

2015 Annual Report

Canadian Cancer Survivor Network

CCSN Highlights

Special points of interest:

- 'A Seat at the Table' which aims to increase the number of informed cancer patients, survivors and caregivers sitting on cancer and other healthcare Boards and committees

- Webinars, website & social media

- Annual Legislative Reception and meetings with decision makers across Canada

- Election campaign Q&A's during multiple provincial elections & the federal election

- Conferences & speaking engagements

- Health Ministers' Meeting in January 2016



CCSN presented with the "Dried Prostate" award from PCCN Ottawa - June 2015



CCSN President & CEO Jackie Manthorne speaks to guests during World Cancer Day - February 2016



(Left to right) CCSN's Jackie Manthorne with Ontario Premier Kathleen Wynne at CCSN's Legislative Reception at Queen's Park - September 2015



(Left to right) CCSN's Jackie Manthorne & Louise Binder with France Gelinas & Andrea Horwath at CCSN's Legislative Reception - September 2015



CCSN's Mona Forrest & Jackie Manthorne (Left & right) with Ontario Progressive Conservative Health Critic Jeff Yurek - February 2016



CCSN's Jackie Manthorne with Dr. David Swann, MLA Calgary-Mountainview, during a meeting in Edmonton - November 2015



CCSN's Jackie Manthorne & Louise Binder at the Health Ministers' Meeting in Vancouver BC - January 2016

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*The objective of **A Seat at the Table** is to increase the number of informed cancer patients, survivors and caregivers sitting on cancer and other healthcare Boards and committees.*

CCSN's Vision

The Canadian Cancer Survivor Network works to ensure that:

- Patients and survivors will easily access tools to understand decision making processes for positive change on issues critical to optimal patient care.
- Patients and survivors will be supported to make a difference through working with others to take action on those issues.
- Patients and survivors will obtain current knowledge about cancer treatment, options, and outcomes and be able to work together to end disparities in patient care and treatment.
- A network of patients, survivors, friends, families, community partners and sponsors will work together taking action to promote the very best standard of care, support, follow up and quality of life for patients and survivors.

A Seat at the Table Program

A Seat at the Table is a multi-year project. Its objectives include:

- Building future advocates and assuring leadership succession planning in Canada's cancer patient community.
- Increasing the number of informed cancer patients, survivors, caregivers and family members sitting on cancer and other healthcare Boards, committees and research peer review committees where decisions are being made about cancer diagnosis, treatment, post-treatment care, Health Technology Assessment procedures and processes and research funding.
- Development of a patient education training program entitled *Science of Cancer E-education course* to ensure that patients, survivors, caregivers and families are prepared to meet the challenges of sitting on these Boards, committees and research peer review committees.
- Development of additional patient education training programs on varied topics, including the ABCs of advocacy and HTA, for example.



This project is undertaking the following activities:

- Research has been undertaken to identify Canadian cancer organizations which fund research. Each organization has been contacted to ascertain whether patients, survivors, caregivers or family members sit on research peer review committees and under what conditions. Information on organizations which have patients on their research peer review committees is being gathered and posted on CCSN's website. CCSN is discussing why patients should sit on research peer review panels with those organizations which do not have patients on these committees with the objective of raising awareness about the skills and perspectives that cancer patients bring to the table. This work is ongoing.
- Research is being undertaken to identify all **patient and family advisory councils** at hospitals across Canada with the objective of informing the cancer patient and survivor community in Canada about opportunities in their communities.
- Research is also being undertaken to identify **other cancer and healthcare Boards and committees** on which cancer patients, survivors and caregivers should be at the table and work to educate organizational decision makers of the value of having patients, survivors and caregivers participate in their decision-making processes, including:
 - Regional health network patient and family advisory councils
 - Cancer-specific patient and family advisory councils.

CCSN has formed a **Curriculum Committee** composed of experts to develop a patient education training program entitled *Science of Cancer E-education course* as well as additional patient education training programs. Curriculum development and the creation of e-education courses is taking place in 2015 and will continue in 2016.

Promoting Cancer Patient Engagement through Educational Webinars

The CCSN webinar series is of interest to patients, survivors, family, friends, caregivers and any member of the community interested in the best possible care and follow-up for cancer patients and survivors. The impact of volunteering and taking positive action to effect change are important elements in the transition to post-treatment life, and the objective of CCSN's webinar series is to provide everyone in the cancer community with the information and tools to promote change and build future advocates in the cancer and wider chronic disease communities.

Webinars are generally held biweekly on Thursdays from 1-2 PM EST.

Topics range from advocacy how-to's to HTA to cancer specific. Examples include:

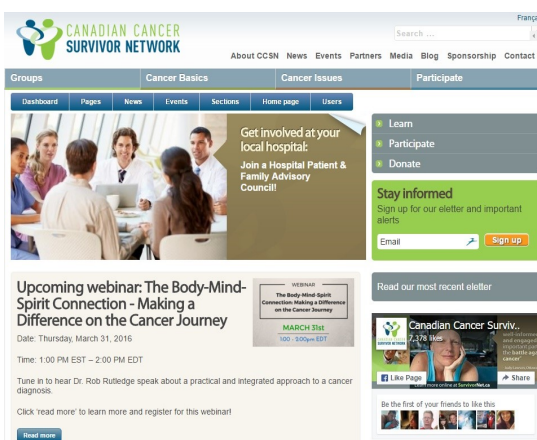
- The IBM report on the pCPA (Pan-Canadian Pharmaceutical Alliance)
- Informing treatment decisions for women with Ductal Carcinoma in Situ
- How patient groups can have more say in the drug approval process
- Social Media for Non-Profits - What Works, & What Doesn't?
- How Prescription Drugs are Approved in Canada
- Healthcare in Canada - Who Does What?
- How to Engage the Media to Support Your Advocacy Activities
- Drug Access Navigation - An Insider's Perspective
- Engaging Your Local Political Representative
- Examining Models for a National Pharmacare Program
- Marijuana for Medical Purposes Regulation (MMPR) - What Do I Need to Know?
- What Chronic Disease Advocacy Can Offer Cancer Survivors
- Understanding Your Health Insurance at Work
- Developing an Advocacy Plan
- Federal Election Special - What are the Parties Saying about Healthcare and Cancer?
- Biologics and biosimilars
- Challenges and Innovation in Canadian Access to Treatments and Innovation
- How can Canada's HTA systems evolve to meet patient needs
- The Cancer Medication Geographical Roulette in Canada!
- Changing HTA in Canada: what can patients do to promote improvements

These webinars can all be accessed online on [our website](#).

CCSN's Website & Social Media

Since its inception, CCSN has prioritized the development of its bilingual website and social media. Currently, CCSN is in the process of revising its website to constantly improve information and opportunities for patients/survivors.

Initially, CCSN concentrated on providing information on topics and issues related to prostate cancer, breast cancer, lung cancer and metastatic cancer. Gradually other cancers have been added: gastric/stomach cancer, metastatic breast cancer, melanoma and non-melanoma skin cancers, and a new website portal on cervical cancer will be launched later in 2015.



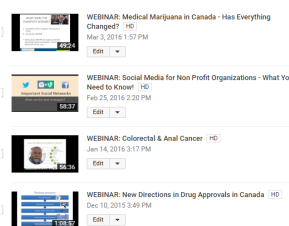
CCSN hosted its first webinar live from an event in 2015. It was broadcast from the Expert Patient Advocates & 21st Century Therapies Forum in Toronto.

CCSN's Mission

1. To promote health by conducting educational activities for cancer patients, caregivers and survivors on the physical and financial impacts, and other relevant topics, associated with managing cancer.
2. To promote health by providing individuals living with and survivors of cancer, and their caregivers, with access to related counselling, information, or support group programs.
3. To advance education by organizing and participating in conferences and speaking engagements to the public on topics related to cancer.
4. To advance education by conducting research on cancer patients' and survivors' physical, emotional, and financial well-being and disseminating the results of the research to the public.
5. To undertake activities ancillary and incidental to the attainment of the above charitable purposes.



As of March 2016, CCSN's main twitter feed @survivornetca has surpassed 4,000 followers.



All of our webinars are now archived on our YouTube channel for easy access and viewing.

In 2015, CCSN hosted another highly successful Legislative Reception at Queen's Park in Toronto. It was attended by Ontario Premier Kathleen Wynne, MPP Andrea Horwath, Leader of the Ontario NDP, and many more. Find out more about the reception and its impact on page 5.

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Website & Social Media, continued

In addition, CCSN's website houses an important section entitled *Participate*, which includes sections on A Seat at the Table, CCSN's Webinar Series and Election Campaigns, a repositories of CCSN's questions and answers to these questions from political parties and candidates in federal, provincial and territorial elections.

CCSN's social media reflect priority cancers and issues. In addition to our main Twitter feed @survivornetca, CCSN hosts the following Twitter feeds:

[@bestbreastnews](#) - information on breast health and breast cancer
[@prostatepost](#) - news, events and resources about prostate cancer
[@canadianmeso](#) - information on asbestos and mesothelioma
[@LungCancerCan](#) - focuses on lung cancer news, events and awareness
[@CCSNpoli](#) - general, non-partisan talk about the politics of healthcare and cancer care
[@MedMarijuanaCan](#) - news and information regarding medical marijuana
[@stomachcancerca](#) - information and resources about stomach cancer
[@cervicalcanca](#) - information and news about cervical cancer
[@melanomacan](#) - information and news about melanoma

CCSN also hosts the following social media:

- **Facebook:** General CCSN Facebook page as well as pages dedicated to prostate cancer and asbestos and mesothelioma.
- **YouTube:** CCSN's YouTube account contains our on-demand webinars as well as other videos about CCSN's work.
- **Slideshare:** CCSN's Slideshare page contains our website PowerPoint presentations as well as CCSN presentations given at various meetings and conferences.
- **Pinterest:** CCSN hosts a Pinterest page dedicated to cancer care and healthcare issues and activities.
- **Blogs:** CCSN's main blog is entitled Jackie Manthorne's Cancer Blog; in addition, CCSN hosts a blog about asbestos and mesothelioma.
- **CCSN's weekly newsletter:** CCSN hosts a weekly newsletter on Paper Li. It contains information about cancer care and healthcare.

Raising Awareness Among Decision Makers and Health Policy & Treatment Monitoring and Evaluation

This CCSN program includes:

- Ongoing coordination of cancer groups involved in monitoring and evaluating alignment activities of pCODR and CDR within CADTH.
- Responding to consultation opportunities at CADTH, within federal, provincial and territorial programs, policies and laws.
- Monitoring and evaluating pCPA and involvement in consultations regarding this program.
- Co-facilitating patient Pharmacare roundtable and monitoring activities.
- Responding to pharmacare consultations.
- Involvement in development of patient "value" formula for HTA consultations in spring 2016.
- Involvement in patient working group developing immuno-oncology strategic plan.
- Involvement in monitoring and responding to private payer treatment access issues.
- Ongoing meetings with federal, provincial and territorial politicians and bureaucrats in health, industry, finance on health policy-related issues.
- Continuing to advise stakeholders on patient perspectives on health policy and treatment access vision and future directs.

CCSN raises awareness among decision makers through receptions and meetings, including:

Ontario Legislative Reception

CCSN regularly meets, consults with and informs politicians and other decision makers. In 2015, CCSN hosted its 4th annual Ontario Legislative Reception at Queen's Park on September 16. This reception was hosted by Ann Hoggarth, MPP for Barrie, and was attended by:

- Premier Kathleen Wynne.
- MPP Andrea Horwath, Leader of the Ontario NDP.
- John Fraser, MPP for Ottawa South, who provided remarks on behalf of The Honourable Eric Hoskins, Minister of Health and Long-Term Care.
- Bill Walker, MPP for Bruce-Grey-Owen Sound, who said a few words on behalf of the Ontario Progressive Conservative Party.
- France G  linas, MPP for Nickel Belt, and New Democratic party Critic for Health and Long-Term Care, who spoke for a 4th consecutive year.
- A large number of MNAs and staff.

Other speakers included:

- Stuart Edmonds, VP of Prostate Cancer Canada.
- Three prostate cancer survivors: David Brittain from Ottawa, Paul Henshall from Brampton, and Mike Preston from Toronto.

Several other groups attended this legislative reception, including Willow Breast & Hereditary Cancer Support, the Ontario Chapter of the Canadian Breast Cancer Foundation, Lung Cancer Canada, and Prostate Cancer Canada.

Meetings in British Columbia

In the spring of 2015, meetings were also held about survivorship issues with decision makers in British Columbia, including:

- Fiona Walks, VP Safety, Quality and Supportive Care, BC Cancer Agency.
- Dr. Arminee Kazanjian, Co-director Survivorship Research Centre, BC Cancer Agency.
- Sabrina Loiacono, Chief of Staff to Health Minister Lake.

Edmonton Legislative Meetings

In November 2015, CCSN met with several MLAs in Edmonton:

- Dr. Turner, NDP, MLA for Edmonton-Whitemud (NDP).
- Mr. Dave Rodney, PC, MLA for Calgary-Lougheed (PC).
- Mr. Ric McIver, PC, MLA for Calgary-Hays (PC).
- Dr. David Swann, AL, MLA for Calgary-Mountain View (Liberal Party).

Federal, provincial and territorial election questions

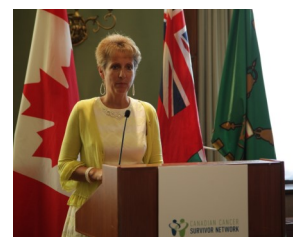
CCSN asks questions to political parties and candidates during federal, provincial and territorial elections. To date, CCSN has engaged in 11 election campaigns, including the recent federal election. Questions and responses from parties and candidates can be found [here](#).



CCSN's Louise Binder & Jackie Manthorne with Ontario Premier Kathleen Wynne during CCSN's Legislative Reception - September 2015



Stuart Edmonds, VP of Prostate Cancer Canada speaking during the Legislative Reception - September 2015



France G  linas, MPP for Nickel Belt, and New Democratic party Critic for Health and Long-Term Care speaking during the Legislative Reception - September 2015



CCSN's Jackie Manthorne (left) and Dr. Bob Turner, MLA Edmonton-Whitemud (right) during a meeting in Edmonton - November 2015

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CCSN's Jackie Manthorne speaking at LEO Pharma about Thrombosis - February 2016



CCSN's Louise Binder & Jackie Manthorne pose at the Canadian Health Coalition's "Put the Heart Back in Healthcare" event during the Health Ministers' Meeting in Vancouver - January 2016



Representatives from CCSN and Prostate Cancer Canada Network Ottawa meet with Ottawa Mayor Jim Watson on National Cancer Survivors Day - June 2015

Speaking engagements and attendance at conferences

- Presentation at the Economic Club of Canada on What Cancer Patients Want, April 2014.
- Addressed the audience at an evening with the Mayo Clinic: Enhance your lifestyle and reduce cancer risks at the Casa Loma in Toronto, September 2014.
- Panelist at The Winds of Change are Blowing: Will coming changes to pharmaceutical access hurt patients? In Toronto, September 2014.

Recent conferences attended:

- CIRH Institute of Cancer Research Institute Advisory Board Meeting and Community event, Winnipeg, April 2015
- Conférence nationale pour vaincre le cancer, Montreal, April 2015.
- CADTH Symposium, Saskatoon, SK, April 2015
- Canadian Association of Psychosocial Oncology, Montreal, April 2015.
- Janssen Second Annual Patient Summit, October 2015, Toronto.
- Rx&D Conference, November 2015, Montreal.
- Canadian Association of Healthcare Reimbursement National Day, November 2015.

Federal, Provincial & Territorial Ministers of Health Meeting, January 20-21, 2016

CCSN travelled to Vancouver when the federal, provincial and territorial Ministers of Health meeting was being held. Before the meeting, CCSN issued a media release entitled *Health Ministers' Meeting: cancer groups support improved access for cancer patients falling between the cracks* in collaboration with several other organizations:

- Save Your Skin Foundation
- Life Saving Therapies Network
- Anal Cancer – A Bum Rap
- Hair Donations Ottawa
- Canadian CML Network
- GIST Sarcoma Life Raft Group Canada

CCSN had the opportunity to meet informally with several health ministers and health ministry staff. During and after the meeting, CCSN issued several updates:

Health Ministers' Meeting Update #1 (<http://bit.ly/1RKSSep>) contains the following articles:

- Oncology patient groups support expanded drug access.
- Cancer groups support improved access for cancer patients falling between the cracks
- What you can do.

Health Ministers' Meeting Update #2 (<http://bit.ly/201sdrl>) contains the following articles:

- Cancer patient groups hopeful prescription drug talks will eliminate existing drug access disparities across Canada.
- Oncology groups laud federal government's decision to join the pan-Canadian Pharmaceutical Alliance (pCPA).
- What you can do.

Health Ministers' Meeting Update #3 (<http://bit.ly/1IO4BnD>) contains the following articles:

- Cancer patients see promise in renewed collaboration between federal, provincial and territorial health ministers.
- What you can do.

Each update was sent to all the Ministers of Health; select media; and to CCSN's elist of 8,000 individuals and groups as well as posted on CCSN's website and tweeted to the Ministers and select media.

Drug approval submissions

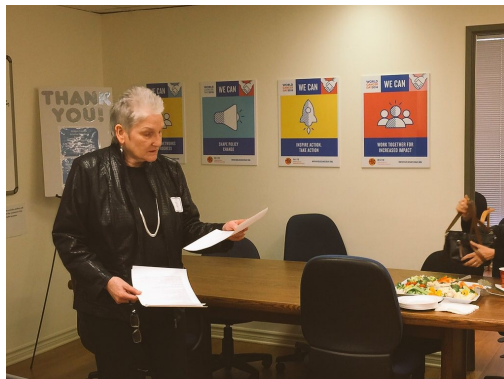
Finally, CCSN regularly makes submissions to pCODR and the Common Drug Review at CADTH, INESSS and other drug approval bodies in Canada.

Canadian Cancer Survivor Network



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Thank you to all of CCSN's hard working board, staff, & volunteers for an extremely successful 2015!



Jackie Manthorne speaking at CCSN's World Cancer Day open house - February 2016



CCSN's Volunteer Appreciation party - January 2015



CCSN's Jackie Manthorne takes a selfie with Ontario Premier Kathleen Wynne during CCSN's Legislative Reception - September 2015



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