



National Cancer Leadership Forum

Forum national de leadership sur le cancer

National Cancer Leadership Forum Year-end Update*

November 20, 2005

"The NCLF is clearly emerging as an important, collective voice for the cancer community in Canada. It is my understanding that all players have now made a commitment to the NCLF process and are willing to work together toward a successful outcome of a well-informed national direction for cancer control. It is important to now consider the long-term goal and not sacrifice a unified effort in the urgent and passionate desire for change. Of significant importance as you move forward this year will be the capacity for all stakeholders to demonstrate flexibility and be pragmatic on positions in light of the broader public good."

Message from then-MP Nick Discepola to the NCLF- February 2004

Dear NCLF Members:

As Nick prophesized almost two years ago, this has been a tremendous year for cancer leadership in Canada. As the following achievements indicate, the cancer community has created unprecedented interest in cancer control reform and the implementation of the CSCC is getting closer and closer to being a reality.

- **"If you knew what we know about cancer ... it would only make you angry" - January 19 – launch of the Campaign to Control Cancer with full-page ads in the Globe & Mail and La Presse resulting in an estimated 20 million Canadians hearing the message**
- **May 19 – article in the Globe & Mail by André Picard – "It's a disgrace not to have a (cancer) strategy"**



* La version française de ce bulletin sera disponible sous peu.

- **May 31, 2005 – New Brunswick provincial legislature passes motion “calling upon the federal government to implement and fund a national strategy on cancer control in collaboration with all the provinces and all the stakeholders”**



- **June 7 – Federal Government motion presented by Official Opposition Health Critic Stephen Fletcher passed in the House of Commons to “fully fund & implement the CSCC”**

- **June 7 – the New Brunswick provincial legislature passes a motion “to implement a provincial cancer control strategy in collaboration with all stakeholders by March 2006”**

- **June 22 – second ad in the Campaign to Control Cancer series – “When we first told Canadians about our plan to cut cancer down to size, they paid attention. On June 7th, so did Parliament.”**

- **June 22 – letter from federal Minister of Health Ujjal Dosanjh to all MPs and Senators, “to explain the Government of Canada’s position on the adoption of the June 7, 2005, Opposition Day motion dealing with the Canadian Strategy for Cancer”**

- **Sept. 9-10 – Leadership Training Workshop in Kelowna establishes BC Provincial Leadership Team and Action Plan for 2005/6**

When we first told Canadians about our plan to cut cancer down to size, they paid attention.

On June 7th, so did Parliament.

The Campaign to Control Cancer suggests a national action plan to...
 To help get it right, we need to make sure it's...
 Expanded cancer prevention programs...
 Increased attention to screening...
 Accelerated the application of knowledge...
 Applied consistent treatment standards and uniform end-of-life care...
 Advanced clinical trials and cancer control systems...
 To make the...
 The Campaign to Control Cancer is a national coalition of more than 40 leading cancer organizations...
 The members of the Campaign to Control Cancer include...
 To learn more about the campaign to control cancer, visit our website: www.cccan.ca

- **Sept. 24-25 – Leadership Training Workshop in Toronto establishes Ontario Provincial Leadership Team and Action Plan for 2005/6**



- **Sept. 24 – the Globe and Mail publishes Mary Janigan’s article - “Fighting over the war on cancer – in the midst of the fundraising season, an innovative national strategy on the disease has sparked a nasty backroom battle among bureaucrats and politicians”**
- **Sept. 26 – letter from Nova Scotia Premier John Hamm in support of the Campaign to Control Cancer and the CSCC, in which Premier Hamm “recommended funding for its implementation to Prime Minister Paul Martin at the First Ministers’ meeting in September, 2004”**
- **Oct. 15-16 – Leadership Training Workshop in Halifax establishes Provincial Leadership Team and Action Plan for 2005/6**
- **Oct. 20 – Federal Health Minister Ujjal Dosanjh’s announcement of \$59.5 million over five years to control cancer as a start on a federal investment**

- Oct. 22 – on the opening day of the 1st International Conference on Cancer Control in Vancouver, BC, the National Post and Canwest Global launch 5-part series on cancer control in Canada “Over the Next 30 years 2.4 million Canadian workers will get cancer ... 872,000 will die of it ...”
- Oct. 22 – National Post and Vancouver Sun publish letter “*Broken Promises and Misplaced Priorities*” “I am not surprised that a Government that sends its troops into harm’s way ill-equipped and underfunded would do the same to those of us on the front line in the battle against cancer” by Kelowna, BC, Radiation Oncologist, Islam G Mohamed, BSc MD FRCPC



- Oct. 23 – at the invitation of Ontario’s Minister of Health, George Smitherman and New Brunswick’s Elvy Robichaud along with a number of the other ministers, NCLF supporters made the first-ever presentation regarding the CSCC to the federal, provincial, territorial meeting of the Ministers of Health
- Oct. 25 – NCLF and the Campaign to Control Cancer – Symposium presentation sponsored by AstraZeneca at the 1st International Conference on Cancer Control attended by 300 international delegates
- Nov. 5 – NEW one-day Leadership Training Workshop successfully piloted in Regina, aligns Provincial Leadership Team and Action Plan for 2005/6
- Cancer control on 2006 federal election agenda for opposition parties
- NCLF membership is up from 27 stakeholder groups in 2004 to 50 in 2005 + counting!

NCLF PROVINCIAL PROGRESS REPORT

On the heels of our fall training workshops, provincial teams have been hard at work advancing the Canadian Strategy for Cancer Control.

Please note that all NCLF supporting organizations and any interested groups or individuals can now help collect names for the petition calling upon the federal government to fully fund and implement the Canadian Strategy for Cancer Control. **The petition is now available on-line** at the website for the Campaign to Control Cancer (C2CC) at www.controlcancer.ca

Groups can also create a link to the C2CC website and the petition by contacting the C2CC webmaster at frank@salvatori.ca

Lets all work to reach that goal of gathering 1 million signatures to present to the next federal government before April 1st 2006!

Local Highlights:

British Columbia Group

Here's an inspiring update we just received from Islam Mohamed.



I wanted to follow-up with you on one of my recent actions: writing a letter to the editor. Just before the 1st International Cancer Control Congress, I wrote a 500-word piece regarding the CSCC and the Health Minister's announcement of \$59.5m in funding to support it.

The letter was published by the *Vancouver Sun* and the *National Post*, two of the three newspapers I sent it to. The letter was shortened by the editors for publication, but the full text of the letter appears in some of the newspaper clips services. For good measure, I also sent the letter to about

10 politicians. Some of their replies are enclosed as attachments as well (Stockwell Day, Gordon Campbell, and the PMO).

I would not have thought to send such a letter before September. I am fortunate to have a worthwhile cause to champion in pursuit of excellence in cancer care for my patients. Soon, another stakeholder alert will be issued in advance of the publication of a new C2CC advertisement. I encourage each of you to act beyond your daily routine and make your voice heard.

Best regards,
Islam

In addition, Shannon Lavell, Jerilynn Kiely, Lynn MacDonald met last week with Sindi Hawkins, their MLA, in Kelowna, although early reports indicate that the response was not encouraging.

Nova Scotia Group

Action plan follow-up is underway in Nova Scotia. Advocacy actions by individuals include: an Op-Ed piece in the *Halifax Chronicle Herald* by Rosanna Bechtel (a piece strongly encouraged by the paper's health reporter). CCS has planned a major presentation to the cancer community on November 25 on the Canadian Strategy and what it means for Nova Scotia. Strong support at the provincial government level, and the provincial government and federal politicians from NS are invited to the event.

Here's an excerpt from Rosanna's Op-Ed in the *Halifax Chronicle Herald*, Friday Oct. 21, 2005:

Feds renege on cancer control

By ROSANNA M. BECHTEL

Late last week, I learned that the Canadian Strategy for Cancer Control, which received unanimous support from Parliament in a resolution passed last June 7, is not going to be implemented after all. My disappointment is both personal and "professional": I am a breast cancer survivor coming up on her five-year anniversary and a volunteer with Breast Cancer Action Nova Scotia as well as with Reach to Recovery and the Cancer Connection, two programs of the Canadian Cancer Society. So now, I have to do something more. I have to remind you that your MP has already voted in favour of the CSCC; and for that matter, Premier John Hamm endorsed it in a letter to Dr. Simon Sutcliffe of the National Cancer Leadership Forum dated Feb. 24, 2005. Now you need to remind your MP to tell the government that you want the whole loaf, not just the crumbs.

Ontario Group

In October, Ontario Team representative Amanda Kusick from CCS Ontario Division sent an initial contact email out to everyone from the conference and informed them that the NCLF petition was up and running on the CCS advocacy site. She attached the link to the site and asked everyone to sign it and forward it to their family and friends. With the federal election imminent, CCS is ready to mobilize its volunteer base as needed in support of the CSCC. Additionally, NCLF has again been invited by the Honourable Dwight Duncan, Minister of Finance for Ontario, to participate in a discussion on the 2006 Ontario Budget.

Saskatchewan Group

Less than two weeks ago the NCLF piloted a new one-day workshop to an enthusiastic group from Regina (with a few Albertans participating as well!). They have tabled an ambitious plan to network with other groups to raise awareness and support for the CSCC, to promote all-party resolutions in Saskatchewan and Alberta, to meet with politicians and attract media interest.

On Nov. 17, Richard Schick from the Saskatchewan workshop reported, "There was a session at the legislature yesterday. Carrie Lozinski (from the Regina workshop) was interviewed by the media after the opposition raised the SCT program vulnerability in the house. It was on CTV, Carrie and I have it on tape, all 30 seconds! But we got the message out there, and the minister gave assurances the program would continue....."

Here's a contact list of provincial NCLF leaders FYI:

BC:

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Mary Klaassen
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NB:

Michelle Michaud
506-634-6272
mmichaud@nb.cancer.ca

**... and we still have a long way to go
to ensure sustainable support for the Canadian Strategy
for Cancer Control with all federal and provincial
governments ...**

The NCLF Leadership Team (LT) recognizes that our interdependence as a community is the key success factor in these collective achievements – and in going forward. In order to support these ongoing efforts, the Leadership Team will continue to build upon the 2005 successes through open and regular communication with supporters and our genuine commitment to achieving the agreed-upon goals. A brief review of the Leadership Team's purpose and mandate from the December 2003 Forum follows:

Purpose:

1. To champion a fundamental improvement in how Canada responds to the problem posed by cancer.
2. To serve as a catalyst for connections within the cancer sector, outside of sector and with government.
3. To serve as a conduit for knowledge, perspective, information, dialogue and debate in giving Canadians a voice on the cancer issue.
4. Increase networking, trust and shared understanding of goals within the community of cancer stakeholders.
5. To champion a collaborative action plan to support the timely and effective implementation of the Canadian Strategy for Cancer Control in 2004.
6. Increase available resources; reduce duplication and fragmentation of advocacy efforts.
7. Increase advocacy capacity – defined as the assets, strengths, qualities and characteristics that enable cancer organizations to survive and grow.
8. Increase public and media attention to the growing burden of cancer in 2004.
9. Increase public and political understanding of the need for increased and specialized resources to meet citizen expectations for excellence in cancer control.

The Right Image

While advocacy has traditionally focused on identifying and communicating about gaps, deficits and weaknesses in the system, the NCLF has had greater impact by taking an affirmative, positive and visionary approach to the issue of cancer care and implementation of the CSCC, actively setting the agenda, providing an informed perspective of the challenges ahead. As a result, we have drawn the cancer community, civil servants, elected officials, the media and Canadians toward a more comprehensive, patient-centered cancer care system.

This positive positioning has done more than shape the image of the CSCC. It has motivated key constituents including stakeholders, the media and the public to think differently about the issue.

The Right Influence

In the crowded healthcare marketplace, there are numerous advocates fighting for their share of politicians and stakeholders attention. Securing the right level of attention and resources has required NCLF to use its leadership expertise to profile the CSCC and cancer in a way that will allow it to stand apart from other health care issues – including the current policy climate of advancing a chronic-disease management approach.

As evidenced by the HIV/AIDS movement, effectively breaking through the cluttered healthcare environment requires creating new demand for a new kind of care. By defining the CSCC and what is needed in the next decade and beyond, the NCLF has built critical mass among Canadians, which will in turn create sustainable public pressure for a more comprehensive, and patient centered cancer care system.

COMMITTEES:

Public Relations/Communications Committee:

Chair: Mark Sarner, Manifest Communications

The objective of the Public Relations/Communications Committee is to create/increase awareness of the “Cancer problem”, educate Canadian citizens about the issue, emotionally connect them to the importance of Cancer control and inspire them to take effective action targeted at moving the CSCC to implementation.

Stakeholder/Networking Committee:

Co-Chairs:

Elisabeth Ross – eross@ovariancanada.org

Fiona Mitchell – FMitchel@bccancer.bc.ca

Stakeholder Relations Manager: Beth Kapusta – bkapusta@sympatico.ca

The objective of the Stakeholder/Networking Committee is to galvanize the efforts of cancer stakeholders groups around a common message and direction to mobilize their individual and collective clout to influence government to support the CSCC.

Government Relations Committee:

Co-Chairs:

Brent Schacter – brent.schacter@cancercare.mb.ca

Charles Beer – cbeer@counselpa.com

The objective of the Government Relations Committee is to build new relationships and strengthen current relationships with the key government contacts to influence them to support the CSCC in a public manner. The anticipated federal election has been identified as a strategic opportunity for advancing the CSCC and the GR committee is developing both a long-term and immediate approach to gaining federal commitment and to ensure provincial governments’ on-going alignment.

The Right Decisions

NCLF AT THE CROSSROADS:

"Individuals can know when they are right or wrong, not by the intensity of an inner feeling of absolute truth, but only through a process of seeking consensus with others, a process which is in essence a free public dialog governed by respect rather than rules."

– Quaker Beliefs

NCLF is at a crossroads, great work done...great work facing us. As we think about the future, we are looking to define how we want to move forward. The decisions regarding the future for the NCLF will be made by representatives of the supporting organizations at the upcoming 2006 Forum. In anticipation of that event, we will be undertaking a survey of key opinion leaders inside and outside the cancer community and the findings will be shared in a pre-Forum report, along with recommendations for future actions and decisions. The current Principles for Action and process for decision-making are outlined below:

Principles of Action for the NCLF

We are a collective body representing all our members regardless of size and have an elected body that provides structure and direction to the NCLF

We are accountable to the NCLF Forum members for doing what we say we will do and are also responsible for creating the next Forum structure and process for leadership selection.

To the degree possible we advance information to our partner organizations in seeking the implementation of the Cancer Strategy. We are acting on behalf of the public and patients and are not representing a staunch position of any specific organization.

We see the NCLF as a network, not a separate freestanding organization (Network Definition: A system over an interconnected body) and deliberately do not prescribe, own or dictate individual organization policies. Rather we come together to serve a common goal and act to achieve the goal.

We are flexible and tolerant with a certain degree of uncertainty and ambiguity. We are responsive to being shaped by the direction required in the moment and drive behavior in alignment with the NCLF vision.

We believe in constructive engagement. It is our intention to achieve our shared vision through a community consultative process.

When the community at large will be impacted by our actions, we intend to be transparent, open and accountable to our members.

We anticipate they will be equally informing to their constituency of our actions and identify the role their constituency could have in moving our shared goals forward.

The leadership question we ask ourselves in the midst of change is *"Do we have sufficient support to move forward, knowing that perhaps a few members might say*

they can't join us in the direction we are taking?" We, in effect, agree to disagree. If this case arises, we are always open to the opportunity for those members to join us on issues where for them, there is alignment.

In terms of stakeholder participation, we strive to assure that size does not play a deciding role. It is our intention that all views are heard, considered and forge our direction.

The LT recognizes that a participatory process does not always mean that everyone decides everything. Setting limits to participation is both reasonable and necessary, as long as the intention is to establish a functional process and not to protect a closed inner circle. The challenge is to establish clear criteria for participation and then enforce them in a fair and equitable manner.

The principle that applies is transparency about setting the limits to participation. Who can participate? Who can decide? Under what circumstances? The LT has created a highly-functional structure and process that is consistent with community values, has portrayed it graphically in the organizational chart, and is prepared to take responsibility for decisions and make future adjustments as necessary. The LT sets limits to participation not as a way to "keep people out" – but as a way to respect the functionality of the established team and the hard work of those who have been consistently and substantially invested and involved in the group's evolutionary process.

The 2006 Forum is Ready, Set & Go for Feb. 23-26, 2006!



June Callwood, Keynote Speaker

Join us once again at the Château Cartier in Aylmer, Québec (near Ottawa) for the 2nd National Cancer Leadership Forum – open to all members of the NCLF coalition of supporting organizations.

With the current level of achievement and excitement, the 250 places available at the 2006 Forum will fill up fast.

Register early in order to guarantee your spot and take advantage of early-bird savings.

Info: www.cancerforum.ca
or call 514-481-7408, ext. 228

Federal Election Alert! Coming December!

If you would like to receive regular Action Alerts from the NCLF about upcoming workshops, election news and advance copies of the newspaper ads for the Campaign to Control Cancer, please send your contact information to us at info@cancerforum.ca and we will add your group to the e-mail list of more than 650 advocates from across Canada.

Be a Leader! Join the Campaign to Control Cancer!

Join the NCLF before December 1 – and be among Canada's 50+ leading cancer organizations recognized in the national ad series – Campaign to Control Cancer!

Send your official letter of support to the NCLF at info@cancerforum.ca and be part of the 3rd ad in the series – to be published in 2005!



Your Secretariat

In skating over thin ice, our safety is in our speed.

Ralph Waldo Emerson

N.B. La version française de ce bulletin sera disponible sous peu.