

Many Faces...  
**One Voice**

FAMILIES

PATIENTS

## Our Vision:

- To have the best cancer system in place for Canadians at both the national and provincial level. (A system that is comprehensive, accessible, sustainable, affordable, universal and equitable.)
- To optimize quality of life and respect for the patient in all aspects of cancer care from prevention and screening, to diagnosis and treatment, through to palliation.

## Our Mission:

To advocate for the implementation of the best possible national cancer control strategy by:

- Being a vehicle for identifying issues common to all volunteer-driven, national cancer organizations/groups.
- Bringing the perspective of those affected by cancer directly into the policy-making process.
- Creating linkages and partnerships in order to achieve results both provincially and nationally.


## Our Mandate:

- To represent the interests of all Canadians affected by cancer.
- To work with federal and provincial decision makers to ensure a pan-Canadian system evolves that optimizes care and treatment outcomes through all phases of the cancer continuum.

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In 2001, there was a strong belief that a coordinated, unified organization comprised of patient-centered organizations was needed in order to fill a unique niche in the Canadian cancer landscape. As a result, the following founding organizations were instrumental in building the Canadian Cancer Action Network:

[Brain Tumour Foundation of Canada](#)  
[Canadian Breast Cancer Network](#)  
[Canadian Cancer Society](#)  
[Canadian Prostate Cancer Network \(now Prostate Cancer Canada\)](#)  
[Cancer Advocacy Coalition of Canada](#)  
[Colorectal Cancer Association of Canada](#)  
[Childhood Cancer Foundation Candlelighters Canada](#)  
[Leukemia Research Foundation of Canada](#)  
[National Ovarian Cancer Association](#)  
[Neutropenia Support Association](#)

## WHO ARE WE?

The Canadian Cancer Action Network Members Council is comprised of seventeen prominent national cancer-site organizations; five population organizations; nine provincial CCAN chairs and seven Canadian Partnership Against Cancer Action Group representatives. In 2009, CCAN welcomed two new organizations to the Council table: Myeloma Canada and Young Adult Cancer Canada.

## HOW WE MAKE A DIFFERENCE:

Working with CCAN Members Council and other key stakeholders including the Canadian Partnership Against Cancer, our primary focus is to ensure that a strong, informed patient voice remains a key part of the work of the emerging cancer control strategy. The strength of CCAN lies in an ability to engage our members who, in turn, represent an enormous network of cancer patients and their families across the country. This is achieved by playing an active role in various working groups, activities and initiatives of the cancer control strategy and by bringing a unique patient perspective forward.

## 2008-2012 GOALS:

- To ensure issues relevant to cancer patients and their families are addressed by the national 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 across Canada.
- To cultivate and pursue opportunities for effective dialogue and interaction with key stakeholders.

# Message from the Chair, Jack Shapiro

## Connected by circumstance – committed to change!



“As Chair, I am honored to lead the Canadian Cancer Action Network forward as together, we ensure the voices of cancer patients, survivors and their families remain influential in reshaping the cancer landscape for Canadians.”

### Nothing speaks like experience.

In 2008, the Canadian Cancer Action Network (CCAN) adopted an ambitious four year strategic plan entitled, **“Making Our Voices Heard”** – a blueprint to help us ensure that patients and family members are welcomed wherever their interests are involved, especially at tables where cancer policy issues are considered.

Supported by CCAN Members Council, our value as an organization lies in our unique ability to act as a key source for patient input. It is our belief that no matter how experienced the professionals, they can always benefit from the unique lens of a patient perspective.

### Moving forward.

As CCAN continues to move forward with a coordinated and focused approach, our patient voice representatives are all intent on bringing about a more equitable and accessible health care system. Our evolving role as a conduit for the patient voice is one we take very seriously. CCAN has undergone an enormous transformation over the years. From those early days in 2001 when a group of concerned individuals recognized the need for an organization of this scope to today, CCAN remains an organization that is strongly connected to patient constituents.

Our work is continuing to unfold in 2009-2010 where we are focused on bringing together key stakeholders to not only engage in open dialogue, but to work collaboratively in order to achieve a stronger future for ourselves, for our children and for future generations to follow.

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 strong and essential that patients are widely and effectively represented on cancer-system committees and decision making bodies in an effort to ensure patient needs remain a key priority.

As Chair, I am often asked how patients and family members can help ensure their voice is heard...the answer is simple. Become involved!

I invite you to play an active role with CCAN by helping ensure we are representing cancer patient, survivors and family members to the very best of our abilities. I encourage you to make today the day that you reach out and support the work of CCAN, our valued member organizations and the cancer control strategy as it continues to evolve.

## Reflecting on the past—Anticipating our future.

When the seeds of CCAN were sown at our first meeting in June of 2001, there was great enthusiasm to see an improved cancer system for all Canadians.

Today, with funding from our partner the Canadian Partnership Against Cancer, CCAN Members Council has grown to include thirty-eight voices each representing the interests of cancer patients and their families across Canada.

Not only has CCAN taken significant strides toward establishing provincial chapters in recent years, we continue to welcome new organizations to CCAN Members Council including recent additions Myeloma Canada and Young Adult Cancer Canada in 2009. CCAN has accomplished much but there is still so much more to do. Hiring our first Executive Director in 2008 was absolutely essential to moving forward with a number of key activities.

We've been busy! In 2009, CCAN was responsible for seeing a quantitative research report published entitled, "Access to healthcare and support for people with cancer in Quebec" providing a much broader perspective of the cancer landscape in this province. The same may be said for "Access to cancer services in Manitoba," a 2008 report derived exclusively from the perspective of patients and families living with a cancer diagnosis.

These are but two examples of our work and our commitment to addressing patient interests from all areas of the country.

Challenges still exist; we're a vast country with great diversity but by continuing to work together in a coordinated manner, we will reach our objective to ensure the patient perspective remains at the forefront of the national cancer control strategy. There is no room for complacency in the world of cancer – you can bet we will remain steadfast to our mission!

## A firm foundation. A firm future.

We all know about the infamous house that was built on sand. Like houses, organizations need a firm foundation. The correct pieces or building blocks have to be in place if an organization is to deliver its mission and prosper.

The 2008-2009 timeframe was a period of exciting, groundbreaking investment in our infrastructure, governance and systems that will pave the way for an eventful future.

The highlights are varied and plentiful. From incorporation, to the development of our inaugural by-laws and a unique partnership/funding agreement with CPAC, to the recruitment of our first Executive Director, the Board and its membership have worked hard to **do first things first** and the **right things right**.

The development of print materials such as our CCAN newsletter entitled, "**Dialogue**" as well as a very successful internal grant competition signal a maturing CCAN and a deepening capacity to deliver on our challenging mandate. As we focus on the future, we can reflect with satisfaction on the many accomplishments during our first year as an incorporated organization. As we move forward, the hard work must continue for CCAN to be successful in its efforts to ensure an improved and effective cancer control system, equitably applied and accessible for all Canadians.



ELIZABETH (LIZ )  
WHAMOND  
Founding member,  
Vice-Chair and  
Past Chair of  
Patient Voices Committee



DAVID STONES  
Past Vice-Chair and  
Past Chair of  
Communications /Marketing  
Committee

## Message from the Executive Director, Marjorie Morrison Making our voices heard!

As the Executive Director of CCAN, it gives me a great deal of satisfaction to produce **“Many Faces...One Voice,”** our first report providing stakeholders with an informal snapshot of our work to date.

In the often complicated world of cancer control, our strategy for success is really quite simple: stay true to the voice of the cancer patient while ensuring patient interests and issues remain at the forefront of the emerging cancer control strategy.

As CCAN moves forward, we are committed to pursuing collaborative opportunities that allow us to engage in dialogue, address core patient issues and advance patient interests. As we strive to ensure that a strong, informed patient perspective is successfully represented at all levels where decision and policy making takes place, there is a realization that our strength lies in the ability we have to represent cancer patients with a voice that is strong, persistent and influential.

This past year presented a number of valuable opportunities for our organization to better understand the cancer landscape in Canada—an effort that will allow us to further advance our agenda through the work of our expanding provincial CCAN teams across the country. While we collectively celebrate each milestone as if it were the first, there is a sense of pride that our work in addressing the area of cancer drug access for Canadians has moved forward significantly. After many years of focus in this priority area, and following the April 2008 update of our report, **“Issues of Access to Cancer Drugs in Canada,”** CCAN partnered with the Public Policy Forum and the Canadian Cancer Society to realize our goal of hosting a multi-stakeholder symposium.

Through our continued support and commitment of both national and provincial CCAN-driven initiatives, as well as innovative projects geared toward identifying gaps in regions across Canada, we are inspiring positive changes to the cancer system for all Canadians.



### GOVERNANCE

CCAN Board of Directors  
(2008-2009)

CCAN Board of Directors  
(2009-2010)

#### JACK SHAPIRO

Chair

#### DAVID STONES

Vice-Chair / Chair of  
Communications &  
Marketing

#### ELIZABETH (LIZ) WHAMOND

Vice-Chair, Chair of  
Patient Voices

#### JACK BUTT

Treasurer / Chair of  
Finance

#### HEROLD DRIEDGER

Director, CCAN  
Chair, Regional  
(Provincial) Initiatives

#### PAM DEL MAESTRO

Director / Chair of  
Patient Issues

#### JACK SHAPIRO

Chair

#### MURRAY GORDON

Vice-Chair

#### ELIZABETH (LIZ) WHAMOND

Vice-Chair

#### AARON LEVO

Treasurer / Chair of  
Finance

#### LOUISE FREDERICK

Director / Chair of  
Patient Issues

#### HEROLD DRIEDGER

Director / Chair of  
Regional (Provincial)  
Initiatives

#### ARCHIE McCULLOCH

Director / Chair of  
Communications &  
Marketing

#### TRACY TARNOWSKI

Director / Chair of  
Patient Voices

# CCAN Members Council

## CANCER-SITE ORGANIZATIONS

### BRAIN TUMOUR FOUNDATION OF CANADA

Pam Del Maestro / Femma Norton

### CANADIAN BREAST CANCER NETWORK

Diane Spencer

### CANADIAN LIVER FOUNDATION

Annette Martin

### CANADIAN LUNG ASSOCIATION

Kelly-Jo Pfaff / Vacant

### CANADIAN PROSTATE CANCER NETWORK (NOW PROSTATE CANCER CANADA)

Murray Gordon

### CANADIAN SKIN PATIENT ALLIANCE

Christine Jackson / Tanny Nadon

### CANADIAN THYROID CANCER SUPPORT GROUP

Mia Guillo / Rita Banach

### CARCINOID NEUROENDOCRINE TUMOUR SOCIETY

Maureen Coleman

### CHILDHOOD CANCER FOUNDATION OF CANADA

David Stones / Meagan Davidson

### COLORECTAL CANCER ASSOCIATION OF CANADA

Jack Butt / Vacant

### KIDNEY CANCER CANADA

Deborah Maskens

### LEUKEMIA & LYMPHOMA SOCIETY OF CANADA

Rudy Putns

### LUNG CANCER CANADA

Peter MacKenzie

### LYMPHOMA FOUNDATION CANADA

Alyssa Burkus Rolf

### MYELOMA CANADA

Aldo Del Col

### OVARIAN CANCER CANADA

Elisabeth Ross

### YOUNG ADULT CANCER CANADA

Leslie Kean

## POPULATION ORGANIZATIONS

### ASSEMBLY OF FIRST NATIONS

Corrine Caplin / Tracy Tarnowski

### CANCER ADVOCACY COALITION OF CANADA

Dr. William Hryniuk

### CANADIAN CANCER SOCIETY

Aaron Levo

### CANADIAN PARTNERSHIP AGAINST CANCER

Lianne Kitchen-Clarke

### INUIT TAPIRITT KANATAMI

Soha Kneen

## ACTION GROUP REPRESENTATIVES

### CANCER GUIDELINES ACTION GROUP

Diana Ermel

### CANCER JOURNEY ACTION GROUP

Elizabeth (Liz) Whamond

### HEALTH HUMAN RESOURCES ACTION GROUP

Ron Reavley

### PRIMARY PREVENTION ACTION GROUP

Dr. Eugene Vayda

### RESEARCH ACTION GROUP

Jack Shapiro

### SCREENING ACTION GROUP

Archie McCulloch

### STANDARDS ACTION GROUP (NOW STANDARDS WORKING GROUP)

Deanna Silverman / Louise Frederick

### SURVEILLANCE ACTION GROUP

Herold Driedger

## PROVINCIAL CCAN CHAIRS

### CCAN BRITISH COLUMBIA

Jane Ambrose / Vacant

### CCAN MANITOBA

Pam King

### CCAN NEW BRUNSWICK

Julie Easley

### CCAN NEWFOUNDLAND/LABRADOR

Jeff Blackwood

### CCAN NOVA SCOTIA

Shirley MacLeod

### CCAN ONTARIO

Antonia (Toni) Codispoti / Vacant

### CCAN PRINCE EDWARD ISLAND

Catherine Thomas

### CCAN QUEBEC/COALITION PRIORITÉ CANCER AU QUÉBEC

Gilles Leveille

### SCAN-SASKATCHEWAN CANCER ACTION NETWORK

Ron Reavley / Louise Frederick



“By working in collaboration with the Canadian Cancer Society (CCS) in Manitoba, we were able to validate the core issues of concern to Manitoba residents—issues that we realize are evident across Canada. In 2009, CCAN Manitoba is committed to continuing to work closely with CCS to further assess social safety net options and their adequacy within the province. We feel strongly that our work will support CCAN efforts to advance the strategy in relation to promoting care, treatment and health care for cancer patients.”

PAM KING, CHAIR  
CCAN MANITOBA

In 2008, CCAN Manitoba and the Canadian Cancer Society (Manitoba Division) worked collaboratively to commission and release **“Access to Cancer Services in Manitoba: The Patient Perspective,”** a report summarizing the results of a series of patient-centered focus groups held throughout the province.

Aimed toward gaining insight into patient experiences in terms of access to cancer services in Manitoba, the report enabled CCAN and our partner 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 ninety-eight patients and caregivers participated in this process lead by Pele Research. The data collected will help further identify, explore and pursue changes for residents of both rural and urban communities in Manitoba.



**“The Canadian Partnership Against Cancer is committed to ensuring the patient/survivor voice is reflected in cancer control, and we are pleased to work with CCAN to achieve this. We thank the many patients and survivors who have shared your voice and passion as we work together to implement the pan-Canadian cancer control strategy.”**

Jessica Hill, CEO  
Canadian Partnership Against Cancer

In recognition of the critical need to focus on the survivorship issues faced by cancer patients and their families, CCAN proudly partnered with the Canadian Prostate Cancer Network (now Prostate Cancer Canada) to support the development of a patient survivorship-based handbook –a resource that once completed, will be shared as a potential model for other cancer-site and population organizations.

In early 2009, CCAN formally welcomed CCAN Prince Edward Island to Members Council. CCAN-PEI will work with the Canadian Cancer Society (CCS-PEI) to advance the delivery of those services identified by Island patients in a 2007 study. The needs are known, now action must be taken to fulfill those needs. CCAN believes this collaborative partnership will move forward the work of the cancer control strategy by focusing on important issues of concern to residents including equitable access to care. By working in partnership we will advance specific patient needs resulting in anticipated improvements to the delivery of cancer patient care and services.

“With the support of CCAN, our organization can focus on the development of a survivorship-based handbook. This resource will make it easier to maintain a network of support groups throughout the country by providing a framework of best practices for a diverse range of topics. Overall, this project will strengthen our ability to effectively meet the needs of prostate cancer survivors and their families, increase public awareness, stress the importance of early detection and appropriate treatment, and hopefully, decrease the number of prostate cancer deaths.”

MURRAY GORDON  
PROSTATE CANCER CANADA

“CCS-PEI has worked diligently over the years to identify and assist in meeting cancer patient needs. A collaborative approach between CCAN-PEI and CCS-PEI will avoid duplication of effort and maximize opportunities for advancing patient needs in a constructive way.”

CATHERINE THOMAS, CHAIR  
CCAN PRINCE EDWARD ISLAND



# “Optimizing Access to Cancer Drugs for Canadians” Symposium

## Engaging in dialogue

In partnership with the Public Policy Forum and the Canadian Cancer Society, CCAN hosted **“Optimizing Access to Cancer Drugs for Canadians”**, a multi-stakeholder symposium held September 15, 2009 in Ottawa, ON.

This unique event brought together a diverse group of key stakeholders from across Canada, many of whom held divergent views, to address the accessibility of quality cancer drug treatments in a neutral forum where opinions could be freely expressed and debated. In total, more than 60 participants attended representing patient groups, cancer control, public and private drug plans, the pharmaceutical industry and professional organizations.

### Our strategy in convening the symposium:

- To bring together key stakeholders in order to develop a set of recommendations for action.
- To work in partnership with the Canadian Cancer Society call to action to urge politicians and private sector stakeholders to work collaboratively in order to make changes to the system.
- To inform the public through the resulting symposium outcomes report.

### Symposium topics of discussion:

- Provincial gaps and disparities; system sustainability; best practices and potential solutions.
- The impact of cancer drug prices on drug plans and patients.
- Pan-Canadian standards of coverage linked to clinical guidelines.

### Areas of consensus:

A general consensus emerged around certain key principles. First, Canadians need universal, equitable and affordable cancer drug access. Above all, cancer drug treatment should not impose added emotional strain or financial hardships on patients and their families. And secondly, stakeholders, including governments, need to develop strategies to increase the sustainability of cancer drug coverage.

To view the **Optimizing Access to Cancer Drugs for Canadians** outcomes report, please visit [www.ccanceraction.ca](http://www.ccanceraction.ca).



# CCAN in ACTION

“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 M.

“I have learned so much about the value of one voice joining others to verbalize our needs to society.”

-DIANNE H.



“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 M.



“Each province and territory has their own unique issues when it comes to health care and therefore, patient issues are different too.”

-HEROLD D.

## Advancing patient interests

- As a newly incorporated organization, CCAN established a national office, signed an agreement with our funding partner (Canadian Partnership Against Cancer) and embarked on our four-year plan, **“Making Our Voices Heard”**.
- Through collaborative efforts, CCAN identified key areas of concern faced by Quebec patients in a quantitative research report, **“Access to Healthcare and Support for People with Cancer in Quebec”**.
- In recognition of the need to invest in survivorship-based initiatives, CCAN partnered with the Canadian Prostate Cancer Network (now Prostate Cancer Canada) to develop a resource handbook for cancer patients and their families.
- CCAN commissioned **“Maximizing Patient Voices – Phase 2”**, a report drawing on qualitative interviews with official representatives of committees and decision-making bodies with patient voice representation in order to provide greater depth and detail as to the nature of patient involvement in the Canadian cancer system.

## Building capacity

- With a focus on meaningful dialogue with national cancer site organizations, CCAN welcomed two additional national cancer organizations to Members Council increasing total membership at Council to thirty-eight members strong.
- In order to ensure an informed patient perspective remains at the forefront of cancer control activities in Canada, CCAN strategically expanded our pan-Canadian network of patient voices.

## Working in collaboration

- In support of the Canadian Cancer Research Alliance (CCRA) efforts to develop the first pan-Canadian Cancer Research Strategy, CCAN ensured patient voice representatives were engaged in regional consultation meetings held across Canada, as well as key informant interviews.
- CCAN worked closely with the Canadian Partnership Against Cancer to ensure patient voice representatives played a key role in the development of Cancer View Canada, a portal to comprehensive cancer control resources.
- CCAN partnered with divisions of the Canadian Cancer Society in order to deliver a number of key initiatives relevant to core patient issues faced by Canadian cancer patients today.
- To ensure an informed patient perspective is included in all areas of the cancer continuum, CCAN ensured patient voice representation on each of the Canadian Partnership Against Cancer Action Groups: Cancer Guidelines, Cancer Journey, Health Human Resources, Primary Prevention, Research, Screening and Surveillance.
- CCAN partnered with the Assembly of First Nations to support the abstract, **“First Nations in Canada and Cancer Screening: Addressing the Needs of Indigenous Peoples”**.



## AUDITORS' REPORT

**BRIAN R. METCALFE**  
**CHARTERED ACCOUNTANT**

**To the Members of the Canadian Cancer Action Network:**

I have audited the balance sheet, the statement of operations, the statement of fund balances and the statement of cash flow of the Canadian Cancer Action Network for the year ended March 31, 2009. These financial statements are the responsibility of the organization's management. My responsibility is to express an opinion on the financial statements based on my audit.

I conducted my audit in accordance with generally accepted auditing standards. Those standards require that I plan and perform an audit to obtain reasonable assurance whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation.

In my opinion, these financial statements present fairly, in all material respects, the financial position of the organization as at March 31, 2009 and the results of its operations for the year then ended, in accordance with Canadian generally accepted accounting principles.

Toronto, Canada  
May 27, 2009



**CHARTERED ACCOUNTANT**

## YEAR ENDED MARCH 31, 2009

### Balance Sheet

	Members' Fund	General Fund	Consolidated
<b>CURRENT ASSETS</b>			
Cash & short term investments	54,431	74,321	128,752
Accounts receivable	-	1,125	1,125
Total assets	54,431	75,446	129,877
<b>LIABILITIES</b>			
Accounts payable and accruals	-	10,900	10,900
Total liabilities		10,900	10,900
<b>SURPLUS</b>			
Accumulated surplus	54,431	64,546	118,977
Total liabilities and surplus	54,431	75,446	129,877

### Statement of Operations

	Members' Fund	General Fund	Consolidated
<b>REVENUE</b>			
CPAC grant	-	375,000	375,000
Membership Dues	55,550	-	55,550
Interest Income	1,035	-	1,035
Total revenue	56,585	375,000	431,585
<b>EXPENSES</b>			
Compensation & administration	25	104,113	104,138
Projects	-	110,284	110,284
Conferences & meetings	-	89,468	89,468
Media & materials	513	8,205	8,718
Total expenses	538	312,070	312,608

## YEAR ENDED MARCH 31, 2009

### Statement of Fund Balances

	Members' Fund	General Fund	Consolidated
<b>FUND BALANCES, beginning of year</b>			
Excess (deficit) revenue over expenses	56,047	62,930	118,977
Transfers	(1,616)	1,616	-
Fund balances, end of year	54,431	64,546	118,977

### Statement of Cash Flow

	2009	2008
	\$	\$
Excess, revenue over expenses for the year	118,977	-
Cash generated from, or used by, net current assets	9,775	-
Cash flow from operations	128,752	-
Cash balance, beginning of year	-	-
Cash balance, end of year	128,752	-
The cash balance is composed of:		
Bank cash accounts	88,417	-
GIC Investments	40,335	-



OUTREACH  
MOMENTUM  
DIALOGUE  
SUPPORT

**CANADIAN CANCER ACTION NETWORK**

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