

EPILEPSY TASMANIA

44TH ANNUAL REPORT 2019

Our vision is for all Tasmanians who have epilepsy to have the same opportunities as the broader community.

epilepsy
tasmania

TASMANIA'S VOICE FOR EPILEPSY

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Epilepsy Tasmania acknowledges and pays respect to the Tasmanian Aboriginal Community as the traditional and original owners, and continuing custodians of this land, and acknowledge Elders – past and present.

ABN 18 186 427 891

CHAIR REPORT



Gustavo Bodini - Chair

With the support of the Tasmanian Government, Epilepsy Tasmania is now a genuine, broadly-based resource for people who have this affliction, or those who support them.

In Tasmania at least, epilepsy is now out of the dark corners and in the light, where it needs to be. Our people now talk about epilepsy in schools and workplaces. It is discussed regularly in the media. People drop into our offices for a chat about the condition. We refer them for support or treatment. We talk to GP's and specialists.

It is fair to say that epilepsy is now much better understood in Tasmania than it was even five years ago. It has taken sustained effort and support from a broad range of people – volunteers, people who can give peer support and our staff, who are out and about. With particular mention of Claire Burnett from 147 East for her outstanding work with communications and media.

There remains energy in the organisation, and that pushes our services out to people who have epilepsy or who support those who have it.

Our Board has been active too. We are two years into our three-year strategic plan. We want people with epilepsy to have the same life opportunities as anyone else – and that includes freedom from stigma and equal opportunity in the workplace. Our Board is undergoing change. I will step down as Chair and retire from the organisation after a long innings. New Board members have been appointed and will shortly take up their positions. They will come to an organisation which is strong and active.

I would like to thank the Tasmanian Government for their support of Epilepsy Tasmania, and through us, the many people who have epilepsy within this State. In the past, they have not had the support they need, but they do now. The Tasmanian Government has given us the financial support to allow this to happen and it should not go unremarked.

Our CEO Wendy Groot and her staff have been remarkably active and the Board members are proud of them. They are 'goers'. I thank my fellow Board members and all staff and volunteers and supporters.

A handwritten signature in black ink, appearing to read 'Gustavo Bodini', written in a cursive style.

BOARD DIRECTORS

Position

Name

Chair:

Gustavo Bodini

Vice Chair:

Mark O'Brien

Treasurer:

Terry Long

Secretary:

John Frankcom

Directors:

Katie Dineen
Kathleen Brient
Lila Landowski

CEO REPORT



The last 12 months has been a period of significant achievement and growth thanks to the energy and commitment of the Friends of Epilepsy Tasmania and its dedicated staff team.

People of all ages and locations have generously volunteered their time to raise awareness of epilepsy and begin conversations about the impact it has across the breadth of the Tasmanian epilepsy community.

Some of the highlighted achievements have been:

Communications and Engagement

This year we continue working hard to engage and communicate with people who are living with epilepsy, and those around them. Our Friends base continues to grow and we have significant increase in people accessing the organisation.

We have developed new partnerships which have enabled us to provide more streamlined and less 'silo' pathways, information and referrals. These also included access to suppliers for epilepsy equipment. This has reduced costs for equipment and other resources for people.

We conducted our second annual survey, a Health and Wellbeing survey and a NDIS survey. We will continue to build on the rich information provided.

There has been significant growth in Epilepsy Tasmania's social media platforms. At their request we developed a Family and Friends Facebook group and an age 13-24 Facebook group. These are currently mostly managed by staff and into the future it will become part of Epilepsy Connect.

Throughout the last 12 months, the number of times we have been called upon to provide information services or support from people continues to increase from (June 2018), 1131 to (June 2019) 2791. Through our efficiencies we are responding faster to those requests. This demonstrates to us that the work we have collectively achieved to raise the organisations profile through many mediums and processes are working.

More people are dropping into our offices in Launceston and Hobart, and staff have been actively outreaching into other locations across the state. March 2019 (Purple Month) saw a spike of over 30 groups and individuals wanting to host a purple-themed fundraising event. We held 7 internal events. The Government House open gardens had 200 in attendance and we are very thankful to Her Excellency Professor the Honourable Kate Warner, AC, Governor of Tasmania, Mr Warner, and Government House staff.

As part of Australia's national coalition for epilepsy organisations (Epilepsy Australia), Epilepsy Tasmania supported a national campaign called 26 Ways. This collaboration was well received in Tasmania and along with our local initiatives achieved much media coverage and opportunities to engage with people about epilepsy.

CEO REPORT

CONT...

Education and Training

Epilepsy Tasmania's educators have been busy delivering training and education through our programs - Educate Me Include Me Smart Schools: schools resources and training, Know Me, Support Me: disability resources and training, Understand Me, Support Me: epilepsy in later years, and Epilepsy Friendly Workplaces.

The full roll-out of the Smart Schools program began in February 2019. The Education Minister launched this program with our first school. At the end of June we had 40 schools who had registered to become an Epilepsy Smart School. We are already seeing how this is bringing great improvement to the support of people with epilepsy who are part of the education system and their families.

Advocacy and Influence

Throughout 2018- 2019 we have taken advantage of many opportunities to meet key stakeholders, politicians, government and community organisations to advocate and influence systemic thinking and practices that feed the stigma around epilepsy.

There were 45 media opportunities with some being broadcast outside Tasmania.

We have particularly developed strong relationships with Primary Health, the Education Department and the NDIS. There is much to do in this space and we will continue to develop and where possible address the needs of the Tasmanian epilepsy community.

Through our membership of Epilepsy Australia we are able to raise the issues affecting Tasmanians with the other state and territory member organisations and collectively provide a national voice. Our participation provides Epilepsy Tasmania with increased support and networks through a national peak body. Also providing us with opportunities to work collaboratively on a range of national projects, campaigns, submission papers and reports.



CEO REPORT

CONT...

Growth and Capacity Building

With growth comes increased staffing requirements.

This has led to an expansion in our staff and skill-set which has meant that we have increased the hours of our current staff & welcome two new staff to our team. It is pleasing to provide services to more people who contact us for assistance.

Sheralyn began in August 2018 in the role of Volunteer Services Coordinator and Liz in May 2019 in the role of Epilepsy Smart Coordinator.

Sheralyn has been recruiting requests from people who are wanting to volunteer. This has been 25 potential volunteers including for the Epilepsy Connect Peer Support program.

Epilepsy Tasmania has increased its profile and footprint dramatically and the organisation has achieved its goals to be the peak “go to” organisation in Tasmania. In Launceston to keep the infrastructure costs down we have created a smaller neuro hub, with MS Limited and MND and leased out floor space to another organisation as well.

Our paid staff team are a vibrant, energetic group and it is a pleasure to see them all working coherently together. They take great pride and satisfaction in their work and enjoy hearing the positive responses of the people to whom they provide services.

Looking forward, there is much more to be done as we continue to work with, advocate for, and deliver services to one-fifth of Tasmania's population. Our purpose continues to be that of improving the quality of life for people with epilepsy, and those around them, through education, coordination and support.

Wendy Groot
CEO



STRATEGIC FRAMEWORK

VISION

All Tasmanians who have epilepsy have the same opportunities as the broader community.

PURPOSE

Epilepsy Tasmania will improve the quality of life for people with epilepsy, and those around them, through education, co-ordination and support.

The Framework features 6 Themes as follows:

THEME 1

Increase community awareness, understanding and acceptance of epilepsy.

THEME 2

Build a service and support system that is able to respond to the needs of people with epilepsy, and those around them.

THEME 3

Ensure epilepsy services and support are available and accessible throughout Tasmania.

THEME 4

Continuously improve and deliver services and support that meet the needs of the epilepsy community.

THEME 5

Be a proactive voice for epilepsy in Tasmania.

THEME 6

Continuously improve the strength and financial security and sound governance of the organisation.

THEME 1

Increase community awareness, understanding and acceptance of epilepsy.



What we want to achieve:

- a community that is able to understand and respond appropriately to people with epilepsy, and those around them
- increased knowledge and understanding of epilepsy by the 'friends of epilepsy' members
- use of a range of media and technology to effectively connect with the community and stakeholders
- ability to measure community understanding and acceptance of epilepsy

THEME 2

Build a service and support system that is able to respond to the needs of people with epilepsy, and those around them.



What we want to achieve:

- increased numbers of people and organisations able to provide appropriate services and support for people who have epilepsy
- advanced the skills, knowledge and attitudes of staff and volunteers of community organisations and other service and support providers
- performance measurement to further develop capacity to meet epilepsy needs

STRATEGIC FRAMEWORK

THEME 3

Ensure epilepsy services and support are available and accessible throughout Tasmania.



What we want to achieve:

- increased range and volume of services and support provided by Epilepsy Tasmania
- increased range and volume of services through facilitation and brokerage of relationships and partnerships
- stronger relationships with health professionals, clinical discharge staff and social workers
- implement Epilepsy Smart Schools in every school in Tasmania

THEME 4

Continuously improve and deliver services and support that meet the needs of the epilepsy community.



What we want to achieve:

- delivery of programs and support (including Epilepsy Connect) that is recognised in Tasmania and beyond
- development, trialling and implementation of innovative and significant research, projects and activities
- development and delivery of programs that are based on recognised 'good practice and knowledge; contemporary practice/thinking; and evidence
- credibility and recognition for the organisation through the delivery of professional, contemporary and evidence based services and support
- high profile Board members and associates who can contribute to the advancement of Tasmania's response to epilepsy

THEME 5

Be a proactive voice for Epilepsy in Tasmania.



What we want to achieve:

- systematic change to better meet epilepsy needs
- effective and meaningful relationships with research, service providers and policy organisations in Australia and beyond – including the Neurological Alliance of Tasmania and the Menzies Centre
- development and implementation of the best possible structure for the epilepsy sector
- recognition as an expert voice on epilepsy in Tasmania
- meaningful contributions to the epilepsy evidence base

THEME 6

Continuously improve the strength and financial security and sound governance of the organisation.



What we want to achieve:

- a continually developing Board and Chief Executive Officer who meet the needs of the organisation and the epilepsy community
- a financial structure of Epilepsy Tasmania capable of delivering long term financial security
- new income and funding streams
- planned achievement and measurement of goals and priorities at both an organisational and program delivery level
- a learning and developing organisation with a culture of frank, fearless and honest review and reflection

PURPLE MONTH 2019

2019 drew a phenomenal support for Epilepsy Tasmania during purple month. It was a resounding success in raising awareness of the condition that touches so many Tasmanian's.

With the help of both businesses and individuals holding their own fundraisers we sold over 200 soft toys, 60 keep cups plus numerous items from our general merchandise line.

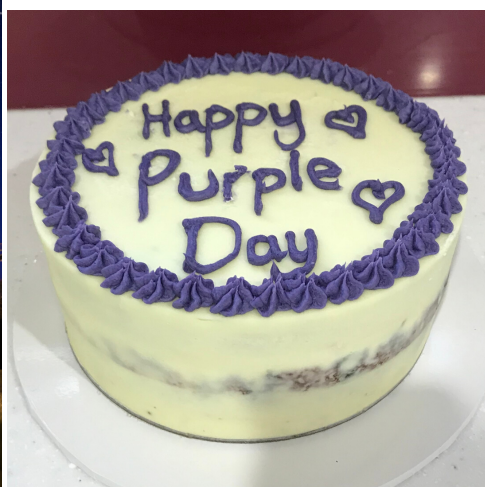
Our staff were all in attendance at the 2019 Government House Open Garden day, our biggest event to date with over 200 people in attendance. Later in the month our friends at Flick the Bean on High St & Invermay had a massive day at both sites with a 'free coffee' (pay what you can) day, the response was brilliant & across both sites the team raised over \$5000! We can't thank these guys enough, as they continue their support for us by stocking our keep cups, thank you Flick The Bean!

Special mention must go to 4 extraordinary girls. Lily & Harper Smith made over 300 soaps & succulents & selling them at their school fair and to friends, they raised over \$3000!

Esther & Heidi Bryan held a pamper day at home, they painted nails & held a morning tea, these girls raised over \$600, what an outstanding effort!



2019 PURPLE MONTH PICS



2019 PURPLE MONTH PICS



2019 PURPLE MONTH PICS



2019 ACHIEVEMENTS

Direct contact with Epilepsy Tasmania has nearly doubled from 660 in July 2018 to 1131 in June 2019.

Epilepsy Tasmania has experienced a dramatic 273% increase in the number of new people referred in to the organisation from 52 in July 2018 to 751 in June 2019.

The number of Support Services provided to individuals has increased from 509 in July 2018 to 1034 in June 2019.

GP presentations that were prevented have increased 207% from 57 in the 6 months prior to Dec 2018 to 175 in the six month period to June 2019.

Provision of epilepsy education has increased 57% from 71 in the 6 months prior to Dec 2018 to 112 in the six month period to June 2019.

Hospital emergency department admissions that were prevented have increased from 1 in the 6 months prior to Dec 2018 to 11 in the six month period to June 2019.

ENGAGING WITH THE TASMANIAN EPILEPSY COMMUNITY

Our followers increased 24% to 2269
Likes increased 19% to 2221
Total people reached 207,383



Brainwaves newsletter
12 issues with 10,000+ recipients
across all issues



Brainwaves subscribers
increased 61% to 791



45 media opportunities
across the year



Surveys Responses
NDIS 15 Health and wellbeing 21
People with epilepsy 43
Family and Friends 22
Total 101

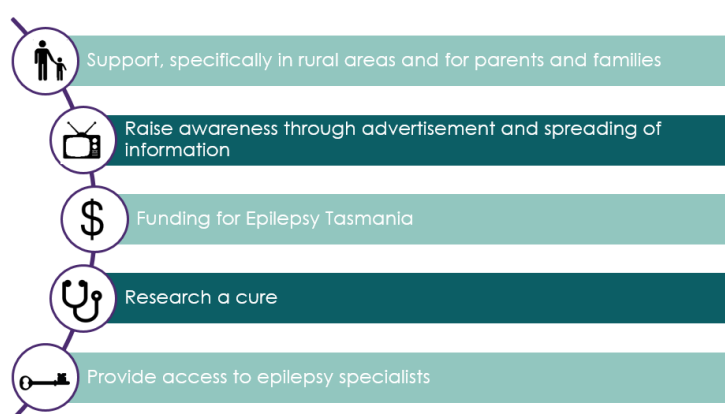


9 anti stigma awareness
campaigns from July to Dec
then 37 from Jan to June
2019



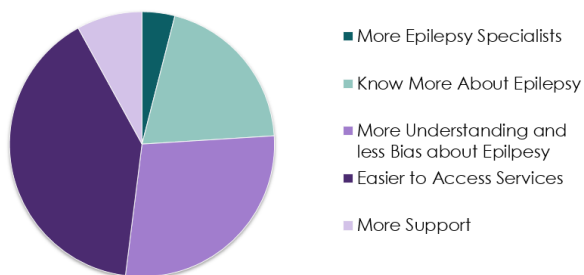
HEALTH AND WELLBEING SURVEY

What People Most Want From Epilepsy Tasmania



What People with Epilepsy want most from Their Health Service Providers

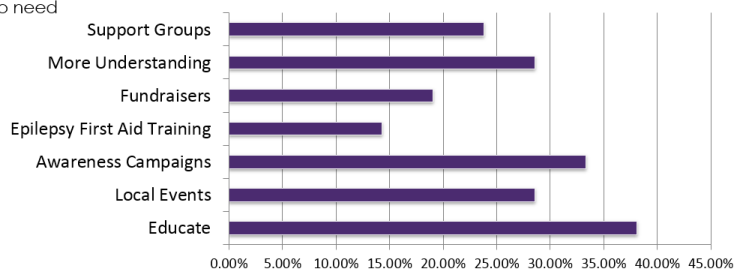
2019 Health and Wellbeing Survey



When surveyed about what their health service providers could do for them in various areas participants said they wanted services to be more accessible. They want health service providers to be more educated and understanding of epilepsy. They also need more support and specialists for epilepsy.

What People Want From Their Local Communities

2019 Health and Wellbeing Survey



When asked what they wanted from their local community the most common responses were epilepsy education, local support groups, and events. People also wanted their community to have more understanding of epilepsy and to run local awareness campaigns and fundraisers.

EPILEPSY AUSTRALIA

A NATIONAL SCENE...

Epilepsy Australia comprises the Epilepsy Foundation, Epilepsy Queensland, Epilepsy ACT, Epilepsy Tasmania, Epilepsy SA & NT and Epilepsy WA.

Epilepsy Australia offers support across Australia and Member organisations are moving towards an evidence-based Knowledge Translation focus that is building the understanding of epilepsy in the health, education, workplace and the aged sectors.

Our goal is that all people with epilepsy have access to best practice evidence-based supports.

At the AGM in November 2018 I was nominated to take on the Chairperson role. This has provided opportunities to meet some of the key contacts that Epilepsy Australia has with Government, ambassadors, funders and researchers. There have also been a number of national media opportunities and it has been good to add Tasmanian experiences and stories to those.

A focus for Epilepsy Australia this year has been the Epilepsy Smart School initiative - all Epilepsy Australia members are working towards enabling schools to become Epilepsy Smart. 1 in 200 students are living with epilepsy.

The Federal Government have committed \$20 Million over 4 years through the Epilepsy Foundation for the roll out of the Epilepsy Smart Australia programs.

Through the online learning platform over 15,000 Teachers, Disability Support Workers and family members were trained in Understanding and Managing Epilepsy and Emergency Medication Administration in the last 12 months

Epilepsy Australia organisations provided phone support to over 15,000 inquiries per year.

Psycho-social research: Analysis of Wave 4 of the Australian Epilepsy longitudinal study into the impact of epilepsy on people's lives has been completed. The Wave 5 survey has been sent out to the 1,700 participants in the Australian Epilepsy research Register. The Australian Epilepsy Research Fund was established with a seed grant from the department of Health of \$2mil for genetic epilepsy research. The objectives of the fund are available from www.epilepsyfoundation.org.au

Epilepsy Australia commissioned Deloitte to create a research document titled The Economic Burden of Epilepsy in Australia. This report will be formally launched in February 2020.

Graeme Shears CEO of the Epilepsy Foundation has been appointed to the Board of the International Bureau of Epilepsy, and to the Congress Council of the International League Against Epilepsy.

Wendy Groot, Chair, Epilepsy Australia



STAFF PROFILES



Wendy
CEO
3.5 years of service



Rebecca
Administration
Manager
5.5 years of
service
*inc 12m maternity leave



Shirley
Education Coordinator
- Social Worker
3 years of service



Emma
Education Coordinator
- Registered Nurse
1 year of service



Sheralyn
Volunteer Services
Coordinator
1 year of service



Liz
Epilepsy Smart
Coordinator
6 months of service

WITH SPECIAL THANKS TO...



We would like to thank the many businesses, individuals, schools, workplaces and community groups who have assisted Epilepsy Tasmania to support the Tasmanian epilepsy community.





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TASMANIA'S VOICE FOR EPILEPSY