

SINGAPORE EPILEPSY FOUNDATION *Newsletter*



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Activities and News

Public Forum "Women With Epilepsy"

A public forum "Women with Epilepsy" was held on Sunday 21 March 2004 at the Pan Pacific Hotel with an aim to address health issues faced by women with epilepsy.

The panel of speakers comprised the following:

- Dr Martha J Morrell, Professor of Neurology at the Columbia University.
- Dr Lim Shih Hui, Senior Consultant Neurologist, National Neuroscience Institute, Singapore, and
- Dr Tay Sun Kuie, Obstetrician & Gynaecologist, Singapore General Hospital.

Dr Morrell shared with the participants on the issues affecting women with epilepsy:

- Pregnancy and Family Planning
- Menopause
- Polycystic Ovary Syndrome (PCOS)
- Bone Health

Dr Lim presented data and statistics on the "Psycho-Social Issues in Women with Epilepsy-Singapore Experience." Dr Tay shared his views on the worries faced by epileptic women planning to start a family and on common problems relating to pregnancy. During the Qs & As session, there were numerous questions and concerns raised by the participants.

Participants at the forum were those affected by epilepsy and their family members. They expressed that the forum had been useful and informative.

SEF expressed its sincere appreciation to the panel of speakers and GlaxoSmithKline for sponsoring the event. Special thanks to Ms Cecilia Tan for translating the presentations in Mandarin to the participants.



Audience at the forum



Panel of speakers



The registration booth...

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International Epilepsy Day

The Singapore Epilepsy Foundation organised the 1st International Epilepsy Day on 7 December 2003 at the HDB HUB Toa Payoh with an aim of creating greater awareness and knowledge about epilepsy and how to have a quality lifestyle for those affected by epilepsy. In addition, the event reached out to employers so that they had a better understanding about employing people with epilepsy and giving these people an opportunity to excel in careers.

The event was graced by Mr Zainudin Nordin, Member of Parliament for Toa-Payoh Bishan GRC. There were publicity of the event on TV Channel 8 and Newsradio 93.8FM,. Press releases were published in Lianhe Zaobao and Today „Triumph of Ignorance“ published on 8 December 2003. Positive feedback was received from the general public with one writer who wrote “that increasing awareness and educating potential employers and fellow colleagues will remove stigma faced by people with epilepsy.”

The one-day event filled with dance and song performances. A sketch on „Do’s and Don’ts on First Aid Seizures“ was presented by the nurses from Ward 74, Singapore General Hospital. The 15-minute sketch focused on the knowledge and importance of proper handling of fits and seizures and how the public could render first aid assistance when they encounter similar situations. Besides the performances, games, lucky draws and quizzes were held and participants walked away with fabulous prizes

SEF placed on records its sincere thanks and appreciation to all supporters, volunteers, participants, sponsors and donors in contributing to the success of the International Epilepsy Day!

An artist drawing a picture of Mr Zainuddin Nordin, our Guest of Honor.



Volunteers managing the food stall sponsored by Singapore Buddhist Lodge

First Aid seizures demonstration by nurses from Ward 74, Singapore General Hospital



Audience at Toa Payoh Hub watching the performance....



R-L Mr Lee Bock Guan, Guest of Honour, Mr Zainudin Nordin (MP Bishan-GRC), Prof Lee Fook (Chairman Singapore Epilepsy Foundation), Dr Lim (Medical Advisor)



Welcome speech

Prof Lee Fook Hong

Chairman, Singapore Epilepsy Foundation

Good afternoon

Guest of Honour, Mr Zainudin Nordin, Member of Parliament for Bishan-Toa Payoh GRC, Distinguished Guests, Ladies and Gentlemen

Today is Sunday and it is a family day for relaxation, but many of you still make an effort to be present here today. I thank you all for your presence. Special thanks are particularly due to our Guest of Honour, Mr. Zainudin Nordin, Member of Parliament for Bishan-toa Payoh GRC.

Despite his busy schedule, he attends our function and will address us later. This is very encouraging and we are very much honoured and grateful to him for his kindness and presence.

The Singapore Epilepsy Foundation is a non-profit organization incorporated as a company limited by guarantee on 31 December 1994. It is an approved charity and it has also been granted the status of an Institution of Public Character (IPC) and is a member of the Health Endowment Fund. All donations to our Foundation are tax exempt. In other words those who make donations to our Foundation will be able to claim their tax-exempt donations against their taxable income.

There is an international organization founded in Rome in 1961. It is known as the International Bureau for Epilepsy (IBE). The membership of this Bureau consists of national organizations known as Chapters of IBE. The Singapore Epilepsy Foundation has been admitted and is now a Singapore Chapter of IBE.

Over the years the Foundation has been organizing support group meetings, seminars, talks, public forums and Work Skills Training Programme (WSTP) which is funded by the Ministry of Manpower. In

addition to publishing newsletters for free distribution from time to time, the Foundation has been organizing counseling sessions to help people with epilepsy to cope with their daily life.

One of the objectives of the Foundation is to provide a broader understanding of the nature of epilepsy and the needs of people with epilepsy. It aims to improve the quality of life of persons affected by epilepsy. Epilepsy may sound familiar to some people, but to many others, epilepsy may not be well understood. Persons with epilepsy may

sometimes experience discrimination against them. They have difficulty in seeking employment. Some members of the public are not aware that seizures can be under control by medication. Epilepsy is not a disease, but is a condition of the brain. It is not mental illness as mistaken by some who do not know about epilepsy.

You may be pleased to know that today given training and opportunity some people with epilepsy have excelled in their careers and are economically active to contribute towards economy and society. They should be given every encouragement and support to live like ordinary people.

The Foundation intends to set up a Shattered Workshop and a Day-Care Center or a Nursing Home for people with epilepsy. This may be a dream, but we hope some supporters and sponsors will come forward to respond and make this dream a reality for the benefit of people affected by epilepsy.

Before I conclude, I would like to express my sincere thanks once again to our Guest of Honour, Mr Zainudin Nordin for gracing this occasion despite his busy schedule on Sunday.

Finally I would like to say "thank you" to Mr Lee Bock Guan, for his presence here today but also his organisation's generous donation in cash and contributions in kind, including his arrangements for the supplies of food and volunteers who work very hard to make this event a possibility. I would also like to acknowledge our gratitude to the following sponsors:-

1. Novartis Singapore Pte Ltd –
2. UCB Singapore Pte Ltd –
3. Sanofi-Synthelabo Singapore Pte Ltd –
4. Healing Room Products and Services –
5. Business Casual Pte Ltd –

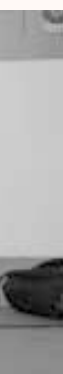
Last but not least, I wish to thank members of my Council of Management, our staff and all the volunteers of all races for their efforts and hard work to make this event a possibility.

To all of you who attend the Foundation's event here today, I thank you for your participation and also to all members of our support group, sponsors, and donors who have been giving us continuous support and encouragement all these years.

I hope you will stay on to enjoy the rest of the programme here today, and wish you all a happy and eventful International Epilepsy Day.

Thank you.

sponsored



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r Zainudin
Toa Payoh
ok Hoong
e Epilepsy
n Shih Hui

KEYNOTE ADDRESS BY MR ZAINUDIN NORDIN, MP FOR BISHAN-TOA PAYOH GRC AT THE INTERNATIONAL EPILEPSY DAY AT HDB HUB CENTRE ON 7 DEC 2003

Distinguished guests

Ladies and Gentlemen

I am honored to be invited to this meaningful event today. Epilepsy is not a disease. Hence, it is not contagious. It is a common neurological disorder that causes sudden, uncontrollable electrical surges in the brain. There is no cure for epilepsy yet but there are many treatments available to control the condition.

People suffering from this condition have the same range of abilities and intelligence as the rest of the population. Some however have severe seizures and cannot work. But there are also others who are successful and productive in challenging careers. Employers are understandably hesitant in employing people suffering from chronic illnesses that could require frequent clinic visits and off from work. They should however also look at the education level and job exposure of the applicant to determine their suitability to the job other than their medical condition.

I note that the Singapore Epilepsy Foundation is a non-profit organization dedicated to promoting public awareness and education on topics surrounding

epilepsy for the welfare of the sufferers and those who have to attend to them. Therefore the public's generous contributions will bring greater hope to these epilepsy sufferers.

It is perhaps appropriate to borrow a quote from the late Bob Hope, comedian and film star who once said, "If you haven't any charity in your heart, you have the worst kind of heart trouble."

Today we are all here with the people suffering from epilepsy and their families and friends. We are reminded that though we are living in a prosperous and safe environment, there are people out there who are less fortunate who need our care, concern and help. In fact, Christmas is just round the corner and being the season of giving, we should all contribute in our own little ways to bring brighter hope to all those less fortunate out there.

Once again, let's all pray in hope of better health for all the epilepsy sufferers and all those less fortunate out there.

Thank you



在新加坡癫痫协会上的献词 -

新加坡佛教居士林林长李木源

2003年12月7日

尊敬的各位嘉宾、各位朋友：

我很高兴代表新加坡佛教居士林，来出席今天的活动，感谢新加坡癫痫学会的朋友们，给予我们佛教居士林这样一个奉献爱心的机会。

对于“癫痫”，在座的专家医师都是内行，我所知道的一点有关知识，则多是民间的经验。在我们华人中间，它俗称羊角风、猪宝风或羊癫风，平时人很正常，发作时会突然昏倒，全身痉挛，意识丧失，口吐泡沫，症状是相当令人惊恐的。过去人们无知而迷信，说这是因为邪神附体，现在科学昌明，人们都知道这个病的病因在脑部，由病患和脑外伤引起的。

但是，即使是到今天科学昌明，医术发达，但病人的痛苦依然还是相当大的，不仅受病痛之苦，还要饱受失业的歧视之苦。想想看，谁敢去雇用这种会突然发作症状恐怖的病患者？他们的委屈和痛苦靠什么来缓解和拯救。当然，首先要靠我们医师的爱心和高明医术。对此，我本人是十分佩服和敬重的，医师专家们用他们精湛的医术拯救了多少痛苦的癫痫患者？

但是，请允许我冒昧地说一句，在高明精湛的医术之外，还存在着一门同样复杂，不容易做好的科学或者说功课，这就是围绕癫痫患者开展的社会救济和慈善工作。这种社会工作，决不是一朝一夕可以一蹴而就的，靠的是真诚的爱心、丰富的经验、相当的组织能力和实施技巧，这中间就贯穿一个复杂的耐心的系统工程在里面。我们不能要求，我们的医学专家们在奉献爱心和医术之后，还要把这个复杂繁重的社会工作、系统工程完全地承担起来，这不公平、这就要求我们长期从事社工的人们勇于挺身而出，见义勇为，站出来和我们的医学专家们一道，来为癫痫病患者服务，为他们提供一个首尾相继，前后呼应的医疗和社会保障系统。

正是缘于这个目的、愿望，今天我们佛教居士林的几十位义工放弃休息，从自己舒适安乐的家庭走出来，走到这里来为大家服务。

我们愿意和大家一起把这个美好崇高的事业，长期不懈坚持下去。

谢谢大家！

Social Integration Workshops

Dates : See below

Duration : 1.30pm – 3.30pm

Venue : Singapore General Hospital, Block 6 level 2 – 01

Aims:

- To address concerns and issues persons with epilepsy and their families might have.
- Emotional and social support for patients in the form of group therapy and sharing sessions.
- Communications skills and tips on improving memory and attention.

Workshops

Saturday, 03-04-2004

Talk – Dr. Ng Beng Yong (Psychiatrist)– Psychological impact of epilepsy

- Psychological impact of developing epilepsy and its implications on patients' mental well being.
- Depression, Anxiety, Self esteem, Stigma, etc.

Group psychotherapy - Mr Chris G, Mr Donald Yeo, Ms Esther (Psychologists)

- Psychological triggers and possible stressors – depression, anxiety, adjustment & management

Saturday 4, 17-04-2004

Talk – Mr Donald Yeo (Psychologist)– Memory issues

- Tips on how to develop skills to improve cognitive functioning.
- What types of cognitive deficiencies to expect throughout course of illness?
- Common concerns about cognitive deficiencies in epilepsy.

Group psychotherapy - Mr Chris G, Mr Donald Yeo, Ms Esther (Psychologists)

- Memory training, discussion of memory deficiencies and its impact

Saturday, 08-05-2004

Talk- Mr Chris G (Psychologist)– Self-esteem issues

- Impact of Epilepsy on self esteem.
- Tips on methods on improving self esteem, empowerment.

Group psychotherapy - Mr Chris G, Mr Donald Yeo, Ms Esther (Psychologists)

- Understanding self & improvement, positive self-image, interpersonal relationships, (family & emotional difficulties)

Saturday 6, 22-05-2004

Talk – Patient – Successful Integration

- To provide inspiration and encouragement to fellow patients.
- To provide useful tips how to develop skills and techniques for better chances of successful integration.

Group psychotherapy - Mr Chris G, Mr Donald Yeo, Ms Esther (Psychologists)

- Discussing successful coping strategies, brainstorming adaptation strategies, round up of workshop.



Social Integration Workshop for Persons with Epilepsy

- Dealing with the different aspects of epilepsy.

It is becoming increasingly recognized that there are more than just medical aspects in coping with epilepsy. Epilepsy often has profound psychological and social effects on the individual. There are common reports from persons with epilepsy that their seizures interfere with their potential for full and satisfying lives. As such, understanding and treating epilepsy should focus not only on medical aspects like medication and surgery, but also on the psychological and social impact of the seizures:-

- What are the common stresses persons with epilepsy have to deal with?
- What is the impact of stress on epilepsy?
- How do one deals with everyday stress?
- What should caregivers expect?

Likewise practical skills on improving memory, attention and communication can help in handling financial concerns and in seeking employment. These skills are important in helping patients obtain social integration and gain independence.

The Social Integration Workshop

The Department of Behavioural Medicine and the Department of Neurology of the Singapore General

Hospital, in partnership with the Singapore Epilepsy Foundation (SEF) will be organizing workshops to help persons with epilepsy and their families learn more about the medical, psychological and social aspects of epilepsy. The workshop includes sharing sessions with members who can facilitate the gaining of practical skills as well as improve social support.

- The workshops will commence on 3 April 2004 and will take place on every alternate Saturday afternoon. (*See details on attached programme*). Please note that due to the Labour Day Holiday on May 1st 2004, the workshop will be postponed to 8 May 2004.
- We strongly encourage persons with epilepsy to attend the workshops. These workshops are also extended to family members and/or caregivers (up to a maximum of two members)
- The workshops will take place at the Singapore General Hospital, Block 6 Level 2 Room 01.

For further information, please call Ms Jamilah at 6334-4302 or via email at : jamilah@epilepsy.com.sg.

Editorial

The past months have seen a flurry of activity for the Singapore Epilepsy Foundation (SEF). This issue reflects on some of the SEF activities. This month the public forum on „womens issues in epilepsy“ was the first of its kind in Singapore. The distinguished speakers, Dr Martha Morrell from USA and Dr Lim Shih Hui and Dr Tay Sun Kuie, Singapore, were able to share with a broad audience the distinct problems women with epilepsy face. Creating awareness of the problems people with epilepsy suffer from in everyday life was a major issue at the 1st International Epilepsy Day held on the 7th December at HDB HUB Toa Payoh. The social integration workshops held at the Singapore General Hospital have also started having commenced March 6th. Meetings will be held alternate Saturdays from 13.30-15.30. Make a special effort to attend these, as at these meetings specialists will be sharing important information on psychosocial issues and their treatment in epilepsy.

The Editor