



Epilepsy Tasmania CEO Report

epilepsy
tasmania

It is with pleasure that I present you with the CEO report.

This is my first annual report for Epilepsy Tasmania. This time last year I had only been with the organisation for four months, and I instead presented an Aspirations document focusing on our strategic and operational directions for the next 12 months.

In this annual report, I will speak about the progress we are making towards achieving each of these Aspirations.

Creating a supportive environment for all Tasmanians living with or affected by epilepsy:

- Changed the staffing structure to one nurse educator and one social worker. We will employ an occupational therapist when further funds are available.
- Established where and how to meet the increasing needs of people in the Northwest.
- Improved how we communicate and engage with people - an evolving process.
- Dramatically increased our number of statewide referrals – up from 53 in period June 2016 - March 2017 to 129 for the four months of March - June 2017 alone.
- Developed and fine-tuned our volunteer peer support service Epilepsy Connect.
- Facilitated focus groups across the state and through social media to explore how to connect and engage with the Tasmanian epilepsy community.

Bringing epilepsy out of the shadows:

- Raising issues, awareness and anti-stigma messages and platforms.
- Developed monthly “Brain Waves” Newsletter.
- Developed an ongoing Open Gardens for Epilepsy initiative across the state.
- Increased our presence and engagement on social media platforms.
- Created significant engagement with the Tasmanian media.
- Participated in a National TV epilepsy awareness campaign.
- Developed a number of partnerships.

Actively encouraging and facilitating the health sector to achieve more research, better treatments and cure:

- Promoting the outcomes of the research paper.
- Regularly meet with the Tasmanian Government and Health Minister, Shadow Minister and independents from a state and federal level.
- As part of the Neurological Alliance Tasmania, submitted a submission to the Acute Health Legislative Council enquiry.
- Developed a closer working partnership with Primary Health Tasmania and UTas.

Raising awareness of the risk of epilepsy among older Tasmanians:

- Developed new promotional material called Epilepsy Among Older Tasmanians.
- Member of the government Older Persons reference group.
- Member of COTA Tasmania.
- Active in our engagement and media coverage proposed for Seniors Week.
- Will roll out the Understand Me, Support Me: Epilepsy in Later Years project and services in 2018.

Ensuring Tasmanian children with epilepsy receive a good education and adults can gain and maintain regular employment:

- Formalized and developed linkages with Schools (private and state) and the Education Department.
- Will roll out the Educate Me, Include Me: Epilepsy Smart Schools project and services in 2018.
- Developed and implemented the Epilepsy Friendly Workplace training project and services and will continue to grow this.

Growing the financial security and capacity of Epilepsy Tasmania so we can continue our services:

- Continue to meet and lobby government for increased funding based on evidence of demand and gaps
- Appeals and fundraising, eg. Donate to the Lavender, Christmas Appeal, Open Gardens for Epilepsy, Purple Month (International Epilepsy Awareness Month).
- Developing corporate partnerships.
- Employing skilled staff and providing professional development opportunities.

Moving forward:

Given all the structural and operational changes and positive responses from Government, Community Organisations, Disability Service Providers, Primary Health Tasmania, the NDIS and people living with or affected by epilepsy, the next 12 months is shaping up to be full of opportunities such as increased support, service delivery, advocacy, and capacity building to assist in the health and wellbeing of the Tasmanian epilepsy community.

At Epilepsy Tasmania we take seriously our position as the primary organisation in Tasmania and ensure that all of the funds available to us and gained through donations and fundraising remain in Tasmania to provide services and support for Tasmanians.

We have a great staff team with Bek, Bec, Joanne and Shirley, and I thank them for all their energy, enthusiasm and commitment.



Wendy Groot