



The logo for Epilepsy Tasmania features the word "epilepsy" in a large, lowercase, purple sans-serif font. Below it, the word "tasmania" is written in a smaller, lowercase, black sans-serif font. The logo is set against a light teal circular background.

epilepsy
tasmania

TASMANIA'S VOICE FOR EPILEPSY

45TH ANNUAL REPORT 2020

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

A series of parallel, light teal diagonal lines in the bottom left corner.A circular pattern of parallel, light teal diagonal lines in the bottom right corner.

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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



Epilepsy Tasmania is a not-for-profit community organisation that has been improving the quality of life and community participation of Tasmanians affected by epilepsy for over 40 years. It is the only epilepsy organisation based in Tasmania that delivers local services and support to Tasmanians.

Epilepsy Tasmania educates, trains and provides support in the form of liaison between families and the healthcare sector (GPs, hospitals, specialists etc.). In addition, it offers programs and initiatives that can be implemented by schools and workplaces that improve the lives of people with epilepsy and those around them.

In the second half of this year we have all encountered significant new challenges, brought about by the COVID-19 pandemic. I am extremely proud of the work of CEO Wendy Groot and the rest of the team for their innovative approach to this continually changing environment. Not only have they maintained a sense of equilibrium themselves while working from home, but they also undertook a series of difficult outreach “welfare check” phone calls to families known to the organisation.

Epilepsy Tasmania continually contributes to the State Government’s approach to creating a positive impact on Tasmania’s social determinants of health. I would like to thank the Tasmanian Government and the Department of Health for their ongoing support this year. The funding we have received has enabled the organisation to achieve more positive health outcomes for our clients than ever before, and to significantly reduce pressure on Tasmania’s clinical health services. We look forward to continuing this work.

I am thankful to all the staff, volunteers and supporters who have enabled the work of Epilepsy Tasmania to continue, and allow the organisation to assist with changing lives and providing hope to those dealing with the wide-ranging challenges that epilepsy brings.

Kat Brient

BOARD OF DIRECTORS

Position Name

Chair: Kat Brient

Vice Chair: Vacant

Treasurer: Peter Hicks

Secretary: John Frankcom

Directors:

- Lila Landowski
- Luke Ogden
- Julie Martin
- Katie Dineen
- Terry Long (12-month leave of absence until Feb 2021)

MEETING ATTENDANCE

v

REQUIRED ATTENDANCE

Gus 0 of 1

Kat 4 of 4

Terry 1 of 1

John 4 of 4

Katie 4 of 4

Lila 2 of 4

Luke 4 of 4

Julie 2 of 4

Peter 2 of 2

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

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

CEO REPORT



This year has certainly felt like six months operating as usual followed by a complete shift to finding different ways to continue supporting Tasmania's epilepsy community. The community sector has always worked together well and it has been heartening to see this increase as we all responded to COVID-19.

2020 has been a year where the board, staff, volunteers, the Friends of Epilepsy Tasmania, and our donors have shown their compassionate support for people with epilepsy. I thank you. It is because of your actions that we continued to provide a wide range of programs and services to people with epilepsy and their families. I would further thank the Tasmanian State Government for their continued funding to the organisation.

As our State went into the COVID-19 lockdown and our staff were required to work from home, we were acutely aware of the impact this was having on the Tasmanian epilepsy community. Within a matter of days we developed a new Health and Wellbeing service which included COVID Connect, a telephone check in with our participants and their families. This service was to address the social isolation and loneliness that our community were exposing to us and supporting other psychosocial and situational distress. We also provided extra resources and support to workplaces, other health professionals, and service providers, including new information on our website. An outline of this initial three-month program is detailed within this report.

HIGHLIGHTS

Despite COVID-19, the past 12 months has seen many highlights and activity. Some of these have included -

- The release of our latest research paper- "Epilepsy - A Focus on Tasmania"
This report was the first of its kind to be released within the state.
- "The economic burden of epilepsy within Australia, 2019-2020" national research commissioned from Deloitte Access Economics
- Tasmanian State Government budget Community consultation submission
- Continuation of Tasmanian State Government funding
- Community Services Industry COVID -19 Response and Recovery forums
- Partnerships developed, including Disability Employment and Medical Service providers and suppliers
- Tasmanian School Principals Conference
- University of Tasmania Business interns and Social Work placements.
- Royal Commission people with disability consultations
- Epilepsy Smart Australia Commonwealth Government Pilot Project
- My Journey exhibition
- My Journey podcasts
- TV and cinema advertising.

CEO REPORT CONT

In conclusion I would like to specifically thank each staff member and others who contribute to making this organisation achieve significant outcomes in what has been a year like no other:

- To Bec for all the work she does to manage our administration and finances.
- To Emma for her dedicated contributions as our Registered Nurse and trainer.
- To Shirl for her dedicated contributions as our Social Worker and trainer.
- To Sheralyn for the great work she does developing our volunteer workforce and Epilepsy Connect program.
- To Liz for the great work she does supporting our education and training services.
- To Colin Dean who began with the organisation just prior to COVID-19 and is doing a great job in our new role of community engagement.
- To Claire Burnet for all she does with our organisation's communications and public relations.
- To The Website Clinic for the work they do on our website and digital marketing.

Finally, a personal thank you to our Board of Governance volunteer members. During the last 6 months in particular, you have needed to change some aspects of Governance to meet the changed circumstances sometimes in quite short notice and provided me with new thoughts, guidance, directions and support.

I look forward to the next 12 months, of which although we can't predict, we can continue to grow and support those living with epilepsy in Tasmania, and those around them.

Wendy Groot



OUR PEOPLE



Wendy Groot
CEO

4.5 years of service



Bec
Administration
Manager

6.5 years of service



Shirley
Education Coordinator
- Social Worker

4 years of service



Emma
Education
Coordinator
- Registered Nurse

2 years of service



Sheralyn
Volunteer Services
Coordinator

2 years of service



Colin
Community Engagement

0.5 years of service



Liz
Epilepsy Smart Coordinator

1.5 years of service

COVID-19 RESPONSE

Epilepsy Tasmania has always been diligent and innovative and the COVID-19 pandemic has been no exception. Since March 2020, Epilepsy Tasmania responded quickly and dynamically to ensure Tasmanians affected by epilepsy remain connected and supported.

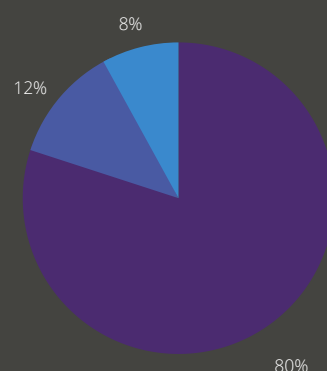
The organisation has rallied to meet new needs and increased support requirements.

Specifically, Epilepsy Tasmania:

- Implemented a phone-call service to connect with its registered participants to check on their mental and physical wellbeing. Many of these requested follow-up calls and Epilepsy Tasmania has so far made 269 phone calls to 76 people. This initiative remains ongoing and the organisation is preparing to increase its phone support as the pandemic progresses and health specialist delays continue.
- Initiated direct contact with businesses to ensure they are able to support employees and customers who have epilepsy. 42 workplaces have been contacted so far and this initiative remains ongoing. In partnership with the TCCI, a mailout of support information was sent to 9,000 people during April and May.
- Is conducting 'foot in the door' visits to healthcare providers, including so far over 164 General Practice clinics (91 South, 44 North, 29 Northwest), 7 Neurologists, 18 Paediatricians and 25 Psychologists, plus statewide out-patient clinics and allied health centres.
- Developed a resource pack for healthcare providers to ensure awareness of all services Epilepsy Tasmania can provide to them and their patients. This initiative was developed in response to the devastating death in June of a teenager with epilepsy whose paediatrician and psychologist had not referred him or his family to Epilepsy Tasmania for support and specialist epilepsy advice.

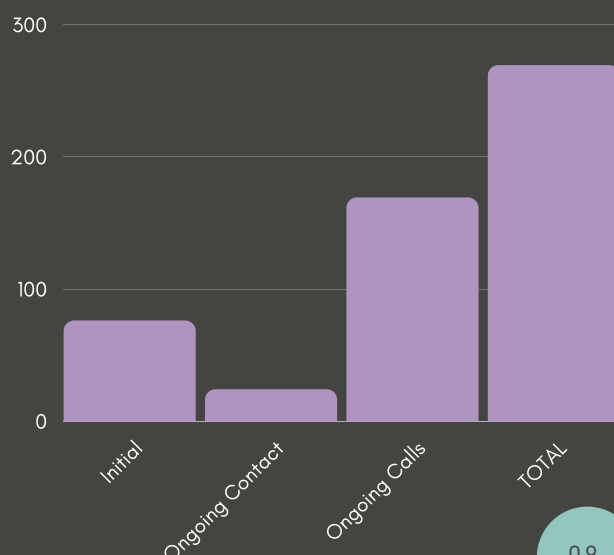


COVID-19 Workplace Friend interactions
March -June 2020



NEW Healthcare Provider resource packs include:

- NEW Epilepsy Tasmania Service Snapshot – services available for providers and patients.
- NEW Epilepsy Tasmania Resource list – printable and online forms and brochures for providers to give patients.
- NEW Epilepsy Tasmania Person-Centred Support Guide.
- Referral forms to Epilepsy Tasmania and SEER diagnostics.
- Epilepsy Management Plans.
- Seizure-monitoring diaries.
- Seizure first-aid posters.



2019-20 AWARENESS & ENGAGEMENT

1 private Facebook group created to support families and friends



2542 Facebook followers

1 private Facebook group created to support young Tasmanians with epilepsy

135,000 people reached via Facebook during 2019/20



1080 people registered as Friends of Epilepsy Tasmania



EPILEPSY TASMANIA'S WEBSITE

- 34% increase in visitor traffic
- 3 seizure first-aid posters downloaded every week
- 1 referral form downloaded every week
- 8 online resources downloaded every week



12 issues of our Brainwaves e-newsletter:
12,960 copies sent



Publicity reached:

- 2,076,306 people via TV and radio
- 19,530,346 via print and online media
- 11,797 additional people were reached via 84 externally-shared social media posts



Did you spot our TV Advert?
Watch it on our YouTube page.



Publicity to raise awareness about **Sudden Unexplained Death from Epilepsy** reached 97,000 Tasmanians



Publicity for **Epilepsy Smart Schools** reached 2,270,832 Australians

Publicity for the Government House Open Garden (*that never happened!*) reached 291,045 Tasmanians



The research paper

"Epilepsy: A focus on Tasmania"

reached 14,613,000
Australians

WorkSafe Month 2019



Cinema & Television
advertising
reached 160,234
Tasmanians

OUR VOLUNTEERS

There are currently 38 members of our volunteer workforce, including 2 Corporate groups and 1 school. Twelve have been new registrations over 2019/20.

Volunteers help at our events; fundraising; selling merchandise etc. as well as with our peer-support service Epilepsy Connect and assisting with administrative tasks. The Friends School recently provided 3 students to complete a stocktake for us.

There has been a gradual increase in our volunteer enquiries:

EPILEPSY CONNECT PEER-SUPPORT

- 5 peer-support client enquiries
- 2 new peer-support volunteers

VOLUNTEERING AT EVENTS

- Apart from the Bunnings BBQ at Glenorchy on 15th March, which was very successful, other scheduled BBQs were cancelled due to COVID-19 restrictions.
- Government House Open Garden tours were cancelled due to COVID-19 restrictions, however, they have kindly agreed to host another one for us in March 2021.
- A team of 11 volunteers helped Epilepsy Tasmania staff at the My Journey Exhibition in Launceston.
- Isa Kingston organised 4 businesses to do some fundraising and we have had other Friends volunteer to run their own fundraising campaigns for us.

COVID-19 SUPPORT CALLS

- One of our volunteers contacted 32 people as part of our COVID Connect support calls.
- Through these calls, one client registered to receive Epilepsy Connect Peer-Support and 3 enquired about volunteering themselves.

Sheralyn Jackson, Volunteer Support Coordinator



2020 PURPLE MONTH

2020 *promised* to be a magnificent year to help raise awareness and funds for Epilepsy Tasmania. But COVID-19 threw a spanner in our works and we didn't get to celebrate Purple Month (March) quite as we had planned.

We had to cancel the Government House Open Garden event, three Bunnings BBQ's and a fundraiser from our long-time supporter Flick the Bean Coffee (Launceston).

However, we did manage to hold our 2020 photo-story exhibition just before gathering restrictions came into force and we were delighted with the attendance and support shown for our 'My Journey Exhibition' which was held at the Tailrace Centre over 3 days.

We were also very proud to present our first podcast audio series - a collection of honest, confronting and inspiring reflections on a condition that is often hidden. Our My Journey podcasts feature twelve Tasmanians who share their journey with epilepsy, in their own words, to raise awareness and understanding of a condition that affects 1 in 25 Australians.

Check out Purple Month and My Journey photos on pages 14 to 19

We thank Sam Ikin from **Ikin Media** for the quality production of these. The cocktail launch event for our podcasts was kindly sponsored by **AtWork Employment**.

This year we had a significant increase in the number of individual fundraisers and those who held their own events to raise funds for Epilepsy Tasmania, and we particularly thank these supporters.

To celebrate on Purple Day (26th March) we held a live Facebook event that included: songs written and sung by Colin Dean from **AntipoDean**, a GP Q&A session, and staff interviews with our CEO and Social Worker/Educator. Watch a video of this on our YouTube channel.

Despite having to change our plans, we felt a phenomenal support for Epilepsy Tasmania during Purple Month and it was still a resounding success in raising awareness of a condition that touches so many Tasmanians.

We are very much looking forward to seeing where 2021 Purple Month will take our organisation and welcome you to celebrate with us bigger and better than ever!



PURPLE MONTH IN PICTURES









2020

MY JOURNEY EXHIBITION

My Journey Podcasts

12 personally told
experiences with
epilepsy:

Over 800
downloads





My Journey...

...everyday Tasmanians
living with or affected by epilepsy.



EPILEPSY SMART SCHOOLS

Some Finger Knitting feedback...

"We've had such a terrific term doing this challenge in our class and look forward to future projects."

*

"What a great promotion! We have enjoyed it."

Some Training feedback...

"I found this training really informative. I've been in the workforce for almost 30 years and this is the first session like this I've attended."

*

"I really enjoyed the session and took a lot away from it. The presenter was very good and explained things clearly and audibly."

*

"Very informative and makes me more confident to know what to do if my colleague has a seizure. Thank you!"

*

"Good course and well run. Some great awareness around epilepsy."

*

"Great training content - I went in knowing nothing and came out after thoroughly enjoying the session much more informed and aware."

*

"You guys are doing a fabulous job and I am keen to run more of these sessions going forward."

*

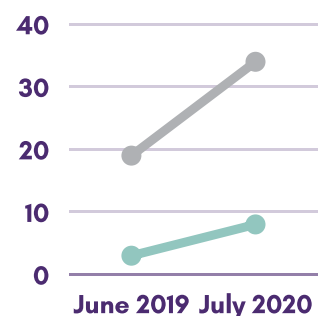
"I found the training very informative and received a lot of good feedback afterwards."

852 people
attended Smart
School training

42

Epilepsy
Smart Schools
so far!

Completed Smart Schools Registered Smart Schools



FINGERKNITTING CHALLENGE



Our first #FingerKnittingChallenge for Tassie schools was a great success.

- 24 schools registered to participate
- 12 submitted a final entry

Schools were challenged to drape a room, piece of furniture or anything at all in purple finger knitting.

They were encouraged to share their efforts on social media using the hashtag #FingerKnittingChallenge to improve awareness of epilepsy in Tasmanian schools.

Photos showed some amazingly creative finger knitting items, including murals, collages, clothing, a dream catcher, sea creatures, a diorama, a draped cow statue with saddle and a rein, and draping of furniture, trees, poles, and a balcony. WOW!!!

3 schools became Epilepsy Smart Schools by completing the finger knitting challenge as step 3 of the three-step process. Congratulations to Campbell Town District High School, Waverley Primary School and Latrobe High School.

Some schools even incorporated learning about epilepsy into the challenge which was great to see, for example Latrobe High School included information about epilepsy in their mural and Mount Stuart Primary School had a 'What do you want to know about epilepsy?' board where students could write questions on post-it notes and add to the board.

And finally, what you've been waiting to read...the winners of our 2020 #FingerKnittingChallenge were: Latrobe High School and Mount Stuart Primary School. Well done to our winners and thank you to everyone who took part.





Epilepsy Australia comprises Epilepsy Tasmania; Epilepsy Foundation (VIC & NSW); Epilepsy Queensland; Epilepsy ACT; Epilepsy SA & NT; and Epilepsy WA.

Epilepsy Australia offers support across Australia and its member organisations are moving towards an evidence-based knowledge translation focus that builds understanding of epilepsy in health, education, workplace, and the aged sectors.

Epilepsy Australia's goal is for all people with epilepsy to have access to best practice evidence-based supports.

2019-20 Highlights

All member organisations responded quickly to the Covid-19 pandemic by pivoting to a virtual delivery of services. By working collaboratively, they grew the volume and consistency of service offerings through the year. A recent example of adaption was the virtual Walk for Epilepsy, with 1,205 participants from ACT, Tasmania and Victoria walking 79,199 kms or three times around Australia. We hope to make this a national event next year.

A focus for Epilepsy Australia over the last year has been the Epilepsy Smart School initiative - all members are working towards enabling schools to become Epilepsy Smart (1 in 200 students have epilepsy) and the Federal Government has funded \$20 Million over 4 years to rollout the Epilepsy Smart Australia program.

The Epilepsy Foundation formed a strategic alliance with the Epilepsy Foundation of America. This will form the foundation for collaboration and sharing of best practice on an international level.

Psychosocial research

Analysis of Wave 5 of the Australian Epilepsy longitudinal study into the impact of epilepsy on people's lives has commenced.

Important News for Researchers

The Australian Epilepsy Research Fund was established with a seed grant from the department of Health for \$2 Million. The objectives of the fund are available from epilepsyfoundation.org.au

6 projects have been funded to date:

- Improving first seizure assessment and management.
- Preparing Australia for precision medicine in the developmental and epileptic encephalopathies.
- Uncovering the hidden genetics of non-lesional focal epilepsy.
- A Clinical Liquid Biopsy to Diagnose Epilepsy.
- Phenotyping depression and anxiety in people with epilepsy.
- SYNGAP-1 GENE PROJECT.

A further call for funding requests is expected within the next 12 months.

Wendy Groot, President

WITH SPECIAL THANKS TO...



We would like to thank all of our Friends ...
the many businesses, individuals, schools, workplaces and community groups
who help Epilepsy Tasmania support the Tasmanian epilepsy community.





epilepsy
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TASMANIA'S VOICE FOR EPILEPSY