

“Epilepsy Tasmania provides information, education and advocacy for people who are living with, or are affected by epilepsy.”

2013-2014 Annual Report

epilepsy
tasmania

September 2014



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About Epilepsy Tasmania

The Epilepsy Association of Tasmania was formed by a group of concerned parents in 1975 to provide support and information to all Tasmanians affected by epilepsy. The Association has worked for over 30 years to inform the people of Tasmania about epilepsy and appropriate care for people who experience seizures. Working with limited resources and supported by volunteers, the Association has always aimed to provide services of the highest quality.

Today Epilepsy Tasmania provides, support, advocacy, referral and accurate, concise information to people with epilepsy and promotes understanding of epilepsy through education programs and raising community awareness. We are working within a holistic framework to enhance the quality of life for people living with epilepsy, and to improve community awareness, understanding and acceptance. We work to raise awareness of epilepsy in organisations and the broader community to reduce the stigma and create a more welcoming and inclusive society.

Our Mission

Epilepsy Tasmania will be a sustainable organisation that is improving the quality of life and community participation for Tasmanians with and affected by epilepsy.

Staffing & Resources

Our services are provided across Tasmania and are coordinated from our head office in Launceston - now located at 30 Brisbane Street, Launceston.

We employ two part time Epilepsy Education and Training Coordinators, 1 in the North/North West and 1 in the South of TAS. Our Educators deliver services throughout Tasmania, together with an Executive Officer and an Administration Manager who are both employed on a part-time basis.

Epilepsy Tasmania is managed by a voluntary board which has a variety of skills and experience including but not limited to Education, Medicine, Governance, Banking, Marketing, Risk Management, Strategic Planning and Political networking.

Membership Profile

As at 30 June 2014 Epilepsy Tasmania has 40 financial members, which consists predominately of people who have or are affected by epilepsy. Membership numbers are down on the previous year and it is a focus of Epilepsy Tasmania to improve membership numbers, both for new and renewing members in order to create a growing, committed and involved database of members going forward.

The Presidents Report

Epilepsy Tasmania continues to benefit from assistance provided by the Department of Health and Human Services (DHHS), to the tune of approximately \$161,000 last financial year. The continuation of similar funding is guaranteed for the next two years.

Details of the Research Grants referred to in last year's Annual Report and funded from the Kathleen Grace Bequest were finalised by April 2014 and totalled \$337,500, having increased from the original bequest of \$265,000 in 2008. Most of it (\$267,500) was awarded to a research project headed by Professor Sam Berkovic of the University of Melbourne. The remaining \$70,000 was allocated to a research project led by Professor Wendyl d'Souza of St Vincent's Hospital, Melbourne. Payments to the projects will be staged over three years and both projects will provide us with regular financial and progress reports. Both projects will make use of the Tasmanian Epilepsy Register and use Tasmanians as their subjects.

Prof Berkovic's project is conducting research into the underlying genetic causes of Infantile Epileptic Encephalopathies (IEE). This severe condition frequently results in hospitalisation for uncontrolled seizures, adding significantly to the stress of families and the costs to the health system. A genetic diagnosis would mean that the underlying causes were known at an early age, and receiving the most appropriate treatments at that stage would lead to an improved quality of life. The project will be valuable for healthcare planning in Tasmania but the data it collects will also be of interest world-wide.

Prof d'Souza's project is for research into possible genetic causes of some forms of epilepsy (Idiopathic Generalised Epilepsy) which occur in children; it is hoped that this research will lead to an improved understanding of how best to treat the psychological and social difficulties experienced by people with these forms of epilepsy.

During the year the association was grateful to receive a bequest of almost \$100,000 from the estate of Paul McDermott.

Along with other states and territories involved with Epilepsy Australia and the Joint Epilepsy Council of Australia (JECA), we have been fortunate to be given free access to the high quality information materials developed by the Epilepsy Foundation of Victoria and generously made available to all state associations for nothing more than a nominal fee.

In many other ways this has been a year of significant change for the association:

- As a result of redevelopment work at St Giles in Newstead, Epilepsy Tasmania was asked to move three times within less than six months into rooms that were cramped. Combined with the fact that St Giles was unable to offer a guarantee of more appropriate accommodation in the long term, it was decided to move head office to a more permanent location at 30 Brisbane St, Launceston, as of early August 2014.
- The managerial experience of new Board members has led to the Board embarking on new initiatives designed both to tide us over what may well be tougher financial times and also to increase the public profile of Epilepsy Tasmania.

- Recognising that the continuation of the same levels of DHHS funding could not be assured into the future, the Board determined that there should be an increased emphasis on fund-raising so that the association would have the financial reserves to survive independently. It was also accepted that publicity surrounding the recently announced research grants would reflect well on Epilepsy Tasmania and that there should be an increased emphasis on raising funds specifically for research into epilepsy.
- In light of these decisions a new strategic plan was developed to incorporate these aims. It envisages the continuation of the Educators' work in providing information to the public and assisting with neurology clinics, but in addition it seeks to establish the association's financial independence via two funding initiatives. The first of these is the establishment of an Endowment Fund which will earn sufficient interest to cover a significant part of the association's running costs; the second is to establish a separate fund dedicated to supporting research projects related to epilepsy.
- It was recognised that such ambitious plans could not be achieved with a State Manager working only twenty hours per week, so the Board agreed to raise them to thirty. At that stage Helen Davis, who had been happy to work for twenty hours per week, announced that she did not wish to work for thirty hours per week and advised that she would be resigning. After more than a year of diligent and professional service to the association, Helen stood down in May. As of June 23rd, Phil Baker was appointed to replace Helen; he holds the title of Executive Officer.
- Shortly after Helen's resignation, Leanne Eastham also decided to seek a new career path and, after four years of sterling service to Epilepsy Tasmania, sometimes as Acting Manager, resigned from the position of Administrative Assistant. The new Administrative Assistant, since early July, is Rebecca Wylie.
- Because our previous State Educators contract expired in June, the Board used the opportunity to review the effectiveness of having just one Educator for the whole of the State. Given that the costs of travel, accommodation and time associated with driving from Launceston to Hobart and back each week totalled over \$10,000 per annum, it was decided that such a use of funds was not a practice that should be continued. Accordingly, it was agreed to advertise for two part-time Educators, one in the north and one in the south. When the positions were advertised, Freda did not reapply; as a result, two new Educators will be appointed in September.

I wish to acknowledge the excellent work done by Helen, Leanne and Freda in their respective roles and to wish all of them well in their future endeavours. I especially appreciate Freda's willingness to continue as State Educator until the end of July so as to ensure that there was no major break in the service offered to clients.

A new chapter now starts for Epilepsy Tasmania as we welcome Phil, Rebecca and the new Educators and look forward to working with them over the next few years. We anticipate that the appointment of two part-time regional Educators will be the first step towards the long-term goal of re-establishing a presence on the North-West Coast.

Finally, I wish to express my sincere thanks to all Board members: to Peter Button and Sharon Pendergast who were unexpectedly obliged to leave us during the year; to Kim Wilson and Kristine Wye, who have both reluctantly resigned from the Board recently due to increased work pressures, for their dedication and professionalism - we will sorely miss them both but wish them well and thank them for their years of service to the Board; and to Gustavo Bodini, Gary Morgan and Ian Sauer for their enthusiasm and vision.

Brian McNab
President

August 15th 2014

Executive Officers Report

As previously outlined in the President's Report, Epilepsy Tasmania is moving again towards a new structure and now coordinates state-wide operations from our new office base - 30 Brisbane Street, Launceston. The move was both busy and exhausting and as many of you may know packing and unpacking isn't the easiest task, however we are now settled into our 'new home' and invite you to visit us should you be in Launceston.

As the new Executive Officer I have many challenges ahead building on the work that has gone on before me and getting the organisation ready for the NDIS and working through the transition from one Government funding model to a new one under the National Disability Scheme. With new staff, a new office, a new strategic plan and new ideas for fundraising and with the development of new education and training tools also on the drawing board – our road ahead is both exciting and challenging. As always our income, comprising grants, memberships, donations and fees for service delivery will determine what level of resources we can apply to these tasks to achieve the best possible outcomes for our clients in the most cost effective manner.

I commenced work with Epilepsy Tasmania on 23 June this year and Rebecca our Administration Assistant commenced 2 weeks later. We envisage our two new Education and Training Coordinators will be on board by mid September and will commence their training in Melbourne under the guidance of the Epilepsy Foundation who is at the forefront of NDIS requirements. They are also trialling and developing best practice training and education models for the future that meet NDIS requirements.

Thankfully Emergency Management Plans, personalised support and assistance for members and their carers with epilepsy related issues continued to be provided through our counterparts in both Queensland and Victoria. We sincerely thank them for their time and valued assistance during the period we were without Education staff being available for our clients.

Over the coming weeks we will recommence regular education and training field representation in both Northern and Southern Tasmania West as our new Education and Training Coordinators begin to reconnect with all our clients and valued stakeholders.

Epilepsy Tasmania has continued to foster relationships with Epilepsy Associations around Australia and as a participating Board member at the National level of Epilepsy Australia we will continue to access the best resources available from other States and Territories to bring to Tasmania for the benefit of our clients.

Epilepsy Australia is our peak body with emphasis on the sharing of knowledge, appropriate resource tools and lobbying of government in areas of awareness and advocacy for epilepsy. Both Brian McNab and myself attended the Joint Epilepsy Council of Australia conference in Melbourne mid July and were warmly welcomed by all and were made well aware that the sharing of newly developed resources would greatly benefit our ability to deliver training and education products in an improved and cost effective manner.

Purple Day 2014 was held across the state with increased awareness of both epilepsy, and Epilepsy Tasmania with purple merchandise out on the streets and in public malls, and retailer/ business promotions. We would like to sincerely thank the following organisations who helped promote Epilepsy Awareness Month 2014.

Warrane Pharmacy
Devonport Super Clinic
Jessie Lee's - Kings Meadows
Glenda Lee, Lee's Coaches
Kathy Hoare - UTAS Student Centre, Launceston
New Town Primary School
Tasmania Fire Service – Launceston
St Giles – Launceston & Hobart
Springfield Gardens Primary School
C.L. Storer - Member
Helen Smith - Member
St Lukes Health – Launceston
Royal Hobart Hospital
Coventry Pharmacy – Latrobe
Foot & Playsted
Peak Computers
and last but not least - our ever growing number of
Epilepsy Tasmania Volunteers

To you all we say a BIG

THANK YOU

Together we can make Purple Day 2015 the best yet and with help again from our Members, Sponsors and Volunteer work force we can raise even more funds for the continuation and improvement of those services we offer. Our client centric business model and our excitement at being able to commission medical research has empowered us to strive for even greater goals and with our new team in place that is what we intend to do. Thank you.

Phil Baker

Executive Officer

Education and Training Coordinators Report

Fred Bjarnoe was our full time Educators for the state until July 2014. For the 2013-2014 year Freda worked hard to continue to support the following Neurologists in our public hospitals. Going forward our new Education and Training Coordinators will continue these relationships and grow them to support our members.

Burnie Hospital – Dr. Wendyl De Souza

LGH Hospital – Dr. Simon Bower

Royal Hobart Hospital – Dr. Dean Jones & Dr. Simon Harvey (Paediatrics)

Education –

Previously we have delivered education and training programs to a growing number of schools with a strong enquiry level continuing. Our programs cover Prep age through to High School with relevance to both students and staff. These activities are key to changing cultural attitudes and increasing community awareness.

We are conscious of the need to market ourselves in this area, and with employers emphasising the need for a duty of care towards children and /or employees.

We now have access to the new Accredited Training packages developed by Epilepsy Australia ACT and are authorised to deliver the only “accredited” Epilepsy training available in Australia at this time.

A key focus of our new Education and Training Coordinators will be education for all avenues mentions above and the growth of education into other sectors such as Aged Care.

Member Support –

Members are reminded that our Education and Training Coordinators are available to them for Epilepsy Management Plans (EP), Education, Advocacy and information services, it is expected our new staff will be up to date with these services in the near future. Should you wish to be informed of the availability of our Education and Training Coordinators services through email we do ask you as members to continue to maintain and monitor your current email address to ensure you receive our communications and latest news.

We also encourage all members to take up the option for an EMP; these will help our members integrate well within schools and work places and as a result of making people aware of the benefits and the safety needs for them.

Member benefits –

It is our aim to increase Membership benefits for the coming year including:

- Free Member drinks and nibbles “get together “ by region
- Free Member Lapel Pins
- Free Member certificates
- Free Medical Research Week Researcher Q&A Lectures/briefings
- Free Member Christmas get togethers
- Free Brain memory workshops
- Member meet the Board events
- Member Purple Day briefings

The Board for 2013 - 2014

The committee of management (Board) for Epilepsy Tasmania is responsible for the corporate governance of the organisation. They guide and monitor the business affairs on behalf of the members.

The committee are committed to demonstrating high standards of corporate governance, and to making the best decision for people who are living with epilepsy. The Associations Incorporation Act and the Epilepsy Association of Tasmania's Constitution govern the regulation of meetings and proceedings of the board.

The Committee traditionally will consist of president, vice president, treasurer, secretary and ordinary members. Each member elected commits to a two year term. All members donate their time and attend quarterly on Saturdays, with members travelling to the central location of Campbell Town (up to 2 hours travel time) for board meetings.

The relationship between the committee and the management team of staff of the organisation is important to the long term success of the work completed by Epilepsy Tasmania. The day to day operations, administration and client services, implementation of policy are delegated to the Executive Officer who attends the committee meetings to deliver reports and receive such delegations.

The Board 2013 - 2014 comprised:

President:	Brian McNab
Vice President:	Vacant
Secretary:	Kim Wilmot
Treasurer:	Kris Wye
Ordinary Members	Gustavo Bodini Gary Morgan Ian Sauer
Patron :	Kerry Finch MLC

Acknowledgements

We would like to take this opportunity to thank those who have supported the work of Epilepsy Tasmania during this past year through their financial, in kind or fundraising generosity. We also thank our donors, some of whom prefer to remain anonymous, for their support of Epilepsy Tasmania. This support is very much appreciated and contributes to the achievement of our goals.

The Hon. Kerry Finch MLC (Patron)

UCB Australia Pty Ltd

Foot & Playsted

St Giles Launceston & Hobart

Lees Coaches

Launceston Preparatory School

Tasmanian Government through DHHS

Southern Cross Television

The Examiner Newspaper

Epilepsy Australia

Epilepsy ACT

Epilepsy Foundation Vic.

Epilepsy QLD.

Epilepsy South Australia

Epilepsy Western Australia

Direct Design

Westpac

The Mercury Newspaper

