



*Parliamentary Friends of Epilepsy*

**INFORMAL INQUIRY INTO  
THE IMPACT OF EPILEPSY IN AUSTRALIA**

**PARLIAMENT HOUSE CANBERRA 30 NOVEMBER 2009**



*Epilepsy is one of the most misunderstood, and therefore least understood, conditions of our time. It does indeed 'stay in the shadows' of our community.*

*Some of the earliest writings on this disease reveal that it was once known as the 'Holy Sickness' and notably studied by the Greek physician Hippocrates. Recent translations of a Babylonian tablet dating from about 500 BC have revealed even earlier descriptions of epilepsy.*

*St Mark in Chapter 9, Verses 17-18, indicated an incident of epilepsy; "he has an evil spirit in him and can not talk. Whenever the spirit attacks him, it throws him to the ground, and he foams at the mouth, grits his teeth and becomes stiff all over." Today the condition would most likely be diagnosed as a grand-mal seizure, but at the time, traditional healers would most likely surmise that there had been an act committed against God, along with the presence of demons, that caused the horrific episode.*

*Although times have changed and diagnosis and treatments improved, sadly, the wider public still has little knowledge of the condition.*

*It is time that all sectors of the community, from politicians to shopkeepers, neighbours, employers and particularly those in the public sector charged with assisting people with disabilities, unite to ensure that awareness raising and education of this disabling condition becomes a social priority.*



## **PARLIAMENTARY FRIENDS OF EPILEPSY: THE IMPACT OF EPILEPSY IN AUSTRALIA IN 2009**

### **Parliamentary Members**

Jill Hall MP, Senator Gary Humphries, Damian Hale MP, Mark Coulton MP

### **BACKGROUND**

The Parliamentary Friends of Epilepsy group was formed in 2008 following lobbying by members of JECA.

Subsequently, the Parliamentary members group resolved to further the support provided to this large, but not widely known or accepted condition, by calling for submissions from interested parties, particularly patients and carers. The submissions were sought with a view to holding an informal hearing to gain views of patients, carers and professionals involved with Epilepsy.

Some comments on those submissions are included in this report.

### **THE HEARING**

The informal hearing was held in Parliament House Canberra on Friday 30 November 2009, commencing at 9.30 am. The Parliamentary members welcomed participants and expressed thanks for their co-operation in making themselves available at short notice.

All participants expressed their thanks for holding the inquiry, as it was the first time the condition was having a national voice, the opportunity to come out of the shadows, and to raise awareness of the condition for politicians and the general public.

Two main sessions were held, one in the morning for the professional and organisation support groups, and an afternoon 'round table' session to provide an opportunity for persons with epilepsy and their carers, to provide input to the discussion.

## RECOMMENDATIONS:

1. That the Government undertake a comprehensive education/awareness raising program on epilepsy for all sectors of the community, including government agencies such as Centrelink.
2. That Government departments, especially Centrelink, be required to review their policies to include a new definition of disability that includes epilepsy, provide better access to services and benefits for those affected by epilepsy and one application to cover access to services in all government agencies.
3. That positive employment and support services in government agencies be developed to recognise the needs, abilities and contributions of those with epilepsy, thereby removing barriers to employment for this group.
4. That additional questions regarding epilepsy be included in the National Health Survey to provide accurate data on incidence, treatment etc.
5. That greater emphasis be placed on research, data collection and standardisation of data regarding epilepsy.
6. That adequate government funding be made available to the various Epilepsy support groups and that they be encouraged to work together to ensure they attract maximum funding.
7. That initial training and ongoing medical education for GP's and nurses be reviewed and improved to ensure training is adequate in quantity, is of a high quality and is current in relation to diagnosis, treatments and impact in individual lives. Ongoing education and training to be provided through the Urban Division of General Practitioners and existing Nurse Education Networks..
8. That given the unique transport difficulties, including public transport, experienced by those with epilepsy resulting from the nature of sudden, episodic seizures and the aftermath; State Governments be encouraged to review taxi voucher eligibility criteria to better accommodate the needs of those with epilepsy.
9. That the Parliamentary Friends of Epilepsy support recommendation No 6 of the 'Who Cares' Report:  

**“Recommendation 6**  
That the Australian Government consider consolidating portfolio responsibility for people with disabilities, people with mental illness, the frail aged and their carers into a single Australian Government department.”
10. The Parliamentary Friends of Epilepsy believe that the process for approving new treatments and technologies for epilepsy needs to be responsive to the latest scientific developments.
11. That investigation into ways to improve access to services, doctors and specialists for rural and regional areas be undertaken.
12. That the Federal Government support a system of Epilepsy Ambassadors across Australia.
13. That the Federal Government write to the States and Territories to ensure that epilepsy is covered by the criteria for disability in all areas.

## SUBMISSIONS RECEIVED

Over 360 submissions were received, including one from New York, USA.

The majority of individual submitters have specifically requested anonymity for a range of reasons, not the least being that many have found it necessary to not disclose their epilepsy to employers in particular.

Submissions from organisations such as the Epilepsy Action Australia and a number of Epilepsy support groups in SA, Victoria, NSW and Qld, plus eminent medical practitioners/specialists provided a wide range of diverse background documentation. Some of the information related to WHO 2005 statistics indicating that Epilepsy affects over 50 million people at any one time and is predicts that over 100 million are likely to develop the condition during their life.

The Bionic Ear Institute reported that Professor Mark Cook (mentioned elsewhere in these notes) is working with them on epilepsy research. Dr Deepak Gill, head of the comprehensive epilepsy program at Westmead Children's Hospital in NSW, and a member of the newly formed State-wide Comprehensive Epilepsy Network of NSW, provided some interesting information including: approximately 51,000 NSW people have epilepsy, including around 10,000 children of which around 1100 have poorly controlled epilepsy. He also includes information about access waiting times.

Most individual submissions were heart-rending, covering issues of: discrimination in schools; lack of sleep for parents; usually resulting in the need to leave employment, continual major injuries received through sudden 'dropping' in grand - mal seizures; frustration with Centrelink; employment discrimination and job loss; transport issues; 'trial and error' concept of medication through to non availability of respite care; and the cost of providing the first Victorian Seizure Response Assistance Dog to alert the carers.

An ongoing theme in submissions was lack of proper, timely diagnosis. Continuing instances of vague diagnosis, continuing consultations before eventual referral to a specialist with an unconscionable wait for a specialist appointment were reported. The cost of MRI's, the difficulty in obtaining ongoing specialist (or even GP appointments) and especially the attitude of 'we'll just try this one' (medication), the ongoing trial and error of trying to control epilepsy are draining for the patient, carers and wider family.

Many problems with every day life were revealed and apart from medical and pharmaceutical issues, loss of awareness from drug regimes, difficulties for other siblings, lost time schooling, particularly difficulties of being 'different during teen age years and the special concerns of ageing parents.

The majority of submissions indicated the problems of social isolation whilst discrimination in education and employment and the need for 24 hour care and surveillance were common.

The cost of medications and transport are drains on all participants. Submission No 245 came from a 59 year old mother on a pension, trying to support her adult daughter who is endeavouring to live alone in a 1 bedroom flat at \$200 per week rental in an unsuitable location and environment, because "there is nowhere else and nobody cares". Consequently, the mother has to pay for all the medications and wonders what will happen if she dies.

### **Constant themes throughout submissions were:**

- Difficulty in obtaining appropriate, non discriminatory **education** for child sufferers.
- **Employment discrimination.**
- Difficulty in timely **access to specialists.**
- **Waiting times for MRI's** plus waiting at clinics with episodic child.
- Lack of overnight **respite access.**
- Difficulty in obtaining a **correct diagnosis.**
- Lack of knowledge (& narrowness of criteria) at **Centrelink.** (Epilepsy not seen as disability).
- Depression.
- **Sleep** deprivation for parents and carers (waiting for next seizure) and need to resign from employment to take on caring role
- **Transport,** many do not qualify for taxi vouchers, resulting in further isolation. Even when adults are granted a driving licence there can be an issue with non availability of comprehensive insurance.
- Problem of **many GP's not au fait with whole spectrum of epilepsy,** therefore misdiagnosis and inappropriate medication. Continual trial & error with drugs.
- **Emergency ward hospital staff** often not trained or aware of epilepsy emergencies.- Medication often provided with drastic side effects.
- Difficulty in **access to specific drugs** such as Sibelium (needs a Specific Access Script) and general **costs associated with pharmaceuticals,** even with Health Card – where available- some take 4 different medication, several times daily. Medical alert bracelets can be expensive.
- Lack of services, medical/specialist advice for regional and country residents, including MRI appointments in early morning when needing to travel long distances.
- Need for massive increase in community education/awareness raising. Epilepsy known since biblical times, but still treated like 'lepers'. Autism, although relatively new, is widely known and accepted.
- Need for increased funding and support for various Epilepsy organisations eg Diabetes organisations received good govt support.

## **SUGGESTIONS FROM RESPONDENTS.**

- Increased visibility and community acceptance of Epilepsy.
- Improved transport arrangements- taxi vouchers.
- Improved medical education on all aspects of Epilepsy.
- Encourage Dr's to take more time with patients and fully discuss drugs used.
- Bulk billing would greatly assist those without health card.
- Early intervention programs- education based.
- Increased research funding.
- Employer education and employment support – such as appropriate work training.
- Improved access to services, doctors and specialists for rural and regional areas.
- Simplify applications for assistance – 1 application to cover all issues and departments.
- Appropriate funding for Epilepsy support organisations.

## THE HEARING

### Session One – Participants,

Parliamentarians: Jill Hall MP, Senator Gary Humphries, Damian Hale MP, M Coulton MP (Apology)

Staff Members : Mark Raper ( J Hall MP) Pat Davies (Sen Humphries) and Judith Satrapa Departmental representative from Mr Bill Shorten's office (FHaCSIA).

Participants: Dr Sophie Calvert. Paediatric Neurologist, Co-Chair Qld Epilepsy Network  
Dr Kate Riney. Paediatric Neurologist, Co-Chair Qld Epilepsy Network  
Prof Mark Cook. Neurologist. President Epilepsy Victoria  
Mr Graeme Shears. CEO. Joint Epilepsy Council of Australia (JECA)  
Clare Thorn State Manager Epilepsy Tasmania  
Helen Whitehead CEO Epilepsy Queensland  
Glen Moore Director of Aurora Bio-Science  
Judy Southwell & David Southwell, parents of Erin a VNS recipient.  
Alison Johnston VNS recipient  
Dr Christine Walker. EO. Chronic Illness Alliance.  
Jacinta Cummins CEO Epilepsy Assn ACT  
Robert Cole CEO Epilepsy Assn SA & NT  
Helen Whitehead CEO Epilepsy Qld  
Denise Chapman Exec Officer Epilepsy Assn & JECA

**1. Mr. Graeme Shears, Joint Epilepsy Council of Australia (JECA) and his Associates raised the following issues:**

- JECA thinks nationally, acts locally.
- The JECA submission is evidence based, reflecting non medical issues.
- Of around 630,000 minors in Australia who may have condition, only 3-4% were correctly diagnosed.
- Of those, approximately 10% had seizures.
- With an ageing population, many more over 60's were being diagnosed'
- Aim is for all with the condition to participate in all facets of life, without discrimination, which sadly is not the present case.
- There is widespread evidence that the current health paradigms applied are not working, hence many are taking up space and valuable resources in Emergency units.
- JECA seeks partnerships to harmonise resources and services.
- The isolating effects of the condition for the patient, carers, families and the effect on siblings are important factors for consideration.
- Correct, timely diagnosis would be of immeasurable value to families.

## **2 Professor Mark Cook, Paediatric Neurologist (and other participants)**

Prof Cook indicated that everyone has the potential for epilepsy. Often small scars on the brain (of unknown origin- possibly from birth) were the cause, not sudden traumatic events as often supposed, but sleep deprivation often one of the triggers for seizure. Onset after a stroke is fairly common. Professor Cook raised the following issues:

### **Medical Training is a big issue.**

- The appropriate training of medical and nursing staff is a major problem, as many patients he saw had been inaccurately diagnosed, many have one had one isolated seizure, while up to 20% of those presenting to him do not actually have epilepsy.
- Quality of diagnosis, and ascertain the best treatment pathways is important for the patient.
- A major problem is that there is limited training available for medical practitioners and limited interest, as it is not a 'sexy' practice area. It is hard work, with patients often seeing the specialist as their only contact/hope. The remuneration is not high.
- Reimbursement for an investigation is around \$750 in Australia against \$10,000 in USA.
- Lack of funding, both State and Federal, results in very few residence positions available in Australia, possibly only 3. (Specialist training mainly overseas eg UK)
- Many GP's lack up to date knowledge (a problem also with medical educators in universities) and therefore the skills to recognise symptoms and therefore diagnose correctly.
- Medical education is often outmoded, with some medical educators unaware of latest trends.
- Eg. Huntington's disease, relatively rare in Australia compare to Epilepsy, is given far more teaching time.

### **General Epilepsy issues.**

- Humiliation is a very real factor (and fear) for patients. They often have no after knowledge of the seizure, which may involve incontinence, undressing or aggressive behaviour.
- Many have no prior warning of seizure.

- Finding non medical support (such as State Epilepsy Councils) is difficult for some, particularly in more remote regions.
- Depression and social isolation are major factors for not only the patients, but also their families.
- For non medical support- so important to patients and their families- SA/NT does not have any funding through State Governments, while Tasmania receives \$26 per person, \$16 in Victoria, \$19 in ACT.
- In answer to issues of best practice in treatment, Prof Cook indicated that there are 3 major centres in Victoria. Qld is setting up an holistic treatment network as is the case in NSW.
- Specialists are limited; some States have only 1 specialist Paediatric/Neurologist. Northern Tasmania is reliant on a visiting Victorian specialist.
- Problems with access to appropriate specialists in Queensland and Tasmania were highlighted, with associated long waiting lists for attention.

#### **Drugs –**

- Most anti convulsants could be classified as poisonous, can cause malformation in foetus, they are expensive, hard to obtain in many situations such as overseas successful drugs, and there is the need to obtain special permission for some drugs which again is time consuming and an added cost.
- Some 60-70% of seizures controlled by medication, but many have enormous side effects including drowsiness, hair loss, vomiting etc.
- around 2% of cases have surgical intervention.

#### **In answer to a question from the parliamentary panel regarding what are the most pressing needs, Prof Cook indicated:**

- Epilepsy questions to be included in National Health Survey to provide useful data.
- An Australian study of the social- medical modalities to raise treatment awareness.
- Encourage training of neurologists (currently no funding in hospitals)
- A full time research position for a longitudinal study of the psycho-social aspects to see if lifestyle can be improved.
- Adequate funding for the various Epilepsy support groups as most patients and their families/carers could not function without that support, as this is often the only place they receive information about the condition.

### **3 Glen Moore, Director Aurora BioScience - David and Judy Southwell, Alison Johnston.**

Mr Moore spoke regarding the Vagus Nerve Stimulator (VNS), a non pharmacological treatment for pharmacological resistant epilepsy, often seen as a last resort treatment. The VNS is aimed at reducing the frequency and severity of seizures and involves implantation of the device under the skin (in similar manner to a pacemaker).

The VNS has been used in Australia for Over 15 years. Currently about 30 -40 per annum are implanted, with approximately 1/3 being in children (the youngest around 3 years of age).

- Although approved by the TGA, a recommendation for a Medicare number through the Medical Services advisory Committee (MSCA) has not received approval.
- The VNS generator/battery has been listed on the DoHA Prothesis List for approximately 5 years which enable those with private health cover to a rebate (RA001 & RA002) of \$16,070 and \$3,400 respectively.
- However, changes to the Prothesis List policy, and the refusal of a Medicare number, leaves patients with no public or private funding for the VNS system in Australia.
- Cost effectiveness studies on the system in 2007 indicate that significant savings could be made on emergency and hospital admissions if those for whom the system would be appropriate, could be financially supported.

**Mr & Mrs Southwell and Alison Johnston** spoke of the benefits of utilising the system from a recipient/carer view.

- Benefits which Alison identified from using VNS, were an improvement of around 70% to her memory and seizure control, allowing her to resume working. She has now been 2 years seizure free.

The response to an enquiry from the parliamentary panel regarding the ability to appeal the MSAC decision, indicated that there was no formal appeal process, just a new application should new evidence become available.

- The evidence previously supplied was from clinical enquiries in 1990's in key overseas countries, apparently not acceptable by MSAC.

The panel resolved that given the improvement of life quality to those utilising the VNS system, they would take up the issue of timely approval of new technologies and treatments.

#### 4 Dr Kate Riney and Dr Sophie Calvert.

The Drs responded to panel questions on the nature of epilepsy. An increased number of genes have been identified. If it can be identified and genetic, it narrows the field of treatment.

Drs Riney and Calvert spoke to their in depth submission which contained a range of information papers on epilepsy.

They identified a number of issues including:

- Difficulty of making a correct diagnosis.
- 
- Approximately 1 in 4 of those referred do not have epilepsy.
- Misdiagnosis can lead to death. (Attachment A to their submission contains 2 papers on this issue)
- Those with epilepsy face a myriad of problems in their daily lives, apart from the burden of seizures.
- Stigmatisation is a major problem, not least for those who suffered a childhood category that they grow out of- once labelled the stigma tends to stay.
- Depression is a major problem.
- Sleep disorders such as sleep apnoea, restless leg syndrome and narcolepsy are problems .
- Memory loss associated with the process of ageing.
- Bone health can be affected by the drug regime, often resulting in osteoporosis.
- The Queensland Paediatric Epilepsy Network has been established with a view to improving the health care outcomes for children and teenagers with epilepsy.
- A managed network allows care in a State or country to be treated in an holistic fashion. Attachment D provides details of managed clinical networks elsewhere.
- Re- enforced comments by others regarding lack of medical training and relevant funding. There have been rapid advances in treatments over the past 2 years.
- The managed network system allows treatment of the person as a whole human being, not just the seizures and has the potential for savings.
- A large problem in Australia is lack of adequate local data.

## 5 **Dr Christine Walker, Sociologist.** Chronic Illness Alliance.

Dr Walker spoke to her submission indicating that those with epilepsy, and their families, suffered many disadvantages.

- Australian sociological research indicates that they are socially excluded with resultant impacts on quality of life as they are unable to participate fully in the lives of their communities.
- There is a lack of appropriate, current data on all issues associated with epilepsy.
- Epilepsy is poorly understood, suffering from confused definitions, often being defined as a mental disability.
- There are huge gaps in policies, particularly in health.
- Though a chronic condition and likely to increase with age, little planning has occurred.
- Discrimination legislation falls short of addressing the associated stigma. The current complaint based system is inadequate.
- Affirmative Action for those with epilepsy is required in all areas.
- Employment policies such as 'Welfare to Work' focus on unemployed individuals and do not deal with the systemic barriers, including employer misconceptions. People with epilepsy may meet all the requirements and still not be successful due to the stigma.
- Education is a problematic area. Peer and teacher discrimination, based on poor awareness/information and sheer frustration on the part of the affected student.
- Schools and employers often do not realise that after a seizure, whilst appearing normal, a person may just simply need to sleep for some time.

In response to a panel question of what could be done with \$500,000 Dr Walker indicated several areas to choose from:

- A public awareness campaign (probably need double)
- Tenders for a chronic disease management program.
- Job Capacity Assessors training (Centrelink) Staff often see people in controlled mode and therefore have misconceptions of their work capacity, with memory loss being an unseen problem.
- Improve national data collecting capacity.
- Ensure epilepsy plans in all schools with improved teacher education on the topic.
- Schools are the best place to begin awareness raising of issues around epilepsy.

## 6 Joan Hughes, Carers Australia

Joan spoke of the vital role of the unpaid carers and the number of families affected and that they are the invisible workforce. As such these carers should be able to fully participate and share in sound policies related to health, welfare, education and employment. Other points raised:

- There are 380,000 carers under 26 years of Age in Australia, with 170,000 under the age of 18. The latter group suffer a range of added problems, education, etc.
- Lower government support for epilepsy places a greater burden on carers.
- Gaps in community awareness also has effected on carers and their role.
- Shift away from institutional care has also had an effect on carers.
- Due to broken employment patterns of carers, superannuation becomes a problem.
- The emotional toll on parent carers, ie waiting for warning signs of seizures, coupled with lack of adequate sleep cause emotional and health problems.
- The increased incidence of single parent families presents problems of continuity of care.
- In general carers suffer social isolation, and costs associated with their loved one, they are generally unable to save for their old age/ retirement, they suffer from lower health and wellbeing for their corresponding age groups.
- This older group of carers is particularly at risk when patient falls etc.
- The improvements in the Carers Allowance are appreciated, but still more needs to be done for them.
- The recent government announcement of funding to double the sample size of carers for ABS surveys will be of assistance. (result of Who Cares..... report)
- Respite care that is appropriate and accessible is an on-going problem, especially in relation to epilepsy.
- Development of and access to a type of home care packages would be of assistance, particularly to older carers, who are not necessarily meet age pension criteria.

## The Afternoon 'Round Table' Session

### Participants.

Parliamentarians: Jill Hall MP, Senator Gary Humphries, Damian Hale MP, M Coulton MP (Apology)

Staff Members : Mark Raper ( J Hall MP) Pat Davies (Sen Humphries) and Judy from Mr Shorten' s office (FHaCSIA).

Participants: Professional and Organisations:

Dr Sophie Calvert. Paediatric Neurologist, Co-Chair Qld Epilepsy Network

Dr Kate Riney. Paediatric Neurologist, Co-Chair Qld Epilepsy Network

Prof Mark Cook. Neurologist. President Epilepsy Victoria

Mr Graeme Shears. CEO. Joint Epilepsy Council of Australia (JECA)

Clare Thorn State Manager Epilepsy Tasmania

Helen Whitehead CEO Epilepsy Queensland

Glen Moor, Director of Aurora Bio-Science

Judy Southwell & David Southwell, parents of Erin a VNS recipient.

Alison Johnston VNS recipient

Dr Christine Walker. EO.Chronic Illness Alliance.

Jacinta Cummins CEO Epilepsy Assn ACT

Robert Cole CEO Epilepsy Assn Sa & NT

Helen Whitehead CEO Epilepsy Qld

Denise Chapman Exec Officer Epilepsy Assn & JECA

Participants- Individuals

Katherine Rose

Kerry Flanagan

Jean Foster

Ian Thompson

Yesser Rimes

Jason Gordon

Kay Pilkington

Stuart Poole

David Chan

Kerrie Newell

Socrates

Each participant was invited to speak about their particular situation or involvement. Those from the organisations who had spoken at the morning sessions, spoke reconfirming their earlier input.

For privacy reasons, the individual comments are not listed, however, the similar recurring situations identified were:

- Thanks to Parliamentary Friends of Epilepsy for giving them a voice.
- Gratitude to the various Epilepsy Support groups.
- Realisation of the effect on their siblings.
- Difficulty in obtaining correct diagnosis.
- The cost of, and ongoing need for MRI's etc.
- The continual need to change medication with changing side effects.
- Loss of driving licence and subsequent difficulties with public transport, especially the fear of having a seizure whilst using public transport.
- Discrimination in education by peers and many teachers.
- Discrimination in employment. Employers and Centrelink do not readily understand that sleep/rest is often a consequence of a seizure.
- Dealing with depression and social isolation often through loss of friends.
- Loss of self esteem.
- Lack of public awareness and medieval view of epilepsy, often mistaken for mental illness.
- Problems in accessing Disability Support Pension- Centrelink often took the view that the applicant was 'not sick enough'. This is part of the lack of awareness which needs to be addressed by the department.

## **Conclusion of proceedings**

The Panel thanked all participants, professional, NGO's and private individuals for their attendance and generosity in sharing their experiences and thoughts.

The participants were advised that the process would be to discuss the issues with Mark Coulton MP and Clare Moore MP, who had both tendered apologies for the day.

The recommendations would be tabled in the House of Representatives and the Senate with hopefully a Private Members Bill developed around the recommendations.

The proceedings concluded at 3.00 pm

Subm No.	Vol	Name	Organisation
P&S1	V1	Drs K Rigney & Sophie Calvert	Qld Epilepsy Network (Useful chart roles of various groups - Drug Side effects)
P&S 2	V2	Carol Ireland	CEO Epilepsy Action Australia (indicates Aust wide) (Incidence figures (WHOrg) ,nature of condition, lack of Aust. Research)
P&S 2	V2	Prof Mark Cook	Neurologist Vic
P&S 5	V2	Ms Glenis Cook	Bionic Ear Institute Vic
P&S 6	V2	Louise Maniatakis	Former employee Epilepsy . Foundation Victoria
P&S 7	V2	Kim Jones	Epilepsy Supp Group. Newcastle
P&S 8	V2	Prof B Stokes	WA Dept Health
	V3	Mr Glenn Moore	Aurora BioScience Pty Ltd (Re: VNS Therapy)
P&S 9	V3	S Gray	Goulburn Valley Epilepsy Support Group
P&S 10	V3	Joan Hughes	Carers Australia
P&S11	V3	Dr Christine Walke	Chronic Illness Alliance
P&S 12	V3	Davis Sharp	Epilepsy Association WA
P&S 13	V3	Sue Pinkerton	Tuberous Sclerosis Association
P&S14	V3	Craig Anderson	Sydney Institute
P&S 15	V3	Dr Ken Baker	National Disability Services
P&S 16	V3	Dr Deepak Gill	Westmead Children's Hospital
P&S17	V3	Dr Simon Harvey	Royal Children's Vic ( Including Limited Training and Employment opportunities in Epilepsy area)
P&S 18	V3	Dr S Malone	Paediatrician / Neurologist
P&S 19	V3	Sue Pringle	Cooinda Family Support Group Albury /Wodonga
P&S 23	V3	Linley Klopper	Colac Support Group
P&S 19	V3	Graeme Shears	JECA

**Plus 329 confidential submission from individuals.**