

# European Association of NeuroOncology Magazine

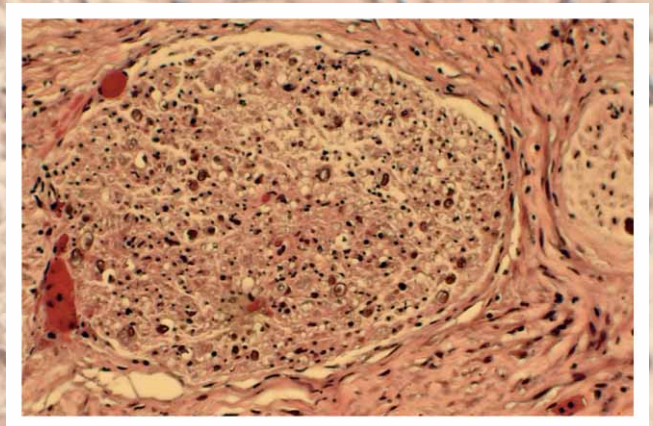
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## Why Do We Need Brain Tumour Patient Advocates?

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*European Association of NeuroOncology Magazine 2011; 1 (1)*

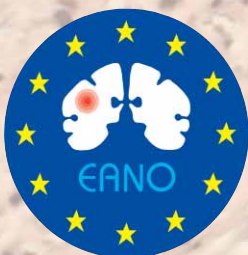
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THE EUROPEAN ASSOCIATION OF  
NEUROONCOLOGY

# Why Do We Need Brain Tumour Patient Advocates?

Kathy Oliver

Patient advocacy may be more of an art than a science, but without it brain tumour patients may find themselves consigned to the shadows on the cancer map.

Each year, there are 200,000 people in the world who develop a primary malignant brain tumour [1]. Even in the most powerful countries on earth, these people and the many, many thousands of others who develop low-grade, benign, and metastatic brain tumours can be lost in a maze of uneven and inequitable care. In the poorer, less-developed countries, even the most basic of brain tumour therapies and elements of palliative care are still not available.

Additionally, many governments and major cancer control organisations have prioritised prevention, screening, and healthy lifestyle campaigns in the fight against cancer. These are all excellent initiatives, of course. But unfortunately brain tumours cannot be helped by this approach as there is no realistic screening for them and their causes are, as yet, generally unknown.

Brain tumour advocacy groups – whether local, regional, national, or international – have an important role to play in ensuring that patients' views are listened to and acted upon so patients are not marginalized, discriminated against, or excluded in any way from obtaining optimal care.

Brain tumours are the only cancer to directly attack a person's physical, behavioural, and cognitive abilities and this, combined with their dire prognosis, means that most patients, their families, and caregivers are often too debilitated and mentally and physically exhausted by the disease to have the energy to fight for better therapies, care, and support themselves.

The lack of durable therapeutic options, the fact that brain tumours are responsible for the highest cancer burden with an average of over 20 years of life lost per patient [2] and the significant economic strain that these rare tumours inflict – because cutting-edge brain tumour therapies certainly do not come cheap – all add up to a tremendously daunting challenge.

This is clearly a patient population in desperate need of highly focused advocacy efforts in order to ensure that (1) there is much more research funding available for the development of new therapies; (2) there is adequate support and information available for patients and carers, and (3) there are safety nets in place for patients facing an assault on their economic stability.

In the last decade or so, a number of very determined brain tumour advocacy groups have, despite the enormous odds, arisen – many of them from the grass roots. Some of these have been established by carers or former carers of brain tumour patients. It often falls to this group of people to advocate for their loved ones who may not be able to do so themselves. And, in some cases, brain tumour patients have become involved in advocacy groups because, even in the brain tumour

arena, there is a small cohort of patients who confound the statistics and survive for an extended period.

The International Brain Tumour Alliance has encouraged brain tumour advocacy organisations in Lithuania, Cyprus, Belgium, Spain, Denmark, South Africa, Zimbabwe, and Australia. These organisations augment those advocacy groups which have already been firmly established in places such as the United States, Canada, some countries in mainland Europe, and the United Kingdom.

So, how can brain tumour patient advocacy organisations help keep brain tumours out of the shadows on the cancer map?

Advocates can vigorously lobby governments for more recognition of the very specific and unique challenges which brain tumours present. They can campaign for increased levels of government spending on brain tumour research. They can communicate with regulators and health technology assessment (HTA) bodies to highlight the patient's perspective.

Brain tumour advocacy groups can provide input into the design of clinical trials, even at the early stages, to help ensure that such studies are more efficient, effective, and more widely acceptable to patients. Indeed, a 3-year European-Union-funded project called "PatientPartner" suggests that the vast range of experiential knowledge which patient advocates can bring to the research arena results in better recruitment strategies, more patient-relevant research findings, wider dissemination of those findings, and improved information leaflets [3]. Brain tumour advocacy groups can also bridge any gaps in understanding between the scientific and medical community on the one hand and patients and carers on the other.

The collective voice of brain tumour patient advocacy groups around the world is growing in intensity. International cooperation between such organisations benefits patients and their carers by providing greater knowledge, greater collaboration, and greater hope.

## References:

1. Kruchko C, Propp J, Schellinger K, et al. Worldwide incidence of primary malignant and non-malignant brain tumors. Study commissioned by the International Brain Tumour Alliance, 2007.
2. Burnet NG, Jefferies SJ, Benson RJ, et al. Years of life lost (YLL) from cancer is an important measure of population burden – and should be considered when allocating research funds. *Br J Cancer* 2005; 92: 241–5.
3. PatientPartner. [www.patientpartner-europe.eu/en/home](http://www.patientpartner-europe.eu/en/home) [accessed May 20, 2011].

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