



EPILEPSY AUSTRALIA

The national coalition of state and territory epilepsy associations

ANNUAL REPORT 2008

Financial Report for the Year Ended 31 August 2008

Epilepsy Queensland
Epilepsy Association of the ACT
Epilepsy Association of South Australia and the Northern Territory
Epilepsy Foundation of Victoria
Epilepsy Association of Tasmania
Epilepsy Association of Western Australia

An Associate Member of the International Bureau for Epilepsy
And a Member of the

**JOINT EPILEPSY
COUNCIL OF AUSTRALIA**

Australian Chapter of the International Bureau for Epilepsy



DIRECTORS REPORT

LINDSAY VOWELS

President and Director



RUSSELL POLLARD

Executive Officer and Company Secretary



We share a common bottom line with the Joint Epilepsy Council of Australia . . . the development of an epilepsy movement based on principles of high trust, mutual respect, mutual obligation and mutual benefit with any governance being democratically shared in order to give effective voice to the issues raised by ALL Australians living with epilepsy.

Epilepsy Australia has continued to operate as the peak body recognized by the vast majority of state and territory epilepsy associations in Australia.

While The Joint Epilepsy Council of Australia [JECA] is the only member of the **International Bureau for Epilepsy [IBE]** in Australia [they only have one member in all but a few founding countries], like a number of other epilepsy groups in Australia we have become an Associate Member of the IBE.

The truth is, much of the work we do is of a similar nature to that of JECA but more as an accident of the history of the Australian epilepsy movement than anything else. We were unable to find an agreed structure that the IBE would recognise until we came up with the notion of the Joint Epilepsy Council.

The major distinction between the two organizations is that while JECA's directors are the chief executives of Australia's state and territory epilepsy associations, the directors of Epilepsy Australia are, for the best part, selected from the Management Committees of each of the state and territory associations.

This of course befits a community organization such as Epilepsy Australia but we have always welcomed chief executives and other senior staff such as services managers and fundraisers to our meetings.

We have always tried to work to maximise opportunities rather than to limit them in any way around one particular group's ideas of what should be done. This about finding what is often called the highest common multiple factor rather than the lowest common denominator.

It does not mean that everything that is thought of get attended to. Sometimes it makes no sense to pursue particular ideas when other important ideas are more able to be brought to fruition. This is a critical area for us all to think about.

We all know only too well that there are many unmet needs for people living with epilepsy. So many issues to deal with and it would seem so few people to get the work done. Issues about risk taking might seem important to some people but for a person who faces the unnerving unpredictability of when they might next have a seizure, the idea of risk management is very real. It covers everything from getting out of bed, leaving the house, crossing the road, driving a car ... and so many other things that impact

on a person's ability simply to take part in life as a parent, a partner, a student, a sports participant and so on.

Issues that are identified by people working in a field such as epilepsy, or by people who sit on Boards and Management Committees, are not always those raised as important by people living with epilepsy.

Think about having your licence removed from you. While you're thinking about it, imagine you live in the country and there is no public transport available to you. Imagine that as a part of how you support your family you operate machinery – a tractor or a hay baler.

Imagine your social network depends on your participation in a sport like football or bowls or netball in the country town where you grew up. Imagine that the club committee decided they cannot let you play unless you guarantee that you are free from seizures.

We're reporting these issues because they are the issues that have been reported to us through important work done by one of our members, the Epilepsy Foundation of Victoria, when it decided to partner the Chronic Illness Alliance to gather evidence, real evidence, from people living with seizures.

And so we have been delighted with the work of JECA as it has worked to establish the Parliamentary Friends of Epilepsy. Many of our Board attended the launch in Parliament House and we were thrilled to hear the Labor Co-convenor and Member for Shortland announcing the idea of holding inquiries, much like senate committee inquiries, and asking people living with epilepsy to present the realities they face in their day to day lives.

And so in Adelaide last year, Epilepsy Australia joined JECA. We are keen to lend it support. We are keen that it be given every chance to succeed.

Why would we not want it to succeed. If it eventually eclipses us it will be because it has continued to manage to raise the voice of the epilepsy movement. But we see even greater possibilities. We see the possibility of having a closer relationship and we are prepared to explore it with the Council.

The thing we bring is a broader based idea of community governance. We are not confused by nor worried about having many voices – so long as they are mutually respectful and not engaged in internecine competition at the expense of each other.

We've said it before many times, and we'll say it again. We need the support of everyone who can give it to us. The last thing we need to spend time on is defending our right to do what we do to the best of our abilities ... with real success!

There is much to gain from listening to each other and working together. But for this to happen we must ensure that the structures we work with foster mutual respect, mutual obligation and mutual benefit.

One of the things we are keen to look at is how we can expand our financial base without causing the financial bases of the state and territory associations to lose donors or support.

One of the key activities in which we have engaged has been to speak with all state Health Ministers and to gain their support for putting epilepsy on the agenda for the State and Commonwealth Health Ministers Forum. To a person they have agreed to follow through with this and we will brief them during the year ahead on how their support might make a real difference.

At the moment the Victorian Government leads the way in terms of the support it gives to people living with epilepsy. In fact the EFV receive almost a million dollars annually from the state government – a grant that is not matched elsewhere in Australia. Like it or not, state funding is the current reality in health and disability funding and in community services funding generally.

In the hard and uncertain financial times ahead we have to make sure that the case we make for funding reflects a great value for each dollar spent. The EFV returns over \$9 in value for each dollar received from their state government – they raise almost another 4 million dollars through their own efforts and they gain volunteer services of hundreds of Victorians on a regular basis. All of this is a bonus for government and for people living with epilepsy.

The work therefore that the Joint Epilepsy Council of Australia is doing with the Federal Parliamentarians needs to run in parallel to the work we do with the state and territory governments. Saying that the federal system is not an ideal one when it comes to health, is an argument that is often heard.

There is however a great deal to commend federation. There is a great deal to commend having decision made nearer rather than further away from the people who are affected by them. Nonetheless, whatever the rights and wrongs of the system we have, we are pleased to report that in conjunction with the JECA we seem to be gaining traction. We are actually making progress.

Epilepsy Australia continues to set goals that relate particularly to improving service delivery and the resources available to those who are involved in that delivery.

We are proud of ***The Epilepsy Report***, a truly ground breaking magazine that is subscribed around the world and which is sent to all federal Members of Parliament and to the MP's in each of our affiliate state and territories.

The Epilepsy Report is edited by Denise Chapman who is employed by the Epilepsy Foundation of Victoria. However it receives articles from around the country. Its editorial panel includes national executive officer Russell Pollard, IBE Editor's Network Chair and South Australian & Northern Territory Association chief executive Robert Cole, Health lawyer Fiona Tito Wheatland from the ACT, and former ESA President and currently Director of the Australian Epilepsy Pregnancy Registry Professor Frank Vajda.

Regular contributors include Dr Christine Walker, CEO of the Chronic Illness Alliance, Dr Michelle Bellon from Flinders University, Dr Jaya Pinikahana, Mark Francis and Robert J. Mittan. It features reports on applied social research, and on just about every aspect of living with and managing epilepsy. It is subscribed to in 11 different countries and is used as a vehicle for communicating with all Federal members of Parliament and with parliamentarians in JECA states.

Our new epilepsyaustralia.net website is also something of which we are justifiably proud. Check it out and you may be surprised at the amount of activity that is occurring throughout the Australian epilepsy movement.

Three years ago we worked in partnership with Epilepsy Bereaved from the United Kingdom to canvass views about Sudden Unexpected Death in Epilepsy [SUDEP] from around the world – from neurologists, from families and friends, from lawyers and from people working with families living with epilepsy. Contributions came from as far away as Canada, Chile, China, Cuba, Germany, Greece, India, Ireland, Kenya, Niger, Pakistan, Romania, the United Kingdom, and the United States of America.

Not only was this initiative the first such attempt to have a truly global conversation open to all people who have something to say, it was, on any measure, a resounding success. Indeed one of the editors, Denise Chapman, has just returned from London where she addressed the 2008 Annual General meeting of Epilepsy Bereaved.

This was unimaginable as little as 10 years ago. We have come a long way, and while we still have a long way to go, we are on the right track.

If we are to seek the support of our national leaders we need to be able to tell them what is happening elsewhere

with the authority that comes from actually working with our IBE colleagues.

We are working with JECA to produce a range of briefing papers for Parliamentarians and anyone else who might find them useful. We have commissioned one on Sudden Unexpected Death in Epilepsy and we are completing one on generic medications.

We do not yet have a loud voice in Canberra, nor indeed in our state and territory homes, but we can ensure that our voice is a clear one. It has taken a lot longer than it otherwise needed to because of active opposition that has been put our way in years past. Let's hope that all that is a thing of the past and that sooner rather than later, those few people who are not convinced of the benefits of working together cooperatively and of abiding by principles of mutual respect, obligation and benefit, will realize that they have everything to gain by supporting our collective efforts.

We've said it before many times, and we'll say it again. We need the support of everyone who can give it to us. The last thing we need to spend time on is defending our right to do what we do to the best of our abilities ... with real success!

We have no issue with other groups working to support people living with epilepsy. What we do take issue with is the rhetoric that there is no effective national epilepsy consumer body, or that we do not deserve your support, or that they represent a national constituency simply because they say so.

Epilepsy Australia has come a long way.

Our development of nationally accredited training materials for people undertaking Certificate III and Certificate IV modules of training in the disability and carer areas of human services, has been an important milestone which are keen to expand further.

We are also keen to promote greater accountability in terms of professional certification and supervision of our counselors. This is no easy task but it is one we have been slowly addressing for several years and about which we have published a number of articles.

Our aim is to impact positively on the work of our state and territory affiliates. It is our role to help them all build capacity to meet the many challenges that they face every day and that people living with epilepsy face every day.

MEETING ATTENDANCE

[including teleconference meetings and face to face meetings] for 2007-2008

Director	Organisation	% of 10 Meetings Attended
Lindsay Vowels [President]	Epilepsy Foundation of Victoria	70% + proxy 30%
Jan Taylor [Vice-President]	Epilepsy Queensland	50% + proxy 50%
Richard Eccles	Epilepsy association of the Australian Capital Territory	40% + proxy 60%
Michelle Bellon	Epilepsy Association of South Australia [trading during the period as Epilepsy Association of South Australia and the Northern Territory]	90% + proxy 10%
Robert Cole	Epilepsy Association of South Australia [trading during the period as Epilepsy Association of South Australia and the Northern Territory]	100%
Glen Renes	Epilepsy Association of Tasmania	60% + proxy 40%
David Sharpe	Epilepsy Association of Western Australia	50% + proxy 50%

Other people attending meetings have regularly included non-Board members: Russell Pollard [Executive Officer and Company Secretary], Kay Elphinston, Jacinta Cummins, and Helen Whitehead.

The **Annual General Meeting** is held by proxy towards the end of the calendar year. Meetings are usually held by teleconference but where possible we meet in person at least once a year. A great deal of discussion also occurs among the Directors and their colleagues as they engage with one another on the tasks at hand.

All the indications are good. While we are far from complacent, we have been heartened by the enormous support we have received from all parts of the epilepsy movement, both nationally and internationally. We have a role to play and it is no doubt a role that will be refined as the organisation grows and cements its relationships and partnerships.

All that remains is for us to congratulate the Joint Epilepsy Council of Australia, to congratulate all the state and territory epilepsy associations for continuing to do outstanding work under what are often difficult circumstances, made more difficult at times than they need be, and to thank everyone who has worked to keep faith with the vision of an organisation based on principles of high trust, mutual respect, mutual obligation and mutual benefit, where governance is shared by all directors who are committed to giving voice to issues raised by Australians living with epilepsy.

Epilepsy Australia Ltd

818-822 Burke Road
Camberwell VIC 3124

Profit & Loss [With Year to Date]

July 2008 through August 2008

	Selected Period	% of Sales	Year to Date	% of YTD Sales
Income				
Donations	\$210.00	39.5%	\$3,463.10	20.6%
Ritches Stores	\$57.02	10.7%	\$1,642.00	9.8%
Activities Income	\$0.00	0.0%	\$11,252.25	66.9%
Talks income	\$264.00	49.7%	\$264.00	1.6%
Miscellaneous Income	\$0.00	0.0%	\$210.45	1.3%
Total Income	\$531.02	100.0%	\$16,831.80	100.0%
Cost of Sales				
Gross Profit	\$531.02	100.0%	\$16,831.80	100.0%
Expenses				
Dues & Subscriptions	\$33.00	6.2%	\$401.00	2.4%
Conference Fees	\$1,384.00	260.6%	\$1,384.00	8.2%
Friends of Parliament	\$802.91	151.2%	\$802.91	4.8%
Legal & Accounting	\$0.00	0.0%	\$3,245.00	19.3%
Employment Expenses				
Printing	\$362.70	68.3%	\$4,823.20	28.7%
Government Fees	\$145.00	27.3%	\$415.00	2.5%
Web Hosting	\$247.50	46.6%	\$247.50	1.5%
Web Development	\$0.00	0.0%	\$3,850.00	22.9%
Domain Name registrations	\$0.00	0.0%	\$207.90	1.2%
Advertising	\$2,460.50	463.4%	\$7,102.00	42.2%
Meals etc	\$353.10	66.5%	\$353.10	2.1%
Travel - Fares	\$0.00	0.0%	\$240.59	1.4%
Conference Attendance Reimburs	\$828.81	156.1%	\$10,828.81	64.3%
Bank Charges	\$13.00	2.4%	\$78.00	0.5%
Total Expenses	\$6,630.52	1,248.6%	\$33,979.01	201.9%
Operating Profit	-\$6,099.50	(1,148.6%)	-\$17,147.21	(101.9%)
Other Income				
Interest Income	\$0.00	0.0%	\$112.73	0.7%
Interest Received Trust Compan	\$0.00	0.0%	\$2,113.11	12.6%
Total Other Income	\$0.00	0.0%	\$2,225.84	13.2%
Other Expenses				
Net Surplus / (Deficit)	-\$6,099.50	(1,148.6%)	-\$14,921.37	(88.6%)

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Balance Sheet

As of August 2008

Assets	
Current Assets	
Cash On Hand	
Cheque Account	\$579.54
Epilepsy Aust Donation Fund	\$10,090.66
Total Cash On Hand	<u>\$10,670.20</u>
Deposits paid	\$770.00
Investments	
Trust Company of Australia	\$57,347.22
Total Investments	<u>\$57,347.22</u>
Total Current Assets	<u>\$68,787.42</u>
Property & Equipment	
Furniture & Fixtures	
Furniture & Fixtures at Cost	\$2,341.00
Furniture & Fixtures Accum Dep	-\$39.00
Total Furniture & Fixtures	<u>\$2,302.00</u>
Total Property & Equipment	<u>\$2,302.00</u>
Total Assets	<u>\$71,089.42</u>
Liabilities	
Current Liabilities	
Trade Creditors	\$2,460.50
Total Current Liabilities	<u>\$2,460.50</u>
Total Liabilities	<u>\$2,460.50</u>
Net Assets	<u>\$68,628.92</u>
Equity	
Retained Earnings	\$83,550.29
Current Year Surplus/Deficit	-\$14,921.37
Total Equity	<u>\$68,628.92</u>