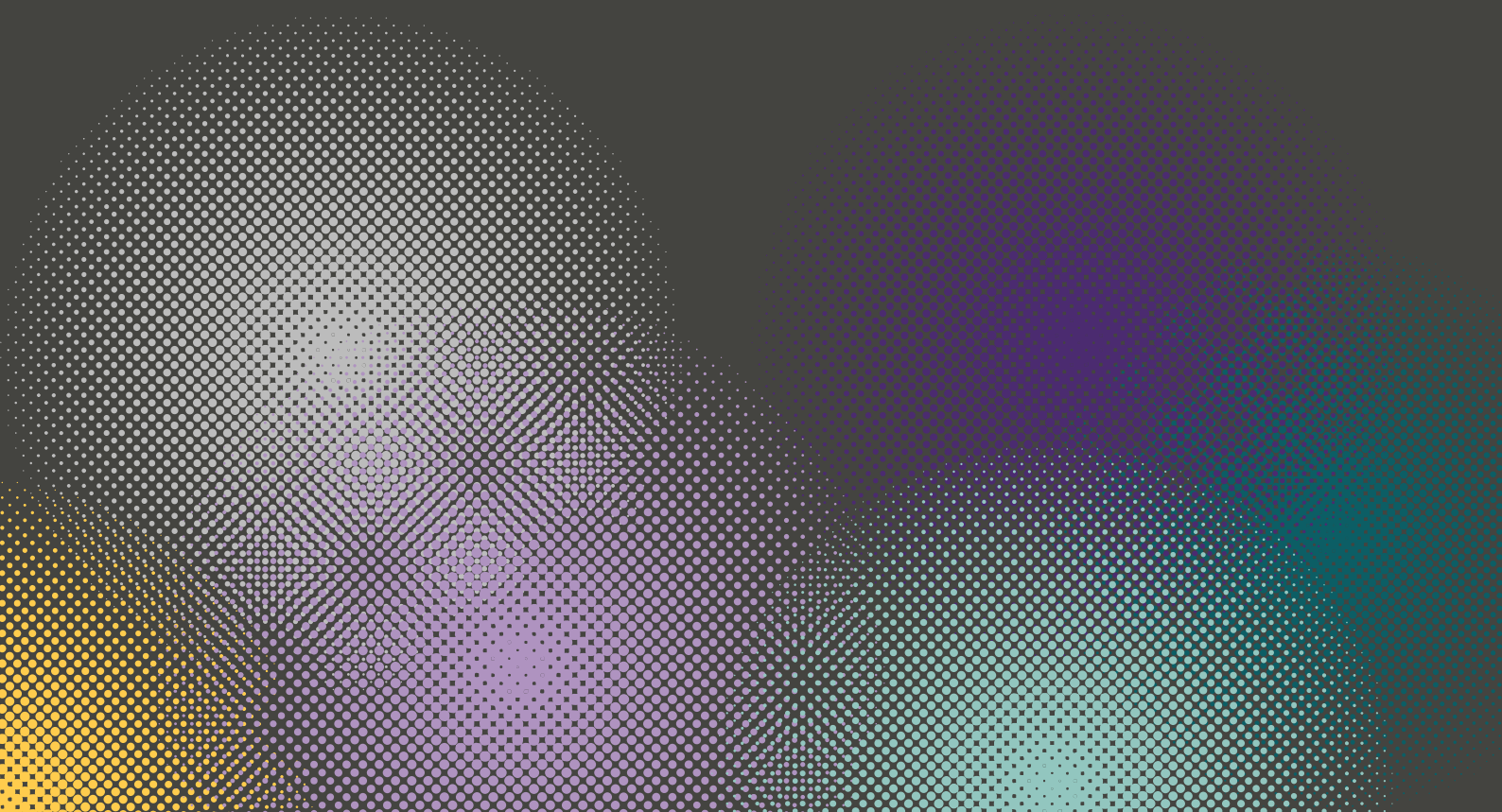




TASMANIA'S VOICE FOR EPILEPSY

46TH ANNUAL REPORT 2021

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



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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 the peak 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, there are programs and initiatives that can be implemented in schools or workplaces which assist people with epilepsy and those directly affected.

Earlier this year the Board commenced a review of our Strategic Framework and Risk Register. Both aspects underpin the direction of the organisation and although some changes were recently made, the fundamental direction is unchanged. The ongoing challenges brought about by the COVID-19 pandemic remain and have evolved. The organisation’s agility in responding to varying needs and already demonstrated flexibility in delivery are key priorities.

The Board have also taken the opportunity this year to reset the standards for our operation and outlined good governance principles in a recently adopted Board Charter, ensuring all Directors understand their obligations and maximise their effectiveness.

I continue to be extremely proud of the work of CEO Wendy Groot and the rest of the team for their efforts in this continually changing environment. Although our State has not had as many direct impacts from COVID-19 over the last 12 months as others, the team have had to adapt and work differently to deliver a wide range of support services.

Epilepsy Tasmania makes an ongoing contribution to the State Government’s approach to having a positive impact on Tasmania’s social determinants of health. Our funding from last year has now been followed by certainty for the next 3 years. We will also seek additional funding for specific projects over the years to come.

I thank the Tasmanian Government and the Department of Health for their support.

I am ever thankful to all the staff, volunteers and supporters who have enabled the work of Epilepsy Tasmania to continue throughout this ongoing and challenging year.

Kat Brient

BOARD OF DIRECTORS

Position	Name
Chair	Kat Brient
Vice Chair:	Vacant
Treasurer:	Peter Hicks
Secretary:	John Frankcom
Directors:	<ul style="list-style-type: none">• Lila Landowski• Luke Ogden• Julie Martin - 12 month leave of absence• Terry Long

MEETING ATTENDANCE
v
REQUIRED ATTENDANCE
Kat 4 of 4
Terry 1 of 2
John 3 of 4
Lila 4 of 4
Luke 3 of 4
Peter 2 of 4

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



These last 12 months have seen many of the same challenges we faced last year when the COVID-19 pandemic began. Some of the initiatives we rolled out in immediate response to coronavirus restrictions are being continued due to their success in supporting Tasmania's epilepsy community and we continue to re-evaluate our work and priorities in order to put Tasmanians first.

Our Board, staff, volunteers, Friends of Epilepsy Tasmania, and our donors have shown compassionate support for people with epilepsy and I thank them all for this. It is because of their actions that we continue 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.

It is pleasing that we have developed some trial models to extend services across the North West, West and North East and our relationship with Neurologists and GPs has also born positive growth.

In conclusion, I would like to individually thank the following people who contribute to helping Epilepsy Tasmania achieve its goals:

- To Bec for all the effort and work she puts into managing 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 her great work developing our volunteer workforce and Epilepsy Connect program.
- To Liz for her professional work supporting our education and training services.

- To Kassia, our most recent addition to the team, who quickly made a positive impact.
- To Colin Dean for his video creations and great work with our Awareness events during March.
- 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.
- To Sam at Ikin Media for his compassion and professionalism while producing our excellent podcast series.

Finally, a personal thank you to our Board of Governance volunteer members for their guidance, directions and support.

I look forward to the next 12 months as we continue to grow and support those living with epilepsy in Tasmania, and those around them.

Wendy Groot



HIGHLIGHTS

- Continued engagement with the research paper- "Epilepsy - A Focus on Tasmania"

This report was the first of its kind to be released within Tasmania.

- Submissions- Rural Health Services enquiry.
- NDIS Disability enquiry.
- Tasmanian State Government budget Community Consultation submission.
- Continued Tasmanian State Government funding.
- TV advertising campaigns to raise awareness of epilepsy.

- Community Services Industry COVID -19 Response and Recovery forums.
- Partnerships developed including Disability Employment and Medical Service providers and suppliers.
- CEO's continued role as Epilepsy Australia Chair.
- Tasmanian School Principals Conference.
- Epilepsy Smart Australia Commonwealth Government Pilot Project.
- My Journey photo-story exhibition.
- Symphony of the Brain podcast series.

OUR PEOPLE



Wendy Groot
CEO

5.5 years of service



Bec

Administration
Manager

7.5 years of service



Shirley

Education Coordinator
- Social Worker

5 years of service



Emma

Education
Coordinator
- Registered Nurse

3 years of service



Colin

Community Engagement

1.5 years of service

Liz
Epilepsy Smart Coordinator

2.5 years of service



Sheralyn

Volunteer Services
Coordinator

3 years of service.



Kassia

Administration Assistant

0.5 years of service

OUR VOLUNTEERS

by Sheralyn

Volunteers play an important role across the organisation. They provide peer support, input into our services and invaluable support during organisational activities as well as hosting their own fundraising and awareness events. As a small charity, we are immensely grateful for all that our volunteers do here in Tasmania.

To recognise the vital role volunteers play around Australia, National Volunteers Week is held annually every May and is an event Epilepsy Tasmania is proud to be part of. This year we thanked our volunteers in our e-newsletter Brainwaves; on social media with individual story-posts; via personal email; and with a Certificate of Appreciation.

The following events held during March for Epilepsy Awareness Month relied on almost every Epilepsy Tasmania volunteer helping out, as well as two staff from CVGT (Disability Employment Services) who came along as volunteers:

Government House

- A raffle of donated goods.
- Every attendee was provided with a gift bag of Government House homemade shortbread.

Bunnings BBQs

- Kingston: Again due to COVID-19 Safe restrictions, our processes were slightly different. However, this didn't stop people from buying their much-loved Bunnings' sausage. A total of 6 volunteers and 2 staff helped throughout the day.
- Launceston: A team of volunteers organised a sausage sizzle at Bunnings Invermay.

My Journey Exhibition

- Volunteers assisted daily with welcoming attendees.
- Students from The Friends School were keen to help and covered the weekend roster.
- Employees from At Work Australia recently came on board as Corporate Volunteers.

Other activities where we relied on our volunteers were:

Stocktakes

- 2 volunteers carried out our Launceston stocktake and put together information packs for distribution to GP clinics.
- 2 students from The Friends School helped with our Hobart stocktake and put together information packs.



EPILEPSY AWARENESS MONTH

by Bec

Epilepsy Awareness Month in March 2021 *promised* to be a magnificent year to help raise awareness and funds for Epilepsy Tasmania. Unfortunately, once again COVID-19 threw a spanner in our works and we were unable to celebrate in March quite as planned.

We were able to hold a small Open Garden event at Government House following the cancellation of our usual planned one in 2020. It was a beautiful day with 70 attendees who walked the gardens in small groups, guided by Epilepsy Tasmania staff and 5 wonderful volunteers. Despite being a touch chilly, the day was a great success and attendees were treated to homemade shortbread from the Governor's kitchen!

There were two Bunnings BBQs held: one at Kingston with 6 volunteers and 2 staff in attendance and one at Invermay that was run completely by volunteers – the first time we have been lucky enough to have this happen and a great achievement by this fabulous team.

The My Journey exhibition returned to Hobart in 2021 with a bang! Paint and Sip nights were run through the week prior and a celebration event was also held.

Check out our Epilepsy Awareness Month and My Journey photos on pages 10 to 13



We were blown away by the efforts of our individual fundraisers in 2021: Isa Kingston in particular went to great lengths to raise funds and spread epilepsy awareness. There were also a number of schools that went purple and many are now accredited as Epilepsy Smart Schools.

The 26th March is Epilepsy Awareness Day and Flick the Bean Coffee (Invermay and High Street Launceston) kicked the day off early with a community fundraiser. Much discussion was had about epilepsy and it was wonderful to see increased understanding, with many people commenting how great it was to be among 'people who understand'. An amazing \$7,878 was raised by Flick the Bean Cafes and we can't thank them enough for their support.

Many of our Tasmanian Landmarks also lit up Purple, there are some fabulous pics of these throughout this report.

In time for March events, we launched **Just Go Purple** – a new website that provides resources to inspire and help people raise awareness and funds for Epilepsy Tasmania: <https://justgopurple.org.au> Schools, workplaces and individuals can download and print tailored resources. Fundraising events can now also be registered online.

We are looking forward to seeing where Epilepsy Awareness Month 2022 will take our organisation. With COVID-19 restrictions we are reviewing our fundraising opportunities so please get in touch and ask how you can join in and help.

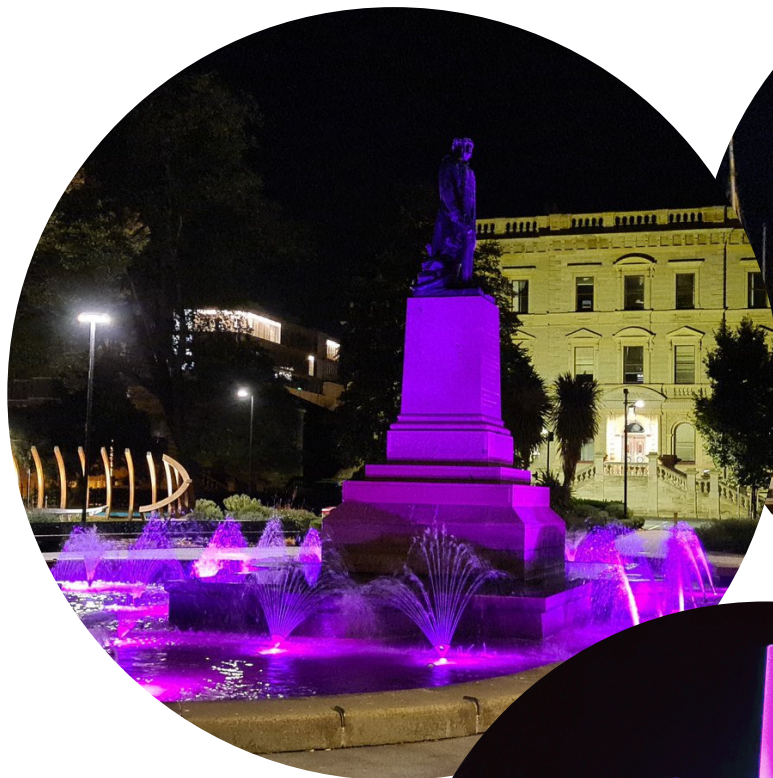
Warm regards,

Bec Wylie

Administration Manager



PAY Epilepsy Tasmania		DATE 7th October 20
THE SUM OF One hundred and	NOT NEGOTIABLE OR BEARER	\$ 134.15
Thirty four dollars and fifteen Cents		
Sage and Sidney at the SNE SHED		MEMO





MY JOURNEY EXHIBITION

In 2021 our My Journey exhibition returned to Hobart.

It was held in conjunction with celebrity Paint n Sip nights that were kindly run by Archaica Schola and it culminated in a Starry Starry Night Purple Party at the Town Hall.



COMMUNITY ENGAGEMENT

by Colin Dean

Community engagement has been challenging, with COVID-19 requiring many restrictions around gathering numbers and the postponement of many group talks and visits to workplaces.

Having said that, we used our initiative and still had a great year creating awareness in many other ways:

Local theatre group, The Bawdy Panto Company, kindly held three fundraising Bunnings BBQs for Epilepsy Tasmania and our staff had many laughs with them as everyone joined together for a great cause.

The Tasmanian Police Charity Trust Bike Ride chose Epilepsy Tasmania as a recipient, and I rode along with them over the three days on my Vespa. This also raised valuable funds and gave me the opportunity to enhance media events, as well as the chance to talk with the riders directly about their personal journeys with epilepsy.





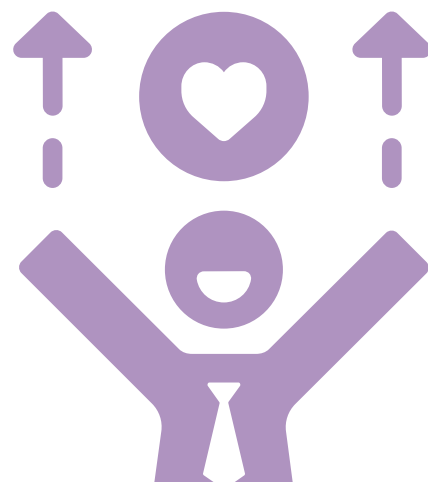
Outdoor theatre events were held in partnership with OPTUS at both Longford and Strahan. All overheads were donated or sponsored which in itself involved talking with many businesses in the areas involved. This works to engage the community as much as the events themselves. The events were well supported by the public as well as local service groups.



I was more involved with Epilepsy Awareness Month this year and helped create community awareness through lighting buildings purple, arranging Paint and Sip evenings and setting up the My Journey exhibition in the Hobart Town Hall. On the evening of Epilepsy Awareness Day, 26th March, we held a party in the Town Hall however a person unfortunately had a seizure which resulted in the evening finishing early. I also assisted as a guide through the gardens of Government House.



The playing field continues to change, and community engagement is challenging, however, as long as we keep our passion about the need to educate the community about epilepsy and its effect on the lives of so many, we will always find a way.



EDUCATION

by Emma and Shirl

In Tasmania's North

2021 has seen an increase in the provision of education and training sessions for schools, disability support workers, family, and carers with over 147 sessions provided. This training consists of the Understanding and Management of Epilepsy, Individualised Epilepsy Management training and Individualised training for the Administration of Emergency Medications.

We continue to engage with the community to develop awareness around our organisation and the services we can provide. This year we have had over 129 new referrals into our service.

We continue to promote the importance of individualised epilepsy management plans and have aided in the development and review of over 73 epilepsy management plans to ensure that they are a useful and beneficial document for both the person living with epilepsy and those providing support.

We continue to provide support to individuals living with epilepsy and those affected by and caring for people with epilepsy with over 1782 supports provided.

Emma, Education and Training Coordinator - Registered Nurse.

In Tasmania's South

- Education and training sessions have increased in our schools and disability sectors. There has also been more family meetings and training for awareness and understanding.
- From January 2021 to June 2021 we have had 101 new referrals.
- 584 support services were provided.
- Social media activity has increased in our Family Friends and Carers private Facebook group from 80 members in 2020, to 106 in 2021. There were 144 posts and 43 interactions.
- 104 Emergency Management Plans have been developed or updated, helping to prevent 50% of GP and Emergency Department epilepsy-related presentations.
- We were excited to hold our first-ever training session with a support worker and a seizure dog!

Shirley, Education and Training Coordinator - Social Worker.



EPILEPSY SMART SCHOOLS

by Liz

Some of our Training feedback...

"The training session was extremely helpful. I did not know much about epilepsy, so I found it really beneficial."

*

"The trainer was very knowledgeable of our participant's condition and how best to support her."

*

"The session was informative and I am now more confident in supporting a person with epilepsy."

*

"The presenter did a fantastic job! All support workers should do this training."

*

"Thank you so much for taking the time to help me understand Epilepsy/seizure. The training provided was very helpful."

*

"So glad to have completed the course. I few myths that I thought correct now rectified."

*

"Fabulous PD, easy to listen to and understand."



722 people
attended Smart
School training



76
Epilepsy
Smart Schools
so far!



1069
people attended
training sessions
statewide



by Wendy Groot, Epilepsy Australia President

Epilepsy Australia

Epilepsy Australia comprises the Epilepsy Foundation, Epilepsy Queensland, Epilepsy ACT, Epilepsy Tasmania, Epilepsy SA & NT and Epilepsy WA. Epilepsy Australia works as a collaborative community of practice.

The Epilepsy Australia network offers support across Australia and Member organisations are working together through the Federally funded Epilepsy Smart Australia program to deliver nationally consistent, evidence-based service delivery, that delivers better outcomes to people living with epilepsy no matter where they live.

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

2020-21 Highlights

All Epilepsy Australia organisations responded to the COVID-19 pandemic by quickly pivoting to virtual delivery of services. By working collaboratively, we have grown the volume and consistency of service offerings through the year.

Last year we reported on the virtual Walk for Epilepsy, with participants from ACT, Tasmania and Victoria. This year the walk went truly national with participants in every state and territory. The event raised significant awareness, funds, and received great media coverage.

The focus for EA members this year has been the Epilepsy Smart Australia initiative.

The Federal Government has provided funding for 4 years through the Epilepsy Foundation for the rollout of the Epilepsy Smart Australia program. We look forward to the ESAP delivering a greatly expanded, nationally consistent platform of services to people living with epilepsy.

The Epilepsy Foundation continues to derive value from its strategic alliance with the Epilepsy Foundation of America. This forms 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 continues. The Wave 5 survey was sent out to the 1,500 participants in the Australian Epilepsy Research Register. Please help build this register by directing your patients to epilepsyfoundation.org.au/research to find how to join the register.

Important News for Researchers

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

To date the following projects have been funded:

Improving first seizure assessment and management

Lead Researchers: Professor Terence O'Brien and Dr Emma Foster

Preparing Australia for precision medicine in the developmental and epileptic encephalopathies

Lead Researcher: Professor Ingrid Scheffer

Uncovering the hidden genetics of non-lesional focal epilepsy

Lead Researcher: Associate Professor Piero Perucca

A Clinical Liquid Biopsy to Diagnose Epilepsy

Lead Researcher: Associate Professor Michael Hildebrand

Phenotyping depression and anxiety in people with epilepsy

Lead Researcher: Dr Genevieve Rayner

SYNGAP-1 GENE PROJECT

Lead Researcher: Professor Steven Petrou

Reducing epileptic seizure frequency with transcranial direct current stimulation in patients with drug-resistant temporal lobe epilepsy: A placebo-controlled randomised trial

Lead Researcher: Dr. Maryam Zoghi

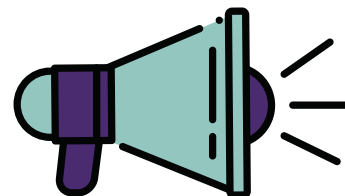
The next round. A further call for funding requests is expected within the next 12 months.

I finish in thanking the many specialists, and organisations who have supported the development of our epilepsy smart programs, and who have supported symposiums, family information days, webinars etc.

2021 STATISTICS



- 2 private Facebook groups are being moderated for Families, Friends and Carers and for 13-24-year-olds to encourage epilepsy-related content and discussion.
- 2,639 Facebook Followers on the Epilepsy Tasmania main page. Posts reached 127,173 people during 2020/21.



12 Awareness & Anti-Stigma campaigns reached over 417,232 Australians.



59 Tasmanians created teams to participate in the inaugural national Walk for Epilepsy event.



EPILEPSY TASMANIA'S WEBSITE

- 4 Seizure First-Aid posters are downloaded every week.
- 3 Emergency Management Plans and Seizure Event recorders are downloaded every week.
- 1 NDIS Epilepsy Support sheet is downloaded every week.
- 1 Driving with Epilepsy booklet is downloaded every week.



TV and Radio publicity reached 2,076,306 people.



1,449
Friends of Epilepsy Tasmania

Print and Online publicity reached 19,530,346 people.



11 issues of Brainwaves e-newsletter sent to 1,449 subscribers

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 Tasmania's epilepsy community.

epilepsy
tasmania

TASMANIA'S VOICE FOR EPILEPSY