



Brainwave Parent Advisory Group (PAG)

Terms of Reference

Purpose

The Parent PAG (PAG) provides advice on the needs and rights of children and their families and to inform related priorities and programs. The PAG will provide feedback to Brainwave Board Directors and Staff from a Parents' perspective on their experiences of caring for a child living with a brain illness or injury, or as a young adult with a history of a childhood brain illness or injury¹.

Background

The PAG is being established to provide input into the strategic development of Brainwaves services and support programs.

Role

The role of the PAG is to provide advice to the Brainwave Board on important issues including, but not limited to:

- addressing specific issues faced by families and children living with a brain illness or injury
- the implementation of the Brainwave Strategic Plan Strategy 2021-23
- the impact of government policies
- advocacy issues
- our programs, services, resources & events

The Group will also consider any other issues, as deemed relevant to the Group's rationale

Focus

PAG focus is on ensuring the voices and experiences of children living with a brain illness or injury and their families are central to the Brainwave strategy.

The PAG will comprise up to 12 Parent members and one Board Director, the Brainwave CEO, and the Brainwave Programs Manager. Parent members will be identified through an expression of interest process and meet Brainwave Australia's definition of a Parent by being:

- parents/guardians of children with a brain illness or injury
- carers, family members and friends of children with a brain illness or injury
- a young person (18-23) living with a history of living with a childhood brain illness or injury
- the Parent community (which includes those who engage via our advocacy work).

¹ Brain illness or injury including: Acquired Brain Injury, Cerebral Palsy, Epilepsy, Hydrocephalus, Stroke, Brain Cancer, Tubular Sclerosis, Multiple Sclerosis, Duchenne Muscular Dystrophy.



BRAINWAVE

Supporting children with
neurological conditions

Members of the PAG will draw not only on their own life and healthcare experiences, but also on the needs and concerns of other consumers within their communities.

The PAG recognises that for particular issues relevant to the terms of reference expert advice may be required and be sought through seeking presentations to be made to the PAG.

Tenure

Parent members are appointed for one year with the option of one further year. If a member is unable to continue the PAG, Brainwave requests minimum notice of one month (a family member nomination may be considered). One of the Board Director members will chair the PAG and serve a one-year term.

Chairperson

The PAG is chaired by a member of the Brainwave Board of Directors.

Responsibilities

The key roles and functions of the PAG members are to:

- provide leadership on the needs and rights of clients and their families, particularly those groups recognised as vulnerable, and to inform related priorities and programs
- provide advice to the Board on the 2021-23 Brainwave Strategic Plan

Meeting Frequency

Face to face meetings will be scheduled for February and July 2021 (for members located in Melbourne only). All other meetings will be held on a bi-monthly basis and held primarily by webinar/teleconference. All members are notified of the meeting date as early as possible.

Attendance

If an individual member cannot attend the PAG meeting:

- members will make every effort to advise of nonattendance at the earliest possible time
- proxies will not normally be permitted to attend meetings

Other consumers may be seconded to this PAG for defined periods of time, or to liaise on particular issues.

Communications

Agenda and relevant documents will be circulated to PAG members via email at least one week prior to meeting. Minutes will be sent out via email up to two weeks after meeting. Additional correspondence will be communicated via email.

Document Controls and Confidentiality

It is expected that all documents circulated to PAG members are not shared with anybody outside of the Group. Topics discussed in PAG meetings are not to be shared with anybody outside of the Group unless otherwise specified.

[Access the application form here.](#)