

Annual report 2009–10



Dedicated to enhancing
the quality of life
of people living with epilepsy
through information,
education, advocacy,
support services
and research

Our purpose

The Epilepsy Foundation of Victoria is dedicated to enhancing the quality of life of people living with epilepsy through information, education, advocacy, support services and research.

Our approach

Ensuring the Epilepsy Foundation of Victoria develops a high-performing culture, one which utilises and extends our capabilities by working collaboratively where possible, and which works in accordance with our values, in a sustainable way, to deliver on our purpose.

Our values

Equity and access: Ensuring that people living with epilepsy get a fair go and can connect to appropriate supports and services.

Participation and inclusion: Engaging people and building effective relationships based on a shared purpose.

Resourcefulness and innovation: Seeking better ways to do more with the resources available to us.

Trust and integrity: Displaying integrity in everything that we do thus enabling the people who rely on us to have confidence in our motives and abilities.

Accountability: Fulfilling our responsibilities and obligations.

www.epinet.org.au

Epilepsy Helpline 1300 852 853

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Epilepsy Foundation of Victoria
818 Burke Road
Camberwell Victoria 3124
phone (03) 9805 9111
fax (03) 9882 7159
web www.epinet.org.au

The Epilepsy Foundation of Victoria would like to thank the clients who have willingly and openly told their stories throughout these pages.

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Our organisation



Highlights of 2009–10 at a glance

This year, the Epilepsy Foundation of Victoria:

- Worked with the Joint Epilepsy Council of Australia (JECA), to raise the profile of epilepsy within the Australia Government, resulting in the first-ever federal Inquiry into Epilepsy, held in October 2009
- Refined our service delivery model to ensure greater efficiencies in the way we provide services and better matching of skills with client needs
- Provided services to 5012 people with epilepsy, family members, and those who support people with epilepsy
- Increased our work in education and training to deliver epilepsy programs to four key target groups: Employment and Assessment, Health and Community, Schools and Early Childhood and Aged Care and Disability resulting in greater knowledge of epilepsy, seizure first aid and emergency medication management
- Undertook a pilot training program for Centrelink Job Capacity Assessors to increase their understanding of epilepsy and the capacity of people with epilepsy to undertake employment, leading to the program becoming available nationally and greater opportunities for people with epilepsy to participate in the workforce
- Partnered with the Epilepsy Society of Australia on a number of joint initiatives and projects. Eight neurologists and other specialists participated in our Understanding and Managing Epilepsy Series and Epilepsy Specialist Series
- Increased our involvement in seizure clinics, with additional weekly clinics now operating at Ballarat Base Hospital and Western Health, Footscray, and a second clinic at Royal Melbourne Hospital
- Developed and strengthened a working relationship with Dr John Carnie, Chief Health Officer of Victoria, who has been instrumental in helping us to progress our Epilepsy Smart Schools Program, designed to educate principals and teachers in managing epilepsy in schools, and to develop an epilepsy awareness DVD targeting the medical profession
- Created the Epilepsy Management Plan and Support Package, a comprehensive suite of documents to assist people with epilepsy, or parents of children with epilepsy, and those who support people with epilepsy, to create epilepsy plans to better manage their condition
- Commenced the first Australia-wide longitudinal socio-economic study of epilepsy, to be conducted over 10 years
- Reached 20,180 school students from 134 primary schools and 27 secondary colleges with our Trivia Challenge competition
- Achieved a 31 percent increase in appeal donations (up \$105,828) and a very pleasing increase of 40 percent in donors who gave to the Epilepsy Foundation
- Saw donations from our telemarketing program increase by \$44,684
- Successfully negotiated with the Melbourne Racing Club to be named as the official charity partner of the 2010 Caulfield Spring Racing Carnival BMW Pin & Win program
- Undertook a comprehensive media campaign to promote Epilepsy Awareness Week 2010, resulting in wide-ranging coverage in suburban, regional and online newspapers and several radio interviews in metropolitan Melbourne and regional Victoria
- Together with Real Time Health, participated in the development of a multi-media resource for schools on the needs of children and teenagers with a chronic illness
- Installed a new telephone system at the Epilepsy Foundation's head office and new audio visual equipment across our two sites in Camberwell and Geelong, to improve communication and workflow

Our aspirations

We aim to achieve our aspirations by working collaboratively with governments at all levels and other health and community-based organisations, to identify existing programs to which we can add value, or potential joint programs, and to ensure the appropriate and optimum use of our resources.

We work with children, young people and adults with epilepsy so that they:

- experience increased self-esteem and connectedness
- experience better educational outcomes
- have increased opportunities to participate in community life
- have knowledge and skills to achieve their own wellbeing
- have access to support services and learning opportunities

We want families and support networks of people with epilepsy to:

- be confident and knowledgeable
- have access to opportunities for support and networking
- have access to learning opportunities

In our ideal world, the community:

- provides increased opportunities for participation
- gives people living with epilepsy a national voice
- responds to the needs and aspirations of people living with epilepsy
- understands epilepsy
- affirms people living with epilepsy as valued members



That the Epilepsy Foundation of Victoria:

- is well led
- is sustainable
- grows, both in knowledge and capacity
- has the right people and enough resources

In the Epilepsy service sector we:

- share knowledge and experience to create positive change
- work together so people living with epilepsy are living richer lives with more opportunities in education, employment and lifestyle

About the Epilepsy Foundation of Victoria

The Epilepsy Foundation of Victoria is this state's community support agency for people living with epilepsy and their families. Services have been provided since May 1964, across Melbourne and regional Victoria, from our offices in Camberwell and Geelong.

The Epilepsy Foundation also supports other state service providers and has played an active role in the national peak body, the Joint Epilepsy Council of Australia (JECA), and the national federation of state-based epilepsy associations, Epilepsy Australia.

The Epilepsy Foundation provides support for people living with epilepsy and their families to help them achieve their goals. We work to raise awareness of epilepsy in the community to reduce the stigma and create a more welcoming and inclusive society.

People seek our services for a variety of reasons, depending on their age, stage of life, individual needs, the unique problems or issues they may be facing and their personal goals and aspirations.

Our services depend very much on individual needs. One of our primary aims is to see people managing their epilepsy in a way that enables them to live, study or work and participate in the activities they enjoy. Many people with epilepsy are able to play sport, swim, go to the movies and, under certain circumstances, drive a car. Importantly, we work with people to help them regain their confidence so that they can continue to do the things they love or that matter most to them.

Services can be accessed in person, over the telephone, via email or in a range of community settings such as a person's home, school or workplace, and include:

- **Information, library and resources** on all aspects of living with epilepsy
- **Individual and family support** including advice, epilepsy counselling, case management and practical assistance
- **Support for groups** that gives an opportunity for people to talk with others, share experiences, problems and solutions for coping with epilepsy and enjoy activities
- **Advocacy** for individuals and families living with epilepsy
- **Education and training** to schools, the health profession, aged care and disability services, government departments and the wider community
- **Psychological/social research and policy reform** to understand more about the psychological and social aspects of living with epilepsy and ensure systemic change and advocacy for people with epilepsy at all levels of government and in the community.





Helen and Rosalie Forno: Childhood epilepsy an ongoing battle

For single mum, Helen Forno, and her four-year-old daughter, Rosalie, life has centred on battling epilepsy almost since Rosalie was born.

Rosalie has Myoclonic-Astatic Epilepsy (MAE), or Doose Syndrome, an early childhood epilepsy syndrome which is often resistant to medication and can be difficult to treat.

According to Helen, Rosalie was always a 'problem child' who would never settle and even now doesn't sleep well – often only an hour at a time. She was a late developer and didn't walk until about 16 months old.

"Rosalie first started having 'absence' seizures when she was 10 months old," says Helen. "Once she could walk, the 'drop' seizures started. She would fall on her bottom or her head and bounce off the floor. It was awful to see."

It was only when she was almost two that Rosalie was diagnosed with epilepsy. She is now on medication and although 90 percent of her seizures have stopped Rosalie still has problems, particularly if she has a high fever. As she is photo-sensitive, flickering lights can also set off seizures.

Epilepsy has had a major impact on other areas of Rosalie's life. Because she has constant brain disruptions, she has problems with attention and concentration, which has resulted in learning difficulties. "She also has a terrible short term memory," says Helen.

As a single mum, Helen had been living in Townsville and was forced to leave her family and friends in search of specialist treatment for Rosalie; they moved to Melbourne about 18 months ago.

Since then the Epilepsy Foundation has proved to be a godsend. "Within two weeks of getting here, the foundation was on my doorstep. The biggest issue was my lack of knowledge. They explained the condition to me and supplied me with pertinent reading material and guidance."

"They told me where to find help, showed me how to do seizure first aid and helped me get an early appointment with epilepsy specialist, Professor Ingrid Scheffer. They also recommended that I place Rosalie in a childcare with a kindy. She now goes to Bright Horizons kindergarten at North Croydon. The kindergarten is in the process of getting Rosalie an intervention aide and she is getting therapy from a speech pathologist and physiotherapist. She's being seen by some of the best in the business."

Helen says with all the assistance, Rosalie has made marked progress, but they have a long way to go.

"Rosalie is a beautiful child. If it wasn't for her difficulties, she would be such a bright, lovely child. You just want to cry with happiness when she has a good day."

Our strategy

Four Strategic Outcomes underpinned our work during 2009–10. These Strategic Outcomes were first developed in June 2008 as part of a three-year plan.

Strategic Outcome 1 – Services aligned to need

To develop an improved and more sustainable service delivery model, based on a deep understanding of the needs of people living with epilepsy.

Strategic Outcome 2 – Effective community engagement

To create effective stakeholder and community engagement programs to enhance our ability to deliver services, to create opportunities for learning and education, and to develop a social research policy and strategy.

Strategic Outcome 3 – Effective and respected advocate

To become the key voice for people living with epilepsy within government, the medical and other health professions and the wider community in order to ensure the needs of people with epilepsy and their families are heard and met in future years.

Strategic Outcome 4 – Sustainable organisation

To work towards the better use of existing resources, identify new funding streams and work collaboratively wherever possible to enable the Epilepsy Foundation to continue supporting people living with epilepsy now and in the future.



About epilepsy

Epilepsy is a significant community problem. People living with uncontrolled epilepsy suffer from wide-ranging physical, psychological and social issues, as epilepsy impacts on every aspect of their lives and the lives of their families and carers. These include being disadvantaged in obtaining an education, loss of employment or limited employment prospects, social isolation, loss of enjoyment or participation in everyday life, relationship problems and, potentially, chronic depression.

Epilepsy is also a silent problem. The social stigma, coupled with the emotional and physical trauma associated with uncontrolled epilepsy, means many people avoid revealing they have epilepsy – to their employer, their friends, even their loved ones – for fear of rejection, ridicule or lost opportunity. These are very real fears, as stigma and ignorance still exist today.

What is epilepsy?

Epilepsy is a disorder of brain function that takes the form of recurring seizures. Our thoughts, feelings and actions are controlled by brain cells that communicate with each other through regular electrical impulses. A seizure occurs when sudden uncontrolled bursts of electrical activity disrupt this regular pattern.

This can be confined to just one part of the brain or can occur right across the brain. Communication between cells becomes scrambled and our thoughts, feelings or movements become momentarily confused or uncontrolled.

While seizures can be frightening, in most instances they stop without intervention. Once the seizure is over the person gradually regains control and reorients themselves to their surroundings, generally without any ill-effects. Approximately 70 percent of people diagnosed with epilepsy will have their seizures controlled with medication.

Epilepsy takes many different forms

There are many different types of seizures, depending on which part of the brain the seizures occur and how much of the brain is affected, making epilepsy an extremely difficult condition to accurately diagnose and treat.

Sometimes a person with epilepsy will experience only one type of seizure throughout their life, while others may experience different types. It is also sometimes difficult to tell if a person is actually having a seizure – they may simply look like they are daydreaming or lose concentration for a moment.

Generally, seizures fall into two categories: focal or partial seizures and primary generalised seizures. The difference between these types is how they begin.

Focal or partial seizures

Focal or partial seizures start in one part of the brain (that is at a focal point in the brain) and affect that part of the body controlled by that part of the brain.

Simple partial seizures

Simple partial seizures are localised seizures, affecting only one part of the brain. The symptoms the person experiences will depend on the function that part of the brain controls. The seizure may involve the involuntary movement or stiffening of a limb, feelings of déjà vu, an unpleasant smell or taste, or sensations in the stomach such as ‘butterflies’ or nausea. The person remains alert throughout the seizure and can remember what happens. The seizure usually lasts less than two minutes. A simple partial seizure can progress to a complex partial seizure and/or a secondarily generalised seizure.



Jeff 'Joffa' Corfe, Collingwood Football Club cheer squad leader and a great supporter of the Epilepsy Foundation, in his famous gold jacket, with daughter Emma who has epilepsy.

Complex partial seizures

This type of seizure also affects only one part of the brain but the person's conscious state is altered rather than lost. The person may often appear confused and dazed and may do strange and repetitive actions like fiddling with their clothes, making chewing movements or uttering unusual sounds. These behaviours may also be described as trance-like or robot-like and are called automatisms. The seizure usually lasts for one to two minutes but the person may be confused and drowsy for some minutes to several hours afterwards and have no memory of the seizure or the events just before or after it. This type of seizure can be mistaken for drug or alcohol-affected behaviour or psychiatric disturbance. At times complex partial seizures can spread to become secondarily generalised seizures.

Primary generalised seizures

Primary generalised seizures involve the whole brain and therefore involve the whole body. There are many types of generalised seizures, some convulsive and others non-convulsive.

Absence seizures

(previously called petit mal seizures)

This is a brief, non-convulsive event, usually occurring in the young, and involves the whole brain. With this type of seizure, the person's awareness and responsiveness are impaired. They simply stare and their eyes might roll back or their eyelids flutter. It can be difficult to tell the difference between absence seizures and daydreaming. However, absence seizures start suddenly, cannot be interrupted, last a few seconds, and then stop suddenly and the person resumes what they were doing. Although these seizures last less than 10 seconds, they can occur many times daily, and thus be very disruptive to learning.

Myoclonic seizures

Myoclonic seizures are brief, shock-like jerks of a muscle or a group of muscles, usually lasting no more than a second or two, which at times can result in a fall. There can be just one, but sometimes many will occur within a short time.

Atonic seizures

Atonic seizures cause a sudden loss or decrease of normal muscle tone and the person often falls to the ground. Seizures usually last less than 15 seconds. Often called 'drop attacks,' these seizures can cause head or facial injury. Wearing protective headwear may avoid injury.

Tonic seizures

Tonic seizures greatly increase normal muscle tone and the body, arms or legs make sudden stiffening movements. These seizures often occur in clusters during sleep, although they can occur when the person is awake. If the person is standing they will fall quite heavily, often injuring their head. Protective headwear may avoid injury. Seizures usually last less than 20 seconds.

Tonic-clonic seizures

(previously called grand mal seizures)

During a tonic-clonic seizure a person's body stiffens, air being forced past the vocal cords causes a cry or groan and they fall to the ground (tonic phase). Their limbs then begin to jerk in strong, symmetrical, rhythmic movements (the clonic phase). The person may dribble from the mouth, go blue or red in the face, or lose control of their bladder and/or bowel as the body relaxes. As consciousness returns, the person may be confused, drowsy, agitated or depressed. They may have a headache and want to sleep. This drowsiness can last for a number of hours.

Although this type of seizure can be frightening to watch, the seizure itself is unlikely to seriously harm the person having the seizure. They may, however, vomit or bite their tongue and can sometimes injure themselves if they hit nearby objects as they fall or convulse.

Tonic-clonic seizures generally last from one to three minutes. **If the active movements of the seizure last FIVE minutes it is advisable to call an ambulance.** Prolonged seizures, or a series of seizures without a normal break in between, indicate a dangerous condition called convulsive status epilepticus and demands emergency treatment.

Status epilepticus

Status epilepticus ('status') is the term used to describe prolonged seizures of 30 minutes or more, or the occurrence of repeated seizures without regaining consciousness between attacks.

It is now widely accepted that after five to 10 minutes, damage is being done to neural tissue, hence the definition of status epilepticus is currently being reviewed, with some suggesting five minutes for convulsive seizures and 30 minutes for non-convulsive seizures constitute status epilepticus.

'Status' can occur with any type of seizure and is categorised as either convulsive or non-convulsive. 'Status' can last from hours to days or, in the case of non-convulsive 'status', even weeks or months.

Factors that may lead to 'status' include sudden withdrawal from medication, illness, fever and infections.

Convulsive 'status' may ultimately lead to brain damage and death unless stopped quickly – usually with the administration of emergency medication. Non-medical people such as parents and teachers can be trained to administer midazolam for someone who has a tendency to have prolonged seizures or clusters. This option would need to be discussed with a doctor who may prescribe emergency medication.

It is recommended an Emergency Medication Management Plan be completed by the prescribing doctor and attached to the person's Epilepsy Management Plan when emergency medication has been prescribed for epilepsy. Emergency plans are available from the Epilepsy Foundation of Victoria. Training in the administration of emergency medication is strongly recommended and can be provided by the Epilepsy Foundation.

Epilepsy syndromes

A seizure is the physical sign that there has been a disruption to the normal functioning of the brain. If a person is told they have epilepsy it simply means that they have started experiencing seizures on a recurring basis. The seizures in epilepsy may be related to a brain injury or a family tendency, but often the cause is completely unknown. They tend to be unpredictable and occur without provocation.

While epilepsy is also known as a seizure disorder, it is not just one disorder. As there are different types of seizures, so too are there different types of epilepsy disorders, called the epilepsies, each with its own particular set of features. When a disorder is defined by a characteristic group of features that usually occur together, it is called a syndrome. Epilepsy syndromes are defined by a cluster of features including:

- Seizure type/types and their severity and frequency
- The age of onset
- The causes of the seizures and whether there is a familial link
- The part of the brain involved
- Electroencephalograph (EEG) activity
- Seizure-provoking factors and
- The presence of other disorders in addition to seizures.

By understanding the nature and presentation of a particular syndrome the treating doctor can implement the most appropriate form of treatment and may be able to predict whether seizures will lessen or disappear over time.

How many people are affected by epilepsy?

- Approximately 4 percent or 220,000 people living in Victoria will have epilepsy in their lifetime.
- The number of people who are significantly affected by epilepsy including, for example, family members and carers, will be four times this number, or 880,000 people.
- Up to 10 percent of people in Victoria will have a seizure in their lifetime, due to epilepsy or other health conditions. This represents 550,000 people who are directly affected or 2.2 million people indirectly, yet significantly, affected. Seizures from epilepsy make up the major proportion of total seizures.
- Epilepsy was ranked in the top five avoidable causes of death in young people aged 5–29. (The Victorian Government's report *Avoidable Mortality in Victoria – Trends between 1997 and 2003*.) Despite this alarming figure, it was also noted that epilepsy is a condition that can be well-managed and responds to early detection and treatment, typically in a primary health care setting.
- Recent US studies estimate 7 percent of people over the age of 65 will develop epilepsy. As at June 2009, there were 2.9 million people aged 65 and over in Australia. Within this age group it is therefore estimated that approximately 203,000 people will develop epilepsy.

About funding

The Epilepsy Foundation receives funding from the Victorian Government Department of Human Services. This funding applies to people living with epilepsy who meet strict disability criteria and excludes the majority of those diagnosed with epilepsy who seek our services.

In the 2009–10 year, the Epilepsy Foundation provided advice, information and support to more than 5,000 people, an increase of 6 percent over the past year. We support people of all ages, from babies and children through all stages of adulthood.

In the 2010 financial year, we received \$1,022,634 in government funds, which covered approximately one-third of the cost of providing services and met only the most urgent needs.

We receive no government funding to support children who are under school-age, people who develop epilepsy over the age of 65, or those who have not started receiving services from us before 65.

However, we continue to provide services to these groups from our charitable funds. These two demographic groups are particularly important to the Epilepsy Foundation given the number of young children who present with often uncontrolled and difficult to manage epilepsy (such as Dravet Syndrome, a particularly severe form of childhood epilepsy), and the fact that our ageing population means more and more older Victorians will experience their first seizure beyond the age of 65.



Our annual fundraising efforts are vital in ensuring we are able to meet the significant shortfall and can continue providing services at the current level. While our limited financial resources were fully utilised in providing services to all those who sought assistance in the past year, we know that there are many thousands of people living with epilepsy, as well as many more family members and carers who are affected by epilepsy, whose needs are not being met and for whom we simply do not have the resources to help.

We know that some people with epilepsy are able to live well and with little support, as their seizures are well under control. However, many people who could benefit from our services are not seeking help, either due to a lack of referral or awareness, or because of the perceived stigma associated with seeking help. We are also mindful of the growing strain that is being placed on our resources by our ageing population, and will continue to do so as many more older people experience their first seizures.

The prevalence and predicted growth in demand means a growing pressure on our limited resources which, in turn, means we must continue seeking new, sustainable and collaborative partnerships and strategies for delivering services.

Our aim is to continue to develop a sustainable organisation that has the capacity to not only meet the current needs, but can expand services to those not currently being assisted and cope with the growing demand, while undertaking proactive programs to increase awareness of epilepsy and seizure first aid in the community.



Corporate governance



President's report



We want a society which understands and is inclusive of people with epilepsy.

As epilepsy awareness grows, so does the demand for our services, with the call for support services in the early childhood area continuing to grow. This is a good sign that awareness is increasing, but also a challenge as we must use our limited charitable funds to undertake this work.

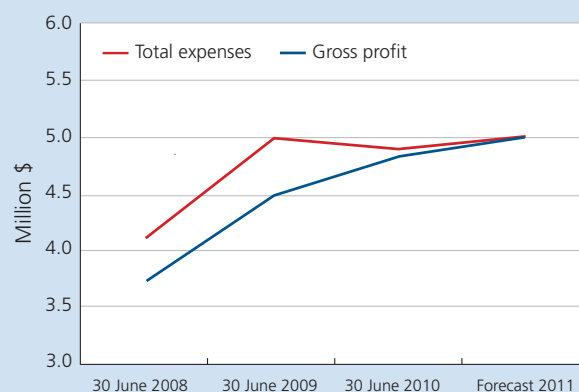
The combination of an ageing population and the substantially higher incidence of first seizures in people over 60 years of age means demand for services will continue to grow significantly in this age group over the next 10 years.

Funding does not keep pace with current, let alone growing, demand. Raising funds to support services is always challenging and this year continued on from the previous 12 months in being more difficult than usual due to the global economic crisis. It was pleasing to see that the number of people supporting us continues to rise as we get the message out about epilepsy and the work that is yet to be done.

The Epilepsy Foundation has been working through the Joint Epilepsy Council of Australia (JECA) to raise the profile of epilepsy within the Australian Government. Successful lobbying of Federal Parliamentarians through JECA resulted in the first-ever federal Inquiry into Epilepsy held in October 2009. A report arising from the Inquiry comprising 13 recommendations was put to both Houses of Federal Parliament.

Work continues on achieving a national federation of all epilepsy agencies in Australia. Epilepsy Australia is the leading consumer-based federation of epilepsy agencies, with members providing services in all states and territories.

Over the last three years we have invested in improving our service capability and the financial position of the Epilepsy Foundation. We believe our financial position is best viewed by removing the unpredictable bequest income from the analysis. If we chart our gross profit (revenue less direct cost of sales), against our expenses for the three years, we see a very good improvement both in terms of growth and a reduced gap between gross profit and expenses. This means we no longer need to rely on unpredictable bequest income to make ends meet and, instead, can use bequest funds to invest in future service capability.



The 8th Asian and Oceanian Epilepsy Congress will be held in Melbourne in October 2010. The highly regarded speakers and exciting program will raise the profile of epilepsy. The event will bring approximately 2,000 people from across the world to Melbourne. An Epilepsy and Society day focused on psychosocial issues will attract people living with epilepsy from the region.

I thank the Board members for their valuable contributions and diverse perspectives that have contributed to robust and constructive dialogue. I am confident we have a Board with the right vision to guide the Epilepsy Foundation.

I also thank the staff, volunteers, philanthropists and others who have contributed to another successful year for the Foundation.

PROF. MARK COOK

Chief Executive Officer's report



*Understanding makes the difference.
Raising awareness is simply not enough.*

The Epilepsy Foundation works purposefully to increase understanding of epilepsy among individuals and their families, and within workplaces, schools and the wider community.

This year, we commenced the first Australia-wide longitudinal socio-economic study of epilepsy. This research, to be conducted over the next ten years, will develop understanding about the impact of epilepsy by describing the needs, perceptions and experiences of people living with this condition.

Our services continued to grow in both geographic reach and sophistication, supported by our new service model, which is focused on support for individuals. We also developed our knowledge and practice using the latest evidence-based research and there has been an ongoing investment in information technology to enable staff to operate effectively wherever they are providing services across Victoria.

People with epilepsy need to be understood. A sustained investment in training and education was required to help achieve this and staff resources have been increased to meet the need. We developed new vocationally-tailored training programs for nurses, Centrelink Job Capacity Assessors and teachers. Creating understanding in the general community is a goal that will require a sustained effort.

In recognition of the value of educating people early, we are extending the reach of our programs in schools. Trivia Challenge, our schools awareness program, involves approximately 10 percent of Victorian children. We are working to expand this program in combination with professional development for teachers, to create inclusive and understanding school environments for

children with epilepsy. This understanding will then be carried by these children and teachers into the broader community.

We continue to actively promote stories about epilepsy in the media. Notable media coverage has been achieved and many community interest articles were published in suburban and regional papers. Epilepsy Awareness Week provided a focal point for these efforts.

The Epilepsy Foundation has grown in capability throughout the year, however, the challenge remains that there will always be more to do than our resources allow. Staff and volunteers continue to work very hard to meet these challenges.

We understand many things that can be done on behalf of people living with epilepsy. The rate at which we progress is determined by the funds we have available.

I thank everyone who has contributed to the success of the Epilepsy Foundation over the past year and look forward to working in partnership on the challenges ahead.

A handwritten signature in black ink, appearing to read 'Graeme Shears'. The signature is fluid and cursive, with a large initial 'G'.

GRAEME SHEARS

Message from the Chair of the Patrons Council



I am confident the organisation is well governed and has a strong leadership team supported by hardworking staff and volunteers.

Epilepsy's impact can be devastating and is often hidden, yet the condition is widespread. People with epilepsy, their families and carers experience epilepsy in different ways, and its effects are as varied as the condition itself.

From my regular meetings with Graeme Shears, the Epilepsy Foundation's Chief Executive Officer, I know that he has sought and received valuable support and advice from members of the Patrons Council during the year.

The patrons' media committee, assisted by television personality, Peter Smith, has met on three occasions to support the Foundation's aims of raising awareness among a wider audience in the community and supplementing its limited resources.

Philip Brady has again participated in the very moving bi-annual Epilepsy Foundation Memorial Service, when families and friends remembered those who have died from epilepsy.

It is important that patrons have a good understanding of epilepsy and the Foundation's initiatives. To achieve this aim, there will be regular information sessions held over the coming year and I encourage all patrons to attend one of these interesting events. The first information session for patrons was held in the offices of JBWere in June 2010.

I am confident the organisation is well governed and has a strong leadership team supported by hardworking staff and volunteers.

There is much yet to be done to improve the lives of people living with epilepsy. With a clear understanding of both epilepsy and the Foundation's initiatives, the patrons can make a significant contribution to the organisation's future success by applying their considerable influence.

DAME BERYL BEAUREPAIRE

Patrons Council

Dame Beryl Beaufrepaire AC OBE (Chair)
Ted Baillieu MLA
John Blackman
The Hon. Justice Bernard Bongiorno
Philip Brady
Julian Burnside QC
Prof. Ed Byrne
The Hon. John Cain
The Hon. Joan Child AO
Paul Cronin
Sean Cummins
The Hon. Justice Linda Dessau
Ivan Deveson AO
Melanie Eagle
David Galbally QC
Rhonda Galbally AO
Bev Genser
Petro Georgiou MHR
Stera Gutnik
Prof. David Hayward
The Hon. Brian Howe
John Jost
Robert Kirby
Judy Maddigan MLA
Neil Mitchell
Dame Elisabeth Murdoch AC CBE
Emeritus Prof. Sir Gustav Nossal AC CBE
Janet Powell
Barbara Rozenes
Ross Smith AM
Richard Stanley QC
Michael Stillwell
Claude Ullin
Luisa Valmorbida



Graeme Shears with Dame Elisabeth Murdoch and Dame Beryl Beaufrepaire

Our structure

The Board of the Epilepsy Foundation of Victoria Inc. is responsible for the corporate governance of the organisation. It guides and monitors the business and its affairs on behalf of the members, to whom it is accountable. Its focus is to enhance the interests of members and the wider constituency of the epilepsy community.

The Board is committed to achieving and demonstrating the highest standards of corporate governance. The relationship between the Board and senior management is important to the Epilepsy Foundation's long term success. Day-to-day management of the Epilepsy Foundation's affairs, operation and administration, and the implementation of the corporate strategy and policy initiatives, are formally delegated by the Board to the Chief Executive Officer (CEO). The Board, CEO and Management Team set the corporate strategic direction.

A description of the Epilepsy Foundation's main corporate governance practices is set out below. All these practices, unless otherwise stated, were in place for the entire financial year.

Composition of the Board

The Board consists of up to nine persons who are all non-executive members. The Board comprises persons with an appropriate range of qualifications and knowledge of finance, business, law, marketing, information technology, property, epilepsy, disability and consumer issues. Members act in a voluntary capacity and do not receive remuneration.

Board members' responsibilities

The Board acts on behalf of, and is accountable to, the members. It identifies the expectations of members and the wider constituency and monitors changes in government policy and community expectations.

The Associations Incorporation Act and the Epilepsy Foundation's Constitution govern the regulation of meetings and proceedings of the Board. The Board meets regularly and monitors the achievement of agreed targets and financial objectives against budget.

Relevant staff members attend Board meetings.

Board members' terms of office

The Epilepsy Foundation's Constitution specifies the terms for Board members.

Risk assessment and management

The Board is responsible for ensuring there are adequate policies in relation to risk oversight and management, and internal control systems. Policies are designed to ensure strategic, operational, legal, reputation and financial risks are identified, assessed, addressed and monitored to enable achievement of the Epilepsy Foundation's business objectives.

Sub-committees

To maximise its efficiency and effectiveness, the Board has formed a number of sub-committees that consider specific areas of the Epilepsy Foundation's activities and report back to the Board, including:

Finance, Audit and Risk Management Sub-committee

This sub-committee provides strategic advice to management and monitors and reviews the effectiveness of the control environment in the areas of operational and balance sheet risk, legal/regulatory compliance and financial reporting. The committee provides an independent and objective review of financial and other information prepared by management, in particular that to be provided to members and/or filed with regulators, and reviews the adequacy and scope of the audit plan of the external auditor.



Fundraising Sub-committee

This sub-committee provides an efficient mechanism for reviewing fundraising results, while overseeing the general fundraising strategy of the Epilepsy Foundation.

Research Sub-committee

The primary role of this sub-committee is to provide an efficient mechanism for reviewing, assessing and recommending to the Board research policies and procedures while overseeing the research strategy of the Epilepsy Foundation.

Each sub-committee operates under its own Charter. The Chair of the Board is an ex officio member of each sub-committee. Relevant Epilepsy Foundation staff are members of the sub-committees.



Fundraising Sub-committee

Jim Campbell (Chair)

Sally Genser

Tony Mooney

Graeme Shears (Staff)

Jeremy Maxwell (Staff)

Finance, Audit and Risk Management Sub-committee

Jock MacAdie (Chair)

Jim Campbell

Victoria Funnell

Graeme Shears (Staff)

Jeremy Maxwell (Staff)

Wayne Pfeiffer (Staff)

Diana McNamara (Staff)

Bronwen Kohne (Staff)

Research Sub-committee

Lindsay Vowels (Chair)

Dr Christine Walker

Jacqueline Branston

Vici Funnell

Kevin Brown (External researcher)

Graeme Shears (Staff)

Wayne Pfeiffer (Staff)

Pauline Brockett (Staff)

Dr Jaya Pinikahana (Staff)

Jean Ewing (Staff)

The Board (as at 30 June 2010)



Prof. Mark Cook – President

Currently Chair of Medicine and Professor of Neurology at St Vincent's Hospital Melbourne, Prof. Cook is a neurologist specialising in the treatment of epilepsy. After completing specialist training in Melbourne, he undertook an MD thesis at Queen Square, London. He returned to St Vincent's Hospital, Melbourne, to continue his interest in epilepsy and has formed a large research group with a broad range of interests across epilepsy, neuromuscular disease, multiple sclerosis and Parkinson's disease. Clinical and basic science research concerning epilepsy and neuromuscular disease is carried out in the department. For the last four years, Prof. Cook has been involved in a project to treat epilepsy via novel methods, including electrical stimulation and polymer-based drug delivery. He is President of the Epilepsy Foundation of Victoria and an Editor of *Epilepsia*.

Dr Christine Walker

Christine is currently Executive Officer of the Chronic Illness Alliance Inc., a peak body representing more than 50 consumer and advocacy organisations for people with chronic illness. In this role, she works collaboratively with a number of organisations, government departments and universities, to further the Alliance's aims of improving the lives of people with chronic illness. Christine completed a PhD in 1995. She has experience in qualitative research and has published many journal articles. Christine is a member of the Community Quality Use of Medicines Working Group for the National Prescribing Service and the Primary Care Sub-committee of the Australian Commission for Safety and Quality in Healthcare. She is Vice President of Epilepsy Australia.

Jacqueline Branston

Jacqueline has been a member of the Board since 2002, as a parent representative. For the past ten years, Jacqueline has been a counsellor, educator and public speaker in a voluntary capacity for the Epilepsy Foundation of Victoria. Married with four children, her third child, Rhys, is profoundly disabled and has refractory epilepsy. Lack of information at the time of his diagnosis has made Jacqueline passionate in her efforts to ensure all parents, support workers, teachers and the public have access to ongoing training and accurate information. Jacqueline holds qualifications in counselling, psychotherapy and hypnotherapy. She has been a volunteer in a range of community organisations over a 30-year period. A member of the Research Sub-committee, Jacqueline is keen to make any contribution that may help identify areas where services for people with epilepsy can be improved.



Jim Campbell, AM

Jim has 25 years of experience in driving change in Australian Government departments and public and private companies. Over the past seven years, he has worked in the not-for-profit sector successfully completing major restructures and integration projects with Vision Australia, Multiple Sclerosis Limited and St Vincent de Paul, as well as a joint venture that led to the creation of VicBionics. Jim has undertaken work with Boards and executives on strategic planning, governance, business planning and performance evaluation and acts as a coach and mentor to directors and CEOs. He has practised as a company director for more than 18 years. Jim serves on the Fundraising Committee and the Finance, Audit and Risk Management Sub-committee. Jim is an Arts graduate of the Royal Military College of Australia and a business postgraduate of Monash University. Jim also has had personal family experience with epilepsy.

Jock MacAdie

Jock's background is in corporate finance, corporate restructuring, health, hospitality and property. He worked for Rothschilds and Schrodgers and for Elders in Australia and New Zealand, where he set up their finance operations. He worked with the provisional liquidators of Hooker Corporation and HIH Insurance, advising on restructuring options, stabilised and managed various assets and undertook their disposal. Jock was the Finance Director/CFO of Australian Hospital Care Limited for eight years, where he undertook assignments including major equity raisings, the initial public offering (IPO) of the group and various acquisitions, debt refinancings and organisational restructurings. In the hospitality and property area, Jock worked with the Century City/Paliburg/Regal Hotels group in Hong Kong, a large hotel owner and operator in Asia and the United States as well as a major property developer and investor in Hong Kong and the People's Republic of China. Jock is Chairman of the Finance, Audit and Risk Management Sub-committee.

Sally Genser

Sally Genser has been a member of the Board for four years. She was also a Board member of Yarra Health Services and President of the Richmond Creche Society for many years and is now a Life Member of Richmond Creche Society. Sally is a licensed estate agent and has been a director of The Belgrave Group of Companies for more than 15 years. The Belgrave Group is a boutique, family-owned property development group, which has been in business for more than 50 years, completing projects in residential, office, commercial, industrial, aged care, child care and hospitality and which has expanded to China. Sally was, for many years, an advisor to The Meat Workers Union Industry Employees Superannuation Fund advising on its property investment portfolio. She is also Managing Director of Quest Phillip Island (Serviced Apartments).



Dr Lindsay Vowels

Dr Lindsay Vowels' career has spanned more than 40 years in the disability sector, working primarily with people with a neurological disability. She is a consultant Neuropsychologist and Clinical Psychologist and works in a voluntary capacity with several applied research projects including the MS Longitudinal Database. Lindsay joined the Board in 1992, holding the positions of President and Vice President, and is the founding and past Chair of Epilepsy Australia. Her interests lie in the quality of services available to people with epilepsy, the education and training available to professional staff employed by the Foundation, and support and education services in rural and remote areas. She is involved in research into the psychosocial impact of epilepsy on individuals and their families, having convened the Research Working Party since 2004. Her hope is for a national research body to ensure all issues affecting people with epilepsy are adequately documented, investigated and publicised.



Tony Mooney

Tony Mooney currently works with several companies operating in the metal and plastic components market, working on product development through to full product manufacturing and providing advice on plant equipment and other business areas. Over the past 10 years, he has been heavily involved in the management of various companies in the manufacturing sector, working in roles from team leader through to Chief Executive Officer for a period of three years. Tony has epilepsy and brings to the Board a personal understanding of the condition.



Vici Funnell MHA, BSc (Hons), FACHSE, MAICD

Vici is a consultant with more than 25 years of experience as a Director and Chief Executive Officer. Her roles include nine years as CEO of Scope (Vic) Ltd, formerly the Spastic Society of Victoria, Chief Executive Officer in Victorian hospitals and several directorships. Vici is committed to creating a more welcoming and inclusive community for all, and has presented to audiences in the United States, Japan and United Kingdom on projects she has been involved with. She is an honorary member of the Harvard Club of Australia and a member of the Box Hill Central Rotary Club. Vici was awarded the inaugural Harvard Club Non-Profit Fellowship in June 2001 to study Non-Profit Management at Harvard Business School and was awarded a Centenary Medal 'for services to the community through people with disability'. Vici and her husband Steve own and operate a boutique vineyard, Hat Rock, on the Bellarine Peninsula.



Roger Smith: Acquiring epilepsy in later life

Roger Smith had no signs of epilepsy until his late 40s, but believes his seizures were brought on by the stress associated with his mother's death from cancer.

"She was diagnosed with lung cancer and, for the last two to three months of her life, I was going to visit her in Kew every night," says Roger, who lived in Altona at the time. "Also, dad had multiple sclerosis and was in a home in Armadale. I was trying to see him a couple of nights a week as well. The whole thing compounded."

After about three weeks of nightly visits to his parents, Roger had his first tonic-clonic seizure at work. "I just conked out having a sandwich at my desk," he says.

Roger then had another seizure a few weeks later, which preceded an increase in the number and frequency of his seizures. "I started having absence seizures and it just got progressively worse."

Roger was diagnosed with temporal lobe epilepsy caused by Mesial Temporal Sclerosis, a type of focal (or partial) epilepsy in which the seizure initiation point can be identified within the temporal lobe of the brain.

The impacts of epilepsy on Roger's life have been significant, affecting his ability to drive and work and, ultimately, having a detrimental effect on his and wife Wendy's financial situation.

At the time, Roger was working in real estate, a job that required him to be mobile. "I had good support but it did impact on work and, after leaving that job for other reasons, I am now having trouble getting another job."

After a period when Roger's seizures became much more frequent, on the suggestion of his neurologist he was referred to another specialist at the Royal Melbourne Hospital and underwent a week of tests to determine whether surgery was an option. He was told there was an 80 percent chance surgery would be successful.

Now seizure-free, Roger says, "I had no hesitation in undergoing the surgery – even if it wasn't successful I needed to know that I had done everything possible to stop the seizures. I had a couple of tonic-clonic seizures within the first couple of months after surgery, but haven't had one since, to my knowledge."

While Roger considers the surgery successful, he admits there have been some negative side-effects. His memory has been badly affected, another barrier to remaining employed, and he developed depression, which he says, "he is not quite on top of yet".*

He credits the Epilepsy Foundation of Victoria, in particular epilepsy counsellor, Maree Kearton, with helping him to understand his epilepsy and the effects of surgery. "As Maree had already had surgery herself, she was a big help."

Roger has spoken about his condition to other people considering surgery at the Epilepsy Foundation's surgery information sessions. Wendy has also spoken about how Roger's epilepsy impacted on her, as his spouse, providing another valuable viewpoint.

* Risks such as depression and memory loss do not affect everyone who has surgery (approximately 30 percent of people who have surgery experience depression afterwards).

Client Services highlights

Overview

During 2009–10, our services assisted 5,012 people. We continued to focus on our core purpose of responding to the needs of people with epilepsy, their families, service providers and the broader community, while undertaking significant internal change in the way we operate and progress our strategic outcomes.

Service improvements

This year we continued to refine our service delivery model and increased our work in education and training. Our education and training strategy has been developed following the recruitment of additional staff, and training needs were clearly identified and defined into four distinct areas:

- Employment and Assessment
- Health and Community
- Schools and Early Childhood
- Aged Care and Disability.

Our initiative to increase the recruitment and retention of people with epilepsy into employment received a boost with the endorsement by Centrelink of a pilot training program for Job Capacity Assessors (JCAs). The training aims to increase their understanding of epilepsy and the capacity of people with epilepsy to undertake employment.

Service improvements included a review of position descriptions of Client Services staff to enable a better allocation of skills and knowledge to client needs, and establishment of a peer case review process, whereby members of the epilepsy counselling team can reflect on their practices to develop a shared understanding of the issues and best approaches.

Each month, designated staff members present anonymous, but real, case studies, either to discuss difficult cases and seek advice or to illustrate a successful practice. This provides support and guidance to the team in their work and achieves improved outcomes for people with epilepsy.

A quality framework, including policies and procedures, was established to meet the State Government of Victoria's Disability Standards.

Partnerships

The Epilepsy Foundation's partnership with members of the Epilepsy Society of Australia (ESA), representing neurologists across Australia, was strengthened with a number of joint initiatives and projects. Eight neurologists and other specialists took part in our Understanding and Managing Epilepsy Series and Epilepsy Specialist Series to help people with epilepsy and their families better understand the condition.

A number of staff also attended the ESA Conference held in Perth in November 2009. Our service delivery model was presented to the Victorian Epilepsy Centre meeting of neurologists, with feedback on the model provided and service delivery gaps identified, particularly for people with intellectual disability who also have epilepsy.

Our involvement in seizure clinics increased this year with additional weekly clinics now operating at Ballarat Base Hospital, Western Health and Footscray, and a second clinic at Royal Melbourne Hospital. Patients who attend the clinics are provided with support and information during their visits to hospital or seizure/neurology clinics, including access to travel and accommodation information.



We were also pleased that following the presentation of the Mary Davis Oration by Dr John Carnie, Chief Health Officer, at our annual dinner in November 2009, a public health response to epilepsy is being developed through his office. Initiatives that have been discussed and progressed throughout the year include our Epilepsy Smart Schools Program, for which Dr Carnie is garnering support within the Education Department, and an epilepsy awareness program via a DVD targeting medical students and general practitioners.

The team

The Epilepsy Foundation applies a multidisciplinary approach to service delivery. Our staff have experience and qualifications in social work, counselling, nursing, youth work, welfare studies, communication, marketing, primary and secondary education, workplace training and assessment and management.

Alison Hitchcock	Education and Training Manager (Health and Community)
Colleen Weir	Epilepsy Counsellor/Educator
Gillian Davies	Epilepsy Counsellor/Educator
Jan Burns	Client Services Manager Barwon South West/Grampians and Volunteers
Janita Keating	Education and Training Manager (Employment and Assessment)
Jaya Pinikahana	Principal Research Officer
Jean Ewing	Client Services Manager Melbourne and Gippsland
Linley Klopper	Epilepsy Counsellor/Educator
Lisa Rath	Client Services Manager Loddon Mallee and Hume
Maree Kearton	Epilepsy Counsellor/Educator
Mark Green	Epilepsy Counsellor/Educator
Pat McGuirk	Reception/Administration
Pauline Brockett	Librarian
Peter Hoyle	Education Coordinator (Disability and Aged Care)
Sue Stubbs	Epilepsy Counsellor/Educator
Troy Johnson	Epilepsy Counsellor/Educator
Val Bates	Education and Training Manager/ Schools and Early Childhood
Wayne Pfeiffer	General Manager Client Services



Better communications

Callers to the Epilepsy Foundation might have noticed an improvement in the speed with which we are able to answer incoming calls and a reduction in the number of lost calls, following the installation of a new telephone system in December 2009. The purchase was made possible by the generous donations of the Collier Charitable Fund (\$10,000), the William Angliss Charitable Fund (\$2,000) and many others. The new telephone system has greatly increased productivity and enhanced the incoming call flow.

Regional services

We continued to provide quality support services across all areas of the state, within the constraints of our limited resources. To further increase our coverage, we explored the option of building the capacity of local organisations to support people with epilepsy and their families; this concept shows great promise and will be developed in the future.

People from regional Victoria have been supported to access other Epilepsy Foundation services such as the Family Respite Weekend, the Adult Get Away, Parent/Carer Days, the Women's Epilepsy Network and the Parent Epilepsy Support Network. Several families have had Epilepsy Management Plans developed for their children, along with several adults for whom a well-developed support plan has increased their access to the community.



Surgery gathering in Bendigo.

Gippsland

From July 2009, the Epilepsy Foundation has increased its service to Gippsland. Several trips to the region were made for home visits to families and people living with epilepsy and to service providers, in Bairnsdale, Sale, Traralgon, Moe, Morwell, Cape Patterson and Wonthaggi.

Loddon Mallee

We continued our long-standing involvement with Dr Mark Newton's seizure clinic in Bendigo, helping people to understand their condition and the adjustments that some people with epilepsy require. Adults and families throughout the region were supported and professional development was provided to teachers and staff at schools in Tylden, Heathcote, Echuca, Kyneton, Swan Hill, Woodend, Castlemaine and Bendigo and the Mildura Specialist School.

The highlight of the year was a surgery gathering in Bendigo that brought together seven women with epilepsy who had had surgery, along with their families, from Central Victoria and Echuca.

Hume

Our attendance at the Shepparton Epilepsy Clinic, Goulburn Valley Health, continued. Individuals, families, schools and service providers received support in Albury/Wodonga, Myrtleford, Wondilagong, Wangaratta, Shepparton, Seymour, Kilmore, Mansfield and Puckapunyal with 15 Epilepsy Management Plans developed.

The Goulburn Valley Epilepsy Support Group meetings continued to be held in Shepparton and education and training was provided to disability services in Shepparton and Wangaratta. Dr Wendy D'Souza, St Vincent's Epileptologist, provided an epilepsy information session in Shepparton at the School of Rural Health, which was attended by more than 50 people from across the region.

Barwon South West

The role of the Barwon South West regional office was expanded to incorporate support to the Grampians region from the Geelong office. We continued to support the weekly epilepsy clinic at Geelong Hospital every Tuesday, seeing an average of five people per week.

The Adult Getaway at Anglesea in October 2009 and Family Respite Camp in March 2010 were supported by the invaluable input of the Geelong Client Services staff. Similar support was provided to the Women's Epilepsy Network weekend conference held at Queenscliff in April.

Grampians

The Epilepsy Foundation's Geelong office also assumed responsibility for the Grampians region in November 2009 and worked with parents of children with epilepsy to re-establish a Ballarat support group. In May 2010, a weekly Thursday epilepsy clinic also commenced in Ballarat.

Metropolitan Melbourne

The Client Services team at Camberwell has continued to provide support, information and epilepsy counselling to a wide range of people whose lives are affected by epilepsy.

Staff were involved in organising and presenting 16 Understanding and Managing Epilepsy information sessions, including both general epilepsy sessions and the Epilepsy Specialist Series, which is focused on areas of particular interest such as surgery, memory and paediatric epilepsy.

We have also helped clients develop Epilepsy Management Plans and access community services, supported children in kindergartens and schools and assisted adults in their workplaces.



Individual and family support

An important component of our work is epilepsy counselling – helping clients to come to terms with their epilepsy and the implications this has on their life. Our aim is to work with people with epilepsy and their families to enable them to manage their epilepsy to enhance their quality of life and achieve their goals.

In a three-month survey conducted during the year, 200 enquiries for services were received at the Camberwell office, including 50 from hospital clinics.

Information and resources

The last year has seen a dramatic growth and improvement in the number of information products and resources available to support people with epilepsy, their families and others who provide support to the person with epilepsy.

Epilepsy Management Plan and Support Package

The Epilepsy Foundation recognised that its existing epilepsy management resources needed review and would be more effective in the form of a comprehensive package incorporating guidelines and practical tools. As a result, the Epilepsy Management Plan and Support Package was developed following many months of work and consultation and captures the latest approaches to meet requirements across aged care, disability, schools, health and employment.

The primary purpose of the package is to help people caring for or involved with a person living with epilepsy to recognise when seizures are occurring and to give clear directions about the appropriate support and first aid to be provided.

The package is available in printed form as well as in pdf and electronic form, to enable the forms to be easily updated to reflect changes in medication or circumstances, then saved and printed. Each package is accompanied by a feedback and evaluation form to ensure the ongoing quality of the package, and that the needs of people with epilepsy and their families are being met.

What's in the package?

Section 1: Management Plans

- Epilepsy Management Plan
- Seizure Record
- Emergency Medication Management Plan – Midazolam and Rectal Valium

Section 2: Guidelines and Support Materials

- Guidelines for Creating an Epilepsy Management Plan
- Guidelines for Recording Seizures
- When an Ambulance is called in an Emergency for Epilepsy
- Guidelines for Creating an Emergency Medication Management Plan
- Use of Midazolam and Rectal Valium for the Emergency Management of Seizures
- Training for Families in the Emergency Management of Seizures
- Training for Organisations in the Emergency Management of Seizures
- Epilepsy Support and Management Training for Organisations

The package is available for download on the Epilepsy Foundation website at www.epinet.org.au.



Library

During 2009–10, support was provided to staff, people with epilepsy and their families, health personnel and the wider community, including the provision of information and resources through both the Library collection and other sources.

Recognition of this support was provided to our Librarian, Pauline Brockett, by Prof. Yukio Fukuyama, Director of the Child Neurology Institute, Tokyo, in the introduction to the 10th edition of her publication, *Epilepsy Bibliography – Books and Monograph*.

As the organisation broadens its services, the level of information support that will be required will become more diverse and complex. One of our future challenges will be making information available in accessible formats.

Young People and Epilepsy DVD

In July 2009, the Epilepsy Foundation was approached by Real Time Health to participate in the development of a multi-media resource for schools on the needs of children with a chronic illness. The DVD was commissioned by the Curriculum Corporation, a Council of Australian Governments (COAG) body of which the directors are state and federal Ministers of Education.

We supported seven teenagers with epilepsy, aged 13 to 19, from rural and city areas, to relate their experiences of living with epilepsy and, in particular, their life at school. A parent of one of the participants was also interviewed. Launched in May 2010, the DVD is available to teachers and schools across Australia.

Website

The Epilepsy Foundation website (www.epinet.org.au) was re-instated and launched during the year with a new design and format and updated information. The project was undertaken with the financial support of the Department of Human Services, which provided \$64,000 to develop the design, content and on-line marketing strategy. Two volunteer students from Hong Kong Baptist University assisted with development work.

Already, we have seen a growth in the number of people using the website, particularly those who sought our services online – over a six-week period, a total of 14 people used the Request a Service feature and we expect this will increase over time. A key component of our marketing activities in the future will be participation in on-line social forums to engage with people with an interest in epilepsy and drive traffic to our site.

Group support

Providing opportunities for people with epilepsy and family members to come together through self-help and facilitated groups continued to be an important approach to supporting people during the year. These opportunities enabled participants to share experiences, problems and ideas about managing their epilepsy and create connections with other like-minded people.

The Epilepsy Foundation provides support to the groups as required and has assisted some of the regional groups to establish a resource of books, DVDs and videos for loan by group members.

Women's Epilepsy Network and Weekend Conference

The Women's Epilepsy Network is a thriving group of enthusiastic women. The network organised a regular Saturday lunch and the venue rotated between Melbourne and regional centres so members could attend at least one lunch per year.

During the year, the small but committed coordinating group met three times and held two lunches, in Melbourne and Geelong, with 18 and 10 women attending respectively. A \$2,700 Self-help Grant from the Department of Planning and Community Development enabled the group to cover running costs and maintain the network.



A grant of \$5,160 from The Marian EH Flack Trust provided an opportunity for women from across the state to take some time out and meet others with epilepsy. Twenty-six women enjoyed a wonderful three-day weekend conference at Whitehall Guesthouse in Queenscliff in April 2010.

Funds are being sought to run conferences in other parts of the state and effort is also being put into the creation of a website to enable members to stay in touch with each another, independent of the Epilepsy Foundation.

Family Respite Camp

The Family Respite Camp was held at Anglesea in March 2010 with 21 families attending. The wind-up of the weekend was mixed with sadness, as the parents shared their feelings about the experience and how valuable they had found it.

Several young children had visited the beach for the first time. They were thrilled to have a new network of friends who understood what they were going through and that they would be there to listen or help in the future. Many parents exchanged phone numbers or email addresses; several related how it enabled them to escape the usual exhausting routine and were enriched through sharing stories, feelings and strategies, with a great sense of unconditional acceptance and support.

We thank and acknowledge the Camberwell Rotary Club, which provided support for six families in financial difficulty to attend the Family Respite Camp with a donation of \$4,300. A presentation and formal thank you was provided at the Rotary Club's April 2010 meeting. This brings the total amount of support to \$13,300 over the last two years, a fabulous effort!



**ROTARY CLUB OF
CAMBERWELL INC.**

Adult Getaway Camp

Our Adult Getaway weekend was held at Anglesea from 23–25 October 2009 with 25 adults attending, supported by four staff and seven volunteers. The Rotary Club of Camberwell generously helped 10 people to attend by providing \$3,000 towards their costs. For many people this was their first opportunity to be independent and away from home, helping them to build self-confidence and make lasting connections with other people in a similar situation.

“Great to meet other families dealing with epilepsy.”



“It was great having the parents’ session, but also fantastic to get together after all the kids had settled.”

Superfits

Superfits, a group of adults living with epilepsy, enjoyed an active year in keeping with members’ attitude to life and living with epilepsy. Events included a Christmas get-together at Gumbuya Park, which was attended by 12 people and seven volunteers, bowling and a visit to the Melbourne Aquarium.

Ballarat Parent and Carers Support Group

The inaugural meeting to re-establish the Ballarat Parents and Carers Support Group was held at the Ballarat Specialist School in May 2010. All 12 attendees were keen to meet regularly and contributed ideas for the future, most important being to meet and talk with others who understand their issues.

Geelong Adults and Parents Groups

At the initial meeting for the year, the group established a calendar of activities and events and took responsibility for organising them. A wide range of events was held including lunch and a show at the Shell Club, the annual AFL Grand Final Day event at the home of one of the members, a tour of Skilled Stadium, a sausage sizzle at Eastern Beach and a ferry trip to Sorrento followed by lunch. The Christmas event was a picnic at Werribee Mansion followed by a tour; as it was rehearsal day for Carols at the Mansion, members were able to enjoy Christmas music during the picnic and the whole event was greatly enjoyed.

Colac Support Group

The Colac Support Group meets every second month, enjoying events that are informative as well as social. Activities included lunch at the Botanic Gardens, a talk from a pharmacist, a barbecue at the farm of one of the regular members and a computer skills session.

Hamilton/Portland Group

This group meets twice each year and the event is always well attended and enjoyed by members, providing a chance to catch up on each other's news, share experiences and discuss progress with their epilepsy. Family members and carers are also involved at these functions.

Epilepsy Parent Support Network

Formerly the Uncontrolled Epilepsy Parent Support group, this group changed its name to better reflect the people involved. A meeting was held in Caroline Springs after the Understanding and Managing Epilepsy information seminar. Future opportunities for parents to get together are planned for other outer-Melbourne and country areas.

Carers Week

As part of Carers Week 2009, carers of people with epilepsy luxuriated in a pampering day at the Beauty Therapy School of Gordon TAFE. Participants were treated to a manicure or pedicure given by students of the school followed by lunch at a nearby restaurant. All enjoyed their session and welcomed the opportunity to indulge themselves with some pampering and time away from their responsibilities.

Memorial Service

The 5th Epilepsy Memorial Service was held at St Mark's Church Camberwell on Sunday 16 May. More than 140 family members and friends of those who have died through epilepsy joined in a moving tribute to their memory at this bi-annual event. Parents, Glenys and Rodger Coates addressed the gathering, sharing the thoughts and emotions of a family that experienced the shock and sorrow of the unexpected death of their son, David, through epilepsy. Professor Terry O'Brien also spoke about Sudden Unexpected Death in Epilepsy. Staff offered words of comfort through poetry readings, and members of Opera Australia presented a beautiful musical performance. This event was supported by the Pierce Armstrong Trust with a \$5,000 grant.



Education and training

Building the capacity of the Epilepsy Foundation to deliver more education and training to people with epilepsy, their families, professionals and community service organisations has been a key focus for the year. Two new team members joined the education and training team to enable us to plan more programs to schools and the disability and aged care sectors, and to ensure that people with epilepsy have access to, and are retained in, employment.

We regularly deliver education and training programs to a range of organisations including aged care, Home and Community Care (HACC) and disability service providers, the Department of Human Services, early childhood and childcare facilities, schools, hospitals and workplaces. During the year, our programs reached 3,590 people.

Most programs are delivered on a fee-for-service basis, structured on current research and delivered by qualified professionals who have the appropriate workplace training and specific areas of expertise. Sessions are tailored to the needs of organisations, which might include, for example, catering for a child with epilepsy in the classroom and the administration of emergency medication to control seizures.

Our expanded education and training program has been defined into four distinct areas of focus with highlights and outcomes outlined over the next few pages.

1. Aged Care and Disability
2. Employment and Assessment
3. Health and Community
4. Schools and Early Childhood

Improved training facilities

Our presentation equipment received a boost with the contribution of \$12,000 from Perpetual Trustees (Estate Daniel Scott) and \$5,000 from The Danks Trust for the purchase of mobile equipment including a data projector, screens, PA system and laptop computers. The Borrodell Bequest – ANZ Trustees and Goldman Sachs JBWere Foundation each provided \$5,000 grants towards new equipment, including tables and chairs and an electronic whiteboard, to increase the number of programs that can be delivered.

1. Aged Care and Disability

Providing disability support workers with the knowledge and skills to support a person with a disability who has epilepsy continued to be a strong focus. The Epilepsy Foundation has a long history in this sector and not only delivers the required training but is able to provide ongoing advice, information and epilepsy counselling to the person with a disability and their support team.

Education and training sessions in the disability and aged care sector are typically run over three hours and centre on the development of an epilepsy support and management plan tailored to the individual's epilepsy, while ensuring the support staff understand the person's condition.

The risks associated with inappropriate care of the person with epilepsy in a disability service are considerable, particularly where the person may have complex communication needs. Instances of epilepsy-related deaths in disability services have increased the need for disability organisations to ensure that the care provided is of the highest standard. Some disability organisations have made epilepsy education and training a core component of their induction process, ensuring that support workers and coordinators have a good understanding of the condition.

The new Epilepsy Management Plan and Support Package has been effective in ensuring all aspects of the person's epilepsy are understood and managed appropriately.

In addition to a presentation to 60 disability support workers at the Australasian Society for the Study of Intellectual Disability Support Workers Conference in Melbourne 2009, some of the organisations that undertook education and training included:

- SCOPE
- Karingal
- Department of Human Services North and West
- Department of Human Services South
- Department of Human Services Gippsland
- Department of Human Services Loddon Mallee Interchange
- Yooralla

- ASCO
- Villa Maria
- Home and Community Care South.

Given that the incidence of epilepsy is high for the over 65 years age group, further work is needed to support the aged care sector in understanding epilepsy.

2. Employment and Assessment

In partnership with Centrelink, the Epilepsy Foundation developed a targeted epilepsy workshop for Job Capacity Assessors (JCAs). The goal is to better enable JCAs to recognise the barriers and challenges associated with employment for people with epilepsy and to make appropriate referral or intervention recommendations.

The training workshop, which runs for three and a half hours, was piloted with Centrelink JCAs in Victoria and received excellent feedback, particularly for its practicality and comprehensiveness. Centrelink has endorsed the program, leading to it becoming available for delivery nationally by other Joint Epilepsy Council of Australia (JECA) members.

3. Health and Community

The delivery of education and training to support the administration of emergency medication, where prescribed for prolonged seizures, continues to be in demand in a variety of health and community settings.

Emergency medication training for the control of seizures

This year has seen consolidation of our emergency medication education delivery, completion of the Epilepsy Management Plan and Support Package, of which a large component relates to emergency medication, and development of our emergency medication resources.

Prolonged seizure activity is increasingly being managed by emergency medication, with midazolam typically being prescribed. Consequently, requests for training have increased across all sectors of disability, schools and families, with a doubling of requests over the previous year from 43 to 87 sessions.

The development of the Epilepsy Management Plan and Support Package has also led to more training and an opportunity to ensure clear and concise instructions are available for carers or staff supporting a person with epilepsy. The appointment of an Education and Training Manager and part time Epilepsy Nurse Educator during the year will help to meet the increased demand.

In June 2010, a referral process for families who had recently been prescribed midazolam was established with the Royal Children's Hospital. Already we have received more than 10 referrals, leading to many training opportunities. We aim to establish this partnership with many of the public hospitals over the coming year.

That same month, we also piloted an analysis of epilepsy and emergency medication training for the Department of Human Services North Western region. The results and report from the pilot have been used as the basis to open dialogue with the department on supporting people with epilepsy in the disability sector as well as epilepsy plan development and education and training opportunities.

Understanding and Managing Epilepsy series

Supporting people with epilepsy and their families to understand their condition and feel empowered to live the life they want was supported through the delivery of regular Understanding and Managing Epilepsy sessions and the delivery of our Epilepsy Specialist Series, drawing on various health and community service professionals to provide detailed information on specific topics of interest to people with epilepsy.

"Congratulations on a first rate job of getting the issues across."

The Understanding and Managing Epilepsy series is a monthly, two-hour information session offered to people living with epilepsy and their families. An epilepsy counsellor/educator facilitates the session and works with a volunteer community educator, a person with epilepsy trained to share their experiences and strategies in understanding and managing epilepsy. Each session allows an informal question and answer discussion.



The Epilepsy Foundation's Education and Training team (clockwise from back): Peter Hoyle, Val Bates, Nicole Lloyd, Janita Keating and Alison Hitchcock.

“This should be required for every carer’s training.”

A total of 202 people attended 16 sessions for a mix of people with epilepsy, family members, teachers, integration aides, health professionals and support workers.

These sessions have historically been run from our head office in Camberwell but this year we moved a session to Caroline Springs in Melbourne’s outer west to increase access. The response was very pleasing with 36 people attending and the Melton Shire Council giving strong support and publicity to the event. A network of local parents was also established following the session. This was the first session in our outreach program, which will see other Understanding and Managing Epilepsy sessions delivered in outer-Melbourne and other areas of the state.

“Admirable job, most informative.”

Epilepsy Specialist Series

Providing access for people with epilepsy and their families to expert opinion and information is important in ensuring all aspects of their particular form of epilepsy are properly understood.

Whether it is a person considering surgery or trying to develop the best strategies to cope with memory loss, a woman considering pregnancy, or a parent determining the most appropriate solutions for their child with epilepsy, our Specialist Series enables people to make informed decisions and better manage their condition.

We thank all of the speakers for their time, effort and commitment in making this series possible.

“Guest speaker excellent – I was so moved to hear what it is really like to live with such an unpredictable and cruel condition.”

4. Schools and Early Childhood

A key objective of the Epilepsy Foundation is helping children with epilepsy to participate fully in the classroom or in an early childhood learning environment.

In 2009–10 we commenced discussions with the Department of Education and Early Childhood Development (DEECD) to progress our Epilepsy Smart Schools Program. This included feedback to the DEECD on the current epilepsy descriptions and management policies used in its student well-being policies and procedures guide.

The Chief Health Officer’s Senior Medical Advisor, Dr Michael Ackland, has also been engaged to support these discussions. Adoption of the Epilepsy Management Plan and Support Package is being explored with the DEECD, including making this available on its website. Strategies to address the high rate of avoidable mortality in school-age children is a key focus, as epilepsy is one of the top five causes of avoidable mortality for all age groups between 5 and 29 years.

We continued to support schools and teachers with education and training through the delivery of Understanding and Managing Epilepsy sessions in schools and early childhood services. A session was also held in March 2010 at our Camberwell office, attended by 16 people. We also continued to develop Epilepsy Management Plans for individual students and provided emergency medication administration training or support for their school and teachers, where required.

Trivia Challenge

Trivia Challenge is an educational, fun-packed activity that has been designed to develop an understanding of epilepsy among school children while enhancing their general knowledge, using a specially-developed questionnaire. This year, we achieved the participation of 20,180 school students, from 134 primary schools and 27 secondary colleges, for the program.

Throughout the year students, teachers and families who participated in or supported Trivia Challenge were exposed to video and text information and questions relating to epilepsy. They were encouraged to increase their epilepsy awareness and knowledge through research, learning seizure first aid and developing positive attitudes towards all members of the school community, including those with epilepsy.

The Trivia Challenge Final, held at Monash University on 18 October 2009, was a successful day with involvement of schools from across Victoria. The winners for each year were:

- Year 3 – St Kevin's College (National Champion)
- Year 4 – Mt Waverley Primary School
- Year 5 – Doncaster Primary School
- Year 6 – St Kevin's College



Students from St Kevin's College won the 2009 National Trivia Challenge Championship.

Research

In 2010, the Epilepsy Foundation reviewed the governance of the Research Committee and established it as a formal sub-committee of the Board in order to streamline the organisation's research agenda. The Research Sub-committee finalised its Terms of Reference and developed a strategic plan for the next five years to 2015, taking into account the national research priorities; this plan was adopted by the Board in February 2010.

Some key research milestones achieved during the past year included:

Epilepsy Foundation Research Register

Since its inception in 2006, the Epilepsy Foundation Research Register database has grown to more than 700 people willing to participate in epilepsy research. The register invites people with epilepsy and their carers who are interested in participating in psychosocial research to register their names on a confidential database. This take-up rate is expected to grow steadily over the next few years, not only in Victoria but across Australia as the register becomes national.

Ethics approval process

A three-year agreement has been established with Deakin University's Human Research Ethics Committee, which sets out a process for all research undertaken by the Epilepsy Foundation to be considered for ethics approval. This ensures research participants are dealt with according to the National Statement on Ethical Conduct in Human Research 2007; it ensures a process for addressing any concerns that may arise and the testing of research methodology against ethical standards and quality measures.

Longitudinal survey on epilepsy

The first longitudinal socio-economic study of epilepsy, looking at the needs, perceptions and experiences of people living with epilepsy, is underway in Victoria, with human research ethics approval from Deakin University. The study has been made possible through the establishment of a psychosocial research program aimed at providing the necessary evidence to argue for improved policies and services at the government and community levels.

The research offers a unique opportunity to collect information over a period of the person's life and give a voice to the realities of living with epilepsy. We expect the study to continue for up to 10 years, occurring on a bi-annual basis. It will document the changing impact of epilepsy and establish data on issues such as stigma, education, employment, social support, quality of life, mental health status, physical health cost and treatments.

Of the 702 people initially contacted in the first survey, 346 responded, giving a 55.7 percent response rate. Of these, 246 (71.1 percent) were people with epilepsy.

Self-management of epilepsy pilot program

The effectiveness of self-management in the treatment of chronic conditions, such as mental health, diabetes and stroke, is strongly supported by evidence-based research. The use of this approach with epilepsy has, however, been limited. We believe self-management may offer people with uncontrolled epilepsy a viable option, whereby they can be supported to understand their condition better and manage their lifestyle and triggers to improve their quality of life, in cases where anti-epileptic medication and surgery have failed.

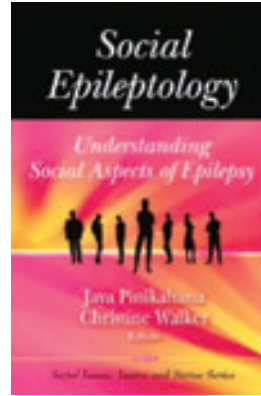


Over the past year, we have put forward proposals for funding of a pilot to evaluate this approach. Unfortunately, our submission to the National Health and Medical Research Council (NHMRC) to carry out a randomised control trial of self-management was unsuccessful, despite favourable external examiner comments (scoring was very positive with 5.8 out of 7).

To strengthen the case for NHMRC funding, a partnership was formed with St Vincent's Frameworks for Health to trial the use of a mental health self-management program and evaluate its use in managing epilepsy. This model was chosen as the level of anxiety and depression can be high for people with epilepsy, especially those with uncontrolled epilepsy. A joint pilot project will be implemented with a trial of the approach with a group of people living with epilepsy in Melbourne and one in Geelong.

Publications and conference posters

A conference abstract was accepted for the Asia and Oceania Epilepsy Congress in October 2010, titled, *The lived experience of initial symptoms of epileptic seizures: An Australian Study*.



Dr. Jaya Pinikahana, Principal Researcher with the Epilepsy Foundation, and Dr Christine Walker, Chronic Illness Alliance, have edited a book called *Social Epileptology: Understanding Social Aspects of Epilepsy*. Thirteen international authors have contributed to this volume and we believe that this is the first use of the phrase

'social epileptology' in epilepsy literature. The book was released in May 2010 by Nova Science Publishers in New York.

Fundraising and communications

Highlights

Our fundraising and communications team has delivered a strong result at a time when global economic pressures have generally affected community confidence.

Strategically, we are looking towards the introduction of a Total Development Program, using multiple fundraising initiatives to reduce our risk against a downturn in any one area. Our reliance on non-government income brings with it the challenge of maintaining sustainable income levels.

The primary roles of the fundraising and communications team are to raise sufficient funds to enable the Epilepsy Foundation to support people living with epilepsy and to create effective engagement programs for all of our stakeholders.

Our success can be attributed to a three-way partnership between the Epilepsy Foundation, our clients and our loyal supporters.

The Epilepsy Foundation – as a sustainable organisation

The perennial pressure of producing surpluses to maintain services has meant that building capacity in service delivery, and in income generation programs, has rarely been possible.

We have been fortunate that the large bequests of Charles Hodgkinson and Joan Bell, received last year, are helping us to build capacity in all areas, from Client Services and Research to Education and Training.

At the core of our sustainable approach to fundraising is our Total Development Program, the concept of which is to ensure that the fundraising and communications mix is the one that best suits our requirements for income generation and awareness-raising, while respecting the privacy, dignity and needs of our clients.

Underpinning the mix is our philosophy on how we relate to the people who want to support us by giving them choice, information, involvement and commitment:

- **Choice** – giving supporters the opportunity to support them in the way that best suits them

- **Information** – providing information about what we do in a way that makes it understandable, relevant and motivating to our supporters
- **Involvement** – finding ways for our supporters to be engaged in our work in deeper and more meaningful ways than just giving money
- **Commitment** – finding better ways to build long term commitment from our supporters.

Fundraising highlights

- Our appeals program performed strongly with a 31 percent increase in funds (up \$105,828) and a fantastic increase of 40 percent in donors who gave
- Centralising our fundraising databases to better manage donors and appeal recipients
- Our use of online fundraising, particularly Everyday Hero (www.everydayhero.com.au), improved substantially from \$5,170 in 2008–09 to \$107,020 during the past year. We give special acknowledgment to Sann Meagher and her brother Anthony Steains who raised more than \$56,000
- In response to challenges associated with raffle telemarketing, including substantial drops in successful acquisition rates, we adopted a more targeted approach that has seen total fundraising contributions drop by \$100,000 but our surplus from contributions increase by \$32,342 and donations from that program improve by \$44,684.

Fundraising challenges

- Bequest income was down from \$1,038,109 to \$11,000
- Challenging conditions meant a shortfall in quality stock being available for resale in our Epilepsy Op Shops; however, by expanding our product mix with the purchase of some product, sales increased by \$43,985
- Significant challenges operating in school environments saw income drop by \$11,092.

Communications highlights

Our communications programs and activities are thoughtfully produced to maximise awareness of the issues associated with epilepsy. While we continue to operate within an environment of constrained resources, the need to gain greater awareness of the issues people living with epilepsy face is always present. Furthermore, increasing stakeholder engagement is a major objective of our communications strategy.

We use a range of communication tools to inform our clients, health care providers, other stakeholders and the public about the programs and services we deliver. This includes the placement of articles and case studies in newspapers and interviews on radio and television, as well as brochures, mail-outs, newsletters, quick reference guides and fact sheets, plus our website and our growing social media presence. We ensure that we are responsive, open and transparent in our dealings with the media and others, and produce high-quality information products.

Communications initiatives during the year:

- We engaged with local, state and national print and electronic media to promote public understanding of issues associated with living with epilepsy.
- A media relations and publicity campaign was undertaken for Epilepsy Awareness Week, including preparation of media releases, articles and case studies, supported by personal media liaison and interviews, which led to 17 newspaper articles in regional and suburban media, 12 radio interviews state-wide, and approximately 10 online articles, featuring the Epilepsy Foundation CEO and clients. This work helped to foster favourable relationships with journalists, while helping the general public to understand more about epilepsy; furthermore, many people and families who took part said this made them more comfortable in talking about their epilepsy and helped them feel they were giving back to the community.

- After being cyber-attacked, our website (www.epinet.org.au) was reinstated, with a new design, enhanced navigation and updated information, and subsequently re-launched in March 2010
- Internally, the Epilepsy Foundation reviewed and upgraded much of its epilepsy information with significant achievements including the development of seminar and promotional fliers, fact sheets on various aspects of epilepsy, new service brochures and collateral for our education and training programs.
- As part of the development of new resources, we introduced the new, comprehensive Epilepsy Management Plan and Support Package.

Charitable status, tax concessions and fundraising

Epilepsy Foundation of Victoria Inc.
ABN 75 967 571 784 is an incorporated association – Reg. No. A0022674D.

Epilepsy Foundation of Victoria is a Public Benevolent Institution (PBI). It is endorsed as an Income Tax Exempt Charity (ITEC) and enjoys certain other tax concessions and exemptions consistent with its status as a PBI, which relate to Goods and Services and Fringe Benefits taxes.

Epilepsy Foundation of Victoria has been endorsed by the Australian Taxation Office as a Deductible Gift Recipient (DGR).

Epilepsy Foundation of Victoria is registered with Consumer Affairs Victoria as required by law to raise funds – Reg. No. 10685 (expires 9/11/2012).

Epilepsy Foundation of Victoria is a declared charitable organisation for minor gaming purposes with The Victorian Commission for Gambling Regulation – Reg. No. 40315.

Our fundraising staff are members of Fundraising Institute Australia (FIA) and subscribe to the FIA Codes of Professional Fundraising Practice.

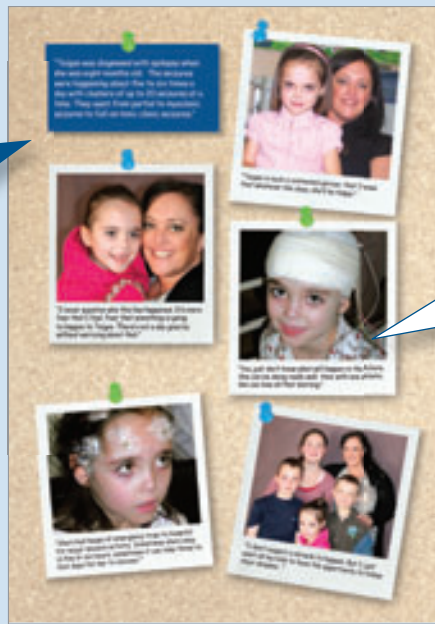
We encounter many acts of generosity over any given year and we could never recount them all, as much as we would like to. Thank you to all who have helped in some way – you are all making a difference.

Major Appeals

'People giving to people' is at the heart of all philanthropy. The generosity of our donors and supporters is matched by the courage of our clients as they give us access to their lives and those of their families. As much as possible, we seek to include as many stories as we can about our clients to show every supporter the challenges they face, what we think needs to be done and the things that we have done to change their lives.

2009 Christmas Appeal – Teigan

"Teigan was diagnosed with epilepsy when she was eight months old. The seizures were happening about five to six times a day with clusters of up to 20 seizures at a time. They went from partial to myoclonic seizures to full-on tonic-clonic seizures."



"You just don't know what will happen in the future. She can be doing really well, then with one seizure, she can lose all that learning."

2010 Tax Appeal – The Walker Family

Four out of five members of the Walker family have epilepsy – the three children, Cassandra, Daniel and Ronan, and Darrell, their dad.



These are the things that matter to people with epilepsy ... These are the things we need your support for.

Trusts and Foundations

The support of all our donors, both large and small, gives the Epilepsy Foundation the ability to not only undertake its regular services, but to take on special projects and maximise opportunities to help people with epilepsy. Each year, we submit funding applications for various projects to charitable foundations and trusts and, this year, we received support from the following:

- SUDEP Research: Matthew Callaghan Memorial Fund
- Mobile Training and Awareness Program: Estate Daniel Scott – Perpetual Trustees, The Danks Trust
- Women in Epilepsy Network: The Marian and EH Flack Trust
- Telephone Network Upgrade: The William Angliss Charitable Fund, Collier Charitable Fund
- Training Room Equipment: Goldman Sachs JBWere Foundation, The Borrodell Bequest – ANZ Trustees Foundation
- Client Services Programs: Bell Charitable Fund

Community education expense allocation

Many other organisations separate the education costs and transfer them out of the fundraising area prior to reporting. Our enclosed accounts show the full costs; when required, we will internally take up the community education and public relations costs to reflect what they might otherwise cost the Epilepsy Foundation.

By program type (percentage of gross expenses)

Raffles	55%
Donations:	
Donor Renewal programs	50%
Donor Acquisition	65%
Op Shops/Recyclables	50%
Trivia Challenge	95%
Volunteer fundraising	55%
Bequests	50%
Grants	20%

Our volunteers

Volunteers continued to play an important role in the delivery of our services. Many activities, administrative tasks and services could not function without their continued support. Their participation covers organisation and support for the Family Respite camp and Adult Getaway, help with the op shops, support groups and helpline, assistance with administration, fundraising, public speaking and community education activities, as well as participation on our Board and various sub-committees.

All volunteers participating on the Adult Getaway camp were volunteers who had previously helped and who returned again this year to lend a hand. Volunteers included one from the Austin Hospital and five others who are either adults with epilepsy or parents who support a child with epilepsy.

A mixture of existing and new volunteers, plus student placements, helped at the Family Respite camp, including 10 youth work students from Victoria University who participated as part of a student placement, eight volunteers with epilepsy or parents of children with epilepsy and five new volunteers.

Our special thanks go to Leslie Ridgeway who was responsible for overall programming at both events.

10-Year volunteer award

Marla Wiseman
Hazel Broadberry
Donna Heath

5-Year volunteer awards

Sara Tnay
Neil Atwood

Special Long Service Award (19 years)

Jean Jasper



Honour roll

\$20,000 +

Mr Anthony J Steains
Bell Charitable Fund

\$10,000 – \$19,999

Estate Late Daniel Scott
Dr D Fraser
Collier Charitable Fund

\$5,000 – \$9,999

Joe White Bequest
Moore Stephens
Mr J Maxwell
Bib Stillwell BMW SMG European Cars Pty Ltd
The Marian and EH Flack Trust
Mr John Floyd
Estate of Ellen Hutton Mary Cummins
Goldman Sachs JBWere Foundation
The Borrodell Bequest – ANZ Trustees Foundation
Mr Wayne King
Danks Trust
Consolidated Chemical Co.
The Alfred and Jean Dickson Foundation

\$2,000 – \$4,999

Ritchies Stores
Lauriston Girls' School
Kew Primary School
Rotary Club of Camberwell
Mrs June FM Smith
Mr Ross Seaman
Mr James Kelly
Ms Andrea Neilson
St Agatha's Primary School
The Isabel and John Gilbertson Charitable Trust
Dr FG Donaldson
Dame Elisabeth Murdoch
Mrs M O'Sullivan
Mr Graeme Shears
The William Angliss Charitable Fund
Mr Richard J Stanley
Mr and Mrs M and S Edwards
The Shulu Foundation
Mr Richard Elman
Estate of Trevor Ernest Strangward

\$1,000 – \$1,999

Mr Peter B Board
Mrs Marie Jones
Ms Low Geok Kee
Oakleigh Greek Orthodox College
Mrs Bella Shanon

Ms EM Neilsen
Malvern Primary School
Lions Club Of Mordialloc – Mentone Inc
Mrs G Way
Mr Douglas Hewitt
Himax Investments Pty Ltd
St Kevin's College
Templestowe Valley Primary School
Ms Samantha Meagher
Loreto Mandeville Hall
Mont Albert Primary School
Mr Greg Shalit and Ms Miriam Faine
Mr Graeme R Blair
Mr Griffith Young
Mrs Joan Steains
Gippsland Grammar
Beverley Hills Primary School
Mr and Mrs Vikram and Parveen Samra
Mr and Mrs Paul and Patricia Lightfoot
Mr Paul Schorr
Mentone Girls' Grammar School
Mrs M Coles
Taroona High School
Estate of LI Roach
Mr Darren Dunne
Kilvington Girls' Grammar
Mr and Mrs John and Marie Warnock
Mr Edward J Miller
Mr Ian C Curry
Ballarat Grammar School
Allbeau Pty Ltd
Mrs Diana M Lowe
Mrs Margaret Rafferty
Mr CD Turnbull
Mr Robert G Kirby
Mrs Rose Perich
Mrs Flora Wong
Mrs Barbara Shearer
Nielsen (Vic) Pty Ltd
Dr James Lewis
Mr John Shalit
Mr Andrew Padgham
Ms Catherine Hall
Dr Lloyd Kenda
Mr Timothy Andrew
Mr John Studzinski
Mr Dong Hyun Lee
Mr David Fleming
Mr Michael Reddrop
Mrs Kristen Harris
Mr Peter Steven

Honour roll

\$500 – \$999

Ms Tracey Gower
Mrs Yvonne Hinds
Ms Linda J Barbour
Belmore Park Pty Ltd
Ms Patricia M Holmes
Kyabram Secondary College
Mrs Joan OA Gibbs
Mr Yang Zhizhong
Rangebank Primary School
Ms Nan Brown
Mr Howard W Paul
Mrs Jean Williamson
Miss Kay Edwards
Mr Kok-Hoong Chong
Ms Victoria White
Mr Derek Kozub
Mrs Norma Minney
Ms Megan McDonald
Mr Wayne Simms
Mr James Searle
Dr Melvin Goh
St Joseph's Primary School
Mr Trevor O'Connell
Mount Waverley Primary School
Mr Edward Haldane
Mrs Marion Sheehan
Dr Nicholas Ferris
Sunbury College
Traralgon (Stockdale Road) Primary School
Mr George Gilbertson
Mr JC Ellson
Malta Star of The Sea Incorporated
Rye Primary School
Mr Terry Williamson
Highvale Secondary College
Mrs Rosemary Southgate
Mr John Stephens
Cranbourne West Primary School
Kilberry Valley Primary School
Ms Judy Maddigan
Mr Francis J Shelton
Mr Leonard E Smith
Mr Andrew Vaccaro
Mrs Heather Sandford
Mr Michael Pridgeon
Mr Sam Miller
Mr Scott Hartley
Mr Henry Mignot
Mr Moodie Chit

Mr Randal MacDonald
St Virgil's College
Creswick Primary School
Mrs Megan Rankin
Mrs Suzette Main
Gardenvale Primary School
Mr Steven Jones
Mrs Patricia McIntyre
City of Casey
Mr Stephen Schwarzman
Mrs Betty Towie
Mr Ray Woods
The Blackstone Group
Mrs Doris Jones
Jells Park Primary School
Mr Keith Taylor
Mr James David Kisby
Ormond Primary School
Mr Richard A Juska
Mrs Susan Spence
Ms Felicity Teague
St Leonard's College, Brighton Campus
Matthew Callaghan Memorial Fund
Mr David and Mrs Elizabeth Ebert
Brentford Square Traders Association
Mrs F Pinney
Mrs LM Mason
Mr and Mrs J and S Long
Mrs Marion M Harper
Mr GR Sellars-Jones
Mr William A Manwaring
Mr TC Johnston
Mr Leo Lazarus
Ms Elizabeth Russell
Mrs Peggie Payne
Mr and Mrs Francis and Helen Musk
Instanza Pty Ltd
Mrs M Graham
Ms Ruth Gross
Ms Barbara Haynes
Blue Label Pty Ltd
Mrs Pearl Lubansky
Ms Maureen Reynolds
Mr and Mrs Ian and Gail McKay
Mr W Hogarth
Mr DG Moynihan
Mr John W McPhee
Neil Heron Operations Pty Ltd
Mr Jeffrey Harris
Mr Paul Barnett

Ruth Fagg Foundation
Mrs Dung Doan
Mr Brian Wansbrough
Miss Catherine Coghlan
Mrs Ann Davies
Lions Club of Paynesville
Mr RF McDonald
Ms Cathy Almond
Mrs Maureen L Crawford
Mr John Cotter
Ms Alison M Eva
Mrs A Cauley
Ms Tracey Macmillan
Mr Norman McMaster
Mr Steven Palamara
Mrs R Holmes
Mr Arthur Kearton
Mr Ingo Helbig
Mr Simon Holden
Australian Legion of Ex Service Men and Women
Mr Felix Huang
Mr Ronald Steains
Mr Daryn Steains
Mr William Nichol
Miss Kathy Honeywood
Mr Johan van Jaarsveld
Mr Peter Cook
Mr Robert Jackson
Mr Greg Zaritski
Mr George Pappas
Mrs Robyn Kimpton
Mr P and Mrs A Nicholls
Mr Blaise Vinot

Ann Rendell: Lifting the lid on epilepsy



Ann Rendell, teaching Ryan Baker, 18, who has severe autism, intellectual disabilities and compulsive disorder, to swim.

Six years ago, 43-year-old Ann Rendell, from Port Fairy, was living life to the full, running her own business, travelling and sailing competitively. But then she experienced her first seizure. Immediate hospitalisation and tests revealed a lesion on Ann's brain was causing her seizures and she was diagnosed with epilepsy.

Ann was trialed on various medications but her seizures continued. Subsequently, she was not permitted to drive, she could no longer operate in the workplace effectively and safely, and her self-confidence and independence evaporated.

"My world turned upside down. All of a sudden I was no longer permitted to drive a car, take a bath, swim alone ... and I withdrew into my family and closest friends. This was the beginning of the psychological effects I experienced through living with severe and uncontrolled complex partial seizures. The fear of the next seizure was a constant monkey on my back."

At the start of 2007, Ann had reached the lowest ebb in her life and, desperate for seizure control, was referred to specialist Professor Terry O'Brien. In his care, Ann underwent two, week-long tests at the Royal Melbourne Hospital neuroscience ward to determine whether she was a candidate for surgery. The tests revealed that Ann, was in fact, a suitable candidate, with a 70 percent chance of significant improvement in seizure control and a 2-3 percent chance her seizures could be worse.

After carefully evaluating the pros and cons, Ann went ahead with the surgery. "I wasn't really living life - I had nothing to lose and everything to gain."

She was immediately seizure-free and has remained that way since, and continues to control her epilepsy with daily, low-dosage medication.

However, the road to recovery has been tough, with overwhelming side-effects including anxiety, depression, fatigue and reduced attention span. But as her rehabilitation progressed, so did her self-confidence and Ann now has her life back again, along with her self-confidence, independence and, importantly, her driving licence.

Ann is now a part-time qualified Learn to Swim instructor and TAFE teacher and is back sailing again. In February 2009, she flew to Vietnam and cycled from Hanoi to Ho Chi Minh City, well away from medical teams, family and friends.

Ann says she is especially grateful to the Epilepsy Foundation for the wonderful support they provided. "The Epilepsy Foundation has been with me all along the journey and I am grateful for their understanding, encouragement and support."

She is now a volunteer at Epilepsy Foundation family camps, having participated in the family respite weekend for children with epilepsy held in Anglesea in March, and is involved with the Women and Epilepsy Network (WEN).

"In my spare time I look to do what I can to raise awareness, reduce the stigma and encourage everyone I meet to help in whatever way they can."