



epilepsy
tasmania

**ANNUAL
REPORT**
2018

MESSAGE FROM THE HEALTH MINISTER

“As the Tasmanian Minister for Health, I warmly appreciate the opportunity to work with and support the efforts of the Chief Executive Officer and board of Epilepsy Tasmania.

Tasmania has come a long way in terms of working to minimise the impact of epilepsy broadly and also on an individual level. This includes the employment of Tasmania's first Paediatric Neurologist, Dr Tyson Ware in 2015 by the Department of Paediatrics at the Royal Hobart Hospital, with clinics also being run at the Launceston General Hospital.

Going forward, I note the tremendous work Epilepsy Tasmania undertakes to educate, train and also provide support leading up to and at the conclusion of appointments with doctors. This is in addition to programs and initiatives that can be implemented in schools or workplaces and assist people with epilepsy and those directly affected with returning to a normal life.

I am thankful to the amazing staff, volunteers and supporters who ensure Epilepsy Tasmania change lives and provide hope to those dealing with the wide-ranging challenges epilepsy brings. Importantly, these resources extend to parents, family, friends, carers, employers, medical researchers and healthcare professionals.

These valuable services are not always appreciated and it is an amazing privilege as Minister to witness a not-for-profit organisation genuinely impacting lives through the support and services they offer.

The Liberal Government's recent election commitment will provide Epilepsy Tasmania with an additional \$440,000 a year for two years, from 1 July 2018. This funding will provide an opportunity for Epilepsy Tasmania to broaden its service reach and maintain services for individuals that are not covered by the National Disability Insurance Scheme.

These measures will contribute significantly to the care of children with epilepsy, although demand remains high and I am fully aware of the challenges still ahead.

While there is no cure yet, Epilepsy Tasmania is working hard to improve understanding and promote more research.

Once again, I want to acknowledge and thank all the wonderful supporters including staff and volunteers of Epilepsy Tasmania for all the work they do."

Kind regards,

Office of the Hon. Michael Ferguson MP

Minister for Health, Minister for Police, Fire and Emergency Management,
Minister for Science and Technology
Leader of the House, Liberal Member for Bass, P: 03 6777 1034



CONTENTS

Chair Report_____ 4

CEO Report_____ 6

Strategic Framework_____ 8

Epilepsy Connect_____ 10

Purple Month_____ 12

Epilepsy Smart Schools_____ 13

My Journey Photo Exhibition_____ 14

Engaging with the Epilepsy Community_____ 16

With Special Thanks To..._____ 18

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

BOARD CHAIR REPORT

There is a buzz about Epilepsy Tasmania that inspires confidence in its Directors. It comes from the energy within the organisation and a definite idea of where it is going, and why.

Here is our vision –

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

That simple statement underscores a fundamental set of beliefs shared by staff, volunteers and the Board that drives the delivery of activities and services, including the de-stigmatisation of epilepsy in the broader community, acceptance of the condition in the workplace and access to support for people living with epilepsy.

In the year under review, your Directors continued to guide the organisation towards a broader and stronger future through careful management of its finances and attention to key risks. As expected, financially we finished the year in the red, but that should be considered against a background of continued rebuilding of the organisation and preparing for an expansive future.

As mentioned in the introduction, Epilepsy Tasmania has energy. It is “out there” - within the community, in the media, at functions, and present at other events. It has built a strong relationship with other related organisations and relevant government agencies, as well as Members of State Parliament.

It has provided extensive services to people who have epilepsy, and those around them. It has a peer support service which is the first in the nation and its enhanced public profile means people with epilepsy in Tasmania are making it their first port-of-call.

As the financial year drew to a close, the Board decided to embark on a strategic planning exercise and that is where our vision for the future comes from. It would be an egalitarian society indeed if everybody with epilepsy had the same opportunities as others. Over the longer term, that is what we aim for and we apply all of its programs to underpin that goal.

Looking at the future, our newly-minted strategic plan will guide our work for years to come, and I invite you to enquire about the details as they pertain to you. We have secured more funding, through a generous grant from the Tasmanian Government, to fully realise our ambition for the organisation.

There will also be more education about the condition in schools and workplaces and a range of public events to draw attention to Epilepsy Tasmania's work.

The organisation is in a strong position, both financially and strategically and the Board is confident in the continued provision of services to people with epilepsy, and those around them, with the addition of services where they are needed.

Epilepsy Tasmania has competent and energetic staff, led by its CEO, Wendy Groot.

Your Directors have put in the effort this year, and it shows. I would like to thank each of them and all members of staff for their work and enthusiasm, which have lifted us into a future that will much better meet the needs of Tasmania's epilepsy community.

Gustavo Bodini
Chair, Epilepsy Tasmania

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



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 members.

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. In this report, we have included photos of some of the activities that have occurred.

Communications and Engagement

This year we have been working hard to engage and communicate with people who are living with epilepsy, and those around them.

Two years ago we started two surveys, one for those with epilepsy and another for those who care for someone with epilepsy, we have collated these surveys and will continue to build on the information provided.

There has been significant growth in Epilepsy Tasmania's social media platforms and we have an increasing number of people wanting to become a Friend of Epilepsy Tasmania - a new initiative that has replaced our old membership database.

Throughout the last 12 months, the number of times we have been called upon to provide information services or support has increased from 134 to over 1200. That's a 795% increase! This demonstrates to us that the work we have collectively achieved to raise the organisation's 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.

Epilepsy Connect telephone-based peer support service has seen growth and next year we will

expand this service beyond the telephone in order to provide more flexible support options.

Epilepsy Tasmania's partnership with Blooming Tasmania has led to significant growth in its Open Gardens for Epilepsy initiative with some beautiful gardens opening across the state to raise funds and awareness of epilepsy within relaxing outdoor environments.

March 2018 (Purple Month) saw a spike of over 34 groups and individuals wanting to host a purple-themed fundraising event. And 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.

The inaugural My Journey photo-story exhibition (12 everyday Tasmanians' journey with epilepsy) exceeded all expectations and we were touched by how much our intent to reduce the stigma of epilepsy must be working due to the number of people happy to share their story publicly compared to only a few years ago. We have many more people keen to be part of our next exhibition, so watch this space!

Education and Training

Epilepsy Tasmania's educators have been busy delivering training and education through our programmes: 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 programme will begin in 2019 and we anticipate this will bring a great improvement to the support of people with epilepsy who are part of the education system.

Advocacy and Influence

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. Through one of these opportunities, Epilepsy Tasmania was successful in receiving a much needed boost to its funding and we are now able to grow the organisation and its services to reach more Tasmanians across our state.

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 influence to address the needs of the Tasmanian epilepsy community.

Through our membership on the Neurological Alliance of Tasmania (NAT) we contributed to a submission into the Legislative Council sub-committee inquiry into acute health services.

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 as a member provides Epilepsy

Tasmania with increased support and networks through a national peak body as well as providing us with opportunities to work collaboratively on a range of national projects, campaigns, submission papers and reports.

Growth and Capacity Building

With growth comes an increased staffing requirement, so there has been an increase in the number of our staff and skill-set which has resulted in more services able to be delivered to people who contact us for help. The individualized support offered to people with epilepsy or their family/carer has been maximized and the response time to requests has reduced considerably.

Epilepsy Tasmania has increased its profile and footprint dramatically and the organisation is fast approaching its goal to be the peak "go to" organisation in Tasmania. With new offices in Hobart and Launceston and plans for further locations, we are set to continue to expand and extend to meet more of the needs that are being identified.

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 they contact.

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 and 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, Epilepsy Tasmania



Our Strategic Framework Features 6 Themes:

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 Friend of Epilepsy Tasmania 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

EPILEPSY CONNECT

What is Epilepsy Connect?

Epilepsy Connect is a free and confidential telephone-based peer support service for Tasmanians affected by epilepsy. Peers are trained volunteers who have either been diagnosed with epilepsy or have a family member with epilepsy and are backed by a team of health professionals.

Epilepsy Connect was established in 2016 to assist in improving the health and wellbeing of Tasmanians by providing equitable access to peer support for people living with or affected by the condition. It is an innovative community-based program run by Epilepsy Tasmania and developed in partnership with the University of Tasmania.

Why Epilepsy Connect?

Epilepsy is a common neurological condition in which a person has a tendency to have recurring seizures. It comprises many seizure types and can develop at any age regardless of gender or background. There is no single cause and there is no cure.

As many as 1 in every 100 Australians will have epilepsy at any given time; that's over 5,000 Tasmanians. The true number who are affected, including family members, is proposed to be four times this amount.

The impact of epilepsy on an individual and their family is much more than just the seizure itself, which in most cases only lasts a few minutes. More broadly, epilepsy can result in:

- Memory loss
- Decreased cognitive ability
- Fatigue
- Loss of driver's license
- Medication side effects
- Social stigma
- Bullying
- Discrimination
- Isolation
- Reduced educational opportunities
- Job loss
- Economic hardship
- Sudden unexpected death in epilepsy (SUDEP)

This is by no means an exhaustive list but provides an indication of some of the issues faced by people living with epilepsy and those around them every day.

It is not surprising then that people with epilepsy report increased levels of anxiety, depression and poor self-esteem. In Tasmania, high to very high levels of psychological distress have been observed in patients with epilepsy compared with the general population.

Peer support has been shown to improve psychosocial wellbeing for a range of health conditions including depression, type 2 diabetes, and multiple sclerosis. Peer support has also been shown to reduce the stigma of epilepsy.

Epilepsy Connect is Making a Difference

A recent evaluation showed that Epilepsy Connect provides equitable access to peer support, with almost half of the participants living in outer regional and remote Tasmania, and a third living in the most socioeconomically disadvantaged areas of Tasmania.

Epilepsy Connect was found to have a positive impact on the overall wellbeing of participants, their mental health, and their ability to cope as a carer. These results reflect the original objective of the program in reducing the impact of epilepsy in Tasmania.

One of the most powerful stories demonstrating the impact of Epilepsy Connect was published by Primary Health Tasmania in their December 2017 issue of Primary Health Matters. The article describes a mother's experience of caring for her young daughter with epilepsy. Skye describes how learning to manage her daughter's condition really took a toll on her own mental health; she was not coping and everything was falling apart. She said talking to an Epilepsy Connect Volunteer was like "somebody had switched on a light in a dark room" and that it was a "massive relief" to talk to a mum who had been through the same experience.

For Skye, getting involved with Epilepsy Connect made a huge difference. She described being able to cope with her daughter's epilepsy a lot better because she was aware that everything she was feeling was normal.

"The peer support volunteer showed me there is always a way to live a normal life as a family with epilepsy."



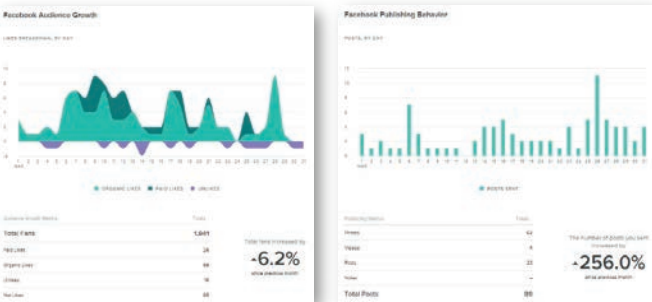
PURPLE MONTH 2018

Purple Month has been a wonderful success in raising awareness of the condition that affects around 100,000, (1/5th) of Tasmanians.

We were positively overwhelmed by the number of people who asked to sell stock at their workplace or host epilepsy awareness events. Across the state over 32 (12 in 2017), workplaces, cafés, schools, sports groups, aged care facilities and individuals chose to show their support for Tasmanians with epilepsy by hosting some exciting and innovative activities and events. Epilepsy Tasmania would like to thank each and every volunteer, staff, participant and media for their valuable contribution towards increasing awareness of epilepsy, and therefore reducing the stigma that surrounds it. And of course, for raising the much-needed funds that help Epilepsy Tasmania provide its broad range of services and support across the state.

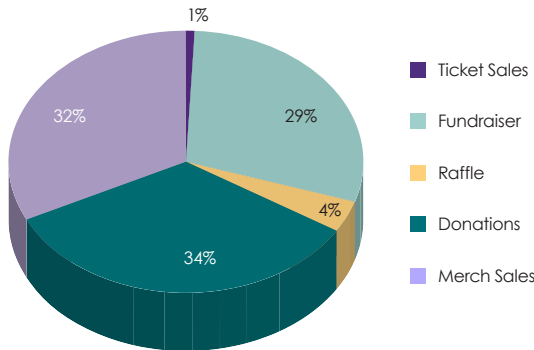
The National campaign was a buzz on social media and many posts and photos were shared on our platforms by everyone involved.

National Campaign Summary for Purple Month

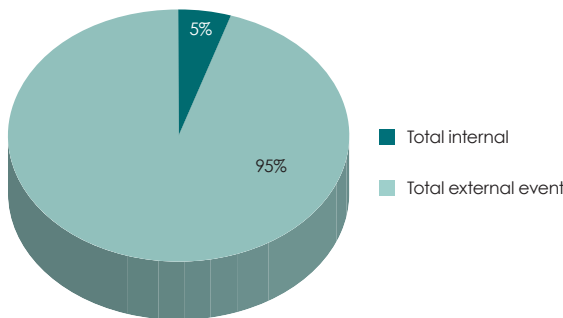


Facebook Page	Total Fans	Fan Increase	Posts Sent	Impressions	Impressions per Post	Engagements	Engagements per Post	Link Clicks
Epilepsy Tasmania	1,841	6.17%	89	96,948	1,089	2,768	31.1	128

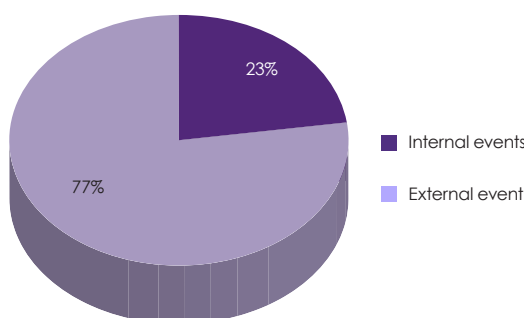
Types of Income for Total External Events



Internal and External Event for Net Profit in 2018



Internal and External Event for Net Profit in 2017



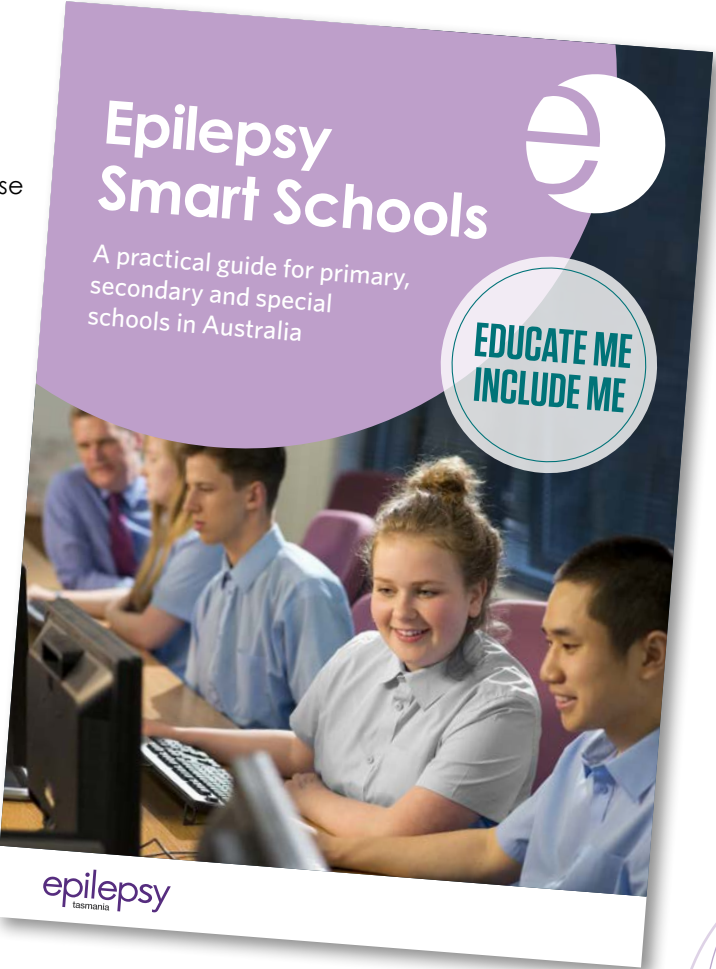
EPILEPSY SMART SCHOOLS

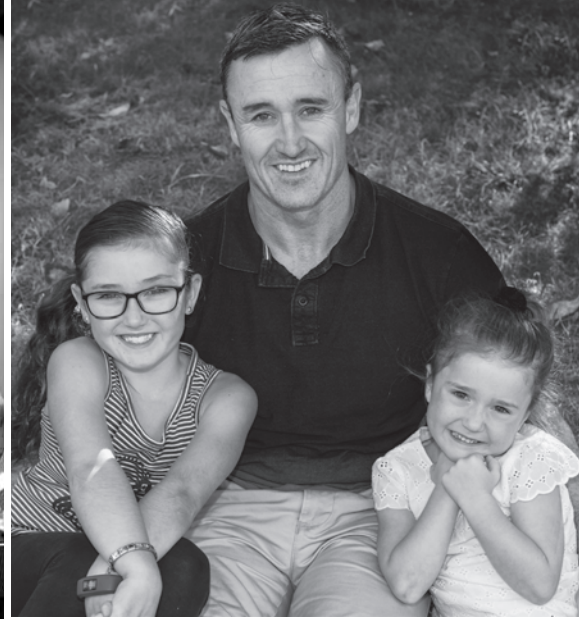
Epilepsy Tasmania is excited to be extending our work with schools across Tasmania and implementing Epilepsy Smart Schools. This is a national initiative and provides the framework, information and training tools to promote best practice epilepsy management in schools. With 1 in 200 Australian students living with epilepsy the impact on them and their education experience is significant. Epilepsy is one of the most misunderstood conditions in our community. The impact of epilepsy on a student is often far greater than the seizure itself. The obstacles they face include, not being able to participate in activities, such as sports and camps, missing classes, embarrassment due to seizures, anxiety, depression and moodiness, being alienated due to people not understanding what epilepsy is and how to respond.

An Epilepsy Smart School is a school which embeds inclusive, safe and educationally sound practices for primary, secondary and special school students living with epilepsy. Every person with epilepsy has different needs and requires a different supportive approach. Our evidence based training ensures schools have the required skills to support each student in need.

There are three steps to be completed to be recognised as an Epilepsy Smart School:

- Where school staff are aware of a student with an epilepsy diagnosis, a current Epilepsy Management Plan is held. Additionally for those students living with epilepsy who have been prescribed emergency medication, a current Emergency Medication Management Plan (EMMP) is held.
- School staff understand the possible impact of epilepsy on students, ideally through participating in training. Where a student has an EMMP, all school staff with a duty of care responsibility for that student have received student specific epilepsy training.
- School staff educate students about epilepsy using resources from the Epilepsy Smart Schools website either through embedding education within curriculum or supporting campaign, such as a purple day event.





My Journey...

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

"The greatest art in the world is the art
of storytelling." Cecile B De Mille

A particular highlight this year was the launch of our inaugural
photo-story exhibition, **My Journey**.

Twelve Tasmanians, aged between seven and seventy, shared their
photos and stories publicly through this exhibition. With the stigma
often worse than the condition itself, the courage shown by these
people to share their journey shone a light on the range of experiences
epilepsy brings to families and communities.

We hope this exhibition will create a ripple effect where every Tasmanian
can feel confident sharing their journey with others. The more we are able to talk
about epilepsy, the safer people feel talking about their epilepsy. Just two years ago we
struggled to find anyone who felt confident and safe talking publicly - our media releases would often not
have a photo of the interviewee due to their lack of confidence with how their story would be perceived, so
we are over the moon about the progress of our campaign to reduce the stigma of epilepsy.

Featured in My Journey, Shaun, who lost his wife and the mother of his young daughters to epilepsy two
years ago said: "I wanted to share our journey so that other families who are suffering loss realise they are not
alone."

The exhibition was open in Hobart for two weeks and we are looking at ways to take the exhibition to other
parts of Tasmania.



"It's been heart-warming and emotional
seeing the generosity that people from
all walks of life have showed me in my
journey through Purple Month."

Isa.

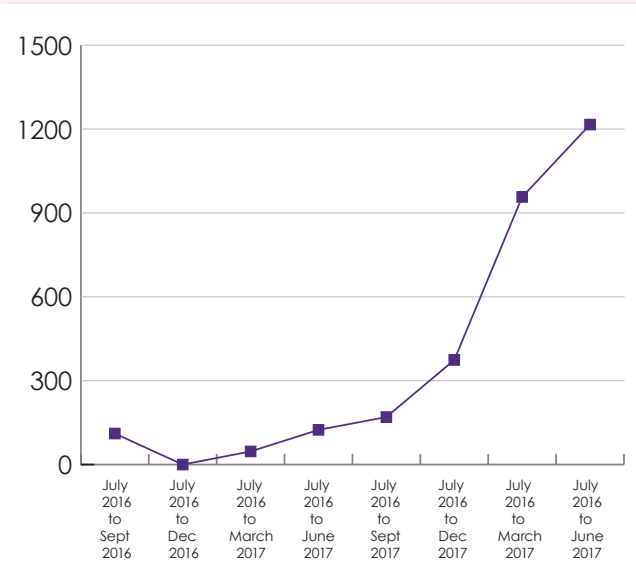


ENGAGING WITH THE TASMANIAN EPILEPSY COMMUNITY

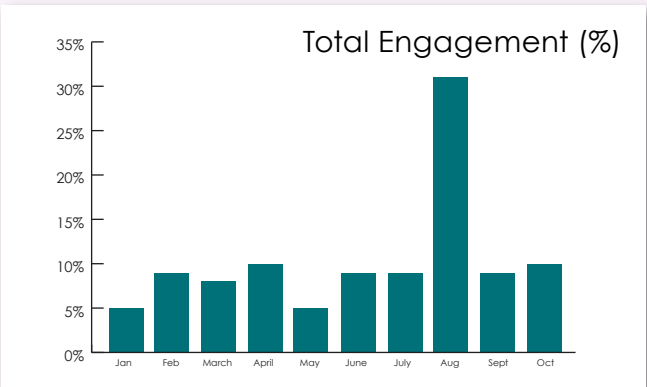
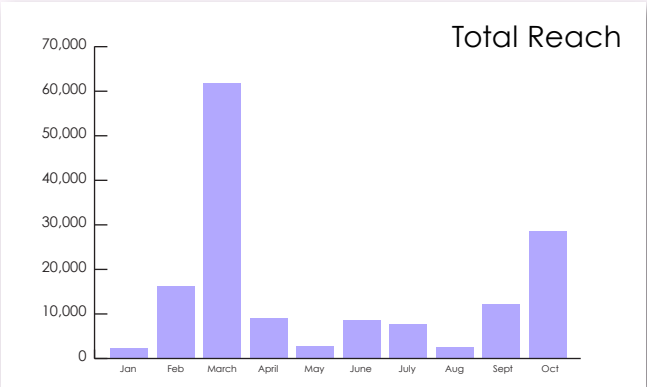
Every quarter Epilepsy Tasmania reports to the State Government the numbers of people who have made contact with the organisation.

The specialized staff provides direct support to people with epilepsy and their families. Further requests include, education and training, workplace training, training and direct support to disability, aged care, childcare centres, education (schools, colleges, tertiary), provision of epilepsy specific equipment, and generalised information.

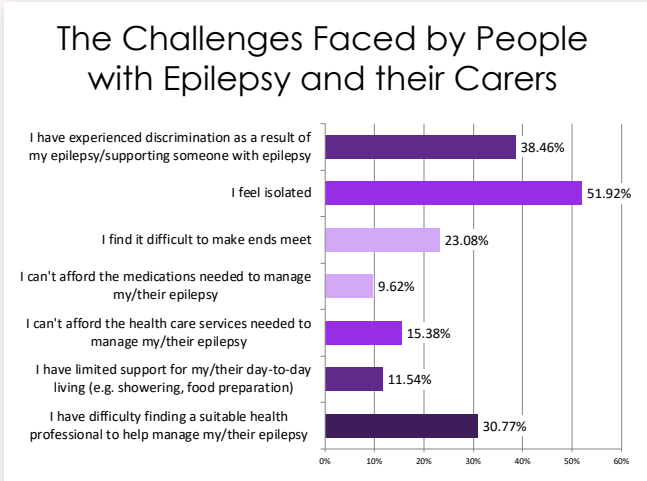
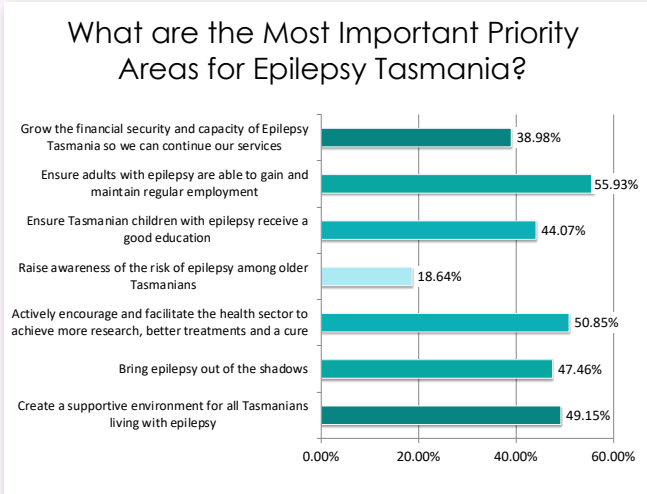
The graph below shows the significant increase in those contacts. From June 2017- June 2018 they increase from under 200 to over 1200.



Engagement Through Social Media



Summary of the 2016-2018 Survey



“Epilepsy Connect made me feel really good. I had a lot of problems socialising - a very nervous person - and now I’m starting to get out of my comfort zone and become more confident.”





Yes, I've had to make changes and some have been hard, but I'm thankful for what I have had. If my story helps change things and brings understanding for those who need help, I'll be glad."

Ian, featured in 'My Journey' exhibition.

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

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