

Abstract

OBJECTIVE: To assess the availability of support resources for patients with skull base tumors.

METHODS: We searched for websites that offer information, advice, and support for patients with skull base tumors. We compared the number and types of resources available with those for patients with other head and neck cancers, pituitary tumors, brain tumors, breast cancers and lung cancers.

RESULTS: There are a total of 16 organizations found to provide support to skull base tumor patients – either by access to an online support group or to patient blogs or stories. Of these organizations, 6 are non-profit, 6 are academic institutions or medical centers, 2 are registered charities, and 2 are private companies. The academic establishments only offered patient stories for public reading. The non-profit, charity, and private organizations (often founded by patients or caregivers) sponsored actual support groups. In contrast, there are as many as 30 (combining in-person and online) support groups for patients with pituitary tumors, 75 support groups for patients with other head and neck cancers, and at least 100 support groups available to those with brain cancers. These patients have the opportunity to join support groups sponsored by large-scale organizations such as the Support for People with Oral and Head and Neck Cancer, the American Brain Tumor Association, and the Pituitary Network Association as well as by major academic institutions and medical centers.

CONCLUSION: There are sparse support resources available for patients with skull base tumors, compared with other more common head and neck cancers or pituitary tumors. The support that is currently available to skull base tumor patients is mostly sponsored by non-medical professionals. While these resources are highly valuable and must be sought out and made more accessible, it is necessary to look at the source for these web-based support groups because of potential misinformation. There is a significant need for academic institutions and professional medical societies to create a platform for support for skull base tumor patients.

Introduction

Treatment of head and neck cancer may include surgery, radiation, and/or chemotherapy; after surviving such aggressive measures, many patients are left to deal with significant sequelae, including cosmetic and functional deficits. They may have problems swallowing, chewing, eating, maintaining weight, speaking, or even socializing. Patients with skull base tumors such as craniopharyngiomas, chordomas, olfactory neuroblastomas, and other types also may experience dramatic changes in quality of life after treatment. Psychosocial support is essential for these patients, to provide an outlet to discuss specific challenges and peer support in finding others who are experiencing similar struggles. Most support groups available for head and neck cancer patients are geared towards oral and laryngeal cancer patients who may face different issues than patients with skull base tumors.

Methods

Google, Bing, and Yahoo search engines were queried using the terms: skull base tumors, head and neck skull base cancer, pituitary, chordoma, brain tumor, craniopharyngioma, nasopharyngeal cancer, meningioma, esthesioneuroblastoma, and olfactory neuroblastoma

Results

All brain tumors
Support Groups:
American Brain Tumor Association Social & Emotional Support
 One-on-one support: Patient Mentor Request
 https://www.tfaforms.com/361615?tfa_5=Request%20Support
 One-on-one support: Caregiver Mentor Request
 https://www.tfaforms.com/361771?tfa_5=Request%20Support
American Brain Tumor Association – In-Person Support Groups (search by state) <https://www.abta.org/about-brain-tumors/social-emotional-support/find-a-support-group/>
American Brain Tumor Association – Online Support Group & Discussion Community <https://www.inspire.com/groups/american-brain-tumor-association/?origin=freshen>
Facebook Support Groups for patients, caregivers, parents of children diagnosed with a brain tumor, or young adults with brain tumors: <https://www.thebraintumourcharity.org/living-with-a-brain-tumour/get-support/facebook-support-groups/>

Chordoma
Support Groups:
Chordoma Foundation:
Online Community - Chordoma Connections <https://community.chordomafoundation.org/home>
One-on-one peer support program - Peer Connect <https://www.chordomafoundation.org/chordoma-support/>
Chordoma Survivors Support Group on Facebook – Private group, email help@chordomasupport.org to join OR answer administrator questions on <https://www.facebook.com/groups/ChordomaSurvivorsPrivate/>
Smart Patients Chordoma Support Group (online support group) <https://www.smartpatients.com/forums/chordoma>

Craniopharyngioma
Support Groups:
Brain Trust – Craniopharyngioma Support Group (online): <https://braintrust.org/groups/cranio/>
 Email group
 Liaison program during active hospital stays
 Member’s only website with searchable archive of all group messages since April 2000, member photos and stories, and more
Craniopharyngioma Survivors Awareness – Open Facebook Group for support and discussion: <https://www.facebook.com/Craniopharyngioma-Survivors-Awareness-72939739993/>

Nasopharyngeal Cancer

Support Groups:
None found specific to NPC.

Pituitary Tumors

Support Groups:
In-Person Pituitary Network Association (Support Groups across 10 different states): <https://pituitary.org/medical-resources/support-groups/support-groups>
Online Pituitary Network Association Facebook Group for Patients <https://www.facebook.com/groups/PituitaryNetworkSupportGroup/>
Online Pituitary Network Association Facebook Group for Spouses & Family <https://www.facebook.com/groups/pituitaryfamilysupport/>
Pituitary Patient Support Group Meetings: <https://www.hormones411.org/meetings>
For patients with Cushing’s Disease: Cushing Support & Research Foundation Support Groups – <https://csrf.net/news-events/local-support-groups/>

Skull Base Meningiomas/Other Rare Skull Base Tumors

Support Groups:
None found that are specific for skull base meningiomas.
Meningioma Facebook Support Group: <https://www.facebook.com/groups/MeningiomaMommas/>

Esthesioneuroblastoma, Olfactory Neuroblastoma

Support Groups:
Esthesioneuroblastoma online forum support group – <https://csn.cancer.org/node/155606>
Olfactory Neuroblastoma online forum support group – <https://csn.cancer.org/node/236539>
Parents of children with neuroblastoma (Email Listserv) - <http://listserv.acor.org/scripts/wa-ACOR.exe?A0=N-BLASTOMA>

Conclusion

There are limited support resources available for patients with skull base tumors. There is a sparse network of online support groups, which are mostly sponsored by non-medical professionals. The Skull Base Surgery Section of the American Head and Neck Society plans to increase online content for patients, including patient educational materials concerning skull base tumors, treatment, sequelae of treatment, etc. Links to support groups for various organizations/websites/blogs for patients with skull base tumors will provided, as well as an opportunity to develop a patient blog on the AHNS Skull Base website or on the AHNS Facebook page, with educational webinars for skull base patients.