

CANADIAN CANCER
SURVIVOR NETWORK



RÉSEAU CANADIEN DES
SURVIVANTS DU CANCER

2022 Annual Report



Connect → Learn → Act

*Coming together is a beginning. Keeping
together is a progress. Working together
is a success.*

-Edward Everett Hale

A message from Our CEO:

Jackie Manthorne

The pandemic: Cancer Can't Wait

While the Canadian Cancer Survivor Network continued to organize its regular activities and start new ones in 2022, its main concern was to identify the impact of the COVID-19 pandemic on cancer patients, caregivers, and survivors. Between 2020 and 2022, CCSN commissioned Leger to conduct four surveys of Canadian cancer patients, caregivers, and those in the process of being diagnosed to identify the impact of the COVID-19 pandemic on their lives and their access to cancer care. CCSN's report of the findings of the first three surveys, *Thrown Under the Bus! Disruption of cancer care in Canada during the COVID-19 pandemic*, and the report of the fourth survey, which asked patients and caregivers about their concerns about society opening and dropping COVID-19 restrictions, *For Cancer Patients and Caregivers, the Pandemic is Not Over*. CCSN will continue this work in 2023 and has already commissioned Leger to conduct a fifth survey on the impact of long COVID in cancer patients and caregivers.



President & CEO Jackie Manthorne with the Jack Shapiro Lifetime Achievement Award

Right2Survive Lung Cancer Screening Initiative

CCSN is the lead partner in the Right2Survive Lung Cancer Screening Initiative, with the Lung Health Foundation and Lung Cancer Canada as partners. The project website is www.right2survive.ca, with over 2,400 on a mailing list and four newsletters a year. This program's first objective was to speed up new treatments for lung cancer, and in 2022, added lung cancer screening as a priority. Lung cancer screening can help find lung cancer early, when treatment has a better chance of working. Low-dose computed tomography (CT) scans search the lung cancer as well as other lung diseases. Early detection using low-dose CT scanning has been shown to reduce lung cancer deaths by 20 per cent. CCSN is in the process of creating a new aggregate prostate cancer website. Work completed in 2022 included the creation of a Steering Committee composed of prostate cancer patients, caregivers, and healthcare researchers and clinicians to oversee the project and the creation of a site map.

CONNECT

"BEING WELL-INFORMED AND ENGAGED IS AN IMPORTANT PART OF THE BATTLE AGAINST CANCER."

Judy Lawson, Ottawa, ON



SURVIVORNET.CA

OUR VISION

The Canadian Cancer Survivor Network will work 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

Thank you to our 2022 CCSN Board of Directors and Staff!

CCSN Board of Directors

Jackie Manthorine - President & CEO
Mona Forrest - Operations Manager
Richard Vroom - Treasurer
Alexandre Chevrette - Assistant Treasurer
Casey Hurrell - Secretary
Tina Raser - Legal Counsel - BrazeauSeller LLP

Members

Ella Forbes-Chillibeck
Claude Richer
Lauren Koshurba
Nancy Clifford

CCSN Staff

Jackie Manthorne - President and CEO
Mona Forrest - Operations Manager
Jennifer Spence - Bookkeeping and Administration
Lindsay Timm - Community Engagement Manager
Connor Mulders - Public Policy Coordinator
Trevor Smith-Millar - Communications Manager
Martin Dufresne - Translator
Édouard Beaudry - Translator

We are hoping to welcome back volunteers in the new year!

CCSN Funders

Abbvie

Acart

AMGEN

AstraZeneca

Astellas

BrazeauSeller LLP

Bridgehead

Bayer

Eisai

Energi PR

Bristol-Myers Squibb

Keurig

Merck

Janssen

Pfizer

Phirelight

Novartis Oncology

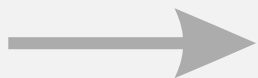
Roche

Sanofi

Government of Canada/Canada

GSK Canada

Summer Jobs



CONNECT



After Breast Cancer	AYA CAN	Alberta Health Coalition	Alberta Lymphedema Association	Canadian Virtual Hospice
Alliance for Safe Biologic Medicines	Anal Cancer - A Bum Rap	Bladder Cancer Canada	Better Pharmacare Coalition	Biosimilars Working Group
Canadian Cardiac Oncology Network	Breast Cancer Action Ottawa	Breast Cancer Support Services	Brain Tumour Foundation of Canada	
Canadian Lymphedema Framework	Canadian CML Network	Cancer Advocacy Coalition of Canada	Canadian Lung Cancer Advocacy Breathe Hope	
Canadian Melanoma Foundation	Canadian Psychosocial Oncology Partners	Canadian NeuroEndocrine Tumour Society (CNETS Canada)		
Colorectal Cancer Resource & Action Network (CCRAN)		Canadian MPN Network		
Institute for Optimizing Health Outcomes		Coalition Priorite Cancer au Quebec		
		Coalition Priorité Cancer au Quebec	CanCertainty	
	Debbie's Dream Foundation: Curing Stomach Cancer	Dense Breasts Canada	Hair Donation Ottawa	

Our 2022 Partner Groups

Healing and Cancer Foundation	Fertile Future	Life-Saving Therapies Network	
Ovarian Cancer Peer Support Network	Georgian Bay Cancer Support Centre	Gilda's Club - Greater Toronto	
Lymphedema Association of Ontario	Lung Cancer Canada	Mesothelioma.com	
the Mesothelioma Center at Asbestos.com	Make-A-Wish Foundation of Canada	Melanoma Canada	National Ovarian Cancer Coalition
Mesothelioma Group	Mesothelioma Vets	Metastatic Breast Cancer Atlantic	Mesothelioma + Asbestos Awareness Centre
Nankind	The Centre for Health Innovation (The CHI)	Ontario Health Coalition	Ottawa Regional Cancer Foundation
Ontario Parents Advocating for Children with Cancer (OPACC)		Patient Experts in Health Technology	Philippine Breast Cancer Network
Pancreatic Cancer Canada	Rural Woman's Network Nepal	Save Your Skin Foundation	Prostate Cancer Support Ottawa (PCSO)
Prevent Cancer Now	PYNK: Young Women with Breast Cancer	Testicular Cancer Canada	Young Adult Cancer Canada
			Team Shan

LEARN

Over **750** Attendees

For **15** Webinars

With Over **4000** Total Views

CCSN would like to thank all our 2022 Webinar presenters.

The CCSN webinar series is of interest to patients, survivors, family, friends, caregivers, and any member of the community looking for information on 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.

All webinars can be found at <https://survivornet.ca/learn/ccsn-webinar-series/>

- CCSN's Cancer Can't Wait: Self-Advocacy in the Time of Covid-19
- Anal & Colorectal Cancer: An Information Webinar
- Mindful Eating for a Healthier Lifestyle
- Engaging Patients and Caregivers with Clinical Trials
- How to Create (and Break) Habits to Maximize Your Health and Happiness
- Surviving Several Cancers through Support, Stubbornness and even a Smile
- The Importance of Cancer Rehabilitation
- Cancer Can't Wait! CCSN's Fourth Leger Survey on COVID-19 and cancer care
- Why Cancer Still Sucks, and So Does Access to Treatment in Canada
- When a Loved One has Cancer - Ten ways to support someone with a cancer diagnosis
- What's Next for the Patented Medicine Prices Review Board (PMPRB)?
- Cancer-associated Thrombosis - What patients and caregivers need to know
- The Power of Reframing on the Cancer Journey
- Equity-oriented lung cancer screening: key concepts and future directions
- Young Adult Cancer Canada & the 8 Things you Need to Know About Cancer in the Prime of Your Life

LEARN

A Brand New Educational Series



CCSN is working to create a new educational series geared towards the financial health of survivors. Cancer Survivor to Financial Survivor debut in the fall of 2022. The objective of this series is to provide information and resources to help improve the financial situation experienced by cancer patients, caregivers, and families. This series will continue into 2023.

Currently, the series consists of five of webinars, which include:

- The Impact of Cancer on Income
- Disability Benefits Overview Part 1
- "The Disability Test"
- Balancing Work and Caregiving
- Navigating Your Private Health Insurance Plan

→ **LEARN** ←

Website and Social Media

**756 Youtube
Subscribers**

**8800+ Likes and
8400+ Followers
on Facebook**

**Throughout the Pandemic, CCSN has maintained
a major social media presence as we continue our
programming**

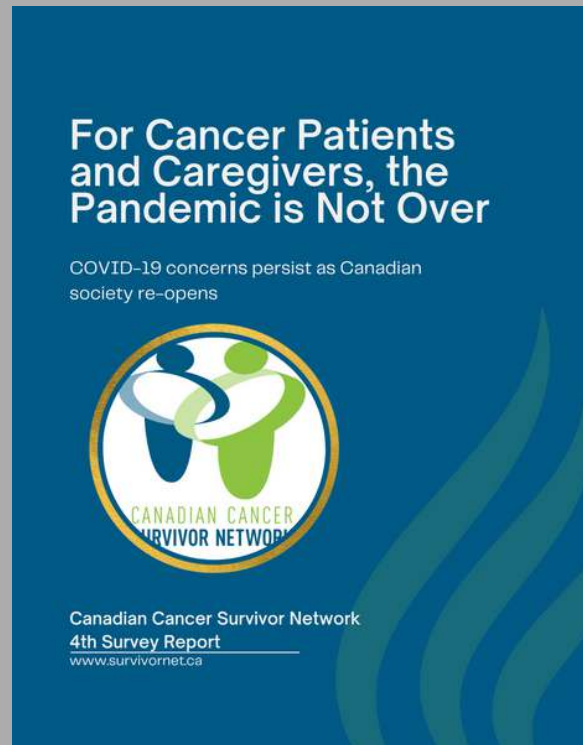
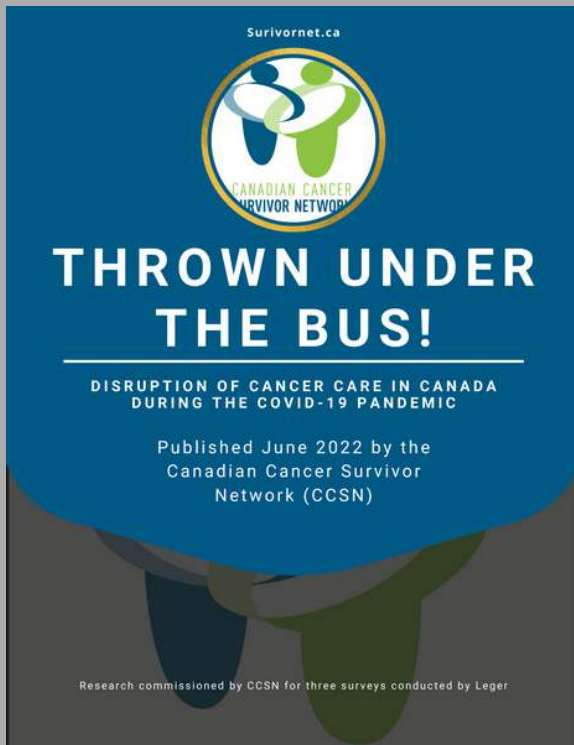
**223,858 People
Reached in November
Alone**

**683 Followers on
Instagram**

27,000 Website Visits

**Over 14,000 Followers Across our 13 Twitter
Accounts**

ACT



Four surveys, one message: **CANCER CAN'T WAIT**

The Canadian Cancer Survivor Network has published four surveys of patients, caregivers and pre-diagnosis patients in Canada. Across the board, it has shown that the COVID-19 pandemic has had a great impact on these groups, and has tracked their responses from the early days of the pandemic, to the vaccine rollout, to the lifting of public health restrictions.

These surveys have formed the basis for our Cancer Can't Wait campaign, bringing the concerns of cancer patients and caregivers to provincial parliaments.

ACT



CCSN held the All-party Cancer Caucus on October 26th to discuss pressing concerns about cancer care with Ontario MPPs. The Caucus meeting's purpose was twofold: to urge policy makers to increase accessibility to lung cancer screening, and to convey the concerns among cancer patients that they are being put at risk by the easing of COVID-19 public health measures.

During 2022, CCSN met virtually with over 50 elected politicians and staff in nearly every province across the country. Topics discussed at these meetings were lung cancer screening and the impact of COVID-19 restrictions being lifted on cancer patients and caregivers.

In Attendance

- Two Parliamentary Assistants to the Minister of Health
 - MPP Robin Martin of Eglinton-Lawrence
 - MPP Dawn Gallagher Murphy of Newmarket-Aurora
- Official Opposition Health Critic France G  linas, MPP for Nickel Belt
- Liberal Health Critic MPP Dr. Adil Shamji from Don Valley East
- Conservative MPP Daisy Wai of Richmond Hill and
- NDP MPP Bhutla Karpoche of Parkdale-High Park
- MPP Lorne Coe of Whitby and Parliamentary Assistant to the Premier
- Director of Stakeholder and Member Relations for Sylvia Jones, Alex Millier.

CCSN Staff and Advocates

- Connor Mulders - Public Policy Coordinator
- Lindsay Timm - Community Engagement Manager
- Dr. Paul Wheatley-Price
- Advocate MaryAnn Bradley
- Advocate Laura Greer
- Advocate Reno Leone
- Advocate Julianna Leone





ACT

CCSN Election Campaigns

"If you win this election, will you ensure that when the next variant of COVID-19 emerges or when the next wave arrives, or in future pandemics or natural disasters, cancer screening, testing, treatment and elective surgeries for cancer will never be disturbed?"

-Question posed to Quebec Candidates in the 2022 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.

In 2022, we sent questions to candidates standing in the Ontario and Quebec provincial elections. These questions revolved around COVID-19's suspension of cancer care, expanding access to lung cancer screening, and lowering the age for self referral for mammograms.

Read More at <https://survivornet.ca/act/ccsn-election-campaigns/>



Patient Input Submissions & Surveys

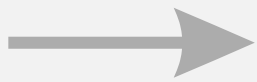
CCSN regularly works with patients and caregivers to collect input for various reports and submissions. This includes submissions for drugs under review through the Canadian Agency for Drugs and Technologies in Health (CADTH) and the Institut national d'excellence en santé et en services sociaux (INESSS), as well as internal CCSN reports which assist us in defining key asks to bring to decision-makers.

The process typically includes developing an online survey for patients and caregivers to provide feedback on which symptoms and side effects are most important to them, expectations or experiences with various treatments, as well as emotional and financial issues if present.

Receiving direct input from patients, caregivers and survivors is extremely valuable. CCSN is proud to help provide a bridge to health technology assessment (HTA) & policy-makers.

Here are the titles from the surveys for the HTA submissions that we either ran or we were part of during 2022.

- Canadian Cancer Survivor Network patient & caregiver questionnaire on cervical cancer - Keytruda
- Canadian Cancer Survivor Network Darolutamide for metastatic castration-sensitive prostate cancer Drug Questionnaire for Patient & Caregiver Input
 - Biliary Tract Cancer (BTC) Patient & Caregiver Questionnaire - Imfinzi
 - Prostate Cancer Patient & Caregiver Questionnaire - Lutetium
- Canadian Cancer Survivor Network Patient & Caregiver Questionnaire on Lung Cancer - Lumakras
 - Patient & Caregiver Questionnaire on Hepatocellular Carcinoma - Durvalumab+Tremelimumab



ACT



Oncology policy and collaborative activities

CCSN was a charter member and is very active in the **International Liver Cancer Movement (ILCM)**, created two years ago. CCSN is on the Steering Group, and CCSN's President & CEO was Interim Chair since summer 2022 and has been re-elected to the Steering Group in November 2022 elections.

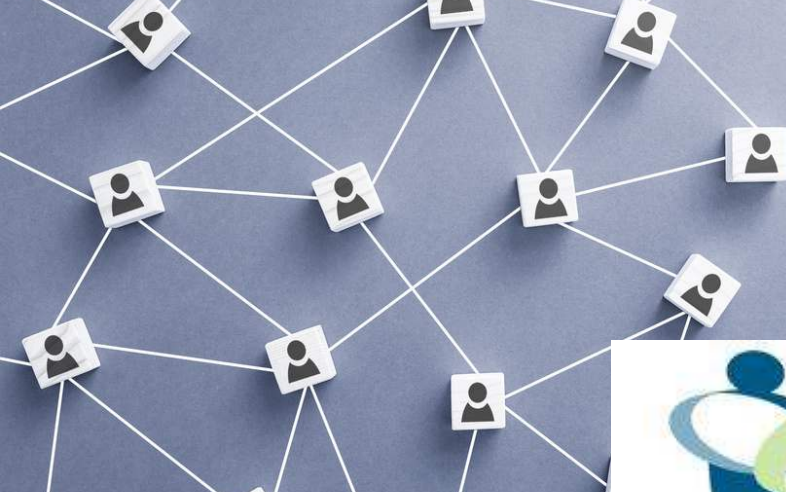
CCSN was a charter member of **Cancer Action Now Alliance**, a national alliance of patient organizations, professional associations, and life sciences companies who are witnessing the magnitude of the problem our cancer care system and its patients are facing in light of the pandemic. CANA has come together to call on governments to address the issues in our cancer care systems so that Canadians with cancer have a chance to live longer, better lives than anywhere else in the world. CCSN is also a member of the Steering Committee and the 2023 Planning Committee.

CCSN's research on **disease-free survival meaningful end point for lung cancer patients**, undertaken in collaboration with Broadstreet Health Economics & Outcomes Research in Vancouver, was accepted as a poster presentation at the European Respiratory Society Virtual Conference in September 2021 at the Canadian Association for Population Therapeutics (CAPT) 2021 Virtual Conference in October 2021, and as a workshop topic given at the CADTH November 2021.

CCSN has joined with many patient groups to prevent changes to **the Patent Medicines Prices Review Board** that may cause fewer new treatments to be approved in Canada as well as reduced R&D funding and clinical trials. On October 6, 2022, CCSN held a webinar entitled What's Next for the Patent Medicine Prices Review Board, given by Nigel Rawson.

CCSN also works actively on the following files: tumour-agnostic treatments and next generation sequencing (NGS); national pharmacare; budget submissions; real world evidence; legislative monitoring. CCSN is also a patient group partner in several ongoing research projects and applications for research funding.

CCSN is a member of the following coalitions and organizations: Best Medicines Coalition; Beat Cancer Coalition; Alberta Health Network; MedAccessBC; CanRehab; CanCertainty; Coalition priorité cancer au Québec; BioCanRx Patient Stakeholder Alliance; and other ad hoc committees established to collaborate on issues as they arise.



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Facebook

www.facebook.com/CanadianSurvivorNet

Instagram

http://instagram.com/survivornet_ca

Pinterest

<http://pinterest.com/survivornetwork/>

Twitter

@survivornetca – primary account

@bestbreastnews – breast cancer

@prostatepost – prostate cancer

@canadianmeso – mesothelioma
(cancer caused by asbestos)

@lungcancercan – lung cancer

@CCSNpoli – non-partisan talk of

politics of healthcare and cancer care

@medmarijuanacan – medical cannabis

@Stomachcancerca – stomach cancer

@cervicalcanca – cervical cancer

@melanomacan – melanoma (skin cancer)

@livercancerca – liver cancer

@headandneckcan – head and neck cancer

Charitable registration number:

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