



CANADIAN CANCER SURVIVOR NETWORK

2017 ANNUAL REPORT

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Jackie Manthorne Recognized with Jack Shapiro Lifetime Achievement Award

Jackie Manthorne, President and CEO of the Canadian Cancer Survivor Network (CCSN), has spent over twenty years giving a voice to cancer patients, survivors and caregivers. This fall, that dedication was recognised by the Canadian Cancer Action Network (CCAN), which awarded Manthorne the 2017 Jack Shapiro Lifetime Achievement Award at their Annual General Meeting on September 14th.

CCAN is a not-for-profit that connects cancer care organizations across Canada, seeking to foster dialogue and improve cancer care throughout the country. Its annual Jack Shapiro Lifetime Achievement Award recognises individuals who have contributed to the empowerment of patients and caregivers and demonstrated a deep passion for advancing work in cancer care. It is the highest honour conveyed by the CCAN, and Manthorne expressed gratitude.

“It is a real honour to have received an award named after Jack – he worked so hard to make sure that patients have a role to play in cancer care, and both CCAN and CCSN are very involved in increasing that role,” said Manthorne.

After a celebrated career in the non-profit and charitable field, including 12 years as the CEO of an Ottawa-based national healthcare charity working in breast cancer, Manthorne founded CCSN with several others who had been personally affected by cancer. Like anything worth doing, this venture would take hard work. She volunteered a year of time establishing the organization, and over five years later, she hasn’t slowed down.

“The purpose of CCSN has always been to educate, empower and connect patients, caregivers, survivors, cancer care groups and healthcare providers so we can work together to improve our healthcare and cancer care systems,” she said.



Manthorne has gathered a team of like-minded individuals, most of them volunteers, who work together to make the CCSN’s programming a success. Working with organizations across the country, the CCSN team runs programs like *A Seat at the Table*, which focuses on identifying opportunities for patients and survivors to participate on boards and committees and educating patients in the science of cancer to prepare them to sit on research peer review panels and clinical trial design committees.

This program’s name is a reflection of Manthorne’s drive toward an inclusive, open national approach to cancer care.

CONNECT



“Being well-informed and engaged is an important part of the battle against cancer.”

- Judy Lawson, Ottawa, ON

Our 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.

Our Mission

- 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.
- 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.
- To advance education by organizing and participating in conferences and speaking engagements to the public on topics related to cancer.
- 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.
- To undertake activities ancillary and incidental to the attainment of the above charitable purposes.

CONNECT

To Our 2017 Board, Staff & Volunteers: Thank You!

CCSN Board of Directors

Jackie Manthorne, President & CEO
Mona Forrest, Secretary
Richard Vroom, Treasurer
Travis Neumann, Assistant Treasurer
Ella Forbes-Chilibeck, Member
Arushi Shorma Fraelic, Member
Trina Fraser, Legal Counsel –
 Brazeau Seller.LLP

CCSN Staff

Jackie Manthorne, President & CEO
Mona Forrest, Operations Manager
Chad Scanlan, Communications & Social Media Coordinator
Allison MacAlister, Communications & Social Media Coordinator
Charity Chavez, Bookkeeper
Kati Oliver, Program & Projects Manager
Ashley Mahoney, Administrative Coordinator
Stephanie Wilson, Special Events/Canada Summer Jobs
Karlo Varga, Fundraising Assistant/Canada Summer Jobs
Elinor Cowper, Website Researcher/Canada Summer Jobs

CCSN Volunteers

Public Policy Assistants:

Marina Canalejo
 Jaymee Maaghob
 Harika Ozhalepi
 Faisal Omar

Administrative Assistants:

Kori Calderon Chilquillo
 Isemene Isidore
 Prajna Suvarna
 Laura Yee

Fundraising:

Viet Hoang
 Arkati Sarswat

Curriculum Committee:

Casey Hurrell
 *Don Krug
 (Deceased April 2, 2017)
 Ryan O'Meara
 Peter Wilton



CCSN Summer Staff Members
 Karlo Varga & Stephanie Wilson

CCSN Funders

Abbvie	Employment and Social Development Canada - Canada Summer Jobs
Amgen	Janssen
AstraZeneca	Leo Pharma
Bayer	Lilly
Boehringer Ingelheim	Merck
BristolMyersSquibb	Novartis
Innovative Medicines Canada	Pfizer
Eisai	Roche



Jackie Manthorne & Mona Forrest at the Lung Cancer Canada Evening of Hope Gala, Nov. 2017

CCSN Partner Groups

Cancer Knowledge Network	Patient Experts in Health Technology
Carcinoid-NeuroEndocrine Tumour Society-Canada (CNETS Canada)	PYNK Breast Cancer Program for Young Women
cure: blood cancer	Lung Cancer Canada
DisAbled Women's Network (DAWN) Ontario	GTA Ovarian Cancer Peer Support Network
Life-Saving Therapies Network	Mesothelioma+ Asbestos Awareness Centre
Breast Cancer Support Services	Ontario Health Coalition
Cancer Advocacy Coalition of Canada	Save Your Skin Foundation
Canadian Melanoma Foundation	Hair Donation Ottawa
Canadian Lymphedema Framework	Healing and Cancer Foundation
Canadian CML Network	Hereditary Breast and Ovarian Society (HBOC Society)
Consumer Advocare Network	Rural Women's Network Nepal
Canadian Psychosocial Oncology Partners	Pancreatic Cancer Canada (CC)
Canadian Cardiac Oncology Network	Breast Cancer Action Ottawa
BrightBod	Brain Tumour Foundation of Canada
Debbie's Dream Foundation: Curing Stomach Cancer	Olive Us Care
Fertile Future	Philippine Breast Cancer Network
Georgian Bay Cancer Support Centre	Mesothelioma Cancer Alliance
Prostate Cancer Canada Network (PCCN) Ottawa	Young Adult Cancer Canada
Make-A-Wish Eastern Ontario Canada	Wellbeing After Cancer
Self Help Resource Centre	Treat Mesothelioma
Mesothelioma Center at Asbestos.com	Testicular Cancer Canada
National Ovarian Cancer Coalition	Bladder Cancer Canada
Ottawa Integrative Cancer Centre	Better Care Faster
Ottawa Regional Cancer Foundation Maplesoft	Anal Cancer – A Bum Rap: Anal Cancer Support Group
Prevent Cancer Now	Team Shan

LEARN

CCSN Webinar Series

The CCSN webinar series participants are 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 on Thursdays at 1:00 PM EST.

2017 CCSN Webinars:

- Reframing Distressing Thoughts, Self-Compassion and other Mind-Body Techniques on the Cancer Journey
- Healthcare in the Federal Budget and How it may Affect Patients
- New Diagnostics Guiding Oncology Treatment Decisions
- My Journey Through Melanoma and My Hope for the Future
- Health Canada Calls for New Tools to Control Drug Prices: What Will it Mean for Patients?
- Unpacking the OHIP+ Pharmacare Plan for Kids & Youth in Ontario
- Learn About CAPCA from its Executive Director Heather Logan
- How Changes to the PMPRB Could Affect Patients' Access to Drugs
- Cancer-Associated Blood Clots
- What is a Biosimilar? The Current Biologics and Biosimilars Landscape in Canada
- Clinical Trials 101
- Navigating Private Insurance in Canada

Our webinars may be viewed at any time here:
<http://survivornet.ca/act/ccsn-webinar-series/>

OVER

1,000

REGISTRATIONS FOR

12

ENGAGING WEBINARS

WITH OVER

6,000

TOTAL VIEWS

POST-RECORDING

LEARN

Website & Social Media

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

CCSN also maintains an active presence on Facebook, Instagram, Pinterest, YouTube and ten different Twitter accounts.

8,000

FACEBOOK FOLLOWERS

10

DEDICATED TWITTER ACCOUNTS

5,540

FOLLOWERS ON
@SURVIVORNETCA

In May 2017, CCSN launched a newly revamped website.

The redesigned website offers quick and easy access to vital information for the cancer community.

It features three main highlighted sections titled Connect, Learn and Act.



32,053

WEBSITE VISITORS

61.5%

CANADIAN VISITORS

38

CANCER TYPES
PROFILED ON WEBSITE

ACT



Ottawa Mayor Jim Watson proclaims that the month of June will be known as National Cancer Survivor Month - June 2017

The Canadian healthcare system has a variety of moving parts, it is crucial to stay up-to-date as well as informed on how we can positively impact cancer care in the country.

The Canadian Cancer Survivor Network strives to undertake activities to promote health and well-being of cancer patients through education, advocacy and influencing decision-making.

First-Ever Ontario All-Party Cancer Caucus at Queen's Park

CCSN hosted the first-ever All-Party Cancer Caucus, which took place November 22nd at the Ontario Legislature 41st Parliament 2nd Session at Queen's Park, Toronto.

The focus was on **Gaps in Cancer Rehabilitation**, and in most attendees' view, there is very little rehabilitation offered to cancer patients after surgery or treatment compared to such surgeries as joint replacement or heart surgery.

MPPs in attendance included:

- Liberals: John Fraser, Ann Hogarth, Ted McMeekin
- Conservatives: Jeff Yurek, Michael Harris, Lisa Thompson
- NDP: Frace Gélinas, Percy Hatfield, Monique Taylor

CCSN & cancer community representatives included:

- Jackie Manthorne, President & CEO, CCSN
- Mona Forrest, Secretary, CCSN Board of Directors
- Jaymee Maaghop, CCSN Public Policy Volunteer
- Dr. Sara McEwen, scientist, St. John's Rehab Research Program, Sunnybrook Research Institute, Assistant Professor, Department of Physical Therapy and Rehabilitation Sciences Institute, University of Toronto
- Eileen Dahl, breast cancer patient & caregiver



L to R: CCSN President & CEO Jackie Manthorne, Public Policy Assistant Jaymee Maaghop & patient advocate Doug Nugent on the steps of Queen's Park



L to R: Patient advocate Eileen Dahl, MPP Ted McMeekin and MPP Ann Hogarth.

Legislative Reception on Cancer-Associated Thrombosis

CCSN held their annual Legislative Reception at Queen's Park On October 26, 2017.

The Reception was an opportunity for patients, MPPs and doctors to discuss **cancer-associated thrombosis (CAT)**, and, despite the ongoing election-prep furor in the Ontario Legislature, the turn out to the event surpassed that of previous years.

Over 30 MPPs attended including 6 ministers, and representatives of several organizations including Thrombosis Canada, Prostate Cancer Canada and the Brain Tumour Foundation of Canada.



Jennifer Hazel (centre), Brain Tumour Foundation of Canada, speaks with reception attendees



PC MPP Jeff Yurek speaks on taking action to increase awareness of CAT



Liberal MPP Ann Hoggarth calls attention to the cause of thrombosis awareness



NDP MPP France G  linas stresses the need for awareness, especially amongst cancer patients themselves

A Seat at the Table

CCSN is building a powerful cohort of trained patient-leaders in cancer diagnosis, treatment, and survivor care to participate in growing opportunities for the patient voice on healthcare decision-making bodies.

The project, known as Seat at the Table is building an eLearning platform for training patients (Science of Cancer Training Program), updating a registry of opportunities across the provinces as they open, matching and supporting patients in working together to shape programs to improve cancer diagnosis, treatment, and survivor care. When the program is finalized 575 patients would be trained in the science of cancer, working with others, targeting the right body for the change they want, and following up in a positive way to improve healthcare systems. Cancer patients often report feeling isolated, and feel powerless against the disease.



In 2017, the Canadian Cancer Survivor Network progressed rapidly with the Seat at the Table Program. As a part of its mandate to increase the number of cancer patients, survivors and caregivers who participate in the program, the Canadian Cancer Survivor Network has developed a series of committees, groups and volunteers that are working together to finalize the program. The curriculum committee, a flexible and responsive volunteer group, have immediately begun work on the program, considering the costs of learning platforms (performing cost-benefit analysis) for the Science of Cancer Training Program, performing environmental scans on external opportunities, and have kept pace with advancements in applicable learning theory and digital systems. Subject matter experts, composed of cancer scientists, researchers, oncologists and external organizations, help write the content of each module and work with the design team through the production of the module. Patient reviewers evaluate the modules, providing feedback and invaluable support. Through the work of our various volunteers, the Canadian Cancer Survivor Network has performed research, conducted webinars, developed a curriculum map for the Science of Cancer Training Program, and completed two pilot modules currently being evaluated by our team of patient reviewers.

The Canadian Cancer Survivor Network is now looking to develop the remaining 8 of the 10 e-module program, in order to train patients, survivors and caregivers who want to engage with clinicians in their community to develop their clinical, research and knowledge based-skills, and to support them in accessing positions in health and advisory committees. This 10 e-module program will train patients on the science of cancer (general knowledge), drug policy, clinical research, critical analysis, and evidence-based healthcare. Patients who complete the program will gain confidence to engage in research committees, and they will be given certificates (for each module) as a sign of their newfound expertise. The program will then strive to empower and encourage patients and survivors to become involved with peer review research, funding panels, clinical trial design committees, patients and family advisory councils (PFAC), and other bodies where patients are able to express their voice and have an impact on cancer policy and research.

Drug Pricing Policy Summit 2017: Measuring Progress and Making Our Mark

On November 15 & 16, 2017, the 2nd annual **Drug Pricing Policy Summit** was held in Toronto, Ontario.

The **Canadian Cancer Survivor Network**, **Schizophrenia Society of Ontario**, and **Save Your Skin Foundation** were joined by a number of patient groups, volunteers, panelists and other collaborators. **42 patient & caregiver groups** were represented at the 2017 summit, almost doubling from the previous year.



Kathy Barnard, President & CEO of Save Your Skin Foundation, delivers the welcome address at the Drug Pricing Policy Summit

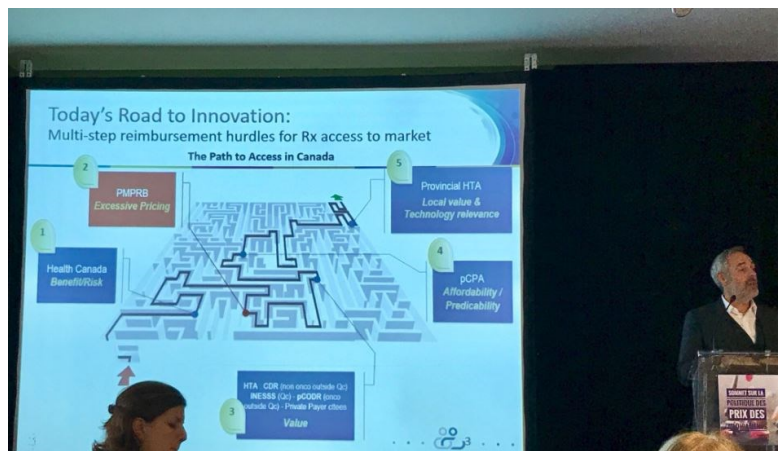
Panel topics included:

- Value-Based Health Outcomes Measurement
- What's Hot and What's Not Under "Sunny Ways"
- Not Such "Sunny Ways" for Those Who Write The Cheques?
- Creative Ideas to Manage Cost and Sustainability
- Implications for the Pharmaceutical Industry in Canada
- How do We Get There from Here? Words to the Wise

A full report of the Summit in English and French is available through our website:
<http://survivornet.ca/act/drug-pricing-policy/>



Attendees listen to Louise Binder of Save Your Skin Foundation introduce the keynote panel



Mark Legault speaks of implications for the pharmaceutical industry in Canada at the Drug Pricing Policy Summit

CCSN Election Campaigns

The Canadian Medical Association Journal published research in 2014 that showed one in twelve 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?

- an example of the questions we asked MPPs for the 2017 Nova Scotia Provincial Election

The Canadian Cancer Survivor Network engages patients, caregivers & families in election campaigns whenever a federal, provincial or territorial election is called.

CCSN 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 2017 CCSN provided questions for both provincial elections, which took place in British Columbia and Nova Scotia.

<http://survivornet.ca/act/ccsn-election-campaigns/>

Meetings, Workshops, Conferences and More!

On Friday, February 3rd, CCSN opened their doors in recognition of World Cancer Day.

An annual event held at the CCSN office, this year's edition was a huge success with many people in attendance, including partner groups, friends and our office building neighbours.



In 2017, CCSN attended and presented papers at:

- Canadian Association for Healthcare Reimbursement Western Day 2017: Adapting to Survivor-Innovation in Reimbursement in Edmonton, AB—Sept. 11 2017

CCSN also attended:

- Advocacy Summit, Astellas, Washington DC, Mar. 30-31
- Patient-Leader Education Summit on Immuno-Oncology, Toronto, Mar. 31 - Apr. 1
- Role of Innovative Medicines and Therapies, Economic Club, Ottawa, May 31
- Clinical Trials Ontario Patient Organization and Health Charity Workshop, Toronto, June 5
- Summit for Cancer Immunotherapy Conference, Lac Leamy, June 24 -27
- Meeting of Canadian Blood Cancer Patient Organizations, Toronto, Sept. 2
- Official Opening of Shire Canadian Office, Toronto, Sept. 28
- Companies & Causes, Toronto, Oct. 10-11
- Award Ceremony at CCAN of Jack Shapiro Lifetime Achievement Award to Jackie Manthorne, Oct. 10
- Canadian Association for Population Therapeutics Conference, Toronto, Oct. 22-24
- Economic Club of Canada—Life Sciences Industry of Tomorrow: Healthy Canadians, Healthy Future, Oct. 31
- Lung Cancer Canada Evening of Hope Fundraising Gala, Nov. 23



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Instagram

http://instagram.com/survivornet_ca

Pinterest

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Twitter

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[@bestbreastnews](https://twitter.com/bestbreastnews) – breast cancer
[@prostatepost](https://twitter.com/prostatepost) – prostate cancer
[@canadianmeso](https://twitter.com/canadianmeso) – mesothelioma
(cancer caused by asbestos)
[@lungcancerca](https://twitter.com/lungcancerca) – lung cancer
[@CCSNpoli](https://twitter.com/CCSNpoli) – non-partisan talk of
politics of healthcare and cancer care
[@medmarijuanacan](https://twitter.com/medmarijuanacan) – medical cannabis
[@Stomachcancerca](https://twitter.com/Stomachcancerca) – stomach cancer
[@cervicalcanca](https://twitter.com/cervicalcanca) – cervical cancer
[@melanomacan](https://twitter.com/melanomacan) – melanoma (skin cancer)
[@livercancerca](https://twitter.com/livercancerca) – liver cancer
[@headandneckcan](https://twitter.com/headandneckcan) – head and neck cancer

Charitable registration number:

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