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Ependymoma Key Issues

A collaborative exercise to raise awareness of the unique issues facing a rare brain and spinal cord tumor community



Ependymoma is a rare tumor of the brain and spinal cord that affects both children and adults. A collaborative effort between ependymoma advocacy groups across the world was organized in order to prioritize and articulate the unique key issues facing the ependymoma community. The Ependymoma Key Issues tie into the International Brain Tumour Alliance (IBTA)-initiated *Brain Tumour Patients' Charter of Rights* in order to

amplify the voice of the ependymoma community within the larger brain and spinal cord tumor community and international medical professional network in a cohesive and unified format.

Brain Tumour Patients' Charter of Rights history

On July 3, 2020, the National Brain Tumor Society (NBTS), along with more than 70 of our colleague organizations from across the international brain tumor community, welcomed the IBTA's release of an updated *Brain Tumour Patients' Charter of Rights*. The document represents the perspective of brain tumor patients and caregivers and provides a

set of standards for the healthcare experience to which all brain tumor patients and caregivers should be entitled - wherever they reside - while they navigate their treatment and live with this devastating disease.

This advocacy-based document creates a framework to help initiate positive change in the care of people diagnosed with brain and central nervous system tumors around the world. Ultimately, the goal of *The Brain Tumour Patients' Charter of Rights* is to achieve the best possible health and quality of life for adults, children, and adolescents living with brain tumors by encouraging and supporting quality standards, policies, and practices. It can be

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EPENDYMOMA KEY ISSUES

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- 1 EDUCATION & AWARENESS**
 Since there is no established standard of care for ependymoma, we call for local emergency providers and community neurosurgeons to have greater awareness of the unique medical needs of the ependymoma community, access to expert physician to physician consultation, and more educational opportunities for community providers on the latest ependymoma research and clinical practices. In addition, families should have a clear understanding of the capabilities and services offered at the facility that relate to the care they require.
Building on the IBTA Charter of Rights - Clause 2: Appropriate Investigation of Signs and Symptoms
- 2 CLINICAL COORDINATION**
 Care for patients with ependymoma requires significant coordination and collaboration. Ependymoma patients require access to multidisciplinary care throughout the trajectory of illness and survivorship. Providers should work with the family to identify who is involved in the patient's medical team, establish a point of contact for each provider, and identify who is the coordinator. The rarity and complexity of the disease requires collaboration between all members of the patient's medical team on an ongoing basis with the goal of prioritizing the patient's outcome and quality of life.
Building on the IBTA Charter of Rights - Clause 3: Excellent Treatment and High-Quality Follow-Up Care
- 3 TRANSPARENCY**
 The ependymoma community has an enhanced need for evaluation or consultation by an expert neuro-oncology team at diagnosis and before any non-immediate treatment is done. This can be done in coordination with local providers or outside of that relationship. The family should receive transparent and timely communication throughout the diagnostic process and support when seeking second opinions.
Building on the IBTA Charter of Rights - Clause 2: A Clear, Comprehensive, Integrated Diagnosis
- 4 SURVIVORSHIP & SUPPORT**
 It is essential that ependymoma families have a clear understanding of survivorship and known effects of treatment that can impact quality of life. Our personal goals should always be considered in each discussion about treatment and outcomes.
i.e. This might include testing like cognitive and neuropsychological evaluation done at the time of diagnosis and when possible, monitored throughout survivorship.
 Building on the IBTA Charter of Rights - Clause 4: Appropriate Support

Summary Statement: People with ependymoma have an urgent need for increased funding for rare disease research that provides better targeted treatments for the different ependymoma subtypes, increases access to these treatments, and evaluates impact on quality of life. The Ependymoma Key Issues establish a framework upon which to build greater awareness and understanding of the critical issues facing patients and healthcare providers.

administrator@cern-foundation.org | May 2021, Version 1

Ependymoma Key Issues graphic



Members of the Ependymoma Advocacy Group (EAG) during a conference call including (top row left to right) Tamiko Toland, Kim Wallgren, and (bottom row) Kim Wark

used both by professional organizations and advocacy groups as a guide for the achievement of strategic objectives to better serve the brain tumor community, and by individuals and patients to underpin particular aspects of their care.

In preparation for the 2021 Ependymoma Awareness Day virtual program, Kim Wallgren, Executive Director of the CERN Foundation (Collaborative Ependymoma Research Network), a program of the National Brain Tumor Society (NBTS), sought to further engage the ependymoma community in discussions based on the ideals set forth in the *Charter*. Following the suggestions of her colleague Danielle Leach, Chief of Community and Government Relations at NBTS, who played a role in the recent updating of the *Charter*, Kim Wallgren set out to develop key issues unique to the ependymoma community that tied into the larger international effort.

Danielle Leach said: "The opportunity to convene these groups to develop a set of issues unique to the ependymoma community sparks the advocacy efforts to create real change for this community. The robust discussion and input by these groups developed a strong statement of key needs. Basing their principles on *The Brain Tumour Patients' Charter of Rights*

illustrates how the *Charter* can be a catalyst for coalescing communities and rights-based advocacy efforts."

Creation of Ependymoma Key Issues

The initial meeting of the Ependymoma Advocacy Groups (EAG) in March 2021 included foundations that focus specifically on ependymoma, organizations that are led by an individual with a direct connection to ependymoma, and online support groups, all of which had a previous relationship with the team at the CERN Foundation and the National Brain Tumor Society. The EAG set out to identify and prioritize five key issues as a starting point with the intent to build on those initial key issues in the future.

The international group included Allyn Campbell from the **PNOC Foundation**, Liz Dawes, Kim Wark, and Cheri McCusker from the **Robert Connor Dawes Foundation**, Tamiko Toland from **Ependy Families/ Ependy Parents**, Bruce Blount from the **Adult Ependymoma Online Support Group**, Linda Rickford from the **Astro Brain Tumour Fund**, Christine and Andrew FitzPatrick from the **Tommy Strong Foundation**, and Danielle Leach, Rachael Kittleson, and Kim Wallgren from the **National Brain Tumor**

Society. In addition, Chas Haynes from the **Society for Neuro-Oncology (SNO)** and Kathy Oliver from the **IBTA** joined the discussion and provided feedback.

Through online discussions, surveys, and multiple rounds of editing, the group was able to distill the initial ideas into four ependymoma key issues along with a summary statement. Each participant contributed important experience and feedback that helped to shape each issue. The final Ependymoma Key Issues were released at the 2021 Ependymoma Awareness Day virtual program through the voices of the contributors themselves. Ependymoma Advocacy Group members submitted videos of themselves or a stakeholder reading one Ependymoma Key Issue. In addition, a creative graphic was designed in order to share and distribute the Key Issues document through professional and patient channels as a means to raise awareness about the effort.

Different Approach Needed for Rare Disease Advocacy

Relationships are key to any collaboration. In addition, when focusing on rare disease advocacy, it is imperative to think outside the box of traditional nonprofits

and organizations. For example, CERN has been collaborating with Tamiko Toland and Bruce Blount for years. Both of these individuals lead online support groups that aren't traditional 501c3 organizations or formal groups with a budget and staff. However, they make a tremendous impact in the ependymoma space and have unparalleled experience with ependymoma as a rare disease. Input from Tamiko Toland and Bruce Blount is vital to any activity designed to raise awareness and impact change and illustrates the need to include non-traditional efforts if we are going to capture the true nature of this community.

Though differences exist between the diagnosis and treatment of adult and pediatric ependymomas, when representatives from these respective populations work together the collective advocacy voice for the ependymoma community benefits. Together, we are able to make a larger impact while also beginning to bridge the gap and represent the young adult population into which many ependymoma survivors fall.

This Ependymoma Key Issues effort serves as a critical example for other groups that are looking for a launching point to address how their unique challenges and opportunities fit within the larger narrative needs of the global brain tumor community. It shows how even disparate groups with limited resources can band together, leverage existing infrastructure and create a meaningful advocacy and awareness effort.

"With some frequency, we talk with advocates and community members and they ask, 'Why hasn't this been done before?'" said Kim Wallgren. "Chances are it has or has at least been considered. We need to take the time to evaluate and understand what tools, programs, and knowledge already exist and work with groups to customize initiatives to meet the unique needs of their group or organization, without duplicating efforts. When you focus on a rare disease, you are forced to look for opportunities to join larger efforts, while keeping the important independent focus at the forefront of decisions and strategy. By the nature of rare disease work, we have to collaborate and rely on each other and that is best done within a community built on trust and mutual respect."



Ependymoma Key Issue shared by Christine and Andrew Fitzpatrick from the Tommy Strong Foundation in the 2021 Ependymoma Awareness Day virtual event



Ependymoma Key Issue shared by Allyn Campbell from the PNOC Foundation in the 2021 Ependymoma Awareness Day virtual event

It is intended that *The Brain Tumour Patients' Charter of Rights* will be reviewed and updated periodically. NBTS will continue to sit on the *Charter* drafting committee to contribute to this update and review process. Other organizations can still sign on as supporters of the *Charter* and will be added on a rolling basis. Likewise, a date and version number were included on the first iteration of the Ependymoma Key Issues because like the *Charter*, the content was developed through a multi-stakeholder and iterative process and is a "living document", subject to annual review. We hope to build out these key issues and possibly add further criteria to support the unique challenges experienced by those affected by ependymoma. ■

If your group or organization has a specific interest in the ependymoma discussion, please contact kwallgren@braintumor.org

To read *The Brain Tumour Patients' Charter of Rights* (available in multiple languages), please see magazine pages 115-127 and visit <https://theibta.org/charter/>. If your organization is interested in becoming a supporter of *The Brain Tumour Patients' Charter of Rights*, please contact kathy@theibta.org