

## CCAN takes action for access to effective drug treatments

By Susan J. Turner, Turner & Associates Inc.



**Nothing speaks like experience.**

*Cancer patients know what works and what doesn't.*

**Many Faces...  
One Voice.**

The lives of many Canadian cancer patients are being saved and extended by new health technologies, including medications. The high costs of these advances however have revealed inequities in how Canadians can gain access to these treatments. "Optimizing Cancer Drug Access for Canadians" is a springboard for informed stakeholders to deliberate about the serious gaps in our current system.

Working with the Public Policy Forum and the Canadian Cancer Society, CCAN is leading a collaborative approach that holds leaders accountable for ensuring Canadians receive a high standard of care by convening a multi-stakeholder symposium to draw attention to gaps, and seek solutions.

**How are Canadians benefitting from new cancer drugs?** There is no question that new advances in cancer drug therapies have saved and extended lives. For example, nine out of ten patients with chronic myelogenous leukemia treated with imatinib (Gleevec®) now live for many years after their diagnosis. Other cancer drugs prolong survival of terminally ill patients by several months, which may mean a doubling of their remaining life expectancy.

**Why is there a problem?** While the benefits of these newer cancer drugs are being reaped, their cost has risen dramatically. Many more cancer drugs are used today than in the past, and their price tags are much higher. This dynamic situation has exposed inequities among Canadians—*inequities that must be addressed.*

## OPTIMIZING CANCER DRUG ACCESS FOR CANADIANS

SYMPOSIUM ISSUES

**Coverage for Canadians:** Because drugs taken at home are not automatically covered by our public health system, Canadians' access to these treatments depends on how well – or even whether – they are insured. Over half of Canadians are covered privately for health benefits through their employer. Losing a job could mean losing coverage for life-saving treatments – a significant risk in today's economy. For those without insurance, high drug costs can be catastrophic and there is no uniform system of coverage across Canada.

**Pan-Canadian standards of treatment:** Canadians need to be assured that wherever they live and regardless of their economic status, they will be able to receive the drugs recommended by their oncologist. In our present fragmented system, each drug plan makes a separate decision about which drugs it will fund. A cancer patient in one province may be denied an effective treatment that is provided to a patient in another province. Agreement is needed across the country on what the standards of treatment should be.

**Cancer drug prices:** CCAN believes that the prices of cancer drugs must not be allowed to limit Canadians' access to new treatments now or in the future. Solutions are needed that balance the need for an environment conducive to the development of new therapies with the sustainability of systems of drug coverage.

## Cancer drugs: Only the best should do!

Submitted by Pam Del Maestro, Brain Tumour Foundation of Canada

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*"Both my parents have had cancer. They've survived but it was a struggle for the whole family. There have been many challenges but what we didn't anticipate were the issues we faced related to the availability and cost of recommended drug therapies."*

This can be an all too familiar story in Canada today.

The majority of persons diagnosed with cancer in Canada will at some point be offered some form of drug or chemotherapy. In the past, any mention of the word chemotherapy would have triggered many concerns such as how hard it would be to tolerate, how many trips it would mean to the hospital, and most importantly, if the treatment would work.

But in today's world, Canadians have another, more troubling worry: they must face the very real possibility that the drug of choice for their specific cancer will be one of the more potent biological agents which are supplanting standard chemotherapy and, because of their expense, may not be accessible to them in their province or territory in spite of being approved for use by Health Canada.

In the past 10 – 20 years, the protocols related to the use of drugs in the treatment of cancer have changed dramatically throughout the world. Previously, treatment consisted largely of agents known as chemotherapy which had considerable toxicity and which were generally used after surgery to prevent a tumour growing back or after radiation therapy when a tumour recurred.

Today, there are increasing numbers of new cancer drugs, called biological agents, which are used in new situations: before surgery, in conjunction with radiation therapy, after radiation therapy and even on an ongoing basis. These cancer drugs tend to be targeted therapies which may be more effective and, in general, less toxic than traditional chemotherapy.

With these newer drugs, cancer patients can have a better quality of life and delay progression of disease; cancer survivors can live longer and better today than ever before. However, these newer drugs cost more in terms of research and development, regulatory approvals and marketing. Costs for the new therapies can run into thousands per month.

In the past, the cost of cancer drugs was almost always paid for publicly (by our provincial and territorial governments) as treatments were administered in the hospital. With oral medications, hospitalization is no longer necessary. Increasingly, private drug plans and the patients themselves are being asked to pay for these "out of hospital" treatments, or sometimes even "in hospital" treatments depending on the specific drug.

Jane Hauser, a facilitator of a Brain Tumour Support Group underscores the issue: *"Every month I meet many families with many questions about drug coverage. Surely, they have enough to worry about. If and how their drugs will be paid for should not be one of them."*

Today, drug therapy for cancer in Canada can be paid for by public (government) drug plans, private drug plans, patients themselves or by a pharmaceutical company on a compassionate basis. Publicly funded health care in Canada is mandated federally but delivered provincially. What this means is that each individual province makes its own decisions as to how to use the funds that have been transferred from Ottawa. These decisions are based on economic considerations as well as provincial standards. Just because the federal government approves a medication for use in Canada does not necessarily mean that it will be on the formulary of all provinces. Approval and coverage for cancer drugs varies from province to province.

Depending upon where you live, the drug you need may or may not be covered under your government health plan, may or may not be covered by private insurance (if you are lucky enough to have it) or, in the worst case, may or may not even be available for your doctor to prescribe (on the provincial formulary) should you have the means to pay for it yourself.

Your neighbours in another province or territory might have easy access to the very medication that you cannot get, simply because of where you live. Most Canadians assume that universal coverage means that everyone in Canada has access to the same level of health care benefits. **Not so.**

Unfortunately, most Canadians also assume, incorrectly, that health care in their province is immediately transportable and transferable across the country. In fact, there is almost always a three month waiting period to acquire the benefits of the new province and the benefits of that province will almost certainly be different. Universal does not mean the same or equitable coverage, but simply that some form or level of coverage is provided across the country.

In some provinces, a number of cancer drug therapies administered at home are paid for publicly. But more often than not, the expectation is that they will be paid by the patient or the patient's private drug plan.

The problem is that not all Canadians have a drug plan and particularly, many self employed individuals and a small number of retired persons do not have coverage. Even those who do have a drug plan may find that the drug they need is not covered by their particular plan or that the co-pay (see below) is more than they can afford. In order to pay for the drugs themselves, some Canadians mortgage their homes, use up all their retirement savings... and some simply don't get the drugs they need because the money is just not there.

With increasing prices it is not surprising that employers and insurance companies are now starting to ask patients to share the financial costs. This is reflected in caps on insurance (where a subscriber has a lifetime amount that can be spent), higher premiums, and increasing deductibles and co-payments (This is where the company pays a certain percentage and the employee pays the other).

Such cost-sharing arrangements can result in budget-breaking charges for some drugs and may put some critically important drugs out of reach for ordinary Canadians.

There is now an increasingly heated debate taking place in Canada by concerned citizens as to how decisions are being made by the provinces to determine which drug therapies should be listed.

Canadians need to be better informed about how cancer drugs are approved in Canada, how they are paid for, and most importantly, how they can access them.

Canadians can no longer sit back and tell themselves that they have universal health care and hence have nothing to worry about.

This paradigm shift will continue in the future to more targeted, biological therapies in the treatment of cancer. Persons with cancer will be on these therapies longer and the cost increases to the system will be inevitable. Individual provinces and territories will set their own priorities based on economics and standards when it comes to the approval and funding of cancer drugs.

The Canadian Cancer Action Network (CCAN) recommends that Canadians understand the nature of their own provincial or territorial public drug plan as well as their own particular private plan, if they are fortunate enough to have one. The time to examine this is now, today, and not in a crisis situation.

Cancer agencies such as CCAN are working vigorously toward creative solutions that will ensure that cancer patients, wherever they may live in Canada, have appropriate access to a clinically proven drug therapy through an affordable means.

Government agencies (public coverage), private insurance companies, pharmaceutical companies and interested cancer groups all need to be part of the solution.

To find out more information about the complexities of coverage of cancer drugs in Canada, read the Canadian Cancer Action Network report, **Issues of Access to Cancer Drugs in Canada** at: [www.ccanceraction.ca](http://www.ccanceraction.ca)

## ABOUT THE AUTHOR



PAM DEL MAESTRO

Pam Del Maestro graduated from the University of Western Ontario in 1972 with her Bachelor of Science in Nursing. She was awarded the Gold Medal in Nursing. She worked in psychiatry and community health before "joining forces" in 1979 with her husband and neurosurgeon, Dr. Rolando Del Maestro.

Pam worked in his neurosurgical practice and ran his Brain Tumour Clinic for over 20 years and is one of the founding Directors of the Brain Tumour Foundation of Canada and the founder of the Support Group Program.

Pam is past Chairperson (and first Canadian Chair) of the North American Brain Tumour Coalition based in Washington, DC. A past board member of CCAN, Pam represented the Brain Tumour Foundation of Canada at CCAN Members Council and was head of the CCAN committee that first began addressing patient issues.

# Uniting patient-oriented cancer groups from across Canada to ensure one unified voice on patient issues.



## Many Faces... One Voice.

### CCAN MEMBERS COUNCIL (2009-2010)

#### Cancer-Site Patient Organizations

Brain Tumour Foundation of Canada  
Canadian Breast Cancer Network  
Canadian Liver Foundation  
Canadian Lung Association  
Canadian Skin Patient Alliance  
Canadian Thyroid Cancer Support Group (Thry'vors Inc.)  
Carcinoid NeuroEndocrine Tumour Society Canada  
Childhood Cancer Foundation Candlelighters Canada  
Colorectal Cancer Association of Canada  
Kidney Cancer Canada  
Leukemia & Lymphoma Society of Canada  
Lung Cancer Canada  
Lymphoma Foundation Canada  
Myeloma Canada  
Ovarian Cancer Canada  
Prostate Cancer Canada (formerly Canadian Prostate Cancer Network)  
Young Adult Cancer Canada

#### Population Organizations

Assembly of First Nations  
Canadian Cancer Society  
Canadian Partnership Against Cancer  
Cancer Advocacy Coalition of Canada  
Inuit Tapiriit Kanatami

## WHO ARE WE?

In 2001, there was a strong belief that a coordinated, unified organization comprised of patient-centered organizations was needed to fill a niche in the Canadian cancer landscape. As a result, CCAN was created in order to ensure that as work in cancer control progressed, patient interests and the unique patient perspective remained integral to the national cancer control strategy.

Comprised of prominent national organizations and key representatives from across Canada, CCAN works in collaboration with those represented at Members Council—voices who represent an enormous network of cancer patients and their families.

Representing those impacted by cancer, CCAN informs the Canadian Partnership Against Cancer on issues pertaining to the cancer continuum.

### 2008-2012 CCAN GOALS:

- *To ensure issues relevant to cancer patients and their families are addressed by the emerging cancer control strategy.*
- *To empower and encourage the cancer patient voice to be heard resulting in positive and quantifiable change.*
- *To establish a strong, active and recognized CCAN presence in each province and territory.*
- *To cultivate and pursue opportunities for effective dialogue and interaction with stakeholders.*

#### Provincial CCAN Members

British Columbia  
Manitoba  
New Brunswick  
Newfoundland & Labrador  
Nova Scotia  
Ontario  
Quebec (Coalition Priorité Cancer au Québec)  
Saskatchewan (SCAN)

#### Representatives on CPAC Action Groups

Cancer Guidelines  
Cancer Journey  
Health Human Resources  
Primary Prevention  
Research  
Screening  
Surveillance