

Many Faces...
One Voice.



Dialogue

Winter 2009 Issue

CCAN Members Council To Focus On Identified Core Patient Issues

By Marjorie Morrison, Executive Director

During a recent issues identification and engagement exercise, CCAN Members Council (comprising 15 cancer-site patient organizations as well as a number of population organizations, provincial CCAN delegates and designated CCAN representatives on CPAC Action Groups) successfully identified and prioritized a framework of core cancer patient issues to address during the next four years.

The issues, ranging from equitable access to psychosocial support, will serve as the building blocks for the development of an innovative MATRIX (or moving landscape) of cancer patient issues. Scheduled to be introduced to the public in 2009, the MATRIX will effectively allow CCAN to inform and engage a broader pan-Canadian audience of patients and key stakeholders in the cancer care and cancer control communities. Approached in phases, the MATRIX will provide an ongoing summary of each issue and an up-to-date status report providing cancer patients, families and caregivers with an opportunity to assess how the patient voice is impacting the emerging pan-Canadian cancer control strategy.

The CCAN Issues Committee, functioning under the direction of Chairperson Pam Del Maestro and consisting of seven key CCAN members, is currently in the preliminary stages of formulating a strategy to address existing provincial disparities. This will not be an evidence-based approach highlighting statistical data but rather an exploration of the issues through the use of stories written by cancer patients interested in sharing their personal experiences.

"The CCAN Issues Committee is dedicated to identifying and pursuing opportunities for change on a pan-Canadian scale through a coordinated approach. We are determined to move forward those patient issues identified at Members Council as directly impacting the broader cancer patient constituencies they represent," says Pam Del Maestro. *"This is an opportunity to present the true face of cancer...the patients who navigate their way through a cancer diagnosis, and the family members who walk with them on the journey".*



Pam Del Maestro, Chair
Issues Committee

CORE PATIENT ISSUES

- Equitable Access
- National Standards
- Prevention
- Screening
- Financial Burden
- Navigation
- Research
- Communication
- Development for Health-Care Professionals
- Psychosocial Support
- Information & Education

Access to Cancer Care Impacts Canadians

In 2008, the Canadian Cancer Action Network (CCAN) released a report entitled, "Issues of Access to Cancer Care in Canada" which underscores the similarities, differences and inequities in our national cancer care system.

If you would like to gain a better appreciation of the Canadian cancer care landscape, an executive summary (as well as the report) may be downloaded by visiting the CCAN website.

A Message from the Chair, Jack Shapiro



In late 2008, I attended a presentation by a federal agency on the subject of “palliation and end-of-life care.” When I inquired if a patient voice perspective was sought in the development of the presentation, I was told that at the time the presentation was prepared, inviting the cancer patient

perspective was not on their radar, but it certainly would be today. That was a gratifying response reiterating the fact that the CCAN message of patient involvement is not only reaching a broader audience, but positioning the patient voice to be present and recognized whenever patient interests are involved.

As Chair of CCAN Members Council, I am pleased to report that CCAN has developed an ambitious program to ensure that patients (or close family members) are welcomed wherever their interests are involved, especially at tables where cancer policy issues are considered. No matter how experienced the professionals, they can always benefit from the unique lens of a patient perspective. As this program unfolds in 2009, it is my hope that cancer communities across Canada will be encouraged to pursue opportunities that allow the patient voice to be heard.

In 2009, with the support of our national office established in Toronto our provincial arms will be an important resource for continued patient input, as will the patient constituents of the fifteen national cancer-site organizations that form the core membership of CCAN. We all know that there are many cancer survivors who experience their own unique journey as they navigate their way through various stages of a cancer diagnosis. However, the cancer patient that is part of a provincial CCAN or a cancer-site support organization – the patient with a knowledgeable constituency behind them – is most likely to bring forward a stronger and more helpful voice.

As CCAN continues to move forward with a coordinated and focused approach, we are positioned to lead a network of patient voice representatives all intent on bringing about a more equitable and accessible health care system. With the patient-centered perspective a critical and contributing ingredient to achieving a more accountable and responsive cancer-system, it is imperative that we all continue to ensure the patient voice remains an influential part of the emerging national cancer control strategy.

Expanding the Patient Voice

CCAN continues to focus on expanding our network of patient voice representatives across Canada in order to ensure patients have a strong and influential role in the emerging pan-Canadian cancer control strategy.

It is essential that patients are widely and effectively represented on cancer-system committees and decision-making bodies in order to ensure patient needs remain a key priority and consideration. By advancing patient issues that are most relevant to the patient constituencies of Members Council, CCAN is positioned to offer a patient-centered perspective in order to realize our goal

of seeing a more equitable and accessible health care system emerge for Canadians.

To become an informed CCAN patient voice, or to lend your voice to a Provincial CCAN functioning in your area, please call 416.619.5784.

ON THE ROLE OF THE CANCER PATIENT VOICE

“To me, it’s all about perspective! I believe that my value as a patient representative is that I bring a unique perspective, strongly influenced by my cancer experience, and anchored to reality”.



Archie McCulloch, Nova Scotia Screening Action Group Representative

Moving Forward in 2009

An Interview With *Leanne Kitchen-Clarke*, Vice President, Strategy, Performance Measures and Communication, Canadian Partnership Against Cancer

Q. How imperative is it to include cancer patients as the Partnership works toward an improved pan-Canadian cancer control system?

A. Many patient and survivor voices were involved in developing Canada's cancer control strategy. As the strategy is implemented, it is vital that our work is grounded in the realities and challenges of cancer control from the perspective of those who have experienced the system firsthand. Including the views of cancer patients, survivors and their families brings greater relevance to our work and will lead to more meaningful and tangible outcomes.

Q. What steps or initiatives is the Partnership taking to ensure the inclusion of the patient voice?

A. Among the initiatives, we are working with patients and survivors, among others, to develop tools to support people with cancer as they navigate through the health system. As well, the patient and survivor perspective is helping to inform the development of another key initiative - the Portal - that will link the cancer community across Canada to information and resources that will directly benefit all Canadians. For areas like prevention and screening, we must engage the broader public, since our efforts will focus on increasing awareness of how to prevent cancer or detect it early in those cancers where screening is possible. We are also building community linkages with Canada's First Nations, Inuit and Métis peoples to ensure we are culturally responsive to the needs of these communities as we advance Canada's cancer control strategy.

ON THE AFFILIATE RELATIONSHIP WITH CCAN

"To ensure that a collective patient voice is supporting and informing our activities, the Partnership is actively working with CCAN and has representation from patients and survivors on our Board, Advisory Council and across our priority areas."



Leanne Kitchen-Clarke, Toronto
CPAC

Q. What can CCAN Members Council do to ensure that the cancer patient perspective remains a key element in the emerging strategy as the Partnership moves forward in 2009?

A. The ability for CCAN to tap in to its member organizations' networks is critical to ensuring the voice of patients, survivors and their families is brought forward to the work of the strategy. Equally important is to ensure that patients have access to information and that the progress being made across the priority areas of the strategy is proactively disseminated. The CCAN Members Council plays a central role in facilitating this information exchange. By regularly and proactively communicating with its own network of stakeholders and partners about the work of the Partnership, there is a greater opportunity to ensure effective dialogue and input from patients, survivors and their families as the strategy for cancer control is implemented nationwide.

Q. In terms of the Partnership's key areas of focus, how does the patient perspective impact or influence advancements in the cancer control domain?

A. Each area of focus within the strategy was drawn from the priority areas in cancer control from prevention, to screening, to surveillance, to palliative and end-of-life care, and also survivorship, among others. We seek ways across priority areas to ensure the patient voice is informing the work and in some cases leading the efforts, as is the case with the National Survivorship Working Group co-chairs - one is a cancer survivor and the other represents a patient/survivor organization. The work in this area will lead to the development of resources and programs for those living beyond cancer treatment to support their psychological and physical well-being.

Advancing the Patient Perspective

When a cancer patient steps forward to speak with conviction and strength, their voice has the power to silence the room. Through the coordinated efforts of CCAN, the patient voice is the vehicle that both supports and demands changes to the existing cancer landscape.

SPOTLIGHT ON MANITOBA

The Provincial CCAN in Manitoba and the Canadian Cancer Society (Manitoba Division) recently released “**Access to Cancer Services in Manitoba: The Patient Perspective**,” an interim report summarizing the results of a series of focus groups held throughout the province. Aimed toward gaining insight into patient experiences in terms of access to cancer services in the province, the report is enabling CCAN Manitoba to gain a better perspective on access issues ranging from patient experiences at the time of initial diagnosis, to the challenges encountered in communication between patients, families and health care professionals.

A total of 98 patients and caregivers participated in this report lead by Pele Research—valued perspectives that will help to further identify, explore and pursue changes for residents of both rural and urban communities in Manitoba.

ON THE VALUE OF THE PATIENT PERSPECTIVE

“The more opportunities cancer patients have to express their personal experiences, the stronger the chance of ensuring the patient voice is not only heard, but valued where it counts the most.”



Jack Butt, Ontario
Colorectal Cancer Association of Canada

Building a Provincial CCAN Presence: *How You Can Help*

ON VOLUNTEERISM

“You can’t say NO if you haven’t been asked. This is where the rubber meets the road.”



Herold Driedger, Manitoba
Surveillance Action Group Representative

Become a CCAN PATIENT REPRESENTATIVE

- Offer leadership and support to coordinated efforts to move the patient voice forward through all stages of the cancer control continuum.
- Present a patient perspective in support of efforts to see a more accountable and responsive cancer-system emerge.
- Offer a patient perspective to discussions and initiatives that serve to address the changing pan-Canadian cancer control landscape.

Act as an informed CCAN PATIENT VOICE

- Speak from experience to ensure the patient perspective remains a critical ingredient in the work of cancer-specific committees, working groups and decision-making bodies.
- Through dialogue, ensure the cancer system becomes more aware and responsive to the diverse needs of cancer patients and their families.
- Maintain and apply a strong understanding and appreciation for patient needs and priorities.

The Face of Cancer: A Series of pan-Canadian Patient Stories



As a patient-focused organization, the identity of CCAN is irrevocably linked to the cancer patient voices we represent. In this issue of *Dialogue*, I am pleased to launch the first in a series of pan-Canadian cancer patient stories by introducing my mentor and valued friend, Dianne Hartling.

I first met Dianne in 2005 while she was undergoing chemotherapy to treat breast cancer. Throughout her cancer journey, Dianne has never wavered in her commitment to act as a strong patient advocate for herself, and for others. The work she continues to do to advance the patient perspective is a true reminder of how critical it is that the patient voice be heard.

Marjorie Morrison, Executive Director

Dianne Hartling, Ottawa, ON

My journey with breast cancer began in the fall of 1988. Since then, I have seen many positive changes over the years in the world of cancer. It has been a long, hard fight with no “magic bullet” in sight, yet progress has been made.

In the spring of 1990, I had my first recurrence. It was a shock since previous surgery had shown no lymph node involvement. This time I had the usual course of radiation therapy followed by “brachytherapy”. Since then I have had several more recurrences.

By 1992, women who had survived their diagnosis of breast cancer began to organize to help others voice their concerns about the lack of information and methods of treatment for breast cancer. When I learned an Ottawa-based organization called Breast Cancer Action (BCA) was opening a support and resource center in the fall of 1993, I volunteered and eventually served 4 years there as President.

I may have grown up in the 60’s and 70’s, but I would never have considered myself an “activist”. Cancer changed all that! I have learned so much about the value of one voice joining others to verbalize our needs to society. As Margaret Mead once said: “Never doubt that a small group of thoughtful committed citizens can change the world; indeed it’s the only thing that ever has.”

Women across Canada deserve recognition for their efforts. From the first World Conference on Breast Cancer in 1997 where over 1000 delegates attended, grass root organizations began to spring up globally. In Ontario, the Ontario Breast Cancer Information Exchange Project was born out of the 1993 Montreal Forum on Breast Cancer.

In the realm of pharmaceuticals, more drugs have been added to the arsenal. Anti-nausea drugs improve the quality of life for those undergoing toxic chemotherapies. Radiation is more targeted and the new virus trials show promise. The medical community was forced to listen to a patient’s perspective of the disease and survivors were forced to listen to scientists and realize just how complicated cancer is and that an instant cure was not in the foreseeable future. The people of Canada have been very supportive in funding their local cancer centres and scientific research. We have to continue to support clinical trials to test new therapies.

Today, I serve on the board of the Canadian Breast Cancer Network, a member of CCAN Council. With existing medical care, there are currently many inequities. CBCN is involved in several projects such as problems experienced by young women, rural women with breast cancer and problems related to job re-entry and personal financial costs.



Recently I attended two meetings of organizations that I had been totally unaware of. The first was on Palliative Care, the second was on Episodic Disabilities. Each gave me new insight into what living with cancer entails. I was very impressed with all the volunteers from many different disease groups that are working collaboratively to provide their expertise to improve the quality of our lives.

I am certainly not alone in my advocacy work. Thousands of women and men across Canada have already made, or are making a difference in the world of breast cancer and I am proud to be among them. In closing, I wish to thank CCAN for inviting me to be the first cancer patient to share my story in *Dialogue*.

CCAN Member Profile: Carcinoid NeuroEndocrine Tumour Society Canada

At the recent 2008 International Carcinoid / NeuroEndocrine Conference & Symposium for Patients and Medical Professionals (Toronto) Dr. Kjell Oberg (Dean of the Medical Faculty in Uppsala, Sweden) introduced the first series of lectures on diagnosis and treatment of Carcinoid-Neuroendocrine tumours.

Referencing statistics from the last four decades from the US and Sweden, Dr. Oberg demonstrated a staggering discrepancy in patient survival rates between US and Swedish patients. There were no statistics for Canada as Carcinoid NETS Cancers in Canada are folded in with other diseases such as diseases of the GI tract so there is currently no database for researchers to work with.

WHO ARE WE? Registered in 2008 as a charity, the Carcinoid Neuroendocrine Tumour Society Canada began as a desperately needed patient support network in 2001 for patients successfully diagnosed with a Carcinoid-NET or GastroEnteroPancreatic Neuroendocrine tumour. (GEP-NET) Carcinoid NeuroEndocrine symptoms include major flushing, diarrhea, shortness of breath, and heart damage much of this caused by hormones including serotonin which corrode veins, causes right sided heart valve damage, and sparks tumour growth with the liver as the most frequent site for metastases.

Article written and submitted by Maureen Coleman, President. Note: Dr Robert H Reid, of the London Health Sciences Centre and the University of Western Ontario, and Maureen Coleman, President CNETS Canada, were co-chairs of the October 2008 Carcinoid NET International Conference. The LHSC is the pre-eminent centre for diagnosis and treatment of Carcinoid NeuroEndocrine Tumours in Eastern Canada. UWO was the Continuing Medical Education sponsor of the Conference.



Dr Walter Kocha, Medical Oncologist with the London Health Sciences Centre (LHSC) has a practice which now focuses exclusively on neuroendocrine patients.

Recent US research (such as that of Dr Irvin Modlin) demonstrates a diagnosis rate of between 3-5 cases per 100,000 population, per year. Every age group and nationality can be affected, with men and women almost equally represented. Canadian physicians use specific diagnostic tests. However only a minority of specialists are familiar with the tests or implications of the tests.

CNETS Canada's patient support network has expanded across Canada in the last three years. One of the priorities as a network is to educate patients as much as possible about physicians who do know something about our disease so they can receive the best possible treatment. Our mandate of "Research, Education, Awareness and Support" has been partly met by our recent International Conference which can be viewed on www.cnetscanada.org.



...Nothing speaks like experience.

Seated at CCAN Members Council are cancer-site organizations who work collaboratively to represent the interests of patient constituents from across Canada.

To learn how you can mobilize the patient voice in your community—how your experiences as a cancer patient can move change forward—please contact CCAN, or a CCAN member organization today.



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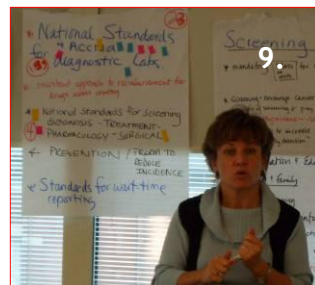
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CCAN PHOTO GALLERY

1. CCAN Issues Committee during a November Workshop held at the Canadian Cancer Society National Policies office, Ottawa, ON. (FRONT ROW: Pam Del Maestro, Christine Jackson, Liz Whamond, Diana Ermel, Toni Codispoti. BACK ROW: Gilles Leveille, Aaron Levo)
2. Dr. George Browman (BC Cancer Agency) pictured with Jack Shapiro. (Chair, CCAN)
3. CCAN Board of Directors Herold Driedger (Surveillance Action Group Representative), pictured with Jack Butt. (Colorectal Cancer Association of Canada)
4. Jack Shapiro (Chair, CCAN) and David Stones (Vice Chair of CCAN and CEO Childhood Cancer Foundation) presenting a Certificate of Membership to Leanne Kitchen-Clarke (CPAC)
5. Aaron Levo. (Canadian Cancer Society)
6. Diana Ermel (Cancer Guidelines Action Group) and Louise Frederick. (SCAN Chair)
7. Gilles Leveille. (Coalition Priorite Cancer au Quebec)
8. Murray Gordon. (Canadian Prostate Cancer Network)
9. Christine Jackson. (Canadian Skin Patient Alliance)

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
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

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

Representatives on CPAC Action Groups

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

CCAN Board of Directors

Jack Shapiro, Chair

Liz Whamond, Vice-Chair /
Chair of Patient Voices Committee

David Stones, Vice-Chair /
Chair of Communications and Marketing

Jack Butt, Treasurer /
Chair of Finance Committee

Pam Del Maestro, Director /
Chair of Issues Committee

Herold Driedger, Director /
Chair of Regional (Provincial) Initiatives

Marjorie Morrison, Executive Director
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ON THE NEED TO WORK COLLABORATIVELY

"Access to cancer medications is hugely different from province to province. As cancer patients and survivors, we need to work together to create a fair and equal system for all Canadians."



Deb Maskens, Ontario
Patient and Vice-Chair, Kidney Cancer Canada /
Association canadienne du cancer du rein

www.ccanceraction.ca