JECA welcomes the Parliamentary Friends of Epilepsy Group

Jim Chambliss
Sparks of Creativity
the influence of epilepsy in art

Allison Clarke
the impact of epilepsy on young people

Michael Kendrick
on designing services for people

New website for Epilepsy Australia
www.epilepsyaustralia.net

Martin Raffaele
mastering epilepsy

EFV’s world first!
research participant register
WELCOME

The exciting development in this issue is the formation of the Parliamentary Friends of Epilepsy Group, to be convened by Jill Hall MHR. The Group will be launched in Canberra on the 28th May.

The Joint Epilepsy Council of Australia (JECA) lead by Jacinta Cummins and Russell Pollard spent many months lobbying Members of Parliament to gain support for JECA’s submission to government titled: A National Strategy for Epilepsy. Coming from a background in disability and rehabilitation, Jill Hall, the Member for Shortland in NSW, knew very well the many disadvantages people with epilepsy experience, and with a record for advocating for fairness and justice, put JECA’s concerns on notice to the House.

With bipartisan support, the debate took place on the 17th March, with each speaker commending Jill’s motion to the House. Extracts from their speeches can be read on pages 6 and 7.

Seizures force many to turn their lives around and rechart their future course. Martin Raffaele had to do just that. In redefining himself, epilepsy is now the focus of his life as he seeks way to help others.

A theme running through this issue is about ‘making a difference’ and whether it occurs in the halls of power or in those communities living in rural or remote areas of Australia, whether it is working in research laboratories or as a volunteer at outdoor adventure camps, or investigating the social impact epilepsy has on young people, you will read about those who believe making a difference is possible.

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Editor
Denise Chapman
Epilepsy Australia recently launched its new website with the national helpline number 1300 852 853 prominently displayed on every page. Getting help when you need it from your state or territory Epilepsy Australia affiliate is now at your fingertips. The design is clean and bright and the home page is very user-friendly. The **What's new** box on the right hand side is our way of alerting you that something new has been added to the site. So each time you visit, don’t forget to check out **What's new** it will keep you up-to date with all the latest news.

The Epilepsy Report, published by Epilepsy Australia, is freely available to all who subscribe to our mailing list. Just click on the subscribe button, email your details and you can look forward to receiving future copies of The Epilepsy Report.

Navigating the Epilepsy Australia website is very easy. By clicking on the tabs on the left hand side of the page, you can access a range of information about Epilepsy Australia, its member organizations, up-to-date information about epilepsy and its management including answers to the questions so frequently asked of our counsellors, and how volunteering can help your state or territory epilepsy association assist those who access our services.

**Epilepsy Information** is located in four clearly identified sub-sections: **Epilepsy Explained, Treatment, Epilepsy and risk, and Epilepsy and lifestyle**. Written in plain English, information, where appropriate, is presented in a question and answer format, while the more complex issues of seizure types, antiepileptic medications and their management demand a more detailed explanation.

**Seizure First Aid** is clearly described for the most common seizure types and visitors can download an A4 seizure first aid poster for home, workplace or school. The poster can also be downloaded from the home page.

Downloadable Epilepsy Action Plans and Epilepsy Management Plans can be found in the Epilepsy Information section **Epilepsy and risk** should you need to provide a plan for respite care, your workplace, school or pre-school. Instructions for completing these plans are straightforward. In complex cases, the plan is often completed and authorised by the treating doctor.

Workplace training in epilepsy first aid and management is provided by all Epilepsy Australia affiliates. Just click on **Epilepsy Training** and you can arrange a training session for your organization by emailing the contact listed in your state or territory. Community and professional training programs are offered as well as the accredited module “Skills in Epilepsy Care & Management” (National competency unit Assess & Deliver Services to Clients with Complex Needs CHCCS6B) taken from the Community Services Training Packages that includes courses such as Certificate III and IV in Disability Work and Certificate IV in Aged Care Work.

**Publications** brings up a list of printed and recorded community resources and includes an image of the publication, dvd or resource kit, a summary of the content, the targeted audience, whether it is a free resource or for sale, and who to contact should you wish to acquire it. A collection of interesting epilepsy articles from past issues of The Epilepsy Report is also available for review.

Published social research can be found under **Current Issues**, while **Upcoming Events** provides a calendar of the many special interest epilepsy information sessions, community programs, fundraising events, camps and social events happening around the country.

If you are studying or engaged in research or seeking more specialized information about epilepsy for personal reasons, a visit to the **Library** is a must.

The Epilepsy Foundation of Victoria maintains the largest epilepsy-specific collection in the southern hemisphere. The collection can be viewed by clicking on the embedded link. Requests to the librarian can be emailed directly from the page, although if you want to borrow from the library, membership of the EFV is required. Should you wish to join the EFV and avail yourself of the many benefits membership brings, click on the link to download a membership form, complete it and forward to the Foundation by fax or mail.

The **Australian Pregnancy Register** is a voluntary Australian-wide registry of patients who become pregnant while taking an antiepileptic drug. This registry follows, in large numbers, women throughout their pregnancy and helps to determine the real factors for this increased risk in birth abnormalities. Internationally respected neuropharmacologist Prof Frank Vajda is Director and Principal Investigator of the Australian Pregnancy Register.

Epilepsy Australia has placed this link to the Register in order to raise awareness in those who visit our site of the issues women with epilepsy face when deciding to start a family, to encourage those women with epilepsy who may be pregnant to register, and as our ongoing commitment to support and promote this most important study.

The above is an overview of the content available. A quick review of the site will find the information quite comprehensive, in many instances providing links to relevant articles for further reading. We invite you to visit us at [www.epilepsyaustralia.net](http://www.epilepsyaustralia.net)

Epilepsy Australia would like to publicly thank the Sydney-based web developers *Isilla*, especially Chris Johnson and Mark Davies, for their generosity in offering all their incredible creative skills pro-bono. We are forever grateful for their sponsorship.
On the 17th March 2008, Jill Hall, Member for Shortland, on behalf of the Joint Epilepsy Council of Australia, called upon the Australian Parliament to accept the challenge to take steps to make lasting changes to the lives of people with epilepsy and their carers.

Ms Hall reminded the House that while the recent mental health initiatives are a good example of what governments can achieve, there has been a failure to address many of the issues facing people with epilepsy.

Referring to the World Health Organization’s Global Campaign that identified epilepsy as arguably the most misunderstood, most stigmatised and most under-resourced health condition in the world today with an estimated 60 million plus people with epilepsy in the world, Ms Hall went on to say that “While Australia has a great deal to be proud about in its medical treatment of people with epilepsy, there are many for whom current medical treatments are woefully inadequate. At any one time around 200,000 Australian citizens have epilepsy. As many as 10 per cent of those have poor control of their seizures and for a smaller percentage there is so little control that life is almost unbearable for them and for those who love and care for them. I have experienced this at a personal level.

“My sister-in-law has suffered from uncontrollable epilepsy since she was 10 years of age, and I know the impact that it has had on her and her family’s lives.”

Drawing from the submission A National Strategy for Epilepsy prepared by JECA for government, Ms Hall further informed the House: “The JECA has asked that a national epilepsy working group be established and resource to oversee a national public education program, in tandem with an applied social research program to ensure that the right messages are being targeted to the right people, and to develop strategies to address many of the issues faced by people with epilepsy based upon credible, rigorous applied social research.

“Areas requiring urgent attention include looking at the impact of epilepsy in Aboriginal and Torres Strait Islander communities; developing a better formed and more workable national response to the transport and driving difficulties faced by people living with epilepsy; ensuring appropriate, timely diagnosis and assessment is possible for all Australians who experience seizures, not just those living in selected capital cities; and making it possible for people whose seizures are totally uncontrollable to access longer term, up to nine months, reassessment and treatment centres. The critical role of trained epilepsy counsellors working throughout Australia with state and territory epilepsy associations needs to be recognized and given consistent support by the states, led by the Commonwealth.

“We need to listen to expert groups such as the Epilepsy Society of Australia and the American Academy put an immediate end to prescribing and dispensing practices that are high risk to people with epilepsy.

“The Joint Epilepsy Council has asked the parliament to form a Parliamentary Friends of Epilepsy Group. I am pleased to advise that this will take place. In conjunction with Senator Humphries, I will convene this group. We hope to launch it on 27 May* this year. I hope that those people who are speaking in the debate will become members of this group because I believe it is a way by which we can make real changes. We will work to ensure that people living with epilepsy are able to be included in the mainstream life of Australia and, as the World Health Organization global campaign puts it, come out of the shadows.”

The bipartisan debate in the House continued with Members for Fisher, Parkes, Blair, Forrest and Dobell, each commending the motion to the House. (Ref: Hansard, 17 March 2008).
For JECA, the 17th March 2008 will be remembered as a watershed for the Australian Epilepsy movement.

However, it is the fruit borne of some very hard labour.

The JECA submission was the first agreed submission to the Federal Government from the epilepsy movement in the last 20 years.

In the 1980’s the former National Epilepsy Association of Australia [NEAA] and the ESA engaged with the Federal Government to move towards the development of epilepsy centres able to comprehensively support the proper diagnosis and treatment of refractory epilepsy. A government report was even published but in the absence of sufficient support among the political decision makers of the day, the enterprise floundered.

We are determined this time around that we will have the political groundwork in place. Almost three years ago the CEOS of all of Australia’s epilepsy associations decided that, whatever our differences, we could not wait any longer to get on with this essential groundwork. Both Epilepsy Australia and Epilepsy Action, the two national organizations that function as service deliverers, agreed for JECA to take the running in this. It was argued that a unified approach to the federal government was the only approach that stood any chance of working. While it was seen as something we all had to be getting on with, it was also seen as an opportunity to help us continue to work together, to build much needed dialogue, on truly significant policy development issues.

In lobbying for the submission A National Strategy for Epilepsy JECA Board Members met with, corresponded with, lobbied federal and state parliamentarians. In particular, JECA Chairman Jacinta Cummins, and Secretary Russell Pollard, met with many politicians in Canberra and with their senior advisors – including the senior policy advisors to the Prime Minister and the Health Minister in the Prime Minister’s Office.

Through this work JECA gained the very supportive attention of a great many Members of Parliament and was able to discern a good deal more than we previously knew about who has particular interests in epilepsy and why.

Both Jacinta and Russell were co-sponsored for lobbyist passes by Annette Ellis [Labor MHR for Canberra] and Petro Georgiou [Liberal MHR for Kooyong] and put forward by Jill Hall. Jill Hall went as far as putting our expressed concerns on the The Parliament of the Commonwealth of Australia Parliamentary Notice Paper, and together with the leader of the Health and Aging Committee in the Senate [Senator Gary Humphries, Liberal, ACT] Ms Hall has taken the lead in forming a Parliamentary Friends of Epilepsy group.

The purpose of this Parliamentary Friends Group is to meet with us on a regular basis in order to advance the epilepsy cause based around our earlier agreed Pre-budget Submission to Parliament. We have given them our agreed outline of what we are after which followed several years of discussion and negotiation.

We have asked for
• A public awareness campaign run in parallel with a national survey conducted with credible research methodology.
• A number of major research projects each looking at practical outcomes around vexed issues facing Australians living with epilepsy.
• The removal of generic substation practices in the prescription and distribution of anticonvulsant medications.

To achieve this we have asked that a national working party be established with JECA a key advisory body.

* The launch date is now the 28th May 2008.
PRIVATE MEMBERS’ BUSINESS – Epilepsy

Debate resumed, on motion by Mr Hall:

That the House:

(1) recognises that epilepsy is the most common serious brain disorder and is the most universal of all medical disorders;

(2) acknowledges that 200,000 people live with epilepsy at any one time in Australia and that up to three times as many Australians will have epilepsy at some time in their lives;

(3) that people living with epilepsy are disadvantaged by lack of research into the disorder and by the lack of a national plan for epilepsy or deeming it a disorder that is a national priority;

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(4) acknowledges the impact that epilepsy has on the lives of people living with it;

(5) calls on the Australian Government to fund greater research into epilepsy; and

(6) calls on the Australian Government to establish a nationwide educational strategy on epilepsy modelled on the World Health Organisation’s global campaign.

Mr CRAIG THOMSON (Dobell)

I rise tonight to speak in support of the motion brought to the House by the member for Shortland… and I thank the member for Shortland for once again bringing a motion to the House that advocates fairness and justice…

There are many burdens placed on the men and women of Australia who live with epilepsy. The Joint Epilepsy Council lists some of the problems as: a lack of acceptance by people in many sporting clubs and other significant social activities; reduced opportunities for education; difficulties gaining employment and sometimes in keeping it; a host of safety concerns, both in the home and in the community; having to learn how to deal with rejection by peer groups, exclusion, marginalisation and loneliness; living with the fear of never really knowing when the next seizure event will take place or how bad it will be; being unable to drive unless you have fully controlled seizures for mandatory periods of time; knowing that most people are afraid of seizures when they see them happening and are ill prepared to deal with them.

The new government, the Rudd government, has a vision for a more inclusive Australia… reducing disadvantage is now both a moral and economic imperative for Australia. As people who suffer from epilepsy have reduced opportunities for education, difficulties in gaining employment and increased difficulty in retaining employment, it is essential that our government look to fund greater research into epilepsy.

… This is an opportunity for the government to bring in policies of compassion that will make our community and our economy stronger. The Joint Epilepsy Council of Australia, … has asked parliament to work with it to develop a national strategy for epilepsy. A national epilepsy working party should be established—and the member for Shortland has already spoken on that. It would include representation from the Joint Epilepsy Council of Australia, which could act as a key advisory body. … Research reports that were sent to members of the last parliament by the Joint Epilepsy Council of Australia demonstrated how important it is to look beneath the surface when investigating issues like stigma, isolation, depression and any of the other burdens associated with epilepsy. Why does one football club allow a player with epilepsy to participate in the team when in another town a player with epilepsy may be left out of the team—and to all intents and purposes out of the life of his peer group? Why do people who have seizures take the risks they do? Why do they keep standing up, going out in public, driving to the supermarket, taking part in sport, attempting to study and all the rest of it, when a seizure could put an end to what they are doing with unexpected and unpredictable ferocity? What are the relative risks for people living with epilepsy compared to those for people with other health conditions?

Social inclusion is at the very heart of this government. The motion moved by the member for Shortland is congruent with the values and spirit of social inclusion. I commend this motion to the House.

Mr NEUMANN (Blair)

…In my family we have had our own experience. In Maryborough on 26 December 1990, my eldest daughter, Alex, had seizures. After fitting for some time she lay motionless in my arms, lifeless as I took her to the Maryborough Base Hospital. She was hospitalised for many days. My wife was pregnant with our second daughter. I did the night shifts and Carolyn, my wife, did the day shifts. Subsequently, Alex had further seizures in Ipswich, our home town, and was hospitalised yet again. I worked out then that medical diagnosis was problematic, confused and often difficult.

Alex was put on Epilim and she was on it for a long time. Her prognosis was uncertain, and we lived with the memory and with fear and anxiety about what might happen in the future. Fortunately… Alex has become seizure free and she no longer requires medication. She is now a very happy, healthy and opinionated young woman nearly 19 years of age. But… I will not forget it as long as I live… I can barely imagine what life must be like for those parents and children who suffer and for sufferers generally…

We must help. We must do more. We must lift the veil of ignorance. We must fund more research. We must engage in education programs to improve community awareness. We must encourage philanthropic donations and support families and individuals better with confidence-building assistance and practical help. … I urge the federal government to heed the voice of the Joint Epilepsy Council of Australia… I call on the government to place a greater emphasis on dealing with this very important issue accordingly.
Mr COULTON (Parkes)
I rise tonight to speak in support of this motion as I believe that greater research into epilepsy should be a priority for the federal government. ... Epilepsy sufferers usually rely on regular medication to help control their illness. Other treatments include controlled diets, alternative therapies and in some cases surgery. These treatments are not only costly but can have a big impact on the lifestyles of epilepsy sufferers. Other lifestyle issues associated with epilepsy can include the loss of a drivers licence, the effect that the disease can have on relationships and the effect that it can have on finding and maintaining a job. Dealing with epilepsy can also be that much harder for those living in rural areas such as my electorate. In country areas, it becomes much harder to access medical services. The lack of public transport makes it a lot more difficult for those epilepsy sufferers who can no longer drive. Also, a lack of support groups in rural areas can make it very much harder to cope. As an MP representing a large rural electorate, I support this motion, as it addresses some of the major issues faced by epilepsy sufferers within my electorate of Parkes.

... My first personal experience with epilepsy came as schoolboy footballer. One of the players in my team had a seizure in the middle of a game. He was the biggest, strongest, toughest and meanest player we had, and the seizure rendered him completely defenceless. At that stage I realised how absolutely debilitating this disease could be. It also frightened me and, I suspect, my team mates as well, because we did not know what to do.

We did not know how to help him. There was talk—'Be careful that he doesn't swallow his tongue,' and other such things that I now believe may or may not happen. But it was a great shock and a wake-up call to us about how prevalent this disease was in society.

From my personal experience, I fully support the motion that the Australian government establish a nationwide educational strategy. People need to understand what epilepsy is and how to deal with the situation if someone you know has a seizure. An educational campaign would also go a long way in addressing some of the social stigma attached to the disease. In conclusion, I would like to put on record my support for this motion and I urge the Labor government to seriously consider the items that are being proposed.

Mr SLIPPER (Fisher)
... this is a disease that really needs more research... we, as a country, simply have not done enough to improve our community store of knowledge of this insidious disease... have not spent the money... to ensure that research is undertaken... to both find a cure for this disease and make sure that those living with this disease are able to do so in the best possible manner.

... the unease such people carry as a result of not knowing when or where an episode could occur is clearly a matter that must be a constant worry... those who have been unable to manage satisfactorily their condition have been forced to give up pursuits such as swimming or driving a car, which of course puts further demands on their loved ones.

... were a seizure to occur in the workplace... even though the person concerned could well have the same capacity as anyone else to carry out a particular role, if there were a collapse at work, particularly a dramatic collapse, that would work to their disadvantage... loss of job opportunity and prospects... loss of promotion... loss of job.

... There is a group of people who suffer from epilepsy in their families and who do warrant, in my view, additional research to make sure that we are able to get more positive outcomes to let those living with epilepsy have a very much higher quality of life.

Ms MARINO (Forrest)
I rise to speak on the motion moved by the member for Shortland.

... the Australian government, through the National Health and Medical Research Council, provided $8.3 million in funding. Professor Peter Gage... from Canberra’s Australian National University received $400,000 to undertake research... to better understand the function of anti-epileptic drugs, anaesthetics and tranquillisers, which act by modulating specific protein receptors in the brain. ... if the properties and actions of anaesthetics, tranquillisers and anti-epileptic drugs are better understood, it is possible that new, more selective drugs could be discovered.

... Anybody who has lived with, worked with or been affected by those who have epilepsy could only support a greater level of funding for all forms of research and for that which assists people to integrate with their local communities and families.
The impact of epilepsy on the wellbeing of young people

Background

It has been estimated that there are 100,000 Australians with epilepsy and that 20,888 of these are aged between 12 and 24 years [1, 2]. However it is not possible to be definite given that epilepsy is not a notifiable condition and at least some Australians with epilepsy prefer to conceal their condition for fear of stigma and to avoid driving restrictions [3, 4].

Many young people with epilepsy experience some difficulty in the developmental transition from childhood to adulthood. It is a period dominated by “firsts”, the first time for being out of the direct control of parents, the first time for living away from home, the first time for forming sexual relationships, and the first time transitioning from school to work. All of these critical transitions can be made more difficult as a result of epilepsy and its treatment. Young people who have epilepsy often find that their epilepsy becomes more unstable due to difficulties in balancing anticonvulsant medication in the context of puberty, including hormonal and weight changes [5, 6]. Moreover, epilepsy may impede their opportunities for social interaction. It can interfere with school attendance and involvement in recreational activities such as swimming and team sports due to seizures or safety concerns. It can also affect participation in social events as a result of limitations on the quantity of alcohol that can be safely consumed. Young people with epilepsy may also have difficulties gaining and maintaining a driving licence [7].

Aim of this research

The aim of my doctoral research was to develop a model that identified which demographic, medical and psychological factors discriminate between good and poor wellbeing amongst young people with epilepsy. It is hoped that we will be able to target these factors in future interventions so that young people who really struggle through this period today might be able to function better tomorrow.

Research design

Participants completed either paper or Internet versions of a self-report survey that asked questions about the participant, their medical condition, and how they lived with their epilepsy. The survey was designed in two parts. The first part focused on demographic and medical information and the second part included a series of psychological scales that measured family functioning, coping skills, anxiety and depression, quality of life, and concerns about epilepsy.

Who participated

My sample included 114 young people aged between 10 and 24 who had self-reported epilepsy.

Of the total 114 participants, 74 were female with an average age of 8.5 years and 40 were male with an average age of 16.9 years. Seventy six resided in Australia (66.7%), eight resided in New Zealand (7.0%) and 30 resided in other countries (26.3%), including USA, UK, Canada and Ireland. Fifty per cent were classified as living in a metropolitan area, 16.7% in an inner regional area, 21.9% in an outer regional area, 6.1% in a remote area and 5.3% could not be classified due to insufficient information.

Thirteen Australian participants received assistance from a parent or carer in completing their paper survey. Fifty-one Australian participants completed a paper survey without any assistance. Twelve completed Internet surveys. Eight participants resided in New Zealand and of these four completed a paper survey unassisted, one completed a paper survey with assistance and three completed an Internet survey. Participants from all other countries completed Internet surveys.

As would be expected for this age group, the majority of participants lived with either one or both of their parents and their siblings. Three participants lived alone and seven lived with a partner. Over 40% of the sample was attending TAFE...
or university. Twenty-three per cent had received integration assistance during their education. Three participants identified themselves as intellectually disabled.

The participants were first diagnosed with epilepsy between birth and 22 years of age, with an average age of 10.3 years at time of diagnosis. Of the total sample, 8% had been diagnosed within the previous year and 10.6% within the previous two years. The average duration of the condition was 7.6 years. Of the 114 participants, 57 were classified as having generalised seizures, 48 were classified as having partial seizures and nine could not be classified due to insufficient information.

Additional medical characteristics are shown in the following table.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family history of epilepsy</td>
<td>34.8%</td>
</tr>
<tr>
<td>Other chronic illnesses</td>
<td>27.9%</td>
</tr>
<tr>
<td>Seizure in last year</td>
<td>83.3%</td>
</tr>
<tr>
<td>Seizures in last month</td>
<td>48.2%</td>
</tr>
<tr>
<td>High seizure severity</td>
<td>64.9%</td>
</tr>
<tr>
<td>Lost consciousness from a seizure</td>
<td>28.1%</td>
</tr>
<tr>
<td>Hospital stay due to seizure</td>
<td>14.2%</td>
</tr>
<tr>
<td>Video monitoring for seizures</td>
<td>45.6%</td>
</tr>
<tr>
<td>Changed medication in past 3 months</td>
<td>51.4%</td>
</tr>
<tr>
<td>Medication adherence problems</td>
<td>58.6%</td>
</tr>
<tr>
<td>Other traditional treatments</td>
<td>16.7%</td>
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<tr>
<td>(e.g. brain surgery, ketogenic diet, vagal nerve stimulator)</td>
<td></td>
</tr>
<tr>
<td>Complimentary and alternative treatment</td>
<td>37.0%</td>
</tr>
</tbody>
</table>

In addition to epilepsy, thirty-one participants had one or more chronic illness. Ten had asthma, six had headaches, five had allergies, including hayfever and eczema, four had diabetes and three had arthritis.

Naturopathy and relaxation or meditation were the most common complementary and alternative therapies used. Other therapies included: acupuncture, Bowen massage therapy, chiropractic care, counselling, hypnotherapy, osteopathy and vitamin or herbal supplements.

### Analysing the data

After excluding cases that had significant missing data, there were 98 cases available for analysis. The four outcome measures, anxiety, depression, health-related quality of life and concerns about epilepsy, were subjected to a cluster analysis that revealed two groups.

The first group was strongly representative of participants with higher levels of psychosocial function, with lower anxiety, higher health-related quality of life and lower concerns about epilepsy.

The second group had the reverse pattern and was strongly representative of participants with lower levels of wellbeing.

To predict membership of the good or poor wellbeing outcome groups, the independent variables were entered into a series of hierarchical logistic regression models. The final model was a good fit with the data and explained 66% of the variance in wellbeing. The model correctly predicted 84.1% of cases.

### Conclusion

Participants were more likely to be members of the poor wellbeing group if they had had a seizure in the last month, had poorer family functioning and made greater use of emotion-focused strategies. The psychological factors did make a unique and significant contribution to wellbeing in addition to the medical and demographics factors.

It would be worthwhile to design and implement intervention studies that focused on seizure management, family functioning and emotion-focused coping. For more difficult-to-manage epilepsy, psychosocial variables are likely to be more amenable to change and facilitate increases in health-related quality of life [8]. Much can be gained from the successful management of epilepsy during this critical period of development. Unfortunately, much can also be lost when epilepsy is not successfully managed. The impact that epilepsy can have on young people’s capacity to form strong social networks, complete formal education, move from school to work, develop a goal-oriented view of the future and gain the self-sufficiency of adulthood may prove costly for the affected individuals, their families and, ultimately, their communities.

### References


Allison Clarke completed her Doctorate in Psychology (Health) at Swinburne University of Technology under the supervision of Dr Christine Critchley. Approval to conduct this study was received from the Swinburne University of Technology Human Research Ethics Committee.

Now living in Canberra, Allison is a registered psychologist in private practice with Optimal Health and Performance. Allison is also a member of the board of Epilepsy ACT.

If you would like find out more about Allison’s research, her doctoral thesis can be accessed at the Swinburne Research Bank website http://researchbank.swinburne.edu.au or you can contact Allison at aclarke@iinet.net.au
Childhood epilepsy research offers new hope for seizure control

Scientists still do not know what causes epileptic seizures, but researchers from Melbourne’s Howard Florey Institute are one step closer to solving this puzzle with the help of their newly developed genetically modified epileptic mouse.

This is the first human genetic mutation based mouse model in the world that mimics childhood absence epilepsy (CAE). The mouse is now helping Dr Steven Petrou and his team to understand the genesis of epilepsy, which will aid in the development of better anti-seizure drugs.

CAE involves brief staring spells, during which the child is not aware or responsive. These episodes can occur one to 50 times per day and the age of onset is usually three to 10 years.

In about 30% of people, anti-epileptic drugs do not adequately control their seizures and many drugs have side-effects such as rashes, lethargy and memory problems.

Dr Petrou said new treatment strategies were urgently needed to create beneficial drugs without side-effects.

“The problem with current drugs is that they treat the symptoms, not the root cause,” Dr Petrou said.

“To develop new treatment strategies we need to understand the genesis of epilepsy, and this mouse model should provide a window into that fundamental process.

“We all know seizures occur if the brain’s cortex goes haywire, but something is happening prior to that event to cause neurons to misfire, and we want to understand that initial event.

“Because mice grow so quickly, changes in the brain can be readily seen and measured.

“In a week the mouse can go from no seizures to seizures, so we can investigate what changes are occurring in that period and what is happening in the critical time window that leads to seizures.

“Initial findings suggest there is a defect in the brain’s cortex which may be related to the beginning of seizures in CAE but we are delving into deeper brain structures as well,” Dr Petrou said.

The inherited human gene mutation that causes CAE was first detected by Dr Petrou’s collaborator, Prof Samuel Berkovic from Austin Health. Through genetic manipulation, Dr Petrou has introduced this human mutation into the mouse DNA, allowing the researchers to study a mouse version of the human condition.

The mutation itself is rare in humans but it causes CAE, which is one of the more common forms of epilepsy.

Dr Petrou said that modelling genetic epilepsies in mice will allow researchers to understand epilepsy from the molecular level all the way through to physical behaviour.

“Creating this link in the human brain is impossible due to the highly invasive methodology required, so mouse models provide us with a unique opportunity to discover mechanisms of seizure genesis,” Dr Petrou added.
From ancient to modern times, epilepsy has carried with it an ‘undesirable’ amount of social stigma that affects people with epilepsy in varying degrees in diverse cultural settings. The father of sociology of stigma; Goffman (1969) defines stigma as ‘an undesired difference’. He argues that the stigmatised are seen by others as ‘not quite humans’ who are legitimate targets for discrimination. Link and Phelan (2001) define stigma contextually; that stigma exists ‘when elements of labelling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them’. Even in industrial nations like America, epilepsy carries a stigma that dates back to ancient civilisations. Some argue that stigma related to epilepsy is worse than the stigma of cancer or HIV/AIDS. Misunderstanding, fear, and anxiety resulting from stigma hampers care and public recognition and results in social and even legal discrimination against those living with epilepsy. In a WHO document ‘Epilepsy: social consequences and economic aspects’, some misunderstandings about epilepsy from around the world have been summarised:

- In Cameroon, it is believed that people with epilepsy are inhabited by the devil;
- In China, epilepsy diminishes the prospects of marriage, especially for women.
- In some parts of India, attempts are made to exorcise evil spirits from people with epilepsy by tying them to trees, bearing them, and cutting a portion of hair from their head;
- In Indonesia, epilepsy is often considered as punishment from unknown dark forces;
- In Liberia, the cause of epilepsy is perceived as related to witchcraft or evil spirits;
- In Nepal, epilepsy is associated with weakness, possession by an evil spirit;
- In Swaziland, many traditional healers mention sorcery as the cause of epilepsy;
- In Uganda, epilepsy is thought to be contagious and so people with epilepsy are not allowed to join the communal food pot.

Research shows that people with epilepsy in developing countries particularly in Africa, suffer substantially from stigma and social exclusion and they are more likely to be unemployed, get less educated and get less married.

Fernandes et al (2007) in a recent study in Brazil found that the magnitude of stigma is different within segments of the local society, highlighting that socio-cultural factors such as gender, religion, level of education may be important predictors of stigma. In a Korean study by Lee et al, (2005) involving 400 adults with epilepsy indicated that 31% of them felt stigmatised by their condition.

Dilorio et al (2003) reported that people reporting higher levels of stigma were those who had their first seizure before the age of 50. In an Estonian study, Ratsepp and his colleagues (2000) found that overall 55% of people with epilepsy believed that they had been treated unfairly at work or when trying to get a job, 51% of respondents felt stigmatised by epilepsy, and 14% of them highly so. Baker et al (2000) in a review on ‘stigma of epilepsy; a European perspective’ involving more than 5000 people with epilepsy in 15 countries in Europe found that 51% of respondents reported feeling stigmatised, with 18% reporting highly stigmatised. Paradoxically, one British study found no evidence that stigma affects the lives of those whose epilepsy was not complicated by other pathologies (Britten et al, 1984).

Research shows that stigma has a negative affect on the quality of
life (QOL) of people with epilepsy (Jacoby, et al, 1996; Baker et al, 1997). Hermann et al (1990) found that stigma is one of seven key predictor variables when studying significant causes and processes in the development of mental illness (psychopathology). Perceived stigma was ranked fourth in importance in predicting quality of life, after psychological stress, loneliness and adjustment (Surmaijer et al, 2001). Stigma is also associated with reduced self-esteem, anxiety, depression, and helplessness (Jacoby, 1994; Dilirio et al, 2003; Westbrook et al, 1992)

Educating people on the true causes of epilepsy is the key to address the issue of stigma associated with this disorder. Knowledge gaps have the potential for discriminatory behaviour. Misunderstandings coupled with ancient mythologies surrounding epilepsy haunt many parts of resource poor countries. The social value of people with epilepsy has been so devalued for so long. We need to cut across the message that epilepsy is not a disease and it is a disorder that is not contagious. People with epilepsy can lead normal lives and work regular jobs. A crucial part of getting rid of epilepsy stigma is to raise public and professional awareness together with changes in legislation which reinforces fear and discrimination (WHO, 2001). The role of the media in this noble exercise is paramount, perhaps in collaboration with health professionals, especially GPs and neurologists.

Epilepsy social research in Australia is ‘uncharted waters’ where no investigation into knowledge of, and attitudes towards, epilepsy or epilepsy stigma in either the general public or specific significant populations such as teachers, nurses or employers has been carried out. As Brown (2006) indicates Australian social research into epilepsy has been a ‘shadow-dweller’ for too long. We are lagging behind even some developing countries such as India, Zambia, Kenya, Vietnam or Brazil in terms of social research into epilepsy.

Research program at the Epilepsy Foundation of Victoria (EFV)

The EFV has already initiated a major research program into Australian’s knowledge of and attitudes towards epilepsy together with many other social and applied research projects. To begin with, the EFV will adopt a ‘micro’ research approach focussing on ‘small sample studies’ in Victoria before adopting a ‘macro’ research approach focusing on wider national surveys in future.

The EFV’s Research Participant Register (RPR)

The RPR founded by Dr Kevin Brown, reached the 548 mark by the end of March 2008. This is the only register of its type in Australia and we have not so far learned of another anywhere else in the world. We are very hopeful that we will be able to achieve our target of 1000 before the end of 2008. The RPR is a voluntary cohort of people with epilepsy and their carers who have expressed their willingness to participate in social research into epilepsy and it will provide the basis for a series of psychosocial research projects into epilepsy and seizure in future.

The EFV has already completed a baseline survey on ‘Characteristics of the Research Register Participants Living with Epilepsy in Victoria. In April 2007, we sent out a short survey to everyone who had registered (N=520), just to capture some basic details about your lives. This data will be our baseline information giving us a ‘snapshot’ of what life with epilepsy is like in 2007. Three hundred and thirty eight (N=338) surveys have been returned, a response rate of 65%.

Of 338 respondents, 212 were clients, 95 were carers, 6 were carers and/or clients and 15 were concerned. 50% of the respondents graduated from high school (year 12 or equivalent) and 38% had diploma or university degree. 25 % of persons with epilepsy were employed full time and 43% were unemployed. 46% of those who answered the survey informed that their weekly income is less than 400 dollars. About 62% of people with epilepsy own their home and 24% were renting. Out of 212 clients, only 118 persons (57%) had a driving licence. The number of women (60.8%) who were living with epilepsy was significantly higher than the number of men (38.7%). A more detailed survey data analysis will be produced in the next edition of The Epilepsy Report.

References

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Suurmeijer TPBM, Reuvekamp MF Aldenkamp BP (2001) Social functioning, psychological functioning and quality of life in epilepsy, Epilepsia, 42, 1160-68
In the previous issue of *The Epilepsy Report* we looked at animal studies of convulsive epilepsy that were conducted in our laboratory and how they revealed a surprising increase in the strength of fast EEG rhythms before seizures – where fast means around 30-100 oscillations per second. These fast rhythms are known as ‘gamma’ rhythms and are normally the rhythms the brain uses when we think.

In our studies, we have used two different drugs to cause generalised tonic-clonic convulsive epilepsy in rats. The effects of the drugs represent the two extremes of the background problem we think is behind generalised convulsive epilepsy. For one of the epilepsy states we use a drug that increases all neuronal activity in the brain, “flooring the accelerator!”, and for the other epilepsy state we use a drug that removes all inhibiting neuronal activity, “dismounting the brakes!” Both drugs lead to brain activity increasing until seizures occur. These two drugs give somewhat different convulsive seizures and EEG activity, but both produced an increase in the gamma rhythms mentioned above. The rhythms were seen to build up before any seizures started (see figure 1).

*Figure 1* from work of Dr Marita Broberg showing, from left to right, a 30 minute experiment in a rat in which gamma band activity developed after the convulsant drug was given. During this time the animal behaves apparently normally, and does not seem stressed. After about 15 minutes, 4 seizures occur (top graph). The gamma band activity is buried in the EEG signal, and is shown by special analysis in the lower graph. We think this gamma band activity is one of the brain processes triggering seizures.

Even with these findings, and with others to be reported in our next article, we have been unable to win research grant funding to continue this work. Such are the challenges of doing research. It seems we may have to close our Rat Lab after so many years!

**Part 2: Gamma rhythms & seizures?**

**Very fast brain rhythms – rats**

After finding increases in gamma rhythms in rats, we were excited to examine people with different forms of epilepsy to find out if there were any instances of increased gamma activity in humans. With Sean Fitzgibbon, we originally studied 10 people with generalised (inherited epilepsy) and 10 people with focal (brain lesion-induced) epilepsy. In fact, we did find 3 people with generalised epilepsy who also had increased gamma activity! On the right, figure 2 from our original study illustrates the increase in gamma EEG.

The frequency of the increased activity is around 40 per second. This is therefore a new, though unusual, finding in generalised epilepsy.

This early finding led the Human Lab to investigate a much larger group of people, many with epilepsy, and others with different conditions (like migraine, MS, Parkinson’s Disease and so on). Many of you may have been involved in our studies which are still incomplete. However, our early results indicate that increased strength of gamma rhythms is sometimes seen with inherited forms of epilepsy. (Fig. 3)

In Part 3, we will explain why we think ‘resonant gamma’ is likely to be important in predisposing to epilepsy. This will require a return to the Rat Lab…!
I developed epilepsy due to scar tissue that formed on my left temporal lobe following two periods of complicated febrile convulsions in my first two years of life.

I experienced absence and simple partial seizures during my teenage years, but these were not recognized as seizure activity. At the time it was thought that the auras I was experiencing were occurring due to sinus problems.

It was in my early twenties when I began to experience complex partial seizures. Tests detected the tissue damage caused by those febrile convulsions so many years before and I was finally diagnosed with epilepsy.

Singing was always an important part of my life, and from the age of fifteen I received many scholarships to further my singing studies. However the scholarships discontinued not long after I began to experience regular seizures, and while I had been training and working as a professional singer, the increasing frequency of the seizures forced me to abandon my singing career.

Not having received any epilepsy education or support, I was unaware that there were any guidelines for living with epilepsy. I believed if I could relax enough and breathe through it, I could control my seizures. The consequences of performing certain actions were incomprehensible, such as swimming alone in the surf. As a result I had a seizure while swimming and drowned. Thankfully a surf lifesaver was on the beach and dragged me from the surf and resuscitated me.

When I regained consciousness I found myself in the Intensive Care unit of Warrewood Hospital. I was told that I had a large amount of sand in my lungs and that I was only alive because my lungs were so well developed due to my intensive singing training. All of this occurred because I had never been told of the dangers of swimming alone.

Over time I have experienced many physical injuries, including a dislocated shoulder, broken foot, falling off a railway platform onto tracks, plus others too numerous to mention, due to my seizures.

Until I was made aware I was eligible to receive a disability pension, I worked at any job I could find. A stint at waiting tables saw me spilling red wine on models dresses while they were attending important gatherings, and dropping trays of glasses and plates due to shaking, a side effect of taking high levels of epilim. Understandably, this career did not last long.

With the lack of understanding in the community I began to withdraw from being involved in social activity. However, I was determined not to allow my condition to control me and in 1997, at the age of 26, began studying at The University of New England.

However I continued to have, on average, seven complex partial seizures a week even though I was taking high levels of a combination of three medications. Surgery was recommended and in 1998 I had a left partial temporal lobectomy.

In 1999, around six months following the operation, I recommenced my studies at the University of Sydney. I had been seizure free but by the June of ’99 began, once again, to experience a high level of seizure activity. Further neurological tests were carried out and it was found that the previous surgery had not been completed correctly and I underwent a second partial temporal lobectomy in October, 2000.

I received no support or education following either surgery on the implications of this procedure. It was only my own investigation and the reading of books such as, The Comprehensive Evaluation and Treatment of Epilepsy (Steven C. Schachter, Donald L. Schomer), that I became aware of the symptoms and
consequence of a seizure, allowing me to recognise the actions of the pre-ictal and post-ictal period. This knowledge gave me the opportunity to not only recognise and understand why particular emotions are experienced prior to the convulsion, but also an ability to return back to regular activities without emotions such as depression, a factor of the post-ictal period for many, from strongly affecting me.

I purchased the audio recording of a book titled, *Practicing the power of now*, written and read by the author, Eckhart Tolle and listened to this CD series every night as I went to bed. This book was extremely helpful and provided an insight into the personal and social difficulties I was experiencing.

It is unfortunate that epilepsy education services are not readily made available to both a person with epilepsy and those who are closest to them as the onset of epilepsy in adulthood can often lead to a division in relationships and in the family environment.

This lack in knowledge was a strong influence in the separation and ending of my two marriages. It has been these two experiences in combination with the ability to develop a third person perspective when reflecting on them, that I adopted following the reading of Tolle’s book. This has enabled me to objectively understand the difficulties that the partner experiences.

The major difficulty that I experienced following the separation in my second marriage in 2003 was the need to depend completely upon myself. This meant walking for 30 minutes to the closest supermarket, and bringing home several bags of groceries by bus on a weekly basis. I was now required to take care of both myself and the home, including paying the bills and maintaining the home, which was difficult to perform.

It was at this time that I began not only to keep a diary to remind me of all the activities I needed to do, but also a journal to understand the emotional difficulties I was experiencing.

Adopting the advice of my mother to keep a journal, writing on a daily basis the actions that I had performed and the emotions I was experiencing, was a great breakthrough after having been through long periods of depression. This action saw me stepping from darkness into the light. I became not only aware of the impact of surgery and seizures on my memory, but also the psychological effects created by the lack of knowledgeable support and this allowed me to recognise the difficulties I was experiencing. In fact it was this need to understand that developed my strength and dedication to continue my studies and offer understanding and education to others.

The two operations, and the periods of recovery saw my Bachelor of Arts (Sociology) degree taking seven and a half years (June 2005) to complete. I began studying a Graduate Diploma in Psychology in the second semester of 2005, and due to the completion of relevant subjects while studying my B.A., I was able to complete this degree at the end of 2006. I began my present degree, the Masters of Philosophy at the beginning of 2007. This two year degree will be completed this year (2008).

Following the submission and marking of this research paper I will begin my Doctor of Philosophy (PhD) studies, 2009.

The use of computer programs, such as Kurzweil and Dragon Naturally Speaking, has assisted my academic studies immensely. There have been times in the past when I have been advised by academics and specialists to “forget it all” and find some job in a supermarket. It has been my own beliefs that by achieving these goals I can offer the inspiration for others to attempt to accomplish what seem to be unattainable goal, and also perform academic research on epilepsy, offering knowledge and understanding from an angle that, to this point, has not been shown.

At times I have felt that the hurdles before me were insurmountable, but I have learnt to access help through disability services. During my journey I have had help from some wonderful people, but I had to find my way first before I could start helping others.

As well as studying and singing in the University choir, I also offer support for men who have developed epilepsy as an adult and their families, assisting them to understand the changes that are required to be made, both physically and socially.

I believe that many people have the ability to attain what seem to be impossible dreams if the necessary knowledge and support are readily made available to all concerned.

Martin has chosen epilepsy as the area of study for his thesis and is still recruiting participants for this project. A detailed description of Martin’s research project and a call for participants can be found on the following page.
An invitation from the Epilepsy Foundation of Victoria

The Epilepsy Foundation of Victoria (EFV) invites you to become an occasional participant in the Epilepsy Foundation’s ongoing research programme into the social effects of living with epilepsy and caring for those with epilepsy. We need people to tell us about their experiences and views of living with epilepsy.

What is EFV Research Participant Register (RPR)?
The Epilepsy Foundation of Victoria’s Research Participant Register is an ongoing initiative created in 2006 to establish a unique research source from which we can learn much valuable information about epilepsy that can be used to improve the lives of people affected by this condition. This is the only register of its kind in Australia and we have not so far learned of another anywhere else in the world.

Why is it important to join in this register?
The World Health Organisation has stated that: the social consequences of epilepsy are often more difficult to overcome than the seizures themselves. They are talking about issues like finding and keeping a job, transport and driving and the attitudes of other people towards epilepsy. Yet in Australia, there is hardly any reliable research into these social consequences. If the Epilepsy Foundation of Victoria gathers detailed factual evidence of this kind, we will be even more successful in lobbying governments for a better deal and a fairer go for all those living with epilepsy.

Who is eligible to join in RPR?
Following individuals are eligible to join the register.
- Individuals who have epilepsy/seizure disorder
- Carers who look after someone with epilepsy/seizure disorder

Are there risks to me as a research register participant?
This is not a medical or clinical research register. From time to time, we might contact you and ask if you would be prepared to answer some questions over the phone or fill in a mailed questionnaire. Sometimes there will be small group meetings of participants at the Foundation’s office in Camberwell or a regional centre to which you might be invited.

Does putting my name in the RPR obligate to participate in future research projects?
Putting your name does not obligate you in any way. You may be too busy or just not feel like participating at that time – that’s fine! But if you do, any information you provide will be confidential, anonymous, safeguard and only used for specified research purposes.

How would I benefit by joining the register?
There may be opportunities to talk with people living with epilepsy and those who work with them. Most importantly, this is an opportunity to be part of a longitudinal study of living with epilepsy – the first of its kind.

If you are interested in learning more about this research contact:
Dr Jaya Pinikahana
Principal Social Researcher
Phone: (03) 9805 9125 Fax: (03) 9882 7159
jpinikahana@epilepsy.asn.au

Participants sought for epilepsy research project

Martin Raffaele is currently studying for his Masters in Psychology at The University of Sydney. His research project is titled:
An exploration of the psychosocial effects that school-age children with Childhood Onset Absence Epilepsy (CAE) experience when their condition is misdiagnosed as Attention Deficit-Hyperactivity Disorder (ADHD).

Project Overview
The aim of this research is to create an understanding of the psychosocial effects on school-age children with childhood onset absence epilepsy (CAE) when their condition is misdiagnosed as attention deficit-hyperactivity disorder (ADHD). The nature of psychosocial effects that are evident in CAE children when misdiagnosis and inappropriate labelling is experienced will be explored. The aim is to understand the reactions of those closest to the child with childhood onset absence epilepsy (CAE) at the time of the attention deficit-hyperactivity disorder (ADHD) diagnosis and sequentially, and how these reactions affect/affected the child with CAE psychologically will be investigated.

Participation
I am seeking five adolescents/young adults with childhood onset absence epilepsy (CAE), whose condition at an earlier age was misdiagnosed as attention deficit-hyperactivity disorder (ADHD) to participate in the study. The identification of the participants will remain confidential. In-depth personal interviews will be of approximately one hour duration. A second interview can be made available if further time is needed to discuss the experiences and answer further questions. Each interview will be audio-recorded with participants’ consent. Based on the decision of each participant, the interview/s will take place either at their residence or in a private office at The University of Sydney. The parent (guardian) of each participant will also be interviewed on what effect they feel the diagnosis of ADHD and the later correct diagnosis of CAE played on the child at the time of diagnosis. The result of these interviews will be shared with the participants for their approval.

This research study has been approved by the Human Ethics Research Committee, The University of Sydney.

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Everyone deserves the opportunity to be understood. Artistic expression can serve as a visual dialogue of what happens within the lives, the minds and the feelings of people with epilepsy.

The human brain is the most complicated organ with more than a billion nerve cells and a trillion supporting cells. The microscopic connections and neurological sequences that interact in a way that produces thought, action and behavior have been extraordinarily difficult to map and grasp by even the most sophisticated medical experts and technology.

The nature of epilepsy and migraine is an involuntarily altered behavior and functioning of the brain caused by the misfiring of electrical impulses. The point of disruption in the natural flow of brain activity that causes seizures and the changed behaviors in between seizures, is hard to pinpoint and trace. When discovered, the impact of seizures remains difficult to predict. The exact consequences vary widely depending on the individual and the part of the brain affected. What is far too often overlooked is the impact of epilepsy on the unique person beyond the condition.

It is often said that a picture can speak a thousand words. There is an ongoing study called “Sparks of Creativity: the influence of epilepsy and migraine in art” that will evaluate how epilepsy can influence artistic expression.

This study is collecting and evaluating more than 1,000 images of the visual art of people with epilepsy in order to better understand the condition and the person. It will look beyond how epilepsy can be disabling toward a focus on how epilepsy can be enabling through artistic expression. An art exhibition stemming from this study will be held in Sydney, Australia on 5-7 November 2008, and will coincide with the 23rd Annual Scientific Meeting of the Epilepsy Society of Australia.

The door is open for adult artists by hobby and by profession to submit artwork that will help bring about a more enlightened understanding and appreciation of people with epilepsy. Numerous artists from Australia and other countries will participate. There will be prizes and purchase awards for chosen artwork as selected by a jury.

Epilepsy in some circumstances can stimulate and enhance artistic expression. This is not to say that epilepsy is the sole cause on one’s creativity. It is however, for some, one of the multiple elements that make up what a person experiences and who one is. Epilepsy can open a window to experiences and visual perceptions that can inspire some remarkably creative art.

Some of the world’s most creative minds are thought to have been influenced by epilepsy and/or migraine, such as Michelangelo, Vincent van Gogh, Lewis Carroll and Giorgio de Chirico. However, there were no EEGs or brain scans during their lives to affirm a neurological diagnosis. This research will serve as a foundation to evaluate whether artists had epilepsy based on comparisons with the artwork and writing of living artists who are confirmed to have epilepsy or migraine by modern methods of diagnosis.

If you wish to participate in this study and/or the exhibition about how epilepsy can influence art then please contact Jim Chambliss by mobile phone in Australia at 0430 043 400 or by e-mail at jimchambliss@msn.com.

Examples of visual art collected by Jim Chambliss for the Sparks of Creativity study.

Far left: Woman Butterfly by Catriona Russell  
Centre: Fear on Fear by Vicki Deutsch  
Right: Cat and Mouse by Jude Rouslin
For the past 3 years, the Tuggeranong United Football Club (TUFC) have joined forces with Epilepsy ACT to hold two annual events, the ‘Adam Fry Memorial Shield’ and the ‘Dawn to Dusk 12 Hour Non Stop Football Match’.

Both days operate around two themes, one is the celebration and enjoyment as a player and spectator in one of the world’s greatest games – football. The other, and this is even more important, is that the days are dedicated to raising awareness and funds for epilepsy. Through sausage sizzles, raffles, player and spectator donations, the events have managed to raise over $3000 towards local charity Epilepsy ACT.

In 2006, Tuggeranong United Football Club decided it would also like the challenge of putting together a non-stop football match for 12 hours straight and for the past two years have been successful at it. The day has also been dedicated to raising much needed monies for Epilepsy ACT through participant donations. Participants in the day include males and females, young and old, professional and amateur players. The game is split between two teams, the Kambah United “Greens” and the Wanniassa “Golds”, and involves a series of 20-minute “roll-on, roll-off” matches. At the end of the day the scores for both sides are added up, with the first year ending in an 83 all draw while in 2007 the “Greens” defeated the “Golds” 109 to 104. The event is held every November in conjunction with the Tuggeranong Community Festival.

‘It’s a great way to remember our friend who loved the game of football and its also a day to allow everyone in the club and the community to show its support for Epilepsy ACT,’ said ‘Macca’ McDonald.

Tuggeranong United Football Club Patron and Federal Member for Canberra, Annette Ellis MP on attending this year’s event said ‘It was a great afternoon and most enjoyable for me, I was particularly pleased to see Adam’s parents were able to attend. This event is a terrific concept that honours the memory of Adam and maintains the connection between Adam’s family and Epilepsy ACT. My congratulations to the Tuggeranong United Soccer Club and to the other teams who competed. The funds raised will be welcome by Epilepsy ACT who provide wonderful support to the community.’

Tuggeranong United Football Club hopes to be able to continue these two events well into the future, with the expectation that they will continue to get bigger and better.
The Governor of South Australia, His Excellency Rear Admiral Kevin Scarce AC CSC RANR, in the presence of The Epilepsy Centre’s Chief Executive Officer, Robert Cole, together with the Board and more than 120 special guests, officially opened The Epilepsy Centre in Hindmarsh, on Thursday, 1 May 2008.

When asked the reason for the move Robert Cole said “The Epilepsy Centre relocated offices to Hindmarsh to allow greater access to the region’s most vulnerable consumers and that the new space is well suited to the needs of The Epilepsy Centre, offering a balance of meeting and office space.

“The relocation was a great move as it allowed staff to work closely with the community on projects improving services to people living with epilepsy.

Robert added, “This Centre continues the tradition of excellent response to people living with epilepsy. The Epilepsy Centre has a 32 year track record of helping those who need us most and this service centre will help us to deliver our services more effectively and efficiently.

“In the past 12 months alone, we have assisted over 6,500 people. Over half of those enquiries were dealt with face-to-face. I’m sure the new location will ensure The Epilepsy Centre assists even more people needing assistance.

“We have grown to become the major organisation in South Australia and the Northern Territory representing people living with epilepsy. We exist to improve the health, well being and quality of life of people with Epilepsy by providing services in the areas of: Advice, Advocacy, Community Education, Referral Services, Counselling and Support.”

The Epilepsy Centre relocation was driven by a need for more efficient space utilisation, and reduced operating expenses noted Mr Cole.

The historic Hindmarsh Memorial Institute, built as a tribute to the citizens of Hindmarsh commemorating The Great War 1914-1918, was opened in 1922 by Governor Weigall. It is now home to The Centre and is located at 266 Port Road, Hindmarsh, South Australia.

The Epilepsy Centre can be contacted on 1300 852 853 or for more information, visit www.epilepsycentre.org.au .

Photos: Robert Cole, His Excellency Rear Admiral Kevin Scarce AC CSC RANR Governor of South Australia, Mrs Scarce and Barbara Rajkowska, President The Epilepsy Centre SA/NT at the official opening of The Epilepsy Centre and The Epilepsy Centre’s new premises, the historic Hindmarsh Memorial Institute.
Standardized service models; innovation and the life potential of persons who receive services

Though many of us prefer to think of ourselves as responsive to people and their needs, the reality of many everyday services practice is not at all consistent with this self-image. This is not meant to suggest that many people are lacking these traits; but rather, the possession of these attributes does not apparently have a large effect on service patterns “per se.”

People receiving services are typically offered what amounts to standardized service packages or fixed models of care and support options. What is meant by “standardized” or “fixed models” is that the pattern of service is largely pre-set. Thus, the person is fit into the services available. Subsequently what a person needs to maximize the inherent potential of his/her life is often not available from standardized service delivery models. Alternatively, a good or beneficial service evolves to each situation so that supports are customized to an individual’s unique needs. Such individualization cannot occur when the person’s uniqueness is substantially ignored by systems level service practices.

Fixed service models are designed prior to the person’s arrival.

The vast majority of service models are designed without reference to the service user and usually at a point well before the person arrives seeking support. Designing services in advance of the person arriving significantly diminishes the likelihood that the services available are the best option for the person. The problem, among others, is that the designers are guessing or speculating about what the person actually needs. This error is further accentuated if what is eventually offered draws from a fixed menu of options.

When one lacks vital specific knowledge and understanding of a person it is likely impossible to do any more than just guess or speculate about what someone might need. Guessing about people in the absence of knowing them well leaves organizations with the option of having to design their services based on generalizations drawn from other service users. Predictably, this will result in that person receiving something more akin to a “one size fits all” solution to their needs. Generalizations of service needs, in the absence of personalized information, cannot help but result in service models that only partially meet specific personal needs at best.

Fixed service models are designed (by others) for people rather than with people.

It is not always recognized how few decisions about service design and implementation are actually made by service users. This may be due to our predilection of seeing ourselves as more empowering than we really are. When people other than the person served make design decisions, there is a great risk that such decisions may reflect the service designer’s priorities and needs rather than those of the service user.

Fixed service models are usually substantially non-negotiable.

In order to be responsive to the needs of people who do not fit a fixed pattern,
the provider must be willing to negotiate helpful changes in service. Unfortunately, very few providers state and follow through on a pledge to make service features that are consumer friendly and flexible. As a result, service users are presented with a “take it or leave it” proposition. Naturally, once fixed patterns become entrenched, service practice responds poorly to the potentially legitimate demands of service users for reasonable flexibility and responsiveness. This preference for upholding standardized practice may predictably defeat efforts to change services to make them more effective for a given person (i.e. allow services to evolve in non-standardized ways).

**Fixed service models are based on assumptions of routinized needs.**

It is not uncommon for standardized service models to assign a common number of hours, days, weeks or months of service to a group of individuals and then set those assignments in place for prolonged periods of time (e.g. weeks, months or even fiscal years). In such models, an individual’s needs are presumed to be unvarying. Thus, the service patterns are generic across service recipients. Without flexibility in service responses, generic service patterns become routinized and eventually institutionalized virtually ignoring variability in needs. Often, financing for standardized services are based on algorithms that use generalized assumptions about people rather than tailoring to individual variances of need. Notably, even some “individualized funding” models use standardized financing formulas.

**Fixed service models are driven by staffing patterns not individual needs.**

It has already been said that standardized service models try to fit the person into what is available as opposed to designing individualized service patterns. This lack of flexibility can often be systemic and pervade beyond the broad service pattern to all methods and the human beings who actualize them. In many instances, the deeper driver of service models may actually be the staffing pattern in that the logic of this pattern preempts service user priorities. This is most often seen in the restriction of service only to those hours of conventional operation, such as is typified in the “9 a.m. to 5 p.m.” availability of service.

**The need for innovation related leadership in order to fulfill human potential.**

If the possibility for people to realize their dreams and inherent life potential is to be optimized, it will inevitably require personalized lifestyle and support innovations that arise out of the specific needs of a given individual. Innovative support options are often limited because of the overly standardized nature of today’s dominant patterns of service. Ironically, this is occurring at a time when the rhetoric of “person centered” service is highly prominent. The losers in all of this are the people whose lives and life prospects are not receiving the precise supports and catalysts they need to thrive. Clearly, unless we see a new generation of service leaders who commit to this goal, the entrenched nature of our services and systems will preclude many people from exploring the real potential of their lives.

To transform into truly individualized and person centered services service leaders will need to:

- Develop service arrangements one person-at-a-time.
- Cease developing services “for” people
- Make all aspects of service models negotiable
- Move the necessary authority and resources to sustain and guide service model implementation into the hands of the people most directly affected.
- Provide the supports to assist people to “imagine better” on an ongoing basis.
- Provide the various supports to better enable people to “start from scratch” and to experiment with imaginative or innovative ideas for life or service improvements.
- Expose people to options and examples that enable them to see beyond the options they are currently most familiar and comfortable with.
- Limit the extent to which invasive and prescriptive bureaucracy or management practices impairs the ability of people to develop more responsive personalized service models.
- Ensure that service users and their allies are sufficiently educated and supported to be more empowered and effective in their service design and implementation negotiations with agencies.
- Devote a small percentage of agency and system resources each year to efforts to “remodel” services that may have become outdated and entrenched, in favor of more personalized service options.

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**References**


Children with epilepsy – like all children – need to experience and enjoy outdoor recreation. Supervised camps provide a safe environment in which this can be achieved.

meeting the gang again

Clare Thorne reports on Epilepsy

A guiding principle of Epilepsy Tasmania’s community education program is to build self esteem and confidence in children with seizure disorders. The friendships and learning experiences camps provide is one of the best ways to do this.

Epilepsy camps were initiated in Tasmania in December 1999 because of requests from parents and people with epilepsy to meet others who had similar conditions and experiences. They have always proven to be the highlight of every year.

Camps are often the only place a parent will feel confident that their child’s epilepsy will be properly managed and the only opportunity they have to get a break. Many parents find that their family members may be happy to look after their other children but are not willing to take care of a child with epilepsy in case they have a seizure.

While the major focus of our camps is to have fun, opportunities for counselling and education are built into the program. One of the best outcomes, people tell us, is just the chance to spend time with other people who really understand.

In February the annual Epilepsy Junior Camp was held at the fantastic Camp Clayton on the North West Coast of Tasmania. Children, families and volunteer carers from all over Tasmania travelled to attend.

Campers arrived on Friday evening and that time was spent getting settled in our cabins and playing some getting-to-know-you games. It was lovely to see a real mix of first time campers and others who had been coming for many years.

Saturday morning began with a talk about our epilepsy over breakfast followed by a swim at the beach. After morning tea the very brave then went over to the Giant Swing, while others spent time in the games room. After lunch it was off to the Flying Fox – which was fantastic, even if the weather was a bit damp.

As part of the evening’s entertainment, each regional group was to perform a skit based around something to do with
Tasmania’s Junior Camp 2008

epilepsy so in the afternoon everyone broke into their groups to begin work on their skits. We were very lucky to have Mr Danny Gibson, a local Musical Theatre Director come along to give us some tips. After dinner and with much anticipation, the show began. This year the North West region proved victorious with a very colourful and thought provoking performance. The South and North also did a fantastic job.

The rest of the evening was spent on the Karaoke machine, which was met with lots of enthusiasm!! While there were a few sleepy heads about the next morning, enough energy was found to tackle the ‘Challenge Course’ working in teams to achieve the various challenges.

It was wonderful to see everyone work so well together.

After yet another fabulous meal we packed up our cabins, and the Hobart/Launceston Bus left around two o’clock, with lots of sleepy people on board.

Thanks must go to the Community Support Levy through the Tasmanian Government who funded this camp, as well as the Lions Clubs of Kings Meadows and West Tamar and the Carer Respite Centre in the North.

The biggest thank you, however, must go to the volunteer carers who gave up their weekend to enable us to have the Camp.

Comments taken from Camp Evaluation Forms

my favourite thing about camp?

Playing in games room
Getting together
Anything
Swimming and Karaoke
Karaoke night and swimming
Everything
The get together and have fun and laughs
Making new friends
Everything
Everything – I had a great time
Flying fox and giant swing
Meeting new people and sharing stories about epilepsy
The games room
The food and activities
Everything
Meeting new people and having fun
The people
Getting together with other families that love having a great time
Just being around people and friends
Sneaking out at night
Giant swing
Meeting all the gang again
Great company
Everything – it was good
Food !!!
Back in 1998, I took myself off to Bendigo to complete a degree in Outdoor Education. At that time, I had been involved in camp programs, team building/personal development and train the trainer programs for 5 years. In my final year in 2000, I was required to do various forms of field placement. It was there on the noticeboard of potential placements that my relationship with the Epilepsy Foundation of Victoria began.

I made an appointment with Lisa Rath in order to learn more about it all and for Lisa to assess my suitability as a volunteer. The contact up to this point was impressive. I had spoken to Rosemary from Melbourne and Lisa from Bendigo and enjoyed the friendliness and professionalism that was given. After my appointment with Lisa, I intuitively knew that I was going to be more involved with this organisation that just a once off camp experience. I sensed and liked the nurturing and highly organised feeling that I had so far. Lucky for me that Lisa assessed me as a suitable volunteer.

I attended the adult camp that year, re-acquainting with Lisa and meeting Jan Burns, the camp co-ordinator. Another staff member, Camille Heagney was brilliant with the volunteer ‘get to know you’ activities and with the overall camp activity program. Again, I was impressed with the efficiency, organisation and professionalism in which the camp was run.

The following year, I attended the Family Camp to find that it was Camille’s last camp as she was soon to be leaving the Epilepsy Foundation. I mentioned to Jan that I would be happy to co-ordinate programs in the future if they needed someone. Jan thought that sounded like a good idea. That was eight years and 16 camps ago.

I have really enjoyed each and every camp experience, but it is more than that for me. It is about friendships and relationships. I have developed lovely friendships with Jan and Lisa, two women that I highly respect for what they do and how they do it. The love, the care, the warmth that they give to children and their families, and adults with epilepsy is inspirational. I have learned from them and continue to do so. Talking with and listening to people at camp, particularly mums and dads is so very eye opening, rewarding, sad, joyful, heart breaking and also very funny at times. I may never see them again or they may come to several more camps.

As a volunteer, I am giving of myself and expect nothing in return. But there’s the catch because I get so much in return. I get enrichment in so many ways. Sharing in people’s lives for a few days, people with, or affected by, epilepsy offer insight into their world – hardships and struggles, joys and disappointments, hilarity and sadness. You know, it is largely hardships and struggles, but for most people on camp, they find others in their very same predicament, they share stories, they make friends, they swap numbers, they cry (for all sorts of reasons), they laugh and relax for the first time in ages.

Seeing people relax, talk and laugh together. That is what is special. That is what makes me feel enriched because I am a very small part of this wonderful process.

I walk away from each camp having experienced all this, having the honour of seeing inside and sharing other people’s worlds. My experiences at camp make me a better person and no amount of money or reward can do that. It is the role of a volunteer and the relationships that allow me to receive more than I give.

The photo is of a mural made at the last family camp. Every family is represented in their own individual unique and beautifully creative way. We have just started doing these at the last few camps. We will need a lot of walls to hang them on if we keep doing it. This mural can be viewed at the Foundations’ office in Camberwell.
Providing epilepsy services to a region covering almost 2.5 million square kilometres – unimaginable? … not for Mark Francis, Services Manager for The Epilepsy Centre of South Australia and The Northern Territory. For this is his ‘office’ and the isolated communities he assists, his ‘clients’.

Epilepsy Awareness Program
assisting rural and remote communities

The Epilepsy Awareness Program has been a major focus for The Epilepsy Centre.

The aim of the project is to provide quality services for people with epilepsy, their families and the community throughout regional South Australia and The Northern Territory.

The State of South Australia covers an area of 1,043,514 sq. km. so as you can imagine many miles have been covered along highways and unsealed dusty roads since this program began.

Just to give you an idea of the distances covered since the program began – Coober Pedy to the north is approximately 835 kms, west to Ceduna is around 770 kms, the most southern region of Mt Gambier lies 435 kms from Adelaide and to the east it is 245 kms to Renmark. And this is only one way! A reliable vehicle is essential and we were delighted when Community Benefit SA funded the purchase of a vehicle that could handle the many road conditions one encounters on these trips.

Many rural and remote areas have been visited and assistance has been provided to indigenous communities, school communities, rural support groups, nursing and medical staff in rural hospitals and nursing homes, hospitals, child care centre, GP clinics, libraries, field days and workplaces.

The Epilepsy Awareness Program provides these communities with a comprehensive range of services.

Assistance varies from providing general epilepsy education, teacher training, medical staff training, formulating care plans, referring clients to health and welfare agencies, counselling, advocacy and support.

The results of this program are tangible. There is now greater awareness and knowledge about epilepsy in all the communities and the provision of new support groups and counselling services for those people living with epilepsy in such remote locations have had a marked effect on their self esteem and confidence. We have also seen improvement in the health and independence of people living with epilepsy in these communities.

The program has gone a long way in demystifying epilepsy, particularly in indigenous communities.

To date, twenty one schools have participated in the program. This expansion of our services for schools in regional areas has resulted in school communities becoming ‘Epilepsy Aware’. But our work here has only begun as there are over 310 schools yet to be visited in rural areas.

Similarly, the expanded service is well regarded by regional medical providers as the provision of current information on epilepsy, seizure recognition and medications has greatly increased their epilepsy knowledge.

In the Northern Territory, we have begun to mirror our services offered in rural and remote SA. So far, we have provided support, training and information services to areas such as Tennant Creek, Jabiru, Humpty Doo, Katherine and Pine Creek. We have established relationships with a number of Aboriginal Health Centres and have partnered with other Disability and Health Support Agencies to deliver services collaboratively throughout the Northern Territory.

As part of our commitment to rural and remote communities, we are about to embark on an exciting project to connect people in rural and remote areas to the Epilepsy Centre via Video Link up. We plan to pilot the project in Mt Gambier in the South East of South Australia. This project will enable support groups to have access to our facilitators via video link as well as enabling our workshops to be streamed live giving participants in rural areas the ability to interact with the speakers and other participants. Our plan is to extend this service throughout South Australia and The Northern Territory.

The Epilepsy Centre provides support to people living with epilepsy and their families and the community throughout regions that cover nearly 2.5 million square kilometres which is why this project is so important for us to continue to deliver vital support services to rural and remote communities.

10,000 people assisted in rural areas ...
- 1360 students and over 100 education staff across 21 schools in rural areas
- Education was provided to 200 nursing and medical staff in rural hospitals and nursing homes
- Delivered over 5000 pamphlets to hospitals, schools, child care centres, GP clinics and libraries etc
- Support groups set up in Mt Gambier and Pt Lincoln with more planned for Whyalla, Naracoorte and Pt Pirie
- Provided community education / information to over 1000 people through field days, general information sessions and workplaces
Epilepsy Australia & miVitals partners in promoting personal health management
Access your health records anytime, anywhere!

Living with any chronic health condition requires keeping a record of doctor’s appointments, who you saw, what tests were carried out and when, and the results, a history of the medications and doses prescribed, and in the case of epilepsy, a record of seizure frequency, hospital admissions and injuries to name just a few.

And how often do we misplace our old diaries, or lose them when moving, or depend on our doctor to keep the records for us only to find that when we change doctors it’s not as easy as we thought to have our records passed on.

Managing and monitoring our health requires a fair bit of organisation on our part and quite frankly, we are generally not very good at it.

However there is now an innovative secure health management system, miVitals, that allows you to store and manage your health records online.

miVitals is like an online filing cabinet for your personal health and lifestyle information. It enables people to record, manage and access vital information 24/7, from anywhere in the world. Information from traditional and complementary medicine, optical, dental, fitness, pregnancy and chronic illnesses such as epilepsy is centralised and integrated. Members can also attach, or have their health professionals attach documents such as reports, test results, and scans. Respecting privacy issues, miVitals members have the ability to share select information with professionals or family involved in their health management. Vital information is also accessible in the event of an emergency.

Developed by an Australian company, miVitals Technology Pty Ltd brings together twenty years of knowledge and networks in health care with state of the art and commercially successful internet innovation. It is among the first of its kind and currently available.

The driving force behind miVitals Technology Pty Ltd and its Chief Executive Jude Foster says “I wanted to develop a system that promoted health and wellness and didn’t define people by their illness.”

In assessing the system, it became clear to Epilepsy Australia that miVitals offers a unique tool that could greatly assist people with epilepsy in their self-management. Epilepsy Australia and miVitals agreed to work together to raise awareness that for many people epilepsy is a chronic health condition that requires ongoing monitoring and that this can be easily achieved by using miVitals.

miVitals is easy to use and allows you to record your medical history, keep track of changes to medication/s and changes to doses, add seizure activity and record notes for each event, attach test and scan results, store, update and access your Epilepsy Management/Action Plan, along with any other information you consider relevant.

To help you get started there is a Getting started video which clearly demonstrates how to complete each category in the core health module.

Simply entering your health information or the information of someone in your legal care on miVitals means that you no longer have to rely on your memory or the memory of others when providing medical information about yourself or the person in your care.

And if you find it difficult remembering appointment dates and times, you can schedule miVitals to send you a free reminder by SMS text or email.

“We are delighted to partner with Epilepsy Australia and offer miVitals to members and the wider community at large, says Jude Foster, Chief Executive, miVitals Technology Pty Ltd.

Epilepsy Australia CEO, Russell Pollard, says “the advantages of this technology for people living with a chronic health condition like epilepsy means your records can be accessed anywhere, anytime via a computer, whether that be at your doctor’s surgery, hospital emergency departments, or anywhere in the world, ensuring those responsible for treating you have your medical history and current treatment regime at their fingertips.”

“At Epilepsy Australia we are continually on the lookout for resources that enable people with epilepsy to actively participate in their health management and miVitals offers the most comprehensive online resource currently available.

“miVitals leads the way in consumer driven health management and as Epilepsy Australia is Australia’s leading consumer-led epilepsy organization, it is most appropriate that we join forces in promoting the active participation of all consumers in their personal health management.”

The Epilepsy Report invites readers to register with miVitals (its free), test drive the system and email your feedback to dchapman@epilepsyaustralia.net

Registering with miVitals www.mivitals.com may be the best health decision you ever make.
Where did you come from?
I was created by Anne Little (author) and Denise McMahon (illustrator). My birth certificate shows I was born in Ningaloo in Queensland.

I hope you won’t take this personally, but I have heard people debating what species you are.
Don’t worry, I’m used to that. I’ve been mistaken for a bunny, a cat and a rat, but I’m actually a brushtail possum. My name is Little Poss, poss being short for possum.

Best friend?
Buck (mascot of the Brisbane Broncos), Ruby Rosella and Gertie Goanna (read the books!!).

Pet hate?
People pulling my tail.

As this is an interview for Australia’s leading epilepsy publication, The Epilepsy Report, I guess we should stop beating around the bush and ask you what’s your involvement with the epilepsy community?
I have epilepsy. It started when I fell out of a tree and bumped my head. My epilepsy journey has involved scans, and EEGs to find out what was going on, and then medication for treatment. As long as I look after myself and keep doing the right thing, my seizures are pretty much under control. I became the star in Anne Little’s children’s books – the original book (1994) and the sequel are all about me – and epilepsy. The publications were so successful there’s now a Little Poss Club for kids, a website, merchandise, and activities too. And this all started because Epilepsy Queensland’s research identified there was a need to teach children about epilepsy to combat the lifelong stigma and discrimination that can be such a hurdle.

What’s been the highlight?
I thought we’d never top winning an international award for being the world’s best not for profit site for kids at a time when many places hadn’t even ventured into cyberspace, but there have been more highlights since. I’ve met more VIPs than you could poke a paw at and been to some amazing events. The Brisbane Broncos featured prominently last year – they hosted my birthday party. I got to meet Queensland icon Wayne Bennett and many Broncos players. I even helped entertain the crowd at a Suncorp stadium match – performing for a thirty something thousand strong crowd is hard to beat. I love signing autographs although it can be a bit tricky with my possum paws. I have to cope with the usual problems associated with stardom - I can’t walk down the street without people pointing and staring! and then there's the paparazzi…. Just joking. But I was on the television news the other week – when we were involved in a Channel 9 – 4BC event for the great Wally Lewis. The way he’s brought epilepsy out of the shadows is amazing.
However, when I kick back and reflect, the biggest buzz of all is that I’ve helped thousands of children with epilepsy. I know I help them understand what epilepsy is, how to help people with epilepsy, and that people with epilepsy can achieve great things. I get beautiful letters from members of the Little Poss Club sharing their experiences, frustrations, and hopes.

How do you get to be in the Club?
You have to be 12 years old and under. Members of Epilepsy Queensland get free Club membership, or you can take out a special membership for $10 per year.

If you could have one wish, what would it be?
Just one wish? That this year’s Little Poss Appeal will make a gazillion dollars so that I can help more children. And that Australian children with epilepsy get all the help and support they need.

For more information:
Epilepsy Queensland
P O Box 1457, Coorparoo BC Q 4151
phone 07 34355000
www.littleposs.com
photo: Wally Lewis and Little Poss
Who would make your financial, medical and lifestyle decisions if you couldn’t?

Considerations for appointing a Power of attorney

A power of attorney is a document that authorises another person to make decisions on your behalf. This can assist you when you are temporarily or permanently unable to manage your own affairs.

It is worthwhile thinking about appointing an attorney now while you are still of sound mind and able to do so, particularly if you have been diagnosed with a serious illness or are about to have major surgery.

You are the only person who has the right to make decisions about your assets and if you are ever unable to manage your own financial affairs – for whatever reason – your assets will be effectively frozen unless you have previously authorised another person to look after your finances on your behalf by signing a power of attorney, or another person applies to the relevant board, court or tribunal in your state for an order allowing him or her to handle your financial affairs.

Appointing an attorney enables you to have someone you trust manage your affairs and make decisions on your behalf should you be unable to do so.

Choosing an attorney

The only legal requirement is that the person you choose to act as your attorney is over a certain age specified in the legislation (e.g. 18 in Victoria) and is mentally competent. Often an attorney will be a relative, close friend or an independent person such as a lawyer, accountant or an employee of a trustee company.

Keeping in mind the following points, choose a person who:

- is trustworthy.
- does not have a conflict of interest that would make it impossible to act in your best interests.
- knows you and understands your wishes e.g. Is there any medical treatment you would not want? Some people write down their wishes to avoid conflict at a later date.
- can do the job. The person you appoint to make financial decisions may not be the same person you would want to make lifestyle or medical decisions on your behalf. If your State/Territory legislation allows, you can choose more than one attorney. While two attorneys might disagree about the decision to be made, two attorneys can be handy if one is likely to be away a lot or you don’t completely trust one to make decisions alone.

If, for some reason you are unhappy with your attorney, the power of attorney can be cancelled and you can appoint someone else.

Types of powers of attorney

There are different types of powers of attorney each designed to cover different situations and different types of decisions: temporary and permanent situations, and personal, lifestyle, financial, legal and medical decisions.

- General power of attorney
- Enduring power of attorney (financial)
- Enduring power of attorney (medical) (not in all States/Territories)
- Enduring power of guardianship

Which powers do I need?

The powers you need will depend on your wishes, and your personal, financial and family circumstances. Provided the legal requirements are met, you can make whichever powers you wish, and you can appoint whoever you wish to take on those powers. For example, you may choose to make only an enduring medical power of attorney, or you may choose to make all three enduring powers of guardianship and attorney. Similarly, you may choose to appoint only one person for all the powers you make, or you may choose different people for each of the powers you make.

In deciding which powers you want to make, take note of the type of decision covered by each document.

However, it is important to note that there is potential overlap between an enduring power of guardianship and an enduring power of attorney (medical) in relation to medical decisions, because both have the power to make medical decisions. However, in practice, a guardian can make medical decisions only if there is no medical attorney. If a medical attorney has been appointed, their decisions take precedence over those of the guardian.

General power of attorney

A general power of attorney is a legal document that authorises another person to manage your legal and financial affairs on your behalf and can take effect for a specified time only, or it can be indefinitely.

The powers given to the attorney can be as extensive or as restrictive as you choose. For example, they can be responsible for all your financial and legal transactions including selling your house, or they can be responsible for only some, such as writing cheques and paying bills or signing a particular document.

However if you become incapable of providing your attorney with clear instructions this document automatically becomes invalid.
Enduring power of attorney (financial)

An enduring power of attorney (financial) is a legal document that authorises another person to make financial and legal decisions on your behalf. It takes effect from whatever time you nominate: immediately, on a specific date, or if you so specify, when you become mentally incapacitated.

The powers given to your attorney can be as extensive or as restrictive as you choose. For example, they may be responsible for all your financial and legal transactions, or they may be responsible for only some, such as writing cheques and paying bills.

The enduring power of attorney (financial) can also be used for temporary circumstances, such as a stay in hospital or a trip overseas. However, because it is enduring, it will also automatically take effect if and when you become permanently incapacitated.

Financial attorneys are legally obliged • to act in your best interests at all times • to keep their property separate from yours, except when the property is jointly owned • to keep accurate records of all dealings and transactions • to follow any specific instructions set out in the power of attorney document • to maintain confidentiality.

You can specify the principles and philosophy that should underpin the way your financial affairs are managed. However, remember that the more specific and detailed your instructions, the harder the document is to prepare effectively. If your instructions are complex, consider seeking help from a lawyer.

There may be occasions when your financial attorney and your guardian (appointed under an enduring power of guardianship) need to work together. In these circumstances, your financial attorney is responsible only for carrying out the financial transactions associated with implementing your guardian’s decisions.

If the power of attorney operates only in specific circumstances, your attorney may need proof that the circumstances have occurred. For example, your attorney may need to provide your bank with a letter from your doctor stating that you are no longer capable of managing your affairs. However, privacy laws mean that you must have given your doctor permission to write such a letter beforehand. Clearly, this may not be possible if you are incapacitated. Therefore, be prepared for such eventualities by obtaining any authorisations that may be needed at the same time as you prepare the power of attorney.

Enduring power of attorney (medical treatment)

An enduring power of attorney (medical treatment) is a legal document that authorises another person to make decisions about your medical care and treatment on your behalf and takes effect if and when you become incapacitated. The incapacity can be temporary, for example, due to a loss of consciousness after a car accident, or permanent, for example, due to dementia. However, it does not take effect if your decision-making capacity has been reduced only briefly or mildly.

Your attorney holds the same powers (rights) to accept, request or refuse treatment that you had previously and is obliged to make the same decisions they believe you would have made.

Take the time to make sure your proposed guardian is aware of your personal views and desires, so they can take account of them when making decisions on your behalf.

An enduring power of attorney (medical treatment) does not permit your attorney to refuse you reasonable medical procedures for the relief of pain, suffering and discomfort or the reasonable provision of food and water. Your attorney can refuse other forms of treatment however the decision may be overridden by the relevant board, court or tribunal in your state under certain circumstances.

Enduring power of guardianship

An enduring power of guardianship is a legal document that authorises another person to make personal and lifestyle (non-financial) decisions on your behalf. The guardianship takes effect if and when you become incapacitated. The incapacity can be temporary, for example, due to injury, or permanent, for example, due to intellectual disability.

The powers given to your guardian can be as extensive or as restrictive as you choose. For example, they may be responsible for all your lifestyle decisions, such as where you live, whom you live with, where you work, who can visit you, and what health care you receive. Alternatively, they may be responsible for only some decisions, such as whom you live with.

Your guardian is obliged to act in your best interests. Take the time to make sure they are aware of your personal views and desires, so they can take account of them when making decisions on your behalf.

If you don’t specify the powers you wish to confer on your guardian, their power automatically defaults to that of a parent over their child. Such powers include making personal day-to-day decisions as well as decisions about accommodation, general lifestyle and employment. You can also give the person the power to make decisions about your medical treatment, except when an enduring power of attorney (medical) has also been signed.

Your guardian cannot allow you to be sterilised, have a pregnancy termination, or participate in medical research and organ transplants. Permission for these procedures must be sought from the relevant board, court or tribunal in your state.

The legal requirements for preparing a power of attorney are governed by State/Territory laws. For information and advice about guardianship and power of attorney matters please contact The Office of the Public Advocate in your state or territory.

This article was adapted from information prepared by John Berrill from Maurice Blackburn Cashman for the Chronic Illness Alliance. The Epilepsy Report kindly thanks the Chronic Illness Alliance for permission to draw from this material.

For more information about the Chronic Illness Alliance visit www.chronicillness.org.au
Australia 2020 Summit: no vision for people with epilepsy.

On the weekend of 19 and 20 April 2008, one thousand people will gather in Canberra to contribute their views on the future of Australia to public policy development by the new Federal Government. The stream to discuss a long term national health strategy contains many well-known names in the health area, particularly those associated with ageing, disabilities, indigenous health, general practice and health promotion. There are also people well-known for their views on reform of the health system. As well, there is at least one elite sportsperson. His presence, it was explained was that sport would play a role in the future to address the ‘obesity epidemic’ and its associated ‘lifestyle diseases’ of Type 2 Diabetes, heart disease, cancers and musculoskeletal problems.

There is no clearer an example of the continuing marginalisation of people whose chronic diseases are not life-style related, including people with Type 1 diabetes, cystic fibrosis, multiple sclerosis, thalassaemia, Crohn’s and colitis and of course, epilepsy.

Recent research on the personal impact of epilepsy demonstrated that most people with epilepsy felt marginalised because of their epilepsy by the wider community. People with epilepsy found it difficult to obtain employment, felt their mobility problems were widely misunderstood, and were often socially isolated because many members of the community did not like to associate with people with epilepsy. Ironically, one of the outstanding examples of social exclusion came from rural people with epilepsy, who found they were often excluded from participating in local sports activities, even though they felt up to the task. The language the participants in this study used to describe their plight was the language of social exclusion. They were ‘left out’, ‘avoided’, ‘shunned’ and were social pariahs. These participants wanted to actively address these problems; they were not passive victims and they called for campaigns on community awareness to dispel some of the community myths around epilepsy so they could take a greater role in their communities.

The Chronic Illness Alliance has argued on behalf of all people with chronic illnesses that the impact of illness cannot be managed by health care alone. Policy needs to include a focus on employment opportunities, income and relationships. It also needs to consider health reforms that deliver affordable medicines, aids and equipment and affordable health care.

The current composition of the Australia 2020 health stream is unlikely to present an integrated framework of these concerns because of its focus on health promotion in ‘lifestyle’ illnesses and because there are too few people there to promote the needs of a substantial number of Australians with chronic illnesses that cannot be prevented through exercise and diet.

If people with epilepsy as well as other people with serious chronic illnesses that are not amenable to behavioural change, are to receive any benefits from new public policy including that of social inclusion, their voices must be represented in the discussions that will drive those policy developments.

Christine Walker
Chronic Illness Alliance

[Christine was unsuccessful in her nomination to Australia 2020.]
Jacinta Cummins joined Epilepsy ACT in 2000 as Executive Director and is the current Chair of the Joint Epilepsy Council of Australia (JECA). Jacinta’s achievements during this time include delivering the nationally accredited course in epilepsy training, developed by Victoria University in collaboration with the Foundation of Victoria, throughout the ACT, developing an award winning information resource for indigenous Australians, and raising the bar on community service delivery within the ACT.

Jacinta works tirelessly for the Australian epilepsy movement. As Chair of JECA and lobbyist, the recent announcement of the Parliamentary Friends of Epilepsy group is evidence of her determination to give epilepsy a voice in the halls of power.

Married with two adults sons, I have lived in the ACT for most of my adult years. I grew up with three sisters on a farm in the middle of nowhere that didn’t have electricity until I was about 10 years old. I went to a primary school that had 18 kids in a good year and was in a class of my own. I moved to Melbourne for my secondary education and during this time I did volunteer work at Kew Cottages, a residential service for the intellectually disabled. I guess you could say my interest in disability stemmed from there.

In 1988 I was employed as a Home and Community Care Case Manager for the Aged, Younger People with Disabilities, people of Non English Speaking Backgrounds, Aboriginal and Torres Strait Islanders and their Carers. The ethos of the service was to achieve excellence in the provision of services to prevent inappropriate admission to institutions within a HCAA Case Management Framework.

Since joining Epilepsy ACT I have been privileged to speak on behalf of the epilepsy community at both Federal and Territory level. Such advocacy has included input in getting the question on seizures included in the Child Disability Assessment Tool, sitting on the committee for the ACT that produced the report *Raising the Standard. A Manual to Guide Quality Improvement in the ACT Community Service Organization*. 2002, and sitting on the Access Equity and Funding Committee for Disability Services. I am currently a member of the National Disability Services Committee.

At Epilepsy ACT our mission is to ensure that epilepsy information is accessible to all within our community and with this in mind we undertook a program to develop appropriate literature and counselling services for our local indigenous community. In consultation with local groups a culturally sensitive Epilepsy Information & Resource Kit for Aboriginal People was produced. In addition, an indigenous person was employed and trained as an epilepsy educator and counsellor to work within the community. This program was awarded the Pfizer Foundation Award from America.

With our continuing focus on community education and training, I completed Cert. IV in Workplace Assessment and Training enabling me to deliver an accredited training program developed by Victoria University and the Epilepsy Foundation of Victoria. (CHCCS6C “Assess and deliver services to clients with complex needs” from the Community Services Training Package CHC02). Delivery of this program has further enhanced the standing of Epilepsy ACT within the disability sector. In addition, professional qualifications in Solution Oriented Counselling have given depth to our counselling services.

In 2003 Epilepsy ACT became an inaugural member of The Joint Epilepsy Council of Australia (JECA) and I have held the Chair since 2006. During this time JECA has conducted Australia’s largest nationwide survey of people with epilepsy and made the first agreed submission to the Federal Government from the epilepsy movement in the last 20 years.

After Russell Pollard and I lobbied for the submission, several politicians including Labor’s Jill Hall MHR and the National’s Mark Coulten MHR have taken the lead in forming the Parliamentary Friends of Epilepsy group. This can only augur well for the epilepsy movement in Australia.

I am proud to be part of the JECA and Epilepsy Australia team as we are all working together to achieve the best outcomes for people with epilepsy.
Sparks of Creativity Art Exhibition
5 - 7 November 2008 Sydney, Australia