

# About brain tumour awareness

There are a number of organisations and not-for-profit groups that are actively working to raise awareness of brain tumours and brain cancer. Patient and/or health advocacy groups aim to support and promote the rights of patients and their carers in the health care system. Some advocacy groups consist of consumers only while others are collaborations between health professionals and consumers. Some of these groups are:

## Brain Tumour Alliance Australia (BTAA)

BTAA is a national brain tumour advocacy group established in 2008 by a group of brain tumour patients and caregivers. BTAA seeks to represent the brain tumour community from the viewpoint of the patient, family and caregiver. They work closely with the International Brain Tumour Alliance (IBTA) in its promotion of their annual awareness week in November. They also provide a free copy of the American Brain Tumor Association (ABTA) resource *A Primer of Brain Tumors: Patient Reference Manual* on request.

Phone: 1800 857 221 (not to mobile)

Website: [www.btaa.org.au](http://www.btaa.org.au)

International Brain Tumour Alliance (IBTA)

Website: [www.theibta.org](http://www.theibta.org)

## The Brainchild Foundation

This Brisbane based charity was established in 2010 with the aim of helping children affected by brain and spinal cord tumours, and their families. The foundation is made up of a community of medical professionals, parents and friends of children affected by tumours of the brain or spinal cord. It aims to raise awareness of the challenges faced by families dealing with these diseases, to raise funds for research and provide support to families.

Website: [www.brainchild.org.au/](http://www.brainchild.org.au/)

## Brain Cancer Action

Brain Cancer Action is an initiative of Cancer Council NSW and the Cancer Institute NSW's Oncology Group Neuro-Oncology. They held an inaugural Brain Cancer Action Week in 2010 and collaborate with consumers in order to raise awareness around brain cancer and funds for brain tumour research. Their website has brain tumour specific information.

Website: [www.braincanceraction.com.au](http://www.braincanceraction.com.au)

## Pediatric Brain Tumor Foundation

The world's largest nonprofit funder of childhood brain tumor research, serving more than 28,000 children in the United States who are living with the diagnosis of a brain tumor.

[www.curethekids.org](http://www.curethekids.org)

## CanSpeak Queensland

CanSpeak Queensland is a state-based, community organisation which aims to provide a unified, independent voice for all Queenslanders affected by cancer.

By developing partnerships with cancer patients, survivors, family members and health professionals working in cancer care, CanSpeak Queensland seeks to provide a forum to share issues, experiences and ideas common to all cancer types.

The goal of CanSpeak Queensland is to promote a better quality of life for those affected by cancer.

The objectives of CanSpeak are to:

- Provide a voice for those affected by cancer in Queensland.
- Define the issues important to consumers and advocate for measures to address those issues.
- Seek greater consumer involvement in decision making at all levels in the health system to ensure policies and programs reflect consumer views.
- Develop partnerships to pursue improvements in areas of common interest or concern.
- Reduce the impact of cancer by promoting a better quality of life for those affected.
- Assist in the promotion, establishment and employment of cancer advocacy and support groups.

CanSpeak Queensland Inc.

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Website: [www.canspeakqld.org.au](http://www.canspeakqld.org.au)

## Calendar - Annual Brain Tumour Awareness Events

**May** - Brain Cancer Action Week

**October** - International Brain Tumour Awareness Week

**November** - Brainchild Awareness Day