EPILEPSY out of the shadows

Asian-Oceanian Declaration on Epilepsy

New Delhi - November 13, 2000

A meeting "Epilepsy : A Public Health Priority in Asian & Oceanian Region" was held in New Delhi on November 10,2000. Over 600 professionals from health and social sciences sectors and representatives from many other organisations of the region unanimously agree on November 13, 2000 to the following declaration:

CONSIDERING THAT IN ASIA/OCEANIA:

- At least 30 million people have the common brain disorder - epilepsy. This compares with approximately 50 million people with epilepsy world-wide.
- Epilepsy can have serious medical, psychological, social and economic consequences for people with epilepsy and their families.
- Epilepsy affects people with epilepsy and their families irrespective of race, religion, gender, age or socio-economic status.
- Although epilepsy is a brain disorder, it is often mistakenly believed to be a mental illness, or to be caused by supernatural powers.
- It is erroneously, yet widely, believed that epilepsy is an infectious disease and seizures are contagious.
- It is often not realised that epilepsy is treatable, and that most people with epilepsy can lead productive lives as a result of relatively inexpensive, cost-effective treatment.
- The majority of people with epilepsy are treated inadequately and inappropriately because of ignorance, discrimination and limited health resources.
- Good quality standard anti-epilepsy drugs are not regularly available in many countries.
- Disability and mortality are greater because epilepsy is inadequately treated.
- Epilepsy impacts most severely on the period of greatest development, namely childhood, adolescence and young adulthood. Yet it is during this time of life that it is most readily and successfully treated.
- The preventable causes of epilepsy such as poor perinatal care, infectious diseases, parasitic infestations, head trauma and consanguineous marriages are particularly prevalent.
- Epilepsy has not been included in most National Health Care plans.

PROCLAMATION

We call on the governments and other health providers of the Asian and Oceanian region, to join us in taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy launched by the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE).

Specifically, we urge every government in this region to:

- Educate people with epilepsy, their families and the general public about epilepsy as a wide-spread, non-communicable and treatable chronic brain disorder. Educational means appropriate to all levels of literacy should be used.
- Educate and train health care and other relevant professionals about epilepsy, its prevention and its treatment.
- Provide access to trained personnel, modern diagnostic equipment and appropriate medication and/or surgical treatment for epilepsy.
- Promote and support research in Asia and Oceania into the basic processes, clinical aspects, and psycho-social consequences of epilepsy.
- Promote social integration and eliminate discrimination against people with epilepsy in all spheres of life, especially school, work and marriage.
- Include epilepsy in their national health plans, just as they do maternal and child health, mental health, infections and immunisation.
- Encourage cooperation between modern medical, traditional and other healing systems for the treatment of epilepsy.
- Encourage the public and private sectors, as well as relevant Non-Governmental Organizations to actively support local activities related to the Global Campaign Against Epilepsy.
- Raise public awareness of epilepsy by proclaiming a National Epilepsy Day, and supporting the establishment of a World Epilepsy Day.
- Encourage regional and global cooperation in dealing with epilepsy.

IBE WHO ILAE

Activities and News - "SINGAPORE EPILEPSY DOCIETY"

The Singapore Epilepsy Foundation would like to congratulate a group of medical professionals working in the field of epilepsy for forming the Singapore Epilepsy Society (SES). The primary objectives and activities of the SES are to advance and disseminate knowledge concerning epilepsy to medical professionals. SEF looks forward working closely with SES to help educate the public about epilepsy.

SES Committee:

President	:	*A/Professor Dr Lee Wei Ling*
Vice-President	:	*Dr Puvanendran*
Secretary	:	*Dr Lim Shih Hui*
Treasurer	:	*Dr Ong Hian Tat*
Committee Members	:	*Dr Sitoh Yih Yian*
		Dr Ng Beng Yeong
		Dr Einar Wilder-Smith

November 2000 saw the Asian and Oceanian Epilepsy Congresses meeting in New Delhi India. SEF delegates from Singapore were: Prof Lee Fook Hong (chairman SEF), Mr David Lee (Hon .Treasurer), Dr Lim Shih Hui (invited speaker) and Dr Wilder-Smith (presenter). An important statement , the Asian-Oceanian declaration on Epilepsy was formulated and published at this meeting and is printed in full below. It marks a vital step forward in the increasing efforts being made to advance the cause for epilepsy in our region.
(Please insert the separate file)

We also congratulate Dr Lim Shih Hui on his appointment as the SEF's delegate to the Asian Oceanian Epilepsy Association (AOEA). AOEA is a non-medical professional epilepsy organisation in the Asian and Oceanian region, supported by the International Bureau For Epilepsy. The Chairman of the AOEA is Dr Marchal Mo-Song Hsi, who is also the
Ex-Chairman of the Taiwan Epilepsy Association.

Singapore Epilepsy Foundation

SINGAPORE EPILEPSY FOUNDATION (SEF) & SINGAPORE EPILEPSY SOCIETY (SES)

Public Forum

Venue : Mandarin Hotel, Level 5, Reception Hall
Date : Saturday, 17th February 2001
Time : 1:15 pm - 5.00 pm

P·r·o·g·r·a·m

Time	Topics	Speakers
1.15 pm - 1.40 pm	**Registration**	
1.40 pm - 1.50 pm	**Welcoming Addresses**	A/Prof. Lee Fook Hong, Chairman, SEF Dr Puvanendran, Vice-President, SES
	Session A: Chairpersons:	Dr Lim Shih Hui Dr Puvanendran
1.50 pm - 2.05 pm	Fits, Convulsions, Seizures and Epilepsies	Dr. Einar Wilder-Smith, NUH
2.05 pm - 2.25 pm	Medications for Epilepsy	Prof. Simon Shorvon, NNI
2.25 pm - 2.40 pm	Surgery for Epilepsy	Dr. Lim Shih Hui, SGH
2.40 pm - 3.00 pm	Management of Children with Seizures and Epilepsy	A/Prof. Lee Wei Ling, NNI & NUH
3.00 pm - 3.15 pm	**Questions and Answers**	
3.15 pm - 3.40 pm	**TEA BREAK**	
	Session B: Chairpersons:	A/Prof. Lee Fook Hong Dr Einar Wilder-Smith
3.40 pm - 3.55 pm	Does my child with epilepsy need special care?	Dr. Ong Hian Tat, NUH
3.55 pm - 4.10 pm	How to Overcome Depression Resulting from Epilepsy?	Dr. Ng Beng Yeong. IMH
4.10 pm - 4.25 pm	How can I help myself?	Mr. Nikhil Nicholas
4.25 pm - 4.40 pm	Can I Drive?	Dr. Puvanendran, SGH
4.40 pm - 4.55 pm	**Questions and Answers**	
4.55 pm - 5.00 pm	Closing Remarks	Prof. Lee Fook Hong

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SINGAPORE EPILEPSY FOUNDATION

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editorial

One of the main concerns of the Singapore Epilepsy Foundation to promote public awareness and education on topics surrounding epilepsy. As part of this drive, we are continuing the series on the ABC of epilepsy and issues touching on epilepsy. The letters D, E, F and G are addressed in this issue. As Epilepsy in children is not uncommon, we find it is important to provide with some more general background information on childhood epilepsy in this issue.

We also present you with original research concerning the public attitudes toward epilepsy in Singapore. The information was gathered last year in Singapore and shows that we need to do more public education on epilepsy. For this reason the SEF is organising a public forum on epilepsy, Saturday the 17th of February. The meeting takes place in the Ballroom of the Mandarin Hotel and starts at 13.15. A timetable can be found on the back page.

We always emphasize that this series is designed to be interactive with you, so we are waiting to hear your thoughts and ideas. Just send a letter or email to the SEF office. Pertinent correspondence will be published in the newsletter for all to participate in.

Please enjoy the issue and pass it on to someone who might benefit from it!

The Editor
"Epilepsy education"

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Dr Wilder-Smith E

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Dr Wilder-Smith E

ABC of Epilepsy

Déjà vu

This expression describes the feeling of re-experiencing a previous experience. The person with dÉj‡ vue will say that there is a feeling of familiarity, of already having been to that place or type of situation previously. The experience can be either "good" or "bad". It is important to identify these episodes as they often signal the start of a complex partial seizure. DÉj‡ vue is a type of "aura" and can help localise the area of the brain that is malfunctioning.

Diazepam

This is the name of the medicine contained in Valium(r) and Stesolid(r). It is used for the acute treatment of a seizure and is then administered through the veins or into the muscle. The main side effect of the medicine is drowsiness.

Driving

In Singapore, under the current road Traffic Act, people with epilepsy are prohibited to drive any type of vehicles, regardless of whether they have been seizure free for 2 or more years. Such people must declare their epilepsy condition when applying for a driving license. Once declared, application will automatically be rejected. For those who have already obtained their driving licenses, it is their duty to inform the authorities should they develop epilepsy subsequently.

At present there is no statutory requirement for doctors to notify the Traffic Police or Land Transport Authority should they come to know that their patients with epilepsy continue to drive. The Singapore Medical Council has stated that there is no breach of medical confidentiality if doctors notify the authorities of the patient's unfitness to drive if their driving will post a definite danger to the public.

In 1997, the Singapore Medical Association prepared medical guidelines for medical practitioners in Singapore to assist them in advising and certifying their patients with regards to fitness to drive. The guidelines recommended that people with epilepsy may be allowed to drive a private vehicle if a person has (1) no structural brain lesion, (2) normal EEG, and (3) been seizure free for 3 years and off all anti-epileptic drugs for at least 1 year. For those who have seizures only during sleep, the minimal seizure free period is 2 years whilst for those who wants to drive public vehicle, the minimal seizure free period is 10 years. However, the guidelines recommended have not been implemented as the Road Traffic Act has yet to be amended.

Drop attacks

The name drop attacks describes the phenomenon of a generalised epileptic fit resulting in a loss of muscle tone and strength resulting in a sudden "drop". Severe injuries may be a result from these attacks and may require the person to wear a helmet.

EEG (Electroencephalogram)

The electrical activity of the brain can be detected using a machine, which greatly amplifies the brains electrical fields. Little metal plates called electrodes are fixed to the surface of the scalp which then transmit the electrical impulse to either a computer screen or paper where it is then read by a neurologist or neurophysiologist. If necessary the electrodes can also be placed inside the head to get a more accurate picture of the abnormality. However this is not done frequently. The normal EEG will show a typical wave pattern during wakefulness called alpha rhythm. The main use of the EEG is in helping the doctor decide on what type of epilepsy the patient is suffering from.

Epilepsy

This is the name given to a brain disorder where there are repeated epileptic seizures. Epileptic seizures are divided into two types: generalised and partial depending on how much of the brain participates in sudden abnormal activity. It is estimated that about 1 per hundred of the population suffers from some form of epilepsy. The cause of epilepsy varies considerably with the most common causes being "Idiopathic" (meaning unknown or not clearly known) developmental abnormalities, strokes, tumours and infection of the brain. The aim of treatment is to completely control seizures which in most cases is done by taking medicines. Some types of epilepsy can be treated surgically.

Fit

This is another term for seizure.

Focal seizure

Focal seizures are due to part of the brain suddenly discharging excessively. Depending on which part of the brain is malfunctioning, the resulting abnormality can be motor, sensory or rarely autonomic. Involuntary movements of the arm or leg or face often accompany motor seizures.

Gabapentin

This is the name of a more recently introduced antiepileptic medicine. The trade name is Neurontin(r).

Generalised seizures

The whole of the brain is affected in this type of seizure. Since all of the brain is involved, consciousness is rapidly lost. There are different clinical variations of generalised seizures. The most common are tonic clonic seizures, absence seizures and myoclonic seizures.

Grand Mal Seizures

This description of a generalised seizure is derived from the French language and means "major illness". It is a general term and does not accurately reflect the type of a seizure a person is suffering from.

"Glimpse into Research"

The full article was published in the Neurological Journal of Southeast Asia, 2000; volume 5; Page 5-10.

Public awareness, attitudes and understanding toward epilepsy among Singaporean Chinese

Dr Andrew Beng-Siong PAN , Dr Shih-Hui LIM Department of Neurology, Singapore General Hospital

Objectives: To explore the public awareness, attitudes and understanding among Singaporean Chinese toward epilepsy and to compare this with similar surveys in the region. Methods: A public survey conducted at a half-day community health fair in a local housing estate. Results: Of 214 respondents sampled, 85% had heard or read about epilepsy, 56% had witnessed a seizure, and 36% knew someone with epilepsy. Forty-four percent of the respondents did not know what to do if they witnessed a seizure but 32% would put something into the mouth of someone having a seizure. Whilst only 13% would object to their children associating with epilepsy sufferers, 36% would object to their children marrying an epilepsy sufferer. Thirty-eight percent would not employ an epilepsy sufferer though 66% would do so should seizures not interfere with the applied job. Sixty-eight percent associated an epileptic attack with convulsions but most were unaware of non-convulsive forms of epilepsy. Twenty-two percent did not know what treatment to recommend their friends and relatives should they suffer from epilepsy but 60% would recommend Western medicine. In the similar surveys conducted in Taiwan (1992) and China (1988), more respondents seemed to know someone with epilepsy (70% and 77% respectively). The proportion of Singaporean & Malaysian Chinese who would object to their children marrying an epilepsy sufferer (36% & 43% respectively) is very much lower than that encountered with Chinese from Taiwan (72%) and China (87%). With regards to understanding the cause of epilepsy, symptoms and treatment recommendations, Chinese in our survey seem to respond similarly with those from Taiwan, China and Malaysia.
Conclusion: A high proportion of Singaporean Chinese lack adequate knowledge about epilepsy and its immediate and long-term management. Reluctance with marriage and employment is still evident. There appear to be differences with regard to attitudes toward epilepsy sufferers between Chinese in this region.

"MY CHILD HAS EPILEPSY" - INFORMATION FOR PARENTS

Dr Ong Hian Tat, Consultant & Clinical Lecturer, Division of Neurology, Department of Paediatrics, National University Hospital

It is always a frightening experience and a great shock to parents and caregivers when a child has a seizure. Nevertheless seizures are quite common in children, with 3 to 5 % having febrile seizure where the prognosis for seizure remission is excellent, and 0.5 to 1 % having epilepsy defined as a tendency to experience recurrent unprovoked seizures. About one-third of all the patients with epilepsy had their seizures beginning in childhood.

"Your child had recurrent SEIZURES and yes this means that he has **EPILEPSY** and ....". With these words resonating through their minds, most parents have difficulty coming to grasp with further explanation offered by their child's doctor or paediatrician. However, after the initial shock and anxiety, most parents return with many more questions regarding epilepsy that they wish to understand so as to help their child in the best way they can.

"What is epilepsy?" is a difficult question to answer in a simple yet accurate way. Epileptic seizures are caused by sudden and unusual discharges of the brain nerve cells. This results in a brief alteration of the person's consciousness, sensation, movements or actions and is called a seizure.

"What caused my child to have epilepsy?" There are many different causes or triggers for the abnormal behaviour of brain cells resulting in seizures. The more common ones in children are:

1. Abnormal or impaired development of the brain structure during pregnancy. This may be due to
   a) genetic disorders
   b) infections during pregnancy e.g. German measles
   c) alcohol or drug abuse
2. Brain damage due to complications during delivery or related to extreme prematurity, such as oxygen deficiency during birth or following birth trauma
3. Infection to the brain such as meningitis or encephalitis
4. Traumatic brain injuries caused by falls, road traffic accidents, and vigorous shaking of infants
5. Brain tumour
6. Progressive brain diseases with premature death of groups of nerve cells in the brain from inborn errors of cellular metabolism.

Despite the use of the most modern laboratory tests and neuro-imaging techniques, the origin of the seizures/epilepsy cannot be conclusively determined in some children. Nevertheless, in these cases treatment is also necessary and a complete cure is still possible.

"Is epilepsy an inherited condition?" Epilepsy is generally not a hereditary disease, i.e. the condition is not directly passed down from parent to child. However, everyone inherits some susceptibility to seizures or a "seizure threshold" - that is the point at which we may have a seizure if the brain is sufficiently irritated. People with lower seizure thresholds tend to develop seizures with less irritation compared to others. This susceptibility to epilepsy varies from family to family. Children born of parents with epilepsy have a higher chance of developing the condition than other children with no family history of epilepsy, but it is still much more likely that they will not have epilepsy. Moreover many children with high susceptibility may not have seizures unless there are additional triggering factors such as sleep deprivation, visual exposure to flashing lights, or brain injury. Recently, doctors have shown that some rare forms of epilepsy have a genetic basis. The genetic abnormality has been localized to a specific gene.

"Will my child stop having seizures eventually?" The prognosis for seizure remission is closely related to the underlying cause for the child's epilepsy. Some of the adverse prognostic factors include proven brain injury or abnormality as the cause for the child's seizure, presence of mental and/or physical handicap, epilepsy beginning in the first year of life, poor initial response to appropriate anti-epileptic medication, and a long duration of seizures prior to treatment. On the other hand, there are some childhood epilepsy syndromes where the prognosis is excellent with more than 90% spontaneous remission in adolescence e.g. benign childhood epilepsy with centro-temporal spikes (benign Rolandic epilepsy) and childhood absence epilepsy. A recent longitudinal study reporting on the long term prognosis of seizures with onset in childhood showed that after 20 years of follow-up, 64% had remained seizure-free for at least 5 years, with 47% being off all anti-epileptic medication. However, the authors of this publication emphasized the increased risk of social and educational problems in this study cohort. Thus, it remains a challenge for the paediatric neurologist and epileptologist not only to improve seizure outcome, but also to improve the quality of life and the likelihood of gainful employment and successful social integration for children with epilepsy.

"First Aid of Seizures"

At the last SEF meeting in December we heard that inserting objects into someone having a seizure is a common problem. Even cell phones (yes! incredible but sadly true) have been forced into peoples mouths resulting in severe unnecessary injuries! If you happen to witness a generalised convulsive seizures the most important thing is to make sure the person does not harm him/herself during or after the seizure.

1) Lie the person on his side in the recovery position.
2) Keep the airways free. Remove loosely fitting dentures and solid objects that may have been vomited up during the seizures.
3) DO NOT insert a spoon or any other object into the mouth as this will result in two things: Injury to the mouth and teeth of the person and potential injury to you! (the person will often bite as a reflex action and fingers may be severely damaged or even lost!!)
4) Do not restrain the convulsive movements as you may injure the person.
5) Call for medical help.
6) Time the duration of the seizure.