Healing Circles

A six-week group for men and women with cancer who are undergoing treatment. It is a time to share your thoughts and learn about the mind/body connection, relaxation, and develop your own imagery techniques. This group is offered several times a year.

Contact: Liane Murphy MSW RSW

## Healthy Living for Women with Breast Cancer

An eight-week group for women

with breast cancer who are receiving treatment or have finished treatment. Receive support and learn about healthy lifestyle choices. Learn about diet, exercise, complementary therapies and lymphedema. This group is offered four times a year.

Sponsored by: The Canadian Breast Cancer Foundation

Contact: Michel Holwell MSW, RSW

## Family Matters

Learn to cope with cancer together. A once a month group for adults, that is open to anyone with cancer and those close to them.

Contact: Linda Corsini MSW, RSW

## What About my Kids?

A once-a-month workshop for parents living with cancer. An opportunity for parents to understand how cancer affects their children. Acquire communication skills, resources and support.

Contact: Linda Corsini MSW, RSW

## Kidz Time

A once-a-month group for children aged 8-16, whose parent or family member has cancer. An opportunity

for children to connect with other children, and to learn about cancer in a safe environment.

Contact: Linda Corsini MSW, RSW

## Healthy Connections

A once-a-month group for men and women who have finished treatment, who want to learn about health related topics and connect with new and old acquaintances.

Contact: Linda Corsini MSW, RSW

## Adult Brain Tumour Group

A once-a-month support group for those with brain tumours and their loved ones. An opportunity to share with others who understand and learn from guest speakers.

Contact: Diane Ford MSW, RSW

## Living for Today

A weekly, Wednesday morning support group for men and women living with metastatic cancer. Develop coping strategies and share your thoughts and feelings, your tears and laughter, as well as information and experience.

Contact: Diane Manii MSW, RSW

## *Some frequently asked questions by patients and families:*

### ***How do I access the service?***

You can call the Social Work Counselling line: 737-7700 ext 6025 and a social worker will call you back, or you can call one of the social workers directly. Your physician, nurse, staff member or volunteer may make a referral on your behalf.

### ***Is the service confidential?***

The service is confidential to ORCC. The social worker will record that she has met with the patient and or family, and the issues discussed, particularly those issues that may impact the patient's ability to continue treatment. If a patient reports that they are about to harm themselves or others, this is very serious and must receive immediate action from the most appropriate professional. This is one time that con-

fidentiality will be broken.

### ***Is the service long term?***

Due to the volume of patients seen at ORCC, it is not possible to see patients/families long term. It is more usual for patients and family to access individual service at particular periods of difficulty, but this may be spread over a number of years. The mandate of counselling services at ORCC is to help patients and families cope with cancer. If patients have long standing problems e.g. marital problems, they will be referred to specialized counselling services outside ORCC.

### ***I am not sure how I will manage financially. What can an ORCC social worker do?***

This is a frequent issue for many patients, Social Work staff can direct you to the most appropriate resource and offer guidance in the application process. (See Diane Ford's article on page 14 of this issue.)

### ***Is there a charge for the service?***

There is no charge for the service as the social workers are paid a salary from ORCC, and funding for this comes from Cancer Care Ontario. However, to provide specialized services for a particular type of cancer, gender or age group, funding is sought from outside agencies such as The Breast Cancer Foundation of Canada.

The Social Work Team at ORCC looks forward to hearing from you.

## An overview of Cancer Care Ontario Regional – Eastern Ontario

To ensure appropriate communication and representation from the regions within Eastern Ontario, CCOR-Eastern Ontario council has recommended the formation of “nodes.”

These “nodes” cover the regions served by Pembroke, Renfrew, Perth, Cornwall, Hawkesbury, Winchester-Kemptville and the Regional Municipality of Ottawa-Carleton.

The Ottawa Regional Cancer Centre is a key member of CCOR-Eastern Ontario and Cancer Care Ontario.

### Ottawa Regional Cancer Centre Community Oncology Program

The Community Oncology Program focuses on ORCC supported cancer care outside of the Ottawa Regional Cancer Centre in Eastern Ontario.

Activities include the operation of oncology clinics outside of the ORCC, delivery of chemotherapy outside of the ORCC, the Maurice Grimes Lodge, the coordination of the rapid palliative program, education, training and communication with the community.

Specific programs include Community Chemotherapy Clinics, Community Oncology Clinics, Satellite Oncology Clinic, The Lodge, CHIPP and Rapid Palliative Radiation.

### Community Chemotherapy Clinics (CCC)

Community chemotherapy clinics are located at the Hawkesbury General Hospital, the Perth and Smith Falls hospital, and the Cornwall General Hospital deliver low acuity chemotherapy to patients who live near these hospitals.

The physicians, pharmacists and nursing staff at the CCCs are trained in the preparation and administration of chemotherapy and the management of the side effects of chemotherapy following provincial standards of care.

The Winchester District Hospital is a Level 2 chemotherapy clinic, which administers more complicated chemotherapy. In addition, to the delivery and management of the side effects of chemotherapy, these sites provide supportive care assessment and delivery of services in collaboration with the local CCAC (Community Care Access Centres) and other community services.

### Community Oncology Clinics

Community Oncology Clinics have been hosted by the ORCC in communities outside of Ottawa since the 1970s. These clinics are attended by a medical and a radiation oncologist and provide follow-up care to cancer patients who have been treated at the ORCC. Clinics are held once a month at the Cornwall Hotel Dieu Hospital, the Pembroke General Hospital and the Perth & Smith Falls District Hospital.

### Satellite Oncology Unit

A satellite oncology unit is located at the Renfrew Victoria Hospital. In this unique clinic, local family physicians trained in oncology provide follow-up care for cancer patients in the region and supervise the administration and management of the side effects of chemotherapy. All types of chemotherapy are administered at this site.

A formal clinic is held at least three times a month to provide consultation and follow-up care.

All sites have new patient information packages and the Crossroads

video to provide information on the ORCC to newly diagnosed cancer patients and their families before their first visit to the ORCC.

### The Maurice Grimes Lodge located at the Civic Site

Provides free weekday accommodation for patients outside the Regional Municipality of Ottawa-Carleton who are receiving daily radiation or multiple days of chemotherapy. In addition, cancer patients who require more than one day at the Ottawa Hospital for diagnostic testing may also use this facility. ORCC nurses to ensure that they are well enough to stay at the Lodge assess all patients scheduled to stay at the lodge.

### The “Continuous Home Infusion Pump Program” (CHIPP)

Is operated by the Victorian Order of Nurses, the CCAC in collaboration with the ORCC. Patients who require continuous infusion of chemotherapy agents for more than seven hours are eligible for the program. This program is designed to reduce the need to hospitalize patients for the sole purpose of infusing chemotherapy. All chemotherapy administrations follow preset protocols and are monitored by VON nurses.

### Rapid Palliative Radiation Program

Provides consultation with a radiation oncologist, simulation, and one fraction of radiation for palliative intent to patients in our community. It is operated in collaboration with the Radiation Oncology Program and the Community Oncology Program.

## Options available for coping with loss of income

By Diane Ford

Some people who have cancer may be unable to continue to work either temporarily or permanently. This loss of income can cause additional stress to an already stressful situation. Here are some options to explore to replace lost income:

### 1 Human Resources

Talk to the Human Resources personnel at your place of employment about your coverage for sick leave, vacation leave, short term/long term disability.

### 2 Employment Insurance Sickness Benefit

This is a federal program run by Human Resource Development Canada. Sickness benefits are paid up to 15 weeks.

- **Eligibility:** 600 hours of insurable employment in last 52 weeks or since the start of last EI claim. Some exceptions are allowed.
- **How Much:** Most claimants receive the basic rate of 55 per cent of their earnings to a weekly maximum. If you are a low income family with children, you could receive a higher rate.
- **When Benefits Start:** There is a two-week waiting period. However, if you get paid sick leave from your employer or group insurance benefits you may not have to wait the two weeks. Takes four to six weeks to process. Ontario Works (Social Service) may assist in the interim.
- **To Apply:** Application forms are available from a social worker at the Hospital/ Cancer Centre or at a

Human Resources Centre of Canada (HRCC). For more information on Employment Insurance Sickness Benefit contact your local HRCC (for phone numbers and addresses look in the blue pages of the telephone directory) or see their web page: [www.hrdcdrh.c.gc.ca/insur/claimant/201017.shtml](http://www.hrdcdrh.c.gc.ca/insur/claimant/201017.shtml)

### 3 Canada Pension Plan (CPP) Disability Benefit

This is a federal program run by Human Resources Development Canada, Income Security Programs. Qualification for this program is based on "medical need" not "financial need."

- **Eligibility:**
  - between ages 18 & 65
  - have enough CPP contributions
  - have a disability that is "severe and prolonged"
- **How Much:** Dependent on contributions to the plan. Call 1-800-277-9914 to determine the amount for which you might be eligible. CPP Disability Benefits are deducted from the Ontario Disability Support Program or from your private insurer. Benefits are taxable.
- **Disabled Contributor's Child Benefit:** Dependent children may be eligible for benefits if they are less than age 18 or are between 18 and 25 attending school full time.
- **When Benefits Start:** the fourth month after you are deemed to have become disabled. You can receive up to 12 months of retroactive payments.
- **To Apply:** Applications forms are available from a Social Worker at the Hospital/Cancer Centre or from



Employment interruption: Loss of income

Human Resources Development Canada.

For more information on the Canada Pension Plan call 1-800-277-9914 or, see their Web page: [www.hrdcdrhc.c.ca/isp](http://www.hrdcdrhc.c.ca/isp)

### Quebec Pension Plan (QPP)

- Disability benefit is similar to CPP disability benefits. If you have contributed only to the QPP or if you contributed to both plans but reside in Quebec, you should contact La Regie des rentes du Quebec at (819) 772-3049, 1-800-4635185.

### 4 Ontario Works

Ontario Works replaces General Welfare Assistance. This program is for people who need financial assistance to pay for day to day living expenses such as food, housing and utility costs.

- **Eligibility:** It is based on a financial needs test. You can only have a certain amount of assets. People applying for the Ontario Disability Support Program are allowed higher levels of assets.

# Community Support

A comprehensive round-up of local resources



Some can add to the stress of illness.

- **How Much:** Dependent on various factors. An Ontario Drug Benefit Card is provided.

There is extra financial help for: special dietary needs, medical transportation, dental/vision care for children, balance for-medical equipment/prosthesis not covered by the Assistive Devices Program.

- **To Apply:** Phone your local office:

- **Ottawa** (613) 560-6000 (ask for intake)

- **Lanark County** (Smith Falls, Perth, Almonte, Carleton Place) (613) 267-4200

- **United Counties of Leeds/Grenville** (Brockville) (613) 345-4101, 1-800-267-8146

- **Renfrew County** (Renfrew, Pembroke, Arnprior) (613) 433-9846, 1-888-281-7526

- **Stormont, Dundas, Glengarry County** (Cornwall) (613) 933-6282

- **Prescott, Russell County** (613) 675-4642, 1-800-667-9825

- For more information on Ottawa-Carleton Ontario Works see their Web page: <http://www.city.ottawa.on.ca>

(check section financial and employment assistance)

- Quebec residents: Contact your local CLSC for information on financial resources. Hull 770-6900, Gatineau 561-2550, Aylmer 684-2251.

## 5 Ontario Disability Support Program (ODSP)

ODSP replaces in part the old Family Benefits Program. This program is based on medical needs as well as financial needs. An application for ODSP goes through a medical determination process by the Disability Adjudication Unit in Toronto (medical decisions are not made locally.)

- **Eligibility:** Have a substantial health condition expected to last more than one year. ODSP allows you to have more assets than what is allowed by Ontario Works.

- **How Much:** Dependent on various factors. Amount received is higher than what is received under Ontario Works. An Ontario Drug Card is provided.

- **When Benefits Start:** Application process can take three to four months or longer. If you do not have other income/assets you should apply for Ontario Works in the interim.

- **To Apply:** Social Services Dept. takes applications for Ontario Works and ODSP. If you don't qualify for Ontario Works, call ODSP directly:

- **Ottawa** (613) 234-1188

- **Lanark County** (613) 283-1165, 1-800-267-7911

- **Leeds-Grenville County** (613) 345-1200, 1-800-267-0834

- **Stormont, Dundas, Glengarry County** (613) 932-3381, 1-800-565-5374

- **Prescott, Russell County** (613) 632-1171, 1-800-565-4431

- **Renfrew County** (613) 735-1073, 1-800-267-0112

- For more information on ODSP contact your local office or see their Web page: [www.gov.on.ca/CSS/page/brochure/odspisfs.html](http://www.gov.on.ca/CSS/page/brochure/odspisfs.html)

## 6 Private Retirement Plans/ CPP/OPP Retirement Plans

Some people may choose to take any early retirement. Talk to the Human Resource personnel at your place of employment. C/QPP benefits are accessible as early as age 60, but are reduced by 0.5 per cent for each month that the beneficiary is away from age 65.

## 7 Other sources of financial assistance

1. Check if you have a disability insurance on your mortgage, line of credit etc.
2. Essential Health & Social Support (EHSS)

In Ottawa, for those of low income, financial assistance may be provided for:

- Trillium Prescription Drug Plan Deductible
- Dental & Vision Care for Children & Adults
- Medical Transportation Mobility Aids
- Assistive Devices Program Top Up

If you live in Ottawa-Carleton, call Social Services at 560-6000. If you live outside Ottawa, call the Social Services in your local municipality to determine if they provide any financial assistance for the above mentioned items.

3. Disability Tax Credit (Revenue Canada – Taxation Office: Form T220 1) This is a non refundable tax credit that reduces the amount of federal income tax you pay. Apply if you “have a severe and prolonged (at least 12 months) mental or physical impairment such that you are markedly restricted in your ability to perform a basic activity of daily living.”

For information on financial assistance, the social workers at the Ottawa Hospital or the Ottawa Regional Cancer Centre will gladly assist you.

## Support Groups and Can for the Cancer Care Ontario

*"I am not sure how this group works but I know it does. If someone comes in with a particular worry we are able to help them. I know this group has helped me when I've been worried. It feels comfortable here."*

It is well documented that people living with cancer benefit enormously from speaking to others in the same situation.

The support groups listed have all been developed because of patients' interest in receiving support and information, and also in giving support

and information to others.

One of the major benefits is that joining a group lessens the isolation and anxiety of dealing with cancer. Many of the groups raise awareness and fundraise for research and services. This is another way of gaining control and finding hope.

### About Face

- Purpose: To give support to people with facial difference.
- No regularly scheduled meetings.
- Call Anne Charbonneau at (613) 837-7154 for more information.

### Arnprior & District Breast Cancer Support Group

- Purpose: Support and encourage breast cancer patients in the Arnprior and surrounding area.
- Meets every third Tuesday, 7:00-9:00 p.m.
- Arnprior & District Hospital, John Street, Arnprior
- Call Elta Watt at (613) 623-7455 for more information

### Barry's Bay Cancer Support Group

- Purpose: Support group for patients, families, caregivers and survivors
- Monthly group meetings, individual support and counselling
- Contact 613-756-2759

### Bereaved Families of Ontario, Ottawa-Region

- Purpose: Mutual aid/self-help following a death. Also provides education in anticipatory grief situations.
- Meets the first Tuesday of each month, 7-9 p.m.
- St. Timothy's Presbyterian Church, 2400 Alta Vista Drive. (downstairs hall)
- Call (613) 567-4278 for more information.

### Breast Cancer Action (BCA)

- Purpose: To inform, educate and support women and men living with breast cancer, their families, and the community. Provides one-on-one peer support.
- Support and Resource Centre at 739A Ridgewood Ave., Riverside Mall, Ottawa. Open from 10:00 a.m. to 3:00 p.m. - 5 days a week.
- Call (613) 736-5921 for more information.



### Brockville Breast Cancer Support Group

- Purpose: To support women diagnosed with breast cancer with occasional guest speaker.
- Meets the second Thursday of the month 7:00 p.m. - 9:00 p.m.
- Trinity Anglican Church, George Street (red door), Brockville
- Call Carole at (613) 923-5017 or Wendy at (613) 342-5078.

### Canadian Thyroid Cancer Support Group

- Purpose: Small informal group providing on-line support, friendship and guidance to thyroid cancer survivors through email contact, with occasional meetings.
- Provides information, including referral to outside sources, in dealing with diagnosis, treatment and management of thyroid cancer.
- Contact Diane Dodd (613) 836-3996 or Dianne\_Dodd@pch.gc.ca

### Canadian VHL Family Alliance – Ottawa Area Branch

- Purpose: Dedicated to Improving Diagnosis, Treatment and Quality of Life for People with von Hippel-Lindau Disease (VHL)
- Toll free US Hot Line Support at 1-800-676-4VHL
- Call Tania Durand (613) 622-7976 (day) for more information (or email: tania@igs.net)

### CancerConnection (Canadian Cancer Society Program)

- Purpose: A toll-free telephone support service that matches people with cancer and caregivers with trained volunteers who have had a similar experience.
- Support is provided within 48 hours
- Call 1-800-263-6750 for more information.

### Cancer Information Service (Cancer Care Ontario and Canadian Cancer Society Program)

- Purpose: A toll-free information service to answer your questions and provide information on various aspects of cancer.
- Staffed by professionals and specially trained lay volunteers.
- Call 1-888-939-3333 for more information.

### Candlelighters Childhood Cancer Trust of Eastern Ontario and Western Quebec

- Purpose: Provide support and comfort items to child patients and their families.
- Meets the first Tuesday of every month, except July and August.
- 7:00 p.m.
- Boardroom, MDU, 6 West, Children's Hospital of Eastern Ontario (CHEO).
- Call Jocelyn Lamont (613) 851-1979 for more information.

### Colorectal Cancer Association of Canada – Ottawa Support Group

- To provide support and information for those living with colorectal cancer, families, friends & caregivers.
- Meets 2nd Tuesday of each month, 7:00 - 9:00 p.m.
- Viewing Room, 2nd Floor, The Palisades, 480 Metcalfe Street, Ottawa.
- Call (613) 839-2075 for more information. Also, Colorectal Cancer Association of Canada: 1-888-318-9442 (e-mail: info@ccac-acc.ca) (Web site: [www.ccac-acc.ca](http://www.ccac-acc.ca))

### Courage Canada – Ottawa Branch

- Purpose: Self-help group for people post-radiation treatment.
- Call Anne at (613) 737-7882 for more information.

### Dundas County Hospice

- Purpose: Support to anyone with a life-threatening or terminal illness and their family/caregivers
- Bereavement support.
- Library material for loan.
- 4324 Villa Drive, Williamsburg, ON, K0C 2H0
- Call Reina DeJong (613) 535-2215

## Cancer Information Services Ottawa Region of Eastern Ontario

### (The) Hospice at May Court Caregiver Support Group:

- Relaxing environment for individuals caring for a loved one diagnosed with a life threatening illness.
- Opportunity to share experiences with other caregivers in discussion group or one-on-one.
- Individual support offered by staff and volunteers.
- Reiki, foot massage, art and resource centre available.
- Monthly information sessions presented on specific topics.
- A program geared towards children and youth is also available.
- Meet every Wednesday evening at the Hospice (114 Cameron Ave.) from 7-9 p.m.
- Call Anne at the Hospice for further details or to confirm your attendance to the evening, (613) 260-2906.

### Living with Cancer Support Group of Brockville

- Purpose: Self-help group for people living with cancer, their families and friends.
- Meets the first Tuesday of the month.
- 7:00 p.m. - 9:00 p.m.
- St. Lawrence Lodge, Prescott Road, Brockville (directly across Highway #2 from Brockville Psychiatric Hospital). Use main entrance and follow the signs.
- Call the Canadian Cancer Society (Unit Office in Perth) 1-800-367-2913 for more information.

### Living with Cancer Support Group of Mississippi Mills and Carleton Place

- Purpose: Participants in this group will be supported and encouraged to work through issues while living with cancer. Sessions will include topics of interest to participants, videos, guest speakers, etc. Refreshments provided.
- Meets the fourth Tuesday of the month.
- 7:15 p.m. - 8:30 p.m.
- Almonte United Church Parlor, 106 Elgin Street, Almonte
- Call the Canadian Cancer Society (Unit Office in Lanark, Leeds and Grenville) 1-800-367-2913 or 267-1058 for more information. E-mail address: lanarklg@ccsont.org

### Look Good ... Feel Better Program

- Purpose: For women on cancer treatment wanting to know more about facial skin care, makeovers and options for hair loss. Free workshop.
- Meets the fourth Tuesday of each month, 2-4 p.m.
- Maurice Grimes Lodge, 3rd. Floor, Ottawa Regional Cancer Centre, 200 Melrose Avenue. OR
- Meets the second Tuesday of each month, 2-4 p.m.
- Ottawa Regional Cancer Centre, 503 Smyth Road
- Pre-registration required at (613) 737-7700 ext. 6455



### Lymphoma Support Group (LSG)

- Purpose: For lymphoma patients, their families and friends. Share your experiences and learn from others
- Meets the first Tuesday of each month
- For more information, call: Miriam at (613) 224-8509 or Evelyn at (613) 232-7795.

### Nu-Voice Club of Ottawa

- Purpose: To meet with fellow laryngectomies to discuss issues of concern and share information.
- Meets the fourth Wednesday of each month (Mar.-June/Sept.-Dec.)
- 2:00 p.m. - 3:30 p.m.
- Ottawa Civic Hospital, Civic Parkdale Clinic, 1st. Floor, 737 Parkdale Avenue, Ottawa
- Call (613) 798-5555 ext. 13416 for more information.

### Ottawa Hospital – General Campus

#### Gynaecologic-Oncology Program – “Time for Ourselves”

- Purpose: Learn some relaxation strategies and share your concerns/feelings with others.
- Meets every Thursday
- 10:30-12:00 noon
- 8 West Lounge, Ottawa Hospital, General Campus
- Call Pat O'Manique (613) 737-8600 for more information or to sign up

### Ottawa Regional Cancer Centre Beattie Library

- Purpose: Although primarily intended for Cancer Centre staff, the Beattie Library is open to patients, healthcare workers in the community, or to anyone who is looking for cancer information.
- Beattie Library, 503 Smyth Road, Ottawa, ON K1H 1C4
- Phone: (613) 737-7700 ext. 6984
- Hours: Monday - Friday, 8:30 a.m. - 12:00 noon, 1:00 p.m. - 4:30 p.m.

### Ottawa Regional Cancer Centre Ninon Bourque Patient Resource Library

- Purpose: Provides up-to-date cancer information for cancer patients and their families, and members of the general public.
- Main Level, 503 Smyth Road, Ottawa
- Phone: (613) 737-7700 ext. 6980
- Hours: Monday - Friday, 9:30 a.m. - 3:00 p.m.
- Please call to confirm.

### Ottawa Regional Cancer Centre Social Work Support Groups

- Purpose: ongoing support groups offered by ORCC Social Workers:
- 1. **Coping with Cancer Stress** (a 4-week classroom style course for men and women with cancer, and their loved ones)
  - This course is of particular interest to those who are newly diagnosed.
  - Learn methods of coping with the emotional aspect of cancer as well as stress management techniques.
  - For information and registration, call Diane Manii at (613) 737-7700, ext. 6852.
- 2. **Healing Circles** (a support group for patients undergoing treatment for cancer)
  - who wish to learn about the mind-body connection
  - relaxation and imagery techniques
  - Must pre-register; space is limited. To register and for information, please call Liane Murphy at (613) 737-7700 ext. 6858.
- 3. **Healthy Living for Breast Cancer Patients** (a support group for any breast cancer patient who has been treated at the Ottawa Regional Cancer Centre within the past 12 months)
  - To provide breast cancer patients with support
  - Decision making skills
  - Behavior change strategies
  - To help maintain a healthy lifestyle
  - Must pre-register; contact Michele Holwell (613) 737-7700, ext. 6855
- 4. **Family Matters** (a monthly support group for all persons with cancer and the adults close to them)
  - Impact of cancer on you and those around you
  - Learn coping skills
  - Meet other families like yours
  - Must pre-register; contact Linda Corsini (613) 737-7700, ext. 6856.
- 5. **“What about my kids?”** (a monthly workshop for parents living with cancer), both ill and well parent, support person are all encouraged to attend. A helpful workshop to consider before children and youth attend Kidz Time workshop program. (see listing for Kidz Time). Focus on:
  - Understand how cancer affects your children and you
  - Communicating with your sons and daughters (little and big)
  - Resources, when and where to go to get help
  - Meet, share wisdom and concerns with other parents
  - Must pre-register; contact Linda Corsini (613) 737-7700, ext. 6856.

Continued on page 18

# Community Support

*A comprehensive round-up of local resources*

*Continued from page 17*

- 6. Kidz Time** (a monthly workshop for children and youth, age 8 to 18, who love someone with cancer. Focus on:
- Understanding cancer and the changes in your family
  - Learning what to do, how to be and where to go to get help
  - Meeting others like you
  - Learning about cancer at ORCC
  - Meet ORCC staff and tour the centre.
  - Must pre-register; contact Linda Corsini (613) 737-7700, ext. 6856.
- 7. Healthy Connections** (a monthly support meeting for all ORCC cancer survivors)
- Learn about health related topics
  - Meet new and old acquaintances
  - New topic each month
  - Must pre-register; contact Linda Corsini (613) 737-7700, ext. 6856.
- 8. Adult Brain Tumour Support Group** (a support group for people with brain tumours, and their family/friends)
- Meets the first Tuesday of each month
  - 7:00 p.m. – 9:00 p.m.
  - Ottawa Citizen Building, 1101 Baxter Road, Ottawa
  - Call Diane Ford (613) 737-7700 ext. 6292, Kathleen Greene (613) 820-4289, Linda Durocher 737-8899, ext. 78053.
- 9. Living for Today** (a weekly support group for men and women living with metastatic or recurrent cancer)
- Share thoughts, emotions, information & experience.
  - Develop coping strategies for getting the most out of each day.
  - Must pre-register, contact Diane Manii (613) 737-7700 ext. 6852

## **Pink Ribbon Voices Support Group**

- Purpose: Support to individuals with cancer; fundraising activities for cancer research; specialized programs for survivors
- Call 230-7702 for more information.

## **Prostate Cancer Association of Ottawa**

- Purpose: Provides support and information, interacts with health community, co-operates with groups having similar interests and promotes awareness of prostate cancer.
- Meets the third Thursday of each month, 7:00- 9:00 p.m.
- New members start time: 6:30 p.m.
- St. Stephens Anglican Church Hall, 930 Watson, Ottawa
- Call (613) 828-0762 for more information.

## **Reach to Recovery (Canadian Cancer Society Program)**

- Purpose: Provides emotional and practical information to women undergoing treatment for breast cancer.
- One-to-one peer support with a trained breast cancer survivor
- Call (613) 723-1744 for more information.

## **Regional Palliative Care Consortium**

- Purpose: To improve the quality of care provided to patients, their families, and friends affected by terminal illness.
- Call (613) 562-6363 for more information.

## **Renfrew County Prostate Cancer Support Group**

- Purpose: Support group to assist all men with prostate cancer and their families, to increase their ability to cope with this disease
- Meetings first Wednesday of the month at 7:00 p.m. in the cafeteria of the Renfrew Victoria Hospital
- Contact 613-432-6471 or 613-432-6911

## **Renfrew Victoria Hospital Cancer Support Service**

- Purpose: Supportive care assessment for all newly diagnosed cancer patients
- Support and teaching given in regards to diagnosis and treatment
- Assistance and referrals for other community services
- Counselling and support re: living with cancer and associated fears related to treatment, recurrence and survivorship
- Contact: Renfrew Victoria Hospital Oncology Clinic, Renfrew Victoria Hospital, 499 Raglan St. N. 613-432-4851 fax: 613-432-8649

## **Renfrew Victoria Hospital Palliative Care Services**

- Purpose: Multi-disciplined team approach for people with a terminal illness in hospital, community or long-term care facility
- Services: Pain and symptom management, patient and family consultation and support, scheduled relief for families and caregivers by trained volunteers, grief and bereavement follow-up
- Contact: Palliative Care Coordinator – Connie Legg, Renfrew Victoria Hospital, 499 Raglan St. N. 613-432-4851 fax: 613-432-8649

## **Stepping Stones**

- Weekly support group for women newly diagnosed with breast cancer (six weeks in duration).
- Become a partner in your health care
- Develop new coping skills
- Find out about community resources
- Learn methods of relaxation/imagery
- Offered at The Ottawa Regional Women's Breast Health Centre. For more information call Sabrina Goan (613) 798-5555, ext. 16563.

## **Sylvia House Hospice Program**

- Purpose: Provides in-home volunteer support, caregiver support and bereavement follow-up.
- Day Hospice: Meets each Tuesday at Bells Corners United Church in Nepean
- 10:00 a.m. - 3:00 p.m. No charge for this service.
- Call (613) 599-9272 for more information.

## **United Ostomy Association**

- Purpose: Provides support and education to people with ostomies, and the public.
- Meets the third Thursday of every month, except July and August.
- 8:00 p.m. - 10:00 p.m.
- Westminster Presbyterian Church, Lower Level, 470 Roosevelt Avenue.
- Call (613) 722-7944 for more information.

## **Victorian Order of Nurses (VON) – Ottawa-Carleton Branch – Supportive Cancer Care**

- Purpose: Supportive Cancer Care Program enables individuals and their families to access the care and support which they require

at all stages of their illness.

- St. Laurent Shopping Centre, South Court, Lower Level, 1200 St. Laurent, Ottawa, ON
- Call (613) 749-7557 e-mail: von@vonottawa.on.ca

## **VON Breast Cancer Network (Cornwall)**

- Purpose: Information and discussion for cancer patients and their loved ones.
- Meets every third Thursday of the month
- 7:00 p.m.
- VON Office, 2nd floor, 205 Amelia Street, Cornwall
- Call Stephanie Ruckstuhl, VON office (613) 932-3451

## **VON Prostate Cancer Support (Cornwall)**

- Purpose: Information and discussion for prostate cancer patients, newly diagnosed, and their loved ones.
- Meets every second Thursday of the month
- 7:00 p.m.
- VON Office, 2nd floor, 205 Amelia Street, Cornwall
- Call Stephanie Ruckstuhl, VON office (613) 932-3451

## **Willow Breast Cancer Support and Resource Services**

- Purpose: To provide information, support and networking for women with breast cancer.
- Trained volunteers who have experienced breast cancer.
- Call 1-888-778-3100 for more information or visit the Web site: [www.willow.org](http://www.willow.org)

## **Youth/Pelvic Pouch Group**

- Purpose: Education and emotional support of those who have had pelvic pouch or ileostomy surgery, with particular emphasis on the problems of the young.
- Call Jennifer Bisson: 839-7427 or Rachel Seed: 832-3522.

*If you would like your Support or Information Group mentioned in the next edition of Challenge...Life with Cancer contact Lynn Crosbie, Education Department, Ottawa Regional Cancer Centre at 613-737-7700 ext. 6588.*

## **Cancer Information Service**

The Canadian Cancer Society's trained and motivated professionals and volunteers at the Cancer Information Service (CIS) are waiting for your call today. They can give you information on: causes of cancer, treatments, rehabilitation, home care, and more. Phone **1-888-939-3333**. If you are on the Web, you can access information relevant to your situation and geographical area on 44 different topics by simply using the site: [www.ontario.cancer.ca](http://www.ontario.cancer.ca) and your area postal code.

## Patients really appreciate services close to home

By Louise Rachlis

It has been three years since Renfrew cancer patient Linda Hisko first went to the community oncology department at the Renfrew Victoria Hospital.

She was delighted to find a multi-disciplinary team that is able to focus on client and patient needs.

"I was diagnosed there," says Linda, 39, who works in a local dental office. "I had two surgeries at Renfrew and I was very lucky to have chemo there as well. However, I had to travel to do my radiation out of Ottawa."

She was so pleased to have the majority of her treatment close to home. "In my case, I was able to work right through," she says. "It was so convenient. Even now, my three-month follow-up oncology visits are all done out of Renfrew. It means a lot."

Because she had "never had anything to do with cancer before I was diagnosed," she was totally unaware of what the hospital had to offer. "It was unbelievable; amazing. They were there for you; they were so good," she says. "I was at the hospital almost every day. It would have been so much harder if I'd had to travel. I found that travelling for my radiation was the hardest part."

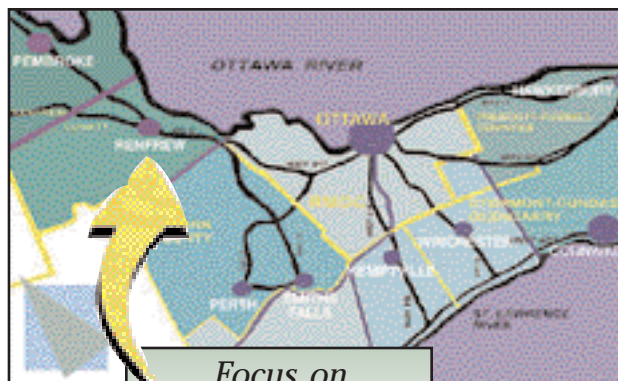
"What the clinics offer patients is services closer to home," says Randy Penney, CEO of the Renfrew Victoria Hospital and the St. Francis Memorial Hospital in Barry's Bay.



The Ottawa Regional Cancer Centre's satellite clinic at



Linda Hisko and her family were pleased she could have the majority of her cancer treatment nearby at Renfrew Victoria Hospital.



Focus on  
**RENFREW**

the Renfrew Victoria Hospital is the only satellite clinic in the region. "Renfrew has been able to achieve great success with the support of the Ottawa Centre," he says. He says that partnering with the major centre in Ottawa has allowed them to offer a comprehensive range of programs and services. That goes from prevention activities, right through to supportive care and palliative care.

Follow-up treatment and diagnostics are also provided in Renfrew, as well as certain oncology surgeries.

"It provides the patients in the com-

munity access to cancer services in their community that meet the same standards as the ORCC in Ottawa," says Cindy McLennan, nurse manager for oncology

at the Renfrew Victoria Hospital. "We provide all the same services they do, except radiation therapy and clinical trials. I don't think people in the urban areas appreciate the hardships of travel."

Some people don't have the finances and the resources for travel, she says. "For those people it becomes quite critical – it provides a better quality of life for them because they don't have to be away from their families. It takes minutes out of their day instead of hours. Many people are able to come to us, have their chemo and go back to work."

## You don't have to go to the big city to get the treatment you need

**E**ven a few kilometres can make a difference.

"When you're tired from taking the chemo, the distance to the hospital is important," says Bill Sheldrick of Morrisburg, Ontario, 72, a patient at Winchester District Memorial Hospital.

"The hospital is half an hour from Morrisburg. They've got well qualified nurses and a good pharmacy to mix the medicines," says Mr. Sheldrick, who has been going to the hospital for over a year for cancer treatment. "They seem to put you through quite quickly. The staff all seem to know what they're doing ... I find it works very well."

"It's very economical too," he adds. "Patients pay just \$2 for parking; it costs much more in other places."

The Winchester District Memorial Hospital (WDMH) was the first to establish a Community Chemotherapy Clinic in Eastern Ontario. It was opened in conjunction with the Ottawa Regional Cancer Centre, and the Kemptville Hospital. Drugs are mixed at the Winchester Hospital.

Patients are usually first seen by ORCC oncologists who determine their course of treatment. If appropriate, the patients have the option of receiving their chemotherapy at the Winchester hospital, after which their Kemptville or Winchester family doctor follows their progress and provides follow-up care.

Patients now keep regular appointments with oncologists and ORCC and their chemo orders are faxed to WDMH where care is coordinated with the pharmacy, physicians and nurse.

Level II started in November 2000 for all drugs except Taxol.

"It's a Godsend for a lot of people," says Linda Johnson R.N., the clinic's coordinator and "nurse navigator" for Winchester.



Bill Sheldrick of Morrisburg is happy to receive care in Winchester.



### Focus on WINCHESTER

"We have a very large catchment area, stretching from Cornwall in the east to Brockville in the west," Ms. Johnson explains. "While there are people who might still have to drive some distance to get here from either of those two extremes, at least they're not fighting traffic or paying an arm and leg for parking."

Ms. Johnson says that people are also more comfortable in their own rural hospital. "They meet people they know, it's more friendly and it's a more comforting experience for them. For elderly patients, travelling to Ottawa is especially difficult, since they most often have to rely on someone else."

Five Winchester nurses, as well as a number of local family physicians from Winchester and Kemptville, have taken training at the ORCC in administering chemotherapy. All patient records are computerized and accessible from Winchester or the ORCC, another plus for the continuity of patient care.

Thanks to a donation from the Hough family in Finch, the hospital has opened the Brian Hough Unit for chemotherapy and other medical treatments, which accommodates four patients at a time.

"Sometimes people think that care is better in larger centres, but that's simply not the case," she says. Indeed, chemotherapy services offered at the Winchester Hospital have to meet the same standards as services offered by the ORCC. "With the input of our community advisory committee and the support of the ORCC and our hospital staff, we have been successful in achieving those standards," she says.

"And we're very pleased with the results. This is only the first step in working with the ORCC and our community to plan and coordinate the continuity of care and to provide access to additional services closer to home. It is an education process to let people know about the care and facilities that are available in their own backyard."

WDMH staff have access to ORCC staff education sessions, she says, and the ORCC has been very supportive in assisting with education sessions for WDMH staff and community forums for public education.

Surgery done at WDMH includes gynecological, breast, colon, and thyroid, with chemotherapy done there for all. The hospital has several general surgeons and gyn surgeons.



**Special people:** This past year volunteers gave the ORCC more than 13,500 hours of their time.

## CCS and ORCC: A partnership that works

By Tom Sparling

**C**anadian Cancer Society volunteers and the Ottawa Regional Cancer Centre team up to provide volunteer services at the ORCC's two campuses.

The volunteers and the Volunteer Resources Coordinator staff are members of the Canadian Cancer Society and office space for the Volunteer Coordinator and the volunteers is provided by the ORCC.

At present 106 Society volunteers provide support and assistance to patients, their families and staff at the two clinics and the Maurice Grimes Lodge. This past year these volunteers gave the ORCC over 13,500 hours.

### Who are our volunteers?

As with most volunteers, many are retired from the regular work world, most but not all live near the site they volunteer at, and many have been themselves patients of the Ottawa Regional Cancer Centre.

The volunteer base at the ORCC can be divided into three major groups: Those who are former patients, those who had families who lived with cancer and students who are interested in health care and research. These three groups of people are all very motivated to 'give something back' or 'make a difference' as many of them would say. This approach makes these volunteers a joy to work with from my perspective. I feel both blessed and honoured to spend my days working as part of the team with these special people.

### What do volunteers do?

The volunteer roles can be generally divided into three areas: Volunteers who greet patients and assist in their registration, volunteers who provide information and resource materials to patients and their families and volunteers who socialize and assist with recreational programs at the Maurice Grimes Lodge. (The Lodge provides a place to stay for those people who live more than 40 km outside of Ottawa

and are undergoing treatment here at the ORCC from Monday to Friday.)

### How do I become a volunteer?

The first step is to call the Volunteer Resources Coordinator at 737-7700 ext. 6054 or 6480. Leave your name and a contact phone number or numbers. The second step is a meeting at the ORCC location where you are interested in volunteering. During this visit we will tour the location and discuss your interests and experience to determine how best to meet both volunteer and organizational needs. You will receive the volunteer application package and volunteer information handbook. The third step is an interview to finalize your acceptance as a volunteer, and to coordinate the hands-on training sessions in your volunteer role.

*Tom Sparling is Canadian Cancer Society Volunteer Resources Coordinator at the ORCC.*

## Community care during cancer treatment: Early intervention improves outcomes

By Judi Panter

**T**he Oncology Service of the Ottawa Community Care Access Centre (OCCAC) has been available to clients of the Ottawa Regional Cancer Centre since 1984.

We like to think of the service as a partnership in cancer care. It offers care and support in the community to the clients of the Cancer Centre while they are undergoing treatment. Community health care professionals visit clients in their homes to assist with the management of their illness and any side effects of their treatments, to teach about prescribed medication and to administer home chemotherapy and home intravenous therapy if prescribed.

The Ontario Ministry of Health and Long Term Care funds the Ottawa Community Care Access Centre and there is no direct cost to the client for the services provided.

To qualify for the OCCAC Oncology Service a client will:

- Reside in Ontario
- Hold a valid Ontario Health Number
- Require symptom management during cancer treatment
- Be willing to learn and participate in their care

If you require care at home during cancer treatments, your physician or another professional in the Cancer Centre will refer you to an OCCAC case manager working on site at the Centre. You may also refer yourself. The case manager will review your file and meet with you to discuss your individual service needs.

Together you will develop a service plan that will address those needs. The OCCAC purchases, on your behalf, many of the services you will require.

However your case manager will also advise you about additional services and supports not available from the OCCAC and can assist you to access them.



Your service plan usually includes scheduled nursing visits from one of four contracted agencies. The nurse visits you as soon as possible after your first treatment. Your case manager may also arrange nutritional counseling, physiotherapy, occupational therapy, speech therapy, physical care, psychosocial support and respite care, should you require these services.

You will receive a drug card from the Ontario Drug Benefit Program, if you do not have drug coverage through another source. This card covers a portion of prescription costs and is valid while you are receiving OCCAC services. Short-term equipment rental and medical supplies are available too.

Your case manager co-ordinates your services and reviews and adjusts the service plan routinely in consultation with you and the professionals who visit you. She provides ongoing support, education, advocacy, problem solving, counseling, and information and referral to other community resources. Your case manager will see you if you are admitted to the Oncology floor at the Ottawa hospital and

will reassess your needs prior to your discharge from hospital. The OCCAC case managers who work at the Cancer Centre are responsible for ongoing service co-ordination for approximately 400 Cancer Centre clients. They also assess and arrange CCAC services for other clients admitted to the Oncology floor at the Ottawa Hospital that reside in Ottawa and in other Ontario communities.

A recent Canadian survey of Cancer patients identified a need for better, more accessible information on symptoms and symptom management.

We believe the OCCAC Oncology Service offers this to Cancer Centre clients in Ottawa. Our clients report that they appreciate the nursing visits and the information, education and support provided.

Studies have shown that early intervention for treatment of side effects at home and preventative teaching by the visit nurse does result in cost savings, reduced hospitalizations and improved quality of life for clients undergoing cancer treatment.

Some clients tell us that they could not have managed their treatment without this service.

*Judi Panter is OCCAC case manager.*

### *What the ORCC logo means*

**The green triangle surrounded by the blue square represents the Ottawa Regional Cancer Centre's large catchment area that covers the geographical area from Cornwall to Ottawa to Deep River and includes 1.2 million people.**

**The abstract form represents the 'modern' technological approach to treatment and the state of the art equipment used. Finally, the use of blue and green communicates life and living and signifies the caring nature of the staff.**

## Creating a new definition of 'hospice'

By Beth Collison

**T**raditionally, the term "hospice" has been associated with emotions of sadness and loss.

Although these emotions continue to be present in hospices today, it is clear that many other feelings play a part.

I had the privilege of spending a day at the Sylvia House Day Hospice Program and at the Hospice at May Court Day Program.

In my time at both Ottawa programs, I met people who, despite coping with serious illness, were full of life, laughter, and hope.

Some participants credited the programs with adding months to their lives, while others spoke of the joy it brings them to spend time with others in such a caring atmosphere.

Not only do these programs become a special time for participants, they also offer peace of mind to caregivers and loved ones. All are free of charge.

Although they provide support to people with life-threatening illnesses and their loved ones, the Hospice at May Court and the Salvation Army Sylvia House Hospice are also places of hope, laughter, light, and living.

The Hospice at May Court offers four 'circle of caring' programs: Home Support, Day Program, Caregiver Supports, and a Residential Program. In the Home Support Program, volunteers offer non-medical support ranging from friendly conversation to help with grocery shopping.



- Ottawa Citizen file photo

**Money for renovations:** Left to right, Bob Buchans, now past chairman of The Hospice of May Court board, enjoys a cup of tea with Patricia Burroughs, past president of the Association of May Court Clubs of Canada; Lillian Smith, past president of the May Court Club of Ottawa, and Barbara O'Connor, Executive Director of The Hospice. When the photo was taken two years ago the May Court was presenting a cheque for \$45,000 for new beds at The Hospice and challenging other organizations to come up with the remaining funds. There are now nine new beds at The Hospice.

The three-day-a-week Day Program provides opportunities for activities, socializing and enjoying a meal with other participants, staff, and volunteers. The Day Program takes place in a beautifully renovated and peaceful space.

A Caregiver Support program is also available for family and friends of people with life-threatening illnesses. There is a support group for adults and a separate group for children. The fourth program is a residence with nine private rooms for people who are in the final weeks of their illness and do not need to be in a hospital setting. The residence offers 24-hour-a-day medical care.

The Sylvia House Hospice offers an In-Home Volunteer Program, Day Hospice Program, Caregiver Support Groups, and Bereavement Support. Ranging from reading and compan-

ionship to fixing lunches and dog walking, the In-Home Volunteer Program provides non-medical support to people in their home or retirement residence.

The Day Hospice program runs every Tuesday at Bells Corners United Church and offers its 'members' social and recreational activities, time to socialize, and a home-cooked meal.

The Caregiver Support group is an eight-week program that begins in the spring, while a Bereavement Support group takes place in the fall. The Bereavement Support program also has a staff person who devotes one day per week to following up with members' loved ones in their homes or by phone.

Both hospices have a strong volunteer base, and provide services to people living in the City of Ottawa; although Sylvia House directs its services more to the west, and May Court, in Ottawa South, directs its services more to the east. Anyone can make a referral, including potential participants and their loved ones.

The Salvation Army Sylvia House Hospice Program is at 599-9272, and the Hospice at May Court at 260-2906.

Thanks to Don Ciavaglia, Program Manager at Sylvia House Hospice, and Meagan Doyle, Director of Development at the Hospice at May Court, for their insights.

Beth Collison is a Social Work student at ORCC.

*Caring for body, mind and spirit:*

## The Palliative Care program at the SCO Health Service

By Valerie Fiset and Mary Ann Murray

**P**alliative care is the medical term for comfort care at the end of life.

The goals of palliative care are to help people who are living with advanced cancer and other terminal illnesses to achieve the best quality of life possible, and to relieve suffering.

The focus of care is based on the whole person – body, mind, and spirit. Care planning involves the patient and those who are close to them. Over time, palliative care providers have developed specialized expertise in managing symptoms such as pain, nausea, and breathlessness. These specialized palliative care providers work closely with oncologists and healthcare professionals in the community to promote comfort and support for those living with a terminal illness.

Strong partnerships between acute care treatment centers, community care teams, local hospices, and healthcare academic institutions help patients, their families, and professional caregivers to gain timely access to palliative care services.

The Palliative Care program at the SCO Health Service provides patient care services in an inpatient setting at the Élisabeth Bruyère Health Centre and outpatient support and consultation through the Pain & Symptom Management Team.

Patients are admitted to the 36-bed Palliative Care Unit based on their symptom and care needs – for either pain and symptom management or to provide care until the end of life. An interdisciplinary team provides care in an open, friendly environment,



**An open, friendly environment**

where different cultures and beliefs are respected.

Team members work together with the patient and family to address a wide range of supportive care needs. Some people may need help with complex pain management, others may benefit from emotional support, and others may require assistance to maintain their independence. Communicating with bereaved relatives and providing bi-annual memorial services represent some of the ongoing support provided to patients' loved ones.

The Pain & Symptom Management Team is a bilingual service funded by the provincial government and sponsored by the University of Ottawa Institute of Palliative Care.

People from the five Eastern counties, the Ottawa region, and Renfrew County can access the Consumer Telephone Service for information regarding community resources related to palliative care.

The professional Telephone Consultation Service consists of an interdisciplinary team of healthcare providers offering telephone consultation for professionals 24/7. Education sessions and resource material on palliative care are also available.

Support is available to primary care professionals in the Ottawa region who are caring for patients and families living with a terminal illness through the In-home Palliative Care Consultation Service. A physician or nurse from the team will assess patients and families at home, in a long-term care facility or in a residential care setting. They will then partner with the patient, family, and primary care team to address identified issues.

The University of Ottawa Institute of Palliative Care is a unique Canadian academic centre for interdisciplinary research and palliative care education. Established in 1993, the institute provides specialty palliative care education for nurses, physicians and other healthcare providers. Research initiatives have focused on developing current knowledge about how to become more effective in relieving suffering and improving quality of life.

Palliative care is about life and living to one's full potential. The staff and volunteers associated with the Palliative Care program are dedicated to helping people achieve their goals in an environment that blends skillful symptom control with a recognition of the unique choices, goals, and experiences of each patient and family.

*Valerie Fiset, RN, MScN, CON(C) is a Clinical Nurse Specialist, Palliative Care.*

*Mary Ann Murray, RN, MScN, CON(C), is an Advanced Practice Resource Nurse.*

# Flexible work hours can provide diversion from illness

**Q:** *I want to keep working during my cancer treatment, but I feel guilty taking time off and not being able to give 100 per cent because my mind is on other things and my energy is down. What should I do to be fair to my employer and fair to myself?*

**A:** Well, my first response would be to say abandon your feelings of guilt! You did not ask for this illness, and should not feel guilty about the collateral damage of its having visited itself upon you. Physical and mental frailties are an integral part of the human condition, it seems to me, and since we are all human, we are all susceptible to them. Guilt is an unproductive waste of your energy. So first off, readjust your focus, and set your mind to resolving how you can best cope with your situation.

You do not mention the type of work you do, so it is not possible to know the demands it places on you physically or mentally, what the effects of your work are and can be on others. These would be important factors to take into account when you are deliberating about your approach to working through treatment. Of course, the nature and duration of your treatment, and its side-effects would also be factors to take into account, as would the types of employment benefits to which you are entitled and your own or your family's ability to meet your financial obligations during this period. It is important to contact your human resources professional to determine what your entitlements are. Then, do an evaluation of your financial obligations to determine what your needs (not necessarily your wants) are during the time your treatment will run.

Then have a talk with your oncologist to get his or her thoughts on the side effects your chemotherapy, drug, or radiation regimen tend to cause. Discuss the nature of your employ-



ment, its demands, the rigours of your treatment, and your own health situation to get a sense of how you may be able to manage through out your treatment. It may well be that you can schedule your treatments to allow you to continue at work.

During my chemotherapy and radiation, I worked flexible hours, and because I very much enjoyed the work I was doing, I found it a wonderful diversion. It allowed me to avoid being consumed by my cancer and its related medical demands: appointments, treatments, and so on. Work also allowed me to maintain an element of control in my life, which had suddenly become so much less subject to my direction than I would have liked. Probably best of all is that while I was working, I was absorbed; I was myself again and not the newly "debilitated" cancer person I had become. My work allowed me to feel whole, competent, and fulfilled. It reminded me that although I may not understand the technicalities of treatments, tests and test results, and while I may feel uncertain and unsure about many facets of my new daily life, that I did have a sphere of expertise, an area in which I was still in control. My work allowed me to focus on other people and other things. It was a welcome, if sometimes tiring, diversion from what my life had so quickly turned into.

My return to work also allowed my family a sense of stability ... the feeling that life was returning to normal.

However, not all work situations are gratifying, absorbing or rewarding. If your work situation does not offer these opportunities, but instead is stressful, unpleasant, exhausting, or otherwise difficult, you may question the value of returning to work full time, or at all. Of course, for most of us, these decisions are inevitably influenced by financial demands, employment benefits, and insurance issues.

Discuss your situation and concerns with your employer and determine what your employer has done in other, similar circumstances, and how they see your situation unfolding. Find out how flexible they are able to be, so that if you wish to try to continue to work through out your treatment, but find yourself worn down, or in need of an early departure from time to time, that might be available to you. Honesty with yourself, your employer, and your colleagues will help you achieve a balance between your sense of duty to your work and your responsibility to yourself and your family to facilitate your own recovery. Work should be part of your healing and recovery process; in my view, it should not be a further obstacle or impediment to achieving that recovery.

Finally, be aware of your limitations, stay attuned to your body, and pace yourself accordingly. An honest dialogue with your employer and colleagues about your progress may make it easier for them to understand your situation, and perhaps more willing to pitch in to help when you signal a need.

*Kate Murton is an Ottawa lawyer and a cancer survivor.*

# K.C. Jones Brain Tumour Binder funded by friends to honour his memory

By Diane Ford

**L**iving with a brain tumour is a complex process for both the patient and his/her family.

An organizational binder, called the K.C. Jones Brain Tumour Binder, has been developed to aid people in the Ottawa area who are living with a brain tumour and their families. It is a local initiative, modeled after a similar binder produced by the Gerry & Nancy Pencer Brain Tumour Centre (Princess Margaret Hospital, Toronto).

It is a tool which will provide a single place to keep track of all information related to the medical care of a brain tumour. This binder complements the "Brain Tumour Patient Resource Handbook," produced by the Brain Tumour Foundation of Canada, which provides medical information.

The purpose of the K.C. Jones Brain Tumour binder is to allow a person with a brain tumour to:

- take an active role in his/her medical care plan
- gather information to share with the medical team
- become aware of available resources that can assist.

In addition to having a place to keep a summary of a patient's personal health history, test results, symptoms, medications, important phone numbers etc, it provides sample questions to ask a neurosurgeon, medical oncologist or radiation oncologist.

As coping with a brain tumour involves not only the medical aspects, this tool gives advice on dealing with the emotional and practical issues as well.

Also included are personal stories from some of the members of the Ot-

tawa Adult Brain Tumour Support Group, describing their journey from time of diagnosis, through treatment and beyond.

As one patient described the binder: "The binder seems to have all the information one would need. I think it's great as one central focal point. There's no need to run around to find information on topics like finances and sick leave."

Being in a binder format makes for flexibility – patients can use just what they need at any particular time.

The binder has been made possible due to the generous moral and financial support of the K.C. Jones Memorial Derby. Keith Jones died of an inopera-


ble brain tumour in 1987. His friends decided to honour his memory by forming the K.C. Jones Memorial Fishing Derby. Every year, Keith's friends pursue fish and fun for the benefit of others. We are immensely grateful to this group of businessmen for sponsoring this binder.

Also our deepest appreciation goes to Jennifer Bulman who donated countless hours of her professional expertise to edit the binder into its final format.

The K.C. Jones Binder will be available this fall from the social workers at the Ottawa Regional Cancer Centre or the neurosurgery in-patient unit at the Ottawa Hospital.

For information about the Ottawa Brain Tumour Support Group, which meets on a monthly basis, please call one of the facilitators: Diane Ford, 737-7000 ext 6292; Katheen Greene, 820-4289; Linda Durocher 737-8899 ext 78053.

*Diane Ford MSW, RSW is a social worker with the Ottawa Regional Cancer Centre.*



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# Where to start when you are looking for information about brain tumours

The Ninon Bourque Patient Resource Library at the Ottawa Regional Cancer Centre has prepared the information sheet below to help people with brain tumours find information and support.

“Where to Start? Sources of Information on Brain Tumours” is one of 14

“Where to Start” sheets, available also in French (“*Par où commencer...*”)

You can find these and other information resources for patients and families on our Web site at [www.orcc.on.ca](http://www.orcc.on.ca). Or phone the Ninon Bourque Patient Resource Library at 737-7700 ext. 6980.



*Prepared by the Ninon Bourque Patient Resource Library*

Basic Information	<b>Brain Cancer: What You Need to Know:</b> 8-page booklet providing information about the diagnosis and treatment of brain cancer. Produced by the Canadian Cancer Society. Also available online at <a href="http://www.cancer.ca/files/braincancerblk_e.pdf">http://www.cancer.ca/files/braincancerblk_e.pdf</a>
More Information*	<b>Brain Tumour Patient Resource Handbook*:</b> A 172-page manual providing more detail to assist patients and families in understanding brain tumours and the treatment options. Produced by The Brain Tumour Foundation of Canada in 1996. No charge. To obtain a copy, call 1-800-265-5106. (Online at <a href="http://www.btfc.org">www.btfc.org</a> ) <b>KC Jones Brain Tumour Binder.</b> To help you keep track of all the information related to the medical care of your brain tumour. Free For details, contact the social workers, Ottawa Regional Cancer Centre at 613-737-7700.
Newsletters*	<b>Brainstorm.</b> Quarterly newsletter from the Brain Tumour Foundation of Canada. 1-800-265-5106. <b>Brainscan.</b> Quarterly from the Gerry & Nancy Pencer Brain Trust. 416-946-4565 or <a href="mailto:holly.pencer@uhn.on.ca">holly.pencer@uhn.on.ca</a> .
Telephone Hotlines	<b>Brain Tumour Foundation of Canada 1-800-265-5106.</b> <b>Cancer Information Service 1-888-939-3333.</b>
Books*	<b>Navigating Through a Strange Land: A Book for Brain Tumour Patients and their Families</b> by Tricia Roloff, Indigo Press, 1995. <b>A Primer of Brain Tumours: A Patient's Reference Manual</b> American Brain Tumour Association, 1998. (online at <a href="http://www.abta.org">www.abta.org</a> )
Video*	<b>Living with a Brain Tumour</b> Brain Tumour Association of Canada and the British Columbia Cancer Agency, 1999.
CD-ROM*	<b>Understanding Brain Tumours</b> Jackdigital Oncology Interactive Series in collaboration with Princess Margaret Hospital. Toronto, 2001. A Computer CD-ROM that provides information about diagnosis and treatment, coping.
Support Group	<b>Adult Brain Tumour Support Group</b> Provides support and information for people with brain tumours, and their family/friends. For more information call Diane Ford – (613) 737-7700 ext. 6292.
Web Sites	<b>Brain Tumour Foundation of Canada – <a href="http://www.btfc.org">www.btfc.org</a></b> <b>American Brain Tumour Foundation – <a href="http://www.abta.org">www.abta.org</a></b>

**\*Available at the Ninon Bourque Patient Resource Library at the General Division of the Ottawa Regional Cancer Centre. For more information call (613) 737-7700 ext. 6980.**

The above resources are provided for information only and are not intended to replace medical advice. If you have any questions about your cancer treatment, please ask your doctor or nurse.

# Hormone Replacement Therapy: A case study in media coverage

By Douglas Gray

**O**n the Frontier was conceived as a vehicle for conveying to the readers of Challenge magazine some of the excitement of the research currently conducted at the Ottawa Regional Cancer Centre.

In other words, you should at this moment be reading about something in which we thought you should be interested.

This edition of On the Frontier will be a little different, written to address an issue that is of demonstrable and general interest.

It addresses the second most frequently asked question that is posed to me as a cancer researcher (the number one question is “so when are you going to come up with a cure?” which can be answered in a number of ways, all of them unsatisfactory.)

The runner-up question is generally put to me along these lines: one day I read in the papers that such and such is good for me, and the next day it is reported to cause cancer, so which is it, and why can't scientists agree? Ouch.

Scientists read newspapers too, and seldom without wincing. As a cancer researcher, I mainly wince at the cancer reportage, which has led me to propose Gray's Law of Media Discomfort (like many such laws, this is also recognizable as plain old common sense). The law states that when reading a newspaper, the frequency of wincing is directly related to the proximity of the story to one's own field of interest.

Science is very specialized, and a story related to a distant field cause no discomfort, whereas a story from closer to home is sure to generate a wince or two.

In my experience, a story about one's own research can leave the facial muscles exhausted. The law is not restricted to cancer scientists, and I suspect that it applies to particle physicists, as well as economists,



politicians or whatever. How could physicists not wince when the subject of a lifetime of study is portrayed in the form of a hopelessly simple analogy? Who could blame them?

The real trouble arises when contradictory stories appear, and I would argue that it is here that biomedical stories get special interest. If contra-

## **A sampling of Ottawa Citizen headlines related to HRT**

**Tuesday,  
June 29, 1999**

**Shunning estrogen  
replacement: Women just  
don't believe that it works**

**Thursday,  
September 30, 1999**

**Hormone therapy unlikely  
cause of cancer: Only  
tenuous link exists,  
leading health researcher  
tells conference**

**Saturday,  
July 13, 2002**

**Medical research is  
as much about fashion  
as fashion is**

dictory stories appear from the realm of particle physics, the public is unlikely to be terribly discomfited. If the prevailing wisdom regarding the Higgs boson were overturned tomorrow it would be unclear how we should modify our day-to-day behavior in response.

If however one reads on a given day that cell phones cause brain cancer and on the next that they are perfectly safe, what should one do? Carry on as before? Throw the thing away? Have shorter conversations?

From my reading of the popular media, confusing reports can be categorized as arising from one of just a few root causes. It is possible to illustrate the various roots of the problem using just one example from the recent cancer literature, and the media reports that flowed from it. The example I have chosen is the risks and benefits associated with hormone replacement therapy (HRT). Note that I am not a physician, and it is not my intention to dispense medical advice on the subject. Rather my purpose is to highlight the nuances of this issue that have generated such a flurry of seemingly contradictory messages in the media.

## **Source of confusion number one: Making general conclusions from specific findings.**

It was recently reported that a major trial to determine the efficacy of hormone replacement therapy was stopped due to increased risk to the women involved.

Many menopausal and post-menopausal women use HRT as a means of reducing the physiological disturbances associated with the decrease in estrogen production in their bodies, others rely on it to offset a decrease in bone mass that may lead to osteoporosis.

Having been told by their physicians that they may benefit from HRT (and in many cases having experienced such benefits firsthand) some

women reacted with outrage, even fury, to the news that HRT had fallen from medical favour. Women interviewed on the evening news stated that they would stockpile a supply of their drugs, and when that ran out find new sources on the Internet. But was such hysteria warranted? (And hysteria is not an altogether inappropriate term, given its origins as an intense psychological state related to female hormones.) Not when one looks at the matter a little more closely.

The source of the news story was a press release from the National Institutes of Health (NIH) in the United States, reporting that they had closed one component of a major clinical trial on the risks and benefits of HRT. The trial, which involved over 16,000 women, compared the health of women receiving a combination of the hormones estrogen and progesterone to women receiving inactive (placebo) pills. Although the trial was scheduled to conclude in 2005, ongoing examination of data showed that women receiving the hormones were experiencing elevated rates of breast cancer, heart attacks, and strokes. The risks were such that continuation of the trial was deemed unethical (details of the trial, its results, and the worldwide media coverage it generated can be seen on the website of the Women's Health Initiative, the NIH program responsible for the study ([www.whi.org](http://www.whi.org))).

This study did not dispute that HRT had benefits (indeed it provided further evidence for reduced hip fractures and colon cancer in women receiving HRT). What it said is that HRT involves risk; these risks are real and are now known. What at first seems like conflicting advice is not at all contradictory, and every physician I have heard to opine on the issue has said the same thing: HRT has risks in some areas which must be considered against its benefits in others. In this sense it is like every other drug therapy.

**Source of confusion  
number two:  
The measure of relative risk.**

If the HRT drug trial was stopped three years early, the risk must have been considerable, and in a sense it was. For every thousand women taking the hormones, in each year it was

calculated that there would be an additional eight cases of breast cancer, eight strokes, and seven heart attacks.

To consider only heart attacks, this would have meant a rise from 30 heart attacks per thousand women to 37. The trial was stopped because to continue it would have meant cancers, strokes, and heart attacks that could have been avoided.

Whereas the risk of a particular woman having health problems connected to the study was reasonably low, the enormous number of women in the study meant that associated deaths were very likely. Similarly, the individual risk to a woman taking HRT to offset osteoporosis or severe menopausal symptoms remains low, but must be taken into account when contemplating therapy.

Saturday,  
July 13, 2002

**Eat to Beat Menopause  
A prescription to eat cake  
to ease menopause: British  
readers swamp newspaper  
with thousands of requests  
for recipe for loaf**

Saturday,  
July 20, 2002

**An Rx for all: Is everyday  
life a disease that can be  
cured if only we could find  
the right pill?**

Wednesday,  
July 24, 2002

**Avoiding menopause  
panic: Physicians are of-  
fering practical alterna-  
tives to hormone replace-  
ment therapy which has  
been linked to an increase  
in lethal health problems**

As is evident from the HRT media frenzy, confusion is generated when individual risk is not separated from population risk. To cite a familiar example, your insurance agent has no particular insight as to when you might die, but he has actuarial tables that tell him how many people out of a thousand can be expected to die at each year of human life. If you take up smoking your insurance rates will go up not because the insurance company knows anything about your genetic constitution and individual ability to resist lung cancer, but because of the known risk to smokers as a population. Like casinos, insurance companies survive because they pay out with a frequency that is predictable, arising as it does from large numbers.

Parenthetically, people have a perverse ability to invert probabilities when it suits them. Witness the fellow in line at the convenience store buying a lottery ticket and a packet of cigarettes. Doing so requires a belief that the lottery odds are reasonable, while lung cancer is a real longshot. Go figure.

**Source of confusion  
number three:  
The inherent messiness  
of biology.**

When people want to portray something as being straightforward, they will say it is not rocket science.

To a biologist, this is an amusing anachronism, a historical relic. Comparatively speaking, rocket science is easy. It is composed of physics (the sort of physics that were known to Isaac Newton) and chemistry.

Rockets we can build, and send them to Mars if we so choose, because we understand the laws of physics and chemistry with sufficient precision. Biology is another story. We have succeeded in determining the sequence of all the genes of a particular man, but we know painfully little about how this information was put to work in building him from the single cell he once was. We do not know how the trillions of connections were established in his brain, or how this generates the thoughts he is currently thinking. We cannot predict

*Continued on page 30*

what will make him sick, or in many cases know how to make him well. Truly, this is not rocket science.

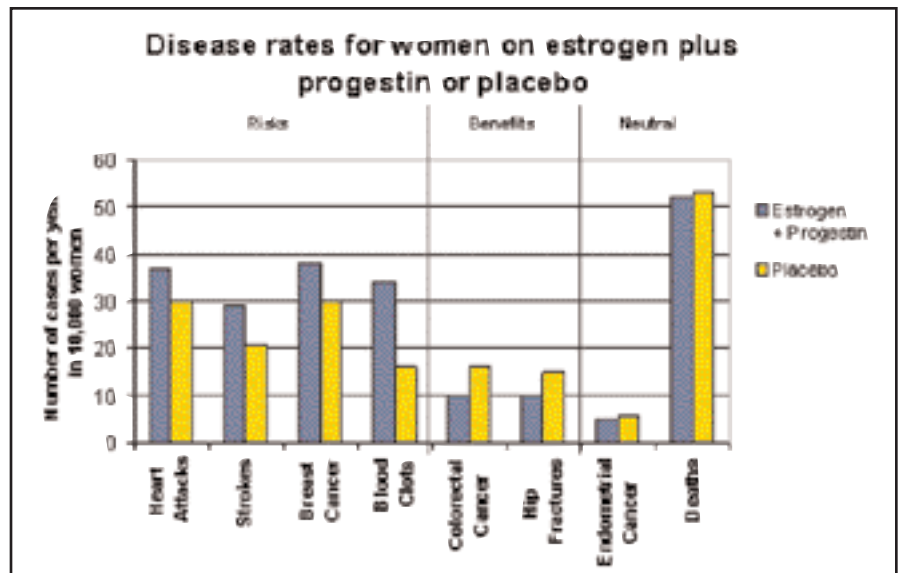
With respect to the HRT issue, it is not at all surprising that there are serious and complex side effects, given the number of cells in the body that can respond to steroid hormones like estrogen.

And if things were not complicated enough, estrogen exists in a biosynthetic pathway that includes a number of other steroid hormones, subject to interconversion. Layered on these metabolic pathways are intricate feedback systems to regulate hormone levels in response to varying conditions. One is bound to get a number of effects, some good, some bad, with an agent like estrogen, and one must gather data and examine the specifics of the intended therapy. If you do not consider this logic compelling, consider Coumadin. Coumadin is an anticoagulant drug, and is used in a number of medical conditions where clotting is a problem. Coumadin is more generally known as warfarin, or rat poison. The point is that one must consider the effects of a biological agent in their proper context.

### Source of confusion number four: Bad science.

It will be evident that in the writer's opinion science is a noble undertaking, but like any human endeavor it has its good and bad practitioners. The beauty of science is that if the question is answerable, the truth will eventually emerge, even if the trajectory from ignorance towards knowledge is not a direct one (in other words even if we are thrown off course by some shoddy work). Science is inherently self-correcting, because anything worth knowing will be of interest to multiple parties whose work must be reproducible by their competitors. One can have a moment of fame by announcing something irreproducible (cold fusion comes to mind), but lasting success in science is only granted to those whose discoveries can be verified.

For present purposes – evaluating science stories in the popular media –



– image from the Women's Health Initiative Web site.

### Confusion is generated when individual risk is not separated from population risk.

it is not possible to apply this standard (and it is very unlikely that a clinical trial with 16,000 participants will be repeated in any case), but there is a simple expedient that will help to weed out the worst sort of junk science. Look at where the data was published.

Most times the press release that initiated the news story was released to coincide with the publication of an article in a scientific journal. If that article appeared in one of the eminent medical journals (The New England Journal of Medicine, Lancet, and so forth) or one of the premier science journals (Nature, Science, Cell, etc.) the article has withstood the scrutiny of anonymous expert critics, and has more credibility than articles appearing in very obscure journals where the quality control is more variable.

The HRT data, by the way, appeared in the Journal of the American Medical Association, a highly respected source. If the story is based on data that has not been published it simply cannot be believed. The least credible stories will contain a built-in conspiracy theory, stating that the science elite are threatened by the new work and refuse to publish it, but don't buy it. Science journals love to publish articles that shake the foundations of science – there is no better source of free publicity.

Finally, and perhaps most importantly, one must consider whether one

is reading about anecdotal evidence or the results of a properly conducted 'double blind' study. The recent HRT study was very much the latter, comparing similar groups of women who were randomized to establish whether they would receive active drugs or inactive placebos. These women would not have known which pills they were receiving, nor would their physicians.

The confounding effects of expectations and wishful thinking could thereby be minimized. Only a standardized clinical trial of this sort, incorporating large numbers of test subjects, can deliver meaningful data (particularly where the effects are small or infrequent). In evaluating therapies there is no substitute for such trials, expensive and protracted though they may be.

To paraphrase Churchill, no one is saying that clinical trials are perfect or all-wise; they are the worst approach except for all others that have been tried.

Douglas A. Gray, PhD, is Senior Scientist, Centre for Cancer Therapeutics at the Ottawa Regional Cancer Centre.



# Ottawa Regional Cancer Centre Foundation

## Third party fundraising is community's gift to cancer care

**T**hird party fundraising is a great way to support the Ottawa Regional Cancer Centre and to raise money for patient care and research in your community.

Third party fundraising simply means that an organization, group or even a bunch of friends holds an event to raise money and sends the proceeds to their charity of choice.

With so many wonderful organiza-

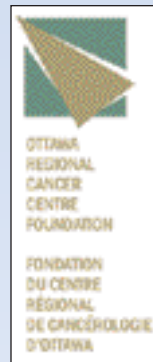
tions to support, the Ottawa Regional Cancer Centre is fortunate that so many people understand its importance in Eastern Ontario.

Third party fundraising events are appreciated not only for the funds they raise, but also for the recognition they bring to the Cancer Centre and the excellent work it does.

Known as a Centre of Excellence in many of its programs, the Cancer Centre's positive image is further enhanced when the community steps up

to raise money for it. Often people will host third party events as a way of thanking the Cancer Centre for the care it has provided to a family member, friend or colleague.

An example of third party fundraising is our cover story about Paul "Boomer" Throop and his Ride to Survive. While most people will not take it to Boomer's extreme, third party fundraising is a great way to support Eastern Ontario's only cancer treatment facility and it's fun too!



### A "How-to" guide to third party fundraising

*Here are a few guidelines that make third party fundraising simple. Each guideline is in place to ensure that events run smoothly and assist the Foundation in complying with the Canada Customs and Revenue Agency regulations.*

- Organizers must complete an application form available from the Foundation for special events and sign the "Fundraising Initiative Agreement" and submit it for approval.

Once approved, a letter will be provided to the organizing committee from the Foundation. It is important to note that the Foundation does not provide seed funding to third party fundraising events.

Third party events are intended to operate their financial arrangements independent and separate from the Foundation. If your event requires public liability insurance please contact the Ottawa Regional Cancer Centre Foundation Office in writing six weeks prior to the event. The Ottawa Regional Cancer Centre Foundation must not be party to any liability coverage without prior approval by the Foundation.

- Advertising materials must be approved before production by the Foundation to ensure proper wording and materials (logo etc.) are used. The Foundation will make every effort to assist in the promotion of events throughout the Centre by means of our newsletter, e-mail and posters.

- Resources are available through the Foundation to assist you with the event (promotion materials, administrative support, logos, etc.) The responsibility remains with the host organization and or organizing person(s), for the selling of tickets and volunteer recruitment.

- Speakers may be provided upon request (subject to availability) with reasonable lead-time.

- Ensure that for those individuals requiring a receipt that their full name, address, postal code and a corresponding cheque for the amount to be receipted is provided. According to Revenue Canada Regulations, a receipt cannot be issued without a donation of equal amount. For more clarification on the Foundation's receipting policy, please contact Annie Parker, Special Events Coordinator at 247-3527 or by e-mail at [Annie.Parker@orcc.on.ca](mailto:Annie.Parker@orcc.on.ca)

- Proceeds from your event should be received in the ORCCF office no later than three weeks from the date of the event in a cheque made payable to The Ottawa Regional Cancer Centre Foundation.

#### ***Thanks to our third party fundraising events***

Fay Bisailon Memorial Dinner and Auction  
Rhapsody in Gold  
Lida Boutique "Celebration of Life" Fashion Show  
Annual Cuts for Cancer  
An Evening with Abigail Silent Auction  
Children for Charity Celebrity Auction  
Robert Bateman Walk  
The Motorcycle Ride for Dad  
Challenger's Softball Tournament  
ORCCF Meadows Golf Classic  
Lindsay Service Golf Tournament  
Thomasville Home Furnishing Silent Auction  
Rotary Club of Ottawa South Golf Tournament  
O'Brien & Friends Golf Tournament  
Mid-Summer Jamboree, Royal Canadian Legion  
Dinner and Dance, Moose Lodge  
Annual ORCCF Charity Golf organized by the Army, Navy and Air Force Veterans in Canada, Ottawa Valley Unit #396 and the Carlbeck Golf and Country Club  
Brockville Prostate Cancer Research Golf Tournament  
Betty Tweedy Golf Tournament  
Svend Peterson Memorial Golf Tournament  
Cruise for the Cure  
Boomer Throop Ride to Survive  
Quest for a Cure Adventure Race

# JOIN THE FIGHT!

Unfortunately, everyone knows someone who has been touched by cancer. Our hockey family is no exception. Hockey Fights Cancer is committed to raising money and awareness for hockey's most important fight.

To make a donation or find out more information, call 1-800-540-6500 or log on to [www.hockeyfightscancer.com](http://www.hockeyfightscancer.com).



[www.hockeyfightscancer.com](http://www.hockeyfightscancer.com)

**1-800-540-6500**



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