

The Unicorn Foundation – Consumer Advisory Group – Terms of Reference

Background

As a non for profit medical foundation, acting in the public interest, The Unicorn Foundation aims to educate and support Australian sufferers of neuroendocrine tumours (NETs) and their families by increasing their awareness and knowledge of the disease.

We also aim to direct donations to Australian researchers and institutions who will work towards a cure for this rare and unpopular group of cancers. By working closely with medical groups we hope to raise the profile of neuroendocrine cancer and foster greater knowledge and involvement of primary health care practitioners and help ensure best practice care for patients with this rare group of tumours.

The Consumer Advisory Group (CAG) functions as a consumer representative voice for people who have been diagnosed with NETs, and their carers. By working together, the CAG provides a mechanism for the consumer voice to be addressed, with the overall goal of providing better services and outcomes for people and communities affected by NETs.

Terms of Reference

In line with The Unicorn Foundation's strategic direction, the Consumer Advisory Group will:

- Maintain a strong and positive partnership between The Unicorn Foundation and people affected by NETs, to represent the wider community affected by NETs.
- Promote sensitivity and attention to meeting the needs of different consumers and communities affected by NETs
- Actively seek feedback from consumers affected by NETs
- Address issues and priorities identified by consumers as appropriate
- Suggest service delivery solutions that are well matched to consumer needs
- Provide input into resources and programs developed for communities affected by NETs
- Support The Unicorn Foundation in working to reduce variations in outcomes experienced by people affected by NETs.
- Provide advice on emerging issues nationally and internationally to inform The Unicorn Foundation's work.

The group may also be involved in providing guidance into the development of clinical research programs.

In doing the above, the group will:

- Support opportunities for joint consumer and organisational initiatives
- Work with people of diverse backgrounds and experiences
- Maintain confidentiality regarding sensitive information and organisational matters discussed with the group
- Act as the primary source for consumer consultation for The Unicorn Foundation
- Provide a representative view of the community affected by NETs

Membership

- Approximately eight to ten consumer representatives, with a mixture of patient and carers. Ideally representation will be from a wide range of states and territories (from both regional

and metropolitan areas), with a mix of gender, age and ethnicity. Ideally there will be representation from Aboriginal and Torres Strait Islander heritage.

- The Unicorn Foundation will be represented by the NET Patient Support Nurse, who will also serve as group coordinator, reporting to the CEO. This person will be responsible for the coordination of meetings (including meeting invitations, agendas and minutes), recruitment, orientation of new consumer members, facilitating the group activities and ongoing support and facilitation of training for consumer members as required.
- The Chair of the CAG will be initially appointed by the CEO of The Unicorn Foundation, with re-appointment to be determined on an annual basis.
- The CAG may invite any person or body of persons to attend and assist the group as an invited participant

Tenure

- Consumer members of the CAG will be appointed for two years with the opportunity for reappointment of two further terms.

Meetings

- The CAG will meet bi-monthly throughout the year via teleconference
- A quorum shall consist of at least one Unicorn Foundation representative and 30% of the number of consumer representatives. It is expected that all members will attend at a minimum 75% of meetings per annum
- Meetings will be via teleconference, with the aim of an annual face to face gathering (dependent on funding)
- The agenda (and other relevant notes) will be provided to group members at least one week prior to scheduled meetings. Minutes will be circulated no more than two weeks following the meetings.

Reporting

- The CAG will provide an annual report, made available to the board and other relevant individuals, with other brief activity reports provided as appropriate.

Recruitment

- Consumer representative members of the CAG will be appointed through a formal recruitment process. Positions will be advertised via processes decided as appropriate at the time.
- Applicants to the CAG will undergo a telephone interview with the CEO, Coordinator and Chair. The registration process will require both a valid Police Check and Working with Children Check, both of which will be coordinated via the Coordinator.
- The position description, application form and selection criteria will be reviewed at a minimum every two years by the Chair and Coordinator.

Orientation/Training

- The Chair and Coordinator will provide initial orientation to the new consumer member, as well as providing an ongoing point of contact for any questions the consumer members may have.
- Further training will be provided as deemed appropriate

Reimbursement

- The CAG does not hold any budget. Membership of the group is a voluntary position, but funding may be available for reimbursement of extra costs in consultation with the Coordinator.

Review

- These terms of reference will be reviewed every two years as a minimum.