



Invitation to Join CCSN's Head and Neck Cancer Advisory Council

The Canadian Cancer Survivor Network is a national network of patients, families, survivors, friends, community partners, funders and sponsors who have come together to take action to promote the very best standards of care, whether it be early diagnosis, timely treatment and follow-up care, support for cancer patients, or issues related to survivorship or quality of end of life care.

While the number of cases continues to increase for most cancers, earlier diagnosis and better treatment have resulted in a decrease in mortality. Thankfully, many more people are surviving cancer, which has led to increased need for new programs and activities to serve survivors and to ensure that they are fully re-integrated into society once treatment ends and recovery begins.

CCSN works to connect patients, survivors and other stakeholder groups with decision makers and the wider community to engage in discussion and to act on evidence-based best practices to alleviate the medical, emotional, financial and social costs of cancer and encourage research on ways to overcome barriers to optimal cancer care for survivors in Canada.

CCSN informs and trains patients and survivors to enable them to self-advocate, speak to media and decision makers about survivorship issues, and sit at every table where decisions about cancer care and research are being made.

CCSN has an established Head and Neck Cancer Advisory Council to help direct our work on behalf of head and neck cancer patients and their families. Several head and neck cancer survivors have already become members of this Council, and we invite you to join them.

The following page details the Terms of Reference for the Head and Neck Cancer Advisory Council, and the responsibilities that may become available for Council members to take part in.

We hope you will join! Please get in touch with me if you would like additional information.

Best,

Jackie Manthorne

The Terms of Reference of the Council are as follows:

The Head and Neck Cancer Advisory Council of the Canadian Cancer Survivor Network provides expert advice to the Board and CEO. It is made up of head and neck cancer patients, survivors, caregivers, family members and healthcare professionals interested in working hand in hand with patients.

The main responsibilities of the Head and Neck Cancer Advisory Council are to:

- **Tell your story.**
 - Provide insight, positive and negative alike, about your cancer experiences.
 - Help CCSN in initiatives to better understand how the patient experience can be improved.
 - Share your cancer story with CCSN for the website, if comfortable doing so.
- **Assist with education & information materials.**
 - Contribute to creation of supportive material such as forms, handouts and educational tools.
 - Provide advice about the relevant cancer section(s) of CCSN's website, and help CCSN keep existing website information relevant & up to date.
 - Write relevant articles for CCSN's blog (subject to review).
 - Get involved in tweeting on CCSN's head and neck cancer Twitter feed.
 - Suggest topics and/or presenters for CCSN webinars
- **Publicize.**
 - Help promote CCSN news & media releases through local media channels (television, radio, online)
 - Speak to fellow cancer patients, survivors and caregivers about the advisory council and other CCSN initiatives.
 - Assist in distributing studies, surveys and research as well as personally participating in them.
 - Help locate patients and families to tell their story on CCSN's Cancer Journey Stories web portal.
- **Advocate.**
 - Represent CCSN at conferences and to media on important cancer issues.
 - Promote awareness of opportunities and key resources that will help patients and family members navigate the healthcare system.
 - Accompany CCSN Board and staff on visits to politicians and other decision makers.
 - Suggest topics and speakers for CCSN educational meetings, webinars or conferences.
- **Advise.**
 - Suggest ways in which CCSN can better respond to the needs of cancer patients, survivors, caregivers and families.
 - Partner with CCSN on other projects as they arise.

Teleconference meetings will be held periodically; all costs related to your participation in the Advisory Council will be covered by CCSN.