CCAN RALC
Canadian Cancer Action Network
Réseau d'action de lutte au cancer

Dialogue

Fall 2008 Issue

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In the complex and often overwhelming world of cancer control, it is essential that the collective voices of our Canadian Cancer Action Network (CCAN) Members Council —*voices tasked with ensuring the cancer patient voice is heard and understood* — remain strong, focused, persistent and influential.

Some of us become immersed or involved in the cancer community due to our affiliation as caregivers, family members, partners or close friends of those diagnosed. Others become involved as a result of a private battle with cancer. Regardless of how we come together, whether we are volunteers or staff, there is an unmistakable common thread that links each of us to the other. Our CCAN membership is motivated and empowered by an unwavering determination to move forward improvements to a cancer system that does not currently offer equality or sufficient accessibility for all Canadians.

With the support of a strong and diversified CCAN Members Council and our affiliate partner, the Canadian Partnership Against Cancer (CPAC), CCAN will focus on five key strategic priorities in the next four years—priorities that will effectively position us to actively identify, pursue and implement measurable changes to the pan-Canadian cancer landscape from a patient perspective.

Entitled ***Making Our Voices Heard*** this comprehensive four year "road map" will help CCAN ensure the following:

- *Key patient issues common to patient constituents of those at CCAN Members Council are addressed with visible results, and leave a lasting imprint.*
- *Provincial initiatives and projects geared toward identifying and resolving gaps in regions all across Canada are not only brought to the forefront, but become catalysts for change.*
- *The critical patient voice is successfully represented in all areas of decision and policy making.*

Marjorie Morrison, Executive Director

CCAN Members Council Meeting, TORONTO, ON (June 2008)

CCAN Strategic Priorities (2008-2012)

PATIENT ISSUES
To ensure all issues relevant to cancer patients and their families are appropriately addressed by the Canadian Partnership Against Cancer, and the emerging national strategy.

PATIENT VOICE
To empower and encourage the cancer patient voice to be heard resulting in positive and quantifiable changes.

REGIONAL INITIATIVES
To establish a strong, active and recognized CCAN presence in each province and territory through provincial CCAN representation.

EDUCATION & AWARENESS
To ensure effective internal and external vehicles for communication and interaction with all relevant stakeholders are cultivated and maintained.

GROWTH & SUSTAINABILITY
To establish and implement a strong, effective governance model for CCAN.

A Message from the Chair, Jack Shapiro

I am pleased to report that these past few months have seen dramatic changes in the CCAN landscape. More specifically; we were incorporated; we concluded an agreement of affiliation with the Canadian Partnership against Cancer; we hired an Executive Director...and we established a Toronto office for CCAN. It's all a far cry from the fragility of our earlier years!

However, all of our work will count for little unless we can continue to mobilize strong patient and community support for the goals and activities of the Partnership. Essentially, that's the reason for our very existence. With a 4-year strategic plan recently developed, we now have the necessary tools in place and a clear sense of direction in order to accomplish that purpose. As your Chair, I believe our strong CCAN Members Council is up to the task.

In order for CCAN to successfully move forward, the work of our *Regional Initiatives Committee* needs to be reflected in energetic and passionate education at the provincial, territorial and local level.

In future, our *Issues Committee* will be required to focus on insightfully defining the issues which are of greatest concern to cancer patients and their families.

Our *Patient Voice Committee* will be expected to be forceful and determined in order to ensure that patient voices are heard clearly, wherever cancer policy decisions are formulated.

Lastly, it will fall to our *Communications and Marketing Committee* to be creative as they consider and employ whatever steps are necessary to ensure that the patient perspective is understood across the country.

...From Our Communications Chair, David Stones

It's proven time and again in the annals of business management: solid internal and external communications are critical to an organization's success. From keeping your members and external audiences informed; to engaging your constituents; to building prospective new membership: the reasons for focusing on communications are numerous.

This inaugural issue of ***Dialogue*** marks a turn in our efforts to communicate more vigorously with our members and external stakeholders. We hope that all CCAN members will read it carefully, share it with friends and business colleagues, and use it as a handout at every opportunity. In doing so, we're not only communicating who we are and what we're doing, we're also developing and entrenching the CCAN "brand" within Canada's cancer control landscape. We're reminding people of the importance of ensuring that the patient perspective is infused into all key decision making related to our country's cancer control system.

So read, enjoy and share your stories with our ED and editor, Marjorie Morrison. Through ***Dialogue,*** we will be a stronger more unified organization.

David Stones
Vice Chair, CCAN
Chair, Communications and Marketing Committee

Provincial Chairs

Manitoba
Pam King

New Brunswick
Julie Easley

Nova Scotia
Shirley MacLeod

Newfoundland & Labrador
Jeff Blackwood

Ontario
Toni Codispoti

Quebec
Gilles Leveille

Saskatchewan
Ron Reavley

Regional Initiatives Portfolio: CCAN Manitoba

It is widely recognized that access to care for cancer patients in Canada has been a national and provincial issue of concern for many years. Within the province of Manitoba, growing concern for Manitobans accessing the cancer system resulted in the development of a new collaborative partnership between CCAN Manitoba, and the Canadian Cancer Society, Manitoba Division.

With Winnipeg being home to approximately 700,000 people, access poses an entirely different challenge for those residents living in rural or remote communities in Manitoba. Entitled, **"Access to Care from a Patient Perspective,"** this project will provide a much needed forum for Manitoba cancer patients, their families and caregivers to "share their story" of personal experiences relevant to access issues by means of six focus groups hosted throughout the province. The project also includes a focus group dedicated toward issues experienced by the First Nations population in more isolated areas, as well as the option to complete a questionnaire for all those who are unable to be part of a facilitated focus group.

Delivered in stages, Phase I of the project will focus primarily on recruiting focus group participants in order to gather evidence-based data of the patient experience relevant to: *access to care (diagnosis, treatment, rehabilitation), communication, coordination challenges, financial and emotional stress.* A report, commissioned by an external research company, will allow CCAN to analyze the data in order to develop a proactive position to substantially improve access to care issues.

For further information, please contact:
Pam King, pkking@mts.net

VOLUNTEER PROFILE: Herold Driedger

Six years ago, I came to CCAN as an alternate for the Canadian Prostate Cancer Network. Shortly afterward, I was asked if I would begin the challenging process of building an active Provincial CCAN in Manitoba. Currently, my role with CCAN is to help facilitate this process so that our collective patient voice continues to gain strength and momentum in the coming years.

Through the "lean years" I worked with volunteers from across Canada as we tirelessly forged ahead with the development of the Canadian Strategy for Cancer Control. I made it a point to remain very involved with the efforts that eventually led to the Strategy's adoption by Paul Martin's government, and implementation by the government of Stephen Harper—efforts that have now morphed into CPAC. The goal then, as it is now, is to represent the patient voice…to articulate the needs and concerns of those afflicted by cancer in the most forceful and most effective way possible.

Today, I represent CCAN on the CPAC Surveillance Alliance Working Group, and have been asked to lead CCAN's Regional Initiatives portfolio, which is tasked with building patient voice committees across Canada. Each province and territory have their own unique issues when it comes to health care, and therefore patient issues are different too. While some provinces are further along this path than others, we are proving that *we can* and *we are* learning from each other. Because changes to the delivery of health care in Canada frequently are made without the input of patients or their families, it is important to have committed individuals in all regions—in every province and in each territory—who will advocate for equal access for all regardless of where they reside. It is time that there is a patient, a survivor or a family caregiver representative at every table where cancer related health decisions are being made. *...That is my goal.*

Maximizing Patient Voices—Phase 2 Report

Submitted By Liz Whamond, Chair of Patient Voices Committee

In a proactive effort to better appreciate the state of patient representation in cancer-specific and cancer-related government committees and decision-making bodies in Canada, CCAN commissioned a report in 2007 entitled, **"Maximizing Patient Voices."** The report, released in October of 2007, contained core data collected through an environmental scan with a process that involved surveys, one-on-one interviews and an exhaustive search process of key stakeholders.

CCAN followed-up with Phase 2 of the report in June of 2008 focusing on the results of qualitative interviews with official representatives of committees and decision-making bodies with patient representation. The information contained within Phase 2 offered a greater depth and detail as to the nature of patient involvement within the Canadian cancer system as it stands today. The findings of Phase 2 are divided into two parts, namely: the responses of officials and of patient voice representatives. While the primary objective of the Phase 2 report was to determine the level of participation of patients on committee and decision-making bodies (as identified in Phase 1), the report also focused on: *determining the function of patient representatives, providing necessary "plain language" statements relevant to the value of patient representation in the cancer-system* and *providing clarification on the definition of "informed" patient voice.* Further, the key themes covered in Phase 2 are reflected in the definition of the "informed patient voice," and the rewards and challenges of patient voice representation.

THE RESULTS: Although the importance and usefulness of patient involvement on cancer-system committees and decision-making bodies has been widely recognized, it is evident that less is known about how patient representation in Canada has actually been implemented. The information contained with this report will help to further clarify the value of patient representation by drawing on interview data with patient voice representatives. The next steps will be to closely examine the key findings of the report.

Patient Issues

"A cancer issue is a perceived obstacle to the best interests of patients and families throughout their cancer journey."

Pam Del Maestro, Chair Issues Committee

The primary role of the Issues Committee is to identify and prioritize patient-related issues, inclusive of all cancers. Spearheaded by Pam Del Maestro, the Issues Committee is currently involved in the complex process of identifying patient issues that either directly or indirectly affect a cancer patient and their families in order to recruit active working groups to move forward the issues in the 2008 / 2009 timeframe.

How are issues identified? CCAN identifies issues by utilizing mechanisms that encourage dialogue and engagement of those seated at CCAN Members Council, particularly stakeholders who represent cancer patient constituents. In the coming months, the Issues Committee will focus on the development and implementation of a multi-dimensional matrix that will allow CCAN to effectively track (or monitor) the status of any identified issue through postings to the CCAN website, information bulletins and press releases.

Some of the primary issues currently on the CCAN agenda include:

- *Access to cancer drugs*
- *Cancer prevention*
- *Increased screening*
- *Reduced wait times*
- *Equal access to all forms / levels of treatment*
- *First Nations care*

For further information:
www.ccanceraction.ca

International Union Against Cancer (UICC) World Congress

Submitted By Liz Whamond, Vice-Chair CCAN

In August of this year, I was pleased to represent CCAN at the UICC World Congress held in Geneva, Switzerland where approximately 2,500 people gathered. Lending the voice of CCAN to this initiative demonstrates that we care well beyond our invisible borders and I believe that CCAN has a moral obligation to join in the global fight against cancer.

WAIT A MINUTE...WHAT IS THE UICC?

The UICC World Cancer Congress brings together the world's leaders in the fight to control cancer. Leading clinicians, practitioners, government agencies and NGOs, patient-care providers and advocates, researchers and behavioral scientists and public health experts focus on transforming the latest knowledge into strategies that countries, communities, institutions and individuals can employ to reduce the cancer burden. The first International Cancer Congress was held in Madrid in 1933. It led to the foundation of the International Union Against Cancer (UICC) in 1933. As of 2006 the UICC World Cancer Congress will take place every two years. The objectives of the 2008 congress included:

- *Translating scientific/behavioral research into relevant prevention, early detection, treatment, psychosocial support, palliative care, etc..*
- *Understanding the economic implications of cancer control interventions in both developed and developing settings and determining which interventions produce the best results*
- *Promoting the development of national cancer plans as building blocks of an anti-cancer strategy worldwide*
- *Stimulating capacity-building among UICC member organizations and cancer NGOs*
- *Strategic planning and sharing and exchanging best practices*
- *Implementing effective tobacco control and public health programs*
- *Engaging donor organizations in cancer control effort*
- *Developing north south partnerships*

Pictured above is Liz Whamond

SO...WHAT DID I LEARN AT THE CONGRESS?

While Canada unquestionably has many problems with cancer control, we are beginning to address them through the Canadian Partnership Against Cancer. The UICC wants national control strategies in all countries by 2020. Here are some interesting facts:

- *There were 7.9 million deaths due to cancer in 2007 – 80% of these were in low or middle income countries*
- *In the year 2000 there were 11 million people diagnosed with cancer worldwide*
- *The World Health Organization (WHO) put cancer as a priority on its agenda in 2005*
- *It is estimated that 43% of cancer deaths are due to tobacco, diet and nutrition*
- *Cancer is a looming disaster in developing countries;*
- *Palliative care is an urgent need in all countries – 80% of palliative drugs are used in the developed world*
- *The UICC currently has 322 member organizations in 102 countries*

As well as the plenary sessions, there were five congress tracks *(cancer prevention and control, tobacco control, research and treatment, supportive care and capacity building)* and lots of great topics. Of interest to me was the plenary on cervical cancer, the place for vaccination. (To date 27,000,000 vaccinations have been given to young women world-wide.) During the conference, a reception for Canadians was co-hosted by the Canadian Cancer Society and the Canadian Partnership Against Cancer. Jimm Simon (President of the CCS) and Jeff Lozon (Board Chair of CPAC) both spoke to the group in attendance.

Assembly of First Nations: Cancer and First Nations

Submitted By Elisa Levi, Assembly of First Nations

In an effort to gain a better perspective on the cancer landscape amongst First Nation populations from the viewpoint of patient experiences, CCAN funded a project undertaken by the Assembly of First Nations. The project, entitled **"Cancer and First Nations"** shared the experiences of 6 individuals who were either personally affected by cancer, or had a family member who was.

THE FINDINGS: Research states that cancer is now the leading cause of death amongst some First Nation communities, and is the third leading cause of death amongst Aboriginals across Canada.

While 38% of First Nations people live off-reserve in urban and rural areas throughout Canada, 60% of First Nation communities are considered remote. With over 60 FN languages, 1 in 6 Aboriginal people speak only in their native language which can be a barrier to health care access.

Although it is unknown how many First Nations have cancer screening in their communities, project findings identified that amongst the population, access to health services is inadequate with cancer screening being low. Further, health services delivery varies across the First Nations communities with 1 in 5 adults not having access to a doctor or nurse. It was recognized that health professionals are often not connected to the community as very few doctors or nurses are from First Nation communities.

In terms of treatment, First Nation patients seek healthcare from 3 jurisdictions. Namely: 1.) First Nations, or on-reserve care 2.) Provincial, or off-reserve care 3.) Federal, or non-insured health benefits for drugs, medical supplies and medical travel coverage. The 3 jurisdictions (or systems) do not always communicate with each other resulting in significant delays, lack of coordination, and time spent by patients who are ill in dealing with bureaucracies. The Assembly of First Nations has developed a Cross-Jurisdictional Policy Framework with Health Canada in order to improve services and establish a more seamless system.

With First Nations culture and tradition playing a significant role, a lack of cultural sensitivity is experienced in many areas of the health care system. 51% of First Nations people reported having used a traditional Aboriginal healer or medicines; of those, 37% had done so in the previous six months.

Aboriginal people are pressing for medical care that integrates traditional services with traditional medicine, referring to both traditional healers and medicines. Traditional healing is holistic and the western approach to cancer treatment is sometimes not accepted.

ABOUT THE AFN:

Historically the First Nations have a unique and special relationship with the Crown and the people of Canada, as manifested in treaties and other historical documents. In essence, the special relationship is one of (negotiated agreement with a view toward) peaceful coexistence based on equitable sharing of lands and resources, and ultimately on respect, recognition, and enforcement of our respective right to govern ourselves. The AFN exists to promote the "restoration and enhancement" of this relationship and to ensure that it is mutually beneficial to the First Nations people. The Assembly of First Nations is a national aboriginal advocacy organization. The Assembly of First Nations (AFN) is the national representative organization of the First Nations in Canada. There are over 630 First Nation's communities in Canada.

For additional information, please visit the Assembly of First Nations website at: www.afn.ca

SOURCES: Assembly of First Nations, Health Canada. *A Statistical Profile on the Health of First Nations in Canada.* Health Information and Analysis Division First Nations and Inuit Health Branch Health. 2003. Canadian Hospice Palliative Care Association. *Moving forward by building on strengths: A discussion document on Aboriginal hospice palliative care in Canada.* Ottawa, Ontario. March 29th, 2007. 2006 Census; *National Reports for the First Nations Regional Longitudinal Health Survey (RHS)*, 2002-2003. First Nations Centre, National Aboriginal Health Organization (NAHO). *Our Journey: First Nations Experience in Navigating Cancer Care;* June, 2005. Aboriginal Cancer Care Unit. Cancer Care Ontario. 2) Prince, H. and Kelley ML. *Palliative care in First Nations Communities: The perspectives and experiences of Aboriginal Elders and the educational needs of their community caregivers.* A report prepared for the Kenora Chiefs Advisory. February 2006. Assembly of First Nations, www.afn.ca.

CCAN Member Profile

Canadian Breast Cancer Network (CBCN)

Submitted by Diana Ermel, CBCN President and Cancer Guidelines Action Group Representative

The Canadian Breast Cancer Network is the only national survivor-driven and survivor-focused organization in the breast cancer sector. The Network exists to voice the views and opinions of breast cancer survivors and promote the improvement of services as a strong advocate for access to optimal care for breast cancer patients.

Since 1994, CBCN has worked on policy issues to improve access to services, conducted research, produced publications, advised sector policy makers and supported the development of over 225 provincial and community level networks of support for breast cancer survivors in Canada. CBCN provides programming in the areas of networking, information sourcing, psychosocial research and education.

In the past year, the Canadian Breast Cancer Network:

- *Produced the National Conference for Young Women Living with Breast Cancer, a first in Canada!*
- *Developed and published the Breast Cancer Wait Times in Canada 2008 Report Card on diagnosis and treatment of breast cancer in Canada. (Public relations agency Manning Selvage & Lee conducted the media relations campaign on behalf of CBCN and reported generation of almost 30 million media impressions, which means that we saturated the country with information on this topic!)*
- *Responded to media in favour of breast cancer self -exam*
- *Acted to assure inclusion of trained breast cancer survivors on research panels*

Ongoing concerns include work on the issues affecting breast cancer survivors – the economic impact of having breast cancer; the impact on rural and Northern women who lack access to diagnostic facilities, family and community issues; difficulties faced by women living with metastatic breast cancer in accessing information and support; and continuation of our well-received and important work to advocate for improvement in wait times for diagnosis and treatment.

The Canadian Breast Cancer Network works to advocate the best care, quick response times from our medical system, support networks and strategies for living with breast cancer.

Pictured above is Diana Ermel at the launch of *The Report Card on Breast Cancer Wait Times in Canada,* WINNIPEG (June 2008)

At the June World Conference on Breast Cancer held in Winnipeg, CBCN launched the CBCN *2008 Report Card on Breast Cancer Wait Times in Canada*. The *Report Card* came about because we were hearing stories about increasing wait times and the resulting unnecessary suffering. Our research questions revolved around finding out the actual wait times and how they compared across the country. Our idea was that we would be able to identify the best practices that led to shorter wait times and encourage the duplication of those practices across Canada. Unfortunately, what we found was that we can't compare wait times in the different jurisdictions. There are no standards for or consistency in reporting wait times, so the numbers cannot be compared. We were able to identify some glaring gaps as well as some best practices.

The *Report Card* received an unprecedented amount of media attention. Since the launch, several jurisdictions have contacted us to update their information. We are confident our next *Report Card* will be more comprehensive and hopefully reflect more consistent reporting across the jurisdictions.

For further information:
www.cbcn.ca
1-800-685-8820
e-mail cbcn@cbcn.ca

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.

FOR FURTHER INFORMATION, PLEASE CONTACT:

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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
Ovarian 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

CCAN Manitoba
CCAN New Brunswick
CCAN Newfoundland & Labrador
CCAN Nova Scotia
CCAN Ontario
SCAN (Saskatchewan)
Coalition priorité cancer au Québec

Representatives on CPAC Action Groups

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

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Jack Butt, Treasurer

Herold Driedger, Provincial Initiatives

Please visit us at:

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