

2016 Annual Report

Canadian Cancer Survivor Network

CCSN Highlights

Special points of interest:

- The Canadian Cancer Survivor Network, along with the Save Your Skin Foundation and the Schizophrenia Society of Ontario hosted a Summit about drug pricing policy in Canada

- Fifth Annual Legislative Reception help at Queen's Park in Toronto

- CCSN Webinars continue to grow in registrants and views

- Conferences & speaking engagements

- Health Ministers' Meeting in January 2016



CCSN President & CEO Jackie Manthorne and CCSN Board Secretary Mona Forrest meet with Ontario Progressive Conservative Health Critic Jeff Yurek - February 2016



Ottawa Mayor Jim Watson proclaims that the month of June will be known as National Cancer Survivor Month - June 2016



CCSN supports National Cancer Survivors Day by hosting an office coffee party to make a positive impact on the lives of people in need. - June 2016



CCSN President & CEO meets with Ontario Minister of Health and Long-term Care Eric Hoskins and cancer survivor and caregiver. CCSN Legislative Reception - October 2016



"Being well informed and engaged is an important part of the battle against cancer."
- Judy Lawson, Ottawa, ON



CCSN's Jackie Manthorne opens Drug Pricing Policy in Canada Summit in Toronto - November 2016

The Summit held on November 15th and 16th involved over 40 patient organizational representatives who were interested in drug pricing policy in Canada.

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.

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Drug Pricing Policy in Canada

On November 15 and 16 of 2016, Drug Pricing Policy in Canada: Mobilizing Patients to Action (the Summit) was held in Toronto. The event stemmed from the collaborative efforts of the Canadian Cancer Survivor Network, the Save Your Skin Foundation and the Schizophrenia Society of Ontario, with the contributions of several volunteers, panelists and other collaborators.

The Summit offered a space for patients, patient advocates, caregivers and their groups from all disease and disability areas to come together and examine how they can meaningfully participate in and influence regulatory, public and private drug pricing policy processes in Canada. In addition to hearing recommendations and ideas from key stakeholders to inform and guide their discussions on these issues, participants worked to identify tangible strategies and action items in the short, medium and long term to shape drug pricing policy in Canada, and to make related processes more transparent, accessible and inclusive.



A Patient Vision, Values and Principles of a National Pharmacare Program

In 2016, CCSN convened a roundtable in partnership with allied mental health groups to formulate a common patient position and perspective on Pharmacare at a daylong event at the Vaughn Estate located on the grounds of Sunnybrook Health Sciences Centre on June 1st. CCSN was supported in this effort by a Steering Committee including representatives from Save Your Skin Foundation, Lung Cancer Canada, The Schizophrenia Society of Ontario, The Carcinoid Neuroendocrine Tumour Society and The Colorectal Cancer Society of Canada.

Our Principles

- **Protect or Improve** existing individual access to therapies at or above their current level.
- **Ensure** universality and equality that recognizes diversity in all its formats and accommodation for disability.
- **Safeguard access** to medically necessary therapies for uninsured and underinsured residents of Canada regardless of ability to pay or place of residency.
- **Recognize** the discrete needs of people with life threatening and serious debilitating illnesses that significantly impact quality of life.
- **Accept, assess and value** real world evidence in determining therapeutic value.
- **Reinvest** pharmaceutical system savings back into the Pharmacare budget in order to provide increased access to therapies.
- **Build on** the foundation of health care mechanisms and systems already in place.
- **Develop** value-based drug pricing contracts, including systems for sharing data and other relevant information.
- **Analyze** the value of a drug or treatment for a Pharmacare system to include savings in other parts of the health care budget and broader socio-economic impact.
- **Expand** health technology assessment processes to measure the value of all components of the health care budget.

Supported by: CNETS Canada, The Canadian CML Network, The CML (chronic myelogenous leukemia) Society of Canada, GIST Sarcoma Life Raft Group Canada, Life-Saving Therapies Network, Lung Cancer Canada, Lymphoma Canada, Schizophrenia Society of Ontario, Sickle Cell Disease Association of Canada.

To learn more, please visit www.survivornet.ca/act/

CCSN Continues to Promote Cancer Patient Engagement through Webinar Series

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:

- Colorectal & Anal Cancer
- Social media for non-profit organizations-What you need to know
- Medical Marijuana in Canada: Has Everything Changed?
- The Body-Mind-Spirit Connection-Making a Difference on the Cancer Journey
- CADTH-Why is it important & what now?
- Pharma Funding of Patient Groups-The Building Blocks of Ethical & Appropriate Relationships
- Pharmacare: Caveat Emptor (Buyer Beware)
- Private Insurance Plans-Do They Have a Future in Canada?
- A pan-Canadian Pharmaceutical Alliance (pCPA) Update-Optimizing the Process for Patients
- What Patients Should Know About the Patented Medicines Prices Review Board (PMPRB)
- Q&A with Expert about Blood Clots & Cancer
- Drug Approval Bodies in Canada 101: The Elevator Pitch
- Engaging Your Local Political Representatives
- Developing an Advocacy Toolkit
- Precision Medicine in Oncology
- Rare Cancers: How to Empower Patients and Advocacy Organizations through Collaboration
- Medical Marijuana: Does it have a role in the treatment of cancer patients?

These webinars can all be accessed online at www.survivornet.ca/act/webinar-series/2016-webinars-on-demand/

CCSN's Website & Social Media

Since its inception, CCSN has prioritized the development of its bilingual website and social media.

Throughout 2016, CCSN has been working towards developing a new, easy-to navigate website that will allow visitors to easily access the information that they require. A screenshot of the new website can be seen to the right.

In 2016, CCSN website saw an increase in traffic compared to 2015 and all social media channels continue to grow at a steady rate.



CANADIAN CANCER SURVIVOR NETWORK RÉSEAU CANADIEN DES SURVIVANTS DU CANCER

The body-mind-spirit connection:
Making a difference on the cancer journey

Rob Rutledge, MD, Radiation Oncologist
Associate Professor, Dalhousie University
CEO, The Healing and Cancer Foundation

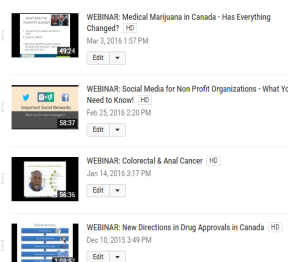
CCSN's most-attended webinar of 2016 was titled "The body-mind-spirit connection: making a difference on the cancer journey" and was presented by Oncologist, Dr. Rob Rutledge.

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 December 2016, CCSN's main twitter feed @survivornetca has surpassed 5,000 followers.



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

On October 5, 2016, the Canadian Cancer Survivor Network welcomed MPPs, staff, prostate cancer patients, survivors and caregivers and community partners at its fifth annual Legislative Reception at Queen's Park in Toronto. Find out more about the reception and its impact on page 5.

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A Seat at the Table program

The objective of the Canadian Cancer Survivor Network's *A Seat at the Table* program is to increase the number of informed cancer patients, survivors and caregivers 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 and research funding.

This objective will be accomplished in several ways, by:

Educating organizational decision makers of the value of having patients, survivors and caregivers participate in their decision-making processes.

Ensuring that Canadian cancer organizations which fund research include informed patients, survivors, caregivers or family members on their research peer review committees, ethics boards and other appropriate committees.

Ensuring that cancer centres and hospitals providing cancer treatment include informed patients, survivors, caregivers or family members on appropriate boards and committees.

Developing a ten-module science of cancer e-education course to prepare cancer patients, caregivers and survivors to participate in research peer review panels.

Read more about the Seat at the Table program by visiting www.survivornet.ca/act/a-seat-at-the-table/

Election Campaigns

The Canadian Cancer Survivor Network engages in election campaigns whenever a federal, provincial or territorial election is called. The Network works with patients and survivors to frame questions about cancer care and healthcare issues nationally or in their province or territory. Once questions are prepared, CCSN sends them to all political parties and to all candidates for these parties. Responses are posted on our website and disseminated through our blog and social media.

Patient/survivor advocates also use CCSN's questions during all-candidates meetings and when they meet candidates at the door or in their offices.

In 2016, there were provincial elections in both Manitoba and Saskatchewan.

An example of the questions that were asked can be found below:

Question 1

The Canadian Medical Association Journal published research in 2012 that showed one in ten Canadians report they skip doses or decide not to fill prescriptions because of cost.

If elected to government, what will your party do to make prescription medications more affordable?

To read more about our election campaign initiative, please visit www.survivornet.ca/act/ccsn-election-campaigns

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 2016, CCSN hosted its 5th annual Ontario Legislative Reception at Queen's Park on October 5th. The reception was once again hosted by Ann Hoggarth, MPP for Barrie, who opened the event. She was followed by John Fraser, MPP for Ottawa South, who spoke on behalf of the Honourable Eric Hoskins, Minister of Health and Long-Term Care; Gila Martow, MPP for Bruce-Grey-Owen Sound who spoke on behalf of MPP Jeff Yurek, Conservative Party of Ontario Health Critic; and France Gélinas, MPP for Nickel Belt and New Democratic Party Critic for Health and Long-Term Care.

Key community representatives included:

- Dr. Stuart Edmonds, Prostate Cancer Canada
- Judi Perry Binkert, Wellspring
- Eric Thompson, Crohn's and Colitis Canada
- Sarah Strota, Canadian Cancer Society
- Dr. David Josephy, GIST Life Raft Group

And many others.

While in Toronto, CCSN also met with:

- MPP Ann Hoggarth, Parliamentary Assistant to the Minister of Community and Social Services, Liberal Party of Ontario.
- MPP John Fraser, Parliamentary Assistant to the Minister of Health and Long-Term Care (Health), Liberal Party of Ontario.
- MPP Michael Harris, Critic for Research, Innovation & Science, Progressive Conservative Party of Ontario.
- MPP France Gélinas, NDP Health and Long-Term Care Critic.
- MPP Jeff Yurek, Conservative Party of Ontario Health Critic.
- The Honourable Dr. Eric Hoskins, Minister of Health and Long-term Care.

One of the most exciting developments was the involvement of patients, survivors and caregivers and how well they represented the issues of the prostate cancer community in their regions of Ontario. Heather Redick, caregiver, from Zurich, ON and Preston Harris and Germaine Gould from the Windsor Prostate Cancer Support Group each attended some of the meetings with MPPs with Jackie Manthorne, CCSN President & CEO, where they brought their concerns to the forefront.

Richard and Pam Olley, cancer survivor and caregiver share their thoughts on the Reception:

"I was heartened to find representatives from each caucus who take special interest in health care issues and in issues around cancer research, diagnosis, critical and chronic care. I was pleasantly surprised at how approachable and eager they were for survivor input. They obviously understand there's nothing like having experienced the system to know what's working and what needs improvement. It was a special bonus to run into partner groups like Wellspring and Crohn's and Colitis Canada and be able to network with them too!"



MPP Catherine Fife stopped in at our 5th Legislative Reception on prostate cancer survivor needs at Queen's Park



Honourable Dave Levac, Speaker of the House speaks with CCSN's Jackie Manthorne at 5th Legislative Reception at Queen's Park.



France Gélinas, MPP for Nickel Belt, and New Democratic party Critic for Health and Long-Term Care speaking during the Legislative Reception - October 2016



CCSN's Jackie Manthorne and France Gélinas pose with cancer survivor and caregiver at 5th Annual Legislative Reception.

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



CCSN's Jackie Manthorne and conseiller senior of the Coalition priorité cancer au Québec Gilles Léveillé take a selfie at the 2016 Astellas Patient Advocacy Summit: Changing tomorrow together: Partnering to improve lives, held April 4-5 in Washington, DC.

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 who are falling between the cracks* (<http://bit.ly/2u71uip>) 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 who are falling between the cracks

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).

Health Ministers' Meeting Update #3 (<http://bit.ly/1lO4BnD>) contains the following articles:

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

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.



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



Guests & CCSN Staff chat while enjoying drinks and snacks during CCSN's World Cancer Day Open House - February 2016

Meetings, Conferences and Workshops

In 2016, CCSN attended and presented papers at:

- The World Cancer Congress, sponsored by the Union for International Cancer Control, Paris, Oct. 31-Nov. 3.
- The Canadian Association of Psychosocial Oncologists 2016 conference, Halifax, May 11-13.

CCSN also attended:

- Private Payer Thinktank, Toronto, Feb. 10
- Benefits Cancer Oncology Conference, Toronto, Feb. 25
- The 2016 Adolescents and Young Adult (AYA) Cancer Stakeholders' Workshop, Toronto, Feb. 27
- *Changing Tomorrow Together: Partnering to Improve Patients' Lives*, Astellas' Second Annual Patient Advocacy Summit, Washington, DC, April 5
- Amgen Oncology Global Patient Advocacy Advisory Boards, Prague, April 9-15
- Canadian Agency for Drugs and Technology in Health Conference, Ottawa, April 10-12
- Coalition priorité cancer au Québec, Montreal, April 14-15
- Masterclass on the conduct and use of patient-oriented research (SPOR), Toronto, April 18-20
- PharmaFocus Health Access and Outcomes, Toronto, April 18
- Applied Research in Cancer Control Conference (ARCC), Toronto, May 10
- International Society for Pharmacoeconomics and Outcomes Research (ISPOR), Vienna, May 21-25
- American Society of Clinical Oncologists, Chicago, June 2-7
- Inaugural Summit for Cancer Immunotherapy, Halifax, June 26-29
- Companion Diagnostics and Personalized Medicine Conference, Toronto, Sept. 14
- Lung Cancer Canada Gala and Patient Summit, Toronto, Nov. 17-18
- Innovative Medicines Conference, Toronto, Nov. 22

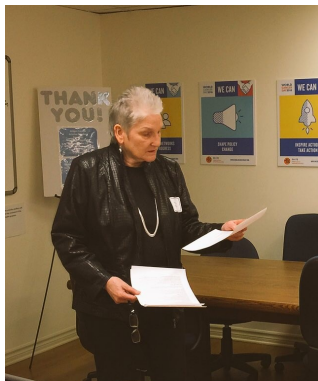


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Thank you to all of CCSN's hard working board, staff, & volunteers for an extremely successful 2016!



Jackie Manthorne speaking at CCSN's World Cancer Day Open House - February 2016



Jackie Manthorne poses with other attendees while at the 2016 Conference of the Canadian Association of Psychosocial Oncology - May 2016



CCSN meets with IMS Brogan - March 2016



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Canadian Cancer Survivor Network

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