



Dialogue

Summer 2009 Issue

Symposium on Cancer Drug Access for Canadians: CCAN takes action for access to effective drug treatments

By Susan J. Turner, Turner & Associates Inc.

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. Co-sponsored by the Public Policy Forum, the Canadian Cancer Action Network is convening a multi-stakeholder symposium in September of 2009 to draw attention to these gaps, and to 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. Newer cancer drugs are generally much better tolerated than traditional chemotherapies and many are taken at home, significantly improving patients' quality of life.

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. CCAN plans to address three areas of concern at the symposium this fall.

AREAS OF CONCERN

1. 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.

2. 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.

3. 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.

"The symposium will be a springboard for action. Once stakeholders are informed about the serious gaps in our current system, CCAN will continue to work with cancer patients, oncologists and the general public for system change. Working with the Public Policy Forum, our goal is to lead a collaborative approach that holds leaders accountable for ensuring that all Canadians receive a high standard of care and brings together stakeholders to develop effective solutions for continuing drug access."

SUSAN J. TURNER – Cancer Drug Access for Canadians symposium consultant / author of "Issues of Access to Cancer Care in Canada" report





As I write this piece, Mother's Day was just recently celebrated. In my own family, five young children lost their mother when she succumbed to cancer while still youthful in her mid-forties. Needless to say, for all of us, every day is Mother's Day.

Today, I note that National Cancer Survivors' Day is being celebrated on June 7th but, as with Mother's Days, we celebrate cancer survivors every day of the year. Fortunately, survival rates for many cancers have shown significant improvements – we all want to see these rates continue to improve until the disease is fully conquered.

This is the 22nd year of NCSDF which is recognized in Canada - and around the world - as an opportunity to demonstrate that we have an active and productive cancer survivor population. This is reflected in the exceptional growth and effectiveness of the Canadian Cancer Action Network in advancing the interests of cancer patients, survivors and their families. However, in spite of major advances in cancer prevention, diagnosis and treatment, a host of problems still confront the cancer community including:

- *Access to promising new treatments which can be very expensive*
- *Unavailable and/or inadequate public or private insurance coverage for these treatments*
- *Physical, emotional and financial hardships which can persist years after treatment*

As National Cancer Survivors Day approaches, CCAN can pay no greater tribute to all cancer survivors and their families than to constantly renew our commitment to seek improvements in all of these areas.

For further information on National Cancer Survivors Day 2009, please visit: www.ncsdf.org

CCAN MEMBERS COUNCIL EXPANDS IN 2009!

CCAN is very pleased to welcome the addition of two new cancer-site organizations to Members Council.

Myeloma Canada was created in 2004 to provide people living with myeloma educational resources and emotional support, as well as provide access to information. Myeloma Canada is the only national organization that is uniquely devoted to the Canadian myeloma community.

Young Adult Cancer Canada (based in Newfoundland) provides Canada-wide programs to young adult patients and survivors. The vision of this organization is to eliminate the isolation for young adults with cancer, delivering a variety of national education and support programs.

...A word from Aaron Levo, Canadian Cancer Society

CCAN is pleased to announce that Aaron Levo, Canadian Cancer Society has accepted the role of Chair of the 2009 symposium, **Cancer Drug Access for Canadians**.



"Drug access issues affect patients more than anyone else. The 2009 Cancer Drug Access for Canadians Symposium is a unique opportunity for CCAN to represent the patient voice and impart a sense of momentum for policy changes to improve cancer drug access. Through collaboration, CCAN is striving for patient-focused solutions that improve our health system for generations to come."

Aaron Levo, Manager of Public Issues
National Public Issues Office Canadian Cancer Society
Ottawa, ON

The cancer landscape in Québec:

Access to healthcare and support for people with cancer in Québec

By Marjorie Morrison, Executive Director

In an effort to better understand the cancer landscape in Québec, the firm of *Leger Marketing* was hired by the Coalition Priorité Cancer au Québec to conduct a survey evaluating accessibility to care and support for people with cancer in different regions of Québec. This initiative was funded by CCAN.

The survey was administered in April of 2009 to 800 residents of Québec (in both urban and rural communities) who were either diagnosed with cancer in the past two years, or who knew someone close to them who had been diagnosed within that timeframe.

In total, 300 telephone interviews and 500 web interviews were completed offering an insightful picture of the various concerns relevant to cancer care in Québec. Of the 800 respondents, 44% were male and 56% were female with the highest number (22%) in the range of 45-54 years old. Of these, 21% had been diagnosed with cancer; 64% of the respondents had a family member diagnosed and 13% reported it was a close friend who had battled cancer in the last two years.

Upon analysis of the data compiled by *Leger Marketing*, it was realized that there were a total of 21 types of cancer that formed the basis for respondent responses. (Of these, the highest percentage of respondents were linked to a breast cancer diagnosis (23%), followed by lung cancer (17%) and colorectal cancer (6%).)

When the 800 respondents were asked about access to drug insurance for cancer patients, 45% indicated drugs were paid for in full by either public or private drug insurance, while 32% indicated they had to pay a portion of the drug cost direct. 22% declined to answer, or were not aware.

Costs remain an obstacle for people with cancer. *Leger Marketing* reported that a considerable proportion of respondents feel that the financial assistance offered to people with cancer (35%) and those close to them (46%) is insufficient to cover all the expenses and loss of revenues. In fact, 60% of patients did not receive any financial support.

However, despite the deficiencies encountered in treating their cancer (or in supporting someone close to them who is sick) respondents remain optimistic about how the situation is evolving to treat people with cancer in Québec. The majority think that chances of survival are better than five years ago (77%) and that the healthcare system treats people with cancer more effectively (63%). They also believe that the system will be even more effective in five years (60%). The healthcare system is still nonetheless perceived as slow. In fact, respondents are uncertain whether or not cancer treatment is faster than five years ago or if it will be quicker five years from now (respectively 52% and 47% of respondents answered in the affirmative).

Reference: *Quantitative Research Report—Access to healthcare and support for people with cancer in Québec.* Leger Marketing.

To read the entire report by *Leger Marketing*, please visit www.ccanceraction.ca.



Gilles Leveille (Coalition Priorité Cancer au Québec/Chair CCAN Québec) with Natalie Rodrigues. (CCAN Québec)

ADDITIONAL KEY FINDINGS

Not all people with cancer obtain quick and easy access to healthcare.

Access to diagnostic tests, the results of these tests, as well as an oncologist was considered a difficult and lengthy process by a proportion of respondents ranging between 10% and 23%, depending on the case. (We observed marked difficulties in Outaouais with respect to diagnostic tests.)

18% of people with cancer had never had contact with a nurse navigator or coordinator. Those who were fortunate to have a nurse navigator were satisfied with his/her availability (in 89% of cases).

14% of patients who received psychological support experienced a long wait and difficult access.

17% of people who needed rehabilitation had difficulty gaining access to these services.

15% of people with cancer did not have a family doctor at the time of diagnosis and 21% of people did not have access to a CLSC either.

To circumvent problems with access to health care, 16% of people with cancer relied on the private healthcare system.

People with cancer do not receive all the available information.

30% of patients did not receive information on community organizations and support groups that could offer them certain services. Also, in 14% of cases, no information on these groups was available at the location where the people received treatment.

The possibility of participating in clinical studies was only suggested to 17% of people with cancer. Doctors suggested types of alternative medicine to only 6% of patients.

Cancer drugs: Only the best should do!

By Pam Del Maestro, Brain Tumour Foundation of Canada



“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 advocacy groups 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

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 by the university. She worked in psychiatry and community health before "joining forces" in 1979 with her husband and neurosurgeon, Dr. Rolando Del Maestro. She worked in his neurosurgical practice and ran his Brain Tumour Clinic for over 20 years. Pam is one of the founding Directors of the Brain Tumour Foundation of Canada and is 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. The Brain Tumour Foundation of Canada is a founding member of this group thanks to Pam. A past board member of CCAN, Pam represented the Brain Tumour Foundation of Canada and was head of the committee that addressed core patient issues.

In December 2000 Pam and her husband were selected as "Heroes of Health Care" by the National Post for their contribution to the care of brain tumour patients in Canada and, in 2008 they were nominated for the Canadian Medical Hall of Fame.

COMING SOON!**Canada's gateway to cancer information and resources Cancer View Canada to launch in Summer 2009**

Which cancer studies are currently recruiting patients in Canada? What peer support services are available for people diagnosed with cancer or their family members? Where can cancer patients find out about local cancer care resources and services?

For each of these questions and many others, the answer will be found at **Cancer View Canada**, an ever-evolving online community and work space for people interested in improving cancer control in Canada.

An initiative of the Canadian Partnership Against Cancer, **Cancer View Canada** is launching in the summer of 2009. It aims to help people personally affected by cancer, as well as people working in cancer control, by providing a single online location for the best available cancer knowledge. It also connects people affected by cancer to one other and to services and resources specific to their individual needs.

"Canada's cancer community is vast. Amazing work is happening across the country and new information is emerging all the time -- but it can be difficult to stay up-to-date," says Lee Fairclough, vice-president of knowledge management for the Partnership.

"**Cancer View Canada** has been created as a gateway for people to easily find selected and credible information, services and resources from Canadian sources and to connect with others facing similar situations either personally or professionally."

STAY TUNED—Updates about **Cancer View Canada** will be provided in future issues of *Dialogue*.

In Ontario: Patients at the heart of regional cancer care enhancement

By Cathy DeGrasse, BScN, MScN, Senior Advisor, Regional Cancer Operations, The Ottawa Hospital Cancer Program



Patient and population engagement is at the heart of all strategies aimed to enhance access to quality cancer services. The Champlain Regional Cancer Program (RCP), under the leadership of The Ottawa Hospital Cancer Program, has undertaken an innovative approach to ensuring patient and population input into improving regional cancer care.

Through a community nomination process, individuals affected by cancer were recruited for Champlain Regional Community Advisory Committee membership, to bring the consumer perspective to the Champlain RCP development. The committee ensures adequate and meaningful patient input regarding quality improvement initiatives across the full cancer care journey.

Members have played an active role in ensuring patients have a smooth transition through the system and have an understanding of, and input into, their planned care. More specifically, they have participated in clinical pathway (care maps) development for various points on the continuum such as cancer surgery.

Access to information and other supportive care services is an important aspect of cancer care. Members have reviewed several draft patient educational materials

and have had representation on our new Psychosocial Oncology Program Committee.

Members have participated in up front planning of cancer services by attending a regional systemic therapy workshop to develop a Systemic Therapy Enhancement Plan, and reviewing architectural plans for our new cancer centre. It was invaluable to have the patient perspective embedded within these interdisciplinary, regional planning processes.

Finally, committee co-chairs are active members on the Champlain RCP Steering Committee. As a result, they contribute to the process of performance review and priority setting, thereby, ensuring patients can more easily navigate through the cancer system.

To date, committee members have had a direct impact on shaping the regional program and also on initiatives to improve the experience of patients, quality of life, knowledge of cancer and the overall regional cancer system.



Building momentum...coast to coast

By Marjorie Morrison, Executive Director



In February of 2009, CCAN welcomed representatives from Prince Edward Island to CCAN Members Council solidifying PEI as the *ninth province to form a provincial CCAN*.

In a matter of months, this dedicated group of individuals from PEI have made tremendous strides. With the support of the Canadian Cancer Society—PEI Division and direction from the CCAN national office in Toronto, CCAN PEI will begin to focus on key patient issues relevant to their provincial jurisdiction.

This scenario is unfolding across Canada as CCAN continues to invest in the growth and development of an expanding network of informed patient voices working collaboratively to introduce much needed changes to the pan-Canadian cancer landscape. Currently, the provinces of British Columbia, Saskatchewan, Manitoba, Ontario, Québec, New Brunswick, Nova Scotia, Newfoundland/Labrador and Prince Edward Island all have a provincial CCAN in place. This is an amazing testament to the spirit and determination of a growing network of patients determined to ensure patient interests remain a key priority on the emerging cancer control strategy agenda.

THE ROLE OF A PROVINCIAL CCAN: All provincial CCAN teams (under the guidance of a provincial committee and the leadership of CCAN) function as a core part of the regional initiatives portfolio managed by Herold Driedger, Chair. By mobilizing patient voices, a provincial CCAN is able to support the overarching agenda of CCAN Members Council by actively exploring, identifying and acting on patient issues or concerns considered most critical to patient constituents in that particular province.

For example, in the province of Manitoba the key area of focus for 2008/09 was to explore access to cancer services in the province from a patient perspective. By hosting focus groups across the province, in collaboration with the Canadian Cancer Society-Manitoba Division, CCAN Manitoba (lead by Pam King) has successfully engaged patients and stakeholders in an effort to (a) bring awareness to the report and (b) prepare to advocate on behalf of Manitoba cancer patients and their families.

In Ontario, the newly expanded provincial CCAN team (lead by Antonia Codispoti) are reviewing how best to link CCAN Ontario with the Local Health Integration Network (LHIN) by exploring opportunities created through the adoption of a community cancer advisory committee model.

These are exciting times for CCAN! Manitoba and Ontario are two fine examples of coordinated provincial efforts to bring the patient perspective forward—efforts that are being duplicated in the other provinces using a variety of avenues, vehicles and/or means.

Indeed, from coast to coast a strong CCAN network of informed patient voices (reflective of a range of cancers, demographics and backgrounds) are working together to ensure cancer patients are engaged in dialogue with stakeholders working in the cancer control continuum.

NOTHING SPEAKS LIKE EXPERIENCE

To reach your provincial CCAN representative, or to express an interest in joining our growing network of patient voices, please contact:

NOVA SCOTIA: info.ns@canceraction.ca
 NEWFOUNDLAND/LABRADOR: info.nfldlab@canceraction.ca
 NEW BRUNSWICK: info.nb@canceraction.ca
 PRINCE EDWARD ISLAND: info.pei@canceraction.ca
 QUEBEC: info.qc@canceraction.ca
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CCAN

WHO ARE WE?

The Canadian Cancer Action Network (CCAN) is a volunteer-driven, incorporated organization dedicated to ensuring patient interests remain a key priority on the national cancer agenda. CCAN was created in order to ensure that the patient perspective is (and remains) an integral part of the national cancer control strategy.

CCAN unites all cancer-site patient support organizations from across Canada in support of the Canadian Partnership Against Cancer (CPAC) agenda.

Functioning as a key voice, CCAN informs CPAC on issues pertaining to cancer from prevention, early detection, screening, education, control, research, treatment, care and the pursuit of a cure.



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

CCAN Members Council

Cancer-Site Patient Organizations

Brain Tumour Foundation of Canada
Canadian Breast Cancer Network
Canadian Liver Foundation
Canadian Lung Association
Canadian Prostate Cancer Network
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
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

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

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If you wish to submit an article of interest for publication, or to discuss any of the highlighted initiatives or projects, please contact CCAN today.

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www.ccanceraction.ca