2014 Annual Report

Canadian Cancer Survivor Network

Special points of interest:

- Our Facebook microtargeting campaign, which increased our Facebook reach to hundreds of thousands of impressions
- Our webinar series, which has become increasingly popular with time
- Cancer as a chronic disease research
- '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
- World Cancer Day open house
- Another year of hosting our annual legislative reception at Queen's Park

In this report:

Message from the Chair

In 2014 there were over 190,000 new cases of cancer in Canada. Cancer is the leading cause of death and is responsible for 30% of all deaths. According to the World Health Organization, at a global level the number of cancer cases is set to rise, by more than 5 million cases from 2012 to 2025.

Being diagnosed with cancer is something no one wants to hear, for ourselves or our loved ones. After a cancer diagnosis, there are many different challenges, complicating factors and concerns patients, families and their caregivers are confronted with.

The Canadian Cancer Survivor Network (CCSN) is here to help Canadians, as patients, survivors and caregivers, experiencing their own journey with cancer. I have been a CCSN Board member for several years, including this past year serving as volunteer Board Chair. These years have been foundational ones for CCSN, as we continue to establish ourselves as a new organization. We are now entering our fourth year. As a Board, we're proud of the progress we've been making.

Elaine Dean, Chair of the Board of Directors

What makes the CCSN unique is our ability to work at both the national and local levels, and our focus on many different types of cancer - both what makes them similar and what makes them different. We are focussed on helping Canadians stay informed, connected and to take action, to ensure they are receiving optimal cancer care and follow-up care. We support caregivers, who are faced with their own challenges along the cancer journey with their loved ones.

We work to maximize the quality of life of patients, their families and caregivers, who we help understand and respond to the full impact of cancer on their emotional, mental and physical well-being. We believe all Canadians have a right to access quality, effective cancer treatment and services on equal terms, regardless of geography and without suffering economic hardship as a consequence. And we work to ensure the availability of, and access to, the best available early detection programs for all forms of cancer.

Over the past year, we had success at positioning cancer as a chronic disease. As more people thankfully live through their cancer diagnosis, as I have, they are often confronted with complications and other diseases that come with an aging population.

As a governance Board, we have increased our capacity again this year. We continue to update our policies and our positioning papers, and to provide guidance and support to operational staff.

We have progressed in our strategic planning exercise, which has resulted in new policies and programs. Our website is undergoing a transformation, as we focus more on telling the stories on cancer patients, families and survivors. We recently updated our objects, to lay a stronger foundation to function as a charitable organization in the future.

As patient advocates, we are committed to finding an end to cancer. We participate alongside the medical and scientific community in ensuring the voice of cancer survivors are heard, and in communicating the latest advancements and challenges with others, through our social media platforms, our surveys, our enewsletters and our webinars. We partner with other organizations and individuals who have goals similar to ours, so that together we can create a significant impact.

On behalf of the CCSN Board, I invite you to read through this year's annual report to learn about our significant accomplishments at the programming level. We appreciate your collaboration and your support.

Elaine C Dean

Elaine Dean
CCSN Board Chair

Message from the President & CEO

Jackie Manthorne, President & CEO

This was certainly a year of growth and expansion for the Canadian Cancer Survivor Network's activities, programs and funding.

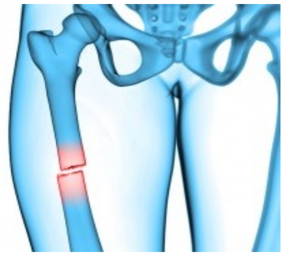
This section of our Annual Report will provide you with an overview of our activities and programs.

A Seat at the Table

The overall objective of this new, multi-year project 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. An important part of this program is the development of a patient education training program 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. Research has been completed to identify all cancer organizations in Canada which fund research and the next step is to contact them to identify which groups include patients on their peer review committees and to encourage those which don't to begin including them.

> *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.*

Bone Health in Cancer Program



One of the images circulated on Facebook is shown above.

Activities for this multi-year, Canada-wide program included public awareness campaigns about cancer as a chronic disease and the impact of ongoing and often lifelong side effects from cancer or treatment, and the launch of a successful Facebook microtargeting campaign in Alberta and British Columbia which resulted in over 4,000 new "likes" on Facebook, an additional 2,000 subscribers to our monthly eletter, and about 50 personal cancer journey stories to be featured on our website.

Website & Social Media

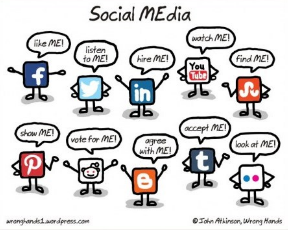
CCSN's Twitter account has grown to over 2,800 followers.

CCSN's Board and staff realized that our website (www. survivornet.ca), launched in 2012, was in need of realignment and redesign. Our IT committee, composed of expert volunteers, staff and interested Board members met for a full day in September 2014 to discuss issues like website accessibility, information gathering and sharing, reporting on new treatments and calls to action. The Committee debated challenges and opportunities, and looked at adding more ways for priority groups – patients, survivors and caregivers – to tell their stories, build a community, how to illustrate the cancer journey, and how to promote the patients' voice in healthcare decision-making.

CCSN utilizes social media to inform and educate patients, survivors, caregivers and other cancer communities about CCSN activities, events and news as well as activities, events and news from other organizations, mainstream media and other social media. We currently have nine Twitter feeds, including our general Twitter account @survivornetca as well as feeds relating to or emphasizing our priority cancers, such as breast, prostate, lung and gastric cancers. We also have Facebook, Pinterest, YouTube, SlideShare accounts, and a weekly paper.li newsletter and three blogs.

Webinar Series Program

This year, we were able to successfully grow our webinar series, with attendance ranging from 30 to nearly 100 attendees at each webinar. The objective of this series is to inform and educate patients, survivors, families, friends, caregivers and community organizations and to provide them with the tools to promote patient involvement. Webinar topics range from understanding Canada's healthcare system to using social media to promote patient involvement, from demystifying private drug plans to new directions in drug approvals in Canada.



Our social media webinar was one of our most attended webinars of 2014, with over 70 registrants and 50 attendees.

Drug Approval Submissions

CCSN is a registered patient group and makes submissions about cancer drugs to the pan-Canadian Oncology Drug Review (pCODR); the Common Drug Review (CDR); the Ontario Public Drugs Program (OPDP); the British Columbia Pharmacare Program; and l'Institut national d'excellence en santé et en services sociaux (INESSS) in Quebec.

Part of this process involves surveying patients about the impact of cancer on their quality-of-life; what treatments they are currently taking and any side-effects they have experienced.

Caregivers are also given the opportunity to share the impact of their loved one's cancer. This past year CCSN made six drug approval submissions.

At a higher level, CCSN is a member of an ad hoc coalition of patient groups concerned about the integration of pCODR into CADTH.

CCSN surveys patients and then makes submissions on new cancer drugs based on patient input.

Advisory Councils

CCSN's Medical Advisory Committee, Breast Cancer Advisory Council, Prostate Cancer Advisory Council, Asbestos and Mesothelioma Advisory Council and Stakeholder Engagement Committee added new members this past year. Council members provide advice, insight about living with cancer, attend meetings and conferences, speak at events and to the media, and accompany CCSN Board and staff to meetings with decision makers.

Partnerships & Coalitions

CCSN has nearly 50 partner groups with which we work on common issues, share information across groups, and consult on priorities. CCSN is also represented on several coalitions, including the Ontario Health Coalition; Cancer Advocacy Coalition of Canada; Better Care Faster; CanCertainty; Canadian Cancer Action Network and the Metastatic Breast Cancer Coalition.

Legislative Reception

CCSN holds an annual non-partisan Legislative Reception at Queen's Park in Toronto to inform and educate Members of the Provincial Parliament (MPPs) and other decision-makers to raise awareness of metastatic or advanced prostate cancer. Our third reception, held in November 2014, had more than 30 guests. Speakers included metastatic prostate cancer patients, a medical oncologist, a representative of the Ministry of Health and Long-Term Care and the Conservative and NDP health critics.

From left to right: Derek Lawrence, Jackie Manthorne, Dr. Andrew Feifer & Sapna Mahajan at our annual legislative reception held at Queen's Park in Toronto.

Conference Presentations, Speaking Engagements

To educate the public and policy makers, CCSN makes presentations at meetings and conferences and undertakes speaking engagements.

CCSN President & CEO Jackie Manthorne's presentations included:

- Presentation on CCSN at the Mayo Clinic event at Casa Loma in Toronto in September, 2014

- What do patients want?, a speech given at the Economic Club of Canada in April, 2104

- Presentation on issues impacting cancer survivors at the 2014 conference of the Canadian Association of Psychosocial Oncology in Winnipeg

Questions Asked During Election Campaigns

CCSN asks questions related to cancer care and healthcare during provincial, territorial and federal election campaigns. Questions, developed with input from patients & partner groups, are sent to the main parties and to all candidates to raise awareness of the issues and to identify champions.

Responses are posted on CCSN's website and sent out in an eblast to CCSN's elist.

This year, we asked questions during the New Brunswick, Ontario and Quebec elections.

Metastatic Breast Cancer Awareness Day

CCSN conducted a campaign to promote Metastatic Breast Cancer Awareness Day in Canada on October 13, 2014 to raise awareness of the issues facing women living with advanced breast disease and to draw attention to the gaps in support and treatment to this population. An important part of this campaign was the launch of a new section on our website, with the personal stories of women living with metastatic breast cancer.

CCSN Events

Elaine Dean (left) and Jackie Manthorne (right) posing in front of Oncology on Canvas artwork at CCSN's World Cancer Day open house.

World Cancer Day: CCSN hosts an annual open house to recognize and raise awareness of cancer on World Cancer Day. This global event takes place every year on February 4 to unite the world's population in the fight against cancer. World Cancer Day 2014 focused on Target 5 of the World Cancer Declaration, which aims to reduce stigma and dispel myths about cancer, under the tagline "Debunk the myths."

National Cancer Survivors Day: CCSN participates with groups and people worldwide on the first Sunday in June to celebrate those who have survived cancer. This day is an inspiration for those recently diagnosed, a gathering of support for families, and an outreach to the community. The event raises awareness about cancer patients living longer (surviving) due to improved screening and treatment but with physical, financial, and emotional hardships which often persist after diagnosis and treatment.

Some of the Oncology on Canvas artwork on display at CCSN's World Cancer Day open house.

Research

CCSN conducts psychosocial or community-based research on a variety of topics related to cancer. This year our two main research areas were:

Cancer as a chronic disease supportive care research: CCSN polled just over 1,000 randomly selected Canadian adults in May 2014 to determine their knowledge about how many people are surviving cancer and for how long, and what their main needs are. This research indicated that Canadians are not aware of how long people live after cancer and what their needs as survivors are, which led CCSN to issue a media release to draw attention to the fact that many survivors have side effects from cancer or cancer treatment that require long-term medical assistance. CCSN then conducted a successful media campaign that received over 12 million media impressions, and have been meeting with decision-makers to stress that cancer is a journey, not an event and therefore resources must be made available to survivors through this journey.

Research into the financial, decision-making and emotional impact of the disease on cancer patients and caregivers: This research, conducted in 2013 and launched in early 2014, identified gaps in support and financial support for patients and caregivers, which led to recommendations of making life-long medical navigation available to cancer survivors, making rehabilitative services available to cancer patients post-treatment, and providing ongoing support services to caregivers. Again, the concept of cancer as a journey and not an event was stressed during media events relating to the release of this

Research conducted by CCSN found that Canadians "are not aware how long people live after cancer and what their needs as survivors are."

CCSN Board, Staff & Volunteers

The Canadian Cancer Survivor Network thanks its staff, Board of Directors, volunteers and funders for their contribution to the Network. Without their help, CCSN would not have been able to grow and flourish.

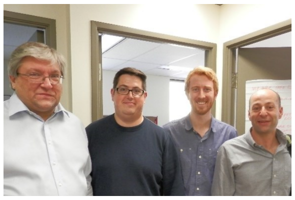
Some of CCSN's wonderful volunteers pose with Jackie Manthorne at CCSN's Volunteer Appreciation party.

2013-14 Board of Directors: Elaine Dean, Chair; Jackie Manthorne, President & CEO; Jay Rampersad, Treasurer; Mona Forrest, Secretary; Mike Fletcher; Sapna Mahajan; Cathy Enright; Valérie Villeneuve; Tushar Shakya. Board volunteers contributed 475 hours of their time.

Legal Counsel: Trina Fraser, BrazeauSeller.LLP.

Staff: Jackie Manthorne, president & CEO; Matthew Handy, Website and Social Media Coordinator; Akane Peters, Office Administration; Laurena Smith, Features Writer; Tiffany Glover, Government Relations and Community Engagement Manger (partial year); Charity Chavez, Bookkeeper; Chaniqua Davis, Social Media Coordinator (partial year); Martin Dufresne & Michele Briand, Official Translators.

Volunteers: Cassandra Carmant, Office Administration; Meritxell Currius Soler, Office Administration; Melanie Demers, Fund Raising; Josephine Dimmell, Office Administration Intern; Zeng Gang , Office Administration Intern; Lisa Halliday, Office Administration Intern; Katherine Inomata, Research and Fund Raising; Suganthy Jey, Office Administration; Maxime Landriault, Administrative Assistant; Franice Lanoix, Translation Reviser; Naomi-Jessica Mpana Tsango, Translation Intern; Pratibha Pandey, Human Resources; Rebecca Sturdevant, Office Administration; Doni White, Office Administration; Jiuling Zhang, Office Administration Intern. Office volunteers contributed 2112 hours of their time and skills.



From left to right: Todd Kasenberg, Cory Page, Matthew Handy, & Andrew Buzzel at CCSN's website redesign meeting in September 2014.

Ad hoc IT Committee: Andrew Buzzell; Mona Forrest; Todd Kasenberg; Cory Page.

Medical Advisory Committee: Dr. Andrew Feifer; Dr. Bobby Shayegan; Dr. Ellen Warner; Dr. Natasha Zajmalowski, Dr. Roanne Segal; Dr. Rob Rutledge; Dr. Sandy Sehdev; Dr. Terry Hill; Laveena Kamboj.

Funders (thank you!)

Individual donors; Amgen; Astellas; Bayer; Boehringer-Ingelheim; BristolMyersSquibb; CannTrust; Eisai; Janssen; Lilly; Merck; Pfizer; Novartis; Rx&D; Sanofi.

Thank you to all of CCSN's hard working board, staff, & volunteers for an extremely successful 2014!

1750 Courtwood
Crescent
Suite 210
Phone: 613-898-1871
E-mail:
info@survivornet.ca
www.survivornet.ca


Photos from CCSN's World Cancer Day open house!

Photo from CCSN's Volunteer Appreciation party!